

HOW DOES IT FEEL FOR me?



Kari's story summary report

Context

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: case note reviews, understanding what citywide complaints tell us, and developing a set of metrics that will be used to measure joined up health and care services. The project involves all health and care partners, including representatives from 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. It is designed to support them to understand what people's experiences are like as they move through 'the system'; identify what is working and what is not; and to think about how they can plan and deliver services better. Increasingly, as health and care services work more and more in partnership, this work will feed into the development of the Integrated Care Partnership for Leeds.

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

Kari is 60 years old. She describes herself as a straight-talking poet who 'tells it as it is' and lives in Middleton. She has various health conditions including Chronic Obstructive Pulmonary Disorder and heart failure which often mean she spends periods of time in and out of hospital. She also has a Bipolar diagnosis. Her conditions mean that it is difficult for her to get out as much as she'd like, which can feel isolating and frustrating. She tells us about her good experiences and also what she thinks can be improved, some of it in the form of her brilliant poetry. She wanted to take part in the project as she wanted to be the voice for people who don't have one.

We followed Kari's journey between July and December 2019, and then again between August and November 2021. Updates were a combination of filmed updates and written updates transcribed from recorded conversations.

Themes and key messages

Good communication with service users

Like other participants in the 'How does it feel for me?' videos, Kari's experience of how professionals communicate with her is variable. Sometimes it is really good, such as with her community matron, whilst at other times it is sorely lacking, leaving Kari feeling let down, depressed and at times angry.

She describes how her community matron listens to her, is open with her and calls her back if he can't answer the phone:

"You never feel like he's in a rush. He probably is but he doesn't make you feel rushed." (September 2019)

She also alludes to sensitive and empowering conversations with her social worker about her housing options

"We're communicating and that's good. We're all on the same page at last." (September 2021).

In August 2019, she felt let down by the heart failure team who promised home visits following a discharge from hospital and then didn't deliver or follow up to explain why.

"I felt dumped, that was cruel. They shouldn't tell you a load of stuff while you're in hospital knowing they're not even going to see you at home. Who benefits from that? I don't." (August 2019)

Kari gives several other examples of where care hasn't gone according to plan such as home carers repeatedly not turning up (September 2021), or visits from the community matron stopping during the pandemic (August 2021). When there are problems such as these, Kari just wants to be kept in the loop. She calls it a 'courtesy call' to explain what is happening and she describes how it feels for her when this doesn't happen:

"As long as someone will tell me what's happening, I'll work around them... [If not] it leaves me sat here on my own, depressed, thinking 'I'm too bad. I've done something wrong'. Old feelings coming back... I felt used and abused again and that made me angry." (August 2021)

In the case of her home care, the impact of unreliability and lack of communication meant that Kari cancelled the care provider, even though by her own admission she probably needed the care.

Co-ordination of care

Kari's experiences highlight how important the consistency and co-ordination of care by a Community Matron can provide reassurance and support for patients, and also help relieve pressure from family carers and other GP services.

"It was great because I could ring him, it stopped my hospital admissions, [and] it must have given the GP a rest. It couldn't have been good, and the costs for them." (July 2019)

She describes how her community matron can prescribe medications (September 2019) and ensure that she has appropriate access to treatment, for example by enabling her to bypass A&E during an admission to hospital (July 2019).

It is clear Kari relies heavily on her community matron who she knows can help keep her out of hospital. On one occasion, his actions probably saved her life when he found her unconscious on the floor during a routine visit. She says, *"I could have been there days,*

so that's how important his role is.” (November 2019). Her reliance on this role means that when he is not there, it has an impact. She recounts one time when he went on holiday, and she ends up being admitted to hospital (August 2019). And she also feels very isolated and “off the radar” when his visits stop for a period during the pandemic (August 2021), highlighting the vital role community health professionals play in reducing isolation.

Person-centred care - understanding Kari's needs and wishes

“I felt very much included... [it] makes you feel good, you're part of it, you've been acknowledged.” (November 2021)

Good person-centred care for Kari is when professionals really listen to her and take on board what is important to her. It is also about keeping her informed, and not making assumptions about her. Good person-centred care makes her feel validated, like she's a person rather than a diagnoses or just another patient. When care isn't person-centred, it can have the opposite effect of making her feel like she doesn't matter. For Kari, compassion and good communication are integral parts of person-centred care.

