

HOW DOES IT FEEL FOR ME?



Mercy's summary report



Context

Healthwatch Leeds follows the experiences of people who have multiple health conditions and use different health and care services on a regular basis. 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 following real-time journeys, there are three additional components 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, 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 helps these organisations to:

- Understand what people experience as they move through 'the system'.
- Identify what is working and what is not.
- Think about how they can plan and deliver services better.

As health and care services work together more and feed directly into the Integrated Care Partnership for Leeds people will experience improved care.

For more information on this project, please visit our website

<https://healthwatchleeds.co.uk/our-work/how-does-it-feel-for-me/> or

contact harriet@healthwatchleeds.co.uk

Background

Mercy lives in Chapeltown but is originally from Zimbabwe. She describes herself as a people person and loves knitting and crochet. She has cataracts and dry macular degeneration which massively affects her sight. Mercy wanted to take part in the project to help raise awareness of the difficulties that older people and people like her, with sight loss have in accessing services.

We followed Mercy's journey between November 2023 and May 2024 in a series of filmed updates.

Themes and key messages

We have summarised some of the key themes from Mercy's experiences. We start with the '3 Cs' – communication, compassion, and coordination – essential building blocks for good person-centred care. We have also summarised further themes that came up in her interactions with health and care services.

Communication

Mercy's videos cover several aspects of the theme 'communication':

- Being kept informed.
- Importance of information being clear and jargon-free.
- Meeting Mercy's communication needs in line with the Accessible Information Standard.

Being kept informed

In several of Mercy's videos, she describes not receiving timely information that is needed for her to understand treatment options and next steps regarding her eye conditions.

"I wanted to know what help I could get with the cataracts to be removed or anything, but I didn't get any explanation, and I had to go home, and I went to Feel Good Factor where I got a lady who was willing to help me with the information because she has gone through a similar situation of having cataracts and having them to be removed." (November 2023)

She also mentions being referred to a private clinic by Vision Express where she is told by a specialist that she needs to push to get her cataracts removed as soon as possible. The specialist also registers her blind and tells her that this should have been done by the eye clinic when she was first diagnosed with partial sight (November 2023).

On returning to the eye clinic, she is told that removing her cataracts won't make any difference to her vision. These mixed messages are confusing and disappointing for Mercy who says that it makes her lose trust in the system and is a deterrent to continue accessing services (May 2024).

"I was reassured by the lady who saw me at the private place, and I had all the confidence that they were going to do something... but then they [the eye clinic] were just negative, like your eyes are already damaged so there is no need to remove the cataracts." (May 2024)

"Thinking of all that has happened, I can't really be bothered. I'd rather just keep myself to myself in my house and whatever happens, it happens." (May 2024)

Clear information

Mercy is confused about her discharge from the podiatry service, having previously received routine nail care which she understood was because of her vision loss. The reason for this change in service does not appear to have been made clear to Mercy who feels she is given options, none of which she wants to pursue such as going private or having some toenails removed.

"Due to my condition, being severely partially sighted, I expected my toes to be continually looked into by the podiatry, but then the last time I went to see them down Chapelton there, it's like they just said, "We are discharging you. Either you go private, or you just stay, or if you want, we

can book you down for an operation and we can remove your big toenails.” (February 2023)

Mercy’s experience trying to find the eye clinic at Seacroft Hospital highlights the need for people to have good clear information both prior to the appointment and on arrival on how to navigate their way to the relevant clinic. It is particularly important that any information is accessible to people with visual impairments.

“With the ophthalmology they referred me to Seacroft hospital, and it took me about 15 minutes to find the place.” (February 2024)

Accessible Information Standard and digital access.

Mercy’s videos highlight the impact on her of services not adhering to the Accessible Information Standard. She explains that this is one of the reasons that she decided to change her GP surgery.

