



What I Would Like to Change...

Whatever It Takes – Cancer Care for Everyone

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Foreword

Whatever it Takes—Cancer Care for Everyone is an ambitious programme led by Help & Care to engage widely around experiences of cancer services to understand inequalities and co-create solutions to address them. The first step of this programme was '[What I Would Like to Say](#)', which was reported in 2023.

In 2024, the project's two disabled and neurodivergent community researchers revisited phase 1 research participants further to understand the cancer experiences of disabled and neurodivergent people and to explore with them ways in which these experiences could be improved. Our two researchers, supported by Help & Care and Macmillan Cancer Support, continued to utilise the arts-based approaches to engagement that have been developed and that you will read about in this report, 'What I Would Like to Change'.

Looking to the future, I am delighted to report that this research is now informing the next stages in the Whatever it Takes—Cancer Care for Everyone programme. In the spring, we will commence co-design and solution testing of screening services at two NHS Trusts, bringing together those with lived experience and NHS colleagues to move from research into action.

We thank Macmillan Cancer Support and Wessex Cancer Alliance for sponsoring this project. Without them, we would not have been able to undertake this work and achieve what we have. Thanks also go to our third-sector organisation partners and all the research participants who have entrusted us with their voices and experiences.

And finally, a huge thank you to Rosie and Katie, our community researchers whose dedication, commitment, professionalism, and humour have made this project what it has become.

Thank you and enjoy the report.

Neil Bolton-Heaton

Head of Programme – Involving People

Meet the Team

Katie Munday

Community Researcher

Katie conducts research with neurodivergent, disabled, and trans+ people. They are interested in the healthcare accessibility of these groups. They have worked in the charity sector for over 10 years with disabled and neurodivergent young people. They were drawn to this project to support others with similar life experiences.



Roseanna (Rosie) Tansley

Community Researcher

Rosie is a PhD researcher interested in using participatory and creative approaches to involve neurodivergent and disabled people in the research process. She became a community researcher on this project as a disabled individual herself, wanting to help those who need them access and experience more inclusive cancer services.



Tracy Street

Patient Experience Facilitator

Tracy has over 20 years of non-clinical experience within the NHS and Macmillan Cancer Support, working with those affected by cancer, enabling and empowering them to share their story and experiences to inform and improve cancer services. Tracy has supported this project through her knowledge and expertise in working with a diverse and vast cancer support network.



Lucy Fitzgerald

Macmillan Professional

Lucy has over 15 years of experience within the third sector, working with communities for better outcomes. Lucy spent 10 years at Rose Road working with parents and carers of disabled children and has worked at Healthwatch, and with young people experiencing homelessness and other challenges. Lucy is passionate about listening to people and ensuring their voices are heard and central to their care/lives.



Neil Bolton-Heaton

Head of Programme - Involving People

Neil is Head of Programme at Involving People at Help & Care and currently leads our Community Researcher workstreams. Neil has worked in patient and public involvement across health, social care, and social enterprises. Neil is passionate about authentically involving people in designing, developing, and delivering health and social care services.



Executive Summary

Introduction

Disabled people face significant challenges when trying to access cancer services, such as inaccessibility and discrimination within healthcare. Disabled and neurodivergent groups are additionally at greater risk of underdiagnosis and undertreatment for cancer compared with their non-disabled peers. Consequently, it is essential that the needs of disabled and neurodivergent communities are understood and listened to so that cancer services can adapt to be more responsive, appropriate, and inclusive of all communities they serve.

What we did

This project built upon the creative workshops completed in the initial 'What I Would Like to Say' pilot. Using a mixture of arts-based methods and discussion, we explored the views and experiences of four community groups. These were MS Centre Dorset, Bournemouth Lymphedema Group, Autism Hampshire (part of Avenues Group), and Winchester Go LD. Accessibility was embedded throughout the project by arranging each workshop according to the needs of each group.

The goal of these workshops was to think about potential solutions that might address barriers faced by disabled and neurodivergent communities in cancer-related healthcare. A community-based participatory research approach was used to promote equitable collaboration between the research team, community members, and other involved stakeholders. The contributory factors to disabled and neurodivergent peoples' experiences of cancer services were analysed and themed accordingly.

What we found

Four main themes were identified from the workshops with attendees:

- Support patients' understanding
 - Including a need to improve accessibility of resources and clearer communication
- Take a holistic approach
 - Such as appreciating the importance of individualised care and broader support needs
- Ensure the accessibility of practice
 - Through improved access to healthcare settings, screening, and appointments for everyone
- Expand knowledge of disabled experiences
 - Including the importance of empathetic care and appreciating national disability initiatives

Reflections

The research team reflected positively on their experience working on this project and expressed their excitement about participating in its next steps. They also shared the challenges faced during the project and how everyone was able to support one another when needed to keep the momentum going. They described their involvement in the project as 'illuminating', 'valuable', 'an absolute pleasure', 'amazing', and 'a privilege'. They hope this report and other associated outputs do justice to all attendees' contributions.

