A photograph of a woman with dark curly hair holding a baby. The woman is looking down at the baby with a gentle expression. The baby is looking towards the camera. The background is a soft-focus indoor setting with light blue walls and some toys on a table.

Supporting women to manage gestational diabetes and prevent future risk of type 2 diabetes

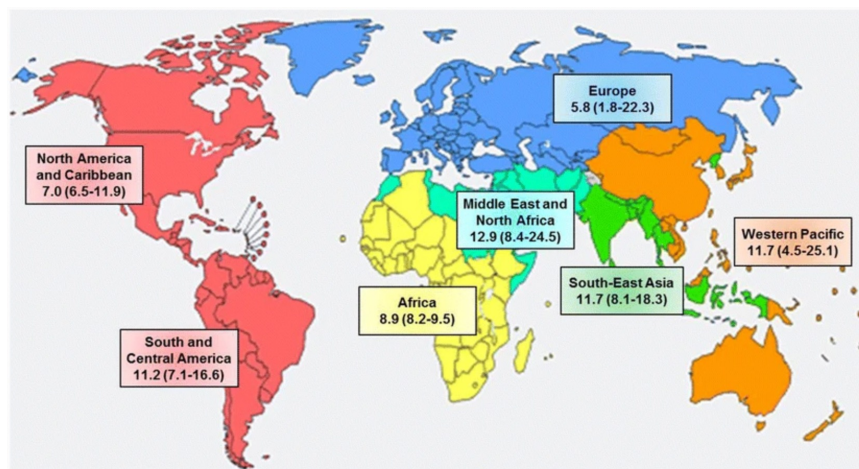
Findings from the ELOPE-GDM interview study

Welcome

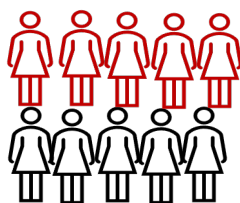
- Research team:
- Dr Shoba Poduval, Dr Jamie Ross & Dr Amanda Moore (UCL)
- Agenda for today's event:
 - 13.00 – 13.05: Diabetes in pregnancy and background to the study
 - 13.05 – 13.15: Introduction to Cambridgeshire Community Services involvement
 - 13.15 - 13.45: Research findings
 - 13.45 – 13.50: A participant perspective
 - 13.50 - 14.10: Public & community input
 - 14.10 - 14.20: Q & A
 - 14.20 - 14.30: Close



Gestational diabetes is a key point to intervene



35,000 UK pregnancies/year

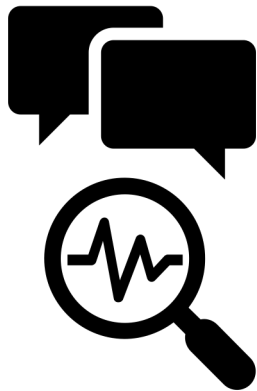


50% type 2 diabetes later

- Risk factors:
 - Ethnicity
 - Increased BMI
 - Maternal age
 - Social deprivation
- Implications:
 - Risk to mother and child
 - Increased risk of type 2 diabetes & metabolic conditions
- Lifestyle management is the cornerstone of care in pregnancy and postpartum

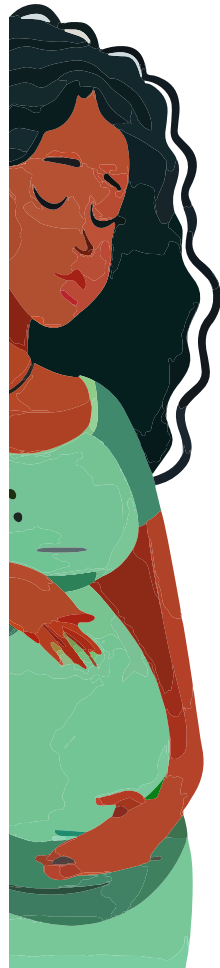
Aims and methods

Explore factors influencing engagement with GDM self-management & lifestyle guidance during pregnancy and beyond amongst a diverse sample of UK women



- Semi-structured interviews online and face-to-face (Nov 22-Mar 23)
- Thematic analysis (Braun & Clarke, 2006)
- Data sessions with stakeholders to validate interpretations

Inclusivity



Examples of under-served groups:

- Women of childbearing age
- Ethnic minority groups
- Educational disadvantage
- Socioeconomically disadvantaged/unemployed./low income
- Language barriers

Barriers:

- Poor publicity
- Lack of incentives
- Lack of interest
- Negative attitudes to research

<https://www.nihr.ac.uk/about-us/our-key-priorities/under-served-communities.htm>

