

IOLANTHE MIDWIFERY TRUST AWARD 2021/22 REPORT

Award title: Midwife Award

Awardee: Veronica Blanco Gutierrez

Project title: The impact of ethnicity on perinatal urinary incontinence.

Project supervisors: Professor Vanora Hundley and Professor Sue Way
(Bournemouth University).

I would like to thank the Iolanthe Midwifery Trust for believing in me and giving me the opportunity to undertake this project. I have thoroughly enjoyed it. During the past year, I have had the opportunity to build networks, meet and listen to women, nurture my research skills and welcome new opportunities. I believe this award has truly helped me in achieving my dream of starting a PhD in my topic of interest, which is a great continuation of this project. Thank you from the bottom of my heart.

I also would like to thank my supervisors, Professor Vanora Hundley and Professor Sue Way, for their support, dedication and hard work. You have been an inspiration and midwifery role model. Thank you.

SUMMARY OF ACTIVITIES

Meetings and networking:

- ✓ Supervisory meetings with Professor Vanora Hundley and Professor Sue Way-between May 2021 to present.
- ✓ Meeting with Prof Maria Stokes and Olatundun Gafari- 23/08/21.
- ✓ Meetings and discussions with Patient Engagement team at the University Hospital NHS Foundation Trust and the University of Southampton- September-November 2021.
- ✓ Race Matters, meeting with Jane Bejoe, from the RCM, to discuss the importance of project, learn about the actions that the RCM is taking in regards to race in midwifery/maternity, to discuss my project and network- 15th November 2021.
- ✓ Faiza Rehman, midwife and founder of the Raham project. Faiza has reviewed the posters and helped me disseminate them and recruit participants- November 2021.
- ✓ Sandra Igwe, founder of The Motherhood Group. Sandra has reviewed the posters and has helped me to disseminate them and recruit participants.

Courses and other activities:

- ✓ PPI strategy, recruitment and dissemination activities (social media, Facebook, Twitter and Instagram)- see appendix 1.
- ✓ Systematic Reviewing to Inform Practice. Bournemouth University- January-April 2022.
- ✓ Public engagement course: high quality public engagement. Bournemouth University. 26th April 2021.
- ✓ Evaluation of public engagement events. Bournemouth University. 21st April 2021.
- ✓ Evaluating PPI for researchers. NHIR Cambridge BRC. 18th August 2021.
- ✓ Cultural competence (Health Education England). 8th September 2021.
- ✓ The NHIR-INCLUDE project course. 8th September 2021.

- ✓ Increasing Participation of Ethnic Minorities in Health And Social Care Research. NIHR Applied Research Collaboration East Midlands. 8th September 2021.
- ✓ Equality, Diversity and Inclusion course. NIHR. 8th September 2021.
- ✓ Public and Patient Involvement Training: skills-based sessions for researchers. NIHR, SOAR, University of Southampton and University Hospital NHS Foundation Trust- 20th October 2021 (Session 1: What is the right way to involve people; Session 3: Working with the public –getting the most out of your PPI activities; Session 5: Communicating in lay language).
- ✓ EoE Maternity Black History Month- Covid and Pregnancy and understanding and supporting the health needs of asylum seekers and refugees webinar. 3rd November 2021.
- ✓ Race and health system. 18th November 2021

PPI activity

Between 17th November 2021 and 20th June 2022, I met remotely via Zoom with five women from different ethnic backgrounds to learn from their experience with perinatal urinary incontinence and to learn about future recruitment strategies and their interest in the topic, identifying barriers and facilitators to their participation in a prospective research study on perinatal urinary incontinence.

Women's backgrounds included: Indian, British/Pakistani-Muslim (2nd generation); British/Black-African/Caribbean (1st generation); Nigerian, and British/Bangladeshi (1st generation). All women thought this research topic was interesting, valuable and worth undertaking. Some women highlighted that rather than religion, culture plays a vital role in seeking behaviour and discussing incontinence. For example, some women saw males as gatekeepers in the community, which could compromise women's participation in this type of research. It was also mentioned that it is not a topic many would discuss during or after pregnancy.

