Patient and family participation in healthcare design and delivery in a psychiatry and a type 2 diabetes service

A Dissertation Submitted to the School of Medicine, Trinity College Dublin

Presented in fulfilment of the requirements for the Degree of Doctor of Philosophy in Health Systems Research

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Declaration

I hereby declare that this thesis is entirely my own work and has not been submitted as an exercise for a degree at this or any other university.

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Name: Lucy Whiston
Signature: __________________
Date: _________________
Summary

Introduction
Participation is ‘a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (1). This can occur at a number of levels including the patient level (e.g. decisions about individual patient care pathways), the service level (e.g. decisions made about healthcare service design and delivery) and the national level (e.g. decisions made about national health policy) (2–4). The activities and intensity of participation vary along a continuum from consultation to partnership depending on how active the patients’ or family members’ role is. Examples include patient or family involvement on boards or committees (5–7), patient charters (6,8) and health panels (9). Benefits of participation include better health and treatment outcomes, more relevant services, greater legitimacy of decision-making, increased sense of dignity and service user satisfaction (10–16). Despite the positive rhetoric surrounding participation this has not been accompanied by developments in operationalisation with a lack of consensus on the definition and components of participation and how best to achieve participation (17).

Objectives
To develop, implement and evaluate the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in a psychiatry service and a type 2 diabetes service.

Methods
This research was conducted in an adult outpatient psychiatry service and an adult outpatient type 2 diabetes service. A mixed methods approach was adopted across five studies. This was guided by the theoretical framework of Arnstein’s Ladder of Participation (18) and the CLEAR Framework (19). In Study 1 researcher administered questionnaires with 738 patients and family members from both services established the amount of ongoing participation and support for greater participation. Study 2 employed Interpretative Phenomenological Analysis of interviews and focus groups with patients
(n=20), family members (n=20), clinicians (n=24) and policy leaders (n=15) to explore understanding, opinions, barriers and facilitators of participation. Study 3 identified preferences for the intensity and implementation of participation through two three-round Delphi Technique Experiments (DTE). One DTE was conducted in the psychiatry service (n=31) and the other in the diabetes service (n=29). Both included patients, family members and clinicians. Study 4 developed and evaluated the attempted implementation of the psychiatry pilot intervention of patient and family representatives attending sector management meetings. Study 5 developed, implemented and evaluated the feasibility of the diabetes pilot intervention of patient and family representative meetings with clinicians supported by a forum. Medical Research Council guidelines were employed with evaluation through questionnaires, interviews and focus groups.

Results
There is a gap between what we are saying and doing. Patient and family participation at the service level is restricted to the provision of information. Typically no involvement in discussions or the decision-making process is reported. However, participants favour greater patient participation (537/669; 80.3%) and family participation (374/676; 55.3%) at the service level. Interventions to encourage greater participation need to; include patients, family members and clinicians in development, link with wider patient and family populations, provide training and support, and consider process and structure. The psychiatry pilot intervention was not implemented. This was due to a decision by clinicians to review representative attendance at management meetings after 3 months, linked with fears and anxiety, and a lack of structure in management meetings. The diabetes pilot intervention of representative and clinician meetings supported by a forum was feasible with the support of the research team. This led to increases in the intensity of participation, changes in the service and improved communication. Identified challenges included attitudes, the capacity of patients, family members, clinicians and the service, implementation and sustainability.

Conclusion
This is the first time the intensity and support for greater participation has been identified at the service level in Ireland. It is also the first time consensus has been obtained between patients, family members and clinicians on what participation should look like.
using a Delphi Technique Experiment. Services should identify the intensity of and preferences of participation and provide opportunities for participation. Policy needs clearly defined goals and objectives relating to participation that need to be enacted and include supports for service implementation including resources for training and facilitation and leadership. Standardised measurement of participation needs to be developed. Future research should focus on outcomes from participation with expansion to a broader variety of services alongside a continued focus on family member participation and service level participation.
Acknowledgements

This PhD would not have been possible without the continued support and guidance from many people.

First of all, my two supervisors Catherine Darker and Joe Barry. I am forever indebted to both of whom have always had an open door and were ready to provide feedback, regardless of anything they may have been experiencing. They generously gave of their time, knowledge and expertise at all points for my PhD but also my research career in general. I have been very fortunate and am very grateful for the support, guidance and friendship of both throughout the course of my PhD. Thank you.

I would like to thank each and every participant from all five studies in my PhD. Without patient, family, clinician and policy leader participants sharing of their knowledge, expertise and time none of this would be possible. My thanks to Carol Cooney for providing the patient and family perspective to the research design and process, to Veronica O’Keane and Mark Sherlock for guiding me on context specific issues for their services and Emer Barrett for invaluable advise on Delphi Technique Experiments. The Irish Research Council and the Adelaide Health Foundation funded this research allowing me the opportunity to embark on my PhD, thank you.

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# Table of Contents

## Chapter 1: PhD Candidate and Patient and Family Participation background and introduction

1.1 PhD Candidate ...................................................... 1  
1.2 Policy context ................................................... 2  
1.3 What is participation? ............................................ 4  
1.4 Participation methods ........................................... 7  
1.5 Support for participation ....................................... 7  
  1.5.1 The emergence and impact of participation .............. 7  
  1.5.2 The importance of family member participation ....... 9  
1.6 Experiences of participation .................................. 10  
1.7 Barriers ............................................................. 12  
1.8 Participation at the patient, service and national levels .................................................. 14  
1.9 Conclusion ......................................................... 15

## Chapter 2: Theoretical Framework

2.1 Introduction ....................................................... 18  
2.2 Available frameworks .......................................... 18  
  2.2.1 The Capabilities Approach ................................ 18  
  2.2.2 Theory of Change ............................................ 20  
  2.2.3 Choice and voice .............................................. 21  
2.3 The chosen theoretical frameworks ........................ 22  
  2.3.1 Arnstein’s Ladder of Participation ...................... 22  
  2.3.2 The CLEAR Framework ...................................... 26  
2.4 Rationale for the chosen theoretical frameworks .......... 28  
2.5 Application of the theoretical frameworks to this thesis ................................................. 30  
2.6 Research questions .............................................. 32  
2.7 Aim and objectives .............................................. 32  
  2.7.1 Aim .................................................................. 32  
  2.7.2 Objectives ....................................................... 32

## Chapter: 3 Methodology

3.1 PhD Design ......................................................... 34  
  3.1.1 Mixed methods research .................................. 34  
  3.1.2 Application of mixed methods research ............... 37  
3.2 Philosophical approach ......................................... 39  
  3.2.1 Phenomenology ............................................... 39  
  3.2.2 Justification of selection .................................... 40  
3.3 Study settings ...................................................... 42  
  3.3.1 Rationale for study settings ............................... 42  
  3.3.2 Study setting descriptions ................................. 44  
3.4 Patient involvement in research .............................. 47  
3.5 Research participant eligibility criteria ...................... 50  
  3.5.1 Inclusion criteria ............................................ 50  
  3.5.2 Exclusion criteria ............................................ 51  
3.6 Ethical approval .................................................. 52  
3.7 Individual study methodologies .............................. 52  
  3.7.1 Study 1 .......................................................... 52  
  3.7.2 Study 2 .......................................................... 56  
  3.7.3 Study 3 .......................................................... 64  
  3.7.4 Study 4 .......................................................... 67  
  3.7.5 Study 5 .......................................................... 72
7.1 Introduction ................................................................................................................. 135
7.2 Methodological Highlights ..................................................................................... 137
7.3 Results ..................................................................................................................... 139
  7.3.1 Response rates and demographics .................................................................... 139
  7.3.3 Intervention development ............................................................................... 141
7.4 Discussion ................................................................................................................. 152
  7.4.1 Discussion of findings ..................................................................................... 152
  7.4.2 Strengths ......................................................................................................... 154
  7.4.3 Limitations ....................................................................................................... 155
  7.4.4 Conclusion ....................................................................................................... 155

Chapter 8: Implementation and feasibility of an intervention to encourage greater patient and family participation in a psychiatry service
8.1 Introduction ............................................................................................................. 156
8.2 Methodological Highlights .................................................................................... 157
8.3 Results ..................................................................................................................... 158
  8.3.1 Response Rates ............................................................................................. 158
  8.3.2 Demographics ............................................................................................... 158
  8.3.3 Intervention implementation ......................................................................... 158
  8.3.4 Process evaluation ......................................................................................... 161
8.4 Discussion ................................................................................................................ 169
  8.4.1 Discussion of findings .................................................................................... 169
  8.4.2 Strengths ......................................................................................................... 173
  8.4.3 Limitations ....................................................................................................... 174

Chapter 9: Implementation and feasibility of an intervention to encourage patient and family participation in healthcare design and delivery in an adult outpatient type 2 diabetes service
9.1 Introduction ............................................................................................................. 177
9.2 Methodological Highlights .................................................................................... 178
9.3 Results ..................................................................................................................... 179
  9.3.1 Response Rates ............................................................................................. 179
  9.3.2 Demographics ............................................................................................... 181
  9.3.3 Process evaluation ......................................................................................... 181
  9.3.4 Intervention assessment ............................................................................... 195
9.4 Discussion ................................................................................................................ 202
  9.4.1 Discussion of findings .................................................................................... 202
  9.4.3 Limitations ....................................................................................................... 206
  9.4.4 Conclusion ....................................................................................................... 206

Chapter 10: Integrated Discussion of Findings
10.1 Introduction ........................................................................................................... 208
10.2 Difference between what we are saying and doing ............................................ 210
  10.2.1 Understanding and support for participation ............................................... 210
  10.2.2 How much participation is taking place? ....................................................... 212
10.3 What does patient and family participation at the service level need to look like? 212
  10.3.1 Involvement of all stakeholders in development .......................................... 213
  10.3.2 Intensity of participation ............................................................................. 214
  10.3.3 Representation .............................................................................................. 215
  10.3.4 Link with wider patient and family populations .......................................... 216
  10.3.5 Training and support .................................................................................... 217
  10.3.6 Processes and structure ............................................................................... 218
10.4 Impact of patient and family participation at the service level ......................... 219
10.4.1. Impact on patient and family participation ...................................................... 219
10.4.2 Impact on the service .................................................................................. 220
10.4.3 Impact on participants ................................................................................ 221
10.5 Challenges and sustainability of patient and family participation at the service level . 223
  10.5.1 Attitudes ........................................................................................................ 223
  10.5.2 Capacity ........................................................................................................ 225
  10.5.3 Implementation ............................................................................................ 226
  10.5.4 Sustainability .............................................................................................. 228
10.6 Differences in participation in a psychiatry and a diabetes service ................ 229
  10.7.1 Arnstein’s Ladder of Participation .............................................................. 231
  10.7.2 The CLEAR Framework .............................................................................. 233
10.8 Summary ........................................................................................................... 235

Chapter 11: Conclusion and Recommendations
  11.1 Conclusion ....................................................................................................... 236
  11.2 Recommendations .......................................................................................... 237
    11.2.1 Recommendations for practice ................................................................. 237
    11.2.2 Recommendations for policy ................................................................. 239
    11.2.3 Recommendations for research ............................................................... 241

Bibliography ........................................................................................................... 243

Appendix .................................................................................................................. 267
List of tables

Table 2.1: Arnstein’s Ladder of Participation (3,151) .........................................................23
Table 3.1: Gender and age of patients attending type 2 diabetes service ......................46
Table 3.2: Study 2 sample by service, stakeholder group and interview type ..............57
Table 3.3: Study 2 patient and family member samples and populations by service ....59
Table 4.1: Sample demographic description by service and stakeholder group (248) ..........84
Table 4.2: Reported amount and intensity of patient and family participation by service and stakeholder group (248) .................................................................85
Table 4.3: Reported support for greater patient and family participation by service and stakeholder group .........................................................................................86
Table 4.4: Factors Associated With Supporting Greater Patient Participation at the Service Level (n=616; 83.5%) ......................................................................................88
Table 4.5: Factors Associated With Supporting Greater Family Participation at the Service Level (n=632; 85.6%) .........................................................................................89
Table 6.1: Psychiatry and diabetes sample description by DTE round .........................124
Table 6.2: Psychiatry DTE Consensus Answers .................................................................125
Table 6.3: Diabetes DTE Consensus Answers .................................................................127
Table 9.1: Demographic description by samples ................................................................182
Table 9.2: Patient and family forum meeting attendees, duration and topics ..........190
Table 9.3: Clinician and representative meetings attendees, duration and topics ......190
Table 9.4: Clinician and representative training ..............................................................191
Table 9.5: Intervention attendees and population comparison ........................................192
Table 9.6: Study 5 impact of the intervention on participation .....................................196
Table 9.7: Study 5 impact of the intervention on service experience ..........................200
List of figures

Figure 3.1: PhD studies and flow of study designs .........................................................35
Figure 3.2: Study 2 IPA coding frame superordinate and subordinate themes ..........63
Figure 3.3: Study 4 IPA coding frame superordinate and subordinate themes ........71
Figure 3.4: Intervention and research components .......................................................73
Figure 3.5: Study 5 IPA coding frame superordinate and subordinate themes ........79
Figure 7.1: Summary of research themes as identified by participants relating to the
prototype interventions ........................................................................................................142
Figure 8.1: Gantt chart intervention attempted implementation overview ..............159
Figure 9.4: Summary of topics discussed in the process evaluation and intervention
assessment ..........................................................................................................................180
List of appendices

Appendix A: Participation intervention options ................................................................. 267
Appendix B: Literature review search strategy .................................................................. 270
Appendix C: Application of the GRIPP2 short form checklist (2) .................................... 271
Appendix D: Ethical approval letters ................................................................................ 272
Appendix E: Study 2, 4 and 5 Application of the Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32 item checklist ....................................................... 274
Appendix F: Study 4 and 5 Application of the Template for Intervention Description and Replication (TIEDieR) checklist and guide ....................................................................... 282
Appendix G: Study 1, 2, 3, 4 and 5 Flow Charts ................................................................. 284
Appendix H: Study 1 questionnaires .................................................................................. 293
Appendix I: Study 2 interview schedules .......................................................................... 297
Appendix J: Study 2 Coding Frame .................................................................................... 303
Appendix K: Study 3 questionnaire ................................................................................... 316
Appendix L: Study 4 Proposed Psychiatry Pilot Intervention Protocol ................................ 336
Appendix M: Study 4 and Study 5 intervention development sample by service, stakeholder group and interview type .................................................................................. 339
Appendix N: Study 4 and Study 5 Intervention Development Interview Schedules ......... 340
Appendix O: Study 4 and study 5 intervention development coding frame ...................... 344
Appendix P: Study 4 process evaluation interview schedule ............................................. 346
Appendix Q: Study 4 process evaluation coding frame ..................................................... 347
Appendix R: Study 5 Diabetes Proposed Pilot Intervention Protocol ............................... 348
Appendix S: Study 5 Patient and family forum recruitment leaflet ..................................... 356
Appendix T: Study 5 Patient and family forum feedback summary .................................... 357
Appendix U: Study 5 Communications leaflet .................................................................... 359
Appendix V: Study 5 Representative training summary .................................................... 361
Appendix W: Study 5 Representative language summary sheet ....................................... 362
Appendix X: Study 5 clinician training slides ..................................................................... 363
Appendix Y: Study 5 Measures – justification, method and measurement ........................ 365
Appendix Z: Study 5 Questionnaires .................................................................................. 369
Appendix AA: Study 5 Interview Schedules ...................................................................... 375
Appendix BB: Study 5 coding frame .................................................................................. 377
Appendix CC: Dissemination Strategy ................................................................................ 379
Methodological Glossary

**Convenience sampling:** Where participants are selected based on accessibility or proximity to the researcher (20).

**Data saturation:** A criteria commonly used in qualitative research to decide when to stop data collection based on no new themes arising (21).

**Delphi Technique Experiment:** DTEs are a method of achieving consensus through multiple iterations of a questionnaire completed anonymously by a panel of experts (22).

**Epistemology:** A theory of knowledge concerned with nature and the scope of knowledge (23).

**Inter-rater reliability:** A process in qualitative research whereby data is independently coded and the codings compared for agreement (24).

**Interpretative phenomenological analysis:** An inductive form of analysis concerned with exploring a person’s lived experiences and how he or she makes sense of important transitions and decisions in life (25).

**Mixed methods:** Mixed methods research is research focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies (26).

**Ontology:** The study of reality or things that comprise reality (23).

**Phenomenology:** A philosophical approach and set of qualitative methods which aims to deepen and enlarge understandings of how others see and experience the world with a focus on the common experience of the many (27).

**Purposive sampling:** Where participants are selected based on having or not having specific criteria determined in advance by the researcher (20).

**Qualitative:** A scientific method of observation to gather non-numerical data (28).

**Quantitative:** Research which aims to count and classify features building statistical models to explain what is observed (29).

**Reflexivity:** Reflexivity refers to recognition of the influence a researcher brings to the research process (30).

**Research paradigm:** A cognitive perspective or set of shared beliefs to which a particular discipline adheres (23).
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>CC</td>
<td>Carol Cooney, Patient and family representative for research process and design</td>
</tr>
<tr>
<td>CD</td>
<td>Catherine Darker, Primary supervisor</td>
</tr>
<tr>
<td>COREQ Guidelines</td>
<td>Consolidated criteria for reporting qualitative research (COREQ) guidelines</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive behavioural therapy</td>
</tr>
<tr>
<td>CLEAR Framework</td>
<td>A diagnostic tool designed to understand the barriers and facilitators of effective participation (31). It proposes that participation occurs when people Can, they Like to participate because they feel part of something, people participate when they are Enabled, when they are Asked and if they anticipate a Response (19).</td>
</tr>
<tr>
<td>DTE</td>
<td>Delphi Technique Experiment</td>
</tr>
<tr>
<td>EOLAS</td>
<td>Support group for family members of patients with a mental health illness diagnosis</td>
</tr>
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<td>EU</td>
<td>European Union</td>
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<td>HSE</td>
<td>Health Service Executive</td>
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<td>IPA</td>
<td>Interpretative Phenomenological Analysis</td>
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<tr>
<td>JB</td>
<td>Joe Barry, Secondary supervisor</td>
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<tr>
<td>MDTs</td>
<td>Multidisciplinary teams</td>
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<td>MRC Guidelines</td>
<td>Medical Research Council Guidelines</td>
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<td>NICE</td>
<td>National Institute for Healthcare Excellence (NICE)</td>
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<td>NPES</td>
<td>National Patient Experience Survey</td>
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<td>TIDieR</td>
<td>Template for Intervention Description and Replication checklist and guide</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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List of Publications

Published
Whiston L, Barry J, O’Keane V, Darker C. Patient, family and clinician preferences for the intensity and implementation of patient and family participation in healthcare design and delivery in psychiatry. The European Journal of Psychiatry [Internet]. 2018; Available from: https://doi-org.dcu.idm.oclc.org/10.1016/j.ejpsy.2018.07.001


In preparation
The following publications are in preparation for international peer-reviewed journals such as Value in Health, Journal of Clinical Nursing and the Journal of Health Services Research and Policy.

Whiston L, Barry J, Sherlock M, Darker C. Implementation and feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult outpatient type 2 diabetes service. In preparation;


Whiston L, Barry J, O’Keane V, Sherlock M, Darker C. Development of an intervention to encourage patient and family member participation in a psychiatric and a diabetes service. In preparation.
Whiston L, Barry J, O’Keane V, Darker C. Implementation and testing of an intervention to encourage patient and family member participation in an adult outpatient psychiatry service. In preparation.

Whiston L, Barry J, Sherlock M, Darker C. Implementation and testing of an intervention to encourage patient and family member participation in an adult outpatient diabetes service. In preparation.
Chapter 1:
PhD Candidate and Patient and Family Participation: background and introduction

1.1 PhD Candidate

The PhD candidate is Lucy Whiston. Her undergraduate degree is in sociology and social policy (2011) and she has an MSc in Applied Social Research (2012). She has been working in research since 2011 and currently holds a research fellow post in Dublin City University (DCU) on the DCU PPI Ignite project. To date she has 12 peer-reviewed publications (32–43) and has presented at 6 national and international conferences. Lucy’s work primarily focuses on the area of health services research having worked on numerous projects in this area while research assistant in the Department of Public Health and Primary Care in TCD from 2012 to 2018. Projects include; ‘Views and Opinions of the General Public on Universal Healthcare (UHC) in Ireland’, ‘Health Asset and Need Assessment of Tallaght’, ‘Chronic Disease Management in Ireland’ and ‘An RCT to assess the feasibility of brief interventions for alcohol and illicit drugs in a methadone maintained cohort’.

In 2014 a submission was made to the Irish Research Council Employment Based Postgraduate Degree Programme with the Adelaide Health Foundation as the Employment Partner to secure funding for the candidate’s PhD. This was successful and Lucy commenced her PhD in 2015. The topic of patient and family participation was chosen based on the candidate’s work and research experience. As research assistant on the RCT assessing the feasibility of brief interventions the candidate was in contact with the patient forum UISCE (the Union for Improved Services Communication and Education) (34,42). This experience illustrated the role of forums and networks in supporting patients. Through work on UHC the importance of the voice and opinions of the public and patients has been emphasized to the candidate (41). Emphasizing the voice of patients has woven throughout the candidate’s research to date. Her MSc dissertation focused on the experience of service users in addiction treatment, research on the introduction of UHC has focused on the views of the general public while a health asset and need assessment of Tallaght was based on the opinions of those living in Tallaght (44).
1.2 Policy context

The 1978 Declaration of Alma-Ata stated that ‘people have a right and a duty to participate individually and collectively in the planning and implementation of their healthcare’ (2) placing patients and the public at the centre of healthcare. This sentiment has been reiterated in various World Health Organisation (WHO) documents, such as the Ottawa Charter (45) and more recently the 2017 WHO Community Engagement Framework (46), as well as by numerous countries and international organisations. The importance of patients and the public in all areas of healthcare from clinical decision making to research funding has been well established globally (2,47,48). Service user involvement in healthcare has been a key element in many healthcare strategies around the world (10) in countries including the United Kingdom (49), Australia (13) and New Zealand (12). The National Priorities Partnership in the United States with 32 national organisations identified patient and family engagement as one of six national key priorities (50). The United Kingdom have gone so far as to make patient and public involvement in healthcare a democratic right regulated by laws and guidelines (51).

Canada has a history of public participation in their healthcare system with citizens given largely symbolic positions on governing or planning bodies or asked to provide their views on a narrow range of issues usually determined by somebody else (5). In 2002 GIN-Public, an international cooperative initiative, was established aiming to support the development, implementation and evaluation of service user and public involvement in guidelines (15).

Despite these developments, there are concerns that the rhetorical development of patient and public involvement has not been accompanied by adequate progression in how it is operationalised (52). For example, a recent King’s Fund report assessing public and patient involvement in England stated that patients are not as involved in healthcare as they would like to be. This report concluded that the idea of ‘putting patients first’ is aspirational, with the current programme of action lagging behind the rhetoric of patient and family participation (17).

This difference between discussion on participation and action is also evident within the policy context in Ireland. The importance of patient involvement has been acknowledged in numerous policy documents such as ‘The National Health Strategy: Quality and
Fairness- a health system for you’ (53), the Madden Report (54), ‘Healthy Ireland’ (55) and ‘Slaintecare’ (56) as well as in numerous Health Service Executive (HSE) national service plans (57–61). For example, ‘The National Health Strategy: Quality and Fairness- a health system for you’ placed patients at the centre of the delivery of care and emphasised the need to make provisions for participation in decisions about the delivery of health and personal social services (53). The Madden Report identified the entitlement of patients to be involved in their own care and healthcare services linking patient involvement with patient safety and the quality of care (54). Engagement is one of the principles of the Slaintecare report with the implementation plan including patient advocates on the newly established HSE board and public engagement on health outcomes planned (56,62). Focusing on HSE National Service Plans the service priorities in the 2015 HSE National Service Plan included improvements in quality and patient safety such as patient, service user and staff engagement (61). This was continued in the 2016 HSE National Service Plan which included priorities to encourage patient involvement in services and care with an implementation plan to enable and empower people to be at the centre of service delivery (60). Furthermore the 2017 HSE National Service Plan aimed to strengthen engagement through embedding a culture of person-centred care, measuring and responding to complaints and implementing the findings of the National Patient Experience Survey (59).

To operationalise the acknowledged important role of patients, family members and the public in healthcare a number of steps have been taken. One of the pivotal policy steps for participation in Ireland was the publication of the National Service User Strategy 2008-2013 (6). It stated that ‘the service user should be central to their own care and to the design and delivery of health and personal social services’. It was based on three levels of involvement: 1) individual service user’s involvement in their own care, 2) community involvement in local service delivery and development, 3) national strategic policy informed through involvement of service user organisations in partnership with healthcare professionals (6). The guiding principles for this strategy included: service users having the right to being involved in the development of services, commitments of management at all levels, service user involvement in their own care, open dialogue, trust and mutual respect, inclusion, diversity and equity, clear channels of communication with accurate and timely feedback to service users and systematic evaluation of learnings to
be disseminated. This strategy was to work towards seven goals which encompassed planning for involvement in a systematic manner, development of the role of the ‘expert patient’, a patient charter to outline what patients should expect from health services, groups to ensure involvement of children, young people and socially excluded groups and programmes to identify the needs of patients and clinicians to encourage participation (6). Other steps include establishing a National Consultative Forum, development of ‘A National Comments, Compliments and Complaints’ policy (10), publication of a ‘National Healthcare Charter’ (63). Some hospitals released their own plans to encourage patient participation (3). More recently a package of patient safety reforms was launched in 2015 by the then Minister for Health, some of which apply to participation. For example, an annual National Patient Experience Survey (NPES) was developed and a National Patient Safety Office and National Patient Advocacy Service were established (64).

Despite these steps, participation appears to be somewhat limited. ‘The National Healthcare Charter’ (63) published in 2012 focuses on involvement at the individual clinical decision making level. ‘The National Strategy for Service User Involvement’ did little to enforce participation. Developments overall have been ad-hoc and isolated and a subsequent strategy dedicated to service users has not been reiterated since the timeframe of this strategy ran out in 2013 (10). There is no measurement of participation in healthcare design and delivery (55). The NPES asks a total of 58 questions, one of which focuses on participation. However, in line with the purpose of the NPES this question focuses on participant’s involvement in their own individual treatment and care.

1.3 What is participation?
The imbalance between rhetoric and action is complicated by an absence of clarity in the definition of participation (65) and information on participation in general (17). Patient and family participation is when the views of patients and family members are sought and taken into account in designing, delivering and improving new and existing healthcare services. There is consensus in the belief that patient participation is positive, being referred to as ‘the holy grail of healthcare’ and ‘the next blockbuster drug of the century’ (4). However, patient participation has become a buzz phrase with the result that it now has multiple meanings (66). The terms within patient participation are used
Participation is used interchangeably with activation, patient and family centred care, co-production, involvement, empowerment, shared decision making and engagement (4,17,67). Different labels are used to refer to those who partake in participation such as patients, consumers, users, client, citizens, the public, carers, or family members (16,67). This adds to confusion and alienates some who may be in favour of participation as different terms have varying supporters and critics (10).

Participation can occur at a number of levels of healthcare; the patient level (e.g. decisions about individual patient care pathways such as changes to medication), the service level (e.g. decisions made about running a service such as how the appointment system works) and the national level (e.g. decisions made about future plans for national health policy) (2–4). At the patient level participation is focused on integrating patient and family values, experiences and perspectives related to prevention, diagnosis and treatment. At the service level the focus is on organisational design and governance. Participation revolves around integrating patient and family values, experiences and perspectives in the development and governance of healthcare services at the level of ward, department, clinical speciality or hospital level. At the national level the focus is on developing, implementing and evaluating national, state and local healthcare policy and programmes (3,4).

The activities and intensity of participation vary along a continuum from consultation to partnership, depending on how active the patients’ or family members’ role is (4). Numerous models have been developed to identify types and levels of participation including Feingold’s five rung ladder, Charles and De Maio’s 3 step ladder and Health Canada’s Public Involvement Continuum with the most recognised being Arnstein’s ladder of participation (10,18,68) (See Chapter 2 for further discussion).

Understanding of patient participation is influenced by the role that people play (16). Interviews with patients, providers and policy makers in England highlighted the different views which people have in relation to the aims of patient participation (47). Healthcare managers and public health experts viewed participation at the national level with the purpose of improving health services for the public as a whole, based on scientific methods such as surveys. Healthcare professionals thought of participation at the patient
level where the healthcare professional made the decisions based on evidence but took into account their knowledge of the patient with interaction between the patient and healthcare professional being paramount. Patients and allied healthcare professionals took a broader view of participation beyond the individual clinical decisions to the development process and political arena and supported patients having a role in the decision making process (47). Similarly a Norwegian study with patients, public representatives and healthcare professionals in a mental healthcare setting illustrated different opinions on the definition and components of participation between the groups (51).

Further adding to this complexity is the difficulty in measuring participation. Measurement of patient participation in healthcare is a relatively new concept, introduced in western Europe, North America and Australia over the previous 25 years (69). As a result there are no set tools for measurement and those that are used are not used in a meaningful or systematic manner (70). Furthermore, measures which are available focus primarily on involvement at the individual direct care level. For example, the Patient Activation Measure focuses solely on individual direct care (71).

Lack of clarity in the definition and components of participation have resulted in complexity and complications with no agreed definition of patient participation. This is important to be aware of as the definition of patient participation impacts on the meaning, what the aims are, who is to be involved in what areas and how participation is to be achieved. Differing understanding of participation can lead to decreased efficiency in communication and collaboration between different groups and a hindering of work towards increasing and improving patient involvement in healthcare (51). Without any accepted international definition of patient participation the definition adopted by the Department of Health will be employed for this PhD. Participation is ‘a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (1).
1.4 Participation methods

Participation takes multiple forms in healthcare. As result there is not one single method that can be considered to reflect best practice (72). Potential methods for participation include questionnaires (52), involvement in development of information material (73), workshops (16), forums (74), representatives (75), patient or family involvement on boards or committees (5–7), patient charters (6,8), health panels (9), civic juries (76) and setting of priorities (77) (See Appendix A: Participation intervention options). For example, health panels were employed in the United Kingdom in the Somerset Health Panels to explore people’s views on ‘live’ policy issues such as resource allocation. Participants are selected using quota sampling with membership refreshed on a regular basis (9). Patients or their representatives were involved in quality improvement measures across 7 countries in Europe with methods including surveys, development of a written policy on patient rights, patient information material and discharge fact sheets (73). Family caregivers’ were involved in multidisciplinary meetings facilitated through video conferencing in Texas to ensure patient centred care for hospice patients (78). The most appropriate method of participation depends on the desired intensity and the level of participation. For example, a health panel of a civic jury would not be a suitable method of participation for the patient level but could work for the service or national levels. All potential methods listed above are suitable for the service level and are discussed in more detail in Chapter 7.

1.5 Support for participation

1.5.1 The emergence and impact of participation

The reasons why patient participation emerged and why it has gained support are multifaceted, stemming from the democratic context, the healthcare context and the potential impact of patient participation.

Participation within democracies can lead to more effective learning and better decisions as a properly organised democracy increases our capacity to address fundamental social problems (79). As such, participation is of key importance in today’s world. This is due to the growth of welfare states and public expenditure alongside the emergence of
cosmopolitan democracies increasing the influence and power of international organisations such as the European Union (EU) (79). These developments have been accompanied by a decrease in public confidence and trust in democracy, traditional political institutions and their ability to deliver the society that people want (10,19). Frustration with the status quo has emerged with renewed interest in more direct involvement in policy development and decision-making (10) through the establishment of lobby groups (17,80) and an acknowledgement of the right to participate (3,10). Inclusion of the public increases accountability and trust (3,7,8), ensures the development of relevant and effective services with better quality (3,7,8,16) while fostering social legitimacy (16).

Achievements in modern medicine relating to diagnostic procedures, interventions, pharmaceuticals and health promotion have resulted in healthcare systems facing new challenges with a shift in the burden of disease from infectious to chronic illnesses alongside an ageing population (50,81). This has led to a shortage of supply of resources with spiralling costs and diminishing quality with concerns relating to patient safety (4,50). Patient safety is now a global issue. At any one time over 1.4 million people worldwide are suffering from infections acquired in hospitals with up to 10% of patients admitted to modern hospitals in the developed world acquiring one or more infections (81). To overcome these challenges a call has emerged for a new focus on the demand side of the system - the patient, family, community, and society side (4,50,81). Patients have been identified as a possible solution (82). Patients and members of the public can bring great clarity, practicality and transparency to the development of healthcare services with the ability to articulate both the problems and as well as the solutions (6,83). Taking account of the perspectives of patients and their families is crucial to articulating the reality and identifying the gaps between the patient safety measures and the levels of safety being experienced (82) with truly safe and effective care only being achieved when patients are ‘present, powerful and involved at all levels’ (84). Despite this, patients are an underutilised resource with the lack of patient and family participation in healthcare identified as one of the weaknesses of current healthcare systems by the WHO (81,85).

The potential impact of patient participation has been illustrated in relation to patient
health and healthcare services. Patient and public participation offers a pathway to improved population health (4), better health and treatment outcomes for patients (3,4,12,14,69), greater quality of life (69) and increased patient self-dignity, self-worth and self-esteem (69,86,87). The possible impacts on healthcare services include the provision of more appropriate services that are more relevant and responsive to patients’ needs, values and priorities (6,16,88), increased legitimacy and credibility of decision making (11,13), higher quality services (4,6) with greater compliance, satisfaction (6) and efficiency (4) alongside greater control of healthcare costs (4) and accessibility (69). For example, the inclusion of patients in the decision-making process in Canada resulted in the changes proposed being implemented addressing the needs of patients (89). A Cochrane review with quantitative methods found moderate quality evidence that service users’ involvement in producing patient information resources results in materials that are more relevant, readable and understandable to them and can improve their knowledge (87).

1.5.2 The importance of family member participation

Families and carers should be considered at all stages of care-planning, decision–making and delivery, with the same thought and attention as for patients (17). This has been identified as an essential principle for a number of reasons.

Involving families and carers is an essential part of good patient care. Families and carers play a diverse number of roles including providing emotional, social and financial support, domestic assistance, monitoring health and well-being, providing basic health and personal care, providing professionals with information about the individual, advocating for individuals and proactively seeking out care and treatment options (17). As much as 80% of people requiring long-term care will receive their care from spouses, relatives and friends (67). The involvement of families has been found to increase patients’ knowledge, confidence and understanding in dealing with their health problems, reducing rates of relapse and admissions and aiding recovery (90–92). In addition a report from the WHO reported that providing unpaid support to family members or friends is a major contributing activity to the health and welfare of society (67).
Despite the importance of the role that family members can play in supporting the treatment of their loved ones during their illness the involvement of carers is subject to the agreement of the individual for whom they are caring. Data about carers’ contact with health systems is not routinely collected so we do not know a lot about family member participation (17). In addition with a focus on mental health services family members caring for those with a diagnosis of serious mental illness are disproportionately at risk of carer burden when compared with those supporting people with other long-term conditions (93).

1.6 Experiences of participation

Key to the formation of opinions which people hold and to the development of participation going forward are the experiences of participation which patients, family members and clinicians have to date. Some evidence is available on the experience of patients and clinicians. However, this is generally secondary to the primary purpose of these pieces of research. For example, some information on the experience of participation is available from a survey of staff, patients and the community of mental healthcare services in the United Kingdom. However, the primary purpose of this piece of research was to assess the impact and overall level of participation (94).

Information which is available points towards overall positive experiences of participation demonstrated in different countries, including the United Kingdom (15,94,95), Canada (89) and Sweden (96) and in different treatment settings such as mental healthcare services (15,94), respiratory services (95) and coronary care (96). Reported positive experiences of patient participation include patient empowerment (94), greater social interactions between healthcare professionals and patients (94), the inclusion of a different point of view and information which is only available from patients (89) and service improvements (88). An appreciation for the knowledge provided by patients through participation and the acknowledgement of the value of this unique knowledge was identified through interviews with patients involved in the development of National Institute for Healthcare Excellence (NICE) guidelines for mental healthcare services in the United Kingdom (15).
Positive experiences of patient participation serve to allay some fears that present barriers to patient participation. For example, concerns have been raised about the ability of patients to impact on the decision making process, the ability of patients to see past their own needs and experience. Contrary to these concerns questionnaires completed by coronary care nurses in Sweden revealed that from their experience patient involvement in priority setting resulted in professionals changing their opinion to be more favourable towards patient participation (97) and patients involved in the development of NICE guidelines for mental healthcare in the United Kingdom reported feeling able to influence research questions and treatment priorities (15). Reported patient experiences of participation highlight the ability of patients to see past their own personal health and healthcare experience. A study in the United Kingdom reported that severely ill patients were equally aware of changes within health services as those with better health and patients were not only aware of trends in healthcare provision but were able to interpret changes in the light of local and national events (95). The introduction of service users to the Irish Health Service Accreditation Board was reported by service users and professionals to have resulted in greater objectivity and credibility (98).

Previous negative experiences have been demonstrated to impact on opinions and willingness to participate in the future (99). While the overall reported experiences of participation are positive some negative elements have also been reported. Mental health patients participating in guideline development in the UK identified technical language, the unspoken rules and customs of the decision making process and the unbalanced group dynamic as negative elements in their experience of participation (15). Similarly the balance of knowledge skewed towards clinicians was also identified as a negative element of clinicians’ experiences of participation. Clinicians reported to find it easier to work alongside patients who had some experience and expertise especially in the health field (89). Further research with staff and patients in community mental healthcare services in the UK pointed towards tokenism and negative impacts on the health of those who become involved as negative elements of the experience of patient participation (94).

However, while there is some work on experiences of participation it is evident that people are not as involved as they want to be in decisions about health and care (17). For
example, a cross sectional multilevel study from seven countries in Europe illustrated that current levels of participation in quality management functions in European hospitals are low at hospital level and even lower at departmental level. Patients and their representatives are rarely involved in developing quality criteria, designing or organising processes of care, participating in quality committees or discussing results of quality improvement projects (73).

1.7 Barriers

While there are many key reasons supporting the uptake of patient participation it is important to note that participation is challenging and there are barriers to be overcome. Participation challenges orthodoxies, vested interests and established ways of doing things. It requires professional communities to do things differently and to relinquish responsibility. It requires patients and citizens to think about their health and their care in different ways. ‘It poses a fundamental cultural and behavioural challenge to our systems of health and social care’ (p. 7) (17).

Patient and public participation is in opposition to the neoliberal context of today’s society in which market imperatives reign supreme and people are perceived to be self-interested actors seeking to maximise their own material gain as demonstrated in the Marmot Review (100). From a healthcare perspective this neoliberal approach leads to an individualist clinical model which is a contradiction of the participation model and the social contract of communities (2). Essentially there are tensions between the individualised society in which we live in today and the collective perspective necessary for patient participation (16). The ‘capability approach’ developed by Amartya Sen and Martha Nussbaum has been proposed as a way to overcome the tensions between individualism and collectivism. Employing the capabilities approach makes central the question ‘what are people actually able to do and be?’ This enables a paradigm shift from the provision of a patient focused sickness services to a citizen focused wellness society (101).

Cultural issues are sometimes identified as barriers to system changes. Cultural issues refer to professional and organisational attitudes and behaviours that are resistant to
perceived interference and an antipathy towards change (82). Patient participation in healthcare is an idea that faces considerable resistance from clinicians (87,95). An ethnographic study of clinicians’ attitudes to engaging respiratory patients in England and Wales reported clinicians’ lack of support for patient participation (95). Healthcare professionals are hierarchically socialised and organised to view themselves as authorities who know better than patients (87,102). Patient participants in the development of NICE guidelines in England identified group dynamics with varying statuses as a challenge to participation (15). Interviews with patients, the public and providers in Norway revealed healthcare providers concerns about patients or the public making decisions without them (51). It should be noted that there is some evidence in the literature illustrating healthcare professional support for patient participation. For example, interviews with healthcare professionals in an ethnographic study with healthcare professionals in respiratory services in Scotland and England concluded that healthcare professionals’ motivation for patient involvement may be underestimated (95). Clinicians’ attitudes towards patient participation are key as negative views of participation decrease and limit the intensity of participation (7,96). A cultural shift with a change in the mind set of healthcare providers may be required for patient involvement in healthcare to be implemented (7,95,103).

There are a set of barriers and concerns that relate to patients, their experience of participation and their ability to participate. Patient participation requires patients and the public to think about their health and care in a different way, the ability to see past personal experiences and aspects of care and to switch between roles of being a patient and a participant which may pose a barrier for some people (17,87,95). To overcome this barrier a clear definition of participation, the aims of participation and the role of participants needs to be identified (2). Participation can be challenged by low levels of education, health literacy, limited availability and sharing of understandable and culturally appropriate information and educational materials (81). Interviews with mental healthcare patient participants in the development of NICE guidelines identified technical language, unspoken customs or rules surrounding how decisions are made and the group dynamic as barriers to participation (15). In focus groups and interviews healthcare professionals in Canada reported patient representatives’ own health problems or physical limitations to be the greatest barrier to participation e.g. missing meetings due
to illness (89). The combination of these barriers has been reported to lead some patients to question the relevance and feasibility of their input (15,104).

Underpinning the cultural and social barriers, a pivotal challenge in the implementation of patient participation, is the paucity of consensus, clarity and information in this area. The ability to overcome any of the previous mentioned barriers and fully implement participation is stifled by this lack of clarity and consensus.

1.8 Participation at the patient, service and national levels

Participation at the patient level refers to participation of patients or family members in the care of an individual patient. Systematic reviews bringing together knowledge on what we know about participation at the patient level have focused on barriers and facilitators to participation from the perspective of patients (105) and clinicians (106). For patients barriers to participation stem from the opportunities for participation at the patient level not existing. To overcome this patients need to be provided with knowledge and the power imbalance between patients and clinicians needs to be addressed through attitudinal changes. This echoes clinician reported barriers to participation at the patient level which include a perceived lack of applicability of participation to the patient population due to patient characteristics. Despite this identified facilitators in this area include clinician motivation and the positive impacts of participation on the clinical process and patient outcomes (106). Recommendations for interventions to encourage patient level participation have been made. Whether from the perspectives of patients or clinicians it is clear that any intervention should be multifaceted, addressing a range of factors (105,106). For example, the attitudes of patients, clinicians and organisations are to be addressed at the same time for participation to be improved (105).

Participation at the service level is participation of patients or family members in healthcare design and delivery within individual healthcare services. Sources synthesising the evidence on service level participation tend to focus on the impact or effects of participation. Impacts reported include a range of impacts on healthcare services specifically within the NHS but also more broadly particularly in relation to changes in the attitudes of services alongside changes to service provision and quality improvements
(69,107,108). However, it is clear that the evidence base in this area is weak. It has been noted that there are few studies that focus on the impact of service level participation (69), with those that are reported being weak. A systematic review on the impact of patient and public participation on NHS healthcare highlighted that literature on the effects of participation at the service level is of poor quality with a lack of detail or theoretical underpinnings limiting the evidence base (107). Furthermore, a scan of the literature on reporting of previous participation initiatives in primary care led commissions in the NHS concluded that research shows little evidence of effective methods or outcomes (108).

Participation at the national level relates to patient or family participation in national healthcare policies. Synthesis of evidence at this level focuses on methods of participation. A Cochrane review of methods of participation including for involvement in policy concluded that there is little evidence on the effects of participation at the population policy level (87). A systematic review on citizen juries reported mixed results for representation with citizen juries often being implemented for shorter durations than recommended and rulings not being considered by decision making bodies resulting in limited impact on policy (5).

1.9 Conclusion
Patient and family participation is where patients and family members are asked what they think and their opinions taken into account in a meaningful way in all changes within healthcare. Support for participation is evident in international and Irish policy documents with identified positive impacts on healthcare systems and services as well as for patients and family members. However, there is a gap between what we are saying and doing, as patients and family members are not as involved as they want to be and we are not measuring the amount or intensity of participation in Ireland. This gap can be linked with cultural, attitudinal and societal issues as well as a lack of consensus surround the definition and components of participation and what needs to be done to encourage greater participation.
It is evident from the literature that additional research in this area is required. An acknowledged barrier to any advances or implementation of patient and family participation is the lack of clarity or consensus on the components of patient participation. The need for future research to focus on defining the components of participation has been identified by multiple sources (47,65,109). No clear consensus has been reached on the best ways to achieve strong and lasting participation (16). Existing research is weak due to heterogeneity in the interventions tested, the patient groups employed and underlying health systems. Interventions tested have included patient involvement through priority setting in primary care services in Canada, patient involvement through an evaluation of mental health services in Ireland (110) and the use of citizens’ juries with patients to investigate e-health in the United Kingdom (111).

There appears to be a limited focus within the current literature on the opinions and experiences of participation within the literature (112). Research that has been conducted in this area has only a secondary focus on opinions and experiences of patient participation. More research is required to validate views expressed by staff and patients (7) to improve participation going forward (96,109).

In relation to the level of participation there appears to be a divide within the literature. Focus tends either to be on participation at the patient level or at the national level with a limited focus on participation at the service level. Patient participation in individual and clinical decision making has been extensively studied. However, how patients can effectively be involved in collective healthcare decisions affecting the population has not been trialled (97), with a similar conclusion being drawn in a recent Cochrane review (87).

A considerable gap within the current literature is the lack of inclusion of family members, with little to no consideration of the role of family members or support for family member participation. Terms within participation are used interchangeably with the result that family members are often included within other larger groups such as service users (16). This gap has been acknowledged by the World Health Organisation (WHO) who have identified this as an area meriting further study (81).
A longitudinal multicentre study across Europe illustrated that patients’ desire for participation varies by location (32). The social, cultural and political contexts have all been acknowledged to play a key role in opinions, uptake and implementation of participation. However, there is a dearth of Irish based research in this area with no baseline data on the current amount or intensity of participation (17). Studies conducted have focused on niche areas concentrating on specific services or groups. For example 'Engaging children in planning, design, development and delivery of services' (113), 'Evaluation of the Patient Partnership Group at St. Luke's Hospital' (114) and 'Consumer Participation by Older People in Health and Social Services' (115). Better information about who does and does not perform participation behaviours will allow strategic decisions about the kind of information, guidance and support that are needed by their patients, members or constituents to participate effectively in their care and thus to benefit optimally from it (116).
Chapter 2:
Theoretical Framework

2.1 Introduction
There are no widely accepted guidelines for the use of conceptual or theoretical frameworks to guide inquiry in mixed methods research (117). However, theoretical frameworks are commonly employed as organisational hooks upon which research can be hung acting as a navigational device increasing credibility and transferability (118). They can be employed to highlight the significance of research, assist in guiding design decisions and dissemination providing a system for linking observations and findings (117,119,120). This is particularly pertinent for research where complex phenomena are an aspect of the inquiry, such as work in the area of health and social care (120,121).

In this Chapter the available frameworks considered for this PhD are outlined alongside a detailed critique of the chosen frameworks, Arnstein’s Ladder for Participation (18) and the CLEAR Framework (19). The rationale for decisions made and the application of the theoretical framework are presented. An overview of the aims and objectives of the PhD are also provided.

2.2 Available frameworks
The theoretical frameworks employed were not the only frameworks that could have been used as is often the case in research (122). Without careful consideration a theoretical framework could be chosen that has a poor ‘fit’ with the study, distorts the data or fails to describe the reality under study (123,124). In line with this, a number of available frameworks were considered for this research, each of which are discussed below.

2.2.1 The Capabilities Approach
The Capabilities Approach is a way of thinking about how advantaged or disadvantaged people are. The roots of the Capabilities Approach can be traced back to Aristotelian ideas about human flourishing, although more recently it has been developed for work on
human development and social justice by authors including the economist Amartya Sen and philosopher Martha Nussbaum (125–127). Key features include a focus on ‘functionings’, doings or ways of being and ‘capabilities’, genuine opportunities to achieve functionings. This approach encourages an evaluative focus on the extent to which people are free and able to be and do what they have reason to value being and doing (128). Essentially it is a question of ‘What are people actually able to do and be?’ (129). It allows for the assessment of individuals as well as institutions, policies or contexts that may influence individual well-being (129). The Capabilities Approach has been adopted in a variety of fields and to achieve various aims. For example, consideration in the measurement and performance of evaluation of social change efforts to allow for a broad consideration of impacts (129). It has been suggested as a method to consider the social model of mental healthcare (130), measurement of poverty (131) and assessment of the well-being of adult learners with disabilities (132).

Benefits of this approach include a broad scope for study, pluralistic thinking and a recognition that capabilities are shaped by interactions between individuals and their surrounding environments and social relationships (128). This means that there is flexibility in the capabilities and functionings that you consider and the importance you place on each. On the other side capabilities and functionings can’t be easily measured. There is no agreement on what is included within capabilities or functionings and it is expected that this approach will undergo considerable changes and refinement in the future (129). For this PhD it is in keeping with the phenomenological approach adopted. There is a focus on the social and environmental contexts of capabilities which is in line with the argument that health system reform cannot ignore the political and cultural contexts with allowance for varying experiences and opinions of stakeholder groups (128,133). It was decided not to include the Capabilities Approach in the theoretical framework for this research due to the overlap with the CLEAR Framework. Both frameworks focus on influential factors impacting on peoples’ ability to achieve a given task. However, the CLEAR Framework has been developed and focuses particularly on influential factors for participation giving guidance on important components to consider in participation and suggestions for encouraging participation. The Capabilities Approach focuses on factors for a given phenomenon. It is often used to assess criteria such as the common good, inclusion, deliberation, independence, participation and equality (101).
These criteria are considerably broader than the scope of this PhD, which is focused on participation.

2.2.2 Theory of Change

The Theory of Change was developed from the tradition of theory driven evaluation (134). It is defined as an approach which describes how a programme brings about specific long-term change through a logical sequence of intermediate outcomes (135). A process for developing and assessing initiatives for change at all stages is provided. It is discursive and visual, making assumptions explicit, realistic and feasible with critical thinking at all stages (135). Essential basic elements include; an assessment of the context, a focus on long-term change and a process working towards long term outcomes with assumptions, diagrams and a narrative summary. This theory is widely used in public health literature, often in the development or evaluation of interventions (134). Examples include employment in the development of plans for improving mental healthcare services in low and middle income countries (136), development and implementing an approach to interagency planning in child mental healthcare services (137) and in the evaluation of comprehensive community initiatives in America (138).

Benefits of this approach for this PhD include a focus on intervention development and evaluation with inclusion of a wide range of stakeholders in the process (134). However, this theory was not suitable for inclusion in the theoretical framework for this PhD for a number of reasons. The Theory of Change focuses on long term change while this PhD, due to the duration of time available, was focused on evaluating change over a shorter period of time. This theory requires that there is a system already in place to change. However, there is no existing process for participation already in place in either service. In addition this theory provides no understanding or explanation of the phenomenon of participation, the potential roadblocks or what needs to be considered to encourage participation.
2.2.3 Choice and voice

This is an argument based on the idea that those in receipt of public services have two options when they want improvement: ‘choice’ (act as a consumer and choose to get your service elsewhere) or ‘voice’ (act as a citizen and participate for improvement) (139). The ‘choice’ agenda positions the public as consumers, driving improvements through choosing good providers or services over bad, with reforms in this area centring around making public services more locally responsive. The ‘voice’ agenda positions the public as citizens. Improvements are achieved through accountability with mechanisms such as elections or the public playing an active role in how services are run. Citizens have a right to participate in public services, either through political means or in the running and delivery of services (139). While a clear distinction between methods for participation are presented there are a number of concerns about this theory. Terms employed, such as consumer, are particularly loaded in the healthcare setting. It assumes that patients have a choice to move provider or service. This is not an option that is available to all members of the healthcare system in Ireland, with only those who can afford to pay for private health insurance having the ability to change service. In addition, the ‘choice’ option focuses on complaints. There is already a concern within the healthcare setting about too much focus on complaints with patient advocacy services often becoming equated with complaints. Applications of this theory include; comparing options to address bureaucratic inefficiencies and insensitivities with an example of schools in Australia (140), in an assessment of available options of public involvement in services in England and Wales (141) and how do public service users experience and evaluate the alternative ways in which their interests may be represented, and what factors guide their ‘choice about voice’ in housing, healthcare and leisure services in the United Kingdom (142).

Choice and voice has not been included within the theoretical framework for this PhD for a number of reasons. The ‘choice’ option does not apply to many within the healthcare services. This is particularly the case within the services in questions in this PhD given the location of these services within a deprived suburb of Dublin and lack of choice in what services to attend if you do not have the ability to pay. Additionally this theory is typically used as a justification for participation or understanding available options (140–142) and the needs of the theoretical framework in this PhD go further than this. The theoretical framework for this PhD needs to provide an understanding of the phenomenon of
participation, how it can be encouraged and the potential roadblocks that may be encountered.

2.3 The chosen theoretical frameworks

The chosen theoretical frameworks in this PhD are Arstein’s Ladder of Participation (18) to measure the amount and intensity of participation and the CLEAR Framework (19) to guide what is required to encourage participation.

2.3.1 Arnstein’s Ladder of Participation

One of the best known models for participation is Arnstein’s Ladder of Participation. Published in 1969 it is a typology based on the author’s work in urban planning (18) which has since been used in a wide variety of settings including healthcare (3,10,143–149). Presented on a ladder each rung corresponds to the extent of citizen’s power with increasing intensity as you move up the ladder (18). Participation is viewed as a redistribution of power from those who have power to those who do not, from the haves to the have nots. The purpose of participation is to ensure that those who are currently excluded from political and economic processes are deliberately included in the future so that the have nots can encourage significant social reform and share the benefits of affluent societies (18).

An adapted version of the Ladder of Participation with five rungs has become a standard reference point for policy makers and practitioners promoting participation and is illustrated in Table 2.1 (3,10,148,149).
Table 2.1: Arnstein’s Ladder of Participation (3,149)

<table>
<thead>
<tr>
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<th>Description</th>
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<tbody>
<tr>
<td>5. Devolving</td>
<td>Placing decision making in the hands of the community and individuals.</td>
</tr>
<tr>
<td>4. Collaborating</td>
<td>Working in partnership with communities and patients in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.</td>
</tr>
<tr>
<td>3. Involving</td>
<td>Working directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered.</td>
</tr>
<tr>
<td>2. Consulting</td>
<td>Obtaining community and individual feedback on analysis alternatives and or decisions such as surveys and focus groups</td>
</tr>
<tr>
<td>1. Informing</td>
<td>Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities, solutions. For example, websites, newsletters and press releases.</td>
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The bottom step of ‘informing’ is where the have nots are provided with information about what is happening, their rights, responsibilities and options. This is a one-way flow of information with no opportunity for the have nots to provide feedback or to become involved in negotiations. The second step is ‘consulting’ where the opinions, experiences or preferences of have nots are collected by the haves who are in power. These steps of ‘informing’ and ‘consulting’ are considered to be ‘tokenistic’ forms of citizen involvement and power sharing where citizens can hear and be heard but have no way to ensure that their views and opinions are heeded (18). The third step is ‘involving’ where the have nots and haves work together to ensure understanding of the concerns and aspirations of the have nots. However, this is viewed as a higher level of tokenism as the ground rules have not changed as the haves retain the right to decide. Step four is ‘collaborating’ where the have nots work in partnership with the haves in all aspects of decision making. Step five is ‘devolving’ where the have nots take complete or majority control of decision making. These final steps of ‘collaborating’ or ‘devolving’ participation are classed as citizen power sharing and involve high levels of participation for the have nots (18,68).

Arnstein’s Ladder has been a key part of the debate surrounding participation and its versatility has resulted in use in a variety of settings. For example, Arnstein’s Ladder has been employed in settings including business (147), environmental studies (143), public administration and governance (144,145), education (146) and healthcare (3,10,148,149). Focusing on healthcare examples of use include employment in a mixed methods exploration of older people’s participation in discharge from hospital in the UK (150), in a
guide for hospital staff for public and patient participation (3) and for participation within health and care in the UK more generally (20). However, there has been debate about its limitations (148,151,152). Criticism centres around three areas.

First, is the emphasis placed on power. Arnstein’s Ladder reduces participation to the redistribution of power from one group to another. It has been proposed that this constrains the potential of participation by limiting the methods used to encourage participation and fails to take in to account that for some participation is the end goal in itself (148). This stems from ignoring the existence of different forms of knowledge and expertise while assuming power has a common basis for both groups which are presented as homogenous (148,152). Arnstein has acknowledged and discussed this limitation explaining that the focus on power and division between two groups is driven by the way in which both groups view power. The have nots perceive power as a monolithic system while the haves view the have nots as a sea of ‘those people’ with little comprehension of the diversity and complexities within this group (18). For this PhD this means that while the phenomenon is simplified in line with the way in which both groups view power and each other influential factors are ignored. For example, factors that encourage participation such as a sense of belonging or being listened too are neglected (19,153) or components that alter opinions of participation such as gender, education or health status (154–156). This leads to a limitation in the factors considered or addressed in interventions to encourage participation.

Second, are concerns relating to oversimplification. It has been put forward that Arnstein’s Ladder focuses too much on the outcome as opposed to the process of participation (148,152). This results in limited insight in to how participation might be progressed, sustainably maintained or to the roadblocks to participation (18,148,152). There is a lack of focus on context and no acknowledgement or differentiation between methods of participation, outcomes, or stakeholders. This is of particular importance for the healthcare setting. This is because the simplistic explanation of participation presented in Arnstein’s Ladder does not take into account participation in different healthcare settings, such as in specific services or the healthcare system as a whole. It does not consider those who must rely on others to participate on their behalf or where the size of a population leads to difficulties balancing numbers with the intensity of
participation (148,152). For this PhD this is important as it does not allow for participation through family members which may be necessary for some patient who are unable to participate themselves and poses difficulties for large cohorts of patient, such as the 2,200 in the psychiatry service and the 4,884 patients in the diabetes service in this PhD.

Third, are matters relating to hierarchical structure with linear progression and the greatest intensity, or top rungs of the ladder, being viewed as preferable (7). This may lead to the promotion of decisions based on ‘the tyranny of the majority’ and a mismatch between the motivation for individuals or contexts embarking on participation (148,152). Indeed, importantly for the healthcare sector in some situations the lower rungs of participation are more applicable (157). For this PhD this raises concerns about balancing what Arnstein’s Ladder says is the preferable intensity of participation with the context of participation in both services, the size of the patient population and stakeholder preferences none of which are aligned with what Arnstein’s Ladder advocates.

Many of these limitations have been acknowledged and discussed by the author (18). In general they centre around the issue of the simplification of participation, be that the sole focus on power, the outcome of participation or the hierarchical structure. However, it should be noted that Arnstein’s Ladder is put forward as a typology of participation (18). Typologies do not set out to identify relationships between components and outcomes, but to simplify and provide a standardised system of classification for a phenomenon (158). Therefore, criticisms of the sole focus on power, oversimplification or the hierarchical structure point towards a lack of understanding of the purpose of Arnstein’s Ladder as a typology. In addition it is in the simplicity of the Ladder from where much of the appeal for the wide ranging audience of the Ladder stems (152). The Ladder provides a clear depiction of participation with distinct differences between the each rung of intensity to allow easy identification as to whether or not participation is taking place and if so how intense participation is.

Arnstein’s Ladder has become a standard reference point for academics, policy leaders and practitioners to critique, design, implement and evaluate participation in a variety of settings (152,159). In line with this Arnstein’s Ladder was employed in this PhD. It presented a clear and simple system to identify the amount and intensity of ongoing
participation as well as preferences of participation going forward which can and have been adapted to a healthcare setting (157). However, it assumes that the greatest levels of intensity of participation are preferable and does not offer any guidance on how to encourage sustainable participation or on the potential roadblocks that may be encountered. To overcome this issue the CLEAR Framework was employed alongside Arnstein’s Ladder in this PhD to provide guidance on important elements for participation and potential challenges.

2.3.2 The CLEAR Framework

The CLEAR Framework of Factors Driving Public Participation was designed to understand the barriers to and facilitators of effective participation (31). The framework was developed from case studies in contrasting English speaking localities assessing factors underpinning citizens’ responses to participation (153). It proposes that participation occurs when people Can, they Like to participate because they feel part of something, people participate when they are Enabled, when they are Asked and if they anticipate a Response (19). The underpinning argument is that citizens engage depending upon the resources to which they have access, the extent to which they feel linked in a wider community, whether they are helped to participate by supportive organisations, if they are mobilised and if they experience or anticipate a response (19).

‘Can do’ refers to the socio-economic arguments that when people have the appropriate skills and resources they are more able to participate. Skills and resources are broad ranging from the ability and confidence to speak in public, read or write, to access to resources to facilitate events such as photocopying or internet access. These skills and resources are more commonly found among those who are better educated or in employment, i.e. those of higher socio-economic status. However, they can be bolstered by individual’s resources or community and public organisations. For this PhD this suggests the use of capacity building efforts such as provision of training or support to develop skills and resources necessary for participation (19,153).

‘Like to’ relates to the importance and impact of a sense of community as a basis for engagement. It is argued that you are more likely to participate if you feel that you are
part of something. Formal and informal networks create trust, mutuality and reciprocity which enable people to work together and cooperate. For participation this can be enhanced by understanding identities, loyalties and ensuring people believe that they are part of a wider group or community (19,153).

‘Enabled to’ is the premise that most participation takes place through groups or organisations. Individual participation is less sustainable without the continuous reassurance of relevance and value that collective participation provides. For participation intervention the key here is the development of groups that have an impact on the decision making process (19,153).

‘Asked to’ is based on the idea that people participate more often and more regularly when they are invited to do so. For encouraging participation this means providing opportunities for participation. Ideally, the request to participate should come from those with responsibility for the decision making process with consideration of how people are asked and to whom they respond (19,153).

‘Responded to’ is the idea that in order for people to participate sustainably they have to believe that their input is making a difference. They need to believe that they will be listened to, their opinion taken into account and responded to. This has been put forward as the most difficult factor but also the one most open to influence (19,153). For participation interventions this could mean provision of feedback on how decisions are made and the role of the public within that process (19,153).

It is important to note that this framework was developed for citizens and the general public, not patients in a healthcare setting. As the focus is on citizens the leaning of the framework is towards a focus on participation at the national level as opposed to the service level participation, which is the focus of this research. However, this framework has previously been applied in healthcare settings (9,31), the factors of the CLEAR Framework are still applicable to participation at the service level and factors, such as the interpretation of skills and resources, are broadly applied allowing for understanding of the elements within a healthcare setting as opposed to democracy more generally.
The CLEAR Framework is employed in this PhD to identify and understand the necessary components of an intervention to encourage participation. This framework was selected as it aims to help policy makers and practitioners to understand what may block and what might drive citizen participation in their communities, thereby helping them to enhance citizen engagement (19). The role of socio-economic status is highlighted within the CLEAR Framework. This is key to employment of this framework in this PhD. Both services included are located within a deprived suburb of Dublin impacting on the resources available to patients and family members to participate, included with the ‘Can do’ element. It places an emphasis on the citizens’ perspective (19), providing an opportunity for reflection by all those involved on the strengths, barriers and gaps in participation with consideration of strategies for improvement (31). This is in line with the phenomenological underpinning of this research that focuses on the experience of the many with all data and understanding coming from those with experience of the concept being studied. There is an acknowledgment and recognition of the need for interventions to be sensitive to local context (153). The CLEAR Framework has been employed in participation research in Denmark (160) and in England through an assessment of the Somerset Health Panels (9) as well as in an evaluation of family members’ capacity for the development of an intervention to aid responses to crises (31). In Ireland, this framework has been recommended for assessment of patient and citizen participation (161) and utilised to assess recent recommendations for active citizenship (162).

2.4 Rationale for the chosen theoretical frameworks

In choosing the theoretical frameworks for this research available options were assessed in relation to their strengths and limitations and suitability to the aims, methods and philosophical approach of this PhD. Arnstein’s Ladder and the CLEAR Framework were chosen as the theoretical frameworks for the following reasons.

Arnstein’s Ladder has become an enduring part of academic enquiry, policy and practice used to critique, design, implement and evaluate participatory processes since its development (152). Although developed outside of the health sphere it is commonly used in the area of health, providing a clear depiction of the levels of intensity enabling
identification of the amount of ongoing participation and preferences of participation without too much complexity resulting (148,152).

However, Arnstein’s Ladder does not provide any guidance on what needs to be done to encourage participation or the roadblocks to participation. To overcome this limitation of Arnstein’s Ladder the CLEAR Framework was also employed to enable the research questions posed by this PhD to be answered. Concerns have been raised about the ability of Arnstein’s Ladder to identify and analyse roadblocks to participation (18), limiting the options for participation (148). This has led to the suggestion that Arnstein’s Ladder should be supported by an outside structure (157). Following this the theoretical frameworks in this PhD has combined Arnstein’s Ladder with the CLEAR Frameworks. The employment of multiple frameworks is common place, as illustrated in a systematic review of public and patient involvement in intellectual disability research where 16 of the 26 included studies used more than one theory to guide their methodology (163). Employing the theoretical frameworks of Arnstein’ Ladder and the CLEAR Framework supported exploration of all research questions posed in this research. Arnstein’s Ladder enabled identification of the amount and intensity of ongoing and preferred participation, while the CLEAR Framework was used to establish barriers, facilitators and key elements of the interventions for participation. Using either on its own would not have provided guidance for all elements of this work. Therefore, Arnstein’s Ladder was employed to identify the intensity of ongoing participation and preferences for future participation while the CLEAR Framework was used to balance limitations of Arnstein’s Ladder, providing guidance on the essential components for encouraging participation.

The theoretical frameworks employed were chosen on a practical level, taking into consideration the methods employed, samples and populations. For example, this PhD required understanding of participation by large numbers in a short period of time. The chosen theoretical frameworks provide a simplification of a complex phenomenon enabling research to be conducted and advances in knowledge to be made. It has been noted that while Arnstein’s Ladder is simplistic it usefully presents a number of elements to the developmental process of participation (1).
Finally, the focus and issues underpinning the development of Arnstein’s Ladder and the CLEAR Framework are similar to issues and concerns within the services in this PhD. For example, Arnstein’s Ladder includes a focus on tokenism and the CLEAR Framework includes consideration of training and support which has also been acknowledged as important by both services in this PhD.

2.5 Application of the theoretical frameworks to this thesis

The theoretical frameworks of this PhD were applied in each aspect from research design to the discussion of results with Arnstein’s Ladder used to guide understanding of participation and the CLEAR Framework to identify and understand the necessary components to encourage participation.

In the research design the theoretical frameworks were employed in the development of research instruments, sampling and development of the interventions in the following ways:

- Arnstein’s Ladder was used as the basis for questions identifying the amount and intensity of ongoing participation in Study 1, Study 2, Study 4 and Study 5.
- Arnstein’s Ladder was used to establish preferences for the intensity of participation in Study 3.
- Arnstein’s Ladder was employed in the development of the interventions in Study 4 and Study 5, particularly in relation to intensity of participation.
- Arnstein’s Ladder guided measurement of change to participation in Study 5.
- Sampling in each Study was informed by the CLEAR Framework with the adoption of a multi-perspective approach including patients, family members, clinicians and policy leaders in each Study.
- The CLEAR Framework informed demographic questions in Study 1 and Study 3.
- The CLEAR Framework provided prompts for the interview schedules in Study 2.
- The CLEAR Framework assisted in the development of questions for the Study 3 survey on the key components of the interventions to be developed.
- The CLEAR Framework was employed in the development of interview schedules and questionnaires in Study 4 and Study 5.
• The CLEAR Framework also informed the development of interventions in Study 4 and Study 5. For example, considerations relating to training, supports and resources and links with the wider community.

