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Methodological reflections on the recruitment and engagement of people for cancer screening research in Wales

Abstract

Cancer is a major threat to public health and the second leading cause of death globally. Population-based cancer screening is an effective way to improve the early detection and reduce mortality. Increasing research has explored factors associated with participation in cancer screening. The challenges to undertaking such research are evident, but there is little discussion about how to address such challenges. This article discusses methodological issues associated with the recruitment and engagement of participants in research, drawing upon our experience of undertaking research exploring the support needs of people residing in Newport West, Wales, to participate in breast, bowel, and cervical screening programmes. Four key areas were addressed: sampling issues, language barriers, IT issues, and time demand for participation. It highlights the importance of ongoing community engagement, the provision of appropriate study materials, and the adaptation to different data collection modes to meet participants' needs to participate in research, to enable people who are usually excluded from research to have a voice and make a significant contribution to research.

Keywords:

Cancer screening, collaboration, engagement, inclusion, primary care, public health, recruitment, Wales

Running head:

Recruitment and engagement in research

Introduction

Cancer is a major threat to public health and the second leading cause of mortality worldwide, with 9.6 million deaths (17% of total deaths) in 2018 (WHO 2020). Globally, the burden of cancer continues to increase rapidly, imposing enormous physical, psychological, and financial pressure on individuals, families, communities, and health and social care systems (WHO 2022). While in countries with good healthcare systems, cancer survival rates are improving owing to accessible early detection services, high quality treatment, and survivorship care (WHO 2022).

Cancer screening is an effective way to improve the early detection of a cancer and reduce mortality (Heinävaara et al. 2016; Koo et al. 2017; Broeders et al. 2018; Jansen et al. 2020). In many developed countries, the infrastructure and resources for routine cancer screening are in place. For example, in Wales, free population-based cancer screening is routinely offered to eligible populations via the National Health Services (<https://phw.nhs.wales/services-and-teams/screening/>). Currently, Breast Test Wales offers breast screening to women aged 50-70 every three years; Bowel Screening Wales offers bowel screening to people aged 55 -74 every two years; Cervical Screening Wales offers cervical screening to people with a cervix aged 25-64 every five years.

Cancer screening inequalities have been frequently reported in many countries (Campbell et al. 2020; Miller et al. 2020; Public Health Wales 2020). Lower uptake has been found to be associated with ethnicity, socio-economic deprivation, and disabilities (Kinnear et al. 2011; Miller et al. 2020). For instance, Miller et al. (2020) reported that mammogram uptake was lower in Asian American women than in White women in the United States; Campbell et al. (2020) found that uptake of bowel screening was lower in men of South Asian origin than in White men in Scotland; Massat et al. (2015) showed that uptake of cervical screening was lower in ethnic minority women than in White women in England. In Wales, lower uptake of cancer screening is found in more deprived areas (Public Health Wales 2020).

Research has increasingly explored the factors associated with the uptake of cancer screening. The challenges to undertaking such research are evident, for example, reaching and hearing from those who do not often participate in cancer screening. However, there is little discussion about how to address such challenges. This article seeks to explore and address some of these challenges of recruitment and engagement by drawing upon our experiences of undertaking research seeking to understand what support people might need to participate in breast, bowel and cervical screening programmes (Yu et al. 2022, 2023). The research was commissioned by the Newport West Neighbourhood Care Network (a primary care cluster of eight GP practices, health care agency, and third sector partners) in Wales to inform future planning of cancer screening services in the cluster. Group concept mapping (GCM) was applied. Using an integrated mixed-method design, GCM is a sophisticated, structured approach to generate consensus among a range of stakeholders (Kane & Trochim 2007). In a GCM study, qualitative components (ideas generation) are systematically integrated with quantitative components through the representation of ideas in visual maps/reports. Participants may complete one, two, or all three activities (brainstorming, sorting and rating) depending on the stage they are recruited. In this research, three GCM studies (breast screening study; bowel screening study; cervical screening study) were run concurrently. In this paper, we seek to discuss methodological issues and considerations regarding recruitment and engagement based on our experiences

of undertaking this research. Four key areas are addressed: sampling issues, language issues, IT issues, and time demands for participation.