Most women said they would have more trust if midwives/GPs promoted the study, although dissemination through social media was also acceptable to them. One

woman, in particular, described how she had felt racism within the health care system and lost her trust in doctors.

I discussed with women that I was a white woman talking to women from different ethnic groups. Only one woman mentioned the possibility that some women might feel more comfortable talking to someone who looks like them, although this could also be seen as negative and could feel judged by people from the same background. Women expressed that the ethnic group of the interviewer/researcher was not an issue. Women stated that it was more important to them how the interviewer/researcher made them feel and whether they were approachable and listened to them respectfully and without judgements. This point was also highlighted in the feedback forms I received after the meetings (3 out of 5).

Regarding future research, it was clear that women want to be informed and aware of perinatal urinary incontinence before it happens. Some women suggested that it would be good to empower and inform women about their anatomy and physiology due to the current embarrassment and lack of knowledge of their own sexual and reproductive anatomy. Women also felt it was important for them to be listened to; they also thought that questions needed to be asked and that it was necessary to discuss incontinence and break the silence. Looking after themselves needs to be made a priority, and women feel they need to understand the importance of this, as some incontinence might not be an “urgent” matter.

I have enjoyed meeting with and listening to women, it has been a fantastic experience, and I feel lucky to have been given this opportunity to carry out this project and meet the fantastic women I have met.

Thanks to the networks and experience I gained with this project I was given the opportunity to undertake another PPI activity as a research assistant. In this role, I conducted individual meetings with women from ethnic minority backgrounds to learn from their experiences and understand their willingness to participate in a future research study about using the birth ball at home in early labour. This research is conducted by Dr Dominique Mylod, at Bournemouth University.

Next steps

- Blog submission: “Minoritised ethnic women and perinatal urinary incontinence: a patient and public involvement project”, currently under reviewed (all4maternity) (see appendix 2)
- Paper for publication “Ethnic minority women’s experiences of urinary incontinence: a systematic review” in the Journal of Transcultural Nursing. Currently preparing the submission.
- Potential second publication regarding the PPI activity undertaken, aiming to publish it in a PPI journal.
- To commence an EPSRC Centre for Doctoral Training in Digital Health and Care at the University of Bristol on the 19th September 2022. I will have the opportunity to develop my project on bladder health (see email attachment).

APPENDIX 1: PPI STRATEGY

ETHNICITY AND PERINATAL URINARY INCONTINENCE PATIENT AND PUBLIC INVOLVEMENT PROJECT STRATEGY

Objective of the project

This project's rationale originates in the unrepresentativeness of Black, Asian and ethnic minority women in perinatal UI research, which implies that the real impact of how UI may affect them is not understood. A better understanding of what women from ethnic minority groups think about research related to UI issues, the acceptance of this type of research and potential recruitment strategies would seem appropriate.

Although ethnicity does not seem to be a recognised risk factor for UI, such as age, parity, mode of delivery or baby's weight, Wilson¹ included race/ethnicity as part of a predictive score of future pelvic floor dysfunction following childbirth. In non-pregnant populations, women from Black, Asian and other ethnic minority groups seem to report higher levels of discomfort with stress UI than White and Hispanic women², despite presenting the lowest UI numbers. Several factors could explain this variation between ethnicities³:

- Research groups tend to have small sample sizes.
- Barriers to access health care may explain the low incidence of UI among minorities.
- Women are often excluded from research participation due to language barriers. A multi-ethnic research study⁴ on pregnant women revealed similar results to those in non-pregnant women. The authors acknowledged that:

- Lower numbers of UI among African origin women could be explained potentially by stronger pelvic floor muscles and collagen fibres. This assumption could be regarded as racial bias.

- Most prevalence studies have targeted Caucasian populations.

- European/North American women tend to have higher participation rates.

