

Priorities for Research in Miscarriage: A Priority Setting Partnership Between People Affected by Miscarriage and Professionals Following the James Lind Alliance Methodology

Prior et al. (2017)

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For which topic were research priorities identified?

miscarriage

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Despite substantial evidence about the appropriate place for medical, surgical and conservative treatment for ongoing miscarriage, there remain gaps in our knowledge about how to minimise psychological sequelae. There is also uncertainty about the appropriate investigation for women who have had particular numbers of miscarriages. The best way to care for women experiencing miscarriage is uncertain, both when it occurs and in subsequent pregnancies. Which of these areas of research should be a priority? Traditionally, the research agenda has been set by the pharmaceutical industry and researchers themselves. A large proportion of miscarriage research has been funded by charitable trusts, but little consideration has been given to the priorities of women who have experienced miscarriage, their partners and the healthcare professionals (HCPs) who care for them.

What was the objective?

to identify and prioritize important research questions for miscarriage

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

July 2015 - October 2016

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: key stakeholder groups identified, scope defined. Step 2: identifying questions: survey asking participants: What unanswered questions about miscarriage would you like to see answered by research?, 3279 questions submitted via survey, additionally 64 questions identified via literature search. Step 3: data processing: removing non-questions and questions not related to miscarriage, resulting in 58 summary questions, full list of 58 summary questions checked and agreed by steering group, all summary questions checked against evidence, 58 summary questions remained for interim ranking. Step 4: interim ranking: survey asking participants to identify their 10 priorities, questions then ranked based on frequency they had been chosen, top 25 questions taken forward to workshop. Step 5: final prioritization: workshop: prior to meeting participants individually prioritized top 25 questions, series of small group discussions and small group rankings, aggregate ranking and plenary discussion

Which stakeholders took part?

Women and those affected by miscarriage working alongside healthcare professionals. Survey: 1093 participants: 932 women who have experienced miscarriage, 8 partners, 17 family members, friends or colleagues, 104 healthcare professionals and 8 charitable organizations. Interim ranking: 2122 participants: 1797 women who have experienced miscarriage, 22 partners, 68 family members, friends or colleagues, 185 healthcare professionals and 31 people whose experience of miscarriage was unclear completed the survey. Workshop: 21 participants: 11 women who had experienced miscarriage, 2 male partners of women affected by miscarriage and 8 healthcare professionals.

How were stakeholders recruited?

The survey was distributed by partner organizations using their own networks; promotion in newsletters and conferences; printed flyers in clinics; online forums and social media. For the second survey, participants invited by partner organizations and advertised using newsletters, online and social media.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of women affected by miscarriage, charities representing them and healthcare professionals. The members identified partner organizations and were involved in the process.