Kari gives some good examples of when care feels person-centred:

- When the stroke team involves her family and works towards her personal goals. (December 2019)
- When she describes how one carer knew that she liked drinking Lucozade but that she found it difficult to remove the lids. The carer would take off the lids from a few bottles and leave them lined up in the fridge for her. Kari says: *“Little things like that that mean more than the shower even sometimes.”* (September 2021)
- The move to assisted living is an excellent example of person centred and co-ordinated care and is clearly a positive experience for Kari who feels included throughout the whole process by her social worker. (November 2021)
- When the manager of the assisted living offers Kari accommodation that has good flooring in as she recognises Kari is on a tight budget. (November 2021)

There are also times when things are not so good:

- She explains how she feels like she is treated differently when her blood results come back normal in hospital, but she's still very poorly. *“They're not interested. You're hurried up, it's like a conveyor belt.”* (July 2019)
- When she gets the Age UK Hospital to Home service which she thinks is given to her because they assume she is older than she is (58). *“They thought I was a pensioner”* (July 2019)
- When she is really struggling with her mental health following her stroke and is told that it's very common to feel low after a stroke, and she says, *“Yeah it might be, but then there's me on top of that”* (December 2019)

Involvement of family carers

Kari gives an example of where she really valued her children being involved in the plans for her care, but implies that this isn't the norm:

“On the rehabilitation ward, they work as a team, but they include the family. They said, ‘We want a meeting with the kids.’ And I was really impressed, nobody’s ever done that... And we had this meeting, and you could ask questions or whatever. They were included in my care after, when I got home and everything, which I thought was very, very good.” (November 2019)

Importance of compassionate care

“I couldn’t believe that two different departments, all part of the NHS could be so different when they’re all in one.” (July 2019)

Kari has variable experiences of care, giving examples of both compassionate care as well as times when the way she has been treated has made her feel degraded and worthless. An example of this is her experiences of how she is treated when professionals realise that she has a palliative diagnosis. She describes one time where she sees an instant negative change in a paramedic’s attitude when he realises she has a DNAR (Do Not Attempt Resuscitation) in place. She says this “isn’t the first time” this kind of thing has happened, and describes how it affects her trust in services.

“It was like whatever bit of dignity I had left they’d wiped away. I wasn’t a person, I was nothing, I was a DNR form, and I didn’t even want to go to hospital because I thought that at the other end I’d get the same attitude.” (July 2019)

Conversely, she also has good experiences with hospital staff and the contrast in how it makes her feel is stark.

“The consultant said, ‘Don’t you worry, I will respect your DNAR form. Just because we can’t resuscitate doesn’t mean there’s not a lot we can do’... they listened a bit longer, were extra caring and you felt it.” (August 2019)

Interplay of physical and mental health

Kari has both mental and physical long-term health conditions, and it is very clear that they both affect each other.

“At times if I’m really bad I’m housebound, and I’m a people person so it effects my mood. I can get quite low which triggers off everything else. It’s a vicious circle.” (July 2019)

An example of this is following her stroke (Dec 2019) when she talks about the significant impact it’s had on her mental health. She doesn’t feel that the impact on her as a person with bipolar is really understood, or that there is enough immediate specialist support available.

Impact of Covid

“I never felt so lonely. Lonely enough to accept any care, good or bad, because it was an adult conversation.” (August 2021)

Kari's feelings of isolation from living alone and being housebound are exacerbated during the course of the pandemic. Not only was she cut off from family and support networks such as her church, but she also describes the impact of reduced in person contact with health professionals. For Kari, an important element of visits from health professionals is just to have human contact, and the lack of this really compounds her isolation. This is particularly the case with her community matron who was so responsive pre-pandemic.

The move to digital

"It's leaving me behind. I might be able to write but I'm very slow with technology and digital. My grandkids have to teach me, and it makes you isolated, it's awful." (August 2021)

Kari understands the need for remote contact during the pandemic, but her experiences act as a reminder for the system that virtual and telephone appointments are not accessible for everyone. There is a danger of excluding people, some of whom may already be vulnerable and isolated.

For Kari, face-to-face appointments are about having personal human contact which massively affects the quality of her experience. On her experience of phone appointments, she says:

"I know it was some communication, but they couldn't see you. You know, they could say, 'How are you today?' and I could say, 'Oh I'm fine', and be crying my eyes out. And they'd think, 'Oh you're fine.' Tick a box. (August 2021)

In November 2021, Kari got a call from her GP to say that that she needed to "go online to sort the eye thing out." despite her lack of digital access. This was a breach of the Accessible Information Standard where health services should be asking about, recording and acting on communication preferences. It highlights the need for different ways to access services as well as ensuring digital support where no alternative to digital is available.