-Language barriers or cultural factors could affect the disclosure of UI. Therefore, there is a potential gap in the awareness, diagnosis and disclosure of perinatal UI. The underrepresentation of ethnic minorities seems a more plausible explanation of the lower reported rates of UI, highlighting health inequalities.

Rationale

Female UI is caused, in great measure, by pregnancy and childbirth⁵, affecting women's physically and mentally, and ultimately impacting negatively on their quality-of-life and health care costs⁶. This situation is reinforced by the lack of direct enquiry by health care professionals during and after pregnancy translated into a lack of conversation on UI prevention and diagnosis⁷ and lack of consensus on UI definitions, leading to underreports, and contributing to the great variations of prevalence in the literature⁸. Additionally, women and professionals lack awareness and knowledge on UI promotes its normalisation⁹.

Value of the project

The evidence gained from this project will enable me to apply for an NHIR doctoral study award on perinatal UI in women from ethnic minority groups. Funding from the Iolanthe Midwifery Trust will offer me an invaluable opportunity to gain a more in-depth knowledge of PPI and systematic reviews, from theory to its application in real life. Moreover, I will have the opportunity to learn more about UI from ethnic minority women's experiences, create links with different communities, and become aware of cultural safety practices, aiming to eradicate institutional racism and improve the quality of care I provide. This project will return the voice to ethnic minority women, by co-creating research with me and empowering and engaging them in a vital aspect of women's health. This PPI experience will make women aware of their power to change and improve maternity care. The literature review and its publication in a high impact factor journal is expected to trigger a much-needed discussion on the impact of ethnicity on perinatal UI.

By gaining a better understanding of the needs of ethnic minority women regarding UI, health professionals will be placed in an advanced position to engage women in

research. This project is also expected to significantly impact future practice, aiming to inform health care providers of the gaps identified in current evidence and break the cycle of health inequalities. Listening to women's experiences will also inform professionals on improving the care provided to women from ethnic minorities with UI.

Strategy

The project proposed encompasses a PPI activity, which aims to understand the acceptability of women from ethnic minority groups taking part in research in this area. This PPI strategy has been created to promote and secure the involvement of Black, Asian and Ethnic minority women who suffer or have suffered urinary incontinence during or after pregnancy to achieve the aim and objectives of the project.

Aim

To increase the likeliness that Black, Asian and Ethnic Minority women will agree to participate in a prospective perinatal urinary incontinence study.

Objectives

- To establish the acceptance of this type of research by Black, Asian and Ethnic minority women.
- To identify avoidable barriers to study participation.
- To explore potential recruitment strategies.

1. What problem are you trying to solve?

Low rates of Black, Asian and Ethnic minority women included in perinatal urinary incontinence research studies.

2. How can insight from women help you solve this problem?

Women have a unique perspective and may be able to help identify what the barriers or concerns could be for women.

3. What questions do you need to ask them to gather this insight?

How would they feel about the study and why? What are their thoughts on the purpose of the research? Would they be willing to take part and why? What would make them want to sign up or what would prevent them from doing it?

This strategy will refer to involving women as “to work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered”. This definition is included in the Spectrum of Public Participation designed by The International Association for Public participation (IAP2)’s.

Target audience

- ✓ Black, Asian and Ethnic minority women who have had a baby in the past 5 years and have suffered with urinary incontinence problems during and/or after pregnancy.
- ✓ Women over 18.
- ✓ Aiming to recruit 5 women.
- ✓ Due to limited budget, it will not be possible to provide translators, therefore women can bring a friend to translate for them if wanted.

Recruitment

Advertisement: two different posters have been created (see appendix 1), one targeting Black women and other targeting Asian women. In order to recruit women, I will contact local communities and places of faith, and promote this project among friends and colleagues.

A recruitment flyer has been created to support the recruitment and provide further information (see appendix 2).

If I am not able to recruit any participants, the next step will be to advertise in INVODirect and recruit women nationally, regardless of their location.

PPI method

Informal discussion via groups or individual meetings, depending on women’s preferences.

Date and time that suits participants, face to face or telephone/video calls depending on participant’s preferences and Covid-19 restrictions at the time.

