



## What I Would Like to Say...

# Whatever It Takes – Cancer Care for Everyone

Project Team:

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# Forewords

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## Steve Bond

**Dr Steve Bond works for Involving People at Help and Care and is the programme lead for the Cancer Care for Everyone programme. He is passionate about understanding and resolving cancer inequalities, and the use of community research as a means of really listening to what people want to say to cancer service providers.**



Whatever it Takes – Cancer Care for Everyone is an ambitious programme developed by Help & Care and Wessex Cancer Alliance to engage widely around experiences of cancer services with a view to understanding inequalities and co-creating solutions to address them. The first step in this journey is reported in this paper, where two disabled and neurodivergent community researchers set out to understand the cancer experiences of disabled and neurodivergent people, and to think with them about ways in which these experiences could be improved. These two researchers, supported by PIER - Partnership from Bournemouth University, developed the arts-based approaches to engagement that you will read about in this report, and carried out the peer-based engagements, which led to a depth of insight that is quite astonishing.

For me, if there is one testament to the success of this approach, it is that those who were sharing their cancer experiences truly enjoyed the process and have, in some cases, wanted to help more – proving that reliving cancer experiences does not have to be painful.

With thanks to the sponsors of this project – Macmillan Cancer Support and Clinical Research Network Wessex – and the whole team who worked tirelessly to deliver it, let's build on this work and truly listen to our community voices. I firmly believe that they have incredible stories to tell and that community-led approaches will create solutions that will eradicate inequalities providing better, more effective Cancer Care for Everyone.

But don't take my word for it... have a read!

Dr Steve Bond

Cancer PPI Head of Programme for Involving People

## Mel Hughes

**Dr Mel Hughes is an Associate Professor in Social Work at Bournemouth University (BU). Mel champions lived experience expertise through her roles as Academic Lead for the PIER (Public Involvement in Education and Research) partnership and Deputy Director of the Research Centre for Seldom Heard Voices. Mel is committed to ensuring that those who are most affected by social, economic and health inequalities have a voice in shaping and informing research, education and practice. She has a track record for developing inclusive, arts-based, co-created and community-led research, and co-designed and co-delivered research training and coaching.**

The Bournemouth University PIER Partnership are proud to be involved in supporting the What I Would Like to Say project, which places lived experience expertise at the heart of its work to develop inclusive approaches to cancer care.



Those who are most affected by social, economic and health inequalities are often the least involved in identifying research priorities or shaping services which directly impact them. This can result in treatment outcomes reflecting wider social inequalities and divisions. Building capacity in the voluntary and social care sector to engage in and conduct research within their own communities is one approach to tackling issues of equality, diversity and inclusion, and addressing health, economic and social inequalities. The BU PIER Partnership and Research Centre for Seldom Heard Voices approach reflects an asset-based model, which focuses on the strengths and assets of a community, alongside its needs. It involves drawing on the expertise of communities to understand lived experiences and to identify solutions. Rather than leading on the What I Would Like to Say project, the BU team have provided support and mentoring to enable the community researchers to shape how they wanted to capture a diverse range of voices and lived experiences. Throughout this report you will see how Rosie and Katie (the community researchers) and Kate and Stevie (from Bournemouth University) worked together to create safe spaces for disabled and neurodivergent adults, and individuals with long-term health conditions, visual impairments to play an active role in shaping cancer services. The results, shared in this report, illustrate the power of harnessing lived experience expertise.

Dr Mel Hughes, Associate Professor in Social Work

Academic Lead for the BU PIER (Public Involvement in Education and Research) Partnership

Deputy Director of the BU Research Centre for Seldom Heard Voices

## Meet the Team

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### Katie Munday

#### Community Researcher

Katie conducts research with neurodivergent, disabled and gender diverse people. They are interested in the accessibility of these groups within healthcare. They were drawn to this project as they wanted to support others with similar life experiences.



### Roseanna (Rosie) Tansley

#### Community Researcher

Rosie is a PhD researcher who is 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 others' access and experiences to cancer services.



### Amanda Durrant

#### Clinical Nurse Specialist

Amanda is a qualified nurse working as a Cancer Clinical Nurse Specialist (CNS) in hospital and community settings across the cancer journey, including pre-diagnosis, diagnosis, treatment or palliative care. She provides physical, emotional and psycho-social assessment with expert information and advice using an evidenced-based practice model. She was recently involved in a project to bring a personalised care approach and care plan to cancer patients and families.



### Stevie Corbin-Clarke

#### Research Assistant (Bournemouth University)

Stevie has a degree in primary education and is part of a research team working across The National Centre for Post-Qualifying Social Work and The Centre for Seldom Heard Voices and Marginalized Communities. She specialises in qualitative research methods and working with vulnerable groups, particularly regarding sensitive issues. Stevie enjoys exploring creative methods of research and dissemination.



### Katherine (Kate) Jupp

#### Public Involvement Officer (Bournemouth University)

Kate has a clinical background as a physiotherapist and rehabilitation specialist for people with long-term, complex neurological disabilities. After completing a Stroke Association funded PhD Kate worked as a healthcare trainer and guest lecturer. As a PIER officer her role includes building relationships with community organisations that make positive differences for those most affected by social, economic and health inequalities. In partnership with these networks, Kate helps to identify and support community researchers with lived experience expertise to design and deliver the best possible inclusive community-led research.



# Executive Summary – What I Would Like to Say...

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## **Introduction:**

This report explores disabled, chronically ill, visually impaired and neurodivergent people's experiences of cancer services, to support us in developing recommendations aimed towards improving the accessibility of these services. We also explore how using the BU PIER Community Researcher Model provides a level of shared understanding between the research team and community members to enable us to capture the perspectives of individuals currently underserved by health and social care research.

This project was commissioned by Macmillan Cancer Support and Wessex Cancer Alliance, and overseen by Involving People – Help & Care, Bournemouth University's Public Involvement in Education and Research [PIER] partnership and the Research Centre for Seldom Heard Voices. Two disabled and neurodivergent community researchers were supported to lead the project, and a clinical nurse specialist who works across hospital and community settings to support patients during their cancer journey was recruited.

This report is supplemented with case studies and quotes, drawn from workshops with community groups, from which we developed a set of recommendations that we hope can support cancer service providers to improve their practice.

## **What We Did:**

To understand the experiences of cancer services for disabled people, we carried out creative and engaging workshops and interviews. We worked with various community groups to learn about their experiences of cancer services, including Autism Hampshire's Fareham Serendipity group; the Dorset Blind Association; the MS Centre Dorset; and the Bournemouth and Poole Lymphoedema and Lipoedema Support group. These findings were supplemented by an online interview with a member of the Royal National Institute of Blind People (RNIB). Overall, we spoke to 45 disabled and neurodivergent people.

We built a rapport with the leaders of these groups, allowing for discussions around the accessibility of the workshops.

We explored themes, such as 'what would you like to say about your experience with cancer services?', 'what has brought you comfort?' and 'what is your story?' and made notes of attendees' responses. Attendees were provided with various arts and craft materials, as well as paper (including paper with hand shapes printed on them) and were encouraged to create a piece of art that they felt represented them.

The community researchers led on all aspects of the project. Their presence at the creative workshops was fundamental in connecting openly and honestly with attendees through shared understanding and culture.

## **Outputs:**

Outputs from the workshops took the form of the artwork created by attendees, with added quotes about their experiences captured during the workshops. Photographs of the workshops in process were taken, and a video has been developed of attendees' creations voiced over by the community researchers to give visual and audio insight of what our attendees 'would like to say'.