“They don’t write to me in large prints. All my letters come in small prints, and I’ve got to find someone from one of the groups to come and read that for me. With the old surgery I asked for the large prints, and I never got any until the time I switched off from them.” (Communication and cultural needs, November 2023)

However, things did not improve with the new GP surgery where she describes additional barriers she faces from the requirement to use digital systems:

“Everything has gone digital, which is very difficult for me irregardless of the issues of my eye problems. I have no experience with IT... I’ve got to do this form filling on my phone which is very complicated, and I can’t do it and I haven’t got a smart phone that can do me that thing that they want me to do, so it’s quite difficult.” (Communication and cultural needs, November 2023)

“It's via text messages, which is so complicated for me... It's like the words are so small and I haven't got a bigger phone to change them to be big, and I don't know how to do it. I don't like receiving the appointments through my phone because I've got to log in and put in my date of birth, my telephone number of which it's so difficult for me... I have to probably try it 6, 7, 8 times and at times it doesn't even work.” (Experience of accessing services, February 2024)

She expresses frustration about how services have become more difficult for her to access since Covid because of the increase in the use of digital systems. These have resulted in a loss of independence for her because she has to rely on others, such as third sector organisations for help in accessing online platforms and reading correspondence that doesn't meet her communication needs.

“It's like everything just started in the period of the Covid. That the GP's were not seeing anyone, and things just started to become so complicated, and it's like after that they started introducing the online

bookings and everything has to be done online. You can do your blood tests online, you can do this online, which is so complicated for me because I can't do anything like that by myself.” (Experience of accessing services, February 2024)

Mercy is concerned about the impact on other people with sight loss as well as older people who do not have digital access or good levels of digital literacy.

“I think the old system needs just to be left in place for people like me and people like the elderly people who cannot access Internet or mobile phones or smartphones.” (Introduction, October 2023)

Coordination

Mercy's experience at the eye clinic makes her feel as if professionals are just focusing on one condition rather than looking at all her conditions together.

“She just said, “I'm taking you to this room, I need to do some scanning, and then we'll go to another room. We'll do some X-rays”, I said that's fine and then after she finished the last bit, I had to ask her to say, “What about my cataracts? Because I've been advised from the private place that I had to get my cataracts removed.” And this person... had no idea

of what I was talking about because all she was concentrating on was my dry macular degeneration and not the cataracts.” (February 2024)

Throughout the videos, Mercy expresses frustration about her struggles in navigating care pathways, something that is made even more difficult by her sight loss. She says she would really value having someone who could help with coordination of services rather than her having to rely on third sector organisations.

“I would prefer to have someone who is medically professional to talk to and who can communicate with all the areas where I need to get the help from. Rather than to start thinking that I have to go to Feel Good Factor or to go to BID* to ask and find out what to do, who to go to and things like that.” (February 2024)

*BID services is a third sector organisation that provides support for people with visual and/or hearing impairments.

A particular challenge for Mercy is trying to access her GP. Trying to get an appointment can be difficult.

“It’s very hard when you phone them for an appointment, because at times you don’t even get an answer, or at times they answer you and they will say there is no appointment.” (Communication and cultural needs, November 2023)

Also, she finds being sent to see different professionals confusing and unhelpful. In May 2024, she describes being sent to see the pharmacist which she doesn't find helpful and in February 2024, she describes not expecting to see a paramedic when she visited her surgery for what she thought was an appointment with a doctor.

“I just feel baffled because I didn't expect to be seen by a paramedic... I was expecting a female doctor, not a male person... It seemed like he wasn't very certain of what to do because he was like, “I need to consult someone else in regards to your condition”, so I felt like, why did I really come to see him?”” (February 2024)

She talks about a different occasion when she was sent to the walk-in clinic because there were no appointments left with her GP (February 2024). Because of a previous bad experience of the walk-in clinic, she decides to stay at home. Off camera, she explained that her bad experience involved being turned away when she had tried to access the walk-in clinic in the past, possibly because she tried to access the GP surgery next to the walk-in clinic by mistake. Again, this highlights the additional practical navigation barriers faced by people with sight loss and the need for better communication.

