



Multiple Long-Term Health Conditions Report

August 2025

Your
healthwatch
Leeds

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Summary

Background

Healthwatch Leeds (HWL) was approached by West Yorkshire ICB to support them with a piece of work called Health Working Lives. This is part of a service improvement programme for people with Multiple Long-Term Conditions (MLTCs), including those with mental health conditions.

To make sure the new approach works for as many people as possible, Healthwatch Leeds was asked to support the ICB to hear from people living with MLTCs and their carers.

Local Primary Care Networks identified working age people with multiple long-term health conditions. We contacted these people and asked them to fill in a survey and attend an interview for a more in-depth conversation.

23 people responded to the survey, and we interviewed 8 people.

Key Findings

- People with MLTCs would like longer appointments with a GP or healthcare professional to be able to discuss all their health concerns at once.
- Most people have issues with booking GP appointments. Therefore, often wait until health problems are at a critical level and go to A&E.
- Many people with MLTCs struggle to attend appointments due to transport costs/time needed for multiple appointments, clinics and services across the city and sometimes out of area.
- Most people were not aware of having a care plan but would like to be involved in developing their own.
- Most people have had to give up work due to their health conditions and were not aware of any support that can help them get back to work, due to having multiple health conditions.

Key Recommendations

- Longer appointments with a GP or another healthcare professional, where they can discuss all their concerns.
- A proactive care approach, for example, by having a monthly appointment to discuss all health conditions and review medication.
- Involve people with MLTCs in creating a care plan that includes medication, diagnoses, communication needs and personal goals.
- Appointments closer to home, to reduce transport issues.
- More support for people with MLTCs in work to enable them to keep working.
- Understand individual support needs of people with MLTCs who are unemployed, for example, support people to access courses or volunteering to help keep up motivation.

Introduction

Healthwatch Leeds (HWL) was approached by West Yorkshire ICB to support them with a piece of work called Health working lives. This is part of a service improvement programme for people with Multiple Long-Term Conditions (MLTCs), including those with mental health conditions.

The University of Leeds and the NHS have been working together to improve support for people living with more than one health condition. People had already shared their experiences, and these have been used to help develop better ways of supporting people. This includes trying out new ways to help people better manage their conditions and reduce the number of times people are admitted to hospital.

To make sure the new approach works for as many people as possible, Healthwatch Leeds was asked to support the ICB to hear from people living with MLTCs and their carers. People's experiences can then be used to influence and shape the new approach.

What we did

We developed a survey and shared it with working-age people who were identified as having one or more of the following MLTCs:

- Heart Failure
- Diabetes
- Chronic Kidney Disease
- Stroke
- Hypertension (High Blood Pressure)
- Atrial fibrillation (AF)
- Chronic Obstructive Pulmonary Disease (COPD)
- Peripheral artery disease (PAD)
- Coronary Heart Disease (CHD)
- Mental Health Conditions

The people we sent it to give permission to be contacted by their local Primary Care Network (PCN), and the focus was on people from the following pre-identified areas (West Leeds, Seacroft, Burmantofts, Harehills and Richmond Hill).

23 people with MLTCs completed the survey.

As part of the survey, we asked if they would like to speak to us in more detail about their experiences, and for this, we provided a thank-you voucher. 8 people with MLTCs said that they would like to do this, and HWL then carried out several face-to-face and over-the-phone interviews with these people.

Who we spoke to

Survey respondents who provided demographic information are between 46 and 75 years old. 8 respondents are female and 12 are male.

The respondents have a range of long-term health conditions:

- Heart failure – 6 people.
- Diabetes – 17 people.
- Chronic kidney disease – 5 people.
- Stroke – 5 people.
- Hypertension – 14 people.
- Atrial fibrillation – 7 people.
- Chronic obstructive pulmonary disease – 7 people.
- Coronary heart disease – 5 people.
- Mental health problems – 6 people.
- 13 people who shared data were living with 2-3 MLTC's
- 12 people who shared data were living with 4-5 MLTC's
- 2 people who shared data were living with 6-7 MLTC's

People with MLTCs access a range of services to help manage their health. Most people mentioned accessing GPs. Other services include specialised clinics for conditions such as diabetes, Crohn's disease, asthma and lymphoma. Many respondents discussed how they access different services across different locations in Leeds. One person receives care from their GP, St James' Hospital and Chapel Allerton Hospital. Another discussed that they regularly access 5 different services to help manage their care, this included their GP, asthma clinic, heart team, physios and Forward Leeds. These responses highlight that care for people with MLTCs is not integrated.

