

Patient and public involvement in research: Reflections and experiences of doctoral cancer nurse researchers in Europe

Mary Anne Tanay^{a,*}, Celia Diez de los Rios de la Serna^b, Vanessa Boland^c, André Manuel Da Silva Lopes^d, Karen Wingfield^e, Daren Chircop^f, Mark Dornan^g, Grażyna Suchodolska^h, Gülşah Yıldız Aytaçⁱ, Berna Kurt^j, Sara Colomer-Lahiguera^d

^a Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, United Kingdom

^b School of Nursing, Faculty of Medicine and Health Sciences, Barcelona University, Spain

^c School of Nursing and Midwifery, Trinity College Dublin, Ireland

^d Institute of Higher Education and Research in Healthcare-IUFRS, University of Lausanne, Lausanne University Hospital, Switzerland

^e School of Healthcare Sciences, Cardiff University, United Kingdom

^f School of Health Sciences, University of Southampton, United Kingdom

^g Institute of Nursing and Health Research, Ulster University, United Kingdom

^h Department of Oncology & Radiotherapy, Faculty of Medicine, Medical University of Gdańsk, Poland

ⁱ Faculty of Nursing, Psychiatric Nursing Department, Hacettepe University, Turkey

^j Faculty of Nursing, Internal Medicine Nursing Department, Hacettepe University, Turkey

ARTICLE INFO

Keywords:

Patient and public involvement

PPI

Qualitative research

Doctoral students

Junior researchers

Early career researchers

Thematic analysis

Cancer nursing

Cancer research

Reflections

ABSTRACT

Purpose: Early career researchers lack guidance about patient and public involvement (PPI). The overall aim of the study was to explore the knowledge and experiences of using PPI in research among doctoral students who are registered nurses.

Methods: This qualitative study included findings generated from reflective essays and focus groups involving ten registered cancer nurses who are undertaking doctoral research. The study has two stages of data collection. Participants initially wrote a reflective essay using a set of guiding questions to structure a response which was subsequently analysed. Two focus groups were then conducted to provide further insight into the themes identified in the reflective essays. Reflective thematic analysis was used to identify, name, and define the final themes.

Results: There were ten participants from seven countries and were at various stages of their doctoral study. Analysis of data from reflective essays ($n = 10$) and focus groups ($n = 2$) identified four themes namely, (a) evolving recognition and appreciation of PPI, (b) embracing PPI and impact on doctoral studies, (c) the influence of the research environment, and (d) the need to empower doctoral students to integrate PPI in their research journey.

Conclusion: Participants reported differing experiences of PPI awareness showing disparity in guidance about PPI for junior researchers across Europe. We recommend provision of early PPI training for doctoral students to support and encourage involvement of patients and the public in their research. Opportunities for sharing PPI experiences to help improve PPI culture in research environments that support doctoral students should be explored.

1. Introduction

Patient and public involvement (PPI) in research is encouraged as a means of improving the validity and relevance of research. The National Institute for Health Research (NIHR) defines public involvement in

research as *research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*. (National Institute for Health Research (NIHR), 2021). The core concept underlying PPI is an active partnership between patients, carers, members of the public and researchers, that actively shapes research.

* Corresponding author.

E-mail address: mary.tanay@kcl.ac.uk (M.A. Tanay).

<https://doi.org/10.1016/j.ejon.2023.102351>

Received 7 October 2022; Received in revised form 23 January 2023; Accepted 21 May 2023

Available online 29 May 2023

1462-3889/© 2023 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

The introduction of PPI in research brings benefits at different levels: limiting power imbalances between researchers and patients; enhancing the effectiveness and value of research, hence increasing its relevance; improving recruitment and retention rates of research participants, broadening the range of people represented in studies; and helping to disseminate results beyond the academic setting (Knaapen and Lehoux, 2016; Skovlund et al., 2020). Furthermore, involvement of patients in research enables the personalization of clinical care through knowledge co-constructed by researchers and the public; it increases accountability and transparency of research and can be an effective way to attract future or ongoing funding (Boote et al., 2002; Greenhalgh et al., 2019).

However, the implementation of PPI in the research culture faces several challenges, such as competing organizational priorities, time, resources, funding, or lack of training or experience (Brett et al., 2014; Merle et al., 2022; Ocloo and Matthews, 2016). Researchers' familiarity and attitude towards PPI are key factors facilitating PPI adoption (McKenzie et al., 2016; Miller et al., 2017) and education emerges as a critical mean to achieve it (Boylan et al., 2019). Training for researchers appears as one of the main principles in several PPI models and frameworks (Abelson et al., 2016; Baines and Regan de Bere, 2018; Boote et al., 2006; de Wit et al., 2018) and is recognised as a priority by the National Institute for Health and Care Research (NIHR, 2021).

Several studies have shown that PPI training raises awareness and increases the understanding of how involvement can add value and relevance to research (Dudley et al., 2015; Thompson et al., 2009; Yu et al., 2021). Additionally, specific training serves as a mechanism for developing researchers' experiences and attitudes towards PPI (Dudley et al., 2015; McKenzie et al., 2016; Thompson et al., 2009) and to ensure that they have the necessary skills to involve patients in the research process (Boote et al., 2006). Yet, theoretical concepts and practical application of PPI is rarely part of the current curriculum for researchers (de Wit et al., 2018).