Once women agree to participate, they will be given a pre-read document to prepare them prior to the PPI activity (see appendix 3).

Delivering PPI activity

In May 2021 I received an award from the Iolanthe Midwifery Trust (£1500). Please see appendix 4 for budgeting for involvement according to NIHR guidance.

Due to the nature of the topic, if any participant discloses the existence of a concern or disease or is affected by the discussion, it will be referred to community services available, such as GP and other health care professionals.

An discussion transcript has been created to assist with the delivery of the PPI activity (see appendix 5).

Evaluation

A feedback form has been created to improve my skills in facilitating PPI activities and to review the usefulness of the activity for the participants (see appendix 6).

Output

The output will consist of a summary of the PPI activity and summary of feedback. I will create a poster to share with participants and disseminate the results in a clearer manner.

Participants will be encouraged to provide their contact details so that these outputs can be shared with them. Participants will also be asked about their willingness to be involved in future activities.

I will complete a learning log after the activity to help me develop my skills.

Data analysis

Qualitative data will be coded into common themes following the Generic Learning Outcomes framework.

Demographic data (ethnicity, age, type of incontinence, age of baby/s) will be collected to describe the characteristics of the women who participated in this activity.

Feedback, dissemination of results

I will ask participants for their permission to contact them again via email with a summary of findings and feedback, next steps of the project and future opportunities to collaborate.

The GRIPP2-SF reporting checklist (Staniszewska et al. 2017) will be used to report Patient and Public Involvement in research.

Time frame

I expect to have completed this PPI activity by 15th December 2021.

Cultural competency

As a white woman, I am aware of the potential bias I might introduce into this project. To minimise the inclusion of bias, I have undertaken a series of cultural competency and awareness courses and I will be taking into consideration the following points from the toolkit 'Increasing participation of Black, Asian and minority ethnic (BAME) groups in health and social care research' (2018):

- The utilisation of reflective diaries as a process of self-awareness and self-evaluation.
- Culture bias: this occurs when there is a tendency to judge another culture or a group of people solely by the values and standards of one's own culture or background.
- That the emphasis should be on understanding and appreciating an individual's beliefs and activities in terms of that individual's own culture.
- Stigma and discrimination have a direct impact on how an individual participates in the wider community and society.

Internalised stigma is an individual's own sense of devaluation and discrimination (Owuor and Nake, 2015).

- To avoid the effects of stigma, consider whether the topic being researched is considered taboo or stigmatised by certain communities, and if so, careful consideration must be given to such sensitive issues.

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RECRUITMENT POSTERS



Do you identify as Black?

Have you had a baby in the past 5 years?

Have you had problems with holding your urine after having your baby?

WE WANT TO HEAR FROM YOU!

Join me for an informal chat and have your say on future research

This project is supported by an Isobrite Midwifery Trust Award

Your time and contribution will be reimbursed.

The meeting can last between 1-2 hours.

We can meet online or face to face, in groups or alone, as you prefer.

If you want to know more, call me or text me on 07742 787748 (Veronica)

Or email me at maternityinvolvementgroup@gmail.com

BU
Bournemouth University

Maternity Involvement Group



Do you identify as Asian?

Have you had a baby in the past 5 years?

Have you had problems with holding your urine after having your baby?

WE WANT TO HEAR FROM YOU!

Join me for an informal chat and have your say on future research

This project is supported by an Isobrite Midwifery Trust Award

Your time and contribution will be reimbursed.

The meeting can last between 1-2 hours.

We can meet online or face to face, in groups or alone, as you prefer.

If you want to know more, call me or text me on 07742 787748 (Veronica)

Or email me at maternityinvolvementgroup@gmail.com

BU
Bournemouth University

Maternity Involvement Group

RECRUITMENT FLYER

MATERNITY INVOLVEMENT GROUP

REGISTRATION FORM



Why we need your views?

