

Original Research Paper

DOI: [10.82005/NC.03.02.01](https://doi.org/10.82005/NC.03.02.01)

'What I Would Like to Say...': The effectiveness of the BU PIER Community Researcher Model in capturing the voices of disabled people's experiences of cancer services in the UK

Katie Munday

University of Portsmouth, England

katie.munday@port.ac.uk

Roseanna Tansley

University of Southampton, England

r.l.tansley@soton.ac.uk

Amanda Durrant

University Hospital Southampton,
Englandamanda.durrant@uhs.nhs.uk

Stevie Corbin-Clarke

Bournemouth University, England

scorbinclarke@bournemouth.ac.uk

Katherine Jupp

Bournemouth University, England

kejupp@bournemouth.ac.uk

Mel Hughes

Bournemouth University, England

mhughes@bournemouth.ac.uk

Received 05 February 2026 / Accepted 22 February 2026 / Revised 02 September 2026 / Published 17 October 2026

Abstract

Disabled people experience persistent inequities in accessing cancer screening, diagnosis, treatment, and care in the UK, shaped by structural ableism and inaccessibility. These inequities contribute to delayed diagnosis, reduced uptake of screening programmes, and poorer experiences of cancer care when compared with non-disabled populations. Despite this, disabled people remain underrepresented in health and social care research. The BU PIER Community Researcher Model was applied within a 10-month pilot study, 'What I Would Like to Say...', in which data were generated through four face-to-face arts-based workshops involving 45 disabled participants. Creative methods were used to support accessible engagement with a sensitive topic, enabling participants to share their experiences through handprint artworks and informal semi-structured discussions. Data were analysed using collaborative thematic analysis integrating lived experience, clinical, and academic perspectives.

Three key themes emerged: the importance of accessibility, the value of fostering a relaxed, supportive environment, and the need for participants to feel heard and valued. These processes enabled us to co-create suggestions for improving practice in asymptomatic screening and primary cancer care. The paper concludes that the BU PIER Community Researcher Model offers an effective approach for inclusive research with disabled communities with the potential to inform improvements in equitable cancer service provision.

Keywords: Community Research, Participatory, Disabled, Cancer, Primary Care

1. Introduction

Disabled people face significant barriers in accessing cancer services due to interpersonal ableism, stigma and discrimination, and systemic structural factors including physical inaccessibility (World Health Organisation, 2023). Disabled people face various barriers when trying to access asymptomatic screening and primary cancer care in the UK, including invalidation of their needs, being misunderstood or ignored, and being perceived as a 'low priority' within healthcare (Gibson & O'Connor, 2010; Sakellariou et al., 2019). These issues lead to people with disabilities being underdiagnosed and undertreated at higher rates than non-disabled people (NHS, 2022).

Individuals with learning disabilities and mental health issues encounter more obstacles in accessing cancer screening services, resulting in more instances of late-stage cancer diagnoses (Heslop et al., 2022; Satgé et al., 2014). Research by Mencap (2019) found that only 19% of people with a learning disability engaged with cervical screening, compared to 77% of all people invited. Similarly, only 33% of people with a learning disability engaged in breast screening, compared to 70% of all people invited (Mencap, 2019). Forgoing screening means many learning-disabled people have their cancer discovered at later stages, with 46% of all cancers in adults with learning disabilities being diagnosed at stage IV when the cancer has already metastasised to other parts of the body (Heslop et al., 2022; Satgé et al., 2014).

As the population ages and more people live with cancer and disabilities, it is important that we understand and respond to the needs of this group to ensure services are accessible, appropriate, and affirming. This is especially pertinent as disabled people diagnosed with cancer are also more likely to report low satisfaction with care and have higher cancer-specific mortality compared with their non-disabled counterparts (Cuypers et al., 2020; Tosetti & Kuper, 2023). People with disabilities consistently report receiving poorer quality cancer care, including delays in treatment, excessively invasive treatment, and less access to pain medications and state-of-the-art care (Tosetti & Kuper, 2023).

