

'What I would like to say' findings: cancer care for everyone

Roseanna Tansley, Stevie Corbin-Clarke, Katie Munday, Dr Katherine Jupp, Amanda Durrant, Professor Mel Hughes

As part of the 'Whatever It Takes — Cancer Care for Everyone' programme (Wessex Cancer Alliance [WCA], 2023), the 'What I would like to say...' project involved two disabled researchers carrying out creative and engaging workshops and interviews with 45 disabled and neurodivergent people, with the support of Bournemouth University's Public Involvement in Education and Research [PIER] team. These individuals were from various community groups in the Wessex region, including Autism Hampshire's Fareham Serendipity group; the Dorset Blind Association [DBA]; the Multiple Sclerosis [MS] Centre Dorset; the Royal National Institute of Blind People [RNIB]; and the Bournemouth and Poole Lymphoedema and Lipoedema Support group. This article reflects on the deep and rich insights shared by attendees, which were facilitated by the PIER community researcher model, and which have already begun to impact practice. It is hoped that the outcomes of this project will contribute to improving disabled people's experiences of accessing cancer services.

KEYWORDS:

■ Cancer care ■ Disabled and neurodivergent people ■ Insights

overseen by Help & Care (Involving People), Bournemouth University's Public Involvement in Education and Research [PIER] Partnership and the Research Centre for Seldom HeardVoices to delve deeper into the experiences of cancer services for disabled people. This study was carried out in collaboration with Bournemouth University, with a secondary aim of building an empirical evidence base for the Bournemouth University Public Involvement in Education and Research (PIER) community researcher model. The purpose of this model is to ensure that lived experience expertise is central to all stages of research, by supporting community members' involvement as both researchers and public contributors.

APPLYING THE BOURNEMOUTH UNIVERSITY PIER COMMUNITY RESEARCHER MODEL

In line with the model, Bournemouth University research staff provided support and mentoring to two community researchers with lived experience of accessing cancer services, as disabled and neurodivergent individuals. The community researchers led on all elements of the project and were fundamental in developing a safe space for open and honest connection with attendees at the creative

Wessex Cancer Alliance's [WCA] strategy for 2019–24 focuses on a requirement to identify and reduce inequalities in the cancer pathway, from prevention to care (WCA, 2020). WCA recognises that some patients are not currently well-served by existing pathways. Its goal is to improve patient outcomes and experiences during one of the most emotionally straining periods in their lives, by ensuring that cancer is prevented where possible and managed proactively and equitably when it is detected. Recognising that there is a wide range of inequalities that require further consideration, WCA commissioned an independent literature review on the equitability

Roseanna Tansley, community researcher; Stevie Corbin-Clarke, research assistant, Bournemouth University; Katie Munday, community researcher; Dr Katherine Jupp, PIER officer, Bournemouth University; Amanda Durrant, clinical nurse specialist, University Hospital Southampton; Professor Mel Hughes, professor of social work, Bournemouth University

of cancer services (WCA, 2022). From this, WCA recognised the necessity to gain a deeper insight into disabled people's experience of cancer care. Nationally, there is a significant amount of literature that supports and further explores how disabled peoples' needs are often misunderstood, and their experiences of not feeling listened to, that they are perceived as patients of low priority due to their pre-existing conditions. This suggests that they may be less likely to be treated as effectively or quickly compared to their non-disabled counterparts (Sakellariou et al, 2019).

WCA's equality health impact assessment stated that they would 'work with disabled people and other partners to ensure [they] continue to learn and adapt [their] communications to meet individual needs' (WCA, 2021). To this end, a pilot study was commissioned by Macmillan Cancer Support and WCA and

Practice point

The 'Whatever It Takes' programme was developed as an approach to address the issues raised by the cancer patient experience survey carried out by Macmillan that highlights inequality in experience for particular groups, including those with long-term health conditions.

workshops, through their shared understanding and culture. A specialist cancer nurse, with expertise across hospital and community settings in supporting patients during their cancer journey, was also an essential presence at all workshops. Their understanding of individualised cancer care meant that they were able to signpost attendees towards resources where needed, and provide specialist knowledge, which was vital in developing a safe environment for attendees to share their experiences.