## What We Found:

From the creative workshops we developed the following eight themes that we felt best captured what attendees wanted to say about their experiences of cancer services:

1. I felt inappropriate assumptions made about me affected the quality of my care
2. I felt unsafe during my cancer journey
3. I could not physically access services
4. I feel that information about my healthcare is not accessible for me
5. I felt isolated and lonely
6. I felt like I constantly had to advocate for myself because no one was listening to me
7. I felt like there were multiple issues compounding my access to cancer services
8. I feel like there is a resistance to change and adaptation to support me

Please see our **Project Summary** video [www.youtube.com/watch?v=HbgEbtYfE18](https://www.youtube.com/watch?v=HbgEbtYfE18) or by scanning the QR code



## Feedback:

The creative workshops proved very successful in terms of providing a safe space for attendees to share their views and experiences. Feedback was positive, with attendees reporting feeling listened to and relaxed. Some attendees even asked, "when are you coming back?".

## Reflections:

The community researchers reflected on how their personal experiences supported shared understandings with workshop attendees and the importance of providing spaces for disabled and neurodivergent groups to have their voices heard, in whatever format that might be. They also spoke of how welcome they felt in the spaces and that the workshops left them feeling validated in their experiences too.

The clinical nurse specialist reflected on finding it extremely difficult to hear attendees' negative experiences of cancer services, but also invaluable in raising awareness of the issues and consequences frequently faced by disabled and neurodivergent communities.

The BU researchers reflected upon the significant growth of the community researchers throughout the project, as well as the importance of building safe spaces, to develop an enabling environment and an approach that empowered all members.

## Conclusion:

In using the BU PIER Community Researcher Model, the project team were able to reach and engage with community organisations offering support for disabled and neurodivergent people. The research team successfully captured the experiences and rich insights of 45 attendees through individual and group conversations. Multiple themes were identified from the experiences of positive care, and barriers or



challenges faced when accessing cancer services. Suggestions for possible service improvements were also captured.

Changes in practice have already commenced 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. The BU PIER Community Researcher Model proved to be a trusted, accepted, and effective approach that enabled equitable, diverse, and inclusive involvement with this project. Having the community researchers at the heart of all aspects of this project was essential in hearing, understanding, capturing, and amplifying the voices of *all* attendees. This project will provide the foundations for further research into inequalities in experiences of cancer services and ongoing development of the BU PIER Community Researcher Model.

## Introduction

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Those who are most affected by health inequalities are often the least involved in identifying research priorities, or shaping and conducting research which directly impacts them. As such, they remain under-served by health and social care research (NIHR Include project 2020). Building capacity in the voluntary sector to conduct and engage in research within their own communities is one approach to tackling issues of equality, diversity, and inclusion in health. The BU PIER partnership and Research Centre for Seldom Heard voices approach reflects an asset-based model which focuses on the strengths and assets of a community alongside its needs. They follow the principle that those most affected by an area of research should be involved in shaping and directing all stages of the research cycle, from the beginning stages of idea development, through to evaluating the impact. This involves drawing on the expertise of members of a community to understand their lived experiences and to identify solutions. Well planned and supported public involvement in research can lead to increased, and more diverse recruitment, research tools which are more relevant and easier for participants to engage with, broader interpretations of what is of significance in the data, and increased impact when engaging the wider community (Hughes and Duffy 2018).

Community organisations and local charities are experts in their fields and have well established links and relationships within their own communities, making them well placed to conduct research which reflects the needs of these diverse communities. However, they are often gatekept from conducting and publishing research due to their perceived lack of capacity and confidence. The Bournemouth University team provided the scaffolding, training, and mentoring to enable Help and Care and the community researchers (people with lived experience) to conduct the research. The community researchers were supported in their leadership, including how they would like to capture a diverse range of voices and lived experiences from people and communities currently under-served by health and social care research. The aim of this pilot project was also to build capacity for engaging and leading on inclusive research, and to further develop the BU PIER Community Researcher Model for use in the wider Whatever It Takes Project. The PIER partnership and Centre for Seldom Heard Voices have a track record for engaging marginalised communities in co-produced research using a range of approaches, including arts-based interventions, which harness the expertise of marginalised and seldom heard groups.

### Language

We want attendees to feel represented in a way which makes sense for them, so have used a mix of identity-first and person-first language in this report (e.g., people with disabilities vs. disabled people).

### Disability and Cancer

Involving People was asked by the Wessex Cancer Alliance to propose an approach that would address the perennial issue, whereby the Cancer Patient Experience Survey shows that there is inequality in experience, particularly for ethnic minority groups, those who experience deprivation (low income) and those with **disabilities**. We adopted the BU PIER Community Researcher Model approach to engaging 'easy to ignore' communities to generate the insight and culture change that will encourage the NHS to provide equitable cancer services in the Wessex region and propose a model nationally.

The Centre for Seldom Heard Voices at Bournemouth University is experienced in undertaking qualitative research using creative, participatory methods with diverse and seldom heard groups. Our aim in this

pilot was to involve disabled<sup>1</sup> people, using a range of innovative and creative methodologies to inform future development.

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<sup>1</sup> Where specification is not made, the terms 'disability' or 'disabled' refers to those who are disabled, chronically ill, visually impaired and neurodivergent.

# Methodology

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## Why We Chose Our Methods

Choosing the most appropriate methodology is crucial to any project's success and requires the researchers to have a solid grasp of the approaches available to them. This means that whilst planning a research project, researchers will lean towards the methods they are most familiar with. However, using non-traditional creative methods to engage participants, can enable collection of data *outside* that of traditional research methods, which may not be able to address a research topic or question fully and comprehensively.

Arts-based research focuses on using the artistic process (in various forms including written, physical, auditory, visual, spoken, performance) as a way of exploring experiences of a topic by the researcher and the participants. Artistic methods are useful to gather data, and to disseminate and share findings. Additionally, it can be an effective method of exploring peoples' subjective experiences, sensitive topics or topics focused on exploring feelings and emotions. These methods can also be useful to individuals with communication differences and for groups with mixed abilities. It can also enable the exploration of more complex research questions, particularly in relation to new trends or aspects of social life, where more traditional methods are not always sufficient to answer these questions (Social Change UK).

## What We Did

To understand the experiences of cancer services for disabled people, we carried out creative and engaging workshops and interviews. We worked with various community groups to learn about their experiences of cancer services for disabled and neurodivergent people, including Autism Hampshire's Fareham Serendipity group; the Dorset Blind Association; the MS centre Dorset; and the Bournemouth and Poole Lymphoedema and Lipoedema Support group. These findings were supplemented by an online interview with a member of the Royal National Institute of Blind People (RNIB). Overall, we spoke to 45 disabled and neurodivergent people.

Early contact was made with potential groups and organisations, to build a rapport with the leaders of these groups and to allow for discussions around accessibility of the workshops. The groups were given the choice of where they wanted the workshop to take place and, in most cases, the research team went to the premises of the group to make this as easy as possible. The Dorset Blind Association requested that their workshop took place on Bournemouth University premises.

Our creative workshops were a maximum of 2 hours long, with a semi-structured, flexible agenda. Time was allowed at the beginning for introductions, questions, checking attendee's understanding of the workshop plan and what will happen with the information they share, and gaining consent.

The group activity lasted approximately 90 minutes, during which each team member moved around the room, engaging with group members and asking questions, such as 'what would you like to say about your experience with cancer services?', 'what has brought you comfort?' and 'what is your story?' and made notes of attendee's responses. Attendees were provided with a large box, which held various arts and craft materials, as well as paper (including paper with hand shapes printed on them) and were encouraged to create a piece of art that they felt represented them. Some attendees included their thoughts on their cancer service experiences on their hands, however some were added to the hands after the workshops by the research team. Photographs were taken at each workshop.

The contribution of the Clinical Nurse Specialist, with their depth of cancer knowledge and connections to the NHS, was key. Their understanding of individualized care involvement, ability to support both

attendees and researchers, signpost where needed, and ensure everyone was in a safe and supportive environment, was vital. They were also able to begin putting into practice the learning from the workings, immediately taking it back to the NHS and sharing best practice with their colleagues.

An exploration of information and support services available across Wessex was undertaken to identify material to offer if needed, Macmillan Helpline and Cancer Matters Wessex were selected. These resources provide help, support and signposting for anyone who is affected by cancer.