In addition to cancer care inequity, disabled people are often overlooked in health and social care research and public health interventions. Despite their lived-experience expertise, disabled people often remain excluded from health and social care research due to inaccessible and limited opportunities to participate, and activities that fail to recognise the barriers to engagement (NIHR, Include Project, 2020). Building capacity within the voluntary and community sectors to conduct research with their communities is one approach to improve equity in health and social care research and provision (McDonald & Raymaker, 2013). Community organisations and charities have well-established relationships within their communities, often making them well-placed to conduct research that reflects the needs of their members (Department for Digital, Culture, Media and Sport, 2022). When used with disability communities, participatory approaches could be more accessible and inclusive, with participants respected and valued as partners in knowledge creation (Blumenthal et al., 2013; Lawson et al., 2015; Isaacs et al., 2020). One such approach is the Community Researcher Model used by Bournemouth University Public Involvement in Education and Research (BU PIER), which supports and mentors people with lived experience to undertake research. This article reflects on the effectiveness of the BU PIER Community Researcher Model on capturing and representing disabled people's experiences of cancer care, and shares recommendations to improve practice within asymptomatic screening and primary cancer care for disabled patients.

1.1 A note on language

Language can be a powerful tool to express an individual's experience, as well as perspectives towards disability and identity (Bottema-Beutel et al, 2021). Participants and community researchers used a mixture of language to express their disabled embodiment and experiences. Therefore, we use a mix



of identity-first (i.e. disabled person) and person-first language (i.e. person with disabilities) to best represent everyone involved in this project.

2. Approach

The 'What I would like to say...' project involved two disabled community researchers (K.M. and R.T.) to carry out creative and engaging workshops and interviews with 45 disabled people, with the support of Bournemouth University's PIER team (K.J. and S.C-C.), and a cancer Clinical Nurse Specialist (A.D.). This pilot project was a part of the 'Whatever It Takes — Cancer Care for Everyone' programme (Wessex Cancer Alliance, 2023).

The aims of this pilot project were threefold: 1) to build capacity within a community for engaging and leading on inclusive research; 2) to understand and share the cancer service experiences of disabled participants across Wessex; and 3) to further develop the BU PIER Community Researcher Model. We have shared the specific cancer care experiences of participants elsewhere (Tansley et al., 2024). In this article we focus on how the BU PIER Community Researcher Model built the capacity of the community researchers and has led to further work to improve access of cancer services in both academic outputs and applied practice in Wessex hospital settings.

The BU PIER Community Researcher Model enables individuals who have personal experience with the subject being discussed to feel at ease in sharing their perspectives, while also fostering their confidence to take on roles as peer mentors and community researchers. The model follows eight principles:

1. Listening and insight gathering.
2. Leadership engagement and commitment.
3. Collaboration and community engagement.
4. Empathy and understanding.
5. Building trust through relationships.
6. Flexibility and person-centred approaches.
7. Awareness and education activities.
8. Cultural and perceptual shifts.

These principles have been developed throughout different projects (Hand et al., 2026; Hughes, 2025; Munday & Tansley 2026) and are based in the understanding of the differences between priorities and motivators in the system world and the lifeworld. Within the system world, research is often perceived as a clearly outlined process: objective and transactional, where participants supply data to researchers, often leading to an imbalanced power dynamic (Farr, 2018). In contrast, the lifeworld involves individuals collaborating on projects with their own motivations and desired results, with priorities generally stemming from values, relationships, communication, and everyday experiences (Green & Johns, 2019). The BU PIER Community Researcher Model was chosen for the current project as it involves lived experienced experts and community collaborators setting the priorities, while being assisted by the wider research team, shifting the conventional research power dynamic.

Cancer and healthcare (especially that which involves intimate care) can be difficult experiences to discuss. The psychological safety of participants and the research team was vital. Throughout the workshops, the cancer Clinical Nurse Specialist (A.D.), with her depth of cancer knowledge and connections to the NHS, supported participants and researchers through. A.D. ensured everyone felt supported whilst sharing their cancer service stories, and signposted when needed.



This study was carried out in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Bournemouth University (Date 21/10/22, No.45815).

2.1 Data Collection and Analysis

We used convenience sampling (Galloway, 2005), drawing on our networks of community connections across the Wessex region, including Autism Hampshire's Fareham Serendipity group; the Dorset Blind Association; the Multiple Sclerosis Centre Dorset; and the Bournemouth and Poole Lymphoedema and Lipoedema Support Group. These findings were supplemented by a semi-structured video call interview with a member of the Royal National Institute of Blind People recruited through purposive sampling (Patton, 2002) after they shared their experiences of local breast cancer care on national radio. Overall, we spoke to 45 people with a range of disabilities, ages, genders and experiences through four face-to-face creative arts-based workshops.