What we found from surveys

Self-Management

Most people listed going to appointments, taking their medications and monitoring bloods as part of their self-management. Many people listed positive actions like healthy eating, avoiding smoking and alcohol, keeping mobile and exercising. Some people included how they reduce their risk of falls by using sticks and scooters, and the importance of knowing when to rest. Getting support from family and friends is important, and a few people also mentioned being involved in community groups, both of which help them to reduce stress and keep a positive attitude.

When asked what made it hard to self-manage multiple LTCs, many people said a lack of motivation, feeling tired all the time and other symptoms, stress and low mood were shared by most people. A few people are struggling with access problems at their homes and feel trapped. Other factors included caring responsibilities, waiting for medication and appointments, and conflicting advice online.

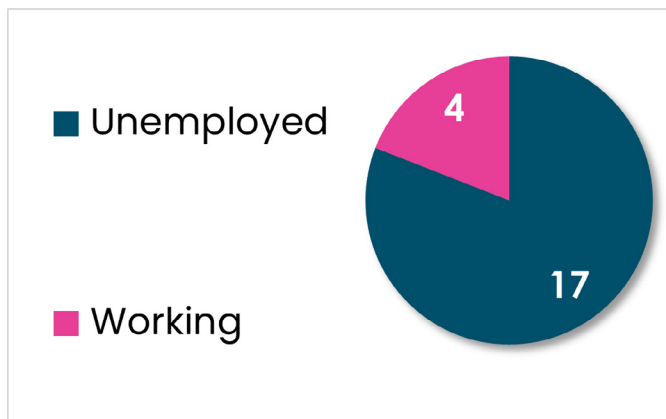
When asked what would help to manage their conditions better, 12 survey respondents said a care plan, 10 said joined-up care, and 9 said appointments closer to home. Other suggestions included full blood test results, specific dietary recommendations and clearer information from medical professionals.

Hospital Admissions

Out of 23 survey respondents, 9 had been admitted to hospital in the last year for something that wasn't planned. Two people had been admitted once, six people had been admitted twice, and one person had been admitted three times. The reasons for admissions included pneumonia, gastric bleed, intestinal blockage, chest infection and cardiac arrest.

Work

Are you employed?



17 out of 23 survey respondents have had to give up work or reduce their hours due to their health conditions. Just 4 people are working, 2 of those are self-employed and as a result have the flexibility to help them manage their conditions and so continue to work. One of the others has a very supportive manager, and the other has reduced their hours and is looking for a homeworking role.

There were a range of reasons why people had to give up work. These included poor mental health, inability to drive, mobility issues and being in hospital more than at work.

When asked what would support people in getting back to work, 9 people said nothing would help as they have too many health problems. The only suggestion for extra support was helping to find a home-working role.

What we found from interviews

Hospital Admissions

Out of the 8 people we spoke to in interviews, 5 had been admitted to hospital in the last year for something that was not planned.

One person felt that their GP had let them down as their hospital admission was due to dangerously low iron levels, which had been declining over a 2-year period, but they were not aware of this until they were seriously ill and needed an ambulance.

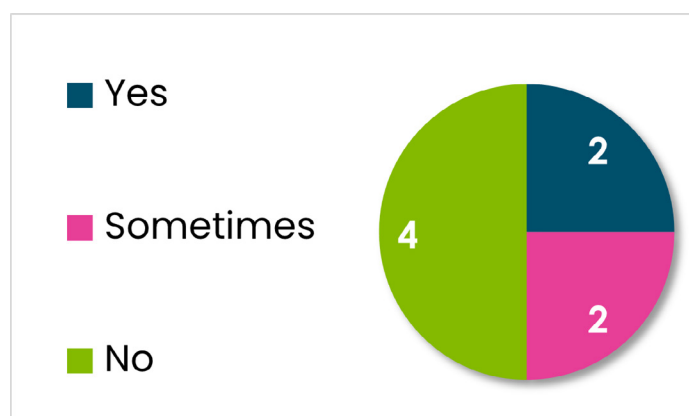
There were varied answers to whether the care met their needs; some said the care they received did meet all their needs. Others discussed issues with the care in hospital, such as not being able to access their regular medication on time or receiving the same treatment every time they are admitted, which does not appear to be helping.

