

Involving women with a learning disability in research: A reflection of practice and academic barriers

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Summary of PhD research



Benefits and drawbacks of working
across academic and NHS services
from a practice perspective



Benefits (1)

- Kate and Hannah constantly reviewed the language and symbols used in the study documents and Q methodology statements to ensure they were accessible and suitable for women.
- The range of sites enabled a diverse sample to be recruited, accounting for differing experiences, support received, ages and locations.
- Hannah was based on site which meant she could support staff who were identifying women, to review their caseload and ensure the staff were supporting the research to be completed to time and target.
- Hannah has embedded understanding of the service and the women who were involved in the service. This meant that women were approached to take part based on their ability and personal circumstances.



Benefits (2)

- The women were being approached and told about the research in a suitable way, by someone they knew, to reduce their fear or anxiety about being involved.
- Balance clinical expertise with academic expertise.
- Planning to do is implementable in practice to do the research and recommendations are aligned and meaningful to recommendations made
- Drawing academic and practice links together – eg talking mats and q methodology are similar
- Hannah had clinical context and knowledge from working in services for people with learning disabilities which meant parallels could be drawn from other areas not related to cancer (such as dental), that academics may not know about (e.g. presentation of symptoms and diagnostic overshadowing).



Drawbacks (1)

- Kate relying on others to identify and approach women, which meant she had little control.
- Staff may not be research aware and struggle to complete tasks such as screening their caseload against inclusion and exclusion criteria.
- Women with learning disabilities may not be invited to take part in research regularly so they may be apprehensive to take part, which may have made identification and awareness of research.



Drawbacks (2)

- Gatekeepers may have had competing demands - extra workload pressures which meant that gatekeepers clinical work was prioritised. Hannah regularly made sure staff who were acting as gatekeepers spoke to women.
- Relying on Hannah's professional networks within the Trust may have meant there was a possible biases sample. This was mitigating by having multiple recruitment sites in the region.

Recommendations for future
research on how to involve people
with learning disabilities in research

What worked:

- Discuss terminology, language and images with professionals/those who work within the services you are recruiting from.
- Work closely with gatekeepers (e.g. leads the service) as they will know the services well and can support other staff who can also act as gatekeepers.
- Involve people who would be eligible to take part in designing study material to ensure language is appropriate e.g. using 'boobs' instead of 'breasts'.
- Use a range of recruitment sites (including NHS and non-NHS) to get a spread of participants.
- Having a clinical lead as an advisor through the PhD journey to ensure balance between academic and practice for recruitment and data collection.

What we recommend for the future:

- **Involve service users and carers from the start** of the research, such as establishing advisory groups, to ensure involvement through every stage of the research.
- **Involve gatekeepers and recruiters in study design** to understand services and how identification of eligible people may need to be tailored and be different for different services/research sites.
- **Disseminate the research findings in partnership** with women with learning disabilities.

Thank you for listening.

Does anyone have any questions or comments?

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