

Neighbourhood health

Listening to people in Leeds about neighbourhood-based approaches to health and care services

Summer 2025

Your healthwatch Leeds

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Contents

Introduction 6

Executive Summary 7

Integrating services 8

Self-care and self-management of disabilities and long term conditions 8

Being in community spaces 9

Being online 9

Preventing ill health 10

Findings from the unpaid carers' survey 10

Findings from the children and young people's and parents' and carers' surveys 11

Desktop review 12

Background 13

What is neighbourhood health? 14

National aims 15

Our mission 15

What we did 16

The general population 17

Current users of community health services 18

Children and young people 18

Parents and carers 19

Unpaid carers 19

Voluntary and community sector workers 19

Groups we attended 20

Chapter 1: Results of the General Survey 24

1.1 About our respondents 24

a) Demographics 24

b) Face-to-face responses vs online responses 30

c) Our respondents and IMD deciles 32

1.2 Integrated services 38

a) Where have you had appointments with a health professional in the past 12 months? 38

1.3 Self-care and self-management of disabilities and long term conditions 46

a) When you are worried about your disability or condition or feel it's getting worse, who do you get in touch with? 46

b) Please tell us how well this usually works for you as a way of getting help with your condition 52

c) Is there anything that makes it difficult to look after your health the way you would like to? 58

d) Where our respondents without a health condition or disability look first for help 65

1.4 Being in community spaces 71

a) In your day-to-day life, do you use public spaces like libraries and community centres? 71

b) Would you feel comfortable having appointments with a health professional in public places? 74

c) What worries might you have about coming to a health appointment in a public place like a library or community centre? 78

1.5 Being online 84

a) Are you able to use the internet every day? 84

b) How would you like to use the internet (or already use the internet) to connect with health and care services? 90

1.6 Preventing ill health 98

a) Do you worry that things about your life now might affect your health, now or in the future? 98

b) Are there any changes you would like to make which might help to keep you healthy? 104

c) What is stopping you from making those changes, if anything? 113

d) In the past couple of years, have you had to think about paying for health treatment that previously you might have got via the NHS? 116

1.7 Case Studies 119

Leeds Community Healthcare's Diabetes Groups 119

Leeds Community Health Care's Youth Board 119

ASHA Neighbourhood Project 120

Better Leeds Communities 121
Association of Blind Asians Carers Group 123
DASSI 125
Hamwattan Men's Group 127
Kushy Nanas Older Women's Group (Health for All) 128
The Old Fire Station Café, Gipton 130
Sanskar Women's Group, the Cardigan Centre 131
Sawan Vihar's Women's Group 132
St Martin's Coffee Morning (Polish Centre, Chapeltown) 134
Tech, Talk and Toast (Gipton Old Fire Station) 134
The Friends and Family Test 136

Chapter 2: Unpaid Carer 138

Demographics of survey and focus group participants 138
Survey respondents 138
Carers 138
Person who is cared for (data provided by carer respondents) 139
Focus group participants 140

2.1 Carers' own health and access to health and care services 142

2.2 Supporting the person you care for to look after their health and access services 146
Getting an appointment(s) 146
Communication 147
Co-ordination 149
Lack of ongoing support 150

2.3 Carers and the person they care for accessing services together 151
Accessing online health and care services together 151
Accessing local services together 153

Conclusion and recommendations from carers 155

Chapter 3: Children and young people 157

Demographics from the children and young people survey 157

3.1 Learning about health 158

3.2 Confidence in looking after your own health 159

3.3 Mental health 160

Chapter 4: Parents and carers 162

Demographics of parents and carers 162

Chapter 5: Third Sector 171

5.1 About the Third Sector 171

5.2 Readiness to deliver care 172

5.3 NHS support for the Third Sector communities 173

Chapter 6: Desktop Review of Engagements Focussing on Community Services 174

6.1 What is insight and what can it do? 175

6.2 Three Cs: communication, compassion, coordination 176

Communication 177

Compassion 178

Coordination 179

The Three Cs: where to start 180

6.3 Timely community services 181

Timely services: where to start 182

6.4 Service availability 184

Service availability: where to start 185

6.5 Geared up for complexity 186

Gearing up services for complexity: where to start 189

6.6 Understanding the role of the unpaid carer 190

Services' support for carers: where to start 192

6.7 Digital technology 193

Services and digital technology: where to start 196

6.8 Understanding how other public services contribute to health and wellbeing 198

Services and wider public wellbeing: where to start 202

6.9 Adhering to the Accessible Information Standard 204

Services and AIS: where to start 205

Service provider response 206

Raise LCH staff awareness about the findings 206

Preventing ill health 206

Children's services 206

Carers 207

Partnership working with the Third Sector 208

Next Steps 209

Acknowledgements 210

References 211

Introduction

This report details the findings from a series of groups in Leeds that we visited and from listening to people in Leeds to understand how they experience neighbourhood health and what such an approach could mean for them in the future.

Neighbourhood health refers to organising health services so that they are closer to where people live and work, easier to access, and better at preventing illness. It is an important part of how the UK government wants to change health services.

We hope readers get an overarching impression of how neighbourhood health and people's experience relate to one another. Just as importantly, the report seeks to highlight the complexities and tensions that must be addressed as neighbourhood health becomes a priority for the city, and it acknowledges the diversity of views and experiences among Leeds' residents. By adopting an early focus on people's experiences, Leeds is putting itself in a good position to create a neighbourhood health model that flexes to meet the needs of as many residents as possible.

This project was commissioned by Leeds Community Healthcare and led by Healthwatch Leeds, in partnership with Carers Leeds and Forum Central, and supported by numerous third sector organisations. On behalf of all these partners, we would like to thank everyone who took part in the engagements. Their willingness to share their thoughts and their time with us could not be more crucial or more valued.



Executive Summary

This report looks at the views and experiences of:

- 513 adults with and without health conditions and disabilities.
- 24+ children and young people.
- 44 parents and carers.
- 231+ unpaid carers.
- 47 voluntary and community sector organisations.

It organises the information we gathered into five themes. Because the health and care world in Leeds aims to improve the health of the poorest, the fastest (as stated in the Leeds Health and Wellbeing Strategy 2023 to 2030), there is a strong focus on inequalities throughout the report. Our analysis identifies parts of the neighbourhood health approach which have the potential to narrow inequalities, as well as the risks of these widening if we don't get the model right. The dedicated sections about unpaid carers, children and young people, and parents and carers each have their own key learning, and readers are encouraged to consider this summary alongside the targeted findings.

The following is an introduction to some of the themes' key points included.

Integrating services

People were more likely to use a high number of services annually if they were aged 56 or older, had difficulties getting out of the house, had a mental health or neurodivergent condition, or received state benefits.

People living in the most deprived postcodes tended to have contact with fewer services, despite being more likely to have a disability or health condition.

Self-care and self-management of disabilities and long term conditions

Groups reporting lower satisfaction with ongoing support with their health condition included people under retirement age, people who have difficulties getting out of the house and people facing the greatest poverty.

People with disabilities reported that they perceived their health condition as their biggest barrier to self-care, particularly for those living in the deepest poverty.

Any community-based service development must take into account that people's attitudes to GPs are the most valued first port of call for health worries.

Being in community spaces

Most of our respondents were not users of community spaces, including those at greater risk of inequalities.

Most of our respondents were open to having appointments in public spaces, provided privacy is guaranteed, except for people with difficulty getting out of the house. Hesitancy was also greater among our Black and mixed Black respondents, and our respondents facing the greatest poverty.

Concerns about privacy, accessibility, infection control and other issues will need to be addressed with the public.

Being online

There remain important groups of people who can't use the internet daily and don't want to, notably older people, people with difficulty getting out of the house, and younger people in receipt of state benefits. A minority of them would be motivated to use digital functions if enabled to do so.

Digital services that are most attractive to the respondents tend to imply a more responsive, two-way relationship with the services.

Preventing ill health

People are most open to support with changing their lifestyle between the ages of 46 and 55.

Any support aimed at helping people live healthier lifestyles should be tailored based on age and gender, as motivations differ.

Interventions targeting younger people could have a big impact, given their high motivation to change their behaviour.

Guidance on stress management and improved sleep could be impactful for people concerned about the health effects of their lifestyle. People facing the greatest poverty are more interested than other groups in getting more rest and quitting smoking.

Busyness (including work-related busyness) is a barrier that gets in the way of people changing their lifestyles.

Findings from the unpaid carers' survey

"There was a lot of support from carers for health and care services being closer to home and the idea of 'hubs' where services were co-located. Many carers could see the benefit of more health and care services being delivered from local venues, especially if it was easy to get to and inclusive of the additional needs of carers and those they care for. The biggest concern for carers was the ease, flexibility and timeliness of appointments." For more, please turn to p140.

Findings from the children and young people's and parents' and carers' surveys

Parents and carers were supportive of having appointments in community settings but would like to know how noise would be managed.

Parents and carers can struggle to manage multiple accounts for themselves and their children when accessing online services.

Young people, parents, and carers named friends and family as the greatest source of health advice. They reported not always feeling truly listened to by health professionals.

While schools have been an important source of mental health information for some young people, parents, and carers, over half reported not having received any guidance.

For more, please turn to p145.

Desktop review

In addition to the findings from our focused engagements (primary research), you can read a desktop review (secondary research) summarising "what good looks like" in community-based services (p163). The review outlines eight principles that should serve as the foundation for any neighbourhood health service. The principles state that good community services are:

- Shaped by the Three Cs: communication, compassion, coordination.
- Timely.
- Available.
- Geared up for complexity.
- Understanding of the role of the unpaid carer.
- Sensitive to people's comfort with digital technology.
- Understanding of how other public services contribute to health and wellbeing.
- Compliant with the Accessible Information Standard.

We hope this report gives you a grounding in people's experiences of and attitudes towards neighbourhood approaches to health and care. We hope it inspires you to continue the commitment to making people central to health and care service development and to include their views and voices in every stage of the journey.

Background

Leeds Community Healthcare NHS Trust

This engagement was commissioned by Leeds Community Healthcare (LCH) in early 2025. LCH set out its reasoning as follows:

"The ultimate aim of the engagement work is to produce a report, and other associated materials, that provides additional insight in describing what does good look like for the people of Leeds in relation to community-based healthcare – i.e. anything that is delivered outside of a traditional hospital setting."

Shifts in national policy around neighbourhood health made this piece of work particularly pertinent. The NHS in England has described the need to transform health and care as "urgent" and said that an integrated response to the current system's problems is crucial.

What is neighbourhood health?

In, the NHS in England guidelines, it states that:

"Neighbourhood health aims to create healthier communities, helping people of all ages live healthy, active and independent lives for as long as possible while improving their experience of health and social care, and increasing their agency in managing their own care. This will be achieved by better connecting and optimising health and care resource through 3 key shifts at the core of the government's health mission:



- **from hospital to community – providing better care close to or in people's own homes, helping them to maintain their independence for as long as possible, only using hospitals when it is clinically necessary for their care.**

- **from treatment to prevention – promoting health literacy, supporting early intervention and reducing health deterioration or avoidable exacerbations of ill health.**





- **from analogue to digital – greater use of digital infrastructure and solutions to improve care."**

These three shifts, therefore, informed the questions we asked the public.



National aims

While designing the engagement, we also considered the second and third of three "aims for all neighbourhoods over the next 5 to 10 years" set out nationally, which are:

- **"NHS and social care working together to prevent people spending unnecessary time in hospital or care homes.**
- **Strengthening primary and community-based care to enable more people to be supported closer to home or work.**
- **Connecting people accessing health and care to wider public services and third sector support, including social care, public health and other local government services."**

Our mission

Our mission was to engage with people to improve our understanding of:

- The extent to which the aims are already being met within people's experience of health and care.
- The ways in which the aims could be enacted to fulfil people's needs.
- Any ways in which the aims could prove problematic to people's experience (such as any practical barriers that could preclude their achievement and any ways in which the aims don't marry well with what people say they need and want).

What we did

Given the broad scope of our mission, this was a complex project. The neighbourhood health approach is relevant to everyone who uses or will use NHS services, regardless of age or health. We needed to include a real diversity of demographics, protected characteristics and experiences, which is why unpaid carers, children and young people, and parents and carers were approached using tailored sets of questions. We also wanted to ensure people currently using community services – Leeds Community Healthcare NHS Trust's patients – were given opportunities to take part.

We responded to the challenge by identifying our target groups and designing a range of ways for each to have their say. We approached community organisations that offered access to people within our target groups (such as culturally diverse communities) and / or people who are typically less likely to respond to feedback-seeking exercises without being prompted (such as men in employment). We liaised with LCH so that we could speak to users of some of its most widely used services (such as Musculoskeletal) and access patients across different geographies of the city, including those that are most deprived and / or culturally diverse.

The general population

We wanted the engagement to be relevant and accessible to everyone in Leeds, so we offered a range of different ways for them to have their say, all of which fed into a survey for adults with or without health conditions. Some questions were for all respondents; others were only for people with a long-term health condition or disability; and others were only for people without a condition or disability.

The survey was shared online via social media platforms, targeting people who wished to contribute remotely and independently.

It was also taken out to a range of settings so that our community project workers could talk people through the survey face-to-face. This was important because people at risk of health inequalities are less likely to engage with online surveys for many reasons. (For example, they might be unable to get online; they might struggle to find the time; they might not have the language or literacy skills and confidence needed to fill in a survey independently; or they might not trust that their views will be listened to.)

The engagements took place in a range of settings to engage with a real diversity of groups, including community centres and third sector-led groups, workplaces, and health and care settings, such as recovery hubs. For full details of where we engaged with people, please turn to the section titled “Groups we attended” on page 20.

For more information about the differences between our respondents who engaged online and those who involved in person and the importance of diversity in engagement methods, please turn to the section titled "Face-to-face responses vs online responses" on page 30.

Current users of community health services

We collaborated with Leeds Community Healthcare NHS Trust to send a paper copy of the survey to patients attending clinics in late June and early July 2025. In parallel with the face-to-face engagements in health settings, this approach ensured that current community service users had a strong voice in the project. Phone calls were also made to people who could not leave the house to attend clinics, and a special question was added to the Friends and Family Test (p126).

Children and young people

A tailored version of the general survey was sent out via clinics so that young people could contribute. Our face-to-face engagements also included visits to young people's groups.

Parents and carers

Parents and carers had their own version of the survey, which was sent out via Leeds Community Healthcare clinics.

Unpaid carers

Leeds Community Healthcare identified unpaid carers as a group they wanted to hear from. Carers Leeds partnered in the project to ensure carers' voices were heard. They engaged with unpaid carers at their regular meetups and online, with a tailored survey.

Voluntary and community sector workers

People who work in the voluntary and community sector have an important role to play in any shift towards community-based services, not least because they may be implicated as partners depending on how neighbourhood health is rolled out in Leeds. A tailored survey was sent out to workers via another project partner, Forum Central.



Groups we attended

The engagements took place in June and early July 2025. They were led by staff from Healthwatch Leeds, with volunteer support, except for those run by Carers Leeds (marked by the Target Population being Carers)..

Healthwatch Leeds and Leeds Community Healthcare NHS Trust (LCH) are members of the People's Voices Partnership (PVP), a grouping of engagement leads from health and care and related organisations. The PVP encourages health and care decision-makers to engage, so they can hear for themselves what matters most to people. With that principle in mind, LCH staff were encouraged to attend the engagements. Dates where a senior health and care worker attended are marked with a DM (decision-maker) in the 'Date' column.

Target population	Date	Group description	Location	Method
Deprivation	28 May	Tech, Talk and Toast	The Old Fire Station, LS9	Focus Group
People receiving care at home	29 May	Individual calls	N/A	Survey
Deprivation	30 May	Tech, Talk and Toast	The Old Fire Station, LS9	Survey
Culturally diverse	4 June	Women's group	Asha Neighbourhood Project LS11	Focus group
Bed / housebound	4 June	Wharfdale Recovery Hub	Wharfedale General Hospital, LS21	Survey
Culturally diverse	5 June	Coffee morning	Polish Centre, LS7	Survey
Culturally diverse	7 June	Skilled workers and migrants	Chapeltown Road, LS7	Survey
LCH service	9 June	Diabetes programme	Armley Moor Health Centre, LS12	Survey
Culturally diverse	9 June	Sikh elders	Polish Centre, LS7	Survey
Men and mental health	11 June	Gipton men's group	Church of the Epiphany, LS9	Survey
Culturally diverse	11 June	Women's group	Better Leeds Communities, LS6	Focus group
Carers	12 June	Dementia carers support	Church of the Nazarene, Morley, LS27	Focus group

Target population	Date	Group description	Location	Method
LCH service	12 June	Diabetes programme	Reginald Centre, LS7	Survey
Partially sighted or blind	12 June	Association of Blind Asians	Muir Ct, LS6	Survey
Culturally diverse	13 June DM	Sawan Vihar women's group	Holy Trinity, LS6	Focus group
Deprivation	17 June	Hunslet Elders Group	Involve Learning Centre, LS10	Focus group
Young People	17 June	SEND Students	Leeds City College, LS11	Survey
LCH service	18 June	Musculoskeletal (MSK) and Pain	Armley Moor Health Centre, LS12	Survey
Carers	18 June	City Centre	Age UK, Bradbury Building, LS2	Focus group
Deprivation	19 June DM	People's pantry	Middleton Family Centre, LS10	Survey
LCH service	19 June	Musculoskeletal	East Leeds Health Centre, LS9	Survey
LCH service	23 June	Pulmonary Rehab Clinic	Woodhouse Health Centre, LS6	Survey
LCH service	24 June	Pulmonary Rehab Clinic	The Old Fire Station, LS9	Survey
Young people	25 June	Youthwatch	NIHR Leeds Biomedical Research Centre, LS7	Survey

Target population	Date	Group description	Location	Method
Carers	26 June	Pudsey	Pudsey Wellbeing Centre, LS28	Focus group
Parents	26 June DM	Mums and tots	Beeston Village Community Centre, LS11	Survey
Culturally diverse	26 June	Kushy Nanas	Building Blocks Centre, LS11	Focus group
LCH staff	26 June	LCH Clinical Conference	St George's Centre, LS1	Survey
Men	30 June	Hamwattan men's group	Hares View, LS8	Focus group
Carers	1 July DM	Horsforth	The Grove Methodist Centre, LS18	Focus group
Men	2 July DM	Men at work	Welfare Area, LS3	Survey
Carers	2 July	Crossgates	Crossgates and District Good Neighbours, LS15	Focus group
Culturally diverse	2 July	Dassi group	Dewsbury Road Community Centre, LS11	Survey
Culturally diverse	2 July	ABA Carers Group	Community Wellbeing Hub, LS7	Focus group
Carers	3 July	South Leeds women's group	Cardinal Court Extra Care Scheme, LS11	Focus group
Young people	7 July	LCH Youth Board	Online	Focus group

Chapter 1: Results of the General Survey

1.1 About our respondents

a) Demographics

Demographics at a glance

- 513 responses.
- 62% had a long-term condition or disability.
- 18% had some level of difficulty leaving the house.
- 71% were White British.
- 67% were female.
- 54% were aged 56+.
- 19% were unpaid carers.
- 44% were in employment.

How these demographics compare with Leeds' population as a whole

It was important that our project included the views of people with a disability or long-term health condition, and it was designed to reach them. For that reason, we got a greater proportion of responses from people with disabilities compared with Leeds as a whole (7.6% of people in Leeds had a disability according to the 2021 census data).



The proportion of our respondents belonging to an ethnic group other than White British was also higher than Leeds a whole (79% of Leeds residents described themselves as White British in 2021). This was due to our efforts to ensure the project included a diverse range of views. Unpaid carers were also over-represented (they make up 4.3% of Leeds' population).



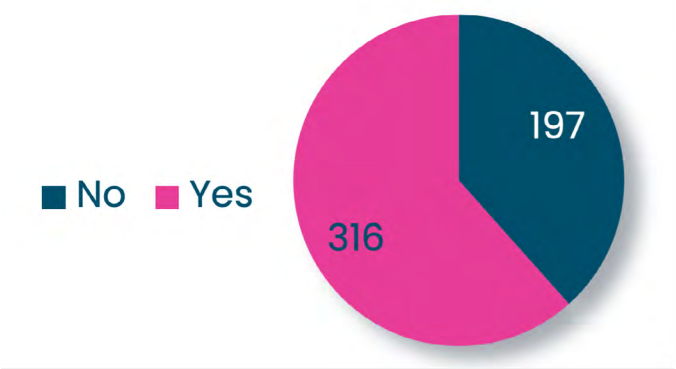
People in employment made up a smaller share of our survey respondents compared with the population of Leeds (54% of which was employed in 2021). This may be due to our focus on speaking with people with health conditions.

We spoke to a larger proportion of women compared with Leeds' population, despite our efforts to seek out men's voices. While this is common in engagements aimed at a broad audience, there is more work to be done to include men in patient voice projects.

Our respondents tended to be older than Leeds' population, the median age of which is 36. For more information about Leeds' population, please refer to the 2021 cencus data and the Leeds Observatory cencus 2021.

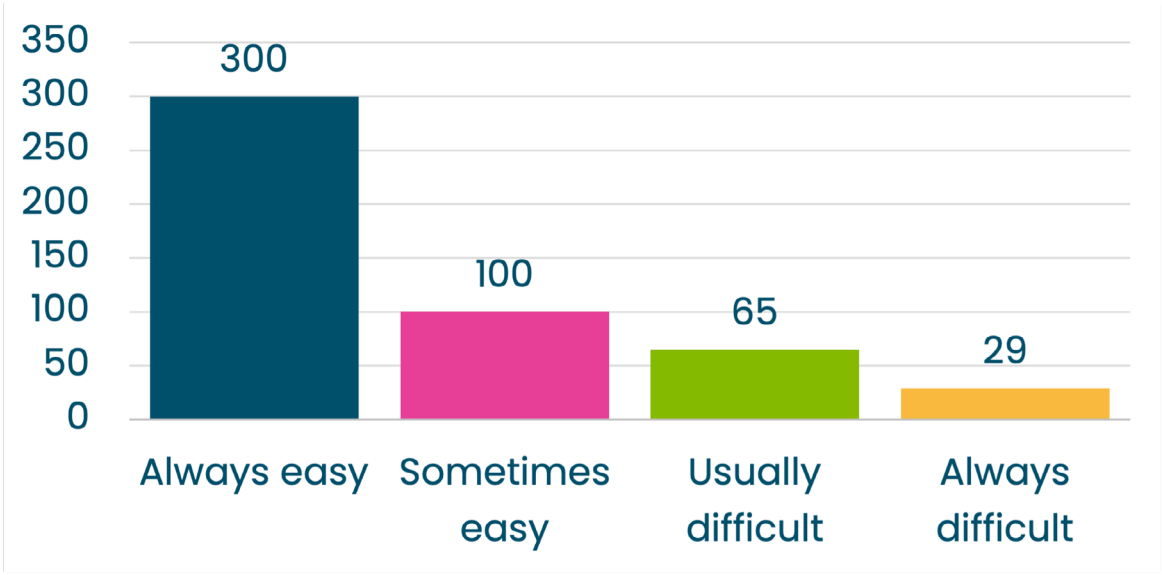
We received 513 responses to our general survey.

Figure 1: Do you have a disability or long-term health condition?



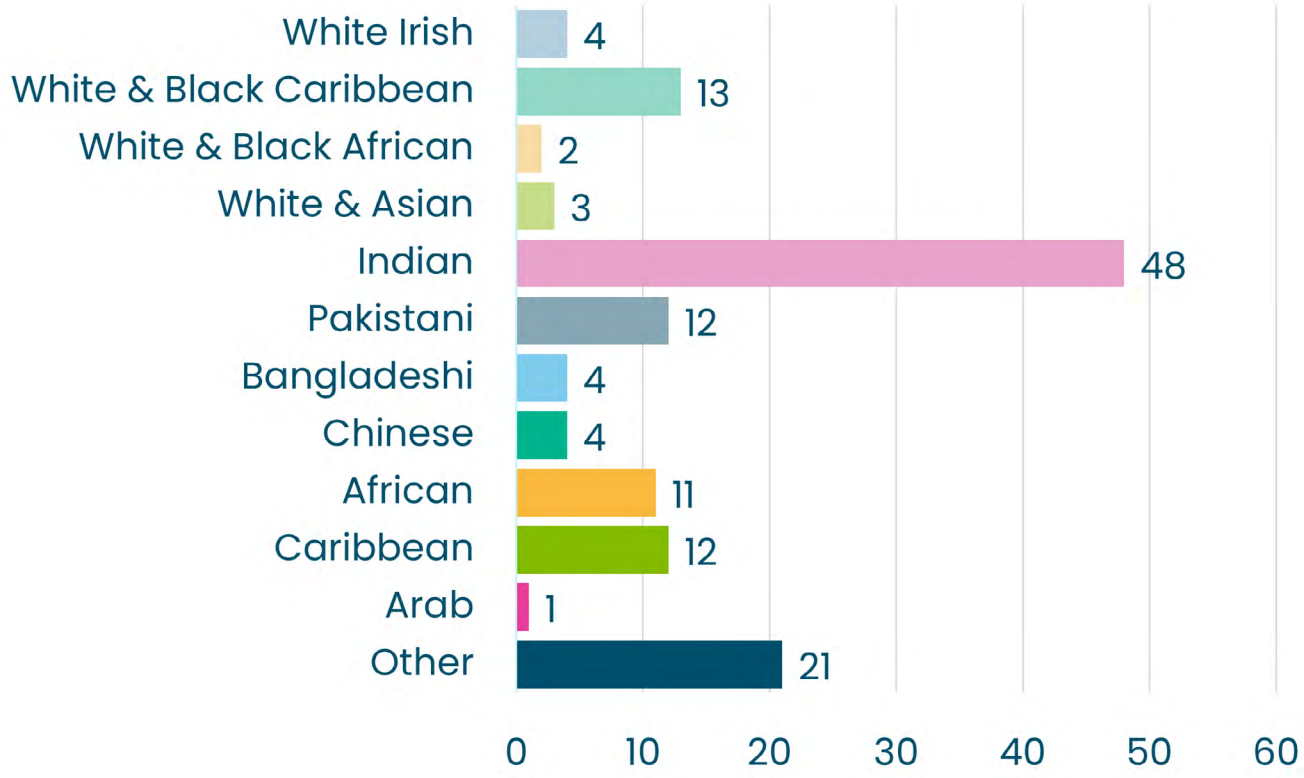
The majority of our respondents had a disability or long-term health condition.

