

HOW DOES IT FEEL FOR me?



Abdul's summary report



If you need this report in another format, please contact Healthwatch Leeds.

Examples of other formats are large print, plain text document, easy read, audio or other languages, including British Sign Language.

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Context

Healthwatch Leeds follows the experiences of people with multiple health conditions who use different health and care services regularly. This work is part of a wider approach being taken in Leeds to understand people's experiences as they move around health and care services, called the 'How does it feel for me?' programme. As well as the real-time journeys that we are following, there are three additional components to the programme that are used to measure joined-up health and care services:

- case note reviews (looking at medical records to see what happened and when),
- understanding what citywide complaints tell us, and
- developing a set of metrics (data measures for tracking progress).

The programme involves all health and care partners, including representatives from Healthwatch Leeds (chair), Leeds Teaching Hospitals Trust, Leeds Community Healthcare NHS Trust, GP Confederation, Leeds and York Partnership NHS Foundation Trust, Leeds City Council, Carers Leeds, Age UK and St Gemma's Hospice.

The programme is designed to help these organisations to:

- Understand what people's experiences are like as they move through 'the system'.
- Identify what is working and what is not.

- Think about how they can better plan and deliver services.
- As health and care services work more closely together, this collaboration will feed into the Integrated Care Partnership for Leeds to improve people's experiences and in future, the Leeds Provider Partnership development.

For more information on this project, please visit our website

healthwatchleeds.co.uk/our-work/how-does-it-feel-for-me/ or

contact tatum@healthwatchleeds.co.uk

Background

Abdul Rahman Jalloh is a retired education officer and maths teacher originally from Sierra Leone. He lives in Harehills, North Leeds, with his wife. Abdul enjoys reading, helping children solve maths problems, and doing crosswords.

Abdul experienced a stroke in early 2024 and has since faced a series of health challenges, including being diagnosed with prostate cancer. He has received care across a range of settings – including Leeds General Infirmary (LGI), Chapel Allerton Rehabilitation Centre, St James's Hospital, and North Leeds Medical Centre. Throughout his journey, Abdul provided positive reflections on the services as well as the support he gets from his faith. Abdul wanted to take part in this project to give something back to the health and care system that has supported him and say thank you.

Themes and key messages

Below, we have summarised key themes arising from Abdul's journey. We start with the '3 Cs' - communication, compassion, and co-ordination - essential building blocks for good person-centred care, but also cover some other themes that come up in Abdul's experiences.

Communication

Abdul's experienced both good and poor communication. Abdul valued clear and caring communication in some of his experiences with staff at Leeds General Infirmary and St. James' Hospital, which significantly helped reduce his anxiety. He felt reassured when the staff explained things clearly.

"The care was very good. The information I got about my health was very good. They made me feel that I'm going to be okay."

He particularly appreciated this when he was diagnosed with cancer. He initially felt scared, but the information and the time taken to explain the treatment, the success rate, and that he was still able to carry out his religious activities made a great difference to his experience and recovery.

He also appreciated ongoing contact from the Stroke Group once he had been discharged.

“The Stroke Group have always wanted to know what was going on, and they wanted to advise me who to call, what to do... and that has been very nice.”

However, there were moments when he felt excluded from decisions about his own care. For example, at mealtimes, staff initially said “This is the way we serve it,” until he shared his preferences and they adapted.

“Well, after a while, they start to realise, if this person wants it this way, probably we should ask them... And within a short time, it just changed.”

On another occasion, Abdul received unclear communication, leading to confusion about the type of appointment and who the appointment was with. It created unnecessary stress for Abdul and his wife when they were already going through the stress of cancer treatment.

“I was supposed to be there for nine o’clock, only to get there and find out that, that nice o’clock appointment was actually a telephone appointment.”

“We went very early, with no breakfast, just wanting to be there, my wife and I. And it was not very comfortable.”

One idea that Abdul had was to receive a text reminder before an appointment to confirm the date, time and location/type of appointment. Despite the confusion, the service was able to adapt to make sure that Abdul was seen more quickly to minimise his distress, which Abdul greatly valued.

The methods that were used to provide Abdul with communication (text, letters, telephone) weren't always effective and created confusion for Abdul. Also, Abdul experienced a gap in communication about his cancer treatment, which greatly worried him. When Abdul couldn't get the information he needed, he felt his only option was to go to the Urology department in person despite the physical challenges he experienced to do this.

Abdul describes how it would be better and easier for him to understand if the information was coordinated and directly communicated by his GP, rather than receiving information from multiple places. Receiving information from multiple places at once can be overwhelming and confusing.

Coordination

Abdul's care involved several services, including the Neurology Department at Leeds General Infirmary, North Leeds Surgery and Community Rehabilitation teams. Abdul described where coordination had worked well with the same doctor across the hospital and rehabilitation setting.

“She always wanted to know what is happening, how am I improving.”

Abdul also described having a good experience of being discharged from hospital and being checked in on when at home before his referral to the Stroke support service.

