



# Identifying the top research priorities for miscarriage

## Survey

### Why we need your help

We are asking for your help because we want to improve care and treatment for women who experience miscarriage and those affected by it. We want to set the priorities for research that will make the biggest difference. From our previous survey and a comprehensive search of published research, we have devised a list of 58 unanswered research questions. We now need your help to prioritise these questions.

### Who you are

We would like the following groups of people to fill out this survey:

- \* Woman who have had a miscarriage.
- \* People affected by miscarriage e.g partners, family members, friends, colleagues.
- \* Professionals involved in caring for women who have experienced miscarriage – doctors, nurses, sonographers and other professionals with experience of miscarriage.
- \* Professional bodies, patient groups, charities and other organisations involved with miscarriage.

We are not just asking women who miscarry but also seeking the views of those affected by miscarriage and professionals involved in caring for women who have had a miscarriage. This is because all groups have ideas about what research questions need to be asked, and which criteria they would use to judge success or failure.

### What we are asking you to do

**Please identify the 10 questions that matter to you the most.** We want to prioritise the top 10 questions from the list of 58 questions.

The order in which the questions appear will be different for each person completing the survey so that the questions which appear top of the list don't get more attention than the bottom.

Each person filling out the survey will have different reasons for choosing their 10 questions and that is absolutely fine – you do not have to justify your choices.

### About you

We also ask for a little information about you. Most of the questions in this section of the survey are optional.

### What will happen to your choices

We will take the questions with the most votes from this survey forward to a final workshop. At this workshop we will bring together groups of women, partners, family members and healthcare professionals to look at these questions and identify the most important ones based on the results of the survey.

This will result in a 'top 10' list of research topics which we will use to influence future research. For example, it could help decide which research projects should get funding.

## Guidance

Please identify the 10 questions that matter to you the most. These questions have been derived from over 2000 original submissions to the Miscarriage PSP survey in November and December 2015. We also searched existing scientific literature to develop questions that women, those affected by miscarriage and clinicians want answering. You need to select the ten questions on this form that matter to you the most. All the results we get from everyone who takes part in this survey will be gathered together and kept anonymous. We will bring together groups of women, partners, family members and healthcare professionals to look at the top questions from this survey at a final workshop later this year. This will result in a 'top 10' list of research topics which we will use to influence future research. For example, it could help decide which research projects should get funding.

### 1. What are the top ten questions you would like answering by future miscarriage research? (PLEASE SELECT 10 OPTIONS)

- Are miscarriage rates affected by gestational age, geography, maternal age?
- Can miscarriage of a current pregnancy be predicted? (e.g. by ultrasound, blood test or vaginal tests).
- Could women be better prepared for the possibility of miscarriage?
- Do dedicated early pregnancy units offer benefit to women having a miscarriage?
- Do embryos feel pain?
- Do immunological abnormalities cause miscarriage?
- Do lifestyle factors (diet, stress, exercise, weight, alcohol, sexual activity, smoking, night shifts or flying) cause miscarriage?
- Do medical tests cause miscarriage? (such as internal examination, ultrasound scanning, amniocentesis or chorionic villous biopsy)
- Do medicines cause miscarriage? (e.g. contraceptive pill, progesterone, vaccines, antidepressants, antibiotics, antihistamines, or vitamin supplements)
- Do uterine muscle relaxants treat threatened miscarriage?
- Does a dedicated recurrent miscarriage clinic with reassurance scans reduce the rates of miscarriage?
- Does alternative or complimentary medicine prevent miscarriage? (e.g. traditional Chinese medicine, acupuncture)
- Does breastfeeding when pregnant cause miscarriage?
- Does counselling improve the likelihood of a subsequent successful pregnancy?
- Does ethnicity affect miscarriage?
- Does fetal gender cause miscarriage in some women?
- Does health professional follow up improve the likelihood of a subsequent successful pregnancy?
- Does infection cause miscarriage?
- Does levothyroxine reduce the risk of miscarriage in women with thyroid antibodies?
- Does preimplantation genetic screening improve outcome versus natural conception in women with unexplained recurrent miscarriage?
- Does previous surgery on the uterus cause miscarriage?
- Does super fertility (more frequent implantation and ease of pregnancy) cause miscarriage?
- Does taking folic acid reduce the risk of miscarriage?