In line with the phenomenological approach to this PhD analysis is primarily inductive, informed by the data collected and the views and opinions expressed by participants. However, to ensure understanding of findings and links with the wider literature the theoretical frameworks also inform analysis in the following ways:

• The CLEAR Framework informs analysis conducted in Study 1 with exploration of the association between preferences and opinions and demographic details highlighted as important by the CLEAR Framework such as education.
• Arnstein’s Ladder has been employed to discuss the findings of each of the five studies of this PhD.
• The CLEAR Framework has been employed to discuss the findings of each of the five studies of this PhD.
• Arnstein’s Ladder has been employed in the integrated discussion of findings to add greater depth and understanding to results as well as put them in context with the body of work available on participation.
• The CLEAR Framework has been employed in the integrated discussion of findings to add greater depth and understanding to results as well as put them in context with the body of work available on participation.

The theoretical frameworks, Arnstein’s Ladder and the CLEAR Framework, were not used more explicitly in the analysis of the implementation process as this is in line with the philosophical approach of the PhD, the method of analysis employed as well as the topic that is being studied. An inductive approach was employed in analysis, with findings emerging from the data with a focus on participants’ opinions and experiences. This inductive approach is in line with the phenomenological philosophical approach adopted in Study 3 and the process evaluation in Studies 4 and 5 of this PhD and the interpretative phenomenological analysis approach employed for qualitative elements. The focus is on the experience of the many with exploration of peoples’ lived experiences and how they make sense of important changes and decisions (25). This is key for the topic of participation that is being explored, as the cultural and social contexts in which
participation takes place are influential. The value of people’s tacit knowledge concerning a phenomenon and why it does or does not work has been acknowledged and suggested as an informal non-codified theory and noted as necessary to use alongside deductive application of theory (164).

2.6 Research questions

1. How much patient and family participation is taking place in healthcare design and delivery within a psychiatry and a diabetes service in Ireland? (Study 1)

2. What are the opinions and beliefs of patients, family members, clinicians and policy leaders in relation to patient and family participation in healthcare design and delivery? What is their understanding of patient and family participation? Are there any barriers to patient and family participation? What are the facilitative factors? (Study 2)

3. What do patients, family members and clinicians think is the most appropriate type and intensity of participation to encourage patient and family involvement? (Study 3)

4. Is the implemented psychiatry pilot intervention feasible and what impact does it have? (Study 4)

5. Is the implemented diabetes pilot intervention feasible and what impact does it have? (Study 5)

2.7 Aim and objectives

2.7.1 Aim

To develop, implement and test an intervention to encourage greater patient and family participation in Irish healthcare design and delivery in an adult outpatient psychiatry service and an outpatient type 2 diabetes service.

2.7.2 Objectives

1. (a) Develop a baseline of the amount and intensity of patient and family member
participation in the psychiatry service and the diabetes service (Study 1).
(b) Identify patient and family member support for greater participation in the psychiatry service and the diabetes service (Study 1).

2. (a) Establish understanding, views and opinions of patient and family participation in the design and delivery of Irish healthcare services in a psychiatry and a diabetes service (Study 2).

3. (a) Identify the most appropriate type and intensity of participation to encourage greater patient and family participation (Study 3).

4. (a) Develop
(b) Implement
(c) And evaluate an intervention to encourage greater patient and family participation in a psychiatry service (Study 4).

5. (a) Develop
(b) Implement
(c) And evaluate an intervention to increase patient and family participation in a diabetes service (Study 5).
Chapter 3: Methodology

3.1 PhD Design

This PhD aims to develop and test an intervention to encourage greater patient and family participation in healthcare design and delivery in a psychiatry and a diabetes service. This includes; identification of the amount and intensity of current participation, exploration of understanding, opinions, barriers and facilitators to participation and examination of preferences for the intensity and implementation of participation. To achieve these aims a mixed methods approach has been adopted with employment of surveys, interviews, focus groups and Delphi Techniques Experiments (DTEs) (Figure 3.1: PhD studies time and flow of study designs).

3.1.1 Mixed methods research

Mixed methods research is research which collects, analyses and mixes both quantitative and qualitative data in a single study or series of studies (26). Qualitative research is a scientific method of observation to gather non-numerical data (28). The qualitative research paradigm is based on an idealist ontological view in which reality depends on one’s mental structure and activity. There is no one single reality, instead multiple realities based on individuals’ interpretation and understanding (23,165–168). Researchers and participants are interdependent with findings mutually created within the context of the situation. As such, things can not be described as they really are but only how we perceive them or interpret them. Stemming from this epistemologically, the qualitative paradigm is subjective. This is where facts can not be separated from values, absolute objectivity is unobtainable and truths or findings interpreted based on researcher’s and participant’s values, interests and purposes (23,168). In line with this qualitative research is concerned with how the social world is perceived, understood and experienced (169). It aims to produce fully rounded understandings on the basis of rich, contextual and detailed data (169) with particular emphasis on the views and experiences of participants (170). As such, the focus is on meanings, definitions, characteristics, metaphors, symbols, and
Figure 3.1: PhD studies and flow of study designs

**Study 1**
Aim: Identify the amount and intensity of participation and support for greater participation
Objective: 1a and 1b
Methods: Questionnaires
Sample: Psychiatry and diabetes patients and family members
Time: May 2015 - May 2016

**Study 2**
Aim: Establish understanding, opinions, utilisation, barriers and facilitators to participation
Objective: 2a
Methods: Interviews and focus groups
Sample: Psychiatry and diabetes patients, family members, clinicians and policy leaders
Time: June 2015 - Feb 2016

**Study 3**
Aim: Identify preferred intensity and components of an intervention to encourage greater participation
Objective: 3a
Methods: Delphi Technique Experiment
Sample: Psychiatry and diabetes patients, family members and clinicians
Time: June - August 2016

**Study 4**
Aim: Develop, implement and assess the feasibility of an intervention to encourage greater patient and family participation in a psychiatry service
Objective: 4a, 4b and 4c
Methods: Interviews and focus groups
Sample: Psychiatry patients, family members and clinicians
Time: Feb-Sept 2017

**Study 5**
Aim: Develop, implement and assess the feasibility of an intervention to encourage greater patient and family participation in a type 2 diabetes service
Objective: 5a, 5b and 5c
Methods: Interviews, focus groups and questionnaires
Sample: Diabetes patients, family members and clinicians
Time: Feb-Oct 2017

Integration of data for discussion and recommendations
Draft thesis
Final thesis
descriptions of phenomena as opposed to their ‘counts or measures’ (171). Qualitative methods include interviews, focus groups and observation. These methods are particularly helpful if your research questions cannot be simply or briefly answered, if you think you will need to ask participants to explain their answers or give examples, if you want to describe or evaluate a process or are exploring deeply personal issues (172). They have the ability to explore in more detail areas not amenable to quantitative methods, to explore why and how relationships work. Advantages include in depth data, data stemming from interaction and the flexible nature of qualitative research (173–175). Limitations include the time consuming nature of qualitative work, bias or researcher effects due to the role of the researcher at all stages, lack of replicability and generalisability of findings beyond the sample of participation or research setting (173,176–178).

Quantitative research aims to count and classify features building statistical models to explain what is observed (29). The quantitative paradigm is positivist. Ontologically it holds that an objective reality exists independent of human perception, an ultimate truth exists and there is only one truth. Researchers and research participants are independent entities and therefore the researcher can study a phenomenon without influencing it or without being influenced. Stemming from this, epistemologically the quantitative paradigm argues that facts can be separated from values so researchers can achieve truth and research findings are valid as long as prescribed procedures are rigorously followed (23). Essentially, something either exists or it does not and its existence is tested by collecting numerical data such as numbers, percentages or averages (166,179). When conducting quantitative research the researcher knows clearly what they are looking for in advance with all aspects of the study designed prior to data collection (180). Data is in the form of numbers or statistics. Quantitative research methods typically include questionnaires or surveys. Advantages include being more efficient as statistical data can be calculated and conducted by a computer saving energy and resources, ability to test hypothesis, researchers remain objective, results can be generalised to wider society and repeated elsewhere once adequate information is reported (175,177). Disadvantages include lack of detail provided due to the numeric nature of data and the detached role of the researcher, lack of flexibility during data collection and generally being more suited to later stages of research projects where there is a clear hypothesis (175,177,180,181).
Mixed methods research involves the intentional collection of both qualitative and quantitative data with the combination of the strengths of each to answer research questions (181). These research methods come from different paradigms with varying ontological and epistemological underpinnings. Some argue that this means that these methods can not be used together due to the implications for sampling, recruitment, methods and analysis (23). However, mixed methods research has become commonplace, particularly within healthcare research (23,182). There is general agreement that qualitative and quantitative research methods can be used together with an additive outcome with the philosophical approach of one paradigm employed (23,182). The philosophical underpinnings of this PhD are discussed in further detail in Section 3.2.

Benefits of mixed methods include: development of a more comprehensive understanding of the topic being researched, greater validity, offsetting of weaknesses, enabling different research questions to be answered, greater explanation of findings (26,183). Mixed methods research is now commonplace in health related research. It has been identified as particularly helpful in addressing new issues within health care (181) and in evaluation of complex health interventions (184). This method has been chosen in this PhD as it enables collection of a more comprehensive picture and evidence of the topic being studied than the use of qualitative or quantitative methods alone (26,183,185). The use of mixed methods has been shown to lead to a more robust understanding of the processes and outcomes of engagement, aiding momentum to effect changes to service delivery (186). It also allows for complementarity at design stages with each study informing the next (187). For example, findings from Study 1 and Study 2 were employed in the development of the round one questionnaire in Study 3.

3.1.2 Application of mixed methods research

A multistage mixed methods framework was employed. This is where researchers use multiple stage of data collection with a combination of sequential and convergent approaches (188,189). In this PhD a mixture of exploratory sequential and convergent approaches are employed. An exploratory sequential design is where one phase of a mixed method study builds on another, typically with qualitative data collection informing subsequent quantitative data collection (188). Convergent design is where qualitative and
quantitative data are used to explain the same phenomenon with comparing and contrasting of qualitative and quantitative data (26). In this PhD Study 1 and Study 2 explored the amount, understanding, barriers and facilitators to participation through questionnaires, interviews and focus groups. This informed the questionnaire which was employed in within the Delphi Technique Experiments in Study 3. Findings from Study 1, Study 2 and Study 3 informed the development, implementation and evaluation of interventions in Study 4 and Study 5 with convergent qualitative and quantitative data.

The unique aspect and one of the most difficult challenges of mixed methods research is the integration of data (181). In this PhD this will be achieved through embedding. This technique includes linking data collection and analysis at multiple points with recurrent linking of qualitative and quantitative data (188). This occurs through a combination of ‘connecting’, ‘building’ or ‘merging’. ‘Connecting’ is where data is linked through samples (188). There were links in the samples between the Study 1 sample and the samples for Study 2 and Study 3. ‘Building’ data from one study informs the data collection approach of another study. Study 1 and Study 2 informed the questionnaire in Study 3. Findings from Study 1, Study 2 and Study 3 informed the development and evaluation of the interventions in Study 4 and Study 5. ‘Merging’ multiple databases together in to one (188). This occurred in Study 4, Study 5 and in the discussion of findings from the PhD as a whole (Figure 3.1: PhD studies time and flow of study designs).

Difficulties have been acknowledged in the reporting of mixed methods research. To counteract this an assessment of the quality of mixed method studies in health services research advised giving more consideration to the description and justification of the design, being transparent about qualitative components and attempting to integrate data and findings from the individual components (190). This advice will be followed; a description and justification of the design has been provided above. Consolidated criteria for reporting qualitative research (COREQ) guidelines (191) will be employed in the reporting of qualitative components and findings from each study will be integrated and discussed in Chapter 11.

Methodological explanations, considerations and discussions for each study are presented below. As appropriate the connections between qualitative and quantitative
studies and how studies build on each other are also highlighted. The strengths and limitations for each study design are presented within the chapter for each study. Key considerations pertinent to all five studies are presented within this chapter including study settings, the underlying philosophical approach, the theoretical frameworks’, participant eligibility criteria and ethical approval.

3.2 Philosophical approach

3.2.1 Phenomenology

The philosophical approach adopted for Study 3 and the process evaluation in Studies 4 and 5 was phenomenology. Phenomenology is both a philosophical movement and a family of qualitative research methodologies (192). It is derived from Husserl and further developed by authors and philosophers such as Heidegger, Sander, Koch and Luckman (193,194). Phenomenology views the world as comprising of two main components. The social world, which consists of everyday familiar actions and experiences, and the life world, the forms and structures within which actions and experiences take place (27).

The aim of phenomenology is to deepen and enlarge understandings of how others see and experience the world. The common experience of the many is the focus of phenomenological enquiry (27). Descriptions are reduced to the essential components or the ‘universal essence’ through an eidetic reduction where outlook is free from everyday assumptions (192,195). Reductions, also referred to as bracketing, are a key component of phenomenology. This is where the researcher sets aside all of their prejudgements and experiences to approach the field with an open mind, imagination and intuition (173). However, there is also an acknowledgement of interpretation as an integral part of the process as the researcher exists in a culturally and historically conditioned environment from which they cannot remove themselves (194). These cultural and historical conditions influence the understanding of the experience resulting in a final description which is a fusion of the researchers’ form of reference and the experiences being interpreted known as a worldview (27,174,192).
3.2.2 Justification of selection

In selecting phenomenology as the philosophical approach for Study 3 and the process evaluation in Studies 4 and 5 of this PhD alternatives of ethnography and grounded theory were explored.

Ethnography stems from cultural anthropology (27). It aims to give a holistic picture of the social group studied, attempting to explain the ways that culture and social systems are constructed and maintained (27,173). It is based on a social constructivist assumption that people create their own realities in the course of interacting with one another and their environment (196). The culture of the group being studied is understood through the researcher experiencing their way of life first hand, immersing themselves in the culture before attempting to derive explanations of their attitudes to behaviour (197). Ethnographic enquiry is also reflexive with an understanding that the researcher is part of the world that is under study and is consequently affected by it (27). An ethnographic approach was suitable for this PhD due to employment in similar publications in this area (65,95,104), recognising the role of the researcher in the world being studied in addition to providing rich in depth detail which is necessary to answer the research questions posed in this study. However, an ethnographic approach was not deemed suitable for this PhD due to the aim and research questions. The focus of this PhD is on the understanding, opinions and experiences of the phenomena under study. While the central question of an ethnographic approach focused on the culture of the group of people under study (174).

Grounded theory is traditionally associated with sociology, nursing, health and organisational research, grounded theory evolved from the writings of Glaser and Strauss (1). Its origins include symbolic interactionism which proposes that individuals engage in the world through reflexive interactions which drive behaviour (1). The primary aim of this philosophical line of enquiry is the generation of a theory which is grounded in the words and actions of the individuals being researched (1, 7). As such, this approach is suited to the study of any behaviour which has an interactional element (1). Research starts with an area of inquiry as opposed to set research questions allowing theoretically relevant questions to emerge during data collection (3). To achieve this the literature is not exhausted prior to data collection. Instead, it is consulted as part of an iterative,
inductive and interactional process of data collection, simultaneous analysis and emergent interpretation. Through this process theory begins to develop, directing the researchers towards relevant concepts, theories and literature (1). It differs from other qualitative approaches particularly through sampling which is generally a ‘common sense’ process of talking to informants who are most likely to provide early information directing the researcher to further theoretically identified samples, locations and forms of data until data saturation is reached (1). A grounded theory is developed through analysis. Constant comparison between transcripts leads to the identification of concepts and one core category. The core category brings all comparisons and categories together to form a theory to explain the phenomena under study (1). The strengths of grounded theory include all possible interpretations being applied before developing the final concept, rigorous, systematic and specific procedures which ensure resulting theory is in line with data collected, researchers can refine, check and develop ideas as data collection is ongoing and it has been used in numerous disciplines for investigations in numerous topics. However, this approach was not suitable for this PhD as it requires the investigator to set aside theoretical ideas or notions so as new theories can emerge (4). It is not the aim of this PhD to develop a theory.

A phenomenological philosophical approach was selected for a number of reasons. The aims of phenomenology are in line with the aims and research questions of this PhD. Phenomenology aims to provide rich detailed description of experiences (195) while grounded theory strives to develop theories and ethnography focuses on culture. Guidance on sampling and participants is again in keeping with the aims and research questions posed in this PhD on the views, opinions and experiences of patients, family members and clinicians. Phenomenology focuses on the experience of the many with data coming from the views and experiences of participants with knowledge of the topic being studied (27). Interpretative phenomenological approaches recognise the role of the researcher in understanding the experiences of participants (198). This is key to the PhD, particularly for later studies due to the pivotal role of the researcher in the development and implementation of the intervention with immersion in the environments and cultures of both study sites. Finally, phenomenology is popular in health and social sciences (195) and has been employed in previous research on participation in healthcare (52,99,199).
There are weaknesses of phenomenology that will need to be addressed. Phenomenology requires at least some understanding of the broader philosophical assumptions of the topic being studied prior to data collection (195). This limitation will be overcome through a literature review conducted in advance of data collection (See Chapter 1 and Appendix B: Literature review search strategy). Results and success depends upon the participants selected and their ability to articulate their experiences. The researcher (LW) is experienced in conducting interviews and focus groups, attended the DCU Qualitative Research Summer School and will be given additional training and feedback by supervisors (CD & JB) during data collection. Interview schedules will be piloted, time will be spent building rapport with participants and explaining the phenomena being studied. The non-prescriptive nature of phenomenology has been criticised for difficulties in replication when compared with positivist approaches (198,200). Where possible guidelines and standards for reporting such guidelines for reporting DTEs (201), qualitative research (191), PPI (202) and interventions (203) will be employed.

3.3 Study settings

The study settings for this research were an adult outpatient psychiatry service and an adult outpatient type 2 diabetes service.

3.3.1 Rationale for study settings

This PhD was conducted within two services for two key reasons. Current literature on participation is limited by heterogeneity in a number of aspects, including the settings in which research has taken place. Learning from the literature this PhD set out to explore patient and family participation in two different services settings to expand the applicability of findings. In addition, the inclusion of two service allows for comparisons in the practice and attitudes to participation between services adding to the depth and breadth of understanding of participation.

The service settings were selected from an epidemiological standpoint. Both services represent illness constructs that are non-communicable diseases identified as challenges for healthcare services. The need for the inclusion of patients, particularly those with long-term illnesses such as diabetes, has been highlighted in the National Strategy for
Service User Involvement in the Irish Health Service 2008-2013 (6). Worldwide prevalence of diabetes is expected to reach over 4% by 2030 (204). Research focusing on encouraging patient and family participation within services with patients with a long-term illness such as diabetes is key. Physical healthcare patients have been included in research aimed at increasing patient participation in rehabilitation services for older people (205) and setting up a consumer panel for maternity services (206).

Conditions for a focus on participation within psychiatry services are ripe (207). The World Health Organisation (WHO) has reported that by 2020 depression will be one of the leading causes of disability (208). In Ireland, mental healthcare policy has been undergoing vast changes over the past thirty years with a focus on greater emphasis on the inclusion of patients (209,210). To date this has primarily been done through nurses involving patients in care planning, interacting with them regularly and using different communication approaches (211). Mental healthcare patients have been included in an evaluation of national counselling services (212), in the publication of a report on the experience of patients of mental health services (110) and in the development of plans on how to include patients and family members in the development of the service (210).

Involving families and carers is an essential part of good patient care. Families and carers play a diverse number of roles including providing emotional, social and financial support, domestic assistance, monitoring health and well-being, providing basic health and personal care, providing professionals with information about the individual, advocating for individuals and proactively seeking out care and treatment options (17). However, the role of family members in psychiatry services differs significantly. This is due to the potential role that family members can play in involuntary admission of patients to psychiatric services under the Mental Health Act 2001 (213). Under this act patients can be admitted to inpatient psychiatric services against their will when there is a possibility that a patient with a ‘mental disorder’ may cause immediate and serious harm to themselves or others. Involuntary admission can be triggered by a relative, medical doctor or member of the Gardai. This is a last resort intervention. Family members were the most prevalent applicant at 44% of all admissions in 2016. However, there is a downward trend for this with a reduction from 69% in 2007 (214). This gives family members considerably more power in the psychiatry service than in the diabetes service,
which may impact on views and opinions surrounding participation in healthcare design and delivery.

3.3.2 Study setting descriptions

Psychiatry service

The psychiatry service is an adult outpatient psychiatry service based in a deprived suburb of Dublin. The service is split across two community based locations. Four consultants lead multidisciplinary teams (MDTs) consisting of psychiatrists, psychologists, nurses, social workers and occupational therapists. Treatments available within the service include: cognitive behavioural therapy (CBT), depression groups, stress counselling, an anxiety/stress management programme, behavioural family therapy, a ‘healthy living’ programme and family member education programmes.

Approximately 2,200 patients attend the service. It is not possible for a breakdown of the full population to be provided by the service due to information technology constraints. Typical diagnoses include mood alterations where a patient’s mood is altered for a prolonged period of time with intense and persistent mood changes which are clearly maladaptive such as depression and schizophrenia, which is a group of disorders characterised by a more or less sharp break with the world in which most people live (215).

Patients can be referred to the psychiatry service by their GP, a hospital or after previous treatment with the service. A supervised initial assessment is conducted by the registrar under the consultant’s supervision. The consultant then reviews the assessment, meets with the patient and decides on the treatment pathway. The treatment pathway depends on the type and severity of the diagnosis. For example, a typical treatment pathway for a diagnosis of depression includes a prescription for antidepressants and possibly a sleeping tablet, with the prescription to be reviewed at a later date depending on the situation. The duration of time between appointments varies from one to six months. Once the patient is stable then some form of psychological treatment is recommended. Family members are generally involved in the development of discharge plans. They may be involved at an earlier stage in treatment if necessary and often play a role in encouraging
patients to attend appointments or certain types of treatment such as CBT. Patients tend to be accompanied more at the start of their time with the service or when they are not doing well.

A sector management meeting takes place once a month in which discussions about how the service runs take place. It is attended by representatives from all clinical disciplines. Typical topics include capital expenditure, office allocation or setting up of a family member support group. There is no patient or family member representation on this group or any way for either group to feed in to these discussions.

Type 2 Diabetes service

Diabetes Mellitus (Diabetes) is a chronic metabolic disorder defined by persistent high blood glucose levels resulting from either inadequate production of insulin or the body not responding properly to insulin (216). Symptoms include increased frequency of urination, excessive thirst, weight loss, increased hunger and blurred vision (216). There are two types of diabetes. Both type 1 and type 2 diabetes are associated with complications and comorbidities. Common comorbidities include cardiovascular disease (217)), stroke (217), retinopathy (218), renal disease and neurological conditions (219).

The focus of this research is on type 2 diabetes. This is where there is a deficiency in the secretion of insulin or where the body has become resistant to insulin (220). In the early stages of type 2 diabetes insulin resistance is present (3). As the illness progresses the production of insulin by the body slowly decreases, resulting in a gradual increase in the concentration of glucose in the blood (221). Due to this progression there is often an asymptomatic period at the start with a diagnosis of type 2 diabetes only being made when complications occur (222). Typically those with type 2 diabetes are over the age of 40, although the age of those presenting with this illness is decreasing due to increases in obesity (223). Risk factors include family history, a history of gestational diabetes, low birth weight, high BMI, physical inactivity, hypertension, smoking and consumption of high levels of alcohol (224). The global prevalence of diabetes in 2014 was 8.5% (225). Similarly the prevalence of type 2 diabetes among adults over the age of 45 was 8.5% (226).
The diabetes service is an outpatient service operating within the grounds of a hospital based in a deprived suburb of Dublin. It caters for both type 1 and type 2 patients. However, this research focuses on only type 2 patients. It is primarily a nurse led service with a MDT including endocrinologists, registrars, nurses, podiatrist and dieticians. Registrars change over each July and generally do not stay for more than one year.

There are a total of 4884 type 2 diabetes patients attending the service. As illustrated in Table 3.1 there are more males than females and more older than younger people attending the service.

**Table 3.1: Gender and age of patients attending type 2 diabetes service**

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>2998</td>
<td>61.3</td>
</tr>
<tr>
<td>Female</td>
<td>1886</td>
<td>38.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>18-39</td>
<td>174</td>
<td>3.5</td>
</tr>
<tr>
<td>40-59</td>
<td>1382</td>
<td>28.3</td>
</tr>
<tr>
<td>60-69</td>
<td>1536</td>
<td>31.5</td>
</tr>
<tr>
<td>70+</td>
<td>1792</td>
<td>36.7</td>
</tr>
</tbody>
</table>

New patients can be referred by their GP, by a practice nurse, by themselves or by the hospital. Most often new patients are inpatients in the hospital having entered for another reason and then finding out they have diabetes. New patients link with the nursing team first for monitoring of bloods and provision of a prescription if necessary. They will be advised to attend an educational session run by the nursing team for patients and their family members. Currently it takes an average of two years to get an initial appointment with the consultant. During this time new patients are reviewed by the nursing team every three to six months depending on the severity of their diabetes with regular contact on the phone. Patients also generally attend their GP during this time.

A typical visit to the type 2 diabetes clinic to see the consultant consists of: registration with reception, checking in with the nursing team for measurements including weight, and blood pressure, consultant visit and depending on how the patient is progressing they may also have an extra visit with the nurse if there is something which needs to be
discussed e.g. a reminder on education if sugars not doing well. This may be requested by either the consultant or the nursing team. A stable patient may just see the consultant every two years. However, more complex patients may see the consultant more regularly, may have contact with the nursing team or other disciplines (e.g. podiatry) in between consultant appointments and some may also have contact with their own GP. A top up educational programme is run a number of times a year as a reminder of the educational programme for those who have been attending the clinic for a number of years. With permission from the patient, family members are encouraged to attend appointments and educational sessions. If permission is granted staff will speak with family members over the phone, but only once the patient is aware that the family member is making contact.

There is no formal mechanism to discuss or change how the diabetes service runs with no process or structures in place for patients and family members to input to how the service works.

3.4 Patient involvement in research

Over the past few years public and patient involvement (PPI) in research has become good practice. What this means is that when any research is being conducted that those whom the research impacts or affects are actively and meaningfully involved in decisions about research topics, design, methodology, instruments, analysis and dissemination from study conception to dissemination (227). PPI is now supported by those in the research process from funders and regulators to conference organisers and publishers (228). This comes from the argument that the people who benefit most from research in healthcare are often patients and the public. Democratically, as those who will be affected by research, patients and the public have a right to have a say in what and how research is undertaken (229–231). PPI in research has been shown to result in more credible, higher quality research (229–233). This stems from more appropriate and relevant research being conducted. Involving patients and the public results in more user friendly research aims and objectives, questions, protocols and outcomes due to the development grounded in the day-to-day reality of patients and the public (229,230,232). PPI enhances recruitment of research participants and retention rates with more
appropriate recruitment strategies, identification of new ways to access participants and
the development of user friendly material such as information sheets and consent forms
(229,230,233,234). Benefits of PPI for research come from better quality data collection
as a result of user-friendly information, and fuller information being collected from
research participants with more user friendly questionnaires and interview schedules
including questions that resonate and are important to participants (229,232). Patients
and the public bring a new perspective resulting to enhanced data collection and analysis
(229,231,232). In addition, PPI enhances implementation and dissemination of findings
(231–233).

In line with this, a patient and family representative was recruited to feed into the
research design and process of the current PhD. The aim of PPI within this PhD was to
ensure that patient and family perspectives were included in planning, implementation,
analysis and dissemination. Methods for employing PPI in research are vast and varied.
Alternative methods such as a patient research advisory group and numerous PPI
representatives on the research team were considered in this project. Due to budget
constraints, the size of the research team (3-4 members depending on the study) and the
preferences of the recruited patient and family representative the method outlined
below was employed.

A patient and family representative was recruited through the volunteer service within
the hospital associated with both services in this PhD. This ensured that the
representative was not a patient or a family member in either service within the PhD but
had experience of being a patient and a family member in the hospital associated with
both services. The researcher (LW) met with the representative at regular intervals
throughout the course of the PhD, typically at the beginning and end of each study. This
follows guidance for PPI to involve patients at an early stage and throughout the research
process (234). The purpose of these meetings was for the representative to provide
feedback from the perspective of patients and family members on the design of the
research and findings. For example, feedback on questionnaires, interview schedules,
coding frames, draft pilot interventions and the research process. In early meetings time
was spent designing the representatives’ role and how PPI would be incorporated within
this PhD (229,232). For example, when and where meetings would take place, who would
attend, intensity of PPI. The representative was keen that meetings would occur in the hospital where they volunteered and as much as possible at the same time when they were volunteering. To accommodate this it was the researcher (LW) who met with the representative and acted as a link between the representative and the rest of the research team. At the start of each meeting the researcher (LW) provided an update on the research and how the feedback from the representative was being used to ensure the representative impacted on the PhD.

The inclusion of PPI in the PhD ensured that the perspective of patients and family members was included in all key research process and design decisions that were made. The PPI representative fed in to all key research process and design decisions made throughout the PhD. For example, the PPI representative fed into research protocols at the start of each Study, qualitative analysis through draft coding frames, intervention protocols and resulting publications. This required additional time and resources throughout the PhD with the provision of support and training for the representative and consideration of points and arguments made by the PPI representative. For example, consideration of how data was collection from patients and family members separately and together as a family. Refining the PPI role with the PPI representative encouraged continued participation throughout the course of the PhD as meetings were held in a location and at times that were suited to the PPI representative. While this meant that the PPI representative did not attend research team meetings steps, were taken to counteract this and worked well for the PPI representative. For example, at the start of each meeting the representative and researcher discussed how the representative’s feedback at the last meeting was used and acted upon. Involvement of the same representative throughout the course of the PhD enabled a strong relationship to be built between the candidate and representative strengthening the input and impact of PPI. However, the inclusion of more representatives would strengthen input further. To avoid confusion throughout the PhD the patient and family representative will be referred to using her initials CC. The short form GRIPP 2 Checklist (202) for the reporting of PPI as a secondary component of research has been employed in the reporting of PPI in this PhD (See Appendix C: GRIPP 2 Checklist).
3.5 Research participant eligibility criteria

The employment of inclusion and exclusion criteria is key to increasing credibility, transparency and coherence, particularly in qualitative research (235). The following inclusion and exclusion criteria will be employed in recruitment of patient, family member and clinician participants across all of this PhD’s studies. Where appropriate, additional criteria will be discussed within individual study Chapters.

3.5.1 Inclusion criteria

Patient, family member and clinician participant inclusion criteria were:

- Outpatients who have completed initial assessment and have had at least one other contact with the psychiatry or diabetes service (i.e. have been engaged with either service for a minimum of 3 months).

- In the psychiatry service patients of all diagnoses were eligible for inclusion while in the diabetes service only Type 2 diabetes patients were eligible.

- Family members are those who attend either service with patients in a caring or supportive capacity. It is assumed that by attending the service with the patient that family members are attending in a caring capacity.

- Family members of outpatients who have completed their initial assessment and have had at least one other contact with the psychiatry or diabetes service will be eligible to participate (i.e. have a family member who has been engaged with either service for a minimum of 3 months).

- Clinicians employed for at least three months in either the psychiatry or diabetes service.

It was considered to narrow the psychiatry sample to only those with a particular diagnosis as the sample is narrowed to Type 2 in the diabetes service, to enable targeting of certain services of clinics and to manage the symptoms displayed as a result of various types of mental illness. However, all patients attending the psychiatry service were eligible for inclusion. This is due to lack of computerised records within the psychiatry service whereby it is not possible to obtain a list of patients with a particular diagnosis or in receipt of a certain prescription. The literature on patient and family participation
research focused on patients engaged in mental healthcare services have included those with all diagnoses and have not focused on particular types of diagnoses (94,103). Similar research on nurses’ perspectives on the involvement of patients in care planning in a mental healthcare perspective acknowledged the inclusion of a wide range of experiences relating to a diversity of mental health problems providing deeper insights into the issues at play (236).

A 3 month period was set for the inclusion criteria of clinicians to ensure the inclusion of registrars. Registrars generally spend a period of 6 months in either service and then move on to another rotation. It was felt that a 3 month period allowed a period of time for the registrars to gain experience of the service while allowing the inclusion of this important group of clinicians at a more junior stage of their training. The 3 month time period also corresponds to the time period set down in the inclusion criteria for patients and family members.

3.5.2 Exclusion criteria

Patient, family member and clinician participant exclusion criteria were:

- Those who are under the age of 18.

- Those who do not fully comprehend the explanation of the study, e.g. those with language difficulties or intellectual disabilities as determined by clinical staff, due to the inability to provide informed consent if the explanation of the study is not understood.

- Those currently experiencing a psychotic episode as determined by their consultant.

Those with literacy problems were not be excluded. The researcher addressed literacy problems ensuring all material for consumption by patients or family members was suitable for a reading age of 11. An oral explanation of the research aims, procedure and consent was also be provided by the researcher where necessary.
3.6 Ethical approval

Ethical approval for this research was granted by the St James’ Hospital/Adelaide and Meath Incorporating the National Children’s Hospital Research Ethics Committee, under approval number 2015-03. Ethical approval letters are attached in Appendix D: Ethical approval letters.

3.7 Individual study methodologies

The following sections include details on the individual Studies in the PhD. The Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32 item checklist (191) was employed for qualitative work (Appendix E: Study 2, 4 and 5 application of the COREQ: a 32 item checklist). The Template for Intervention Description and Replication (TIEDieR) checklist and guide was employed for reporting of the interventions in Study 4 and Study 5 (Appendix F). For reporting of results participants’ identities have been anonymised with pseudonyms assigned. Participants will be identified by their pseudonym and stakeholder group. For example, ‘Shauna, diabetes clinician’.

3.7.1 Study 1

This study aimed to identify the current amount and intensity of patient and family member participation at the patient, service and national levels in a psychiatry and a diabetes service in Ireland. The level of support for greater participation was also established.

Study design

To best answer the research questions in this study while taking into account the size of the population in both services quantitative methods were employed. Researcher-administered questionnaires were completed by 738 participants; 261 patients and 44 family members from an outpatient psychiatry service and 356 patients and 77 family members from an outpatient type 2 diabetes service, both in Dublin, Ireland.
Sampling

A sample of patients and family members attending a psychiatry service and a sample of patients and family members attending a diabetes service were recruited. Power calculations for the patient samples were made based on a 95% confidence level and a 5.7% margin of error for the psychiatry service and a 5% margin of error for the diabetes service. Calculations for family member samples were based on a pilot conducted in both services. Inclusion and exclusion criteria were employed to increase credibility, transparency and coherence (37, 38). This resulted in the exclusion of 50 participants in the psychiatry service and 61 participants in the diabetes service. This process is illustrated in Appendix G: Study 1, 3, and 5 Flow Charts. Section 3.5 provides further detail on inclusion and exclusion criteria.

Convenience sampling was employed in the recruitment of both samples. Numerous options are available when sampling in quantitative research. Options are generally within one of two camps; probability sampling or nonprobability sampling. In probability sampling every participant has an equal chance of being selected from the population through a random selection process (20,237). For example, simple random sampling, systematic random sampling, stratified sampling or cluster randomised sampling. Nonprobability sampling is where randomisation is not important, instead subjective methods are employed to decide who is in the sample. This means that not all members of the population have an equal chance of being included in the sample. Nonprobability sampling options include purposive and convenience sampling. Purposive sampling is the selection of participants based on having or not having specific criteria determined in advance. Convenience sampling is the selection of participants based on accessibility, availability or proximity to the researcher (20).

There are a number of limitations to convenience sampling. As it is a form of nonprobability sampling the process is subjective in nature, potentially resulting in a sample which is not a good representation of the population. However, there are times when convenience sampling is necessary such as when randomisation is not possible and there are large populations (20). This was the case in this research due to access to data issues and lack of electronic records. However, where possible steps were taken to address the limitations of this sampling method. In the diabetes service statistics relating
to the age and gender of the population of patients attending the service were obtained and assessed at regular intervals in the patient sample throughout data collection to ensure that the sample was reflective of the overall patient population. It was not possible to ensure a reflective sample within the psychiatry service due to a lack of electronic records.

Research instruments
Measurement of patient participation in healthcare is a relatively new concept, introduced in western Europe, North America and Australia over the previous 25 years (69). As a result there exists a lack of consensus in the measurement of patient experience in healthcare (70). Measurement of patient participation and experience involves the measurement of ambiguous concepts with multiple cross cutting terms (70). There are no set measures to be used and those that are used are not used in a meaningful or systematic manner (70). Reviewed instruments for measuring patient involvement in shared decision making found existing instruments not to have been specifically developed to measure patient involvement, have not been validated and are not used in a systematic manner (70,238). Furthermore, measures which are available focus primarily on involvement at the individual direct care level. For example, the Patient Activation Measure focuses solely on individual direct care (71).

Questionnaires employed in this study were based on a literature review with standardised questions used where possible. Questions from the Picker Patient Experience Questionnaire (239) and the Irish Society for Quality and Safety in Healthcare Questionnaire (240) were included. Measurement of intensity of participation is based on Arnstein’s ladder of engagement and participation (18). Topics included the amount and intensity of participation, support for participation and service satisfaction (See Appendix H: Study 1 questionnaires). Patients and family members were asked the same questions except for one section on waiting times. To ensure good measurement and that all participants were working from the same definition, the definition of participation used for this study was provided on the questionnaire (See Appendix H: Study 1 questionnaires). A patient and family member representative (CC) provided feedback on the questionnaire and a pilot was conducted with patients and family members in both services. Modifications made to the questionnaire following piloting included changing
the order of questions, adding a specific ‘why’ for questions 3f, 6f, 7f, 13f, 20f and 20g and the addition of questions on waiting times for patients.

Procedures
Data collection was conducted in the waiting areas of each service between May 2015 and May 2016. Posters were placed in waiting areas alerting patients and family members to the research and the researcher (LW) approached possible participants in waiting areas. The questionnaire was researcher-administered by the researcher (LW) and took between five and seven minutes to complete. Informed written consent was obtained and participants were provided with an information sheet.

Analysis
Descriptive statistics and chi square analysis was conducted to identify the characteristics associated with support for greater participation.

The outcome variable was support for greater patient and family member participation. Participants were asked if they wanted patients to be more involved in decisions made at the patient, service and national levels. They were also asked if family members should be more involved in decisions made at the patient, service and national levels. Answer options were; ‘yes, definitely’; ‘yes, to some extent’; and ‘no’ (See Appendix H : Study 1 questionnaires). The answer categories were collapsed into ‘yes’ and ‘no’ to make a binary variable for analysis.

Reported support was examined in relation to independent variables age, gender, education, relationship to the patient/family member, service attended, duration of attendance, service satisfaction and awareness of the patient charter ‘You and Your Health Service’. For ease of analysis the following categories in variables were collapsed together. Age categories ‘30-39’and 40-49’, and ‘50-59’ and ‘60-69’. ‘Degree qualification’ and ‘postgraduate qualification’. ‘Sibling’, ‘not related’ and ‘other’. Level of satisfaction ‘1’ and ‘2’. All other variables were left as they were asked during the analysis.

All analysis was completed using SPPS (version 22; SPSS Inc; Chicago, IL, USA).
3.7.2 Study 2

Study 2 aimed to explore opinions, experiences and utilisation of patient and family involvement in healthcare design and delivery.

Study design
A qualitative design with Interpretative Phenomenological Analysis (IPA) of semi-structured focus groups and interviews with patients, family members, clinicians and policy leaders was employed. IPA is an inductive form of analysis concerned with exploring a person’s lived experiences and how he or she makes sense of important transitions and decisions in life (25). It is discussed in more detail in the Analysis section below. These methods were chosen as they were most suitable to the research questions exploring people’s experiences and requiring in depth detail. Qualitative methods have been employed in healthcare research to explore participants’ views and experiences in healthcare and to identify modifiable factors for improving healthcare (191).

Sampling
A total of 20 patients, 20 family members, 24 clinicians and 15 policy leaders were recruited for Study 2 (see Table 3.2: Study 2 sample by service, stakeholder group and interview type). This is in line with the convention in qualitative research, particularly IPA, whereby smaller sample sizes have the aim of achieving an in-depth understanding of the phenomenon being studied, not generalising findings to an entire population and data collection continuing until saturation is reached (174). Data saturation is a criterion commonly used in qualitative research to decide when to stop data collection based on no new themes arising (21). This is a widely accepted approach viewed as the gold standard for determining sample size, particularly in qualitative health research, and is one of the most frequently provided guarantees for rigour in qualitative work (21,241,242). This was applied in Study 2 through the researcher (LW) and supervisor (CD) reviewing field notes and transcripts during data collection to determine when the point was reached where further data collection would be counterproductive by not adding anything new to the existing data (21).
<table>
<thead>
<tr>
<th>Service</th>
<th>Stakeholder Group (n)</th>
<th>Interview Type</th>
<th>Number Completed</th>
<th>Number of focus group participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Patients</td>
<td>10</td>
<td>Focus group</td>
<td>2</td>
<td>2,7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Face-to-face interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Family members</td>
<td>10</td>
<td>Focus group</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Face-to-face interview</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>9</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Clinicians (12)</td>
<td></td>
<td>Focus group</td>
<td>3</td>
<td>2,2,7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Face-to-face interview</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up interview</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Psychiatry Patients</td>
<td>10</td>
<td>Focus group</td>
<td>0</td>
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<td></td>
<td>Phone interview</td>
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<td></td>
<td></td>
<td>Follow-up interview</td>
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<tr>
<td>Family members</td>
<td>10</td>
<td>Focus group</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Face-to-face interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Clinicians (12)</td>
<td></td>
<td>Focus group</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Face-to-face interview</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up interview</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Neither Policy leaders</td>
<td>15</td>
<td>Focus group</td>
<td>0</td>
<td>-</td>
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<tr>
<td></td>
<td></td>
<td>Face-to-face interview</td>
<td>15</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up interview</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Totals</td>
<td>All groups (64)</td>
<td>Focus group</td>
<td>7</td>
<td>-</td>
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<tr>
<td></td>
<td></td>
<td>Face-to-face interview</td>
<td>19</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Phone interview</td>
<td>26</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Follow-up interview</td>
<td>3</td>
<td>-</td>
</tr>
</tbody>
</table>

* Some participants took part in both a focus group and a follow-up interview
Purposeful sampling was employed in Study 2. Inclusion and exclusion criteria outlined in Section 3.5 were employed to increase credibility, transparency and coherence and to provide the homogenous sample necessary for IPA (235,243).

Purposive sampling is non-random selection of participants on the basis of having particular characteristics or knowledge (174). Information rich cases are those from which a great deal can be learned about issues of central importance to the purpose of the research (174). It is based on the premise that certain categories of individuals may have unique, different or important perspectives on the phenomenon in question and their presence in the sample should be ensured (235). A purposive sampling strategy has been employed in a number of similar studies employing qualitative methods to investigate perspectives on patient and family participation in healthcare design and delivery (7,89), including diabetes services (68) and mental healthcare services (103).

The aim of purposive sampling in this Study was to recruit participants with experience of the services in the Study as opposed to experience of patient and family participation. This is in keeping with the phenomenological approach being utilised in this study which aims to recruit and understand the common experience of the many (27). From this, the experience of typical patients, family members and healthcare providers should be recruited, not just the apparent exceptions who have experience of patient and family participation at the level of healthcare design and delivery within either service.

Due to the role of demographic characteristics on opinions of participation and the size of the populations in both services key demographics including age, gender and level of education were taken into account during sampling. As this is a qualitative study the aim was to ensure general alignment of the sample and the wider population, and not necessarily representative of the wider population.

Socio-economic markers have been frequently employed when recruiting patient or family samples in similar studies (68,97,103,111,244). Level of education is important for this study as in line with the CLEAR Framework (19), levels of literacy have been shown to impact on a person’s ability to be involved in decisions about their health (244). Gender is important to take into account during recruitment of participants (7,51,95,97). It has
been illustrated that female patients are more likely to favour participation than male (154,155). Age is also key as it is evident in the literature that younger participants, particularly below the age of 45 (155), are more likely to be in favour of participation and of a greater intensity with more responsibility in the decision making process (7,112,154). Population data for age and gender of patients attending the diabetes service were determined by information from electronic health records. All other demographic characteristics for patients and family members were based on Study 1. Table 3.3 outlines the demographics for patients and family members attending both services and samples achieved.

Table 3.3: Study 2 patient and family member samples and populations by service

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Service</th>
<th></th>
<th>Psychiatry Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Population</td>
<td>Study 2 Sample</td>
<td>Population</td>
</tr>
<tr>
<td>Gender</td>
<td>4884 A</td>
<td></td>
<td>261</td>
</tr>
<tr>
<td>Male</td>
<td>2998</td>
<td>61.4</td>
<td>109</td>
</tr>
<tr>
<td>Female</td>
<td>1886</td>
<td>38.6</td>
<td>152</td>
</tr>
<tr>
<td>Age</td>
<td>4884 A</td>
<td></td>
<td>261</td>
</tr>
<tr>
<td>≤49</td>
<td>640</td>
<td>12.9</td>
<td>165</td>
</tr>
<tr>
<td>≥50</td>
<td>4244</td>
<td>87.1</td>
<td>96</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ Junior Certificate</td>
<td>200</td>
<td>57.4</td>
<td>117</td>
</tr>
<tr>
<td>≥ Leaving Certificate</td>
<td>148</td>
<td>42.5</td>
<td>133</td>
</tr>
<tr>
<td>Family members</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>76</td>
<td></td>
<td>44</td>
</tr>
<tr>
<td>Male</td>
<td>14</td>
<td>18.5</td>
<td>22</td>
</tr>
<tr>
<td>Female</td>
<td>62</td>
<td>81.5</td>
<td>22</td>
</tr>
<tr>
<td>Age</td>
<td>75</td>
<td></td>
<td>44</td>
</tr>
<tr>
<td>≤49</td>
<td>16</td>
<td>21.3</td>
<td>17</td>
</tr>
<tr>
<td>≥50</td>
<td>59</td>
<td>78.6</td>
<td>27</td>
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<tr>
<td>Education</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>≤ Junior Certificate</td>
<td>44</td>
<td>59.5</td>
<td>26</td>
</tr>
<tr>
<td>≥ Leaving Certificate</td>
<td>30</td>
<td>40.5</td>
<td>17</td>
</tr>
</tbody>
</table>

A = Data from the service. All other data is from Study 1.
B = Junior certificate is the state exam sat at approximately aged 15 and the leaving certificate is the state exam sat at approximately 18 years old

Follow-up Interview Sample

Follow-up interviews were conducted with a selection of participants from the clinician focus groups. Purposive sampling was employed to select follow-up interview participants. Follow-up interviews targeted those who had more to add after taking part
in the focus group or those who were constrained due to the focus group format. A similar strategy was employed in a study assessing healthcare workers’ and managers’ perceptions of engaging patients in healthcare redesign (89).

Research instruments

Semi-structured interview schedules were developed based on a comprehensive review of the literature with feedback from PhD supervisors (CD & JB), practicing clinicians external to both services and the patient and family representative (CC). Interview schedules included open-ended questions with prompts used as required. Piloting was conducted to ensure understandability as well as use of appropriate prompts and for the researcher to become comfortable with the interview schedule. Topics included understanding, opinions, experience, barriers, facilitators and expected impact of participation (See Appendix I: Study 2 Interview schedules).

Procedures

In Study 1 patient and family member participants were asked to provide contact details if they were interested in taking part in future research. This list was used to recruit patient and family participants for Study 2. Posters were placed in waiting areas and patients were asked to invite their family members to take part. Clinicians were invited to take part after the researcher (LW) presented the aims of Study 2 and what participation entailed at the multidisciplinary team (MDT) meeting. Policy leader participants were contacted through email with details of the study and invited to participate.

Data collection included focus groups (n=7), face-to-face interviews (n=18) and phone interviews (n=26) with patients, family members, clinicians and policy leaders as illustrated in Table 3.2. Of the face-to-face interviews three were follow-up interviews. Phone interviews were completed at the request of participants. In the psychiatry service all clinicians took part in one focus group. In the diabetes service following the advice of those working in the service separate focus groups were conducted for different disciplines to ensure participants felt comfortable to have honest and open discussions.
Data collection was conducted between June 2015 and February 2016 at a place of convenience for participants such as the relevant service or office. The PhD candidate (LW), who is experienced in conducting interviews with similar cohorts, conducted data collection. The researcher had met most of the clinicians and all patients and family members in advance of data collection. This was in the context of presenting the aims and procedures or completing questionnaires for Study 1. Previous meetings had taken place with two of the policy leaders, one relating to a separate research project, and for the second providing an overview of the aims of the PhD. All participants were informed that the researcher was a PhD student, the aims of the PhD and funding sources. Interviews and focus groups were audio recorded and transcribed verbatim and lasted on average 25 minutes (20 minute minimum- 55 minute maximum). Informed consent was obtained. Field notes were made at the end of each focus group or interview. Participants were informed that they could access transcripts but no participant requested access. However, the researcher summarised key points as interviews and focus groups progressed.

Analysis

This research is underpinned by a phenomenological approach which focuses on gaining an in-depth understanding of a phenomenon (27). In line with this, the phenomenological methodology of IPA was employed in analysing interviews and focus groups. IPA is an inductive form of analysis concerned with exploring a person’s lived experiences and how he or she makes sense of important transitions and decisions in life (25). The aim of IPA is to explore the sense that participants make of their personal and social worlds while recognising the contribution of the researcher in understanding the participant’s view of their experience (245). This methodology allows for greater creativity and freedom than other approaches and as such is suited to unusual groups, situations or topics which are new to participants (198,246). The idea of patient and family participation, particularly at the service level, is new to both service settings as illustrated in Study 1 (33). It has also been employed in previous research focused on participation (52,99,199).

All transcripts were coded simultaneously by the researcher (LW) and the primary supervisor (CD). The initial coding frame was developed based on the analysis of a
selection of transcripts using an idiographic approach with rigorous line-by-line coding. Feedback on the coding frame from the patient and family perspective was also provided by the patient and family representative (CC). Patterns in the data were clustered into a thematic structure which was reviewed regularly with recoding as necessary as this coding frame was applied to all transcripts (See Appendix J: Study 2 Coding frame). Connections between emergent themes were identified to enable the combination of separate themes into superordinate and subordinate themes as illustrated in Figure 3.2.

To ensure reliability and avoid bias inter-rater reliability was conducted by the secondary supervisor (JB) who was less familiar with the transcripts. Inter-rater reliability relates to data being independently coded by two or more researchers and the codings compared for agreement (24). It can also be referred to as investigator triangulation (247). The aim is to ensure that themes are reliable, can be reproduced and are consistent (247). In Study 2 this provided an inter-rater reliability of 0.77, demonstrating an acceptable level of agreement between the raters (248). This is based on Cohen’s Kappa which measures the extent to which two raters assign the same code to the same piece of qualitative data taking chance into account. It is the most commonly used method of measurement for inter-rater reliability (249). Scores between 0.61-0.80 are deemed to have substantial agreement (248). Differences in interpretation were resolved through discussion.

No software was used during data analysis. Computer assisted qualitative data analysis can be employed to overcome one of the key limitations of the resource and time intensive nature of qualitative research (176,178,250). During analysis computer software can be employed to add efficiencies to this process through an organised and structured approach whereby software can be used not to do ‘the thinking’ but the ‘office process’ (250). Software was not used during data analysis in this PhD, including in this Study.
Instead traditional qualitative techniques of coding, summarising and development of patterns and explanations were employed (250). While computer software for qualitative analysis is well established reporting levels are low (251). In line with typical reasons put forward for low uptake of this software, the current study did not employ any analysis software due to the time required to fully train in a new software, the potential impact due to restrictions on researcher’s ability to tailor design and execute research to specific
projects and the risks outweighing the benefits as traditional methods of analysis allowed the researchers to become completely immersed in the data to the extent required for IPA (251,252).

3.7.3 Study 3

Study 3 aimed to identify preferences for the amount of intensity and type of intervention to encourage participation in healthcare design and delivery in an outpatient psychiatry service and an outpatient type 2 diabetes service. This is achieved through two Delphi Technique Experiments (DTEs): one with patients, family members and clinicians from within the psychiatry service and a second with patients, family members and clinicians from the diabetes service.

Study design

DTEs are a method of achieving consensus through multiple iterations of a questionnaire completed anonymously by a panel of experts (22). In each round, participants complete a questionnaire that is returned to the researcher. The researcher removes questions in which stable group consensus has been achieved. The remaining questions are returned to the participants with controlled feedback. This is where participants are given an overview of the answers from the entire group. Participants have the option to change their answer or leave it the same (22) (See Appendix K: Study 3 questionnaire). This process continues until a stable group consensus is obtained, determined by predefined stopping criteria.

Conventionally, a 15% change or lower between rounds (253) with levels of agreement of 51% and above (201) are acceptable stopping criteria. The stopping criteria employed for this study were a 15% or less change in opinions between rounds and more than 65% of panellists in agreement (201,253). Likert scales with four answer categories were employed. For scoring and analysis answer categories were collapsed with ‘1’ and ‘2’ together and ‘3’ and ‘4’ together to give two answer categories.
Sampling
The selection of participants for DTEs depends on the expertise of the panellists in the services being examined (22). Panellists were experts in the disease and service attended, rather than patient and family participation, which is the topic of the DTE. Previous research in the same services has illustrated that neither service routinely implements patient and family participation in healthcare design and delivery (33). Similar research on patient participation has also included participants who had not yet taken part in participation (254).

This study included 31 participants (13 patients, 9 family members, 9 clinicians) in the psychiatry DTE and 29 participants (12 patients, 6 family members, 11 clinicians) in the diabetes DTE. This sample size reflects previous research which supports a maximum panel size of 30 as larger panels seldom improve results and can result in low response rates (255). The breakdown of the sample by stakeholder groups is also within suggestions in the literature of having 5 to 10 members in a panel from the same grouping (255).

Patients and family members
The sampling frame for the patient and family member samples in both services consisted of participants from Study 1 who consented to be invited to take part in future research. Further detail on this sampling frame is provided in Section 3.7.1. Random samples of patients and family members from each service were selected. To allow for refusals oversampling was conducted. The percentage of oversampling was based on response rates for Study 2. Oversampling has been identified as a useful recruitment approach when working with a list of names, particularly within healthcare research (256). This process is illustrated in Appendix G: Study 1, 3 and 5 Flow Charts.

Clinicians
All members of the full MDT in both services who were in employment for at least three months were invited to take part (See Appendix G).
Research instruments

**Round 1 Questionnaire**

The Round 1 questionnaire was a structured questionnaire informed by a literature review, the theoretical framework of Arnstein’s Ladder of Participation (18), the CLEAR Framework (153) and Study 2 interviews with patients (n=20), family members (n=20) and clinicians (n=24) from both services, and policy leaders (n=15) from relevant services. It is an acceptable and common modification in the DTE process to use a structured questionnaire in Round 1 based upon an extensive literature review or prior qualitative data collection (22,201,257). A patient and family member representative provided feedback on the questionnaire. A pilot was conducted using a ‘Think Aloud’ methodology (258) with a separate sample of patients (n=8) and family members (n=4) from both services, and clinicians (n=3) external to either service.

In Round 1, 65 questions were included in the psychiatry DTE and 64 questions in the diabetes DTE. Topics included opinions on participation, intensity and frequency of participation and implementation (See Appendix K: Study 3 questionnaire). Measurement of intensity of participation is based on Arnstein’s ladder of engagement and participation (18). To ensure all relevant answer options were provided, non-standardised questions included an ‘other’ category.

**Round 2 and Round 3 Questionnaires**

Questions that reached a stable group consensus were removed (201,253,259). All ‘other’ options were removed. Where an ‘other’ option was suggested by two or more participants this was added in as a new answer option in Round 2. For each question the answers of the group as a whole was depicted in a histogram, the participant’s answer was circled in red and participants were given the opportunity to change their answer or leave it the same. If a participant chose to remain outside of the group consensus they were asked to explain why (See Appendix K: Study 3 questionnaire).

**Procedures**

Data collection was conducted by the researcher (LW) between June and August 2016 with a two-week turnaround time between rounds. Unique identifier numbers (UIN) were
employed. Questionnaires took ten to fifteen minutes to complete. Informed written consent was obtained.

Patients and family members
The research and DTE process was explained over the phone with an invitation to participate. When a patient or family member agreed to take part they were sent a Round 1 pack in the post. This included an invitation letter, information sheet, consent form, DTE instructions, Round 1 questionnaire and a stamped addressed return envelope. Instructions included a step-by-step guide on how to complete the questionnaire, how the DTE process works, definitions of key words used in the questionnaire and a ‘frequently asked questions’ section. Follow-up phone calls were made 3 days later to ensure the pack had been received and to provide participants with an opportunity to ask questions. A reminder text message was sent or phone call made to those who had not returned the questionnaire after one week.

Clinicians
A presentation on the research and DTE process was made to the MDT with an invitation to participate. Clinicians who expressed an interest in taking part were provided with the Round 1 pack. A reminder text message was sent to those who had not returned a questionnaire after one week.

The same procedures were followed for Round 2 and Round 3 in both services.

Analysis
Descriptive statistics with percentages and counts are presented. All analysis was completed using SPSS (version 22; SPSS Inc; Chicago, IL, USA).

3.7.4 Study 4
Study 4 aimed to develop, implement and test the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult outpatient psychiatry service. However, it was not possible for this intervention to
be implemented so a process evaluation of the attempted implementation was conducted (See Chapter 8 for further discussion).

Study design
A qualitative methodology was employed with IPA of focus groups and interviews with clinicians and patient and family representatives.

Treatment as usual
Each month in the psychiatry service a sector management meeting occurs. This is chaired by the Assistant Director of Nursing and is attended by approximately 12 members of staff, representing administration and clinical disciplines from the four consultant MDTs in the service. Meetings last on average 40 minutes and allow discussion on how the service is run e.g. minor capital improvements, development of a carers’ group, maintenance work. There is no formal process to involve patients and family members in these discussions, with no patients or family members in attendance. Typically patients and family members are not asked what they think about the service, involved in discussions or given a vote when changes are being made in the service (33) (see Chapter 4).

Proposed psychiatry pilot intervention
The proposed psychiatry pilot intervention was two patient and family representatives attending the sector management meeting in the psychiatry service. Further details on the intervention protocol are provided in Appendix L: Proposed psychiatry pilot intervention protocol.

The MRC Guidelines for development of complex health interventions were employed in the development of the intervention (See Chapter 7 for further detail). In line with the MRC Guidelines existing literature was identified along with a theoretical understanding based on Arnstein’s Ladder of Participation (18) and the CLEAR Framework (19). A prototype intervention was developed based on the literature, theoretical framework and findings from previous studies in this PhD. Supervisors (CD and JB), the patient and family representative (CC) and the contact consultant from the service provided feedback on the
prototype. Members of the MDT provided feedback through a focus group (n= 8) and also through meetings with the research team as the intervention developed. Interviews were conducted with patients (n= 5) and family members (n= 2) (see Appendix M: Study 4 and Study 5 intervention development sample by service, stakeholder group and interview type). A patient and family organisation who became involved through the MDT also provided feedback on the prototype intervention. The prototype was refined based on this feedback. Interview schedules for intervention development are in Appendix N: Study 4 and study 5 Intervention development interview schedule and the intervention development coding frame is in Appendix O: Study 4 and study 5 intervention development coding frame.

Sampling
A total of eight clinicians and one patient and family representative took part in the process evaluation that included four interviews and one focus group (n=5). This is in line with the convention in qualitative research, particularly IPA, whereby smaller sample sizes have the aim of achieving an in-depth understanding of the phenomenon being studied, not generalising findings to an entire population and data collection continuing until saturation is reached (174). Data saturation is discussed further in previous Section 3.7.2. Participants who were involved in the development and key steps in the attempted implementation of the intervention were recruited using purposive sampling.

Research instruments
Interview schedules were developed based on a literature review and assessment of key steps in the development and attempted implementation of the intervention. Open-ended questions were used with prompts as necessary. Topics included opinions on the intervention, development of the intervention, difficulties encountered in intervention implementation and participation beyond the research (See Appendix P: Study 4 process evaluation interview schedules).

Procedures
Data collection was conducted by the researcher (LW) in October 2017. All participants had met the researcher prior to conducting interviews or focus groups. This was in the context of developing or implementing the intervention. All participants were informed that the researcher was a PhD student, the aims of the PhD and funding sources.
The patient and family representative was contacted over the phone to invite them to take part in an interview. Clinicians were asked to take part in an interview or focus group through email or in person after a discussion at the MDT meeting on why the intervention could no longer be implemented.

All interviews and the focus group were conducted in a location suitable to participants, such as the service. They lasted an average of 25 minutes, were recorded and transcribed verbatim by a transcriber who signed a confidentiality agreement. Informed written consent was obtained. Field notes were made at the end of each focus group or interview. Participant access to transcripts was highlighted in the information sheet. No participants requested access to transcripts. However, the researcher summarised key points as interviews and the focus group progressed.

Analysis
IPA was employed in analysing interviews and focus groups. In addition to the reasons outlined to the employment of IPA in Section 3.7.2. IPA was selected in this Study due to the role of the researcher (LW) who was immersed in the environment and culture of the service as well as the development and attempted implementation of the intervention, making bracketing required in descriptive phenomenological methodologies an impractical option for this evaluation. IPA recognises the role of the researcher in understanding the experiences of participants, enabling the researcher to hear and understand participants’ experiences (198). IPA has been employed in a number of health service evaluations (260) including chronic illness services (261) and mental health services (262–264). For example, this phenomenological methodology was employed to analyse interviews with eight service users attending early intervention psychosis services in the UK (262) and again at a later date through focus groups to assess the same services (263). IPA has also been employed in research focused on participation (52,99,199).

All transcripts were coded by the researcher (LW). The initial coding frame was developed based on the analysis of a selection of transcripts using an idiographic approach with rigorous line-by-line coding. Feedback on the coding frame from the patient and family perspective was also provided by the patient and family representative (CC). Patterns in
the data were clustered into a thematic structure which was reviewed regularly with recoding as necessary as this coding frame was applied to all transcripts (See Appendix Q: Study 4 process evaluation coding frame). Connections between emergent themes were identified to enable the combination of separate themes into superordinate and subordinate themes as illustrated in Figure 3.3. No software was used during data analysis (See Section 3.7.2). Inter-rater reliability (See Section 3.7.2) was conducted by one of the supervisors (JB) who was less familiar with the transcripts. This provided an inter-rater reliability of 0.71 demonstrating a respectable level of agreement between the raters (248). Differences in interpretation were resolved through discussion.

Figure 3.3: Study 4 IPA coding frame superordinate and subordinate themes
3.7.5 Study 5

Study 5 aimed to develop, implement and test the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult type 2 diabetes service.

Study design
A mixed method study employing questionnaires, interviews and focus groups. This was guided by the Medical Research Council (MRC) Guidelines for development of complex health interventions (265) and the MRC Guidelines for process evaluation of complex interventions (184) (See Chapter 7 and Chapter 8 for further detail).

Treatment as usual
Up until the implementation of this intervention there was no formal mechanism for involving patients and family members in the design and delivery of the service. The MDT met weekly for an educational meeting, typically based around discussion of a journal article or presentation. However, there was no formal time for discussion of how the service works. Design and delivery of the service was not something that the MDT discussed or engaged in routinely, due to the difficulty in making change happen. If these types of discussions did occur it tended to be informally amongst the team. There was no process to gather feedback or involve patients or family members in the design or delivery of the service (See Chapter 4 and 5).

Intervention
The diabetes pilot intervention was patient and family representative and clinician meetings supported by a patient and family forum. An overview of the intervention and how this links in with the research process is outlined in Figure 3.4. Further details on the intervention protocol are provided in Appendix R: Proposed diabetes pilot intervention protocol.

The MRC Guidelines for development of complex health interventions were employed in the development of the intervention. In line with the MRC Guidelines existing literature was identified along with a theoretical understanding based on Arnstein’s Ladder of
Figure 3.4: Intervention and research components

- Pre questionnaire - clinicians
- Intervention development
- Recruitment
- Pre questionnaire - patients - family
- Forum meeting 1
  - Representative and clinician training
- Process evaluation
- Post questionnaire - patients - family - clinicians
- Forum meeting 2
- Representative and clinician meetings

Legend:
- Intervention components
- Research components
Participation (18) and the CLEAR Framework (153). A prototype intervention was developed based on the literature, theoretical framework and findings from previous studies in this PhD. Supervisors (CD and JB), the patient and family representative (CC) and the contact consultant from the service provided feedback on the prototype. Members of the MDT provided feedback through a focus group (n= 7) and also through meetings with the research team as the intervention developed. Interviews were conducted with patients (n= 5) and family members (n= 4) (see Appendix M: Study 4 and Study 5 intervention development sample by service, stakeholder group and interview type). The prototype was refined based on this feedback. Interview schedules for intervention development are in Appendix N: Study 4 and study 5 intervention development interview schedule and the intervention development coding frame is in Appendix O: Study 4 and study 5 intervention development coding frame.

Sampling
Pre questionnaires were completed by 22 participants (patients n=8, family n=1 and clinicians n=13). Patients and family members that attended forum meeting one and all members of the MDT were eligible to complete the pre questionnaire. Post questionnaires were completed by 18 participants (patients n=7, family n=1 and clinicians n=10). Patients and family members that attended forum meeting two and members of the MDT that had attended at least one meeting with the representatives were eligible to complete the post questionnaire.

A total of 4 patients and 9 clinicians took part in a process evaluation focus group (n=2) or interview (n=6). This is in line with the convention in qualitative research, particularly IPA, whereby smaller sample sizes have the aim of achieving an in-depth understanding of the phenomenon being studied, not generalising findings to an entire population and data collection continuing until saturation is reached (174). Purposeful sampling was employed. Representatives, patients and family members that had attended both forum meetings and members of the MDT that had attended at least one meeting with the representatives were eligible to take part in an interview or focus group. One MDT member who had not attended any of the meetings with the representative completed a process evaluation interview. They were included for a number of reasons. In the clinical environment consultants play a unique and pivotal role. No changes can be made without
the approval of consultants. They are the most senior members of the team and have the biggest role to play in service design. Consultants were involved in the development of the intervention which was one of the areas included in the interview schedule. In addition, the fact that consultants did not attend any meetings was a key point to discuss in the evaluation of the intervention.

A flow chart for participants in each component is outlined in Appendix G: Study 1,3 and 5 flow charts.

Research instruments

Measures

The assessment of the intervention was two-pronged, including an intervention assessment alongside a process evaluation with a focus on feasibility. The intervention assessment examined the amount and intensity of participation, service satisfaction, opinions on participation and empowerment. The process evaluation focused on the impact of the development of the intervention, impact of various elements of the intervention, sustainability, fidelity, dose and reach. Process evaluations need to assess the process (how the delivery is achieved) and what is delivered in terms of fidelity (whether the intervention was delivered as intended), dose (the quality of the intervention implemented), adaptations and reach (whether the intended audience comes into contact with the intervention and how) (184). Process evaluations that explore the way in which the intervention under study is implemented can provide valuable insight into why an intervention fails or has unexpected consequences or why a successful intervention works and how it can be optimised (265). In line with MRC Guidelines (184) measures were selected based on the literature, the intervention and what was important to stakeholders. Measures were assessed using questionnaires, interviews or focus groups as appropriate. How these core components were evaluated is outlined in Appendix Y: Study 5 measures- Justification, method and measurement.
Questionnaires

Questionnaires were developed based on a literature review with standardised questions employed were possible. For example, measurement of the amount and intensity of participation is based on the theoretical framework, particularly Arnstein’s Ladder of Participation (18), the NHS Friends and Family Test was used for measurement of service satisfaction, the Kim Alliance Scale (KAS) Revised Measure was used to assess empowerment (See Appendix Y). Feedback was provided by the PhD supervisors (CD & JB) and the patient and family representative (CC). Piloting was conducted with clinicians external to the service (n= 5) and patients (n= 6) and family members (n=3) that did not attend either forum meeting. Topics included the amount and intensity of participation, opinions on participation, service satisfaction, empowerment and demographics (See Appendix Z: Study 5 evaluation questionnaires).