Ethical approval was sought from, and granted by, Bournemouth University.



### **BU PIER Community Researcher Model**

When using the BU PIER Community Researcher Model, the research is both led and conducted by people with lived experience. In the What I Would Like to Say... pilot project, the community researchers both had lived experience of the issues being studied meaning that they were able to affect positive change which matters to them. The community researchers brought a deep, personal understanding to the project. Their lead on all aspects of the project; from study design, development of the arts-based interventions, data collection and analysis, output creation and dissemination of the findings, was fundamental to the success of the project.

Through identifying with potential workshop attendees, the community researchers were able to connect with people who might have been unwilling to engage if conducted solely by the university-based researchers. The community researchers' own lived experiences, knowledge, and insider understanding enabled attendees to respond honestly and openly, and perhaps more informally. Whilst the community researchers' stories might have been different in the details, the experience of prejudice was evidently the same. As a result, the data captured was rich in depth and nuance.

In the initial stage of the project, time was taken to develop a safe and effective way of partnership working. Relationships are at the heart of the BU PIER Community Researcher Model and to work successfully, shared understanding, momentum, and individual and team resilience were all required, this took effort, commitment and buy-in to be fully realised. Importantly framing how we would make decisions was established from the start. Through creating a positive culture and being aware of the complex power differentials, we were able to co-produce the project's vision, values, and goals. There were some setbacks, for example organisational barriers needed to be overcome, and a flexible approach to the community researchers' realistic capacity required time to develop and embed within the project. We worked at the pace of the community researchers, to ensure this was a positive and rewarding experience for all, with a focus on the quality of research rather than the quantity of workshop attendees recruited.

For the BU PIER Community Researcher Model to work effectively, roles and responsibilities needed to be agreed, clearly defined, and understood. Respect for each other's expertise, a willingness for honest conversations, openness to being challenged and to challenge, meant that the team developed a deep understanding and respect for what everyone contributed to the working partnership. While all aspects of the project were led by the community researchers some aspects were carried out collaboratively by the research team, and other aspects were carried out individually.

This pilot is the start of building an empirical evidence base for the BU PIER Community Researcher Model and has identified what works best for an effective community researcher model in terms of approach, support, and resources.

## **Action Research**

Action research involves the researcher and participants in the research process working together to pinpoint what the problem is that needs to be addressed, and then implement a solution based on their understanding of the issue or problem. Action research is solution focused and can help address research questions that seek to find a specific way forward or solution to an issue or problem.

In this report, we reflect on the insights shared by participants, including their recommendations for more accessible cancer services. We also consider the effectiveness of the BU PIER Community Researcher Model in work with marginalised communities. This report provides useful examples and case studies which can support cancer service professionals to do things differently.

## Themes

As a result of the creative workshops, we wanted to understand disabled and neurodivergent individuals' experiences of cancer services. We discussed the factors that contributed towards their positive care and any barriers or challenges faced.

Through this, we identified the following themes:

- I felt inappropriate assumptions made about me affected the quality of my care
- I felt unsafe during my cancer journey
- I could not physically access the service
- I felt that information about my healthcare is not accessible for me
- I felt isolated and lonely
- I felt like I constantly had to advocate for myself because no one was listening to me
- I felt that there are multiple issues compounding my access to cancer services
- I felt like there is a resistance to change and adaptation to support me

Attendees also made recommendations on how cancer healthcare could be improved. They also shared feedback on the set up of this study.

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

Some of the issues discussed in this report are relevant to all people, however some are more specific to disabled people, and many of the experiences that the attendees shared, had more of a “disabling impact” than the attendees' disabilities. These issues include healthcare staff making ableist assumptions, judgements and stereotypes which negatively affected attendees' quality of received care, dignity, and independence. These frequently revolved around the feeling that healthcare is not equipped to provide the care they require:

“Care is predicated towards the ‘normative’ body and the ‘restoration of normality.’”

“I feel like a slab of meat in a process, if I can't fit in the grinder, tough shit, I am discarded.”

Attendees reported on assumptions that healthcare professionals had made in terms of their quality of life, due to being disabled, including being asked “are you the lady with the problem”, in reference to being visually impaired and being told that “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).

Multiple attendees addressed their experiences with age-related stigma:

“Young people find more stigma with being blind, people can't believe someone so young is blind.”

One attendee shared that their practitioner had stopped checking to find out if their cancer had returned, due to being 77, and was told “even if we found it, we wouldn't operate due to your age.” This individual, however, felt that if an operation could help with the pain, they would consider having the operation, because they didn't feel they were ‘too old’ to stop living, and they did not appreciate this assumption.

Another assumption placed on our attendees by cancer service practitioners included that of their intelligence and ability to understand: “Staff assume that a disabled patient cannot process complex

information which is reflected in the way they are spoken to". The implications of this include a lack of autonomy and independence:

"I am not a child or small animal. There should be an expectation that the physician will communicate with their patient openly and honestly and provide the necessary information for the patient to be fully informed about their treatment. This raises issue for giving informed consent."

"I am not stupid. I can take the truth."

One attendee spoke of treatment being "prejudicial and cultural." This reflects another individual's experience of misogyny and body-shaming, prior to surgery, when they were inappropriately asked "would you like a breast reduction and uplift while I am at it? You would be much more comfortable". Similarly, an attendee reflected and questioned "do they look at the person as an individual? They saw me as a widow with no man, if I had a man would they have said different?", implying that they felt their relationship status and gender had an impact on their quality of care.

Making incorrect assumptions and judgements based upon a person's disability has implications on an individual's dignity and self-image. Attendees spoke often of undignified practices and questioned "why should the standards be lowered because I am disabled?". Some reported feeling as though they were "treated more like an object" and "pushed around to get into the correct position for a scan". Experiences were described as "exhausting", "traumatic", "awful", "uncomfortable" and "embarrassing." One attendee reflected on a procedure, during which they "could hear all the doctors talking around [me] as they poked and prodded as it was not done under general anaesthesia".

Another held up a blank hand template during the workshop and said, "stop touching me doctor!"

Speaking on dignity, one individual spoke about how "the little things mean a lot." Others explored how this could involve simply recognising how they like their nails and makeup done to make them "feel more human". This also includes respecting requests for certain staff to accompany patients to appointments and not swapping them mid-scan to someone else. Another attendee spoke of how they did not appreciate being placed as "responsible for practitioners' emotional baggage... like they've bent over backwards for me and it's a lot for them." Patients do not want to feel like a burden and should not have to carry that with them through their cancer journey.

For some attendees, it took some time to get the care they needed, however, they reaped the benefits eventually. For example, one attendee reported that "getting the stockings is like a new pair of legs", as it provided them with more freedom and independence. Another attendee discussed that being allowed to have their husband accompany and assist with scans "was found to be helpful". Lastly, one individual commented on how they "have always been treated very well" and that their overall experience of treatment was mostly positive.

### **I felt unsafe during my cancer journey**

Some attendees shared that they felt physically or emotionally unsafe when accessing cancer services. Several attendees experienced incomplete scans, as they were physically unable to access the screening equipment. One attendee's physician suggested that her carer should check her for lumps instead, as her results came back partly completed.



Many attendees had concerns around accessing cancer-related lymphoedema stockings. Attendees had been left to measure their own legs or arms, with no instruction on how to do so, with one individual wearing the incorrect size for nearly a year before it was corrected at the hospital. He had been wearing a sleeve for five years and not knowing if it was still the correct fit, he felt he had been “forgotten about”. Similar was experienced by an interviewee who was given two incorrect sleeves, before finally buying her own. It was suggested by her GP that she wear gloves instead, but she shared that she would not be able to keep herself safe with gloves on, as the lymphoedema affects her guide arm.

“It’s really important to get measured properly for [lymphoedema] stocking – this needs to improve!”

