



# Living with Multiple Long Term Health Conditions Report

February 2022

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# Introduction

Healthwatch Leicester and Healthwatch Leicestershire (HWLL) are the local independent voice of the public in the delivery of Health and Social Care in Leicester and Leicestershire. We collect feedback from members of the public about their experiences of using health and social care services. One of the ways that feedback is collected is through carrying out Special Projects which is based on the experiences shared by the public and conversations with the local authorities.

Through working with Leicestershire Partnership Trust (LPT), we are aware that Multiple Long Term Health Conditions (LTHC) is quickly becoming a significant focus for many statutory services.

This is also reflected in the NHS England Five year Forward Plan that recognises that ‘long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather than providing single, unconnected “episodes” of care.’ NHS England also state that they understand the need for person centred services where people are empowered to be involved in the decision making about their own care.

Caring for people with multiple long-term conditions means that a number of services and specialities need to work together and with the person receiving care to ensure that care is joined up and seamless. Across Leicester and Leicestershire, the introduction of Integrated Care Services (ICS) will see partners working together to join up care particularly for frail older people, those with LTHC and other vulnerable groups, including carers. As services become more integrated, we wanted to understand how patients and their carers navigate multiple services.

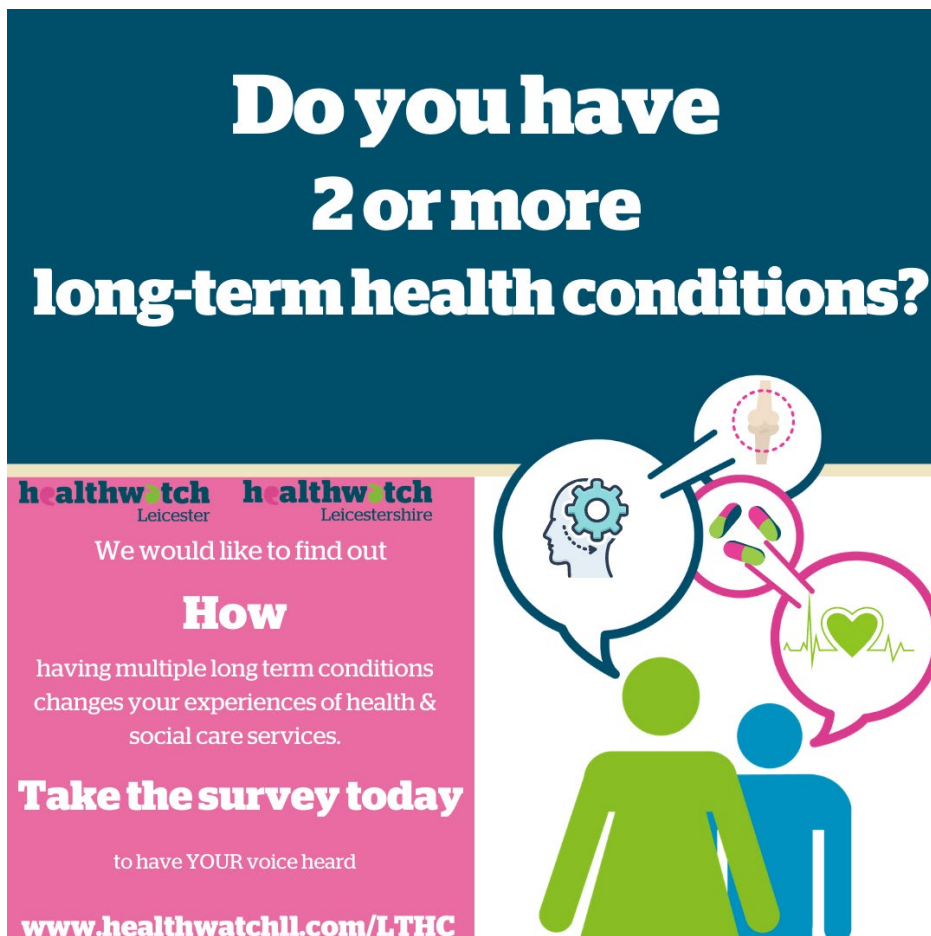
## What we did

For this project we made use of a survey that was available both online and as a paper survey that could be posted back to Healthwatch.