PPI may be a particular challenge for early career researchers or doctoral students as they consider engaging patients (Hewlett et al., 2006; Jinks et al., 2013). Research conducted by Biggane et al. (2019) highlights the reflections of early-stage researchers (defined as researchers in the first four years of their research activity and training) about PPI. The participants described whom to involve as research partners, when to involve them, how to access and keep people involved in a project, defining roles, training and support for PPI members, follow-up plans and dissemination approaches (Biggane et al., 2019). Furthermore, de Wit and colleagues identified challenges for junior researchers – or those who have less than three years of research experience and working on a doctoral research project – related to mentors' expectations regarding PPI (de Wit et al., 2018). de Wit et al. (2018) report different training needs between senior and junior researchers based on their roles and responsibilities. While seniors stated that their responsibilities were to advise, support and supervise juniors in doing PPI, juniors valued a deeper focus on the practicalities of engaging patients in research projects such as how to contact patient representatives, the nature or level of PPI for their individual studies, funding, payment of PPI group and co-authorship. Junior research staff are generally more open to PPI and consider it an aspect of academia and the culture of research (Boylan et al., 2019).

Despite the identified benefits of PPI in research, limited data exist on the reflections of PPI implementation within nursing research. Fletcher et al. (2021) described a practical example of nurse researchers establishing, developing, and refining a PPI group. These researchers acknowledged the challenges associated with effectively maintaining PPI in research such as funding, identifying appropriate members and the responsibility and additional burden of managing effective interaction and engagement (Fletcher et al., 2021). With a myriad of approaches to enabling PPI in research, few resources are available to support nurses, particularly early career nurse researchers, with effectively incorporating PPI.

The third European Oncology Nursing Society (EONS) PhD Research

workshop was held virtually in July 2021 and was attended by 10 nursing doctoral students from across Europe. The workshop covered a wide-ranging program. The topic that created huge interest and discussion was Public and Patient Involvement (PPI). It transpired there was a range of understanding and awareness of PPI across the students, regardless of their stage of doctoral studies. The workshop provided an opportunity for reflections on the current knowledge, opportunities, and challenges of applying PPI as young researchers and at early stages of the research projects. Our discussions motivated us to share our reflections and experiences to highlight gaps in PPI training and support for doctoral students.

The aim of this manuscript is to explore the knowledge and experiences of implementing PPI in research among doctoral students who are registered nurses. Specifically, we aim to (i) compare available training and experience of PPI among participants, (ii) to identify gaps, barriers, and facilitators of PPI implementation in doctoral research projects, and (iii) to make recommendations based on the findings of reflections of cancer nurses undertaking doctoral studies.

2. Methods

2.1. Study design

This qualitative study was approved by the King's College London Ethics Committee (Study reference: MRA-21/22-26317). The study has two stages of data collection. Participants initially wrote a reflective essay using a set of guide questions to structure a response which was subsequently analysed. Two focus groups were then conducted to provide further insight into the themes identified in the reflective essays.

2.2. Participants

The participants of this study were registered nurses completing doctoral research in oncology who are working or residing in Europe. The participants attended a PhD workshop held virtually by the EONS in July 2021. This three-day PhD workshop, delivered over three weeks, aimed to support doctoral researchers in oncology nursing by connecting researchers from across Europe and providing a series of informative and interactive workshops including a session about PPI. The PhD workshop was advertised to members of EONS and through European national cancer nursing societies. Only two workshop participants (MT, CDR) who were EONS working group members knew each other prior to the workshop.

MT, VB and CDR identified the study purpose and design and iteratively developed the protocol and guiding questions to meet the aims and objectives of the study. Participants of the PhD workshop were given access to the study protocol online with details of the study and what were expected if they decide to participate. All doctoral researchers (n = 10) were contacted by email following the workshop and offered participation. Submission of reflections and confirmation of attendance in the focus groups implied consent to participate.

2.3. Data collection and analysis

2.3.1. Reflective essays

Between September and October 2021, each participant was tasked to write a short reflective essay of approximately 500 words on their experience of doing or learning about PPI. Guiding questions were provided to each participant to focus their reflection on five key areas.

- Experiences and knowledge about PPI in research
- How PPI was integrated in one's doctoral research (if applicable)
- How the EONS PhD workshop helped understanding PPI and any actions taken
- Required support to expand understanding and skills of PPI in research

- Any other thoughts about PPI

The reflective essays were analysed using reflexive thematic analysis (Braun et al., 2019); participants were allocated participant codes to maintain confidentiality. Since the study authors were also research participants; several strategies were implemented to maintain rigour and minimise potential bias. Three female group members (MT, VB, and CDR) independently analysed a selection of the responses, excluding their own. At least two independent data analysers were allocated for every reflective essay who familiarised themselves with the content of the essays. Each data analyser recorded and kept notes on each reflective essay. MT, VB, and CDR independently generated codes and initial themes. Through several discussions, the initial themes were compared, reviewed, and defined until agreement was made. Before the themes were finalised, focus groups with all participants took place.

2.3.2. Focus groups

Two focus groups were held virtually in December 2021 with six and four participants in the first and second focus groups, respectively. Each focus group lasted approximately 90 min. Focus groups were audio recorded and notes were taken for analysis. The topic guide for the focus groups was independently generated by SCL based on the data of the reflective essays. The focus groups were also moderated by SCL, a senior researcher with extensive research experience. The focus groups aimed to investigate depth of PPI experiences and validate, strengthen, or make additional recommendations on the themes being proposed. Following the focus groups, the data and focus groups notes were analysed by SCL and deductively integrated into the themes generated through the analysis of the reflective essays. The final themes were collectively named, refined, and finalised by MT, VB, CDR and SCL.

2.4. Participant validation

After completing the analysis, a meeting was held with participants to share the final proposed themes to ensure that they reflected the experience of the group. At this meeting, a consensus was reached that

validated the proposed themes accurately reflected the core of the experiences of PPI, whilst acknowledging the diversity of experiences and opinions of PPI within the group. The final themes are detailed in the findings section below.