A rapport was initially built between the project team and the leaders of the community groups, which allowed for discussions around accessibility of the workshops. This meant that each workshop could be tailored to meet the needs of each group. Attendees were provided with various arts and crafts materials and the option to create a piece of art that they felt represented them, their identity, and their experiences. The group activities lasted approximately 90 minutes, during which each research team member moved around the room, engaging in informal discussions with group members and asking them questions. The relaxed nature of this method meant that the project team were able to successfully capture deep and rich insights from attendees.

LANGUAGE AND TERMINOLOGY

Language use can have powerful implications on perspectives towards disability and identity (Bottema-Beutel et al, 2021), so it is important to provide some context behind this paper's adopted positioning. For example, person-first language emphasises the person before their disability (i.e. 'person with autism' or 'people with spinal cord injuries'). This is often used when describing someone with an illness or disease that can be cured or treated (Botha et al, 2023). Therefore, describing disabled people in this way has been criticised for its stigmatising and ableist connotations which suggest disabled people are 'inferior' to their non-disabled counterparts (Bottema-Beutel et al, 2021). Conversely, identity-first language puts disability first, for example 'disabled person', 'autistic person' or 'blind or visually

impaired person' and recognises disability as part of a person's being. This aligns more closely with the social model of disability and acknowledges the disabling impact that an unaccommodating environment can have on a person, when it fails to address their needs (Pellicano and den Houting, 2021).

As language and terminological preferences vary from person to person, this project adopts the personal preferences of both the workshop attendees and community researchers, so that they can be represented in a way they feel most comfortable. Consequently, this article uses identity-first language, except for when sharing the perspectives of attendees who expressed preference for another term.

FINDINGS

On analysis of the data gathered at the workshops, eight themes were identified as contributing to attendees' cancer service experiences. Although some of the concerns and experiences discussed in this paper are not exclusive to disabled people, many of them are specific to their lived experience of accessing healthcare.

I felt inappropriate assumptions made about me affected the quality of my care

Ableist assumptions, judgements, and stereotypes, left attendees feeling that cancer services are 'predicated towards the "normative" body and the restoration of normality' and this led to decisions and oversights which negatively impacted on their quality of care, dignity, and independence.

One attendee shared that a healthcare professional had said to them: 'with your impaired vision, maybe a shorter life would be better', when discussing the increased risk of breast cancer upon taking hormone replacement therapy [HRT]. Other attendees described their experience of age-related stigma; for example, one attendee felt that 'people can't believe someone so young is blind' and another spoke of how their age had limited their access to treatment, being told 'even if we found [cancer], we wouldn't operate due to your age'.

Practitioners were reported to have frequently made assumptions regarding their patient's intelligence and capacity, impacting upon attendees' feelings of autonomy and independence in making informed decisions about their treatment. Furthermore, attendees described their experiences with health care as 'prejudicial', 'cultural', and 'misogynistic', such that one attendee was inappropriately asked during an examination: 'would you like a breast reduction and uplift while I am at it?'. Another felt stereotypes around their gender impacted their quality of care, asking 'if I had been a man, would they have said different?'

Attendees explored how assumptions and judgements they had experienced made them feel. One attendee questioned 'why should the standards be lowered because I am disabled?' and others described their experiences as 'exhausting', 'traumatic', and 'uncomfortable'. Another held up a blank hand template during the workshop and exclaimed, 'stop touching me doctor!'.

Importantly, attendees discussed the importance of 'the little things', which can help a patient feel 'more human'. This included being supported to carry out self-care tasks and feeling that requests for certain staff to accompany them at appointments were listened to. The attendees shared that their cancer journeys were difficult enough, without the extra layer of feeling like a burden because of their disability.

Some attendees reported that through patience and a lot of self-advocacy, they eventually received the care they required. For one attendee 'getting the [lymphoedema] stockings is like a new pair of legs' and provided them with freedom and independence. Another described being able to have their husband accompany them and assist with scans as 'helpful'. One attendee commented that they 'have always been treated very well' and that their overall experience was mostly positive.