Mercy comes from a generation where in the past she would have seen her doctor for most things. The move to triaging patients to different health professionals is a big culture change and there is a need for good

and sensitive communication around this, recognising the potential mistrust in the ability of other health professionals to be as good as doctors. Mercy's experiences also show that without good communication around these changes, people can feel anger and resentment towards receptionists who can be perceived as gatekeepers.

"I thought I needed to be seen by a GP. I just found it really weird because each time I ring for an appointment, I'm given a negative attitude with the receptionist. I feel annoyed. I feel angry because it's like, I know it's not their duty to tell me that, rather I would prefer they say, "OK, the doctor will call you"." (May 2024)

Again, we see Mercy expressing frustration and distrust with the system that make her want to give up accessing it.

"I was told it was a wrong machine, not by the GP, but by the receptionist. It actually made me feel confused, like, 'What am I doing here? What am I coming for here?'" (May 2024)

Compassion

Mercy gives one example of when she receives compassionate care from her dentist (May 2024). She stated that she really valued how her dentist was "so gentle" with her and that he told her to come back if there were any problems.

Support from third sector organisations

“It's like I can only say I've received better help from Feel Good Factor and BID. And with the GP's I've not got anything. Ophthalmology, I've not got anything, so yeah.” (February 2024)

Mercy speaks highly of two third sector organisations she receives support from – BID services who provide support for people with visual and/or hearing impairments; and Feel Good Factor, a community organisation that supports people to improve their health and wellbeing. Mercy describes how Feel Good Factor, which is located very close to her home, has helped her to access her GP when she has faced difficulties, and also help her understand information that is sent to her in inaccessible formats.

“I've managed to get so much help especially through the GPs, because even with the GP they did have someone who worked at Feel Good Factor who was hand in hand with the [GP] practice and each time I needed anything that was concerning her she would just take me there and then. So, Feel Good Factor has been good for me.” (November 2023)

However, despite the help and support that they provide, Mercy finds it disempowering and does not like having to share her personal information with third sector organisations.

“I would really want to be heard... For me to be heard, I’ve got to go through other people which are charity organisations, of which at times, this is my personal thing which I don’t want to share with anybody, but I have no choice,” (Communication and cultural needs, November 2023)

Health inequalities

Mercy’s is a good example of the impact health inequalities can have on someone. At the time of filming, Mercy is aged 52 and has already experienced poor health for a number of years. On top of her eye conditions, she has also had multiple strokes and survived a brain haemorrhage. She has a strong family history of both these conditions with all seven of her siblings having died from either a stroke or brain haemorrhage, and her mother passed away in 2020 following two strokes. She is from a migrant community and lives in Chapeltown, an area of social injustice, both factors related to health inequalities. We also know from Mercy sharing her experiences, of the multiple difficulties she regularly has in accessing services as well as poor experiences of coordination and communication. She repeatedly says that these experiences make her want to give up trying to continue accessing services.

In the winter she talks about the impact the cost of living is having on her health and wellbeing and how it contributes to her feeling socially isolated.

“I can hardly turn on my central heating because of the energy prices, and I feel I cannot afford to be paying over two hundred pounds for a gas bill. So, I would rather spend the whole day in my bed in blanket just getting myself cosy and warm, but at the same time It’s a stressful situation because I’ve never been a sleeping person. I’ve been an outgoing person and a socialising person, and my socialisation has been cut down completely now.” (November 2023)

She also describes how her care options are limited when it is suggested that she access a private podiatrist to do the nail care that the podiatry service had previously provided.

“I’m not like a rich person. I can’t go private and it’s quite expensive.” (February 2024)

Involvement of the person receiving care

One of the recurring themes from Mercy’s videos is that she just wants to be heard. When she is discharged from podiatry, there is a sense that she is being ‘done to’ and she doesn’t feel at all involved.