3. Findings

Participants were from Turkey, Poland, Switzerland, Malta, Spain, Ireland, and the United Kingdom (UK). At the time of data collection, their cancer nursing experience ranged between three to 25 years; and were in various stages of their doctoral study. Four participants did not use PPI in their doctoral studies, five worked with PPI and one participant who had recently commenced their doctoral study plans to involve PPI. Description of participant characteristics and PPI activities completed at the time of this study's data collection are shown on Table 1. Four out of five doctoral students who involved PPI groups were supported in grant and ethics applications by their PPI groups.

Findings were based on reflective pieces ($n = 10$) ranging between 296 and 1404 words; shorter essays tend to be from those who did not use PPI in their research study. Four themes were identified namely, (a) evolving recognition and appreciation of PPI, (b) embracing PPI and impact on doctoral studies, (c) the influence of the research environment, and (d) the need to empower doctoral students to integrate PPI in their research journey. These themes are illustrated on Fig. 1. All quotes provided in the findings section come from the individual essays.

3.1. Theme 1: Evolving recognition and appreciation of PPI

Most participants mentioned lacking in their knowledge and understanding of PPI at the start of their doctoral studies; one participant came across the concept of the PPI for the first time after conducting their doctoral research.

"Before starting my doctoral studies, I did not have any prior training or knowledge of PPI in research." (DS-7)

Table 1
Summary of participant characteristics.

Participant code (DS: doctoral student)	Country (Where doctoral study is being undertaken)	Stage of doctoral study	Number of years in cancer nursing	Funding Full-funded (FF), Part-funded (PF), or Self-funded (SF)	Used PPI in doctoral research Yes (Y) No (N) Not applicable (NA)	Description of PPI activities ^a
DS-1	Poland	Year 3; part-time	4	FF	N	Not applicable
DS-2	Turkey	Year 4; full-time	13	FF	N	Not applicable
DS-3	UK	Year 1; part-time	25	PF	NA	Has not started but intend to include PPI
DS-4	UK	Year 3; full-time	21	FF	Y	A, B, C, E, F, G
DS-5	Spain	Year 3; part-time	14	SF	Y	A, D, G
DS-6	Switzerland	Year 3; full-time	3	FF	Y	B, E, G
DS-7	UK but working in Malta	Year 5; part-time	5	SF	N	Not applicable
DS-8	UK	Year 3; full-time	5	FF	Y	C, F, H
DS-9	Ireland	Year 3; full-time	4	FF	Y	C, E, G
DS-10	Turkey	Year 6; full-time	12	FF	N	Not applicable

A – Identifying a research problem.

B – Writing the protocol.

C – Collecting data D – Analysing data.

E – Writing the report F – Disseminating results.

G – Grant and ethics application.

H – Study advisory group.

^a Key.

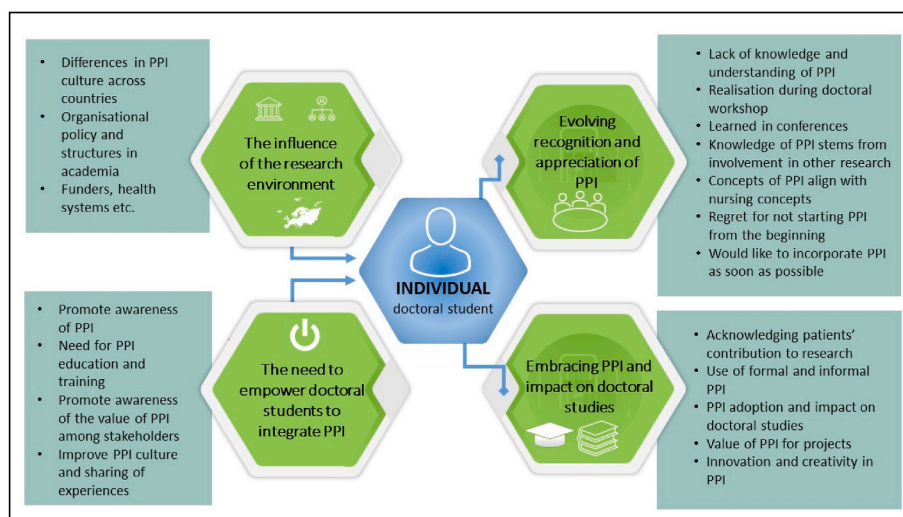


Fig. 1. Illustration of study themes.

"I first came across this concept at the session on PPI at EONS Workshop in 2021. I had no awareness of this concept during my doctoral studies." (DS-10)

A trend across several reflections was the emergence of knowledge of PPI which stems from a foundation of research; this included 'attending research conferences' (DS-6, DS-9), 'carrying out research nurse roles' (DS-4, DS-5) and 'studying about research as part of undergraduate degree in nursing' (DS-6).

"My first contact with a more evolved view of PPI occurred during a conference regarding patient-reported outcomes research. Nurses in Quebec involved patients in planning an electronic application to collect health status data, through patient-reported outcomes ... It was a humbling but invigorating experience and marked the moment when patient involvement in my PhD research transitioned from an abstract ideal to a persistent ambition." (DS-6)

Some participants gained more understanding of PPI while undertaking research-related activities in a country other than where they were undertaking their doctoral studies.

"I worked some years in United Kingdom, and I got a grant to do some part time research, during that time I learnt there were PPI panels with who I could talk about my ideas and get their feedback and involvement from the beginning of my research." (DS-5)

However, for many participants, the realisation of the concept of PPI came about when they heard about how to actively involve patients and the public in research for the first time during the EONS workshop.