My name is Veronica and I am a midwife and researcher. Having problems to control the urine (when laughing, sneezing or coughing) during your pregnancy and/or after the birth of a baby is a common problem. There are not many studies including Black, Asian and Ethnic minority women so we don't know what their experiences are. Therefore, I would like to meet with Black, Asian and Ethnic minority women to understand what they think about this research, how would they feel about taking part in a study on incontinence and what could be done to help them participate.

Who should attend?

I am looking for 5 women who identify as Black, Asian or ethnic minority, who have had a baby in the past 5 years and have experienced problems with holding urine during pregnancy and/or after the birth of their baby. Black, Asian and Ethnic minority women are often not included in this type of research; therefore, this project aims at hearing the voice of these women. Please note that this is not a research study but an activity to help me understand how do you feel about this research being done.

Details of the day

This will be an informal chat about women's views on taking part in a research study on incontinence during and after pregnancy, how women might feel about participating in this research and what could be done to help women take part, if they wanted to.

We will meet individually or in group, depending on your preferences, face to face or online/phone call. The date and the place will be agreed at your convenience. I expect the meeting to last around 1 to 2 hours, there will be refreshments available (if the meeting is face to face) and you will be paid for your participation. At the end of the session, I will give you a short questionnaire to learn how to do things better.

Why are we asking these questions?

It is really important to hear the voices of Black, Asian and Ethnic minority women who experience urinary incontinence during or after pregnancy. This will help improve their participation in research studies with the aim of improving the care and experiences of these women by taking into account their needs.

Who is supporting this project?

In May I received an award from the Iolanthe Midwifery Trust, a registered charity that aims to promote and improve the care of mothers, babies and families through awarding grants and fellowships in support of midwifery education, practice and research. I am also supported by

Professor Susan Way and Professor Vanora Hundley from Bournemouth University.

What to do

If you are interested in taking part or you want to ask more questions, please get in touch. You can also fill in the table on the next page and provide back to maternityinvolvementgroup@gmail.com or send me a text on 07742 787748 and I will call you back.

Name:	
Telephone:	Email:
Experience of urinary incontinence:	<input type="checkbox"/> I have/have had urinary incontinence during pregnancy. <input type="checkbox"/> I have/have had urinary incontinence after pregnancy. <input type="checkbox"/> I have/have had urinary incontinence during and after pregnancy.

PRE-READING MATERIAL

Maternity Involvement Group



PRE-READ

I am so excited for you to join me!

This pre-read will give you an overview of what we will cover at the Maternity Involvement Group meeting and will prepare you to participate in the activity on the day.

IMPORTANT INFORMATION

DATE AND TIME

To be agreed with you.

VENUE

To be agreed with you.

CONTACT ON THE DAY

If you have any issues or need to contact someone, please call me (Veronica) on 07742 787748.

WHAT IS INVOLVEMENT

Public involvement means that people with relevant experience contribute to how research is designed, conducted and disseminated. In other words, it is about listening to people to help developing research, like being a 'critical friend'. Your role in this event will be to inform the researcher so this is not a research study.

WHAT WE'LL COVER DURING THE MEETING

MEETING AIMS

I want to work with you to:

- Listen to your experience with urinary incontinence.
- Explore how would you feel about taking part in urinary incontinence (leaking urine) research.
- Identify what might prevent you from or help you in taking part in a research study on incontinence.
- How would you like to be invited to take part in research in the future.

I will use the insights from this meeting to inform:

- a) A future research project proposal to apply for a doctoral fellowship, what is important to research.
- b) how researchers undertaking similar studies can involve Black, Asian and Ethnic minority women in incontinence research and the best way to involve them.

ABOUT URINARY INCONTINENCE DURING OR AFTER PREGNANCY

Urinary incontinence during and after pregnancy is weeing or leaking urine without meaning to, for example when coughing, laughing, sneezing, exercising or carrying weight. Although this is very common, it is not normal and seeking help it's a good option. Generally speaking, Black, Asian and Ethnic minority women tend to be unrepresented in research studies on urinary incontinence so the real impact is not understood.