The information received by patients when leaving hospital is often useful information, but the same every time. One person was told they needed a blood test after being discharged; however, when they tried to book a blood test, they were told they had to wait four weeks, which worried them.

Communication

During interviews, most people said health and care staff do not share information or communicate with each other well.

Do staff communicate well with each other?

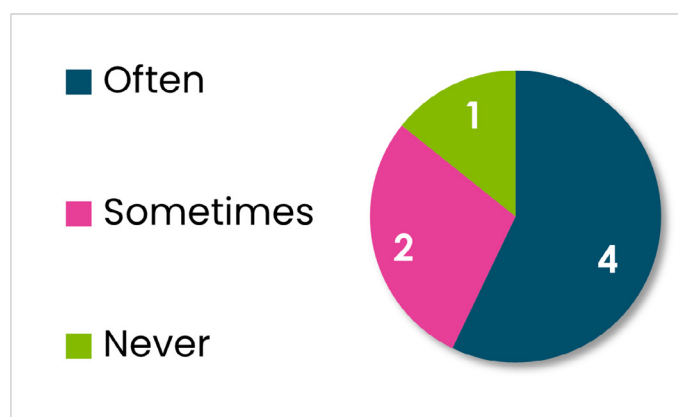


One person mentioned that they have had very positive experiences of doctors and nurses communicating well with each other and themselves. However, multiple people agreed that there is inadequate communication between staff and patients.

Lack of communication between healthcare staff has caused some issues for people. There were two key examples of this, which both involved a lack of communication between different NHS departments, meaning the person did not receive the treatment they needed in a timely manner and therefore got to a critical level and needed emergency care.

When asked if they feel like they are repeating health information, most said they do. For example, repeating the same information to pharmacists every month to get their prescription and explaining their health conditions at every appointment. However, one person said they do not mind this as it is important to check information, but they felt there was a lack of healthcare staff reading over notes before an appointment.

Do you feel you are repeating health information?



Most people who were interviewed said they sometimes feel staff listen to them when they share health information. Some feel that when healthcare professionals do not listen, they end up at a crisis point. However, others said they do feel like staff listen, but sometimes they find it hard to explain exactly how they feel.

Most people found the information they received to be accessible and easy to understand, especially when a healthcare professional explains and answers any questions. However, one person commented that they often cannot act on this information, for example, diabetes support groups are during working hours, so they cannot attend. Multiple participants discussed that they would like more information, for example, full blood test results and an explanation of what it means.

The main suggestions to improve accessibility of information were a reduced use of acronyms and medical language, and translation into their first language.

Appointments

A common theme running throughout all the interviews was struggles with GP appointments. The main issue was only being able to discuss one issue at each appointment, meaning people needed to either book multiple appointments or ignore some problems until they were severe and needed to go to A&E. Multiple people said they would like longer GP appointments to discuss all problems at once.



“I just tend to not bother now with GP appointments. I have to be really ill to see GP because I’ve lost complete and utter faith in them.”



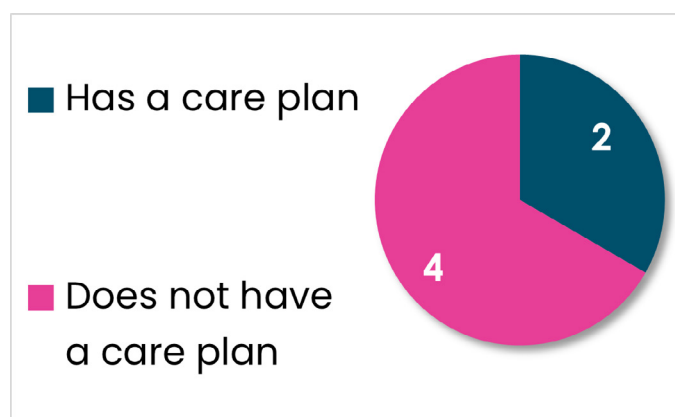
Other issues included struggling to get GP appointments or being given appointments on short notice and not being able to attend due to work commitments or other appointments.