I felt unsafe during my cancer journey

Several attendees shared that they had felt physically or emotionally unsafe

when accessing cancer services. Many attendees raised concerns regarding access to the correct cancer-related lymphoedema stockings and how 'this needs to improve'. This frustration partially relates to a lack of clear guidance around the correct fitting of these stockings, which left one attendee feeling 'forgotten about', and others wearing stockings that were ill-fitted or inappropriate to their needs. Attendees reported that they were frequently forced to attend to their own health needs, such as administering their own blood thinners without adequate support, or arranging post-discharge hospital transportation, often late at night, leading to them feeling unsafe. Attendees felt that these issues were often due to medical professionals being 'rushed off their feet'.

Additionally, mental health and emotional safety were explored, with one attendee describing cancer services as a 'systemic failure' with 'recurring issues that create a threat to patient safety'. Another shared that their experiences were 'frightening because I do not believe I am safe'. Physical access issues for one attendee resulted in an incomplete scan, leading to their practitioner suggesting that a carer should check for lumps instead.

Fear of the unknown and past trauma in medical settings contributed to anxiety among attendees, in addition to a lack of trust and feeling unable to speak up. One attendee shared 'I wouldn't feel able to say anything or say "stop"... if their tone is rubbish, I wouldn't dare say anything' when talking about attending a smear test. Similar issues around autonomy and consent were shared by another attendee: 'I would much rather take my chances than go through [a mammogram]'. The fear of being forced into an uncomfortable situation meant that many of the attendees avoided screenings.

Attendees also discussed some positive experiences of cancer services in relation to feeling adequately supported. One spoke of having an 'amazing doctor' who held her hand through the process of an examination, and another received mental health support from Macmillan Cancer

Support, which enabled them to share their concerns in a space where 'everyone else understood that I might not feel alright, even if I look alright'.

I could not physically access the service

Many attendees shared difficulties in arranging GP appointments, due to confusing and impersonal answerphone services. One person explained that they had received incomplete scan results through the post and were provided with no instruction regarding what would happen next.

Designated 'accessible parking' was often inaccessible to attendees, due to the expense of car parking tickets and being a long distance from the relevant building. This, combined with the need to access various hospital settings due to specialist facilities being limited to one location, made physical access to appointments and treatment more complicated for disabled people. The need to access various hospital settings acted as a barrier to attendees, as it required more complex planning, potentially higher travel costs and exploring unfamiliarity, alongside navigating their cancer journey. One attendee discussed how the removal of council-funded taxis had made getting to appointments more difficult and expensive.

Other concerns were shared regarding step access to screening rooms, narrow doorways, and being unable to move safely within rooms without guidance, which was rarely offered. One workshop attendee shared that in 'having to rely on other people, we lose our independence'. Others reported that the busyness, smells, and noises of hospitals were overstimulating, and they felt there was nothing they could do about it.

Several attendees spoke of difficulties accessing equipment such as computed tomography [CT] and magnetic resonance imaging [MRI] scans, explaining these experiences as 'challenging', 'exhausting', and 'embarrassing'. One attendee described the dehumanising practice of having their 'face crushed against the glass' and being 'knocked about' as

they were unable to fully weight-bear for their mammogram. Another felt that 'the hospital, of all places, is not geared up for disabled people'.

Positive experiences for attendees included hospital-arranged accommodation and transportation, and staff slowing down their walking pace to match the speed of their patients.

I felt that information about my healthcare is not accessible for me

Barriers to accessing information included both verbal and written communication. The consequences of being inadequately informed of their options led to some attendees regretting their healthcare-related decisions; one attendee explained 'if I had known everything, I am not sure I would have made the same decisions'.

Attendees explained that materials are often printed using inappropriate font sizes and are formatted in ways that cannot be read by screen readers, as they 'do not recognise all formats of text'. Some attendees felt there is often a 'misunderstanding of what large print is', as they frequently experienced their documentation being printed on larger paper without an increase in the font size. Similar feelings were shared about online information as many 'accessible' websites are often not actually accessible either.

