

Research and People with Learning Disabilities

Jenny Jones – Greater Manchester Senior Clinical Lead for Learning Disabilities and Health Inequalities

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Maximising *potential*

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Current Programmes of work




Pennine Care
NHS Foundation Trust

- **The Menopause: Knowledge and experiences of women with Learning Disabilities and Autistic Women** – Pennine Care Research capability Funded Project – PPIE Project
- **Do bespoke and reasonably adjusted education workshops improve health literacy in women with Learning Disabilities and in turn improve uptake of the National Breast Screening Programme** – Prevent Breast Cancer Funding - Service Improvement Project
- **Diabetes and Me:** [My Diabetes and Me Study - DESMOND-ID](#)
- **Cervical Screening videos**



The Menopause: Knowledge and experiences of women with Learning Disabilities and Autistic Women – Pennine Care Research capability Funded Project

- People First Tameside were commissioned to co-develop, co-deliver and co-evaluate the project with colleagues from Pennine Care NHS Trust.
 - The project utilised 3 stages:
 - The first phase was a review of the literature of menopause knowledge and experiences for women with Learning Disabilities and Autistic women in the UK, to increase the understanding around the relevant literature.
 - The second phase was the development, delivery, and evaluation of 3 experience based co-designed workshops – 2 of which were delivered face to face and the 3rd online.
 - The 3rd phase was the use of surveys as a method of gathering data from a wider cohort of women, health professionals, families, care staff and wider stakeholders to find out about the opinions and beliefs of participants.
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- Easy read report by PFT
- Accessible video by PFT
- <https://youtu.be/qO437yQjb1M?si=K5l0JD04U3r-KcjZ> [youtu.be]
- Final Report



Menopause Report
(5).pptx



Recommendations



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1. The development of a co-production group, ensuring the creation of any resources and clinical pathways are co-designed.
2. The development of a standardised resource toolkit, ensuring women with learning disabilities, autistic women, families, carers, and health and social care professionals have access to contemporaneous, evidence based accessible information (video's, easy read literature, symptom checkers, care plans, reasonable adjustments to clinical pathways, links to podcasts, websites etc)
3. Development of training packages for social care providers to enable inhouse training, to improve the knowledge and confidence of supporters. This may involve having menopause champions in provider organisations to deliver training and be a point of contact.
4. An awareness raising event across the Greater Manchester Learning Disability and Autism networks to launch any new toolkit.
5. Consideration that the resource toolkit is embedded in the NW Annual Health Check Toolkit, which is utilised in Primary Care.

Prevent Breast Cancer funding - Do bespoke and reasonably adjusted education workshops improve health literacy in women with Learning Disabilities and in turn improve uptake of the National Breast Screening



Support women with
learning disabilities
to take care of
their breasts.



NHS

NHS

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Do bespoke and reasonably adjusted education workshops improve health literacy in women with Learning Disabilities

Jenny Jones – Greater Manchester Senior Clinical Lead for Learning Disabilities and Health Inequalities

Janice Wycherley – Associate Consultant for Pathways Associates

Verity Kay – Expert with lived experience of learning





- People with Learning Disabilities experience major health inequalities, they are more likely to develop long-term conditions and die prematurely. They are at higher risk of preventable and treatable diseases including cancer.
- People with Learning Disabilities can have poorer health literacy. A recent engagement project in GM identified poor health literacy amongst women in relation to knowledge about breast screenings and breast cancers



NHS
People with a learning disability are less likely to access breast screening.

Help make
breast screening
more accessible.



A map of Greater Manchester divided into ten local authority areas, each color-coded: Wigan (green), Bolton (blue), Bury (orange), Heywood, Middleton & Rochdale (teal), Oldham (light blue), Tameside (dark blue), Stockport (dark purple), Manchester (dark red), and Trafford (red).



Co-Production



Improved health literacy

Informed choices

Tailored health information

Learning from experts

Learning from peers

Safe space



The programme will cover: What is cancer, the importance of breast screening, the breast screening journey and breast health.

The workshops will provide a structured platform to share accessible, evidence-based information.

The workshops will provide a supportive, and accessible environment.

Each workshop will be interactive and engaging. We want women to be empowered, to gain a better understanding of breast cancer, the importance of early detection and how to take proactive steps in managing their health.



B I N G O				
Regular Mammograms	Unhealthy Diet	Be Physically Active	Genetics	Smoking
Menopause After 55	Family History	Self-Breast Exam	1 in 8 Women	Gender
Limit Radiation Exposure	Baptist MD Anderson Cancer Center		Breastfeed	Age 50
Fruit and Vegetables	Age	Sedentary Lifestyle	Males	Buddy Check
Control Weight	Race and Ethnicity	Limit Alcohol	Baptist Y Healthy Living Center	

Aims



- Increase awareness of cancer and the importance of screening
- Increased awareness of breast health, including signs and symptoms of cancer
- Increased knowledge and confidence of the breast screening process, leading to increased uptake.

How will we know that this approach has made a difference?

- Self reported increase in knowledge and confidence levels.
- Participant feedback
- Pre and post project knowledge quizzes
- Observation
- Tracking screening rates



The analysis of the project, both qualitative and quantitative findings, will inform research and interventions.

The legacy project would also include more knowledge and empowered experts who can deliver these educational workshops, a suit of interactive learning and resources and an evaluated model.

Diabetes and Me

My Diabetes and Me Study - DESMOND-ID



Thank you
Any questions