Figure 2: How easy is it for you to get out of the house?



Most of our respondents said they find it easy to get out of the house at least most of the time. 94 experienced some level of difficulty.

Figure 3: How would you describe your ethnicity?



71% of our respondents described their ethnicity as White British. Figure 3 shows a breakdown of the respondents who described their ethnicity in a different way.

Other ways in which people described their ethnicity were as follows: “Middle East”, “Other white background - in my case East-European”, “White mixed”, “Kashmiri”, “White Polish”, “other white”, “Indian British”, “I am autistic, and that is my peer group. I experience discrimination from the white British group to which I am assumed to belong”, “Mixed race”, “British”, “Iranian”, “Iranian (Persian)”, “Mixed- African, Arabic and Kashmiri”, “Albanian”, “British Indian”, “Pakistani British”, “French”, “Black British”, “Afghanistan”.

Figure 4:How would you describe your health condition(s) or disability?

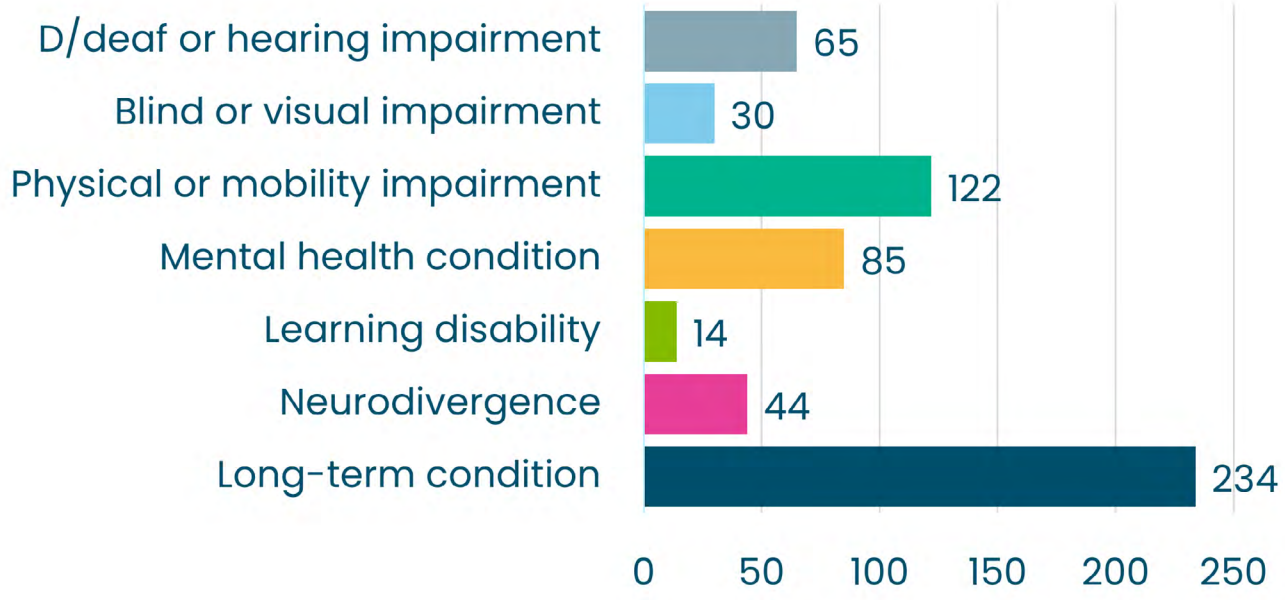
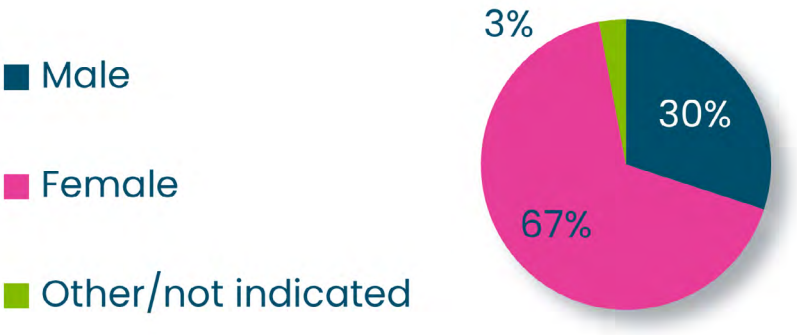


Figure 4 represents how our respondents describe any disabilities or health conditions they have. (Please note that it excludes people who left this question blank or described themselves as not having a disability.)

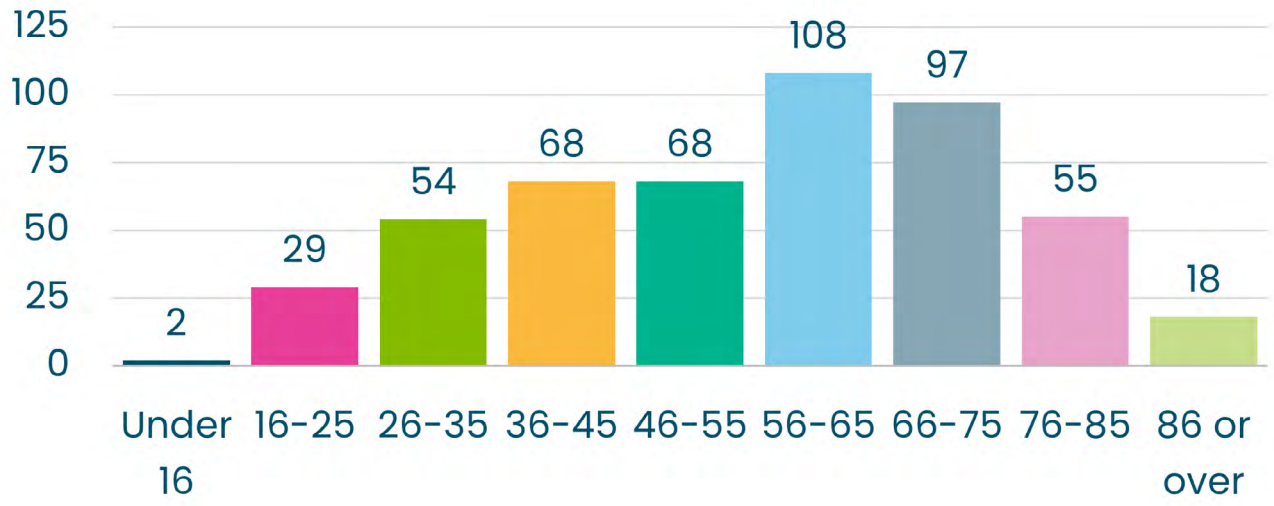
25 people described themselves as having an "other" health issue, but it is worth noting that the majority of these would likely fall into the category of "long-term health condition".

Figure 5: How would you describe your gender?



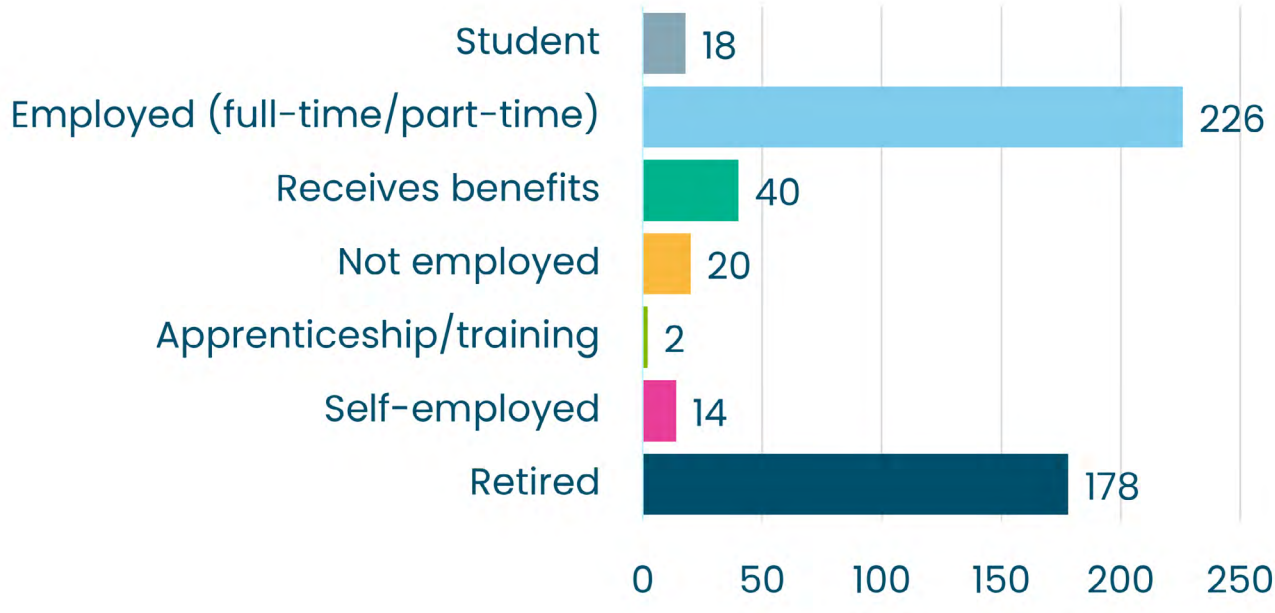
The majority of our respondents were female.

Figure 6: What is your age?



As Figure 6 shows, our respondents tended to skew older. 54% were aged 56 or older.

Figure 7: Respondents occupations



19% of our respondents told us they were unpaid carers. A little fewer than half our respondents were employed either full or part time. The next largest group was made up of retired people.

b) Face-to-face responses vs online responses

Each respondent engaged with us via one of the following methods:

- Face-to-face: via a one-to-one interview or a focus group.
- Online: via a link shared on social media, in online bulletins, etc.
- Paper copies of the survey sent out via LCH clinics.

Figure 8: Number of responses

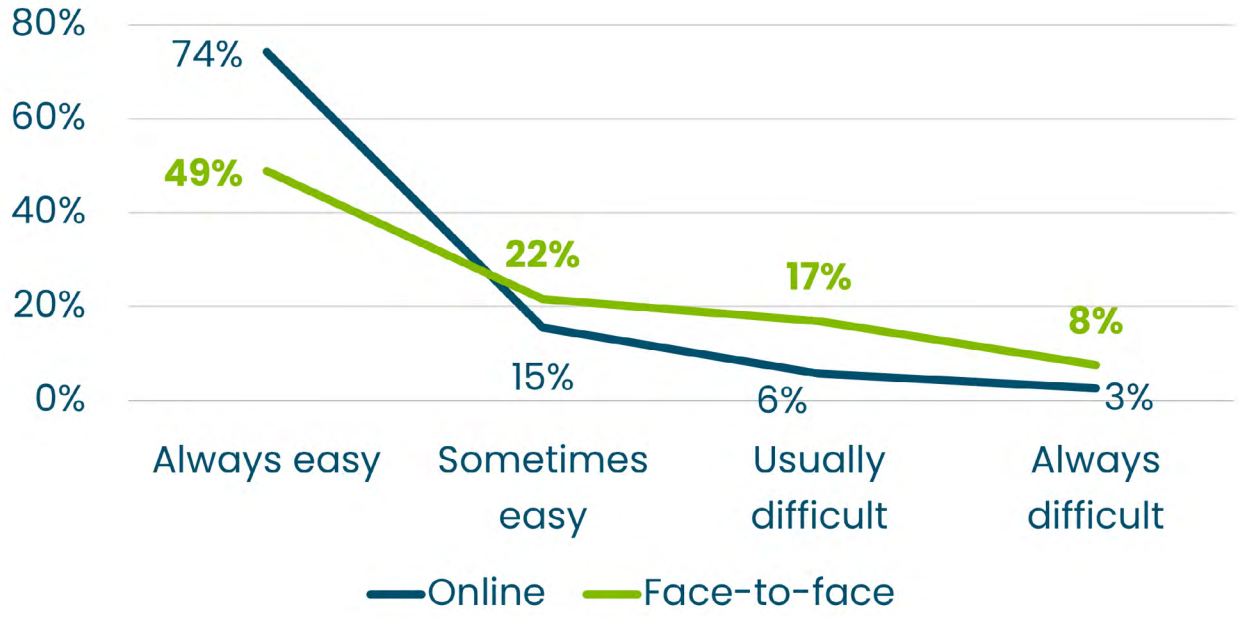


Figure 8 shows how many people we engaged with using each engagement method.

To make our project as inclusive as possible and capture the views of a diverse group of people, we engaged in different ways. By comparing response trends, we can see that combining engagement methods gives us a broader, more complex picture of people's experiences.

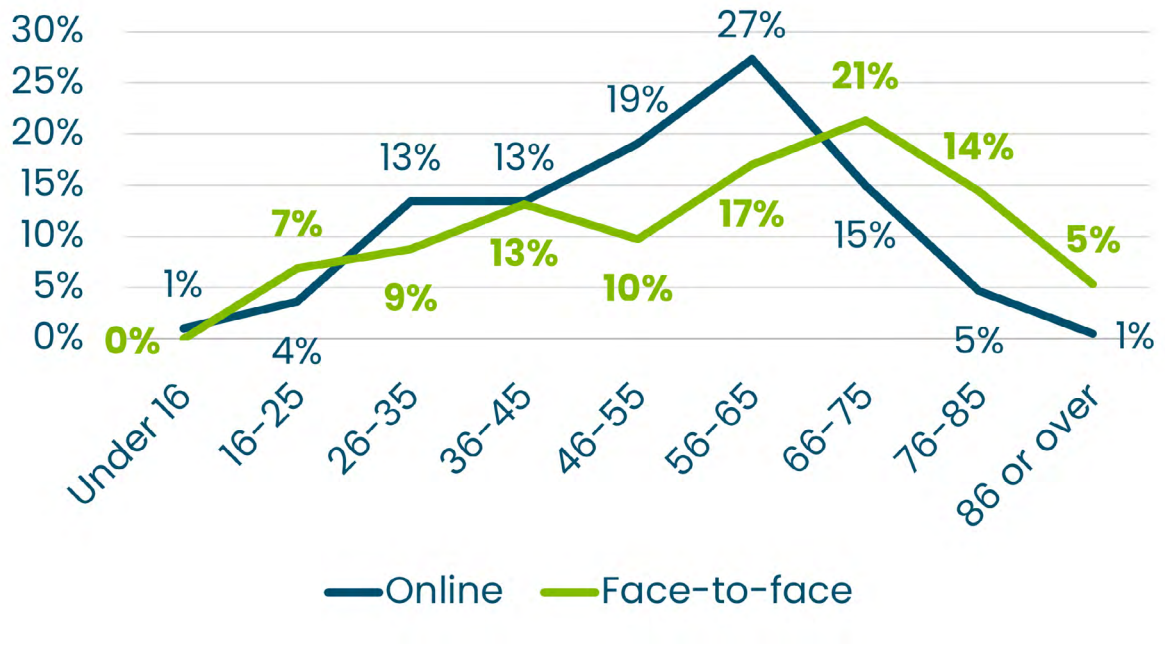
- People we engaged with face-to-face or through hard-copy surveys were generally in poorer health. 69% said they had a health condition or disability, compared with 51% for online respondents. People engaged with face-to-face or through hard copy surveys were more likely to say they have a physical or mobility problem, hearing or sight impairments, or a long-term condition than those engaged with online. Proportions of people with a mental health condition, learning disability or neurodivergent condition were similar across both categories.

Figure 9: How easy is it for you to get out of the house?



- People we engaged with face-to-face or via hard copy were more likely to experience mobility issues and/or difficulty getting out of the house (Figure 9).
- People we engaged with face-to-face or via hard copy were less likely to be White British. 82% of our online respondents described their ethnicity that way, compared with 64% of our other respondents.
- Men made up 38% of the responses we gathered face-to-face or via hard copy, compared with 17% online.

Figure 10: Respondents' ages (online vs face-to-face)



- Those who responded online were younger on the whole (Figure 10)
- 10% of our face-to-face or hard copy respondents received state benefits, compared with 5% for online respondents. The former were also more likely to be retired (41% vs 25%). Our online respondents were much more likely to be in employment (62%) compared with other respondents (33%).

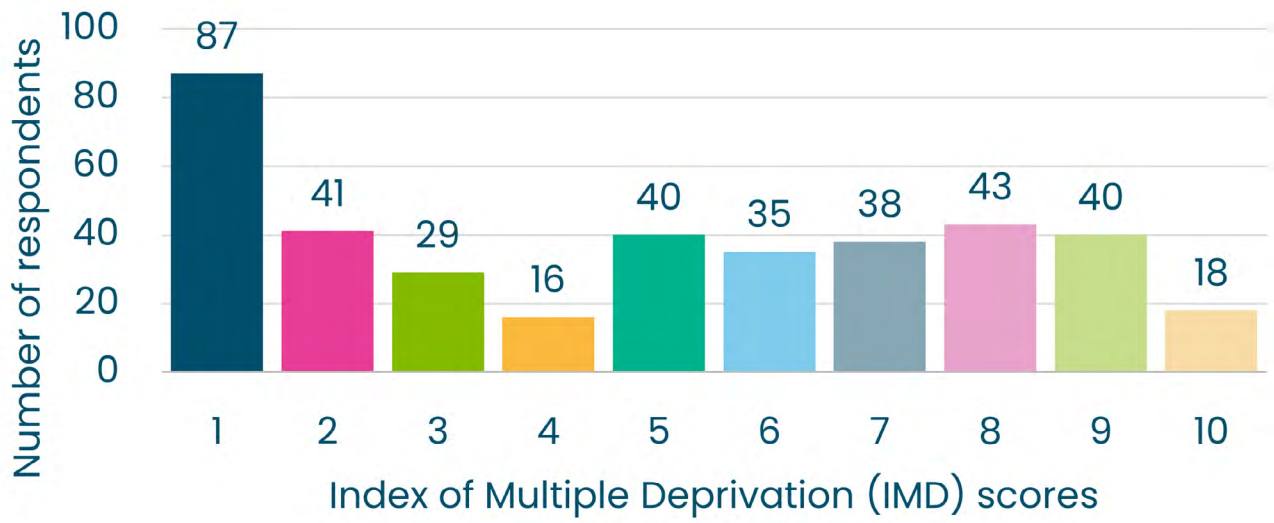
c) Our respondents and IMD deciles

Index of Multiple Deprivation (IMD) scores (2019) are provided by the Ministry of Housing, Communities and Local Government as the "official measure of relative deprivation for small areas in England". For more information about the IMD, please refer to their IMD Frequently Asked Questions document.

They use a variety of criteria, including income deprivation, health deprivation, and disability, to assign a score to each postcode in England. These scores are then grouped into deciles, with 1 representing the most deprived and 10 the least.

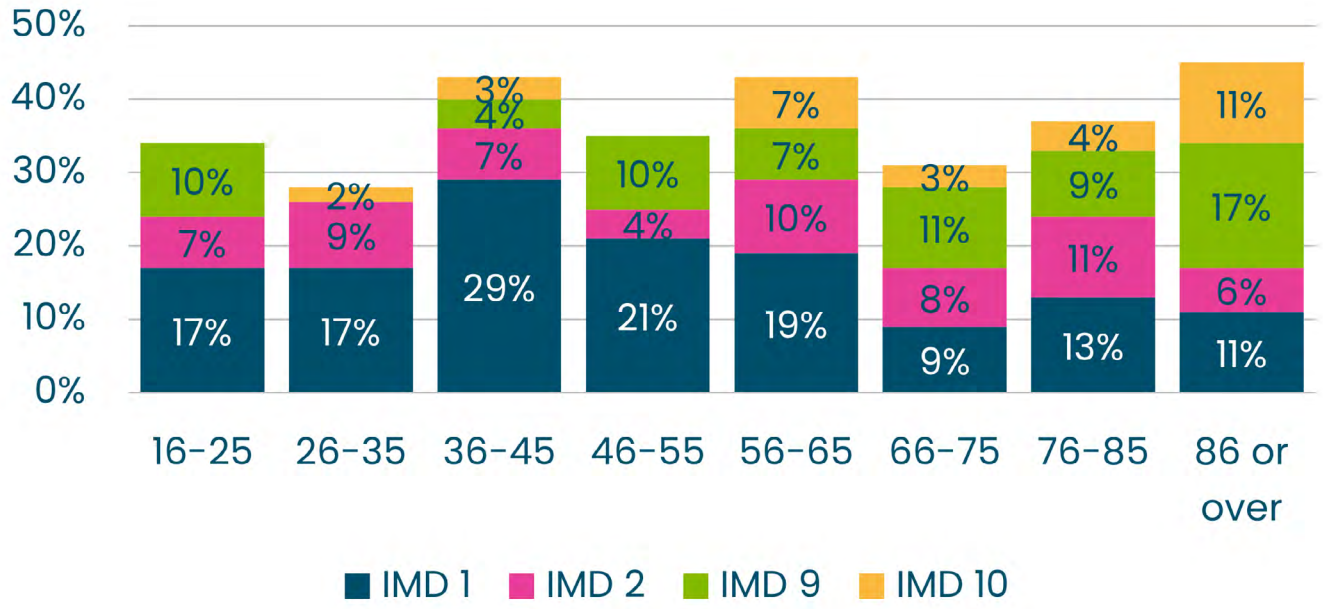
We have assigned a decile to the 75% of respondents who provided a full postcode with their answers (387 people). This gives us an idea of the level of deprivation our respondents may be facing (although we should stress that this is only an idea, in the sense that each person's IMD score is based on the small area where they live, rather than their unique personal circumstances).

Figure 11: Number of respondents per IMD decile



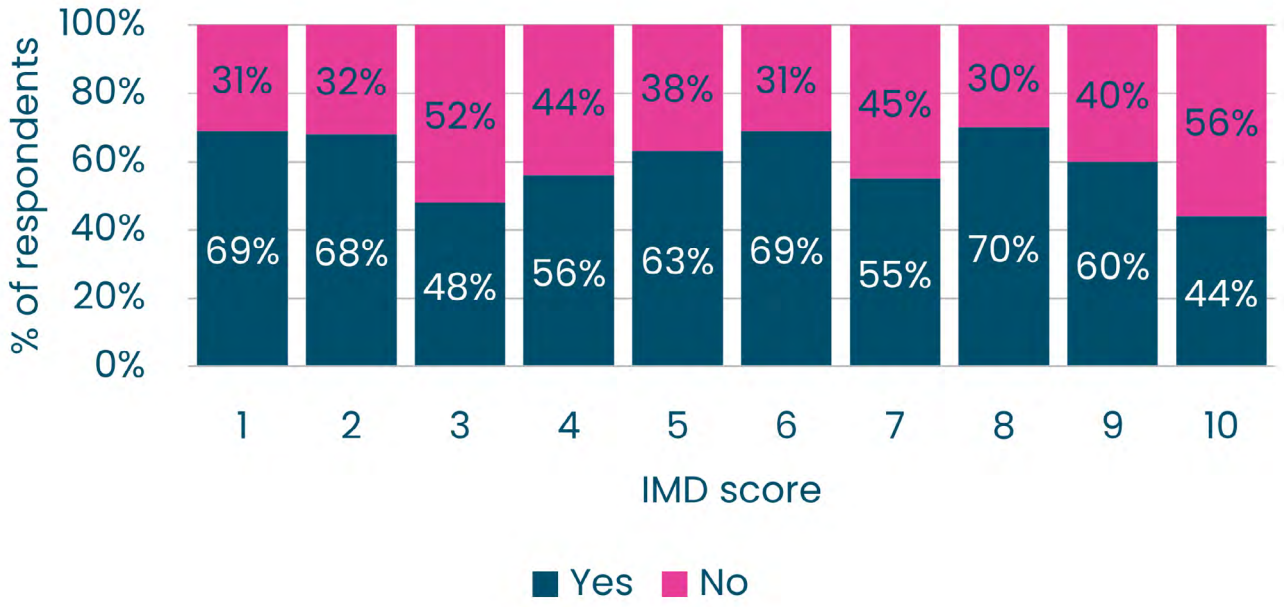
The largest share of our respondents belonged to the lowest deciles.

Figure 12: The percentage of respondents in each age catergory which belong to IMD 1, 2, 9 and 10



On the whole, younger people were more likely to be in deciles 1 and 2 compared with older respondents. However, it's important to note that all age categories included people of all different deciles.

Figure 13: Do you have a disability or health condition? (by IMD decile)



Overall, as our respondents' deciles increased, they were a little less likely to have a disability or health condition. However, it's important to acknowledge that people with disabilities and long-term health conditions made up an important part of every decile.