We decided to use an arts-based method to enable participants to explore their subjective experiences, feelings, and emotions (Leavy, 2020). These methods have proven useful when gathering data and disseminating findings, when exploring complex research topics where more traditional methods are not always sufficient (Holgate et al., 2012; Vaart et al., 2018). Due to the sensitive nature of our research topic, and to make workshops fun and accessible to groups with mixed abilities (Fenge et al., 2011), participants were encouraged to create a piece of art that represented them and their experiences of asymptomatic screening and primary cancer care. Creative workshops lasted up to two hours, with a semi-structured, flexible agenda. During the creative workshops, research team members spent time with participants listening to and capturing what they said using prompts such as 'what would you like to say about your experience with cancer services?', 'What has brought you comfort?' and 'what is your story?' as required.

We used thematic analysis (Braun and Clarke, 2021) to identify similarities and differences across participant experiences. After initial coding by all research members, codes and themes were explored and defined by K.M. and R.T. until an accurate reflection of the data, equally valuing lived experience and clinical and research expertise, was achieved. This ensured that lived experience, practice and academic perspectives were all valued.

3. Results

Participants shared workshop-specific insights around the themes of accessibility, being in a relaxed environment, and feeling listened to and valued, as well as recommendations for improving practice in cancer care. These results highlight the effectiveness of the BU PIER Community Researcher Model for capturing and representing disabled people's experiences of cancer care.

3.1 Accessibility

Adjustments were made throughout the process to meet individual access requirements. The team shared project information at one of the group's drop-in events. The group leader then visited Bournemouth University to complete their risk assessment and shared, "We don't have a community building, so we need to go to places for activities. Research needs to be a trade-off for the group to get a free accessible session [...] the payments towards travel costs really helped make a difference." Additionally, they shared that the room worked well as it was close to the accessible toilets and the lift, and they appreciated being guided by a member of the research team to the workshop room.

On the lead-up to engaging with Autism Hampshire, the community researchers reflected on their autistic lived experiences and offered the group more specific support, including a detailed outline of the workshop plan and a 'meet the team' document with photos and short bios of each research team member. An autistic participant shared, "The purpose of what you were doing and why you were doing it was all very clearly explained beforehand." The BU PIER Community Researcher Model allowed for



more connections between researchers and the participants, connecting through shared experiences was an important part of making the sessions more accessible and more fruitful.

3.2 Creating a Relaxed Environment

Creating and maintaining a relaxed environment with clear choices of *if* and *how* participants engaged allowed participants to “Really relax” and share their experiences on things they “Would not normally talk about”. One participant shared that the art process was a good way to “Express our emotions towards how we feel about our experiences with cancer services”. The Autism Hampshire group leader shared that having a creative activity to focus on enabled their members, “Who are often quite anxious with new people and new activities to really engage, and it really did translate into the message of ownership of the project.”

Figure 1: Participant's hand maps



Note. This figure shows a collection of hand map artworks from the creative workshops. The hands are individually decorated with pom-poms, sequins, feathers and colourful handwriting. The hands are set out to make a large heart shape against a stark white background.

The creative workshop design, often used within the BU PIER Community Researcher Model, was an effective, relaxing and joyful method to gain contributions from participants (many of whom were participating in research for the first time). Creative workshops allowed participants with different needs to join in at a pace and level which suited them, and small group sizes allowed participants to direct the conversation (Coemans and Hannes, 2017; Ørngreen & Levinsen, 2017). Creative workshops were a process of playful and often joyful experimentation, creating the conditions for comfortable sharing of experiences, appreciating participants as experts in their lived experience (Wang et al., 2017).

Another group leader reflected, “The team were fantastic at making everyone feel comfortable. I was amazed at how open and comfortable people were to chat with the team.” They shared that having autistic community researchers made the group feel more comfortable with sharing their experiences as they would “Understand what its like”. This shows the effectiveness of working with community



researchers who share identity and life experiences with participants. Community researcher R.T. reflected:

As someone with Crohn's Disease who has spent a lot of time in hospital and undergoing cancer screening myself, it was eye-opening to realise how much my own experiences resonated with what everyone else had to say. This helped me to both recognise where our recommendations should lie and to look inwards and understand that I was not in fact alone in my own experience.

