



What I Would Like to Change...

Whatever It Takes – Cancer Care for Everyone

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Bolton-Heaton, Lucy Fitzgerald, and Tracy Street

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Foreword

This project is called 'What I Would Like to Change'.

We listened to disabled people's stories and ideas about what might improve cancer care.

We thank our two disabled and neurodivergent community researchers for working with us and everyone that we spoke to.

We thank Macmillan and Wessex Cancer Alliance for funding it.

Lots of things have happened from this research. We talk about it in this report.

Neil Bolton-Heaton

Who are we?

Katie Munday

Community Researcher

Katie does research with and supports neurodivergent, disabled and trans+ people. They want to improve life and accessibility for those with similar experiences to them.



Roseanna (Rosie) Tansley

Community Researcher

Rosie wants to make research fair for everyone. Being disabled and neurodivergent, she wants to improve accessibility. She works with disabled communities to do this.



Tracy Street

Patient Experience Facilitator

Tracy has worked with people who have cancer for years. She helps them share their stories. Tracy hopes this can help improve cancer services.



Lucy Fitzgerald

Macmillan Professional

Lucy has supported the community for over 15 years, helping disabled young people and those facing challenges. Lucy wants to ensure everyone's voices are heard.



Neil Bolton-Heaton

Head of Programme

Neil manages community research at Help & Care. He involves people in health and social care to ensure their voices shape these services.



Summary

Why did we do this project?

Disabled people face problems accessing cancer services, like being unfairly treated and misunderstood. Healthcare workers must listen to disabled patients to make this better.

What did we do?

We did art with four groups: MS Centre Dorset, Bournemouth Lymphedema Group, Autism Hampshire (part of Avenues Group), and Winchester Go LD. We used what we learnt last time with our 'What I Would Like to Say' project to help us.

We talked about how to improve cancer care. We saw everyone as an expert. We grouped our conversations based on similarities.

What did we find?

We found four big similarities in people's stories.

1. Support patients' understanding
2. Take a 'whole person' approach (don't just focus on the illness)
3. Ensure the accessibility of practice
4. Expand knowledge of disabled experiences

The research team enjoyed working with the different groups.

What happens next?

We might go back to the government and share our findings. We are working with the Trans Aware Cancer Care team to help make breast screening more accessible at Princess Anne Hospital.

Why did we do this project?

Disabled people face more challenges than non-disabled people in cancer care, like accessibility problems and not having their needs met. This includes those with learning disabilities, neurodivergent people, and people with a chronic illness.

Problems with screening can mean getting a diagnosis later. It can also make treatment harder. Lots of people with disabilities live with cancer. Cancer services must treat everyone fairly.

Why is language important?

We say 'disabled people' and 'people with disabilities' in this report. This is because not everyone describes themselves the same.

What did we do?

Why did we do art?

We used art to help disabled attendees share their stories and ideas. Art can help people talk about hard topics. In the 'What I Would Like to Say' phase, one person said art helped them talk **“about things I would not normally talk about”**.

Art can also help people who might struggle to share their thoughts through speaking.

What did we do?

In the first phase, participants decorated handprints with what they wanted to say. In phase two, we used lightbulbs for ideas on making cancer care better. We made a guide about the main problems found in phase one to help with this.

We met with the groups before the workshop to learn about their members. We wanted to know their best meeting times and places, their access needs, and what they wanted to do in the session. We use this to make each workshop accessible to everyone in it.

We worked with MS Centre Dorset, Bournemouth Lymphedema Group, Autism Hampshire and Winchester Go LD.

What is Community-based participatory research?

Community-based participatory research was important for this project. It lets researchers and participants work together. It views everyone as an expert who can help make healthcare better.

What did we find?

The conversations we had with the four groups had four big similarities:

1. Support patients' understanding
2. Take a 'whole person' approach
3. Ensure the accessibility of practice
4. Expand knowledge of disabled experiences

Support patients' understanding

Some found easy-read documents helpful, like health check forms, but others didn't. One said, "I was handed a leaflet that I couldn't understand".

Attendees wanted better maps and directions to the hospital. They wanted more autism-friendly guides with "pictures of the room... who you might meet, [and] what will happen".

People wanted health advice that they could trust. Some people found searching online confusing and liked the "human side" better.

Attendees want doctors not to use long words that make them feel "uneducated". They wanted clear instructions before scans, like mammograms (a screening test for breast cancer).

Attendees wanted "time to think... and ask questions". They want doctors to "understand [their] communication needs" and to speak to them directly, not through someone else.

They said taking an "advocate" with you and "writing down what you want to say" before appointments is helpful.

Take a 'whole person' approach

Attendees shared how cancer affects their lives and wanted to be treated as a whole person. They wanted better communication between doctors and hospitals to make care and information better.