Interview Schedules

Interview schedules were developed based on a literature review, previous studies in this PhD and MRC guidelines with feedback from PhD supervisors (CD & JB) and the patient and family representative (CC). Open-ended questions were used with prompts as necessary. Topics included opinions on the intervention, development of the intervention, training and support, forum meetings, representative meetings, impact of the intervention and participation beyond the research (See Appendix AA: Study 5 evaluation interview schedules).

Procedures

In line with MRC process evaluation recommendations (184) the team involved in the selection, development and evaluation of the intervention had expertise on relevant interdisciplinary theories as well as research methodologies. Good working relationships with all stakeholders has also been identified as key while maintaining sufficient independence to observe the work of stakeholders critically (184). The research team (LW, JB & CD) were the intervention developers and the implementers were the patients, family members and clinicians. JB and CD have working relationships with the clinical lead in the service. LW has a working relationship with the clinical lead in the service, has
conducted data collection in the service including focus groups and interviews with staff and made a number of presentations to the clinical teams. All interactions have focused on the development of the intervention to date and as such this has resulted in a good working relationship between the research team and implementers but not to the extent that evaluators are unable to remain credible.

Data collection was conducted by the researcher (LW) between March and October 2017. Informed written consent was obtained. All participants had met the researcher prior to conducting interviews or focus groups. This was in the context of developing or implementing the intervention. All participants were informed that the researcher was a PhD student and of the aims of the PhD and funding sources.

Questionnaires were self-completed by participants and took between three and six minutes to complete. Unique identifier numbers (UIN) were employed. Pre questionnaires were conducted by clinicians prior to involvement in development of the intervention. Patients and family members completed the pre questionnaire prior to the first forum meeting starting. All post questionnaires were completed after the second forum meeting took place.

All interviews and focus groups were conducted in a location suitable to participants, such as the service. Participants were approached face-to-face or through email. The interviews and focus groups lasted an average of 23 minutes, were recorded and transcribed verbatim. Focus groups had 2 and 6 participants. Field notes were made at the end of each focus group or interview. Information sheets included participant access to transcripts. No participants requested access to transcripts. However, the researcher summarised key points as interviews and focus groups progressed.

Analysis

Qualitative

The IPA approach was employed for the reasons outlined in Section 3.7.2 and 3.7.4. IPA was particularly relevant to the aims of Study 5. A hierarchy ranking evidence for evaluating healthcare interventions in terms of effectiveness, appropriateness and feasibility ranking interpretive studies as ‘good’ for assessing appropriateness and
feasibility with ‘good’ meaning the level of evidence provided is a sound basis for clinical practice and at a low risk of error, although often generated from single studies. (266).

All transcripts were coded by the researcher (LW). The initial coding frame was developed based on the analysis of a selection of transcripts using an idiographic approach with rigorous line-by-line coding. Feedback on the coding frame from the patient and family perspective was also provided by the patient and family representative (CC). Patterns in the data were clustered into a thematic structure which was reviewed regularly with recoding as necessary as this coding frame was applied to all transcripts (See Appendix BB: Study 5 evaluation coding frame). Inter-rater reliability (See Section 3.7.2) was conducted by the secondary supervisor (JB) who was less familiar with the transcripts. This provided an inter-rater reliability of 0.79 demonstrating a respectable level of agreement between the raters. Differences in interpretation were resolved through discussion. Connections between emergent themes were identified to enable the combination of separate themes into superordinate and subordinate themes as illustrated in Figure 3.5. No software was used during data analysis (See Section 3.7.2).

Quantitative

Descriptive statistics with percentages and counts are presented. All analyses were completed using SPSS (version 22; SPSS Inc; Chicago, IL, USA). Due to small numbers more advanced statistics were not conducted. Questions that employed an answer scale of 1 to 4 were collapsed with 1 and 2 together for agree and 3 and 4 together for disagree.
Figure 3.5: Study 5 IPA coding frame superordinate and subordinate themes
Chapter 4:
How much patient and family member participation is taking place at present? How much support is there for greater participation?

4.1 Introduction

Support for patient involvement in healthcare has been illustrated in a number of studies from a variety of countries and settings. For example, in Australia 74% of citizens attending two medical clinics were supportive of the use of public preferences to inform priority setting at the national level (267). Pooled analysis of 3,491 cancer patients from six clinical studies in Canada and the United States revealed 75% of patients were in favour of an active role at the patient level (268). Participation is of particular importance in mental healthcare where patients have expressed that only those who have experience of mental illness can understand the emotions and consequences (103).

Opinions of and support for participation are influenced by a number of factors. Gender plays an influential role with females being more likely to favour participation as illustrated in research exploring patient perceptions to participation (154,155). Younger people, particularly those under the age of 45, typically support participation with a greater level of intensity preferred as illustrated in research exploring patient and nurse perceptions of participation (7,96,112). Level of education has also been shown to impact on peoples’ understanding and support of participation with those with a greater level of education more likely to support participation highlighted in research with patients and members of the public (244). Health status is key, with healthier people preferring a more active role in their healthcare demonstrated in research with patients (154).

However, there are gaps in the existing body of literature on opinions and support for participation. Available literature on opinions and support for participation has primarily focused on either the patient or national levels (87,269). There is a need for a greater emphasis on the service level. In addition, there is a dearth of Irish based research in this area with no baseline data on the current amount, intensity or support for participation (55). This lack of data has been illustrated by the first report from the National Healthcare Quality Reporting System, which did not include any domain on the patient experience.
(270), and The National Patient Experience Survey (NPES). Launched in May 2017 the NPES aimed to assess the inpatient experience in Irish hospitals. However, again this does not include any measurement of participation in healthcare design and delivery. As a result there is no baseline measure of how much participation is taking place at present in Ireland. This means that there is no way to identify the impact of policies such as 'Healthy Ireland' (55) which includes increased levels of service user involvement in healthcare is one of the key performance indicators. Furthermore, this limits our understanding of participation in Ireland. A longitudinal multicentre study across Europe illustrated that patients’ desire for participation varies by location (271). The social, cultural and political contexts have all been acknowledged to play a key role in opinions, uptake and implementation of participation (271) (See Section 1.9 for more detail).

This study aims to identify the current amount and intensity of patient and family member participation at the patient, service and national levels in a psychiatry and a diabetes service in Ireland. The level of support for greater participation will also be established.

4.2 Methodological Highlights

- A quantitative design was employed with researcher-administered questionnaires completed by 738 participants; 261 patients and 44 family members from an outpatient psychiatry service and 356 patients and 77 family members from an outpatient type 2 diabetes service both in Dublin, Ireland.

- Power calculations for the patient samples were made based on a 95% confidence level and a 5.7% margin of error for the psychiatry service a 5% margin of error for the diabetes service. Calculations for family member samples were based on a pilot conducted in both services.

- A convenience sample was selected in both services. In the diabetes service statistics relating to the age and gender of the population of patients attending the service were obtained and assessed at regular intervals in the patient sample throughout data collection to ensure that the sample was reflective of the overall patient population. It was not possible to ensure a reflective sample within the psychiatry service due to a lack of electronic records.
- Questionnaires employed in this study were based on a literature review with standardised questions used where possible. Topics included the amount and intensity of participation, support for participation and service satisfaction (See Appendix H: Study 1 questionnaires).
- Data collection was conducted in the waiting areas of each service between May 2015 and May 2016 by the researcher (LW).
- Descriptive statistics, chi square analysis and two logistic regression models were conducted to identify the characteristics associated with support for greater participation.
- All analysis was completed using SPSS (version 22; SPSS Inc; Chicago, IL, USA). Further details on all aspects of the methodology employed are in Chapter 3.

4.3 Results

4.3.1 Refusal Rate

In the psychiatry service 294 patients and 49 family members were invited to participate. A total of 261 patients and 44 family members took part with a refusal rate of 11.2% (n=33) for patients and 10.2% (n=5) for family members (See Appendix G: Study 1, 2, 3 and 5 flow charts). Reasons provided for refusal included a lack of interest in research, not wanting to sign their name or being too stressed.

In the diabetes service 374 patients and 80 family members were invited to participate. A total of 356 patients and 77 family members took part with a refusal rate of 4.8% (n=18) for patients and 3.7% (n=3) for family members (See Appendix G: Study 1, 2, 3 and 5 flow charts). Reasons for refusal included a lack of interest in research, too stressed or not wanting to sign anything.

4.3.2 Demographics

Psychiatry patients were generally younger females with a higher level of education. Diabetic patients were typically attending the service for a longer period of time. Diabetes patients were typically older males with a lower level of education. A total of 34.5% (n=123) diabetes patients reported a level of education of primary level or below.
Attendance for ten or more years was reported by 37.6% (n=134) of diabetes patients while 24.5% (n=64) of psychiatry patients reported attending for less than one year. Family members were most often spouses or partners of patients (See Table 4.1).

4.3.3 Reported Amount and Intensity of Participation
Table 4.2 presents the reported amount and intensity of participation by level (patient, national and service) in line with Arnstein’s Ladder (See Chapter 2 for further detail) broken down by service. Intensity of participation is placed on a five rung ladder. Low intensity participation at the bottom on rung 1 with the provision of information. High intensity participation is at the top on rung 5 with sole control of the decision making process.

Patient level
At the patient level in the psychiatry service patient participation was most frequently reported to be on rung 3 (n=168; 64.4%). In the diabetes service patient participation was most frequently reported to be on rung 2 (n=226; 63.5%). In both services when family participation was reported it was at rung 1.

Service level
At the service level in both services patient and family participation was most frequently reported at rung 1 limited to the provision of information. Beyond this the vast majority reported not being asked what they think about the service or being involved in discussions or the decision-making process for changes.

National level
A similar pattern was reported at the national level. In both services patient and family participation was most frequently reported at rung 1.
### Table 4.1: Sample demographic description by service and stakeholder group (33)

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Diabetes</th>
<th>Patients</th>
<th>Psychiatry</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=356</td>
<td>(100.0%)</td>
<td>N=77</td>
<td>(100.0%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>219 (61.5)</td>
<td>14 (18.2)</td>
<td>109 (41.8)</td>
<td>22 (50.0)</td>
</tr>
<tr>
<td>Female</td>
<td>136 (38.2)</td>
<td>62 (80.5)</td>
<td>152 (58.2)</td>
<td>22 (50.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (0.3)</td>
<td>1 (1.3)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>^</td>
<td>^</td>
<td>41 (15.7)</td>
<td>^</td>
</tr>
<tr>
<td>30-49</td>
<td>46 (12.9)</td>
<td>14 (18.2)</td>
<td>124 (47.5)</td>
<td>14 (31.8)</td>
</tr>
<tr>
<td>50-69</td>
<td>197 (55.3)</td>
<td>42 (54.5)</td>
<td>93 (35.7)</td>
<td>24 (54.6)</td>
</tr>
<tr>
<td>70+</td>
<td>111 (31.2)</td>
<td>17 (22.1)</td>
<td>^</td>
<td>^</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (0.3)</td>
<td>2 (2.6)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Level of Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary or less</td>
<td>123 (34.5)</td>
<td>27 (35.0)</td>
<td>51 (19.5)</td>
<td>17 (38.6)</td>
</tr>
<tr>
<td>Junior cert A</td>
<td>77 (21.6)</td>
<td>17 (22.1)</td>
<td>66 (25.3)</td>
<td>9 (20.5)</td>
</tr>
<tr>
<td>Leaving cert A</td>
<td>78 (21.9)</td>
<td>18 (23.4)</td>
<td>61 (23.4)</td>
<td>9 (20.5)</td>
</tr>
<tr>
<td>Non degree qualification</td>
<td>22 (6.2)</td>
<td>6 (7.8)</td>
<td>29 (11.1)</td>
<td>^</td>
</tr>
<tr>
<td>Degree qualification or above</td>
<td>48 (13.5)</td>
<td>6 (7.8)</td>
<td>43 (16.5)</td>
<td>7 (15.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>8 (2.3)</td>
<td>3 (3.9)</td>
<td>11 (4.2)</td>
<td>1 (2.3)</td>
</tr>
<tr>
<td>Duration of attendance at service</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>11 (3.1)</td>
<td>12 (15.6)</td>
<td>64 (24.5)</td>
<td>15 (34.1)</td>
</tr>
<tr>
<td>2-5 years</td>
<td>114 (32.0)</td>
<td>21 (27.3)</td>
<td>84 (32.2)</td>
<td>9 (20.5)</td>
</tr>
<tr>
<td>6-9 years</td>
<td>95 (26.7)</td>
<td>19 (24.6)</td>
<td>32 (12.3)</td>
<td>7 (15.9)</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>134 (37.6)</td>
<td>23 (29.9)</td>
<td>78 (29.9)</td>
<td>13 (29.5)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (0.6)</td>
<td>2 (2.6)</td>
<td>3 (1.1)</td>
<td>-</td>
</tr>
<tr>
<td>Relationship to patient/to family member B</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>39 (61.9)</td>
<td>33 (50.0)</td>
<td>36 (55.4)</td>
<td>23 (52.3)</td>
</tr>
<tr>
<td>Child</td>
<td>11 (17.5)</td>
<td>16 (24.3)</td>
<td>7 (10.8)</td>
<td>6 (13.6)</td>
</tr>
<tr>
<td>Parent</td>
<td>8 (12.7)</td>
<td>9 (13.6)</td>
<td>17 (26.1)</td>
<td>13 (29.5)</td>
</tr>
<tr>
<td>Other (e.g. sibling, not related)</td>
<td>5 (7.9)</td>
<td>8 (12.1)</td>
<td>5 (7.7)</td>
<td>^</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

- = Not applicable  
^ = Less than 5 participants  
A= State examinations Junior certificate at approximately aged 15 and leaving certificate at approximately aged 18.  
B= Only those who normally attended with a family member were asked this question.
Table 4.2: Reported amount and intensity of patient and family participation by service and stakeholder group (33)

<table>
<thead>
<tr>
<th>Service level</th>
<th>Diabetes</th>
<th>Psychiatry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sole decision making responsibility</td>
<td>30 (8.4)</td>
<td>25 (9.6)</td>
</tr>
<tr>
<td>4. Involved in decision making</td>
<td>58 (16.3)</td>
<td>93 (35.6)</td>
</tr>
<tr>
<td>3. Involved in discussions</td>
<td>158 (44.4)</td>
<td>168 (64.4)</td>
</tr>
<tr>
<td>2. Asked for opinion</td>
<td>226 (63.5)</td>
<td>193 (73.9)</td>
</tr>
<tr>
<td>1. Provided with information</td>
<td>313 (87.9)</td>
<td>195 (74.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Family Members</td>
<td>N=77 (100.0%)</td>
<td>N=44 (100.0%)</td>
</tr>
<tr>
<td>National level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sole decision making responsibility</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Involved in decision making</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3. Involved in discussions</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2. Asked for opinion</td>
<td>12 (3.4)</td>
<td>32 (12.3)</td>
</tr>
<tr>
<td>1. Provided with information</td>
<td>201 (56.5)</td>
<td>157 (60.2)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>2 (0.8)</td>
</tr>
</tbody>
</table>

A = Only family members who attended consultations with the patient were asked to report on patient level participation

4.3.4 Support for Greater Participation

Support for greater patient participation is illustrated in Table 4.3.

Patient level

Between 57.7% (n=25) and 39.3% (n=139) of participants are supportive of greater patient participation at the patient level. Between 38.6% (n=17) and 7.6% (n=27) are supportive of greater family participation at the patient level. Support for greater participation is lowest at the patient level.
Table 4.3: Reported support for greater patient and family participation by service and stakeholder group

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Patients N=356 (100.0%)</th>
<th>Diabetes Family Members N=77 (100.0%)</th>
<th>Psychiatry Patients N=261 (100.0%)</th>
<th>Psychiatry Family Members N=44 (100.0%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive greater patient participation</td>
<td>139 (39.3)</td>
<td>29 (38.2)</td>
<td>132 (50.4)</td>
<td>25 (57.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>17</td>
<td>22</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>Supportive greater family participation</td>
<td>27 (7.6)</td>
<td>16 (20.5)</td>
<td>28 (10.9)</td>
<td>17 (38.6)</td>
</tr>
<tr>
<td>Missing</td>
<td>40</td>
<td>9</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td><strong>Service Level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive greater patient participation</td>
<td>281 (78.9)</td>
<td>63 (82.2)</td>
<td>209 (80.1)</td>
<td>42 (96.1)</td>
</tr>
<tr>
<td>Missing</td>
<td>20</td>
<td>21</td>
<td>10</td>
<td>18</td>
</tr>
<tr>
<td>Supportive greater family participation</td>
<td>154 (43.2)</td>
<td>42 (54.1)</td>
<td>173 (66.4)</td>
<td>35 (79.6)</td>
</tr>
<tr>
<td>Missing</td>
<td>46</td>
<td>5</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td><strong>National Level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive greater patient participation</td>
<td>306 (86.0)</td>
<td>65 (84.8)</td>
<td>228 (87.4)</td>
<td>36 (81.8)</td>
</tr>
<tr>
<td>Missing</td>
<td>35</td>
<td>18</td>
<td>23</td>
<td>11</td>
</tr>
<tr>
<td>Supportive greater family participation</td>
<td>280 (78.8)</td>
<td>62 (80.9)</td>
<td>218 (83.7)</td>
<td>37 (83.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>41</td>
<td>9</td>
<td>22</td>
<td>1</td>
</tr>
</tbody>
</table>

Service level

The majority of patients and family members in both services were supportive of greater patient participation at the service level (78.9%; n=281 - 96.1%; n=42). With the exception of diabetes patients the majority were also supportive of greater family involvement at the service level (43.2%; n=154 - 79.6%; n=35).

National level

The majority of patients and family members in both services were supportive of greater patient participation at the national level (81.8%; n=36 - 87.4%; n=228). With the exception of diabetes patients the majority were also supportive of greater family involvement at the national level (78.8%; n=280 - 83.7%; n=37) (33).
4.3.5 Characteristics Associated With Support for Participation at the Service Level

Patient Participation
The final logistic regression model as determined by the AIC is presented in Table 4.4 with crude and adjusted ORs for participants who support greater patient participation at the service level compared with those who do not support greater patient participation at the service level. The model was statistically significant and fit the data well \[ x^2 (11) = 41.067, p<0.001; \text{Hosmer and Lemeshow, } p >0.05 \]. This was the most parsimonious model with the lowest AIC.

Statistically significant factors associated with support for greater patient participation at the service include age, education, duration of attendance and service satisfaction. Adjusting for the effects of other factors, the odds of participants aged 18-29 agreeing with greater patient participation were greater than those aged 70 or over (OR 2.36, 95% CI (1.35, 4.15)). The odds for those with education of a Leaving Certificate or above supporting greater patient participation were greater than who had a level of education of Junior Certificate or below (OR 1.58, 95% CI (1.00, 2.49)). The odds for those who were attending either service for 2-5 years were greater than the odds of those who were attending either service for one year or less (OR 2.02, 95% CI (1.01, 4.07)). The odds of participants who indicated a low level of service satisfaction were greater than the odds of those who indicated a high level of service satisfaction (OR 1.90, 95% CI (1.14, 3.15)).

Family participation
The final logistic regression model as determined by the AIC is presented in Table 4.5 with crude and adjusted ORs for participants who support greater family participation at the service level compared with those who do not support greater family participation at the service level. The model was statistically significant and fit the data well \[ x^2 (12) = 64.319, p<0.001; \text{Hosmer and Lemeshow, } p >0.05 \]. This was the most parsimonious model with the lowest AIC.
### Table 4.4: Factors Associated With Supporting Greater Patient Participation at the Service Level (n=616; 83.5%)

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Crude OR</th>
<th>95% CI</th>
<th>Adjusted OR A</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>2.79</td>
<td>(1.73, 4.50)*</td>
<td>2.36</td>
<td>(1.35, 4.15)*</td>
</tr>
<tr>
<td>30-49</td>
<td>0.68</td>
<td>(0.25, 1.82)</td>
<td>0.51</td>
<td>(0.16, 1.58)</td>
</tr>
<tr>
<td>50-69</td>
<td>0.96</td>
<td>(0.59, 1.56)</td>
<td>0.80</td>
<td>(0.45, 1.44)</td>
</tr>
<tr>
<td>70+</td>
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<td></td>
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<tr>
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<tr>
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<td>Base</td>
<td></td>
<td>Base</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.59</td>
<td>(1.08, 2.34)*</td>
<td>1.48</td>
<td>(0.96, 2.29)</td>
</tr>
<tr>
<td><strong>Education</strong> B</td>
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</tr>
<tr>
<td>≤ Junior certificate</td>
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<td></td>
<td>Base</td>
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</tr>
<tr>
<td>≥ Leaving certificate</td>
<td>1.86</td>
<td>(1.24, 2.79)*</td>
<td>1.58</td>
<td>(1.00, 2.49)*</td>
</tr>
<tr>
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<td></td>
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<td></td>
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<tr>
<td>Patient</td>
<td>Base</td>
<td></td>
<td>Base</td>
<td></td>
</tr>
<tr>
<td>Family member</td>
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<td>1.92</td>
<td>(0.89, 4.10)</td>
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<tr>
<td><strong>Service</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>Base</td>
<td></td>
<td>Base</td>
<td></td>
</tr>
<tr>
<td>Psychiatry</td>
<td>1.15</td>
<td>(0.78, 1.70)</td>
<td>0.68</td>
<td>(0.39, 1.18)</td>
</tr>
<tr>
<td><strong>Duration of attendance</strong></td>
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</tr>
<tr>
<td>≤ 1 year</td>
<td>Base</td>
<td></td>
<td>Base</td>
<td></td>
</tr>
<tr>
<td>2-5 years</td>
<td>1.61</td>
<td>(0.90, 2.88)</td>
<td>2.02</td>
<td>(1.01, 4.07)*</td>
</tr>
<tr>
<td>6-9 years</td>
<td>1.06</td>
<td>(0.66, 1.71)</td>
<td>1.08</td>
<td>(0.64, 1.82)</td>
</tr>
<tr>
<td>≥ 10 years</td>
<td>1.03</td>
<td>(0.59, 1.78)</td>
<td>0.78</td>
<td>(0.42, 1.44)</td>
</tr>
<tr>
<td><strong>Service satisfaction</strong></td>
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</tr>
<tr>
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<td>Base</td>
<td></td>
<td>Base</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>2.20</td>
<td>(1.36, 3.56)*</td>
<td>1.90</td>
<td>(1.14, 3.15)*</td>
</tr>
</tbody>
</table>

A = Logistic regression- adjusting for other factors included in the model
B = State examinations Junior certificate at approximately aged 15 and leaving certificate at approximately aged 18.
*= Statistically significant
Table 4.5: Factors Associated With Supporting Greater Family Participation at the Service Level (n=632; 85.6%)

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Crude OR</th>
<th>95% CI</th>
<th>Adjusted OR</th>
<th>95% CI</th>
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<tr>
<td><strong>Age</strong></td>
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</tr>
<tr>
<td>18-29</td>
<td>1.59</td>
<td>(1.03, 2.45)*</td>
<td>1.12</td>
<td>(0.69, 1.82)</td>
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<td>30-49</td>
<td>0.22</td>
<td>(0.10, 0.50)*</td>
<td>0.38</td>
<td>(0.15, 0.93)*</td>
</tr>
<tr>
<td>50-69</td>
<td>0.54</td>
<td>(0.37, 0.78)*</td>
<td>0.67</td>
<td>(0.43, 1.05)</td>
</tr>
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<td>Base</td>
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<td>Base</td>
<td>Base</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
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<tr>
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<td>Base</td>
<td>Base</td>
<td>Base</td>
</tr>
<tr>
<td>Female</td>
<td>1.24</td>
<td>(0.92, 1.69)</td>
<td>1.11</td>
<td>(0.79, 1.57)</td>
</tr>
<tr>
<td><strong>Education</strong> ^b</td>
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<td></td>
</tr>
<tr>
<td>≤ Junior certificate</td>
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<td>Base</td>
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<td>Base</td>
</tr>
<tr>
<td>≥ Leaving certificate</td>
<td>1.72</td>
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<td>1.38</td>
<td>(0.96, 1.97)</td>
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<td><strong>Family member normally attends</strong></td>
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<td></td>
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<td>Yes</td>
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</tr>
<tr>
<td>No</td>
<td>0.55</td>
<td>(0.39, 0.77)*</td>
<td>0.59</td>
<td>(0.37, 0.95)*</td>
</tr>
<tr>
<td><strong>Stakeholder</strong></td>
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<td></td>
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<tr>
<td>Patient</td>
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<td>Base</td>
<td>Base</td>
<td>Base</td>
</tr>
<tr>
<td>Family member</td>
<td>1.52</td>
<td>(1.01, 2.30)*</td>
<td>1.41</td>
<td>(0.76, 2.62)</td>
</tr>
<tr>
<td><strong>Service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>Base</td>
<td>Base</td>
<td>Base</td>
<td>Base</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>2.61</td>
<td>(1.90, 3.58)*</td>
<td>1.79</td>
<td>(1.18, 2.72)*</td>
</tr>
<tr>
<td><strong>Duration of attendance</strong></td>
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<tr>
<td>≤ 1 year</td>
<td>Base</td>
<td>Base</td>
<td>Base</td>
<td>Base</td>
</tr>
<tr>
<td>2-5 years</td>
<td>0.54</td>
<td>(0.33, 0.89)*</td>
<td>1.03</td>
<td>(0.58, 1.83)</td>
</tr>
<tr>
<td>6-9 years</td>
<td>0.61</td>
<td>(0.42, 0.90)*</td>
<td>0.61</td>
<td>(0.40, 0.93)*</td>
</tr>
<tr>
<td>≥ 10 years</td>
<td>0.95</td>
<td>(0.62, 1.46)</td>
<td>0.80</td>
<td>(0.50, 1.28)</td>
</tr>
<tr>
<td><strong>Service satisfaction</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>Base</td>
<td>Base</td>
<td>Base</td>
<td>Base</td>
</tr>
<tr>
<td>Low</td>
<td>1.41</td>
<td>(1.01, 1.98)*</td>
<td>1.15</td>
<td>(0.79, 1.65)</td>
</tr>
</tbody>
</table>

^a = Logistic regression- adjusting for other factors included in the model
^b = State examinations Junior Certificate at approximately aged 15 and Leaving Certificate at approximately aged 18.
*= Statistically significant

Statistically significant factors associated with support for greater family participation at the service include age, whether a family member normally attends with the patient, the
service attended and duration of attendance. Adjusting for the effects of other factors, the odds of participants aged 30-49 agreeing with greater family participation were lower than those aged 70 or over (OR 0.38, 95% CI (0.15, 0.93)). The odds for those who do not normally attend with a family member supporting greater family participation at the service level were lower than those who normally attend with a family member (OR 0.59, 95% CI (0.37, 0.95)). The odds for those who attend the psychiatry service support family participation were greater than those attending the diabetes service (OR 1.79, 95% CI (1.18, 2.72)). The odds of participants who have been attending either service for 6-9 years are lower than those who have been attending the service for one year or less (OR 0.61, 95% CI (0.40, 0.93)).

4.4 Discussion

4.4.1 Result summary and connection with literature

Patient participation is advocated for by patients, clinicians and the public (7,95,104). Reported percentage preferences for participation vary from between 50% to 93% across the patient, service and national levels (111,267,268,272). Support for patient participation reported in this study show that what is demonstrated internationally is reflective of the Irish context with the majority of participants in favour of greater patient participation at the service level (n=537; 80.3%) and the national level (561; 86.2%).

Support for family involvement at the service (n=374; 55.3%) and the national (n=539; 81.1%) levels is also evident. Support for family participation at the service level is greater in the psychiatry service. Support for family participation at the national level is nearly equal for both services. This finding addresses a deficit within the current literature, which does not appear to focus on the input or role of family members. The key focus of the literature to date has been the role of patients and the public in healthcare (7,155,267,268) despite the key role of family members in supporting and caring for patients with long-term illnesses.

Patients and family members appeared to be closely aligned in their support for greater participation at the national level. Distinct differences emerge in relation to greater participation at the patient and service levels. More family members than patients
supported greater patient participation at the patient and service level in the psychiatry service. More family members than patients supported greater family participation at the patient and service levels in both the diabetes and psychiatry service. This may be linked with the role that family members play as caregivers when attending and engaging in service with patients and caring for them which already encompasses an advocacy role more link with participation that the role which patients currently have. In the psychiatry service this difference in support between patient and family members may be related to the impact of involuntary committals.

Despite the high levels of support for participation an obstacle facing implementation is the gap between rhetoric and operationalisation (52). A recent report assessing participation in England concluded that the idea of putting patients first is aspirational, with the current programme of action lagging behind the rhetoric of participation (17). This is also evident in Ireland. The importance of participation has been acknowledged in policy documents (54,55,209,273) and the national policy for health and well-being (55). Operationalisation of participation has included the development of a national comments, compliments and complaints policy (10), the publication of a National Service User Strategy (6) and a National Healthcare Charter (63). However, these actions have had limited impact with developments overall being ad-hoc and isolated. This disparity between rhetoric and action is further illustrated in this study. High levels of support for participation are illustrated alongside little to no reported participation beyond informing at the service and national levels (33).

This lack of action may be due to attitudinal, cultural, behavioural and organisational barriers to participation. Participation may require a change in the mind set of healthcare providers (7,102,103) with professional communities being required to do things differently and relinquish responsibility. It requires patients and citizens to behave and think about their health and care (17,87,95). This is underpinned by a paucity of consensus. Confusion remains in relation to what exactly participation is (17,47,52), the best way to implement participation (7,10,16,17,52,269), and the impact of participation (17). Barriers identified in the literature are cultural and societal and as such need to be explored further within these services (33).
A large focus of this research is on participation at the service level. At this level when participation was reported it most often reported to consist solely of the provision of information. Regardless of this the vast majority are supportive of greater patient participation (78.9%; n=281 – 96.1; n=42). There is also support for greater family participation, although to a lesser extent (43.2%; n=154 - 79.6%; n=35). The difference in support for greater family participation is possibly related to the different policy contexts between the services, the perceived capacity of patients and role of family members in care. This research expands the current literature beyond its focus on patient and national level participation to include opinions on participation at the service level (7,155,240).

Characteristics typically associated with support for participation include age, gender and education (154,155,244). This is supported in the current study with younger participants and those with a higher level of education generally being more supportive of participation. Previous studies have reported a change in people’s opinions relating to participation as they get older (155). Similar findings are presented here with younger participants being more likely to favour greater patient participation and greater family participation at the service level. Gender does not appear to play a significant role in participants’ support for greater participation at the service level. Factors such as the type of service being attended, service satisfaction or duration of attendance are significant factors in this study (33). These factors do not appear to have been previously explored. Those attending either service for a shorter period of time were more likely to support greater family member participation at the service level. This may be associated with the trajectory of attendance at the service. Those attending for a shorter period of time are more likely to be accompanied by a family member. During this time there is a lot of information to take on board and family members play a key role. Those attending the psychiatry service were more likely to support family participation at the service level. This may be linked with the policy context in both services, the perceived capacity of patients and the role of family members in care. Those with a lower level of service satisfaction were more likely to support patient participation at the service level.
4.4.2 Methodological critique

Strengths of this research include the sample size with data collected on a total 738 participants. All data was collected by the researcher (LW) with high response rates achieved. This was produced over a 12 month period to allow for data to be collected from a sufficient sample size and for the realities of the clinical environment. For example, in the diabetes service there were only two type 2 diabetes clinics each month run only in the afternoon. Response rates were recorded daily during data collection with the response rate remaining stable throughout data collection. At present in Ireland there is no baseline data for measuring participation (55). This study provides a possible measure, which can be employed to establish a baseline against which progress can be assessed. In addition, the inclusion and focus on family member participation begins to address the current dearth of research in this area (208). Another strength is the inclusion of a patient and family member representative within the research team. Patient involvement in the research process can lead to more meaningful findings (274) with the voice of patients being heard (229) while helping to shape study design and data analysis (275,276).

A limitation of this research is the sample being a convenience sample. In the psychiatry service frequency of attendance is approximately every 3 months. In diabetes due to the number of patients attending the service frequency of attendance is much lower with patients attending once every two years. However, where possible, steps were taken to ensure that the sample was reflective of the overall population attending the service in terms of age and gender. A total of 61.3% of those attending the type 2 diabetes service were male and 87.1% were over the age of 50. In the sample recruited for this study 61.5% were male and 86.5% were over the age of 50. Both services in this study are in the same urban deprived suburb of Dublin. All samples have a high proportion of participants with a lower level of education. For example, 55.2% (n=132) of diabetes patients and 46.9% (n=116) of psychiatry patients have a level of education of Junior Certificate or less. This is in comparison with a national average of 32% reported in the 2011 Census. Socio-economic markers such as education play a key role in participation, making this an important consideration. For example, levels of literacy impact on a person’s ability to be involved in decisions about their health (244).
Given the complexity of the topic being studied it is important to note the short duration of the questionnaire of 5-7 minutes. This was to allow for the practicalities of conducting data collection within the realities of a clinical environment where a longer questionnaire would have resulted in a lower response rate. Steps were taken to ensure understanding of the topic with the use of a standardised definition of participation at the top of the questionnaire and the researcher providing examples of participation as necessary during completion of the questionnaire. In addition, this questionnaire is part of a mixed methods study which includes qualitative exploration of participation providing further detail and meaning that overall findings are not based on questionnaire data alone. Qualitative components discussed further in Chapter 5. A final limitation is the lack of demographic details on those who refused to participate. However, it should be noted that the refusal rate was low and reasons for refusal were recorded. In the diabetes service where demographic details for the patient population are available comparisons were made between the sample and population. It was not possible to do this in the psychiatry service due to lack of electronic files.

4.4.3 Implications and conclusion

Researcher-administered questionnaires with 738 participants revealed that patient and family participation in a diabetes and a psychiatry service in Ireland is limited. At the service and national levels participation is limited to the provision of information, if participation occurs at all. For patients and family members this means that they may be provided with information on the service or national policy but typically they are not asked for their opinion, involved in discussions or play any role in the decision making process. This low level of reported participation is contrasted with strong support for greater participation at these levels where current reported participation is lowest. Support for greater participation is typically associated with characteristics such as age, level of education and service satisfaction (33).

Support for greater patient and family participation, particularly at the service and national levels is evident. However, the current reported participation typically equates to provision of information with no involvement in discussions or the decision-making process. This is at odds with current policy grounded in rhetoric supportive of
participation. Steps need to be taken to bridge this gap. Further research needs to be conducted to identify the best way to implement sustainable and meaningful participation including the identification of barriers, challenges and facilitators. All groups that may have a role in this process need to be involvement in the identification of barriers and facilitators and what the implementation of participation needs to look like. This study focused on participation in a diabetes and psychiatry service. We know that the intensity and implementation of participation differs by service and topic (10). With this in mind the amount and intensity of patient and family participation in healthcare design and delivery in other service areas needs to be established as well as the level of support for greater participation. This will enable exploration of whether or not the support and intensity of current participation illustrated in this PhD are reflected elsewhere and how much participation is taking place in a greater variety and number of services. The need for constant data collection and reflection on participation has been acknowledged (277). A baseline measure of how much participation is taking place nationally needs to be developed so that any future progress can be meaningfully measured. Patients and family members need to be involved in all aspects of these developments to ensure that actions are as successful and meaningful as possible.
Chapter 5:  
Study Two- Understanding of, opinions on and barriers and facilitators to patient and family participation

5.1 Introduction

Patient participation has become a buzz phrase with the result that the key terms are used interchangeably and it now has multiple meanings (4,16,66) (See Section 1.3 for further detail). Confusion remains in relation to what exactly patient participation is (17,47,52), why it should be done (17), how to enact it (7,10,16,17,52,97), what roles patients, family members and clinicians play (95) and the impact of participation (17).

Lack of clarity in the definition and components of participation has resulted in complexity and complications. For example, different understanding of participation can lead to decreased efficiency in communication and collaboration between those involved, hindering work aiming to increase and improve participation (51).

Understanding and opinions of participation can differ by group. This has been clearly demonstrated in a number of research projects with patients, members of the public and clinicians. Lung cancer patients interviewed in the United Kingdom on models of participation viewed making a difference in other peoples’ care as the purpose of participation (52). Similar findings were also reported in a study looking at patients’ opinions on participation in clinical governance. Patients and the public saw improving services for their specific community as the main purpose (68). In comparison, when other groups such as clinicians and management were asked for their opinion on the purpose of patient participation clinicians and management, particularly hospital CEOs, saw participation as a way to manage expectations and to communicate the health agenda (52). Members of the public with experience of participation also saw the purpose of participation to garner public support for a predetermined agenda or as a way for the government to share the blame (99).

Understanding and opinions towards participation can impact on implementation. For example, the opinions of individuals impacts on the intensity of participation (96).
Interviews with cancer patients and healthcare professionals in Canada illustrated that healthcare professionals’ attitudes could limit patient participation (7).

It is evident that there are a number of barriers to participation that need to be overcome. Identified barriers include cultural, attitudinal, capacity and resource issues for all those who have a role to play in participation (7,87,95,103) (See Section 1.7 for more detail). The combination of these barriers has been reported to lead some patients to question the relevance of their input (15,104).

The need for future research to focus on identifying participation and its components has been identified by multiple sources (47,65,109). There is a limited focus within the current literature on the opinions and experiences of participation (112). Research that has been conducted in this area has only a secondary focus on opinions and experiences. More research is required to validate expressed views by staff and patients (7) and to improve participation (96,109). There does not appear to be any literature available including the input of family members or looking at opinions related to their input. In addition, opinions either focused on involvement of the public at a national or patient level and there is a dearth of Irish research in this area (See Section 1.9 for more detail). As such there is a need for Irish research looking at opinions and experiences of participation to establish the most appropriate path forward for participation in Ireland.

This study aimed to explore patients’, family members’, clinicians’ and policy leaders’ understanding, opinions and experiences of participation including perceived barriers, facilitators and impacts at the service level.

5.2 Methodological Highlights

- Study 2 was qualitative in design, employing Interpretative Phenomenological Analysis (IPA) of semi-structured focus groups and interviews with 20 patients, 20 family members, 24 clinicians and 15 policy leaders (see Table 3.2: Study 2 sample by service, stakeholder group and interview type).
- Purposeful sampling was employed in Study 2. Follow-up interviews were conducted with a selection of participants from the clinician focus groups.

97
Semi-structured interview schedules were developed based on a comprehensive review of the literature with feedback from PhD supervisors (CD & JB), practicing clinicians external to both services and the patient and family representative (CC). Topics included understanding, opinions, experience, barriers, facilitators and expected impact of participation (See Appendix I: Study 2 Interview schedules).

Data collection was conducted between June 2015 and February 2016. This included focus groups (n=7), face-to-face interviews (n=18) and phone interviews (n=26) lasting on average 25 minutes (20 minute minimum- 55 minute maximum).

IPA was employed in analysing interviews and focus groups. Patterns in the data were clustered into a thematic structure which was reviewed regularly with recoding as necessary as this coding frame was applied to all transcripts (See Appendix J: Study 2 Coding frame). Connections between emergent themes were identified to enable the combination of separate themes into superordinate and subordinate themes as illustrated in Figure 3.2. Study 2 IPA coding frame superordinate and subordinate themes.

No software was used during data analysis (See Section 3.7.2).

Further details on all aspects of the methodology employed are in Chapter 3.

5.3 Results

5.3.1 Response Rate and Demographics

Flow charts for patient, family member and clinician samples are presented in Appendix G. The response rate for the policy leader sample was 93.7% with one refusal.

A total of 20 patients, 20 family members, 24 clinicians and 15 policy leaders were recruited. Patient and family member samples included a range of males and females, ages and levels of education as illustrated in Table 5.2.

The clinician samples (n=24) included a mixture of males (n=5) and females (n=19), duration of employment from 4 months to 18 years as well as different disciplines including nursing (n=12), endocrinology (consultants and registrars) (n=5), psychiatry (a
consultant and registrars) (n=3) and allied health professionals (psychology, dietetics and occupational therapy) (n=4).

The policy leader sample (n=15) included people from a variety of operational (n=8) and policy (n=7) roles with a diabetes (n=3), psychiatric (n=6) and general healthcare (n=6) background as well as a number of organisations (government departments, health services, NGOs, patient/family member organisations and academic institutions). The policy leader sample also included a diabetes and a psychiatric patient who are involved in the development of services and policy.

5.3.2 Understanding of participation

Participants typically viewed participation at the patient level. ‘Involved in your visits... going with you to see how you are doing.’ (Evelyn, Diabetes, Family member). This was often in terms of educating, understanding and managing care and sometimes being involved in decisions.

“That you are involved in any decisions that are made regarding your own health, that you can involve your family. For example, in dosage of medication that you are fully aware of the decision that you choose, that you are involved in the decision making process.’

(Melanie, Diabetes, Patient)

Confusion and ambiguity emerged in patient, family member and junior clinician groups when service level participation was discussed. ‘How do you mean now with the service, like as in change, like as in clinic changes or?’ (Laura, Psychiatry, Clinician). Generally, only senior clinicians and policy leaders understood participation to include involvement in service level decisions and changes. This was typically demonstrated by those who had experience of the process of change at either the service or national level.

“I think of it at several levels, I suppose I first of all think about individual patients who come in and meeting the families... the other level of course is service, management and structures and planning level.’

(Julie, Psychiatry, Clinician)
During discussions it was evident that many participants understood participation to include informing or gathering feedback from patients and family members with no control or active role in the decision making process.

‘I think people should be informed... if you had any changes or complaints you should know who to go to.’
(Mia, Diabetes, Family member).

5.3.3 Opinions of participation

A strong level of support for patient and family participation was displayed by all stakeholders. ‘Yes, it’s always good to have some sort of input before decisions are made’ (Melanie, Diabetes, Patient). The support and will within services noted ‘There is a real will in the services and a real motivation within services to take this on board’ (George, Psychiatry, Policy leader). Participants questioned how patients could not be involved in service level changes ‘How can a patient not be involved?’ (Katherine, Diabetes, Clinician) with comparisons drawn to how things work in other areas. ‘If you were working in a company that had a quality mark, they would always have customer reaction as to how the customer views the service’ (Matt, Diabetes, Patient).

Participation was viewed by some as a right or entitlement. ‘It’s going to affect them [patients], the changes, so involve them...they have a right to have say in it or to be told anyway’ (Antoinette, Diabetes, Family member). Necessity for participation appears to stem from patients being the ones in receipt of treatment and with relevant experience.

‘They [mental health patients] are the people that are impacted most by the type of service, by the quality of the service... so I think they need to be involved in order to be able to have a say in how the service is, what the philosophy of the service should be and bring their expertise of living with particular issues.’
(Annie, Policy Leader)

Support for family member participation was illustrated.
'I would feel happy that they [family members] are involved and their opinion is being sought and given serious consideration rather than just being railroaded into the changes.'

(Eric, Psychiatry, Patient)

Within the diabetes service concerns were raised about family member participation due to the patient cohort typically having full capacity and support for family participation often being linked with age.

‘The majority of the patients that we would see would have...full capacity to be making their own decisions about things and even resent the implication that family members need to be involved in their care.’

(Mitchell, Diabetes, Clinician)

‘It’s not that simple because it depends on age... if you have an elderly parent, like me, that my daughter would have to look after me or my diabetes, or my son... they should have a say in it.’

(Barbara, Diabetes, Patient)

Some participants expressed negative opinions towards participation. At times this was linked with experience. For example, one patient felt participation was not necessary as he did not have any negative experiences with the service and another felt that family participation would not work as family have not experienced a mental illness themselves ‘They [family members] don’t know what it is like to have depression or anxiety’ (Tara, Psychiatry, Patient). For others this was associated with inability to make changes happen ‘I don’t think... that patients are going to have much of an impact on doctors... as regards changes and making changes’ (Declan, Psychiatry, Patient). For clinicians this appeared to be linked with the capacity of patients and family members.

‘No that’s very dangerous. It’s very dangerous because patients...it’s human nature, you see your own problem, your own disease, your own needs.’

(Debra, Diabetes, Clinician)
5.3.4 Amount and intensity of current participation

Throughout interviews and focus groups it was evident that while there is support for participation this is not something that happens on a regular basis within healthcare services.

‘The first thing that comes to mind is probably the real lack of participation... there has been a lot of talk about the need and the reasons why, but ... I don’t think there is very much real participation in the real sense of the word, there could be a lot of tokenism.’
(Ken, Psychiatry, Policy leader)

Patients and family members report not being asked what they think about services ‘You were the first now to ask, I mean if we had any views on it... this is the first, over the 20 years.’ (Joe, Psychiatry, Patient). They spoke about not been told about changes that have been made ‘Well you weren’t even notified on that [change in the appointment system]’ (Martin, Diabetes, Patient) or being involved in the decision making process ‘They make decisions without informing us about what is going on.’ (Mildred, Diabetes, Family member). This was echoed by clinicians who spoke about the decision making process and work being done to change the service without the knowledge or involvement of patients and family members with no mechanisms to enable this.

‘We do lots of things that we don’t tell people, we don’t tell patients, patients don’t know that we are working on these things in the background.’
(Michael, Diabetes, Clinician)

‘If you’re looking at sector management meetings there’s no involvement of users or carers.’
(Olive, Psychiatry, Clinician)

There were some examples of ad-hoc participation particularly within the psychiatric service. For example, patients were asked to provide feedback on a course run in the
psychiatric service with changes made based on this feedback. However, patients were not involved beyond the provision of feedback and this was not standard practice beyond this one course. The ad-hoc tokenistic nature of participation extended beyond the services on which this research focuses with many policy leaders noting the ad-hoc, siloed nature of participation within healthcare in Ireland in general.

‘You have ad-hoc individual kind of good initiatives but they exist in that space and they don’t go outside of that space.’ (Damien, Policy leader)

Experiences of tokenistic participation were also referenced.

‘On a ground level that is a tick box exercise. That is not real participation ... you are one or two patients sitting in a room of clinicians and other members of the multidisciplinary team who all talk a certain language and to which you are absolutely 100% still excluded and while they offer you the difference of listening to you they are actually not hearing what you are saying.’
(Heather, Policy leader)

5.3.5 Barriers to participation

While supportive of participation policy leaders and clinicians were realistic and shared practical concerns about the reality of implementation and through this identified a number of barriers.

‘I suppose from an idealistic point of view, I wouldn’t necessarily have an objection for patients to have democratic participation to the service, but I think we are a long way off that situation.’
(Jack, Diabetes, Clinician)

Confidentiality

Confidentiality concerns were identified from two aspects. Concerns were raised about confidentiality for patients who do not involve family members in their care. ‘We often have patients here who are very secretive and they actually don’t want their families
involved’ (Felicity, Diabetes, Clinician). Restrictions from management and the HSE were also highlighted as problematic.

‘There would have to be a lot of confidentiality...the patient would have to understand that what they are relaying to other patients...it would have to be a very confidential situation.’
(Linda, Diabetes, Clinician)

In contrast some participants felt that confidentiality could be used as an excuse or identified as an unnecessary barrier. ‘I think sometimes that confidentiality is used as a barrier, when it necessarily doesn’t have to be.’ (Cynthia, Policy leader)

Attitudes and Fear
Some barriers centred around cultural, patient and family and service attitudes. An identified barrier was what was seen as the ‘Irish’ attitude of not speaking up. ‘A typical Irish thing, they complain, but they never say it directly to the people involved’ (Miriam, Diabetes, Family member). This was illustrated by a psychiatry service patient accepting the current appointment system that many patients feel is problematic.

‘It is just the way it [appointment system] is cause, you know, people are all given the same appointment and they all come together and it is just whoever comes first in the queue, like, so that seems to be the way.’
(Declan, Psychiatry, Patient)

This ‘Irish’ attitude is linked with what was perceived by some to be a paternalistic culture within our healthcare system.

‘The culture can be quite paternalistic... we have a culture which has spoon feed people to be more passive participants in healthcare... but there is a two way process, and so until we start seeing ourselves in that light we won’t readily engage in a way which is actually beneficial to all.... It’s a change in mind-set and that’s so strongly embedded in our culture.’
(Janette, Policy leader)
Patient and family member attitudinal barriers focused on concerns about the impact of participating on patient care. ‘You are afraid to tell them and then they kind of disregard you and ... your patient or your partner might not get the same [treatment]’ (Amy, Psychiatry, Family member). More frequently in the psychiatry service feelings of intimidation at the thought of attending meetings with clinicians. ‘People could feel intimidated being around people that are kind of above them in a sense’ (Michelle, Psychiatry, Patient).

Service related attitudinal barriers were also highlighted. Questions were raised about how ready services are for participation.

‘I wonder at the service level, are the services ready to accept patients in? I mean the management of that. If they were to come into a sector team meeting, are they prepared to welcome them with open arms?’
(Samantha, Psychiatry, Clinician)

There is an expectation that there is a defensive attitude within services. ‘The way they [clinicians] look at it is that they are the professionals. We [patients] are not, so why should we have any input?’ (Tara, Psychiatry, Patient). This may be linked with some of the fears expressed by clinicians surrounding participation with defensiveness stemming from not wanting to be judged.

‘We all have our own self-esteem issues and there maybe issues like, ‘God if carers and service users sat in on our meetings what they would they think of them?’ There is a defensiveness on our part not be judged ourselves.’
(Olive, Psychiatry, Clinician)

Fears were expressed about ‘an automatic raising of expectation for the patient’ (Damien, Policy leader) and about losing patient trust, ‘You don’t want to undermine the trust that a patient has in the hospital system’ (Linda, Diabetes, Clinician), as a result of not being able to achieve suggested changes.
'Hearing what should be happening, knowing those things should be happening, but knowing you can’t do anything about it. So that may be one block to actually having patients involved because you know that you are not going to be able to effect what people would want.’

(Mitchell, Diabetes, Clinician)

Barriers relating to attitudes or fear have been linked with a ‘lack of experience of what to do and how to do it’ (Damien, Policy leader) and the difficulty of tackling these issues was acknowledged.

‘That [attitudinal barriers] is probably the hardest one to deal with because the other things are just realities and they need a process to manage. The kind of personal level stuff it can be difficult to identify it and then even if it is owned it can be quite a challenging thing.’

(George, Psychiatry, Policy leader)

Capacity

A group of barriers relating to the capacity of all stakeholder groups were key. Concerns were raised about the ability of patient and family members to participate stemming from feelings of intimidation or a lack of confidence. ‘I wouldn’t, I wouldn’t, definitely not me. I am not confident enough to sit in with them [doctors and nurses] at all.’ (Kelly, Psychiatry, Patient). Queries were raised about the capacity of patients and family members to see past their own individual experiences, ‘It’s about them being able to look at the bigger picture, not just their own mental health’ (Olive, Psychiatry, Clinician), and effectively communicate their experiences.

‘People will come forward who haven’t quite reconciled their emotions around care that they have received or perhaps a family member has received. They haven’t had the opportunity perhaps to work through some of the frustrations and maybe come to it a bit raw...that is the bit in this process where those emotions need to be taken somewhere else because otherwise it can derail what you are trying to do in terms of work.’

(George, Psychiatry, Policy leader)
This was accompanied by concerns that patients and family members may not have the necessary knowledge, experience and skills required for service design and delivery process. ‘People with the condition are generally not au fait with policy and how implementation happens’ (Angela, Diabetes, Policy leader).

Capacity issues were also raised for clinical and policy leader stakeholders. Some of these overlapped with capacity issues for patients and family members, particularly relating to skills and experience for management and service design and delivery.

‘So just like us, just like the healthcare workers, you need the management skills to participate... to negotiate your way around formal meetings... in terms of understanding strategy.’ (Julie, Psychiatry, Clinician)

However, it was noted that often those in management roles within the HSE do not receive any training for these roles. The language typically used at the service level was noted as a barrier to participation.

‘We also need to skill practitioners on how to speak simple and plain... We have a lot of organisational jargon. We have a lot of professional jargon that keeps people marginalised and excluded.’ (Annie, Psychiatry, Policy leader)

The understanding which clinicians and policy leaders have of participation and what they perceive the purpose of participation to be was questioned.

‘Realising that I didn’t come here to tell you my sad story so that you could just tick the box. I came here to tell you what happened to me in the hope that we can change the system together.’

(Heather, Policy leader)

The need for understanding of the patient and family member experience was noted.
‘I think while clinicians obviously have the academic background and medical background and all that, sometimes it would be good for them to hear a little about the carers life and what they do. The feelings they go through and even the fact that they might be struggling financially or emotionally.’
(Cynthia, Policy leader)

This issue of capacity for participation extended to the service and surrounding system with questions raised about whether or not the service is ready and able to change and cope with patient and family participation.

‘I think there is a sort of incompetency within the [system] management, it’s not like bad will... there doesn’t seem to be the skills there to effect change.’
(Julie, Psychiatry, Clinician)

This was linked with the complexity of the system with lack of flexibility, ‘There isn’t the flexibility that exists in other jurisdictions where the resourcing is better’ (Michael, Diabetes, Clinician), integration, ‘I think with the HSE the problem being that it almost acts in separate pockets... there is a silo within their budget’ (Cynthia, Policy leader), and structures to facilitate participation.

‘Well one other barriers it that it doesn’t exist at the moment... there isn’t that kind of set up in Ireland... our system is far more US based in that it is clinician led, it is very management led and the service users are not really as involved.’
(Michael, Diabetes, Clinician)

The lack of structures to involve patients and family members and affect real changes was associated with a lack of resources including time, funding and numbers.

‘If you did have the time and you did have the resources then, you know, it would be great to have everybody involved and have discussions.’
(Laura, Psychiatry, Clinician)
One patient expressed being ‘Too busy.’ (Adam, Diabetes, Patient) to participate while concerns were expressed about the amount of time required for meaningful participation. ‘The concern is that it will slow down the process and the decision making that will happen’ (Richard, Diabetes, Policy leader). Funding issues with recent cutbacks and the impact of who retains control over the budget were discussed with finance concerns acknowledged. ‘Resources are quantifiable and limited and that is a problem. Well, sorry it is a not a problem, it is a reality’ (James, Policy leader). Staffing and particularly in diabetes patient numbers were highlighted as barriers to participation.

‘There is not enough staff I don’t think in the hospitals to cater to the population... Unless they have the staff I don’t think it [patient and family participation] would make any difference.’
(Tiernan, Diabetes, Family member)

‘In the type 2 diabetes clinic... they have very little contact with the service... these guys get seen for 15 minutes every 2 years... I think that’s a barrier as well, that the number of patients been seen in the department is so huge.’
(Jack, Diabetes, Clinician)

Implementation
A set of concerns centred around the implementation of participation with an acknowledgment of the difficulty, ‘That would very hard to implement’ (Shauna, Diabetes, Clinician), and time requirements ‘It would take time’ (Evelyn, Diabetes, Family member) as well as multifaceted issues to overcome.

‘I think patient and family participation can’t happen overnight... we need to look at how we pay and remunerate people... how we manage to work with people who are maybe part of the process but are equally out on sick leave... there is kind of financial barriers, there is attitudinal barriers and there is competency barriers, there is resource barriers.’
(Annie, Psychiatry, Policy leader)
Specific concerns centre around selecting and recruiting patients and family members to participate.

‘Who would be the representative? Who in a cohort of patients of 6000 plus diabetic patients? Who one, two or three people represent that group when we know diabetic patients are a very heterogeneous group?’
(Mitchell, Diabetes, Clinician)

The difficulty in finding those who are interested in participating and who have the necessary skills was discussed.

‘I don’t know how much people really want to be involved. They just want to go along, get their appointment and be seen without it taking so long every time.’
(Miriam, Diabetes, Family member)

‘How do we source them?...you want the person, a suitable person. By suitable I mean somebody that would contribute like that, that would contribute or that would enjoy it or would get something from it themselves.’
(Caroline, Psychiatry, Policy leader)

And particularly within diabetes the impact of the current informal process for making changes was discussed.

‘We would have to look at how do we go about planning our service development because to be honest at the moment... it’s a lot of informal meetings and chats.’
(Linda, Diabetes, Clinician)

5.3.6 Facilitators to participation

Suggestions for the implementation of participation were proposed, particularly by those with experience in healthcare design and delivery. A key facilitative factor was champions ‘You need the few role models or champions’ (Ken, Psychiatry, Policy leader). It was noted
that responsibility for participation needs to be assigned with bottom up and top down commitment.

‘I think what needs to happen is that the Department of Health needs to make patient involvement the remit and the brief of an individual in the Department... it needs to come from the top... if you have that one kind of streamline person with that responsibility it would focus efforts on that... but until there is actually a resource and some funding behind this, you’re only going to get piecemeal stuff... at the same time, there needs to be a kind of community driven effort, that is from the patients themselves and that somewhere these two need to be kind of coming together.’

(Damien, Policy leader)

This needs to be supported with a coordinator and training for all stakeholder groups.

‘You need a coordinator for each hospital, say an outpatient representative coordinator and they would organise how it works and how everyone liaised with each other.’

(Michael, Diabetes, Clinician)

Other facilitative factors discussed included earning small wins, ‘You have got to get some small wins, some maybe even fast wins and then you build on those’ (Colette, Policy leader), changing the culture within healthcare in Ireland so that participation is the norm, ‘Develop a norm where patients expect to be offered an opinion or expected to be offered or approached to comment on the service that they have received’ (Dermot, Policy leader) and taking steps to ensure participation remains action focused.

‘It is a group and not a committee and there will be group discussion followed by decisions and action points and that is the structure that I would put on it to manage out that risk of it becoming a talking shop.’

(Mick, Diabetes, Policy leader)
5.3.7 Perceived impact of greater participation

Participants were asked about the potential impact of greater participation. Some felt that only good things could come from greater involvement of patients and family members. ‘Well you know only good can come from it. I don’t think anything very bad can come from it’ (Marie, Psychiatry, Family member). In line with the realistic approach evident throughout, both positive and negative expected outcomes were discussed.

Service

It is anticipated that patient and family involvement will lead to improvements within the service, ‘The contribution that they [patients and family members] would make would improve the service’ (Tim, Psychiatry, Patient) with more patient centred decisions.

‘A massive difference because it is then patient centred, it is not just the head of department making a decisions, it is actually properly orientated around patients.’
(Mia, Diabetes, Family member)

This is expected to stem from the patient and family member experience being included with new ideas being put forward resulting in greater capacity to bring about change.

‘I think that family members also have a huge amount to offer us ... they would be able to identify gaps in the service that maybe we’re not filling as a lack of awareness as opposed to lack of will.’
(Lynn, Psychiatry, Clinician)

‘It would bring clarity to it, if there were patients involved. Because at least they would be able to say, well actually you know not just from a management point of view, not just from the healthcare workers point of view, but also from the recipients of the service.’
(Julie, Psychiatry, Clinician)

However, it is important to note that this was not a view shared by all participants with some feeling that no change will come from greater participation ‘I don’t think it would
[result in changes]... *we think in Ireland still that participation is letting you tell your sad story*’ (Heather, Policy leader) with efforts to include patients and family members expected to equate to a ‘talking show’ (Brendan, Diabetes, Patient) and suggested changes expected to be unrealistic ‘*You may get concerns or complaints that aren’t feasible to change*’ (Laura, Psychiatry, Clinician).

**Relationships**

While a period of initial tension and conflict is expected discussion and resolution is anticipated to result in stronger relationships between stakeholders with a greater level of understanding and closer relationships.

‘*It may well bring up issues that they haven’t discussed before, so it may also raise some issues or problems, but sometimes those are better being raised and maybe coming out in the open and so it might improve relations.*’

(Cynthia, Policy leader)

‘*It would be nice because we’d [patients and family] be able to do little things together*’

(Jenny, Psychiatry, Patient)

‘*It might give us an extra dimension, an extra understanding of that person or that person and who they are representing... an acquaintance that you know a little bit more about.*’

(Megan, Diabetes, Clinician)

It is important to note in psychiatry particular tensions stemming from involuntary admissions.

‘*Well you’d always be afraid there’d be repercussions for what you say because don’t forget they are the people in control of your life.*’

(Joe, Psychiatry, Patient)
Emotions

A range of emotions are expected to stem from the involvement of patients and family members. It is expected that there would be empowerment of patients and family with a sense of ownership of the service.

‘I would be ecstatic... because you are sitting there with people who have degrees and diplomas and you would feel very important because you are brought in to this and I would feel that I am just as good as anybody else because my opinion is being noticed.’
(Caroline, Diabetes, Family member)

‘The very fact that you get people involved and they are there writing the policy with us and so on means that they have an ownership of it.’
(James, Policy leader)

Questions were raised about possible lower levels of empowerment for some patients if family members begin to play a greater role. ‘You would hope that the patient wouldn’t feel less empowered because the carer is suddenly taking on more.’ (Cynthia, Policy leader). It is expected to be rewarding for clinicians to see their patients doing well and interacting with them in a capacity aside from their illness. ‘I think it’s very good for us [clinicians] as well really to see people who are doing very well, it’s quite inspiring.’ (Julie, Psychiatry, Clinician)

There was discussion on the impact of participation on frustration levels. It is anticipated that greater involvement of and communication with patients and family members will decrease frustration as there is greater transparency in the decision making process. ‘A lot of frustration can stem from just lack of communication... the more informed that patients and their families are the less frustrated you get’ (Laura, Psychiatry, Clinician).
However, if changes are not made concerns were raised that this would increase frustration.

‘You would be quite angry and upset. It is like everything, like it the change doesn’t happen and you were working towards it then you just feel useless.'
Why was I involved? What was the point in this whole thing if you don’t, if my opinion isn’t going to be valid?

(Mia, Diabetes, Family member)

With an expectation that this would eventually lead to ‘I think they [patients and family members] become like us, burnt out and cynical’ (Julie, Psychiatry, Clinician).

5.4 Discussion

5.4.1 Result summary and connection with literature

Ambiguity and confusion around the concept of participation at the service level has been illustrated, particularly for patient, family member and junior clinician stakeholder groups. This reflects the wider literature in this area that highlights the lack of consensus surrounding the definition, components, aims and implementation of participation (4,66). In the current study policy leaders and senior clinicians understood participation at the service level. However, this was a new concept for other stakeholder groups who illustrated understanding this concept at only the patient level. It has been illustrated that understanding of participation is influenced by the role of the stakeholder (16).

Interviews with patients, providers and policy makers in England highlighted the different views which stakeholders have in relation to the aims of patient participation (47).

Healthcare managers and public health experts viewed patient participation at the population level with the purpose of improving health services for the public as a whole, based on scientific methods such as surveys. Healthcare professionals thought of patient participation at the individual clinical care level where the healthcare professional made the decisions based on evidence but took in to account their knowledge of the patient with interaction between the patient and healthcare professional being paramount.

Patients and allied healthcare professionals took a broader view of patient participation beyond the individual clinical decisions to the development process and political arena and supported patients having a role in the decision making process (47). Similarly a Norwegian study with patients, public representatives and healthcare professionals in a mental healthcare setting illustrated different opinions on the definition and components of participation between the stakeholder groups (51).
Once understanding of service level participation was obtained it is clear that there is support for greater participation with overall positive opinions expressed. Participation was viewed by some as a right or entitlement, with support from within services for this noted due to the impact that changes have on patients and family members. This is contrasted with a dearth of demonstrated systematic participation within either service. The policy background for this includes numerous policy documents (6,54,209) and HSE service plans (57,58), acknowledging the importance of participation. This has been reiterated and greater service user involvement in healthcare is one of the key performance indicators of the recent national policy ‘Healthy Ireland’ (55) and most recently the launching of the National Patient Experience Survey (NPES). This matches with international literature where despite varying understandings and opinions of participation there appears to be some consensus that patients should be involved in participation supported by patients, healthcare professionals and the public (7,95,104). The gap between sentiment and action has also been noted with a report from the King’s Fund emphasising the gap between aspirational rhetoric and the policies and actions supporting participation (17).

Barriers and facilitators to participation were discussed with the primary focus being on challenges including attitudinal, implementation and capacity concerns. Attitudinal concerns were voiced for all stakeholders. Questions were raised about the impact of an ‘Irish’ attitude of patients not speaking up linked with the paternalistic culture within the healthcare system. Clinicians noted concerns about raising expectations and not being able to meet them. Barriers to participation presented by attitudes and expectations has been illustrated from a systematic review of patients views on the barriers and facilitators to shared decision making. Presumptions about the patient role and patients undervaluing their knowledge in comparison to clinicians have both been identified as challenges (105). The importance of attitudes cannot be underestimated when it comes to participation. A systematic review of healthcare professional’s perceptions of the barriers and facilitators of implement shared decision making in clinical practice highlighted provider motivation as one of the three most often cited facilitators to shared decision making (106).
In Study 2 skills and knowledge of patients, family and clinicians was queried for the participation process as well as clinicians understanding of participation. Capacity concerns extended to the service with questions about the flexibility and ability of the service to make changes and whether the necessary resources were available to implement participation. The implementation of participation was also queried. There was a lack of clarity over how to implement participation. It was felt that a lot of time was required for implementation with challenges including selection and recruitment of patients and family members and what was perceived as a lack of resources within the healthcare system for implementation. These concerns identified in Study 2 of this PhD mirror challenges identified elsewhere and expand on the meaning of these barriers within the Irish context. Capacity concerns expressed mirror the CLEAR frameworks which focus on supporting and building the capacity of participants to enable them to participate meaningfully (19). The importance of preparing for participation and the process of participation including language and provision of necessary information has been noted by patients (105). Time was identified as a barrier to shared decision making from the perspective of patients in a systematic literature review (105). Using a similar methodology interviews with patients and clinicians in a cancer service Canada lack of insight into the proper methodologies were identified as a barrier to public involvement in health service planning (7).

Considerable time was spent discussing the perceived impact of participation. Participants reported expecting improvements in the service due to new ideas being proposed and the inclusion of the knowledge and experience of patients and family members. It was suggested that it may lead to a greater capacity to bring about changes. Although, some queried the ability of the service to change and doubted if the involvement of patients and family members would make any difference. Impacts on relationships and emotions were also anticipated as a result of participation. Stronger relationships after an initial period of tensions or conflict were expected alongside increased empowerment. These anticipated impacts of participation are in line with what has been demonstrated elsewhere. A systematic review of the barriers and facilitators to shared decision making from the perspective of healthcare professionals identified the positive impact on the clinical process as one of three main facilitators to shared decision making (106).
5.4.2 Methodological critique

This is an in-depth qualitative exploration of the opinions and experiences of Irish patients, family members, clinicians and policy leaders towards service level patient and family participation. All key stakeholder groups that would be involved in this process were included. It adds to and strengthens the current literature, expanding on participants’ understanding and opinions of participation, particularly the motivations and reasons for greater participation while establishing the social and cultural context within Ireland. The practical and realistic approach and discussion of barriers and facilitators bridges the gap in knowledge of how to implement service level participation.