We had initially started the project during the Covid-19 pandemic restrictions, and this impacted on the take up of the survey. Therefore, we revisited the project and promoted it more widely during Autumn 2021.

The survey was promoted with support groups for people with long term conditions such as heart and lung conditions or diabetes. We also shared information about the survey with the Clinical Commissioning Groups in Leicester and Leicestershire and asked them to share details through their networks.

We offered incentives to groups who were able to host us to complete surveys with their members in the form of a one-off donation to their group.



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2 or more  
long-term health conditions?**

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Leicester Leicestershire

We would like to find out

**How**

having multiple long term conditions changes your experiences of health & social care services.

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to have YOUR voice heard

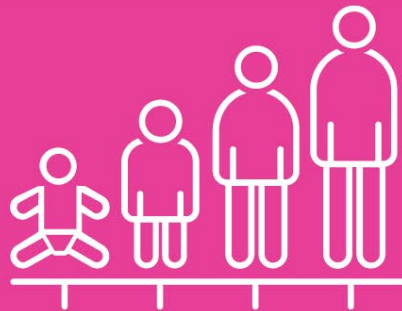
[www.healthwatchll.com/LTHC](http://www.healthwatchll.com/LTHC)

# WHO WE SPOKE TO



60 people completed our survey

2 people are 25 - 34 years  
 9 people are 35 - 44 years  
 11 people are 45 - 54 years  
 16 people are 55 - 64 years  
 14 people are 65 years or above  
 8 people preferred not to disclose their age



- 5 people are Asian/Asian British: Indian
- 1 person is Asian/Asian British: Pakistani
- 1 person is Mixed White and Asian
- 45 people are White: British/English/Northern Irish/Scottish/Welsh
- 1 person is White Irish
- 3 people preferred not to disclose their ethnic background

26 people are Christian

6 people are Hindu



6 people preferred not to disclose their religion

1 person is Buddhist

1 person is Muslim

4 people have another religion or belief

10 people have no religion

1 person is Sikh

50

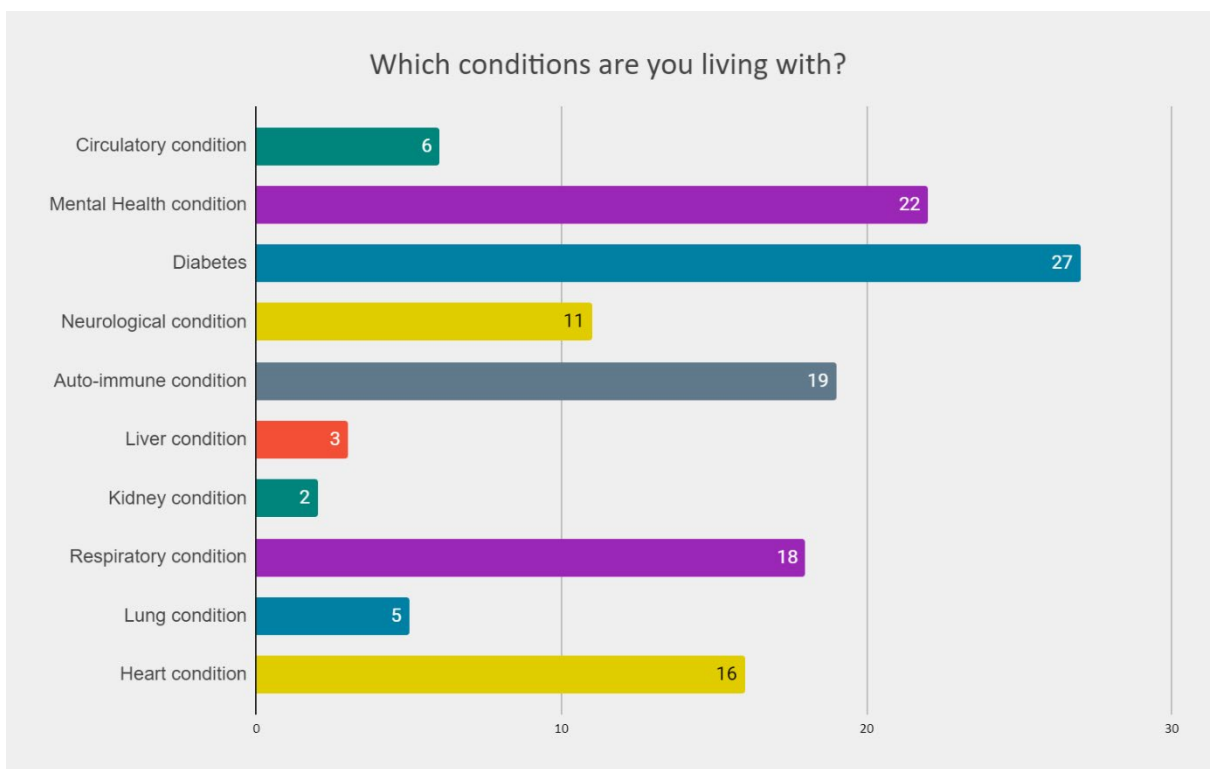
people consider themselves to have a disability or long-term condition



