What maternal health-related research matters to women in the first year postpartum?

Naomi Donaldson & Déirdre Daly

on behalf of

Dr Elizabeth Newnham, Dr Francesca Wuytack, Dr Patrick Moran, Ms Susan Hannon, &
Professor Cecily Begley & all the women in the study
What maternal health-related research matters to women in the first year postpartum?

Today’s presentation

- Context
  - Background to the Maternal health And Maternal Morbidity in Ireland (MAMMI) study
  - The public participation in research initiative (PPI)
- This study’s aim
- Methods
- Findings
- Next step and conclusion
The MAMMI Study
Context

A longitudinal (cohort) study with 3,047 first-time mothers: public, private, semi-private (set up in 2011).

- Self-completion surveys
- Data collection from consenting women’s hospital records
- Interviews (one-to-one conversations) with sub-samples (n=20-30) of women experiencing morbidities

(leaking urine, pelvic & back pain, sexual health problems, post-caesarean section)
**The MAMMI Study**

**Context**

Data collection from consenting women’s records

Interviews with women experiencing a morbidity

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**Survey 1**
Antenatal First booking visit
(includes sections on pre-pregnancy health and health problems)

**Survey 2**
3 months postpartum

**Survey 3**
6 months postpartum

**Survey 4**
9 months postpartum

**Survey 5**
12 months postpartum
The MAMMI Study

Context

Data collection from consenting women’s records

Identify factors that are amenable to intervention in future trials

Trinity College Dublin

Survey 1
Antenatal
First booking visit
(includes sections on pre-pregnancy health and health problems)

Survey 2
3 months postpartum

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Interviews with women experiencing a morbidity
The MAMMI Study Context

Data collection from consenting women’s records

Interviews with women experiencing a morbidity

Identify factors that are amenable to intervention in future trials

Survey 1
Antenatal
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Survey 2
3 months postpartum

Survey 3
6 months postpartum

Survey 4
9 months postpartum

Survey 5
12 months postpartum

Second baby follow-up study
6 & 12 months postnatal

5-year follow-up study
The MAMMI Study
Recruitment and retention

<table>
<thead>
<tr>
<th></th>
<th>Rotunda Hospital (RH) 2012-2014</th>
<th>Galway University Hospital (GUH) 2013-2015</th>
<th>Coombe Women and Infants University Hospital (CWIUH) 2015-2017</th>
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<tbody>
<tr>
<td><strong>Response Rate (n)</strong></td>
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<tr>
<td><strong>Antenatal</strong></td>
<td>38.3% (1841/4809)</td>
<td>44.5% (333/748)</td>
<td>38.3% (873/2685)</td>
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<tr>
<td><strong>3 months</strong></td>
<td>86% (1484/1725)</td>
<td>92.8% (287/309)</td>
<td>89% (699/813)</td>
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<tr>
<td><strong>6 months</strong></td>
<td>84.5% (1381/1634)</td>
<td>87% (260/299)</td>
<td>86% (655/789)</td>
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<tr>
<td><strong>9 months</strong></td>
<td>80% (1301/1627)</td>
<td>83% (239/288)</td>
<td>81% (610/769)</td>
</tr>
<tr>
<td><strong>12 months</strong></td>
<td>78% (1223/1568)</td>
<td>78.6% (214/272)</td>
<td>75% (534/737)</td>
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</table>
Conduct research for and *with* women

Women who participate in research about their health and experiences during and after pregnancy *must be active participants in all aspects of designing and producing the research, and disseminating the findings.*

**1. Involving women from the start**

**2. Engaging with women throughout**

**3. Co-designing research with women**

**4. Co-presenting the study with women**

**5. Co-conducting research with women**

Public Participation in research Initiative (PPI)

Follow-up survey development (2017)

PPI (2018)
Aim: to establish a public participation in research initiative (PPI) with MAMMI study participants

i. host quarterly meetings/discussions
ii. involve women in the development of follow-up study surveys and documents
iii. identify, and prioritise, MAMMI study-related research that women wish to be conducted
iv. conduct 1-2 qualitative sub-studies on topics chosen by women
v. co-present at conferences
The MAMMI Study
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PPI (2018)

1st and 2nd meetings
Generating & refining ideas
The MAMMI Study
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What maternal health-related research matters to women in the first year postpartum
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Methods

- Ethical approval granted by university
- Qualitative study, one-to-one, audio-recorded interviews with 24 women
- Interviews conducted between June and September 2018
- Thematic analysis
- Process for ensuring rigor

Thematic analysis
Braun and Clarke’s (2006) framework
What maternal health-related research matters to women in the first year postpartum?

Findings
What maternal health-related research matters to women in the first year postpartum?