Figure 14: People who find it easy to get out of the house: by IMD decile

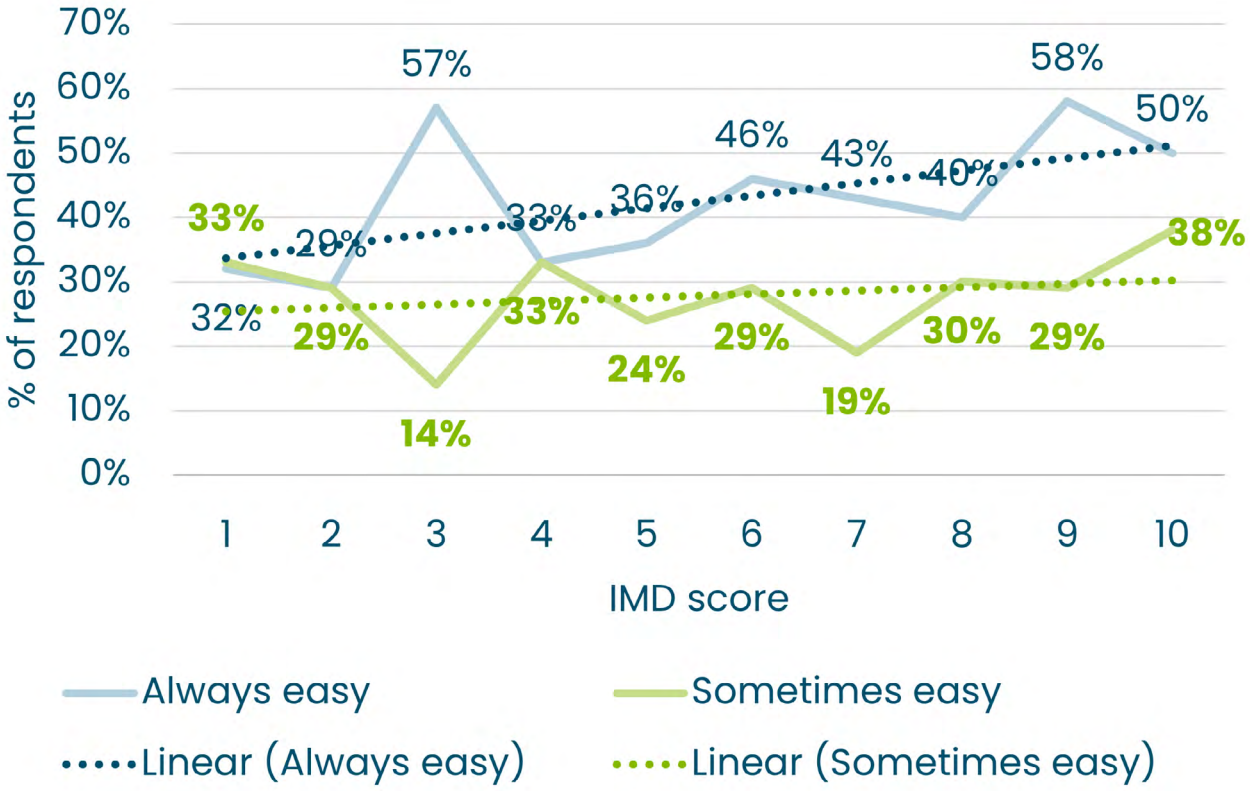
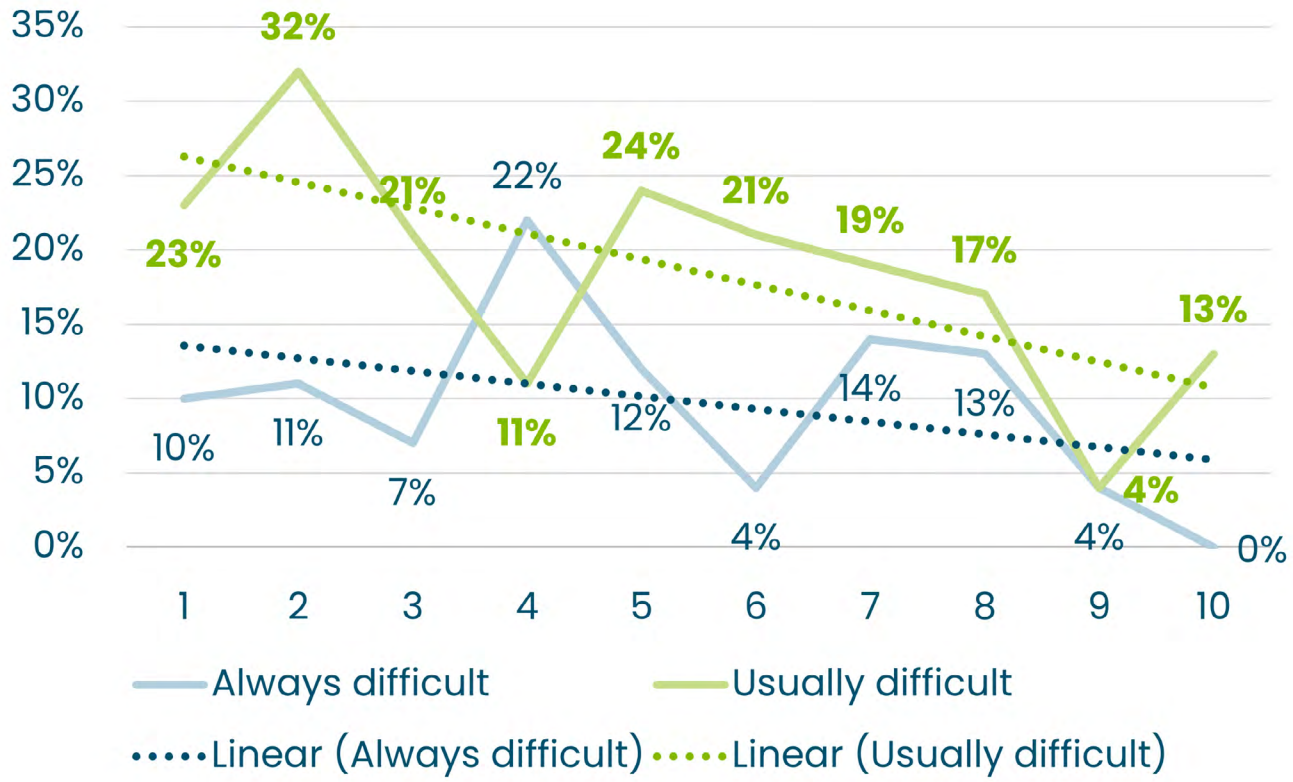
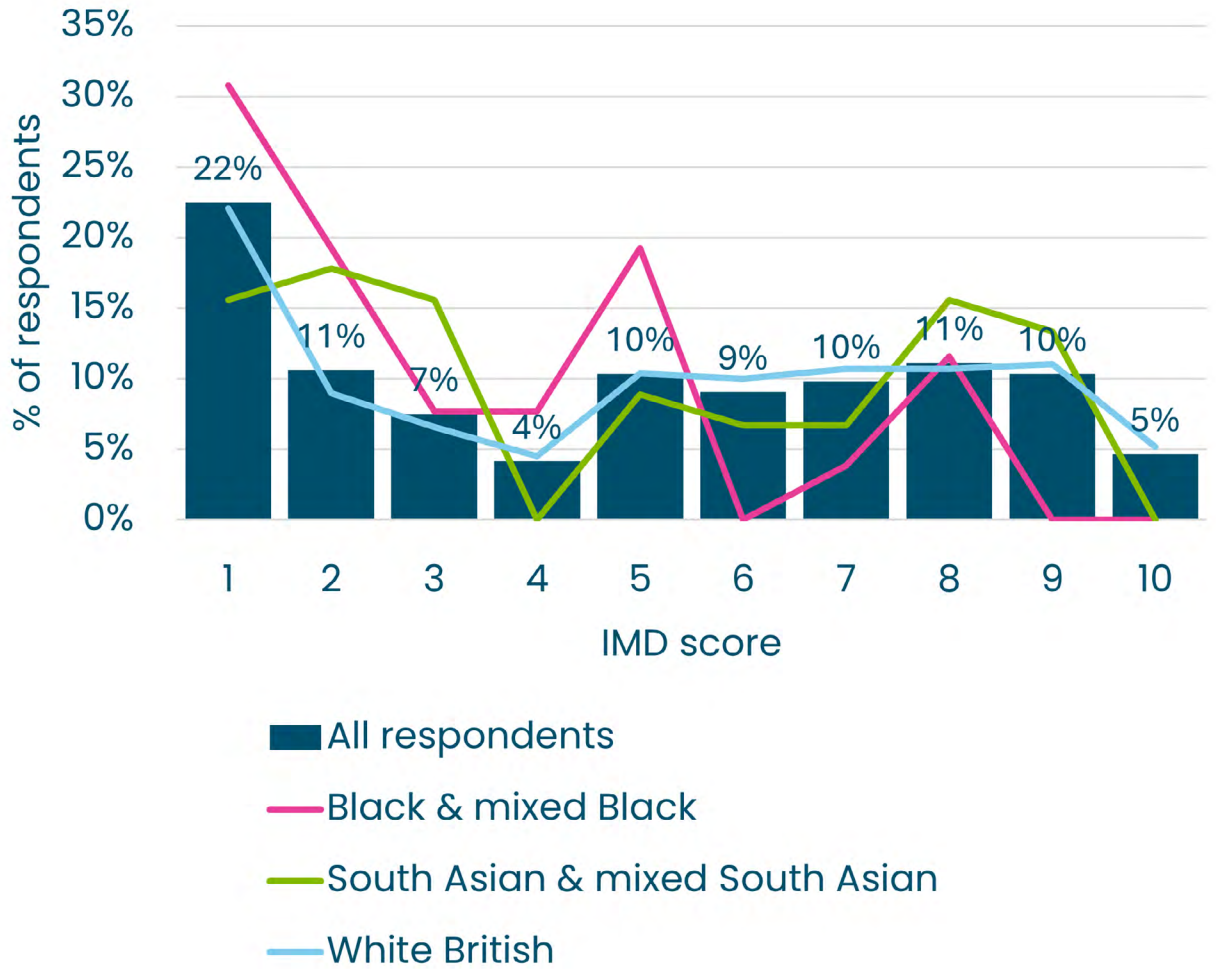


Figure 15: People who find it difficult to get out of the house: by IMD decile



Similarly, people in higher deciles were somewhat more likely to find it easy to get out of the house (Figure 14 with trendlines), while people in lower deciles were more likely to find it difficult (Figure 15 with trendlines). Again, however, we must acknowledge that people in each decile had different levels of mobility.

Figure 16: Ethnicity by decile



Respondents of a Black or mixed Black ethnicity were more likely than our respondents as a whole to be in the lower five deciles. Respondents of South Asian or mixed South Asian descent tended to be at either extreme, belonging in greater than average proportions to the lower and higher deciles.

1.2 Integrated services

a) Where have you had appointments with a health professional in the past 12 months?

Key findings

The question

"Where have you had appointments with a health professional in the past 12 months? (Please tick all which apply.)"

Who was eligible to answer

All respondents

Why this question?

We want to know which services our respondents tend to centre around, but most importantly we want to identify respondents who have contact with lower or higher numbers of services. Neighbourhood health models may present the potential to prevent some people from having to move around multiple services by designing a single or integrated service which meets their needs more comprehensively.

What did we find out?

People's tendency to access a higher number of services (4 or more) increased with age, especially from the age of 56.



People who have difficulties getting out of the house were more likely to have 4+ contacts.

People who have a neurodivergent condition, who are in receipt of state benefits or, most markedly, who have a mental health condition made up a proportionately higher share of people with 4+ contacts.



There are some indications that proportionately fewer people from Black or mixed Black backgrounds or, most especially, South Asian or mixed South Asian backgrounds had contact with 4+ services.

People from the most deprived postcodes tend to see fewer services, despite being proportionately more likely to have a health condition or disability.

What does this tell us?

Any neighbourhood service designed to provide comprehensive care for people currently accessing high or low numbers or services should:

- Be mindful of targeting and meeting the needs of people aged 56 and over (for example, are they inclusive for people who work and / or have caring responsibilities for elderly relatives? Are they tailored to the needs of people with age-related conditions such as impaired hearing or mobility?).
- Work for people who have difficulty getting out of the house (for example, are there options for care at home, or suitable transport provision for very immobile people?).
- Work for people on low incomes (for example, are settings easily reachable via buses? Are they inclusive to people who can't always get online? Do they also provide access to services that people with money worries might benefit from?) They should also bear in mind that our most deprived respondents tended to have contact with fewer services despite their higher levels of disability and are therefore less embedded within present systems.
- Support people's needs in terms of mental ill health and neurodiversity (for instance, making physical settings comfortable and providing routes into care for those conditions).

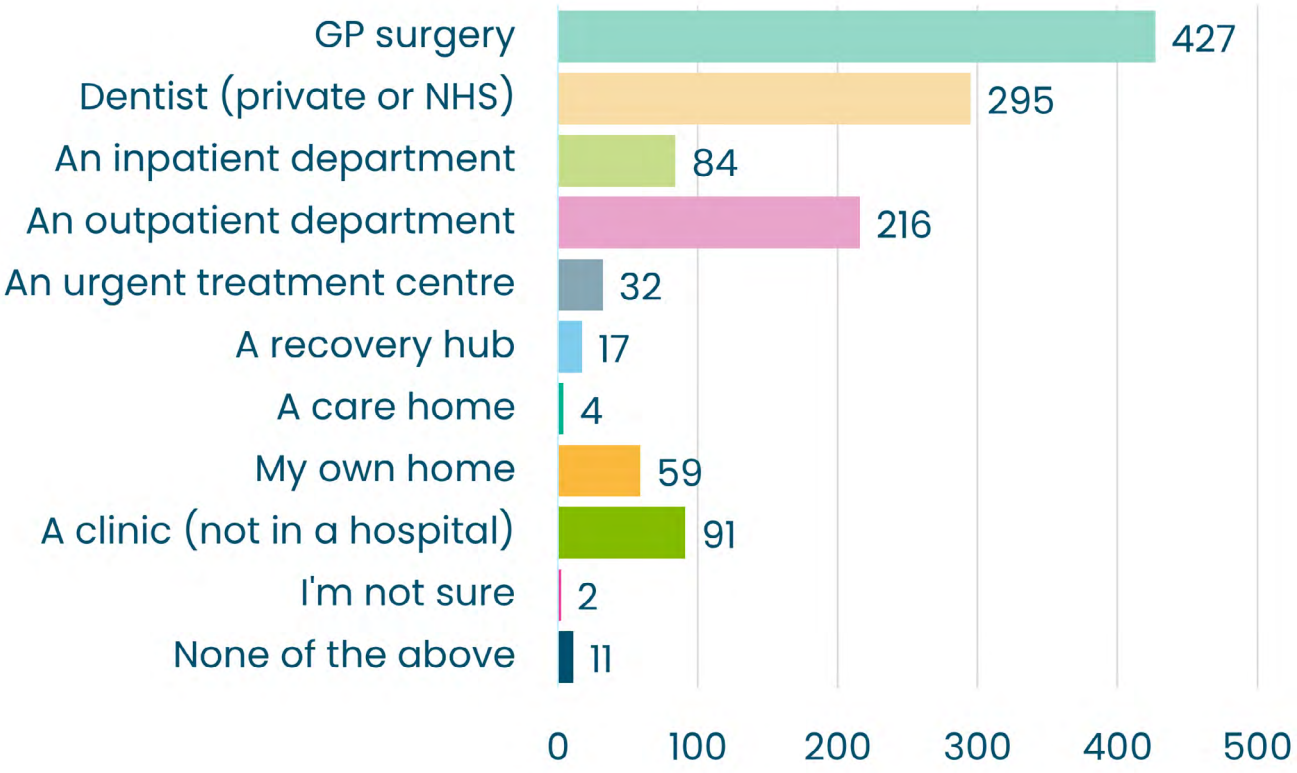
Ideas for further study

It would be helpful to confirm the indications that people from Black and mixed Black and South Asian and mixed South Asian are proportionately less likely to use multiple services and get an understanding of why this might be.

It would also be helpful to have a better understanding of why people from more deprived postcodes have less contact with services.

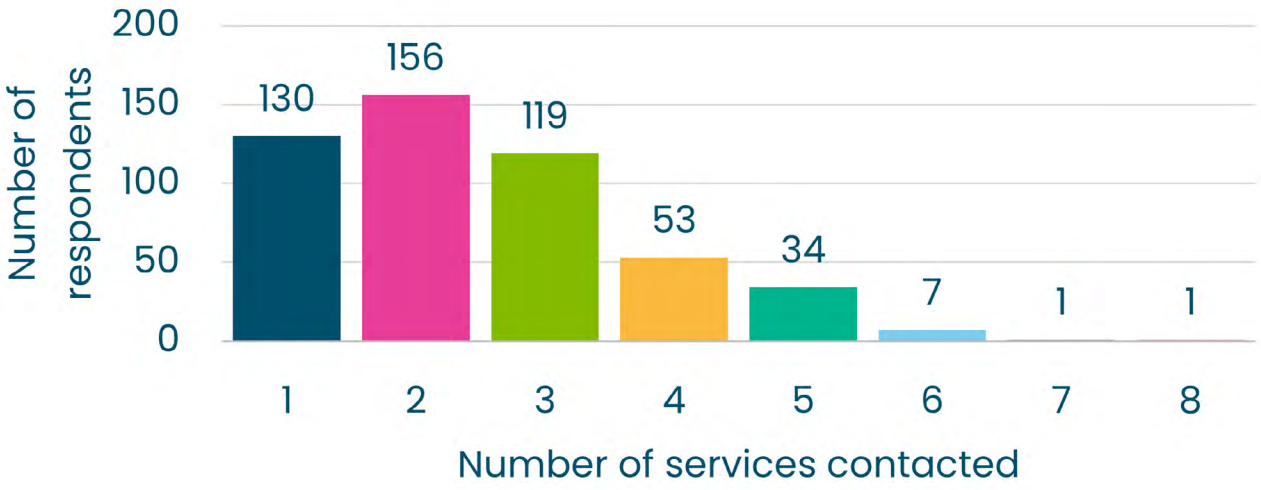


Figure 17: Where our respondents have had contact with services



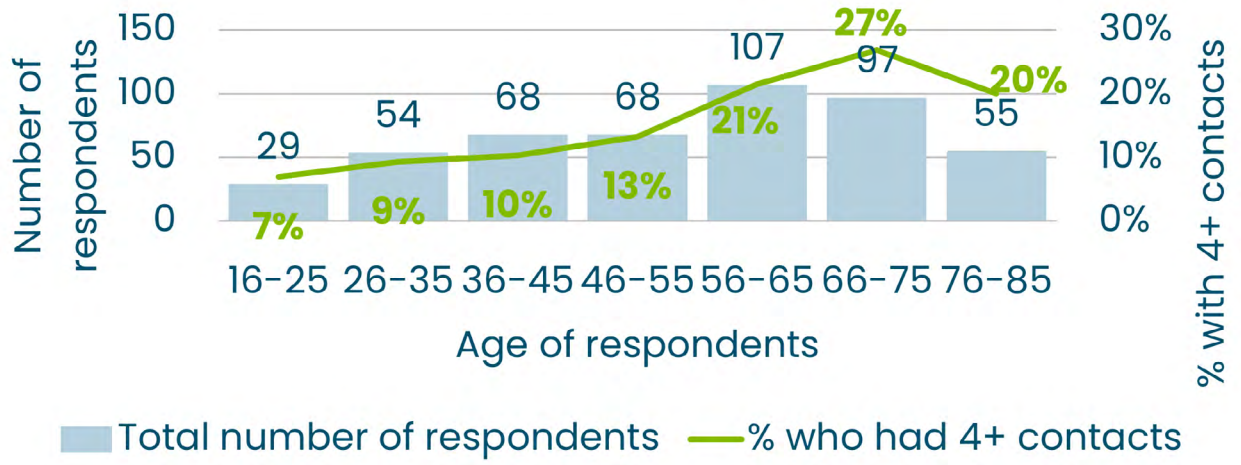
Nearly all our respondents have had contact with services somewhere in the past year.

Figure 18: The number of services respondents contacted in the past year



The median number of contacts was 3. Please note that this question does not distinguish between contacts for routine matters (such as a dental check-up or vaccine) and contact due to a health problem.

Figure 19: Age of respondents who had contact with 4+ services

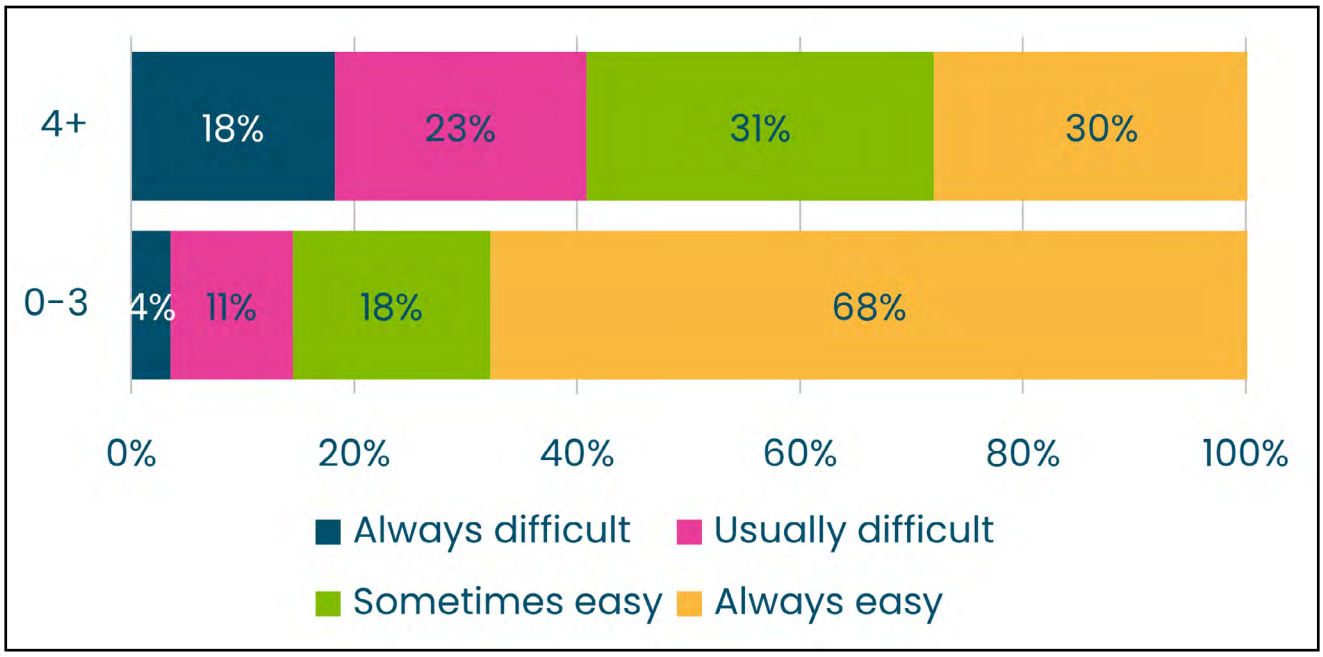


When we look at respondents with 4 or more contacts as a percentage of the total number of people in each age group, we can see that they make up a larger proportion as people get older.

The increase is slow and steady between the ages of 16 and 55, then starts to increase more markedly from age 56. Figure 19 excludes our respondents aged under 16 and 86+ because their sample sizes were small (1 and 9 respectively).

49% of respondents who had contact with four or more services were aged 66 or over.

Figure 20: How easy it is to get out of the house (comparing people with 0-3 service contacts against people with 4+ contacts)



Respondents who had contact with four or more services were more likely to say it was always or usually difficult for them to get out of the house compared with people who had fewer contacts.

Three groups of people contacted four or more services the most. These groups are shown in the table blow.

Groups of people who had contact with four or more services	What % of respondents with 4+ contacts do they make up?	What % of respondents with 0-3 contacts do they make up?
State benefits	28%	18%
Mental health condition	31%	16%
Neurodivergent condition	27%	18%

People who can't use the internet every day or can only do so with help were also more likely to have had four or more service contacts (27%, compared to 17% for people who can use the internet daily). However, bear in mind that older people make up a larger proportion of people who can't use the internet every day in our dataset (see page 86).

There were no differences by gender.

Our respondents from Black and mixed Black backgrounds, and from South Asian or mixed South Asian backgrounds, had comparatively few contacts with services. Only 3% of our respondents of Black ethnicities told us they had four or more contacts. That said, our Black respondents tend to be younger on the whole and report lower levels of disability (39%). However, just 3% of our South Asian respondents also said they had four or more contacts, despite them being closer in age to the data as a whole (although, again, disability levels are proportionately lower than the data as a whole at 46%).

Our respondents in IMD deciles 1 and 2 tended to have fewer contacts with services compared with our respondents, despite them being somewhat more likely to have a disability or health condition. The median number of contacts for all respondents was 3, but 2 for respondents in the lowest deciles.

1.3 Self-care and self-management of disabilities and long term conditions

a) When you are worried about your disability or condition or feel it's getting worse, who do you get in touch with?

Key findings

The question

"When you are worried about your disability or condition or feel it's getting worse, who do you get in touch with (if anyone)?"

Who was eligible to answer

Respondents with a disability or health condition

Why this question?

One aspect of people's ability to self-care and keep as well as possible is knowing when to reach out for help before a problem becomes acute. We wanted to know what our respondents currently do when they feel they need more support.

What did we find out?

GPs remain a key first port of call for people with disabilities or health conditions.



A small proportion of people don't contact anyone when they need help with their health.



People under the age of 46 were proportionately more likely to contact a specialist than people in older categories.

Our women respondents are somewhat more likely to contact a specialist than men.

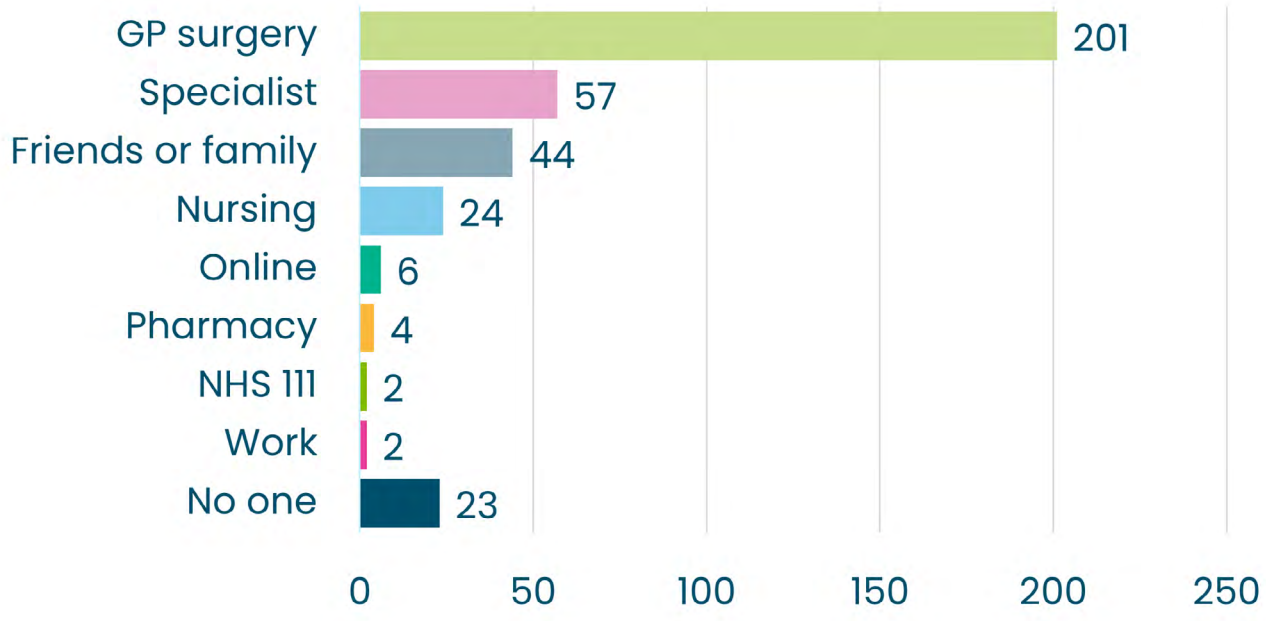
People aged 66+ and people of South Asian and mixed South Asian ethnicities are more likely to turn to friends and family when they are worried about their health. This might be because these respondents are more likely to count on friends and family as carers.