3.3 Ensuring Participants Feel Listened to and Valued

Several participants shared that they felt listened to and valued, "[Members] had one-to-one attention; this is something the group really values and responds to, as they often feel that they don't have a voice." This one-to-one attention was possible due to the amount of research team members in the room, and the ability to use our different skills and attributes to engage people in a personal manner. The community researcher's have had previous experiences of engaging in research that was inaccessible, harmful or felt extractive and they did not want to replicate that, as K.M. reflected:

It was important to me that the sessions were as accessible as possible. I have been a participant in autism research which has been terribly designed and it made me feel invalid... I did not want our attendees to feel this way at any point in our journey together. I want other disabled people to feel listened to, to feel seen, cared for and respected.

One participant explained that they were happy to share their story, especially as it may help other visually impaired people in the future, "I felt listened to today... the more information there is, the better, even if it takes time to filter through." This participant was initially hesitant to come to the workshop due to their anxiety; however, with the support of their carer, they were able to attend and became increasingly comfortable engaging with the workshop. All groups reflected that they felt the workshop was worthwhile and they were happy to have contributed to the 'What I Would Like to Say...' project.

Figure 2: Visually impaired participant's hand map



Note. A large pre-printed hand. Words surround the highly-textured and colourful artwork. Phrases include: I feel unsafe; I feel white fury; care is predicated towards the normative body.

3.4 Recommendations for Improving Asymptomatic Screening and Primary Cancer Care

Facilitating accessible and relaxed workshop environments where participants felt listened to and valued allowed us to effectively capture participant's suggestions for service improvements with three key areas: compassion and reassurance matter; effective communication is key; make accessibility a priority.

3.4.1 Compassion and Reassurance Matter

Many of the participants shared that a person-centred approach would mitigate some of the anxiety they felt when engaging with primary cancer care. Recommendations for practitioners included:

- Provide clear information to patients of what to expect during the process, being mindful to reassure patients where needed.
- Take care not to rush patients through examinations to avoid depersonalising their experience.

3.4.2 Effective Communication is Key

Participants spoke of effective communication as being a core aspect of supporting their understanding during primary cancer care, supporting informed decision-making. Recommendations for practitioners included:

- Support patients to make informed choices through stronger collaboration between physicians and patients.
- Work across specialisms to ensure the right course of action that considers all aspects of a patient's health and care needs.
- Engage in training about patients' different communication needs to support improved information sharing.
- Find ways to identify patients' support needs to help staff recognise where adaptations may be required.

3.4.3 Make Accessibility a Priority

Healthcare settings should prioritise ways of supporting patient attendance through an individualised approach. Recommendations for practitioners included:

- Provide patients with clear directions and information in advance of appointments to allow time for planning.
- Prioritise overcoming physical access barriers in the buildings you work in to avoid incomplete screenings and undignified procedures for patients.
- Improve accessibility by providing patients with options that meet their needs.

4. Discussion



The BU PIER Community Researcher Model follows the principle that individuals who are most affected by an area of research should be involved in directing all stages of the research cycle; this involves drawing on their expertise as community members to understand their lived experiences, and to identify problems and their potential solutions (Wang et al., 2017). Under this model, the community researchers were able to connect with people who may otherwise have been unwilling to engage, allowing the creation of meaningful work *with* participants (Hughes & Duffy, 2018; Shore, 2003). The lived experiences of the community researchers allowed open and honest conversations with participants through shared understanding and culture, as well as shared experiences of cancer care (Emerson et al., 2024; Tansley et al., 2024). This was especially exemplified in the Autism Hampshire group as the community researchers were able to navigate the potential anxiety of autistic group members around a change in routine (Beardon, 2021). Feedback from many of the participants across the workshops was one of *finally* being listened to and understood, and, as a result, the data captured was rich and in-depth.