All data collection was conducted by the researcher (LW). The selected method of analysis, IPA, was well suited to the topic that was novel and new to many participants. Good inter-rater reliability was demonstrated in coding and analysis and this process included members of the team with varying levels of familiarity with the transcripts.

Limitations
 IPA requires at least some understanding of the broader philosophical assumptions (195). A literature review was conducted in advance of data collection and the researcher (LW) and supervisors (CD & JB) had been conducting research in this area for one year previous to analysis, providing an understanding of the underpinning assumptions and surrounding literature. Some focus groups had less than the typical 4-12 participants (191). This was due to advice from a senior clinician for clinician focus groups in diabetes to be discipline specific and in one case low turn out rates for a patient focus group in diabetes. It was felt by the researcher that it would not be suitable to cancel the focus group for those who had arrived and to go ahead with the focus group. The researcher encouraged group discussion between participants to maintain the distinctive data typically resulting from focus group data collection due to group discussion and exploration of topics (191).

Data collection included focus groups and both face-to-face and phone interviews. Traditional qualitative advice puts forwards that telephone is not suited to qualitative interviews primarily due to the restriction on the building of rapport and relationships due to the lack of visual cues impacting on meaning and comprehension, monitoring responses and emotions and engagement. However, more recently alternative methods of conducting qualitative interviews, including over the telephone have become more
popular for practical, budgetary and confidentiality reasons (278). This has been accompanied by comparisons of types of qualitative interviews. A review of face-to-face, telephone, Skype and messenger interviews reported that while visual cues are missing from telephone interviews adequate social cues remained in the form of voice and intonation (278). A review of 11 interviews on mental health and employment busing face-to-face and telephone interviews for practical purposes illustrated that in telephone interviews interviewers provided less vocal acknowledgement while interviewees looked for more assurance that they were providing adequate content and slightly more requests for clarification (279). Despite this qualitative data collection from 12 participants highlighted that the most popular form of interview was telephone when Skype, email and face-to-face interviews were also offered. This was due to the convenience of telephone interviews while also taking into consideration the participants feelings on their ability to be open with the researcher and get a feel for them when discussing a sensitive topic. Following these findings it is advised that researchers consider alternative forms for interviews while taking into account impact on the variety and depth of data (280). In line with this telephone interviews were offered to participants who felt they could not physically attend for an interview or focus group. The researcher (LW) had met all participants in advance of phone interviews being conducted. Rapport had already been established with participants and the supervisor (CD) provided feedback on the researcher’s (LW) interviewing technique to ensure phone interviews were of a good quality.

5.4.3 Implications and conclusion

Despite some initial confusion and ambiguity it is evident that there is support for greater patient and family participation in healthcare design and delivery. However, there is limited participation in either service at present with identified barriers including attitudinal, capacity and implementation issues. Concerns were raised about the capacity of all stakeholder groups and the service to implement participation with questions marks about what participation is and how to implement it. A realistic and practical approach was adopted by participants with facilitators and solutions to implementation barriers suggested as well. There is a need to identify what participation needs to look like and how it should be implemented. This needs to take into account identified barriers and
challenges and include all key stakeholder groups that may have a role to play in participation. Policy needs to be enacted to ensure the amount and intensity of participation taking place matches the sentiment and support for participation. Future research needs to identify the level and components required to increase patient and family member participation in healthcare design and delivery. Exploration of understanding, opinions and experiences of participation needs to be expanded to other services. It is essential that all stakeholders, including patients and family members, are involved in all aspects of these developments.
Chapter 6: What should patient and family participation in healthcare design and delivery look like?

6.1 Introduction

An acknowledged barrier to the implementation of patient and family participation is the lack of clarity or consensus on the definition and components. Participation can occur at different levels in healthcare: patient, service and national levels. In addition to this, the intensity of participation varies from provision of information, to being involved in discussion, to taking on responsibility for decisions (18). Reflecting this there are an array of methods to encourage participation in healthcare including questionnaires (52), involvement in development of information material (73), workshops (16), forums (74), representatives (75), civic juries (76), setting of priorities (77) and involvement in research (234). Often more than one method is required to encourage participation and the appropriate methods may vary depending on the service and issue being discussed (10).

This complexity is highlighted in the content and advice in national and international resources, guidebooks and toolkits (3,67,81,149,281–283). For example, Cork University Hospital Group guidance for participation at the ward or department level includes ensuring leadership for patient and public participation, evaluation and monitoring to promote participation, promotion of the importance of patient feedback, establishing links with relevant groups and organisations and involving patients, family and the public in the development of clinical guidelines and research. Guidance for clinical directorate and senior management teams also includes promotion of working in partnership with patients, family and the public, involving them in planning, evaluation and monitoring of services, and using patient experience surveys to improve service delivery (3). A World Health Organization (WHO) document published in 2015 outlined strategies and tools for engaging patients, carers and the community, including steps such as supporting and empowering patients, families and communities, enabling informed choice, protecting rights and fostering shared responsibility and strengthening health literacy and community development (67). Advice provided is wide and varied, typically with
numerous methods of participation discussed for different levels and intensity of participation, often with generic advice.

Confusion remains about the best way to implement participation (17). No clear consensus has been reached on the best ways to achieve strong and lasting participation (16). Existing research is weak due to variety in the interventions tested, the patient groups employed and underlying health systems (See Section 1.9 for more detail). This current study aims to identify preferences for the amount of intensity and type of intervention to encourage participation in healthcare design and delivery in an outpatient psychiatry service and an outpatient type 2 diabetes service.

6.2 Methodological Highlights

- Two three round Delphi Technique Experiments (DTEs) were conducted. One in the psychiatry service and a second in diabetes service.

- DTEs are a method of achieving consensus through multiple iterations of a questionnaire completed anonymously by a panel of experts (22). The stopping criteria employed for this study were a 15% or less change in opinions between rounds and more than 65% of panellists in agreement (201,253).

- This study included 31 participants (13 patients, 9 family members, 9 clinicians) in the psychiatry DTE and 29 participants (12 patients, 6 family members, 11 clinicians) in the diabetes DTE.

- Random samples of patients and family members from each service were selected. All members of the full MDT in both services who were in employment for at least three months were invited to take part. This process is illustrated in Appendix G: Study 1, 2, 3 and 5 Flow Charts.

- Questionnaires were developed based on a literature review, the theoretical framework and Study 2 findings. In Round 1, 65 questions were included in the psychiatry DTE and 64 questions in the diabetes DTE. Topics included opinions on participation, intensity and frequency of participation and implementation (See Appendix K: Study 3 questionnaire).

- In Round 2 and Round 3 questions that reached a stable group consensus were removed (201,253,259). For each question the answers of the group as a whole
was depicted in a histogram, the participant’s answer was circled in red and participants were given the opportunity to change their answer or leave it the same. If a participant chose to remain outside of the group consensus they were asked to explain why (See Appendix K: Study 3 questionnaire).

- Data collection was conducted by the researcher (LW) between June and August 2016.
- All analysis was completed using SPPS (version 22; SPSS Inc; Chicago, IL, USA). Further details on all aspects of the methodology employed are in Chapter 3.

6.3 Results

6.3.1 Response and Attrition Rates
In the psychiatry DTE the refusal rate was 13.7% (n=4) for patients, 11.7% (n=2) for family members and 0.0% (n=0) for clinicians. The attrition rate between Round 1 and Round 3 was 22.6% (n=8) (See Figure 6.1).

In the diabetes DTE the refusal rate was 6.1% (n=1) for patients, 6.6% (n=1) for family members and 0.0% (n=0) for clinicians. Between Round 1 and Round 3 the rate of attrition was 18.6% (n=6) (See Figure 6.2).

6.3.2 Demographics
In the Round 3 psychiatry sample, 41.9% (n=13) were patients, 54.8% (n=17) were female and 41.9% (n=13) had a level of education of degree or above. Focusing on the Round 3 diabetes sample, 41.4% (n=12) were patients, 58.6% (n=17) were female and 48.2% (n=14) had a level of education of degree or above (see Table 6.1).

6.3.3 Consensus
In the psychiatry DTE stable consensus was achieved in 50/65 questions in Round 1, 53/65 questions in Round 2 and 60/65 questions in Round 3. The remaining five questions did not meet the 65% level of agreement for consensus (See Table 6.2).
Table 6.1: Psychiatry and diabetes sample description by DTE round

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Psychiatry Sample</th>
<th>Diabetes Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Round 1 N=39 (100.0%)</td>
<td>Round 2 N=31 (100.0%)</td>
</tr>
<tr>
<td>Patient</td>
<td>17 (43.6)</td>
<td>14 (45.2)</td>
</tr>
<tr>
<td>Family member</td>
<td>11 (28.2)</td>
<td>7 (22.6)</td>
</tr>
<tr>
<td>Clinician</td>
<td>11 (28.2)</td>
<td>10 (32.3)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18 (46.2)</td>
<td>15 (48.4)</td>
</tr>
<tr>
<td>Female</td>
<td>21 (53.8)</td>
<td>16 (51.6)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>14 (35.9)</td>
<td>13 (42.0)</td>
</tr>
<tr>
<td>40-59</td>
<td>20 (51.3)</td>
<td>14 (45.2)</td>
</tr>
<tr>
<td>60+</td>
<td>4 (10.1)</td>
<td>4 (13.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (2.6)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Junior Cert or less</td>
<td>11 (28.2)</td>
<td>8 (25.8)</td>
</tr>
<tr>
<td>Leaving Cert ²/Non</td>
<td>12 (30.8)</td>
<td>9 (29.1)</td>
</tr>
<tr>
<td>degree</td>
<td>Degree or above</td>
<td>15 (38.5)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (2.6)</td>
<td></td>
</tr>
<tr>
<td>Duration of</td>
<td></td>
<td></td>
</tr>
<tr>
<td>attendance/employment</td>
<td>≤ 4 years</td>
<td>16 (41.0)</td>
</tr>
<tr>
<td></td>
<td>≥5 years</td>
<td>21 (53.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (5.1)</td>
<td>1 (3.2)</td>
</tr>
</tbody>
</table>

² = State examinations. Junior certificate at aged 15 and Leaving certificate at aged 18.

- = Not applicable

In the diabetes DTE stable consensus was achieved in 46/64 questions in Round 1, 48/64 questions in Round 2 and 60/64 questions in Round 3. Unstable consensus was reached for three questions defined as the 65% level of agreement being reach but change between Round 2 and Round 3 being greater than 15%. One question did not meet the required 65% for consensus (See Table 6.3).

6.3.4 Support for and preferred intensity of participation

The vast majority of participants supported patient participation in the planning of services (psychiatry 97.4%; n=38, diabetes 91.4%; n=32). The preferred amount of intensity was for patients to be involved to the point of having a vote when changes are
<table>
<thead>
<tr>
<th>Question</th>
<th>Patient Participation</th>
<th>Consensus Answer</th>
<th>N= (%)</th>
<th>Question</th>
<th>Family Member Participation</th>
<th>Consensus Answer</th>
<th>N= (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Should patients be involved in planning services?</td>
<td>Yes</td>
<td>38/39 (97.4)</td>
<td></td>
<td>Should family members be involved in planning services?</td>
<td>Yes</td>
<td>33/39 (84.6)</td>
<td></td>
</tr>
<tr>
<td>In planning services patients should be...</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Told about changes</td>
<td>Yes</td>
<td>37/39 (94.9)</td>
<td></td>
<td>Told about changes</td>
<td>Yes</td>
<td>32/35 (91.4)</td>
<td></td>
</tr>
<tr>
<td>Asked what they think</td>
<td>Yes</td>
<td>37/39 (94.9)</td>
<td></td>
<td>Asked what they think</td>
<td>Yes</td>
<td>32/35 (91.4)</td>
<td></td>
</tr>
<tr>
<td>Involved in discussions</td>
<td>Yes</td>
<td>32/39 (82.1)</td>
<td></td>
<td>Involved in discussions</td>
<td>Yes</td>
<td>23/35 (65.7)</td>
<td></td>
</tr>
<tr>
<td>Have a vote</td>
<td>Yes</td>
<td>27/31 (87.1)</td>
<td></td>
<td>Have a vote</td>
<td>Yes</td>
<td>19/31 (61.3)^a</td>
<td></td>
</tr>
<tr>
<td>Make decisions on their own</td>
<td>No</td>
<td>30/39 (76.9)</td>
<td></td>
<td>Make decisions on their own</td>
<td>No</td>
<td>30/35 (85.7)</td>
<td></td>
</tr>
<tr>
<td>How often should patients be involved?</td>
<td>Always</td>
<td>22/30 (73.3)</td>
<td></td>
<td>How often should family members be involved?</td>
<td>As problems arise</td>
<td>21/31 (67.7)</td>
<td></td>
</tr>
<tr>
<td>How important is it for patients to be involved in the following stages of planning services...</td>
<td></td>
<td></td>
<td></td>
<td>How important is it for family members to be involved in the following stages of planning services...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suggestion of ideas for change</td>
<td>Important</td>
<td>34/39 (87.2)</td>
<td></td>
<td>Suggestion of ideas for change</td>
<td>Important</td>
<td>31/39 (79.5)</td>
<td></td>
</tr>
<tr>
<td>Before decisions are made</td>
<td>Important</td>
<td>30/35 (85.7)</td>
<td></td>
<td>Before decisions are made</td>
<td>Important</td>
<td>30/39 (76.9)</td>
<td></td>
</tr>
<tr>
<td>After decisions are made</td>
<td>Important</td>
<td>30/39 (78.9)</td>
<td></td>
<td>After decisions are made</td>
<td>Important</td>
<td>23/32 (71.9)</td>
<td></td>
</tr>
<tr>
<td>Who should represent patients?</td>
<td>Patient reps</td>
<td>26/31 (83.9)</td>
<td></td>
<td>Who should represent family members?</td>
<td>Family reps</td>
<td>23/32 (71.9)</td>
<td></td>
</tr>
<tr>
<td>How should patients be picked for participation?</td>
<td>All interested picked</td>
<td>22/32 (68.8)</td>
<td></td>
<td>How should family members be picked for participation?</td>
<td>All interested picked</td>
<td>24/31 (77.4)</td>
<td></td>
</tr>
<tr>
<td>Which of the following factors are when picking patients to participate in planning services...</td>
<td></td>
<td></td>
<td></td>
<td>Which of the following factors are when picking family members to participate in planning services...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health</td>
<td>Important</td>
<td>38/39 (97.4)</td>
<td></td>
<td>Level of education</td>
<td>Not important</td>
<td>21/31 (67.7)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Important</td>
<td>32/39 (82.1)</td>
<td></td>
<td>Age</td>
<td>Not important</td>
<td>28/29 (71.8)</td>
<td></td>
</tr>
<tr>
<td>Level of education</td>
<td>Not important</td>
<td>12/19 (63.2)^a</td>
<td></td>
<td>Length of service attendance</td>
<td>Not important</td>
<td>21/31 (67.7)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Not</td>
<td>29/39 (74.4)</td>
<td></td>
<td>Frequency of service attendance</td>
<td>Important</td>
<td>17/31 (54.8)^a</td>
<td></td>
</tr>
<tr>
<td>Length of service attendance</td>
<td>Attendance</td>
<td>Important</td>
<td>20/31 (64.5) (^a)</td>
<td>Frequency of service attendance</td>
<td>Attendance</td>
<td>Important</td>
<td>17/31 (54.8) (^a)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-----------</td>
<td>-----------</td>
<td>----------------------</td>
<td>--------------------------------</td>
<td>-----------</td>
<td>-----------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Ability to dedicate time</td>
<td>Attendance</td>
<td>Important</td>
<td>-</td>
<td>Ability to dedicate time</td>
<td>Attendance</td>
<td>Important</td>
<td>-</td>
</tr>
</tbody>
</table>

Which of the following are important for patient representatives to take into account when providing input to planning services...  
- Their own experience  
- Discussions with other patients  
- A list of what is identified as important by patients  

Which of the following are important for family representatives to take into account when providing input to planning services...  
- Their own experience  
- Discussions with other family members  
- A list of what is identified as important by family members  

Which of the following are important in training patients for participation...  
- How the service works  
- How changes are made  
- How to work with others  
- Why patients should be involved  
- Communication skills  

Which of the following are important in training family members for participation...  
- How the service works  
- How changes are made  
- How to work with others  
- Why family should be involved  
- Communication skills  

Which of the following are important in training clinicians for patient participation...  
- How to work with others  
- Why patients should be involved  
- Communication skills  
- Decisions need to be justified if different from patient’s opinions.  

Which of the following are important in training clinicians for family member participation...  
- How to work with others  
- Why family members should be involved  
- Communication skills  
- Decisions need to be justified if different from family member opinions.  

Decisions need to be justified if different from patient’s opinions.  
- Patient opinions need to be passed on to those in the decision making process.  
- Patients need to be updated on how their opinions were included.  

- Patient opinions need to be passed on to those in the decision making process.  
- Patients need to be updated on how their opinions were included.  

\(^a\) = Consensus was not reached in this answer as the level of agreement is below 65%.

- = Not applicable
Table 6.3: Diabetes DTE Consensus Answers

<table>
<thead>
<tr>
<th>Question</th>
<th>Patient Participation</th>
<th>Consensus Answer</th>
<th>N= (%)</th>
<th>Question</th>
<th>Family Member Participation</th>
<th>Consensus Answer</th>
<th>N= (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Should patients be involved in planning services?</td>
<td>Yes</td>
<td>32/35 (91.4)</td>
<td></td>
<td>Should family members be involved in planning services?</td>
<td>Yes</td>
<td>25/34 (73.5)</td>
<td></td>
</tr>
<tr>
<td>In planning services patients should be...</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Told about changes</td>
<td>Yes</td>
<td>30/32 (93.8)</td>
<td></td>
<td>Told about changes</td>
<td>Yes</td>
<td>22/25 (88.0)</td>
<td></td>
</tr>
<tr>
<td>Asked what they think</td>
<td>Yes</td>
<td>31/32 (96.9)</td>
<td></td>
<td>Asked what they think</td>
<td>Yes</td>
<td>22/25 (88.0)</td>
<td></td>
</tr>
<tr>
<td>Involved in discussions</td>
<td>Yes</td>
<td>24/32 (75.0)</td>
<td></td>
<td>Involved in discussions</td>
<td>Yes</td>
<td>18/25 (72.0)</td>
<td></td>
</tr>
<tr>
<td>Have a vote</td>
<td>Yes</td>
<td>21/29 (72.4)</td>
<td></td>
<td>Have a vote</td>
<td>No</td>
<td>21/29 (72.4)</td>
<td></td>
</tr>
<tr>
<td>Make decisions on their own</td>
<td>No</td>
<td>23/29 (79.3)</td>
<td></td>
<td>Make decisions on their own</td>
<td>No</td>
<td>19/25 (76.0)</td>
<td></td>
</tr>
<tr>
<td>How often should patients be involved?</td>
<td>As problems arise</td>
<td>24/29 (82.8)</td>
<td></td>
<td>How often should family members be involved?</td>
<td>As problems arise</td>
<td>25/29 (86.2)</td>
<td></td>
</tr>
<tr>
<td>How important is it for patients to be involved in the following stages of planning services...</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suggestion of ideas for change</td>
<td>Important</td>
<td>27/35 (77.1)</td>
<td></td>
<td>Suggestion of ideas for change</td>
<td>Important</td>
<td>25/29 (86.2)</td>
<td></td>
</tr>
<tr>
<td>Before decisions are made</td>
<td>Important</td>
<td>29/35 (89.2)</td>
<td></td>
<td>Before decisions are made</td>
<td>Important</td>
<td>25/29 (86.2)</td>
<td></td>
</tr>
<tr>
<td>After decisions are made</td>
<td>Important</td>
<td>21/29 (72.4)</td>
<td></td>
<td>After decisions are made</td>
<td>Important</td>
<td>25/29 (86.2)</td>
<td></td>
</tr>
<tr>
<td>Who should represent patients?</td>
<td>Patient reps</td>
<td>23/29 (79.3)</td>
<td></td>
<td>Who should represent family members?</td>
<td>Family reps</td>
<td>25/29 (86.2)</td>
<td></td>
</tr>
<tr>
<td>How should patients be picked for participation?</td>
<td>All interested picked</td>
<td>24/29 (82.8)</td>
<td></td>
<td>How should family members be picked for participation?</td>
<td>All interested picked</td>
<td>21/29 (72.4)</td>
<td></td>
</tr>
<tr>
<td>Which of the following factors are when picking patients to participate in planning services...</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health</td>
<td>Important</td>
<td>28/35 (80.0)</td>
<td></td>
<td>Level of education</td>
<td>Not important</td>
<td>18/27 (66.6)</td>
<td></td>
</tr>
<tr>
<td>Level of education</td>
<td>Not important</td>
<td>23/35 (65.7)</td>
<td></td>
<td>Age</td>
<td>Not important</td>
<td>25/29 (86.2)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Not important</td>
<td>23/35 (65.7)</td>
<td></td>
<td>Length of service attendance</td>
<td>Important</td>
<td>22/29 (75.8)</td>
<td></td>
</tr>
<tr>
<td>Length of service attendance</td>
<td>Important</td>
<td>22/29 (75.8)</td>
<td></td>
<td>Frequency of service attendance</td>
<td>Important</td>
<td>23/29 (79.3)</td>
<td></td>
</tr>
<tr>
<td>Frequency of service attendance</td>
<td>Important</td>
<td>24/35 (68.6)</td>
<td>Ability to dedicate time</td>
<td>Important</td>
<td>22/34 (66.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-----------</td>
<td>--------------</td>
<td>--------------------------</td>
<td>-----------</td>
<td>--------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to dedicate time</td>
<td>Important</td>
<td>28/35 (80.0)</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Which of the following are important for patient representatives to take into account when providing input to planning services...

<table>
<thead>
<tr>
<th>Their own experience</th>
<th>Important</th>
<th>28/35 (80.0)</th>
<th>Discussions with other patients</th>
<th>Important</th>
<th>27/35 (77.1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A list of what is identified as important by patients</td>
<td>Important</td>
<td>30/35 (85.7)</td>
<td>A list of what is identified as important by family members</td>
<td>Important</td>
<td></td>
</tr>
</tbody>
</table>

Which of the following are important for family representatives to take into account when providing input to planning services...

<table>
<thead>
<tr>
<th>Their own experience</th>
<th>Important</th>
<th>23/34 (67.6)</th>
<th>Discussions with other family members</th>
<th>Important</th>
<th>25/34 (73.5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A list of what is identified as important by family members</td>
<td>Important</td>
<td></td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

Which of the following are important for patient representatives to take into account when providing input to planning services...

<table>
<thead>
<tr>
<th>How the service works</th>
<th>Important</th>
<th>32/35 (91.4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How changes are made</td>
<td>Important</td>
<td>31/35 (88.6)</td>
</tr>
<tr>
<td>Why patients should be involved</td>
<td>Important</td>
<td>29/35 (82.9)</td>
</tr>
<tr>
<td>Communication skills</td>
<td>Important</td>
<td>31/35 (88.6)</td>
</tr>
<tr>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Which of the following are important for family representatives to take into account when providing input to planning services...

<table>
<thead>
<tr>
<th>How the service works</th>
<th>Important</th>
<th>26/34 (76.4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How changes are made</td>
<td>Important</td>
<td>25/34 (73.5)</td>
</tr>
<tr>
<td>How to work with others</td>
<td>Important</td>
<td>28/34 (82.5)</td>
</tr>
<tr>
<td>Why family should be involved</td>
<td>Important</td>
<td>23/34 (67.7)</td>
</tr>
<tr>
<td>Communication skills</td>
<td>Important</td>
<td>26/34 (76.4)</td>
</tr>
</tbody>
</table>

Which of the following are important for patient representatives to take into account when providing input to planning services...

| How to work with others        | Important | 32/35 (91.4) |
| Why patients should be involved| Important | 29/35 (82.9) |
| Communication skills            | Important | 33/35 (94.3) |
| Decisions need to be justified if different from patient opinions. | Important | 27/35 (77.1) |
| Patient opinions need to be passed on to those in the decision making process. | Important | 33/35 (94.3) |

Which of the following are important for family representatives to take into account when providing input to planning services...

| How to work with others        | Important | 28/34 (82.5) |
| Why patients should be involved| Important | 26/34 (76.4) |
| Communication skills            | Important | 28/34 (82.5) |
| Decisions need to be justified if different from family member opinions. | Important | 21/35 (65.7) |
| Family member opinions need to be passed on to those in the decision making process. | Important | 26/34 (76.4) |

Which of the following are important for patient representatives to take into account when providing input to planning services...

| Decisions need to be justified if different from patient opinions. | Important | 21/35 (65.7) |

Which of the following are important for family representatives to take into account when providing input to planning services...

| Family members need to be updated on how their opinions were included. | Yes | 22/29 (79.5) |

A = Consensus not reach as the change in opinions between Round 2 and Round 3 was great than 15%
- = Not applicable
being made (psychiatry 87.1%; n=27, diabetes 72.4%; n=21). In the psychiatry DTE there was support for patient participation at all times (73.3%; n=22). A lower level of frequency was preferred in the diabetes DTE with a preference for patient participation as problems arise (82.8%; n=24).

Family participation in the planning of services was supported by the majority of participants (psychiatry 84.6%; n=33, diabetes 73.5%; n=25). In both DTEs there was a preference for family participation as problems arise to the point of involvement in discussions.

6.3.5 Representation

In both DTEs there was consensus that patient representatives should represent patients (psychiatry 83.9%; n=26, diabetes 79.3%; n=23) and family member representatives should represent family members (psychiatry 71.9%; n=23, diabetes 86.2%; n=25). A number of characteristics were identified as important to take into account when selecting representatives (See Table 6.2 and 6.3). Capacity to dedicate time was agreed as an important factor to consider for all representatives. Patient’s health and length of service attendance were identified as important for patient representatives. Frequency of attendance was important for all family member representatives and duration of attendance was also important for diabetes family member representatives (86.2%; n=25).

6.3.6 Training

Strong consensus was reached in both DTEs that training was required for patients, family members and clinicians. Training for all groups should include, how to work with others, and why patients/family members should be involved. It was agreed that patients and family members would also need training in how the service works and the process relating to how changes are made. For family members an additional element of training on mental illness in the psychiatry DTE (89.7%; n=35) and diabetes in the diabetes DTE (76.3%; n=26) were also identified as important.
6.3.7 Process

Agreement was reached in both the psychiatry and diabetes DTE that patients and family members should be involved at all stages of the decision making process, including when suggestions for changes are being made as well as before and after decisions are made. It was agreed that the individual experience of the representative, conversations with other patients and family members and pre-identified lists of what is important to patients and family members should all be taken into account when representatives are providing input.

There was also agreement in both DTEs that it was important for patient and family member opinions to be communicated to those involved in the decision making process; decisions contrary to patient or family member opinions need to be justified and patients and family members updated on how their opinions were included.

6.4 Discussion

6.4.1 Result summary and connection with literature

Arnstein’s Ladder of Participation plots the intensity of participation on a scale from being provided with information to taking on responsibility with more meaningful participation at the top of the ladder (3,18). Using this ladder there is a preference for patients in the psychiatry service to be involved to the point of having a say when changes are being made and for psychiatry family members and diabetes patients and family members to be involved to the point of taking part in discussions. This is reflective of work conducted in England on opinions on the intensity of patient participation that point towards a preference for a consultative role for patients with decision making remaining with clinicians. Research with members of the public in England reported a 68% preference for public involvement at the national level but with decision making responsibility retained by healthcare professionals (111). It is interesting to note the preference for a greater intensity of participation by psychiatry patients. This may be associated with the frequency of attendance of this cohort of every few months as opposed to every two years in diabetes or the process of involuntary committals, which can impact on autonomy and personal freedom, and the role of family members in this process.
This is the first DTE to include patients, family members and clinicians in the identification of the intensity and implementation of participation at the service level. Previous DTEs have included combinations of policy leaders, representatives, clinicians, experts, consumers and advocates (254,257). Patients, family members and clinicians, the groups included within the current PhD Study 3, are the key groups that would be involved in participation at the service level and as such the inclusion of their preferences is key to ensuring feasible and sustainable participation. This is in line with Medical Research Council (MRC) Guidelines for developing complex health interventions and the Matrix of Service User Participation, which highlights that appropriate participation methods may differ by service and issue (10,272). Focusing on the psychiatry service this also reflects the triangle of care. This is a holistic methodology that brings together carers, service users and professionals to promote safety and recovery for people with mental health issues and to encourage their wellbeing by including and supporting carers (17).

This is also the first study to focus on the role of family members in healthcare design and delivery. Family participation was favoured through family member representatives to the point of being involved in discussions. Involving families and carers is an essential part of good patient care. Families and carers play a diverse number of roles including providing emotional, social and financial support, monitoring health and well-being, providing professionals with information about the individual as well as advocating for individuals (17). As a result it is argued by some in the literature that families and carers should be considered at all stages of care-planning, decision-making and delivery, with the same thought and attention as for patients (17). Despite this data about carers contact with health systems is not routinely collected (17) and previous research on this topic has not focused on the role of family members (67).

Given the importance placed on the role of family members and the need for research in this it is interesting to note that while there was consensus in support for family participation in healthcare design and delivery there is a lower level of support than for patient participation. This is also reflected in the preferred intensity of participation in the psychiatry DTE. Consensus reached in the psychiatry DTE was for patient participation to the point of ‘having a say’ in the decision making process but for family participation to be consigned to a lower level of intensity of ‘being involved’ in discussions.
A key concern within participation is tokenism where patients or family members become involved in healthcare design and delivery but they are not listened to in implementation (234). There was strong agreement that patients and family members need to be updated on how their opinions are used and if the final decision differs from opinions provided this needs to be justified. Agreement was also reached that when providing input patient or family member representatives should use their own experience alongside discussions with other patients and pre-identified lists of what is important to patients or family members. Representatives being associated with their peer groups is supported within the literature as this can boost their competency and participation (12).

The CLEAR Framework of Factors Driving Public Participation is a process improvement tool to assess encouragement of public participation and recommendations to tackle problems. Part of the argument on which this is based is the idea that people engage depending on the resources that they have access to as well as the help they are provided with (153). High levels of consensus for training to be given to patients, family members and clinicians for patient and family participation are supportive of this. Acknowledged barriers in participation include ‘unspoken rules’ of decision making, use of technical language ‘jargon’ and group and power dynamics (15). Irish research in mental health services identified the need for support for participation to include information on how committees work and the structure of decision-making (75). Separately, a review of strategies to involve patients concluded that clinicians needed opportunities to develop their competencies in this area, particularly their communication skills (284). This is supported by both DTEs in this study which agreed that training for participation needs to include how the service and decision making-process works, how to work with others and communication skills.

Further research needs to be conducted to encourage participation based on the consensus gained from stakeholder groups in this study. Interventions need to be developed based on preferences identified for the intensity and implementation of participation. In line with guidance for participation and the Medical Research Council all stakeholders involved in participation need to play a role in this process. Developed interventions need to be implemented and evaluated. Initially there needs to be a focus
on feasibility and then on outcomes. Research needs to be expanded to additional service settings to establish if similar patterns of preferences are reflected in other service areas. Services need to assess preferences and implement standardised, effective and meaningful processes and procedures to involve patients and family members in healthcare design and delivery. This needs to be supported by policy to provide necessary essential resources and leadership required for sustainable and effective participation, avoiding tokenism. All stakeholders, clinical as well as service users, need to be involved in every stage of this process.

6.4.2 Methodological critique

A key strength of this research is the DTE methodology employed, which has been shown to be suitable for addressing real-world issues, such as participation. This methodology overcomes issues associated with group process research. Data collection is conducted anonymously through the post, with controlled feedback reducing the effects of noise that occurs in a group process (22). Attrition rates of 22.6% for the psychiatry DTE and 18.6% for the diabetes DTE are lower than attrition rates reported for DTEs conducted on similar topics of 25.2% (254), 41% and 23% (257). This research adds to the existing literature with a focus on participation at the service level, the role of family members and identification of intensity and implementation of participation from patients, family and clinicians together. Guidelines for the reporting of DTE research to ensure all necessary information is provided have been employed (201).

Stable consensus was not achieved for all questions. Four questions in the psychiatry DTE remained below the required 65% level of agreement. In the diabetes DTE one question remained below the 65% level of agreement and a further three had more than a 15% change in opinions between Round 2 and Round 3. However, all questions not achieving consensus has been reported in other similar DTEs (254). The samples for both DTEs are highly educated (See Table 6.1). This is due to the inclusion of a cohort of clinicians. This is important to note, due to the reported association between a high level of education and support for participation (155).
6.4.3 Implications and conclusion

There is strong support for patient and family participation with patients having a vote in the decision making process and family members being involved in discussions. Patient and family members representatives are preferred, with involvement at all stages of the decision making process supported by training. DTEs are a successful method of achieving consensus on the level of intensity and implementation of participation within a sample of patients, family members and clinicians. Further research needs to be conducted to develop and test interventions based on the consensus gained from stakeholder groups to encourage participation.
Chapter 7:  
Development of an intervention to encourage greater patient and family participation in healthcare design and delivery in a psychiatry and a diabetes service

7.1 Introduction

Study 4 aimed to develop, implement and test the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult outpatient psychiatric service. Study 5 aimed to develop, implement and test the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult outpatient type 2 diabetes service. This chapter will discuss the development of both of these interventions.

The Medical Research Council (MRC) Guidelines for development of complex health interventions outline best practice for a systematic approach to the development of complex interventions in healthcare (265). They were first published in 2000 to help overcome the practical and methodological issues faced by complex health interventions (285,286). Complex interventions are those with multiple outcomes, groups, behaviours and components that require tailoring to local environments (265). The guidelines include a phased approach with the best available evidence and appropriate theory employed in development, implementation, evaluation and dissemination. Following an update in 2008 these guidelines are now more suited to a wider array of methodologies, allow for greater flexibility in the process of development while emphasizing the importance of tailoring interventions to specific contexts (265,287). This updated version has been criticised since for not fully acknowledging the complexity of the health care setting and complexity science (288,289) and not being suitable for the extent of change that interventions can undergo during implementation (290,291). Despite this, these guidelines have been widely cited and employed in a wide array of research, grant applications and educational material (287). As such these guidelines have been employed in this PhD as particularly following the update in 2008 they are now suitable to the methods employed.
There are an array of methods to encourage patient and family participation in healthcare including questionnaires (52), involvement in development of information material (73), workshops (16), forums (74), representatives (75), civic juries (76), setting of priorities (77) and involvement in research (234). However, no clear consensus has been reached on the best ways to achieve strong and lasting participation (16) with the appropriate intervention depending on the level of intervention (patient, service or national), as well as the intensity and frequency preferred. Based on patient, family and clinician preferences for the intensity and components of participation in Chapter 6 the interventions focused on in this chapter include forums and representatives (See Chapters 3 and 6 for further detail).

Forums have been employed in a variety of settings to encourage participation in healthcare decision making. For example, forums have been used in England to encourage patient participation within the NHS (292) and in Chicago to aid patient, staff and family participation (293). Forums are often associated with a specific service or illness, with forums often being most influential at the ‘grass root’ level (294). In the United States partnership groups were established to enable joint working between cancer service users and healthcare professionals to improve services (294). Forums have contributed to positive care experiences (293), improving the quality of information provided, access to services and care environments (294). This method of participation enables changes to be tracked over time, providing an opportunity for most people to participate, with well informed members and a solution focused approach (281). Patients and family members who have participated in forums have expressed great joy in having their voices heard in order to better the patient experience for others (293). However, it is important to be aware that while forums provide an opportunity for all patients and family members those who attend are a largely self-selected group and as such may not reflect the wider population unless proactive steps are taken to broaden membership (292). There is a need to be clear about the purpose of forums (295), particularly to avoid dropout which has been reported to be 30% in the first year (295) and to ensure participants feel that they are adding value to planning. Patient participants in a forum in England to aid planning of a primary care team reported not feeling they had added any value until 18 months into the forum (295), suggesting that a longer period of time is required to enable forums to mature and have an impact.
Patient, family and community representatives have been employed in numerous settings including on advisory committees (75), as part of a review team for assessing accreditation of Irish healthcare organisations and on committees to plan educational events on healthcare improvement and PPI as well as healthcare improvement projects in London (65). There is no right or wrong way to engage the public and many different opinions exist on who and what constitutes a community representative (292). The use of representatives has been found to encourage debate, ensure accountability, introduce greater objectivity and credibility as well as a medium to long-term perspective (10). However, this requires orientation and support with organisational commitment to meaningful participation and can be expensive (10).

7.2 Methodological Highlights

- The MRC Guidelines for development of complex health interventions were employed in the development of the intervention. A prototype intervention was developed based on the literature, theoretical framework and findings from previous studies in this PhD. Supervisors (CD and JB), the patient and family representative (CC) and the contact consultant from the service provided feedback on the prototype.

- In the psychiatry service the intervention developed was two patient and family representatives attending monthly sector management meetings. Representatives were backed with feedback from the wider patient and family populations on what is important to them in the service, what is good and what is bad. Clinicians were provided with optional training in advance of representatives attending meetings. Additional detail on the intervention developed is provided in Appendix L.

- In the diabetes service the intervention developed was two patient and family representatives attending meetings with the clinical team. Representatives were supported by a patient and family forum providing feedback on what is important, good and bad in the service in the opinions of the wider patient and family member populations. Representatives and clinicians were provided with training in advance of meetings taking place and provided with support throughout the
intervention. After representatives met with clinicians the patient and family forum was updated on how the opinion of patients and family members was used as well as the response from the clinical team. Additional detail on the intervention developed is provided in Appendix R.

- In the psychiatry service feedback on the prototype intervention was provided by the MDT (n=8) through a focus group and meetings with the research team as the intervention developed. Interviews were conducted with patients (n= 5) and family members (n= 2) (See Appendix M: Study 4 and Study 5 intervention development sample by service, stakeholder group and interview type). A patient and family organisation who became involved through the MDT also provided feedback on the psychiatry prototype intervention.

- In the diabetes service feedback on the prototype intervention was provided by the MDT (n=7) through a focus group and meetings with the research team as the intervention developed. Interviews were conducted with patients (n= 5) and family members (n= 4) (See Appendix M: Study 4 and Study 5 intervention development sample by service, stakeholder group and interview type).

- Purposeful sampling was employed. A purposive sampling strategy has been employed in a number of similar studies in the development of interventions (34).

- Interview schedules/topic guides were developed based on a literature review, previous studies in this PhD and the intervention prototypes with feedback from PhD supervisors (CD & JB) and the patient and family representative. Topics included opinions on the overall proposed intervention, recruitment, training of patients, family members and clinicians, utilisation of feedback and communication with the wider patient and family member populations (see Appendix N: Study 4 and study 5 intervention development interview schedule).

- Data collection was conducted between March 2017 and May 2017 within both services. This was conducted by the researcher (LW). Interviews and focus groups were audio recorded and lasted on average 15 minutes.

- Thematic analysis was employed as it is in keeping with the aims of this study and has been employed previously in the development of complex behaviour change interventions in healthcare (34). This entails searching and identifying common threads that extend across all interviews (296). Themes were not predetermined
but emerged from the data (see Appendix O: Study 4 and study 5 intervention
development coding frame).

- No software was used during data analysis.

Further details on all aspects of the methodology employed are in Chapter 3.

7.3 Results

7.3.1 Response rates and demographics

Psychiatry
A total of 17 participants were asked to take part in this study with 15 agreeing giving a
response rate of 88.2% in psychiatry. Flow charts for patient, family member and clinician
samples are presented in Appendix G.

The patient sample (n=5) included males (n=3) and females (n=2) and the family sample
(n=2) also included a gender mix. The clinician sample (n=8) included a mixture of males
(n=2) and females (n=6), duration of employment from 5 months to over 20 years as well
as different disciplines including nurses (n=5), psychiatrists (n=2) and allied health
professionals (n=1).

Diabetes
A total of 22 participants were asked to take part in this study from the diabetes service
with 16 agreeing to take part giving a response rate of 72.7%. Flow charts for patient,
family member and clinician samples are presented in Appendix G.

The patient sample (n=5) included males (n=3) and females (n=2) and the family sample
(n=4) included males (n=1) and females (n=3). The clinician samples (n=7) included those
with a duration of employment from 2 years to over 20 years as well as different
disciplines including nurses (n=5), and allied health professionals (n=2).
7.3.2 Intervention selection

The interventions selected and prototypes developed were based on information about the context, setting and patient, family member and clinician preferences identified in previous studies within the PhD as well as existing evidence.

Previous studies in this PhD study one and study two of the PhD, discussed in chapters 4 and 5, established the current intensity of participation and support for greater participation in both services. Questionnaires conducted with 738 patient and family members from the psychiatry and diabetes service revealed that patients and family members are not involved in healthcare design and delivery beyond being provided with information about services. They typically are not asked what they think about changes, involved in discussions or given an opportunity to have a say when changes or plans are being made (33). In the psychiatry service planning of the service and any potential changes are typically discussed and planned from the monthly sector management meeting that consists of representatives for each discipline within the multidisciplinary team (MDT) and administration staff. In the diabetes service there is no focus on making changes in the service as this is not something staff feel they have any control over. If suggestions for change do arise this typically happens in an informal manner.

Greater patient participation is supported by 81.6% (n=226) of participants in the psychiatry service and 79.3% (n=311) of participants in the diabetes service. Greater family member participation is supported by 68.3% (n=201) of participants in the psychiatry service and 44.7% (n=173) of participants in the diabetes service. This support is also reflected by clinicians and policy leaders in interviews and focus groups.

‘I think that patients know best and that patients and the public have so much to offer in terms of their own experience ... because of the particular issues of concerns and conditions. They bring a sort of dimension that maybe professionals have not thought about.’ (Janette, Policy leader)

‘It is their [patients] service, it is kind of crazy that they haven’t been involved really... It is very hard to make those decisions without people on the ground
being involved.’ (Margaret, Psychiatry, Clinician)

Study Three, discussed in Chapter 6, identified preferences for the level of intensity of participation and key elements of the interventions through Delphi Technique Experiments (DTEs) with patients, family members and clinicians (297). Key elements of the interventions identified included participation through representatives selected based on key characteristics, training for all stakeholder groups and representative input based on feedback from the wider patient and family populations with updates on how their input was utilised. The level of intensity preferred for patients was to the point of having a say when changes are being made and for family members to be involved in discussions.

Existing Evidence
Preferences for the intensity and components of an intervention to encourage participation indicated in previous studies in this PhD excluded many possible interventions, most often due to not being intense enough or being a one-off method of participation (See Appendix A: Intervention options). The two remaining suitable interventions were forums and representatives.

7.3.3 Intervention development
An overview of topics discussed in interviews and focus groups is presented in Figure 7.1.

Participants were happy with the interventions developed based on the literature and previous studies in this PhD.

‘I think it is a great idea because we can always improve the service and it would be nice to get it from a visitor, or a participant in the service, as opposed to ourselves because we … we can be a bit closeted in our perspectives.’ (Megan, Diabetes, Clinician)

‘It sounds like a good idea…it gives more of an understanding and an input from the patient’s and the families’ point of view, I suppose it bridges that gap a little bit.’ (Ben, Psychiatry, Patient)
Figure 7.1: Summary of research themes as identified by participants relating to the prototype interventions

Context - Societal, Organisational and Individual Factors

Prototype Interventions

- Positive feedback
- Concerns e.g. ability to implement changes and manage expectations

Opinions

- Link with wider populations
- Training and support
- Representative and clinician meetings
- Forum recruitment (diabetes only)
- Forum meetings (diabetes only)

Intervention elements discussed

Example changes discussed

- Feedback provided to clinicians in advance, multiple methods of communication with wider populations
- Representatives and clinicians completing training together, timing constraint issues.
- Structure psychiatry agenda so non-relevant topics at the end of the meeting
- Multiple methods of recruit including new ideas of letters to local GPs, concerns about clinician involvement in recruitment.
- Patients and family have forum meetings together, limited clinician involvement to show support

Pilot Interventions
However, some concerns were raised about the detail within the interventions. For example, the ability of the service to implement changes and the need to manage expectations.

‘I wouldn’t have a problem with it at all, em, I think the problem is once you have made a decision which is quite difficult to do it doesn’t seem to be implemented anyway regardless of whether patients are involved or not.’
(Julie, Psychiatry, Clinician)

These concerns fed into the areas of the intervention that were tailored based on stakeholder feedback.

Link with wider patient and family populations
It was important to participants that there was a link between patient and family representatives and the wider patient and family populations. This was seen as ‘the whole point’ (Mabel, Psychiatry, Clinician) of the interventions and that it would provide ‘a general overview kind of what way the system works, any concerns, what can be changed going forward’ (Jack, Psychiatry, Patient) and ‘help other patients and family to understand what is happening’ (Larry, Diabetes Patient).

Feedback from patients and family members centred around three questions: ‘What are the top three most important things to you when you come to the psychiatry service/the diabetes service?’, ‘What are the top three good things in the psychiatry service/the diabetes service?’, ‘What are the top three bad things in the psychiatry service/the diabetes service?’. Suggested questions were based on research previously conducted within the catchment area of both services in which similar style questions worked well. Participants were provided with the suggested list of questions that feedback would be centred on and asked what, if any, additional questions should be asked. Suggestions included:

‘Is it the right kind of treatment that they are getting? Are they happy with their medication?, Are they happy with the service?’ (Jack, Psychiatry, Patient).
Additional questions often overlapped with those suggested and overall participants felt suggested questions were sufficient. ‘No I think you have got everything covered’ (Sam, Psychiatry, Patient).

In the diabetes service clinicians were keen for a summary of the patient and family feedback to be given to the clinical team in advance of meeting with representatives.

‘I think it probably would be a good idea just to kind of ponder over it and you know, so that you are not put on the spot thinking ‘is this realistically possible?’ then you could even do some work in advance to see if you needed to talk to somebody or whatever’ (Chloe, Diabetes, Clinician)

Participants also felt that it was important that the circle was completed and the wider populations updated on how their opinions were used. ‘They should let them know what happened at the meeting so if another meeting comes up they know what happened’ (Eliza, Diabetes, Family member).

In psychiatry, social media, an optional mailing list and verbal contact perhaps through the service Eolas group (a family support group established within the service in late 2016) were suggested as additional ways to inform the wider populations. More passive methods of communication such as posters and leaflets were queried as ‘I think leaflets and posters can go astray’ (Helen, Psychiatry, Clinician) and ‘I don’t think people read anything up there [notice board]’ (Neasa, Psychiatry, Patient).

In diabetes, an informal written update from representatives with time for questions was suggested. A written report was preferred as ‘you have written down in front of you what they were saying’ (Cassie, Diabetes, Patient) and it ‘would be more ... informal and it won’t look like it is a big thing that is happening’ (Larry, Diabetes, Patient). The importance of any written report being clear was emphasised so ‘that it is understood by everybody and...there is no room for misinterpretation’ (Roisin, Diabetes, Clinician). It was also suggested that this could ‘serve as a contract type thing. We are committing to do or to consider a, b and c... it always makes it more official if you have it in writing’ (Megan, Diabetes, Clinician). An opportunity to ask questions was also key as attendees ‘might feel
they are wasting their time if they don’t get to ask questions’ (Max, Diabetes Patient).

More traditional methods such as posters and leaflets were also preferred.

‘I am not on Facebook or online or anything like that so I suppose a leaflet would be enough. I am sure there are a lot of elderly people here today that don’t do Facebook or online’ (Eliza, Diabetes, Family member)

‘I think the notice maybe because you may not get all of the family members together so at least if you say a notice when you were up here for anything, it might not be for a diabetic clinic you could be coming here to see somebody, for a visit’ (Gwen, Diabetes, Family Member)

In both services the issue of confidentiality was raised in relation to the link with the wider population to ensure individual patients were not named or that confidential details about the service were not disclosed.

‘The issue could be to ensure dignity and confidentiality, that you know you could have somebody saying ‘Well I know so and so said that their experience was...’ Just to keep it very clear and keep that dignity. Say that a representative came, no names’ (Katherine, Diabetes, Clinician)

Training and support
Training and support was a key component of the interventions developed. Training was included for patients, family and clinicians. It was felt that this would enable all those involved in the intervention to ‘have the same understanding and training ... so they would be on the same page’ (Ben, Psychiatry, Patient).

‘The doctors could come down and the representatives could come up a bit so that they meet in the middle.’ (Jean, Diabetes, Patient)

Patients felt that this would make them ‘more secure, if they were able to do the same training as the doctors and nurses’ (Max, Diabetes, Patient). Clinicians felt that this would alert them to the language that they use as well as the decision making process.
'It would be very helpful really in a sense...to...kind of, even toning down the language that might be used at meetings.' (David, Psychiatry, Clinician)

'A room full of professionals, particularly that has worked together for a long time, a meeting can lose focus very, very quickly and unintentionally it can become a little bit casual and I think if we have outside people coming in we do need to learn to... structure and be much more focused in our decision making' (Dorris, Psychiatry, Clinician)

The idea of patients, family members and clinicians doing training together in advance of representatives and clinician meetings was explored. Many felt that this would be a good idea as the training was similar and it would enable all those taking part in representative and clinicians’ meetings to get to know each other more informally.

'I suppose that would be a good idea... you are not training them separately so you are not double jobbing' (Eliza, Diabetes, Family member)

'I think that it is a good idea [representatives and clinicians training together]. Cause it is similar training that they are going to need and it is probably going to make them more familiar with each other and it is probably going to help generate more discussion when it comes to the meeting' (Chloe, Diabetes, Clinician)

However, not everybody believed that there would be any benefit from training being conducted together. 'I can’t see it really making a difference whether they do the training together or not' (Gwen, Diabetes, Family Member). It was also noted that there would need to be time for clinicians to think about how they feel about the intervention as part of the training and support provided.

'I do think that at least everybody should be asked to consider what they would think about an outsider coming into the room, how it would make them feel and so that they don’t come across in a negative fashion when we do have a representative here in the room’ (Megan, Diabetes, Clinician)
Most felt that training of ‘an hour would be enough’ (Neasa, Psychiatry, Patient). Challenges in securing a time that would suit all members of the clinical teams was noted.

‘I think probably to get us all in the one place at the one time unless you are going to plan this for the distant future for when clinics haven’t’ already been assigned you are probably going to think about the Wednesday MDT meeting but eh, I think you will need to get buy in from all disciplines that this is the forum to do that’

(Megan, Diabetes, Clinician)

Representative and clinician meetings
An essential topic of discussion relating to the representative and clinician meetings centred on two representatives attending together. The main reason why participants were in favour of this was they felt that this would provide moral support for the representatives.

‘It would be support for one another, just in case they are nervous about what they are doing, they would be support for one another’

(Cassie, Diabetes, Patient)

‘I think that they [representatives] would probably have some mutual support rather than walking into a room of professionals that they don’t know.’

(Dorris, Psychiatry, Clinician)

This would strengthen the input of representatives, ‘Well I suppose it kind of strengthens the point’ (Jack, Psychiatry, Patient). Participants felt it would help to ensure that all aspects of patient and family opinions are outlined to the clinical team ‘If one forgets something then the other person will remember’ (Jean, Diabetes, Patient) and make it easier for the representatives to take on board what the clinical team are saying, ‘You don’t take everything in on your own’ (Sam, Psychiatry, Patient).

In psychiatry as it was proposed that representatives would attend the existing sector management meeting it was noted there would be issues discussed that may not be
relevant to representatives or that may require discussion by only the clinical team. To work around this it was suggested that these issues would be moved to the end of the agenda so that representatives could leave early.

“When we are having sector management meetings we do need a closed session without patients being there because there will be governance issues within the management team that will need to be discussed just among ourselves’
(Julie, Psychiatry, Clinician)

“It usually works better if they come in at the same time and then they leave early’
(Julie, Psychiatry, Clinician)

When asked about frequency of meetings with the clinical team for the diabetes intervention some found it difficult to know how often meetings would need to take place, ‘God I don’t have a clue...I have never been involved in anything like that’ (Eliza, Diabetes, Family Member). Preferred frequencies provided varied from monthly to biannually. When considering the frequency of meetings participants took into account the current pace of change in the service and the need to keep things moving and for attendees to remember discussions.

‘I think once a month... I feel that would be enough’ (Cassie, Diabetes, Patient)

‘I’d say about every three to six months to get the feedback on what was happening because I feel if it went longer everyone might not remember what they have discussed’ (Gwen, Diabetes, Family Member)

‘I don’t think you would need to meet that often, I would say quarterly like. Because not a lot is going to change in a short space of time and you know things are slow to change’ (Chloe, Diabetes, Clinician)
Recruitment
A key topic of discussion in interviews and focus groups relating to the diabetes service was recruitment of attendees for the forum. The researcher (LW) outlined suggestions for recruitment and asked for participants’ opinions on suggested methods and ideas for additional methods of recruitment. Suggested methods of recruitment included posters and leaflets in service waiting areas both on notice boards and being handed to patients, advertisement through local and patient organisations as well as alerting those within the service who expressed an interest in participation throughout the research. Participants were happy with the suggested methods of recruitment overall feeling that they were ‘Very good’ (Eliza, Diabetes, Family Member) and saying that ‘I always sit here and read the notices’ (Jean, Diabetes, Patient).

There was discussion, particularly among the clinicians, about how leaflets would be distributed within the service. It was typically felt that leaflets would need to be handed to people for them to be read. ‘I think you physically need to hand them leaflets because I don’t think everybody reads things on the wall.’ (Chloe, Diabetes, Clinician). Patients felt clinicians advertising the forum was an endorsement ‘If the doctor mentions it to you, you know it is a good idea’ (Jean, Diabetes, Patient). However, clinicians were concerned about the impact that this would have on the type of people that would attend.

‘I suppose the handing out of the leaflets will give the message that we are up for this, we think this is a great idea. But I wouldn’t like us to feel that we are canvassing as in ‘I want you to come to this’. I do think that for true mixture of people you need everybody to be able to come’ (Megan, Diabetes, Clinician)

Secretaries were suggested as an option for distribution ‘Would there be any of the secretaries as they arrive as opposed to us?’ (Roisin, Diabetes, Clinician). Leaving leaflets on seats on the waiting areas was also suggested, ‘What about leaving leaflets on chairs as people sit down?’(Megan, Diabetes, Clinician). However, this had previously been shown to be ineffective, ‘We have done that before and they sit on them!’ (Willow, Diabetes, Clinician). Putting leaflets in with appointment reminder letters was also proposed, ‘The leaflet couldn’t be slotted in their letters?’ (Roisin, Diabetes, Clinician).
Recruitment through GP services was also suggested, ‘People could get a note from their GP’ (Jean, Diabetes, Patient). It was felt that this would enable additional recruitment outside of the service.

‘What about the GP practices that send in, what about leaving leaflets there for family members rather than concentrating solely on the clinic here?’
(Willow, Diabetes, Clinician)

Patient and family forum meetings

Patients and family members together
Discussion in interviews and focus groups in the diabetes service often centred around issues related to how the patient and family forum would be run. A key question posed was whether there needed to be a separate forum for patients and family members or if they should attend one forum together. Clinicians felt that separate groups would ‘probably lead to more open discussion’ (Chloe, Diabetes, Clinician). However, in general patients and family members were supportive of having both groups together in one forum so family members can know more about what is happening ‘Family would know more about what is going on’ (Jean, Diabetes, Patient) for both groups ‘So they have an idea of what is going on for you as well as what is going on for them’ (Cassie, Diabetes, Patient) and be more involved ‘It is good because family members are involved so they can be involved in whatever is going on’ (Eliza, Diabetes, Family Member). However, it was important to family members that patients could retain their privacy if they wanted and family members would only have to attend if they want. ‘I think that is a very good thing, provided they [family] want to…and the patient may want privacy as well’ (Aine, Diabetes, Family member).

Clinician involvement
The role of clinicians in the patient and family forum was discussed. Some patients and family members felt that clinicians in attendance at the forum could be a source of information, answering questions, ‘They [clinicians] would be able to answer questions’ (Eliza, Diabetes, Family Member), providing feedback, explaining how things work and reminding attendees what was discussed at previous forum meetings.
‘I have been in a group before, it was for people who were married to people with schizophrenia and there was a nurse always sitting in taking notes. We never had a problem with it...whatever we were saying among one and other the last day if we forgot the nurse was able to remind us of what we did say and then we could continue what we were saying and finish the conversation’

(Cassie, Diabetes, Patient)

However, the benefit of the clinician in this instance was in taking notes and it was noted that this role could be done by anybody, including another patient.

Others felt that there was no need for clinicians to attend the forum, ‘No, there is no need for that’ (Gwen, Diabetes, Family Member). Concerns were raised about the impact of clinician attendance on open discussion ‘people mightn’t feel as free to speak with the doctor being there’ (Max, Diabetes, Patient). It was suggested that clinician attendance could be limited to opening the forum. ‘I think it is a good idea even just to introduce it and why you are doing it and just to explain the purpose of it all’ (Chloe, Diabetes, Clinician).

Timings
The timing of forum meetings was important to increase attendance. It was noted that we would need to think about when children are in school, how people will get to the meetings, patients and family members attending together and the timing of other appointments.

‘I live in [a local area] and I don’t drive so John would have to take me’
(Eliza, Diabetes, family member)

‘I can’t see any issues as long there was an appointment and things were arranged to suit that. It would have to be the two of us coming together so that I could get a lift’
(Gwen, Diabetes, Family Member)
In general people were supportive of meetings taking place around midday ‘I would rather morning times myself... about 12’ (Eliza, Diabetes, Family Member). It was felt that this was best for people to fit in around their schedules and other commitments.

7.4 Discussion

7.4.1 Discussion of findings

Interventions to encourage greater patient and family participation were developed in this study for a psychiatry service and diabetes service. The interventions were selected based on existing literature and information from previous studies in this PhD on the context and preferences for participation. This is in line with the Matrix of Service User Participation (10,272) which illustrates the appropriate method for participation may vary depending on the service and the issue being discussed. The involvement of key stakeholder groups in setting the intensity of participation and their role has been identified as one method to ensure clarity of purpose, one of the key ingredients of participation (298). Both interventions included multiple components. The psychiatry intervention was patient and family representatives backed with feedback from the wider populations attending sector management meetings. The diabetes intervention was patient and family representatives, supported by a forum, attending meetings with the clinical team. The Matrix of Service User Participation acknowledges that often more than one method is required to encourage participation (10,272).

Both interventions developed included a link between representatives and the wider patient and family member populations through feedback in the psychiatry service and a forum in the diabetes service. It was felt that this was the whole point of the interventions, providing an overview and understanding of the service and what patients and family members think and enabling reporting back of what has been done in a confidential manner. Similarly, research on the key ingredients for effective participation in healthcare highlighted that representatives having their own experience as well as access to a wider group with experience of the service who can be representative of the overall population adds credibility and legitimacy (269). Feedback provided to representatives was from both patients and family members that did and did not attend forum meetings. This is supported by work in England that highlights differences in the
members and opinions of forums when compared with the general population and the need to proactively seek the views of marginalised groups, particularly when forums are being used to inform planning and delivery of services (292).

The CLEAR framework specifies that people participate when they have the resources and knowledge to participate (153), with the skill and capacity of participants identified as one of the key barriers to participation (75). Both interventions included training for patient and family representatives, as well as clinicians. Topics included the importance of participation, how the service works, how changes are made including confidentiality and communication relating to how to work with others. Participants viewed this as important, to have all stakeholder groups on the same page with benefits for representatives and clinicians. The need for training for participation has been acknowledged by the NHS (299) and the WHO (81), contributing to representatives’ sense of credibility, legitimacy and ability to contribute as well as providing an opportunity for representatives to ask questions in a non-threatening environment (269). The importance of building staff capacity has been highlighted in interviews with staff and patient representatives from healthcare organisations that have been successful in improving the patient experience (300). The WHO policy framework for people-centred healthcare identifies the importance of communication skills for meaningful participation in decision making (81). Training on the importance of patient and family participation will be essential in assisting an organisational cultural shift towards a ‘patient focused’ attitude culture (50).

A key component of both interventions was meetings between representatives and clinical teams. Participants supported representatives attending in groups of two for moral support. Representatives attending in groups of two is recommended from research within the Irish mental health services which assessed barriers to participation which included representatives feeling intimidated when attending large committee meetings as the only patient (75). In the psychiatry intervention representatives would attend the existing sector management meeting. In the diabetes service there was discussion on how best to incorporate meetings with representatives and the clinical team within the current schedule. Building initiatives into existing processes and structures such as these can help to ensure sustainability (301).
Much of the discussion on intervention development in the diabetes service focused on the patient and family forum. Overall, participants were happy with recruitment ideas and made some additional suggestions, which were incorporated such as recruitment through local GPs. This is in line with advice for participation which recommends multiple methods of recruitment (302). Participants agreed on midday as the best time for forum meetings to take place. It was important to ask participants about meeting timings as using methods of involvement that accommodate life and work demands are essential for keeping participants engaged and interested (282). The pros and cons of clinician involvement in forum meetings were identified. The involvement of clinicians in forums have been demonstrated in Scotland where community forums were coordinated by NHS staff to whom forum members had phone access (292). This role is also key as the WHO have noted the important of leadership, which could be provided by clinicians, for successful participation (81).

7.4.2 Strengths
MRC guidelines were employed in the development and reporting alongside the Consolidated Criteria for Reporting Qualitative Studies (COREQ): a 32 item checklist (191) as MRC guidelines recommended employed reporting guidelines in line with the methodology employed. All stakeholder groups that have a role to play in the implementation of the intervention were involved in development of these interventions. The prototype interventions were based on the literature alongside preferences and context provided in previous studies in this PhD, strengthening the input of key stakeholder groups and fit of the intervention to the specific contexts and services which are important for complex interventions to work best (265). Findings of this research add to the existing body of literature with two interventions developed based on the preferences of key stakeholder groups. The researcher (LW) was involved in all aspects of the development of the intervention, including previous studies in this PhD on the context and preferences for participation adding to the understanding of the topic and underlying issues.
7.4.3 Limitations

A potential limitation relating to the clinician samples was the impact of hierarchical role. A senior clinician felt that junior clinicians or clinicians from another discipline may not speak openly in front of more senior clinicians. The researcher (LW) sought input from all disciplines and clinicians who took part in focus groups and emphasised the importance and value of input from people with varied and different backgrounds and levels of experience. Follow up interviews were also offered to those who felt they had more to add or who the focus group format did not suit. It is important to note that the clinician focus group in the diabetes service included nurses and allied health professionals: no doctors took part. Interviews and focus groups were offered to all doctors working in the service on numerous occasions. Due to time constraints they did not take part. However, the diabetes service is primarily a nurse led service. In addition, doctors fed into the development of the intervention through two meetings that provided an overview of the intervention with an opportunity to ask questions or suggest changes as well as through previous studies in this PhD which informed the development of the intervention.

7.4.4 Conclusion

MRC guidelines for the development of complex interventions were employed in the development of two interventions to encourage greater patient and family participation: one for a psychiatry service and one for a type 2 diabetes service. Both interventions were based on the existing literature, context and preferences identified in previous studies in this PhD and refined through interviews and focus groups with patients, family members and clinicians. Areas the interventions focused on during development included linking with the wider patient and family populations, representative and clinicians meetings, training and support and running forums. Both interventions need to be implemented and tested with a focus on feasibility and acceptability, including assessment of the impact of involvement in the development process. This research demonstrates the valuable insights and input that patients and family members can have and as such patients, family members and clinicians need to be involved in all aspects of any further related research.
8.1 Introduction

A core value of mental health policies in Europe and the US is to reduce institutional forms of care, develop community-based mental health services and integrate people with mental health disorders in the community. As an essential component of this shift to care in the community alongside the emergence of the recovery model greater emphasis is now placed on participation of patients, families and carers (303,304). This is complemented and reinforced in legislation in numerous European countries such as Norway, Finland and France. In Ireland, participation was supported by the 2008-2013 National Strategy for Service User Involvement (6). Specifically relating to mental healthcare services sentiments supportive of participation are expressed in ‘A Vision for Change’ (209). Published in 2006 this is the current national policy for mental healthcare services in Ireland. The first recommendation in this policy is that involvement of service users and their carers should feature in every aspect of service development and delivery (209). More recently the 2015 HSE National Service Plan priorities for mental health services included ensuring that the views of service users are central to the design and delivery of services (61). Following this in 2016 ‘Partnership for Change’ (210) outlined plans made with patients, family members and carers on how they should be involved in the development of services.

Support for participation within mental healthcare services is evident and some plans are outlined in policy on how this should be done. However, previously identified and discussed barriers and challenges still need to be overcome (See Chapter 1 and 6). Barriers include; low levels of education, health literacy, limited availability and sharing of understandable and culturally appropriate information and educational materials, the lack of population health and public health focus in the health system as barriers to participation (81). Interviews with service users of Irish mental healthcare services identified the need for positive organisational culture and arenas of participation as
additional areas of concern (75). All of which are underpinned by a lack of consensus on understanding of the purpose and components of participation.

Study 4 aimed to implement and test the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult outpatient psychiatry service. The psychiatry pilot intervention developed was patient and family representatives attending monthly management meetings. However, it was not possible for this intervention to be implemented. This chapter outlines a process evaluation with interviews and focus groups conducted to assess difficulties encountered in attempting to implement this intervention.

8.2 Methodological Highlights

- A qualitative methodology was employed with IPA of focus groups (n=1) and interviews (n=4) with clinicians (n=8) and a patient and family representatives (n=1).
- Treatment as usual in the psychiatry service includes a month sector management meeting for the discussion on healthcare design and delivery. There is no formal process to involve patients and family members in these discussions, with no patients or family members in attendance.
- The proposed psychiatry pilot intervention was two patient and family representatives attending the sector management meeting in the psychiatry service. Further details on the intervention protocol are provided in Appendix L: Proposed psychiatry pilot intervention protocol.
- Participants who were involved in the development and key steps in the attempted implementation of the intervention were recruited using purposive sampling.
- Interview schedules were developed based on a literature review and assessment of key steps in the development and attempted implementation of the intervention. Topics included opinions on the intervention, development of the intervention, difficulties encountered in intervention implementation and participation beyond the research (See Appendix P: Study 4 process evaluation interview schedules).
• Data collection was conducted by the researcher (LW) in October 2017. All interviews and the focus group lasted an average of 25 minutes.

• IPA was employed in analysing interviews and focus groups. Patterns in the data were clustered into a thematic structure which was reviewed regularly with recoding as necessary as this coding frame was applied to all transcripts (See Appendix Q: Study 4 process evaluation coding frame). Connections between emergent themes were identified to enable the combination of separate themes into superordinate and subordinate themes as illustrated in Figure 3.3.

• No software was used during data analysis (See Section 3.7.2).

Further details on all aspects of the methodology employed are in Chapter 3.

8.3 Results

8.3.1 Response Rates

The response rate for the process evaluation sample was 81.8% (n=9/11). One clinician was unavailable to take part and one patient and family representative wanted to get approval from the patient and family organisation before agreeing to take part, which was not possible to obtain within the timeframe of the research.

8.3.2 Demographics

The sample included clinicians (n=8) and a patient and family representative (n=1). This included a mixture of males (n=4) and females (n=5) as well as a variety of disciplines including nursing (n=4), psychiatrists (n=2) and allied health professionals (n=2).