What does this tell us?

- Any neighbourhood health model will have to communicate with people about its role as compared with the GP surgery's. For example, does the GP remain the first port of call? Does the neighbourhood health model propose a different route for getting help, in some or all circumstances?
- There may be some work to do in terms of changing people's mindset or culture regarding approaching GPs, and this could take some time.
- It is possible that one reason younger people contact specialists more is that the conditions they tend to be diagnosed with offer more specialist options than the conditions more middle-aged and older people have. (The same reasoning might be applicable to our male and female respondents.) Neighbourhood health models should address disparities or inequalities such as these.
- Some groups of respondents are more reliant on unpaid carers than others. For them, communications about neighbourhood health models should have a dual audience: the person receiving care and the unpaid carer.

Figure 21 When you are worried about your condition, who do you get in touch with?



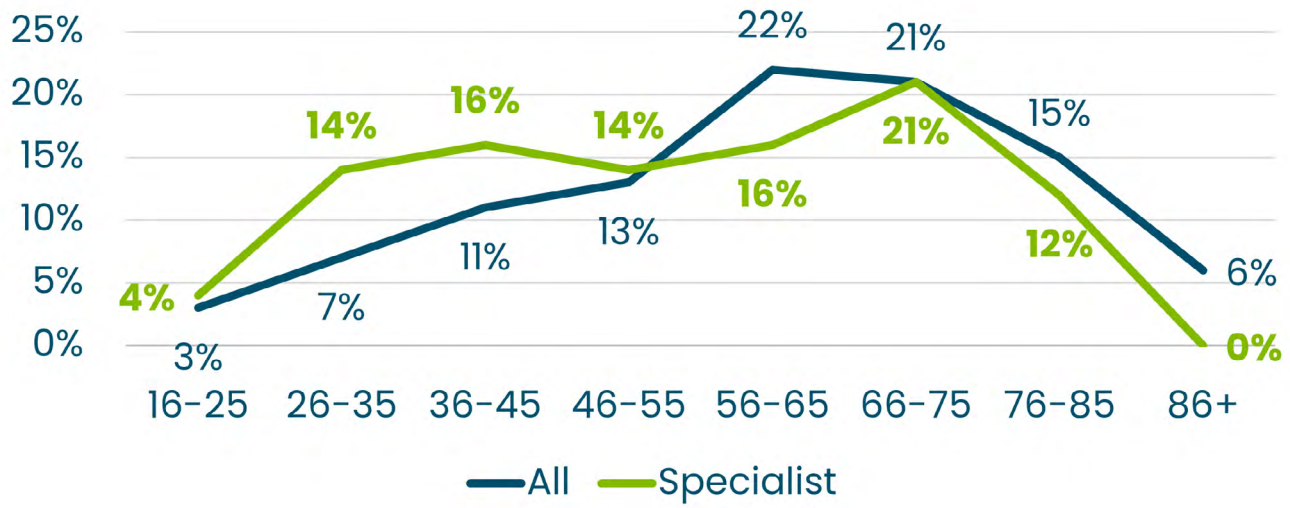
Our respondents were most likely to say they reach out to their GP surgery for help. Please bear in mind that just over a fifth of respondents indicated that they reach out to more than one service.

We looked at which groups of people are under or over-represented among respondents who contact a specialist. We have defined "specialist services" as anything that requires or is likely to require having had a referral into secondary care. Examples included "24/7 line at the diabetes clinic at the hospital", "LCH Spinal Team or MSK", "Rheumatology consultant", "Osteopath or physiotherapist" and "mental health worker".

We noted that while women make up 67% of our respondents with a disability or condition and men 30%, 75% of people who use specialists are women and just 21% are men. People of Black and mixed Black ethnicities and South Asian and mixed South Asian ethnicities are also underrepresented, but only by a small percentage difference.

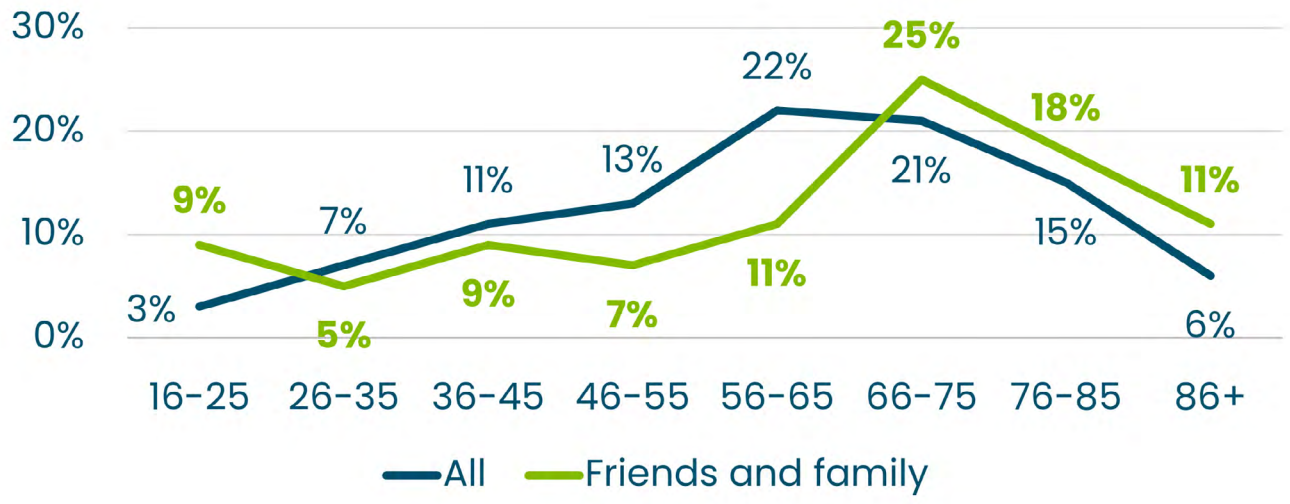
We didn't note any major disproportionality among unpaid carers, people in receipt of state benefits, or people with neurodivergent or mental health conditions.

Figure 22: Age of respondents who contact a specialist vs all our respondents with a disability or health condition



We could also see that people who contact a specialist tend to be younger than our respondents as a whole.

Figure 23: Age of respondents who contact friends or family vs all our respondents with a disability or health condition



Respondents tended to become more reliant on friends and family as a first port of call as they reached the age of 66 and over. This might be due to people receiving more care from family as they age and relying on those unpaid carers to reach out for help on their behalf. Young respondents aged 16-25 also relied on friends and family for support.

White British respondents made up a smaller-than-proportionate share of respondents who contact friends or family, at 59% compared with 76% for our respondents as a whole. Conversely, respondents with South Asian backgrounds were overrepresented, accounting for 18% of people who contact friends or family (compared with their 11% share of respondents overall). Respondents with Black ethnicities were only slightly overrepresented (6% compared with 4% of all respondents.) This may be due to older South Asian respondents being more reliant on family members due to limited English skills and cultural responsiblility to support their family.

Other factors, such as being an unpaid carer, having a mental health or neurodivergent condition and others, did not appear to have a strong effect on whether our respondents contacted family or friends.

We did not note any major over or under-representations among our respondents who contacted a GP.

b) Please tell us how well this usually works for you as a way of getting help with your condition

Key findings

The question

"Please tell us how well this usually works for you as a way of getting help with your condition."

Who was eligible to answer

Respondents with a disability or health condition

Why this question?

By understanding how effectively systems for keeping people well in the community work at present, we can get a sense of where neighbourhood health models can focus on improvement.

What did we find out?

A sizeable group of people suggest that they could benefit from a more effective way of reaching out for help when their health is deteriorating.

While GPs are by far the most commonly used place for seeking out help, they aren't the most positively experienced. We know from responses to other questions in our survey and the desktop review (see page 174) that people struggle to get timely appointments.



People under the age of 66 tend to experience somewhat higher levels of dissatisfaction (as do people with mental health conditions, unpaid carers and people in receipt of state benefits, groups which all tend to be made up of younger people).



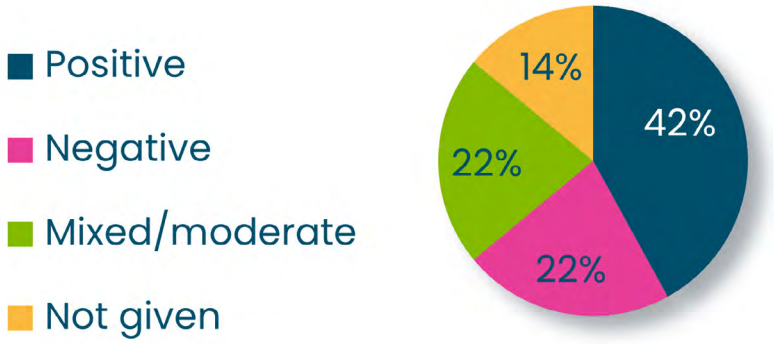
People from the most deprived postcodes were more likely to report a negative experience of asking for help with their existing health condition and were less likely to have access to specialist support.

People who experience difficulties getting out of the house were also more likely to report a negative experience of asking for help.

What does this tell us?

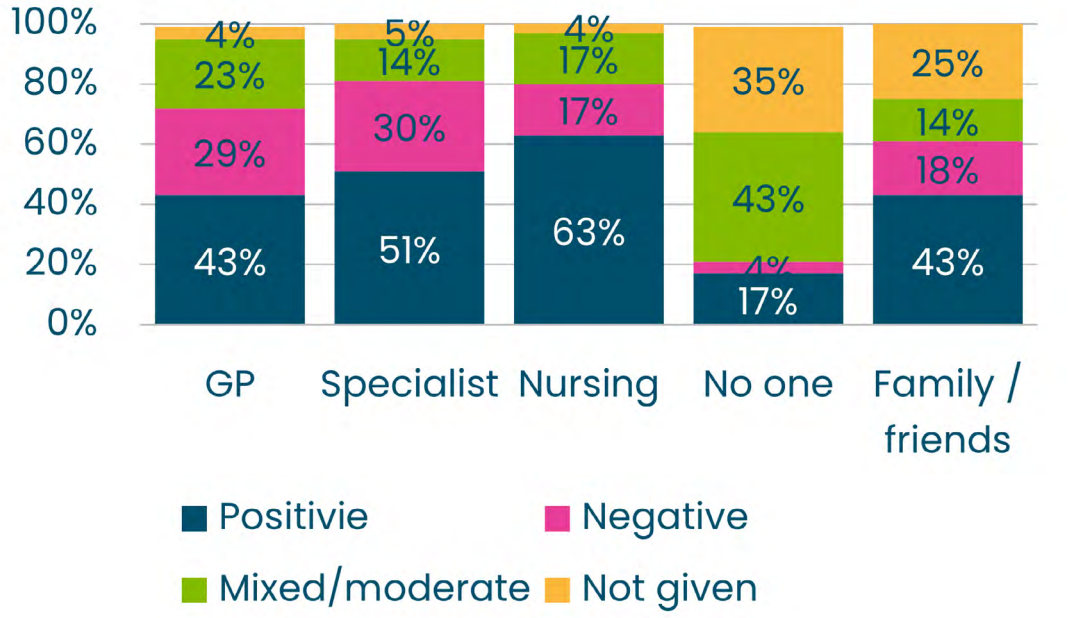
- Greater availability of quality help for people with pre-existing conditions should play a part in neighbourhood health models, especially for people currently reliant on their GP surgery.
- Any model should be designed with our most deprived residents in mind, as they are particularly in need of better support.
- Any model should also include people who struggle to get out of the house.
- Any alternative systems should take into account the needs of working-age people. For example, are they easily accessible to people who work standard hours, and inexpensive enough for people in receipt of benefits? Do they work well for people with caring or family responsibilities?

Figure 24: Sentiment about ways of getting help (all respondents)



42% of our respondents expressed that the way they reach out for help with their health condition usually works well for them. Slightly more (44%) expressed either a negative or a mixed or moderate view.

Figure 25: Sentiment by service



People who contacted a specialist or nursing service reported a positive experience in more than half of cases. Please bear in mind that the number of people who contacted nurses was small (24).

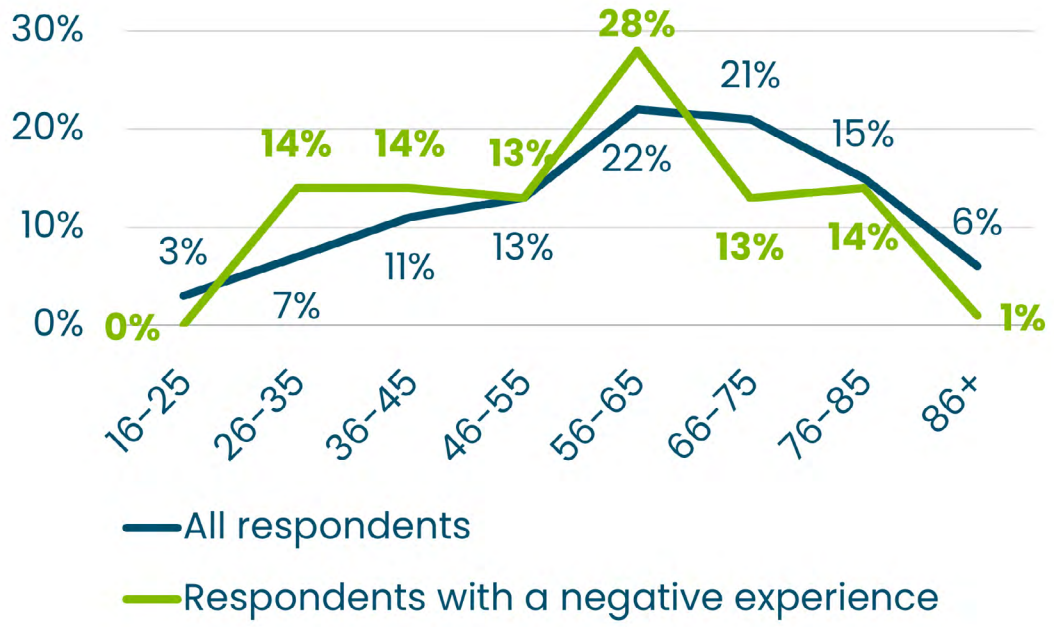
The service with the largest proportion of negative experiences was GP surgeries (23%), although 43% of the people who told us they don't reach out to anyone said this didn't lead to a positive outcome. Only 23 respondents told us they contacted no one when their condition worsened.

Some groups accounted for a larger-than-expected proportion of people who had a negative experience when reaching out for help. These were as follows:

- People who find it difficult to get out of the house accounted for 34% of negative responses (compared with 28% of respondents overall).
- People with a mental health condition made up 32% of those with negative experiences, compared with 25% of all respondents with a disability or health condition.
- Unpaid carers made up 27% of responses (against 19% of responses as a whole).
- People in receipt of state benefits made up 21% of responses (against 12% of responses as a whole).

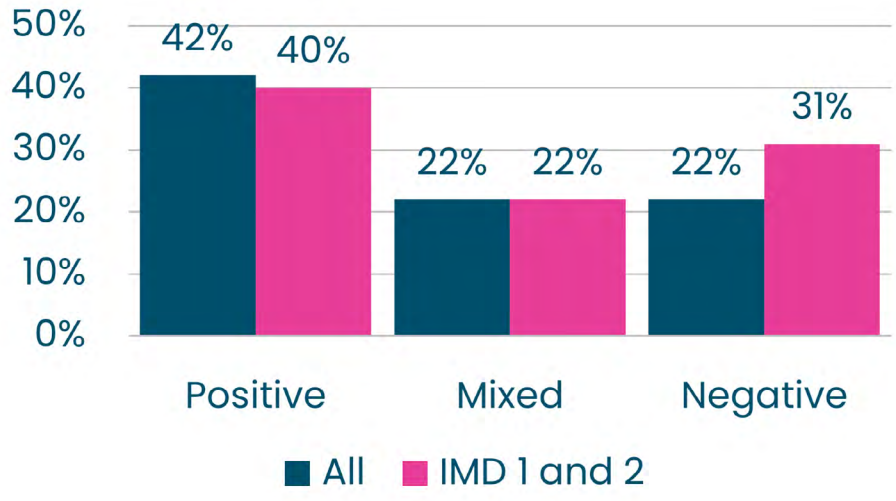
The respondents in the final three of the four categories above all share another characteristic: they tend to be under retirement age.

Figure 26: People with negative views about channels for reaching out for help vs all repondents with a disability by age



We can see in Figure 26 how the proportion of negative responses varies by age among our respondents, with people aged under 66 having a disproportionately negative experience.

Figure 27: How people with a disability experienced asking for people: comparing respondents in IDM 1 and 2 with all respondents



People with disabilities or health conditions in IMDs 1 and 2 were more likely to report a negative experience of reaching out for help, compared with our respondents as a whole.

People in IMDs 1 and 2 with a negative experience reported approaching the GP and nursing services in very similar proportions to our respondents as a whole. However, a smaller proportion accessed specialist services, at only 7%, compared with 18% of all respondents with an IMD score.



c) Is there anything that makes it difficult to look after your health the way you would like to?

Key findings

The question

"Is there anything that makes it difficult for you to look after your health the way you would like to? Please tell us what."

Who was eligible to answer

Respondents with a disability or health condition.

Why this question?

Neighbourhood health models place a greater emphasis on empowering people to take care of their health wherever possible. It's important to understand what might make this difficult for people to achieve, so that appropriate support can be put in place.

What did we find out?

People's physical and (less frequently) mental health problems are by far the most common barrier to self-care, especially for Leeds' poorest residents.



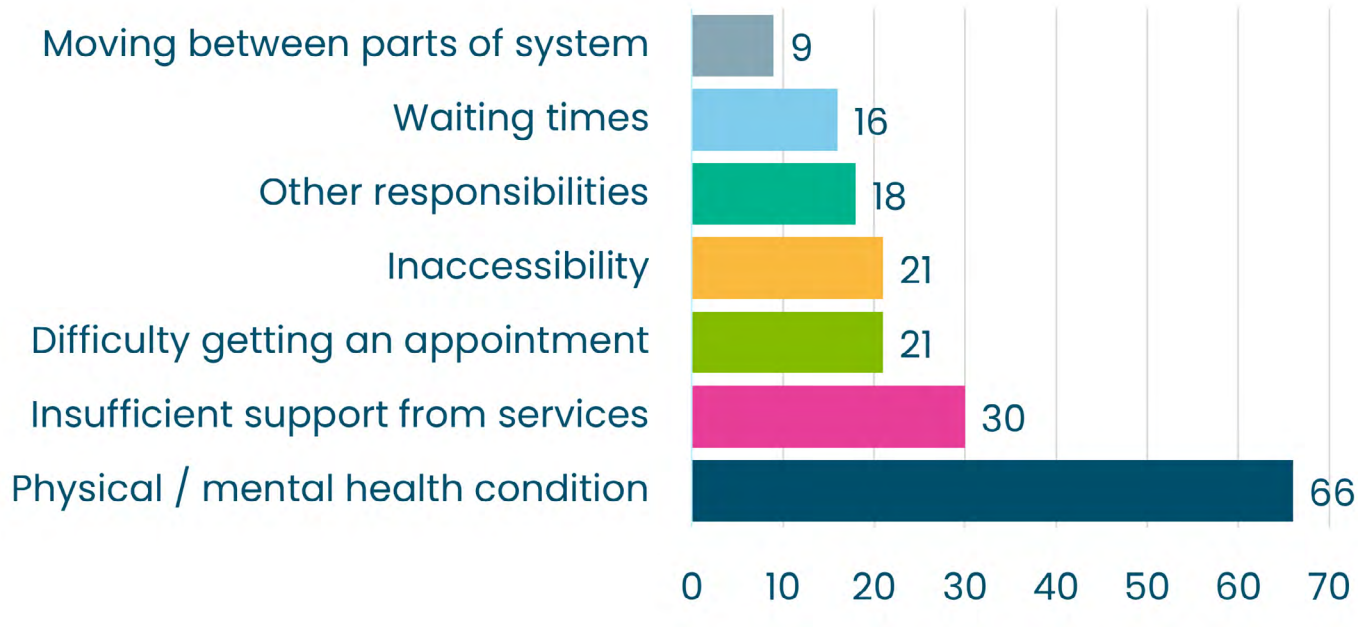


Other factors people mention tend to relate to problems within health services, such as a lack of appointments and access issues. These problems come up very frequently in engagements about health and care, as we have seen in the desktop review (page 174).

What does this tell us?

- For people with disabilities or health conditions to live well in communities for as long as possible, they need specific and tailored guidance about what self-care they can do despite their health-related limitations, such as mobility problems. This guidance should be useable by people on very low incomes.
- For some, the ability to self-care is very tied up in the perceived effectiveness of health services. This tells us, on the one hand, that some people may not be used to thinking about care as being something they can do partly independently (and we should remember that some of our respondents are housebound and / or require extensive support). On the other hand, we perhaps have to consider how the concept of self-care can be introduced to people who don't feel they are well supported by services: will it be well received, if people don't feel like they have a good baseline of care?

Figure 28: Is there anything that makes it difficult for you to look after your health the way you would like to?



We asked people with a health condition or disability to leave a comment about anything that made it difficult for them to look after their health. Figure 28 summarises the most common problems people identified.

People in IMDs 1 and 2 reported similar problems to other respondents in terms of what makes it difficult for them to look after their health as they would wish to, except a larger proportion identified their physical or mental condition as a barrier (31% vs 21%).

The most common issue people identified was problems with their physical or (less frequently) mental health. Examples people gave included limited mobility and pain, or difficulties with interacting with others, heightening their anxiety.

The second most common reason was a lack of support from health services. For some people, this meant a lack of information (or a lack of consistent information), or simply not knowing where to start seeking help. Here are a few examples of what people told us:

"The appointment system at my GP has improved, but the lack of consistency and concern when I have an appointment is very off-putting. In the past, I saw three different GPs for the same condition, each gave me different and conflicting advice. I have very little confidence in any of them. My best experiences have been at the Shakespeare Walk-In Centre and the Living Care Clinic at Thorpe Park."

"Lack of information - e.g. exactly what lifestyle changes I could do to help, understanding what foods are helpful or hinder specific health things, understanding the signs of what to look for so I can change things faster than waiting for it to get bad."

In some cases, people haven't met the criteria for support, but nothing has been put in place to meet their needs. When people fall through the gaps in this way, it can leave them feeling not listened to. Here are a few examples of what people told us:

"The length of waiting lists and my concerns sometimes being dismissed, which prolongs how quickly I get investigated. Doctors ignoring borderline test results and not worrying until is too late and I have a full-blown problem (in my case, severe iron stores deficiency)."

"It was very difficult to get help for my endometriosis; no service seems to want to support with my ongoing chronic pain."

"I would have liked more help with weight loss to help with Asthma and Osteoarthritis, but I don't meet the criteria."

"My mum has asked time and time again for someone to help her do the exercises to stay healthy and for help getting out of the house, but she is ignored."

Sometimes the services people need to keep well aren't provided. Here are a few examples of what people told us:

"I have no support in Wetherby for my bipolar disorder as it's a long-term condition. Yet Live Well Leeds concentrate on short-term interventions. This is not fair as often I have had relapses which means the GP and CMHT have to put in intensive treatment from Psychiatrist to CON and OCC health. If I had a support group I could attend in Wetherby, this would relieve the pressure on the NHS and me having to cope with relapsing and potentially suicidal."

"ADHD medication is provided, but I would like access to a workshop for coping strategies."

"There should be a direct clinic where I can contact when I feel like my breathing is getting worse."

"[There is a lack of] information and advice when I need it instead of going through the GP."

When people talked about having difficulty getting an appointment, they were often referring to GP surgeries. Waiting times for appointments in primary and secondary care were also an issue for some.

Inaccessibility came down to three factors: online services that either weren't usable or didn't provide the services people wanted and needed; clinics that were far away, difficult, or expensive to get to (especially by taxi); and language barriers.

For some of our respondents, having to seek help across multiple services negatively impacted their overall experience. Here are a few examples of what people told us:

"A hernia that took doctors two years to diagnose, even though a physiotherapist identified it immediately, has stopped me exercising at home. Having to repeatedly beg for various diagnoses has left me with no trust in health professionals. Some doctors have ignored my testimonies and just tried to push irrelevant drugs on me, and so I'm more than a little jaded. To hide this, I resort to taking a pleading, vulnerable stance so they don't feel threatened. Trying to get medical help is no good for my mental health."

"Everything being siloed – no one looks at the full picture and listens to me. They focus too much on "ranges" and always put symptoms down to one of my pre-existing conditions, even when I'm telling them it's unusual for me."

"Poor communication, e.g. messages not passed on, misdiagnoses resulting in pointless hours sitting overnight in A and E. Issues with patient transport, especially taxis they use at times. Errors in records, e.g. my GP said in a referral letter to a specialist that I had a stoma, I have no stoma, and that I was not on oxygen when I am, etc. They seem not to control access to records; these get changed to make them incorrect by more or less any Tom, Dick or Harry."

"Lack of communication or connection of records between on systems, so attending two appointments for the same procedure."