Attendees frequently experienced having to attend to their own health needs without instruction, including measuring their limbs for stockings and administering their own blood thinners. One attendee at the lymphoedema group was discharged from hospital at 9.30pm and had to arrange their own transport to get home. As an older person who lived alone, they felt unsafe making that journey at that time of night. Attendees suggested that many of these issues were due to medical professionals being “rushed off their feet”.

The mental health and emotional safety of attendees whilst accessing cancer services was also explored in the workshops. One attendee described cancer services as a “systemic failure” with “recurring issues that create a threat to patient safety”. This attendee added that assumptions and poor treatment may stop those with visual impairment coming back for further care: “it is frightening because I do not believe I am safe. I feel unsafe”.

Many attendees shared that they came to medical services with high levels of anxiety, some of which was due to fear of the unknown - “when you don’t know what is going on, you start to worry” - and some of this was directly linked to past trauma in medical settings. Some attendees shared that they did not trust that medical professionals would focus on their best interests, which was most evident when attendees spoke on smear tests:

“I was anxious about my smear – I don’t trust them.”

“My smear test was really triggering as they used a lot of the same tools as they had for my failed pregnancy. I waited a long time to get my smear because of this.”

“I wouldn’t feel able to say anything during the smear, or say ‘stop’, unless the nurse had specifically said I could speak or say stop. If their tone is rubbish, I wouldn’t dare say anything.”

Similar issues around autonomy and consent were shared by another attendee who suggested “I would much rather take my chances than go through *that* [a mammogram].” The fear of being uncomfortable, whether based on experience or perception, meant that many of the attendees avoided screenings.

Fortunately, the attendee who went for a smear test after her failed pregnancy was supported by an “amazing doctor” who held her hand throughout the process. She was able to access the test with emotional support, which meant she was more relaxed about her upcoming smear test. Many attendees had positive experiences being supported with their mental health after their cancer treatment, by Macmillan Cancer Support. One attendee was referred by Macmillan Cancer Support to Moving Forwards, a mental health support group, 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 services

Attendees shared that they had experienced multiple access issues, from booking appointments and travelling to cancer services, to accessing buildings and hospital equipment. Many attendees spoke of the difficulties involved with organising appointments with their GP due to confusing and impersonal answerphone services and phone calls which cut-off with no call back. One attendee explained that their scan results, which had been posted to them, told them that the scan had only being partially completed. However, the letter did not explain what would happen next and another appointment to re-scan was left unscheduled.

Transport to cancer services was an issue shared across all workshops - two attendees shared how the only accessible parking was a long walk from where they needed to be in the hospital. Attendees found that getting treatment meant "using lots of different hospitals because the technology was limited to one location". One individual reflected on the usefulness of council-funded taxis, which no longer exist. They shared that it was difficult and expensive for them to get to appointments without this taxi service in place.

Similar issues were found when trying to access other medical settings. Many attendees were unable to access screening rooms due to steps, narrow doorways or the inability to move safely within the room without guidance. This was spoken about at length in the Dorset Blind Association workshop, as attendees could not find their way around the services safely and they felt that in "having to rely on other people, we lose our independence." Attendees were dependent on others to get them to their appointments, as signs at the hospital were inaccessible, and one attendee reflected that on one occasion, if they had not been offered help by a stranger, they would have gone straight home without accessing care. Even when buildings were physically accessible, some of the autistic attendees found that they were overstimulating due to various smells, noises and general busyness.

Equipment was also found to be inaccessible, uncomfortable and, at times, dangerous to use. Concerns were raised around getting into and being in CT and MRI scans:

"CT and MRI scanners require you to lie flat – which is difficult when you have a bad back and don't have the support to get off them."

"The screening service itself is challenging and exhausting as you are put in a metal container"

"The process of undressing, preparing for the scan and getting into the correct place for the scan is a challenge for many reasons."

One attendee described the process of being 'helped' into the mammogram as feeling as though they were being "knocked about", before having their face "crushed against the glass" as the machine was inaccessible to them as a person who cannot fully weight bear. Several attendees also shared that getting in the right position for a colonoscopy was difficult and uncomfortable, and that was before the procedure had even begun.

Other attendees found that hospital beds did not go low enough for them to get on without significant help "the hospital has actually had to break the rules in how they get me onto the bed. The hospital of all places is not geared up for disabled people".

Attendees did experience some positives with regards to accessibility. One individual shared how they were provided with accommodation in a local hotel, with taxis to and from the hospital. This attendee

shared how grateful they were for this element of their care. Another attendee said they were thankful that nurses walked at their speed as "I don't walk fast".

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

There were many conversations during the workshops about how individuals had faced barriers to getting the right information to help them navigate their cancer journeys. This covered both print and face-to-face. Several attendees regretted their decisions regarding medical treatment due to not feeling fully informed of their options:

"I realise I made decisions without having all the information I needed to make the decision, for example no one told me that I would lose my sex drive during chemo and as a result I became depressed, it was a very difficult time."

"I wish they had told me [my options] before I decided on the operation."

"If I had known everything, I am not sure I would have made the same decisions."

Issues with printed information, readability, or lack thereof, formed a major concern across our workshop attendees. Specifically, that of print size being too small, inadequate signage, and printed documents being formatted in a way that cannot be read by screen readers. As one attendee commented "screen readers do not recognise all formats of text... if it is in a box for example... this should be recognised when providing printed material to make more accessible".

When talking about print size, individuals reported feeling as if "there is a misunderstanding of what large print is", as sometimes documentation was blown up onto large paper without increasing the font size. This was drawn upon by another attendee who stated that:

"I made a visit to the ward prior to surgery to prepare and gather information, but all papers provided were unreadable to me. Nothing comes in large print and 'accessible' websites are often not actually accessible."

It is important that information is provided in accessible formats to support patients access to cancer services. Without this, there runs the risk of missed appointments and screening. Unfortunately, this was something that had affected our attendees, with one individual speaking of how "there have been times when I would have gone home because I could not get into a building if I had not had help". A second attendee voiced "I haven't had any screenings, despite being 60. I would have the screening if they didn't make it so hard to arrange."

Some attendees felt ill-informed of the various processes within cancer screening and care, resulting in heightened levels of anxiety:

"I'm worried about having my breast checked. It would help if there was information that told you when everything was due. I didn't know... and I have been worrying."

One attendee explored their concerns regarding their lymphoedema stocking fitting several years back and how it "was put on repeat prescription and never checked", so 5 years later, they had no idea if they were still in the correct size or strength stocking, which made them feel "forgotten about". Similarly, one individual commented on the consequences of being ill-informed of their treatment plan:

"I was not advised how to apply the cream correctly... they never told me about the neck and so the skin there broke down and now I have to keep it out of the sun."

It is important to acknowledge that in talking about information access, several of our attendees reported more positive experiences of: using the internet to find out about their conditions; good communication with their doctors; and the benefits of the charity sector.

*“Some hospitals are very good in regard to explaining the processes of what is happening, what is happening next, and what the options are.”*

One individual spoke of having good open communication and accessible information through text from their team around the time of their smear test. Another commented on one specific practitioner’s communication style adequately meeting their knowledge and intellect. Macmillan Cancer Support and the Lymphoedema Network were applauded by some of our attendees, with Macmillan Cancer Support being described as *“tip top [for] sending me loads of info”* and doing a *“brilliant job”*.