Sampling issues

We aimed to recruit a diverse range of people in terms of age, ethnicity, literacy/health literacy skills, disability, health status, socioeconomic status, and cancer screening uptake. The difficulties in recruiting people from our target groups to health-related research have been frequently reported (Yu 2009; Sharif et al. 2020). Two key factors further influenced our access to potential participants. First, many people in ethnic minority communities residing in our target area would often be very reluctant to talk to researchers (outsiders) due to trust issues and language barriers. Second, during the fieldwork (July-September 2021), the researchers' university still had some safety measures in place regarding face-to-face contact for research although Covid-19 related restrictions were relaxed for indoor/outdoor gatherings for the general public. Staff were required to undertake a lengthy risk assessment process to obtain permission by providing a range of information (e.g. health and safety measures of the location; where, when, how long, and how many people for a meeting). It was not always feasible to obtain such information far in advance to gain permission in time to approach potential participants. For example, we were invited to attend meetings to speak to people with learning disabilities about our research just a few days before the meetings, but we did not have sufficient time to obtain permission from our university. Subsequently, we were unable to recruit any individuals with learning disabilities to our study, reflecting the impact of the lack of face-to-face contact on recruitment.

People eligible for any of the three cancer screening programmes (breast screening, bowel screening, and cervical screening) at the time of our data collection and resided in Newport West were invited to take part in their respective studies. We approached a wide range of community networks and GP practices for recruitment. Recruitment leaflets were circulated via email, newsletters, and social media (e.g. Twitter and Facebook). Hard copies of the leaflets were on display in local GP practices, libraries, and community centres. In addition, five community members from ethnic minority backgrounds were recruited as co-researchers, which greatly helped with recruitment and engagement with local ethnic minority communities. The characteristics of the participants across three studies are illustrated in Table 1. We recruited 131 participants from 10 ethnic groups across the three studies (37 for the breast screening study; 24 for the bowel screening study; 70 for the cervical screening study). Of the 127 participants who answered the ethnicity question, 81 were from ethnic minority backgrounds. Seventy-five participants had missed breast, bowel, or cervical screening at least once. Our sample was self-selected and non-representative, but our participants were from 10 ethnic groups and the sample size for each of our studies was within the recommended range (10-40) for a GCM study (Kane & Trochim 2007).

Language issues

Countries like the United Kingdom have become increasingly ethnically diverse due to large-scale migration following the Second World War, which has been changing how healthcare services are delivered in the United Kingdom (Yu et al. 2020). It is estimated that in 2019, 15.2% of the population in England and Wales are of ethnic minorities, of whom Asian/Asian British forms the largest group (8.0%), followed by black ethnic

groups (3.5%), other groups (1.9%), and mixed or multiple ethnic groups (1.8%) (Office for National Statistics 2019). In Wales, the largest proportion of ethnic minorities live in Cardiff (15.8%), followed by Newport (the target area of this research) (12.5%) (Welsh Government 2022).

In this study, some of our target populations were unable to read or write the languages they spoke, or had low literacy or health literacy skills. Our participants spoke 13 languages other than English (Arabic, Bengali, Farsi, Italian, Kurdish, Patwa Creole, Punjabi, Romanian, Spanish, Somali, Urdu, and Yemeni). Forty participants did not speak English. We applied two strategies to address the language issues.

First, the five community co-researchers we recruited greatly helped us with recruitment and data collection. They were fluent in English, as well as in Bengali, Punjabi, Hindi, Urdu, Somali, Arabic, or Yemeni. Two training sessions were provided by the first author. The first session was held online and focused on gaining informed consent, collecting the demographic data, and completing the brainstorming activity. The second training session was held face-to-face with permission from the university due to the complexity of what needed to be covered (e.g. the completion of the sorting and rating activities). As all co-researchers were participants themselves, they completed the data collection activities themselves during the training sessions.

Second, we developed an easy-to-read version of the participant information sheet and the consent form (see Figure 1 for an example) for each of the three studies to address low rate of literacy in our target populations. The provision of culturally appropriate information in plain language has been widely recognised (Bennett et al. 2021). The version was developed by consulting with community members in our target groups and members of the Learning Disability Advisory Group at the authors' university to ensure the content was culturally appropriate and easy to read/understand. All participants were provided with both versions of the information sheet and the consent form for the respective study they participated in. Some English-speaking participants and most ethnic minority participants returned the easy-to-read version of the consent form.