8.3.3 Intervention implementation

There are a number of steps and decisions essential to the attempted implementation of this intervention. An overview of these steps is provided prior to discussion by participants (Figure 8.1).
**Figure 8.1: Gantt chart intervention attempted implementation overview**

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<th><strong>Developments within the service</strong></th>
<th>Feb</th>
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<td>Intervention presented to the contact consultant</td>
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<td>Intervention updated to reflect contact consultant changes</td>
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<td>Patient and family development interviews conducted</td>
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<td>Clinician development focus group conducted</td>
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<td>Intervention updated to reflect feedback from patients, family and clinicians</td>
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<td>Intervention updated to reflect changes requested by clinicians</td>
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<td>Intervention updated to recruit representatives without ACORN</td>
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<td>Representatives recruited and trained</td>
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<td>Sector management meeting 1 not held as quorum not reached</td>
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<td>Sector management meeting 2 cancelled</td>
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<td>Clinicians alerted that the intervention can not be implemented</td>
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<th><strong>Developments with the HSE</strong></th>
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<td>Research approved- Senior Manager Mental Health Engagement</td>
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<td>Further HSE approval requested by clinical team</td>
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<td>Alerted to clinical team contact with the patient and family organisation</td>
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<td>Organisation happy to provide representative for PhD research</td>
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<td>Organisation decide not to provide representatives anymore</td>
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A draft of the psychiatry pilot intervention protocol was first circulated to the contact consultant on the clinical team to provide initial feedback in February 2017. This was approved subject to further inputs from patients, family members and clinicians. Following this, two developments emerged which were outside the scope and function of the PhD.

The first development included HSE Mental Health Engagement, who had appointed a lead for mental health engagement in the area in which the psychiatry service is based. This stemmed from the ‘Partnership For Change’ report (210) published in 2016 developed with patient, family members and carers. It set out how they should be involved in the development of the service. This included appointment of a Head of Service User, Family Member and Carer Engagement with nine area leads for mental health engagement with responsibility for establishing local and area forums. Members of the mental health engagement office had been alerted to the ongoing PhD previously. However, to avoid any later issues a meeting was held with the new lead for mental health engagement in the area of the service to give an overview of the work in the psychiatry service and get approval for this work to continue. This was granted in March and then further senior approval was provided in April and May.

The second development included the clinical team. Separate to this research the clinical team made contact with a patient and family organisation to provide representatives to the sector management meeting. It is a committee of patients and supporters who have engaged with HSE mental health services and undergone training on how to be a representative. It was suggested by the clinical team that these two initiatives merge together with the patient and family organisation providing representatives to attend the sector management meeting as part of the psychiatry pilot intervention to be implemented for the PhD. This was proposed to the patient and family organisation in February who agreed to provide representatives in March. A gap in patient and family organisation meetings taking place meant that representatives were not identified until June when the researcher (LW) met with the representatives and a clinician who supports the patient and family organisation committee to discuss the research and process for involving patient and family organisation representatives starting with the July sector management meeting. In July the patient and family organisation decided that they no
longer wanted to provide representatives. This was due to clinical team deciding to
review attendance of representatives at sector management meetings after 3 months
when the research was complete. The patient and family organisation felt that this was
not within their ethos.

Following this decision the research team worked with the contact consultant and
Chairperson of the sector management meeting to revise the proposed psychiatry pilot
intervention. Instead of representation being provided by the patient and family
organisation the researcher (LW) would select representatives from the patient and
family population attending the psychiatry service using selection criteria identified in
Study 3 (see chapter 6 and 8). Representatives were selected and trained to attend three
sector management meeting starting in August. However, the August sector management
meeting did not reach a quorum and the September meeting was cancelled. At this stage
there was 4 months left within the timeframe of the PhD. The psychiatry pilot
intervention had been updated considerably on four occasions to address challenges that
were outside the control of the research team. It was with great regret that there was
insufficient time to implement and adequately examine the feasibility of the intervention
within the remaining timeframe of the PhD. This was discussed with the clinical team and
representatives. The researcher (LW) offered to support any future endeavours of the
clinical team to involve patients and family members in the sector management meeting.

8.3.4 Process evaluation

When asked what they thought about the intervention participants were happy and
supportive of the intervention developed, ‘I thought it would be good’ (Robert,
Psychiatry, Clinician). Participants were supportive of the intervention as they felt
patients and family members ‘offer a different perspective on the service, from the side of
the service we obviously don’t experience’ (Dorris, Psychiatry, Clinician) which would
‘contribute to better running of the service’ (Derek, Psychiatry, Clinician). The patient and
family representative from the patient and family organisation was also happy with the
intervention as it was in line with the goals of the patient and family organisation and
perhaps ‘changes would be made on some of the things that need to be changed’ (Barry,
One participant expressed confusion over the intervention developed and how it would fit with other ongoing work within the HSE.

‘I’m kind of confused about it, I think…I know there’s HSE employed family representatives, patient representatives are actually employed by the HSE so is this a voluntary role?’
(Rosemary, Psychiatry, Clinician)

Development of the intervention
Clinicians spoke about the development of the intervention. Clinician involvement in development was key as without their involvement the intervention ‘doesn’t stand any chance of success.’ (Conor, Psychiatry, Clinician) and without patients and family members also having a role the intervention would just be a ‘tick box exercise’.

‘If it’s to be a true exercise of engagement, so it’s not a tick box exercise, you need to have their [patients and family members] involvement and you need to know what they want to get from it and what purpose and the meaning’
(Ellis, Psychiatry, Clinician)

This step was important to give clinicians an understanding of the intervention with time to think and talk about the processes and implications of the intervention as they are responsible for the service that is provided.

‘I think it gives people an opportunity and time to think and reflect and maybe discuss it and take on board other people’s points of view’
(Dorris, Psychiatry, Clinician)

‘As the leader of the team providing the service for the area that I serve I am responsible for it ...if it didn’t suit they’d have to be able to change.’
(Robert, Psychiatry, Clinician)

Despite the importance that participants placed on this step they often struggled to remember the process.
'That was where you were talking about bringing some people and getting the ball rolling on it? That seemed sensible enough, I didn’t have any huge reservations about it really...in so far as I remember it’
(Robert, Psychiatry, Clinician).

One participant felt that they would have liked additional information on the selection of the representatives and development of the intervention although noted this may have been provided and forgotten about.

‘I wasn’t too familiar with what was going on, you know, I knew there was information being collected and collated and when it was presented to us I didn’t feel we were as directly involved maybe... Now maybe I had been shown it and I’d forgotten about it’
(Derek, Psychiatry, Clinician)

Review of representative attendance

One of the key steps in the attempted implementation of the intervention was the patient and family organisation deciding that they could no longer provide representatives due to the clinical team wanting to review the attendance of representatives after a 3 month period when the research ended.

‘There was a caginess on the part of management here to say ‘Look let’s have an exit clause if we’re not happy’...the three month piece was we were saying well we have a start and we have an end and we are making an executive decision at the end of the three months and I think that’s probably what put an end to it’
(Rebecca, Psychiatry, Clinician)

Participants spent time discussing this decision and the concerns underpinning the need for the clinical team to review representative attendance. Some members of the team viewed this decision as being standard practice.
‘It’s kind of normal enough if you’re taking on a new role because also there’s a probation period that goes for anyone in a job ... it’s just a general thing that you’d always have an inbuilt period where you’d give something a try and if it’s working you’d continue and if it’s not you’d have to rethink.’
(Derek, Psychiatry, Clinician)

However, most discussions relating to this decision were primarily linked with fear or anxiety. The intervention was viewed as a big change by the clinical team. ‘It was such a big change for us ... I think any change needs an opportunity to test it out, see if it’s working ... we don’t like committing’ (Dorris, Psychiatry, Clinician). It was felt that not all members of the team were supportive of this change with fear of change and possible loss of control.

‘I think a certain number of us are open to it but I think across the board I don’t think people are open to this kind of change and I think people are frightened of change and I think there’s a sense of why do we need service users and their carers and so on I think there’s an angst that they will have some role in directing our clinical judgement pieces and delivery’
(Rebecca, Psychiatry, Clinician)

‘It was probably the control thing, it was probably very important that there was a sense of control over the experiment’
(Rosemary, Psychiatry, Clinician)

Concerns were expressed about the representatives, who they would be, what their motivations were and what their views would be.

‘You want to sort of want to know the motive of why someone would want to get involved and understand a little where they are coming from because sometimes people bring different agendas to the table and try to draw maybe on a negative experience as opposed to a positive one for a reason to
*be included...use it as a forum to maybe get their own view point across as opposed to develop the service’*

(Derek, Psychiatry, Clinician)

It is important to note that much of this fear may stem from a previous negative experience with a patient representative within the service some time previously.

*A patient representative became unwell during their role and it was very, very difficult to manage and he eventually had to be hospitalised but wasn’t...it affected their role...and in fact saw the service in a kind of negative way’*

(Sheryl, Psychiatry, Clinician)

From the perspective of the patient and family representative and organisation the clinical team reviewing their attendance after three months was not an option, *‘we’re there for good, not for three meetings ... we don’t do part-time’* (Barry, Psychiatry, Patient). This stipulation had not been set down by any other committee, *‘Well we’re on a lot of other committees and none of them ever said like you can come for three weeks’* (Barry, Psychiatry, Patient). The key concern from the patient and family representative who explained why this stipulation made the organisation decide not to provide representatives centred around the responsibility which they feel to patients and family members.

*‘If we brought something to a committee and then the three meetings are up, we don’t know what’s happening with the stuff we brought up ... that was one of the major things in the decision.’*

(Barry, Psychiatry, Patient)

Previous experience of the clinical team changing their mind also fed into these concerns expressed by the representative. Separate to the research the clinical team contacted the patient and family organisation asking them to present the team. Following this they requested if they would provided representatives and then subsequently changed their minds.
‘Beforehand we done a presentation for the committee and they kind of emailed us and asked us would we provide representatives on the committee and then all of a sudden like it got changed and we decided no’ (Barry, Psychiatry, Patient)

Sector management meeting changes

Another key step in the attempted intervention was sector management meetings not taking place. Participants spoke about necessary changes in the sector management meetings that representatives were meant to attend. A lack of clarity on the purpose of the meeting was reported ‘different people have different ideas about what is actually the purpose of the sector management meetings’ (Ellis, Psychiatry, Clinician). Poor attendance with fluctuations in attendees was noted, ‘especially over the summer months they tend to be poorly attended’ (Derek, Psychiatry, Clinician). Participants felt that this had led to this meeting becoming chaotic with a process underway at the moment to add greater structure, clarity and commitment.

‘We’re just trying to become a lot more streamlined, it was becoming a little bit not direct, you know it was just a bit chaotic and certainly there was...the buy in from all disciplines was faltering so I think we’re just trying to firm all that up and get a commitment’ (Dorris, Psychiatry, Clinician)

Participants were concerned about representatives starting to attend at this time, ‘We don’t like to demonstrate chaos in front of strangers! It’s in-house stuff!’ (Dorris, Psychiatry, Clinician). It was felt that ‘bringing someone else into the middle of that... it’s not fair on them’ (Ellis, Psychiatry, Clinician) and there were concerns that ‘they might find it frustrating’ (Robert, Psychiatry, Clinician). This lead to the conclusion ‘that it probably wasn’t the best time for service users to get involved’ (Ellis, Psychiatry, Clinician).

One participant queried if the sector management meeting was the most appropriate meeting for representatives.
‘I’m not sure our sector management meeting ... whether it’s the most appropriate place for their input...sector management tends to be about very mundane things like fire escape policies and odds and ends of a very mundane nature ... that meeting is just very businessy type of meeting’

(Robert, Psychiatry, Clinician)

However, others felt that the sector management meeting is the most appropriate meeting for representatives to attend because it is the main meeting that takes place about how the service works. While the topics may not always be relevant it is up to patients and family members to decide whether they would like to attend or not.

‘I think sector management meetings are probably the main meeting here so that would be the one that probably in terms of meaningfulness’

(Ellis, Psychiatry, Clinician)

Sustainability

When asked about the involvement of patients and family members beyond this research project participants felt that there is movement within mental health services as a whole to improve the involvement of patients and family members. They believed that this was something that was going to happen and are supportive of this change.

‘I’m hearing that there are plans afoot...it’s definitely going to happen. I’d be expecting, I’d be more than confident that it will happen... I’ll welcome it when it does’

(Derek, Psychiatry, Clinician)

Participants spoke about supports that are available already for this to happen such as work underway by the HSE Mental Health Engagement department.

‘I think it’s something that in terms of mental health it’s certainly where we’re going, it certainly seems to have a vision, it certainly seems to be laid out in terms of ...the lead for services and that’s what we’re working towards,’
One participant felt that the homecare team could provide support for potential representatives and that a support group for family members could be used to recruit representatives and gather feedback.

‘We have the people on the homecare team so we have the people to do that kind of follow up and encouragement and support with people ... we’ve had a relations group right which functioned you know with this kind of role of discussing various things about the service’

(Robert, Psychiatry, Clinician)

However, it was felt by most that for participation to go ahead ‘there’s a lot of things that need to be thought of and a lot of support needed’ (Rebecca, Psychiatry, Clinician). Most of this related to the service with the need for a good Chair for meetings and clarity on the purpose of the sector management meeting and the role of the representative.

‘You’d need a fairly sort of good Chair to make sure that the agenda item doesn’t end up getting too loose and end up drifting into something that doesn’t have relevance to the patient representative’

(Derek, Psychiatry, Clinician)

‘We’d need to be very clear about what the meetings are and I suppose the purpose of what the service user or carer or family member or engagement’

(Ellis, Psychiatry, Clinician)

A barrier was noted in terms of the often informal nature of service design and delivery.

‘You should be able to just talk to your colleagues on the go, if a problem arises you solve it together, you don’t have to wait for the sector management meeting to bring it to the attention and then make a plan. That’s too rigid and too restrictive’

(Derek, Psychiatry, Clinician)
One participant referenced earlier felt support for participation could be provided from within the team by the homecare staff. Contrary to this most participants were clear that external support would be necessary for representatives but also the clinical team for successful participation

‘If they don’t have supports outside the dynamic is going to completely change if we’re expected to provide that support in-house. I think it just shifts the dynamic completely and not for the better.’
(Dorris, Psychiatry, Clinician)

‘I think someone neutral … a service user coming into the management meetings … our anxieties around how is that sustained if somebody becomes unwell during the period of time that they have a term with a management team, where do we go with that?…you would need a lot of support’
(Rebecca, Psychiatry, Clinician)

8.4 Discussion

8.4.1 Discussion of findings

Interviews and focus groups were conducted with clinicians and a patient and family representative who were involved in the development and attempted implementation of an intervention to encourage greater participation. This provided an overview of key issues and barriers encountered during the attempted implementation of the psychiatry pilot intervention. The intervention was patient and family representatives attending sector management meetings. This was underpinned by the CLEAR framework (19), Arnstein’s Ladder of Participation (18) and developed in line with MRC guidelines for developing and evaluating complex health interventions (265). A trial evaluation process of an intervention for effective public involvement in healthcare improvement and decision-making identified five key necessary ingredients.

Participants were happy with the intervention developed feeling that it would lead to the inclusion of views, opinions and experiences from patients and family members hopefully
resulting in positive impacts and changes in the service. Similarly interviews and focus groups with healthcare providers and managers in Canada following the implementation of an intervention to encourage engagement through patients being partners on care redesign teams found that patients introduced a new point of view to discussions exposing the team to valuable information that had not previously been thought about during decision making (89). This is also illustrated in work in a mental healthcare context. Interviews with service users on their involvement in the development of clinical guidelines for mental health services in the United Kingdom also noted the value of personal knowledge and experience from patients (15).

It is important to note the duration of time necessary for the development and attempted implementation as well as the workload involved. An intervention protocol developed based on the literature and findings of PhD Study 1 to Study 3 was provided to the clinical team in February 2017. It took four months for final sign off from the full clinical team to be granted. During this time considerable adjustments were made to the intervention on three separate occasions. This was to take into account changes requested by patients, family members and clinicians as well as challenges beyond the control of the research team with recruitment of a patient and family organisation by the clinical team. After final approval was granted a further four months was dedicated to attempting to implement the intervention with another redesign of the intervention to deal with the patient and family organisation pulling out of the intervention due to a decision made by the clinical team to review representative attendance after the research was complete.

Key stumbling blocks to the implementation of this intervention included external organisations. Once the intervention was approved by the contact consultant issues transpired relating to ongoing work within the HSE and contact made between the clinical team and a separate patient and family organisation. A review of what is required for healthcare quality improvement has identified organisational context, including outer contexts as a barrier (305). This includes shifting policy agendas and regulatory requirements, which can lead to organisational turbulence, staff distraction and instability of structures and teams. For this PhD study this was illustrated through questions over how the intervention fits with wider HSE policy, ‘Partnership For Change’ (210) and
questions over the intervention, particularly representative selection with the involvement of a patient and family organisation.

Much of the underpinning concern behind clinicians wanting a three-month review of representatives attending sector management meetings was fuelled by fear and anxiety. The patient and family representative organisation had concerns about the responsibility they have to the wider population and what would happen to issues they raised if they were no longer able to attend after three months. Clinicians had concerns about the impact of representatives on the aims, decisions and judgements of clinicians. Some of these concerns stemmed from the expected motivations, aims and views of the representatives and fears about the loss of control. Various reviews of the implementation of interventions and programmes in healthcare settings have identified similar barriers, including tensions between patient and provider perspectives (303,306), tribalism and the risk of unintended consequences (305). A review of models of care which incorporate user involvement and patient perspectives on their care illustrated tensions between patients’ and providers’ perspectives on treatment and carers as a challenge to the implementation of models of care, including patient participation (303). Issues relating to the capacity and competence of both groups and the role that patients want to play were also identified as barriers (303). An ethnographic study of the implementation of user participation and re-socialisation in a long term psychiatric hospital ward identified tensions and challenges including challenges when patients’ viewpoints challenged staff judgements on proper conduct and goals for which patients might aim (306). A review of five programme evaluations of improvement programmes by the Health Foundation in England identified 10 key challenges to improving the quality of healthcare (305). Many of these identified challenges overlap with fears and anxieties expressed by staff underpinning the three-month review of representative attendance such as tribalism with attempts to guard professional autonomy, the risk of unintended consequences and questions about whether the right solution or intervention has been chosen (305).

Challenges also emerged when trying to establish relationships based on equality within a biomedical hierarchal hospital structure (306). Patients have identified this power imbalance in the patient clinician relationship as a barrier to shared decision making
‘Normal’ or ‘good’ patients are expected to be passive, suppose that clinicians will make decisions, not ask questions and fear consequences of being labelled as inflexible or troublesome (105). This expectation of what it means to be a ‘good’ or ‘normal’ patient poses a challenge to those who wish to take on a role in participation as a patient in healthcare service design and delivery. Although much of the research and literature focuses on participation at the patient level this identified barrier of establishing non-hierarchical relationships may apply to the service level in the psychiatric service in this PhD study where non-hierarchical relationships were required for participation yet it was only clinicians who were reviewing participation after a set period of time.

Another key difficulty encountered in the implementation of this intervention was the current state of flux in the sector management meeting. It was clear from the perspective of participants that it was a bad time to involve patients and family members in sector management meetings with lack of clarity of purpose and aims of the meeting leading to poor attendance. This is in line with research which identified the organisational context, including lack of adequate structures for activities and team instability, as a potential barrier to healthcare quality improvement programmes (305) and positive organisational culture and an area to be addressed for participation implementation (75). In addition to this some participants felt that the topics often discussed at this meeting and indeed discussions about what the meeting should focus on were not of any interest to patients and family members. However, patient identified barriers to shared decision making included the perception that patients don’t want to be involved or that they perceive that they do not need to be involved (105).

It has been noted in a King’s Fund report published in 2014 that there is a mismatch between the rhetoric of policy and the action that is taking place (17). This pattern of discrepancies between what is being said and what is being done can also be seen here in this PhD study. Participants express support for participation and the developed intervention. However, contrary to this, obstacles were introduced by the same participants who were supportive of participation and the intervention that resulted in difficulties in implementation. For example, making contact with a patient and family organisation external to the research to take on the role of providing representatives and then introducing a review of participation after three months that resulting in the patient
and family organisation pulling out of the intervention. Participants believe that participation is going to take place at some stage within the mental healthcare services but point towards barriers that the developed intervention had hoped to target. For example, participants felt that more time, structure and supports for possible representatives and clinicians is required for participation to take place and ideally to be provided by a neutral person. The developed intervention included training and support for representatives and clinicians with time to discuss and consider concerns and key elements of the intervention, facilitated by the researcher (LW), who is neutral to either stakeholder group.

There are often unintended consequences of interventions, some of which can be negative, including souring clinicians against further quality improvement measures (305). The research team was cognisant of not wanting to turn the clinical team against patient and family participation in the future given the high level of reported support from within the clinical team and also importantly from patients and family members. The research team were keen to conduct a process evaluation of the attempted intervention so as much as possible could be learned so that clinicians, patients and family member time was not wasted and so that there would be learnings available to the clinical team to take on board. In addition the research team offered to assist should the team want to implement the intervention at a later date. Formal evaluation of improvement efforts enables both gains and losses in improvements to be treated as learning objectives and contributions to improvement science (305).

8.4.2 Strengths

This is a qualitative process evaluation using interviews and focus groups to explore the attempted implementation of this intervention of patient and family representatives attending sector management meetings. It adds to and strengthens the current literature, expanding on barriers to patient and family participation at the service level in healthcare design and delivery, particularly with a focus on Ireland. This is key as many barriers are attitudinal and influenced by culture and society. Qualitative methods are ideal for questions that can not be answered easily, where the focus is on what the participants have to say or think and in understanding processes (174). Qualitative methodologies
have been previously employed to assess reasons why interventions were unsuccessful (307). All key stakeholder groups that played a role in the development and attempted implementation were involved until data saturation was reached. All data collection was conducted by the researcher (LW). Analysis was conducting using IPA, which has been identified as suitable for the exploration of novel topics that are new to participants. Good inter-rater reliability was demonstrated in coding and analysis and this process included members of the team with varying levels of familiarity with the transcripts. MRC guidelines for development and process evaluation (184) were employed at all stages from planning, design, conduct, analysis, through to reporting. MRC process evaluation guidelines advise using reporting guidance specific to methods adopted (184). In line with this the Template for Intervention Description and Replication (TIDieR) checklist and guide (203) was employed in reporting the intervention (See Appendix F) and the Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32 item checklist (191) was used for reporting qualitative data (See Appendix E).

8.4.3 Limitations
Analysis was conducted using IPA. When IPA is employed for evaluation of an intervention it is important that the evaluation is conducted by an ‘independent’ person (263). The researcher (LW) conducting this evaluation was involved in the service in a research capacity for over two years prior to the attempted implementation and in all areas of development of the intervention. To ensure credibility, transparency and trustworthiness standards for conducting good qualitative research were followed. Field notes were made during data collection, the coding frame was reviewed by a patient and family representative (CC), triangulation was conducted, direct quotes were used to ground themes within the text and dissenting ideas were discussed throughout the presentation of results. Similar steps were taken in an evaluation of services for early intervention in psychosis in the UK through interviews assessed through IPA by a member of staff (262). Clinician preferences for optional training and subsequent lack of uptake of optional training was not discussed during the process evaluation. Discussion of this may have shed some light on why the implementation was not able to be implemented as much of this appears to have been linked with fears and anxieties with concerns relating to elements of the intervention that could have been discussed during a training session.
with clinicians. For example, well-facilitated forums enabling discussion and debate on the evidence behind programmes for healthcare quality improvement have been suggested to ensure acceptability of interventions (203). The attempted implementation of the intervention involved two external organisations, the HSE and a patient and family organisation. MRC guidelines recommend the involvement of all key stakeholders in the development of any intervention. However, neither organisation was involved in the development of the intervention. The intervention was developed through the course of the PhD, the HSE had been alerted to the PhD at the start with senior management included in Study 2 interviews. The patient and family organisation were provided with numerous opportunities to input to the development of the intervention. When they appointed representatives much of the intervention had already been cleared with the MDT but opportunities to tweak were still made available and the research team were as accommodating as they could be at that time in the development and implementation.

8.4.4 Conclusion
The intervention of patient and family representatives attending sector management meetings was shown not to be feasible. This was due to a number of organisational and contextual factors. Fears and anxieties of the clinical team lead to the imposition of a three-month review by the clinical team of representatives attending, which led to the patient and family representative organisation pulling out due to concerns about what would happen with points that they had raised during the initial three months. Further barriers came from lack of clarity over the aims and purposes of the sector management meeting. This was a lengthy process contributed to by the involvement of external organisations. Despite this, there appears to be support for implementation of patient and family participation and agreement that this is the direction in which the mental health services are going. It is clear that for this to happen at an early stage all organisations that are to be involved need to play a role, steps need to be taken to ally the fears, anxieties and concerns of all stakeholder groups, with time to process and discuss all elements of participation. If this is to be achieved through representatives the structures and processes that they are to be involved in need to have a clear purpose, aims and decision-making processes. All groups that are to be involved in this process, including patients and family members, should be involved in this process. The involvement of patients and family members is something that needs time and resources
and as such should be supported by national policies, which we have in place through the
sentiments in ‘A Vision For Change’ (209) and ‘Partnership For Change’ (210). In
implementing patient and family participation it is important to be able to assess if what
we are doing is working. With this in mind any attempts to implement this or similar
interventions or ‘Partnership for Change’ need to identify the starting point, how much
participation is taking place at present, and conduct intervention assessments looking at
outcomes as well as process evaluations so we know what elements worked or did not
work and what needs to be changed or improved.
Chapter 9:
Implementation and feasibility of an intervention to encourage patient and family participation in healthcare design and delivery in an adult outpatient type 2 diabetes service

9.1 Introduction

The potential impact of participation has been illustrated in relation to patient health and healthcare services. Participation offers a pathway to improved population health (4), better health and treatment outcomes for patients (3,4,12,14,69), greater quality of life (69) and increased patient self dignity, self worth and self esteem (69,86,87). The possible impact on healthcare services include the provision of more appropriate services that are more responsive to patients needs, values and priorities (6,16), increased legitimacy and credibility of decision making (11,13), higher quality services (4,6) with greater compliance, satisfaction (6) and efficiency (4) alongside greater control of healthcare costs (4) and accessibility (69). For example, the inclusion of patients in the decision making process in Canada resulted in the changes proposed being implemented, addressing the needs of patients (89). A Cochrane review with quantitative methods found moderate quality evidence that service users’ involvement in producing patient information resources results in materials that are more relevant, readable and understandable to them and can improve their knowledge (87).

The methods that can be employed to encourage participation are vast and varied with no consensus on what is the best way to encourage participation, particularly at the service level. Study 5 set out to implement and test the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult outpatient type 2 diabetes service. The diabetes pilot intervention was patient and family representatives and clinician meetings supported by a patient and family forum. This was examined through an intervention feasibility assessment and a process evaluation. Feasibility is about whether an intervention can be delivered taking context and practicalities into account and encompasses elements of fidelity, reach and sustainability (184). Process evaluation is an essential component of designing and testing complex health interventions, such as the diabetes pilot intervention in this study (184).
Medical Research Council (MRC) guidelines provide a framework for conducting and reporting process evaluation studies with a focus on the relationship between intervention, mechanism and context (184). Process evaluations can be used to assess fidelity and quality of implementation, clarify causal mechanisms and identify contextual factors associated with outcomes (265).

9.2 Methodological Highlights

- The assessment of the intervention was two-pronged, including an intervention assessment alongside a process evaluation with a focus on feasibility. The intervention assessment examined the amount and intensity of participation, service satisfaction, opinions on participation and empowerment. The process evaluation focused on the impact of the development of the intervention, impact of various elements of the intervention, sustainability, fidelity, dose and reach.
- Mixed methods were employed with pre and post questionnaires, interviews and focus groups. This was guided by the 2008 Medical Research Council (MRC) Guidelines for development of complex health interventions (265) and the MRC Guidelines for process evaluation of complex interventions (184).
- Treatment as usual in the diabetes service was informal design and delivery of the service with no process to gather feedback or involve patients or family members in the design or delivery of the service (See Chapter 4 and 5).
- The diabetes pilot intervention was patient and family representative and clinician meetings supported by a patient and family forum. Further details on the development of the intervention are in Chapter 7 and the intervention protocol is in Appendix R: Proposed diabetes pilot intervention protocol.
- A total of 4 patients and 9 clinicians took part in a process evaluation focus group (n=2) or interview (n=6). Purposeful sampling was employed. Pre questionnaires were completed by 22 participants (patients n=8, family n=1 and clinicians n=13). Post questionnaires were completed by 18 participants (patients n=7, family n=1 and clinicians n=10).
- Interview schedules were developed based on a literature review, previous studies in this PhD and MRC guidelines with feedback from PhD supervisors (CD & JB) and the patient and family representative (CC). Topics included opinions on the
intervention, development of the intervention, training and support, forum meetings, representative meetings, impact of the intervention and participation beyond the research (See Appendix AA: Study 5 evaluation interview schedules).

- Questionnaires were developed based on a literature review with standardised questions employed were possible. Topics included the amount and intensity of participation, opinions on participation, service satisfaction, empowerment and demographics (See Appendix Z: Study 5 evaluation questionnaires).

- Data collection was conducted by the researcher (LW) between March and October 2017. Pre questionnaires were conducted by clinicians prior to involvement in development of the intervention. Patients and family members completed the pre questionnaire prior to the first forum meeting starting. All post questionnaires were completed after the second forum meeting took place.

- Qualitative analysis was conducted using IPA. Patterns in the data were clustered into a thematic structure which was reviewed regularly with recoding as necessary as this coding frame was applied to all transcripts (See Appendix BB: Study 5 process evaluation coding frame). Connections between emergent themes were identified to enable the combination of separate themes into superordinate and subordinate themes as illustrated in Figure 3.5.

- No software was used during data analysis (See Section 3.7.2).

- Quantitative analyses were completed using SPSS (version 22; SPSS Inc; Chicago, IL, USA).

Further details on all aspects of the methodology employed are in Chapter 3.

9.3 Results

An overview of topics discussed in the process evaluation and intervention assessment are outline in Figure 9.4.

9.3.1 Response Rates

All patients, family members and clinicians asked to complete questionnaires or interviews agreed to take part except for the clinician qualitative process evaluation sample. The response rate for the clinician process evaluation interview sample was
Figure 9.4: Summary of topics discussed in the process evaluation and intervention assessment

**Context:** Societal, Organisational and Individual Factors

**Impact** (What changed?)
- Amount and intensity of participation
- Opinions and attitudes
- Communication, feedback and relationships
- The service
- Emotions/health
- Limited to those directly involved

**Evaluation** (What helped?)
- Intervention development
- Recruitment
- Facilitation
- Communication
- Representativeness
- Logistics
- Space and time to think about concerns

**Future of participation** (What needs to change?)
- Sustainability opinions
- 'Change champion/facilitator
- Involvement of more people
- Emphasis on brevity for representatives

**Patient and Family Participation**
Impact and enablers

**Intervention**
Clinician and representative meetings back by a forum
90.0% (n=9/10). Participant flow charts are presented in Appendix G: Study 1, 2, 3 and 5 flow charts.

9.3.2 Demographics

All samples included variety in terms of gender, age, level of education and duration of engagement with the service. Both questionnaire samples included patients, family members and clinicians. The interview sample included only patients and clinicians. Further detail is provided in Table 9.1. The clinician sample included a mixture of doctors, nurses and allied health professionals. This is not detailed below due to small numbers.

9.3.3 Process evaluation

Development of the intervention

Clinicians were asked about being involved in the development of the intervention (See Chapter 7). They were happy with the level of input they had, ‘That was enough really, I don’t think there was much more needed’ (Felicity, Diabetes, Clinician). However, it was noted that due to time pressures it was difficult to fit this process within the working week.

‘The big issue as you know is time, clinician’s time and the fact that we have so little time for added things. Our week is so chock full and that goes for all the MDT.’

(Jim, Diabetes, Clinician)

Involvement in the development of the intervention was important for patients and family members as ‘they’re [patients] going to be part of it.’ (Erin, Diabetes, Clinician). For clinicians this involvement was key as patients and family members would view the intervention as being reflective of the service.
Table 9.1: Demographic description by samples

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<th>Pre Questionnaire Sample</th>
<th>Post Questionnaire Sample</th>
<th>Post Interview Sample</th>
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<td>N= 22 (100.0%)</td>
<td>N= 18 (100.0%)</td>
<td>N= 13 (100.0%)</td>
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<td>1 (5.6)</td>
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<td><strong>Age</strong></td>
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<td>5 (22.7)</td>
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<td>4 (30.8)</td>
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<td>Degree or above</td>
<td>15 (68.2)</td>
<td>11 (61.1)</td>
<td>10 (76.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Duration of attendance/employment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤5 years</td>
<td>7 (31.8)</td>
<td>5 (27.8)</td>
<td>4 (30.8)</td>
</tr>
<tr>
<td>≥6 years</td>
<td>15 (68.2)</td>
<td>13 (72.2)</td>
<td>9 (69.2)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

^ = State examinations. Junior certificate at aged 15 and Leaving certificate at aged 18.
- = Not applicable

‘It reflects what your practice is so we have questions that we may want to get to and also I suppose patients will always think that ...the research is coming from within the unit so it’s important that we are happy with the research... unless you can stand over it and say yeah this is something, we all signed off on, by all parts of the MDT because we all have our different areas that we would be somewhat more I suppose protective of.’

(Jim, Diabetes, Clinician)

It was also felt that this step increased buy-in and ownership, ‘It probably makes them buy into it a little bit more’ (Jim, Diabetes, Clinician), while enabling issues to be ironed out and structure to be added.

‘We ironed probably out a few issues...stuff like who’s going to Chair the
meeting and who is going to you know so I think if we had of not had that meeting we would have just come in the first day and spent an hour going around in circles.’
(Alana, Diabetes, Clinician)

Opinions and experiences of the intervention
Participants reported to be happy overall with the intervention that was implemented ‘Well I think it’s a good intervention.’ (Evelyn, Diabetes, Patient)

Patient and family forum
In relation to the patient and family forum the most effective method of recruitment was informing people in person in the waiting room or over the phone. Of the 16 patients and family members that attended either meeting of the forum all bar 1 were informed about the meeting by a member of the research team either in person or over the phone. Participants felt that this was effective due to the ‘one on one’ approach.

‘It’s a ‘one to one’ basis and you’re there asking people questions and it’s as if ... you want to know exactly what people think ... It’s all about approach, it’s all about you know being nice.’
(Jacinta, Diabetes, Patient)

Participants were happy with the content, experience and running of forum meetings, ‘I thought it was very well run. The feedback we got back from the meetings we went to was very informative.’ (Timothy, Diabetes, Patient), including the communication with representatives and how feedback from the forum was used. ‘Yes, yes that’s [communication leaflet] good... I think it’s enough detail for starters’ (Stewart, Diabetes, Patient).

Representatives
Participants were generally satisfied with the representatives that were selected. Patients felt they were ‘very helpful when they came back’ (Timothy, Diabetes, Patient) and clinicians felt that they ‘were well able to talk and were well able to share their opinions’
(Megan, Diabetes, Clinician). One patient expressed disappointment in the number of people who put themselves forward for the role of representative while some clinicians had concerns about their representativeness.

‘I was a little disappointed that more people didn’t come forward. I thought maybe three or four people would have come forward.’
(Evelyn, Diabetes, Patient)

‘It was two people representing the patient and I don’t know how they were chosen and I don’t know if they were representative of the voice of the larger group.’
(Eva, Diabetes, Clinician)

However, participants were accepting of working with the group that attended the patient and family forum to recruit representatives, ‘You’ve no other way of recruiting people than to ask so I mean you just had to ask whoever was there’ (Jacinta, Diabetes, Patient). There was an acknowledgement that forum meetings and a representative role are always going to appeal to some personalities more than others.

‘The patient representatives that were here were very good...they did have expectations so maybe from a whole service perspective the representatives were very similar but then the people who were passive wouldn’t necessarily want to be here.’
(Felicity, Diabetes, Patient)

Clinician and representative meetings

Overall feedback on clinician and representative meetings was positive. Participants reported that these meetings were ‘well organised, well structured, focused and ran to time...they were productive’ (Erin, Diabetes, Clinician). It was felt that the meetings covered relevant topics, ‘Yeah well they are the topics that need to be changed’ (Evelyn, Diabetes, Patient), and were well structured.

‘It was very structured. There was a purpose to each of them... you went in
there knowing that this was what you were going to talk about and left having talked about it.’

(Eva, Diabetes, Clinician)

Participants were happy with the timing of meetings, ‘You made it a time that we could possibly come to because it’s really important’ (Sinead, Diabetes, Clinician), as well as the frequency.

‘You kind of did them quite shortly after each other, which was probably the best way to do it because people remembered what they needed to do before the next time.’

(Renee, Diabetes, Clinician)

A number of participants spoke about the facilitation of these meetings and the necessity for this role to be conducted by a neutral person.

‘I thought you [facilitator] were very good actually especially in one of those meetings where there was an awful lot of talk but you brought it back and said now in the interest of time we need to keep moving forward so you kept it quite structured and you got to do what you needed to do which is very important.’

(Harriett, Diabetes, Clinician)

‘I think it did need to be someone neutral out of the two groups ... I think it was good that you were sort of a neutral sort of almost controlling the time rather than letting one group go on or more.’

(Alana, Diabetes, Clinician)

Although, some felt that at times meetings could be moved quicker on to some topics that they felt were of particular importance.

‘There was one meeting because I was kind of conscious that we’d get on with. I suppose diet was the part I wanted to get on to and I think we had maybe 5 minutes left because they had sort of repeated the same story maybe over
three times and we were just sort of going around in circles of us saying ‘Yeah we’ve understood that.’
(Alana, Diabetes, Clinician)

A key topic discussed in relation to the clinician and representative meetings was the attendees. Clinicians were happy with the representatives and their ability to contribute to these meetings while representatives were happy with the clinicians that attended, their attitude and approachability.

‘I found that they’re more normal...they were great to chat to you know and I found them very interested in putting things forward for the diabetes centre.’
(Jacinta, Diabetes, Patient)

‘I’ve got past having doctors and nurses on pedestals you know, there was a time when people bowed to doctors and nurses.’
(Evelyn, Diabetes, Patient)

All clinical disciplines were represented at meetings, ‘We had a very good nursing presence and we had two SERs [senior endocrinology registrars] … podiatry was well represented, dietician was well represented…’ (Megan, Diabetes, Clinician). However, no consultants attending any meetings and the doctors that attended were research registrars. It was proposed that this was due to time constraints, ‘Doing research we have the time, there are no clinical doctors able to do it’ (Renee, Diabetes, Clinician). It was also proposed by one person that understanding or the value placed on the research and research methods employed were a possible reason as to why consultants did not take part.

‘Certain grouping within the multi disciplinary team wouldn’t be as pro action research as others but they would have very fixed ideas about research as a whole... unless it’s a random control trial, it really wasn’t research’
(Megan, Diabetes, Clinician)
It was suggested that not having consultants at these meetings also had positive implications as ‘people may well have talked more openly.’

(Jim, Diabetes, Clinician).

Despite all documentation for these meetings, including minutes, summary patient and family forum feedback and the communications leaflet being circulated to the full MDT and discussed at a weekly education meeting senior members of the MDT did not appear to be aware of the work conducted at the clinician and representative meetings.

‘I think definitely when the results and we kind of get formalised ... I think it just needs to be fed back to everyone.’

(Jim, Diabetes, Clinician)

Training and support

Prior to and during clinician and representative meetings all attendees were provided with training and support. Participants felt that this was important as ‘they were in a different atmosphere, they’re not in their usual role’ (Jacinta, Diabetes, Patient). This provided them with an opportunity to talk and think through any concerns that they may have as well as how they would communicate opinions and feedback.

‘A very necessary step, a forum to actually discuss how we would interact with the patients, what they would expect, what we would expect. So it may not have necessarily have got to learn anything new by doing the training per say but it would give us an opportunity to say ‘Ok right, let’s have a little think about this, what do we need to do, what do we need to say, what do we need to use, what don’t we use, what do we share, what don’t we share.’

(Megan, Diabetes, Clinician)

‘You could go home and think about well what can we think about now, what can we put down on paper for them to see what changes need to be made.’

(Evelyn, Diabetes, Patient)

It was felt that this resulted in better communication and discussions.
‘It needed to be done because if you had gone straight into the intervention, i.e. having the patients there, both for the patients and for the healthcare professionals it might have been a little more stilted and you mightn’t have got as good feedback and people would be a little...especially the patients I would imagine would be a little intimidated if they weren’t prepared and actually knew what people were thinking and what was going to be expected.’
(Megan, Diabetes, Clinician)

One of the representatives spoke about concerns of speaking up in a group setting but found after training and support they were more confident.

‘I’m a person like if I go to a big meeting and that I will sit at the back and be very slow to interact whereas on a one to one I find it much better. I’m not afraid, I’m shy, I just don’t like to you know I’m half afraid if I put my hand up to say something it’s stupid...I was more confident.’
(Jacinta, Diabetes, Patient)

Participants also felt that training ensured that accessible language was used, ‘I got what they were saying. ...No technical bits at all.’ (Jacinta, Diabetes, Patient).

Suggested changes
Participants were asked about any necessary changes to each aspect of the intervention. Suggested changes often centred around involving more people. It was noted that more family members were needed at the patient and family forum, ‘you want to get more family members to go with the patient’ (Timothy, Diabetes, Patient). One person also suggested having more representatives at meetings with clinicians.

‘I’d say if there had been one or two more people...they may have been able to ask a different question ... I’d say you’d probably want to have about 4 ... like their own committee.’
(Timothy, Diabetes, Patient)
Due to the topics that were discussed at clinician and representative meetings additional groups were suggested to attend such as clerical staff, ‘Did you have some of the clerical girls?’ (Harriett, Diabetes, Clinician). Much of the discussions about changes to the intervention centred around the attendance of consultants at clinician and representative meetings, ‘Well ideally I would have liked a consultants presence there’ (Megan, Diabetes, Clinician). This was important for progress ‘I think it would have been useful to have the consultant to sort of be able to sign off with them’ (Alana, Diabetes, Clinician). Patients were happy if consultants were able to attend even some meetings or once they knew that the lead consultant was aware of what was going on at meetings, ‘as Head of the Diabetic Unit he should be well aware of what’s going on and hopefully will make changes’ (Jacinta, Diabetes, Patient).

‘He’s the man in charge so even if he’d come to the second meeting or the third meeting at least he would have put in an appearance, you know ‘I’m the man in charge and thank you for coming and we’ll see what we can do’... it would make a difference to his nurses and his junior doctors and even the dieticians.’ (Evelyn, Diabetes, Patient)

Clinicians felt it was important to ensure that future training and support emphasised to representatives the need for brevity and for only putting a point across clearly ‘just once in a meeting’ (Felicity, Diabetes, Clinician) when it has been acknowledged.

It is important to note that some participants did not feel the need for changes to be made, ‘I wouldn’t say you want to change too much’ (Timothy, Diabetes, Patient), ‘Not from a staff perspective’ (Jim, Diabetes, Clinician), particularly when speaking about training and support, ‘No I don’t think so, no no ‘ (Stewart, Diabetes, Patient).

Feasibility

The intervention was shown to be feasible with the support of the research team. This was assessed in terms of fidelity, dose, reach and sustainability.
Fidelity and dose

To ensure fidelity to the intervention key components and any deviations were documented. This also provided information on the dose of the intervention. Number, attendees, duration and topics for patient and family forum meetings are outlined in Table 9.2 and for clinician and representative meetings in Table 9.3.

### Table 9.2: Patient and family forum meeting attendees, duration and topics

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Number of attendees</th>
<th>Duration</th>
<th>Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meeting 1</td>
<td>9</td>
<td>55 mins</td>
<td>· Background, purpose and aim</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>· Feedback</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>· Patient and family representatives</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>· Communication</td>
</tr>
<tr>
<td>Meeting 2</td>
<td>9</td>
<td>50 mins</td>
<td>· Background, purpose and aim</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>· Future of the forum</td>
</tr>
</tbody>
</table>

Patient and family forum meetings occurred in line with the intervention protocol with one meeting before and after clinician and representative meetings. Clinician and representative meetings were broadly in line with the intervention protocol. The specified number of meetings occurred for the allotted duration of time. Meeting 2 had only one representative in attendance. This was due to the second representative becoming sick at the last minute. The representative who attended was informed and given the option of postponing the meeting. They were happy to go ahead with this meeting as the focus on meeting 2 was on the clinicians and the representative had met most of the clinician attendees in advance. As the representative opted for the meeting to go ahead the researcher (LW), who was facilitating the meeting, ensured to sit with the representative for moral support and spent additional time going through the meeting agenda and purpose with the representative. Key clinical disciplines were represented at
each of the three meetings. However, no consultant attended any of the clinician representative meetings.

Clinicians and representatives were provided with training and support in line with the intervention protocol. The numbers of people trained, duration and topics covered are summarised in Table 9.4. All representatives and clinicians that attended clinician and representative meetings were given training and offered ‘top-up’ training at all stages. All training was based on a number of topics identified in previous studies in this PhD. To ensure fidelity and standardised training representative training was based on a sheet of topics and points to be discussed (Appendix V: Study 5 representative training summary) and clinician training was based on slides and a script that the researcher (LW) administering the training adhered too (Appendix X: Study 5 clinician training slides).

Table 9.4: Clinician and representative training

<table>
<thead>
<tr>
<th></th>
<th>Numbers trained</th>
<th>Average duration</th>
<th>Topics covered</th>
<th>Top-up training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient and family</td>
<td>2</td>
<td>30 mins</td>
<td>- Importance and purpose of participation</td>
<td>‘Top-up’ training was delivered to both representatives before each meeting lasting on average 15 minutes.</td>
</tr>
<tr>
<td>representatives</td>
<td></td>
<td></td>
<td>- Role of the representative</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Process of change</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Meeting format</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Confidentiality</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Language</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Forum feedback (Appendix T).</td>
<td></td>
</tr>
<tr>
<td>Clinicians</td>
<td>9</td>
<td>25 mins</td>
<td>- Importance and purpose of participation</td>
<td>Top-up training was offered to all attendees prior to each meeting but not availed off.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Role of the representative</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Meeting format</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Confidentiality</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Language</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Forum feedback (Appendix T).</td>
<td></td>
</tr>
</tbody>
</table>

Reach

Reach is about whether the intended audience comes in to contact with the intervention and how (184). To assess this key demographic details for clinician and patient and family samples that took part in the intervention were compared with the wider populations (see Table 9.5). The clinician sample that took part in the intervention through attending clinician and representative meetings was in line with the wider population in terms of
Table 9.5: Intervention attendees and population comparison

<table>
<thead>
<tr>
<th></th>
<th>Clinician attendees</th>
<th>Clinician population</th>
<th>Forum attendees</th>
<th>Feedback participants</th>
<th>Patient and family population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N= 9 (100.0%)</td>
<td>N=18 (100.0%)</td>
<td>N= 14 (100.0%)</td>
<td>N=30 (100.0%)</td>
<td>N= 433 (100.0%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>^</td>
<td>8 (44.4)</td>
<td>0 (0.0)</td>
<td>^</td>
<td>18 (4.2)</td>
</tr>
<tr>
<td>40-59</td>
<td>5 (55.5)</td>
<td>10 (55.6)</td>
<td>9 (64.3)</td>
<td>9 (30.0)</td>
<td>142 (32.8)</td>
</tr>
<tr>
<td>60+</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>19 (63.4)</td>
<td></td>
<td>270 (62.3)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3 (0.7)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0 (0.0)</td>
<td>6 (33.3)</td>
<td>6 (42.8)</td>
<td>14 (46.6)</td>
<td>233 (53.8)</td>
</tr>
<tr>
<td>Female</td>
<td>9 (100.0)</td>
<td>12 (66.6)</td>
<td>8 (57.1)</td>
<td>16 (53.3)</td>
<td>198 (45.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2 (0.5)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leaving Cert or less ^</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>11 (78.5)</td>
<td>27 (90.0)</td>
<td>368 (84.9)</td>
</tr>
<tr>
<td>/Non degree</td>
<td>Degree or above</td>
<td>9 (100.0)</td>
<td>18 (100.0)</td>
<td>^</td>
<td>54 (12.5)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>11 (2.6)</td>
</tr>
<tr>
<td>Duration of attendance/employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤5 years</td>
<td>^</td>
<td>8 (44.4)</td>
<td>^</td>
<td>9 (30.0)</td>
<td>158 (36.5)</td>
</tr>
<tr>
<td>≥6 years</td>
<td>5 (55.5)</td>
<td>10 (55.6)</td>
<td>12 (85.7)</td>
<td>21 (70.0)</td>
<td>271 (62.6)</td>
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<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>4 (0.9)</td>
</tr>
</tbody>
</table>

^ = Figures based on previous studies within this PhD.
^ = Four or less participants

age, education and duration of employment. However, no male clinicians took part in the intervention. The patient and family sample that took part through attending forum meetings were broadly representative of the wider population except for in relation to duration of attendance (see Table 9.5). When recruiting patients and family members to validate feedback from the patient and family forum, family members and those attending the service for a shorter period of time were sought to ensure feedback was representative.

Sustainability
All stakeholder groups were supportive of the idea of patient and family participation continuing within the service.

‘Well I just hope it’s not just going to be a project and it’s done and it’s left there. I hope that some good will come out of it… why bother doing it otherwise?’
However, there was a realistic and practical approach to this. Clinicians expressed a supportive sentiment towards participation but highlighted the need for clinical concerns to come first and resource issues that would need to be tackled for this to happen.

‘In all the feedback among ourselves would have said it was lovely and it was a great idea and it was very good and very positive feedback so you would have buy in...I suppose the key to it really is now that you’ve got a group of people that go ‘Yay that’s not a bad idea’, How do you ensure that that keeps going?’

(Megan, Diabetes, Clinician)

‘I think we need to prioritise things that are patient focused as long as they don’t take away from things that we think are outcome focused ... what you try and do is provide an efficient safe service first and foremost and then above and beyond that ... everything is a bonus.’

(Jim, Diabetes, Clinician)

Identified resource requirements primarily centred around a facilitator or ‘change champion’ (Megan, Diabetes, Clinician). In the intervention the researcher (LW) facilitated meetings and provided support in between meetings such as sending reminders about meeting, setting up the patient and family forum and training of representatives. Many participants asked ‘Who will do that in the future?’ (Jacinta, Diabetes, Patient). It was noted that for the intervention to continue this role would need to be filled. However, concerns were expressed by the clinical team about their ability to dedicate time to this role due to current time constraints.

‘There needs to be a person kind of guiding the... I suppose, scheduling the meetings and probably guiding the conversation for those 20 minutes so I don’t know who that directive person would be you know going forward... everybody is busy so.’

(Renee, Diabetes, Clinician)
Some participants expressed that it was important that this role was filled by a constant member of the team perhaps rotating between members.  

‘I think that probably needs to be somebody who is here all the time rather than somebody that is transient and is moving through the service…. it could be a role that could be rotated it doesn’t have to be fixed on a person’

(Megan, Diabetes, Clinician)

While many felt that it was necessary for this role to be filled by a neutral person, ‘somebody that knows both sides is better in charge.’ (Evelyn, Diabetes, Patient). The idea of patient advocacy being involved in this role was discussed and it was felt by most that this would not be appropriate due to the way in which patient advocacy is typically viewed.

‘I think a lot of time patient advocacy is around complaints ...There’s very little in the way of reporting good things in the health service eh particularly within the institution and I think that makes patient advocacy probably the wrong group of people to do it...I think from an on going piece of service development patient advocacy is not the place for service development.’

(Jim, Diabetes, Clinician)

‘Well that’s more or less for complaints and stuff isn’t it?’

(Evelyn, Diabetes, Patient)

In addition to the need for a ‘change champion’ some participants identified other items that they felt would be helpful for sustainability. One person noted the need for demonstrable change, ‘Results are always what win people over... if we can have a little small win by the interventions that you do then that will also help’ (Megan, Diabetes, Clinician). Another noted the need for all members of the MDT to sign off on any continuation, ‘When the results are and everything is put together it’s probably something that should be voted on’ (Jim, Diabetes, Clinician). In addition the need to expand the intervention to more senior policy leaders was also expressed by one participant.
‘I think a lot of the limitations of what we’re able to achieve are outside of what this service can provide so we have absolutely no power over what’s happening out there... it’s the HSE or whoever the decision makers are...I think unless they were involved and they were able to buy into what we were saying are the issues here then I don’t really see...the limitations are not really going to change.’

(Sinead, Diabetes, Clinician)

9.3.4 Intervention assessment

While the main focus of this study was on the process evaluation and feasibility of the intervention there was also some assessment of the impact of the intervention.

Intensity of participation

There is a trend for increased intensity of participation for patients and family members. In pre questionnaires 46.4% (n=13) of participants reported patients being provided with information about the service. In post questionnaires this increased to 64.7% (n=11) with 52.9% (n=9) of participants reporting patients being asked what they think about the service and 64.7% (n=11) of participants reporting patients being involved in discussions about the service. A similar pattern can also be seen in the intensity of family participation reported (See Table 9.6).

Opinion and attitudes

Positive changes in attitudes and opinions towards participation were illustrated in interviews and focus groups with clinicians.

‘[A] member of staff went into the first meeting of the three meetings going ‘Well it’s all well and good but you know it’s not real research, you know it’s not going to be any value’...she came out of the third meeting going ‘Wasn’t that great! Wouldn’t it be lovely if we could keep that going!’’

(Meghan, Diabetes, Clinician)
Table 9.6: Study 5 impact of the intervention on participation

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=22</td>
<td>N=18</td>
</tr>
<tr>
<td></td>
<td>(100.0%)</td>
<td>(100.0%)</td>
</tr>
<tr>
<td><strong>Patient participation amount and intensity</strong> a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients given information about the service</td>
<td>21 (95.5)</td>
<td>17 (94.4)</td>
</tr>
<tr>
<td>Patients asked for their opinion about the service</td>
<td>13 (46.4)</td>
<td>12 (70.5)</td>
</tr>
<tr>
<td>Patients involved in discussions about the service</td>
<td>8 (28.6)</td>
<td>9 (52.9)</td>
</tr>
<tr>
<td>Patients involved in any decisions about the service</td>
<td>5 (17.9)</td>
<td>11 (64.7)</td>
</tr>
<tr>
<td>Patients made a decision on their own about the service</td>
<td>4 (14.3)</td>
<td>5 (29.4)</td>
</tr>
<tr>
<td>Missing</td>
<td>7 (25.0)</td>
<td>5 (29.4)</td>
</tr>
<tr>
<td><strong>Family participation amount and intensity</strong> b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family given information about the service</td>
<td>13 (59.1)</td>
<td>11 (61.1)</td>
</tr>
<tr>
<td>Family asked for their opinion about the service</td>
<td>8 (28.6)</td>
<td>8 (72.7)</td>
</tr>
<tr>
<td>Family involved in discussions about the service</td>
<td>2 (7.1)</td>
<td>6 (54.5)</td>
</tr>
<tr>
<td>Family involved in any decisions about the service</td>
<td>1 (3.6)</td>
<td>5 (45.5)</td>
</tr>
<tr>
<td>Family made a decision on their own about the service</td>
<td>1 (3.6)</td>
<td>1 (9.1)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (7.1)</td>
<td>1 (9.1)</td>
</tr>
<tr>
<td><strong>Patient participation opinions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients should be involved in the planning of services</td>
<td>22 (100.0)</td>
<td>17 (94.4)</td>
</tr>
<tr>
<td>Patients should be told about changes in the diabetes service</td>
<td>22 (100.0)</td>
<td>17 (94.4)</td>
</tr>
<tr>
<td>Patients should be asked what they think about the diabetes service</td>
<td>21 (95.4)</td>
<td>16 (88.8)</td>
</tr>
<tr>
<td>Patients should have a vote when changes are being made in the diabetes service</td>
<td>15 (68.2)</td>
<td>10 (55.5)</td>
</tr>
<tr>
<td>Patients should make decisions on their own</td>
<td>9 (41.0)</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Family participation opinions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family should be involved in the planning of services</td>
<td>22 (100.0)</td>
<td>18 (100.0)</td>
</tr>
<tr>
<td>Family should be told about changes in the diabetes service</td>
<td>13 (59.1)</td>
<td>12 (66.6)</td>
</tr>
<tr>
<td>Family should be asked what they think about the diabetes service</td>
<td>20 (91.0)</td>
<td>14 (77.7)</td>
</tr>
<tr>
<td>Family should be involved in discussions about the diabetes service</td>
<td>20 (91.0)</td>
<td>15 (83.3)</td>
</tr>
<tr>
<td>Family should have a vote when changes are being made in the diabetes service</td>
<td>15 (68.2)</td>
<td>12 (66.6)</td>
</tr>
<tr>
<td>Family should make decisions on their own</td>
<td>11 (50.0)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>12 (54.5)</td>
<td>8 (44.4)</td>
</tr>
</tbody>
</table>

* = not applicable
a = Family members were not asked this question
b = Patients were not asked this question

However, pre and post questionnaires illustrated slightly lower levels of support for patient and family participation after the implementation of the intervention. Support for patient and family participation at all levels of intensity decreased between the pre and post questionnaires. For example, support for patients being asked what they think about the service decreased from 100.0% (n=22) to 94.4% (n=17) and support for family members being asked what they think about the service decreased from 91.1% (n=20) to 83.3% (n=15) (Table 9.6).
Other reported changes to opinions and attitudes included patient and clinician attitudes towards each other

‘It was very helpful because as I said it makes you see a more human side to them rather than the doctor side... I found that being with them there, they were more human to talk to, they were nicer you know and now I feel I have friends up there....I’m a person you know and they accept that I’m a person.’
(Jacinta, Diabetes, Patient)

and clinician expectations. For example, one of the clinicians expected conversations during meetings with representatives to be stilted.

‘I was fearful at the beginning that they [clinician and representative meetings] might be stilted on either side. That the patients would be afraid to talk ...
I was fearful that they would feel that they couldn’t talk and then I was also kind of fearful that I would be the only one talking in the group.’
(Megan, Diabetes, Clinician)

However, on reflection this was not the case when the intervention was implemented.

‘From a patient’s perspective and our perspective there was quite a nice chat going on, some discussion going on ...I felt that was actually very positive.’
(Megan, Diabetes, Clinician)

Communication, feedback and relationships
Participants often spoke about the impact of the intervention on communication and feedback. It was felt that the intervention was a mechanism of ‘bridging the gap between the doctor and the patient’ (Renee, Diabetes, Clinician) and increasing ‘contact between the patients and the doctors and nurses’ (Evelyn, Diabetes, Patient). This provided patients and family members with information and knowledge which some suggested gave them more power.
‘Knowledge is power... even if there was no interventions occurred throughout
the whole process they were informed of what was happening behind the scenes.’
(Erin, Diabetes, Clinician)

Many participants spoke about increased understanding as a result of the intervention for
all stakeholder groups.

‘It clearly highlighted ... the reason why there was frustration on both sides. So
you know they [patients and family members] would have been frustrated
about things that we just didn’t communicate well enough like em you know
about the role of their GP ... and we were frustrated about them you know like
for example medication why were they not bringing them and they didn’t realise
the importance of that.’
(Eva, Diabetes, Clinician)

For patients it was reported that the intervention increased their understanding of the
clinician experience ‘I know there are so many patients that they have to see and I know
that they can’t be blah, blah, blah, all the time’ (Jacinta, Diabetes, Patient). In addition
greater understanding of the limitations within the service and the process of change was
also expected.

‘It informs the patients a bit more about the process and what is involved
and hopefully I suppose the limitations in what the service is able to provide.’
(Erin, Diabetes, Clinician)

‘The fact that they [representatives] actually got to meet some of the
doctors and that that knew more about it [the service and changes] than we
did and they educated them as much as they educated us about it.’
(Timothy, Diabetes, Patient)

Increased understanding for clinicians was also discussed through clarifying or
highlighting to clinicians what patients are aware off ‘the meetings really just kind of
exposed, probably highlighted to me some of the kind of things that the patients don’t know’ (Renee, Diabetes, Clinician) and what they want.

‘To know what kind of things are important for the patients because what’s important for us as clinicians may not be important...as important for patients and vice versa.’
(Jim, Diabetes, Clinician)

‘It’s always good to get their feedback especially for dietetics, I don’t think we knew that patients actually wanted to see us as much as they were saying.’
(Alana, Diabetes, Clinician)

Service

Service satisfaction decreased from 72.7% (n=16) to 55.6% (n=10) while the percentage of participants that would recommend the service to a friend or family member increased from 88.9% (n=8) to 100.0% (n=8) (Table 9.7).

It is expected that the intervention will lead to changes in the service, ‘I’m hoping that it will change things’ (Stewart, Diabetes, Patient), with the belief that if the intervention had not happened the status quo would continue. ‘Without it, things would just plod along. You know they don’t know our opinion and we don’t know theirs so now we do.’ (Evelyn, Diabetes, Patient). Clinicians reported that the intervention provided evidence that would help their arguments for changes to the service.

‘It’s nice to have a bit of evidence behind any sort of changes that we might like to implement if we have got the patients’ feedback and we’ve got the data and we’ve got the research to actually back that up.’
(Megan, Diabetes, Clinician)

Changes made in the service from the intervention are outlined in the communications leaflet (Appendix U: Study 5 communications leaflet). This includes a review of the appointment letter, standardisation of information provided on diet and accessing
Table 9.7: Study 5 impact of the intervention on service experience

<table>
<thead>
<tr>
<th></th>
<th>Pre N=22 (100.0%)</th>
<th>Post N=18 (100.0%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All in all how satisfied or dissatisfied would you say you are with the way in which the diabetes service runs nowadays?</td>
<td>22 (100.0)</td>
<td>18 (100.0)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>16 (72.7)</td>
<td>10 (55.6)</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>6 (27.3)</td>
<td>8 (44.4)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Would you recommend the diabetes service to a friend or family member? a</td>
<td>9 (41.0)</td>
<td>8 (44.4)</td>
</tr>
<tr>
<td>Likely</td>
<td>8 (88.9)</td>
<td>8 (100.0)</td>
</tr>
<tr>
<td>Not likely</td>
<td>1 (11.1)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>I can express negative feelings freely a</td>
<td>9 (41.0)</td>
<td>8 (44.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (62.5)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>No</td>
<td>3 (37.5)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>I am allowed in the decision-making process a</td>
<td>9 (41.0)</td>
<td>8 (44.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (62.5)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>No</td>
<td>3 (37.5)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>I have an active partnership with the provider a</td>
<td>9 (41.0)</td>
<td>8 (44.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (62.5)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>No</td>
<td>3 (37.5)</td>
<td>3 (42.9)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>The provider encourages me to make decisions a</td>
<td>9 (41.0)</td>
<td>8 (44.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>4 (50.0)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>No</td>
<td>4 (50.0)</td>
<td>2 (28.6)</td>
</tr>
</tbody>
</table>

- = not applicable

a = Clinicians were not asked this question

dietician services and presentation of a business case for additional dieticians. This was discussed by a number of participants.

‘I’ve said that they’d give the EXPERT leaflet. I can’t guarantee that they will but you know at least there’s more structure there as to what the doctors are advising on .. it’s clear to all of them now that there is a programme.’

(Alana, Diabetes, Clinician)

‘Now I do believe they are kind of getting one or two more dieticians.’

(Evelyn, Diabetes, Patient)
Other impacts

Participants were asked and spoke about a number of other impacts of the intervention. Patients and family members were asked four questions on empowerment, three of which increased after the intervention. Being able to express negative feelings freely increased from 62.5% (n=5) to 71.4% (n=5), being allowed in the decision process increased from 62.5% (n=5) to 71.4% (n=5) and providers encouraging decision making increased from 50.5% (n=4) to 71.4% (n=5) (Table 9.7). In line with this one of the patients stated that ‘I was more confident’ (Jacinta, Diabetes, Patient) after the intervention.

A small number of participants spoke about other emotions stemming from the intervention. One clinician spoke about frustration relating to the slow process of change ‘It’s probably frustrating on the other side of it because there is very little we can actually do for them at the moment as regards change and service’ (Felicity, Diabetes, Clinician) while another said ‘I think that even the talking part of it was cathartic’ (Megan, Diabetes, Clinician). This idea of the intervention being cathartic was also touched on by a patient who felt that this impacted on his overall health.

‘I wasn’t always taking care of me blood pressure but from starting to go to them meetings and listening to the interaction with different people there, you know because we’re all different in our own ways but the fact that people interacted with each other and they were able to explain how they felt and the way we felt you know I think it’s a very good idea.’

(Timothy, Diabetes, Patient)

Limitation of impacts

One key point that was made in relation to a number of possible impacts of the intervention was that these were limited to those who took part in the intervention. While participants felt that people’s opinions and attitudes changed and communication between stakeholder groups increased these effects were limited only to those patients, family members or clinicians who engaged directly in the intervention through attending forum meetings or meetings between clinicians and representatives.
‘People within the actual discussions maybe their attitudes changed ... I don’t know how much more of an effect it would have on people around us other than myself and Eva who are actually actively involved in the discussions
(Renee, Diabetes, Clinician)

‘Because we only had the direct contact with the two [representatives] ... I know they were representatives of a larger group but it’s hard to say would it affect the relationship with the patient body.’
(Megan, Diabetes, Clinician)

However, it was suggested that as more people become aware of the intervention and the work that was done perhaps the impact of the intervention may become greater.

‘If that word gets out that this happened I think is a positive thing... I think once it’s more widely circulated, what the patients want, I think that will have a big impact’
(Jim, Diabetes, Clinician)

9.4 Discussion

9.4.1 Discussion of findings
The intervention of clinician and patient and family representative meetings supported by a patient and family forum to encourage greater patient and family participation was feasible with support from the research team. The intervention included two key elements: clinicians meeting with patient and family representatives and a patient and family forum. The research protocol was adhered to on the whole, the reach of the intervention was comparable to the overall populations and the specified number of meetings took place. The Matrix of Service User Participation has highlighted that often more than one method is required to encourage participation (33). Having a group element in participation, such as a forum, has been identified as important in the CLEAR Framework as participation through groups is more sustainable with mutual reinforcement (153). Support and buy-in for continued participation was evident.
However, there were concerns about the resources required for this, particularly the need for a facilitator to organise future participation who would ideally be a neutral person.

All stakeholder groups with a role in the intervention contributed to the development of the intervention (see Chapter 7 for further detail). Participants felt that this was important as they had a part to play in the intervention, it increased buy-in and added structure to the intervention. Previous research on the development of complex health interventions has shown that the organisation in which the intervention takes place, including the staff, alongside the intervention developers play a pivotal role in implementation (308). Involving all of these stakeholders in development improves the ‘fit’ of the intervention to the environment (309) as well as increasing stakeholder buy-in (34), which is a key step in the first phase of the Quality Implementation Framework (309). In relation to participation the Canadian Foundation for Healthcare Improvement identified the involvement of patients in determining their role and intensity of participation as one method to ensure clarity of purpose, which is one of the key ingredients of participation (298).

Representativeness of those involved in the intervention was a key point of the discussion relating to the evaluation of the intervention. No consultants took part in the intervention. Some participants attributed this to lack of time. Others attributed this to attitudes towards research suggesting that for some within this discipline unless research is an RCT it is not considered ‘real’ research. The diabetes service is nurse led so both positive and negatives from this were noted. However, the team operates on all disciplines of the team signing off on any key changes and the importance of leadership from the clinical team was noted by participants. The importance of leadership for successful participation has been acknowledged in the CLEAR Framework (19) and the World Health Organisation (WHO) policy framework for people centred care which includes enhancing leadership as one of the steps for healthcare organisations to take when working towards people centred care (81). It is interesting to note that in research assessing team meetings with family caregivers in attendance, while consultants attended it was the nurses who contributed most and took the lead (78). This research was based in a hospice service, which like this diabetes service, was primarily nurse led. While
feedback used in the intervention included a representative proportion of family members. It was noted by participants that it would be beneficial if more family members attended the forum. Poor attendance at forum meetings by family members may be reflective of previously reported lower levels of support for family member participation (33) and a preference for less intensity of participation for family members (35).