# Findings

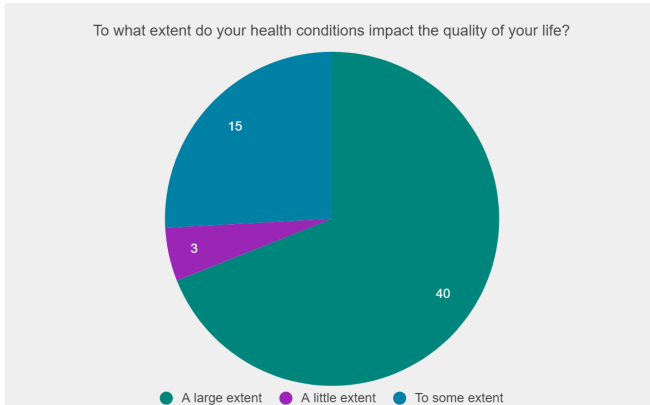
The survey used a mixture of closed and open text questions and therefore responses have been analysed according to the question type. The multiple-choice questions have been quantified and are presented in chart form, the open text questions have been analysed using thematic analysis which reviews all of the feedback and identifies key themes within it.

Participants were asked what conditions they are living with, and they were able to select as many conditions as applied. The chart shows the frequency that the different conditions were selected by participants.



They were subsequently asked to specify their condition if it was not listed in the multiple-choice selection. Some of the most frequently mentioned conditions were arthritis, various types of cancer, bowel or bladder issues, and conditions relating to people's mobility such as hip replacement, joint hypermobility syndrome, or osteoporosis.

Respondents were then asked to what extent their health conditions impact their quality of life. The chart shows the frequency that each response option was selected. The majority reported that their health conditions affected them to a large extent.



Participants were then given the opportunity to explain how their health conditions affect the quality of their life. Responses were analysed to identify themes and six themes emerged.

**Mobility/Pain** was a frequent theme that was discussed in responses, one participant stated that it is *'hard to walk and difficult to breath at all times'*,

Another advised that the pain that they suffer *'limits movement and ability to do chores or walk far'* and went on further to say that the *'debilitating pain stops me enjoying things'*. Someone else reported that they are not able to *'do a lot of physical exercise or activities as I would like to, I can't keep up with my daughter'*.

**Mental Health** was another theme that emerged from the responses, one respondent spoke of how their mental health issues *'compromise my basic, necessary cognitive and coping skills'*, another advised that *their 'mental health condition stops me from doing daily tasks'*, and another told us that *'Post-traumatic Stress Disorder (PTSD) affects most aspects of my life on a daily basis'*.

**Self-care/ Independence** was another theme that was identified from the feedback, we were told by one participant that they are *'unable to work, I am unable to walk more than 15 metres so have to rely on someone to take me out in a wheelchair, I'm unable to leave the house on my own'*, another respondent reported that they have *'severe autism'* which means that they *'cannot live or cope living on my own'* and needs support to manage their other *'lifelong/ life threatening condition that means I need to take medication daily'*.

**Social Factors** were also discussed by a number of respondents, one told us that their health conditions *'limit my enjoyment of life'*, and another reported it *'makes it difficult to continue a normal life'*. One respondent described how various aspects of their life have been affected as they have *'had to move out of my flat due to accessibility and move into mums, it has affected my career and social relationships'*.