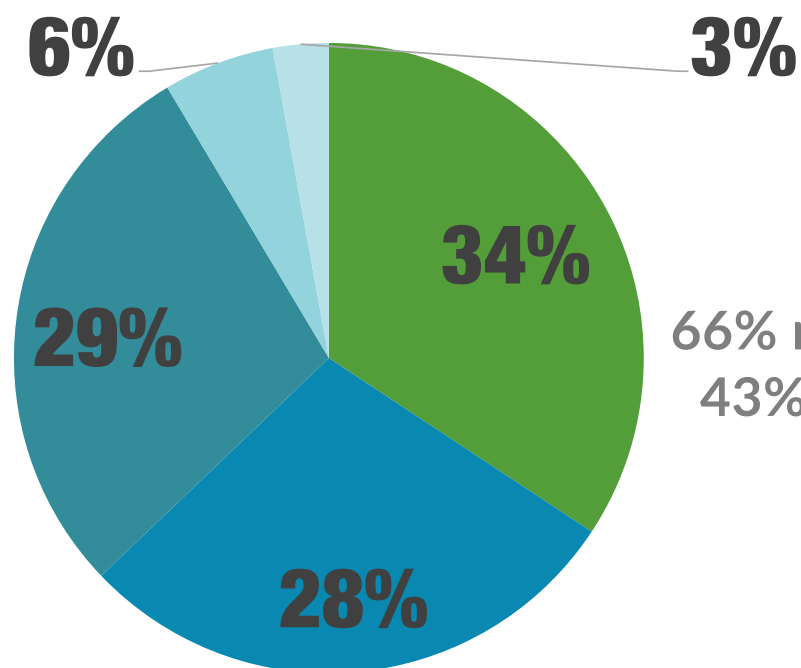
Inclusivity

- Targeted recruitment
- Relationship building
- Accessibility
- Sharing findings through a range of outputs



P.H.♀.E.B.E

- White British/Other
- Black African/ Black British
- S. Asian/Asian British
- SE Asian/Asian British
- Mixed race



n = 35

66% minority ethnicity
43% first generation

Introducing CCS and their role in the study

Katherine Vale, Cambridge Community Services NHS TRUST



Getting involved with ELOPE-GDM

- Why our Health Visitors felt the study was important to support at CCS
- How we invited our families to join the study
- The challenge of language barriers in research, and our hope for future research

The background of the slide is a light cream color with several colorful, stylized speech bubbles in shades of orange, yellow, green, blue, and red. One large orange speech bubble is in the foreground, partially overlapping the text.

What did women say? ***Our headline findings***

Dr Amanda Moore, UCL

Overview



- Increased anxiety
- Loss of control of their plans
- Loss of enjoyment of pregnancy
- Driven to do the best for the baby

The GDM pregnancy



The burden

Coping with everyday

Retaining power



Relational factors

Service provision



Left at sea

Life gets in the way

GDM self-management

T2D risk reduction

A background image showing a pregnant woman's belly in a maroon and grey striped shirt. In the foreground, there is a yellow wooden dinosaur toy, a green apple, and a box with a colorful heart pattern.

Pregnancy... GDM self-management

Theme 1: The burden



- Cognitive burden of practical management
- Guilt & culpability
- Loss of control
- For the baby you find a way

always having to think about food, it becomes completely invasive...set an alarm test your sugars, you've got to time everything (14-WB)

I was put on metformin two days after I was given my test kit...they could have given me a chance to look at my diet. I hadn't had a dietitian appointment by that time... I didn't really have a voice. I feel like my voice wasn't heard'. (10-SA)

Horrendous. It's horrendous, yes. Like, it's so emotive I think for a woman to feel like what she is eating is potentially damaging her unborn child. I was trying really hard to control it....you still feel like, "Yes, I haven't done enough." (3-WB)

Theme 2: Coping with everyday



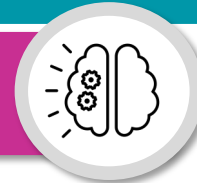
- Social & cultural influences on lifestyle behaviours
- External pressures
- Pregnancy pressures

I stopped recording, stopped checking all the time... they said you don't do it this way. Why did you stop recording?