Poverty

Kari talks about how poverty affects her access to health and care services. On more than one occasion she talks about the cost of home care: *"I do need more but I can only afford two and a half hours a week."* (September 2019). She also mentions not having enough money to get a taxi to see her GP (July 2019). Kari wrote the poem below after one of her stays in hospital where she says she turned up *"as a very smelly person."* It's about the difficult daily choices people living in poverty have to make, that in turn affect their health and wellbeing.

At What Cost by Kari Thomason

"Take more care of yourself
Please take care..."
How could she do that
With little money to spare?
She could get help to shower
Seven days a week
That would leave her
With very little to eat
If she cut it down to three
With incontinence
She would indeed smell
At least it would put
More tins on the shelves
She could get help to dress
Seven days a week
Or live in her night clothes
Facing more defeat
She could add an extra jumper
When her electric is low
Almost on emergency
Almost only five more days to go
She could end up in hospital
Taking up a much-needed bed
Because they have decided

She must pay for her own CARE instead
She has worked most of her life
Not hard to understand
A smoker, self inflicted
Her illness due to her own hand
She hopes her words
Will indeed reach all
Don't be so quick
When making a judgment call
Please don't judge a person's
Poor hygiene
Why in dirty clothes are they dressed
Why they may look angry
Sad or depressed?
Those that are riddled with debt
Not always their doing
Would be a safe bet
Taking away their dignity
Would be just too much to bear
All because they didn't have
Enough money
To pay for their CARE
Her job title.....A CARER

Experience of discharge

During the time we followed Kari's journey, she has some more positive experiences of discharge than she has experienced in the past. She refers to past "soul destroying" waits for medication and patient transport, and the resulting stress that this causes.

- In July 2019, she benefits from the "amazing" Age UK 'The Hospital to Home Service' who helped her get shopping in and settle her back home.
- In August 2019, she talks about the discharge lounge and that although she had to wait 4 hours, the food and drink provided, having a TV and other people to chat to "made the wait bearable".
- In December 2019, she praises how the pharmacist came the day before discharge to order her medication and then on the day of discharge, because it looked like there was still going to be a wait, she was discharged, and a taxi was arranged to deliver her medication later on.

"It was a couple of hours I was waiting each time, maybe less because I just had to wait for the transport...It made a whole lot of difference to coming home positive." (Dec 2019)

Importance of Kari's church and wider community

Kari's church community is really important to her, not only in terms of her faith but it also provides a vital support network for her. Following her stroke (Dec 2019), her biggest goal is to get back to church. During the pandemic, she receives phone counselling via the church and later on, one of her friends from church comes to visit her weekly. Prior to her move into assisted living, it was her friends from church who decorated her new flat for her.

"My friend from church visits me. She's great, she's making all this less of a nightmare for me... She came from church to see me because I wasn't seeing anybody and I was really depressed, I was just isolated. She came as a 'listener' and she takes me to church now." (Nov 2021)

At one of her really low points, it is her pastor she reaches out to when she doesn't know who else to ring (December 2019). And during one of her hospital admissions she is grateful for the efforts made by a nurse to enable her to see a pastor.

"This nurse did everything she could to get me to see this pastor and she kept on until she sorted it. In that respect they were great." (Aug 2019)

Kari also talks about the importance of wider community and how it is really important for her. Kari describes herself as a "people person" and feels isolated in her current housing because she is scared to go out on the busy roads on her mobility scooter. She says she feels excited about moving to assisted living where there is a "little community" and where she will feel safer to get out and about.

These examples highlight the important role faith organisations and supported living settings have in helping people connect with others, reduce isolation and improve people's mental health.

How this report should be used

The insights from this report should be used by all health and care organisations in Leeds as they start to reset their health and care services post-Covid and as part of their ongoing Quality Improvement work. In addition, the reports will feed directly into the new governance for the Leeds Health and Care Partnership, including the citywide Person-Centred Care Board and the Quality and People's Experiences Committee.

Questions for Leeds Health and Care Partnership:

The Leeds Health and Care Partnership will be made up of health and care organisations that will 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 Kari's 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 Kari will always have a good quality experience and good outcomes?
4. How might Kari'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?