Next steps

Outputs following the completion of this project include dissemination of stakeholder groups across multiple formats, including tool development, and the potential to revisit the All-Party Parliamentary Group on Cancer. We are also collaborating with the Wessex Cancer Alliance and the NHS breast screening services within Princess Anne Hospital to create more accessible and trans-inclusive care, aligned with the Trans Aware Cancer Care research project (<https://involvingpeople.org/project/tacc/>).

Conclusion

Through four creative arts and discussion-based workshops, we gained a rich and detailed insight into disabled and neurodivergent community groups' experiences of cancer services. The data gained from these workshops were grouped into themes that explored the barriers faced in healthcare and ways that these might be addressed or overcome. Ongoing developments following this project will see broader dissemination of this project and collaborative involvement with breast screening services to both co-design and implement solutions.

Introduction

Disability and cancer

Cancer is more likely to be underdiagnosed and undertreated for people with disabilities compared to non-disabled people (Tosetti and Kuper, 2023). Disabled people are more likely to experience stigma, discrimination, and inaccessibility in healthcare, including inequalities within cancer services (WHO, 2023). Disabled people diagnosed with cancer are more likely to report low satisfaction with care compared with their non-disabled counterparts (Bone et al., 2014; Cuypers et al., 2020).

Disabled people face various barriers when trying to access cancer services in the UK, including physical inaccessibility and invalidation of their needs (Sakellariou et al., 2019). People with learning disabilities and/or mental health issues were found to experience more barriers when trying to access cancer screening services than the general population (All-Party Parliamentary Group on Cancer [APPGC], 2009). More recent research reported by Mencap suggests this has not improved: only 19% of people with a learning disability engaged in cervical screening, compared to 77% of all people invited. Similarly, only 33% of learning-disabled people engaged in breast screening, compared to 70% of all people invited (Mencap, 2019). Forgoing screening means and experiencing unhelpful primary care 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 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 essential to understand and respond to the needs of this group to ensure services are accessible, appropriate, and affirming.

Language

In this report, we have used a mix of identity-first and person-first language (e.g., people with disabilities and disabled people) to reflect the language used across groups and attendees.

What we did

Why we chose our methods

Arts-based research focuses on using the artistic process to explore the experiences of a topic by the researcher and the participants. Artistic methods are useful to gather data and to share findings. It can be an effective method of exploring peoples' subjective experiences, sensitive topics, topics focused on exploring feelings and emotions, people with communication difficulties, or groups with mixed abilities. It can also enable the exploration of more complex research questions, particularly about new trends or aspects of social life, where more traditional methods are not always sufficient to answer these questions (Busetto et al., 2020).

Arts-based methods were used with great effect in the 'What I Would Like to Say' phase of this work. Participants in that phase shared: **"Doing the artwork, I have talked about things I would not normally talk about"**, and **"By having a creative activity to focus on, autistic members were able to positively engage with individual discussions and questions on cancer screening"**. Working with groups we had previously connected with meant we understood their needs and interests and that this mode of research and communication would work for them.

What we did

The fundamental plan for this project was that it was accessible and adaptable to allow anyone who wanted to be part of it an opportunity to participate in a way that was right for them.

In Phase 1, we offered an art-based activity where participants could decorate their hands with 'What They Would Like to Say'. We offered a similar activity to highlight our focus on solutions, but we used lightbulbs to signify ideas this time. More on the themes of Phase 1 can be read in Tansley et al., 2024.

We collated the 7 key themes from Phase 1 and colour-coordinated them. Under each theme, there were 3 questions to start conversations. We printed these out as a guide, encouraging participants to share their solutions against each discussion point.

We understood that the people/organisations leading the four groups we worked with knew their members and their needs well. Before each workshop, we had a 'pre-meet' and exchanged multiple emails where we discussed the following:

- What was the best time, date, and venue to meet?
- What access needs were there? Could we create easy-read documents, etc?
- What would each group enjoy doing as part of the session?

As a result of these conversations, we could tailor each session, considering various preferences and access requirements.

MS Centre Dorset

Our first session was at the MS Centre in Dorset. This busy session required the team to adopt an adaptable approach.

We spoke to lots of people living with MS, their carers, partners, staff, and friends. We had a separate room where people could come and create a lightbulb, but alongside this, we also moved around the room and had individual conversations. Some chose to create their artwork and make cards instead while talking to us about their experiences and ideas.

Bournemouth Lymphedema Group

Tracy and Lucy attended this friendly group for a 'lunch and chat' session. This worked well. We had a large table in an accessible room frequently used by the group. We offered the chance for individual discussions, but the group opted to have a shared conversation. We worked together on the themes from Phase 1. It felt like a therapeutic discussion, with lots of experiences and ideas shared in a supportive, relaxed way.