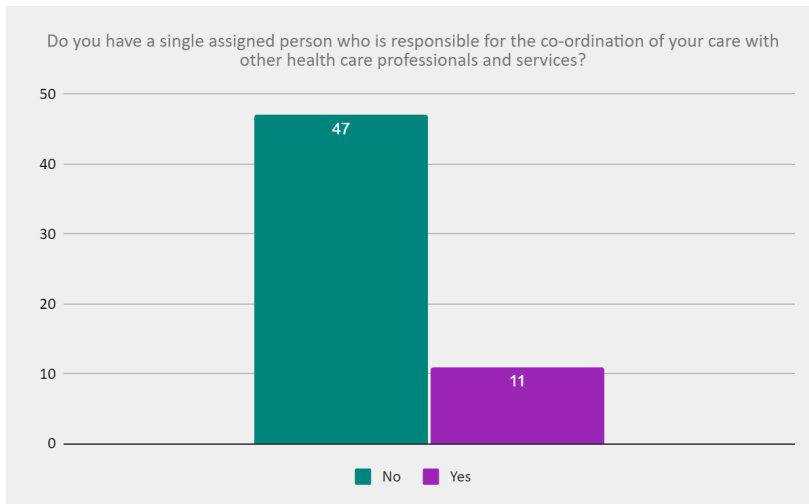
Another theme was **Daily Routine**, one participant advised that they *'have to pace activities'* and *'monitor and assess symptoms to determine medication use'*, they went on further to state that they have to *'constantly adjust what I'm doing to cope with pain and symptoms 24-7'*.

*'my conditions affect me every day now' and 'restrict my activities and affect all aspects of my life'.*

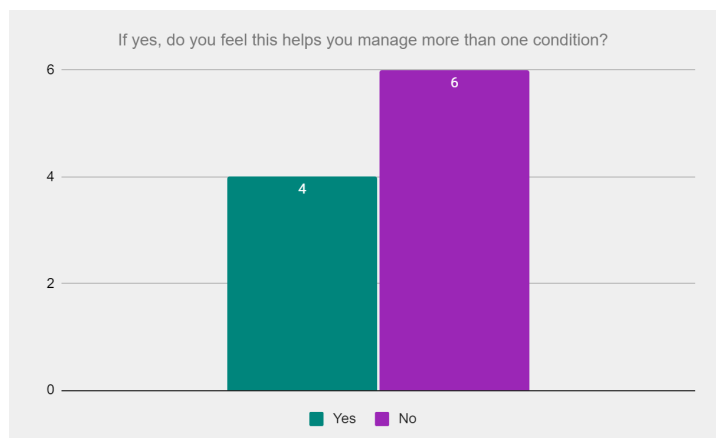
The last theme that emerged from the feedback was **Condition Management**, one person reported that *'I manage my conditions well in partnership with my GP'*, another found that when seeing a doctor or consultant *'they are only interested in the condition that you have come to see them about, they are not interested in the multiple other conditions'*, and another reported that:

*'not one department will communicate with each other'.*

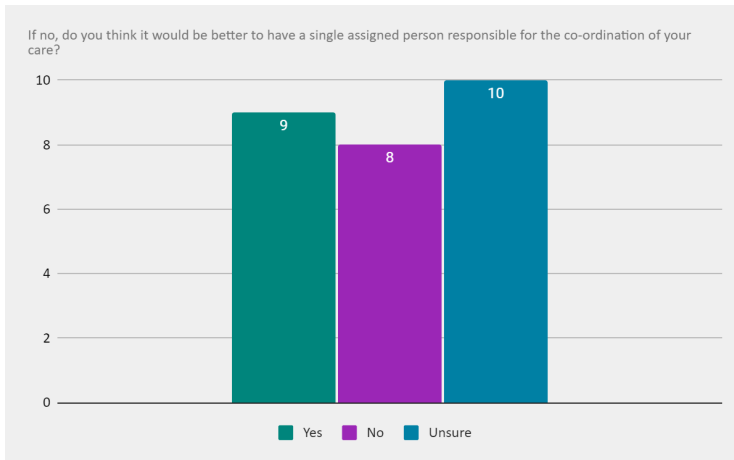
Participants were asked if they had a single assigned person who is responsible for the coordination of their care with other healthcare professionals and services, of the **58** people who answered this question, **47** indicated that they do not.