Questions for individual organisations:

We would like health and care services to use this report and Kari'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 Kari's videos:

1. What would your services need to do differently to make sure Kari always felt like she was treated with humanity, warmth and empathy?
2. What would your services need to change to ensure that Kari was always involved as an equal partner in plans and decisions about her care, and make use of any skills and knowledge she brings?
3. How will you check that people like Kari are always given clear information and advice at every stage in a way they can understand?
4. How can you ensure that people like Kari are always given the choice where possible of how they want to access services, i.e. face to face, phone or digital?
5. How will you consider the emotional impact of having long-term health conditions on both the individual and their family carers when designing, monitoring and improving services?
6. From Kari's experiences, which services appear to be doing these things well already? Why is this? And how can this learning be shared with others?
7. What opportunities exist for staff to work across organisational boundaries so that they acquire new skills, adopt ways of working and communicate better with each other?
8. Within your service what's the smallest change that could make the biggest difference to people like Kari?

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 and York NHS Partnership Foundation Trust	All videos are shown and discussed at the Patience Experience Subgroup meeting for staff to take key messages back to their teams. The other following actions will be made: • August 21 (part 2) - Remind teams to keep open communication channels with their service users and carers • November 21 - Remind staff that people's faiths are so important to them and ensure they can access places where they want to worship/socialise with people from their own faith. Ask staff to consider barriers to accessing treatment (e.g. booking online for people with no digital access)
Leeds Community Healthcare NHS Trust	Share case studies with services to raise awareness of issues with: • Trust Board meetings • Senior Management Team • Clinical/Quality Leads within Business Units. • Vaccination feedback working group • Engagement champions across the Trust Will consider use as part of training/student/preceptorship placements. Update videos will be shared directly with the LCH services named in them. Services will be supported to reflect on the feedback and formulate a response/actions/areas for learning and good practice: • Community matrons and other adult nursing teams (Aug 21 and Nov 21). • Carers Group (Sept 21) November 21 - the video will influence questions staff ask about digital access. Just because someone has a phone/tablet doesn't mean they have digital access.
Carers Leeds	Videos will be shared with staff team at Carers Leeds and on Carers Leeds social media channels. • September 21 - Use this to help us feedback to the providers we work with about the importance of reliability, communication and a focus on the little things that matter. • November 21 - Use the learning to remind the Carers Leeds team of the importance of good communication, joined up working and focusing on the person.
Leeds Teaching	Videos have been shared at Trust Board, Patient Experience Group or both. They have also been shared with the following:

Hospitals NHS Trust	• August 21 (part 1) - Cardio-respiratory CSU and shared as part of 'Perfect ward' brief as a prompt to ensure staff make sure patients in side rooms get frequent contact. • August 21 (part 2) - ensure that consideration is given to people who are not digitally enabled in conversations about how services are provided / accessed and the need to offer choice in appointment formats. Currently thinking about a robust means to get 'general' messages like this one across in a report format. (Video could be embedded) • November 21 - shared with LTHT's group looking at NICE's Guidance on 'Shared Decision Making'.
Age UK	• August 21 (part 1) - Share with all staff to highlight the importance of supporting people to make contingency plans around telecare response service. • August 21 (part 2) - Share with all staff to highlight the importance of our digital inclusion activities. • September 21 - Share the video with our home care staff as a reminder of what's important to people. • November 21 - Share with our staff teams as an example of good practice, asking them to reflect on what the key things were that made this a positive experience for Kari and how this applies to their work.
Yorkshire Ambulance Service	• July 2019 - This video will be used as part of our patient story process, it will be shared at our Public board meeting and will be used within our training school with operational members of YAS. It will also form part of our ongoing work on staff attitude and behaviour complaints which is looking at what we can do to ensure all staff members are living our values at all times. • August 2021 - The video has been shared with teams and the training department as well as the Executive Director for Quality, Governance and Performance Assurance. Will look into sharing it at the Board.
St Gemma's Hospice	• July 2019 - will share to highlight the impact professionals can have on the individual patient - good and bad. Look at the discharge process from the Hospice and the impact it has had. • August 2019 - Share with the team about the importance of delivering what we 'promise'. • September 2019 - Look at our Hospice Clinical Nurse Specialists interaction with the Community Matrons to ensure patients are not overwhelmed. • August 21 (part 1) - Feedback through Involve, especially in relation to maintaining links with patients not actively being seen. • August 21 (part 2) - Share through Involve and Community Strategy.

	• November 21 - Consider how our volunteer community could support our services.
Leeds City Council Adults and Health	• August 21 (part 1) - shared at team meetings within social care and Telecare service. The telecare service has been contacted and records are being looked at. There was an impact on the service due to the pandemic. • August 21 (part 2) - shared across all service areas within the council to help ensure that all services offer both digital support and traditional support mechanisms. • September 21 - shared with home care commissioning team and complaints team as well as usual team meetings in social care and wider directorate. Commissioners have been shown the video. They will be discussing the issues with the provider. Commissioners are reviewing service and communication plans with the provider. This will be monitored during routine contract meetings. • November 21 - will share with 100% digital and digital innovation teams. • All videos to be shared with social work teams and incorporated into newly qualified social worker training.