"The very first time, I became aware of PPI and its importance for research, was when I joined EONS PhD Workshop this year. Being part of the workshop and having discussions with other participants, truly opened my eyes." (DS-1)

"I heard about PPI during the workshop and had the opportunity to read it in detail afterwards. The workshop made such a contribution to me." (DS-2)

"I was very excited to learn that the patient/public takes part in every stage of a research from the beginning to the end (including in the role of researcher) and that there is even a "patient university" where patients are educated and graduated. (DS-10)

"The session on PPI during our workshop has really helped me understand how patients or carers can be actively involved in designing the methods and procedures of the research. This is something that I had never considered before." (DS-7)

As doctoral students developed their awareness of PPI, they realised how many concepts of PPI also align with several nursing skills and concepts such as patient-centred care, nurse-patient communication, and advocacy for patient's voice.

"Unsurprisingly, it blended with the concept of patient-centred care, and its crucial distinctions were occasionally ignored. In fact, patient-centred care was often presented as the preferential and irrefragable way of providing care, and that concept was only opposed to the more paternalistic viewpoint of care." (DS-6)

"As a healthcare professional, I am confident when speaking with patients about their health and social needs." (DS-8)

"Prior to comprehending what PPI was, I would have confidently declared my strong advocacy for the 'patient's voice' in research. However, without meaningful engagement with what constitutes PPI through research that is conducted 'with' or 'by' patients during the research process, the representation of patients, regardless of the intent, may be insubstantial." (DS-9)

For many doctoral students, their awareness brought about an altered perspective of PPI. There was a newly found appreciation of the value of PPI and its potential influence and contribution to the conduct of research. Although late for some, they acknowledged how PPI could have transformed aspects of their doctoral research and came to a decision to promote PPI within their research communities and include PPI in their future research projects.

"From this workshop, discussion, and reflection, I have gained a new appreciation of PPI's influential transformative power and contribution to research. (DS-8)

"Being aware of PPI sooner, would have changed the way we designed the app for breast cancer patients. It would have changed my own PhD project. For me, it was somewhat too late, however I am making sure that my students and my work colleagues are aware of PPI and if necessary, take it into consideration when designing new research projects." (DS-1)

"This session (on PPI) showed me that as a researcher, I did not reflect this on the academic process especially in identifying needs and planning the research; it was a one-sided process just like one-way communication - no feedback This formation seemed quite democratic and egalitarian and once again emphasized the frightening nature of the paternalist approach for me ... I will endeavour to approach my future research from this (PPI) perspective." (DS-10)

Some participants described how their appreciation of PPI also stemmed from the fact that PPI allows patients and other people with relevant experience in the topic of interest to contribute to research concerning them.

“The image of research in healthcare as an exclusive domain reserved only for academics is a persistent one, and often at odds with its end goal: that of improving healthcare for both patients and providers in meaningful ways.” (DS-6)

“The early awareness and realisation of the value of PPI in research allowed me to embrace PPI as a required ingredient of any research project.” (DS-4)

“The ‘main’ priority of a research is on the patient/public side.” (DS-10)

3.2. Theme 2: Embracing PPI and impact on doctoral studies

The participants highlighted how PPI allows patients and other people to contribute throughout the different stages of the research process, from the planning stage until dissemination. Examples of research activities that involved PPI in their research are provided below:

“My research ideas came from talking to patients so I never thought necessary to then ask them if my research was important for them, if it could make any difference in their care as I thought that was exactly what I was doing.” (DS-5)

“I have now been working with the core PPI group for six years, and as a result of the co-design study another participant has expressed interest in getting involved in future research on the same topic/experience as PPI member.” (DS-4)

“As a small research team, we spent time contemplating some of the vital study concepts, and when we piloted our information with patients, after only 5 minutes, our participants were able to identify gaps and misunderstandings within our work.” (DS-8)

“Patient involvement provided an opportunity for patients to assess if the survey content was clear, appropriate, and relevant to cancer survivors.” (DS-9)

“... the carers pointed out that the information sheet was too long to read. Instead, they suggested that I shorten the information sheet and indicated which important information should be included in it. (DS-7)

The participants who adopted PPI in their doctoral studies reported mostly positive but one shared a negative experience.

“A PPI applicant informed me that I would not be paying her enough and she needed more payment in order to meet her financial outgoings. I was stunned by the experience. I had expected someone wishing to help with a cancer study to be agreeable and welcoming.” (DS-3)

Some participants described how PPI generates innovation and creativity in the research process, as well as motivates the researcher to continue with their research. Furthermore, PPI ensures that the researcher does not deviate from the research objectives.

“I have presented my plans to two patient group events where I was able to obtain their views as well as validation of the need of researching the topic ... The contributions of the PPI team were valuable ... their motivation was really helpful.” (DS-4)

This research revealed that the doctoral students made use of both formal and informal PPI in their studies. Most of the participants formally approached patients and other people to participate in their

research and even discussed PPI when applying for grant funding, as illustrated in the excerpt below.

“Most of the funding bodies in the United Kingdom request for information about how patients and the public were involved in the planning and conduct of research ... Through a PPI enablement fund, I was able to conduct two events to form the PPI group of the study; we also reviewed together the initial research proposal during these events, and they were able to give their comments.” (DS-4)

On the other hand, another participant asked for informal feedback from patients regarding her study.

“And for that I looked and listed all the patient organisations I could think of so I could present them in the meeting to make my idea heard. I looked for people on social media that we could informally approach and ask for their opinion.” (DS-5)

3.3. Theme 3: The influence of the research environment

The experiences shared by the doctoral students showed how PPI is promoted and embraced differently across their respective countries across Europe. Some countries such as the UK and Ireland have established agencies that promote PPI and provide guidance for researchers about PPI; some have databases of PPI members and volunteers. However, doctoral students from countries such as Spain, Poland, Malta and Turkey perceived lack of opportunities and support provided for incorporating PPI in their doctoral research. They also mentioned how PPI is not considered an important part of current research and health systems in their countries. This wider attitude towards PPI affected doctoral students who faced challenges in including PPI or not including PPI in their research at all. Exemplars of doctoral students' contrasting experiences of receiving PPI support are presented in [Table 2](#).