Autism Hampshire (part of Avenues Group)

We joined Serendipity, an existing group led by Autism Hampshire. Before the workshop, we met to plan and discuss any accessibility requirements. We created a large print, accessible flyer shared with members to advertise the session. We were told that the group liked Airclay beforehand, so we purchased some. We took all our usual arts and crafts, and the group leaders took board games, which are always popular. There was a mix of craft activities and lots of good discussions at the session. Some took place as a whole group, some in smaller groups, and some one-to-one.

Winchester Go LD

Winchester Go LD put on a session for us to attend at their usual meeting place in Winchester. They invited all their members, and we had great attendance. We had many discussions beforehand and were made aware of some personal, current cancer experiences within the group, which helped us prepare (we were also able to share some resources to help). We sat around a table with biscuits and had a good mix of craft activities and conversation. We went through the themes as a group. Winchester Go LD got further feedback from their other group members, meaning those who couldn't attend on the day could still have a say.

Community-based participatory research (CBPR)

Community-based participatory research (CBPR) is a collaborative research approach that equitably involves community members, researchers, and other stakeholders in the research process. This approach recognises the unique strengths that each person brings, aiming to combine knowledge and action to create positive and lasting social change. CBPR involves the researcher and participants working together to identify problems that need to be addressed and create solutions based on their understanding of the problem. CBPR is a solution-focused, patient-centred, community-driven research approach that addresses growing health disparities (Collins et al., 2019).

What we found

Creative workshops highlighted contributory factors to neurodivergent and disabled people's care, barriers or challenges, and recommendations for cancer service improvements. These were categorised inductively into themes and subthemes below.

Support patients' understanding

Improve accessibility to resources

Attendees shared mixed experiences of easy-read documentation. One shared appreciation for easy-read annual health check questionnaires but not their other medical information. Easy-read resources frequently did not live up to their name, as others expressed, **"I find it difficult to read, and I was handed a leaflet that I couldn't understand"**, and **"I didn't understand the questions, and neither did my dad"**. Attendees suggested the need for clearer documentation on checking for potential cancer symptoms and possible medication side effects. One attendee spoke of having to pay privately to heal scarring that resulted from not understanding how to apply steroid cream properly, and felt **"[doctors] need to ask and to check what I can understand; sometimes it's difficult to tell them if I don't understand something"**. Patients would benefit from information in advance, including directions and hospital maps. Some attendees suggested making this autism-friendly by adding **"pictures of the room and instruments used, who you might meet, what will happen on the day, and easy-read FAQs"**. These might include social stories (step-by-step picture-based instruction) on where they are going, what to expect, or the ability to visit the setting beforehand.

Attendees were keen for more health and general fitness information, sharing concerns about searching online because it is **"hard to know what is legit"**. Some also reported being turned away from charities or organisations, being told **"I don't know"**, or advised to practice self-care to manage their symptoms. Another attendee learned their most convenient hospital entrance by chance as they weren't given appropriate directions. Better signposting and guidance are needed, and attendees felt they would benefit from having a list of reputable websites or organisations from healthcare professionals. Attendees feared making mistakes and preferred the **"human side"** of information exchange to Google. One attendee couldn't access diabetes training because of its duration, online delivery, and involving too many people.

Communicate clearly and effectively

Attendees shared experiences of ineffective communication. They suggested doctors should avoid using long words that make patients feel **"uneducated"** and that this would benefit everyone, not just those with learning disabilities. Clear information shared before a scan would be beneficial, such as the pressure applied to the breast during a mammogram. During one workshop, an attendee left for a medical appointment and returned with an

illegible, handwritten note of instructions from their doctor in red pen for leg exercises. When asked whether they could read the note, they answered, **“I just don’t understand”**. Their doctor had not checked this before they left. Unfortunately, this was not an isolated incident for the attendees whose diabetes diagnosis left them similarly confused, **“I didn’t know that I needed to get medicine for my diabetes until I spoke to [a staff member] at Go LD”**. Not having understanding checked by healthcare professionals was a common experience for many attendees.

Choices around access to information are necessary, for example: **“Ask me my preferred method of contact”**. Some participants felt a lack of human contact when entering healthcare settings (e.g., phone-operated receptions). Similar disconnects were experienced by attendees receiving bad news whilst **“on strong painkillers”**. News should be shared when patients can **“understand or write it down”**, and healthcare professionals must **“give us time to think... and ask questions”**. One attendee shared that **“[healthcare professionals] need to explain slowly and clearly. I am not a child, but it can take me time to process information”**.

One autistic individual shared finding some healthcare questions confrontational, like being asked, **“Why are you here?”**. They suggested needing **“someone who understands me and my communication needs”**. Another spoke of the **“upset and confusion”** caused by a healthcare professional disregarding discussion points the attendee had written down by following their own agenda. Advocacy was harder for some attendees who were accompanied to appointments: **“They spoke to my brother and not me, even though I understood perfectly”** and **“Sometimes my carer is spoken to instead of me”**. One’s personal assistant was mistaken for their parent and all the information shared during the appointment was addressed to them. Another shared, **“If the appointment is about me, the nurse or doctor needs to speak to me and not to my carer”**. One did, however, feel that the doctor was better when their carer was with them.