## **I felt lonely and isolated**

Some of the attendees reflected on the loneliness they felt during and after their cancer care. One attendee said:

*“My treatment was like a ‘cloak’ of being looked after for 8 months. A ‘cloak’ of being looked after, told what to do and sent from here to there. Then on the last day of radiotherapy it was “bye” and that was it. There was nothing. I was left alone in the wilderness, no one wanted to know me anymore. I was alone with my cancer. I had struggled with my disabilities at the best of time, now on top of cancer that felt impossible.”*

This attendee’s structured care and support ended very abruptly, leaving them feeling abandoned. This was echoed by another attendee who shared *“I feel alone, I have no one medically”*. This experience was shared across workshops, and for some, was intertwined with caring responsibilities:

*“Caring for my sick husband meant I had to do heavy work, and this seemed to trigger my lymphoedema about 6 years after my treatment. I am sure that was why I got lymphoedema. There was no choice. I’ve also had cellulitis twice, but I have to care and do all the household jobs.”*

*“My mum was diagnosed with breast cancer, and I had to do all the care as I’m an only child [...] 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.”*

One attendee experienced not being able to contact their husband (who also lived with disabilities) when he went into hospital for cancer treatment. The wi-fi in the hospital was inconsistent and she was unable to visit him in the hospital due to the Covid-19 pandemic. She had to rely on her family for information on how he was doing, which left her feeling anxious. Similar issues around connectedness were explored by another attendee who said that she found technology *“extremely challenging [and it] alienates and makes people more vulnerable”*. Unfortunately for this attendee, they have experienced a rise in technology used in care settings since Covid-19. Technology is used more frequently across different care settings, to help with booking appointments and sharing information, however, as one attendee pointed out the negative impacts of the pandemic:

*“Covid should have made people more caring towards others, but people have become more selfish. Covid has made people less tolerant.”*

Fortunately, many of the attendees were able to find help and support within their support groups. Attendees relied on the members of these groups for information and advocacy but also as a listening ear. One attendee explained: "Peer support has been really important for me, like a lifeline."

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

Attendees shared their experiences of not feeling listened to across cancer services, which resulted in frustration and confusion, and in some instances, was fatal. One attendee said that they felt "white fury at the way [they] have been treated".

Some attendees said they often felt unwelcome in the services they were trying to access, with one individual sharing: "it always felt like they just wanted me to go away. You have to make a lot of noise to get them to listen to you". This sentiment was shared by many others across the workshops: one individual could not access screening due to mobility issues, despite repeatedly asking for help with this, and another was given advice for how to exercise to help with symptoms of lymphoedema, despite the advice not matching his range of mobility. One attendee felt they were "consulted but not consulted", as they were asked questions, but no one seemed to listen to their answers.

Two individuals reflected on their experience of not feeling listened to and how this had ended poorly. One explained that they had complained to their doctor "that the tube in my neck felt wrong from when it went in, but nobody listened and from that I have developed provoked thrombosis", and how this was further compounded by advice, which asked them to inject blood thinners at home, despite them being visually impaired. Another attendee spoke of how their grandad was not listened to despite going to the doctors several times, regarding his extreme weight loss and pain: "he wasn't listened to and died six months later".

The frustration around feeling ignored and a lack of appropriate services, means that many of the attendees had to advocate for themselves and others. The members of the Bournemouth and Poole Lymphoedema and Lipoedema Support Group, which supports over 100 people, had much to share about the empowering element, as well as the strain that comes with forced self- and group-advocacy:

"Information is shared in group, as where else do you get it from?"

"I asked about lymphoedema at an appointment and was told I have it. Would they have told me if I didn't ask?"

"We've got to learn to be more assertive when you go to the doctors - but that's a lot harder when you are not feeling well."

"People with carers need to be able to take their carer with them without being judged - I am made to feel like I am butting in - carers views are often not taken into account when I am advocating for my son, even when he has asked me to do so."

Many of the group's members sought help with their lymphoedema after having this identified by friends and family after their cancer treatment. Many had to inform themselves about their own condition in order to advocate for treatment. Local NHS clinics have even contacted the Bournemouth and Poole Lymphoedema and Lipoedema Support Group leader to ask for guidance. The overall message of this workshop was: "we have to do all the work ourselves to get the treatment and support we need." However, there was a positive element to support explored across the workshops - groups spoke of the significance of peer support, which was seen as a "lifeline":

"I see my role now as to raise awareness of VI and to do anything I can do to make things better for people living with VI. Peer support is so important if it helps someone in the future that would be great."

One attendee shared that they had good relationships and connections with medical professionals. They said that this had been vital in starting their cancer journey, as their optician had found the melanoma. This individual felt that they could ask as many questions as needed and that the professionals in charge of their care were "happy to answer these fully".

### **I feel that there are multiple issues compounding my access to cancer services**

Attendees emphasised during the workshops that their access to quality cancer services and care was negatively impacted by compounding issues. For example, individuals spoke of how:

"Patients are not being taken as a whole person... specialists are only looking at one issue at a time... there are so many appointments for so many different things."

"You can't have district nurses when you aren't house bound... get the GP to clean your legs because it is against their policies... [or] get a referral to the ulcer specialist."

"My doctor calls me a walking disaster because there is so much going on with me. It's difficult to get the right treatment for any one part, including my cancer."

"With a disability, everything crosses over, and you don't fit into the standard treatment plan."

It is important for healthcare settings to acknowledge that for disabled patients accessing cancer services, there might be multiple underlying health conditions, or other intersectional factors contributing to their experience, including accessibility or other support needs. This can result in stress and anxiety around attending healthcare settings, as two of our attendees explained:

"It's stressful enough just thinking about going to hospital for screening appointments. On top of that, if you are visually impaired, there are all the added stresses about access, safety, and negative reactions of others."

"Many autistic people have had multiple previous traumatic experiences with healthcare professionals, and this is their starting point for the next appointment."

As a result, attendees discussed a need for a multidisciplinary approach to overcome what one voiced to be a "systematic challenge and failure" whereby "leadership teams and trust boards need to put their weight behind an inclusive approach... I am not a second-class citizen and I do not appreciate being treated as such... [we need a] leadership buy in and business plan, with a committed HR director". Furthermore, another individual commented on how "all of the experiences put together shows a serious pattern of a lack of multidisciplinary working and that access [to cancer services] is not treated as part of a safe practice."

In addition, it is important to understand the impact of accessing cancer treatment in terms of a person's identity and self-image as this can sometimes be overlooked for disabled people through prejudicial assumptions and stigma:

"Losing my hair was the worst thing. It was my crowning glory and defined me over my disability."

This interviewee is discussing that the importance of their hair to them was trivialized by those around them.

### **I felt like there was a resistance to change and adaptation to support me**

Attendees described their experience as feeling as they were on a “conveyor belt – as if one size fits all.” One commented on their practitioner's own frustration of how poor the quality of care had been for their patients under different medical practices. Another described that they feel there is “culturally, no tolerance for [disabled] people like me”.

Attendees spoke of the need for individualised care and adaptation to support access to cancer services, however they often felt that these were not being met. When questioned as to why this might be the case, we were told that healthcare settings regularly demonstrated resistance to change:

“The principles are not difficult; people are just resistant to change”

Examples given by attendees to illustrate this included:

- Limitations placed on pharmacies to colour-code medication for visually impaired patients to help them differentiate what things are.
- Hospitals made no effort to accommodate patients' access needs in a dignified way when attending scans (e.g., mammograms as a wheelchair user).
- Staff not supporting visually impaired patients to navigate doorways despite being repeatedly informed by the patient that they could not see.
- Not providing information in accessible formats (e.g., digital, large print) due to having to go with the “standard”.
- Disregarding a patient's request to not be in a bed facing a window due to light sensitivity issues.

The consequences of resisting change and adaptation are concerning for disabled individuals, as it results in incomplete or procedures not even being attempted. This has implications for mental wellbeing regarding appointments, patient safety and feeling unimportant or othered.

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

# What We Would Like to Say is...

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## Case Studies

### Interview with RNIB Member

We had the opportunity to speak with a member of the Royal National Institute of Blind People about their experiences going through treatment for breast cancer. The RNIB is the leading sight loss charity in the UK and according to its website offers “practical and emotional support to blind and partially sighted people, their families and carers”, achieved by raising awareness and campaigning to improve accessibility and remove societal barriers to blind and partially sighted people.

The meeting was carried out virtually, following a chance happening across an interview on Radio 4, which was followed up by a member of the research team. The resulting discussion gave the research team a lot to reflect on and it was a powerful contribution of this person’s raw perspectives and lived experience.