Fun things, like music and comfort objects can help them feel less anxious.

They said that pain feels different for everyone and that doctors should treat them as individuals.

One said they had “not seen any improvement in access to services for the disabled over the last 10 years”.

Many people said they don't get enough emotional support. One said, “scars heal, but the mental ones don't”.

One person felt that the “nurses seemed disconnected” when giving them upsetting medical information. They felt lonely and wanted doctors to show kindness by asking them “how are you?”.

Others found care “embarrassing and undignified”.

People said that family, friends, carers, and support groups are important during and after cancer care. They wanted loved ones to get help to support their emotional needs. Often family and carers “find it difficult to ask for help as they are exhausted”.

Ensure the accessibility of practice

Getting to appointments was hard, and some needed help but could not get it. Without help, they couldn't get to their appointment and had to go "back to the start of the [waiting] list".

Others talked about hospitals being "hard to navigate".

Some shared that public transport was unreliable. One said, "it could be two or three buses [to get to an appointment]. There are no directions or advice... they just expect you to get there".

They also felt parking charges were unfair, especially because disabled people often attend more appointments.

Attendees described feeling "trapped" and "manhandled" because equipment did not meet their needs. They wanted adjustable beds, hoists, and accessible equipment.

People felt frustrated having to repeat their needs and wanted doctors to check their histories before appointments.

Some shared feeling scared about not having their needs met. One said that this means they wait "until things get really bad before seeking help".

Attendees wanted record systems to flag patients' needs so doctors can prepare. One said, "if you can see I have a disability, why doesn't this make my treatment easier or more appropriate?".

Attendees said having someone they trust "helping [me] to speak up" at appointments was helpful. They liked Macmillan easy-read books, and bringing a list of things to talk about in appointments.

Expand knowledge of disabled experiences

Attendees said that doctors assuming patients are “well” because they look “young, able, and normal” can make it hard to get help. It can also mean that things get missed.

Others felt they weren’t taken seriously because of their age, weight or gender. One gets her dad to talk for her because she feels that the doctors won’t listen to her. Another said they were “treated like I’m stupid”.

Some said sunflower lanyards “help with misunderstandings”, but not everyone was comfortable with wearing them. Others said that hospital passports “could be helpful”, but not everyone knew about them.

Attendees wanted their support hours not to be used up by appointments so they can use them for things they enjoy, like “swimming or bowling”.

Disabled spaces were too far “away from the main entrance”, and there were not enough of them.

They wanted doctors to better understand their needs. Some suggested that disabled people could be paid to make resources to help with this.

Some felt “unsafe” or worried when given different stories from the doctor about whether they had cancer or not.

They wanted to feel listened to and not be told by their doctors, “I can’t treat you if you won’t do X, Y, Z”.

Reflections

Katie

This project was fun but sometimes sad. We couldn't always meet as often when team members got sick, but this reminded us that health problems can affect work. Sometimes things did get confusing when also working on other projects, but listening to everyone's amazing stories makes me excited about the work still left to do.

Rosie

This project was very important. I missed some sessions because I was in the hospital, but everyone was kind and supportive. The team cares for fairness and accessibility, not just for this project. I felt honoured to hear the thoughts and ideas shared by attendees and look forward to continuing this work.

Neil

Working on phase two has been great. We found ways to make cancer services fairer by treating people as individuals. This improves health, makes patients happier, and gives them back control. Working together and listening can truly make healthcare better.

Tracy

I have loved being part of this project. After supporting patients for 20 years, I know life challenges can make it hard for people to be involved in research. Help & Care makes this happen by working with groups that can help. Hearing attendees' stories and ideas helps us improve cancer care.

Lucy

This project taught me a lot. Listening to people's stories brings helpful ideas for change. Hearing from people who use cancer services is the best way to make things better. This project is a great start, but there is still much work to do.

What happens next?

We will share what we have learned online, with the NHS, our four community groups, and more. We might also share our findings with the Government.

We will make tools to help improve cancer care and help patients advocate for themselves.

Future work

We are working with the NHS, Wessex Cancer Alliance, and our Trans Aware Cancer Care sibling project to make breast cancer screening better. We will think about how things like gender and disability might affect these experiences.

Conclusion

This project looked at how to make cancer care better for disabled and neurodivergent people. Our community researchers helped us to connect with participants.

Attendees wanted kinder treatment, fairness and better accessibility.

We are sharing these findings with healthcare professionals and groups and will keep working to make cancer care fairer for everyone.

Thank you

Thank you, Neil, Lucy, and Tracy, for your support and knowledge on this project. This will shape our research and future work.

Thank you to all attendees for being open and honest when sharing your views. We hope we have done your stories justice.

Katie and Rosie

Community Researchers

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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