He also, though highlighted highlighted how confusing it was to manage the multiple medications that he needed to take for his cancer and diabetes and when he tried to get the information that he needed to do this, he couldn't get it and impacted him. He also described a complex system of trying to get his regular prescription and how this involved needing to book an appointment, travel, and be seen face-to-face when he was already physically limited.

“You have to go in and talk to them before you can be given even the normal prescription.”

Abdul expressed wanting to know about the different ways he can order a prescription and receive his medication in a more simplified way, to avoid creating confusion, anxiety and physical stress.

“If it was possible for these prescriptions to be issued every month, that would help a lot and then, if there is a way of being delivered, because that has been my problem.”

Compassion

Abdul deeply appreciated the kindness and respect for his religious and cultural identity. This made Abdul feel valued as a person.

“I valued the way the nurses, the doctors cared about me as a patient, as an individual. For them to care about myself, my religion, and my culture was very, very impressive.”

He also shared how small moments of understanding can build trust between the person and the professional. Empathy and encouragement were important to his recovery, helping him regain confidence to do everyday tasks such as going up the stairs.

“Somebody to tell you that, believe that you won’t fall down. And I did it. I succeeded... It made me feel that this person is not only a professional. She has the empathy of the patient.”

Support for carers

Abdul lives with his wife, who had to assume the role of the main carer after he was discharged from hospital, providing constant support at home and helping with daily tasks. This was straining both physically, mentally and financially, with no support offered to her. She was vital to his recovery.

“Back home, the strains were getting heavier and heavier, especially with my wife, also retired like me, we are both struggling financially.”

Although some community services were helpful, for example, the Stroke Group arranging home adaptations like installing handrails, there was little mention of formal respite, emotional support, or financial assistance for his wife as a sudden unpaid carer. Abdul’s experience suggests that unpaid carers need to be recognised and be offered support from services. This could include advice, regular check-ins, and signposting to services that can ease both the emotional and financial strain.

His wife has been fundamental in his care since his stroke. He emphasised the importance of involving carers in communication because she was excluded from getting essential information.

“But then me, I am almost half disabled and most of the time, it’s my wife who does the giving me the medicines and the care. I think if the information that I’m given is also given to my wife and they speak to her, I think it will be better, because she, being the carer, knows more. Sometimes I forget to take my medicines... If more communication is done between the patient and the patient’s carer, it will make a big difference for the patient as well as the hospital.”

Financial Barriers

Financial difficulties were a significant concern for Abdul and his wife throughout his recovery and impacted his health.

“My body started getting very cold... If we had the means of buying gas and electricity on a regular basis, probably that would have made things different.”

The cost of travel and reduced benefits added stress to attending appointments and accessing care.

“Travelling for appointments can get expensive, especially when you need a carer with you”.

He also highlighted practical issues, like the end of winter fuel payments, which impacted their ability to manage everyday expenses.

“If there was clear advice about help with costs, that would take some pressure off.”

Cultural and religious awareness

Culture played a significant role throughout Abdul’s care. His religious practices and dietary requirements needed understanding and accommodation. Early on, he was supported to wash in a way that respected his religion.

“They suggested helping me. And they even got a male nurse to come and help me with it.”

When he struggled to be able to perform his prayers physically, the doctor showed empathy by advising him of alternative ways to pray.

“See, you can sit down on your bed and then just do your prayer.”

He also explained to the staff about the different ways in which different cultures eat.

“Not everybody, every black person eats food in the same way.”

He noted that some younger or less experienced staff could benefit from additional training on the diverse needs of the people they will support.

Abdul talked about the importance of his faith in his health and his life. His ability to carry out his religious activities brought positivity to his wellbeing.

Thank you

While Abdul highlights some of the challenges and areas for learning, he has been very grateful for the care he has received. Especially those who have really focused on having good information, caring about him as an individual and the excellent care across services.

“I had really do value the care and the information that I’m given by health professionals... The help that I’ve had from LGI, St Jame’s neurology department, and then this, the North Leeds Surgery and my local surgery. Have always been very helpful. I wonder what would have happened if I had not met these people.”

“The care that people put into saving other people’s lives is a very great thing.”

Abdul also expressed thanks to Healthwatch Leeds for information about carers support and the Stroke Association for all the support that they provided.

How this report should be used

The insights from this report should be used by all health and care organisations in Leeds as part of their ongoing Quality Improvement work. They should also be used by relevant key health and care boards and decision-making groups to inform their thinking. In addition, the reports will feed directly into the Leeds Health and Care Partnership, including the citywide Person-Centred Care Board, The Leeds Committee and the Health Inequalities Oversight Group amongst others.

Please do let us know by emailing tatum@healthwatchleeds.co.uk how you have used this report and any improvements it has prompted within your services or the wider system.

Questions for Leeds Health and Care Partnership

The Leeds Health and Care Partnership is made up of health and care organisations that work together and use their resources collectively to improve people's health and reduce inequalities by delivering joined-up person-centred care. We would like the Leeds Health and Care Partnership to consider the following questions:

1. How can we ensure that appointment systems work for people who are disabled, older, or digitally excluded?
2. How do you maintain continuity of care as a system when patients interact with multiple departments or services?

