

HOW DOES IT FEEL FOR me?



Mark'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 NHS 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 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

Mark is sixty years old, lives in North Leeds and loves cooking, playing golf and family life. He's had many serious health issues over the last twenty years which have impacted his life significantly. He was motivated to be part of this project through his first-hand experiences of the impact of Covid-19 on the health system. He feels his experiences could be used as learning for the future. We followed Mark's journey between November 2020 and May. Updates were a combination of filmed updates via Zoom (due to the Covid pandemic) and written updates transcribed from recorded conversations.

Themes and key messages

Good communication with service users

Communication is key for Mark, and he has the following message for all healthcare professionals:

"People [should] do what they say they are going to do. If I am promised a call back, I expect to see that call back, because if I don't, it adds to my anxiety. So just do what you say you are going to do, and if you are not going to do it, tell me you are not going to do it." (January 2021)

One of the examples he gives is when the GP did not call him to discuss his blood test results that he first sees on his online record (see section on digital).

He also wants good communication when he's been unwell:

“[I need] somebody telling me what has happened, what’s going to happen and what we need to do to make sure what has happened does not happen again.” (November 2020)

Mark also touches on the importance of correct written communication. In his case there was an administrative error about his appointment time (March 2021) and he felt that rather than being understanding of this, the receptionist was “having a go” at him for turning up early and “causing an increased risk of Covid infection”. The appointment he was attending was an investigation for possible cancer and he talked about how this kind of communication and customer service just increased his anxiety and eroded trust in the system. In fact, he said the scan itself was done really professionally and quickly, and staff were really friendly, but that it was, “just the structure in the organization of it that’s letting it down.”

Interplay of physical and mental health

Mark talks about the stigma he sometimes feels for being ill and how this feeling means that he doesn’t want to draw his family into anything to do with his health, but that this can put him at risk of becoming cut off from his family (for more on this, see section on family carers).

“I think when I go to a doctor, and this has been a problem that I have with it mentally, rather than anyone else specifically, it’s almost like going to an AA meeting, where you feel like you’re admitting a failure by being ill. “Oh my god I’m ill, what sort of bad person am I? I’m ill!” (April 2020)

Person-centred care - understanding Mark’s needs and wishes

Mark talks about wanting a more personalised approach when receiving information about potential cancer markers on his blood test results.

“I would like to just be spoken to. I just want them to say, ‘Mark, this is the situation, this is what we are doing, this what we need to do at this stage. After this has happened, we’ll look at it again.’ I just want to know what’s happening and when. You know, I can take bad news, but I need to have it, for me to make my decisions.” (February 2021)

He also talks about the importance of feeling like a partner in his own care in annual medication reviews. He mentions a recent positive experience where he had the opportunity to explain to the doctor that he didn’t think one of his medications was working for him and between them they agreed to change it, which has had resulted in a positive impact in how he feels. He also says how he feels that more thorough medication reviews in the past would have reduced the number of times he had to visit his GP.

“I think that [more thorough medication reviews] would have stopped me having at least four or five visits to the doctor over the last three years.” (November 2020)

Joined up care

Mark shared his experience of trying to chase up his overdue retinal eye screening. He said he didn't get any response from the Leeds Programme because they'd all been diverted elsewhere because of Covid. He doesn't feel like eye screening will be chased up by his GP who is his link for the rest of his diabetes care, because the service is run by Mid-Yorkshire NHS Trust.

"I don't know who to progress about that... when I have spoken to them about the eye screening pre-Covid, they say it's not really their bag, its run separately, So, there's no point trying to chase it with the GP. So, I guess I've just got to wait." (February 2021)

He also talks about seeing two different GPs at the same practice for different aspects of his health and when he tried to talk to one GP about the other issue, he said that her response was that she wasn't dealing with that side of things.

"That's like taking your car into a garage and the wheels fallen off, and they say "Yeah but I'm only dealing with the service..." I'm sure it wasn't meant like that, but it just sounded so disjointed and crazy." (April 2021)

Importance of good compassionate care

Mark frequently comments the care delivered by individual clinicians is excellent, which is reassuring for him, but it is the systems that he feels let them down.

"I've got to say the GP in question was exceptionally good, and she was very empathetic, very professional, very clear. I came away from there thinking 'yes, somebody does actually care and there will be an end product out of this'." (March 2021)

One exception to this is Mark's experience of the Elland Road Covid vaccination centre, where he had a very positive experience of both hands-on care and the organisation of it.