- Does the method of management of miscarriage affect future fertility or miscarriage?
- How can health care professionals be prepared to offer patient's guidance or referral?
- How common is miscarriage in the United Kingdom?
- Is bed rest or any lifestyle or personal interventions effective in preventing miscarriage?
- Is surgery safe and effective for women with uterine anomalies? (septal resection)
- To what extent do genetic and chromosomal abnormalities in the fetus cause miscarriage?
- To what extent do parental factors cause miscarriage? (e.g. genetic, chromosomal, blood group)
- To what extent do pre-existing medical conditions cause miscarriage? (e.g. vitamin deficiencies, diabetes, previous infertility, endometriosis, polycystic ovarian syndrome, menstrual irregularities, cervical factors, uterine anomalies, polyps, immunological factors or previous pregnancy complications e.g. caesarean section or preterm birth)
- What are the appropriate investigations for women after one, two, or three or more miscarriages?
- What are the effective interventions to prevent miscarriage, threatened miscarriage and recurrent miscarriage? (e.g. lifestyle, vitamins, aspirin, early scans, HCG, dopamine agonists, progestogen, polytherapy, steroids, oestrogen, metformin, anticoagulants, intravenous immunoglobulin, intralipid and anti-tnf alpha)
- What are the emotional and mental health impacts of miscarriage in the short and long term for the mother and the father?
- What are the risks after a miscarriage? (Such as change in menstrual pattern or mental health problems)
- What can be done to improve the coordination between different miscarriage services?
- What causes late (after 14 weeks) miscarriage?
- What causes miscarriage?
- What causes missed miscarriage, where the baby dies before the miscarriage occurs?
- What causes preterm spontaneous rupture of membranes as a type of late miscarriage?
- What causes recurrent (more than three to the same woman) miscarriages?
- What factors increase the chance of embryo implantation?
- What investigations are of true clinical value? (e.g. ultrasound, gene sequencing, natural killer cells, thromboelastography (TEG), microarray testing of the fetus, paternal investigations, plasminogen activator inhibitor polymorphism)
- What is the best method of contraception after miscarriage?
- What is the best societal support for women with miscarriage (leave from work e.g. same as stillbirth)?
- What is the best time to conceive after a miscarriage?
- What is the best way to manage the loss of one twin? (including both medical and emotional support)
- What is the best way to support the extended family?
- What is the optimal process for conservative, medical and surgical management of miscarriage? (efficacy, location, safety, pain relief, symptoms, information)
- What is the probability of a further miscarriage after one, two or three or more previous miscarriage(s)?
- What male factors contribute towards the cause of miscarriage?
- What preconception tests or interventions prevent miscarriage? (e.g. vitamin supplements, folic acid, Dehydroepiandrosterone (DHEA), co-enzyme Q-10 or bariatric surgery)
- What type of care reduces anxiety during a subsequent pregnancy after miscarriage?
- What types of care are effective in preventing mental health problems for mothers and fathers during and immediately after a miscarriage?

- What types of emotional support are effective in preventing or treating women or their partners after a miscarriage?
- When should women book with their midwife in pregnancy?
- Which treatments are effective for incompetent cervix? (e.g. progesterone, cervical cerclage or arabin pessary)
- Why does society not talk about miscarriage?

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## Glossary

TEG - Thromboelastogram

HCG - Human Chorionic Gonadotrophin

## About You

We want to make sure we are getting a broad representation of people contributing ideas. Please tell us a little about your experience, background, and how you came across the survey.

### 2. Which best describes you?

- I am a woman who has experienced miscarriage
- I am the partner of a woman who has experienced miscarriage
- I am a family member, friend or colleague of women who has experienced miscarriage
- I am a healthcare professional
- I am a healthcare professional body
- I am a charity
- Other please specify \_\_\_\_\_

### 3. What is your gender?

- Male
- Female
- Prefer not to say

### 4. How old are you?

- Less than 18 years
- 18-24 years
- 25-29 years
- 30-34 years
- 35-39 years

- 40-44 years
- 45-49 years
- 50 years or over
- Prefer not to say

**5. 5. Where do you live?**

- East Midlands
- East of England
- London
- North East
- North West
- Northern Ireland
- Scotland
- South East
- South West
- Wales
- West Midlands
- Yorks and Humber
- Outside the UK
- Prefer not to say
- Other please specify \_\_\_\_\_

**6. What is your ethnic group?**

- White English/Welsh/Scottish/Northern Irish/British
- White Irish
- White Gypsy or Irish Traveller
- Mixed White and Black Caribbean
- Mixed White and Black African
- Mixed White and Asian
- Asian / Asian British Indian
- Asian / Asian British Pakistani
- Asian / Asian British Bangladeshi
- Asian / Asian British Chinese
- African
- Caribbean
- Prefer not to say
- Other please specify \_\_\_\_\_

**7. If you are a woman who has had a miscarriage, how many miscarriages have you had?**

\_\_\_\_\_

**8. At what stages were your miscarriages?**

Before 6 weeks

Between 6 and 12 weeks

After 12 week

**9. How long is it since your last miscarriage?** \_\_\_\_\_

**10. If you are a healthcare professional, which best describes your role?**

Obstetrician / Gynaecologist

General Practitioner

Nurse

Midwife

Sonographer

Healthcare assistant

Counsellor

Other please specify \_\_\_\_\_

**11. Where did you hear about the Miscarriage Priority Setting Partnership?**

Social Media

Email

Flyer or poster

At a conference

In an Early Pregnancy Unit

From a friend

Other please specify \_\_\_\_\_

**12. Thank you for completing this survey. Please provide your email address if you would like to be kept up to date with the project.**

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We're looking for a broad range of people to take part in the survey so please also share it with other friends or colleagues you know.

If you have been affected by miscarriage and would like to access support, the following organisations may be able to provide help and advice (click to link):

The Miscarriage Association Tel: 01924 200 799

Scottish Care and Information on Miscarriage Tel:0141 552 5070

Tommys Tel: 0800 0147 800