Training and support provided in the intervention was important to participants. This is in line with the CLEAR Framework which identifies the capacity and capabilities of patients and the public as a potential barrier to participation (19). Training provided a space for those taking part to think through the intervention, any concerns that they had and what they would need to do on the day. It was felt that this improved communication and discussions in clinician and representative meetings. Similarly, research in Canada reported that training provided to citizen representatives involved in setting priorities for healthcare contributed to participants’ sense of credibility, legitimacy and ability to contribute as well as providing an opportunity for representatives to ask questions in a non-threatening environment (269). An element of the training delivered in this intervention focused on the importance of patient and family participation and the process of change within the diabetes service. This focus on attitudes was important to assist an organisational cultural shift towards a ‘patient focused’ attitude culture (50). This is particularly pertinent to this diabetes service where opportunities for service level changes are more limited as a culture which is supportive of change and learning is essential for successful patient-centred care (300).

While the focus of this research was on feasibility and the process evaluation some impacts were also identified. There was a trend for the intensity of participation and empowerment to increase. Impacts on the service were demonstrated such as a business case for more dieticians being presented, a review of the appointment letter and standardisation of the provision of information on diet and accessing dietician services. Participants reported improved communication and feedback. Clinicians were more aware of what was important to patients and family members while patients and family members had more information about what was happening in the service as well as limitations. This is in line with previous research which reported that forums improve the quality of information provided (294) and the CLEAR Framework. This framework
proposes that collective participation provides continuous reassurance and feedback that the cause of engagement is relevant and that participation is having some value while providing a communication route to decisions makers viewed as vital to the vibrancy of participation (19). The reported trend for empowerment to increase is also in line with previous research. For example, a cross sectional study in community mental health services in England reported increased empowerment as a positive outcome from patient participation (94).

9.4.2 Strengths
This research adds to the currently literature illustrating the feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery and identifying key elements to making this change. To date there has been a limited focus within the literature on patient and family participation at this level. A key strength of this research is the methodology and guidelines employed. A mixed methods approach was adopted with interviews and focus groups as well as surveys. Mixed methods assessment of measures leads to a more robust understanding of the processes and outcomes of engagement aiding momentum to effect changes to service delivery (186). Qualitative methods have been supported for the evaluation of health services. They can illustrate and understand the process of implementation, propose suggestions for modifications and provide a method for service users to become actively involved in evaluation and improvement of the health services that they receive (310). MRC guidelines for development and process evaluation (184) were employed at all stages from planning, design and conduct, analysis through to reporting. In adhering to these guidelines all stakeholders involved in the intervention were involved in development of the intervention that was based on a number of previous studies conducted within the same service by the same research team. MRC process evaluation guidelines advise using reporting guidance specific to methods adopted (184). In line with this the Template for Intervention Description and Replication (TIDieR) checklist and guide (203) was employed in reporting the intervention (See Appendix F) and the Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32 item checklist (191) was used for reporting qualitative data (See Appendix E).
9.4.3 Limitations

Analysis of qualitative data was conducted using IPA. When IPA is employed for evaluation of an intervention it is important that the evaluation is conducted by an ‘independent’ person without vested interests in the intervention (263). The researcher (LW) conducting this evaluation was involved in the service in a research capacity for two years before the intervention commenced and in all areas of development and implementation of the intervention. To ensure credibility, transparency and trustworthiness standards for conducting good qualitative research were followed. The coding frame was reviewed by a patient and family representative (CC), triangulation was conducted, direct quotes were used to ground themes within the text and dissenting ideas were discussed throughout the presentation of results. Similar steps were taken in an evaluation of services for early intervention in psychosis in the UK through interviews assessed through IPA by a member of staff (262). Due to the numbers of participants in the intervention, numbers in quantitative data are small. However, small sample sizes are hard to overcome in studies looking at participation in healthcare as deliberation decision making dictates small groups (311,312). In line with this no inferential statistics have been conducted, the ‘n’ is reported for all figures and the researcher (LW) has been careful with the phrasing of results. In addition it is also important to note that the focus of this study is on feasibility and the process evaluation with most of this data being qualitative. Finally, no family members took part in the evaluation of this intervention. This was due to no family member being eligible to take part in the process evaluation.

9.4.4 Conclusion

Patient and family representatives attending meetings with the clinical team supported by a forum was a feasible intervention with the support of the research team. Stakeholder involvement in the development of the intervention, attendees and communication at meetings and training and support were key elements in the process evaluation. Impacts were reported on the intensity of participation, communication and feedback and the service. Work needs to be continued at the service level to maintain the momentum and buy-in garnered from the intervention to continue the participation of patients and family members. Patients and family members need to continue to be encouraged and facilitated to participate while clinicians also need to be supported in this
process. Support, both attitudinal and in terms of resources, needs to come from all levels from senior members of the clinical team to those working in management in the hospital and at a policy level. Further research needs to be conducted testing this intervention with a focus on outcomes as opposed to feasibility as well as expansion of testing to a wider array of services.
Chapter 10: Integrated Discussion of Findings

10.1 Introduction

Patient and family participation is ‘a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (1). Participation has been accepted as integral to healthcare services and systems (313). Potential impacts include: improved population health (4), better health and treatment outcomes (3,4,12,14,69), greater quality of life (69), increased self-dignity, self-worth and self-esteem (69,86,87) for patients as well as more appropriate, relevant and responsive health services and systems with greater satisfaction and quality (4,6,16,88). International organisations such as the World Health Organisation (WHO) and United Nations (UN) advocate that people have a right and duty to be involved in the planning and implementation of their healthcare (45,314). In Ireland the importance of participation has been noted in numerous policy documents including ‘A Vision for Change: Report of the expert group on mental health policy’ (209), ‘The National Health Strategy: Quality and Fairness- a health system for you’ (53), the Madden Report (54) and ‘Healthy Ireland’ (55) and since 2012 Health Service Executive (HSE) National Service Plans have included outcomes focused on participation (57–61). This demonstrate a rich and supportive policy context for participation nationally and internationally.

However, there is a lack of consensus relating to the definition, components (4,17,52,65,67) and implementation of participation (7,10,16,17,52,97), particularly in achieving strong and lasting participation (16). Participation can occur at different levels; the patient level (e.g. changes to individual care plans), the service level (e.g. how the appointment system works) and the national level (e.g. national health policy) (2–4). In addition to this the implementation and intensity of participation varies along a continuum from consultation to partnership, depending on how active the patients’ or family members’ role is (4). Options for the implementation of participation at the service level include questionnaires (52), involvement in development of information material
(73), workshops (16), forums (74), representatives (75), patient or family involvement on boards or committees (5–7), patient charters (6,8), health panels (9) and setting of priorities (77). There is a lack of consensus in the implementation of participation due to the heterogeneity of existing research in terms of the interventions tested, the patient groups employed and underlying health systems. For example, interventions tested have included patient involvement through priority setting in primary care services in Canada, patient involvement through an evaluation of mental health services in Ireland (110) and the use of citizens’ juries with patients to investigate e-health in the United Kingdom (111). In addition to this there is a lack of focus in existing research on participation at the service level (87,97) and the role of family members. A focus on the service level has been identified as a crucial step towards broader engagement at the national level as patients are better able to imagine the possible impact and see the actual outcomes of their engagement (315). The WHO has identified the need for research on participation to focus more on the role of family (81).

Finally, despite the role of social, political and cultural contexts (316), numerous policies acknowledging the importance of participation (54,55,209), having a National Strategy for Service User Involvement from 2008-2013 (6) and outcomes for participation in HSE National Service Plans since 2012 (57–61) there is a dearth of Irish based research on patient and family participation in healthcare design and delivery. The National Patient Experience Survey (NPES) measured patient participation at the patient level in Ireland for the first time in 2017. However, we do not know how much participation is taking place at the service level or how involved patients and family members want to be. This means that there is no way for us to know if what we are doing to encourage greater participation is working or is satisfactory.

This PhD aimed to develop, implement and test an intervention to encourage greater patient and family participation in healthcare design and delivery in a psychiatry and a type 2 diabetes service. This included identification of the current amount and intensity of participation and exploration of the understanding, opinions, barriers and facilitators to participation.
10.2 Difference between what we are saying and doing

Examination of results from the five studies across this PhD relating to support for participation and intensity of current participation illustrates that similar to what is seen elsewhere there is a gap between what we are saying and doing.

10.2.1 Understanding and support for participation

Interviews and focus groups with patients, family members, clinicians and policy leaders in Study 2 of this PhD revealed limited understanding. Participation was typically understood at the patient level and restricted to passive methods, such as the provision of information or gathering of feedback. Ambiguity and confusion emerged with the concept of participation at the service level. Typically only senior clinicians and policy leaders understood participation to include the service level. This is reflective of previous research on patient involvement in the development of clinical practice guidelines which illustrated understanding of participation being influenced by the participant’s role (16,47). It also demonstrates the documented lack of consensus and confusion surrounding the definition and components of participation (4,17,52,65,67). The relationship between role and understanding is important to explore due to the link between lack of consensus and participation not being implemented (52). Participation needs to be understood to enable implementation (52).

Support for patient and family participation at the service level is illustrated in Study 1, Study 2 and Study 3 of this PhD through researcher-administered questionnaires, interviews, focus groups and Delphi Techniques Experiments (DTEs). In Study 1 80.3% (n=537) of participants support greater patient participation and 55.3% (n=374) of participants support greater family participation at the service level (33). A similar pattern emerged in Study 2 and Study 3. Participation is viewed as a right or entitlement due to patients and family members being the people in receipt of and impacted by healthcare services with relevant experience and knowledge to improve services. This is congruent with what is demonstrated internationally where reported support for participation across the patient and national levels varies from 50% to 93% (111,267,268,272). The identification of support for greater participation at the service level expands the current literature beyond its focus on patient and national level participation (7,155,240). The
inclusion of family participation is also a new addition. To date research has focused on the role of patients and the public in healthcare (7,155,267,268). This is despite the role of family members in the provision of good patient care and advice from the King’s Fund that family should be considered at all stages of care-planning, decision making and delivery, with the same thought and attention as for patients (17).

Logistic regressions based on questionnaires with 738 patients and family members from the psychiatry and diabetes service in Study 1 identified significant characteristics associated with support for greater participation (33). Statistically significant factors associated with support for greater patient participation at the service include age, education, duration of attendance and service satisfaction. Statistically significant factors associated with support for greater family participation at the service include age, whether a family member normally attends with the patient, the service attended and duration of attendance. Characteristics typically associated with support for participation include age, gender and education (154,155,244). The current PhD also identified service satisfaction, the duration of attendance and service attended as new characteristics associated with support for participation at the service level. Those with a lower level of service satisfaction were more likely to support patient participation at the service level. Interviews and focus groups with patients and family members in Study 2 of this PhD helped to explain this finding. Participants spoke about not feeling participation was necessary as they did not have any negative experiences or difficulties with the service. Those attending for a shorter period of time were more likely to support greater family member participation at the service levels. This may be associated with the trajectory of attendance. Those attending for a shorter period of time are more likely to be accompanied by a family member. During this time there is a lot of information to take on board and family members play a key role. Participants attending the psychiatry service were more likely to support greater family participation at the service level. Again interviews and focus groups in Study 2 of this PhD helped to unpick this association. Clinicians in the diabetes service queried the need for family participation due to most of their patients having full capacity and the ability to make their own decisions and may resent the idea of family members being involved.
10.2.2 How much participation is taking place?

In contrast to the rhetoric of policy and support demonstrated by various stakeholders it was evident in Study 1 questionnaires and Study 2 interviews and focus groups that participation does not occur on a regular basis in either service. Participation is limited to the provision of information. Patients and family members are not asked what they think about the service or involved in discussions and do not have a role in the decision making process about the service. Clinicians mirrored this noting that there are no formal mechanisms in place in either service to enable participation. The lack of formal mechanisms for participation hinders participation as we know from the CLEAR Framework that people participate when they can, when they are enabled too and when they anticipate a response (19). Despite the support for participation over a number of years in policy we do not know how much participation is taking place in Ireland. The NPES measured patient participation for inpatient hospital treatment in 2017. While this is a great start, limiting the measurement of participation to the patient level within a specific setting adds further confusion and restrictions to the understanding and implementation of participation. Robust identification of the amount and intensity of participation based on Arnstein’s Ladder of Participation using both qualitative and quantitative methodology in this PhD adds to existing knowledge about participation in Ireland and internationally.

The demonstrated gap between support for participation and ongoing participation in the psychiatry and diabetes services in this PhD is reflective of what is happening elsewhere. The King’s Fund identified a mismatch between the rhetoric and operationalisation of participation in England (17,52). This is key as we know that one of the barriers to participation is attitudes. While lack of support from particular cohorts may still lead to difficulties in implementation it is evident that on the whole there is support for participation.

10.3 What does patient and family participation at the service level need to look like?

Patient and family participation in healthcare design and delivery is supported by national and international policy as well as by key stakeholder groups involved in the psychiatry and diabetes services in this research (33). However, there is no consensus as to what
participation needs to look like. There is no right model as not one size fits all. There is a range of options to suit different situations. Time and attention needs to be given to selecting the most appropriate method of participation (317). An intervention to encourage greater participation was developed for the psychiatry service and the diabetes service in line with Medical Research Council (MRC) guidelines. This was based on; a literature review, the CLEAR Framework (19), Arnstein’s Ladder of Participation (18), input from patients, family members, clinicians and policy leaders from both services through interviews and focus groups in Study 2, DTEs in Study 3 and intervention refinement interviews and focus groups in Study 4 and Study 5. Process evaluations conducted in Study 4 and Study 5 also provide further information on what participation needs to look like.

It is important to note that despite the lack of agreement within the literature a high level of consensus was achieved in Study 3 of this PhD. Two DTEs were conducted, one in each service, with patients, family members and clinicians to identify preferences for the intensity and key elements of the interventions developed. Consensus was achieved in 60 of 65 questions in psychiatry and 60 of 64 questions in diabetes. These DTEs add to the current body of research as the first DTEs to include patients, family members and clinicians in the identification of the intensity and implementation of participation. This is important due to the methods for participation differing by service and issue (10,272) and MRC guidelines for the development of interventions recommending the inclusion of all key stakeholder groups (265).

10.3.1 Involvement of all stakeholders in development

We can see from interviews and focus groups with patients and clinicians from both services in Study 4 and Study 5 that involvement of all stakeholders with a role in participation is key. This reflects guidance for healthcare interventions in general that all those involved in healthcare interventions should have a role in development as the organisation and people involved have a pivotal role in implementation (265,308). It is also in line with advice for interventions focused on participation. Involvement of key stakeholder groups in setting the intensity of participation and their role in participation is recommended as it ensure clarity of purpose (298).
Participants in this PhD felt that involvement in development increases buy-in and ownership and makes participation more successful as structure is added, potential issues ironed out in advance and understanding of participation processes and implications increased. This is important as we know, from a systematic review of healthcare professional perceptions of facilitators and barriers to the implementation of shared decision making, that lack of applicability to the situation has been identified as a barrier and clinician motivation is a facilitator (106). Increased stakeholder buy in (34) and improved ‘fit’ of interventions (309) and more effective participation (269) have also been reported in previous research as a result of stakeholder involvement in the development of participation interventions.

10.3.2 Intensity of participation

Key to the method of participation is the intensity of participation. Arnstein’s Ladder of Participation outlines the intensity of participation on a ladder. Passive participation where patients and family are provided with information about changes is at the bottom. The intensity of participation increases as you move up the ladder to more consultative methods such as patients and family being asked what they think about the service or changes. At the top is active participation where patients and family members take part in the decision making process or perhaps take control completely (18).

Using this ladder of participation DTEs in Study 3 of this PhD identified preferences for the intensity of participation. Participants supported participation to the point of being involved in discussions for psychiatry family members, diabetes patients and family members. A more intense level of participation was preferred for patients in the psychiatry service, participation to the point of having a say when changes are being made. These preferences emulate research conducted in America, England and Australia which also report preferences for consultative methods with healthcare professionals retaining all or some responsibility for decisions made (111,267,315). A DTE with experts including professionals with experience of participation, those who study participation and those who have serviced as patient representatives in outpatient services in America proposed that this intensity of participation was preferred due to its low intensity,
relative familiarity and patient willingness to share their experience in this way (315). Support for more intense participation for patients in the psychiatry service in this PhD may be associated with patients attending the service more frequently, every two to three months as opposed to every two years in diabetes. In Study 2 patients and family members in the diabetes services spoke about not needing to be involved in how the service works as they only attend every two years. The policy context within mental healthcare services where there has been more work done on patient engagement initially through *A Vision For Change* (209) and more recently through *A Partnership For Change* (210), which is currently being implemented, may also be contributing. This is in line with recommendations based on an ethnographic review of participation in quality improvement that engagement approaches should value and give weight to the contribution of every stakeholder (317).

10.3.3 Representation

When implementing patient and family participation we can see from preferences identified through DTEs in Study 3 and interviews and focus groups in Study 4 and Study 5 that it is important that patients represent patients and family represents family. Characteristics such as capacity to dedicate time, patient’s health and duration of family member attendance need to be considered during recruitment and selection of representatives. Representatives need to take their own experience as well as feedback from the wider patient and family populations into account when providing input. For example, in the diabetes pilot intervention this was achieved through representatives identifying with feedback from the forum through their own experience but input at meetings with clinicians being based on feedback from the patient and family forum. This is important of this mix is discussed through the necessity of a link with the wider patient and family populations below. It is also important that everybody involved in participation is made aware of how representatives are selected and what their input is based on. These steps echo findings in that representativeness is a key dimension to consider when designing and executing participation (99). In addition to this the use of selection criteria has been shown to provide legitimacy to representatives in a qualitative process evaluation of public involvement in setting priorities for healthcare improvement in Canada (269).
It is important that there are at least two representatives working together. In Study 5 this was shown to provide moral support, strengthen input and make it easier for representatives to take on board what is being said. Representatives attending meeting in groups of two is recommended from research within the Irish mental health services which assessed barriers to participation that included representatives feeling intimidated when attending large committee meetings as the only patient (75).

10.3.4 Link with wider patient and family populations

Associated with the importance of the representativeness it is key that there is a link between representatives and the wider patient and family population. This was illustrated in preferences from the DTEs in Study as well as interviews and focus groups in Study 4 and Study 5. The link with the wider populations needs to work both ways with populations giving representatives their opinions, experiences and feedback on the service and representatives updating populations. Updates from representatives can be in a variety of formats but work well when written with an opportunity for oral questions and should include how feedback from patients and family members was used, what decisions were made and why. Linking with patient and family populations was viewed as important by participants in interviews and focus groups in Study 5 as the purpose of participation was to include patients and family members in general, not just one or two patients or family members. This supports work conducted in England which illustrated the differences between opinions of forums and opinions of the general public (292).

Representatives being associated with the wider population has been shown to boost competency, participation, credibility and legitimacy as representatives can draw from their own experience as well as information and experiences from the wider population, which is one of the key ingredients for effective participation (12,269). In addition to this it is proposed by the CLEAR Framework that collective participation provides continuous reassurance and feedback that the cause of engagement is relevant and that participation is having some value while providing a communication route to decision makers viewed as vital to the vibrancy of participation (19).

Tokenism is where patients or family members become involved in healthcare design and delivery but their input is not listened too or taken on board when decisions are being
made (234). This was a concern raised by participants during interviews in Study 2 and again in process evaluation interviews in Study 5. Participants spoke about examples where the role of patients and family members has been tokenistic and the need for steps to be taken for this not to occur in this intervention. Building a link between representatives and the wider population introduces more transparency and accountability to the wider populations.

10.3.5 Training and support

Training and support is an essential component of any intervention to encourage greater participation. It was clear from qualitative data collection in Study 2 and a high level of consensus in DTEs in Study 3 that there was support for training for all stakeholder groups including patients, family and clinicians. The need for training stemmed from concerns surrounding capacity to participation and contribute to the decision making process and attitudes. Topics to cover include why patients and family members should be involved, how the service operates, how decisions are made and how to work with others. This is in line with the CLEAR Framework and is reflective of previous research in different settings and countries. The CLEAR Framework specifies that people participate when they have the resources, knowledge and support to do so (19). The need for training for participation has been acknowledged by the NHS (299) and the WHO (81). Support for clinician training has been illustrated in a review of strategies for involving patients (284) and in interviews with staff and patient representatives from healthcare organisations that have been successful in improving the patient experience (300). Identified barriers to participation that training can help include the skill and capacity of participants, cultural attitudes, the ‘unspoken rules’ of decision making, use of technical language and group and power dynamics (15,50,75).

Process evaluation interviews and focus groups in Study 5 of this PhD highlight the impact of training and support. This time provided an opportunity for participants to think through and ask questions about the processes involved and the input that they could provide. Participants reported feeling more confident and that communications and discussions were improved as a result of training and support provided. These findings are in line with a process evaluation conducted in Canada of public involvement in setting
priorities for healthcare improvements which found that training and support contributing to representatives’ sense of credibility, legitimacy and ability to contribute as well as providing an opportunity for representatives to ask questions in a non-threatening environment (269). In an Irish setting an evaluation of a training course for patients and supporters of mental health services to participate in service design and delivery reported greater confidence in expressing views in an organised and constructive way, more knowledge and understanding of mental health services and committees (318).

10.3.6 Processes and structure

Attention needs to be given to the processes and structure of participation. Interviews and focus groups in Study 2 and Study 5 highlighted the importance of building participation into existing structures, ensuring meetings take place at a time and location most suitable to all attendees to increase sustainability and attendance. Facilitation is necessary to ensure attendees feel meetings are worthwhile and productive and comfortable to contribute to discussions. It is best if this role can be taken on by a neutral person so both groups are treated the same and no one group dominates or has more power in the participation process. A non-hierarchical structure needs to be encouraged for example through ice-breakers, name badges, encouraging and noting the importance of input from everybody in attendance a meetings, avoiding the use of technical language. These steps supported by this PhD are also encouraged in other studies. To level power differences public participation in priority settings for healthcare in Canada ensured clarifications were provided when technical language was employed, actively seeking representatives’ opinions during discussion and ensuring representatives were sitting together (269). Similarly, a review of lessons learnt from patient engagement in health services in Canada identified the need to avoid the use of jargon, ensure all participants having an equal voice (319) and build initiatives into existing processes and structures to ensure sustainability (301).

Based on interviews, focus groups and DTEs with patients, family members and clinicians as well as the existing literature there are a number of key things that need to be taken into consideration when developing and implementing participation. All stakeholder groups need to be involved in development for buy-in, fit and effectiveness. A high levels
of consensus between key stakeholder groups is possible. Active methods of participation are preferred with participation in discussions and for psychiatry patients having a say. Patients should represent patients and family should represent family. Linking and communicating with the wider patient and family populations is key to ensure credibility, legitimacy and avoid tokenism. Training and support is essential to overcome barriers, aid credibility, increase legitimacy and build confidence. Participation needs to be built into existing structures, facilitated by a neutral person and steps taken to tackle power differences. From findings of the current PhD we can see that what works in participation at the patient and national levels is reflective of what works at the service level. In addition, what has been shown to be effective in other countries also works in the social, cultural and political context in Ireland.

10.4 Impact of patient and family participation at the service level

10.4.1. Impact on patient and family participation

In Study 5 the diabetes pilot intervention of patient and family representative meetings with clinicians supported by a patient and family forum was implemented and tested. This revealed a trend for increased participation as a result of this intervention. The most commonly reported intensity of patient participation increased from being provided with information to being involved in discussions about the service. A similar pattern was also reported for family members. This increased participation to the preferred intensity of participation as indicated by patients, family members and clinicians in Study 3. It also brought the intensity of participation in line with internationally demonstrated preferences for participation with clinicians retain some or all responsibility for decisions made (111,267,315). Illustrating participation at this level of intensity is key as it highlights that addressing the deficit between what we are saying and doing is possible.

It has been acknowledged that the intensity and methods of participation differ based on the service and topic (10,272). There is no consensus as to what participation needs to look like with time and attention required for selection of the most appropriate method of participation (316,317). Furthermore, a rapid evidence synthesis of patient and public engagement in the reconfiguration of health care services between 2000-2014 concluded
that there is no evidence on the isolated impact of any particular engagement method or collection of methods (316). Following from this it is beneficial to know the exact intensity of participation achieved with individual methods of participation, to enable replication and implementation in future research and healthcare services.

10.4.2 Impact on the service

Interviews, focus groups and questionnaires in Study 5 illustrated that the intervention of representative and clinician meetings supported by a forum resulted in demonstrable changes in the service. Changes to the service included a review of the appointment reminder letter, standardisation of information provided on diet and accessing dieticians. These changes were made based on feedback from the forum, which was reported to clinicians through meetings with representatives who were actively involved in discussions to resolve identified problems. Clinicians also used feedback from the forum to strengthen their argument for changes; for example, in a presentation of a business case for more dieticians in the service. It was felt by participants that over time participation would lead to an improved service.

These changes are in line with anticipated impacts discussed by patients, family members, clinicians and policy leaders in interviews and focus groups in Study 2 and Study 4. Expected impacts included improvements in the service as a result of more patient centred decisions being made and a greater capacity for change to happen. The inclusion of the experience of patients and family members and creation of new ideas for change were anticipated to contribute to these changes. Demonstrated changes also reinforce international research on participation at various levels and in different services. Research has illustrated participation ensuring the development of relevant, effective and improved services (3,4,6–8,16,88) that are responsive to patients needs, values and priorities (6,16,88). For example, having patients being partners on care redesign teams in Canada resulted in the introduction of a new point of view to discussions and exposed teams to valuable information that had not previously been thought about. Changes addressing the needs of patients were implemented as a result (89). An example of participation improving services and the capacity can also be seen in work conducted in a mental healthcare context. Interviews with service users on their
Involvement in the development of clinical guidelines for mental health services in the United Kingdom noted the value of personal knowledge and experience from patients (15).

It is pertinent that demonstrable changes to the service can be illustrated. Identified barriers to participation in Study 2 of this PhD include unrealistic expectations and the service not being able to make any of the changes suggested by patients. Study 5 highlights that not all suggestions from patients and family members are unrealistic, patients and family members are understanding of the limitations that services and clinicians are working within and action can be successfully taken to address feedback from patients and family members. These are important findings as results can be used to ally concerns expressed by clinicians in future participation interventions and provide concrete examples of the impact of participation. In addition, the ability of this research to report demonstrable changes to the service is key as it has been noted that research on participation interventions typically focuses on outcomes relating to process such as views about the service or organisational culture, instead of the direct impact of participation on the service (316).

10.4.3 Impact on participants

Study 5 of this PhD illustrated the impact of participation on participants through qualitative and quantitative data collection, mainly in terms of opinions and attitudes and communication.

Exploring the impact on opinions towards participation is important as it has been shown that negative opinions towards participation by clinicians can limit participation (7,96) and cultural attitudes can be a barrier to participation. The impact of the diabetes pilot intervention in Study 5 on opinions and attitudes towards participation is unclear. In process evaluation interviews and focus groups, examples were provided of positive changes in attitudes towards participation, particularly for clinicians. However, pre and post questionnaires showed a trend for a negative impact on opinions of participation. Support for patients and family members being asked what they think about the service decreased after implementation of the intervention. This was unexpected as a systematic review of papers describing the effects of involving patients in planning and developing
healthcare reported that staff attitudes to patient participation became more favourable when patients participate (69). However, the quantitative findings in Study 5 are based on small numbers and the trend for a negative change in opinions towards asking patients and family members for their opinion is very small with a reduction in both being based on one person answering differently.

Participants in process evaluation interviews and focus groups in Study 5 demonstrated improved communication between patients, family members and clinicians as a result of the implemented intervention. There was increased contact between patients and clinicians. Patients and family members were provided with more information and knowledge, giving them a deeper understanding of the clinician experience and limitations of the service. Clinicians gained a greater understanding of what patients and family members want and what information they need. These impacts emulate what participants expected would result from increased participation in Study 2, particularly in terms of greater understanding of the experience of each group and the decision making process. Similarly, previous research on participation has illustrated greater social interactions between clinicians and patients (94) with more clarity, practicality and transparency in the development of healthcare services (6,83).

The impact of participation was discussed with patients, family members, clinicians and policy leaders in Study 2 of this PhD and again in Study 5, after implementation of the diabetes pilot intervention. Anticipated impacts focused mainly on the service. Demonstrated impacts were generally inline with what was expected from participation but were broader than the service. This is important as it validates the process used to select and develop the intervention as the implemented intervention was in line with what participants expected and supported. It is important to note that the impact of the intervention may be limited to those who took part directly in the intervention. This means that it is unclear what impact the intervention had on clinicians who did not attend meetings with patient and family representatives or patients and family members who did not attend forum meetings. It was suggested that the impact may increase over a longer period of time as more people learn about the work of the forum and representatives. However, a longer study would be required to investigate this. Also, in Study 2, negative impacts from participation were noted such as frustration or tokenism.
due to a lack of change. Again, this did not emerge during the duration of this PhD but a longer follow up period may be required to investigate these concerns.

10.5 Challenges and sustainability of patient and family participation at the service level

10.5.1 Attitudes

A key barrier identified in interviews and focus groups in Study 2, Study 4 and Study 5 was attitudes often underpinned by fear or anxiety. It was proposed that a barrier to participation, particularly for patients and family members, is what was viewed as an Irish attitude of not speaking up or complaining when something was wrong. This was linked with the paternalistic culture within our healthcare system and concerns about implications for care or treatment received. Questions were raised about attitudes within healthcare services and systems and how ready they are for change with a defensive attitude expected by patients and family members. However, clinicians discussed concerns about participation stemming from not knowing what to do, fear of being judged, raising expectations that can’t be met or damaging relationships or patients trust as a result of not being able to make changes happen.

These identified barriers to participation at the service level from the current PhD in an Irish setting are reflective of barriers and challenges to participation acknowledged at different levels of participation and healthcare settings. A DTE on preferences for participation within outpatients settings in America identified attitudes as a barrier to participation. The conclusion was that participation based on equal partnership may not be feasible at present, in part because it may require substantial cultural change among clinicians and staff (315). A systematic review of patient reported barriers and facilitators to shared decision making mirrored barriers associated with expectations of patients and their role. There is an expectation that ‘normal’ or ‘good’ patients are passive and happy to let clinicians to make decisions. Patients are reluctant to step outside of this role as they fear this will result in them being identified as inflexible or troublesome leading to poorer quality care or less attention. In line with this many patients believe that the ‘doctor knows best’ and that their own knowledge is superfluous to the decision making process being trumped by medical expertise and experience (105). This belief has been
shown to be particularly prominent among older patients who believe that they are part of an age cohort that accepts the authority of clinicians which should not be questioned (105,320,321). Similarly an examination of models of user involvement within the mental health context illustrated that while mental health policies call for attention to patient’s perspectives and user involvement, daily work with patients seems to be influenced by the understanding that health providers have the expertise and know what their patients’ best interests are (303).

The potential negative impact of attitudes underpinned by fear and anxiety was demonstrated in Study 4 when the psychiatry pilot intervention of representatives attending management meetings was unable to be implemented. This was in part due to the implication of a clinician review of representative attendance at meetings after the 3 month research period. For clinicians this stemmed from fear about change and loss of control, concerns about the representatives, their motivations and views contributed to by a previous negative experience. This resulted in the patient and family organisation withdrawing from providing representatives over fears about what would happen to issues that they had raised is they were not able to continue attendance after the 3 month period.

Various reviews of the implementation of interventions and programmes in healthcare settings have identified similar barriers, including tensions between patient and provider perspectives (93,303,306), tribalism and the risk of unintended consequences (305). A review of five programme evaluations of improvement programmes by the Health Foundation in England identified ten key challenges to improving the quality of healthcare (305). Many of these identified challenges overlap with fears and anxieties expressed by staff underpinning the three-month review of representative attendance such as tribalism with attempts to guard professional autonomy and the risk of unintended consequences (305). A review of models of care which incorporate user involvement and patient perspectives on their care illustrated tensions between patients’ and providers’ perspectives on treatment and care as a challenge to the implementation of models of care, including patient participation (303). Open ended questionnaires with professionals and family members of those with a serious mental health diagnosis on shared decision making on treatment and care in the United Kingdom reported that some staff felt
challenged by family members who held different and possibly antagonistic views which could lead to them being excluded from decision making (93).

10.5.2 Capacity

A set of barriers to participation identified throughout this PhD were associated with the capacity of patients, family members, clinicians and healthcare services. Concerns were raised about the capacity of patients and family members to see past their own experience, to communicate and have the confidence or skills to participate. Questions were raised about the capacity of clinicians, particularly in relation to their skills and experience of management and communication as well as their understanding of participation. These identified concerns are reflective of the wider literature (303,308,315) and the CLEAR Framework (19) guiding this PhD. For example, a review of models of care which incorporates user involvement and patient perspectives on their care identified issues relating to the capacity and competence of patients and clinicians as a challenge (303). Healthcare systems interested in patient participation may need to build patients’ capacity and educate clinicians on how to work in partnership with patients (315). This PhD provides more detail on exactly what areas of capacity difficulties are anticipated within an Irish context at the service level.

Much of the discussion in this PhD surrounding barriers relating to capacity issues was associated with the capacity of healthcare services and systems. The ability of healthcare services to involve patients and family members and make changes was questioned due to the lack of processes for patients and family members to become involved, the informal decision making process and process for making changes and the perceived inability of services and systems to change due to inflexibility and lack of integration. In Study 4 the capacity of the service presented challenges to implementation as a lack of clarity in the aim and purpose of sector management meetings resulted in poor attendance and a reluctance of clinicians to include patients and family members and reveal this lack of structure.

The role and impact of organisational factors such as capacity has been acknowledged in previous research on the development of complex health interventions which illustrated
the pivotal role of the organisation in which an intervention takes place in implementation (308). Similarly, a review of what is required for healthcare quality improvement has identified the organisational context, including lack of adequate structures for activities and team instability, as a potential barrier to healthcare quality improvement programmes (305). A systematic review of patient reported barriers and facilitators to shared decision making identified a set of barriers relating to the organisation of the health system and concluded that future implementation efforts should address patient reported factors together with known clinician reported barriers and the wider organisational context (105).

10.5.3 Implementation

Within the barrier of capacity one of the issues was a lack of knowledge in how to implement patient and family participation. A set of barriers relating to the implementation of participation emerged in interviews and focus groups with patients, family members and clinicians throughout the PhD. Typically, these discussion focused on two key areas: time and representativeness.

Participants, particularly clinicians, identified that implementation of participation requires time. Time for development, discussions and questioning what participation should look like, the processes and possible impacts as well as time for implementation, recruitment and facilitation. The impact of this was illustrated in Study 4. A total of 8 months was spent refining the psychiatry pilot intervention to obtain sign off from the full clinical and attempting intervention with further updates to the intervention to tackle challenges that emerged. The amount of time required for the development and implementation of participation interventions does not appear to be something that is widely discussed within current research despite the importance of considering this barrier when planning participation. Given the time and resources required for development of participation interventions and implementation this poses a barrier to participation and may also lead to questions about sustainability.

The second key area often discussed for implementation is representativeness. This includes issues relating to recruiting patients and family members for participation that
are interested, have the necessary skills and are representative of the wider population. In the process evaluation for Study 5 some participants felt that while feedback used in the intervention included a representative proportion of family members it would be beneficial for future participation if more family members attended the forum. Poor attendance at forum meetings by family members may be reflective of previously reported lower levels of support for family member participation (33) and a preference for less intensity of participation for family members (35).

This barrier relating to representativeness also extends to clinicians. In Study 5 difficulties emerged in obtaining input and attendance from consultants during implementation of the diabetes pilot intervention. It was suggested that this was due to the workload on consultants and doctors while others thought that there may be some link to negative attitudes towards research methods employed as it was not an RCT. An association between workload and clinician engagement with interventions was reported in a review of clinician involvement in quality improvement activities. Middle managers and frontline staff can be especially difficult to engage in improvements because they already face numerous complex, competing clinical and organisation demands, often with inadequate staffing, limited resources and equipment shortages (322). The difference in input and roles between disciplines echoes findings from previous research that illustrates how different disciplines take on different roles and often have varying opinions. A mixed method evaluation of large scale organisation interventions to improve patient safety in England noted that obstacles to changes and consensus within one profession or discipline were not always shared by others (323). In research assessing team meetings with family caregivers in attendance while consultants attended it was the nurses who contributed most and took the lead (78). This is similar to the experience in this PhD with the implementation of the diabetes pilot intervention in a mainly nurse led service. The nursing team contributed most and provided leadership for participation. Without the engagement of consultants the intervention was still feasible and led to a number of impacts, including demonstrable changes in the service. However, this is an area that could benefit for exploration over a longer period of time to see if additional barriers or negative impacts appear as a result of lack of engagement from consultants as buy in from clinicians has been identified as important for successful participation (316).
10.5.4 Sustainability

As the focus of Study 4 and Study 5 was on feasibility, sustainability was a key consideration with aspects identified as a barrier to participation. For sustainability, long term and meaningful participation, without the research team it was noted that additional resources would be required specifically a neutral facilitator as well as change champions. The previously discussed duration of time for the development and implementation participation interventions may also contribute to issues for sustainability. The need for future research on participation interventions to focus on sustainability (316) and challenges posed by sustainability issues have been acknowledged (305). Initiatives have to be resource neutral or use existing resources more efficiently if they are to continue. Explicit attention needs to paid to spreading learning and sustaining change from the outset (305). Similarly, the Canadian Foundation for Healthcare Improvement identified the need to demonstrate effectiveness (186) and adequate resourcing (324) to tackle sustainability. The importance of leadership for successful participation has been acknowledged in the CLEAR Framework (19) and the WHO policy framework for people centred care which includes enhancing leadership as one of the steps for healthcare organisations to take when working towards people centred care (81).

To tackle these issues related to sustainability leadership and change champions need to be identified and supported at all levels, both bottom up and top down from individual services to the HSE and Department of Health. Consensus needs to be garnered as to what participation is, what the aims and purposes are and supports and resources provided for implementation. This could help to address issues of sustainability from the duration of time required for development and implementation of participation. Indeed the need for a shared understanding of participation and identification of champions was noted in the Framework for Implementation of Community Participation in Primary Healthcare in Ireland (325). For the provision of neutral facilitators an independent organisations not allied to the health service, clinicians or patients or family members needs to be developed with the purpose of providing facilitation support. For example, INVOLVE was established in the United Kingdom to support implementation of participation.
Findings from this PhD relating to challenges and barriers to participation primarily relate to attitudes, capacity, implementation and sustainability. This illustrates that challenges and barriers reported internationally at different levels of participation are reflective of barriers and challenges to participation in Ireland at the service level despite the social, political and cultural context. This is important as identification of barriers and challenges is key in the development of interventions, policies and practices to encourage greater participation. It also enables the development of more sustainable and effective interventions that can take steps to deal with potential difficulties in advance.

10.6 Differences in participation in a psychiatry and a diabetes service

There are a number of differences evident between the two service settings in this PhD: an outpatient psychiatry service and an outpatient type 2 diabetes service. The context for the two service settings in terms of policy and the decision making process have key differences. In relation to the policy context there is greater support and more rhetoric and policy for participation within the context for the psychiatry service. The key policy for mental health services in Ireland is *A Vision For Change* published in 2006 (209). The first recommendation in this report is that service users and their carers should feature in every aspect of service development and delivery. In 2015 the HSE National Service Plan included a priority for mental health services to ensure the inclusion of the views and opinions of service users in service design and delivery (61). Most recently *A Partnership For Change* was published and implementation commenced to formalise and implement the inclusion of patients and carers in the design and delivery of mental health services nationally (210). While support for participation within diabetes services comes from national policies such as *Healthy Ireland* (55) the rhetoric in diabetes is not as strong. A similar difference was evident in the decision making context between the two services. In the psychiatry service a monthly meeting, called the sector management meeting, takes place allowing time and space for the multidisciplinary team (MDT) to meet and discuss issues relating to service design and delivery. A similar meeting does not exist in the diabetes service with no formal meeting, time or space for the MDT to discuss design and delivery.
In Study 1 and Study 2 a slight difference in the amount of ongoing participation was evident. In Study 1 questionnaires participation was reported to be limited to the provision of information in both services. However, in Study 2 examples were provided of informal ad hoc participation within the psychiatry where there is a more supportive policy context for participation. For example, in a stress management course in the psychiatry service, patients provided feedback that was used to inform and update the course. However, this was only for one course, patients did not input to discussion or decision made and were not told how their input was used. In addition the settings different in terms of population characteristics. The population of diabetes patients was typically older age, which is important as there is a link between age and support for participation. The presence of involuntary committals in the psychiatry service in which family members can play a key role leads to a different attitudes towards capacity, autonomy and the role of family members between the two services.

These contextual differences in policy, management, participation and population added to this PhD, particularly in the analysis and findings, in a number of ways. For example, in Study 1, Study 2 and Study 3 the inclusion of differing services enabled exploration of the impact of service setting on attitudes and preferences for participation. In Study 4 and Study 5 the different policy contexts, presence of examples of limited ad hoc participation and management structures in the psychiatry service meant that the pilot interventions were implemented and assessed in differing contexts. This helped to fill a gap in the literature which is often siloed focusing on specific cohorts of patients or types of services allowing for comparison between different service settings and highlighting of similarities and consensus in this area. For example, regardless of the difference in context difficulties were noted in both services in changes actually happening. The difference in the structure for healthcare design and delivery in both services may have been important in the implementation of the interventions. While it is advised to build interventions in to existing structures doing so in the psychiatry service saw concerns about revealing issues with existing structures and concerns about the impact of participation in an existing meeting. Implementing the diabetes pilot intervention with the establishment of an entirely new meeting purely focused on facilitation participation may have led to a process in which fewer barriers or challenges to participation were presented.
The inclusion of two different services also adds to the current literature in a number of other ways. It provides an exploration of participation in two different services at the service level focusing on healthcare design and delivery helping to fill a gap in the current literature. It highlights the key role of attitudes and experiences in participation. Differences in context appeared to feed in to findings related to the feasibility of interventions to encourage greater participation. Despite what appeared to be a more supportive policy and decision making context within the psychiatry service it was not possible to implement an intervention to encourage greater participation within the service due to issues primarily related to fears and anxieties of clinicians. This may be related to a previous negative experience with a patient and family representative and complications related to fitting the intervention within the existing policy context.

10.7 Application of the theoretical framework
There are two components to the theoretical framework for this PhD: Arnstein’s Ladder of Participation and the CLEAR Framework.

10.7.1 Arnstein’s Ladder of Participation
Arnstein’s Ladder of Participation is a typology of citizen participation which presents participation on a continuum of increasing intensity from informing communities and individuals to devolving where decision making is up to the community and individuals (18) (See Chapter 3). It is one of the best known and frequently used models of participation (3,10,148,149). In this PhD it provided a clear structure to identify intensity of participation. It was used in Study 1 to identify the intensity of participation taking place, in Study 2 to guide interviews and focus groups, in Study 3 to identify the preferred intensity of participation and in Study 5 to examine the impact of the intervention on the intensity of participation.

Arnstein’s Ladder was beneficial in simplifying a complex phenomena. This enabled identification of the amount and intensity of current participation, preferences of the intensity of participation and the impact of the diabetes pilot intervention. The ability of Arnstein’s Ladder to simplify participation and present a number of elements in the
The developmental process of participation has been noted in a review of service user involvement in Ireland (10). It was also well suited to this research as it was developed to address issues also identified as potential challenges by participants in the two service settings such as tokenism (18). However, it was not helpful in guiding the development, implementation or evaluation of interventions. The central concern of Arnstein’s ladder is the transfer of power from those who have power to those who do not. In line with this, the most intense forms of participation are deemed to be the most meaningful and the automatic aim of any efforts encourage participation activities. However, this does not take into account the views and opinions of those involved in participation, including patients and family members. In line with MRC guidelines (184,265) and advice from numerous bodies and pieces of research (11,13,88) it is important that those involved in participation have a role in identifying the intensity of participation and resulting intervention. The inability of Arnstein’s Ladder to acknowledge the different forms of participation desired by different groups and the hierarchical structure placing full citizen control at the pinnacle of participation have been criticisms previously made about this theory (148). This sole focus on power limits the potential of participation constraining methods used to enhance participation as varying forms of knowledge and views of power are not considered (148,152). Arnstein’s Ladder was not helpful in this PhD in overcoming challenges encountered, such as tackling issues of capacity and attitudes, as it does not analyse the roadblocks to participation (18). Neither was it beneficial in evaluating the diabetes pilot intervention the impacts of which were broader than increased intensity of participation. To overcome these issues, in this PhD the level of intensity of participation aimed for was determined by key stakeholder groups, not Arnstein’s Ladder of Participation. This led to a wide variety of methods for participation being considered and broadened the focus from merely the outcome of participation but also the process of participation. The CLEAR Framework discussed further below was employed to guide this process further and account for the shortcomings of Arnstein’s Ladder of Participation.

This PhD has illustrated the utility of Arnstein’s Ladder in identifying the amount and intensity of ongoing participation as well as preferences of diverse groups in planning and enacting participation. In doing so it emphasizes that Arnstein’s Ladder achieves its purpose as a typology of providing a simplification of a complex phenomenon. This the
greatest and perhaps most important benefit of this theory when dealing with a phenomenon that in many ways in this healthcare setting is novel and includes the input of a diverse range of groups with varying levels of understanding of participation, the healthcare system and its systems of change and management. In addition this PhD also demonstrates that Arstein’s Ladder can be employed alongside additional theories as a theoretical framework to overcome some of the acknowledged limitations of this theory such as ignoring the contextual factors influencing participation activities. This is key as it broadens the scope of use of this theory beyond the mere understanding of the phenomenon of participation.

10.7.2 The CLEAR Framework

The CLEAR Framework of Factors Driving Public Participation is a diagnostic tool designed to understand the barriers to and facilitators of effective participation (31). It proposes that participation occurs when people Can, they Like to participate because they feel part of something, people participate when they are Enabled, when they are Asked and if they anticipate a Response (19). This is underpinned by the argument that citizens engage depending upon the resources they have access to, the extent to which they feel engaged in a wider community, whether they are helped to participate by supportive organisations, if they are mobilised and if they experience or anticipate a response (19). The CLEAR Framework was employed in this PhD to identify and understand the necessary components of an intervention to encourage participation. The CLEAR Framework involves refining questions and challenges to be addressed, gathering a multi-perspective evaluation beyond public officials and making a judgement about priorities in terms of the factors to be addressed (153). The questions and challenges to be addressed were identified in Study 1 and Study 2. Factors identified as important in the CLEAR Framework were included in research instruments for all studies and discussed within the relevant chapter for each study (See Chapters 3-8). A multi-perspective approach was adopted with patients, family members and clinicians involved across all studies and policy leaders in Study 2. The CLEAR Framework also informed the development of interventions in Study 4 and Study 5.
A key benefit of this framework to the PhD was the exploration of the perspectives for various groups. The CLEAR Framework places an emphasis on the citizens’ perspective (19), providing an opportunity for reflection by all those involved on the strengths, barriers and gaps in participation with consideration of strategies for improvement (31). This is in line with the phenomenological underpinning of this PhD that focuses on the experience of the many with all data and understanding coming from those with experience of the concept being studied. There is an acknowledgment and recognition of the need for interventions to be sensitive to local context (153). The CLEAR Framework has been employed in participation research in Denmark (160) and in England through an assessment of the Somerset Health Panels as well as in an evaluation of family members’ capacity for the development of an intervention to aid responses to crises (31). In Ireland, this framework has been recommended for assessment of patient and citizen participation (161) and utilised to assess recent recommendations for active citizenship (162). This framework was beneficial in identifying potential barriers to participation, such as capacity issues and in the development of the interventions taking these potential issues into account.

It is important to note that this framework was developed for citizens and the general public, not patients in a healthcare setting. As the focus is on citizens the leaning of the framework is towards a focus on participation at the national level as opposed to the service level participation, which is the focus of this research. However, this framework has previously been applied in healthcare settings and the factors of the CLEAR Framework are still applicable to participation at the service level. The CLEAR Framework was not beneficial in measuring participation intensity, in dealing with issues related to attitudes and timing or in evaluation as the focus of this framework is on identifying barriers and challenges.

Use of the CLEAR Framework in this PhD strengthens the available knowledge and literature on this theory. It emphasizes and asserts many of the key points made in this theory. For example, a link with the wider group of patients and family members was important in the diabetes pilot intervention reiterating the argument from the CLEAR Framework that people like to participate because they feel part of something. Similarly in both pilot interventions the inclusion of training and support was key echoing the
proposition of the CLEAR Framework that people participation when they are enabled (19). As noted above this Framework was developed for citizens as opposed to patients. However, it has been used previously in healthcare settings and employment of this framework in this PhD provides another example of the CLEAR Framework being used in a healthcare setting.

10.8 Summary

Participation is supported in national and international policy and literature yet there is a lack of clarity over what participation is and how it should be achieved. There is a lack of focus within existing research on service level and family member participation with a dearth of information on participation within an Irish context. From this PhD in a psychiatry and a diabetes service it is evident that there is a gap between what we are saying and doing. There is strong support for participation identified in policy, questionnaires, interviews and focus groups. However, patient and family participation does not routinely occur in either service beyond the provision of information. When participation is being developed intensity, representatives, links with the wider patient and family populations and training and support need to be considered. Challenges including attitudes, capacity, implementation and sustainability need to be tackled.

These findings add to the current knowledge with a focus on participation at the service level as well as family member participation. The amount of and support for greater participation taking place at present within a psychiatry and a diabetes service in Ireland was established. Preferences for the intensity and implementation of participation were identified through consensus between patients, family members and clinicians. Barriers and challenges to participation within the social, political and cultural context of Ireland were explored, including through the attempted implementation of the psychiatry pilot intervention. The diabetes pilot intervention of patient and family representative and clinician meetings supported by a patient and family forum was demonstrated to be feasible with support from the research team.
11.1 Conclusion

Patient and family participation in healthcare design and delivery is where patients and family are asked what they think about healthcare services and this is taken into account in a meaningful way during the design and delivery of services. Policy rhetoric and reported views and opinions from patients, family members, clinicians and policy leaders in a psychiatry and a diabetes service from this PhD are supportive of patient and family participation in healthcare design and delivery. However, similar to what is reported internationally there is a gap between what we are saying and doing. Patient and family participation at the service level is typically limited to the provision of information. Delphi Technique Experiments (DTEs) are a successful method to identify preferences for the intensity and implementation of participation with input from patients, family members and clinicians. There is agreement that patients should represent patients and family should represent family. Psychiatry patients should have a say when changes are made and all other groups (psychiatry family, diabetes patients and family) should be involved in discussions.

It was not possible to implement the psychiatry pilot intervention of representatives attending sector management meetings. This was due to a decision for clinicians to review representative attendance after a period of 3 months, which appeared to be linked with fear and anxiety and a lack of structure in management meetings. Feasibility of an intervention to encourage greater participation in a diabetes service has been demonstrated. The diabetes pilot intervention of representative and clinician meetings supported by a forum was successfully implemented in a diabetes services with fidelity to the intervention, increased participation, communication and empowerment. The dissemination of findings from this PhD is outline in Appendix CC.
11.2 Recommendations

Based on the findings from Study 1 – Study 5 of this PhD a number of recommendations for practice, policy and research can be proposed for patient and family participation in healthcare design and delivery.

11.2.1 Recommendations for practice

This PhD presents findings from the development of a pilot intervention in a psychiatry service and a diabetes service to encourage greater participation. The implementation and evaluation of the diabetes pilot intervention is provided. From this we can see that there are benefits to be gained from the involvement of patients and their family members. A number of steps are important for services exploring patient and family participation.

1. Services need to identify the intensity of ongoing participation

Before any action is taken it is essential to know where you are starting from. Services need to identify how much participation is taking place at present. Without identification of how much and how intense current participation is there is no way to know if improvements are necessary, and if so, whether steps taken to address the deficit in participation are successful. As the idea of participation is novel, particularly to patients and family members, this works best through face-to-face data collection enabling explanation of the concept with reminders of the concept throughout data collection as necessary. There is no set tool for measurement of the amount and intensity of participation at the service level. However, in this research a questionnaire for identifying the amount and intensity of participation was developed based on Arnstein’s Ladder of Participation (18). This was employed in a psychiatry and diabetes service and shown to be feasible to administer (33).

2. Services need to establish preferences for the intensity and implementation for participation

In order to know whether the current intensity of participation is sufficient, or what level of intensity work to improve participation needs to aim towards, services need to establish preferences for the intensity and implementation of participation. The
appropriate intensity and method of participation differs by service and topic (10). All stakeholder groups that may be involved in participation need to take part in setting the level of intensity and methods of participation. Patients, family members and healthcare professionals as well as any other stakeholder groups should be involved in this process. Doing so will encourage buy-in and ownership while improving the fit and structure of interventions. A successful method that services can use to achieve consensus on what participation needs to look like is DTEs, as illustrated in Study 3 of this PhD.

3. Services need to provide opportunities for participation

There is a gap between what we are saying and doing (17). In psychiatry and diabetes services patients and family members want to be involved in healthcare design and delivery yet participation at the service level is not taking place (33). The CLEAR Framework proposes that people will participate when opportunities are available, when they are supported to and expect to have an impact (19). In line with this, services need to provide opportunities for participation and where possible these opportunities need to be in line with identified preferences for intensity and implementation. When providing opportunities for participation services need to: take challenges and facilitators in to account, build within existing structures, provide training and support allowing time and space for concerns to be addressed, communicate with wider patient and family populations, consider sustainability and evaluate work done to identify whether the desired impact is being achieved.

4. Services need to build on momentum gained

Sustainability with long lasting and meaningful participation can be difficult to obtain and maintain. In services where the process of participation has already begun, such as the diabetes service in this PhD, services need to capitalise on momentum built. Participation takes time, effort and resources so it is important to keep interest in this work ongoing. Demonstrable impacts and results of participation could be employed to retain and bolster enthusiasm. For example, tangible impacts, such as standardisation of information provided on and access to dieticians, could be used to illustrate the impact of participation.
11.2.2. Recommendations for policy

1. **Enact policy to match what we are saying and doing**

There are plenty of international (45,314) and national (6,53,55,57–61,209,210,326) policies that are supportive of participation with encouraging rhetoric and aims associated with participation. However, often these policies not enacted. For example, many elements of the National Strategy for Service User Involvement 2008-2013 were not enacted. Goal 1.3 was for there to be service user involvement and influence over service planning. However, despite being years past the 2013 end date for this policy patients and family members are not routinely involved in service planning as illustrated in Study 1. Policies to be enacted so we can match what we are saying with what we are doing.

2. **Policies need clearly defined goals and objectives for participation**

Numerous key policy documents in Ireland include supportive rhetoric for participation and often go so far as to include increased or improve participation within their outcomes (53,55,57–61,209,326). Unfortunately, when we look at these policies relating to participation they are often lacking in clearly defined goals and objectives. For example, the aims of the HSE National Service Plan 2017 include strengthening engagement, embedding a culture of person centre-care, measuring and responding to complaints and carrying out the National Patient Experience Survey and implementing findings (59). However, no further detail is provided. For example, how do we know a culture of person centred care has been embedded in line with this policy? Policies need clearly defined goals and objectives relating to participation to enable implementation and evaluation of policies to improve participation.

3. **National measurement and identification of preferences for participation**

Similar to individual services we need to establish at a national level how much patient and family participation is taking place and preferences for intensity and methods of participation at the patient, service and national levels. If we continually have policies supporting the expansion and implementation of participation we need to measure participation so we know that we know what we are working towards. The intensity of participation and preferences need to be assessed on an ongoing basis so we know the impact of what we are doing. The National Patient Experience Survey (NPES) provides an
opportunity for measurement. The NPES needs to be expanded beyond inpatient hospital treatment to include other treatment setting such as primary care and outpatient services. Family members need to be included. This needs to occur annually and questions added to assess service and national level participation and associated preferences.

4. Policy needs to support service implementation

Service implementation of participation needs to be supported by policy. Participation requires time, resources and leadership all of which need to come from policy. The time requirements for participation need to be reflected within the day-to-day workload of clinical teams. Resources need to be made available including tools to identify preferences for participation, facilitation supports and training. Facilitation of participation can includes tasks such as organising and chairing meeting or forums, preparing attendees in advance of meetings and recruiting representatives. These tasks can be time intensive and ideally should be undertaken by a neutral person. Policy needs to provide funding and a structure to enable neutral facilitation support to all services.

Training needs to be provided for all stakeholder groups. This needs to include what participation is, the benefits of participation, participation methods with time to discuss concerns surrounding participation. Training should be built into existing curriculums for all clinical disciplines and accredited CPD course developed and implemented for already qualified clinicians to encourage uptake.

Finally, leadership needs to be provided with top down and bottom up support. Those with power and influence such as the Minister for Health, the Department of Health and senior management within the HSE need to lead by example and demonstrate their support for participation. For example, the Department of Health need to emphasis policies to which the public and patients have meaningfully contributed too, how this has been achieved and what the result was. Responsibility for participation needs to lie with a specified person with the power and resources to enact implementation. Clinicians need to argue for participation within their own services and advocate for the involvement and empowerment of their own patients and family members. Patients and family members
need to be made aware that participation is an option and empowered to argue for change in this area themselves.

5. Demonstrate joined up thinking and actions
Policy needs to look and learn from what has been done already internationally and nationally as work towards participation in Ireland can be siloed. For example, a process to involve patients and family members in mental healthcare services has been started with Partnership for Change (210). If this policy is effectively and successfully implemented it may provide a framework on which participation nationally could be based with illustration of the impact and benefits of participation providing examples of small wins with which enthusiasm can be garnered.

11.2.3 Recommendations for research

1. Develop a tool for standardised measurement of participation
There is no standardised tool for the measurement of participation at present. Development of a standardised tool for measurement of participation across patient, service and national levels would enable comparison of the amount and intensity of participation between services and countries. This would aid to identification of feasible, effective and sustainability interventions to improve and encourage participation. Study 1 of this questionnaire developed a questionnaire based on current literature, particularly Arnstein’s Ladder of Participation to identify the intensity of current participation and preference for participation. We know that this questionnaire is acceptable and feasible. Future research could assess this tool in terms of reliability and validity to develop a standardise tool for measurement.

2. Focus on outcomes
There is a need for a greater focus on outcomes within research on participation. This PhD has shown that the diabetes pilot intervention of patient and family representative and clinician meetings supported by a patient and family forum is feasible with support from the research team with trends for outcomes illustrated. Research needs to be expanded to more services for larger numbers to enable a primary focus on outcomes such as the impact on attitudes and service satisfaction the answer to which was unclear
in this PhD. Future research needs to assess the impact of participation over a longer period of time to see what positive and possible negative impacts emerge. It was suggested that the impact of the diabetes pilot intervention may become greater over time as more patients and family members become aware of the work done. However, it was also suggested that frustrations may emerge over a longer period of time due to the impact of the slow pace of change and the perceived inability of the service to make changes. A final area meriting further exploration is the extent of the impact of outcomes from participation. In this PhD queries were raised about the impact of the diabetes pilot intervention on those who were not directly involved in the intervention.

3. Expand to a broader variety of services
As the intensity and methods of participation differ by service and topic, research on participation at the service level needs to be conducted in a broad range of services. This would enable characteristics of services that influence the preferred intensity of method of participation to be established. In addition the diabetes pilot intervention needs to be assessed and evaluated in more services to determine if it is feasible and effective in other services beyond type 2 diabetes.

4. Continue and expand focus on family member participation
Family members play a key role in caring for and supporting patients, particularly those with chronic illnesses. The WHO has identified the need for more participation research focused on family members. We can see from this PhD that family members are not routinely involved in healthcare design and delivery yet this is supported although to a lesser extent than patients. This area needs to be explored further to clearly identify preferences for family participation and importantly the outcomes and impact of family participation.

Pivotal to all of the above recommendations for practice, policy and research is the role that patients and family members need to play. Both groups need to be actively involved in every aspect of these recommendations from as early as possible in development to ensure meaningful and effective participation (33).


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## Appendix A: Participation intervention options

<table>
<thead>
<tr>
<th>Method</th>
<th>Example</th>
<th>Strengths</th>
<th>Limitations/Reasons for exclusion</th>
</tr>
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<tbody>
<tr>
<td>Forums/ Public meetings/</td>
<td>(S) A family advisory council with patients, family staff and hospital</td>
<td>Opportunity for anybody to attend (10). New networks created (10). Forum for debate (10). Opportunity for information dissemination and sharing (10). Early results show high patient satisfaction rates, low staff turnover (74)</td>
<td>Poor attendance (10). Confidentiality (10). Risk of domination by particular individuals or groups (10). Representation (10). Difficult to stay focused on issue (10). Requires a skilled facilitator (10).</td>
</tr>
<tr>
<td>Councils</td>
<td>and hospital administrators meeting monthly to provide guidance on design and delivery (74)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service user representatives</td>
<td>(S) patient representation on advisory committees (75).</td>
<td>Medium to long-term perspective (10). Encourages debate (10). Ensures accountability (10). Introduces greater objectivity and credibility (98) All NICE committees and working groups are expected to have at least two lay members.</td>
<td>Requires orientation and support (10). Costs (10). Organisational commitment to meaningful participation (10).</td>
</tr>
<tr>
<td></td>
<td>(N) consumers on review team for assessing accreditation of Irish healthcare organisations. (N) patient participants on committees to plan educational events on healthcare improvement and PPI as well as healthcare improvement projects in London (65)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suggestion boxes</td>
<td>NA</td>
<td>Not intense enough. No involvement in the decision-making process.</td>
<td>NA</td>
</tr>
<tr>
<td>Activity</td>
<td>Description</td>
<td>Intensity</td>
<td>Involvement</td>
</tr>
<tr>
<td>----------</td>
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</tr>
<tr>
<td>Questionnaires</td>
<td>A description of patient or their representatives involvement in quality management in EU hospitals illustrated surveys seeking patients views as reflecting patient centred care strategies (73). Interviews with clinicians and patients in lung cancer services in Scotland revealed that participation was typically understood to mean satisfaction questionnaires (52).</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Interviews</td>
<td></td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Development of information material</td>
<td>A description of patient or their representatives involvement in quality management in EU hospitals illustrated patient information literature as reflecting patient centred care strategies (73).</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Patient charters</td>
<td>Included as a component of the National Strategy for Service User Involvement 2008-2013 (6)</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Workshops</td>
<td>International workshop with 56 clinical practice guideline developers, researchers and patient/public representatives from 14 countries to develop an international practice and research agenda on PPI in the development of clinical practice guidelines (16).</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Citizen Juries/Health panels</td>
<td>(N) Two modified citizen juries conducted to explore public perspectives on e-health (327). (N) Evaluation of food policy through citizen juries in</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Setting of priorities/ Involvement in guideline development</td>
<td>Australia (76). (47) (311) (269) (328) Assessment of when and how stakeholders are involved in development of indicators and instruments that measure the experiences of patients (77).</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Involvement in research/ Patient reported outcome measures</td>
<td>(R) Assessment of patient involvement in PROM in the Netherlands (329) (R) Assessment of patient involvement in an EU wide research project (234) (R) (232) Assessment of a devolved model for public involvement in mental health research (330). Examination of the involvement of patients and the public in a primary care research centre in England (331).</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

= Not eligible for selection
Appendix B: Literature review search strategy

Patient and Family Participation Literature Review Search Strategy

**Target sources addressing patient and family participation**

#1 'Patient and family participation [Mesh]
#3 Family [tiab] OR family*member [tiab] OR carer [tiab] OR caregiver [tiab]

**Target sources addressing healthcare**

#5 health*care [tiab] OR health [tiab]
#6 system [tiab] OR service [tiab] OR policy [tiab]

**Target sources addressing patient and family participation and healthcare**

#7 #2 AND #3 AND #4
#8 #7 AND #5
#9 #7 AND #6
#10 #8 AND #9

**Target sources addressing patient and family participation in healthcare in English with humans.**

#12 #1 OR #7 OR #8 OR #9 OR #10 limited to English, Human.

**Search Methods for Identification of Studies**

- **Electronic searches of databases**
  Databases will be searched using the string search developed above including:
  - Psychinfo
  - Pubmed
  - Academic Search Complete
  - CINAHL
- **Other sources of literature**
  Contact investigators, relevant study authors seeking information about unpublished or incomplete trials.
- **Grey literature**
  - SIGLE
- **References lists**
  References of the articles obtained by any means will be searched for relevant articles.
- **Institutional repositories**
  Databases of relevant institutional repositories will be searched including:
  - Department of health
  - World Health Organisation
  - The King’s Fund
  - National Institute for Health
  - HSE Libraries
### Appendix C: Application of the GRIPP2 short form checklist (202)

<table>
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<tr>
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<td>1: Aim</td>
<td>Report the aim of PPI in the study</td>
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<td>2: Methods</td>
<td>Provide a clear description of the methods used for PPI in the study</td>
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<td>3: Study results</td>
<td>Outcomes- Report the results of PPI in the study, including both positive and negative outcomes</td>
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<td>4: Discussion and conclusions</td>
<td>Outcomes- Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects</td>
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<tr>
<td>5: Reflections/ critical perspective</td>
<td>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience</td>
<td>Section 3.4</td>
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</tbody>
</table>
Appendix D: Ethical approval letters

Ms. Lucy Whiston
Adelaide Research Assistant/Irish Research Council Scholar
Adelaide Health Foundation/Trinity College Dublin
Department of Public Health and Primary Care
Trinity Centre for Health Sciences
Tallaght Hospital
Dublin 24

3rd March 2015

RE: Patient and Family Participation in Healthcare Design and Delivery from a diabetes service and a psychiatry service perspective

REC Reference: 2015-03 Chairman’s Action (4)
Please quote REC reference on all correspondence

Dear Ms. Whiston,

Thank you for your email correspondence dated 24th February to SJH/AMNCH Research Ethics Committee in which you requested ethical approval the above study.

The Chairman, on behalf of the SJH/AMNCH Research Ethics Committee has given ethical approval pending sight of further methodologies as they become available.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee
Ms. Lucy Whiston
Public Health and Primary Care
School of Medicine
Trinity College Dublin
Institute of Population Health
Russell Centre
Tallaght Cross
Dublin 24 DH74

16th February 2017

Re: Patient and Family Participation in Healthcare Design and Delivery from a mental and a medical Healthcare Perspective

REC Reference: 2017-02 List 5 (13)
(Please quote reference on all correspondence)

Dear Ms. Whiston

Thank you for your recent correspondence to SJH/AMNCH Research Ethics Committee in which you requested an amendment in relation to the above referenced study.

The Chairman, Dr. Peter Lavin, on behalf of the Research Ethics Committee, has reviewed this request and grants permission for this amendment.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

The SJH/AMNCH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Commission (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & RCH OCF guidelines.