What works well

Attendees felt that GPs giving bullet-pointed lists of actions to patients after appointments were helpful, as was the presence of sensory and communication boxes like at Southampton General Hospital’s Neurophysiology department. There was a need for improved signposting and **“lots of communication and support”**, including that of groups and forums, especially at discharge, to help patients’ recovery. To support access to digital information, categorised QR codes might help. Some attendees suggested that GPs become **“health hubs”** for self-referrals and that more disability-specific training was offered for medical **“gatekeepers”**.

Good cervical screening experiences involved being talked through each step to know expectations. Attendees wanted healthcare professionals to be more mindful of patients’ access needs, including wheelchair accessibility and equipment. For patients, they

suggested, **“Take someone with you and... write down what you want to say in the appointment, so you don’t forget”**. Some preferred **“social prescriber”** or **“advocate”** to the term *chaperone*.

Take a holistic approach

Understand the importance of individualised care

Attendees discussed the impact of cancer on their lives and how healthcare professionals limit options due to factors like age. They wished to be viewed as an entire person when receiving support, including information about navigating sex and relationships during difficult times. They felt that communication between service providers (e.g., GPs, hospitals) needs improving to provide better resource sharing and a more holistic care approach. Attendees found services like the Moving Forward programme extremely helpful but felt this should not be limited to breast cancer. They discussed how information given outside of their immediate medical need (e.g., navigating work absences, expectations, and impact of treatment) was lacking and that information sharing needed improving.

Attendees suggested a **“need to be treated as individuals”** to improve their experiences. One expressed how **“music makes me happy”** and that playing the Bee Gees in waiting rooms and scans would alleviate some anxiety. Another suggested the presence of **“George Clooney”** or comfort objects to make mammograms more positive. Comments were also made about the comfort of **“nice images”** used in healthcare settings.

Attendees also spoke of differences in pain thresholds and how pain scales inadequately account for this: **“[I] didn’t know I was in pain until I wasn’t”**. They requested GPs to better their understanding of autism and how sensory triggers (e.g., thermometers) and feelings might differ between individuals. Misunderstandings can cause meltdowns, which might be avoided with individualised care. Some attendees felt healthcare professionals were oblivious to anxiety induced by ambiguity, change, and being touched without warning. For inpatients, providing information about the ward (e.g., mealtimes, medication timings, etc.) might provide respite to those struggling. Attendees also expressed that hospital appointments often felt rushed. Still, small adjustments can sometimes make a huge difference in care, although, unfortunately, one has **“not seen any improvement in access to services for the disabled over the last 10 years”**.

Support patients’ emotional wellbeing

Support was regarded as necessary by attendees, but they generally felt emotional support was lacking: **“Scars heal, but the mental ones don’t”**. Counselling services were wanted for cancer patients and their families so concerns could be shared, listened to, and supported. They felt the emotional impact of cancer is covered in TV soaps, but real life is more medically focused. Cancer is traumatic, and one attendee reported feeling unsafe navigating

their dad's deterioration, knowing his wishes against resuscitation. Loneliness was intense among attendees, in conjunction with wanting support both at the time and beyond, due to the lasting mental and physical effects that make resuming everyday life difficult. They felt that healthcare professionals simply asking, **"How are you?"** makes a big difference in showing compassion for patients.

One attendee shared their shock at the number of stitches and scar size following a small skin cancer removal. She said she would have been more emotionally prepared for these outcomes if she had been explained that they were going to happen. There were also conversations around difficulties understanding distressing information given during cancer treatment, especially if the **"nurses seemed disconnected"**, and the emotional consequences of undignified care were discussed. This included the distress experienced by one attendee during a 10-minute ordeal of getting a cervical smear due to the healthcare professional's inability to support the individual's needs concerning her MS-related leg spasms and rigidity. When discussing this incident with the MS Centre physiotherapist, he couldn't understand why the healthcare professional had such an issue.

Another example involved one attendee sharing how they had been stranded on a hospital trolley in a boot for over eleven hours in discomfort due to being unable to use the toilet. This happened because a nurse didn't believe she could not walk in the boot. Physically and emotionally distressed, she phoned the MS team, who came to the hospital and checked her information. They found she didn't even need the boot. Another found it **"embarrassing and undignified not being able to move and look after myself"** upon losing movement whilst on a drip for their osteoporosis. It was only when she called to ask that the doctor said she could take pain relief.