Appendix 2: Index of Kari's updates

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

Video/ update title	Summary of content	Link
Kari intro film	• Kari is a poet with a wicked sense of humour • Bipolar, Chronic COPD, Chronic heart failure. • Being housebound can be isolating and frustrating • Enjoys getting out when her health permits • Wants to be a voice for people who can't speak.	https://www.youtube.com/watch?v=CX1VEoYcEss
Kari July 2019	• Emergency hospital admission, negative change in attitude from paramedics when realised she was DNR. Affects willingness to access emergency services when she needs it • Variance in attitudes between hospital staff • 'Home to Hospital' service: (Age UK) excellent (although wrongly assumed she was a pensioner) • Previous experience of discharge often very long, waiting for medication and patient transport. Experience is stressful. • Positive experience of community matron	https://www.youtube.com/watch?v=4UpMCJyr9Eo
Kari August 2019	• Emergency hospital admission for heart • Brilliant care on respiratory ward • Raised expectations of heart failure team who weren't able to support on discharge • Felt listened to in hospital • Positive experience of discharge lounge and hospital discharge with reablement team in place again. • Feels like cost of care is unaffordable and means that she has to make choices about other essentials such as food.	https://healthwatchleeds.co.uk/wp-content/uploads/2019/11/Kari-update-Aug-2019-FINAL.pdf
Kari September 2019	• Experience of SKiLs reablement team when discharged. Good service - now trying to cope on own as SKiLs finished and care no longer free. • Rang two care agencies who did not respond • Can only afford 2.5 hours a week of care (even though she needs more) • Community matron very helpful, can ring when she needs him. He takes pressure off other family members.	https://www.youtube.com/watch?v=ZuFz-NZQBy8
Kari November 2019 update	• Two hospital admissions (firstly stroke, then pneumonia) - in hospital for 6 weeks. • Community matron found her on floor and organised emergency hospital admission	Not publicly available. Please contact harriet@healthwatchleeds.co.uk

Video/ update title	Summary of content	Link
	• Detrimental effect on mental health of the way she was spoken to/treated by a staff member. • Positive experience of rehabilitation ward, and how they work together and include family in discussions • Feels health care assistants need more training and need to understand how vulnerable patients can be and how the way you talk to them can really affect them.	k for more details
Kari December 2019 update	• Positive experience of hospital discharge with taxi • Effect on mental health of stroke and last hospital admission. Waiting to see psychologist from stroke team. • Positive experience of stroke team • Stopped the reablement team as didn't feel comfortable with them 'telling her what to do'. Also felt like some of them 'talked at her' not to her.	https://healthwatchleeds.co.uk/wp-content/uploads/2020/02/Kari-December.pdf
Kari 'At What Cost?' Poem	• Cannot afford to take care of her health and afford necessities (e.g. food) • Making her pay for her own care • Smoker - illness viewed as 'self-inflicted' • Dignity being taken away because she cannot afford care	https://www.youtube.com/watch?v=2ZZRX3nGRjc
Kari 'Emotional Constipation' Poem	• Feels that she is not being listened to or properly cared for • Finally got someone to listen to her • NHS need volunteers called 'the Listeners' - no training courses or special equipment needed. They should have life experience and could be in prisons, hospitals, churches, homeless centres, drop-in centres	https://www.youtube.com/watch?v=SKk8asiqGYg
Kari August 2021 part 1	• Describes the impact of the pandemic on her - isolation, loneliness etc • Reduced contact with community matron and impact on her • Recent experience of trying to get emergency help - telecare/paramedics • Good experience of care during recent hospital admission	https://youtu.be/PFGvNPIX_ro
Kari August 2021 part 2	• Talks about how the move to phone calls and digital during Covid has affected her	https://youtu.be/fJO9D9Dpyek
Kari Sept 2021	• Experience of home care • Carers not coming when agreed so cancelled home care	https://youtu.be/lYgZYb2tbH4

Video/ update title	Summary of content	Link
	• Talks about good care received from home carers and the 'little things' that she really values. Her problem is with the management around communication, not the individual carers who were great. • Awaiting an assessment for assisted living.	
Kari November 2021	• Update on moving into assisted living • Good communication between assisted living and social worker - felt included. • Positive experience of community matron • Barriers presented by having to go online to book appointment • Feels care joined up • Importance of care and support given by church community.	https://youtu.be/ZA5L3d7djhg