Those who reported that they do have a single assigned person involved in their care were asked if they feel that this helps them to manage more than one condition, **4** people indicated that they feel it does help whilst **6** people indicated that they feel it does not help.



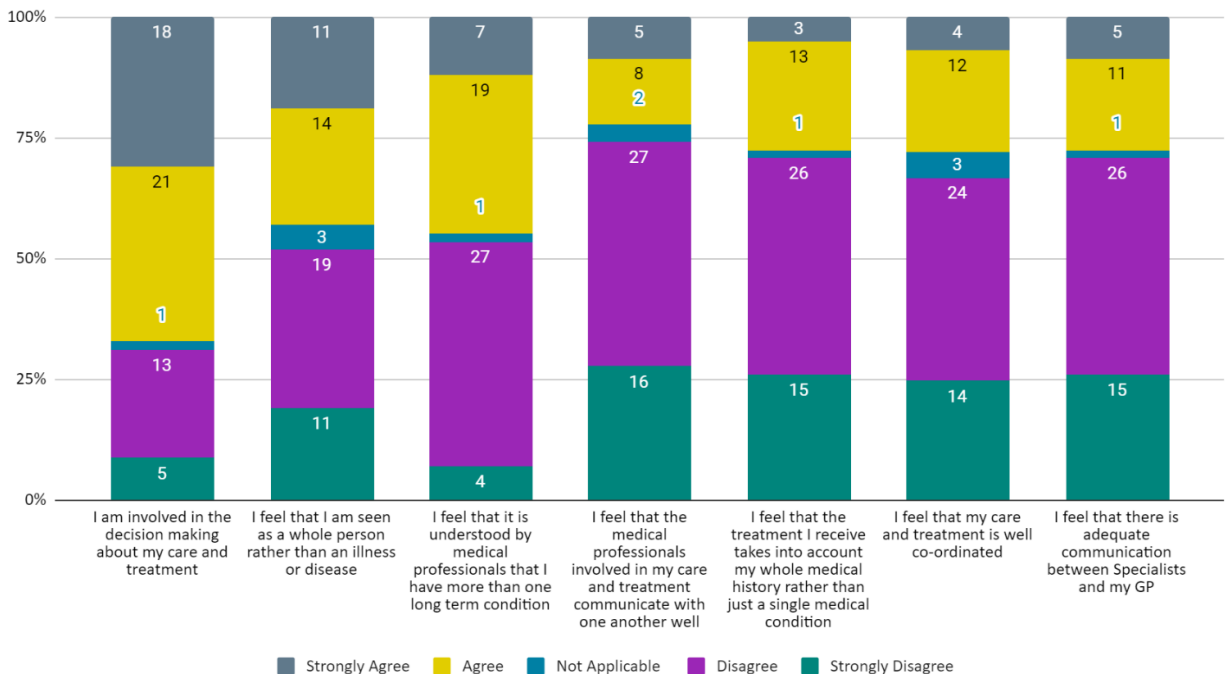




Respondents who had indicated that they do not have a single assigned person responsible for the coordination of their care were asked if they thought it would be better to have one. **9** people indicated that they do think it would be better, **8** people felt that it would not be better, and **10** people were unsure.

Participants were asked to what extent they agree or disagree with **7** statements, the chart below shows the **7** statements and the frequency of each response type.

Please indicate how much you agree or disagree with these statements



The majority of people felt they were involved in the decision making about their care and treatment, **18** people indicated that they strongly agree with this statement and **21** reported that they agree, **13** people advised that they disagree and 5 people strongly disagree with this statement, **1** person stated this was not applicable to their situation.

Patient sentiment was mixed when asked if they are seen as a whole person rather than an illness or disease, **11** people advised they strongly agree with this, **14** stated they agree, **19** people advised they disagree, and **11** people stated they strongly disagree, **3** people reported this was not applicable to them.

Again, sentiment was mixed when respondents were asked if they feel it is understood by medical professionals that they have more than one long-term condition. **7** people stated they strongly agree with this, **19** people reported they agree, **27** people advised they disagree, and **4** people stated they strongly disagree, **1** person reported this was not applicable.