Emphasised within this meeting was the importance of recognising the barriers and access difficulties as system-wide rather than located solely to one aspect of cancer services and healthcare, and the recognition that it is not important to solely focus on individual failings, but the systemic challenges. They spoke on the topics of communication, accessibility, professional training, and stigma that they had faced during their own cancer journey. They discussed the assumptions that are made about disabled patients, e.g., that they cannot process complex information and that they have a lower quality of life.

The discussion evoked, strong feelings, shown with strong language, such as the use of: “white fury”, “I do not believe I am safe”, “second-class” and “shite”. They shared the experiences which made them feel as though care is predicated towards the ‘normative’ body and that no allowance is made for those without a ‘normal’ body. They discussed potential solutions to the issues and felt that “leadership and trust boards need to put their weight behind an inclusive approach”.

### Dorset Blind Association

The Dorset Blind Association supports blind and partially sighted people across Dorset to live happy lives. They were founded in 1918 and believe that “sight loss shouldn’t have to mean missing out, so we work hard to ensure our members can live the life they want. That can be very different from person to person”.

The Dorset Blind Association does not have their own premises, so they often look for groups and spaces that can facilitate them. The group leader asked for members of the research team to meet with them prior to the workshop, to provide more of an understanding of what it would entail, and to reassure them that the attendees would be supported throughout the session. The leader of the group was also provided with a tour around the Bournemouth University building, to gain an understanding of the space and ask questions about accessibility and how the session would run.



Two of the attendees are also members of PIER (Public Involvement in Education and Research) at Bournemouth University, which helped with recruitment, as there was already a relationship and a sense of trust between the group and BU. The research team were able to create a positive atmosphere from the beginning of the workshop, and develop an instant connection with the attendees, supported by an unspoken understanding of shared experiences between the community researchers and the attendees. This encouraged the attendees to share openly, and discuss difficult topics, such as their concerns for their own safety, accessibility issues when going to and from medical appointments, and how having cancer as well as being visually impaired interacts and compounds.

## **Bournemouth and Poole Lymphoedema and Lipoedema Support Group**

The Bournemouth and Poole Lymphoedema and Lipoedema Support Group was started in 2010 by someone with lymphoedema. Stevie had worked with this group as part of previous research projects, and it was originally discussed that the workshop could take place as part of one of the group's monthly meetings in the Eastway Clinic in Bournemouth, where members attend their support group. However, there was hesitation from the group as they felt that research related to Lymphoedema often has a cancer focus and non-cancer-related lymphoedema is rarely focused on.

We worked with the team leader to ensure all members of the group would feel listened to and supported, and it was decided that the workshop would be carried out separately to the monthly meetings, so that people could opt in. This meant that all members were still able to attend their monthly meeting.

The first 30 minutes of the two-hour session involved a group discussion which began organically after group introductions. During the creative arts aspect, attendees shared many examples of where their healthcare needs had not been met by the NHS, and the community researchers were able to discuss these individual experiences in-depth. The theme of self-advocacy and the burden that can accompany a constant need to advocate for yourself and others, was evident throughout the session, with members discussing their reliance on the support group for vital information and support.

## Multiple Sclerosis Centre

The MS Centre at West Parley is a self-funded day and therapy centre for individuals and families in Dorset who are living with multiple sclerosis. Founded in 1985, their vision is to “encourage and support local people living with Multiple Sclerosis in attaining their full potential”. They provide accessible exercise, social groups, day respite and physical activities to support members’ independence through their multidisciplinary team of staff and volunteers.

Kate used her prior connection with the MS Centre to arrange a workshop, which was held on their premises as this was most convenient for the attendees. The session was carried out during one of their day centres and we were privileged to gain a rich insight into their experiences.

A multitude of issues were discussed in the workshop, including access needs and the impact of these not being met. Topics included feeling unimportant or left behind, with many members feeling as though those with MS are not prioritized and that they do not matter. They also discussed the importance of having support from peers, carers and family.

## Serendipity Community Group

Katie used their connections within Portsmouth to organise a session with one of the Serendipity Community groups - social groups for autistic adults operating regularly across Hampshire, run by Autism Hampshire. Autism Hampshire was founded in 1960 by parents with autistic children and the charity is involved in “creating opportunities, challenging perceptions, enhancing choices and providing high quality services to meet the diverse needs of autistic people.”

Prior to the session, the group leader asked for reassurance that the team had the necessary understanding of accessibility issues and appropriate use of neuro-affirming language. We arranged a pre-meeting and created a ‘meet the team’ document - with pictures and small biographies of all the team who were attending the session - for the group leader to share with the group members before the session. The community researchers on this project are both autistic, which provided the group with this understanding and enabled the team to appropriately explore expectations and accessibility for the group.

Attendees shared interesting insights into how they would like their care from professionals to look like. They explored the importance of feeling validated, listened to, and being cared for in a manner which suits their individual needs. Each member of the research team was able to spend 1-1 time with members of the group, to build up rapport. The use of the creative arts within the workshop was particularly useful for the Serendipity group, as many members found the topic particularly emotional to discuss. Many attendees reported finding it easier to approach the difficult topics when done so alongside the relaxing activity.

# Feedback

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## Attendee Feedback

Attendees shared amazing insights about their experiences of accessing cancer services, they also shared their views on the workshops. Many attendees said they enjoyed the sessions, and some even asked us to come back for another workshop. Some reflected that the artistic elements allowed them to relax, enabling them to share their experiences.

The Dorset Blind Association were the most vocal in their enjoyment of the session:

“It’s nice to feel like I’ve been listened to for a change.”

“Doing the artwork, I have talked about things I would not normally talk about.”

“I feel really relaxed; I’m actually really enjoying this.”

“We [the DBA] don’t have a community building, so we need to go to places for activities. Research needs to be a tradeoff for the group to get a free accessible session.”

One attendee was hesitant about attending the workshop as he was unsure that he would enjoy it and he was anxious to try something new. At the end of the session, he asked the team “can we do this again?”

The art element did not suit all attendees, and it took some individuals some time to feel comfortable getting involved in the creative process. One attendee said “I don’t have much imagination since my stroke, so I don’t know what to draw” however this attendee found their flow with one of the researchers creating their own hand beside them. Attendees did not have to engage in the art elements, and those who did get involved had the choice to do whatever they liked with the materials provided. Some attendees made several pieces of art whilst some spent the whole time perfecting one piece.

The overall feeling from the attendees was that of being listened to, having their stories heard and validated. One attendee explained that they were happy to share their story, especially as it may help other visually impaired and disabled people in the future:

“I felt listened to today... the more information there is the better, even if it takes time to filter through.”

## Group lead feedback

### *Fareham Serendipity Group:*

“Given that the team were wanting to ask our members about topics that could create high anxiety for people, the team were fantastic at making everyone feel comfortable. The format of the workshop worked really well – members really engaged with creating their ‘hands’ and it really did translate into the message of ownership of the project.

By having a creative activity to focus on, autistic members (who are often quite anxious with new people and new activities, as well as often having high anxiety around discussions of healthcare) were able to positively engage with individual discussions and questions on cancer screening. I was amazed how open and comfortable people were to chat with the team. Having Katie as part of the group definitely helped people feel more comfortable as well.

The group enjoyed the session so much, they have asked for the team to return to do it again!”

### *Bournemouth and Poole Lymphoedema and Lipoedema Support group:*

“Having discussed the research with some of the participants I am writing to let you know how they felt about the manner in which the survey was conducted. All agreed that as the presentation was informal this helped our members, some of whom had had cancer and they felt you had dealt very sensitively with the subject. As there were a lot of your team there, they also commented on the fact that they felt able to talk on a one-to-one basis and be more open than perhaps in a larger group. Some thought that having some craft work available to do was Ok as it helped them relax, others felt it detracted from the purpose of the meeting. The Tea and cakes also added to the informal atmosphere – as well as lubricating the vocal cords.”