A number of people also told us about things that made it harder for them to look after their health, which were either unusual or unique to them or difficult to categorise. For instance, a few said that a lack of community or family support networks meant they weren't as able to care for themselves as they would want. Two people said their illness was "invisible" or not considered treatable (the condition cited in the latter case was ME/CFS). Three people talked about not having enough money to either buy healthy food or pay for private treatment.

d) Where our respondents without a health condition or disability look first for help

Key findings

The question

"How much do you agree or disagree with the following?

- The GP is always the best person to speak to when I've got a problem with my health.
- There are times when I can get help from my local pharmacist, rather than going to my GP surgery.
- I know when to call NHS 111.
- I know when to go to an Urgent Treatment Centre (St George's at Middleton or Wharfedale).
- I know the different kinds of health professionals I can speak to via my GP surgery (such as physiotherapists, mental health counsellors and nurses)."

Who was eligible to answer

Respondents without a disability or health condition.

Why this question?

Self-care is potentially as important for people who don't have a disability or long-term health condition, although it might look somewhat different. Neighbourhood health models may have the potential to support generally well people more effectively, which could, in turn, ensure that people who are at greater risk of becoming seriously unwell are helped promptly.

What did we find out?

Most people are confident they know what services are available to them when they feel unwell, although some could benefit from more guidance about Urgent Treatment Centres and the different professionals located in GP surgeries.



There are some indications that people of Black and mixed Black ethnicities are somewhat less aware of the different professionals available in GP surgeries.



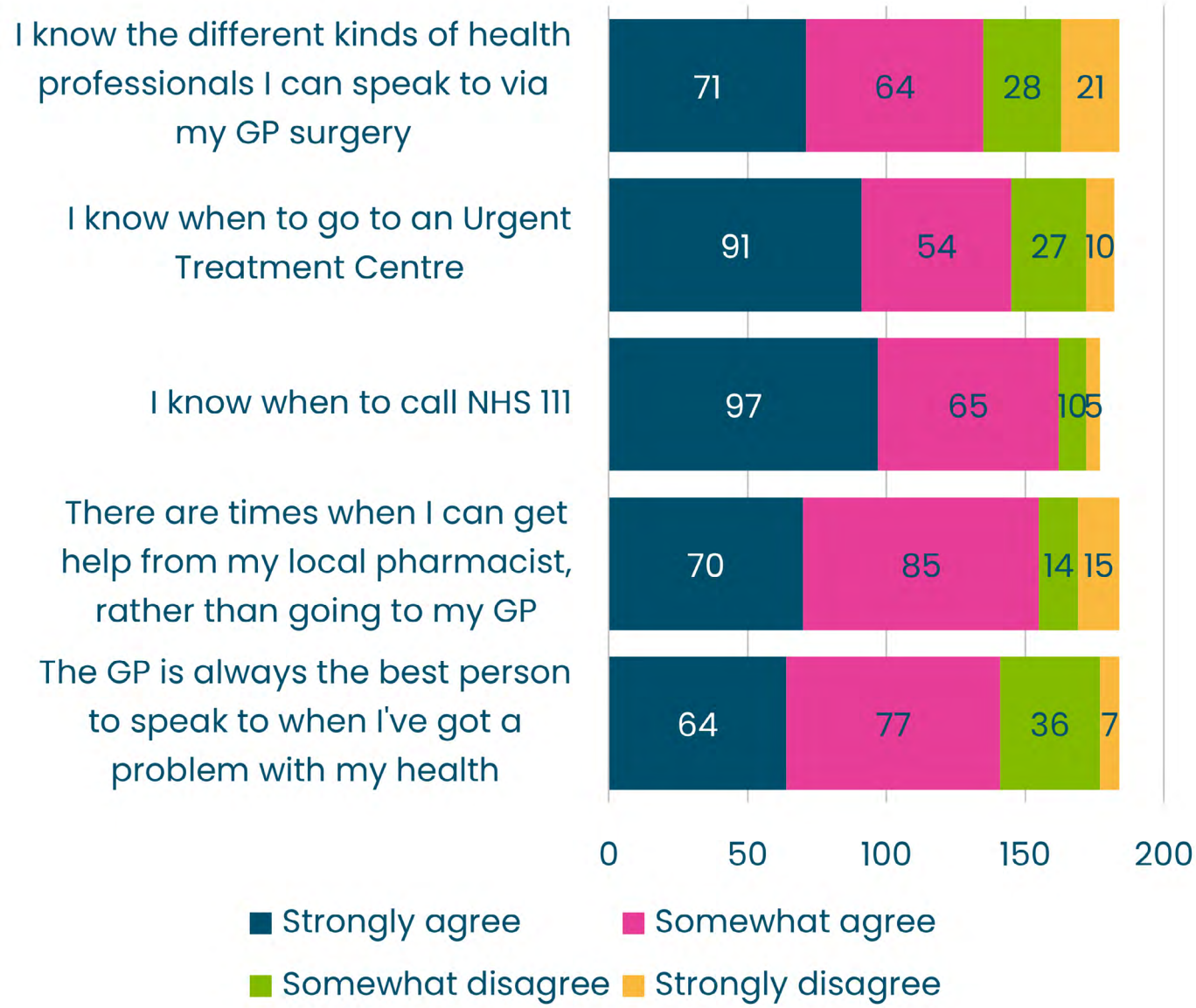
People still tend to think of the GP as the best source of help, despite their awareness of other options. This view is prevalent across different demographic groups.

What does this tell us?

- On the whole, people don't lack information about the different services available to them.
- There may be some work to do to ensure everyone is fully informed about what services they can access at their GP surgery. Care should be taken to ensure Black and mixed Black residents of Leeds are included in this.
- If neighbourhood models want to change how healthy people seek out help for health worries, they may have to challenge people's pre-conceived ideas about GPs, and the primacy GPs are often perceived to hold over other health professionals.



Figure 29: First ports of call for people without a disability or health condition



Starting with the questions beginning "I know", which relate to people's confidence in their understanding of different services, in all cases, most of our respondents were confident they understood to some degree:

- 92% of those who answered the question about NHS 111 said they knew when to use it (agreeing strongly or somewhat).
- 80% of those who responded to the question about Urgent Treatment Centres said they knew when to use them.
- 73% of those who answered the question about the different health professionals at GP surgeries said they knew what roles were available to them.

The other two questions seem, at first glance, to give us paradoxical results. On the one hand, 77% of our respondents agreed that "the GP is always the best person to speak to when I've got a problem with my health". On the other hand, 85% said they agreed that "there are times when I can get help from my local pharmacist, rather than going to my GP surgery". We might have imagined that people who believe the GP is always the best person to speak to would not agree that there are times when they can get help from a pharmacist rather than the GP surgery. One possible reason for this is that people still think the GP is the gold standard – the best qualified, most knowledgeable person – but are aware that other options are sometimes acceptable. We should also bear in mind another possible reason: the GP question is the first in the list, and therefore, people have not been prompted to think about other services, such as pharmacies. With this possibility in mind, it would be interesting to compare results where we ask people again but reverse the order of these two questions. Nonetheless, if either of these two theories are correct, both speak to the primacy and prestige of GPs in our respondents' minds.

Other theories we could consider are that people often assume that all medications require a doctor's prescription and the pharmacist's role is purely to dispense, or that some people don't make a strong distinction between "GP", "GP surgery" and "pharmacist", seeing them all as one service. This might be particularly the case when the GP surgery and pharmacy share a premises.

We analysed responses from people who agreed strongly or somewhat that the GP is the best person to speak to, by gender, age, ethnicity, and carer status, but found that none of these groups were under or over-represented.

Deprivation (as measured by IMD deciles) did not appear to affect our respondents' answers.

We looked at those who disagreed with the statement "I know the different types of health professionals I can speak to via my GP surgery", as this group provides a somewhat larger sample than the other questions (49 people). We noted that a larger-than-expected proportion of these respondents were of a Black or mixed Black ethnicity (26%, as compared with 12% of our respondents who were eligible to answer the question). This is an interesting point to note, but it should be handled with caution, given the small sample.

1.4 Being in community spaces

a) In your day-to-day life, do you use public spaces like libraries and community centres?

Key findings

The question

"In your day-to-day life, do you use public spaces like libraries and community centres?"

Who was eligible to answer

All respondents.

Why this question?

One approach neighbourhood health models can take is to get services out of traditional clinical settings and into community spaces. Ideas behind this approach include that community buildings are physically closer to where people live and work and that they are more familiar and therefore reassuring, especially to people who are at greater risk of health inequalities.

What did we find out?

The majority of our respondents never use community spaces or only do so occasionally. This remains the case across different ages, ethnicities and health statuses.



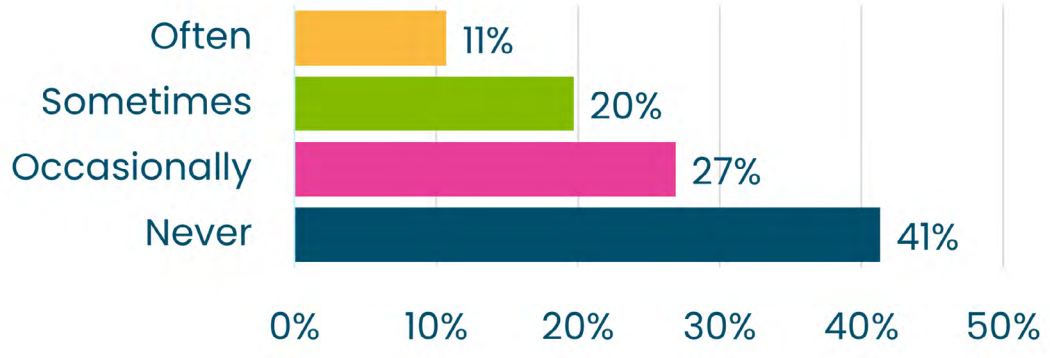




What does this tell us?

- Community spaces are not necessarily familiar places for our respondents. We therefore can't assume that they will feel more comfortable in such settings on the basis of familiarity.
- This is also the case for people at greater risk of health inequalities. Other potential ways of mitigating health inequalities should be considered, rather than relying on the use of community spaces alone.
- This doesn't preclude the use of community spaces for health appointments for other reasons.

Figure 30: Do you use public spaces?



Close to three-quarters of our respondents never use public spaces or only do so occasionally.

These numbers stay notably stable when we compare the responses of people with a disability against those without, and even when we look at responses from people who told us it is always difficult for them to get out of the house. They also stay remarkably similar when we segment for ethnicity and age. A greater proportion of unpaid carers said they regularly use community spaces but over half still said they never or only occasionally did so.

b) Would you feel comfortable having appointments with a health professional in public places (like libraries and community centres) if they could offer a private room?

Key findings

The question

"Would you feel comfortable having appointments with a health professional in public places (like libraries and community centres) if they could offer a private room?"

Who was eligible to answer

All respondents.

Why this question?

This question is designed to further explore the possibility of taking services out of traditional clinical settings and into community spaces.

What did we find out?

The majority of our respondents are open to having appointments in public spaces provided privacy is guaranteed.

The key exception to this is people who have difficulties getting out of the house.



Hesitancy is greater among people from more deprived postcodes.

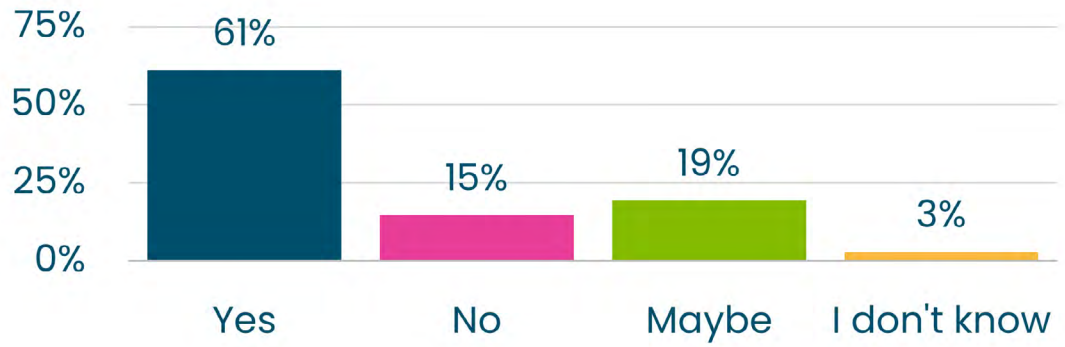
Hesitancy was also higher among people of Black and mixed Black ethnicities and, to a lesser extent, people of South Asian and mixed South Asian ethnicities.



What does this tell us?

- There is good reason to explore the possibility of using community spaces, despite their unfamiliarity to many of our respondents.
- Any move towards community spaces should be carefully balanced against the needs of people who find getting out of the house difficult. What alternative provision could be offered for them, so they are not disadvantaged?
- Any move towards community spaces should be carefully discussed with and communicated to Black and South Asian communities, so that their specific concerns can be understood and responded to.
- More work could be done to understand why respondents living with the greatest poverty were more likely to be hesitant about using community spaces.
- 15% of our respondents said they wouldn't be comfortable having appointments in community settings. If a move into such settings happens, it is important that people have a means to contact services ahead of appointments if they need to voice concerns about the venue; services should also monitor any failures to attend appointments.

Figure 31: Would you feel comfortable having appointments in public spaces?

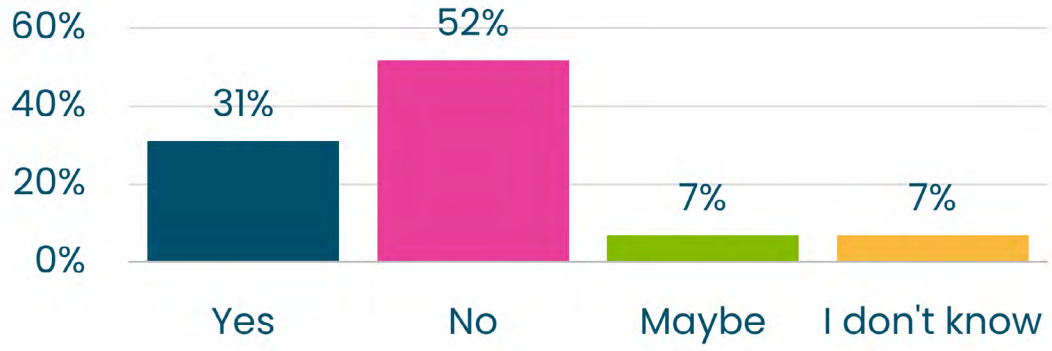


Despite not using them regularly, many of our respondents would be open to having appointments in places such as libraries and community centres.

These numbers remain largely the same for people who have a disability (including people with a mental health condition or neurodiversity), people of different ages and genders, and unpaid carers.

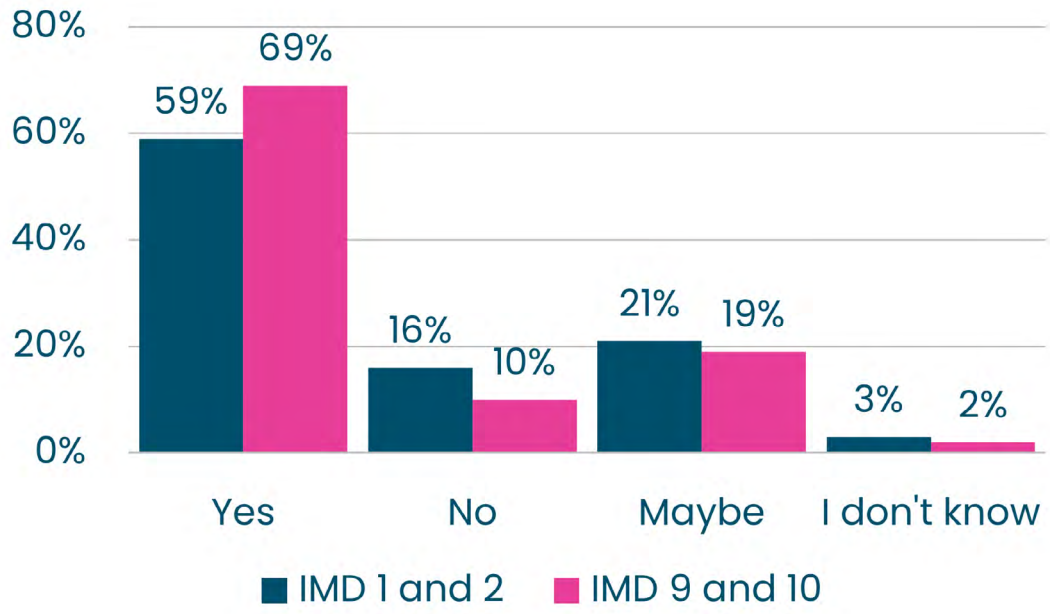
However, people who always find it difficult to get out of the house were much more reluctant about appointments in community spaces.

Figure 32: People for whom getting out of the house is always difficult, would you feel comfortable having appointments in public spaces?



Levels of hesitancy were also higher among people from Black or mixed Black backgrounds. 40% of people of Black ethnicities responded that they would "maybe" feel comfortable (with 42% saying they would feel comfortable). Our responses from people of a South Asian or mixed South Asian background were less distinct from the general trend. However, a somewhat higher proportion (22%) said they wouldn't feel comfortable using public spaces for appointments.

Figure 33: Would you feel comfortable having an appointment in public spaces: comparing IMD 1 and 2 and IMD 9 and 10.



In terms of people's present familiarity with community spaces (see previous question), the responses from people in IMDs 1 and 2 were very similar to the reactions of people in IMDs 9 and 10 (including with disability factored in). People in the lowest deciles were somewhat more hesitant than people in the highest deciles about using community spaces for appointments.

c) What worries might you have about coming to a health appointment in a public place like a library or community centre?

Key findings

The question

"Please tell us any worries you might have about coming to a health appointment in a public place like a library or community centre."

Who was eligible to answer

All respondents.

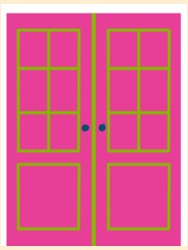
Why this question?

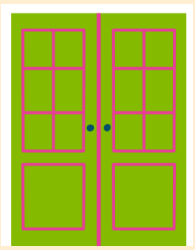
This question is designed to further explore the possibility of taking services out of traditional clinical settings and into community spaces.

What did we find out?

Privacy is the concern people most commonly express. Bear in mind privacy can be especially crucial to people facing vulnerabilities such as being a victim of domestic abuse.

Factors which could help reassure people include soundproofing and separate entrances and waiting rooms for appointments.





People also raised a range of issues about which they would need reassurance (albeit in smaller numbers).

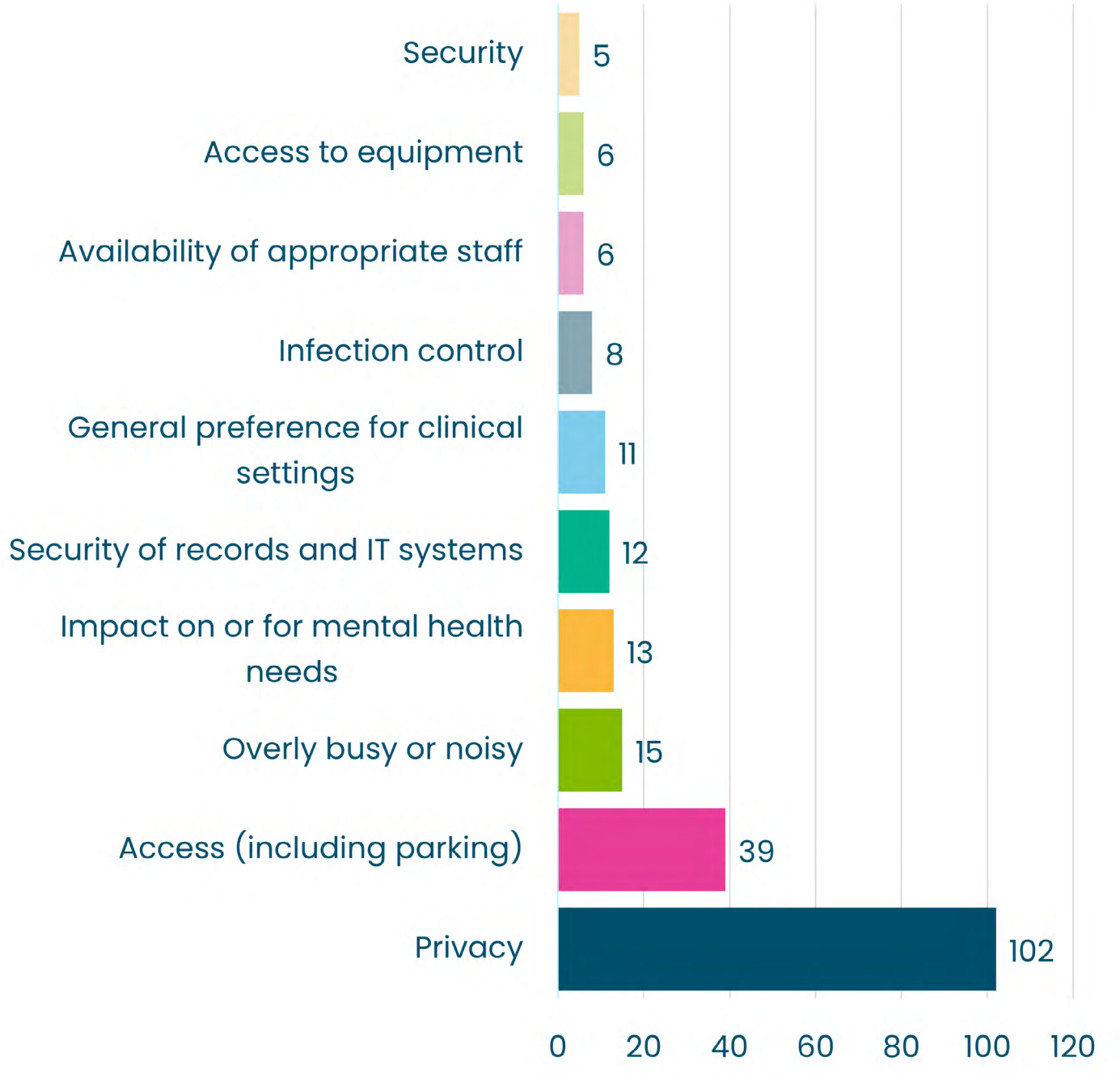
Signage in community spaces is a potentially complex issue which merits further study.

What does this tell us?

- Any decisions about the use of specific community venues should take into account all the issues our respondents raised.
- The introduction of appointments in community spaces should be accompanied by clear and detailed communications about the measures taken to ensure privacy, as well as the other issues our respondents raised such as parking, accessibility and infection control.

By far the most common concern our respondents had about appointments in public spaces was privacy. A few said they would want the room to be soundproofed; others worried about being spotted by people they knew.

Figure 34: Please tell us any worries you might have about coming to a health appointment in a public place



A few examples of what people said about privacy:

"Privacy [is my main worry] - people would know I was going for an appointment unless there were other rooms in the same place after an initial door and people couldn't see which one you were going into."

"Use of receptionist in these places as may not have same protocols for ensuring confidentiality as in a health premise."

"Depends on the appointment, I would prefer things like mental health appointments to be in a discrete place."

Respondents' concerns about access included parking spaces, getting transport to centres (and the cost implications of this), adaptations for people with mobility and hearing problems, the provision of language interpreting and suitably adapted settings for people with neurodiverse conditions.

Other concerns included the following:

- Spaces might be crowded, busy or noisy.
- People talked about the anxiety or other issues they experience when in unfamiliar or busy places; some would need another person to accompany them.
- IT systems and patient records would need to be secure.
- Precautions should be in place to mitigate the risk of passing on infections to people using the space for other reasons.

- A few people raised the idea that spaces might not be staffed appropriately (i.e., that staff could be unqualified or not sufficient in number should an emergency occur).
- Some questioned whether the right equipment would be available.
- Some were concerned about the security of the buildings.

Additionally, a small number of people expressed a general preference for clinical settings, saying, for example, that they felt more "professional".

Two comments about signage provided interesting counterpoints to one another:



"[I would worry about] Signage, e.g. continence clinic in a library would feel very exposing."

"Not [a problem] for me, but for parents who don't speak English. If it's not in a healthcare setting, they won't know where to find it. For example, my parents were sent a diabetic eye screening appointment in Wakefield, and it was in Asda; there were no signs, and they thought it was in the surrounding health care venues. Never would they have thought that the appointment was in a supermarket; they were late to their appointment, and the health care professional was rude rather than understanding. So, if you decide to implement this, make sure there are clear signage outside of the building and in appointment letters."

A few other points raised by our respondents included the following:

"Would I be interrupting the activities going on at the library[?] Would having health appointments put people off using and engaging with library activities due to being interrupted?"

"Some community centres don't feel welcoming - they sometimes feel as though they are for an 'in crowd'."

"I work full time, so these spaces aren't usually open at a time outside of working hours."

"Kids being noisy (my own kids)."

A few people also commented positively about the possibility of attending medical appointments in community spaces. Here is one example:

"Great idea. Keep our libraries and post offices open by making sustainable health and social community hubs!"

1.5 Being online

a) Are you able to use the internet every day?

Key findings

The question

"Are you able to use the internet every day?"

Who was eligible to answer

All respondents.

Why this question?

Internet use is an important part of the government's Three Shifts. Online systems may be able to support the effectiveness of neighbourhood health models, if they are tailored to people's different needs and empower them to take care of their own health in conjunction with services.

What did we find out?



The majority of our respondents can use the internet every day, although that majority does decrease as our respondents age.

Difficulty getting out of the house is another factor that makes people even more unlikely to be a regular internet user.



While higher levels of deprivation do have a moderate effect on whether a person is able to get online regularly, age and, to a lesser extent, disability appear to have a stronger impact.

However, among our younger respondents, those in receipt of benefits are less likely than their peers to be able to get online every day.

What does this tell us?