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
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</table>
| **Pendulum of care (services and information)** | (i) **Information seesaw:** (a) information overload; (b) information deprivation (not knowing what’s normal/what to expect); (c) induced anxiety.  
(ii) **System failure:** (a) access to services and professional support; (b) signposting and streamlining information; (c) inconsistent and rushed.  
(iii) **Invisible women:** (a) all about the baby; (b) attitude of HCPs (not being listened to/being dismissed). |
| **Pivotal partners and peers**             | (i) **Real-time reassurance:** (a) partner support; (b) peer support (in person/online (being/not being judged)); (c) family support  
(ii) **Support for partners.**              |
| **Hype and hope: the transition to motherhood** | (i) **(a) Breastfeeding** (expectations and realities) and culture in Ireland;  
(b) **Artificial feeding** (lack of information).  
(ii) **Returning to work:** (a) flexibility; (b) financial necessity; (c) challenges and expectations of women.  
(iii) **Disappearing into motherhood:** (a) weight of responsibility; (b) change of identity; (c) growing into advocacy (first versus second time around) |
What maternal health-related research matters to women in the first year postpartum?
Focus on one theme

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<td>Interlinked System failure</td>
<td>(a) access to services &amp; professional support; (b) signposting &amp; streamlining information; (c) inconsistent &amp; rushed</td>
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<td>Invisible women</td>
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<td>Information seesaw</td>
<td>‘You were given a mountain, an absolute mountain of paper [on discharge]...you can’t possibly take all of that information on board. It really needs to be streamlined’ [P5]</td>
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<td>Deprivation, overload, induced anxiety</td>
<td>‘When you’re expecting the baby, everything’s looked after...and your six week check up...after that it’s kind of like you’re on your own’ [P7]</td>
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<td>‘I suppose because I was going to that group [breastfeeding support], I saw a public health nurse there every week. So there was always someone there to ask, which was fantastic’ [P8]</td>
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<td>‘...my memories of...the big issues...postnatally, ...just the anxiety, being a first-time parent, and having that kind of information the second time which eased the anxiety’ [P14]</td>
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<td>‘I’m looking at the way other parents are doing things...am I doing that okay...a lot of parents, especially at the start over think exactly what they’re doing...’ [P21]</td>
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<td>‘You’ve got a tiny little person...completely dependent on you...it’s not that easy to just switch off...I’d say it’s so common amongst new mothers to be very, very anxious’ [P22]</td>
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<td>‘...the public health nurse came out and visited me a few days after the baby was born. And then that was it, she never came back out again’ [P10]</td>
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<td>‘What I felt was very minimal support and care from the health care service that really undermined my ability to really enjoy the first few weeks of my new arrival’ [P16]</td>
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<td>‘...it was a bit of a minefield to try and find out where there...none of them is signposted...it’s kind of like you’re thrown into the sea...’ [P5]</td>
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<td>‘The amount of information that is thrown at you and a lot of it is contradictory...not everybody in the health profession is on the same page...’ [P2]</td>
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<td>‘It didn’t seem to be very consistent from one health professional to the next...at one of the meetings...we couldn’t figure out you know if they were using like, you know a checklist of questions...to ask women about themselves after the birth and their own health’ [P12]</td>
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<td>‘...she was literally rushing...saw me really struggling and was kind enough to stop...for 2 minutes...to say ‘are you doing okay” [P19]</td>
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<td>Invisible women</td>
<td>‘The vast majority of health professionals that you’d see after your baby is born, it’s all about the baby. And how the baby is doing and there’s very little focus maybe on the mum or if it does it’s nearly like an add on kind of thing’ [P2]</td>
</tr>
<tr>
<td>It’s all about the baby;</td>
<td>‘I was lucky with my GP....but there was no official channel...once you have the baby no-one checks in on you anymore’ [P17]</td>
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<tr>
<td>attitude of HCPs (not</td>
<td>‘There is no maternal support like kind of once you have the baby...or...the six week check up...here’s your fabulous baby off you go’ [P9]</td>
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<td>being listened to/being</td>
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<td>Invisible women</td>
<td>‘The only health professional that actually listened to me, that was of a real help was my public health nurse’ [P1]</td>
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<td>It’s all about the baby; attitude of HCPs (not being listened to/being dismissed)</td>
<td>‘For me nobody listened. And I don’t blame them I’m not giving out. It’s just they just didn’t hear me when I said...’ [P4]</td>
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<td></td>
<td>‘But they were very dismissive...I suppose it’s, and oh you’re a first time mother that kind of thing...a lot of my friends would’ve experienced that too’ [P10]</td>
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<td></td>
<td>‘Having the baby it is a big deal...they forget that once they're there for a while...it’s...down to attitude, training, maybe even like customer care training for midwives’ [P17]</td>
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Next step

• Some women identified specific maternal health-related research topics, others identified issues and experiences that were really important to them and their families

• The challenge, and next step, is to turn these into actionable research topics
Conclusion

As well as identifying areas of further research that are important for women, this research also contributes to knowledge about motherhood more broadly, and identifies current gaps in maternal health care, which, potentially can impact on the development of healthy families.
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Sincerest thanks to all the women
The MAMMI Study

Special thanks to our funders

Development of a suite of resources for women

Coming in 2019

WHAM (MOOC)

MESSAGES

ON-TRACK