IT issues

Data collection for a GCM study can be carried out either offline usually via face-to-face workshops or online via the GroupWisdomTM software. Considering the restrictions imposed by the Covid-19 pandemic at the time of the research, initially we intended to collect data online only. However, we found at the early stage of recruitment that some participants, especially older people and ethnic minorities, had low IT skills or did not have access to a computer. Some participants were unable to complete the consent form electronically (presented as a Microsoft Word document) or complete the requested activities to participate online.

To address IT issues, we offered participants the options of participating in the research either online via the GroupWisdomTM software or offline by completing relevant paperwork, thus changing our data collection mode to meet people's needs for participation. The same type of data was collected no matter of the mode of participation. This approach considerably increased the workload for the team. First, relevant documentation was printed, and each statement was cut into an individual card for the sorting activity (Figure 2). Statement cards and the rating sheets were posted to

participants or delivered to co-researchers. More than half of all the data were collected offline (most ethnic minority participants and some white participants took part offline). Data collected offline were entered manually onto the GroupWisdom™ software for analysis, which was very time consuming. The approach greatly helped us engage and hear from people who would otherwise be excluded and reflects the importance for researchers to be flexible and adaptive to address different needs of participants to participate in research.

Time demands for participation

There have been considerable reports on how language barriers affect the access and delivery of health and care services (Yu et al. 2017, 2020; Mirza et al. 2022). However, there has been little discussion about the time demands for people who do not speak English to participate in research.

Issues around time demands for participating in research were raised in our studies. As can be seen from Figure 2, the right-hand side of each statement card was left blank, as the original plan was for co-researchers to use the space to write non-English languages to save time when collecting data from participants who did not speak English. However, this was not practical as both co-researchers and participants were not necessarily able to read or write the language they spoke. Therefore, it was not feasible to translate study materials into other written languages and all study materials had to be translated verbally, making it very time consuming to participate. This was especially the case for the sorting and rating activities. In one example, a co-researcher spent three hours supporting a local resident to complete the sorting and rating activities. Some participants felt burdened with the activities. Considering the time required for verbal translation and the complexity of the sorting activity, co-researchers were then asked to focus on the rating activity in the second phase of the data collection. As a result, across the three studies, fewer participants completed the sorting activity than the brainstorming activity and the rating activity.

Discussion and implications

This article has reflected on some of the methodological issues associated with the recruitment and engagement of participants in research drawing upon our research exploring the support people might need to participate in breast, bowel and cervical screening programmes in Wales. Key issues related to sampling, language, IT competence, and time demands for participation in research, and solutions employed to help overcome these challenges and ensure that our studies were more inclusive and that our target audience could meaningfully contribute.

In the United Kingdom, there is a commitment to inclusivity in research and various frameworks are available to enhance inclusion (National Institute for Health Research et al. 2019). In this research, working with local communities on our recruitment strategy and data collection were shown to be invaluable. Without the involvement of our community co-researchers, we would have been unable to obtain rich data from a range of participants in terms of ethnicity, languages spoken, IT competence, and screening uptake. The benefits of patient and public involvement in research have been frequently reported, such as making research more relevant, improving access to community groups, and developing partnerships between research organisations and local communities especially hard-to-reach groups (Lander et al. 2019; Ratneswaren 2020). However, some issues should be

considered as shown in this research. For example, relevant training must be provided to ensure the integrity of research when community members are involved in undertaking research. Of equal importance is the organisational support for ongoing engagement to build a long-term partnership with local communities. It is crucial to engage community members at the inception/development stage of the research to ensure that the research will have a positive impact on the target group and to help researchers anticipate any potential issues and develop a contingency plan to address such issues when they do arise.

Working in collaboration between primary care and Public Health Wales has helped us to achieve a broader perspective on the diverse needs of local population to take part in cancer screening programmes. Benefits of the collaboration included bringing together health needs assessment and health service delivery founded on a research basis drawn from an understanding of the perceptions of residents within a defined geographical area. This is entirely in the spirit of the Primary Care Cluster/Neighbourhood Care Networks and ethos of the Place Based Care model, an ambition of the Welsh Government which recognises the value of collaboration between multi agencies (e.g. health, social care, third sector, education, and housing partners) to inform future service planning and development (Welsh Government 2019).