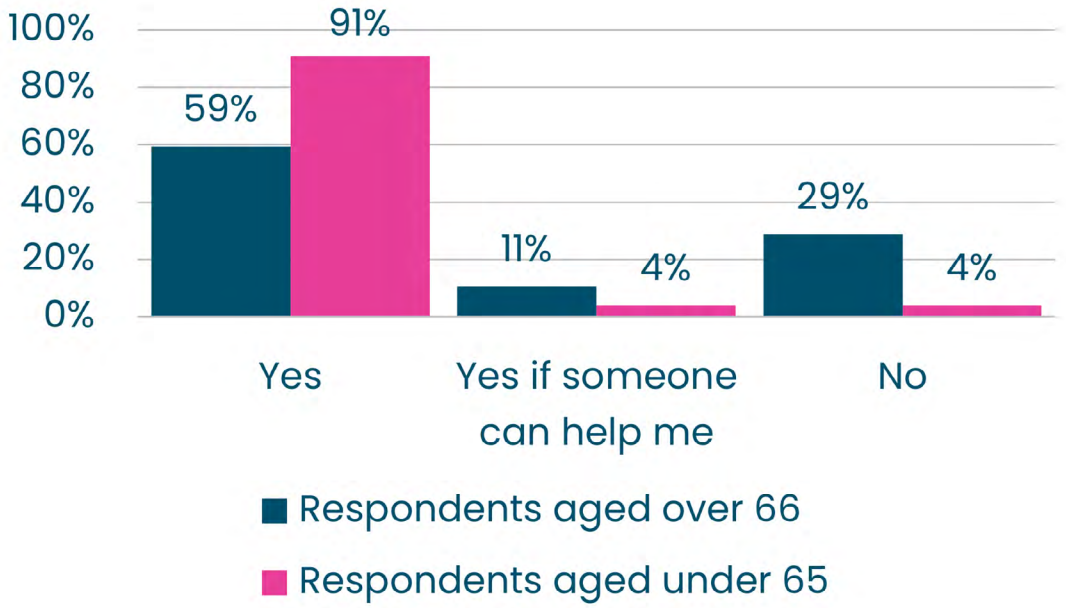
- If online systems are designed in a way that meets people's needs, they have the potential to reach a great number of people.
- There remain significant groups of people who can't get online daily and therefore need alternative ways of connecting with services. These are some of the same groups which have been identified by previous engagements about digital exclusion. Older people's needs are an important place to start in any work to reduce health inequalities related to digital services.

Figure 35: Are you able to use the internet every day?



Most of our respondents can use the internet every day.

Figure 36: Comparing by age, can you use the internet every day?



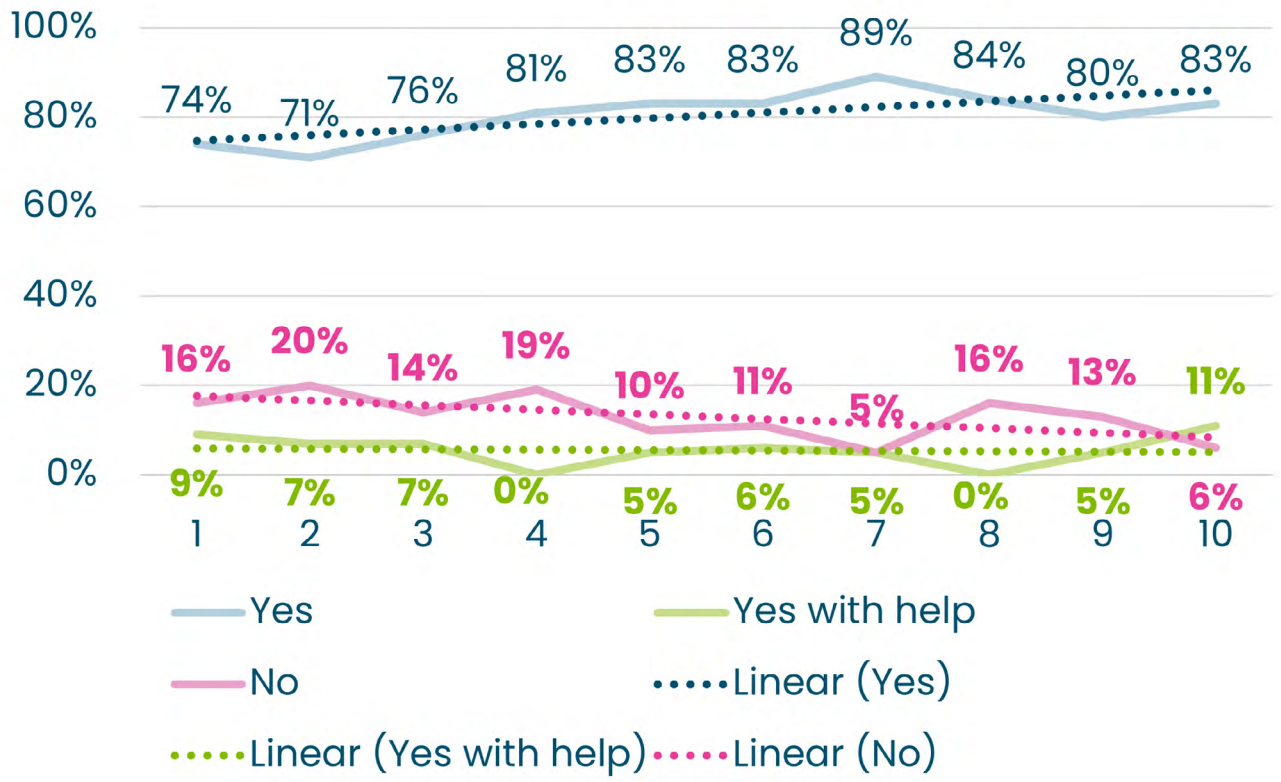
In our data, age is the factor most strongly associated with whether a person uses the internet daily. Our older respondents, particularly those aged 66 or over, were less likely to be able to get online every day.

Nearly three-quarters of our respondents who always find it difficult to get out of the house were aged 66 or older, and they were also less able to use the internet daily.

Similarly, 71% of our respondents with a disability or health condition said they could use the internet daily. When we screened out disabled respondents of retirement age, the amount shot up to 84%. 58% of our South Asian respondents said they could get online every day, but a large proportion of our respondents with a South Asian or mixed South Asian background were aged 66 or over. On the other hand, our respondents with a Black or mixed Black background were generally younger than retirement age, and 87% said they could access the internet.

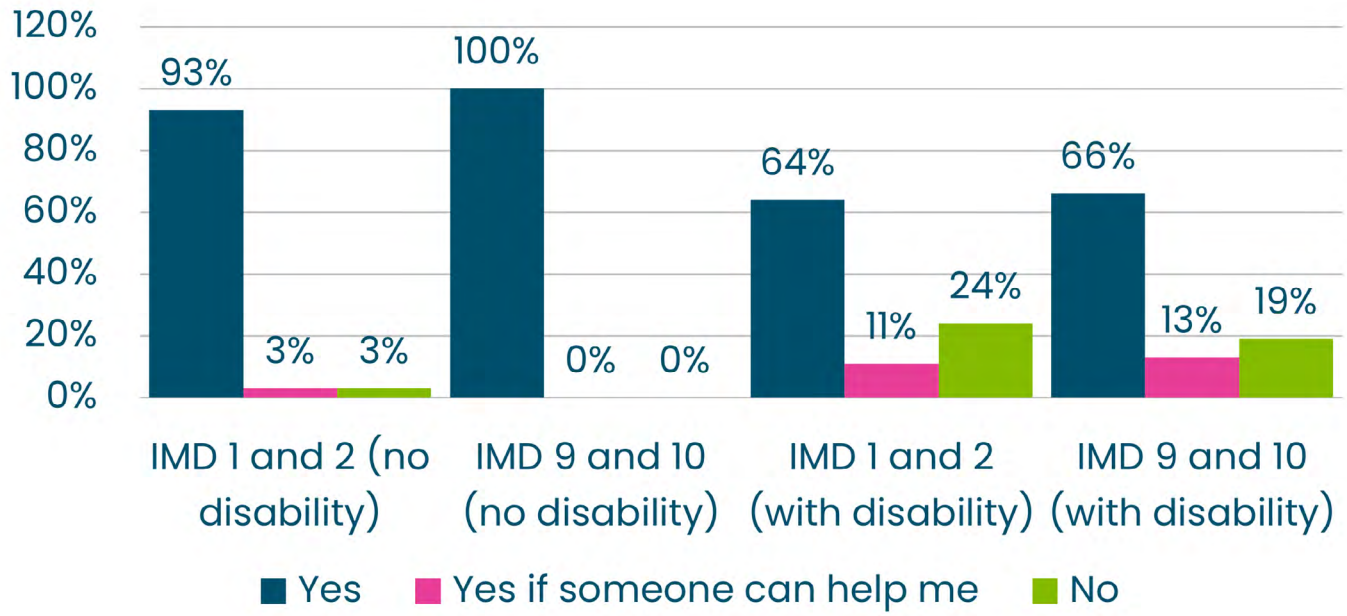
However, there is another factor in our data that may also be significant in terms of a person's ability to get online. 40 respondents told us they receive state benefits such as Personal Independence Payments; the vast majority were under retirement age. Only 65% of them said they could get online daily, while 20% couldn't.

Figure 37: Can you use the internet every day? By IMD decile.



On the whole, people in lower deciles were more likely to say they couldn't get online daily. However, the proportions of people who need help to get online were similar at both ends of the IMD spectrum. Age may be playing a role here, as we know our respondents in the highest deciles tend to be somewhat older, and that our older respondents are less online on the whole.

Figure 38: Can you use the internet every day, comparing IMDs 1 and 2 and 9 and 10 and people with and without disabilities

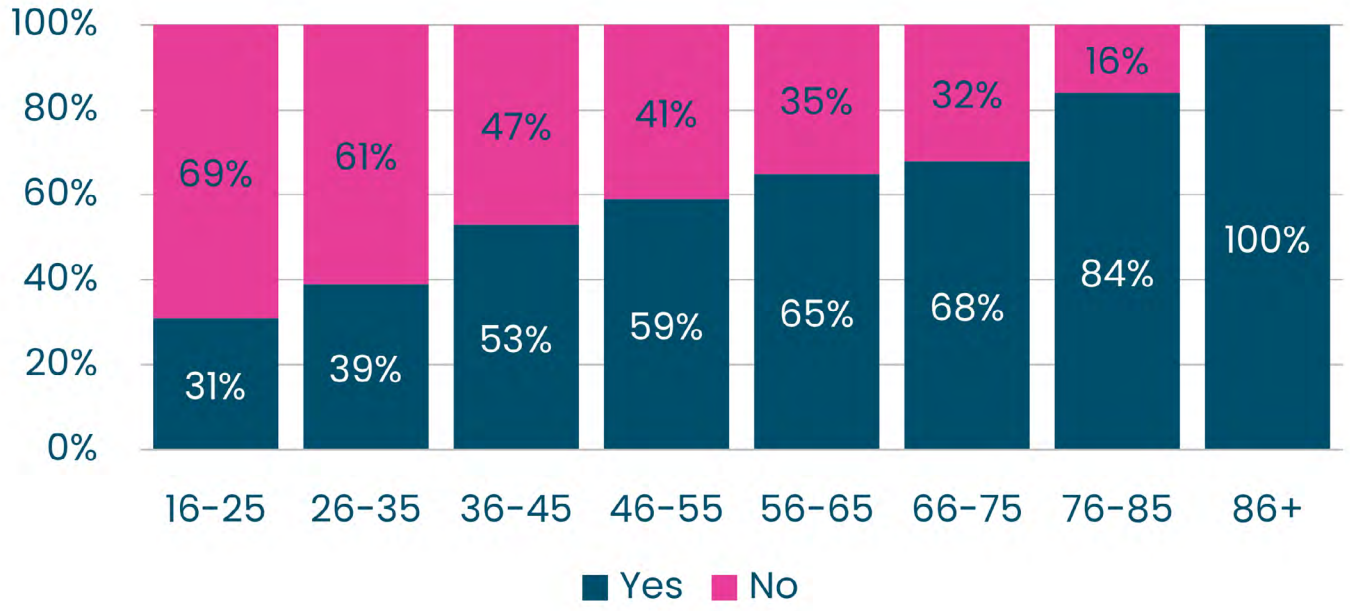


Another important factor in daily internet usage appears to be whether a person has a disability or health condition.

Figure 38 shows that, among respondents with no disability or long-term health condition, the ability to get online is broadly comparable across deciles. However, when we factor in disability, we see internet usage drop dramatically in both the highest and lowest deciles.

Among people with disabilities and/or health conditions, belonging to a higher IMD decile doesn't appear to be a protective factor when it comes to digital exclusion. However, this finding should be treated with caution, as we again need to factor in age, since our older respondents are much more likely to have a disability or health condition.

Figure 39: Do you have a disability or long term condition? by age category



b) How would you like to use the internet (or already use the internet) to connect with health and care services?

Key findings

The question

"Would you like to use the internet (or do you already use the internet) to connect with health and care services in the following ways?

- Booking or changing times, dates and places for appointments.
- Having appointments with members of staff.
- Ordering prescriptions.
- Asking for advice.
- Updating services about my health.
- Getting test results.
- Checking my health records.
- Finding local services.
- Managing care for someone else."

Who was eligible to answer

All respondents.

Why this question?

This question is designed to deepen our understanding of how online systems may support the effectiveness of neighbourhood health models.

What did we find out?



Large numbers of people are either already using or are interested in using digital functions.



The digital functions that offer the greatest potential to meet people's needs are those that allow them to update service providers on their health and ask for advice.

As well as being less able to get online, older people tend to be less motivated to use digital functions.

A minority of people who can get online regularly indicate that they aren't interested in using any digital functions.



Just over a quarter of people who can't get online regularly would like to use at least one digital function. There are some indications that people from minority ethnic backgrounds and men made up a larger-than-expected proportion of this group, although it should be noted that the sample size was small.

What does this tell us?

- There remains a significant number of people who are not motivated to use online services. Neighbourhood health models need to meet their needs as much as they do for digitally enabled people.
- The biggest unmet need that digital functions might be able to fulfil relates to people's ability to reach out to services (as opposed to extracting information from services), especially when something has changed with their health. Here, digital functions aren't a replacement for the patient-clinician relationship, but a way of making it more two-way.
- One issue our engagement didn't cover was the use of AI in digital services.



We asked people about their attitudes to different ways they could use the internet to manage their health. This can be used to get an idea of:

a)What options the largest numbers of people feel positively about (i.e., already do them or would like to).

b)For which options there is the biggest gap between the proportion of people who are already doing them and the proportion of people who would like to do them.

This is expressed in the following table.

The different ways people could use the internet to manage their health	I already do this	I would like to do this	I don't want to do this	I don't need to do this	% of those who feel positively are not yet doing this but would like to
Booking or changing times, dates and places for appointments	57%	18%	16%	4%	24%
Having appointments with members of staff	42%	25%	20%	6%	37%
Ordering prescriptions	58%	16%	12%	9%	21%
Asking for advice	38%	27%	20%	7%	42%
Updating services about my health	33%	32%	18%	8%	49%
Getting test results	49%	21%	16%	6%	30%
Checking my health records	52%	18%	15%	6%	26%
Finding local services	51%	19%	11%	8%	27%
Managing care for someone else	25%	16%	10%	29%	39%

The table suggests that the options for which increased availability would meet people's needs the most are:

- Updating services about one's health.
- Asking for advice.
- Managing care for someone else (but please note that a relatively small number of people said this option would be relevant to them).
- Having appointments.

It is perhaps significant that the first two on this list are about people's ability to reach out to services in times of need, rather than simply extracting information from services (as is the case for options to check health records, order prescriptions, and get test results). So far, digitalised services have perhaps succeeded most in one-way communication, getting information out of services, and there is now an appetite for two-way communication.

Regarding what our respondents don't want to do, a majority (68%) indicated that they would be interested in at least one option. 13% of our respondents said they didn't want to do more than half of the options.

Figure 40: The total number of options each respondent has said they don't want

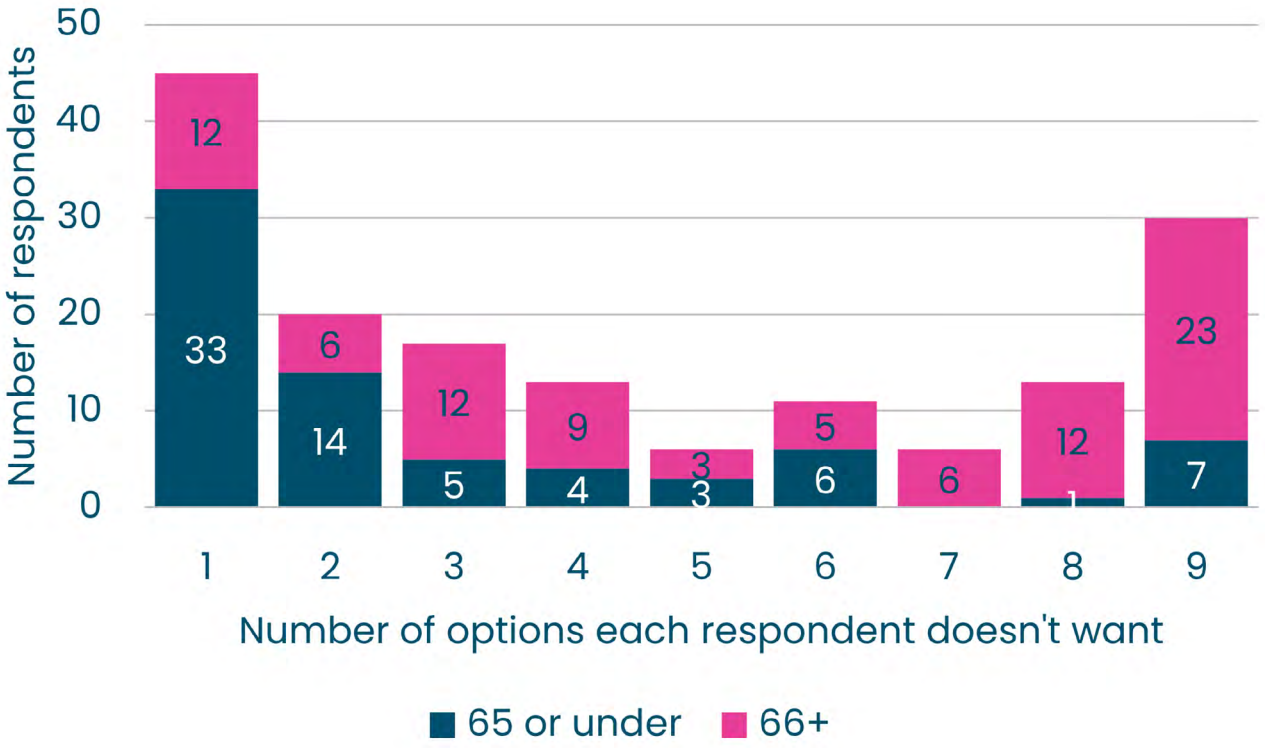


Figure 40 breaks down how many options each respondent said they did not want to do, comparing the responses of people aged 65 and 66+. Older people make up a larger proportion of the people who are not interested in more than half the options, unsurprisingly given what we know about their relative internet use.

Our Black or mixed Black respondents were neither over-represented nor under-represented among the 13% of respondents who indicated they did not want more than half the options. This rose to 25% for our respondents of South Asian or mixed South Asian ethnicities. We know that our Asian respondents were less likely to say they could use the internet every day and were also older on average.

In our data, people who don't want more than half of the online options didn't have notably more contacts with services over the past year.

Figure 41: Ability to get online among people who say they don't want to use 5 or more of the options



People who indicated they didn't want to use more than half the options were quite likely not to be able to use the internet every day. Nonetheless, a third of this group, who consistently were not interested in digital options, were, in fact, able to get online regularly. This suggest that:

- About half of our respondents who are not digitally enabled do not currently see much or any value in becoming so.
- Not being digitally enabled isn't the only factor in the refusal of digital tools.

Figure 42: People who cannot get online daily, what proportions would like to be able to use at least one digital function?



When we look at the responses of people who can't get online every day, we can see that 26% of them would like to be able to do at least one of the options given, indicating that there is a minority of people who might use online tools if they were enabled to do so.

The 26% represents 16 people. Six people in this group indicated an ethnicity other than White British; six were male; and ten were aged 66+.



1.6 Preventing ill health

a) Do you worry that things about your life now might affect your health, now or in the future?

Key findings

The question

"All kinds of things affect our health, from smoking to what we eat, how we sleep, our work and more. Do you worry that things about your life now might affect your health, now or in the future?"

Who was eligible to answer?

Respondents without a disability or health condition.

Why this question?

Prevention is key to any model that seeks to keep people well for as long as possible. We wanted to know the extent to which our respondents felt concerned about their lifestyle's impact on health to give us a sense of which groups are potentially more open to changing their lifestyle for preventative reasons.

What did we find out?



Most people have at least some worries about their lifestyle's impact on their health.

Concerns become more prevalent as people approach middle age, particularly between 46 and 55. Our respondents then gradually become less worried from the age of 56 onwards.



People at the youngest and oldest ends of the age spectrum are the least worried about the impact of their lifestyle. One reason for this might be that ill health seems a remote possibility for younger people, while older people may feel that it has become unavoidable at their age and therefore not worth worrying about. Alternatively, younger and older people may feel that they are good at taking care of themselves and therefore don't need to worry.



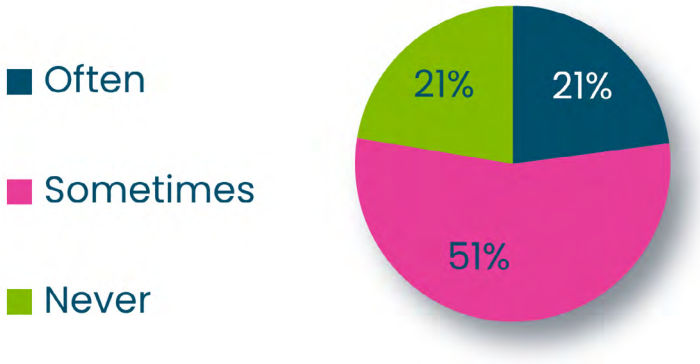
Men tended to worry less aboutthe impact of their lifestyle than women.

There are some indications that Black and mixed Black respondents, and most notably South Asian and mixed South Asian respondents, tend to worry somewhat less about the impact of lifestyle on health.

What does this tell us?

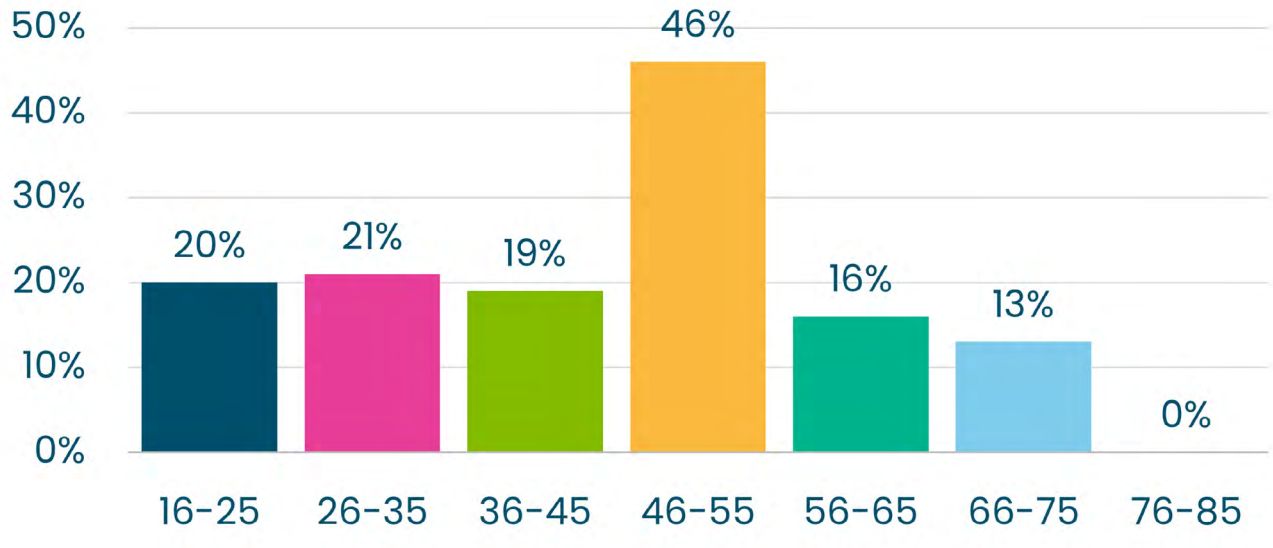
- Assuming that being worried about our lifestyle's impact implies that we are open to change, most people would be open to changing aspects of the way they live to benefit their health. People may be most open to support with changing their lifestyle between the ages of 46 and 55.
- Support for our youngest and oldest people to change their lifestyle may need to be framed in a way which is not focused on worries or risks, because it won't necessarily speak to their current attitudes to their health.
- Similarly, men may be less risk-focused on their approach to lifestyle and health. Any preventative work with them could benefit from an approach rooted in other motivating factors.
- There is some reason to believe that people from minority ethnic backgrounds may also tend to have less risk-focused motivations for changing their lifestyle, but further study would be helpful here.

Figure 43: Do you worry about your health?



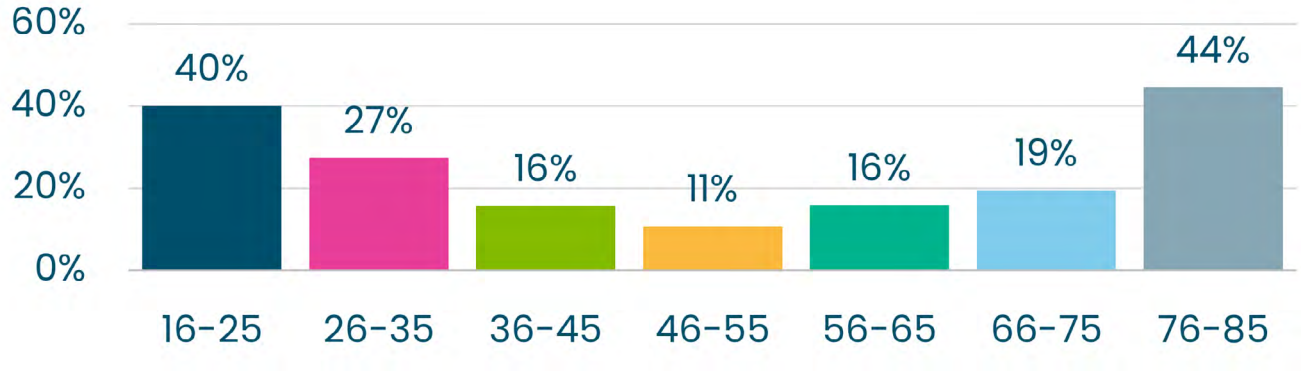
Most people said they worry about the health implications of their lifestyle at least some of the time.

