

Research Priorities in Diabetes and Pregnancy

A James Lind Alliance Priority Setting Partnership

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Background

Over 5% of births in the UK are affected by diabetes. The rate is increasing. Compared to the population of women without diabetes, the risks are two to six times greater for adverse outcomes in pregnancy and birth, and can also affect women and their children in the long-term.

Further research is needed to help provide the best health care for women, with or at risk of diabetes, who are pregnant or are planning pregnancy. It is important that the research undertaken aligns with the priorities of those who will be impacted by it.

Our aim is to produce a **top ten list of priorities** that women, their support networks, and HCPs agree are the most important for research to address in diabetes and pregnancy



Our steering group consists of women with lived experience of diabetes in pregnancy, HCPs and researchers in diabetes and pregnancy, Diabetes UK, JDRF the type 1 charity, and the JLA. Led by: Dr Göher Ayman and Professor Marian Knight, University of Oxford.

Our Scope

The Diabetes and Pregnancy PSP will focus on identifying the priority questions in relation to:

- women, their partners, babies, and families
- diabetes, including pre-existing diabetes of any type and subtype, and gestational diabetes
- the time before, during and after pregnancy, including short to long-term health outcomes
- screening, causes and prevention, diagnosis, management and treatment of diabetes
- physical, social, cultural, economic, and psychological aspects
- co-morbidities (other conditions as well as diabetes in pregnancy) and complications
- genetics, fertility and related aspects
- information, education and service improvement
- relevant to the UK population.

The PSP will exclude questions about:

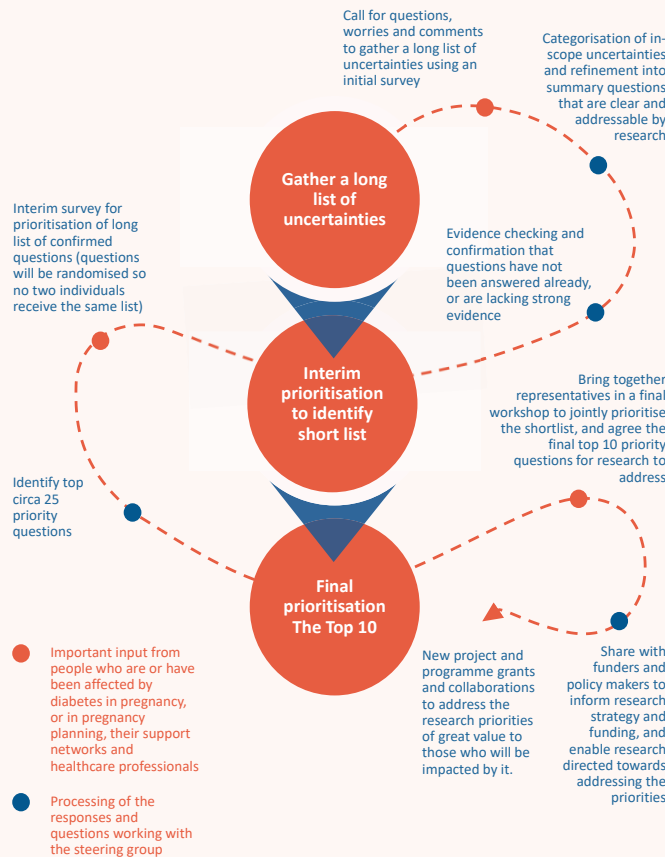
- pregnancy uncertainties not specific to diabetes
- care of the baby on the neonatal unit
- questions or priorities without a UK focus or relevance

The PSP will take a step-wise approach to defining the scope in that it will be led by the responses to the surveys throughout the process.

Methods

A James Lind Alliance Priority Setting Partnership (JLA PSP) in Diabetes and Pregnancy has been established by the University of Oxford, Diabetes UK, JDRF the type 1 diabetes charity, and Diabetes Research & Wellness Foundation.

Over approximately 18 months we will work with women and their support networks (families, partners and friends) affected by diabetes in pregnancy, and healthcare professionals (HCPs), to identify where little is known, or there are uncertainties about, health care and wellbeing in diabetes and pregnancy. The prioritisation process is summarised in the figure below.



Initial Survey

In the first phase, a UK-wide open survey, we invited submission of questions on anything about the time before, during or after pregnancy, with diabetes of any type.

446 surveys were received. 417 of these held a total of 1115 initial questions from 267 (63%) women and family members and 132 (32%) HCPs. The submissions will be analysed for themes and forming indicative questions.

Demographic		Women & support networks		HCPs		All groups aggregated	
Location	England	231	86.5%	116	87.9%	359	86.1%
	Scotland	18	6.7%	7	5.3%	25	6.0%
	Wales	6	2.2%	4	3.0%	11	2.6%
	Northern Ireland	5	1.9%	3	2.3%	8	1.9%
	Crown dependency	0	0.0%	0	0.0%	0	0.0%
	Not in the UK/not answered	7	2.6%	2	1.5%	14	3.4%
Age	19 years old or under	1	0.4%	0	0.0%	1	0.2%
	20 to 29 years old	68	25.5%	5	3.8%	75	18.0%
	30 to 39 years old	154	57.7%	29	22.0%	188	45.1%
	40 years old or over	41	15.4%	95	72.0%	142	34.1%
	Not answered	3	1.1%	3	2.3%	11	2.6%
Ethnic origin	White	204	76.4%	104	78.8%	316	75.8%
	Mixed/multiple	6	2.2%	4	3.0%	12	2.9%
	Asian/Asian British	36	13.5%	15	11.4%	52	12.5%
	Black/Black British	4	1.5%	2	1.5%	6	1.4%
	Other	4	1.5%	4	3.0%	9	2.2%
Not answered	13	4.9%	3	2.3%	22	5.3%	
Education level	School (up to GCSE/equivalent)	19	7.1%	1	0.8%	21	5.0%
	School (A-levels/equivalent)	21	7.9%	1	0.8%	22	5.3%
	Higher education (e.g. college)	47	17.6%	7	5.3%	57	13.7%
	Degree level or higher	172	64.4%	122	92.4%	302	72.4%
Not answered	8	3.0%	1	0.8%	15	3.6%	

Outcomes

The indicative questions not already answered by research will be taken through prioritisation over the coming year. The top ten questions, and full shortlist, will be shared with the public, research funders, national policy makers and clinical studies groups to inform their priorities and strategies for funding research. Thereby, this project will enable funders to support research for which there is great need and that is aligned with the priorities of those impacted by it.

Questions?

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Want to be involved?

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Contact us!



Our thanks to our funders and partners:

