

The top ten research priorities in diabetes and pregnancy according to women, support networks and healthcare professionals

Supplementary information

Table S2: The full list of 60 indicative questions presented in groups by phase of pregnancy, with rank by groups. Darker grey indicates higher number of questions, votes or priority rank. Top ten are highlighted. All – aggregated across all groups; W&SN – Women and support networks; HCP – Healthcare professionals; EM – Ethnic minorities; T2D/other – Type 2 diabetes and other types not separately listed; T1D – Type 1 diabetes; GDM – Gestational Diabetes.

#	Phase of pregnancy	Broad category	Indicative Question	FINAL RANK	Interim survey raking by group							Initial survey submissions count by group			
					All	W&SN	HCP	EM	T2D/Other	T1D	GDM	All	W&SN	HCP	Other/unk
1	Before pregnancy	1. The time before pregnancy	What effect does diabetes, or previous gestational diabetes, have on a woman's fertility (ability to get pregnant and number of pregnancies)?	40	40	18	52	21	59	33	20	7	7	0	0
2	Before pregnancy	1. The time before pregnancy	How can a woman with diabetes best prepare for pregnancy? For example blood sugar level targets, nutrition.	14	12	36	10.5	37.5	18.5	16.5	38.5	10	4	6	0
3	Before pregnancy	1. The time before pregnancy	How much and for how long should women with diabetes take folic acid before pregnancy?	57	57	54	57	44.5	57.5	47	54.5	2	2	0	0
4	Before pregnancy	1. The time before pregnancy	For women with diabetes, what factors (i.e. their age, the duration they have had diabetes, contraception) may be important to consider when planning to have a family?	55	55	52	52	49	44.5	33	53	6	5	1	0
5	Before pregnancy	1. The time before pregnancy	How can care and services be improved for women with diabetes who are planning pregnancy? For example, removing barriers to attending pre-pregnancy clinics.	10	13	47	2	33	2	10	45	37	4	32	1
6	During pregnancy	2. Diagnosis of diabetes, particularly GDM, and understanding the risks and prevention	What is the best test to diagnose diabetes in pregnant women?	1	15	46	7	13	8	43	21.5	14	0	14	0

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7	During pregnancy	2. Diagnosis of diabetes, particularly GDM, and understanding the risks and prevention	What are the different types of diabetes that develop in pregnancy and how can they be promptly and accurately diagnosed?	60	60	60	59	57	60	60	59	3	1	2	0
8	During pregnancy	2. Diagnosis of diabetes, particularly GDM, and understanding the risks and prevention	What is the best way to test for and treat diabetes in late pregnancy i.e. after 34 weeks?	7	16	57.5	4	44.5	3.5	41	43.5	29	1	28	0
9	During pregnancy	2. Diagnosis of diabetes, particularly GDM, and understanding the risks and prevention	Does testing all pregnant women for gestational diabetes improve pregnancy outcomes?	17	8	20.5	5.5	16	7	47	8.5	11	3	8	0
10	During pregnancy	2. Diagnosis of diabetes, particularly GDM, and understanding the risks and prevention	Why do some women develop diabetes in pregnancy and others don't? Can this be predicted for individual women?	30	30	16.5	36.5	5.5	44.5	59	8.5	34	24	4	6
11	During pregnancy	2. Diagnosis of diabetes, particularly GDM, and understanding the risks and prevention	What are the most effective ways (i.e. diet, lifestyle, medication) to prevent a woman developing diabetes in pregnancy?	26	26.5	30	20	8.5	37.5	55	17	28	13	12	3
12	During pregnancy	3. How diabetes, blood sugar or non-blood sugar factors, affects pregnancy (and fetus) and vice versa	What causes women with diabetes in pregnancy to have larger or smaller than average sized babies, and can it be prevented from happening?	38	37.5	20.5	45	21	22	20.5	21.5	10	6	4	0

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13	During pregnancy	3. How diabetes, blood sugar or non-blood sugar factors, affects pregnancy (and fetus) and vice versa	For women with diabetes, what is the best way to monitor the baby's health during pregnancy? For example, timing of scans, in pregnancies where the baby is larger than average size, etc.	23	22.5	11	32	13	37.5	15	15.5	5	1	3	1
14	During pregnancy	3. How diabetes, blood sugar or non-blood sugar factors, affects pregnancy (and fetus) and vice versa	How do we diagnose or predict problems with the baby in the womb caused by diabetes in pregnant women?	42	42	28.5	45	27.5	37.5	40	27	8	6	2	0
15	During pregnancy	3. How diabetes, blood sugar or non-blood sugar factors, affects pregnancy (and fetus) and vice versa	Can the risk of pregnancy loss (miscarriage, fetal death or stillbirth) be predicted in women with diabetes?	27	26.5	25	25	37.5	25.5	22	27	12	4	7	1
16	During pregnancy	3. How diabetes, blood sugar or non-blood sugar factors, affects pregnancy (and fetus) and vice versa	Does variation in a woman's blood sugar (level, range and duration) affect their pregnancy and baby, and if so, how?	29	29	12	40.5	21	40	13	18.5	28	23	4	1
17	During pregnancy	3. How diabetes, blood sugar or non-blood sugar factors, affects pregnancy (and fetus) and vice versa	What factors aside from maternal blood sugar levels have an effect on pregnancy outcomes? Can these be tested for and used to improve the outcomes of the pregnancy?	34	34	42.5	20	37.5	10.5	20.5	37	6	4	2	0

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18	During pregnancy	3. How diabetes, blood sugar or non-blood sugar factors, affects pregnancy (and fetus) and vice versa	For women with diabetes, does pregnancy affect their risks of diabetes-related complications? Does the risk change with further pregnancies?	49	49	38	52	49	49.5	18	52	8	6	1	1
19	During pregnancy	4. How diabetes can be managed and how management is affected by pregnancy/ diabetes type	What is the best way to medically manage blood sugar levels during pregnancy for women with different types of diabetes? This includes finding new treatments.	37	37.5	49	16.5	49	25.5	31	46	43	33	9	1
20	During pregnancy	4. How diabetes can be managed and how management is affected by pregnancy/ diabetes type	For women with diabetes, what is the best way to manage blood sugar levels using diet and lifestyle during pregnancy? Wider factors to consider include maternity leave, dietitian services, safety and effectiveness of specific diets e.g. low carbohydrate, personalised diets.	3	14	8	45	3	37.5	28.5	10	47	23	22	2
21	During pregnancy	4. How diabetes can be managed and how management is affected by pregnancy/ diabetes type	What is the best way to monitor blood sugar levels of pregnant women with diabetes?	44	44	45	36.5	41	54	43	41	8	2	6	0

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22	During pregnancy	4. How diabetes can be managed and how management is affected by pregnancy/ diabetes type	How can diabetes and pregnancy management be tailored for individual women during their pregnancy? Taking into account, for example, different types of diabetes, the phase or type of pregnancy, risk to pregnancy, or women's own preferences.	45	45	37	45	57	47	37	38.5	34	17	15	2
23	During pregnancy	4. How diabetes can be managed and how management is affected by pregnancy/ diabetes type	What psychological interventions can help motivate or support pregnant women in their diabetes management?	31	31	40	14.5	53.5	29	28.5	34	3	0	3	0
24	During pregnancy	4. How diabetes can be managed and how management is affected by pregnancy/ diabetes type	Are diabetes medications (e.g. metformin, insulin) safe in pregnancy and for the baby in the short and long term?	33	33	19	40.5	33	33	50	13	24	16	8	0
25	During pregnancy	5. How pregnancy complications are managed including steroids	What is the best way to manage sickness/vomiting in pregnancy with diabetes? For example, hyperemesis in women with type 1 diabetes.	51	51	51	40.5	59.5	49.5	24.5	56.5	6	3	3	0
26	During pregnancy	5. How pregnancy complications are managed including steroids	How can the diagnosis and management of preeclampsia be improved for pregnant women with diabetes with and without diabetes-related complications e.g. diabetic nephropathy?	56	56	53	52	49	49.5	30	54.5	5	3	2	0

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27	During pregnancy	5. How pregnancy complications are managed including steroids	How can we optimise the benefits and reduce the risks of steroid administration in pregnant women with diabetes?	52	52	59	36.5	44.5	22	47	56.5	9	2	6	1
28	During pregnancy	5. How pregnancy complications are managed including steroids	In women with diabetes, does diabetic neuropathy affect the woman's ability to feel and detect movements of their baby in the womb? What impact does this have on risks and outcomes?	59	58.5	57.5	55.5	53.5	52	55	58	1	1	0	0
29	Labour and birth	6. Labour and birth	In women with diabetes, what is the best way to manage their blood sugar levels during labour and delivery? For example, blood sugar targets, women managing their diabetes themselves, insulin infusions/sliding scale, use of diabetes management/monitoring technology.	15	5	7	8.5	33	5.5	2	15.5	18	14	4	0
30	Labour and birth	6. Labour and birth	Why does being on diabetes medications in pregnancy affect the way women can give birth?	47	47	35	52	27.5	49.5	57.5	29.5	2	1	1	0
31	Labour and birth	6. Labour and birth	When is it safe for pregnant women with diabetes to have a vaginal birth compared to e.g. a caesarean section?	48	48	33	55.5	41	55.5	26	47	19	15	3	1

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32	Labour and birth	6. Labour and birth	Is it always necessary for pregnant women with diabetes to be induced?	18	6	9	12.5	7	13	14	6.5	17	15	2	0
33	Labour and birth	6. Labour and birth	In pregnant women with diabetes, how does diabetes affect whether inducing birth will work?	54	54	40	60	49	55.5	51	43.5	2	2	0	0
34	Labour and birth	6. Labour and birth	When is it safe for pregnant women with diabetes to give birth at full term compared with early delivery via induction or elective caesarean? For example, factors may include managing timing of delivery according to changes in blood sugar levels, insulin requirements, size of the baby.	5	1	3	3	5.5	5.5	4	4	16	9	4	3
35	Labour and birth	6. Labour and birth	When is it safe for women with diabetes to give birth at home or in a midwifery unit/birthing centre compared with a hospital birth?	24	24	22.5	25	27.5	15	37	13	4	0	4	0
36	Labour and birth	6. Labour and birth	Do all women with diabetes need continuous Electronic Fetal Monitoring during labour?	35	35	31.5	32	33	25.5	37	33	1	0	1	0
37	Labour and birth	6. Labour and birth	Is it possible to predict shoulder dystocia in pregnant women with diabetes, and does this improve pregnancy and birth outcomes?	43	43	44	32	27.5	18.5	47	31.5	2	0	2	0

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38	Labour and birth	6. Labour and birth	What are the labour and birth experiences of women with diabetes, and how can their choices and shared decision making be enhanced?	9	11	10	32	21	18.5	8	13	6	3	3	0
39	After pregnancy and birth	7. The time after birth, specifically breastfeeding, and long term effects on the child	How does breastfeeding affect diabetes management for the mother? How can women with diabetes be better supported during breastfeeding?	32	32	28.5	28	27.5	41.5	12	48	37	31	6	0
40	After pregnancy and birth	7. The time after birth, specifically breastfeeding, and long term effects on the child	What effect does diabetes have on breastmilk and breastfeeding? For example, the safety of diabetes medications, and low-carbohydrate diets.	41	41	22.5	48.5	16	44.5	23	31.5	26	21	5	0
41	After pregnancy and birth	7. The time after birth, specifically breastfeeding, and long term effects on the child	How effective is collecting colostrum/breast milk before birth in improving clinical outcomes for the baby when born? When is the best time to collect this?	28	28	26.5	25	44.5	44.5	27	27	8	3	5	0
42	After pregnancy and birth	7. The time after birth, specifically breastfeeding, and long term effects on the child	Does diabetes in the mother affect the short and long-term risk of the child (and future generations) developing diabetes and can it be prevented?	12	9	5	23	21	15	5	11	64	52	8	4

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43	After pregnancy and birth	7. The time after birth, specifically breastfeeding, and long term effects on the child	What are the long-term effects on the child (apart from risk of diabetes) due to the mother having diabetes during pregnancy? For example, weight in the short and long term, and mental development.	11	2	1	8.5	1	3.5	6	2	86	72	12	2
44	After pregnancy and birth	7. The time after birth, specifically breastfeeding, and long term effects on the child	What is the best way to prevent, monitor, and manage low blood sugar levels of babies born to mothers with diabetes during pregnancy?	22	22.5	15	28	13	25.5	7	29.5	18	12	6	0
45	After pregnancy and birth	8. The time after birth, specifically long term effects of pregnancy on the woman with diabetes	In women with diabetes, what effect does pregnancy have on diabetes-related complications (pre-existing and new) later on in their life?	39	39	31.5	36.5	57	29	11	50	29	23	6	0
46	After pregnancy and birth	8. The time after birth, specifically long term effects of pregnancy on the woman with diabetes	In women with gestational diabetes, what is best way to reduce their risk or prevent them from developing other types of diabetes any time after pregnancy?	8	3	6	5.5	2	9	52	3	64	46	14	4
47	After pregnancy and birth	8. The time after birth, specifically long term effects of pregnancy on the woman with diabetes	In women with gestational diabetes, what are the long-term effects of diabetes on their health, such as heart disease, any time after pregnancy? Can this be prevented?	19	18	16.5	16.5	27.5	22	53	6.5	22	16	4	2

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48	After pregnancy and birth	8. The time after birth, specifically long term effects of pregnancy on the woman with diabetes	What are the specific postnatal care and support needs of women with diabetes and their infants? For example, breastfeeding, recovery from childbirth, managing diabetes with a newborn.	6	20	13.5	28	10.5	33	3	35.5	9	8	1	0
49	After pregnancy and birth	8. The time after birth, specifically long term effects of pregnancy on the woman with diabetes	What is the best way to follow-up and screen women with gestational diabetes after their pregnancy?	25	25	34	14.5	21	33	55	18.5	10	4	6	0
50	Cross-cutting	9. Technology in managing pregnancy with diabetes	How can diabetes technology be used to improve pregnancy, birth, and mother and child health outcomes? For example, continuous and glucose flash monitoring, insulin pumps, closed loop systems, apps, etc.	1	4	13.5	1	10.5	1	1	23	10	3	6	1
51	Cross-cutting	9. Technology in managing pregnancy with diabetes	How effective (clinically and cost) is the use of continuous glucose monitoring in pregnant women with diabetes?	36	36	42.5	22	37.5	29	37	35.5	7	2	5	0
52	Cross-cutting	9. Technology in managing pregnancy with diabetes	How safe and effective is the use of closed loop systems (also known as artificial pancreas) in improving outcomes of pregnancy and birth?	50	50	50	40.5	59.5	53	19	60	3	2	1	0

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53	Cross-cutting	10. Mental health and wellbeing before, during and after pregnancy with diabetes	What are the emotional and mental well-being needs of women with diabetes before, during, and after pregnancy, and how can they best be supported?	4	7	4	20	8.5	18.5	9	5	14	12	2	0
54	Cross-cutting	10. Mental health and wellbeing before, during and after pregnancy with diabetes	How can support networks i.e. family and friends, help to support women with the challenges they face in pregnancy? Also, how can support networks themselves be supported?	58	58.5	55	58	53.5	57.5	57.5	51	6	5	1	0
55	Cross-cutting	11. Healthcare services including models and standards of care delivery in managing pregnancy with diabetes	How should diabetes specialists and clinics be involved at all stages, pre-pregnancy to after birth, for women with diabetes?	46	46	40	45	16	33	37	41	3	3	0	0
56	Cross-cutting	11. Healthcare services including models and standards of care delivery in managing pregnancy with diabetes	How can remote clinics (telemedicine) be used to improve care for pregnant women with diabetes?	13	17	56	10.5	41	15	43	49	4	0	4	0
57	Cross-cutting	11. Healthcare services including models and standards of care delivery in managing pregnancy with diabetes	How can community care services for pregnant women with diabetes be improved?	53	53	48	48.5	53.5	41.5	47	41	3	0	3	0

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58	Cross-cutting	11. Healthcare services including models and standards of care delivery in managing pregnancy with diabetes	Why do standards and advice for pregnant women with diabetes vary across NHS Trusts?	16	10	2	32	4	33	33	1	3	3	0	0
59	Cross-cutting	11. Healthcare services including models and standards of care delivery in managing pregnancy with diabetes	How can continuity of care and support services be improved for women with diabetes before, during and after pregnancy?	20	19	26.5	12.5	33	10.5	24.5	24.5	18	14	4	0
60	Cross-cutting	11. Healthcare services including models and standards of care delivery in managing pregnancy with diabetes	What information e.g. on risks or complications, should be given to women with diabetes during their pregnancy? What is the best way to give this information?	21	21	24	18	21	12	16.5	24.5	15	12	2	1