That's not how we can follow good treatment. I did have quite a lot on my mind at that time, that was the least thing on my mind. (26-BA)

We are Bengali people, we eat more rice...your mum she teach you how to just eat rice, rice, rice. Like in the morning rice! lunch rice! dinner rice ! snacks rice! All the thing in mainly carb and in Bangladesh we eat our dinner night-time like 10 O'clock, 11 O'clockso take your dinner before 7...? (24-SA)

Theme 3: Retaining power



- Seeking peer support
- Taking control

I've made a spreadsheet, I make little plots it has the date the timepoint, what I've eaten... (13-WB)

I requested the doctor, could he refer me the dietitian. That time the doctor told me it could be quite long because there is a long queue. I said I don't mind but I wanted to because I wanted to control this diabetes. (24-SA)

That's what the Facebook group is doing, it's people who have gone through the experiences, helping each other. [...] That's what you need support in everything you are doing. More than a half and hour chat midway through your pregnancy. [...] The fact that Facebook pages are being set up to try and support mothers suggests there's a gap. (3-WB).

Theme 4: Relational factors



- Positive reinforcement and empathy
- Judgement and pressure

....why did you eat two pieces of toast? You should have eaten one. I remember that because I felt so bad, like I was being greedy (3-WB)

I'll be honest I lied about my numbers sometimes, I'm not going to lie. Because I thought they didn't give me that care and so why should I? But what I didn't understand is that it is affecting the baby. (34-SA)

I loved the head of my team, she was just calm and nice. She would talk to you about it, she would make you playful but at the same time very serious. She was just amazing, and when she called me on the phone she talks to you like this. And because I'm Black, maybe you don't have many people talk like that or treat me [like that]. My accent is quite heavy right? She would listen to me even if I have to say it 5 times. She will really take her time and check I understand, without feeling agitated. (35-BA).

Theme 5: Service provision



- Education was inconsistent across the sample
- Technology & remote support
- Universal guidance

I thought it was really poor...the kind of NHS typical eat a low fat, healthy plate diet. [...] I always remember them saying for a snack you might want to eat two satsumas... I think I switched off at that point, it was like ok you're talking nonsense. (14-WB)

'I would say I didn't have much information on the Indian stuff, I had to go to YouTube.' (4-SA)

GDm-Health App (used by 37%)

...A major help

...Really clever

....An efficient way to communicate

It was helpful because you could just see it without having to think about what did I eat the other day. Especially if I did not remember what spiked my sugars. It was just easy to just kind of go back and look at it (19-BA).

A large group of yellow rubber ducks is arranged on a blue wooden surface. In the center, one duck is sitting on a white and orange lifebuoy. The ducks are all facing forward, and the lifebuoy is positioned directly in front of the central duck.

**Postpartum...diabetes
risk reduction**

Theme 5: Left at sea



- Dramatic contrast with close monitoring during pregnancy
- Confusion of messages from different healthcare teams
- Confusion in personal risk
- No concrete picture: uncertainty and confusion over what to do next
- Falling through the cracks - It's up to you
- Low awareness of annual screening (46%)

*After [I gave birth] I heard nothing about the diabetes. [...] I heard before that it tends to go away straight after birth, so I kind of figured it was gone. I didn't monitor or check it. They didn't say anything else after, like if I should monitor it myself or whatnot. So - there was no information given after birth
(27-South Asian)*

Theme 3: Life gets in the way



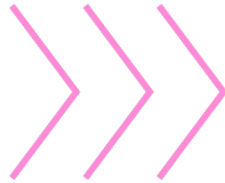
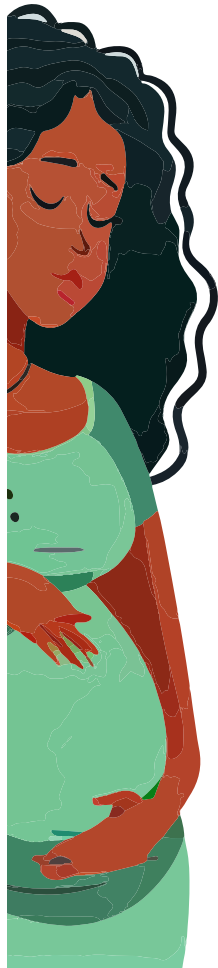
- Social challenges and lack of social support (worse for immigrant women & socially disadvantaged)
- Competing responsibilities of childcare and mothering
- Health challenges – pre-existing & from pregnancy
- Work loads on the pressure.
- GP needs to be my partner

I think I've got some post-natal depression and really crippling anxiety [...] It's a lot of pressure, a lot of stress and where I live is not a family-friendly zone either. I've had issues with the noise from my neighbours and stuff... it's affected my sleep, my stress levels, constant banging on the walls and doors at 3 and 4 in the morning. It's really disrupted my sleep (WB-15)



Implications for policy & practice...?