Central to the BU PIER Community Researcher Model is creating safer spaces for participants to share their experiences without judgement. Conversations were at the pace of the participant, and often many things were discussed before talking specifically about cancer care. This allowed time for participants to relax into the process, and for the research team to contextualise participants' experiences within their everyday lives. Sharing these conversations over tea and biscuits allowed for conversations to feel more relaxed, and for participants to feel listened to and valued. Choice and autonomy were also built within the research team. The community researchers were given choices in how and when they wanted to be involved with the project. They preferred to lead in most instances and provided a safe environment for other team members to ask questions and develop a shared understanding of disability. The choice of language and disability frameworks used within the project were directed by the community researchers and in line with participant preferences, i.e., the Neurodiversity framework (Chown, 2021),

The asset-based approach of the BU PIER Community Researcher Model was an effective method to mentor and build the capacity of the community researchers and community partners. As K.J., BU PIER lead, reflected:

Being involved in this process has furthered my understanding of the demands and rewards associated with using the BU PIER Community Researcher Model. It has cemented my confidence in the power of partnership working where relationships are at the heart of the process. This way of working invites and inspires transformative relationships where all involved have the opportunity to see things from new angles and learn and grow together.

K.J. shared how the 'What I would like to say...' project achieved its third aim of further developing the BU PIER Community Researcher Model. This is the first instance in which the model was used when working with people with disabilities, and shows that it can be adapted to support different research aims and populations.

Additionally, the BU PIER Community Researcher Model has been effective for its second aim: to understand and share the cancer service experiences of disabled participants across Wessex. Shared through academic journals which go directly to community nurses (Tansley et al., 2024), shared at several cancer research conferences, as well as at the All Party Parliamentary Group on Cancer (Munday & Tansley, 2023). This has given the community researchers the confidence and ability to lead the second phase of this work (see Munday & Tansley, 2026). Furthermore, at the time of writing, the community researchers are working with two hospitals in Wessex to improve the accessibility, and gender inclusion, of their screening services. This is in conjunction with another research team who used the BU PIER Community Researcher Model on a previous project entitled Trans Aware Cancer Care (Hand et al., 2026). This is evidence of the effectiveness of the BU PIER Community Researcher Model in its first aim: to build capacity within a community for engaging and leading on inclusive



research. Moreover, the aforementioned anxious workshop participant is now a BU PIER member who contributes their lived experience to research conducted at the centre.

The outcomes of this project were further reaching than was anticipated and included the experience gained by community researchers, improvement of the research team's knowledge, breaking down barriers to participation, and creating epistemic communities in which we all learn from one another. The highlight of such work is not only the methodology, but the ability to underpin accessible practice that leads to better diagnosis and treatment for people with disabilities. We have started to apply this both within our own practice as a clinical nurse specialist (A.D.) and as community researchers working closely with two mammography teams to improve the access, and the potential treatment outcomes, of disabled patients in Wessex.

5. Limitations

Despite a diverse range of abilities, disabilities, age and gender, our participant pool lacked ethnic and racial diversity. Future work in this area must include groups and individuals at the racialised and disabled intersection and include community researchers from more diverse cultural and ethnic backgrounds. This should include working alongside Global Majority disability groups such as ADHD Babes, Scottish Ethnic Minority Autistics (SEMA), and Differently Abled Muslims. Similarly, the participants in the current study were already receiving support through their social group. Future research would benefit from engaging with participants who have less access to support groups, including those from more remote areas, as well as those who are vulnerably housed, unhoused, or live nomadically.

6. Conclusion

The BU PIER Community Researcher Model allowed for community researchers to be at the heart of all aspects of this project, which was essential in hearing, understanding, capturing, and amplifying the voices of participants. Focusing on accessibility, an informal and relaxed atmosphere, and enabling participants to feel valued and listened to produced deep findings from the knowledge and lived experiences of all involved (Tansley et al., 2024). The BU PIER Community Researcher Model offers an effective approach for inclusive research with disabled communities and has the potential to inform improvements in asymptomatic screening and primary cancer care. It is important to note however, that what worked for this group of disabled participants and community researchers may not work for others. The crucial elements for future projects are relationships and trust, building this from the point of recruitment and role-modelling within the research team so that it can be seen, felt and heard within workshops.