Feeling ill-informed of the various processes within cancer services led to attendees experiencing anxiety around their care. One expressed worry regarding mammograms and felt that 'it would help if there was information that told you when everything was due'. Inaccessible information also increased the risk of missed appointments and screenings; one attendee suggested that they 'would have the screening, if they didn't make it so hard to arrange'.

One individual at the workshops exemplified a consequence of being ill-informed with regards to a cream they were instructed to use post-radiotherapy. They explained that they were 'not advised how to apply the cream correctly', which resulted in

the skin on their neck breaking down. This had long-term repercussions, as this attendee must now keep their neck out of the sun to prevent further damage. Many attendees relied on their support groups for sharing and finding out information, asking 'where else is there for you to get it from?'

Positive experiences with accessing information were also shared. This included being able to access useful information via the internet, as well as open communication with doctors, who were 'very good in regard to explaining' the process and available options. The charity sector was also credited for its support, specifically the Lymphoedema Network and Macmillan Cancer Support, which was described as 'tip top [for] sending me lots of info' and as doing a 'brilliant job'.

I felt isolated and lonely

Some attendees reflected on the loneliness they felt during and after their cancer care. One felt their treatment was 'like a cloak of being looked after... then on the last day of radiotherapy, it was "bye" and that was it... I was left alone in the wilderness... I had struggled with my disabilities at the best of times, now on top of cancer that felt impossible'. When structured care and support abruptly ended, attendees were left feeling 'alone', with one person sharing 'I have no one, medically'.

This experience was shared across all workshops, and for some, was intertwined with the strain of caring responsibilities. One attendee's lymphoedema was triggered while caring for their sick husband, but they felt unsupported and that 'there was no choice... I have to care and do all the household jobs'. Another attendee with caring responsibilities explained that 'carers or support people need to be spoken to directly and provided emotional support, as they are going through it too, but they are often ignored'.

As a result of the Covid-19 pandemic, attendees also described feeling unable to connect with their loved ones in hospital due to paused visitation and inconsistent internet connection, which resulted in intense anxiety for many. Attendees did

discuss some benefits to the use of technology, particularly during the pandemic. However, many also felt that it 'alienates and makes people more vulnerable'; for example, individuals that struggle to navigate online booking systems or remember multiple, complex passwords. Another attendee felt that 'Covid should have made people more caring towards others', but in their experience, it has 'made people less tolerant'.

Fortunately, many attendees found help within their support groups, where they could receive information, resources, advocacy, and understanding, with one describing their peer support to be 'really important for me, like a lifeline'.

I felt like I constantly had to advocate for myself because no one was listening to me

Many attendees discussed feeling that they were not listened to during their experience with cancer services, which left them frustrated, confused, and one individual feeling 'white fury at the way [they] had been treated'. Others explained that they have had to make 'a lot of noise to get [healthcare professionals] to listen', and that their multiple requests for help accessing screenings, due to mobility issues, were ignored.

Reflecting on the consequences of not being listened to, one attendee shared how they had 'developed provoked thrombosis', due to disregarded concerns about a medical tube in their neck that they said 'felt wrong' from the moment it was placed. They had then been asked to self-inject blood thinners, despite being visually impaired and unable to see the needle. Another explained how their grandad 'wasn't listened to' when he repeatedly informed his doctor about his extreme weight loss and severe pain and that he died six months later, leading to anxiety that they may have the same experience in the future.

Self- and group-advocacy became an important topic of discussion, where many workshop attendees specifically addressed how it felt both empowering and exhausting. They explained that, although being

assertive is important, it is 'a lot harder when you are not feeling well'. One person questioned whether they would have even received a lymphoedema diagnosis had they not suggested this to their doctor. Those with caring responsibilities discussed being 'made to feel like they are butting in' when advocating for family members on their behalf. In response to a discussion around advocacy, one attendee shared that they 'have to do all the work ourselves to get the treatment and support we need', and that peer support was 'so important'.