"I went to the vaccination centre at Elland Road in Leeds. The wait was non-existent; the volunteers fantastic; marshalled through; spoken to by GP there, painless process; in and out within ten minutes. I've got to say that that is testimony to a lot of hard work and a lot of good organisation." (March 2021)

Role of community services in preventing hospital admission

Mark praises the success and benefits of the Leeds Programme in supporting those recently diagnosed with diabetes to self-manage their conditions and feel supported by professionals and others with the same condition. He talks about the knowledge and confidence it has given him to manage his own condition and also that he can reach out for help, advice and support when he needs it.

He does worry however about what will happen with those patients who are newly diagnosed whilst the Leeds programme has been paused for so long because of Covid.

“Who’s going to be picking those people up, they’re just going to be shoveled into the system later on down the line when they reach critical condition with blood sugar and obesity, etc. Somebody should have been touching base with the diabetes sufferers, at some point, even if it’s just to say, you know, ‘We’re sorry we can’t be with you, at this moment to the same level as we have, but if you have any interim issues, this is how you should access our service.’” (February 2021)

Continuity of care

Mark expresses doubts about the ability of primary care to really “care” for their patients anymore, due to growth in size and mergers of GP practices. This he feels means there is much less opportunity to build relationships with individual GPs, something that he values in terms of building rapport and trust.

“I don’t think I have ever seen the same GP twice at this practice so there is not going to be an affinity between you because you don’t know each other, and all he or she’s got is a three-minute snapshot of your notes when you sit in front of them.” (January 2021)

Importance of family carers

Mark describes his realisation that his long-term conditions will impact his family’s wellbeing. He says this is something that he thinks is often forgotten about but is important because the impact on them as your support mechanism can have the knock-on effect of making you as a patient feel like a ‘burden’. This can negatively affect your mental health as well.

“Not only are you unwell which is bad enough in itself, but you’re dragging the family down with you... I’m sure there are people out there that are thinking ‘I’m feeling ill, my family hate me, I might as well give up’. I’m sure that does happen.” (March 2021)

He touches on the importance of patients being encouraged to think about involving their family in managing their condition, and how their condition may impact them. He cites the Leeds Programme as being a good example in that respect, particularly around dietary choices. GPs and other primary care professionals could be asking, ‘How are your family doing?’

Impact of Covid

In addition to the impact on people with diabetes because of things such as the pause in the delivery of the Leeds programme, and the long wait for retinal eye screening, the other main impact felt by Mark is the effect of the pandemic on his ability to access his GP, particularly during the first lockdown. He acknowledges that this did improve as time moved on.

“I had a period of four months where I was unable to speak to my GP. They disabled the appointment making facility online, changed their phone system, the receptionists were not fielding calls etcetera. So, I felt very much alone.” (November 2020)

He mentions how this made him feel slightly resentful towards his GP.

The move to digital

Mark wants to be able to access his medical records, manage prescriptions and make appointments digitally, but he doesn't want all of his appointments to be virtual. He feels that face-to-face appointments are vital in terms of assessing patients holistically and 'picking things up' that may not be obvious via phone/video. He feels that digital needs to be a choice, not a default.

There are also the unintended consequences of patients accessing their medical records online, such as viewing potentially distressing information. In this case, Mark had logged on to order meds and inadvertently saw information relating to recent blood test results.

“What I can see on my notes is a load of red flags and coded entries, I think they are called, with lots of letters and numbers and abnormal wording which doesn't mean anything to me. And there was a comment about a possible cancer marker” (January 2021)

Mark explains that reading his online record was the first he had heard this information about his blood test results and that three weeks later he had received no phone call to discuss what this potentially very worrying information meant for him. This lack of communication means that he has little confidence in his GP practice proactively contacting him about anything.

Mark's experience highlights the importance of communicating potentially life-changing information such as this in a more personalised way. It requires preparation and support to make the patient feel as reassured and involved as possible. Mark stresses the importance of communicating such information over the phone or in person in a sensitive way and not via a digital record. This can help build rapport and make the journey easier for both the clinician and the patient.

His experience also highlights the need for health professionals to be more aware of the level of information accessible to patients via their online record, the language used, how it will be received and the potential impact. It also raises the question, do patients need to be better prepared for the reality of being able to access their medical records online?

Mark talks about the current online triage system at his GP surgery, which he feels is very in depth and complicated and would be better done face to face.