SHARED PRINCIPLES

For a smooth session, please review these shared principles and think of anything else that we should agree at the beginning of the session.

Respect

There aren't any right or wrong answers – just ideas, experiences and opinions that are all valuable.

Confidentiality

Any personal experiences that are shared should be kept confidential.

Speaking in a group

Only one person should talk at a time and contributions must be relevant to the day's objective.

Inclusion

Everyone's ideas and opinions need to be heard. People who are more confident about speaking should remember to hold back at times and give others a chance – this can be difficult when discussing subjects close to people's heart, so we may need to make an effort.

Agree to disagree

It is important for us to hear all sides of an issue. If people have different views it means we are capturing a variety of opinions and experiences.

Disclosure

We can learn a lot from each other by sharing experiences, but no one should feel obliged to disclose anything they don't feel comfortable with.

Stick to the topic

As we may discuss issues that are close to people's heart and experience, it's natural that we will all have lots of things to say. As we only have a limited time we agree to focus on the objective of each session and to park ideas for later discussion.

Jargon

We need to think about the language and acronyms we use to make sure everyone understands. Please ask if anyone uses a term you don't understand.

Time keeping

We have a lot to get through so it's important we all come back on time after breaks.

Mobile phones

Everyone should agree to keep their mobile phones and technology switched off or on silent. If you need to use your phone, please do so outside of the room to avoid distracting anyone.

CONTACTS

If you have any questions at any point, feel free to get in touch. We look forward to seeing you soon!!

Veronica Blanco

T: 07742 787748

E: maternityinvolvementgroup@gmail.com

APPENDIX 4. COST ESTIMATE

INVOLVE

Title: Maternity Involvement Group

Date: 27/09/21

Section: Payment & Reward

Item: Fees to individuals

Quantity: 5 x Cost: £50/h = £250.00

Section Total: £250.00

Section: Expenses

Item: Subsistence

Quantity: 5 x Cost: £3 = £15.00

Section Total: £15.00

Grand Total: £265.00

DISCUSSION TRANSCRIPT

MATERNITY INVOLVEMENT GROUP

DISCUSSION SCRIPT



WELCOME AND INTRODUCTIONS

Aim: make participants feel at ease and ensure they are clear about what to expect

- Thank them for giving up their time to speak with you (make them feel welcomed and valued)
- Everyone to introduce themselves
- Explain how the group discussion will work
 - Length and format: 1-2 hours.
 - How it will be recorded: notes only
 - Reassure them that you can repeat or clarify questions
 - Reassure them there are no right or wrong answers
 - You can take a break or stop at any time
- Allow for any questions before you provide a brief overview of your research

OVERVIEW OF YOUR RESEARCH

Aim: give participants context and clarify aims

- Provide a very brief description of your research.
- Explain why I am involving participants and how I will use their insights.
- What stage of my research am I in and what is next.
- Allow for any questions before you start the group discussion.

GROUP DISCUSSION QUESTIONS

Aim: gather insights that will help you achieve your participants involvement aims

1.- (ice breaker): When was your baby born, how many children do you have? Where are you from?

Your experience with urinary incontinence.

2.- How would you feel about participating in an incontinence study and why?

3.- What are your thoughts on the idea of doing this research?

4.- Do you have any worries about taking part in research?

5.- What would help you to take part?

6.- How would you like to receive information about a research study?

7.- Why do you think women do not participate in research?

WRAP UP

Aim: make participants feel valued and give them clarity on what will happen next

- Explain what the next steps for you and when can they expect an update on how you used their responses.
- How they claim their honorarium
- Thank them and provide feedback form.

FEEDBACK FORM



MATERNITY INVOLVEMENT GROUP

FEEDBACK FORM

Dear participant,

Many thanks for taking the time to talk to me and share your views and experiences on this topic. I would be very grateful if you could help me improve by completing this form.