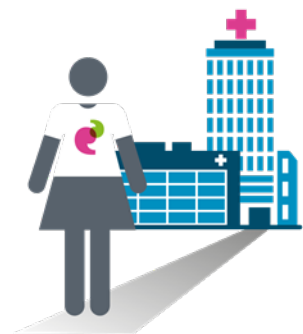
When asked if patients felt that medical professionals involved in their care communicate with one another well, only **5** people strongly agree with this statement, and **8** people agree, in contrast **27** people stated they disagree with this statement, and **16** stated they strongly disagree, **2** people reported that this is not applicable to them.

Participants were asked how much they agree that the treatment they receive takes into account their whole medical history rather than just a single condition, **3** people indicated they strongly agree with this statement, **13** people agree, **26** people disagree, and **15** strongly disagree, **1** person reported this was not applicable.

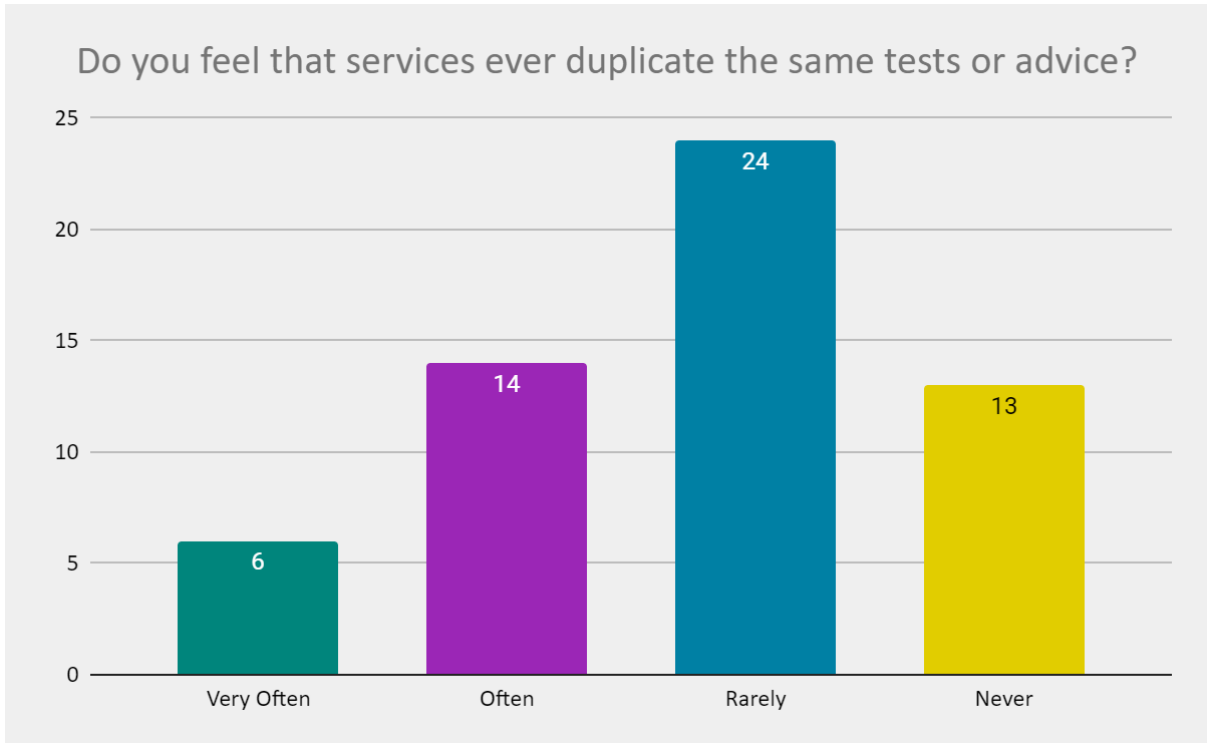
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When asked if their care and treatment is coordinated well 4 people advised they strongly agree with this statement, **12** people agree, **24** people disagree, and **14** strongly disagree, **3** people advised that this was not applicable.