### *Dorset Blind Association:*

“I think it was a really successful workshop although I, personally, felt the art activity could have been more interesting, everyone who took part really enjoyed it and it was not too challenging which meant that they had the bandwidth to answer the research questions about cancer services. It was nice that some carers were able to take part and have a break from the routine of everyday life.

This particular client group is always prone to last minute dropouts due to health issues or transport difficulties so the payments towards travel costs really helped make a difference. Having said that, it was a small group, but this meant that people could feel that they had one to one attention and I have noticed that this is something the group really values and responds to, as they often feel that they don't have a voice.

The refreshments were very welcome as food always brings people together!

The room location was great as it was close to the loos, and we appreciated the guiding from the lobby to the classroom.

I think it was helpful that you and your colleague visited the group prior to the activity to explain in more detail what was going to happen.

As an organiser it was a bit time consuming as I had to check the venue and keep track of who was going to claim travel expenses and attend, but some of this work might not be necessary for future events.

One participant suggested that it might have been easier to pay the expenses into bank accounts as then I would not have needed to collect the cash and distribute it but I appreciate this would have meant more paperwork at your end.

Altogether it was a lovely atmosphere, and everyone was keen to do something similar again. They also felt good that the information given was going to help people in future and that they were able to make a contribution.

Thanks to everyone for all the hard work on this project. I think it was worthwhile.”

## Reflections

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### **Katie's Reflections**

Sharing my lived experience during workshops was helpful in creating trust with attendees and making a safe and non-judgemental environment. It was important to me that all 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 and I did not want our attendees to feel this way at any point in our journey together. I want other neurodivergent and disabled people to feel listened to, to feel seen, cared for and respected. Giving us accessible information and choices and involving us in every aspect of our care would go a long way towards this.

At the beginning of this project, I felt slightly deflated with delays as I knew how important and empowering this project would be. However, I understand how neurodivergent and disabled people can lack the energy and time to be involved in grassroots research. We had to meet the individuals and the groups where they were, not where we expected them to be.

During the project, it was often difficult to disentangle myself from education culture which focuses on 'hard' outcomes and results. I also kept reminding myself that what we were doing was a pilot, so the model itself was as important as the data collected.

Personally, to be in a room full of other disabled people was amazing: the communication was easier, and conversation flowed better, there was no need to hide any parts of us. It doesn't seem to matter what disabled space I go into, or whether I share the same bodymind as those in the group, I always feel welcome and I always feel at home.

The attendees have been amazing with what they have shared with us, and I'm truly honoured by their time and grateful to be a part of this project.

## **Rosie's Reflections**

Coming into this project, I wanted to make sure our workshops provided a platform that put attendees views front and centre in a way that works best for them. This is something I also promote in my own doctoral research in supporting autistic learners in school.

Through our creative hand-making approach, attendees could share their experiences both visually and through spoken word. We had lots of positive feedback about this method and how it was able to support what might otherwise be sensitive topics to discuss. I felt this also gave me a way to initiate interactions with attendees which supported my participation in the workshops too.

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.

From an autistic perspective, I found that the ambiguity at the start of organising workshops to be challenging at times. Although, it was reassuring to have a neurodivergent colleague on the team to speak things through when needed. Having regular check-ins with the team also helped with maintaining a structure for the progression of the project.

Overall, this has been a fantastic experience and I feel so grateful to have been a part of this pilot as a community researcher. To have been trusted by our attendees to share what they would like to say through this project is an absolute honor.

## **Amanda's Reflections**

The CNS role has been welcomed as part of the research team in this community research model. This has been one of the key strengths in facilitating data collection, to ensure participant safety, as well as clarification and context of contributions around this sensitive subject. The workshop design has been demonstrated to be a very effective method to promote relaxation, enjoyment and contributions from participants facilitating open conversational disclosures. During the pilot uncertainty about accessing this difficult experience dissipated as confidence grew in offering workshops with a reflexive approach adopting the best evaluated "bits" taken forward to refine the workshop offer. Over the course of this project the CNS has made contributions during the research process in line with the outlined role at all stages.

At times it has been extremely difficult to hear the lived negative experiences of these champions who have generously recounted and described the personal impact of the issues encountered in cancer health care. To have heard this and to be a healthcare professional in practice has been personally uncomfortable, but clinical supervision with the research team has been invaluable, and the need to raise awareness of issues, potential consequences and recommendations is essential to promote the seldom heard voice authentically captured in this report across all health care settings is a welcome duty as part of this role.

The reflexive approach of this community research pilot project has allowed the CNS role to develop across the research process, an understanding of qualitative research processes has been an advantage, e.g., collaboration with a community researcher during an interview to probe using expert cancer knowledge to gain clarity of an experience. As a nurse involved in direct clinical care currently with a personalised approach this project is of significant interest and has an immediate impact in practice for me and my colleagues as well as the wider nursing community with this report.

## **Kate's Reflections**

Through our work together to create interesting and creative ways of capturing deep, rich, and often complex insights we have contributed to a better understanding of cancer inequalities and change in practise has already begun. 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 could see things from new angles and learn and grow together.

My role has been primarily the support of the community researchers. The flexible approach to mentoring, support and coaching the community researchers was adapted to meet their changing needs as the project progressed. Creating a safe and enabling environment and an approach that was generous, respectful, and empowering was the key to the effectiveness of the support. This was particularly important as the community researchers reported, and at times struggled with, the additional responsibility they felt as identifying with the communities at the heart of this project. I have had the privilege to witness the community researchers' growth in confidence throughout the project. I have watched them change from *hearing* from others that they are community researchers to *feeling* they are community researchers; from *doing* community research to *being* community researchers.

Focussing in on What I Would Like To Say Is... meant that from the very beginning the workshops were about starting a conversation and creating knowing through connection and dialogue. The workshops were not about the creative achievement, there was no right or wrong, instead it was a process of playful experimentation creating the conditions for comfortable and open sharing of experiences. As we started the workshops, I became more comfortable with less predictability, shifting away from the system world that I am more familiar with. I soon realised, and was confident in the knowledge, that we did not need to have all the answers, but instead to listen deeply, capturing and generating questions to facilitate a future change in practise. Contributing to this growth in confidence was the presence of the CSN at all the Workshops. The CSN presence freed the rest of the research team to be more creative and develop and adapt the creative arts activity for the individual community groups, and as the project moved forwards.

My standout moments during the project are the almost immediate rapport and connection that was established between the community researchers and many of the workshop attendees; an unspoken communication of mutual understanding, empathy and trust providing the safety for the attendees to share openly. How quickly the creative arts-based workshops were effective in facilitating the sharing of personal stories really struck me, and interestingly, some of the attendees in the workshops. Many talked about how curious it was that in participating in a creative activity they found themselves sharing things

they might not have done otherwise. A final standout moment for me, was when a simple change to the organisational structure of full-project team meetings early in the project empowered the community researchers to move from 'knowing' they were leading on the project to 'feeling' they were leading, with the solution being identified by the community researchers.

My takeaway from the project, looking to future use and development of the BU PIER Community Researcher Model is just how crucial the upfront investment in the development of relationships with the community researchers is. Time and resources are required to get to know each other, to start to build a greater understanding of each other's expertise and to agree and clearly define roles and responsibilities. There is the risk that when time and resources are tight, and the initial project enthusiasm creates a strong drive to move the project on, the importance of this period is underestimated. It is clear from this project that the time spent in early stages of the project developing relationships and a partnership working approach reaped rewards for both the project outcomes and all those involved. And finally, with the community researchers leading the project had a real authenticity, the community researcher led from both from head and heart, bringing this project alive. It was a real privilege to be part of the research team.

## **Stevie's Reflections**

Immediately after the initial discussions about this project with the two community researchers, I felt excited and ready to get going; the passion that came through from the community researcher was motivating and refreshing. This emotional backing was able to encourage us through the more challenging times in the project and continued to push us to do our best. I feel that each member of team brought a unique strength to the table; a necessary mixture of passion, lived experience, and research skills.