“And all you want to be able to do is spend two minutes talking to somebody and saying that this is the problem. You would convey so much more information than you can on this form.” (January 2021)

Listening to patient feedback

Mark's key message for decision makers is that they need to be prepared to listen and act on feedback.

"It's so very important to all patients that you listen to them. But more than that, it's important that you do something with that information. So, when you leave the meeting room now, don't leave it in your briefcase or on the backseat of your car and forget about it. It needs to be used, because otherwise it just becomes another waste of time." (May 2021)

He talks about how listening to feedback is not only an opportunity to improve services, but can also be empowering for service users who feel listened to and valued.

He makes some suggestions of how people using services could be involved more:

- Patients or laypeople should be involved in complaints investigations as 'experts by experience' (May 2021)
- Patients and professionals could meet virtually to discuss patients' experiences and discuss ways to make improvements (May 2021)
- Having a 'Patient Champion' at each GP practice where once a month, patient feedback could be collected and looked at. (April 2021)

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 Mark'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 Mark will always have a good quality experience and good outcomes?
4. How might Mark'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 Mark'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 Mark's videos:

1. What would your services need to do differently to make sure Mark always felt like he was listened to and heard?
2. What would your services need to change to ensure that Mark was always involved as an equal partner in plans and decisions about his care, and make use of any skills and knowledge he brings?
3. How will you check that people like Mark are always given clear information and advice at every stage in a way they can understand?
4. How could your organisation improve communication between different professionals both within and between services?
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. How can you ensure that people like Mark are always given the choice where possible of how they want to access services, ie. face to face, phone or digital?
7. How will you ensure that any information people like Mark receive via their digital records is accessible and appropriate to be shared in this format? How will you ensure that clinicians always ask the question: 'How would it feel to receive this information digitally?'
8. From Mark's experiences which services appear to be doing these things well already? Why is this, and how can this learning be shared with others?
9. 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?
10. Within your service what's the smallest change that could make the biggest difference to people like Mark?

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?
Health Partnerships Team Leeds	Support meeting with Local Care Partnership teams regarding use of the Marks videos in Local Care Partnership meetings for discussion and improvement of the issues raised. Will also share with: • Partnership Executive Group • Health and Wellbeing Board • Board 2 Board • Strategic meetings • Share with other groups where needed Progress with West Yorkshire and national forums March 2021 update will also be shared in the following places: Feed into work that is going on around digital development and digital inclusion. • Feedback on good practice re Elland Road and organisation of COVID vaccine as basis for further vaccine working to be fed back to vaccination teams at Elland Road. • Workforce team working on vaccine rollout. • The Health Partnerships Team as it links a number of team functions and areas for partnership development together in a powerful way.
Healthwatch Leeds	Shared feedback about Mark's surgery with CQC GP practice lead around communication, online records, difficulty getting through to surgery etc. Mark's Feb 2021 update was shared at the Personalised care steering group and 'Silver group' that is leading on the co-ordination of the 'reset' of services after Covid (Feb update) are using this video to discuss developing an approach in terms of waiting lists, communication etc.
Leeds Community Healthcare NHS Trust	Will share with: • Services to raise awareness of issues. Services will be supported to reflect on the feedback and formulate a response/actions/areas for learning and good practice. • Senior Management Team • Trust Board • Clinical and Quality Leads within Business units • Patient Experience Team Will consider use as part of training/student/preceptorship placements. • Feb 2021 update shared with Dietetics, Diabetes and Tier 3 Weight Management Services as well as the Retinal screening service. • Information is being discussed at the Clinical System Pathway Development steering group for Diabetes/Leeds programme.