More positively, one attendee explored how strong relationships with medical professionals have proved vital in their cancer journey, because it meant that they were able to ask questions about their care and the team were 'happy to answer these fully'.

I felt that there are multiple issues compounding my access to cancer services

Attendees frequently reported feeling that their negative experiences of access to quality cancer services was the result of many compounding issues, and they felt that 'patients are not being taken as a whole person [...] specialists are only looking at one issue at a time'. One attendee explained that 'with a disability, everything crosses over' and another shared how 'difficult' it was 'finding treatment for any one part, including my cancer'. Attendees discussed their difficulty in finding medical professionals who fully understood both their disability and their cancer diagnosis, and how the two may interact or impact one another. One attendee reported feeling that 'all of the issues interact and impact each other, but nobody has a full rounded view of what is going on'.

Many felt that self-image was often overlooked as a factor for disabled people, due to prejudicial assumptions. However, one attendee explained 'losing my hair was the worst thing. It was my crowning glory and defined me over my disability'.

Attendees spoke about the intersectional factors which contributed to their experience, and how these had resulted in

anxiety around attending healthcare settings. One addressed 'the added stresses about access, safety, and negative reactions of others', while another explained how 'many autistic people have had multiple traumatic experiences with healthcare professionals, and this is their starting point for the next appointment'. One attendee spoke about the difficulties getting a district nurse because they were not considered 'housebound', but that they also could not get to the GP or get a referral to see a specialist.

A multidisciplinary approach was discussed as important among attendees, to address the 'systematic challenge and failure' whereby 'leadership teams and trust boards need to put their weight behind an inclusive approach' and not consider disabled patients to be 'second-class citizen[s]'.

I felt like there is a resistance to change and adaptation to support me

One attendee described how through their treatment, they felt as though they were on a 'conveyor belt — as if one size fits all' and that there is 'culturally, no tolerance for [disabled] people like me' — a result of the continuation of their unmet need for individualised care and adaptation to support their access to cancer services. Many agreed upon feeling that healthcare settings are 'resistant to change'.

A visually impaired attendee explained that their pharmacy had refused to colour-code their medication, which would have made the contents easily identifiable to them. Other examples included staff disregarding a patient's request to be facing away from a window due to light sensitivity issues, a lack of effort to find dignified ways of completing patients' scans, and staff not helping visually impaired patients navigate rooms and doorways, despite being aware that they could not see.

Resistance to accommodate disabled patients' needs often left attendees facing incomplete scans, poor mental wellbeing, anxiety, and safety concerns. One attendee shared how their experience left them feeling unimportant and othered:

'I don't need to keep hearing I am not standard; that I don't meet the expected standard'.

CONCLUSION

Engaging with attendees and listening to their experiences of cancer services proved invaluable in developing an understanding of the issues and consequences frequently faced by disabled and neurodivergent communities. From these findings, the following recommendations for accessible practice were drawn:

- ▶ Compassion and sensitivity matter, such as the importance of using a person-centred and empathetic approach. This can contribute towards mitigating some of the anxiety and isolation felt by disabled communities when navigating cancer services
- ▶ Effective communication is key to providing disabled patients with clear and accessible information to support informed decision-making regarding matters of their own cancer care
- ▶ Make accessibility a priority through actively supporting and meeting disabled patients' individual access needs to remove barriers to health care and build more inclusive services.

In this regard, changes to practice have already started as a direct result of the clinical nurse specialist being able to take learning from the workshops immediately back to the NHS to share with colleagues. In addition, Help & Care — a charity which promotes dignity and independence for all people, particularly those in later life across the south coast — has been granted further funding to expand this project.

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Practice point

Further exploration of the above themes can be found in the full report at: www.helpandcare.org.uk/news-and-media/news/cancer-care-for-everyone/. Accessible versions of the report can be provided by Neil Bolton (neil.bolton-heaton@helpandcare.org.uk). A short film, developed from the findings, can be viewed at: <https://youtu.be/HbgEbtyfEI8>