Participants shared how their research environment influenced the integration of PPI in their doctoral research. For some, particularly those in Ireland and the UK, PPI was embedded right from the grant application process. PPI as a funding requirement was the main reason for this. Doctoral students also emphasised the vital role of their colleagues and supervisors in guiding them to involve PPI.

“Whilst developing the study design, it was suggested by one of my colleagues that I should do some reading on PPI and consider asking carers, who were the population of my study, for their opinion regarding whether the information sheet, leaflet and poster clearly illustrated the aim of the study and what is involved or not.” (DS-7)

“PPI has been given due consideration, guided by suggestions from funding applications and supervisory team input.” (DS-9)

On the other hand, several factors such as policy and institutional structures and lack of access to PPI were identified as problematic by the doctoral students. There was worry about sustainability of PPI particularly for those who have limited or lacking in funding and were unable to pay contributors, patients, and members of the public for their time and contributions.

“Unrefined perceptions and methods of PPI dealt limited impact to the underlying care structure. Change in department and hospital-wide policy and practice remained, from my point of view, very elusive.” (DS-6)

“... that meant I had it more difficult to get PPI opinion from the beginning of my research as there was nothing established to help me during the process. With the little knowledge I had and due to the difficulties found, I decided I wanted to have PPI involvement in the middle of my research, for them to have a look at the intervention that we were planning and give us their opinion. I would approach different patients' organisations and ask them to be part of a focus group with healthcare providers.” (DS-5)

Table 2
Experiences of PPI support.

Support for including PPI in research is available	Lacking or limited support for including PPI in research
“Major organisations involved in clinical research, such as the Irish Cancer Society, are committed to placing patients and the public at the forefront of their research plans by also embedding PPI in their research processes. Furthermore, from my current involvement in research, I am aware of the PPI Ignite network, which was formed in Ireland to promote high quality PPI in health and social care research.” (DS-9)	“When I came back to Spain and started my PhD, I realised that PPI was not that incorporated into the hospitals and the research system as in England. There was no PPI panel in the hospital or any teaching about PPI in the PhD programme ... that meant I had it more difficult to get PPI opinion from the beginning of my research as there was nothing established to help me during the process.” (DS-5)
“When I started my research project, I was signposted to Health Care Research Wales in UK (HCRW) who support researchers with many aspects of research including PPI. HCRW have a database of PPI volunteers.” (DS-3)	“I did not participate in such a practice or unfortunately did not have the opportunity to experience it (PPI). In Turkey, this situation is not a frequently used method, anyway.” (DS-2)
“In UK, we have the NIHR which aims to support and promote PPI; they offer guidelines and training for researchers and PPI members alike. Several funding bodies require PPI involvement in its funded studies. The NIHR Research Design Service (RDS) offers opportunities to secure a PPI enablement fund, and as the title suggests, it enables researchers to set up a PPI group at the start of their research planning.” (DS-4)	“I am confused about what can be done about PPI in such a working pattern. I am not sure but maybe inclusion can be done at the reporting stage. However, on the other hand, I think that the participants should have research knowledge for the process to be carried out effectively. I can say that there is no widespread approach in this regard in Turkey currently.” (DS-10) “I qualified as a nurse in Poland in 2005. Nobody mentioned PPI during my undergraduate or even postgraduate nursing studies ... In 2018, oncology nursing caught my attention and I started working as a breast cancer nurse in one of the biggest university hospitals in Poland. I was introduced to clinical trials and academic research, but even then, still not informed about PPI.” (DS-1) “This can be attributed to the fact that PPI is still not considered as an important part of the research and health systems here in Malta.” (DS-7)

“There was a convoluted payment system as I was based in one hospital, the funding sat with my supervisor’s university Going forward I will need to be savvy about PPI payments as I am self-funding for my PhD.” (DS-3)

3.4. Theme 4: The need to empower doctoral students to integrate PPI in their research journey

Findings highlighted the need for raising awareness about PPI among doctoral students as well as those who provide them with guidance and supervision about the conduct of research such as supervisors and lecturers. As one participant mentioned, “in order to give importance to this subject in new research processes I will plan, I should first build up my knowledge” (DS-10). Doctoral students emphasised the need to raise awareness locally and to develop a universal understanding of the value of PPI that is being shared among relevant stakeholders and across European countries.

“I think that PPI awareness should be raised among Polish doctoral students. My personal experience with PPI, or rather lack of it, demonstrates one of many critical differences in nursing research approach between Poland and other European countries.” (DS-1)

“I do think that more emphasis should be made locally on the use of PPI in research. For example, I think that firstly, sessions should be

conducted with doctoral students and lecturers on the benefits of PPI in order to raise awareness about it” (DS-7)

“A key recommendation of this reflection practice is the advancement of promoting PPI in research so that there is a universal understanding of its rationale and so, its value.” (DS-9)

To increase awareness, doctoral students believe the need for structured training about PPI and how they can genuinely involve patients in research. They also highlighted the benefit of listening to case studies and experiences of other researchers such as those presented and shared at the EONS PhD PPI workshop. They valued insights from discussions which also offered support and advice on resolving challenges and barriers concerning PPI. Indeed, those with PPI training or knowledge prior to commencing doctoral studies found the information useful when describing the role of PPI in their doctoral research.