Appreciate the value of good support

Discussions covered the importance of solid support systems, including family, friends, carers, and support groups. They felt this needed to be extended into aftercare. Hospitals were described as a **"safety cloak"**, which is removed, **"leaving you exposed, isolated, and scared"** and **"over a cliff edge"** when discharged. Others felt they were **"forever fighting"**. More positively, one attendee continues meeting with those met in the Moving Forward programme through her group, the **"Pink Ladies"**. Support brought comfort to attendees not just in their cancer journey but also as a person:

"Dad... had a really good relationship with one of the workers [at the support centre] who eventually could make him a proper Italian coffee."

Although support is important for those with cancer, this must extend to families and loved ones with resources supporting their emotional needs and explaining how loved ones with or recovering from cancer might be feeling. One attendee shared that they **"needed people**

to talk to and ask questions about my mum's death", and another **"felt lonely with no one to talk to. My dad got help, but I didn't".**

One husband shared his shock at seeing his wife after her mastectomy and asked, **"What can be done to avoid this for the partner, but also so the patient doesn't have the upset of the shock?"**. Suggesting there should be a meeting for partners where expectations are explained when loved ones have undergone mastectomies. Attendees expressed that **"family and carers feel isolated and lonely – they often find it difficult to ask for help as they are exhausted"**.

What works well

Attendees felt that individualised support needs improving upon diagnosis, especially for those living alone or with limited support systems. This includes text-based grief services, poetry, creative writings, and being seen as **"a person, not a patient"**. Healthcare professionals who care, consult and encourage patients to **"listen to [their] body"** make a big difference. Attendees also suggested that **"help sheets"** given to healthcare professionals about their patients might help them to understand them as a person better. Information sharing needs to be improved between staff **"so they all know what I've told them"**, small changes, such as using pillows to help reposition patients for screening, might provide a more dignified solution for some.

Ensure the accessibility of practice

Improve access to healthcare settings

Attendees described difficulties accessing GP and hospital buildings. Concerns about the distance of cancer services from the main entrance made attendance difficult without support. One attendee needed assistance transferring from the car to their wheelchair to enter the GP for monthly injections; however, health and safety meant staff could not support them, and no alternative arrangement was made, meaning they had to rely on a friend. Reliance on friends, family, and support workers raised concerns about attending essential appointments, as with no one available, patients had to go **"back to the start of the list"**. Some GPs have step or steep slope access, further affecting disabled patients' ability to enter the building unaided.

Hospitals were described as **"hard to navigate"**, entry doesn't guarantee an accessible exit: **"I can't get out"**. Attendees felt better **"signage"** and **"something visual would help"** (e.g., an easy-to-understand map) support patients' access to the hospital. Easy-read information packs given to disabled and neurodivergent patients containing relevant information (e.g., parking, whom you might meet, what to expect, FAQs, images of the hospital/department) might reduce overwhelm and anxiety. Furthermore, attendees suggested having a choice around digital (**"tablet-style"**) or in-person check-in, and difficulties around phone-line

button sequences or **“needing to stand up for yourself”** at reception to get seen were discussed. The unmanned nature of Southampton General Hospital’s night-time reception and phone call reception service was considered **“terrible”**, several attendees felt they had more success booking GP appointments in person rather than over the phone. However, they did suggest a phone line to call when needing support to attend an appointment might be useful.

Some attendees felt that parking was unfair as payment was required even with a blue badge, despite disabled people oftentimes needing to attend more appointments than their non-disabled peers. They described the **“fear”** of cancer services being too far away and **“what would happen”** if they couldn’t attend. Some faced prejudicial assumptions from others around their ability to use the bus due to their learning disability when support was just needed to plan journeys and manage timetables. Reliance on unreliable public transport services, however, can be challenging for disabled and neurodivergent individuals, especially those with physical access needs or who are feeling unwell. This is exacerbated when appointments happen in different locations or require multiple stops and changes:

“Appointments are too difficult to get to – it could be two or three buses. There are no directions or advice given on how to get to appointments despite the fact I have LD/Autistic written in my paperwork. They just expect you to get there.”

Improve access to screening and appointments

Attendees needing support to access screening and appointments shared frustration that this was inadequately met. One who was a wheelchair user couldn’t screen both breasts due to repositioning difficulties. Others were concerned that the time spent repeating medical history in appointments detracted from the time allocated to discuss their issue. Attendees requested that hospitals have **“beds or chairs that can be raised to the height of the machine, or a machine that can be lowered to allow access to chair users”**, and **“machines that allow screening when someone is prone, or bed bound”**. They felt hoists in all consultation rooms, wards, and accessible toilets should be **“standard”**, in addition to having adequate room for wheelchair users and carers to stop patients feeling **“trapped”** or subjected to being **“manhandled”**. Hospital equipment was reported as **“not fit for purpose”** as it assumes everyone is of similar height and mobility: **“Could there not be a step to help smaller people come up to the right level?”** to improve access.