Conclusion

In this article, we have reflected on methodological issues associated with the recruitment and engagement of people for a cancer screening research project in Wales. We have highlighted the importance of ongoing community engagement, the provision of appropriate study materials, and the adaption to different data collection modes to meet participants' needs to participate in research, thus enabling people who are usually excluded from research to have a voice and make a significant contribution to research.

References






- Bennett G, Richmond J, Thompson AJ (2021) Producing health information in consultation with health workers and the hepatitis B-affected communities is worthwhile. *Australian Journal of Primary Health* **27**, 116-121. doi: 10.1071/PY20188
- Broeders MJM, Allgood P, Duffy SW, Hofvind S, Nagtegaal ID, Paci E, Moss SM, Bucci L (2018) The impact of mammography screening programmes on incidence of advanced breast cancer in Europe: a literature review. *BMC Cancer* **18**, 860.
- Campbell C, Douglas A, Williams L, Cezard G, Brewster DH, Buchanan D et al. (2020) Are there ethnic and religious variations in uptake of bowel cancer screening? A retrospective cohort study among 1.7 million people in Scotland. *BMJ Open* **10**:e037011. doi:10.1136/bmjopen-2020-037011
- Heinävaara S, Sarkeala T, Anttila A (2016) Impact of organised mammography screening on breast cancer mortality in a case-control and cohort study. *BJC* **114**, 1038-44. doi: 10.1038/bjc.2016.68
- Jansen, EEL, Zielonke N, Gini A, Anttila A, Segnan N, Vokó Z, Ivanuš U, McKee M, de Koning HJ, de Kok IMCM (2020) Effect of organised cervical cancer screening on cervical cancer mortality in Europe: a systematic review. *European Journal of Cancer* **127**, 207-223. doi: 10.1016/j.ejca.2019.12.013
- Kane M, Trochim WMK (2007) *Concept mapping for planning and evaluation*. (Sage, London, UK).
- Kinnear H, Rosato M, Mairs A, Hall C & O'Reilly D (2011) The low uptake of breast screening in cities is a major public health issue and may be due to organisational factors: A Census-based record linkage study. *Breast* **20**, 460-463. doi:10.1016/j.breast.2011.04.009
- Koo S, Neilson LJ, Von Wagner C, Rees CJ (2017) The NHS Bowel Cancer Screening Program: current perspectives on strategies for improvement. *Risk Management and Healthcare Policy* **10**, 177-187. doi: 10.2147/RMHP.S109116.
- Lander J, Langhof H, Dierks ML (2019) Involving patients and the public in medical and health care research studies: An exploratory survey on participant recruiting and representativeness from the perspective of study authors. *PloS One* **14**, e0204187. doi: 10.6084/m9.figshare.7038680.
- Massat NJ, Douglas E, Waller J, Wardle J, Duffy SW (2015) Variation in cervical and breast cancer screening coverage in England: a cross-sectional analysis to characterise districts with atypical behaviour. *BMJ Open* **5**, e007735. doi:10.1136/bmjopen-2015-007735
- Miller BC, Sarma EA, Sun Y, Messina CR, Moyer A (2020) Psychosocial predictors of mammography history among Chinese American women without a recent mammogram. *Ethnicity and Health* **25**, 862-873. doi: 10.1080/13557858.2018.1447653
- Mirza M, Harrison EA, Roman M, Miller KA, Jacobs EA (2022) Walking the talk: understanding how language barriers affect the delivery of rehabilitation services. *Disabil Rehabil* **44**, 301-314. Doi: 10.1080/09638288.2020.1767219
- National Institute for Health Research, Chief Scientist Office, Health and Care Research Wales, and Public Health Agency (2019) UK standards for public involvement in research: Better public involvement for better health and social care research. Available at: <https://drive.google.com/file/d/1U-JNJCfFepaAOruEhzz1TdLvAcHTt2Q/view> [Verified 18 May 2022]
- Office for National Statistics (2019) Population estimates by ethnic group and religion, England and Wales - Office for National Statistics. Available at