SJH/AMNCH Research Ethics Committee Secretary
Appendix E: Study 2, 4 and 5 Application of the Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32 item checklist

**Study 2 application of the Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32 item checklist**

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#### Reporting

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</tr>
<tr>
<td>27. Software</td>
<td>What software, if applicable,</td>
</tr>
<tr>
<td>28. Participant checking</td>
<td>Did participants provide feedback on the findings?</td>
</tr>
<tr>
<td>Reporting</td>
<td></td>
</tr>
<tr>
<td>29. Quotations presented</td>
<td>Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?</td>
</tr>
<tr>
<td>30. Data and findings consistent</td>
<td>Was there consistency between the data presented and the findings?</td>
</tr>
<tr>
<td>31. Clarity of major themes</td>
<td>Were major themes clearly presented in the findings</td>
</tr>
<tr>
<td>32. Clarity of minor themes</td>
<td>Is there a description of diverse cases or discussion of minor themes?</td>
</tr>
</tbody>
</table>
Appendix F: Study 4 and 5 Application of the Template for Intervention Description and Replication (TIDieR) checklist and guide

Study 4

<table>
<thead>
<tr>
<th>TIDieR Item</th>
<th>Where addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Brief name</strong></td>
<td></td>
</tr>
<tr>
<td>1. Provide the name or a phrase that describes the intervention</td>
<td>Appendix L</td>
</tr>
<tr>
<td><strong>Why</strong></td>
<td></td>
</tr>
<tr>
<td>2. Describe any rationale, theory or goal of the elements essential to the intervention</td>
<td>Appendix L</td>
</tr>
<tr>
<td><strong>What</strong></td>
<td></td>
</tr>
<tr>
<td>3. Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information or where the materials can be accessed.</td>
<td>Appendix L</td>
</tr>
<tr>
<td>4. Procedures: Describe each of the procedures, activities and/or processes used in the intervention, including any enabling or support activities</td>
<td>Appendix L</td>
</tr>
<tr>
<td><strong>Who provided</strong></td>
<td></td>
</tr>
<tr>
<td>5. For each category of intervention provider describe their expertise, background, and any specific training given</td>
<td>Appendix, Chapter 7</td>
</tr>
<tr>
<td><strong>How</strong></td>
<td></td>
</tr>
<tr>
<td>6. Describe the modes of delivery of the intervention and whether it was provided individually or in a group</td>
<td>Appendix L</td>
</tr>
<tr>
<td><strong>Where</strong></td>
<td></td>
</tr>
<tr>
<td>7. Describe the types of locations where the intervention occurred, including any necessary infrastructure or relevant features</td>
<td>Appendix L, Section 3.3</td>
</tr>
<tr>
<td><strong>When and how much</strong></td>
<td></td>
</tr>
<tr>
<td>8. Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule and their duration, intensity or dose</td>
<td>Appendix L, Chapter 7 and Chapter 8</td>
</tr>
<tr>
<td><strong>Tailoring</strong></td>
<td></td>
</tr>
<tr>
<td>9. If the intervention was planned to be personalised, titrated or adapted then describe</td>
<td>Appendix L, Chapter 7</td>
</tr>
<tr>
<td><strong>Modifications</strong></td>
<td></td>
</tr>
<tr>
<td>10. If the intervention was modified during the course of the study, describe the changes</td>
<td>Appendix L, Chapter 7, Chapter 8</td>
</tr>
<tr>
<td><strong>How well</strong></td>
<td></td>
</tr>
<tr>
<td>11. Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them</td>
<td>Not applicable as not delivered</td>
</tr>
<tr>
<td>12. Actual: If intervention adherence of fidelity was assessed, describe the extent to which the intervention was delivered as planned</td>
<td>Not applicable as not delivered</td>
</tr>
</tbody>
</table>
## Study 5

<table>
<thead>
<tr>
<th>TIDieR Item</th>
<th>Where addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Brief name</strong></td>
<td></td>
</tr>
<tr>
<td>1. Provide the name or a phrase that describes the intervention</td>
<td>Appendix R</td>
</tr>
<tr>
<td><strong>Why</strong></td>
<td></td>
</tr>
<tr>
<td>2. Describe any rationale, theory or goal of the elements essential to the intervention</td>
<td>Appendix R</td>
</tr>
<tr>
<td><strong>What</strong></td>
<td></td>
</tr>
<tr>
<td>3. Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information or where the materials can be accessed.</td>
<td>Appendix R-X</td>
</tr>
<tr>
<td>4. Procedures: Describe each of the procedures, activities and/or processes used in the intervention, including any enabling or support activities</td>
<td>Appendix R</td>
</tr>
<tr>
<td><strong>Who provided</strong></td>
<td></td>
</tr>
<tr>
<td>5. For each category of intervention provider describe their expertise, background, and any specific training given</td>
<td>Appendix R</td>
</tr>
<tr>
<td><strong>How</strong></td>
<td></td>
</tr>
<tr>
<td>6. Describe the modes of delivery of the intervention and whether it was provided individually or in a group</td>
<td>Appendix R</td>
</tr>
<tr>
<td><strong>Where</strong></td>
<td></td>
</tr>
<tr>
<td>7. Describe the types of locations where the intervention occurred, including any necessary infrastructure or relevant features</td>
<td>Appendix R, Section 3.3, Chapter 9</td>
</tr>
<tr>
<td><strong>When and how much</strong></td>
<td></td>
</tr>
<tr>
<td>8. Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule and their duration, intensity or dose</td>
<td>Appendix R, Chapter 9</td>
</tr>
<tr>
<td><strong>Tailoring</strong></td>
<td></td>
</tr>
<tr>
<td>9. If the intervention was planned to be personalised, titrated or adapted then describe</td>
<td>Appendix R, Chapter 7</td>
</tr>
<tr>
<td><strong>Modifications</strong></td>
<td></td>
</tr>
<tr>
<td>10. If the intervention was modified during the course of the study, describe the changes</td>
<td>Chapter 7 and 9</td>
</tr>
<tr>
<td><strong>How well</strong></td>
<td></td>
</tr>
<tr>
<td>11. Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them</td>
<td>Section 9.3</td>
</tr>
<tr>
<td>12. Actual: If intervention adherence of fidelity was assessed, describe the extent to which the intervention was delivered as planned</td>
<td>Section 9.3</td>
</tr>
</tbody>
</table>
Appendix G: Study 1, 2, 3, 4 and 5 Flow Charts

Study 1 Flow Charts

Psychiatry Flow Chart

Diabetes Flow Chart
Study 2

Psychiatry flow chart

Psychiatry Patients n=2200

Excluded n=2061 *
Refusal Study 1 n=33
Refusal future research n=122
Not eligible n=50
Not approached n=1688

Sampling Frame n=139

Contacted n=51

Excluded n=14
No answer n=14

Invited n=37

Excluded n=18
Not eligible n=5
Refusal e.g. too busy, not well, not comfortable focus group n=13

Agreed n=19

Excluded n=9
No show/cancelation n=9

Took part n=10

Psychiatry Family Members n=440 *

Excluded n=418 *
Refusal Study 1 n=3
Refusal future research n=22
Not eligible n=2
Not approached n=391 *

Sampling Frame n=22

Contacted n=19

Excluded n=3
No answer n=3

Invited n=16

Excluded n=2
Refusal e.g. too busy n=2

Agreed n=14

Excluded n=4
No show/cancelation n=4

Took part n=10

Psychiatry Clinicians n=12

Invited n=12

Agreed n=12

Took part n=12
Diabetes flow chart

Diabetes Patients: n=4660

Sampling Frame: n=138

Contacted: n=48

Excluded: n=7
No answer: n=7

Invited: n=42

Excluded: n=23
Busy: n=19
Not interested: n=3
Unwill: n=1

Agreed to participate: n=19

Took part: n=16

Excluded: n=9
No show/ cancellation: n=8

Diabetes Family Members: n=972

Sampling Frame: n=22

Contacted: n=23

Excluded: n=3
No answer: n=3

Invited: n=20

Excluded: n=8
Busy: n=6
No interest: n=1
Nothing to add: n=1

Agreed to participate: n=12

Took part: n=10

Excluded: n=2
No show/cancellation: n=2

Diabetes Clinicians: n=13

Invited: n=13

Excluded: n=6
No response: n=6

Round 1: n=12
Study 3
Psychiatry DTE Sample Flow Chart

A = Numbers for family members are based on estimates from pilot data collection.
B = Further information on the collation of the sampling frame is provided in Chapter 5.
C = Round three family member sample size increased as 2 Round 2 non-responders took part in Round 3.
Diabetes DTE Sample Flow Chart

A = Numbers for family members are based on estimates from pilot data collection.
B = Further information on the collation of the sampling frame is provided in Chapter 5.
C = Round three clinician sample size increased as 1 Round 2 non-responders took part in Round 3.
Study 4 and Study 5 intervention development flow charts

Psychiatry stakeholder flow charts

Psychiatry Patients n=2000

- Excluded n=2183
  - Not eligible n=3
  - Not approached n=2180

  Invited n=7

  - Excluded n=2
    - Refusal e.g. not feeling up to it n=2

  Agreed n=5

  - Excluded n=0

  Took part n=5

Psychiatry Family Members n=440

- Excluded n=438
  - Not approached n=338

  Invited n=2

  - Excluded n=0

  Agreed n=2

  - Excluded n=0

  Took part n=2

Psychiatry Clinicians n=12

- Excluded n=4
  - Not approached n=4

  Invited n=4

  - Excluded n=0

  Agreed n=8

  - Excluded n=0

  Took part n=8
Diabetes stakeholder flowcharts

Diabetes Patients
n=4683
  Invited
  n=5
    Excluded n=0
      Agreed
      n=5
        Took part
        n=5

Diabetes Family Members
n=972
  Invited
  n=4
    Excluded n=0
      Agreed
      n=4
        Took part
        n=4

Diabetes Clinicians
n=13
  Invited
  n=13
    Excluded n=6
      No response n=6
        Agreed
        n=7
          Excluded n=0
            Took part
            n=7
Study 5
Patient Sample

Patient and Family Before Questionnaire Sample

Patients n=4633

Excluded n=4647
- No interest n=3
- Not approached n=4644

Invited Forum Meeting One n=216

Excluded n=173
- Not eligible n=2
- Not available n=61
- Refusal - no interest n=51
- No response n=79

Agreed to attend Forum Meeting One n=43

Excluded n=37
- Did not attend n=35

Attended Forum Meeting One n=3

Rated complete before questionnaire n=8

Completed before questionnaire n=8

Patient After Questionnaire Sample

Patients n=4633

Excluded n=4633
- No interest n=1
- Not approached n=4632

Invited Forum Meeting Two n=230

Excluded n=186
- Not eligible n=2
- Not available n=131
- Refusal - no interest n=46
- No response n=107

Agreed to attend Forum Meeting Two n=7

Excluded n=47
- Did not attend n=37

Attended Forum Meeting Two n=7

Asked complete after questionnaire n=1

Completed after questionnaire n=1

Patient Interview Sample

Patients n=4633

Excluded n=4633
- No interest n=1
- Not approached n=4632

Invited Forum Meeting One n=216

Excluded n=172
- Not eligible n=2
- Not available n=61
- Refusal - no interest n=51
- No response n=79

Agreed to attend Forum Meeting One n=43

Excluded n=36
- Did not attend n=26

Attended Forum Meeting One n=8

Excluded n=4
- Did not attend n=4

Attended Forum Meeting Two n=4

Completed interview n=4
Appendix H: Study 1 questionnaires
Example Patient Questionnaire*

---

Patient & Family Participation Scoping/Exercise/Questionnaire!
Diabetes Centre Patients!

Date:__/__/______

Researcher:___________

Participant ID:__________

---

Section A: Screening Questions!

1) Are you a type 2 diabetes patient? [ ] Yes! [ ] No!
2) Have you been engaged with the Diabetes Centre for at least 12 months? [ ] Yes! [ ] No!

---

Section B: Patient Level Participation (individual care with a healthcare professional)

3) If thinking of the last time in which you were involved in diabetes care, please answer these questions...

---

Section C: Programme Level Participation (Diabetes Centre)!

7) If thinking of your experience of the Diabetes Centre in the last two years... please answer these questions...

---

8) Would you like to become involved in the Diabetes Centre makes it's changing and improving its service?

9) Are there any possible benefits or disadvantages to patient participation in the development of the Diabetes Centre?

---

* Iris Research Unit on Acupuncture, Ulster University

---

293
12) Does the same family member normally join you when you come to the Diabetes Centre? ☐ Yes ☐ No
13) Thinking of when a family member has come to the Diabetes Centre with you in the last two years:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Patient Level</th>
<th>Please indicate why</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Was your family member given information about the service?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>b) Was your family member asked for their opinion about the service?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>c) Was your family member involved in discussions about the service?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>d) Was your family member involved in any decisions about the service?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>e) Did family members make decisions on their own about the service?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>f) Do you want family members to be more involved in decisions made about the Diabetes Centre?</td>
<td>☐ Yes, definitely ☐ No</td>
<td>☐ Yes, to some extent</td>
</tr>
</tbody>
</table>

14) Are there any possible benefits of family participation in the development of the Diabetes Centre? ☐ Yes, please specify ☐ No ☐ Don’t know
15) Are there any disadvantages to family participation in the development of the Diabetes Centre? ☐ Yes, please specify ☐ No ☐ Don’t know

16) Thinking of your experience of the Diabetes Centre in the last two years please indicate how much you agree with the following:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Staff encourage me to voice my opinion about the services I receive in the Diabetes Centre.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Staff encourage me to take part in the decisions made about the service in the Diabetes Centre.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17) Thinking of your experience of the Diabetes Centre please indicate:

<table>
<thead>
<tr>
<th>Service</th>
<th>Have you used this service?</th>
<th>Waiting time very unreasonable</th>
<th>Waiting time very reasonable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Diabetes Centre</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b) Consultant (in the last 2 years)</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Nurse (in the last 2 years)</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Podiatrist (in the last 2 years)</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Dietician (in the last 2 years)</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Other service (in the last 2 years)</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

18) How would you rate your satisfaction with the Diabetes Centre? ☐ Satisfied ☐ Dissatisfied ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6

19) Would you recommend the Diabetes Centre to a friend/family member? ☐ Yes ☐ No ☐ Don’t know

Section D: System Level Participation (national healthcare services e.g. local Hospital)

20) Thinking of your experience of national healthcare services… (e.g. UH, local hospital):

<table>
<thead>
<tr>
<th>Statement</th>
<th>Patient Level</th>
<th>Please indicate why</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Were you given information about services?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>b) Were you asked for your opinion about services?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>c) Were you involved in discussions about services?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>d) Were you involved in any decisions about service?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>e) Did patients make the decision on their own about services?</td>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
<tr>
<td>f) Do you want to be more involved in decisions made about general healthcare services in Ireland?</td>
<td>☐ Yes, definitely ☐ No</td>
<td>☐ Yes, to some extent</td>
</tr>
<tr>
<td>g) Do you want family members to be more involved in decisions made about general healthcare services in Ireland?</td>
<td>☐ Yes, definitely ☐ No</td>
<td>☐ Yes, to some extent</td>
</tr>
</tbody>
</table>

Section E: Demographics

21) Are you aware of the Patients’ Charter “You and Your Health Service”? ☐ Yes ☐ No
22) Age: ☐ 18-29 ☐ 39-39 ☐ 40-49 ☐ 50-59 ☐ 60-69 ☐ 70+
23) Gender: ☐ Male ☐ Female
24) Education: ☐ Primary education or less ☐ Junior cert/inter cert/vocational training ☐ Leaving cert/technical training ☐ Non-degree qualification (diploma) ☐ Degree, professional qualification or both ☐ Postgraduate qualification
25) Duration of attendance at service: ☐ < 1 year ☐ 1-5 years ☐ 6-9 years ☐ 10 + years
26) Relationship to family member: ☐ Hub Spouse/Partner ☐ Child ☐ Parent ☐ Sibling ☐ Not related ☐ Other
27) Would you be interested in taking part in further research? ☐ Yes ☐ No

If no, please stop interview. If yes, please provide contact details separately.

*Questionnaires have been altered to remove the names of the services*
Example Member Questionnaire*

Patient and Family Participation Scoping Exercise Questionnaire

Psychiatry Service Family Members!

---

Date: ____________________ Researcher: ____________________ Participant ID: ____________________

Section A: Screening Questions
1) Have you been a patient attending the Psychiatry Service with your family member for at least 3 months?!
   - Yes! - No! - [if no please stop interview]

Section B: Patient Level Participation (individual care with a healthcare professional)
2) Do you normally join your family member when they see a healthcare professional in the Psychiatry?!
   - Yes! - No! - [if no please skip to Question 6]
3) I'm thinking of the last time you saw our inpatient psychiatric service. Have you attended a family member care session with a healthcare professional?!
   - Yes! - No! - [if no please skip to Question 6]

Section C: Programme Level Participation (Psychiatry Service)
4) Do you normally join your family member when they come to the Psychiatry Service?!
   - Yes! - No! - [if no please skip to Question 6]
5) I'm thinking of your experience of the help the Psychiatry Service in the last two years for your family member. Have you attended service offered by the inpatient psychiatric service?!
   - Yes! - No! - [if no please skip to Question 6]

---

6) Would you like to be involved in the decision-making process of the Psychiatry Service?!
   - Yes! - No! - [if no please specify]
7) Is there any possible benefit of family participation in the development of the Psychiatry Service?!
   - Yes! - No! - [if no please specify]

---

*Note: The questionnaire is designed to gauge the level of participation of family members in the Psychiatry Service, focusing on their attendance and involvement in decision-making processes. The questions are structured to ensure that the feedback is comprehensive and reflects the actual experiences and preferences of the family members.
8) Are there any disadvantages to family participation in the development of the Psychiatry Service?  
☐ Yes, please specify _______________________________ ☐ No ☐ Don't know
9) Are there any possible benefits of patient participation in the development of the Psychiatry Service?  
☐ Yes, please specify _______________________________ ☐ No ☐ Don't know
10) Are there any disadvantages to patient participation in the development of the Psychiatry Service?  
☐ Yes, please specify _______________________________ ☐ No ☐ Don't know
11) Thinking of your experience of the Psychiatry Service in the last two years as a family member; please indicate how much you agree with the following...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) As a family member; staff encourage me to voice my opinion about the services my family member receives in the Psychiatry Service.</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ No</td>
<td>☐ No</td>
</tr>
<tr>
<td>b) As a family member; staff encourage me to take part in the decisions made about the service in the Psychiatry Service.</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ No</td>
<td>☐ No</td>
</tr>
</tbody>
</table>

12) How would you rate your satisfaction with the Psychiatry Service?  
Discouraged ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6  Satisfied
13) Would you recommend the Psychiatry Service to a friend/family member? ☐ Yes ☐ No ☐ Don't know

Section D: System Level Participation (national healthcare services e.g. local hospital)

14) Thinking of your experience of national healthcare services as a family member... (e.g. UHI, local hospital)

| a) Were you given information about services? | ☐ Yes | ☐ No |
| b) Were you asked for your opinion about services? | ☐ Yes | ☐ No |
| c) Were you involved in discussions about services? | ☐ Yes | ☐ No |
| d) Were you involved in any decisions about services? | ☐ Yes | ☐ No |
| e) Did patients make the decision on their own about services? | ☐ Yes | ☐ No |
| f) Do you want family members to be more involved in decisions made about general healthcare services in Ireland? | ☐ Yes, definitely | ☐ No |
| f) Do you want patients to be more involved in decisions made about general healthcare services in Ireland? | ☐ Yes, definitely | ☐ No |

Section E: Demographics

15) Are you aware of the Patients' Charter 'You and Your Health Service'? ☐ Yes ☐ No
16) Age: ☐ 18-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ 60-69 ☐ 70+
17) Gender: ☐ Male ☐ Female
18) Education: ☐ Primary education or less ☐ Leaving cert/inter cert/vocational training ☐ Junior cert/inter cert/vocational training ☐ Non-degree qualification (diploma) ☐ Degree, professional qualification or both ☐ Postgraduate qualification
19) Relationship to the patient: ☐ Spouse/Partner ☐ Child ☐ Parent ☐ Sibling ☐ Not related ☐ Other _____________
20) Family member duration of attendance at service: ☐ < 1 year ☐ 1-5 years ☐ 6-9 years ☐ 10+ years
21) Would you be interested in taking part in further research? ☐ Yes ☐ No

If no, please stop interview. If yes, please provide contact details separately

Thank you!

* Questionnaires have been altered to remove the names of the services
Appendix I: Study 2 interview schedules

Example patient/family member focus group interview schedule

1. **What does patient and family participation in healthcare design and delivery mean to you?**
   
   *(Who should be involved, when should it be done, what topics should it involve, what is the purpose)*

2. **Have you ever been involved in patient and family participation in healthcare design and delivery?**
   
   - Have you been involved in patient and family participation?
     
     *(when, what services, what did it entail, who was involved, what did you think about it, good thing, bad thing, did anything come out of it, why did you participate?)*
   
   - If you have not been involved in patient and family participation, why not?
     
     *(opportunity, resources, capability)*
   
   - What would you change about your experience?
     
     *(do you think your experience is ok? What do you think about the current level of feedback provided by/to patients and family members?)*

3. **What do you think about patient and family participation in healthcare design and delivery?**
   
   - Is it a good or a bad idea?
     
     *(why)*
   
     **If a 5 year strategic plan was being developed for the Diabetes Centre/ Psychiatric Service...**
   
     - Do you think patients should be involved in healthcare design and delivery in the Diabetes Centre/ Psychiatric Service?
       
       *(why/why not)*
   
     - Do you think family members should be involved in healthcare design and delivery in the Diabetes Centre/ Psychiatric Service?
       
       *(why/why not)*
   
     - Do you think staff should be involved in healthcare design and delivery in the Diabetes Centre/Psychiatric Service?
       
       *(why/why not)*
   
     - Do you think staff want feedback?
       
       *(why/why not)*
   
     - How much involvement should each group have?
       
       *(patients, family members, healthcare providers)*
   
     - What should patient and family participation be used for?
       
       *(certain topics, certain services, certain groups of patients (children)*
4. Would you like to be involved in patient and family participation?
   (In general, in this service, why/why not (lack of trust of current system), what could help you change your mind, what do you think would happen if you took part?)

5. What are the facilitators of patient and family participation?
   - What exists to help patients and family members participate in healthcare design and delivery?
     (opportunities, resources, knowledge, change in attitude)
   - What barriers exist to patient and family participation?
     (healthcare providers, patients, family members, level of knowledge, lack of resources, attitudes (own, staff, society)

6. What impact do you think patient and family participation in healthcare design and delivery will have?
   - What are the good things that might come from patient involvement?
     (impact on service, impact on health, impact on relationship with staff, relationship with family)
   - What are the good things that might come from family involvement?
     (impact on service, impact on health, impact on relationship with staff, relationship with patient)
   - What are the bad things that might come from patient involvement?
     (impact on service, impact on health, impact on relationship with staff, relationship with family)
   - What are the bad things that might come from family involvement?
     (impact on service, impact on health, impact on relationship with staff, relationship with patient)
Example clinician focus group interview schedule

1. What does patient and family participation in healthcare design and delivery mean to you?
   (Who should be involved, when should it be done, what topics should it involve, what is the purpose)

2. Have you ever been involved in patient and family participation in healthcare design and delivery? (As a healthcare provider!)
   - Have you been involved in patient and family participation?
     (when, what services, what did it entail, who was involved, what did you think about it, good thing, bad thing, did anything come out of it, why did you participate?)
   - If you have not been involved in patient and family participation, why not?
     (opportunity, resources, capability)
   - What would you change about your experience?
     (do you think your experience is ok? What do you think about the current level of involvement of patients and family members?)

3. What do you think about patient and family participation in healthcare design and delivery?
   - Is it a good or a bad idea?
     (why)
   If a 5 year strategic plan was being developed for the Diabetes Centre/Psychiatric Service....
     - Do you think patients should be involved?
       (why/why not)
     - Do you think family members should be involved?
       (why/why not)
     - How much involvement should each group have?
       (i.e. give opinion involvement in discussions, who should have decision making power)
       (patients, family members, healthcare providers, differ by topic)
     - What should patient and family participation be used for?
       (certain topics, certain services, certain groups of patients (children)

4. Would you like to be involved in patient and family participation?
   (In general, in this service, why/why not (lack of trust of current system), what could help you change your mind, what do you think would happen if you took part?)
5. What are the facilitators and barriers of patient and family participation?
- What exists to help patient and family participate in healthcare design and delivery?
  (healthcare providers, patients, family members, level of knowledge, lack of resources, attitudes (own, staff, society))
- What barriers exist to patient and family participation?
  (healthcare providers, patients, family members, level of knowledge, lack of resources, attitudes (own, staff, society))

6. What impact do you think patient and family participation in healthcare design and delivery will have?
- What are the good things that might come from patient involvement?
  (impact on service (complexity and chaos), impact on health, impact on relationships-staff, family)
- What are the good things that might come from family involvement?
  (impact on service (complexity and chaos), impact on health, impact on relationships-staff, patients)
- What are the bad things that might come from patient involvement?
  (impact on service, impact on health, impact on relationships- staff and family)
- What are the bad things that might come from family involvement?
  (impact on service, impact on health, impact on relationships- staff and patients)

That is all of my questions, is there anything that I have missed or anything that you would like to add?
Thank you for taking part.
Example policy leader interview schedule

1. What does patient and family participation in healthcare design and delivery mean to you?
   *(Who should be involved, when should it be done, what topics should it involve, what is the purpose)*

2. Have you ever been involved in patient and family participation in healthcare design and delivery?
   - Have you been involved in patient and family participation?
     *(when, what services, what did it entail, who was involved, what did you think about it, good thing, bad thing, did anything come out of it, why did you participate?)*
   - If you have not been involved in patient and family participation, why not?
     *(opportunity, resources, capability)*
   - What would you change about your experience?
     *(do you think your experience is ok? What do you think about the current level of feedback provided by/to patients and family members?)*

3. How are changes made to services/policy?
   *(where ideas come from? who is involved? How much say does each group have?)*
   - What involvement do patients have?
     *(provided with information? Involved in discussion? Have a vote? Provide new ideas?)*
   - What involvement do family members have?
     *(provided with information? Involved in discussion? Have a vote? Provide new ideas?)*
   - What would you change about this process?

4. What do you think about patient and family participation in healthcare design and delivery?
   - Is it a good or a bad idea?
     *(why)*
   - Do you think patients should be involved in healthcare design and delivery in services?
     *(why/why not)*
   - Do you think family members should be involved in healthcare design and delivery in services?
     *(why/why not)*
   - Do you think staff should be involved in healthcare design and delivery in services?
     *(why/why not)*
   - Do you think staff want feedback?
     *(why/why not)*
   - How much involvement should each group have?
     *(patients, family members, healthcare providers)*
   - What should patient and family participation be used for?
     *(certain topics, certain services, certain groups of patients (children)*)
5. What are the facilitators and barriers of patient and family participation?
- What exists to help patient and family participate in healthcare design and delivery? (attitudes – people think patients and family should be involved, patients and family want to be involved, healthcare system needs new ideas to find solutions to problems)
- What barriers exist to patient and family participation? (healthcare providers, patients, family members, level of knowledge, lack of resources, attitudes (own, staff, society)
- What do patients/family need training in to boost capacity?
  Taking part in the decision making process? Public speaking? Knowledge of mental health and surrounding policy or is their experience as a patient or family member enough? What about training for staff?
- Frustration at lack of service level change
  (patient and family involvement provide extra muscle for change? Make easier to argue for change? Apply pressure from outside of the service?)

6. What impact do you think patient and family participation in healthcare design and delivery will have?
- What are the good things that might come from patient involvement? (impact on service (complexity and chaos), impact on health, impact on relationships-staff, family)
- What are the good things that might come from family involvement? (impact on service (complexity and chaos), impact on health, impact on relationships-staff, patients)
- What are the bad things that might come from patient involvement? (impact on service, impact on health, impact on relationships- staff and family)
- What are the bad things that might come from family involvement? (impact on service, impact on health, impact on relationships- staff and patients)

That is all of my questions, is there anything that I have missed or anything that you would like to add?
Thank you for taking part.
### Theme 1 Service Setting

#### Subtheme: 1A. Description of illness

<table>
<thead>
<tr>
<th>Description: Information on the impact of patients’ illness, the experience of the illness outside of the service</th>
<th>‘Like we had a young woman with psychosis who’s mother just couldn’t tolerate the behaviour, she was sitting in front of a mirror screaming for 3 hours, and the other kids in the family were very distressed, the family was falling apart. But you know, once she got the diagnosis it really eh... it really helped.’ (SIPSFG02, Julie)</th>
</tr>
</thead>
</table>

#### Subtheme: 1B Description of the service

1. **Service structure**
   | Description: Information on how the service works, the services offered, the types and numbers of patients which attend, the attitude towards family members and the role they play in the service | ‘Mental health is the only service where we can detain people against their will and where we are, we can take them in under and act, we can deprive them of their liberty even though they have done nothing wrong. Em, and we can forcefully, eh, treat people so I think that we need to be... that it is different became in physical health for the vast majority of cases I will always be deemed competent’ (SIPLI03, Annie) |

2. **Level of satisfaction with the service**
   | Description: Patients’ and family members’ level of satisfaction with all aspects of the service and staff excluding satisfaction with service level participation | ‘I find them kind off very good up there and my husband is up there all of the time and there is no problem with that.’ (SIDFM09, Dolores) |

3. **Patient led service**
   | Description: Statements and examples of the importance of patient autonomy and the service being patient led | ‘It’s kind of up to the patient’ (SIDSFG02, Katherine) |

#### Subtheme: 1C Description of how change happens

1. **Process of change**
   | Description: Descriptions and details on the process of how changes are made at | ‘How do we go about planning our service development ... at the moment em it’s a lot of, at our level, at this level before we go to the next level, it’s
present and the structures involved  

| present and the structures involved | a lot of informal meetings and chats and kind of ideas and then they are bounced around and things like that. So it’s not necessarily formalised, sit down, multidisciplinary meeting, it’s more of chatting to Julie [nurse] on the corridor saying what do you think about if we did this and then Julie [nurse] telling to the nurses and then you know, that kind of thing.’ (S1DSFG04, Linda) |

(ii) Lack of change in the service/difficulty with change  
Description: Discussions on the level of change which happens in the service and difficulties in making change happen  

| (ii) Lack of change in the service/difficulty with change | ‘The logistics of labelling a clinic a certain way of making sure it’s booked a certain way, of making sure that that is translated to all the various levels in the hospital. We hit walls left, right and centre. So it does happen eventually but it’s usually a very long process and that’s something that you would think is quite simple. So and even when you are looking at more complicated examples it’s just challenging.’ (S1DSFG04, Linda) |

Theme 2: Patient and Family Participation at Present  

Subtheme: 2A. Examples of actual participation  

<table>
<thead>
<tr>
<th>(i) Patient level</th>
<th>Description: Examples of patient or family participation in any service – including services outside of the study- relating to participation in individual patient care</th>
</tr>
</thead>
</table>

| (ii) Service level | Description: Examples of patient or family participation in any service – including services outside of the study- relating to participation in service level changes | ‘Some of our carers would sit on committees we will say the local HSE and maybe somebody from the hospital and that would be about planning the services for the future’ (SIPLI08, Cynthia) |

| (iii) National level | Description: Examples of patient or family participation in any service – including services outside of the study- relating to participation at a national policy level |
### Theme 3: Patient and Family Participation Opinions

#### Subtheme: 3A. Understanding

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<thead>
<tr>
<th>Subtheme</th>
<th>Description</th>
<th>Example</th>
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</thead>
<tbody>
<tr>
<td>(i) Confusion/ Lack of understanding of participation</td>
<td>Description: Including examples of no understanding, confusion and lack of clarity</td>
<td>‘I’m confused, I mean are you only talking about the service or are you talking about the medical part’ (SIDSFG01, Debra)</td>
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<tr>
<td>(ii) Participation understood as being at the patient level</td>
<td>Description: Including examples of participation being understood at the individual patient care level</td>
<td>‘What comes to mind is, we would have a lot of family carers obviously caring for a loved one and quite often we would hear that the carer themselves would feel that on occasion they are not consulted about the care of their loved one.’ (SIPLI08, Cynthia)</td>
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<tr>
<td>(iv) Participation understood at the national/policy level</td>
<td>Description: Including examples of participation being understood at the healthcare design and delivery service level</td>
<td>‘Patient family participation in the development of services and evaluation of service and the delivery of services’ (SIPLI03, Annie)</td>
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<tr>
<td>(iii) Participation understood to include the service level Description: Including examples of participation being understood at the national policy level</td>
<td></td>
<td>‘So I think its’, its’ right across in terms of mental health service delivery but then it is also how do we engage in patient and family participation as the, from a policy participation point of view as well.’ (SIPLI03, Annie)</td>
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<tr>
<td>(v) Participation understood as feedback</td>
<td></td>
<td>‘No that’s very dangerous. It’s very dangerous’</td>
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<td>Subtheme: 3B. Positive attitudes towards participation</td>
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<tr>
<td>(i) Patient level</td>
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<td>‘I think patients who has impairment say, in that</td>
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<td>situation, I mean I had a patient there a couple of</td>
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<td>weeks ago,, and he came in by himself and then that</td>
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<td>situation you really need to have the family member...it would be beneficial’ (S1DSFG02, Sinead)</td>
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<tr>
<td>(ii) Service level</td>
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<tr>
<td>Description: Statements and opinions of patient and</td>
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<tr>
<td>‘I mean it makes no sense not to have them involved</td>
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<td>the patients absolutely whatsoever.’ (SIPLI06, Ken)</td>
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<td>(iii) National level</td>
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<tr>
<th>Subtheme: 3C. Negative attitudes towards participation</th>
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<tbody>
<tr>
<td>(i) Patient level</td>
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<tr>
<td>Description: Statements and opinions of patient and</td>
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<td>(ii) Service level</td>
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<tr>
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<tr>
<td>‘In terms of the family input into changing decisions</td>
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</table>
**Subtheme: 3D. The role of participants**

(i) Patients/Tokenistic involvement  
Description: Examples and discussion of tokenistic involvement  
‘And equality I think it’s all about that they have to be treated as equal partners in the thing.’ (S1PLI06, Ken)

(ii) Family members  
Description: Examples and discussion of family member involvement  
‘Quite often the carer obviously is the person closest to what the patients needs are. And they know what they need, they know what would help in caring for them and supporting them. So most definitely patient and if there is a carer should be involved.’ (SIPLI08, Cynthia)

(iii) Clinicians  
Description: Including if involving patients and family in decisions about the service is part of their role  
‘I think staff should have a say, in the sense of while we need to acknowledge the sense that staff have needs within a service eh, I think we need to be careful that we are not developing a service to met the needs of the staff in the sense of ... but I do think that staff need to have a say’ (SIPLI03, Annie)

(iv) Patient organisations  
Description: Examples and discussion of patient organisation involvement  
‘I don’t think there is very much real participation in the real sense of the word, there could be a lot of tokenism’ (S1PLI06, Ken)

**Theme 4 Barriers/Challenges**

**Subtheme: 4A. No barriers**

**Subtheme: 4B. Patient autonomy and confidentiality**
Description: Conversations about concerns surrounding patient autonomy and confidentiality such as the impact of participation on confidentiality, the role which patient autonomy will play in participation, HSE confidentiality concerns and politics

‘I think in the interest of transparency its actually very important and em I’d say you would probably find the HSE wouldn’t be very eh keen on the idea, because it would give them insight into what actually happens’ (SIDSFG01, Jack)

**Subtheme: 4C. Attitudes and expectations**

(i) Attitudes
Description: Conversations about attitudes towards participation

‘t’s a big cultural shift for people too.’ (S1PSFG02, Margaret)

(ii) Expectations
Description: Conversations about expectations of participation

‘I think as well a lot of families that I would see have a lot of unrealistic beliefs and expectations of what mental health services do’ (S1PSFG02, David)

**Subtheme: 4D. Resource constraints/ Lack of funding**

(i) Lack of funding
Description: Statements or examples of possible barriers posed by various components of resources relating to funding.

‘I wouldn’t expect that any NCHD or consultant for that matter with...eh would have the time to do it.’ (SIDSFG01, Jack)

(ii) Time
Description: Statements or examples of possible barriers posed by various components of resources relating to timing.

‘Obviously the fact that hospitals are understaffed. So sometimes medical people are rushing, they don’t have the time maybe to sit down and take the patient through their care or take the carer through what happens’ (SIPLI08, Cynthia)

(iii) Staff
Description: Statements or examples of possible barriers posed by various components of resources relating to staff.

(iv) Level of patient contact
Description: Statements or examples of possible barriers posed by various components of resources relating to numbers of patients and contact.

‘In the type 2 clinic, like these guys get seen for 15 minutes every 2 years. Yea so if it’s something if you are looking at, what’s a barrier, I think that’s a barrier as well, is that the number of patients been seen in the department is so em huge’ (SIDSFG01,
### Subtheme: 4E. Capacity

| (i) Patients | ‘I see that coming up again and again and again, it actually comes back again the education and training that patients and their families need to kind of leave their jacket at the door, jersey at the the door when they are talking about improving services. Because if you are...obviously if a patient had a bad experience of a service that is going to influence the way in which they interact with it from them on.’ (SIPLI02, Damien) |
| Description: All discussion about the ability of patients to see beyond individual experience, support/training needed |

| (ii) Family members | ‘You’d be surprised how powerfully family members, especially can express themselves. The problem is that they can sometimes over or in a very more personal way rather than thinking that hang on, let’s...and that’s where training comes in’ (SIPLI06, Ken) |
| Description: The ability of family members to see beyond individual experience, supports needed |

| (iii) Clinicians | ‘I think that before that happens probably that there needs to be training particularly with the medical side and the clinicians and that, around the value that that input would give to the system.’ (SIPLI08, Cynthia) |
| Description: The ability of clinicians to communicate with patients and family members during the decision making process, supports needed |

| (iv) System/service | ‘So you have ad hoc individual kind of good initiatives but they exist in that space and they don’t go outside of that space and that is unfortunate because there is no actual system in place then that allows that to grow’ (SIPLI02, Damien) |
| Description: Whether the service can take an added layer of complexity or has the resources to incorporate patients and family in the process of change, inability for change to occur |

### Subtheme: 4F. Fear

| (i) Patients | ‘That they wouldn’t feel oh god, I better keep my mouth shut here now, because this is going to influence how these people treat me in the future.’ (SIDSG02, Megan) |
| Description: Conversations relating the fears which stakeholder groups have in relation to participation |

| (ii) Family members | ‘It’s not just the service user, it’s actually their carers |
| Description: |
**Description:** Conversations relating the fears which stakeholder groups have in relation to participation  

*sometimes can be quite fearful* (S1PSFG02, Siobhan)

| (iii) Clinicians  
Description: Conversations relating the fears which stakeholder groups have in relation to participation |
<table>
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<tbody>
<tr>
<td>‘There is an awful lot of fear out there that they can handle patients on a one on one when it’s the referral or when it’s the typical scenario but when you start giving a kind of level playing field, then it can lead to difficulties.’ (SIPLI02, Damien)</td>
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**Subtheme: 4G. The reality behind participation**

| (i) Ideal world vs reality  
Description: Discussions relating to whether participation will work in reality and the conflict between ideals and reality e.g. It is a good idea but ...) |
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<tbody>
<tr>
<td>‘I think that morally everybody accepts that this is a good thing. I think that effectively, am... not many people know what are the best ways to go about it and that’s where we are currently at really’ (SIPLI02, Damien)</td>
</tr>
</tbody>
</table>

| (ii) Implementation  
Description: Examples and discussion of the necessity for a clear idea of how to achieve participation, what this would entail and require e.g. may require meetings outside or normal hours how report back |
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<tbody>
<tr>
<td>‘I mean if there was someone that would handle this part and just give the information’ (SIDSFG01, Debra)</td>
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</table>

| (iii) The type of participants  
Description: Concerns and ideas about who participations could/should be, the personality they have, the experience they have, the attitude they have, their beliefs |
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<tbody>
<tr>
<td>‘I say the barrier is actually getting the appropriate patients, so I think you can get well educated patients who are specific minded in kind of doing this for the benefit of others as such’ (SIPLI02, Damien)</td>
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| (iv) Recruitment of participants  
Description: concerns about difficulty recruiting participants including reflections on past experiences of recruitment difficulties, issues surrounding how you pick participants and the need for them to reflect a large population |
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<tbody>
<tr>
<td>‘In terms of, patient and family involvement who would be the representative who in a cohort of patients of 6000 plus diabetic patients?, who one or two or three people represents that group’ (S1DSFG04, Mitchell)</td>
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<tr>
<td>Theme 5. Facilitators</td>
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<tr>
<td>Description: Examples of anything that is helpful to participation that exists at the moment or could be developed to help patients and family members become involved in changes in healthcare services</td>
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<tr>
<td>‘You need the few role models or champions.’ (SIPLI06, Ken)</td>
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<tr>
<th>Theme 6. Positive impacts</th>
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<tr>
<td>Subtheme: 6A. Service</td>
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<tr>
<td>(i) New ideas</td>
</tr>
<tr>
<td>Description: Discussions relating to the possible positive impact which participation may have on the service</td>
</tr>
<tr>
<td>‘If you have a patient representative fabulous, great idea they bring a completely different perception and can see things we don’t see, and because we are too close to the thing’ (SIDSFG02, Megan)</td>
</tr>
<tr>
<td>(ii) Patient and family experience included</td>
</tr>
<tr>
<td>Description: Discussions relating to the possible inclusion of patient and family knowledge or experience in decisions</td>
</tr>
<tr>
<td>‘I think the lived experience of an issue gives a very different perspective of it and that can come from the people with self experience of it or the family who are the key supporters.’ (SIPLI03, Annie)</td>
</tr>
<tr>
<td>(iii) Greater transparency</td>
</tr>
<tr>
<td>Description: Discussions relating to the possible positive impact which participation may have on transparency</td>
</tr>
<tr>
<td>‘I think on the flip side of that it could be useful eh when you look at our stats to see the amount of new type 2’s we are getting every year. It might be useful for patients to see that, to be privy to that, to allow them to understand that it’s not like with all these new patients we get in resources we don’t, it’s make do with what we have and it’s adding to the task list’ (S1DSFG02, Katherine)</td>
</tr>
<tr>
<td>(iv) Feedback</td>
</tr>
<tr>
<td>Description: Discussions relating to good feedback provided on the service, clinicians know whether they are advocating correctly for patients at present or if they just think they are</td>
</tr>
<tr>
<td>‘Because maybe sometimes what we think we are doing for them, they may want other things, they have different needs and you know, we do need to find out what they need or you know the service that we are running is there anything we can change to improve on it, what do they want out of it.’ (SIDSFG02, Felicity)</td>
</tr>
<tr>
<td>(v) More change</td>
</tr>
<tr>
<td>Description: all talk relating to the impact</td>
</tr>
<tr>
<td>‘If you have a feedback system you can get a general gist of what the majority of people want to change</td>
</tr>
</tbody>
</table>

311
of participation on change e.g. change at the service level through extra pressure on management or political pressure and then it also gives people who is in the department, who are head of the department to say kind of...the...muscle to actually make changes happen.’ (SIDSFG01, Jack)

(vi) Improved service
Description: All chat relating to the impact of participation on an improved service ‘I think you’ll have a far more efficient and effective system I think you will have better outcomes’ (SIPLI06, Ken)

Subtheme: 6B. Relationships

(i) Patients and family
Description: All chat relating to the positive impact of participation on patient and family relationships ‘I think it might improve relationships in some case, because they would be able to bring their ideas together’ (SIPLI08, Cynthia)

(ii) Patients and clinicians
Description: All chat relating to the positive impact of participation on patient and clinician relationships ‘We see the patient as a patient, somebody who needs our help with their condition. But the patient themselves is trying to live a normal life....So from their point of view, maybe it would kind of open...channels them and make us realise there are other things that we could be doing, and things that we are neglecting to do when we are changing things with the patient.’ (SIDSFG02, Willow)

(iii) Family and clinicians
Description: All chat relating to the positive impact of participation on clinician and family relationships ‘I think it is helpful having the family on board and you now that the patient and the family and the team, all are trying to help and have a common goal’ (S1PS101, Laura)

Subtheme: 6C. Emotional responses

(i) Empowering
Description: Discussion about the impact on participants’ self esteem, dignity and identity and overcoming stigma ‘I think they would feel far more empowered and feel like they are being listened to and feel like their issues or their suggestions are being listened to and are being implemented’ (SIPLI08, Cynthia)

(ii) Less frustration
Description: Lower levels of frustration for any group e.g. patients feel less frustrated as they may feel listened to with greater communication and understanding ‘I think our level of frustration would probably drop as well because you would be getting patients who are coming in happier with the service we are providing’ (S1DSO07, Michael)

(iii) Other positive emotions
The other side is that when you see that happening
### Subtheme: 6D. Health

**Description:** Discussions on any positive impacts which participation is expected to have on participants health

*eh, for other people who are in a position of distress at the time and they see well you know this person has done it. There were where I am so you know you have that … comparity of self that gives people a real sense of hope. Gives people a real sense of if they can do it, so can I’* (SIPLI03, Annie)

### Theme 7 Negative impacts

#### Subtheme: 7A. Service

(i) **Bad feedback**  
**Description:** Concerns raised by any stakeholder group about the negative impact on the service as a result of negative feedback through patient and family participation

*‘I think that’s the negative side that we get absolutely slated.’* (S1PSFG02, Laura)

(ii) **Busier**  
**Description:** Conversations including concerns about the service getting busier as a result of participation

*‘Make it busier!’* (SIDSFG02, Shauna)

(iii) **No Change**  
**Description:** Participation having no impact on change or outcomes

*‘One worry would be that, you would be hearing what should be happening, knowing those things should be happening, but knowing you can’t do anything about it, so that may be one block to actually having patients involved because you know that you are not going to be able to effect what people would want.’* (SIDSFG04, Mitchell)

#### Subtheme: 7B. Relationships

(i) **Patients and family**  
**Description:** All chat relating to the positive impact of participation on patient and family relationships

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313
<table>
<thead>
<tr>
<th>Subtheme: 7C. Emotional responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Fear</td>
</tr>
<tr>
<td>Description: Conversations about a result of increased fear such as increased fear by patients due to decreased trust in clinicians from participation</td>
</tr>
</tbody>
</table>

| (ii) Greater frustration  |
| Description: Examples of concerns surrounding increased frustration from any stakeholder group due to lack of change despite patient and family participation or the amount of involvement |

| (iii) Other negative emotions |
| Description: All other conversations about the negative emotional responses expected from participation |

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<tr>
<th>Subtheme: 7D. Health</th>
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</table>

| (ii) Patients and clinicians |
| Description: All chat relating to the positive impact of participation on clinician and patient relationships |

| ‘It may well bring up issues that they haven’t discussed before, so it may also raise some issues or problems, but sometimes those are better being raised and maybe coming out in the open and so it might improve relation…it might to begin with cause strain or tension’ (SIPLI08, Cynthia) |

| (iii) Family and clinicians |
| Description: All chat relating to the positive impact of participation on clinician and family relationships |

| (iv) Imbalance in representation |
| Description: Any text relating to the idea that participation may give too much power to one or more stakeholder groups or types of services |

| ‘I feel the medical input to the management of major mental illness, em is under recognised and under funded… and so I suppose there is an imbalance there anyway. My fear would be getting patients involved, would further exacerbate that imbalance because why would they represent medical issues.’ (S1PSFG02, Julie) |

<table>
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<th>Subtheme: 7D. Health</th>
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| (i) Fear                          |
| Description: Conversations about a result of increased fear such as increased fear by patients due to decreased trust in clinicians from participation |

| (ii) Greater frustration  |
| Description: Examples of concerns surrounding increased frustration from any stakeholder group due to lack of change despite patient and family participation or the amount of involvement |

| (iii) Other negative emotions |
| Description: All other conversations about the negative emotional responses expected from participation |

| ‘I think that sometimes... you know, frustration can also arise if people feel too involved in something as well’ (S1DSI01, Laura) |

<p>| You would hope that the patient wouldn’t feel less empowered, because the carer is suddenly taking on more’ (SIPLI08, Cynthia) |</p>
<table>
<thead>
<tr>
<th>Description: Discussions on any negative impacts which participation is expected to have on participants health</th>
</tr>
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<tbody>
<tr>
<td>Theme 8. Miscellaneous</td>
</tr>
<tr>
<td>Description: Anything else of interest which does not fit in the above categories</td>
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</tbody>
</table>
Appendix K: Study 3 questionnaire
Round 1 Psychiatry Questionnaire*

Round 1 Questionnaire
Patient and Family Participation in the Planning of Services in the Psychiatry Service

If you have any questions or need further information please contact X on X or X

Participant I.D: ____________________

Section A: Patient Participation

1) Do you think patient should be involved in the planning of services in the Psychiatry Service?
   *Tick one only*
   □ Yes       □ No
   *If no skip to question 3*

2) How involved should patients be in the planning of services in the Psychiatric Service?
   *Tick one on each line only*

<table>
<thead>
<tr>
<th>a) Patients should be told about changes</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>b) Patients should be asked what they think</td>
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<td>c) Patients should be actively involved in discussions</td>
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<td>d) Patients should have a vote when changes are made</td>
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<td>e) Patients should make decisions on their own</td>
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</table>

3) How often do you think patients should be involved in the planning of services in the Psychiatry Service?
   *Tick one only*
   □ Always       □ As problems come up       □ Once-off       □ Never
   □ Other ______________________________________________________

4) Using the scale below please indicate how important it is for patients to be involved in the following stages of the decision making process in the planning of services in the Psychiatry Service?
   *Tick one on each line only*

<table>
<thead>
<tr>
<th>1 Not important at all</th>
<th>2 Not important</th>
<th>3 Important</th>
<th>4 Very important</th>
<th>Patients should not be involved</th>
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</thead>
<tbody>
<tr>
<td>a) When ideas for changes are being suggested</td>
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<td>b) Before the decision is made</td>
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<td>c) After the decision is made</td>
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<tr>
<td>d) Other ___________________________</td>
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</table>
5) Who should represent patients in the planning of services in the Psychiatry Service?

*Tick one only*
- [] Patients should not be involved
- [] Doctors/nurses should represent patients
- [] Patient advocacy (patient comments and complaints office) should represent patients
- [] ‘Patient representatives’ should represent patients
- [] Other ________________________________

6) How should patients be picked to be involved in the planning of services in the Psychiatry Service?

*Tick one only*
- [] Patients should not be involved
- [] All interested patients should be involved
- [] Voting by patients
- [] Names picked from a hat
- [] Patients with relevant characteristics picked (e.g. years attending service)
- [] Other _______________________________________

7) Using the scale below please indicate how important the following factors are when picking patients to be involved in the planning of services in the Psychiatry Service.

*Tick one on each line only*

<table>
<thead>
<tr>
<th>Factor</th>
<th>1 Not important at all</th>
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<th>3 Important</th>
<th>4 Very important</th>
<th>Patients should not be involved</th>
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<tbody>
<tr>
<td>a) Impact of being involved on patient’s health</td>
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<td>b) Diagnosis (e.g. depression)</td>
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<td>c) Level of education</td>
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<td>d) Age</td>
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<td>e) How long attending the service</td>
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<td>g) Ability to dedicate time</td>
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<td>h) Other</td>
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8) Using the scale below please indicate how important the following options are for ‘patient representatives’ to take into account when they are providing input on behalf of other patients in the planning of services in the Psychiatry Service?

*Tick one on each line only*

<table>
<thead>
<tr>
<th>Option</th>
<th>1 Not important at all</th>
<th>2 Not important</th>
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<tr>
<td>c) A list of what patients have identified as important</td>
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<td>d) Other</td>
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9) Using the scale below please indicate how important the following areas are in training patients to be involved in the planning of services in the Psychiatry Service.

*Tick one on each line only*

<table>
<thead>
<tr>
<th>1 Not important at all</th>
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<th>3 Important</th>
<th>4 Very important</th>
<th>Patients should not be involved</th>
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<tbody>
<tr>
<td>a) How the Psychiatry Service works</td>
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<td>b) How changes are made in the Psychiatry Service</td>
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<td>c) How to work with others</td>
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<td>d) Why patients should be involved</td>
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<tr>
<td>e) Communication skills</td>
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<td>f) Other ______________________________</td>
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</table>

10) Using the scale below please indicate how important the following areas are in training doctors/nurses for patients to be involved in the planning of services in the Psychiatry Service.

*Tick one on each line only*

<table>
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<tr>
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11) Using the scale below please indicate how important the following actions are in using patients’ opinions when planning services in the Psychiatry Service.

*Tick one on each line only*

<table>
<thead>
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<td>a) Decision justified if different from patients’ opinions</td>
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<tr>
<td>b) Patients’ opinions need to be passed on to those involved in the decision making process</td>
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<td>c) Other ______________________________</td>
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</table>

12) Do patients need to be updated on how their opinions were included in the planning of services in the Psychiatry Service.

**Tick one only**

- □ No, patients should not be involved
- □ No, patients do not need to be told how their opinion was included
- □ Yes, patients need to be told how their opinion was included
- □ Other _____________________________________________________________________________
Section B: Family Member Participation

13) Do you think family members should be involved in the planning of services in the Psychiatry Service?

Tick one only

☐ Yes   ☐ No

If no skip to question 15

14) How involved should family members be in the planning of services in the Psychiatry Service?

Tick one on each line only

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<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>a) Family members should be told about changes</td>
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<td>b) Family members should be asked what they think</td>
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15) How often do you think family members should be involved in the planning of services in the Psychiatry Service?

Tick one only

☐ Always   ☐ As problems come up   ☐ Once-off   ☐ Never

☐ Other ___________________________________________________

16) Using the scale below please indicate how important it is for family members to be involved in the following stages of the decision making process in the planning of services in the Psychiatry Service?

Tick one on each line only

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<tr>
<th></th>
<th>1</th>
<th>2</th>
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<td>d) Other</td>
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17) Who should represent family members in the planning of services in the Psychiatry Service?

Tick one only

☐ Family members should not be involved   ☐ Patients should represent family members

☐ Doctors/nurses should represent family members

☐ 'Family members representatives’ should represent family members

☐ Patient advocacy (patient comments and complaints office) should represent family members

☐ Other ___________________________________________________
18) How should family members be picked to be involved in the planning of services in the Psychiatry Service?

**Tick one only**
- Family members should not be involved
- All interested family members should be involved
- Family members with relevant characteristics picked (e.g. years attending service)
- Names picked from a hat
- Other

19) Using the scale below please indicate how important the following factors are when picking family members to be involved in the planning of services in the Psychiatry Service.

**Tick one on each line only**

<table>
<thead>
<tr>
<th>Factor</th>
<th>1 Not important at all</th>
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<th>3 Important</th>
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<th>Family members should not be involved</th>
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<tbody>
<tr>
<td>a) Level of education</td>
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<td>b) Age</td>
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<td>c) How long attending the service</td>
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<td>f) Other</td>
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20) Using the scale below please indicate how important the following options are for ‘family member representatives’ to take into account when they are providing input on behalf of other family members in the planning of services in the Psychiatry Service.

**Tick one on each line only**

<table>
<thead>
<tr>
<th>Option</th>
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<td>c) A list of what family members have identified as important</td>
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<td>d) Other</td>
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21) Using the scale below please indicate how important the following areas are in training family members to be involved in the planning of services in the Psychiatry Service.

**Tick one on each line only**

<table>
<thead>
<tr>
<th>Area</th>
<th>1 Not important at all</th>
<th>2 Not important</th>
<th>3 Important</th>
<th>4 Very important</th>
<th>Family members should not be involved</th>
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<tbody>
<tr>
<td>a) Mental health illnesses (e.g. depressions)</td>
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<tr>
<td>b) How the Psychiatry Service works</td>
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<td>e) Why family members should be involved</td>
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<td>f) Communication skills</td>
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<td>g) Other</td>
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</table>
22) Using the scale below please indicate how important the following areas are in training doctors/nurses for family members to be involved in the planning of services in the Psychiatry Service.

*Tick one on each line only*

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<thead>
<tr>
<th></th>
<th>1 Not important at all</th>
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<td>d) Other</td>
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23) Using the scale below please indicate how important the following actions are in using family members’ opinions when planning services in the Psychiatry Service.

*Tick one on each line only*

<table>
<thead>
<tr>
<th></th>
<th>1 Not important at all</th>
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<tr>
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</tr>
<tr>
<td>c) Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

24) Do family members need to be updated on how their opinions were included in the planning of services in the Psychiatry Service?

*Tick one only*

- ☐ No, family members should not be involved
- ☐ No, family members do not need to be told how their opinion was included
- ☐ Yes, family members need to be told how their opinion was included
- ☐ Other ________________________________
Section C: Demographics

25) Age:  □ 18-29  □ 30-39  □ 40-49  □ 50-59  □ 60-69  □ 70+

26) Gender:  □ Male  □ Female

27) Education:  □ Primary education or less  □ Junior cert/inter
cert/vocational training  □ Non-degree qualification
   □ Leaving cert/technical training  □ Postgraduate qualification
   (diploma)
   □ Degree, professional qualification or both

28) Duration of attendance at the Psychiatry Service:
   □ < 1 year  □ 1-5 years  □ 6-9 years  □ 10+ years

29) Discipline:
   □ Nursing  □ Psychology  □ Psychiatry  □ Social work  □
   Occupational therapy  □ Other ________________________________

THANK YOU!

- All contact details and names have been removed for confidentiality.
Section A: Patient Participation

The charts show the answers provided by the whole group in the first questionnaire.
Your answer in the first questionnaire is circled in red.
Please think about this information and answer the question again.
If you choose to remain outside of the group agreement you will be asked to indicate why.

1) Patients should have a vote when changes are made in the planning of services in the Psychiatry Service?

a) Tick one only to indicate your ‘new’ answer:  ☐ Yes  ☐ No

b) If you have not changed your answer can you tell us why?

2) How often do you think patients should be involved in the planning of services in the Psychiatry Service?

a) Tick one only to indicate your ‘new’ answer:  ☐ Always  ☐ As problems come up  ☐ Once-off

b) If you have not changed your answer can you tell us why?
3) Who should represent patients in the planning of services in the Psychiatry Service?

a) Tick one only to indicate your ‘new’ answer:
-Doctors/nurses should represent patients
-‘Patient representatives’ should represent patients
-Patient advocacy (patient comments and complaints office) should represent patients

4) How should patients be picked to be involved in the planning of services in the Psychiatry Service?

a) Tick one only to indicate your ‘new’ answer:
-All interested patients should be involved
-Voting by patients
-Patients with relevant characteristics picked (e.g. years attending service)

5) How important is education when picking patients to be involved in the planning of services in the Psychiatry Service?

a) Tick one only to indicate your ‘new’ answer:
-Not at all important
-Not important
-Important
-Very important

b) If you have not changed your answer can you tell us why?
___________________________________
________________________________________
6) How important is length of attendance at the service when picking patients to be involved in the planning of services in the Psychiatry Service?

- Not at all important: 22%
- Not important: 27%
- Important: 38%
- Very important: 11%
- Patients should not be involved: 3%

a) Tick one only to indicate your 'new' answer:
- Not at all important
- Not important
- Important
- Very important

7) How important is how often patients attend the service when picking patients to be involved in the planning of services in the Psychiatry Service?

- Not at all important: 16%
- Not important: 35%
- Important: 32%
- Very important: 13%
- Patients should not be involved: 3%

b) Tick one only to indicate your 'new' answer:
- Not at all important
- Not important
- Important
- Very important
Section B: Family Member Participation

The charts show you the answers provided by the whole group.
Your answer in the first questionnaire is circled in red.
Please think about this information and answer the question again.

8) Family members should have a vote when changes are made in the planning of services in the Psychiatry Service?

- Yes: 49%
- No: 51%

a) Tick one only to indicate your ‘new’ answer:  
   □ Yes   □ No

b) If you have not changed your answer can you tell us why?

___________________________________________
___________________________________________
___________________________________________
___________________________________________

9) How often do you think family members should be involved in the planning of services in the Psychiatry Service?

- Always: 27%
- As problems come up: 43%
- Once-off: 16%
- Never: 11%
- Other: 5%

a) Tick one only to indicate your ‘new’ answer:  
   □ Always   □ As problems come up   □ Once-off

b) If you have not changed your answer can you tell us why?

___________________________________________

___________________________________________
10) How important is it for family members to be involved after the decision has been made in the planning of services in the Psychiatry Service?

![Bar chart showing percentages of participants' responses to the importance of family involvement.]

- **Not at all important**: 8%
- **Not important**: 25%
- **Important**: 33%
- **Very important**: 8%
- **Family should not be involved**: 6%

**a)** Tick one only to indicate your ‘new’ answer:

- Not at all important
- Not important
- Important
- Very important

11) Who should represent family members in the planning of services in the Psychiatry Service?

![Bar chart showing percentages of participants' responses to who should represent family members.]

- **Family members should not be involved**: 3%
- **Doctors/nurses**: 11%
- **Patients**: 11%
- **Family representatives**: 57%
- **Patient advocacy**: 14%
- **Other**: 5%

**a)** Tick one only to indicate your ‘new’ answer:

- Doctors/nurses should represent family members
- Patients should represent family members
- ‘Family member representatives’ should represent family members
- Patient advocacy (patient comments and complaints office) should represent family members
12) How should family members be picked to be involved in the planning of services in the Psychiatry Service?

![Bar Chart]

- 8%: Family members should not be involved
- 54%: All interested family members should be involved
- 14%: Voting by family members
- 3%: Names picked from a hat
- 19%: Family members with relevant characteristics
- 3%: Other

a) Tick one only to indicate your ‘new’ answer:
- □ All interested family members should be involved
- □ Voting by family members
- □ Names picked from a hat
- □ Family members with relevant characteristics picked (e.g. years attending service)

b) If you have not changed your answer can you tell us why?

__________________________________________________________________________________________

13) How important is education when picking family members to be involved in the planning of services in the Psychiatry Service?

![Bar Chart]

- 24%: Not at all important
- 32%: Not important
- 27%: Important
- 8%: Very important
- 8%: Family should not be involved

a) Tick one only to indicate your ‘new’ answer:
- □ Not at all important
- □ Not important
- □ Important
- □ Very important
14) How important is how long family members have been attending the service when picking family members to be involved in the planning of services in the Psychiatry Service?

<table>
<thead>
<tr>
<th>Percentage of patients</th>
<th>11%</th>
<th>35%</th>
<th>38%</th>
<th>11%</th>
<th>5%</th>
</tr>
</thead>
</table>

a) Tick one only to indicate your ‘new’ answer:

☐ Not at all important  ☐ Not important  ☐ Important  ☐ Very important

b) If you have not changed your answer can you tell us why?

_________________________________________________________________________________________________________________________________________________________________________________________________  

15) How important is how often family members attend the service when picking family members to be involved in the planning of services in the Psychiatry Service?

<table>
<thead>
<tr>
<th>Percentage of patients</th>
<th>14%</th>
<th>35%</th>
<th>35%</th>
<th>11%</th>
<th>5%</th>
</tr>
</thead>
</table>

a) Tick one only to indicate your ‘new’ answer:

☐ Not at all important  ☐ Not important  ☐ Important  ☐ Very important

THANK YOU!

* All contact details and names have been removed for confidentiality.
Round 3 Psychiatry Questionnaire*

Round 3 Questionnaire
Patient and Family Participation in the Planning of Services in the Psychiatry Service

If you have any questions or need further information please contact X on X or X

Participant I.D: ____________

Section A: Patient Participation

The charts show the answers provided by the whole group in the first questionnaire.
Your answer in the first questionnaire is circled in red.
Please think about this information and answer the question again.
If you choose to remain outside of the group agreement you will be asked to indicate why.

1) Patients should have a vote when changes are made in the planning of services in the Psychiatry Service?

- Percentage of participants: 93%

   Yes

- Percentage of participants: 7%

   No

   a) Tick one only to indicate your ‘new’ answer:  
   ☐ Yes  ☐ No

2) How often do you think patients should be involved in the planning of services in the Psychiatry Service?

- Percentage of participants: 65%

   Always

- Percentage of participants: 32%

   As problems arise

- Percentage of participants: 3%

   Once-off
a) Tick one only to indicate your ‘new’ answer:  □ Always  □ As problems come up

3) Who should represent patients in the planning of services in the Psychiatry Service?

- Doctors/nurses: 10% of participants
- Patient advocacy: 10% of participants
- Patient representatives: 80% of participants

b) Tick one only to indicate your ‘new’ answer:
□ Doctors/nurses should represent patients
□ ‘Patient representatives’ should represent patients
□ Patient advocacy (patient comments and complaints office) should represent patients

4) How important is education when picking patients to be involved in the planning of services in the Psychiatry Service?

- Not at all important: 19% of patients
- Not important: 39% of patients
- Important: 29% of patients
- Very important: 13% of patients

b) Tick one only to indicate your ‘new’ answer:
□ Not at all important  □ Not important  □ Important  □ Very important

b) If you have not changed your answer can you tell us why?
___________________________________________
___________________________________________
___________________________________________
___________________________________________
5) How important is length of attendance at the service when picking patients to be involved in the planning of services in the Psychiatry Service?

<table>
<thead>
<tr>
<th>Percentage of patients</th>
<th>16%</th>
<th>29%</th>
<th>45%</th>
<th>10%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

c) Tick one only to indicate your ‘new’ answer:
- [ ] Not at all important
- [ ] Not important
- [ ] Important
- [ ] Very important

6) How important is how often patients attend the service when picking patients to be involved in the planning of services in the Psychiatry Service?

<table>
<thead>
<tr>
<th>Percentage of patients</th>
<th>13%</th>
<th>39%</th>
<th>29%</th>
<th>19%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very important</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

c) Tick one only to indicate your ‘new’ answer:
- [ ] Not at all important
- [ ] Not important
- [ ] Important
- [ ] Very important

b) If you have not changed your answer can you tell us why?
____________________________________________________________________________
Section B: Family Member Participation

The charts show you the answers provided by the whole group.
Your answer in the first questionnaire is circled in red.
Please think about this information and answer the question again.

7) Family members should have a vote when changes are made in the planning of services in the Psychiatry Service?

<table>
<thead>
<tr>
<th>Percentage of participants</th>
<th>Yes 61%</th>
<th>No 39%</th>
</tr>
</thead>
</table>

a) Tick one only to indicate your ‘new’ answer:  
☐ Yes    ☐ No

b) If you have not changed your answer can you tell us why?
___________________________________________
_____________________________
_______________________________
_____________________________
_____________________________

8) How often do you think family members should be involved in the planning of services in the Psychiatry Service?

<table>
<thead>
<tr>
<th>Percentage of participants</th>
<th>Always 27%</th>
<th>As problems come up 67%</th>
<th>Once-off 7%</th>
</tr>
</thead>
</table>

a) Tick one only to indicate your ‘new’ answer:  
☐ Always    ☐ As problems come up    ☐ Once-off

b) If you have not changed your answer can you tell us why?
___________________________________________
_____________________________
_______________________________
_____________________________
_____________________________
9) How important is it for family members to be involved after the decision has been made in the planning of services in the Psychiatry Service?

| Percentage of participants | 10% | 19% | 45% | 26% | 0%
|---------------------------|-----|-----|-----|-----|-----
| Not at all important      |     |     |     |     |     
| Not important             |     |     |     |     |     
| Important                 |     |     |     |     |     
| Very important            |     |     |     |     |     |

b) Tick one only to indicate your ‘new’ answer:
- □ Not at all important
- □ Not important
- □ Important
- □ Very important

10) How should family members be picked to be involved in the planning of services in the Psychiatry Service?

| Percentage of participants | 74% | 0% | 3% | 23%
|---------------------------|-----|----|----|-----
| All interested family members should be involved |     |     |     |     
| Voting by family members |     |     |     |     
| Names picked from a hat |     |     |     |     
| Family members with relevant characteristics |     |     |     |     |

b) Tick one only to indicate your ‘new’ answer:
- □ All interested family members should be involved
- □ Names picked from a hat
- □ Family members with relevant characteristics picked (e.g. years attending service)
b) If you have not changed your answer can you tell us why?

