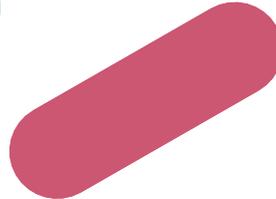




PPI IGNITE
NETWORK

IMPACT CASE STUDY



Let's Talk Menopause – Time to break the taboo

Who was involved?

- One PPI Ignite Network lead site
- PPI contributors – women with intellectual disabilities
- Registered nurses in intellectual disability

Summary

This PhD study explores menopause in women with intellectual disabilities, a population often marginalised when it comes to their sexual and reproductive health.

This project had a positive impact within a number of areas including improved quality and real-life applicability of the research; creating culturally competent research practices; and promoting the voices of women with intellectual disabilities in sexual and reproductive health research.

Our work

This PhD study explores menopause in women with intellectual disabilities. Women from this population are so often marginalised when it

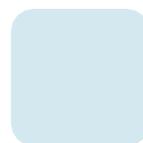
comes to their sexual and reproductive health. Therefore, it is critical to ensure research carried out on the topic is relevant, applicable and useful to the target group. PPI was integral to the project from inception to ensure involvement in all stages of the research cycle.

PPI contributors for the study included women with intellectual disabilities and registered intellectual disability nurses (RNIDs). The women with intellectual disabilities involved were either menopausal or approaching age at menopause. Nurses involved had provided care for menopausal women in the service provider context. Other relevant stakeholders such as healthcare providers, staff, parents and policymakers interested in women's health in women with intellectual disabilities were also consulted throughout the project duration.

Study conceptualisation

PPI contributors were involved in early research discussions. Stephanie Corrigan, a PhD scholar

IMPACT CASE STUDY



at Trinity College Dublin, settled on the topic of menopause through engagement with women with intellectual disabilities as part of field research conducted for a larger research project with older adults with intellectual disabilities (IDS-TILDA). In this way, the researcher learned about their lack of knowledge on their sexual and reproductive health, in particular, menopause.

The PPI contributors validated the topic of menopause as an important topic to investigate – particularly the mental health implications of menopause which were largely under-researched in this group. They also validated the chosen research design (mixed methods explanatory sequential) as it would ensure the voice of the woman with an intellectual disability was heard throughout the study.

They also helped to refine the research questions by giving examples from their lived experience; one contributor reflected on her own lived experience and wondered if she had gone through the menopause “years ago” as she would “snap a lot and have mood swings” which at the time she thought was “just her mental health”. This helped the researcher to refine the research focus to explore menopause-related mental health and how this might manifest in women with intellectual disabilities.

Review of accessible participant information materials

Contributors also reviewed easy-to-read participant materials developed for the recruitment process and interview process. They ensured that the materials were accessible for the target population (women

with mild/moderate intellectual disabilities over the age of 35) by checking that appropriate language, font size and accompanying images were appropriate and comprehensible.

Advice for qualitative interview process

It was critical to work in partnership with women with intellectual disabilities to ensure culturally competent practices were implemented when conducting interviews about a sensitive topic such as menopause. PPI contributors provided suggestions for reasonable adjustments that could be made to ensure study participants felt supported to take part.

Data analysis

Contributors assisted with coding and theme development as part of thematic analysis to enhance reflexivity and interpretative depth.

Our impact

Through working in partnership, this project had impact in a number of ways.

Applicability and real-life context

Working with PPI contributors ensured that the research remained relevant to women with intellectual disabilities. Meeting regularly with contributors reminded the researcher of the real-life implications and potential benefits of the research. This kept the researcher motivated to ensure that the research was carried out to the highest standard and remained relevant to the lived experience of the contributors and therefore the study population.

Ensuring culturally competent research practices

Following the advice of the contributors was paramount in ensuring the comfort of the study participants, particularly around a sensitive topic



Dissemination event involving PPI contributors, research beneficiaries and the research team (2024)

such as menopause. Meeting participants informally in advance enhanced participants' interview experience as they felt more comfortable having built up a rapport with the researcher. This facilitated more open conversation which ultimately enhanced data quality – an unintended but welcome benefit.

Enhancing reflexivity

This was critical for the researcher as an “outsider” to ensure no incorrect assumptions were made about participants in the study. Contributor assistance in thematic analysis was insightful and provided deeper insight and interpretation of the codes and themes developed throughout the analysis.



Dissemination event involving research beneficiaries and the research team (2025)

Promoting the voice of the woman with an intellectual disability

The contributors were extremely helpful in framing the research and ensuring the voice of the woman with an intellectual disability was heard throughout the study. No important study decisions were made without consultation with contributors, which ensured the research was relevant to the target group. This was especially helpful with the development of any easy-to-read materials for the study – ensuring accessibility was prioritised. This will be extremely helpful in the development of the easy-to-read educational materials too – to ensure relevance and applicability.

“Understanding where the health differences between women with intellectual disabilities and women in the general population come from is so important. It helps improve outcomes, ensure equal access to care and share policies and practice that support women better. So many women with intellectual disabilities need support to understand and manage their health and we must make sure they get the help they need.”

Dr Mai Lin Yap, Ambassador Liaison Office, Trinity Centre for Ageing and Disability (TCAID), Trinity College Dublin

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