Without accommodations, one person reported they **“feel more disabled”**, and their frustrations being shared by attendees are unsurprising given shared experiences. Discussions included the need for patients’ access requirements to be better recorded to be proactively met. This would mitigate the frustration of patients who repeatedly advocate for their needs to no avail, like one attendee who reminded the hospital three times before it was acknowledged that their mammogram needed to be in the hospital rather than a mobile unit due to physical access reasons.

Attendees also shared concerns about not being assigned a GP despite complex medical histories. Primary Care Networks meant that GP appointments could be made at any surgery, giving patients additional stress and travel. Another issue was not receiving follow-ups despite being told they would, which, combined with difficulties contacting GPs, discouraged attendees. They raised challenges of needing double appointments but not being allowed and that restricting discussion points during appointments when disabled risked things being missed. Healthcare professionals review patient histories before appointments, which they feel would help with this, but also to pre-identify and meet patients' access needs (e.g., equipment or room adaptations for disability or neurodivergence).

Make services accessible to everyone

Attendees felt that the quality of cancer support (e.g., availability of Well-Woman checks) differed across healthcare services. One had two experiences at the same hospital 10 years apart (one good, one negative). Variability existed between mobile and hospital-based screening equipment like mammograms; one attendee felt **“hurt more in the mobile unit”**. Differences in cervical screening practice meant some attendees' experiences were more successful than others.

Several attendees wait **“until things get really bad before seeking help”** due to difficulties booking and attending appointments, having their access needs met, and fear of embarrassing, uncomfortable screening experiences. Monetary costs of maintaining healthier lifestyles for cancer prevention were a challenge, and attendees described self-care as sometimes the only choice due to not getting the help they needed as **“the place that means to help didn't help at all, it made it worse”**. Some felt healthcare professionals might better understand patients' needs by physically putting themselves in their shoes (e.g., in a wheelchair) to identify and rectify the problems before the patient has a negative experience.

Other suggestions were for patient record systems to flag when adaptations are needed so healthcare professionals can meet these before appointments. This would alleviate unnecessary stress, discomfort, and frustration of patients when attending appointments to find their needs not met: **“If you can see I have a disability, why doesn't this make my treatment easier or more appropriate to my needs?”**. Attendees felt this should extend to patients' living situations to make care and support more individualised. Some also wanted their name asked before their date of birth when accessing their records, so they feel more human.

What works well

Attendees discussed the importance of **“having someone I know well helping [me] to speak up”** and encouraging healthcare professionals to think, **“How can my patient access this?”**. Visual support (e.g., Macmillan easy-read books) was helpful, as was taking a list of

discussion points to appointments. Attendees questioned whether a nurse or guide could meet and accompany learning-disabled patients to their appointment location. Consideration for patients' needs (e.g., screening accessibility) was necessary, and one person was delighted with their **"new bungalow built with accessibility and wheelchair users in mind"**. Furthermore, attendees couldn't stress enough the value of good support systems and groups.

Expand knowledge of disabled experiences

Working through assumptions

Comments like **"you look so well"** by doctors made getting help difficult, and attendees felt that looking **"young, able, and normal"** should not prevent them from receiving support or diagnoses being overlooked. One younger attendee experienced **"sighs and funny looks"** for being slow on the stairs from staff who showed patience to an elderly person behind them. Another felt their age meant healthcare professionals disregarded their views. Some older attendees shared the assumption that **"cancer equals death"** stemming from when they were raised, which made them question the point of screening and treatment. It is essential to recognise this view was not shared by all.

Attendees spoke of a gender divide, and one felt her treatment might have been different if a man had accompanied her. Another felt prostate cancer support overshadows that of other cancer types, describing it as **"everywhere at the moment"**. One female attendee uses her dad as a proxy to speak to doctors to avoid her symptoms being put down to a UTI. She would also bring a completed UTI test to appointments to be taken seriously. Other assumptions included autistic attendees being **"treated like I'm stupid"** and that being overweight was the root of all problems. Attendees did not want healthcare professionals to assume how their bodies would react to medications, surgery, or living conditions. One awaiting a powerchair expressed frustration at her neurologist for saying she would be better off leaving her adapted house for a bungalow and for incorrectly assuming how she navigated her home.

Recognise and appreciate national disability initiatives

Some attendees found sunflower lanyards helpful for awareness: **"People talk to us differently and help with misunderstandings"**. However, these can bring sensory discomfort; others don't wear them, which shouldn't preclude them from support. Similarly, some attendees felt hospital passports **"could be helpful"**. However, these weren't common knowledge: **"What are hospital passports?"** and there were mixed experiences around their acceptance and recognition. The reapplication process for Blue Badges, PIP, and bus passes was questioned, in addition to the usefulness of Blue Badges at hospitals where spaces **"are away from the main entrance"** and there **"seems to be more electric charging points than**

disabled spaces". Concerns were raised about support packages being paused when in the hospital. Similarly, attendees felt it was unfair that support worker hours were used up by appointments, meaning they couldn't be used for things that improved their quality of life: **"I use my PA hours up on hospital visits and doctor's appointments, which means I can't go swimming or bowling instead."**

Take a more empathetic approach

Attendees shared concerns about the consequences of having their medical worries disregarded due to **"power consultants"** having their own agenda. One faced long-term complications and damage following 14 years of misdiagnoses, laxatives, and not being listened to about their persistent rectal bleeding. Others suggested a participatory approach might give healthcare professionals more empathetic insight into patients' experiences and access needs. Discussions included the need for accessibility posters, spaces, and processes to be developed with disabled people with appropriate compensation for their efforts.