“I do however believe I would require further training to involve patients in deeper levels of research design, and it is still unclear to me how I can identify the best educational resources ... From the healthcare professional’s perspective, this is perhaps the greatest barrier in making PPI a standard for research projects”. (DS-6)

“Additionally, during the EONS workshop, a highlight was listening to others within the group share how their PPI groups had been involved with projects over several years and making significant improvements to the research design, implementation, collection, interpretation, and dissemination. Whilst PPI can add exciting, unexpected and unanticipated dimensions to a research project; conversely, it was also insightful to hear and discuss with others that PPI can present some challenges at times. Fundamentally, however, the discussion was balanced with support and advice on promptly managing some challenges and barriers.” (DS-8)

The advantage of PPI education can be seen through one reflection “I already have formed understanding of what PPI should look like. I did not have to discuss PPI so much with my supervisors; because of my attendance in several sessions prior to commencing the doctoral programme, it was easy for me to describe my PPI plans to them.” (DS-4)

4. Discussion

This paper presents personal reflections and experiences of PPI for a small group of European cancer nurses undergoing PhD studies. Participants’ training and experience varied, as well as their years of nursing experience and stage of doctoral studies. Factors impacting the range of awareness and understanding of PPI for this group involved differing foundations of research experience and adoption of PPI by the participant’s country of residence, as PPI is embraced differently across Europe. Barriers to implementing PPI in doctoral research included policy and institutional structures, which limited its accessibility. The availability of funding to facilitate PPI was a key concern for participants. In contrast, facilitators of PPI implementation in doctoral research included students’ supervisory teams, colleagues, and research collaborators.

The EONS PhD workshop allowed participants to reflect on aspects of PPI which were relevant and applicable to their PhD projects, including reflection on how their previously conducted research may have been enhanced by its incorporation. Participants recognised the value of patient involvement in transforming research: from shaping research priorities to formulating research questions to data collection and dissemination of results. The implicit value of PPI comes from its engagement with patients in the research process - an important aspect for ethical and practical reasons (Pii et al. 2019). Similarly, the value of PPI and its beneficial impact on the research process was reported for two health-related doctoral research studies (Coupe and Mathieson 2020).

Even for participants without prior knowledge of PPI, the opportunities and challenges to adopt and implement PPI within their research were noted. Similar to previous research (Biggane et al., 2019), most workshop participants in this study felt the concept was introduced late in their academic education, with limited guidance on real-world implementation. Participants from the UK and Ireland reported a strong culture of PPI in organisations where PPI is mandatory to obtain funding, while other European countries are still in their early stages. Our findings support previous findings from Pii et al. (2019), who noted the variability of PPI implementation in cancer research by country and how the environment supports the development of the doctoral student.

Evidence on the use of PPI in doctoral research projects is lacking. Tomlinson et al. (2019) reported benefits of PPI to student researchers such as improved students' self-esteem and reduced isolation. On the other hand, the findings of this current paper are more broadly applicable to the wider barriers and facilitation of PPI. Overall, the experiences of the participants in this study suggest using PPI in doctoral research is a rewarding experience.

Incorporating PPI in research is closely aligned with the nursing profession and its capacity for patient advocacy. Nurses are rooted in recognising patient rights and their interests (Mallik 1997). As nurses, the PhD students in this group share professional values that motivate them to involve patients in activities related to their health care. However, to include PPI in their doctoral research, knowledge and support are needed. A workshop like the one delivered by EONS for doctoral students enhances the conceptual comprehension of PPI. However, supports at the system level (i.e., governance and funding bodies) is required to orientate early researchers to the 'how'.

As PPI awareness and expertise are essential to implement PPI in research successfully, it is paramount to provide training in the early stages of PhD students' research projects and any research-focused academic programme. Universities and healthcare organisations must foster PPI within their research culture to adequately support researchers and students (Cluley et al., 2022). Therefore, there is a call for a cultural change to support and facilitate the development of practical organisational approaches to underpin the involvement of PPI (Boylan et al., 2019), especially within doctoral studies.

4.1. Recommendations

As the goal of healthcare research is to improve patient outcomes, PPI in research is a pivotal ingredient for many research projects in attaining this. The adoption of PPI appears to surpass the underlying research culture. A move towards the promotion of a universal

understanding of the concept, its rationale, and its use, early in the training of new researchers is needed. This research endeavour has identified a gap specifically within PhD education in Europe regarding the use of PPI. The incorporation of PPI awareness among early researchers is advantageous in building comprehension, awareness and resources that not only foster higher-quality research, but also support patients and healthcare providers in the clinical setting (Biggane et al., 2019; Dijk et al., 2020). Doctoral students are well placed to enhance awareness and understanding of PPI in research, given the rich affiliation and commitment applied to the PhD research process. Recommendations made based on study findings are summarised in Fig. 2.

4.2. Limitations

This study was conducted with a small sample size. The countries of the included participants were represented by a single doctoral student (apart from the UK and Turkey), which limits generalisability to the governing PPI culture and level of development. It is however worth noting that some of these doctoral students had experiences in multiple countries, and yet share the vision of PPI as a highly desirable but not fully developed approach to research. Importantly, the challenges evoked by these doctoral students were similar to those reported by other authors and show that despite hailing from a profession that favours a multilevel, constant patient partnership, still stress the need for more awareness, resources and further clarification of roles and expectations. In addition, differences in countries and characteristics of study participants contributed to the diversity and richness of the study data.

One other limitation of this study is related to its internal group members, who conducted and analysed the written material and focus groups, but simultaneously participated in them as well. Nevertheless, each reflective essay was analysed by two independent researchers, this was distributed to exclude the researcher's own reflections, followed by consolidating the identified themes and results. Participants were also able to review the encoding process and results, and challenge reviewers to ensure representativeness of the material they provided. In addition, all participants were able to review the findings with their peers, on multiple occasions.