3. What mechanisms are in place to ensure that gaps in coordination are identified and addressed promptly?

Questions for individual organisations and front-line services

We would like health and care services to use this report and Abdul's videos within their teams as a learning and development tool. Below are a series of questions that could be used as conversation starters in conjunction with this report and Abdul's videos:

1. How do you ensure people and their carers are fully included in decisions about their care, especially when preferences may differ from standard procedures?
2. What steps could be taken to reduce confusion around appointment types, timings or methods of consultation?
3. How do you train staff to recognise and respond to a person's individual needs, including cultural and religious considerations?
4. How are empathy and encouragement embedded in everyday interactions with patients during recovery and rehabilitation?
5. How do you provide clear guidance on financial support, travel support or benefits for carers and patients?
6. What support and information could be introduced to help patients and carers manage their care?
7. How are individual differences within cultural groups recognised to avoid assumptions about patients' needs?

Appendix 1: Actions from Partners

Organisation	What actions have you taken, or will you take as a result? And where will you share the videos or updates?
Leeds Teaching Hospitals NHS Trust	<p>Videos have been shared with various services in the trust:</p> <ul style="list-style-type: none"> • Oncology CSU • Carers working group meeting • Neurosciences • Chapel Allerton CSUs • Medicines Management • Pharmacy CSU
Leeds and York Partnership Foundation NHS Trust	<p>Encourage staff to take time to learn about their service users other than their diagnosis to help provide personalised care.</p> <p>Encourage services to use the videos to learn and generate discussions.</p> <ul style="list-style-type: none"> • August 2025 service user network meeting
St Gemma's Hospice	<p>Shared with the team to see the importance of taking the time to understand what is important and maintaining contact with patients during their recovery so they don't feel abandoned. They will consider how they communicate with patients and the importance of speaking to carers.</p>
Carers Leeds	<p>Videos have been shared with the Carers Leeds team as a learning and reflection tool.</p>
Other places the videos have been shared	<ul style="list-style-type: none"> • Leeds Integrated Care Board August 2025 Staff Bulletin. • The Leeds Finance Sub Committee.

Appendix 2: Index of Abdul's updates

All Abdul's updates are available at <https://healthwatchleeds.co.uk/how-does-it-feel-for-me-abdul/>

Video/update title and link	Summary of content
<p>Intro – Oct 2024 (2.3mins) YouTube link - https://youtu.be/e8ixInQvLMo</p>	<p>Abdul is a retired education officer and a maths teacher. He was originally from Sierra Leone and now lives in Harehills, Leeds with his wife.</p> <p>He loves reading and enjoy helping children solve maths problems.</p> <p>After a stroke last year, Abdul shared his experience of being in the hospital and the care he receives afterward. He found it made a big difference when staff understood his cultural and religious needs.</p>
<p>October 2024 (5.1 mins) https://youtu.be/FT4kl6XpqTw</p>	<p>Abdul had a very positive experience at both LGI and Chapel Allerton hospitals. He valued how the nurses and the doctors “cared about” him as an individual, especially respecting his religion and culture needs.</p> <p>He suggested the staff, particularly for the young staff, could benefit from involving patients with real life experience. This approach would help staff understand that the best way to</p>

Video/update title and link	Summary of content
	meet diverse needs is to ask the patient themselves.
<p>November 2024 – (7 mins)</p> <p>https://youtu.be/o0swlnBeVbY</p>	<p>This video shares the powerful story of Abdul navigating life after a stroke while undergoing prostate cancer treatment. With his wife as his full-time carer, he opens up about the daily challenges they face, from mobility struggles to financial difficulties and gaps in healthcare communication.</p> <p>He highlights the need for better support for carers, improved access to medication, and clearer medical guidance. Despite these hardships, he expresses deep appreciation for the care he has received and advocates for a more patient-centred approach in the healthcare system.</p> <p>His story offers a personal insight into the realities of long-term illness and the importance of compassionate support.</p>
<p>February 2025 Update (11 mins)</p> <p>https://youtu.be/O2n1mZhoLkg</p>	<p>This video shares the story of Abdul’s cancer treatment and their confusion and distress due to unclear communication about appointment details, arriving for an in-person session when that was actually a phone call.</p> <p>Abdul talks about last minute changes causing unnecessary stress, especially</p>

Video/update title and link	Summary of content
	<p>due to their mobility and treatment, relying on his wife for support.</p> <p>He highlights the need for better, more inclusive and direct communication preferably via phone or text as well as to involve carers like his wife in medical updates, as she helps Abdul to manage his care and medication.</p> <p>His update emphasises that despite initial fears about cancer, he felt reassured by the treatment and care he received from staff. He praised healthcare staff for their dedication and encouraged new workers to take pride in their life-saving roles.</p>
<p>Evaluation (2 mins)</p> <p>https://youtu.be/1EEUrpNMJFo</p>	<p>Abdul shares his thoughts on what has gone well being part of the HDIFFM project and his ideas for how it could be made better.</p>