“I was just given like an option that – ‘take or leave’, that kind of an option. It wasn’t like, “We’ll call you back and maybe talk to you and see how you think about this decision.”” (February 2024)

Mercy also talks about how she feels that services do not take her culture and background into consideration and would like people to ask her more questions about herself to help them to understand her cultural needs

“It’s nowhere that the cultural needs have been met or shown or anything done, so it’s like, I’m just in everybody’s category... it’s just a bowl with everyone in that one bowl, which is just so difficult because I know they’re not aware of my background.” (Communication and cultural needs, November 2023).

How this report should be used

The insights from this report should be used by health and care organisations in Leeds as part of their ongoing Quality Improvement work. The insights should also be used by relevant Population Boards to inform discussions and decisions. In addition, the reports will feed directly into the Leeds Health and Care Partnership, including the citywide Person-Centred Care Board and the Quality and People’s Experiences Committee.

If you use this report to prompt any improvements in your organisation or the wider health and care system, please let us know by contacting harriet@healthwatchleeds.co.uk. This enables us to track impact as well as feeding back to participants the differences they are helping to make.

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. At a system level, what needs to happen differently for all our services to co-ordinate well?
2. What do Mercy' experiences tell us about the importance of having a culture of compassionate care, and how can we ensure that this is consistent across the system?
3. What do we need to do as a system to improve communication so that people like Mercy will always have a good quality experience and good outcomes?
4. How might Mercy's experiences have been different if services had been operating to the principles of an integrated care model – i.e., co-designed, jointly commissioned and delivered in partnership to achieve shared outcomes?
5. How can Leeds Health and Care Partnership consider the direct and wider impacts of service cuts on people, particularly the risk of people being financially excluded from accessing essential health and care?

Questions for individual organisations and Population Boards:

We would like health and care services to use this report and the associated 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 alongside the video updates:

1. What can your service do to make adjustments to improve access for people with communication needs and who face barriers to accessing things digitally?
2. What can you do to consider the impact on specific communities at risk of digital exclusion, of any changes you make in your services involving digital?
3. What can your service do to ensure clear and timely communication to service users and the public when there is a service change or tightening up of eligibility criteria that impacts who can access a service?
4. What can primary care do to improve awareness that there are different professionals people may be signposted to when accessing their GP practice, recognising that this will be a big culture change for some people?

5. How can you work with others to improve the experience and access to your services for people who are experiencing health inequalities to reduce the risk of them disengaging?
6. What would your services need to do differently to make sure Mercy always felt like she was heard?

Appendix 1: Actions from Partners

Organisation	What actions have you taken as a result and where will you share the updates?
Age UK	Videos will be shared with staff as part of a programme of practice reflection that has been initiated.
St Gemma's Hospice	<p>Share through the Involve group that brings together all the hospice's patient and public involvement work with staff inclusion work.</p> <p>Consider how St Gemma's patients might be excluded due to digital literacy/access.</p> <p>Nov 2023 updates – shared with the staff team as a good example of poor practice in relation to the Accessible Information Standard and the impact it can have, as well as reminding staff of culture and accessibility issues.</p>
Leeds Community Healthcare NHS Trust (LCH)	<p>Videos will be shared with:</p> <ul style="list-style-type: none"> • Clinical/Quality Leads to be shared within services/teams. • The LCH services referred to within them directly with an ask to review and consider where improvements can be made/feedback to share. • Trust Boards meetings where appropriate as part of the Patient Story agenda item. <p>Specific actions taken in relation to the following videos:</p>

	<ul style="list-style-type: none"> • Feb 2024 – In June 2024 the Clinical Lead for the Podiatry service contacted Mercy to clarify what they can and cannot provide and the reasons why.
Carers Leeds	<ul style="list-style-type: none"> • All videos will be shared with the Carers Leeds team.
Leeds Teaching Hospitals NHS Trust (LTHT)	<p>Videos have been shared with the following:</p> <ul style="list-style-type: none"> • Intro (Oct 2023) and Communication and Cultural needs (Nov 2023) – shared with the ‘Patient Hub’ (online platform for patients to manage their appointments)- LTHT have just launched a flag on their electronic record system to identify patients who can’t engage digitally, so hopefully this will increase the recording of patients’ access needs. Possibility of ‘Patient Hub’ team publicising the ‘opt out’ from the online appointment system more widely so patients are aware is being discussed. • ‘Communication and cultural needs’ and ‘Experience of accessing services’ videos shared with LTHT staff to raise awareness of the Accessible Information Standard (AIS) and increase the number of patient-facing staff accessing AIS training. • Intro and Nov 2023 videos shared with and Head and Neck Clinical Service Unit (CSU) – Ophthalmology who shared the videos with their Speciality Quality Forum. Lack of information and registration was recognised as an issue. As a result a new Eye Clinic Liaison Officer role now sees newly diagnosed patients and role is expected to result in improvement. Planned new process for low complexity cataract service, which involves