The final statement asked participants to what extent they agree or disagree that there is adequate communication between their specialists and their GP, **5** people advised that they strongly agree with this statement, **11** people reported that they agree, **26** people stated that they disagree, and **15** people advised that they strongly disagree, **1** person reported that this is not applicable to their situation.



The next question asked participants if they feel that services ever duplicate the same tests or advice. The majority, **24** respondents, reported that this rarely happens, **14** stated it often happens, **13** advised that it never happens, and **4** told us that this happens very often.



We then asked participants to explain their answer. Comments were grouped into themes and three themes emerged from the feedback. The most common theme that was discussed was **Service Communication**, and some of this feedback was positive, one person told us that *‘there are agreed protocols between my GP and my consultants. Detailed post appointment consultant notes are forwarded to me and my GP with agreed actions’*, another told us that there is *‘good communication between vocal cord therapist and my GP’*, and some else reported that *‘liaison between GP, MS nurse, diabetes nurse and mental health worker at GP practice avoids duplication’*.

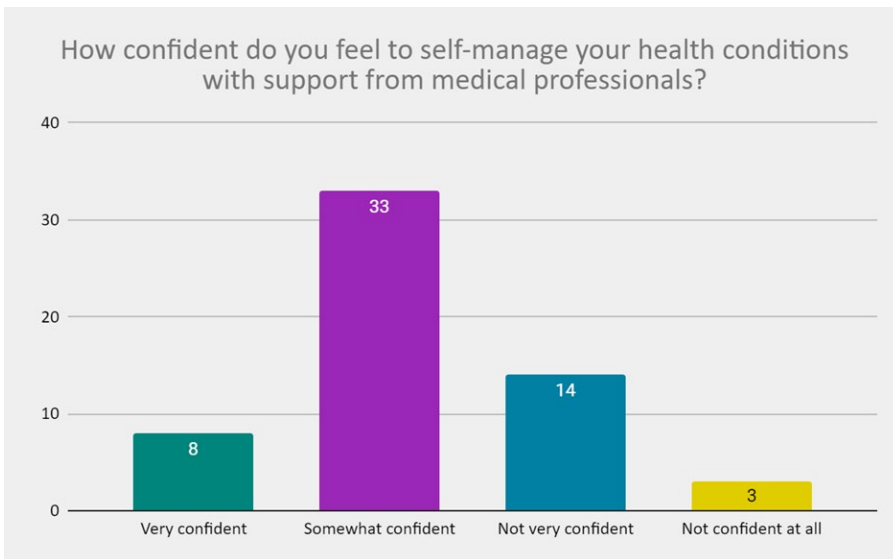
Other feedback we received suggested that communication in some areas could be improved, one participant reported that their *‘GP is always left out the loop’*, someone else told us that the services that they are involved with are *‘not usually connected’*.

*‘Specialist and GP’s need to communicate.’*

Some people spoke about tests being duplicated, one told us that *'problems arise when my GP sends me for tests, he sends me to one place but doesn't update with local NHS'* they went on to say that this *'duplicates resources which does not make any sense'*, someone else reported that they *'have the same group of tests at all departments'* and another stated that *'tests are repeated between surgery and hospital and specialists as they don't communicate effectively'*.

Other comments related to Patient Information and Records, one participant told us that they have to *'repeat the same information regularly between different services'*, another stated that they *'don't get any information from anyone'* as their *'GP cannot answer my questions and I only see my cardiologist once a year so anything I want to know goes unanswered'*, a third person told us that *'a lot is relied on me having to verbally say all the stuff even though it should be somewhere on the computer from the other departments'*.

Participants were asked how confident they feel to self-manage their health conditions with the support they have from medical professionals, **33** people indicated that they are somewhat confident, **14** people selected not very confident, **8** people selected very confident, and **3** people indicated that they are not confident at all to manage their health conditions.



Participants were asked to explain their answer, the comments we received were very much related to the specific experiences or conditions of each participant and as such, no common themes emerged from the feedback.

One of the people who felt confident to manage their conditions with the support of the medical professionals involved in their care and treatment explained that *'over a period of time a level of trust has been built up between myself, my consultants and my GP'*, another person told us that if they were *'unsure, I have always been able to ask for advice and/ or direction for the next step to take'*, another stated that *'everything is explained to me and I have requested that every consultant I deal with communicates with the others'*.