GDM in pregnancy



The burden

Coping with everyday

Taking control

Relational factors

Service provision

• Clinical Practice

- Use language carefully – empathy with balanced risk assessment
- Give advice earlier to those with risk factors
- Recommend the use of GDM apps
- Signpost to more detailed dietary support for those who need more detail or further cultural support
- Signpost to peer support
- Link to community groups to provide cultural-specific support

• Research, intervention & service development

- Develop more detailed NHS online dietary resources
- Consider community-delivered support for those needing it (Cultural or socioeconomic)

Postpartum diabetes risk



Left at sea

Life gets in the way

• Clinical Practice

- Ensure midwife teams & health visitors give consistent discharge messages
- Streamline postpartum post-GDM check with existing care pathways when possible
- Text reminders for HbA1C screen
- Sign-post to simple clear resources
- Flag on system and use touchpoint conversations after 1 year postpartum

• Research, intervention & service development

- Development of stratified risk calculator
- Development of inclusive online resource for more information.
- Developing community services to support disadvantaged women & those with cultural barriers to care.



Dissemination and more information

- Infographic development
- Study findings
- Postpartum guidance in partnership with Sussex NHS Trust



Supporting self-management of gestational diabetes during pregnancy and type 2 diabetes risk reduction after birth UCL

The problem 5% of pregnant women in the UK (around 35,000) are diagnosed with gestational diabetes every year.

How does our research help? Lifestyle change is the first-line strategy for gestational diabetes self-management and type 2 diabetes risk reduction. We interviewed 35 women who have had gestational diabetes (66% from minority ethnicities) to explore how we can support them with lifestyle change.

Key challenges for women

During pregnancy

- I feel anxious and overwhelmed
- I need guidance that applies to my usual diet
- I'll do what I can for the sake of my baby.
- Life is already complicated enough

After pregnancy

- What's my personal risk?
- Life gets in the way
- I don't know about annual screening
- What steps should I take?
- I feel confused about what I should do.

NIHR School for Primary Care Research

7 ways to reduce the risk of Type 2 diabetes for women following gestational diabetes UCL

Women who have had gestational diabetes are more at risk of type 2 diabetes, but did you know that about half of all cases of type 2 diabetes could be prevented or delayed with simple changes to daily habits.

- 1. Know your risk**
HbA1c is your average blood sugar over the last 2 to 3 months. Arrange an HbA1c check with your GP three months after the birth of your baby and every year after that.
Top Tip To help you remember, try to arrange an HbA1c check around your baby's birthday each year.
[read more here](#)
- 2. 30+ active minutes a day**
Whatever your favourite activity is, try to up the intensity, so you feel a little out of breath for at least 10 minutes at a time. Include twice a week resistance training such as Pilates, weight training, sit ups, yoga or digging the garden.
Top Tip Achieving 150 minutes a week of at least moderate-intensity physical activity reduces your risk of type 2 diabetes by up to 50%.
[read more here](#)
- 3. Stand and walk more**
Try taking regular breaks during sitting or TV time, have standing meetings, or walk during lunchtime.
Top Tip Breaking up sitting time with two-minute walks every 20 minutes helps maintain blood sugar and improve insulin response.
[read more here](#)
- 4. Maintain healthy weight or aim for at least 5% weight loss**
Aim to keep your weight within the recommended weight range or if overweight, even moderate weight-loss makes a big difference.
Top Tip Losing at least 5% of extra weight can reduce blood pressure, cholesterol and reduce your risk of developing type 2 diabetes.
[read more here](#)
- 5. Get free support online**
Having had gestational diabetes you qualify to participate in an NHS Diabetes Prevention Programme: call 0133 577 5010 or email info@preventingdiabetes.co.uk.
Top Tip Recommended by 98% of participants. Attend a free class or join online to get support from a trained diabetes prevention coach.
[read more here](#)

Choose your carbohydrate carefully

To avoid sugary foods (fizzy drinks, sweets and cakes) and processed carbohydrates (white bread, chips, pasta, white rice, etc.) and protein can help blood sugar balance.

Top Tip Choosing carbohydrate that releases glucose slowly (such as lentils, beans, oats and brown rice) and eating carbs with healthy fats (like avocados and nuts) and protein can help blood sugar balance.
[read more here](#)

7. Half veggies

Fill half your plate with non-starchy vegetables or use them in starchy curries. Eat with lean protein like fish, chicken, tofu or soy-based protein and high-fibre carbohydrates like beans, lentils and wholegrains.

