Research Needs Experts by Experience: Here is our Story

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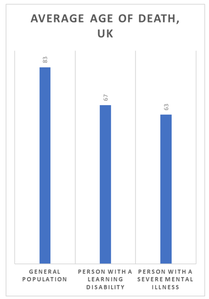
NIHR | Applied Research Collaboration North East and North Cumbria

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1. About the study

Cancer screening uptake for people with severe mental illness and/or learning disabilities is low (NHS Digital, 2021; Public Health England, 2021). We aim to help change this by identifying how the cancer screening services can be adapted to support the uptake of this group. We will do this by:



Phase 1a A mixed methods systematic review of barriers and facilitators for people with severe mental illness accessing cancer screening services.	Phase 1b Semi structured interviews of people with severe mental illness whose voice has not been represented in the systematic review.
Phase 2a Triangulation of phase 1a and 1b, with research already completed involving people with learning disabilities.	Phase 2b Future research planning, recommendations to practice, and protocol development.

2. Our Public Involvement and Community Engagement (PICE)

We presented the research idea, and planned methods to the North-East North Cumbria Research Design Service's patient and public involvement consumer panel. We now have an advisory group involving people with lived experience.

Co-production of the systematic review search strategy and interview schedule



Advising on the ethics application

Recruiting the research associate

Advising on the use of language and terminology throughout the project

Co-producing the conference poster

- Future tasks include engagement in the design, management, analysis, evaluation, and dissemination of research outputs.
- We are using the GRIPP 2 tool to report our PICE activity throughout the project (Staniszewska et al., 2017).
- By reflecting on our communications, we aim to improve the quality, transparency, and consistency of our PICE.



3. Valuing our experience, hearing our voice

- Starting from day one, we feel like a **big** part of the project.
- Everyday can be different for us and we feel **supported**.
- Public involvement is so **important** and needs to continue in the future.
- Being in an advisory group is a great way to have your voice **heard** and get the message out there.
- We feel **respected**, this makes a difference and makes us feel **valued**.
- We may have the same diagnosis, but we are treated **individually**.
- Overall, we are very **happy** with being part of the project and feel **listened** to.

4. Key messages

Inclusion
- "We want to be included and to share our own voice"
- "We need to think of people as people and listen to their needs and preferences"

Accessibility
- "No one is hard to reach if we listen and engage with people. People are not listening appropriately to those who are speaking"
- "It is great to be able to ask questions and to communicate with people at different levels"

Perspective
- "'Research' can be a scary word, but it can make a change for the future"

5. Why we got involved in research

Awareness
- To promote the need for reasonable change to adapt to individual needs.
- Services need to wake up and get to know who we are and what we need.

Stigma
- To reduce the feelings of stigma.
- To stop feeling judged.

Making Change
- To change the ways of working and practices.
- To be able to help others.

6. Recommendations for other researchers

- Researchers need to base the research on **real life and those that experience it.**
- Make our journey easy by giving us **options**, such as; reasonable and negotiated deadlines, prompts and flexibility.
- Ensuring instructions are **clear** and easily understood. **Listening** and **acting** on our feedback.
- Regular **check-ins** to see how we are feeling.
- Not putting everyone in the same box and try to get a range of people with **different** experiences.

7. References

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PECCS Person Centered Cancer Screening Services

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