1. How would you rate your overall experience of being involved in the Maternity Involvement Group? (Please tick one box)

Very good

Good

Neutral

Poor

Very poor

Unsure

☐☐☐☐☐☐

2. Why did you choose to get involved?

3. How did you hear about this project?

4. How did being involved make you feel?

5. What have you learned during this experience?

6. Has this experience helped you to understand the importance of taking part in urinary incontinence research?

7. How did you find talking about this topic with Veronica?

8. Did Veronica listen to your comments and ideas?

9. How would you rate the practical arrangements were suitable (location/venue/catering etc.)

Strongly agree

Agree

Disagree

Strongly disagree

Unsure

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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10. What could have been improved?

11. Would you like to continue collaborating in future activities related to this project, why?

12. Please use the space below to share any other feedback or comments:

Thank you for attending and sharing your feedback! If you would like to receive the results from this project, please write your email address

APPENDIX 2: BLOG SUBMISSION

MINORITISED ETHNIC WOMEN AND PERINATAL URINARY INCONTINENCE: A PATIENT AND PUBLIC INVOLVEMENT PROJECT



Summary

[Urinary incontinence \(UI\) during and/or after pregnancy](#) is a very common issue. However, there are few studies including [minoritised ethnic women](#)*; therefore, their experience and the impact on their lives is unknown. With this project, I aim to meet with minoritised ethnic women to understand how they view research on UI and whether it is acceptable to them. This project covers a critical area of women's health with the objective of respectfully understanding and integrating minoritised ethnic women perspectives on perinatal urinary incontinence.

Objective of the project

This project's rationale originates in the unrepresentativeness of minoritised ethnic women in perinatal UI research, which implies that the actual impact that UI may have on women is not understood. A better understanding of what minoritised ethnic women think about research related to UI issues, the acceptance of this type of research and potential recruitment strategies would seem appropriate.

Although ethnicity does not seem to be a recognised risk factor for UI, such as age, parity, mode of delivery or baby's weight, Wilson¹ included race/ethnicity as part of a predictive score of future pelvic floor dysfunction following childbirth. In non-pregnant populations, minoritised ethnic women seem to report higher levels of discomfort with stress UI than White and Hispanic women², despite presenting the lowest UI numbers. Several factors could explain this variation between ethnicities³:

- Research groups tend to have small sample sizes.

- Barriers to access health care and health inequalities may explain the low incidence of UI among minorities.
- Minoritised ethnic women are often excluded from research participation due to language barriers. A multi-ethnic research study⁴ with pregnant women revealed similar results to those in non-pregnant women. The authors acknowledged that:
 - Lower numbers of UI among African origin women could be explained potentially by stronger pelvic floor muscles and collagen fibres. This assumption could be regarded as [racial bias](#).
 - Most prevalence studies have targeted Caucasian women.
 - European/North American women tend to have higher participation rates.
 - Language barriers or cultural factors could affect the disclosure of UI. Therefore, there is a potential gap in the awareness, diagnosis and disclosure of perinatal UI. The underrepresentation of minoritised groups seems a more plausible explanation of the lower reported rates of UI, highlighting health inequalities.

Rationale

Female UI is caused, in great measure, by pregnancy and childbirth⁵, affecting women's physically and mentally, and ultimately impacting negatively on their quality-of-life and health care costs⁶. This situation is reinforced by the lack of direct enquiry by health care professionals during and after pregnancy, translated into a lack of conversation on UI prevention and diagnosis⁷ and lack of consensus on UI definitions, leading to underreports and contributing to the significant variations of prevalence in the literature⁸. Additionally, women and professionals lack awareness and knowledge on UI, which promotes its normalisation⁹.

Value of the project

To my knowledge and according to some preliminary rapid literature search, there is scarce evidence on minoritised ethnic women expressing the need to learn about perinatal UI. The inclusion of minoritised ethnic women in this type of research is, therefore, limited to date, at least not in during or after pregnancy. Outside pregnancy, Black and minoritised ethnic women have expressed the need to be

screened by health care professionals. On the other hand, other women don't believe they have a problem or minimise its impact (normalisation of urinary incontinence) like their white counterparts.