5. Conclusion

This study explored the diversity of experiences of a small group of European cancer nurses undergoing PhD about PPI awareness, education and practice. The findings point out that the current knowledge of doctoral researchers about PPI is scarce. Participants highlighted the

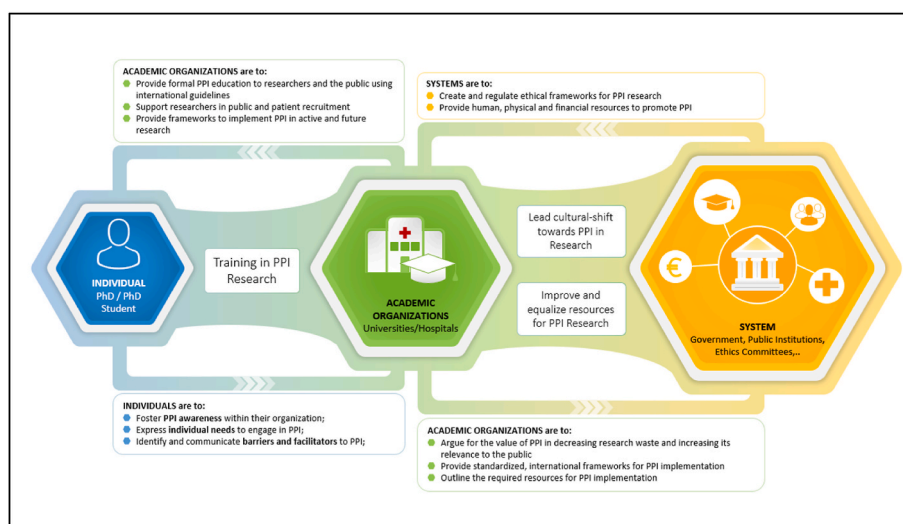


Fig. 2. Summary of recommendations.

importance of introducing the concept of PPI in the early stages of doctoral education. Doctoral researchers in this study, particularly those who used PPI in their research, recognised the value of PPI at every stage of a research process.

There is a need to strengthen the knowledge and skills of doctoral students through the structured trainings to integrate PPI into their research projects. However, the level of familiarity of senior researchers on PPI and differences in the promotion, use and financing of PPI among European countries revealed the necessity of structured and system level supports. Further, opportunities for sharing PPI experiences to help improve PPI culture among research environments that support doctoral students should be explored.

CRediT authorship contribution statement

Mary Anne Tanay: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing, Project administration. **Celia Díez de los Ríos de la Serna:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing, Project administration. **Vanessa Boland:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing, Project administration. **André Manuel Da Silva Lopes:** Conceptualization, Writing – original draft, Writing – review & editing, Resources. **Karen Wingfield:** Conceptualization, Writing – original draft, Writing – review & editing. **Daren Chircop:** Conceptualization, Writing – original draft, Writing – review & editing. **Mark Dornan:** Writing – original draft. **Grażyna Suchodolska:** Writing – review & editing, Resources. **Gülşah Yıldız Aytaç:** Writing – original draft, Writing – review & editing. **Berna Kurt:** Writing – review & editing. **Sara Colomer-Lahiguera:** Conceptualization, Methodology, Formal analysis, Writing – review & editing.

Declaration of competing interest

All authors have no conflicts of interest to disclose.

Acknowledgment

The authors are grateful to the European Oncology Nursing Society for holding the 3rd EONS PhD Workshop which provided opportunity to learn and discuss about patient and public involvement. In particular our gratitude goes to the EONS Faculty, Dr Paz Ortega, Dr Maura Dowling and Dr Sara Colomer-Lahiguera.