	<p>providing information at pre-assessment, is also expected to help once launched.</p> <ul style="list-style-type: none"> • Nov 2023 'cultural and communication needs' and Feb 2023 'experience of accessing services' videos to be shared at event: 'Reducing missed appointments with a focus on inequalities'. This event will have a real focus on patient voices, particularly from communities at high risk of health inequalities. We want to ensure that the solutions being developed by teams at Leeds Teaching Hospitals Trust, Leeds Community Healthcare and Leeds and York Partnership Foundation Trust and primary care, have really thought through these with patients in mind from initial communication to patient experience at the hospital. The event will also be showcasing good practise around reducing missed appointments as well as providing space for action planning improvement activities. • 'Communication and cultural needs' video shared with LTHT Equality Diversity and Inclusion Manager. • Feb 2024 update – shared during the trust launch of the 3Cs as a reminder of the importance of communication and co-ordination for people. • May 2024 update shared with Head and Neck Clinical Service Unit. • All videos – the Patient Experience Team will continue to communicate the need to ensure that patients shouldn't be disadvantaged because they can't use technology.
<p>Leeds Integrated</p>	<p>All videos have been circulated to all GP practices and other primary care services via the Primary care Bulletin. Also shared with the Primary care team who</p>

<p>Care Board (ICB)</p>	<p>are supporting GP practices around the issue of living with and working with patients with sensory impairment.</p> <p>The Primary Care Network (PCN) Manager has contacted Mercy to address her needs and the issues raised. Next steps by her GP Practice include:</p> <ul style="list-style-type: none"> ○ Adding relevant notes, alerts and pop-ups to the patient’s clinical record, in terms of AIS needs and Reasonable Adjustments ○ Invite Mercy into the Practice for their coffee morning for an in-person conversation and engagement, to address issues raised ○ Offer Mercy a dedicated Health & Wellbeing Coach ○ Continuing Cultural Competency training with the PCN ○ Encouraging Practices within the PCN to complete the Accessible Information Standard good practice self-assessment exercise again to identify and close any gaps.
<p>Leeds City Council Adults and Health</p>	<p>Nov 2023 update – shared with Head of Public Health Localities & Primary Care regarding cost-of-living impacts.</p>
<p>Leeds and York Partnership Foundation Trust (LYPFT)</p>	<p>‘Experience of accessing services’ video shared with Head of Health Equity as it would be helpful as a training resource to remind staff that they need to be asking for and importantly recording people’s communication preferences and highlight the impact on people of not doing so.</p>
<p>Other places the videos</p>	<p>Videos have been shown and discussed at the following groups:</p>

<p>have been shared.</p>	<ul style="list-style-type: none">• Leeds Integrated Care Board Finance and Quality and People's Experience committee meetings (April 2024)• Leeds Committee of the West Yorkshire Integrated Care Board (May 2024)• WY ICB Board Informal Briefing on health inequalities (June 2024)• Primary care population board (June 2024)• Reducing missed appointments: Inclusion for all good practice event with LTHT, LCH and LYPFT (July 2024)
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Appendix 2: Index of Mercy's updates