One person mentioned they would like the NHS App to remind them on the day of their appointments as they often forget.

Care Plans

Out of the 8 people interviewed 2 people were aware of having a care plan, only one person was involved in writing it, which they appreciated.

Do you have a care plan?



"I know my body."



All apart from one said they would like a care plan and would like to be involved in creating their care plan.



"Well, that'd be good though. Because I know me, and they don't know me."



The main things that people would like to be included in their care plan were diagnoses, medication and personal goals, such as quitting smoking.

Work

6 out of the 8 people interviewed have had to give up work completely due to their health conditions.



"I miss work and being able to do what I used to."



Most people who have had to give up work said there is no additional support that would help them get back to work, as they have too many health conditions. This could be linked to the low mood and lack of motivation highlighted by survey respondents.



“No one would employ me now. I spend 20 hours a day in bed.”



“I don’t know how to answer that one because there’s that much wrong with me. I don’t know where to begin.”



More Help

Most people discussed that attending appointments are difficult due to transport issues. Multiple people mentioned they used to be able to get NHS transport, but this is no longer available to them. This means many people now rely on family and friends or pay for taxis. One person said the main problem with getting a taxi is that there is no one to help walk them to appointments when they arrive at hospital. Others discussed issues with parking, for example, limited disabled parking spaces at LGI and long walks from the car park.

No one has a social worker, and no one expressed that this would be helpful for them. However, many people discussed that their social circumstances or recent changes at home made it harder to look after their own health. For example, one person discussed how they care for their partner and make decisions for them both, which leads to exhaustion and brain fog. Therefore, they find it hard to attend appointments and make decisions about their own health. Other examples included divorce, bereavement, reduced mobility, and not having any family or friends to help them travel to appointments.

Changing and Improving Health Services

The key things that people found frustrating about the NHS and social care system were:

- Getting GP appointments.
- Feeling as though they will only be seen if they go to A&E.
- A&E waiting times.
- Long waiting lists mean it can be an emergency by the time they are seen.
- Having to relay health information to different healthcare professionals.
- Lack of communication between healthcare professionals and patients.
- Getting to medical appointments (transport, parking).

Finally, people were asked what changes they would like to see in the NHS to allow their needs to be met. The suggestions were:

- Longer GP appointments.
- A monthly appointment to discuss all health conditions and review medication.
- Appointments closer to home.
- Automatic ordering of repeat prescriptions and prescriptions delivered to their door.
- More notice and flexibility for appointments.
- Easier systems to contact healthcare professionals, for example, direct contact with a specialist team.
- Having someone come with them to all appointments who could communicate with different departments.
- Having a list of all diagnoses and medications to take to appointments.
- More disabled parking.

Recommendations

- Longer appointments with a GP or another healthcare professional, where they can discuss all their concerns.
- A proactive care approach, for example, by having a monthly appointment to discuss all health conditions and review medication.
- Involve people with MLTCs in creating a care plan that includes medication, diagnoses, communication needs and personal goals.
- Appointments closer to home, to reduce transport issues.
- More support for people with MLTCs in work to enable them to keep working.
- Understand individual support needs of people with MLTCs who are unemployed, for example, support people to access courses or volunteering to help keep up motivation.
- Allow people with MLTCs easier access to healthcare professionals, for example, direct contact with specialist teams.
- Consider how individual patients' social circumstances affect their ability to look after their own health.
- Improved communication between healthcare professionals and patients around what services are available to them, what each healthcare professional's role is and how to access these different services.
- Improved information to be provided to patients after they leave hospital to improve continuity of care.
- Reduced use of jargon, e.g. abbreviations and hard-to-understand medical language.
- Offer translations of medical information into different languages.
- Review the criteria for patient transport and provide more disabled parking.



“Having to fight for everything needs to stop.”



Thank you

Thank you to West Leeds, Seacroft, Burmantofts, Harehills and Richmond Hill PCNs for identifying participants. Thank you to those who completed the survey and participated in the interviews.

This report was written by Katie Joenn, Project Support Worker at Healthwatch Leeds.



**Committed
to quality**

We were awarded a committed to quality marque from Healthwatch England. To obtain this we did an in depth audit which will be reviewed.

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