References

- Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C., Boesveld, S., 2016. Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool. *Health Expect.* 19 (4), 817–827. <https://doi.org/10.1111/hex.12378>.
- Baines, R.L., Regan de Bere, S., 2018. Optimizing patient and public involvement (PPI): identifying its “essential” and “desirable” principles using a systematic review and modified Delphi methodology. *Health Expect.* 21 (1), 327–335. <https://doi.org/10.1111/hex.12618>.
- Biggane, A.M., Olsen, M., Williamson, P.R., 2019. PPI in research: a reflection from early stage researchers. *Res Involv Engagem* 5, 35. <https://doi.org/10.1186/s40900-019-0170-2>.
- Boote, J., Telford, R., Cooper, C., 2002. Consumer involvement in health research: a review and research agenda. *Health Pol.* 61 (2), 213–236. [https://doi.org/10.1016/S0168-8510\(01\)00214-7](https://doi.org/10.1016/S0168-8510(01)00214-7). PMID:12088893.
- Boote, J., Barber, R., Cooper, C., 2006. Principles and indicators of successful consumer involvement in NHS research: results of a Delphi study and subgroup analysis. *Health Pol.* 75 (3), 280–297. <https://doi.org/10.1016/j.healthpol.2005.03.012>.
- Boylan, A.-M., Locock, L., Thomson, R., Staniszevska, S., 2019. “About sixty per cent I want to do it”: health researchers’ attitudes to, and experiences of, patient and public involvement (PPI)—a qualitative interview study. *Health Expect.* 22 (4), 721–730. <https://doi.org/10.1111/hex.12883>.
- Braun, V., Clarke, V., Hayfield, N., Terry, G., 2019. Thematic analysis. In: Liamputtong, P. (Ed.), *Handbook of Research Methods in Health Social Sciences*. Springer, Singapore. https://doi.org/10.1007/978-981-10-5251-4_103.
- Brett, J., Staniszevska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., Suleman, R., 2014. A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient* 7 (4), 387–395. <https://doi.org/10.1007/s40271-014-0065-0>.
- Cluley, V., Ziemann, A., Feeley, C., Olander, E.K., Shamah, S., Stavropoulou, C., 2022. Mapping the role of patient and public involvement during the different stages of healthcare innovation: a scoping review. *Health Expect.* 25, 840–855.
- Coupe, N., Mathieson, A., 2020. Patient and public involvement in doctoral research: impact, resources and recommendations. *Health Expect.* 23, 125–136. <https://doi.org/10.1111/hex.12976>.
- de Wit, M., Beurskens, A., Pişkur, B., Stoffers, E., Moser, A., 2018. Preparing researchers for patient and public involvement in scientific research: development of a hands-on learning approach through action research. *Health Expect.* 21 (4), 752–763. <https://doi.org/10.1111/hex.12671>.
- Dijk, S.W., Duijzer, E.J., Wienold, M., 2020. Role of active patient involvement in undergraduate medical education: a systematic review. *BMJ Open* 10 (7), e037217. <https://doi.org/10.1136/bmjopen-2020-037217>. PMID: 32718925; PMCID: PMC7389514.
- Dudley, L., Gamble, C., Allam, A., Bell, P., Buck, D., Goodare, H., Hanley, B., Preston, J., Walker, A., Williamson, P., Young, B., 2015. A little more conversation please? Qualitative study of researchers’ and patients’ interview accounts of training for patient and public involvement in clinical trials. *Trials* 16 (1), 190. <https://doi.org/10.1186/s13063-015-0667-4>.
- Fletcher, J., Swift, A., Hewison, M., S, C.C., 2021. Patient and public involvement in research design and oversight. *Nurse Res.* 29 (4), 11–18. <https://doi.org/10.7748/nr.2021.e1786>.
- Greenhalgh, T., Hinton, L., Finlay, T., Macfarlane, A., Fahy, N., Clyde, B., Chant, A., 2019. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect.* 22 (4), 785–801. <https://doi.org/10.1111/hex.12888>.
- Hewlett, S., Wit, M.D., Richards, P., Quest, E., Hughes, R., Heiberg, T., Kirwan, J., 2006. Patients and professionals as research partners: challenges, practicalities, and benefits. *Arthritis Care Res.* 55 (4), 676–680. <https://doi.org/10.1002/art.22091>.
- Jinks, C., Carter, P., Rhodes, C., Beech, R., Dziedzic, K., Hughes, R., Blackburn, S., Ong, B.N., 2013. Sustaining patient and public involvement in research: a case study of a research centre. *J. Care Serv. Manag.* 7 (4), 146–154. <https://doi.org/10.1179/1750168715Y.0000000003>.
- Knaapen, L., Lehoux, P., 2016. Three conceptual models of patient and public involvement in standard-setting: from abstract principles to complex practice. *Sci. Cult.* 25 (2), 239–263. <https://doi.org/10.1080/09505431.2015.1125875>.
- Mallik, M., 1997. Advocacy in nursing—a review of the literature. *J. Adv. Nurs.* 25 (1), 130–138.
- McKenzie, A., Alpers, K., Heyworth, J., Phuong, C., Hanley, B., 2016. Consumer and community involvement in health and medical research: evaluation by online survey of Australian training workshops for researchers. *Res Involv Engagem* 2 (1), 16. <https://doi.org/10.1186/s40900-016-0030-2>.
- Merle, R., Pépin, J.-L., Palombi, O., Pariset, A., Allenet, B., Pison, C., 2022. Successful training of patients to intervene in health education and clinical research at grenoble patient school. *J Patient Experience* 9, 23743735211069810. <https://doi.org/10.1177/23743735211069810>.
- Miller, C.L., Mott, K., Cousins, M., Miller, S., Johnson, A., Lawson, T., Wesseling, S., 2019. Integrating consumer engagement in health and medical research – an Australian framework. *Health Res. Pol. Syst.* 15 (1), 9. <https://doi.org/10.1186/s12961-017-0171-2>.
- National Institute for Health Research (NIHR), 2021. Briefing notes for researchers - public involvement in NHS, health and social care research. Retrieved 15 April from. <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>.
- Ocloo, J., Matthews, R., 2016. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual. Saf.* 25 (8), 626–632. <https://doi.org/10.1136/bmjqs-2015-004839>.
- Pii, K.H., Schou, L.H., Piil, K., Jarden, M., 2019. Current trends in patient and public involvement in cancer research: a systematic review. *Health Expect.* 22, 3–20.
- Skovlund, P.C., Nielsen, B.K., Thaysen, H.V., Schmidt, H., Finset, A., Hansen, K.A., Lomborg, K., 2020. The impact of patient involvement in research: a case study of the planning, conduct and dissemination of a clinical, controlled trial. *Research Involvement and Engagement* 6 (1), 43. <https://doi.org/10.1186/s40900-020-00214-5>.
- Thompson, J., Barber, R., Ward, P.R., Boote, J.D., Cooper, C.L., Armitage, C.J., Jones, G., 2009. Health researchers’ attitudes towards public involvement in health research. *Health Expect.* 12 (2), 209–220. <https://doi.org/10.1111/j.1369-7625.2009.00532.x>.
- Tomlinson, J., Medlinskiene, K., Cheong, V.L., Khan, S., Fylan, B., 2019. Patient and public involvement in designing and conducting doctoral research: the whys and the hows. *Res Involv Engagem* 5, 23. <https://doi.org/10.1186/s40900-019-0155-1>.
- Yu, R., Hanley, B., Denegri, S., Ahmed, J., McNally, N.J., 2021. Evaluation of a patient and public involvement training programme for researchers at a large biomedical research centre in the UK. *BMJ Open* 11 (8), e047995. <https://doi.org/10.1136/bmjopen-2020-047995>.