

500-word thesis

Revealing the attitudes and opinions of women with a learning disability and their carers towards cervical and breast cancer screening

Kate is conducting a PhD in Public Health at Teesside University, under the supervision of Dr Emma L Giles and Dr Grant McGeechan, whilst also working as a Graduate Tutor. As a graduate tutor, Kate teaches across the School of Health and Life Science on research methods and working with people with a learning disability.

Within the United Kingdom (UK), there are three cancer screening programmes that aim to identify and diagnose cancer at an early stage, which can improve survival and reduce mortality of cancer (Foot & Harrison, 2011). The three programmes check for the presence of cancer in the cervix, breasts, and colon. Statistics published by NHS Digital (2020) highlight that people with a learning disability are less likely to attend cancer screening, compared to the general population, with a greater difference being seen for cervical and breast cancer screening. The uptake of women with a learning disability (WwLD) attending cervical cancer screening is as low as 27.7% for those aged 55 to 64, compared to 71.9% of those without a learning disability (NHS Digital, 2020), and 42.9% of WwLD attending breast screening, compared to 55.1%, of those aged between 50 to 54 (NHS Digital, 2020). As a result of the uptake statistics, this PhD programme aims to reveal the attitudes, opinions and knowledge of women with a learning disability, family carers and paid care workers toward cervical and breast cancer screening in England.

This PhD project adopted a mixed-methods approach. The first phase was the completion of a qualitative systematic review to identify attitudes towards cancer screening of people with a learning disability, family carers and paid care workers. The systematic review identified 11 papers which met the inclusion criteria. All studies related to cervical and breast screening. No papers were identified that related to colorectal cancer screening (Byrnes et al., 2020). The result indicates multiple barriers and facilitators for WwLD attending cervical and breast cancer screening, including, not being viewed as eligible for cervical screening and needing support and information to aid in WwLD making an informed choice about attending. After completion of the review, an extensive phase of Patient and Public Involvement (PPI) was conducted. This was to identify preferences from WwLD on how they would like written information to be presented and to ensure easy read documentation was suitable based on their preferences. Their thoughts on the design of a data collection tool were also collected. The results from the systematic review and the PPI informed the development and completion of a Q methodology study. Q methodology is a means of studying a person's subjective opinion (Cross, 2005). The Q study involved 21 participants; 13 WwLD, five paid care workers and three family carers. During the study, participants completed a card-sorting task to indicate their thoughts against a set of 28 predetermined statements, called a Q set. The Q set is comprised of statements covering the array of views on WwLD attending cervical and breast cancer screening. This allows the participants to express their thoughts concerning the statement in front of them (Coogan & Herrington, 2011). It is hoped that this PhD project will better understand the barriers and facilitators of WwLD accessing cervical and breast cancer screening in England, to highlight recommendations

for policy and practice to ensure WwLD have an equal opportunity to access cancer screening and to be adequately supported when doing so.

References

Byrnes, K., Hamilton, S., McGeechan, G. et al. (2020). Attitudes and perceptions of people with a learning disability, family carers and paid care workers, towards cancer screening programmes in the United Kingdom: A qualitative systematic review and meta-aggregation. *Psycho-Oncology*. doi:10.1002/pon.5311

Cross, R.M. (2005). exploring attitudes: the case for q methodology. *Health education research*, 20(2), 206–213. doi:10.1093/her/cyg121

Foot, C. & Harrison, T. (2011). How to improve cancer survival-explaining England's relatively poor rates. The Kings Fund.

Herrington, N., & Coogan, J. (2011). Q methodology: an overview. *Research in Teacher Education*, 1(2), 24–28.

NHS Digital. (2020). Condition Prevalence and Access to Health Services. Retrieved from <https://app.powerbi.com/view?r=eyJrljoiNTYyNDM4MGYtDRmYi00NTAxLTkzY2QtMjcwZTY2YTQ0MzNkliwidCI6IjUwZjYwNzFmLWJiZmUtNDExYS04ODAzLTY3Mzc0OGU2MjllMjlmMiOjh9>