- <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/populationestimatesbyethnicgroupandreligionenglandandwales/2019> [Verified 18 May 2022]
- Public Health Wales (2020) All-Wales annual report screening division Public Health Wales. Available at: <https://phw.nhs.wales/files/screening-division-reports/screening-division-annual-report-jan-2020/#:~:text=The standard is that 70,not meet the 60%25 target.> [Verified 26 May 2022]
- Ratneswaren A (2020) The I in COVID: The importance of community and patient involvement in COVID-19 research. *Clinical Medicine* 20(4), e120-e122.
- Sharif SM, Blyth M, Ahmed M, Sheridan E, Saltus R, Yu J, Tonkin E, Kirk M (2020) Enhancing inclusion of diverse populations in genomics: A competence framework. *Journal of Genetic Counseling* 29, 282-292. doi: 10.1002/jgc4.1263.
- Welsh Government (2019) A Healthier Wales: our plan for health and social care. Available at <https://gov.wales/sites/default/files/publications/2019-10/a-healthier-wales-action-plan.pdf> [Verified 6 June 2022]
- Welsh Government (2022) Local Labour Force Survey/Annual Population Survey: Ethnicity by Welsh local authority. Available at <https://statswales.gov.wales/Catalogue/Equality-and-Diversity/Ethnicity/ethnicity-by-area-ethnicgroup> [Verified 4 November 2022]
- World Health Organization (WHO) (2020) Global health estimates: Leading causes of death, Cause-specific mortality, 2000–2019. Available at <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-leading-causes-of-death> [Verified 18 May 2022]
- World Health Organization (WHO) (2022) Cancer. https://www.who.int/health-topics/cancer#tab=tab_1 [Verified 18 May 2022]
- Yu J (2009) Qualitative research on the attitudes toward teenage sexual behaviour of Chinese British families: Methodological issues. *Journal of Transcultural Nursing*, 20, 156-163. doi: 10.1177/1043659608325842
- Yu J, Saltus R, Jarvis P (2017) A survey of service providers' views on care and support provision for older women from Black and minority ethnic backgrounds in Wales: Implications for policy and practice. *Health Care for Women International*, 38(7), 715-731. doi: 10.1080/07399332.2017.1318881
- Yu J, Saltus R, Jarvis P (2020) Perceived inequalities in care and support for older women from Black and minority ethnic backgrounds in Wales: findings from a survey exploring dignity from service providers' perspectives. *Ethnicity and Health*, 25(2), 222-242. doi: 10.1080/13557858.2017.1399200
- Yu J, Wallace S & Kenkre J (2022) An exploration of the uptake of screening programmes for cancer in Newport West. Report to the Newport West Neighbourhood Care Network, Aneurin Bevan University Health Board.
- Yu J, Wallace S & Kenkre J (2023) A consensus approach to understand the support needs of women in Newport West, Wales, to participate in breast screening. *Health Expectations*, in press.

Table 1: Characteristics of the participants (N=131)

	Breast screening study (n=37)	Bowel screening study (n=24)	Cervical screening study (n=70)
Ethnic groups (10)	White (15) Pakistani (12) Arab (4) Bangladesh (3) African (1) Indian (1) Mixed or multiple ethnic groups (1)	White (16) Pakistani (3) Any other white background (1) Any other ethnic background (1)	Pakistani (18) White (15) Arab (11) Bangladesh (10) African (8) Any other ethnic background (3) Any other White background (2) Indian (2)
Ethnic minorities (81)	22	5	54
Languages spoken (14)	English, Arabic, Bengali, Punjabi, Urdu, Italian	English, Punjabi, Urdu, Italian, Spanish	English, Arabic, Somali, Kurdish, Farsi, Bengali, Punjabi, Urdu, Italian, Patwa Creole, Romanian
Non-English speakers (40)	12	1	17
Had missed screening (53)	13	1	39

	<p>Study title</p> <p>An exploration of the uptake of cancer screening programmes in Newport West (Breast screening)</p>
	<p>Study consent</p>
	<hr/>
	<p>I have been told about the study.</p> <input data-bbox="1211 1193 1396 1301" type="text"/>
	<p>I was able to ask questions.</p> <input data-bbox="1211 1518 1396 1626" type="text"/>

	<p>I know what is involved.</p> <input data-bbox="1209 271 1398 383" type="text"/>
	<p>I understand that I can leave the online study at any time and that I do not have to say why.</p> <input data-bbox="1209 568 1398 680" type="text"/>
	<p>I am happy to take part.</p> <input data-bbox="1209 916 1398 1028" type="text"/>
	<hr data-bbox="592 1279 1155 1283"/>
	<hr data-bbox="592 1532 1155 1536"/>