Top Tip Increasing veg, healthy proteins and high fibre foods can help to balance blood sugar, appetite and provide more health boosting nutrients.
[read more here](#)

Substitute

Substitute with smaller portions of higher fibre carbohydrate like:

- rice
- pasta
- bread
- cereal
- potatoes
- sweet potatoes
- legumes
- chickpeas
- lentils
- bulgur wheat

and healthy proteins like:

- nuts and seeds
- fish
- chicken
- eggs
- vegetarian protein

[click here for recipe ideas](#)

NIHR School for Primary Care Research

Dissemination and more information



- **Infographic development**
 - Study findings
 - Postpartum guidance in partnership with Sussex NHS Trust
- **Conferences**
 - SAPC, HSR, RCOG 2023
- **2 academic papers**
 - Thematic analysis
 - Behavioural analysis
- **Updates on the UCL study web-site**
 - Lay summary
 - Resources
 - Presentations
 - Academic outputs



amanda.p.moore@ucl.ac.uk

The background of the slide is a close-up photograph of interlocking puzzle pieces. Some pieces are white, and others are a vibrant yellow. The pieces are arranged in a way that creates a sense of depth and texture, with shadows highlighting the edges. A semi-transparent yellow rectangular box is overlaid on the right side of the image, containing the title text.

The participant perspective

Thoughts from one of our contributing interviewees

I wanted to help improve experiences of other women with GDM, to help them by sharing my experiences. I think it's great you are taking the time to understand how women feel.

Getting involved was easy, supportive and fun. The interview I had was professional, informative and empathetic....I liked it!

Getting involved in research

A series of blue paper cutouts of human figures holding hands in a line, receding into the distance. The figures are positioned on a light-colored surface, and their shadows are cast onto the surface below them, creating a sense of depth and perspective.

Dr Jamie Ross, QMUL

Involvement in research – You help do it!

- The aim is to do research 'with' people rather than 'about' people
- People who are affected by certain health issues are 'experts by experience'
- They possess a wealth of knowledge that researchers do not have
- Their expertise can help make research better



How PPI was incorporated into the ELOPE– GDM study

- **Who**
 - Two PPI representatives recruited at the very start of the project
 - Both women with recent experience of GDM
- **How**
 - Gave their input into the research questions and protocol (how we proposed to do the study)
 - Helped to devise and refine the questions we asked of the research participants in the interviews
 - Shared ideas on where to recruit participants from
 - Provided insights from their lived experience of GDM into our analysis of the interview data
 - Advised on the best way to make the findings relevant to other people impacted by GDM



Reflections on participation

Being diagnosed with GDM can be a worrying experience, at a time when many women are already experiencing significant stress, and there is a lot of confusion and misinformation about what it means, both for women and their pregnancies...**I don't think it would be possible to reduce the lifetime risk without involving patients and understanding what matters to them in order to make lasting positive lifestyle changes.**

(ELOPE study PPI member)

“Having been diagnosed with GDM in my second pregnancy, the opportunity to contribute to research into the condition was **something that really mattered to me.**”

If researchers get it right the public can benefit from research in a number of ways....



Make a difference to future health and social care research



Helps people who have had a difficult health experience do something positive with it



To ensure the voice of their community/communities are represented in research



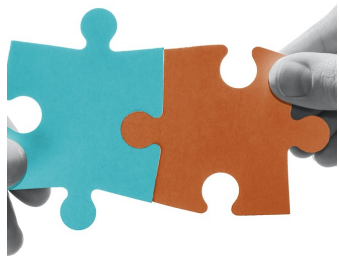
Find it interesting



To develop new skills

How can the public be involved in research?

- Examples of public involvement activities may include:
 - Helping to decide what will be researched
 - Being involved in developing grant applications
 - Providing input into the design of studies
 - Being members of study steering committees
 - Working with researchers to develop patient information materials
 - Undertaking interviews with research participants
 - Carrying out research as user and/or carer researchers



How to get involved

NIHR | National Institute for
Health and Care Research

People in **Research**

Home



View
Opportunities

Add
Opportunity

About Public
Involvement

Community Engagement
Partnerships

[Log in](#)

 My Favourite Opportunities (0)  Print

Opportunities for public involvement in NHS, public
health and social care research.

Find opportunities

I want to get involved

For members of the public who
would like to get involved in
research.

Add opportunity

I want people involved

For researchers who want to find
members of the public to get
involved in their research.

<https://www.peopleinresearch.org>



How to get involved

- Queen Mary University of London

PPI opportunities sign up form

<https://forms.office.com/e/J3zsHU70B2>



Example PPI opportunities

- Panel member for reviewing research funding applications
- Digital health research study
- Early onset type 2 diabetes
- Asthma
- COPD

How to get involved

- University College London PPI opportunities

public.advisors@ucl.ac.uk

Dr Sarah Griffiths & Dr Tom Whitney

Q & A