References

- Beardon, L. (2021). *Avoiding anxiety in autistic adults: A guide for autistic wellbeing*. Sheldon Press.
- Blumenthal, D., DeClemente, R., Braithwaite, R., & Smith, S. (2013). *Community-Based Participatory Research: Issues, Methods, and Translation to Practice*. Springer.
- Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide*. Sage.
- Buckley, D. I., Hsu, F., Dana, T., Blackie, K., Holmes, R., Nygren, P., Horner-Johnson, W., Nicolaidis, C., & Chow, R. (2025). Health Care Delivery of Clinical Preventive Services for People with Disabilities: A Systematic Review. *Ann Intern Med* 178, 671–686. <https://doi.org/10.7326/ANNALS-24-02446>
- Coemans, S., & Hannes, K. (2017). Researchers under the spell of the arts: Two decades of using arts-based methods in community-based inquiry with vulnerable populations. *Educational Research Review*, 22, 34–49. <https://doi.org/10.1016/j.edurev.2017.08.003>.



- Cuypers, M., Tobi, H., Huijsmans, C.A.A., Gerwen, L.V., Hove, M.T., Weel, C.V., Kiemeney, L.A.L.M., Naaldenberg, J., & Leusink, G.L. (2020). Disparities in cancer-related healthcare among people with intellectual disabilities: a population-based cohort study with health insurance claims data. *Cancer Med*, 9, 6888–6895. <https://doi.org/10.1002/cam4.3333>
- Emerson, L.M., Ruth, M., van der Meer, L., Sutherland, D., & McLay, L. (2024). Autistic Co-Led Community Priorities for Future Autism Research in Aotearoa New Zealand. *Autism in Adulthood*, 6 (2). <https://doi.org/10.1089/aut.2022.0109>
- Farr, M.(2018). Power dynamics and collaborative mechanisms in co-production and co-design processes. *Critical Social Policy*, 38 (4),623–44. <https://doi.org/10.1177/0261018317747444>
- Galloway, A. (2005). Non-Probability Sampling. In K. Kempf-Leonard (ed.) *Encyclopedia of Social Measurement* (pp. 859-864). Elsevier. <https://doi.org/10.1016/B0-12-369398-5/00382-0>
- Gibson, J., & O'Connor, R. (2010). Access to health care for disabled people: a systematic review. *Social Care and Neurodisability*, 1 (3), 21-31. <https://doi.org/10.5042/scn.2010.0599>
- Green, G., & Johns, T. (2019). Exploring the Relationship (and Power Dynamic) Between Researchers and Public Partners Working Together in Applied Health Research Teams. *Frontiers in Sociology*, 4 (20). <https://pmc.ncbi.nlm.nih.gov/articles/PMC8022793/>
- Hand, Z., Munday, K., Weyman-Light, E., Rangelov, D., Parkes, A., Durrant, A., & Jupp, K. (2026). Trans Aware Cancer Care: community researchers' report. *Involving People*. <https://involvingpeople.org/wp-content/uploads/2026/03/TACC-Report-Feb-2026.pdf>
- Heslop, P., Cook, A., Sullivan, B., Cakin, R., Pollard, J., & Byrne, V. (2022). Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. *BMJ Open*, 12 (3). <https://doi.org/10.1136/bmjopen-2021-056974>
- Holgate, J., Keles, J., & Kumarappan, L. (2012). Visualising community: An experiment in participatory photography among Kurdish diasporic workers in London. *Sociological Review*, 60, 312-332. <https://doi.org/10.1111/j.1467-954X.2012.02075.x>
- Hughes, M., & Duffy, C. (2018). Public involvement in health and social sciences research: A concept analysis. *Health Expectations*, 21 (6), 1183 – 1190. <https://doi.org/10.1111/hex.12825>
- Hughes, M., Jupp, K., Beresford, C., Robertson, J., Wathen, A., Bailey, T., Lennon-Patience, S., Graham, M., Pickering, D., & Posnett, H. (2025). Designing a Flexible and Inclusive Approach for Public and Community Involvement in Research With People Who Are Homeless or Vulnerably Housed: Critical Reflections From the I Am More Than... Project. *Health expectations : An International Journal of Public Participation in Health Care and Health Policy*, 28(3). <https://doi.org/10.1111/hex.70325>
- Isaacs, S.A., Roman, N., & Carlson, S. (2020). Fostering Family Resilience: A Community Participatory Action Research Perspective. *Child Care in Practice*, 26(4), 358–372. <https://doi.org/10.1080/13575279.2020.1801578>
- Jacobson, D., & Mustafa, N. (2019). Social Identity Map: A Reflexivity Tool for Practising Explicit Positionality in Critical Qualitative Research. *International Journal of Qualitative Methods*, 18. <https://doi.org/10.1177/1609406919870075>
- Lawson, H., Caringi, J., Pyles, L., Jurkowski, J., & Bozlak, C. (2015). *Participatory action research*. Oxford Press.
- Leavy, P. (2020). *Method meets art: Arts-based research practice*. Guildford Press.