Experiences of gaslighting, rudeness, and mistreatment by healthcare professionals who felt they **"knew better"** were common among attendees. For one, changing GP because of this meant finally being diagnosed with kidney failure. Others experienced restraint threats and felt blamed for unsuccessful blood draws and health issues. On her dad's passing, one felt **"unsafe"** when put in a record room of other patients who had passed. Discussions included the emotional turmoil of one attendee's doctor, implying an identified mass was untreatable cancer, to be told it was nothing the next day. A colonoscopy result caused concern for another whose doctor booked an early appointment the following day. She was given the all-clear. Later, she received a letter informing her of the presence of cancerous cells, but the GP couldn't advise as she hadn't seen it. Contacting the consultant confirmed these cells were removed, and there was no cause for concern.

Attendees wanted more empathy in healthcare during appointments and reconsidering the **"harsh"** wording of patient letters. This included being listened to when making suggestions about their care rather than simply being dismissed. They didn't want to feel like they were bothering healthcare professionals when advocating for their needs due to a general reluctance to help: **"I can't treat you if you won't do x, y, z."**

What works well

Attendees recommended improved structure, communication, and **"joined-up thinking"**, where appointments can be coordinated to reduce travel and save patients' time and resources. They also felt that an **"OFSTED"** for healthcare services was required and that PALS and CQC need to be regulated so that inconsistencies in care can be addressed.

Reflections

Katie's reflections

This project was wholesome, fun, illuminating, and, at times, deeply sad. Sometimes, it was difficult to follow as there were gaps in work due to the circumstances of the research team. Chronic illness flares are something we must account for when working as and with chronically ill researchers and participants. This can make it challenging to keep momentum in a project, but that doesn't mean we lose our passion; it just means we lose the thread sometimes. We had to gather up our threads intensely across this project due to the infrequency and inconsistency of meetings. Several team members have also been working on the sibling project Trans Aware Cancer Care, and I think our cancer research brains sometimes get a little confused! However, this cross-working also means that I can see how the barriers faced by disabled and neurodivergent people are similar and indeed overlap with trans+ peoples (and that does not account for people who belong to both communities – like me!). It was great to talk to so many amazing disabled people. They had many interesting and valuable things to share and were generous with their time, emotions, and experiences.

I look forward to the work still left to do.

Rosie's reflections

This project was a journey and a valuable one at that. Unfortunately, I was unable to attend all the groups due to an extended stay in hospital through chronic illness during the workshop phase of the project; however, I felt completely supported and accommodated throughout. On returning, it took a bit of adjusting, but the team was so patient and understanding. Given the field that we are working in, this demonstrated to me how everyone involved has this genuine desire to support neurodivergent, chronically ill, and disabled people, which radiates throughout their lives beyond the research context. This is so important and something that is not always there. Reviewing and analysing the stories shared by community members emphasises where the challenges are and presents ideas of how these might be addressed. It is an absolute honour that they felt comfortable entrusting us with their experiences and gave their time and energy to work with us. Working with such an incredible team of people and attendees has been a privilege. I hope our report and any further dissemination of this work does justice to everyone involved. I am excited to see this work evolve further.

Neil's reflections

Working on phase two of this project has been an absolute pleasure, moving from the point of issue identification in phase 1 to co-designing solutions to improve access to and

experience of services in the future. Genuine, personalised care is central to a person's care journey.

Personalised care matters because it allows individuals to receive healthcare that is tailored specifically to their unique needs, preferences, and circumstances, leading to improved health outcomes, increased patient satisfaction, and a greater sense of empowerment and control over people's own care and lives.

This work highlights the critical relationship between people, professionals, and the health and care system. Creating a positive shift in power and decision-making that enables people to have a voice and be heard must be at the forefront of all service design and delivery.

Tracy's reflections

This has been a fantastic project to be involved in; I have learned so much from all those involved: the peer researchers, the wider team, and most of all from the participants. Having worked in patient participation and support for 20 years, I know how difficult it can be to engage with those with health conditions, not because they do not wish to engage but because they have other challenges that take priority or do not have the time and energy to commit. Working with Help & Care has enabled those conversations to take place, and the ability to reach small charities and organisations who can help to facilitate, and support made so much difference. It has been a privilege to sit and listen to the stories of people who have life challenges and are then faced with accessing and using services that are not designed to be flexible, adaptable, or diverse. Listening to their stories and potential solutions to share with the broader healthcare system can only be positive for everyone.