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

Update title and link	Summary of content
<p>Intro – Oct 2023 (3 mins)</p> <p>https://youtu.be/nddTRQuZ8K8?si=KfvF_k2DRFqSQQVr</p>	<ul style="list-style-type: none"> • Mercy lives in Chapeltown but is originally from Zimbabwe. • Is friendly and 'a people person', likes knitting and crochet. • Recently diagnosed with cataracts, also has tri-macular degeneration which massively affects her sight. • Issues with having to book appointments digitally which presents problems for elderly and people with sight loss.
<p>Nov 2023 update (5.5 mins)</p> <p>https://youtu.be/KD9Fpl-Blsw</p>	<ul style="list-style-type: none"> • Diagnosis of cataracts at St James Hospital. Didn't get any information, had to ask someone from Feel Good Factor for information. • Sight still bad, went to Vision Express and they referred her to a private mobile hospital in Bradford where she's been twice in last month. Told Mercy that she is severely sight impaired and told her she should have been registered blind when first diagnosed. • Feel Good Factor (third sector organisation) – local and convenient, got a lot of help including with the GP.

Update title and link	Summary of content
	<ul style="list-style-type: none"> • Energy prices make quality of life difficult. Doesn't put heating on and stays in bed to keep warm. Knock on effect is that it reduces how much she socialises, which is something she needs.
<p>Nov 2023 – cultural and communication needs (4 mins)</p> <p>https://youtu.be/S7T6LXNFgGU</p>	<ul style="list-style-type: none"> • Having to make appointments digitally is difficult with visual impairment and no experience with IT. • Has to go through BID (third sector organisation) if wants to make an appointment with eye clinic (referred to BID through Feel Good Factor) • All appointment letters etc come in small print and then is reliant on people from third sector groups to help her read them. • Things still same at new GP surgery, asked to fill in online forms, doesn't have a smartphone which makes it difficult. • Doesn't feel services are aware of cultural needs and background. Would like services to ask her about them and she'd be happy to answer. • Wants voice to be heard. For her to be heard has to go through charity organisations and doesn't always feel comfortable sharing her personal information with them but has no choice.
<p>Feb 2024 update (7 minutes)</p>	<ul style="list-style-type: none"> • GP had no appointments, so they told her to go to the walk-in clinic where she's had a bad experience so didn't go. They then referred her to

Update title and link	Summary of content
<p>https://youtu.be/19b3gi9u3Es</p>	<p>the pharmacy, but she needed to see a GP not a pharmacist.</p> <ul style="list-style-type: none"> • Podiatry – no longer cut toenails – given option to go private or be referred to get toenail removed. She can't afford to go private. • Ophthalmology - only concentrating on one condition and not considering cataracts. • She wants someone who is a medical professional to talk to who can communicate all the areas where she needs help rather than her having to feel like she must seek support via Feel Good Factor or BID (third sector organisations).
<p>Feb 2024 – experience of accessing services (3 minutes)</p> <p>https://youtu.be/zEiCnCKTL E4</p>	<ul style="list-style-type: none"> • Having to make bookings or fill in forms online is difficult due to visual impairments. • Struggles to log in and remember her details to book appointments and when she tries it doesn't work and needs to find someone to help which isn't always possible.
<p>May 2024 update (6.5 mins)</p>	<ul style="list-style-type: none"> • Experience of trying to access GP and being signposted to pharmacy. Feels that experience with receptionist is negative.

Update title and link	Summary of content
https://youtu.be/CN3nAVYBhIU	<ul style="list-style-type: none"> • Would prefer to just be able to see the GP not going via receptionist. Finds whole process confusing. • Confused and disappointed by mixed messages about cataracts from private clinic in Bradford and Leeds Teaching Hospitals Trust eye clinic. Experience puts her off from accessing services. • Good experience at dentist – quick, compassionate, and good communication. • Would like it to be easier to access appointments with a GP like it used to be. Feels like there’s lots of barriers now to access.
<p>Evaluation (3.5 mins)</p> https://youtu.be/4-RO0HKGQa0	<ul style="list-style-type: none"> • Mercy shares her thoughts on what has gone well being part of the HDIFFM project and her ideas for how it could be made better.