Please return the consent form to: ab_breast_screening_gcm1@southwales.ac.uk

Thank you

Figure 1: Consent form for the breast screening study (Easy-read version)

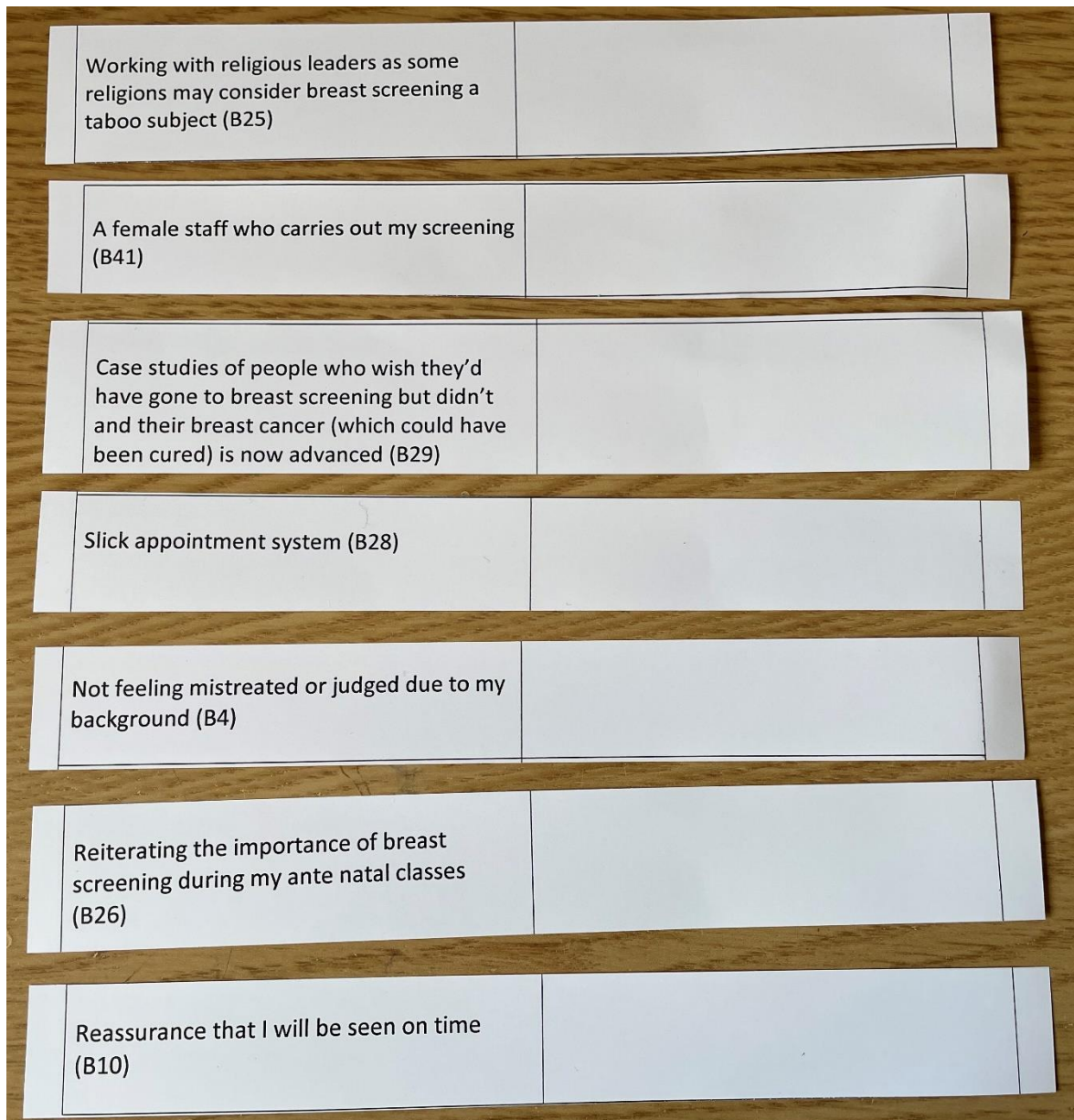


Figure 2. Statement cards (examples)

Data Availability Statement

The data that support this study cannot be publicly shared due to ethical or privacy reasons and may be shared upon reasonable request to the corresponding author if appropriate.

Declaration of Funding

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