11) How important is education when picking family members to be involved in the planning of services in the Psychiatry Service?

| Percentage of patients | 29% | 45% | 23% | 3%
|------------------------|-----|-----|-----|-----
| Not at all important   |     |     |     |     
| Not important          |     |     |     |     
| Important              |     |     |     |     
| Very important         |     |     |     |     |

a) Tick one only to indicate your ‘new’ answer:
- □ Not at all important
- □ Not important
- □ Important
- □ Very important
12) How important is how long family members have been attending the service when picking family members to be involved in the planning of services in the Psychiatry Service?

b) Tick one only to indicate your ‘new’ answer:

- [ ] Not at all important
- [ ] Not important
- [ ] Important
- [ ] Very important

b) If you have not changed your answer can you tell us why?

___________________________________________

13) How important is how often family members attend the service when picking family members to be involved in the planning of services in the Psychiatry Service?

b) Tick one only to indicate your ‘new’ answer:

- [ ] Not at all important
- [ ] Not important
- [ ] Important
- [ ] Very important

b) If you have not changed your answer can you tell us why?

___________________________________________

THANK YOU!

* All contact details and names have been removed for confidentiality.
Appendix L: Study 4 Proposed Psychiatry Pilot Intervention Protocol

Overview
The proposed psychiatry pilot intervention was two patient and family representatives attending the sector management meeting in the psychiatry service. The sector management meeting takes place monthly with senior members of the clinical team representing each discipline discussing matters relating to the how the service is run. This was to be assessed for feasibility over a period of 3 months.

Representatives
Patient and family representatives were to be selected from the population of patients and family members engaging with the psychiatry service. This was to provide two patient and family representatives (one patient and one family member) to attend sector management meetings. Selection criteria for representatives (outlined in Table L.1) were to be employed as this assists in providing legitimacy to representatives (269). Oversampling was to be conducted to ensure at least two representatives would be available to attend all sector management meetings (2 extra patient representatives, 1 extra family member representative). Use of multiple methods of recruitment has been recommended (302). In line with this, recruitment was proposed to take place over a period of four weeks with

Table L.1: Selection Criteria For Representatives

<table>
<thead>
<tr>
<th>Group</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>Health (must be healthy enough to participate, determined by the participant, participation must not negatively impact on the representatives health, determined by the consultant)</td>
</tr>
<tr>
<td></td>
<td>Diagnosis (mental illness diagnosis e.g. depression)</td>
</tr>
<tr>
<td></td>
<td>Length of attendance (how long the person has been attending the service, must be attending at least 3 months)</td>
</tr>
<tr>
<td></td>
<td>Ability to dedicate time (time to dedicate to participation and attending forum and management meetings)</td>
</tr>
<tr>
<td>Family</td>
<td>Frequency of attendance (how often the family member attends the service with a patient family member)</td>
</tr>
<tr>
<td></td>
<td>Ability to dedicate time (time to dedicate to participation and attending forum and management meetings)</td>
</tr>
<tr>
<td></td>
<td>Cannot be from the same family as patient representatives</td>
</tr>
<tr>
<td></td>
<td>Must be attending with a patient for at least three months</td>
</tr>
</tbody>
</table>
posters and leaflets in waiting areas, face-to-face recruitment in waiting areas by the researcher (LW), local patient and community organisations alerting their members as well as the researcher (LW) alerting those who indicated an interest in previous studies in this PhD.

**Training and support**

One of the key barriers to patient and family participation is the capacity of participants and their participation skills (75). Before representatives attended any sector management meetings one hour of training was to be provided by the researcher (LW). Topics identified for inclusion in Study 3 were; how the service works, how changes are made e.g. meeting organisation and confidentiality, how to work with others e.g. communication skills and language used, the process and importance of participation. If possible this training was to take part in the service with introductions to clinicians who normally attend the management meeting and patient and family feedback.

Top-up training and support was also to be offered with the researcher (LW) discussing the agenda of each meeting in advance and debriefing with representatives after each meeting. The researcher (LW) attended sector management meetings since September 2016 to gather information such as the language used in these meetings, how changes were made and topics typically discussed. A key component of this training was based on patient and family member feedback on the service. This was to be collected in waiting areas by the researcher (LW), based on three key questions, ‘What are the top three good things?’ ‘What are the top three bad things?’ and ‘What are the top three most important things to you in the service?’. Representatives were to be provided with this feedback to guide their input in sector management meetings.

Optional training was also to be offered to clinicians who attend sector management meetings, including the purpose and importance of participation, how changes are made and how to work with others including language.
Sector management meetings
Over the course of three months representatives were to attend three sector management meetings. They were to attend in groups of two to provide moral support and boost confidence. Representatives attending in groups of two is recommended from research within the Irish mental health services which assessed barriers to participation which included representatives feeling intimidated when attending large committee meetings as the only patient (75). All attendees at meetings were to wear name badges, meetings were to start with introductions and an ice-breaker. The Chairperson was to encourage input from the representatives on each topic and ensure topics that representatives felt were not relevant to them were at the end of the agenda.

After representatives attended three meetings an update was to be provided to the wider patient and family population through an optional mailing list, posters and leaflets
### Appendix M: Study 4 and Study 5 intervention development sample by service, stakeholder group and interview type

<table>
<thead>
<tr>
<th>Service</th>
<th>Stakeholder Group</th>
<th>Interview Type</th>
<th>Number Completed</th>
<th>Number of focus group participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatry (Study 4)</td>
<td>Patients (5)</td>
<td>Face-to-face interview</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Family members (2)</td>
<td>Face-to-face interview</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Clinicians (8)</td>
<td>Focus group</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Diabetes (Study 5)</td>
<td>Patients (5)</td>
<td>Face-to-face interview</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Family members (4)</td>
<td>Face-to-face interview</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Clinicians (7)</td>
<td>Focus group</td>
<td>1</td>
<td>7</td>
</tr>
</tbody>
</table>
Appendix N: Study 4 and Study 5 Intervention Development Interview Schedules

Psychiatry- Patient and Family Participation Intervention: Development Interview Schedule

Patients and Family members

1. **All of the staff in the service meet once a month to talk about how the service works. This is called the management meeting. Two patient and family member representatives that have completed training will attend these meetings.**
   - What do you think about this? *(necessary, benefits, disadvantages)*
   - What do you think about representatives always attending in a group of two? *(necessary, benefits, disadvantages)*

2. **Before representatives attend meeting they will have completed training to help them in this role as representatives in general.**
   - Do you think representatives needs training on acting as representatives within this service? *(necessary, benefits, disadvantages)*
   - Do you think the doctors and nurses will need training as well? *(necessary, benefits, disadvantages)*
   - What do you think about representatives and doctors doing their training together? *(Benefits, disadvantages)*
   - How long do you think training should be? *(1 hour, half day)*

3. **Before representatives attend management meetings they will also be given feedback on the service from the wider group of patients and family members that attend the service. This will include what is important to patients and family members when they get treatment in the service, what is good and what needs to be changed.**
   - Do representatives need to know what is important to the wider group of patients and family member that attend the service? *(why, benefits, disadvantages)*
   - What other feedback do representatives need from the wider group of patients and family members? *(posters, leaflets, meetings)*

4. **After representatives attend management meetings what needs to happen?**
   - Do representatives need to tell other patients and family members who attend the service what happened? *(why, benefits, disadvantages)*
   - How should representatives tell other patients and family members who attend the service what happened? *(posters, leaflets, meetings)*

5. **Anything else that we have not discussed?**
Psychiatry- Patient and Family Participation Intervention: Development Topic Guide

Clinicians

1. 
   Two patient and family member representatives that have completed training will attend and input at sector management meetings?
   - What do you think about this? 
     (necessary, benefits, disadvantages)
   - What do you think about representatives always attending in a group of two? 
     (necessary, benefits, disadvantages)

2. 
   Representatives will have completed training with ACORN before attending management meetings. This includes training on things like how changes are made.
   - Do you think representatives needs training on acting as representatives within this service? 
     (necessary, benefits, disadvantages)
   - If one session of training was made available to clinicians that attend the sector management meeting before representatives started attending the meeting, is there interest in this? 
     (necessary, benefits, disadvantages)
   - What do you think about representatives and clinicians doing their training together? 
     (Benefits, disadvantages)
   - How long do you think training should be? 
     (1 hour, half day)

3. 
   Before representatives attend management meetings they will also be given feedback on the service from the wider group of patients and family members that attend the service. This will include what is important to patients and family members when they get treatment in the service, what is good and what needs to be changed.
   - Do representatives need to know what is important to the wider group of patients and family member that attend the service? 
     (why, benefits, disadvantages)
   - What other feedback do representatives need from the wider group of patients and family members? 
     (posters, leaflets, meetings)

4. 
   After representatives attend management meetings what needs to happen?
   - Do representatives need to tell other patients and family members who attend the service what happened? 
     (why, benefits, disadvantages)
   - How should representatives tell other patients and family members who attend the service what happened? 
     (posters, leaflets, meetings, clinician input?)

5. 
   Anything else that we have not discussed?
Diabetes - Patient and Family Participation Intervention: Development Topic Guide

Patients and Family members

1. **We want to get patients and family members more involved in how the service works.**
   *We are going to set up a Type 2 Diabetes Group. The group will be for type 2 patients and their family members who attend the service here in Tallaght. The aim of this group is for patients and family members to tell us what you think about the service and then representatives from the group will discuss the feedback with the doctors and nurses that work in the service.*
   - What do you think about this?
     (necessary, benefits, disadvantages)
   - What do you think about having one group with patients and family members together?
     (a separate patient forum and family member forum work better, benefits, disadvantages)

   **What do we need to do to tell people about the Type 2 Diabetes Group?**
   (posters, leaflets, GP, Diabetes Ireland, local organisations, staff)

   **The Type 2 Diabetes Group meetings will take place here in the service.**
   - What time do you think the meetings should take place at?
   - What do we need to do to make it as easy as possible for people to come to these meetings?
     (parking, timing, tea and coffee)
   - What do you think about one of the doctors or nurses attending the start of the first meeting?
     (benefits, disadvantages)

2. **Patient and family member representatives will be selected from the Type 2 Diabetes Group. They will attend meetings with the doctors and nurses that work in the service to discuss what was said at the Type 2 Diabetes Group.**
   - How many meetings do you think would be necessary over three months?
   - What do you think about representatives always attending in a group of two?
     (necessary, benefits, disadvantages)

   **After representatives attend meetings with doctor and nurses what needs to happen?**
   - Do representatives need to tell the Type 2 Diabetes Group what happened?
     (why, benefits, disadvantages)
   - How should representatives tell the Type 2 Diabetes Group what happened?
     (posters, leaflets, meetings)

3. **Before representatives attend meetings with doctors and nurse they will be given training so they know how the meetings will work, who will be there, what will be discussion.**
   - How long? With or separate too clinicians?
     (why, representatives and clinicians receive relevant training together?, clinician training during mdt education session, duration of training)

4. **Anything else that we have not discussed?**
Diabetes - Patient and Family Participation Intervention: Development Topic Guide

Clinicians

1. **A Type 2 Diabetes Group will be established. The group will be made up of type 2 patients and their family members who attend the service here in Tallaght. The purpose of the group will be to identify what is important to those attending the service such as what is good and areas that could be improved.**
   - What do you think about having one group with patients and family members together?  
   (a separate patient forum and family member forum work better, benefits, disadvantages)

The recruitment strategy will include a number of components. 1. Posters in waiting areas, 2. relevant organisations will be asked to alert their members, 3. I will attend the type 2 clinics to alert attendees.
   - What do you think about yourselves as members of the team giving flyers about the group to patients and family members?  
   (necessary, feasible to fit in within current clinical work, how many need per week)

The Type 2 Diabetes Group meetings held within the service. The focus of the first meeting will be on identifying what is important to type 2 patients and their family members.
   - What do you think about one of the members of the team attending the start of the first meeting to open the meeting?  
   (benefits, disadvantages, barriers)

2. **Patient and family member representatives will be selected from the Type 2 Diabetes Group. They will attend meetings with the mdt over three months to communicate what is important and how this can be progressed.**
   - How many meetings do you think would be necessary over three months?  
   - When should these meetings take place?  
   (education session slot suggested at present but there may be an alternative meeting that may work better)
   - Provided with feedback from the group in advance of meeting reps?

After representatives attend meetings with the mdt they will report back to the Type 2 Diabetes Group. This will include an update on the meetings they attended with the mdt, how the opinions of patients and family members was used and included and outcomes of the meetings.
   - What do you think about representatives feeding back to forums?  
   (importance, confidentiality, clinicians work with representatives on what can be fed back?)

3. Previous studies in this research highlighted the importance of training for all stakeholders involved. Training will be provided for patient and family member representatives before attending meetings with the mdt. Topics will include the importance of participation, how changes are made and how to work with others. Over 80% of participants in questionnaires conducted over the summer supported similar training for clinicians.
   - If we provide one session of training at a time and day that suits the team is there interest in this?  
   (why, representatives and clinicians receive relevant training together?, clinician training during mdt education session, duration of training)

4. Anything else that we have not discussed?
Appendix O: Study 4 and study 5 intervention development coding frame

Study Four Psychiatry Intervention Development Coding Frame

1. Context:
   1A. Description of illness:
      (information on the impact of patients’ illness, the experience of the illness outside of the service)

   1B. Description of the service:
      (information on how the service works, the services offered, the types and numbers of patients which attend, the attitude towards family members and the role they play in the service, satisfaction)

2. Intervention opinion:
   (discussion relating to general opinions of the intervention as a whole)

3. Link with wider patient and family populations
   3A. Opinion
      (discussion related to whether this is necessary, role of link)
   3B. Questions:
      (all statements relating to the questions on which feedback from the wider populations will be based)
   3C. Reporting back
      (discussion related to reporting back to the wider populations on the work of representatives)

4. Training and support:
   4A. Opinion
      (discussion related to whether or not training and support is required)
   4B. Logistics:
      (all statements related to areas in which training is required, how long training should be and who should attend)

5. Representative and clinician meetings:
   5A. Opinion:
      (discussions relating to views and opinions of representatives attending meetings with clinicians)
   5B. Logistics:
      (thoughts on the logistics of these meetings such as the number of representatives to attend meetings, frequency of meetings)

6. Miscellaneous:
   (anything else of interest which does not fit in the above categories)
Study Five Diabetes Intervention Development Coding Frame

1. Context:
   1A. Description of illness:
      (information on the impact of patients’ illness, the experience of the illness outside of the service)
   1B. Description of the service:
      (information on how the service works, the services offered, the types and numbers of patients which attend, the attitude towards family members and the role they play in the service, satisfaction)

2. Intervention opinion:
   (discussion relating to general opinions of the intervention as a whole)

3. Patient and Family Forum (Type 2 diabetes group):
   3A. Recruitment
      (discussion related to the patient and family forum recruitment)
   3B. Logistics:
      (all statements related to forum meeting logistics such as timing, meeting attendees or barriers to be overcome)
   3C. Feedback
      (all information relating to gathering feedback on the service from attendees)
   3D. Reporting back
      (discussion related to reporting back to the forum on the work of representatives)

4. Representative and clinician meetings:
   4A. Opinion:
      (discussions relating to views and opinions of representatives attending meetings with clinicians)
   4B. Logistics:
      (thoughts on the logistics of these meetings such as the number of representatives to attend meetings, frequency of meetings)

5. Training and support:
   5A. Opinion
      (discussion related to whether or not training and support is required)
   5B. Logistics:
      (all statements related to areas in which training is required, how long training should be and who should attend)

6. Miscellaneous:
   (anything else of interest which does not fit in the above categories)
Appendix P: Study 4 process evaluation interview schedule

Patient and Family Participation Intervention: Psychiatry Evaluation Topic Guide

6. What do you think about the intervention of representatives attending sector management meetings?
   - What is good about this intervention?
     (representatives, forums, training, facilitation, level of intensity)
   - What could be bad about this intervention?
     (representatives, forums, training, facilitation, level of intensity, frequency of meetings)

7. What did you think about the development of the intervention?
   - What impact do you think being involved in the intervention development process had?
     (good, bad, no impact, what intervention aspects did it affect, ownership)
   - What did you think about involvement through focus groups based on a draft intervention?
     (good, bad, enough/too much involvement, use of draft intervention)
   - What did you think about the involvement of stakeholder groups?
     (enough/too much involvement from patients, family and clinicians, other groups to be included)

8. Can you tell me about why it was important to review representative attendance after three months?
   (why was it important to have an opportunity to review representative attendance after 3 months? Are there any concerns that underpin the need for this process? What stakeholders is this process important for?)

9. Can you tell me about what is happening with the sector management meetings at the moment?
   (frequency of meetings, meeting attendance, meeting purpose)

10. How do you feel about the intervention not being tested?
    - What do you think about representatives attending the sector management meetings in the future?
      (good idea, bad idea, possible, still interested, what needs to happen for this to occur?)

346
Appendix Q: Study 4 process evaluation coding frame

Study Four Process Evaluation Coding Frame V1

1. Intervention:
   1A. Opinion:
       (Opinions relating to the proposed intervention or the idea of patient and family participation)
   1B. Concerns:
       (any discussion relating to concerns or barriers to the intervention or involvement of patients of family members in general)
   1C: Reflections on the intervention not taking place

2. Intervention development:
   (All discussions pertaining to experience, importance and impact of involvement in intervention development including all PhD studies, interviews and focus groups)

3. Participation limited to three months:
   3A. Process:
       (any text relating to discussions or decisions made relating to this limitation e.g discussion by patient and family organisation)
   3B. Underpinning concerns:
       (discussion on the reason why this limitation was important to include)
   3C Why a barrier:
       (thoughts on why this limitation was a barrier)

4. Sector management meeting:
   4A. Context:
       (discussions relating to changes in attitudes or opinions as a results of the intervention)
   4B. Concerns:
       (discussion relating to the sector management meeting being a barrier to the implementation of the intervention)

5. Sustainability:
   5A. Opinions
       (discussion related to whether the intervention is sustainable beyond the research)
   5B. What is necessary:
       (all statements related to necessary supports, resources or changes for the intervention to be sustainable beyond the research)
   5C. What is available:
       (all statements related to supports available for the intervention)

6. Miscellaneous:
   (anything else of interest which does not fit in the above categories)
Appendix R: Study 5 Diabetes Proposed Pilot Intervention Protocol

Diabetes Pilot Intervention

The diabetes pilot intervention was two patient and family representatives attending meetings with the clinical team supported by a patient and family forum. The intervention was facilitated and supported by the researcher (LW). The researcher was involved in the development of the intervention, had conducted research in the service for two years previous to implementation and was immersed in the topic of patient and family participation for a number of years and had published in the area of patient and family participation.

Patient and family forum

A patient and family forum was established in an adult outpatient type 2 diabetes service. The purpose of the forum was to enable selection of representatives, facilitate development of a list of priorities and to provide a platform for reporting the actions of representatives and utilisation of patient and family feedback in the decision making process to the wider population of patients and family members. This is an important component. The underpinning argument of the CLEAR Framework includes the understanding that people participate depending on a number of factors including the extent to which they feel engaged with the wider community. If you feel you are part of something you are more willing to engage (19).

Forum meetings lasted one hour with two meetings taking place over four months – one before representatives met with clinicians and one afterwards. Both meetings were facilitated by the candidate (LW). It is important to find methods of involvement which accommodate life and work demands to keep participants engaged and interested (282). In line with this, forum meetings took place within the service at 12:30pm as this was the time identified as preferable for patients and family members.

Recruitment

Recruitment for the forum was key as people tend to participate when they are asked and importantly when they are asked in the right way (19). In the diabetes pilot intervention
for the month prior to forum meetings posters and leaflets were placed in waiting areas of the diabetes service and GPs in the local area were asked to display leaflets (Appendix S: Study 5 recruitment leaflets). The researcher (LW) attended type 2 clinics to alert those in waiting areas to the upcoming meeting, clinicians were provided with information and leaflets for circulation where appropriate. Relevant patient organisations (n=3) were asked to alert their members. Patients and family members who indicated an interest in the previous studies in this PhD were also informed. Use of multiple methods of recruitment has been recommended in literature focusing on recruitment of patient and family advisors (302). Reminders of meetings were sent through text message one week in advance.

Forum meeting one
Forum meeting one was attended by 8 patients and 1 family member. A member of senior management from the hospital in which the service is based and a clinician from the service attended the first ten minutes of this meeting to open the meeting, provide leadership and emphasise the importance of participation of patients and family members. Staff involvement in forums was demonstrated in Scotland where community forums were coordinated by NHS staff, to whom forums members had phone access (292). The importance of leadership for successful participation has been acknowledged and the World Health Organisation (WHO) policy framework for people centred care includes enhancing leadership as one of the steps for healthcare organisations to take (81). This was also highlighted in interviews with key stakeholder groups from both services in the current research ‘If there is one good leader then everybody will follow’ (Caroline, Diabetes, Family member).

Meeting one of the forum provided the background and rationale for establishing the forum as well as discussion of the purpose of the forum. A key component of successful participation is clarity of purpose which ensures good fit between the objectives, stakeholders’ motivations and strategies for involvement, making optimal use of time and resources and assisting in evaluation (298). Interviews with senior staff and patient representatives in healthcare organisations in the United States that have succeeded in improving the patient care experience highlighted the need for clear communication of
the strategic vision (300). While discussing the purpose of the forum the process of change within the diabetes service was outlined to ensure attendees were aware of the pace of change within the service. Managing and avoiding raised expectations which can not be met are a key consideration when involving patients and family members (282). In the diabetes service there is no established process or history of successful service level changes.

‘How happy patients are with the service you provide from the logistics is something that we really don’t get to because we are so busy trying to keep people alive and do the medical thing...to try and change clinics, the way they are run is very difficult and it is a long process ...the system is not necessarily flexible in how it runs.’

(Michael, Diabetes, Clinician)

To assist representatives in providing input and to ensure credibility and legitimacy a list of priorities were established at this meeting through group discussion. This was based on three questions: ‘What are the top three most important things to you in the service’, ‘What are the top three good things in the service?’ and ‘What are the top three bad things in the service?’ These questions were based on research conducted in the same area as the diabetes service by the research team and reviewed by patients, family members and clinicians during intervention development. The draft list of priorities was assessed by the wider population of patients and family members attending the service. Patients and family members who had not attended the forum were shown the draft list and asked to identify if the order needed to be changed or anything removed or added. Assessment of the feedback provided to representatives was key as evaluation of patient forums in the NHS highlighted differences in the members and opinions of forums when compared with the general population (292). This was conducted in the waiting areas by the researcher (LW). This ensured that patient and family feedback was reflective of the general patient and family population in terms of age and gender. A total of 30 patients and family members fed into this feedback. A summary of this feedback was provided to the representatives and used to guide the meetings with clinicians (Appendix T: Study 5 patient and family forum feedback summary).
Attendees who were interested in the role of representative were identified at this forum meeting and the preferred method of communication for the group was also decided.

Forum meeting two

Forum meeting two was attended by 8 patients and 1 family member. A total of 3 of the patients had attended forum meeting one. Attendees were reminded of the background and purpose of the forum. The Canadian Foundation for Healthcare Improvement includes clarity of purpose as one of the key ingredients of participation which it states can be achieved through aims being clearly and consistently communicated (298). Representatives provided an update on how the feedback from the forum was used and meetings with clinicians. The update was based on a communication leaflet (See Appendix U: Study 5 communications leaflet), which was agreed upon by both the representatives and clinicians. Time was allowed for discussion and questions to ensure attendees were satisfied with the level of information provided. The communication leaflet was displayed in the waiting area of the service. The future of the forum was also discussed. The CLEAR Framework proposes that people participation when they feel responded to (19). For people to participate on a sustainable basis they have to believe that their involvement is making a difference. Similarly, the Ministers Foreword in the 2008-2013 National Strategy for Service User Involvement in the Irish Health Service stated that service users need to get clear feedback and feel that their contribution has been valued (6).

Representatives

Volunteers for the roles of patient and family representative were recruited from the patient and family forum. At forum meeting one the role of the representative was outlined to all those in attendance and contact details taken from those interested. Following a period of 3-4 days the researcher (LW) contacted the volunteers to provide them with additional information on the role, answer any questions they had and confirm if they were still interested in this role.

A minimum of two representatives were required to ensure that at least two representatives were available to attend all meetings with the clinical team.
Representatives attending in groups of two is recommended from research within the Irish mental health services which assessed barriers to participation. Identified barriers included representatives feeling intimidated when attending large committee meetings as the only patient (75). This was supported by patients, family members and clinicians in the development of the intervention. Representative attending together was important to provide moral support, to allow for continuity across meetings and enable representatives to work in a team with both listening and taking on board what clinicians are saying as well as providing input based on feedback from the forum. Three forum attendees expressed an interest in this role with two remaining active in this role throughout the intervention.

Training and support

Representatives were provided with support throughout the intervention. People participate when they feel they are able to, which can be enhanced through capacity building efforts (19). When representatives agreed to take on this role the researcher (LW) provided the representatives with training. This included discussion of the importance and purpose of patient and family participation, the role of the representative, how the process of change works in the diabetes service, the format of meetings, issues related to confidentiality, possible language that might be used in meetings and feedback from patients and family members (Appendix V: Representative training sheet). Representatives having their own experience but also access to a wider group with experience of the service who can be representative of the overall population adds credibility and legitimacy (269). Representatives were provided with a list of common terms that may be touched on during discussion in case they were used out of routine by clinicians (See Appendix W: Study 5 language summary sheet). This was devised during training with clinicians. Training lasted approximately 30 minutes. After each meeting with the clinicians the researcher (LW) contacted the representatives to ensure they were happy with the meeting, the topics that were discussed, the language that was used and to answer any questions or discuss any concern that they had. Before the second and third meeting with the clinicians the researcher (LW) went through the agenda for the meeting with the representatives, checking if there was anything that needed to be added and what might be discussed within each topic or language that
might be used, reminded the representative of their role and the role of the feedback from patients and family members.

Support was provided to clinicians attending meetings with the representatives. The importance of building staff capacity has been highlighted in interviews with staff and patient representatives from healthcare organisations that have been successful in improving the patient experience (300). Prior to the first meeting a 30-minute training session was conducted by the researcher (LW). All members of the clinical team working with type 2 patients hoping to attend meetings with the representatives were invited to attend. This included discussion of the importance and purpose of patient and family participation, the role, selection and preparation of representatives, the process of change in the diabetes service, the format of meetings with representatives and use of appropriate language (Appendix X: Study 5 clinician training slides). A component of this session allowed clinicians to ask questions and discuss any concerns that they had. Throughout the meetings with representatives and in all contact the candidate (LW) asked clinicians about their experience of the meetings with representatives and encouraged clinicians to identify any issues or concerns they had with the process. Clinicians who were not available to attend this session but who wanted to attend meetings with representatives were provided with individual training on the same topics by the researcher (LW).

Training structure and topics were guided by national and international participation resources and guides (149,281,332–334), identified preferences in Study 3 (Chapter 6) and further discussions in intervention development interviews and focus groups (Chapter 7). Duration of training and attendees were discussed in intervention development interviews and focus groups. Content was guided by national and international participation resources, guides and literature (149,332–334) and findings from previous PhD studies.

**Representative and clinician meetings**

Over the course of three months the patient and family representatives and clinicians working in the diabetes service met a total of three times. Meetings took place for 30
minutes before the weekly multidisciplinary team (MDT) educational meeting as building initiatives into existing processes and structures can help to ensure sustainability (301). The purpose of these meetings was to enable patient and family involvement in discussions and patient participation in decisions about healthcare design and delivery within the service. Discussions were driven by the feedback from the patient and family forum. The provided an opportunity for collective participation which the CLEAR Framework identifies as important due to the resulting continuous reassurance and feedback that the cause of engagement is relevant, that participation has come value as well as a communication route to decision makers (19).

Representatives attended two of the three meetings in a pair sitting together to provide moral support, boost confidence and support in providing input based on forum feedback and listening to what clinicians were saying. One meeting was attended by a patient and family representative on their own due to a last minute cancelation due to illness. The decision to go ahead with the meeting was made by the representative. The facilitator (LW) spent additional time preparing the representative for this meeting, sat with the representative for moral support and aided recollection of clinician responses after the meeting took place.

All attendees wore name badges and each meeting started with an ice-breaker and introductions. Introductions at the start of team meetings were employed in a hospice service in which family caregivers were attending team meetings to reduce anxiety and increase understanding (78). Representatives were encouraged by the facilitator (LW) to provide input on each item discussed. Accessible language was encouraged. When this did not happen representatives were asked to highlight this at the time or after the meeting with the researcher (LW) so an explanation could be provided and clinicians reminded to use accessible language. To level power differences public participation in priority settings for healthcare in Canada ensured clarifications were provided when technical language was employed, actively seeking representatives’ opinions during discussion and ensuring representatives were sitting together (269).

Meetings were facilitated by the researcher (LW). They lasted 30 minutes and took place in the diabetes service. All clinical disciplines working with type 2 patients in the service
were represented at the meetings and where possible it was the same person that attended on behalf of each discipline. This included nurses, dieticians, podiatrists and doctors. Minutes were taken and circulated to the representatives and full clinical team. A draft agenda was circulated one week before each meeting to allow those attending to add additional topics for discussion.

Meeting one focused on the representatives giving the clinicians an overview of the feedback from the forum (Appendix T: Study 5 patient and family forum feedback summary) with an opportunity to ask questions. Meeting two focused on clinicians reacting or responding to the feedback from the forum. Meeting three focused on updating the meeting attendees on actions taken based on forum feedback and communication of work done with the forum and wider patient and family populations through a communication leaflet which provided a basis for representatives to report back to the forum (Appendix U: Study 5 communications leaflet).

**Intervention selection and development**

The intervention tested in this study was selected based on information on the context, setting and patient, family member and clinician preferences identified in previous studies within the PhD as well as existing evidence. Arnstein’s Ladder of Participation (18) and the CLEAR Framework (19) were employed in developed. The 2008 Medical Research Council (MRC) Guidelines for development of complex health interventions (265) were followed with development interviews and focus groups with patients, family members and clinicians. Further detail on this process and development of the intervention is provided in Chapter 7.
Type 2 Diabetes Forum

Aim: Involve patients and family members in how the service is run

Where: The education room in the Diabetes Day Care Centre, Tallaght Hospital.

When: 12:00-13:00 Thursday 21st September

Who: Type 2 diabetes patients and family members who attend the Diabetes Day Care Centre in Tallaght Hospital

For more information contact Lucy Whiston on 01-8963737
Appendix T: Study 5 Patient and family forum feedback summary

Type 2 Diabetes Group Feedback Summary

Where does this feedback come from?
The feedback presented below is from Type 2 diabetes patients and family members. A Type 2 Diabetes Group was set up in June 2017 with group discussions providing feedback from patients and family members on the Diabetes Day Care Centre. Feedback was centred around 3 questions: What are the top three most important things to you when you come to the Diabetes Day Care Centre? What are the top three good things in the Diabetes Day Care Centre? What are the top three bad things about the Diabetes Day Care Centre?

After the Type 2 Diabetes Group met and gave feedback. A summary of this feedback was shown to patients and family members in the waiting area. They were asked if there was anything missing or if they would make any changes to the list.

A total of 30 patients and family members contributed to this feedback. They are reflective of the wider Type 2 Diabetes patient and family member population in terms of age and gender i.e. there is similar breakdown of those who inputted into this feedback in terms of age and gender.

What are the top 3 most important things when you come to the Diabetes Day Care Centre?
1. Being seen in a reasonable period of time. Patients would like to be seen as close to their appointment time as possible. For some an acceptable period of waiting was 15 minutes. Others were happy to wait for up to one hour.
2. Being seen first come, first seen basis
3. Being listened too. It is important to patients that any questions they have are answered and any concerns that they have are taken on board. For example, if any changes are being made to medication this is made clear to patients or that the doctor makes sure they know what blood sugar levels they should be working towards.

What are the top 3 good things when you come to the Diabetes Day Care Centre?
1. Friendly, helpful staff. Staff are good as looking after you when you are not well, they do good work and provide good care. Nurses are always available to help on the phone. There is a friendly atmosphere in the Diabetes Day Care Centre. Staff do not get thanked enough.
2. System for getting bloods done. It is quick on the day and results are ready for next appointment in the Diabetes Day Care Centre.
3. Pre-consultation system speeds the process up.
What are the top 3 bad things when you come to the Diabetes Day Care Centre?

* Many people felt that there were no bad things about the Diabetes Day Care Centre. They were very happy about the care they received and the experience that they have had. There was an idea that existing problems are with the system, not the people.*

1. Waiting times. Concerns were raised about the 2 years duration in between appointments and the impact of this medically as it was felt that a lot can happen during this period of time. Waiting times on the day were also identified as an issue with everybody given the same appointment time. There are also delays accessing podiatrists and dieticians.

2. Not enough information on diet. Doctors do not often talk about diet and access to dieticians is poor.

3. Seeing a different doctor each time. Each doctor has a different style and you end up answering the same questions each time e.g you have to give the list of medications you are on every time. You have to give the list of medications. Patients and family members do not know if the consultant looking after their care has looked at their chart and knows what is happening.
Appendix U: Study 5 Communications leaflet

Type 2 Diabetes Group Update

In June 2017 Type 2 diabetes patients and family members met to give feedback on the Diabetes Day Care Centre. Patient and family representatives were selected. The representatives met with staff from the Diabetes Day Care Centre three times to discuss your feedback.

<table>
<thead>
<tr>
<th>What you told us</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Top 3 most important things</strong></td>
<td></td>
</tr>
<tr>
<td>1. Being seen in a reasonable period of time.</td>
<td>A number of different systems have been tested to reduce waiting times. There needs to be one set order in which patients are seen. This needs to be made clear to patients and family members. The appointment reminder letter has been reviewed and discussed. Once a set order has been decided the letter can be updated to reflect this.</td>
</tr>
<tr>
<td>2. Being seen first come, first served.</td>
<td>Being seen on a first come, first serve basis has been tried before. This led to problems with appointment time not being taken into account. There needs to be one set order in which patients are seen. This needs to be made clear to patients and family members. The appointment reminder letter has been reviewed and discussed. Once a set order has been decided the letter can be updated to reflect this.</td>
</tr>
<tr>
<td>3. Being listened too.</td>
<td>Representatives explained to staff that this important to patients and family members.</td>
</tr>
<tr>
<td><strong>Top 3 bad things</strong></td>
<td></td>
</tr>
<tr>
<td>1. Waiting times.</td>
<td>The waiting times in-between appointments is related to this being a time of change for diabetes care in Ireland. Current national policy is for type 2 diabetes care to be done by GPs. However, there is no timeline for when this policy will be put in place and it will not apply to complex patients. Doctors will reassure patients at the end of consultations, remind them of GP care in between appointments and the option to contact the nursing team on the phone.</td>
</tr>
<tr>
<td>- in-between appointments</td>
<td></td>
</tr>
<tr>
<td>- podiatry</td>
<td>Podiatry screening programmes are not available within the Diabetes Day Care Centre. It was suggested that more information should be provided about what is available in the community.</td>
</tr>
<tr>
<td>2. Not enough information on diet.</td>
<td>There is currently 1 dietician for all patients in the Diabetes Day Care Centre (type 1 and type 2). This makes waiting list very long. A business case for a second dietician has been made. Patients with complex issues will be referred to the Diabetes Day Care Centre dietician. Patients with less complex issues can request their GP to refer them to their local community dietician. Doctors have agreed to provide information on XPERT (a dietician led course for type 2 diabetes) to patients who would benefit from group education.</td>
</tr>
</tbody>
</table>

359
3. Seeing a different doctor each time. Junior doctors in the Diabetes Day Care Centre normally change every year. Doctors use patient charts to get the information they need when they see patients. They still need to ask important questions such as about the tablets that you take to make sure they have the correct information. The nurses provide continuity of care.

**Top 3 good things**

1. Friendly, helpful staff. Representatives discussed this with staff.
2. System for getting bloods done. Representatives discussed this with staff.
3. Pre-consultation system (blood pressure and weight checked). Representatives discussed this with staff.
Appendix V: Study 5 Representative training summary

Type 2 Diabetes Patient and Family Representatives
Meeting 1 Preparation

1. Representative role
   - To communicate feedback from Type 2 Diabetes patients and family members to clinicians working in the service.
   - To have the opinions and views of patients and family members involved in discussions about how the service is run.
   - Why is this important? It is important to involve patients and family members in how the Diabetes Day Care Centre works as this can lead to a better service that is more efficient and relevant with improved health and treatment outcomes for patients. Also, the majority of patients and family members want to be more involved in how the service works.

2. Feedback from patients and family members
   - Where came from and how collected.
   - Clinicians already have a summary of this feedback.
   - Summary of feedback.
   - Presentation and use of feedback in meetings.

3. Meetings with clinicians
   - 3 meetings
     Meeting 1 12:20-12:50 12th July- Discussion of feedback from the Type 2 Diabetes Group
     Meeting 2 12:20-12:50 9th August- What can be done to act on/react to feedback?
     Meeting 3 12:20-12:50 6th September- What has been done? Feedback to patients and family members.
   - Important to be aware
     Clinicians training
     How change works in the Diabetes Day Care Centre
     Confidentiality
     Solution focused
     Use of forum feedback
     Language- Ask if acronyms or words you don't understand are used.

4. Meeting 1 with clinicians
   - Meet at 12:10
   - Education room
   - 3-4 Clinicians
   - Agenda
Appendix W: Study 5 Representative language summary sheet

Clinician- The doctors, nurses, podiatrists and dieticians that work in the service.

Multidisciplinary team (MDT)- The team of doctors, nurses, podiatrists and dieticians that work in the service.

HBA1C- Measurement for blood sugars

Registrars- Junior doctors

DNAs- Did Not Attend- when patients do not show up for appointments.

DDC- Diabetes Day Care Centre

Allied Health Professionals- podiatry, dietetics or psychology
Appendix X: Study 5 clinician training slides

27/11/17

Examples of Participation

<table>
<thead>
<tr>
<th>Representation on boards</th>
<th>Developing new areas of research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of information material</td>
<td></td>
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<tr>
<td>Patient hurdles</td>
<td>Setting of priorities</td>
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<tr>
<td>Focus groups</td>
<td>Health panels</td>
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<tr>
<td>Workshops</td>
<td>Workshops</td>
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<tr>
<td>Civic juries</td>
<td>Patient and family consultation</td>
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<tr>
<td>Public meetings</td>
<td>Interviews</td>
</tr>
<tr>
<td>Feedback/satisfaction questionnaires</td>
<td>Suggestion boxes</td>
</tr>
</tbody>
</table>

Why Involve Patients and Family Members?

Impact of participation:
- Health service and health system improvements
- Adequate strategies and tackling of healthcare challenges
- Greater legitimacy and credibility in decision-making
- Sense of self-dignity and self-worth for patients

Expected impact:
- More power for making changes
- Patient and family feedback and experience included

Opinions on participation

Opinions on participation – Support for greater patient participation by stakeholder group

Opinions on Participation

- Support for greater patient and family member participation by stakeholder group

Patient and Family Participation Actions

Development:
- Study 1.3
- Medical Research Council (MRC) Guidelines

Components:
- Type 2 diabetes patient and family group
- Questionnaires
- Training
- Meetings with MDT

Evaluation:
- Process and outcome evaluation (MRC Guidelines)
### Clinician and Representative Meetings

**Dates:**
- Wednesday 12th July, 12:20-12:30
- Wednesday 9th August, 12:20-12:30
- Wednesday 6th September, 12:20-12:30

**Purpose:**
- Meeting 1: feedback from Type 2 Diabetes Group
- Meeting 2: what can be done to act on feedback
- Meeting 3: what has been done? What can be reported back?

**Processes:**
- Representative preparation
- Meeting process: solution focused, language and involvement

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### Feedback from Type 2 Diabetes Group

**Top Three 'Most Important Things':**
- Being seen in a reasonable period of time
- Being seen on a first come, first serve basis
- Being listened to

**Top Three 'Good Things':**
- Friendly, helpful staff
- System for getting blood done
- Pre-consultation system

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### Barriers?

**Possible barriers:**
- Support
- Confidentiality
- Resources: funding, time, staffing
- Capacity: ability of patients and family members
- Fear
- Ability to make changes happen
- ...

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### Thank you, questions?

Lucy Whiston
whistonl@tcd.ie
## Appendix Y: Study 5 Measures – justification, method and measurement

<table>
<thead>
<tr>
<th>Measure</th>
<th>Justification</th>
<th>Method</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Amount and intensity of</strong></td>
<td>The purpose of this research is to develop and test an intervention to encourage patient and family member service level participation. As such this is a key outcome to measure. At present in both services when patient and family service level participation does occur is limited to provision of information with no involvement in the decision making process (33). The CLEAR Framework states that people participate when they like to, when they feel that they are part of a group, when they feel they are listened to, when they are asked for their input and when they are enabled to. Forums will provide an opportunity for these impacts (153). It is expected that there will be an increase in the amount and intensity of participation reported.</td>
<td>Quantitative - Baseline and follow-up questionnaires (Appendix Z) - Patients, family members and clinicians</td>
<td>Question 2* a-e is based on Arnstein’s Ladder of Engagement and Participation (18) and is part of the theoretical framework underpinning this research. Questions 12a and 12b* have been adapted from the Irish Society for Quality and Safety in Healthcare (ISQSH) questionnaire that measure the patient experience of hospital services in 2010. All of these questions were also used in Study One (33).</td>
</tr>
<tr>
<td>participation</td>
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<tr>
<td><strong>Service satisfaction</strong></td>
<td>The assessment of interventions to encourage participation typically focuses on process measurement rather than outcomes (316). A qualitative systematic review of papers describing the effects of involving patients in planning and development in healthcare between 1966 and 2000 reported no evidence base for effects on quality of care or satisfaction as no studies could be found to investigate these outcomes (69). More recently a rapid evidence synthesis questioned current guidance for patient and public involvement calling for clearly reported evaluations of interventions (316). Evidence which is available on participation and service satisfaction reports links between participation and the development of more appropriate services that are more responsive to patient needs, values and priorities (6), higher quality services (4) with greater compliance, satisfaction with care (6), efficiency (4) and accessibility. Interviews and focus groups with stakeholders from both services highlighted an expected link between participation and the quality of the service.</td>
<td>Quantitative - Baseline and follow-up questionnaires (Appendix Z) - Patients, family members and clinicians.</td>
<td>Question 8* will asses satisfaction with the way in which the service is run using the question employed in the British Social Attitudes Survey annually since 1983 (335). Question 10* will employ the Friends and Family Test used in the NHS asked how likely you are to recommend the service to friends and family members (336). Only patients and family members will be asked this question. A modified version of this question has also been used to measure satisfaction with in patient care in Tallaght Hospital and in Study 1.</td>
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</table>
Opinions of participation  
Stakeholder opinions impact on the amount of participation that occurs. Interviews with cancer patients and healthcare professionals in Canada illustrated that healthcare professionals attitudes could limit patient participation (7). Similarly, self-reported opinions on patient participation by coronary care nurses in the United States revealed that nurses who viewed participation to be less of a hindrance were more likely to be responsive to patient needs (96). A systematic review of papers describing the effects of involving patients in planning and developing healthcare reported that staff attitudes to patient participation became more favourable when patients participate (69).

It is expected that participants will have a more positive opinion of participation after taking part in the intervention.

Empowerment  
A cross sectional study with 143 staff and 302 service users in community mental health service in England reported empowerment as a positive outcome from patient participation (94). Similarly in interviews and focus groups in Study 2 of the current research empowerment was an anticipated outcome. ‘The patients themselves I’m sure would feel, well I’d hope they would feel, a bit more empowered’ (Sinead, Diabetes, Clinician)

It is expected that patient and family member empowerment will increase after the intervention.

Self-esteem  
Improved public confidence from increased service user participation at the service level has been reported (1,272).

When asked about the perceived impact of patient and family participation, quantitative and qualitative data were collected:

<table>
<thead>
<tr>
<th>Question (Quantitative or Qualitative)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 2f*</td>
<td>Empowerment as a positive outcome from patient participation. A systematic review of measures assessing empowerment revealed uncertainty in the best way to measure empowerment with immediate to positive COSMIN scores (337). The Kim Alliance Scale (KAS) Revised measure the quality of therapeutic alliance including a subscale on patient empowerment. This scale was selected as it was developed in English for a generic group of patients so it can be used in both services with suitable questions. The empowerment subscale had internal consistency reliability of 0.77 and Pearson product moment correlation of 0.49 (338).</td>
</tr>
<tr>
<td>Questions 3* and 4*</td>
<td>Assess opinions on patient participation. Questions 6* and 7* are based on Arnstein’s Ladder of Participation.</td>
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<tr>
<td>Questions 6* and 7*</td>
<td>Assess opinions on family member participation. All were asked in Study 1 and Questions 4* and 7* are based on Arnstein’s Ladder of Participation.</td>
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<tr>
<td>Questions 13 a-d*</td>
<td>Measures empowerment. A systematic review of measures assessing empowerment revealed uncertainty in the best way to measure empowerment with immediate to positive COSMIN scores (337). The Kim Alliance Scale (KAS) Revised measure the quality of therapeutic alliance including a subscale on patient empowerment. This scale was selected as it was developed in English for a generic group of patients so it can be used in both services with suitable questions. The empowerment subscale had internal consistency reliability of 0.77 and Pearson product moment correlation of 0.49 (338).</td>
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<td>Question 19*</td>
<td>Assess self-esteem using the single item self-esteem scale which employs a five point likert scale to rank agreement with the statement ‘I have high self-esteem’. The most commonly used measure of self-esteem is the Rosenberg Self Esteem Scale.</td>
</tr>
</tbody>
</table>
participation those who took part in focus groups and interviews, particularly psychiatry service clinicians and policy leaders, expected increased self-esteem for patients as a result of participation. ‘It [participation] has huge benefit for their [patients’] self-esteem, em for stigma, you know, they are not somebody just with an illness’ (Julie, Psychiatry, Clinician)

Impact of intervention development involvement

The involvement of all stakeholders in intervention development is recommended in MRC guidelines (265). It is expected that involving patients, family members and clinicians in the development of the intervention will result in a more acceptable, feasible and sustainable intervention.

Impact of intervention elements

Numerous methods were employed to recruit forum attendees such as leaflets distributed in waiting areas, posters, advertisements in local GPs and through patient and community organisations. It was expected that this would increase the number of attendees as well as the representativeness of the sample.

The CLEAR Framework states that people participate when they can, when they have the resources and skills necessary to make their argument (153). In line with this representative and clinicians were provided with training and support throughout the intervention. It was expected that this would enable more effective participation, with more confident representatives and clinicians, and help stakeholder groups to work better together.

If was hope that the forum would impact on healthcare design and delivery providing credible, legitimate representation of the wider patient and family member populations.

The CLEAR Framework states that people participate when they feel they are listened to, when they are asked for their input and when they are enabled to. In line with these representatives meet with clinicians to discuss patient and family feedback to provide an

### Patients and family members

- Patients and family

### Qualitative

- Interviews and focus groups (Appendix AA)

### Clinicians

- Patients and family

### Estee Scale.

This is a ten-item scale that includes questions with statements of a sensitive manner. For example, ‘I certainly feel useless at times’ and ‘I am inclined to feel that I am a failure’. The single item self-esteem scale has been shown to have strong convergent validity with the Rosenberg scale and similar predictive validity (339).

**Impact of intervention development involvement**

The involvement of all stakeholders in intervention development is recommended in MRC guidelines (265). It is expected that involving patients, family members and clinicians in the development of the intervention will result in a more acceptable, feasible and sustainable intervention.

**Impact of intervention elements**

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### Quantitative

- Before questionnaires (Appendix Z)

### Qualitative

- Interviews and focus groups (Appendix AA)

### Patients, family members and clinicians

Before questionnaires completed by those who attended forum meeting one asked how attendees heard about the meeting (See Appendix Z).

In interviews and focus groups patients, family members and clinicians were asked about how they heard about forum and recruitment methods employed, training and support provided, the impact of the Type 2 Diabetes Forum, the impact of representative and clinician meetings. (See Appendix AA)
A key question in evaluating complex interventions is whether they are effective in everyday practice. It is expected that experience of the intervention of representatives backed by forums will change clinicians’ opinions to continuing participation. This will be a topic of discussion in clinician focus groups.

Fidelity is a core component to be assessed in process evaluation in line with MRC Guidelines. It is expected that remaining faithful to the outlined intervention will result in better results. Fidelity will be assessed through the number of meetings held, topics discussed, training delivery and analysis of adherence of the delivered intervention to the intervention outlined in the protocol. For example, documentation of delivery of essential components such as recruitment, training and meeting attendance occurred as well as any deviations from the intervention protocol.

Dose is a core component to be assessed in process evaluation in line with MRC Guidelines. It is expected that the correct amount of the intervention being administered will lead to better results. Dose will be assessed through the number of meetings, the number of people in attendance and the length of meetings. Analysis of video-recorded MDT meetings in a hospice setting with and without caregivers revealed meetings with caregivers were longer, had greater input from social workers and chaplains with an emphasis on biomedical education and relationship building.

Reach is a core component to be assessed in process evaluation in line with MRC Guidelines. It is expected that ensuring a representative sample of patients and family members attending forums and inputting to feedback will lead to better results. Reach will be assessed through demographic details including age, gender, duration of attendance and level of education recorded for those attending forum meetings compared with demographics for the wider patient and family member populations based on figures provided in Study One.

*S= Question numbers provided match up with the patient questionnaires in Appendix Z
Appendix Z: Study 5 Questionnaires

Patient Questionnaire
Patient and Family Participation in the Planning of Services in the Diabetes Day Care Centre

Participant I.D.: ____________________

Section A: Screening Question
1) Are you a Type 2 diabetes patient of the Diabetes Day Care Centre? □ Yes □ No

If no please stop and return your questionnaire to the researcher immediately (Lucy Whiston)

Section B: Patient Participation
2) Thinking of your experience of the Diabetes Day Care Centre in the last two years...

Tick one on each line only

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>a) Were you given information about the service?</td>
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<tr>
<td>b) Were you asked for you opinion about the service?</td>
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<tr>
<td>c) Were you involved in discussions about the service?</td>
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<tr>
<td>d) Were you involved in any decisions about the service? (e.g. did you have a vote)</td>
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<tr>
<td>e) Did patients make the decision on their own about the service?</td>
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<tr>
<td>f) Do you want to be more involved in decisions made about the Diabetes Day Care Centre?</td>
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</table>

3) Do you think patients should be involved in the planning of services in the Diabetes Day Care Centre? □ Yes □ No

4) How involved should patients be in the planning of services in the Diabetes Day Care Centre?

Tick only one for each question

<table>
<thead>
<tr>
<th></th>
<th>1 Strongly Agree</th>
<th>2</th>
<th>3</th>
<th>4 Strongly Disagree</th>
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<td>e) Patients should make decisions on their own</td>
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</tbody>
</table>

Section C: Family Member Participation
5) Does a family member normally join you when you come to the Diabetes Day Care Centre? □ Yes □ No

6) Do you think family members should be involved in the planning of services in the Diabetes Day Care Centre? □ Yes □ No

7) How involved should family members be in the planning of services in the Diabetes Day Care Centre?

Tick only one for each question

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Section D: The Diabetes Day Care Centre

8) All in all, how satisfied or dissatisfied would you say you are with the way in which the Diabetes Day Care Centre runs nowadays?

- Very satisfied
- Quite satisfied
- Neither satisfied nor dissatisfied
- Quite satisfied
- Very dissatisfied

9) How likely are you recommend the Diabetes Day Care Centre to friends and family members if they need similar care or treatment?

- Extremely likely
- Likely
- Neither likely nor unlikely
- Unlikely
- Extremely unlikely
- Don’t know

10) Thinking of your experience of the Diabetes Day Care Centre in the last two years please indicate how much you agree with the following...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Staff encourage me to voice my opinion about the services I receive in the Diabetes Day Care Centre.</td>
<td></td>
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<tr>
<td>b) Staff encourage me to take part in the decisions made about the service in the Diabetes Day Care Centre.</td>
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</table>

11) Thinking of your experience in the Diabetes Day Care Centre how often do you agree with the following statements...

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<tr>
<th>Statement</th>
<th>1 Never</th>
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<tr>
<td>a) I can express negative feelings freely</td>
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Section E: Demographics

12) Age:  
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70+

13) Gender:  
- Male
- Female

14) Education:  
- Primary education or less
- Leaving cert/technical training
- Degree, professional qualification or both
- Junior cert/inter cert/vocational training
- Non-degree qualification (diploma)
- Postgraduate qualification

15) Please indicate how much you agree with the following statement ‘I have high self-esteem’

- Not very true of me
- Very true of me

16) Duration of attendance at the Diabetes Day Care Centre:  
- < 1 year
- 1-5 years
- 6-9 years
- 10 + years

17) Where did you hear about the patient forum?

- Poster
- Member of staff
- Member of research team (Lucy Whiston)
- Another patient or family member
- Patient organisation e.g. Diabetes Ireland
- Other (please specify) _________________________
Family Member Questionnaire
Patient and Family Participation in the Planning of Services in the Diabetes Day Care Centre

Participant I.D.: ____________________

Section A: Screening Question
1) Are you a family member of a Type 2 diabetes patient of the Diabetes Day Care Centre? □ Yes  □ No
   *If no please stop and return your questionnaire to the researcher immediately (Lucy Whiston)*

Section B: Patient Participation
2) Do you think patients should be involved in the planning of services in the Diabetes Day Care Centre? □ Yes  □ No

3) How involved should patients be in the planning of services in the Diabetes Day Care Centre?
   *Tick only one for each question*

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Section C: Family Member Participation
4) Do you think family members should be involved in the planning of services in the Diabetes Day Care Centre? □ Yes  □ No

5) How involved should family members be in the planning of services in the Diabetes Day Care Centre?
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6) All in all, how satisfied or dissatisfied would you say you are with the way in which the Diabetes Day Care Centre runs nowadays?
   □ Very satisfied  □ Quite satisfied  □ Neither satisfied nor dissatisfied  □ Quite satisfied  □ Very dissatisfied

7) How likely are you recommend the Diabetes Day Care Centre to friends and family members if they need similar care or treatment? □ Extremely likely  □ Likely  □ Neither likely nor unlikely  □ Unlikely  □ Extremely unlikely  □ Don’t know

8) Thinking of your experience of the Diabetes Day Care Centre in the last two years please indicate how much you agree with the following...

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371
9) Thinking of your experience in the Diabetes Day Care Centre how often do you agree with the following statements:

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Section E: Demographics

10) Age:  ○ 18-29  ○ 30-39  ○ 40-49  ○ 50-59  ○ 60-69  ○ 70+

11) Gender:  ○ Male  ○ Female

12) Education:  ○ Primary education or less  ○ Junior cert/inter cert/vocational training
              ○ Leaving cert/technical training  ○ Non-degree qualification (diploma)
              ○ Degree, professional qualification or both  ○ Postgraduate qualification

13) Please indicate how much you agree with the following statement ‘I have high self-esteem’

<table>
<thead>
<tr>
<th>Rating</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not very true of me</td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Very true of me</td>
</tr>
</tbody>
</table>

14) Duration of attendance at the Diabetes Day Care Centre:  ○ < 1 year  ○ 1-5 years  ○ 6-9 years  ○ 10 + years

15) Where did you hear about the patient forum?

<table>
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<tr>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Poster</td>
</tr>
<tr>
<td>○ Member of staff</td>
</tr>
<tr>
<td>○ Member of research team (Lucy Whiston)</td>
</tr>
<tr>
<td>○ Another patient or family member</td>
</tr>
<tr>
<td>○ Patient organisation e.g. Diabetes Ireland</td>
</tr>
<tr>
<td>○ Other (please specify)</td>
</tr>
</tbody>
</table>
**Clinician Questionnaire**

**Patient and Family Participation in the Planning of Services in the Diabetes Day Care Centre**

Participant I.D.: __________________

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### Section A: Patient Participation

1) Thinking of your experience of the Diabetes Day Care Centre in the last two years...

<table>
<thead>
<tr>
<th>Tick one on each line only</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Were patients given information about the service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Were patients asked for your opinion about the service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Were patients involved in discussions about the service?</td>
<td></td>
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<tr>
<td>d) Were patients involved in any decisions about the service? (e.g. did you have a vote)</td>
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</tr>
<tr>
<td>e) Did patients make the decision on their own about the service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Do you want patients to be more involved in decisions made about the Diabetes Day Care Centre?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2) Do you think patients should be involved in the planning of services in the Diabetes Day Care Centre?  
- Yes ☐  No ☐

3) How involved should patients be in the planning of services in the Diabetes Day Care Centre?  

<table>
<thead>
<tr>
<th>Tick one on each line only</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Patients should be told about changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Patients should be asked what they think</td>
<td></td>
<td></td>
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<tr>
<td>c) Patients should be actively involved in discussions</td>
<td></td>
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<tr>
<td>d) Patients should have a vote when changes are made</td>
<td></td>
<td></td>
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<tr>
<td>e) Patients should make decisions on their own</td>
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</tbody>
</table>

### Section B: Family Member Participation

4) Thinking of your experience of the Diabetes Day Care Centre in the last two years...

<table>
<thead>
<tr>
<th>Tick one on each line only</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Were family members given information about the service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Were family members asked for their opinion about the service?</td>
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<tr>
<td>c) Were family members involved in discussions about the service?</td>
<td></td>
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<tr>
<td>d) Were family members involved in any decisions about the service? (e.g. did you have a vote)</td>
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<tr>
<td>e) Did family members make the decision on their own about the service?</td>
<td></td>
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<tr>
<td>f) Do you want family members to be more involved in decisions made about the Diabetes Day Care Centre?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5) Do you think family members should be involved in the planning of services in the Diabetes Day Care Centre?  
- Yes ☐  No ☐

6) How involved should family members be in the planning of services in the Diabetes Day Care Centre?  

<table>
<thead>
<tr>
<th>Tick one on each line only</th>
<th>Yes</th>
<th>No</th>
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<td></td>
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</table>

### Section C: The Diabetes Day Care Centre

7) All in all, how satisfied or dissatisfied would you say you are with the way in which the Diabetes Day Care Centre runs nowadays?  
- Very satisfied ☐  Quite satisfied ☐  Neither satisfied nor dissatisfied ☐  Quite satisfied ☐  Very dissatisfied ☐
Section D: Demographics

8) Age: □ 18-29 □ 30-39 □ 40-49 □ 50-59 □ 60-69 □ 70+

9) Gender: □ Male □ Female

10) Education: □ Primary education or less □ Junior cert/inter cert/vocational training
     □ Leaving cert/technical training □ Non-degree qualification (diploma)
     □ Degree, professional qualification or both □ Postgraduate qualification

11) Duration of employment at the Diabetes Day Care Centre:
    □ < 1 year □ 1-5 years □ 6-9 years □ 10 + years

12) Discipline: □ Nurse □ Doctor (Consultant or NCHD)
     □ Allied Health Professional (dietician, podiatrist, psychologist)
     □ Other (please specify) ____________________________________________

THANK YOU!
Appendix AA: Study 5 Interview Schedules

**Patient and Family Participation Intervention: Patient and Family Evaluation Topic Guide**

11. What did you think about the intervention of representatives backed by forums?
   - What was good about the intervention?
     (representatives, forums, training, facilitation, level of intensity)
   - What needs to be changed in the intervention?
     (representatives, forums, training, facilitation, level of intensity, frequency of meetings)

12. What did you think about recruitment of patients and family members for the intervention?
   - What did you think about the recruitment strategies that were used for forums?
     (which worked, which didn’t, any changes)
   - What did you think about the selection of representatives?
     (correct criteria taken into account, selection method, credible representatives)

13. What did you think about the training, support and facilitation provided?
   - What was good about the training and support provided?
     (good idea, bad idea, what you expected?)
   - What needs to be changed in the training and support provided?
     (what worked well, what needs to be changed, what needs to stay the same)
   - What impact, if any, do you think training and support provided had?
     (changed understanding, provided confidence to participate, more effective input)
   - What do you think about the doctors and nurses being provided with training as well?

14. Meetings with the doctors and nurses
   - What did you think about the meetings with the doctors and nurses?
     (good? Bad? What changes need to be made? Anybody missing from the meetings?)
   - What do you think about the topics discussed at these meetings?
     (happy? Enough input?)
   - What do you think about the language used?

15. Impact of patient and family participation intervention.
   - What changed as a result of the intervention?
     (at the level of the service, at the level of the individual, attitudinal changes)
   - What impact did the intervention have on patient and family participation?
     (impact on patient participation, impact on family participation, impact on relationships, impact on decision making/how service is run)
   - What contributed to these changes?
     (representatives attending meetings, forums established, greater communication, training)

16. What do you think about patient and family participation continuing after the research?
   - Do you think forum meetings will continue to take place?
     (frequency, attendance, impact, anything different, if no, what needs to change for this to happen)
   - Do you think there will be any more meetings between representatives and the clinical team?
     (frequency, attendance, impact, anything different, if no, what needs to change for this to happen)
1. **What did you think about the intervention of representatives backed by forums?**
   - What was good about the intervention?
     
   (representatives, forums, training, facilitation, level of intensity)
   - What needs to be changed in the intervention?
     
   (representatives, forums, training, facilitation, level of intensity, frequency of meetings)

2. **What did you think about the development of the intervention?**
   - What impact do you think being involved in the intervention development process had?
     
   (good, bad, no impact, what intervention aspects did it affect, ownership)
   - What did you think about involvement through focus groups based on a draft intervention?
     
   (good, bad, enough/too much involvement, use of draft intervention)
   - What did you think about the involvement of stakeholder groups?
     
   (enough/too much involvement from patients, family and clinicians, other groups to be included)

3. **What did you think about recruitment of patients and family members for the intervention?**
   - What did you think about the recruitment strategies that were used for forums?
     
   (which worked, which didn’t, any changes)
   - What did you think about the selection of representatives?
     
   (correct criteria taken into account, selection method, credible representatives)
   - What do you think about the meetings with the representatives?
     
   (good? Bad? What changes need to be made? Anybody missing from the meetings?)

4. **What did you think about the training, support and facilitation provided?**
   - What was good about the training and support provided?
     
   (good idea, bad idea, what you expected?)
   - What needs to be changed in the training and support provided?
     
   (what worked well, what needs to be changed, what needs to stay the same)
   - What impact, if any, do you think training and support provided had?
     
   (changed understanding, provided confidence to participate, more effective input)
   - Do you think it is feasible for this support to be continued without the research team alongside clinical duties?
     
   (if not what can be done to improve feasibility)

5. **Impact of patient and family participation intervention.**
   - What changed as a result of the intervention?
     
   (at the level of the service, at the level of the individual, attitudinal changes)
   - What impact did the intervention have on patient and family participation?
     
   (impact on patient participation, impact on family participation, impact on relationships, impact on decision making/how service is run)
   - What contributed to these changes?
     
   (representatives attending meetings, forums established, greater communication, training)

6. **What do you think about patient and family participation continuing after the research?**
   - Do you think forum meetings will continue to take place?
     
   (frequency, attendance, impact, anything different, if no, what needs to change for this to happen)
   - Do you think there will be any more meetings between representatives and the clinical team?
     
   (frequency, attendance, impact, anything different, if no, what needs to change for this to happen)
Appendix BB: Study 5 coding frame

Study Five Coding Frame V2

1. Context:
   1A. Description of illness:
       (information on the impact of patients’ illness, the experience of the illness outside of the service)
   
   1B. Description of the service:
       (information on how the service works, the services offered, the types and numbers of patients which attend, the attitude towards family members and the role they play in the service, satisfaction)

2. Intervention opinion and experience:
   2A. Patient and family forum (type 2 diabetes group):
       (discussion related to participant’s opinion or experience of the patient and family forum including recruitment)
   
   2B. Representatives:
       (all statements related to participant’s opinion or experience of patient and family representatives including recruitment)
   
   2C. Representative and clinician meetings
       (discussion related to related participant’s opinion or experience of representative and clinician meetings)
   
   2D. Training and support:
       (all statements related to participants’ opinion or experience of training and support providing including training, facilitation and coordination)

3. Intervention development:
   (All discussions pertaining to experience, importance and impact of involvement in intervention development including all PhD studies, interviews and focus groups)

4. Expectations:
   (conversations about expectations and fears about the intervention prior to implementation)

5. Impact:
   5A. Attitudes and opinions:
       (discussions relating to changes in attitudes or opinions as a results of the intervention)
   
   5B. Communication and feedback:
       (thoughts on the impact of the intervention on communication, feedback and relationships)
5C. Service:
(conversations about impact of the intervention on the service including design and delivery and making changes)

5D. Other impacts
(discussions on any other impacts of the intervention e.g. health, relationships)

6. Suggested changes to improve the intervention:
6A. Patient and family forum (type 2 diabetes group):
(discussion related to suggested changes to the patient and family forum including recruitment and no changes necessary)

6B. Representatives:
(all statements related to suggested changes to patient and family representatives including recruitment and no changes necessary)

6C. Representative and clinician meetings
(discussion related to suggested changes to representative and clinician meetings and no changes necessary)

6D. Training and support:
(all statements related to suggested changes to training and support providing including training, facilitation and coordination and no changes necessary)

7. Sustainability:
7A. Opinions
(discussion related to whether the intervention is sustainable beyond the research)

7B. What is necessary:
(all statements related to necessary supports, resources or changes for the intervention to be sustainable beyond the research)

8. Miscellaneous:
(anything else of interest which does not fit in the above categories)
Appendix CC: Dissemination Strategy

Peer reviewed publications

Published

Whiston L, Barry J, O’Keane V, Darker C. Patient, family and clinician preferences for the intensity and implementation of patient and family participation in healthcare design and delivery in psychiatry. The European Journal of Psychiatry [Internet]. 2018; Available from: https://doi.org.dcu.idm.oclc.org/10.1016/j.ejpsy.2018.07.001

DOI: http://doi.org/10.5334/ijic.3306


In preparation

The following publications are in preparation for international peer-reviewed journals such as Value in Health, Journal of Clinical Nursing and the Journal of Health Services Research and Policy.

Whiston L, Barry J, Sherlock M, Darker C. Implementation and feasibility of an intervention to encourage greater patient and family participation in healthcare design and delivery in an adult outpatient type 2 diabetes service. In preparation;


**Presentations**

National and international conferences


Clinical team meetings
Presentations on the process and findings of each PhD study was made the clinical teams in both services at the beginning and end of each study.
HSE

Regular presentations were made throughout the course of the PhD as results became available to June Boulger the National Lead for Patient and Public Partnership in the HSE Acute Hospitals Directorate and the HSE Patient Advocacy and Liaison Network, which feeds into the National Patient Experience Survey.

Other

Posters


Whiston L, Barry J, Darker C. A study of clinicians’, patients’ and family members’ utilisation, opinions and experiences of patient and family participation in the design and delivery of healthcare services from a psychiatric and a type 2 diabetes service perspective. Institute of Public Health Open Conference. Dublin. October 2015.

The poster from the 2018 SPHERE conference was displayed in the waiting area of the diabetes service to aid dissemination of patients and family members.

Result summaries

A summary of results from Study 3 was circulated to all participants. A summary of the PhD findings will be circulated to organisations with involvement through the PhD such as Diabetes Ireland, Tallaght Hospital Patient and Community Advisory Committee and Mental Health Ireland and HSE Mental Health Engagement.