McDonald, K.E., & Raymaker, D.M. (2013). Paradigm shifts in disability and health: Toward more ethical public health research. *American Journal of Public Health*, 103, 2165–2173.
<https://doi.org/10.2105/AJPH.2013.301286>

Mencap (2019). Health Inequalities. *Mencap*. <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>

Munday, K., & Tansley, R. (Nov, 2023). 'Whatever it takes' cancer care for everyone (presentation). All Party Parliamentary Group on Cancer (London).
<https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/14355-10061/APPGC%20Minutes%2013%20November%202023>

Munday, K., & Tansley, R. (2026). "What I would like to change" about Cancer care accessibility. *Journal of Community Nursing*, 40 (2), 44–49. <https://www.jcn.co.uk/journals/issue/04-2026/article/i-would-like-change-cancer-care-accessibility>

National Institute for Health and Care Research. (2024). Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project. *NIHR*.
<https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435>

NHS. (2024). National Cancer Patient Experience Survey 2024: National report (Quantitative). *NHS*.
<https://www.ncpes.co.uk/latest-national-results/>

Ørngreen, R., & Levinsen, K.T. (2017). Workshops as a Research Methodology. *Electronic Journal of E-Learning*, 15 (1), 70–81. <https://academic-publishing.org/index.php/ejel/article/view/1820>

Patton, M.Q. (2002). *Qualitative research and evaluation methods*. Sage.

Pollard, G., Studdert, J., & Tiratelli, L. (2021). Community power: The evidence. *New Local*.
<https://www.newlocal.org.uk/wp-content/uploads/2021/02/Community-Power-The-Evidence-1.pdf>

Sakellariou, D., Anstey, S., Gaze, S., Girt, E., Kelly, D., Moore, B., Polack, S., Pratt, R., Tyrer, G., Warren, N., Wilkinson, W., & Courtenay, M. (2019). Barriers to accessing cancer services for adults with physical disabilities in England and Wales: an interview-based study. *BMJ Open*, 9.
<https://doi.org/10.1136/bmjopen-2018-027555>

Satgé, D., Sauleau, E-A., Jacot, W., Raffi, F., Azema, B., Bouyat, J-C., & Assaf, N.E.H. (2014). Age and stage at diagnosis: a hospital series of 11 women with intellectual disability and breast carcinoma. *BMC Cancer*, 14 (150). <https://doi.org/10.1186/1471-2407-14-150>

Shore, S. (2003). *Beyond the wall: Personal experiences with autism and Asperger Syndrome*. Autism Asperger Publishing Co.

Tansley, R., Corbin-Clarke, S., Munday, K., Durrant, A., & Hughes, M. (2024). "What I would like to say" findings: Cancer care for everyone. *Journal of Community Nursing*, 38 (1), 46–50.
<https://www.jcn.co.uk/journals/issue/02-2024/article/what-i-would-like-to-say-findings-cancer-care-for-everyone>

Vaart, G., Hoven, B., & Huiden, P. (2018). Creative and arts-based methods in academic research. Lessons from a participatory research project in The Netherlands. *Qualitative Social Research*, 19(2): 1–30. <https://doi.org/10.17169/fqs-19.2.2961>

Wang, Q., Coemans, S., Siegesmund, R., & Hannes, K. (2017). Arts-based Methods in Socially Engaged Research Practice: A Classification Framework. *Art Research International*, 2 (2), 5–39. (2017).
<https://doi.org/10.18432/R26G8P>



World Health Organisation. (2023). Disability. *World Health Organisation*. <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>