Figure 44: Percentage of each age category who often worry about impact of lifestyle on health



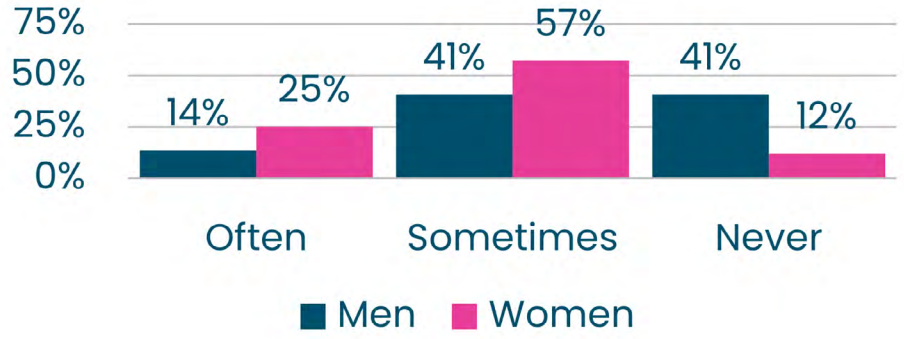
When we look at the proportion of people in each age category who say they often worry about the impact of their lifestyle on their health, we see concerns spike among respondents aged 46 to 55. The chart shows the percentage of each age category who said they often worry about their lifestyle. The proportion gradually increases until the 46-55 age group, at which point it rises more notably, then decreases again from age 56.

Figure 45: Percentage of age category who never worry about impact of lifestyle on health



The proportion of people in each age category who said they never worry about the impact of their lifestyle on their health gradually declines as people approach the 46-55 category, before rising again to its highest levels at the 76-85 category.

Figure 46: Impact of lifestyle on health, percentage of men's attitudes vs womens's attitudes



In addition to age, gender appears to have an effect on people's attitudes toward how lifestyle impacts health. Men are more likely than women to say they never worry about this. When considering Figure 46, bear in mind that our male respondents to this question tended to be somewhat younger than our female respondents.

Another category in which we see somewhat higher levels of worry than the data as a whole is among unpaid carers, with just 14% saying they never worry about how their lifestyle impacts their health. However, our unpaid carer respondents are overwhelmingly female (83%) and over 60% were aged between 46 and 65, so these slightly higher levels of concern are largely in keeping with the data.

In terms of ethnicity, 35% of our respondents with a Black or mixed Black background said they never worried about how their lifestyle impacts their health (against 22% for the data as a whole). However, it should again be noted that our Black and mixed Black respondents were generally younger than our overall body of respondents. On the other hand, the distribution of our South Asian and mixed South Asian respondents' ages was much more similar to the total data, yet slightly more South Asian respondents said they never worried (28%) or often worried (25%) about the impact of their lifestyle.



b) Are there any changes you would like to make which might help to keep you healthy?

Key findings

The question

"Are there any changes you would like to make which might help to keep you healthy?"

Who was eligible to answer?

Respondents without a disability or health condition.

Why this question?

Neighbourhood health models with a preventative focus would benefit from being guided by the changes people are already motivated to make.

What did we find out?

The majority of our respondents have changes they would like to make in aid of a healthier lifestyle.

Young (and relatively young) people are disproportionately interested in making all kinds of changes to their health, despite being less likely to be worried about their lifestyle's impact on their health.

People's interest in changing their lifestyle starts to decline from the age of 56.



Our South Asian and mixed South Asian respondents expressed a disproportionately high interest in eating more healthily and reducing screen time.



Women are generally more likely than men to express an interest in specific lifestyle changes.

People who often worry about the health impact of their lifestyle expressed a disproportionate interest in reducing worry and increasing sleep.

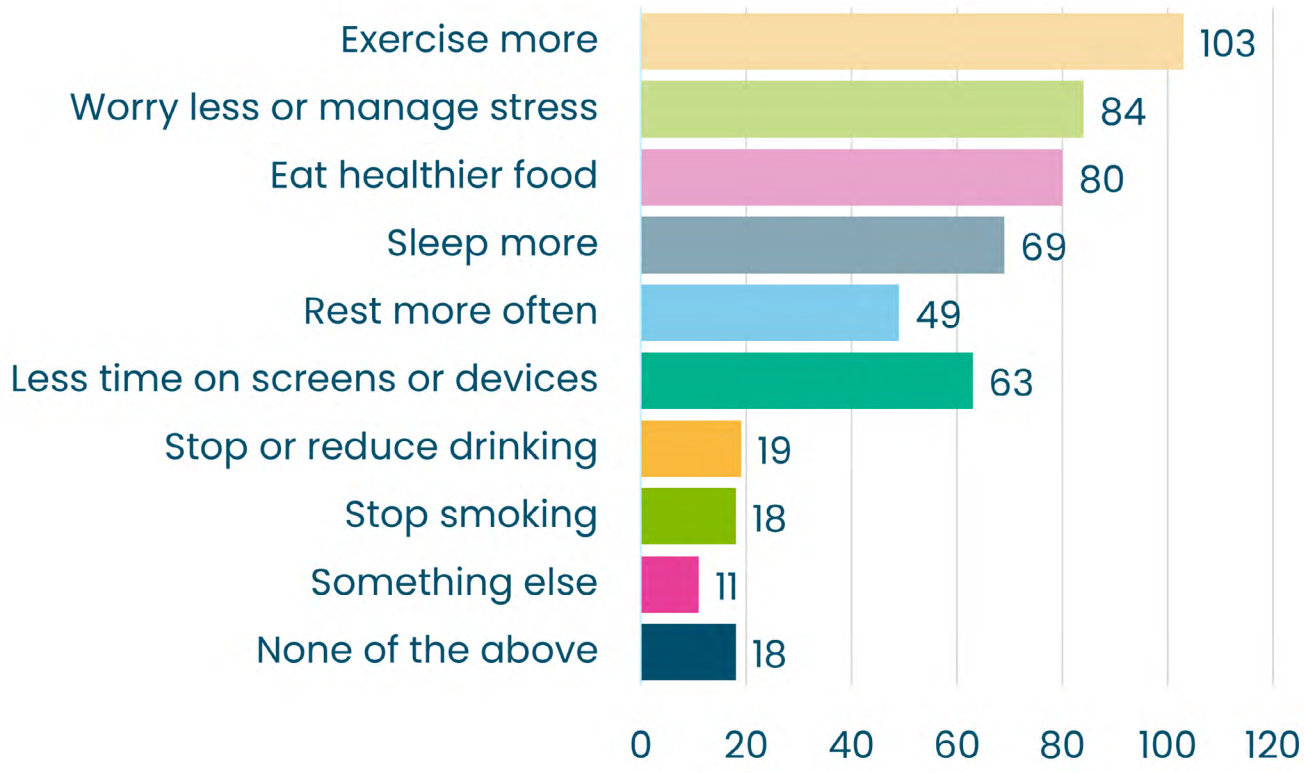


Being able to rest more often and stopping smoking are more important for our most deprived respondents, compared with our respondents as a whole.

What does this tell us?

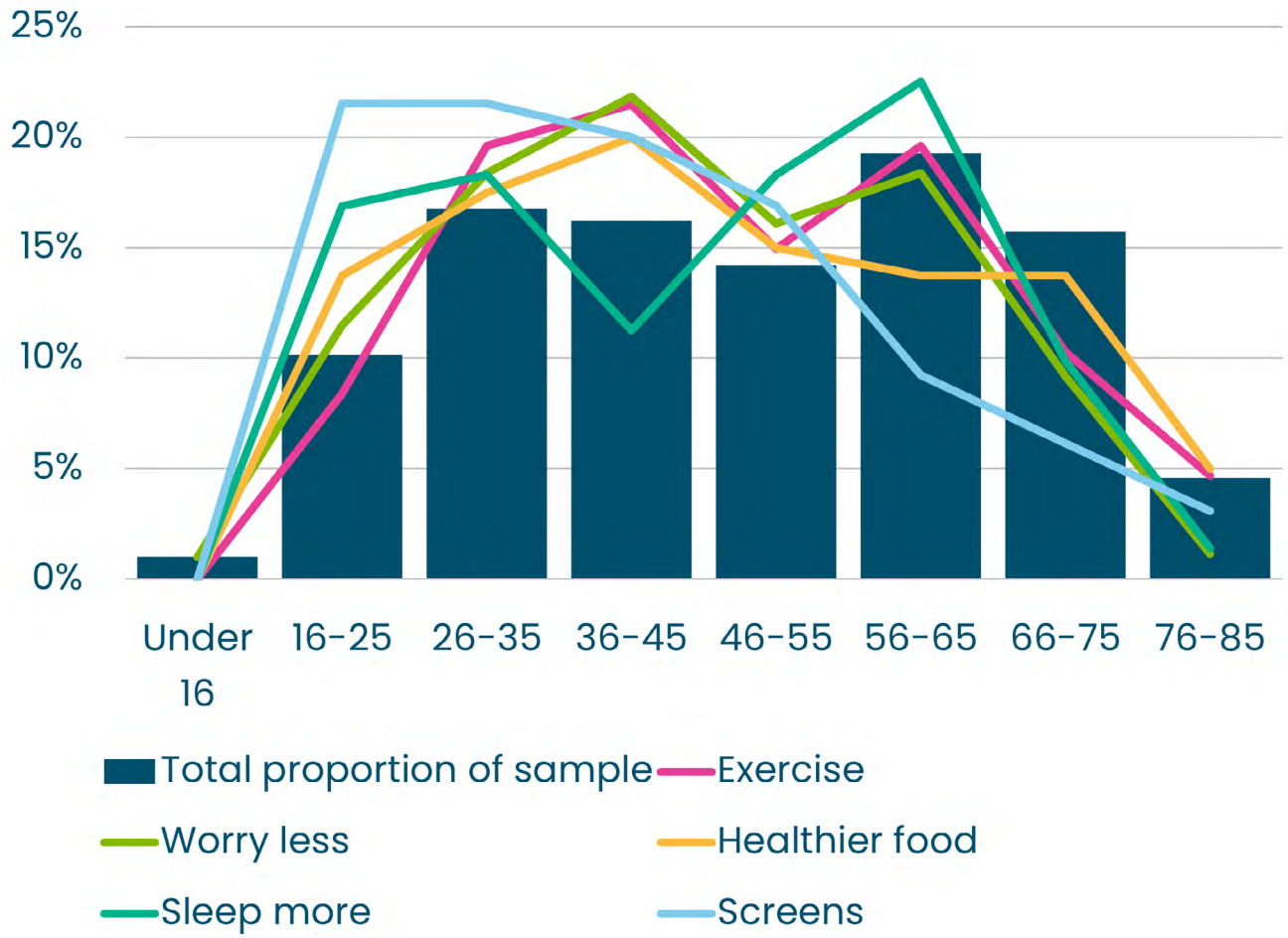
- People are generally motivated to take preventative action.
- Interventions targeted at younger people could make a big impact, given their comparatively high levels of motivation to change their behaviours.
- Interventions aimed at changing the behaviours of people aged 56 and older and men have less motivation to for services to capitalise on. It could be helpful to learn more about what these older age groups are motivated to do and use this as a means to encourage preventative behaviours.
- Preventative work with South Asian people could focus on understanding their barriers to healthier eating and finding ways to overcome them, and on ways of reducing screen time.
- Guidance about stress management and improved sleep could be particularly impactful for people who are frequently worried about their lifestyle.
- Preventative work targeted at Leeds' most deprived residents should include support with smoking cessation. It should also bear in mind that a lack of opportunity to rest is a problem for this group of people.

Figure 47: Are there any changes you would like to make which might help to keep you healthy?



Many of our respondents had one or more changes they would like to make to help keep themselves healthy.

Figure 48: Changes our respondents would like to make by age



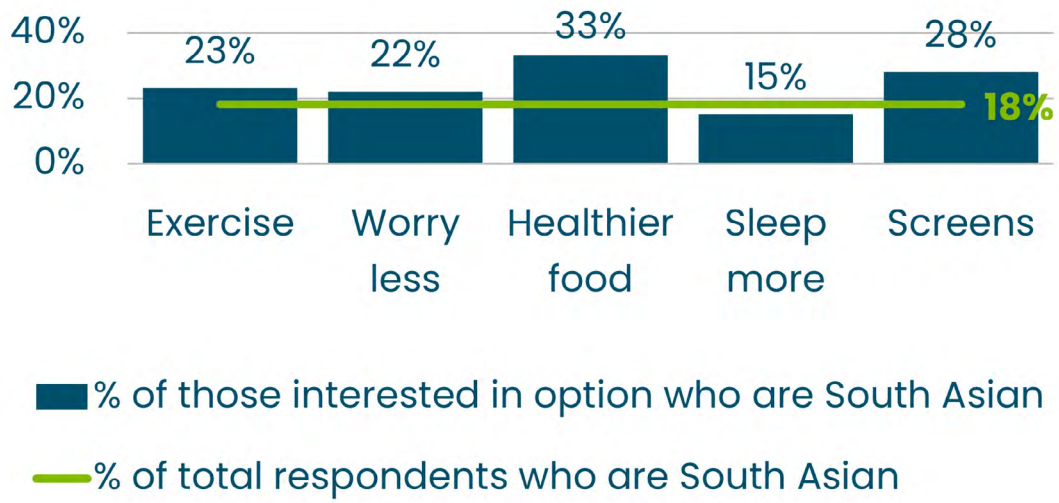
When we look more closely at the five most frequently recorded responses, we can see that people of different ages responded in varying proportions to each. For example, younger people were more likely to want to change their screen time: they made up 10% of our (non-disabled) respondents, but 22% of respondents who said they would like to reduce it.

In fact, our respondents aged 16 to 25 (and, to a lesser extent, 26 to 35 and 36 to 45) were disproportionately likely to say they would like to make changes to help themselves stay healthy. This is despite them being much more likely than more middle-aged respondents to say they never worry about their health (as seen in Figure 45). Feeling concern about health and an interest in health-seeking behaviours don't come as a pair here.

Moreover, we saw in Figure 45 that people in the 46 to 55 age category worried most often about their health. However, when it comes to health-seeking behaviours, they don't appear to make up a notably disproportionate share of our responses, showing an interest in each of the five most popular options in only slightly higher numbers than we might expect.

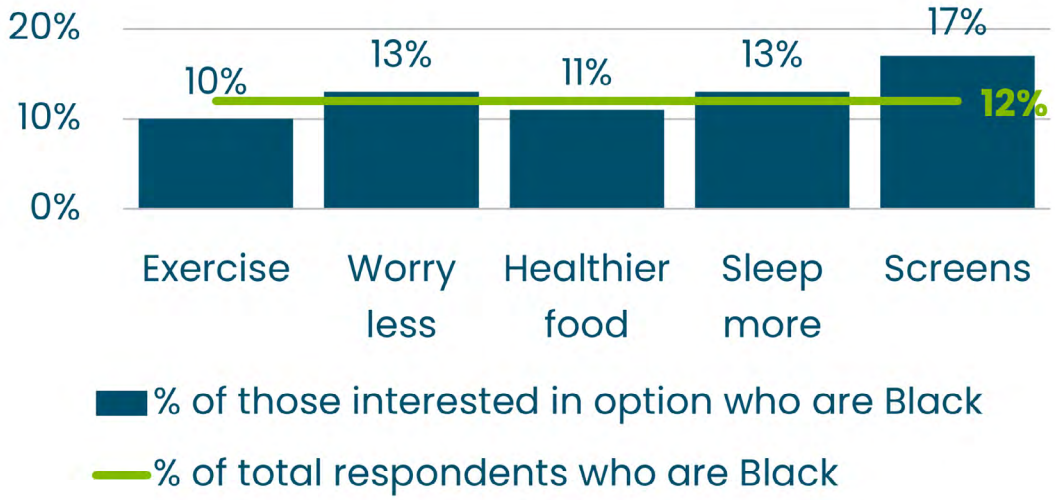
As people approach later middle age, they appear to become less likely to want to make changes that could improve their health. First, fewer people express interest in screen time, managing stress and healthier eating around ages 56 to 65; then they become less interested in all five options at ages 66 to 75.

Figure 49: South Asian respondents as a proportion of the people interested in each health behaviour



Our South Asian and mixed South Asian respondents made up a disproportionate share of those interested in all but one of the top five health behaviours. South Asian people made up a particularly large proportion of those interested in eating healthier food and cutting down on screen time.

Figure 50: Black respondents as a proportion of the people interested in each health behaviour

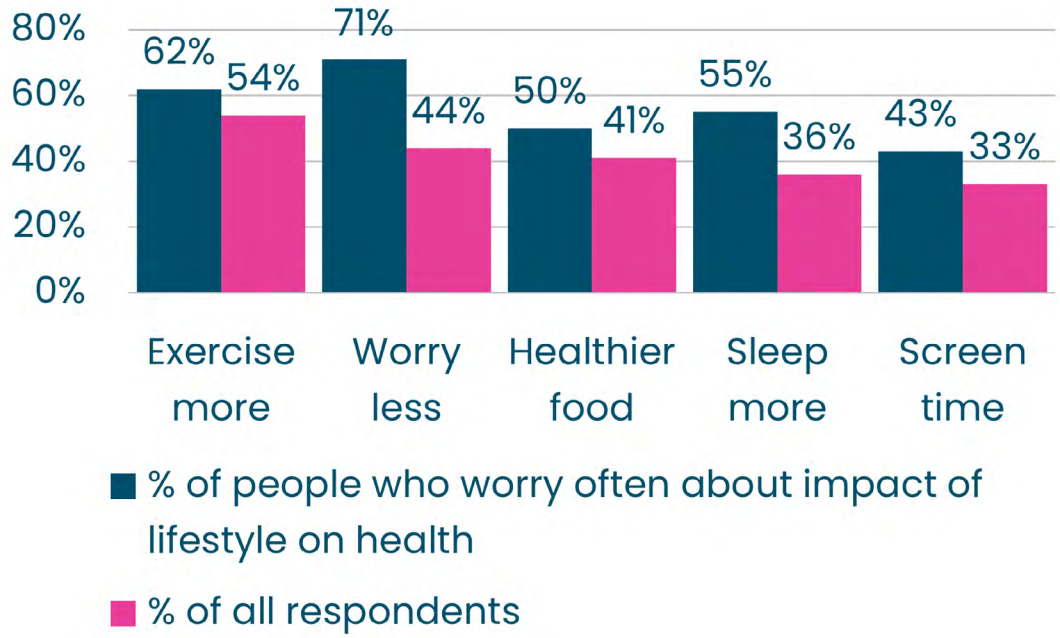


We didn't see as marked an effect among our Black or mixed Black respondents. Black respondents made up a slightly larger-than-expected proportion of people interested in cutting down their screen time, perhaps less surprising given that our Black respondents tend to be younger.

Compared with men, women were somewhat disproportionately interested in making three of the top five changes as shown in the table below.

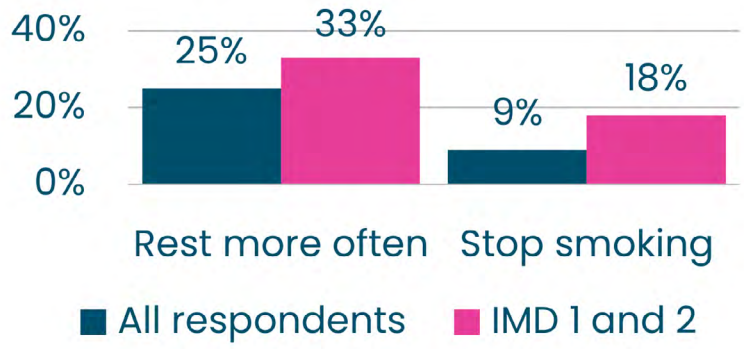
Gender	% of all respondents	% exercise more	% worry less	% healthier food	% sleep more	% screen time
Female	68%	67%	75%	64%	77%	74%
Male	30%	31%	23%	35%	20%	25%

Figure 51: Changes our respondents would like to make: people who worry often about their lifestyle's health impact vs all respondents



When we look at our respondents who often worry about the impact of their lifestyle, we see that a greater proportion were interested in adopting specific healthier behaviours. This was particularly the case for the options to worry less, manage stress better, and sleep more.

Figure 52: Are there any changes you would like to make?: how respondents with IMDs of 1 and 2 differ from other respondents



In most cases, our respondents in the lowest two IMD deciles expressed an interest in making changes to improve health, in proportions similar to those of our respondents as a whole. The two exceptions were the options to get more rest and stop smoking.

c) What is stopping you from making those changes, if anything?

Key findings

The question

"What is stopping you from making those changes, if anything?"

Who was eligible to answer?

Respondents without a disability or health condition.

Why this question?

This question further develops our understanding of the barriers that get in the way of people from taking preventative action.

What did we find out?

Work is the biggest barrier in people's way, but our respondents' answers generally suggest they are busy and find it difficult to prioritise preventative care over other responsibilities.



What does this tell us?

- Any interventions aimed at supporting people to make changes for the long-term good of their health should recognise that some people feel too busy to commit to making changes in their behaviour.
- Workplaces could be an interesting place to consider as a base for preventative action, given that people feel that their professional responsibilities get in the way of change.



Figure 53: What is stopping you from making changes, if anything?



The largest share of our respondents named work as the biggest barrier to changing health behaviours. The top two most common reasons people don't make the changes they want are closely related as well as the third and fourth.

It is perhaps worth bearing in mind that relatively few people answered this question, possibly because they feel nothing specific is preventing them from making changes.

When asked what might stop them from making changes to their lifestyle, our respondents from IMDs 1 and 2 gave answers that were proportionately similar to those of all respondents. They were somewhat less likely to say work pressures were a potential barrier (10% of responses compared with 18%), but more likely to indicate that stress would be a problem (10% vs 6%).

d) In the past couple of years, have you had to think about paying for health treatment that previously you might have got via the NHS?

Key findings

The question

"In the past couple of years, have you had to think about paying for health treatment that previously you might have got via the NHS? (Examples include dentistry, podiatry, ear syringing, physiotherapy, etc.)"

Who was eligible to answer?

All respondents.

Why this question?

This question is intended to give an initial idea of inequalities directly linked to people's access to money. As people find it harder to access timely NHS care, those with more financial resources have the option of paying for private treatment.

What did we find out?

Many people have thought about paying for treatment in recent years.

Most demographic groups told us they had thought about paying for treatment, in numbers largely in line with expectations.

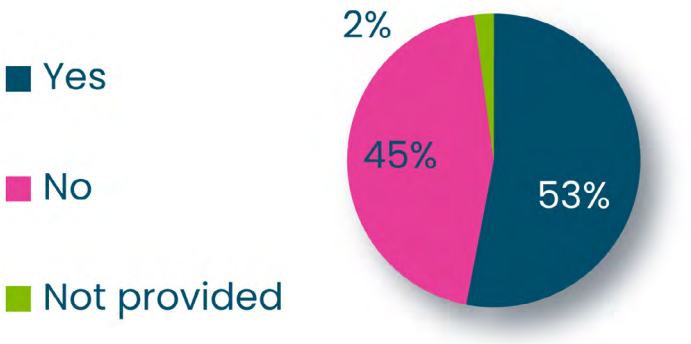


One group that was underrepresented among people who had considered paying for treatment was people in receipt of state benefits.

What does this tell us?

- Seeking out private treatment was commonplace among our respondents.
- Within our pool of responses, demographics didn't appear to have a strong influence on who considered paying for treatment. However, there were some indications that people with a disability on lower incomes didn't think about private treatment in as large numbers, suggesting that, over time, access to private treatment may become a factor in widening health inequalities.

Figure 54: Have you had to think about paying for health treatment that previously you might have got via the NHS?



Just over half of our respondents said they had thought about paying for treatments over the past couple of years. Groups of respondents who were somewhat more likely than expected to say they have thought about paying for treatment are as follows:

- Unpaid carers make up 19% of our respondents, but 23% of the people who have thought about paying for care.
- White British people make up 71% of our respondents, but 80% of the people who have thought about paying for care.

One group which was less likely than expected to say they have thought about paying for care was 4% of people in receipt of state benefits (8% of our respondents overall). Bear in mind that 95% of our respondents who receive state benefits had a disability or health condition.

Groups which said they had thought about paying for care in larger-than-expected numbers were people who said it was difficult to get out of the house, people with mental health conditions, people with neurodiverse conditions, South Asian people, and Black people. Age did not appear to affect whether a person was more or less likely to have thought about paying for care.

1.7 Case Studies

The following case studies are drawn from engagements in which groups preferred to answer questions collectively rather than individual surveys. These are condensed versions of the notes, focussing only on key points.

Leeds Community Healthcare's Diabetes Groups

Podiatry: being referred for podiatry, only to find out upon arriving for the appointment that they weren't eligible for treatment

Annual health reviews: variation across GP surgeries – only some people are prompted to make an appointment

Test results: some people have not been contacted after blood tests when they should have been, only finding out at later appointments that there was a problem

Online services: often felt to be hard to use, leading to a preference for making in-person contact

Leeds Community Health Care's Youth Board

Many people said they relied on websites, AI or social media to learn about health and self-care. Some of the people who used the internet in this way were unsure about its usefulness.

Most are at least somewhat confident about managing their own health. Access to trusted information and personalised support tailored to their condition and wider circumstances would improve their confidence (compared with more generic information).

All board members had received some guidance on looking after their mental health, although this was not always felt to be specific enough to be helpful.

ASHA Neighbourhood Project

The ASHA Neighbourhood Project is an organisation aimed at women and children in South Leeds.