Therefore, with this project, I will have the opportunity to learn more about UI from minoritised ethnic women's experiences, create links with different communities, and become aware of cultural safety practices, aiming to eradicate institutional racism and improve the quality of care provided. Through this project, minoritised ethnic women will be listened to and be empowered to co-create future research. This PPI experience will likely help to raise awareness on the importance of participating in research to change and promote UI.

Since there are not true numbers of minoritised ethnic women affected by perinatal UI as a result of their limited inclusion in research studies, the consequences - benefits and burdens for minoritised ethnic groups, are not yet fully understood. There is evidence of the impact of UI on the quality of life of minoritised ethnic women outside the perinatal period, but not specifically in the perinatal period. The evidence suggests non-pregnant "minoritised ethnic women seem to report higher levels of discomfort with stress UI than White and Hispanic women despite presenting the lowest UI numbers"². Hence, this project aims to start the conversation and encourage further research on the topic.

By understanding the needs of minoritised ethnic women regarding UI, health professionals will be placed in an advanced position to engage women in research. This project is also expected to significantly impact future practice, aiming to inform health care providers of the gaps identified in current evidence and break the cycle of health inequalities in continence health. Listening to women's experiences will also inform professionals to improving the care provided to women from ethnic minorities with UI.

Strategy

The project proposed encompasses a [PPI](#) activity, which aims to understand how women from minoritised ethnic groups view UI research and whether it is acceptable to them. A systematic review will also be carried out to provide the latest evidence on this topic.

Aim

To increase the likeliness that minoritised ethnic women will agree to participate in a prospective perinatal UI study.

Objectives

- To establish the acceptance of this type of research by minoritised ethnic women.
- To identify avoidable barriers to study participation.
- To explore potential recruitment strategies.

Cultural safety

As a white woman, I am aware of the potential bias I might introduce into this project. To minimise the inclusion of bias, I have undertaken a series of cultural competency and awareness courses, and I will be taking into consideration the following points from the toolkit 'Increasing participation of [Black, Asian and minority ethnic \(BAME\) groups in health and social care research](#)' (2018):

- The utilisation of reflective diaries as a process of self-awareness and self-evaluation.
- Culture bias: this occurs when there is a tendency to judge another culture or a group of people solely by the values and standards of one's own culture or background.
- That the emphasis should be on understanding and appreciating an individual's beliefs and activities in terms of that individual's own culture.
- Stigma and discrimination directly impact how an individual participates in the wider community and society.

Internalised stigma is an individual's sense of devaluation and discrimination.¹¹

- To avoid the effects of stigma, consider whether the topic being researched is considered taboo or stigmatised by specific communities and if so, careful consideration must be given to such sensitive issues.

In addition to the previous points, the poster has been co-designed to ensure we are culturally sensitive and mindful of the community we are targeting. We are grateful for the [groups](#) and people that have come forward to support us.



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What problem I am trying to solve?

Low rates of minoritised ethnic women included in perinatal urinary incontinence research studies

How can insight from women help me solve this problem?

Women have a unique perspective and may help identify what the barriers or concerns could be for minoritised ethnic women.

What questions do I need to ask them to gather this insight?

How would they feel about the study and why?
What are their thoughts on the purpose of the research? Would they be willing to take part and why? What would make them want to sign up or what would prevent them from doing it?

Do you identify as Black?



Have you had a baby in the past 5 years?

Have you had problems with holding your urine after having your baby?



WE WANT TO HEAR FROM YOU!

Join me for an informal chat and have your say on future research




This project is supported by an Isobeth Midwifery Trust Award

 Your time and contribution will be reimbursed.

 The meeting can last between 1-2 hours.

 We can meet online or face to face, in groups or alone, as you prefer.

 If you want to know more, call me or text me on 07742 787748 (Veronica)

 Or email me at maternityinvolvementgroup@gmail.com



Do you identify as Asian?



Have you had a baby in the past 5 years?

Have you had problems with holding your urine after having your baby?



WE WANT TO HEAR FROM YOU!

Join me for an informal chat and have your say on future research




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