Lucy's reflections

I have loved participating in this project and have learned so much. It was a privilege to have met and spoken to so many individuals who shared such personal and, at times, difficult experiences with us. The four workshops each highlighted how crucial community research like this is; the solutions shared with us were innovative, practical, and creative and will make a difference in years to come. Everything we heard truly highlighted a belief I have always held that nobody knows the best way for a service to work than the person who uses and experiences it. There is a long way to go to make cancer services accessible for disabled and neurodivergent people, but this project will be a big part of that journey towards a better future.

Next steps

Outputs

- Socialisation and dissemination of this report and findings. This will include:
 - via web and social media,
 - directly to NHS and VCSE providers and commissioners and broader stakeholders,
 - revisiting our community sector partners and the research participants,
 - via partner media channels,
 - attendance at relevant forums and events.
- Development of workforce tools to support improvements in knowledge and practice.
- Development of patient tools to improve self-advocacy and empower individuals.
- Potential attendance at the All-Party Parliamentary Group on Cancer.

Future work

In April we will be embarking on a new project initially collaborating with NHS breast screening services and the Wessex Cancer Alliance. To support this work, we will be utilising data and findings from this project and our aligned [Trans Aware Cancer Care](#) research project, addressing some of the intersectionality issues that we have identified.

We will further co-design and implement solutions, bringing together those with lived experience and NHS colleagues to transform services.

Conclusion

Building upon the work completed in the 'What I Would Like to Say' pilot, this project explored disabled and neurodivergent communities' perspectives of 'What [they] Would Like to Change'. The research team itself is comprised of individuals with lived experience of disability and neurodivergence, cancer services and cancer more broadly, research backgrounds, or a mixture of these, meant that the team was able to both connect and engage with community members on a more personal level within the workshops. This proved critical in providing safer spaces for attendees to share their views and experiences. Four creative arts and discussion-based workshops provided the research team with a wealth of stories and suggestions that lend deep insight into the challenges and barriers faced by many disabled and neurodivergent people when trying to access cancer services. It also highlighted many ways that these experiences could be improved.

Themes included the need for cancer services to be made more accessible to the physical and emotional needs of disabled and neurodivergent patients. They provided suggestions of what this might look like. By looking at the patient as a whole, attendees felt that their care would better suit them individually, as prejudicial assumptions and a one-size-fits-all approach can have dangerous consequences for those who live with disabilities. Attendees additionally emphasised the need for accessibility to be embedded more thoroughly within healthcare and for this to include access to appointments, screening, and healthcare settings. This also improves patients' access to accessible resources and support. Lastly, the importance of healthcare practitioners adopting a more empathetic approach was stressed. Attendees felt that better recognition and appreciation for national disability initiatives was needed, in addition to removing disability and neurodiversity-based assumptions from their practice.

Moving forward with this project involves broader dissemination of this report and findings to stakeholder groups, including healthcare professionals and community groups. Our solutions focus will be explored further in collaboration with NHS breast screening services and the Wessex Cancer Alliance, in partnership with the Trans Aware Cancer Care project.

Thank you

This project was commissioned by Macmillan Cancer Support and Wessex Cancer Alliance.

It was overseen by Neil Bolton-Heaton, the Involving People Programme Manager. We thank you for supporting our participation in this community research project. We value your commitment to the disabled community's perspectives and life experiences.

We also appreciate the ongoing support from Lucy Fitzgerald, Macmillan Whatever It Takes, Project Officer. We are grateful you offered practical and emotional support throughout this project.

We extend our gratitude to Tracy Street, the Patient Experience Facilitator, who has been a fantastic source of knowledge and has offered outstanding and invaluable support to attendees.

Neil, Lucy, and Tracy - you have allowed us to work, grow, and learn together, and this will shape our research practice for years to come.

This project could not exist without attendees' personal insights, honesty, and openness. We hope we do your stories justice through this report, other outputs, and our continued work on the wider Whatever it Takes projects. We have had the privilege to continue building relationships with Winchester Go LD, the Bournemouth and Poole Lymphoedema and Lipoedema Support group, MS Centre Dorset, and Autism Hampshire's Fareham Serendipity group. We appreciate you honouring us with your time and trust.

Thank you.

Katie Munday (Doctoral Student) and Rosie Tansley (Doctoral Candidate)

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MS Centre Dorset

<https://www.mscentre-dorset.org.uk/>



Bournemouth & Poole Lymphoedema & Lipoedema Support Group

<https://www.helpandkindness.co.uk/organisations/3315/bournemouth-&-poole-lymphoedema-&-lipoedema-support-group>



Bournemouth & Poole Lymphoedema & Lipoedema Support Group

Autism Hampshire (part of Avenues Group)

<https://www.autismhampshire.org.uk/>



Winchester Go LD

<https://winchestergold.org.uk/>



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