

# PREGNANCY LOSS RESEARCH GROUP



## How we define recurrent miscarriage matters: Views of people with lived and/or professional experience

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### Background

- **Varying definitions of recurrent miscarriage (RM) in use internationally.** RM affects 1-3% of women/couples of reproductive age depending on the definition used, e.g. whether 2 or  $\geq 3$  miscarriages, and if consecutive or not
- Stakeholders' views of how RM is defined have received limited attention
- **A definition reflects the medical evidence and values of a society at the time**, thus warrants ongoing review

**OUR AIM:** To explore views of women and men with lived experience of RM, and those involved in the delivery/management of services and supports, on how RM is and/or should be defined

### Methods

- Qualitative study design, incorporating **semi-structured interviews**
- Purposive sampling used to recruit participants in the Republic of Ireland, ensuring diverse perspectives were included
- Women (n=13) and men (n=7) with lived experience of  $\geq 2$  consecutive first-trimester miscarriages were recruited via health professionals and social media; others (n=42\*) via the research team's networks
- Interviews were audio-recorded, transcribed, pseudo-anonymised, and analysed using **reflexive thematic analysis**

Find out more about the Project



\*Clinical Midwife Specialists in Bereavement & Loss (8), Consultant Obstetricians & Gynaecologists (5), Specialist Registrars (2), Nurses, Midwives, Sonographers (4), Chaplaincy & Pastoral Care (2), Support Services (PMH, social work, community & voluntary) (3), GPs (4), Practice Nurses (2), Public Health Nurses (2), Maternity Hospital/Unit Level Admin, Governance & Mgt (3), National Admin, Governance & Mgt (7)

### Results

**THEME 1 | The need for a standardised definition of recurrent miscarriage: Finding a balance between research evidence, individual needs, and healthcare resources**

- The need for standardisation in practice
- Following the evidence: who benefits from investigation and treatment/intervention
- Acknowledging complexity and need for flexibility: considerations beyond the number of losses
- Limited resources constrain how recurrent miscarriage is defined and/or how the definition is operationalised

I think it will certainly be useful for us as clinicians in Ireland to have somewhat of a consensus I think of what we define as recurrent pregnancy loss, and what investigations and all of that, just to have some kind of uniformity rather than somebody going to this hospital and having this test done, and then going to another hospital and being denied that test. ... I think it would be useful for clinicians as well as patients (OBGYN-H1)

**THEME 2 | The definition is a route to finding an answer, validating women/couples' experience of loss, and providing necessary supports**

- Looking for a reason/answer
- Feeling frustrated, dismissed when you don't meet the criteria
- Existing in a liminal space, falling between the cracks in service provision

After the first one and the second one it's kind of, I suppose I felt very frustrated and just kind of completely helpless as well. Because it's something that we really wanted. It something that we were absolutely devastated about. And being kind of told, well, look just, you know, dust yourselves off and go for it again... But really just kind of from my own mindset, it's very hard to try and contemplate going through that process again...if it was something that was diagnosable and something that was preventable or something that was treatable you know we'd be in a much better I think headspace to go for it again (PM5)

**THEME 3 | Working around the definition – advocacy and impacts**

- Advocacy efforts: "To hell with the system", "Just lie and say you've had three" [Over-riding the referral criteria]
- Dealing with inappropriate referrals: "They still send in people which is really cruel"
- "If it's not available in the public they will go to the private"

I don't know if we're even supposed to be telling them about the private service, but I do, because I can't bear it like. You know I say to them, you know, you can go private. And I tell them to just ring Hospital D because I know we're not supposed to be giving names and stuff. And I just say look get all of your options. There are options, you know. And yeah, they will then (CMS7)

### Conclusion

**A more nuanced approach to defining RM is warranted, one which is evidence-informed and recognises the needs of women/couples**

**Our findings reinforce international calls for standardisation, and a graded approach to miscarriage care in which women/couples are offered appropriate, individualised, support following one, two and three or more miscarriages**

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