	Operational lead for the Community Diabetes Service is contacting Mark to check he is clear on where he can access support. • March 2021 video will feed into citywide experience of vaccination centres working group. • April 2021 update will be shared specifically to The Leeds Programme. • May 2021 update - Consider how we support patients/carers to share their feedback/feel able to share their experiences. • Review complaint/feedback processes in line with Mark's feedback and continue to improve how we involve families/patients in these processes. • Further consider how we act on this feedback and share learning from HDIFFM and build it into reviews, etc
Leeds Clinical Commissioning Group	We will be using Mark's story which will be presented at the September governing body meeting along with the CCG annual report. On an annual basis we included a patient story relevant to the themes and trends of the report. I think Mark's story fits with the experiences of patients in 2020 as services were halted and patients are telling us that communications which may have gone out didn't reach certain cohorts of patients. This gives us a way of trying to improve these communications to better improve experiences moving forward. I think the story also highlights the feelings of a high proportion of patients challenged with a sense of isolation and the impact that had on not only their mental health but also the impact of their families and carers. We have requested that primary care colleagues in the CCG provide us with the actions that are being/have been put into place as a result of patient feedback, which will also be shared with the Governing Body to evidence the steps being taken. Concern about the current eye screening wording when changes are identified. Patients have no idea where to go. Agreed as a result of the discussion that letter needs to be re-worded and a contact number included for support. I am going to pick this up with the Mid-Yorks team who delivers eye screening, to see if can be changed
Leeds Teaching Hospitals NHS Trust	We will share with: • Specialty Medicine Clinical Support Unit Governance forums • The relevant Clinical Support Unit to share at local Governance forums • LTHT diabetes team (Jan/Feb 2021 update) • Radiology and via their clinical governance groups re:- wrong time on letter (March 2021 update) • CT scanning team (March 2021 update) • the Diabetes team - positive feedback about the Leeds Programme (April 2021 update)

	There is a general point about how results are made available to patients. The Patient Experience team will consider where would be most appropriate for this to be shared? Leeds Cancer Centre CSU Will think about how best to share insights about long-term conditions with relevant clinical teams. Will continue to ensure that conversations about delivering outpatient consultations include the option of face-to-face consultations by preference. May 2021 update - LTHT will be involving patients in patient safety incident investigations in the near future. Patient Experience Team are also establishing a patient panel to review complaints which include discrimination as a subject.
Leeds City Council Complaints	We will be mindful of following things through, not letting things drift, and taking a personalised approach. The importance of doing what we say we will do. Videos are relevant to a lot of situations, so will share very widely.
Age UK	Share updates with staff who will be involved in a research project in primary care where they will be adding notes directly to Electronic Health Records, to support sensitive recording practice and timely communication. Share with staff working in GP surgeries to provide insight into people's recent experiences of primary care. Will share May 2021 update in full team meeting to highlight importance of service user feedback.
St Gemma's Hospice	We will share the importance of connecting, informing, and giving responsibility to the patient/family'
Leeds Community Healthcare / Leeds CCG / Leeds Health and Care Academy	Mark made some audio and video clips to be used as training material for a city-wide Leeds online long-term conditions course for healthcare professionals which has been commissioned by Leeds Clinical Commissioning Group. The training will be hosted by Leeds Community Healthcare and Leeds Health and Care Academy. The content will bring in the valuable perspectives of people living with long term conditions.

Appendix 2: Index of Megan's updates

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

Video/ update title	Summary of content	Link
Mark Intro	• Aged 60 and lives in North Leeds • Enjoys cooking, golf and family life • Has complex medical needs having had a heart attack, kidney cancer and diabetes. Conditions interact with one another. • Wants to use experience to highlight what could go wrong again and help identify solutions for the future.	https://youtu.be/6_frfZFWoe4
November 2020 update	• Experience of GP access during pandemic • Routine diabetes care during pandemic • Experience of medication reviews	https://youtu.be/CfGMROc1Zqw
Mark January 2021 update	• Accessing medical records online • Experience of shielding/being clinically vulnerable • GP access	https://healthwatchleeds.co.uk/wp-content/uploads/2021/03/Mark-Jan-2021-FINAL.pdf
Mark February 2021 update	• Experience of accessing test results via personal electronic record • Experience of self-management of diabetes during the pandemic and how the Leeds Programme helped with this. • Experience of Leeds programme being closed during pandemic	https://youtu.be/upOsqr3lr8o
Mark March 2021 update	• Experience of attending cancer scan • Experience of finding out scan results via electronic record • Experience of Covid vaccine • Experience of in person GP appointment	https://youtu.be/DYiHnI7onTI
Mark April 2021 update	• Impact on family and mental health of being unwell • Leeds programme involvement of families • Lack of joined up care at GP • Good care from individual GP • Delayed diabetic eye testing • Changes in diabetic annual check • Face to face vs phone GP appointments • Difficulty getting through to GP	https://healthwatchleeds.co.uk/wp-content/uploads/2021/05/Mark-How-does-it-feel-.pdf
Mark May 2021 update	• Reflections back over the last year. • Informal evaluation of this project. • Thoughts about digital vs face to face access to GPs	https://youtu.be/Hk-wRh4hwUk

Video/ update title	Summary of content	Link
	• Suggestions on how patient feedback including complaints processes could be improved. • Message for all providers taking part in this project.	