The discussions led by the community researchers opened a whole new world of things to consider when planning this research project, however they provided a safe environment for other members of the team to ask questions, which enabled us to develop a shared understanding of language and culture. This was reciprocated, with open discussions in which the community researchers concerns and queries were addressed by the supporting team members. There were some 'push and pull' moments, in which the career researchers and the community researchers were looking at situations from opposite points of view, with differing expectations, experiences and demands on time, which often took a lot of deliberation to find an appropriate balance. Time was also required for all team members to develop an understanding of each other's communication styles and learning preferences and put plans into place to ensure that each member of the team was always on the same page.

The varied expectations in terms of pace also required some attention. The career researchers did not immediately recognise the importance of a clear and structured plan that was accessible and understandable for all members of the team. However, positive and practical ways of working together and keeping up to date with progress and plans were found quickly e.g. using OneDrive for shared files. I initially struggled with the more heavily structured planning, as I am used to 'getting on' with things as and when they happen and being solely in control of this. However, I quickly learned the importance of working through decisions as a team. A key difficulty here was the varied time demands and locations of the team members, making it difficult to meet frequently and find times for the workshops. We also



wanted to find time for debriefs after workshops, so that we could share our thoughts and improve as we went along, so there were demands on our time that we worked hard to meet.

A key turning point was upon the decision that the community researchers should lead the large team meetings, so that they could control the pace of the meetings, address all their thoughts and queries in the way that was most appropriate for them, and so that the other members of the team understood what they needed from us. I had struggled to find purpose in the large team meetings until this point but found use in getting on the same page as the community researchers once they felt comfortable to take charge. I feel this also marked a larger change in how the community researchers saw themselves; they developed a sense of empowerment and felt more in control of the project direction.

BU staff members were able to support the community researchers through the frequent redesigning of the project and the changes of plan, as they were experienced with the uncertain and changeable nature of research projects, where multiple factors are at play. We were able to talk through formal barriers that research projects bring e.g. ethics applications, so these processes did not feel daunting or concerning.

I feel that the communication with group leads prior to the sessions was vital - they know their group members so well and we were able to ask those questions about how we could make the workshops as accessible as possible e.g. the option of wearing gloves for the Autism Hampshire group to combat some of the sensory concerns and of large print hands for those with a visual impairment. However, it would have been beneficial to have even longer lead-in times for organising groups and communicating with leads, to maximise this. The group members and their leads were very protective of their peers, so it was particularly helpful to have researchers with that shared lived experience to help put the groups at ease.

It has been incredible to see the changes that are already being made in practice, through discussions about this project, and that Amanda, our Clinical Nurse Specialist, is taking back to her team. I am excited to see where the next steps in the 'Whatever It Takes' project takes us and the impact it will have.

### **The potential and future of the BU PIER Community Researcher Model**

1. The BU PIER Community Researcher Model ensures that lived experience expertise is at the heart of all stages of a project from design through to dissemination of the output.
2. The BU PIER Community Researcher Model provides an approach that enables equitable, diverse, and inclusive involvement. The model facilitates connecting and building relationships with community organisations supporting the involvement of people who might otherwise have been unwilling to engage in organisation led research.
3. The BU PIER Community Researcher Model is an effective approach to capturing the deep and rich lived experience insights from people who are currently under-served by health and social care research.
4. The BU PIER Community Researcher Model used in combination with creative arts-based approach supports a research environment that is safe and empowering for everyone involved.
5. The BU PIER Community Researcher Model is a way of working that provides an additional level of understanding and relatability, where everyone involved could see things from new angles and learn and grow together.
6. The BU PIER Community Researcher Model is an approach that can help the build capacity of community organisations to identify both community researchers and research priorities, and lead on future research.
7. The BU PIER Community Researcher Model will continue to develop and evolve as it is used in other projects already underway and in future projects. The BU PIER Community Researcher Model is being used in continued work under the umbrella project Cancer Care for Everyone.

### **DBA Member Story:**

At the workshop held for the Dorset Blind Association, one attendee was particularly hesitant about joining the session at all, discussing their anxiety in trying something completely new. They were accompanied by one of their parents for support, however they were increasingly comfortable engaging with the creative arts and the researcher, throughout the session. They created a hand, which reflected their experience as someone who became visually impaired because of complications from having a brain tumour. They brought with them so many insights from their life in general and about their struggles with accessing healthcare. By the end of the session, they were exuding confidence and were very keen to get involved in further projects and were hopeful that they could be a part of more similar activities. They are now a member of PIER at Bournemouth University and will be contributing their expert lived experience to education and research in the future.

### **Outputs**

Sharing and disseminating research findings in varied formats can increase its reach, and so a film has been developed, using the attendee's artistic creations for the visuals, with the experiences they shared in a voiceover. This film, as well as the physical artistic creations from the workshops, will be shared at a

celebration event, to which healthcare professionals and group attendees will be invited to see what has been developed because of the project.

Outputs will also include blogs, journal articles, infographics, and accessible summaries.

## **Future NIHR projects**

This Community Research approach is being built on in further projects, to develop a shared understanding of the current state of cancer equity for trans+ people and people from Black communities. These projects, led by community researchers, shall reveal comprehensive insights from the perspective of these groups, as well as potential solutions that they believe will better meet their needs.

## **Conclusion**

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In using the BU PIER Community Researcher Model, drawing on the lived experience expertise of the community researchers and the learnt expertise of a cancer nurse specialist and BU researchers, the project team were able to reach and engage with community organisations offering support for disabled people. During 4 semi-structured, flexible creative arts-based workshops and one interview the research team successfully captured the experiences and deep and rich insights of 45 attendees through individual and group conversations.

Multiple themes were identified from the experiences of positive care, and barriers or challenges faced when accessing cancer services that were shared by workshop attendees. Suggestions about possible service improvements were also captured. Three key recommendations for healthcare providers were highlighted: firstly, that compassion and reassurance matter, supporting a person-centred approach to care. Secondly, that effective communication is key, supporting informed decision-making and access to the information required and requested. Thirdly, that making accessibility a priority is essential, requiring listening to, and meeting the individual access needs of patients. Changes in practice have already commenced 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.

The BU PIER Community Researcher Model proved to be a trusted, accepted, and effective approach that enabled equitable, diverse, and inclusive involvement with this project. Having the community researchers at the heart of and leading on all aspects of this project was essential in hearing, understanding, capturing, and amplifying the voices of all attendees. This project has been a rewarding project to be part of for all involved and will provide the foundations for further research into inequalities in experiences of cancer services and ongoing development of the BU Community Researcher Model.

## Thank you

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This project has been commissioned by Macmillan and Wessex Cancer alliance.

It was overseen by Dr Steve Bond from Involving People – Help & Care, and Dr Mel Hughes from the PIER (Public Involvement in Education and Research) Partnership and Research Centre for Seldom Heard Voices at Bournemouth University. We thank you for giving us the opportunity to be a part of this community research project.

Stevie Corbin-Clarke from the National Centre for Post-Qualifying Social Work and the Centre for Seldom Heard Voices, and Dr Kate Jupp from PIER (Public Involvement in Education and Research) at Bournemouth University have been instrumental to this project. We thank them for their invaluable contributions and mentorship throughout.

We extend our gratitude to Amanda Durrant, a clinical nurse specialist from the NHS Right by You team, who has been an amazing source of knowledge, and has offered outstanding and invaluable support to our attendees.

This project could not exist without the personal insights, honesty, and openness of all attendees. We hope that through this report, other outputs, and our continued work on the wider 'Whatever it Takes' project, that we do your stories justice. We also thank the community groups, who honoured us with their time and trust – Dorset Blind Association, the Bournemouth and Poole Lymphoedema and Lipoedema Support group, MS Centre Dorset and Autism Hampshire's Fareham Serendipity group. We were also privileged to have a powerful interview with a member of the RNIB (Royal National Institute of Blind People).

Thank you.

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

Community Researchers

## Contacts

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