One of the people who were not confident reported they felt if they *'had some instructions I'm sure I could'* manage better, another told us that they *'don't really know enough about what causes my problems, the effect of their interaction, or how to manage the side effect of medication'* and another advised *'if I could access professionals when a problem arises, I could adjust whatever is required, both for my heart and diabetes'*.

Participants were asked what single change would make the biggest difference to how they are able to self-manage their health conditions, comments were grouped into themes and 4 themes emerged. The most common theme that was discussed was **Service Coordination**, one person told us that the thing that would make the biggest difference to them is if *'the health professionals coordinated my care'*, another explained that there is a need to ensure that *'any change in professionals involved in my care involves a proper handover'* someone else told us that it would make a great difference to them if there was *'better communication between departments'* and another wanted *'one named specialist'*.

Other participants spoke about **Patient Involvement**, one person told us that it would help them to have a medical professional involved in their care who is *'prepared to talk to me so we could work out what my current/continuing needs are, and how then they'd best be effectively managed'* they went on further to add that this can only be *achieved 'by us both working together'*, someone else explained that it would help them if *'someone treats me as a person not just what's wrong with me'*, and another stated that they need *'someone to talk to'* as *'doctors rush you'* and *'specialists treat you as a nuisance because they are so busy'*. Some people spoke about **Accessibility**, one person stated it would help them if they could *'feel confident'* that they could *'speak to my GP whenever I have any concerns'* and another reported that it would help them greatly to *'know that there was a single person who I could contact who would know my whole health picture so I do not have to explain the problems over and over which makes me feel worse every time I have to do it'* someone else told us that it would help if they were *'able to obtain medical care when I need it'* and another advised that *'having a GP that has time'* would make a big difference to them.

**Support and Treatment** was also identified as a theme, one person spoke about how *'more pain management options'* would make a big difference to them, another felt that *'more information and guidance'* should be available, and someone else told us that *'having extra help'* would benefit them the most.

The last question asked participants if they had any other comments to make about living with multiple morbidities, as the responses we received related to things that were personal to each individual's situation, no themes emerged from the feedback.

One participant told us that it would help if patients' needs *'were treated holistically'*, and another spoke about how it would help to *'be able to talk about multiple issues with one professional'*, another felt that *'community care services are non-existent'* and someone else stated that things would improve if the professionals involved in their care *'all work as one and combine physical, emotional and mental health together'*.

Other comments described good practice that they have experienced, one told us that they *'have generally been happy with the way my GP has dealt with my different conditions'*, another stated that *'their diabetic nurse is fantastic, as is the support I receive for my neuropathy'*, and someone else told us *'when I asked for help with my arthritis, I was quickly referred for an x-ray and put in touch with the practice physio who supplied useful advice'*.

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# Conclusion

The sample size is not statistically significant and therefore, we cannot draw generalised conclusions from the survey but what the project has done is provide insight into the experiences of those people who took part.

Two thirds of the people who took part in the survey said that their health conditions impacted on their lives to a large extent and the comments that were made gave an insight into the range of ways that their lives are affected. These included impacts on mobility, mental health, and their independence as well as how it affected them socially in their relationships and activities and how their daily routine was affected. The responses show how living with more than one long term condition can significantly affect all aspects of an individual's life.

People generally felt that they were involved in the decision making about their care and most people were either very confident or somewhat confident in self managing their conditions.

When asked about if they felt that professionals saw the whole person rather than a health condition there were similar numbers that felt they were seen as a whole person to those who felt that their health condition was seen in isolation.

# Recommendations

1

Further investigate the role of care co-ordinators, such as eligibility criteria to have a care co-ordinator; what the experiences are of those who have a care co-ordinator and what their expectations are of that role.

2

Improve communication between specialists in secondary care and medical professionals in primary care in order to improve the care that individuals receive.

3

Explore ways to reduce the need for people to explain their LTCH and health needs each time they see a new healthcare professional.

4

Improve communication and understanding between different specialisms in order to ensure that people are treated holistically taking into account their whole medical history.

5

GP Practices to look at signposting people with LTCH to appropriate support services to look at ways to improve patients' quality of life.





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