St. George's UTC was repeatedly mentioned as a place that was used regularly.

Six people had a long-term health condition. In addition to health and care services, people said advice programmes, such as for food, diet and exercise, were a good place to get support with health. ASHA itself was mentioned as a trustworthy place to seek advice, due to it being a women-focused centre.

Most people mentioned that to improve their health, they would like to exercise more, such as walking and swimming. Others mentioned that having social gatherings helps to improve their health. Finally, some people discussed wanting to improve their diet. A key barrier to people doing these activities was a lack of motivation, will and commitment.

Everyone in the group can use the internet without help. The ways people use online services to look after their health are through making appointments, using the NHS app, searching symptoms and health problems, finding home remedies and self-help, exercise, for example, through YouTube home workouts, finding recipes and using ChatGPT to plan a routine and activities throughout the day.

Some mentioned how frustrating it is to be seen only about one problem at a time, for example, being told at GP appointments that they need to book another appointment for a separate issue. Most people did not like being told to visit a pharmacy instead, as they said they would go to their GP first anyway and didn't understand how chemists could help.

Better Leeds Communities

15 participants had seen a GP in the last year. Three had seen a health professional in a hospital inpatient department, and eight in an urgent treatment centre. Eight participants had a long-term health condition.

All participants said that GPs usually help them the most with their condition when they are unwell or having problems with it. Some mentioned seeing nurses, doctors and other healthcare professionals within GP practices. Some talked of unhelpful signposting to pharmacies.

When asked what they would do differently to feel healthier, most participants mentioned changing their diets, especially reducing sugar intake. They find this difficult due to a lack of education and information on diets and organic foods, children who dislike vegetables, and the price of unhealthy foods compared to healthy ones. A few participants mentioned being blamed by healthcare professionals for their children's problems due to their diet. Most participants say that they like that the community centre provides free healthy breakfasts. Some mentioned having specific dietary requirements, like lactose or gluten intolerance, and that these are expensive to buy, and they worry about the added preservatives. Most participants would like to exercise more, although most women in the group attend exercise classes and walking activities within Better Leeds Communities.

All participants can use the internet without help. When asked what they do online to look after their health, most of the participants answered that they use the internet to make healthcare appointments and order prescriptions. Many use it for shopping and finding recipes. One participant mentioned using apps like Headspace for relaxation. Another mentioned using it for water reminders. However, some participants reported that they do not have time to access online resources to improve their health.

When discussing the NHS app, a few participants say they use it to book appointments and access their medical records. Several participants were unaware of the NHS app. One participant mentions experiencing barriers to booking appointments this way because they are called and questioned about their reasoning, which makes them feel uncomfortable. Some mention also using the Patient Hub.

Most participants say they are concerned about long waitlists and referrals, and about frequently changing systems within GPs without proper communication. Some participants find this inaccessible.

Most mothers are concerned with the limited resources of school nurses and social services.

Association of Blind Asians Carers Group

Many have health conditions, including diabetes, kidney issues, knee problems, asthma, arthritis, hypertension, sciatica, macular degeneration and other eye problems, iron deficiency and mobility issues in the shoulder. The group also mentioned some of the conditions of the people that they cared for, including some of the above-mentioned conditions, hernias, gallstones and cancer.

Several had been to their GP surgery in the past year, and the GP also made a referral to a pharmacist in some cases. Family and friends were mentioned as a great support for many in the group. While one woman found her pharmacy extremely helpful and said that she would go there before going to the GP, others mentioned that since Covid, when trying to get GP appointments, they were often referred to the pharmacist, which is not what they found useful. In further cases, the pharmacists referred them back to the GP, which became a difficult cycle.

The group mentioned that longer funding for the carers' group would be extremely beneficial, as the group is an outlet needed which brings together people who understand each other. They are also able to share useful health information together here. The group also desired support from Carers Leeds while still being able to have their own independent carer's group. Many women in the group mentioned that they needed 'me time' to keep up with their health; however, because they are carers, the people they care for come first. Many of the women said that they did not identify as a carer, but instead as a person on call and that their responsibility was their duty. Some of the carers felt isolated because their responsibilities mean they are constantly thinking of the person they are caring for. In some cases, this means they have to avoid crowds to prevent illness, because they cannot risk their loved one's health. This is why the carer's group is so important to them.

Many women mentioned that physical leaflets with health information from the GP would be really useful to help them feel healthier, as the physical leaflet is easy to use and understand, and information from the GP makes them think it is reliable and that they are not exposed to misinformation. They expressed that they wanted support to be healthier as well, as they often feel they get advice rather than support when they need a balance of the two.

While some of the women could use the internet regularly, they found it difficult. The wellbeing centre has run IT courses to help those get better at booking appointments and using the internet for other health-related activities. However, this is not free to non-members, which creates an access issue.

Some of the women mentioned PATCHs as being a useful internet resource for their health. The women mentioned that they use the internet when they are first diagnosed with a condition to look into it. They also look for support groups for these conditions. The women also mentioned looking up information on nutrition, diabetes and high blood pressure and getting tips on being healthier in these conditions, such as steaming vegetables instead of frying them to improve nutrition. The women felt that they would like to receive more of this information from GPs.

DASSI

DASSI is a peer support group for mums from Africa and ethnically diverse backgrounds who have children with special needs.

- Would like health professionals to listen more and trust a mother's instinct, beyond just looking for a diagnostic outcome, e.g. for things like autism, where you might be waiting a long time for a diagnosis, professionals sometimes do not take parents seriously if the child is undiagnosed.
- More funding and support for childcare, as childcare costs eat into money for essentials.
- Some primary schools offer information sessions around supporting your child's/cared-for's mental health, but these are usually offered in the evening, and children are not allowed to come. This means that childcare blocks parents and carers from attending the event, so they are left without support for their mental health.

- Regarding the use of community settings for appointments, some women felt that if they had a young baby, they would be concerned about safety, as they cannot guarantee who else would be in public spaces. Even with a private space, you might have to wait in the main room.
- Another said that clinical settings can feel safer.
- Multiple women agreed that managing a child who likes to run around and be active in busy public settings can be challenging.
- One woman explained that the noise and lighting of some places can be overstimulating for their child with additional needs. Another woman said this could be managed by providing a private, quiet space for children with sensory needs.
- One woman said that her GP gives her appointments at the end of the day when the waiting room is quieter, so her children can run around without being unsafe or disturbing people.
- Another woman waits in the car for GP appointments until a receptionist tells them that their appointment time is ready.
- The group overwhelmingly didn't like online services.
- Multiple women expressed finding PATCHs difficult. Agreed that it was challenging and time-consuming to reset a password if you forgot it.
- One woman said that being a mum to many kids meant that she didn't have time to work out new complicated digital services.
- Another woman said that when PATCHs doesn't work it pushes people to go to A&E for non-emergency things. Another said that she prefers to go to walk-in centres rather than using online services.

- Multiple women noted that being responsible for multiple people's care makes it challenging to manage the digital sides of healthcare. Texts that don't have names on them make it hard to tell who the appointment is for. One woman explained that she took the wrong child out of school to attend an appointment without clear information about what the appointment was for and who it was for.

Hamwattan Men's Group

Several people spoke about feeling isolated and alone at home when extended family members are at work or occupied with other responsibilities. They highlighted transport as a barrier, which prevents them from attending the group as often as they would like. They shared that social outings organised by the centre have a positive impact on both their physical and mental wellbeing.

Three people said they are happy to take part in gentle group exercises. At home, they watch TV and browse through videos.

Four people would like to know how to better manage their health conditions with information in plain English and practical solutions, and one noted that "it would be much easier for people with a long-term condition to contact a nurse/professional directly".

Most people use the internet to watch YouTube videos and leave the "official stuff" for their adult children to navigate.

Others said PATCHs is difficult to use, "you need to register, have a password, if you do not log in within the time given, you have to go through the process again".

People have benefited from sessions delivered by Age UK on digital technology, but this is still not enough. “We do not read or write English, [so] how will we start using computers now?”

Others said PATCHs is difficult to use, “you need to register, have a password, if you do not log in within the time given, you have to go through the process again”.

People do not mind having health checks in local centres as long as there is privacy.

Kushy Nanas Older Women’s Group (Health for All)

All the attendees had a long-term condition or disability. The majority mentioned diabetes and body pains, but other conditions mentioned included asthma, arthritis, high blood pressure, knee problems and sciatica.

Treatment options for women limit their ability to feel healthy. Some of the women found that after steroid injections for the conditions, the pain would be relieved for a few months and then come back, so instead they managed pain with painkillers. Another woman said that she was too afraid to get knee surgery, so instead she goes to the physiotherapist, but it does not always help.

Due to the recent warm weather, the group mentioned exercising and gardening to stay healthy. They share different herbal remedies, using hot compresses and balms, and get their children to interpret health issues. The group expressed that they wished to swim, as they had found it helpful for their conditions in the past, before COVID, when there was a women-only swimming session twice a week. Now, the session has been changed to a mixed session, which prohibits them from going due to it not being culturally appropriate for them.

The group said that they had not gotten any information about menopause, and as a result, may have been misdiagnosed and given antidepressants because their symptoms of menopause were not recognised. The group felt that as menopause was a taboo subject in their culture, spreading information about it would be beneficial to prevent misdiagnoses and to further understanding of the process.

Many of the women mentioned having to pay for dentists farther away because many in the area have closed. Because they may not have someone to take them to appointments, they may be late and then taken off the dentist's list.

The group felt that to improve their local community, they need more things to do so that exercise is easier. They want more information about self-managing their conditions in their language, which is also simple, to improve accessibility. Some women mentioned seeking out this information on YouTube in their own language.

Many of the women in this group said they don't know how to use the internet on their own because their husbands haven't let them. Other women from the younger generation were allowed but had children to care for and found it difficult to do so. Therefore, the older generation struggles greatly with this, and the younger generation has some abilities. Women above 80 years old in this group mentioned that if you put something on the internet in front of them, they wouldn't be able to turn it off or on. The middle generation can work some things, but their skills are limited in this area.

Those with diabetes in the group mentioned that they can make check-up appointments through the GP, but they still have to book the appointment with the GP first, which is difficult to do.

When they use the internet, they may watch YouTube videos with herbal remedies to improve their health, but they often do not book appointments themselves. Instead, the other younger generations in the house may do it for them.

The Old Fire Station Café, Gipton

Two people with long-term health conditions said they do not seek help when their condition gets worse, as they can cope with it themselves. The other two people said they contact their GP, which usually works well for them, except when they sometimes struggle to get an appointment.

One person said the only thing that stops them from looking after their health as they would like is not being able to get to appointments easily. The other four people with long-term conditions had no difficulties.

Four of the participants said they never access public spaces like community centres and libraries, and one said they often do. Four people said they would feel comfortable having appointments in community centres, and one said they did not know. The only concern was that they would like these community centres to be close to home and in places they normally access.

Three people were able to access the internet every day; 2 were not. Two people said they would like to book appointments online; 3 said they did not want to do this.

Sanskar Women's Group, the Cardigan Centre

We spoke to 10 women, all of whom spoke Gujarati. Most had at least one health condition.

- For appointments, being one-to-one in a place like a café would be nicer than in a medical setting.
- More comfortable in a community centre/ public place (a safe place to talk).
- Makes it seem more friendly.
- Having a private room is important.
- Would definitely like to have educational information in community-based places – especially regarding mental health, this would be good. One woman spoke about wanting information about depression and how to manage it in safe spaces like this group.
- Would not want to get sensitive health support in a Sikh temple, as they would worry about news spreading.

- Used to have a library in Hyde Park / Burley, but this is now closed. Difficult to get to the next closest library in the city centre or Headingley.
- Mostly contact a GP when worried about a health condition getting worse. One woman said that they would never want to go to a pharmacist.
- A lot [of medical information] gets lost in translation, a few women noted that when languages are translated, it is never Gujarati
- Attendees only use the phone to make calls, and some don't have phones at all. Many people use family members to assist with phone use. Not many people are happy about everything moving online. Online medical forms are difficult to fill in without family members.
- One woman said that she was very disappointed in the digital shift she was seeing – the rest of the room agreed.

Sawan Vihar's Women's Group

People with a long-term condition go to their GP surgery, family or friends, or rely on themselves for help when their health is getting worse. The people who said they get help from family members usually rely on their adult children. Their children often call GP surgeries or hospitals to book or confirm appointments. They also shared that their children frequently act as informal interpreters for them.

People self-medicate or self-help by taking warm baths for aches and pains, using herbal rubs and wheat bags to soothe aching muscles and neck pain.

Participants suggested that NHS services could do more to support non-digital users, including offering in-person support for appointment bookings.

People talked about wanting to be independent and do things for themselves, like booking and attending their own health appointments. They don't like burdening their family members and feel it's unfair that their children must take time off work to interpret for them or drive them to appointments. Being able to do these things on their own would help reduce feelings of guilt and make them feel more confident and in control.

People spoke about attending local groups that help reduce isolation and increase social interaction. At these groups, they take part in activities like yoga and Pilates, which help relieve the pain associated with their long-term conditions (LTCs). They also learn from and support one another, whether by sharing information or offering emotional encouragement. They also give each other lifts; the problem is that they do not receive funding to continue with the group.

Among the minority who can use the internet, they mostly use it to book appointments and order prescriptions. Others fill in an online form, which is better than using PATCHs. PATCHs is a big barrier to access, adding to stress and anxiety. They do not have sufficient time to key in the passwords and then fiddle with the codes. "It needs to be easier". People were not shown how to use online services.

Digitally literate children help their parents register, log in, and book appointments.

People are happy to use local venues for appointments if there is privacy and notes can be recorded properly.

Nine people said they have difficulty using public transport. They find it unreliable, and due to their disability, they cannot stand for long periods.

St Martin's Coffee Morning (Polish Centre, Chapeltown)

What would you like to do differently to make yourself feel healthier?

"I'd like to connect more with others and not isolate myself so much. I enjoy coming to this group."

"I'd like to stay more on top of my appointments and medication schedule."

"I'd like to move more, this is why I join the exercise class here and would like to go on short walks to build strength and energy."

Can you use the internet without help?

- Two said yes, eight said no.
- Some can use YouTube to watch videos but not to do anything else.
- They get family members to help, especially their full-time working adult children.

Tech, Talk and Toast (Gipton Old Fire Station)

Six participants had a long-term health condition or disability; one participant did not.

Four participants said it was always easy to get out of the house, two said it was usually easy, and one said it was usually difficult. Participants mentioned that it is their mental health, as well as physical health, that affects their ability to leave the house.

All participants said they would speak to their GP if they were worried about their disability or health condition getting worse. However, most participants said this was not usually an effective way to get help, as they often cannot get an appointment. One participant mentioned that the only way they can get an appointment is to arrive at their GP surgery at 7 am to secure the first available slot, but this is not an accessible option for everyone.

When asked if anything makes it difficult to look after their health in the way they would like, most participants mentioned cost and money issues. For example, it is very expensive to join a gym or use a personal trainer. One participant mentioned they used a private chiropractor, which they found very helpful, but were unable to continue long-term due to the cost. Participants would like improved access to complementary therapies, such as a chiropractor. Another participant said a barrier to looking after their health is that they are new to the area and have found it hard to find information about the services available.

Five participants use public spaces such as libraries and community centres often; one said they use them sometimes, and one said they use them occasionally.

All participants said they would be comfortable having appointments with a health professional in a public place, if a separate room was used.

All participants said they can use the internet every day [this group is a digital skills support session]. When asked how they would like to use the internet to access health and care services, most participants agreed that it would be helpful to be able to ask for an appointment. However, they mentioned struggling to log in to the NHS app because it asks for ID and does not accept bus passes. Most participants said it would be useful to book or change appointments online; one participant preferred a phone call. All participants agreed that they would like to use the internet to order prescriptions, update medical records, get test results, check health records, find local services, and help manage someone else's care. One participant mentioned that it is important to understand test results; therefore, it should not just be a number.

The Friends and Family Test

All Leeds Community Healthcare NHS Trust's (LCH) patients have the opportunity to give feedback about their experience via the Friends and Family Test, a nationally agreed feedback tool. As part of our engagement, LCH allowed us to include an additional question for a limited period. The question was "What's the best care you've ever had anywhere except a hospital?".

The two most common responses were GP surgeries and the LCH service, where they were getting care at present. In these cases, often people described care in terms of their relationship with a clinician: this one-to-one, interpersonal element is the key. They described the professional as showing a real interest in them and how their health issue affected them. A few examples of this are included below.

"A GP in London who listened to me. With his care, I was able to come off antidepressants - all it took was professional curiosity."

"Generally, I consider the best care to be any place where the person or patient is heard and not treated like a number or a statistic. Where the responses are personalised and where the human approach is used. Respect and dignity are my values, and I appreciate these when I see them."

"Helped with different ideas and solutions for my issues."

"The doctor was thorough and concerned and was prompt at making arrangements to get a thorough check."

"Less Clinical and more personable. Always asked about family and was an extremely professional and Caring Doctor."

"I would say this service [at LCH] rivals any I have had. I would say that the clinical staff anywhere for booked appointments are almost always very attentive."

Additionally, however, some people mentioned care in places that wouldn't ordinarily be associated with health services, such as hotels or airports. One way of interpreting this relates to the comments above. It is not necessarily the level of healthcare expertise that people have really remembered in these non-health settings, but perhaps a wider feeling of being cared about.

Chapter 2: Unpaid Carer

Engagement and reporting by Carers Leeds.

This section is based on the findings of an online carers survey (182 responses) and six focus groups with carers (49 participants). It is focused on:

- Carers' own health and access to health and care services
- Their experiences of supporting the person they care for to look after their health and access health and care services.
- Carers and the person they care for accessing local services together

Demographics of survey and focus group participants

Survey respondents

182 carers responded to our online survey. Below is a summary of the demographic profile of respondents and the people they care for.

Carers

- Age range of respondents between 25 and 90 years old. 54% of respondents were working age (25-65), with the remainder 65+. The largest number of respondents is in the 55-64 age bracket (33%), which is commonly referred to as the 'peak caring' age.

- 81% of respondents identified as female, 16% as male and 1% as transgender.
- 87% of respondents were White British, and 13% of respondents were from other ethnically diverse groups.
- 87% of respondents described their sexual orientation as heterosexual, 3% as lesbian, 1% as gay, and 3% as bisexual.
- 41% of respondents considered themselves to have a disability.
- In terms of employment status, 39% of respondents were retired; 32% were employed, and 17% were full-time, unpaid carers.

Person who is cared for (data provided by carer respondents)

- Age ranged from under 18 to 90+. 54% of the people cared for were aged 70+.
- 58% of the people cared for identified as male, 37% as female and 1% non-binary.
- 84% were White British, with 16% from other ethnically diverse groups.
- 88% described their sexual orientation as heterosexual, 1% as lesbian, 1% as gay, and 1% as bisexual.
- 87% of the people cared for considered themselves to have a disability. Conditions were varied: 50% had a physical disability; 35% a mental health condition, 27% had dementia, and 21% had multiple conditions.
- In terms of employment status, 58% were retired, 24% were unable to work due to health issues, 13% were in education, and 5% were in employment.



Focus group participants

49 carers took part in the six focus groups we ran. Their demographics are as follows.

Figure 55: Carers gender

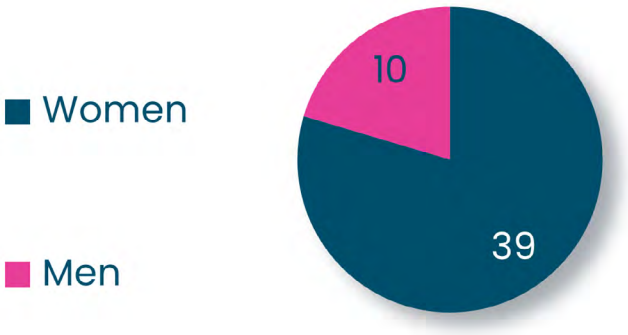




Figure 56: Carers health conditions

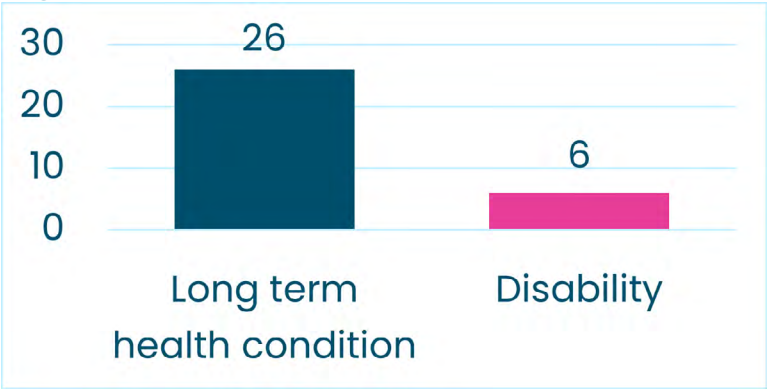


Figure 57: Carers occupations

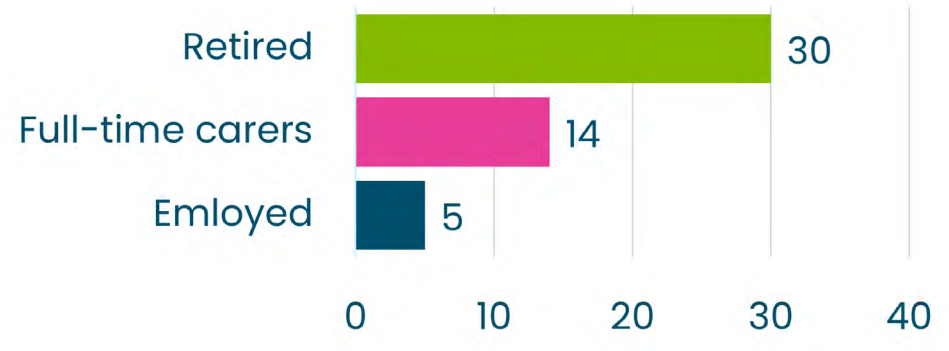
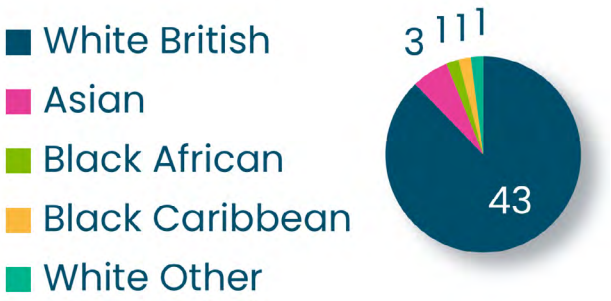


Figure 58: Carers ethnicity



All of their ethnicities were self identified.

The age range of participants was between 20 and 99 years old, with 11 carers aged between 40 and 59 years old, and 34 aged between 60 and 79 years old.

2.1 Carers' own health and access to health and care services

61% of the carers who responded to the survey reported having a disability or health condition. We know from national surveys (State of Caring in the UK) and Carers Leeds' own annual carers survey (The State of Unpaid Caring in Leeds) that caring can have a negative impact on carers' health and wellbeing. In the survey we conducted for this piece of work, 95% of respondents agreed with the statement – 'being a carer impacts on how well I can take care of my own physical and mental health' (67% strongly agreed and 28% somewhat agreed).



"There is no help. I have felt as though I am hitting my head against a brick wall. A few weeks ago, I even struggled to find any point to life but have worked hard to pick myself back up and get my mental health straight."

In the focus groups, many carers talked about putting off appointments or seeking a diagnosis or treatment for their own health conditions. The main reasons for this included that it was hard to make time to focus on themselves, that it was hard to make appointments when they had no one to look after the person they care for, and that it was difficult or inappropriate to bring the person they care for with them to an appointment. This was particularly true for those caring for multiple people, caring for someone with dementia or with complex learning or physical disabilities.

"It is very stressful. It is difficult for me to get to the GP surgery due to caring for my son and daughter with special needs. I am not classed as housebound even though I have lots of health problems, and I don't have anyone to help."

Others spoke about needing an operation or treatment but having real concerns about who would look after the person they cared for during and post op, and how they would be able to recover and care for someone else. This included not having knee operations, hip replacements, hysterectomies or cancer treatment. Many carers we spoke to did not have people they could rely on to step in if they were not able to care.

When asked whether they had accessed appointments with health and care services for themselves in the last 12 months, the most common survey responses from carers were: GP (89%), dentist (72%) and outpatient department of a hospital (48%). Most carers (across the survey and focus groups) said they would contact their GP if they were worried about their own health. A small number said they would speak to family and friends, and a few respondents said no one. Some responses reflected a lack of faith in health services.

"I go to YouTube because the doctor is useless."

"I feel very alone in dealing with my health condition."

When asked about how well this usually works as a way of getting help, carers responded positively overall. Where carers did talk about more difficult or frustrating experiences, this was largely due to the challenges of getting an appointment, or a timely appointment:

"It's a challenge to get an appointment, but once I do, I feel the doctors I see listen to me, and I feel they care."

"There is usually a delay in getting help due to not being able to get an appointment."

Through the survey and focus groups, carers said that health and care services could make it easier for carers to look after their own health. Common themes were:

- Carers wanted to be recognised within the system, to be visible, be listened to and be asked about their caring role and the impact on their health and wellbeing.
- Carers wanted more practical support for the person they cared for, such as home care and respite care, which was flexible and met the needs of the person and the carer.
- Carers wanted services to be more flexible and accommodating, particularly around the timing of appointments, so that carers can fit them around their caring role. Carers would welcome more double appointments for themselves and the person they care for.
- Improved communication and coordination were strong themes, particularly between services. Carers don't want to have to keep repeating themselves, chasing appointments or information.

"Listen, check in about my caring role and be willing to arrange appointments at times that work for me."

"By offering double 'health check' appointments, checking in with us both and seeing how we are both doing."

"I would like free respite as I pay for the extra help needed, even if it is for the many appointments for myself. It feels like hard work getting care services."

Carers spoke about good practice – where health professionals would be responsive, make it easy to book appointments, understand their family circumstances, and know them well. They also gave examples of poor practice – gatekeeping by receptionists, lack of acknowledgement of carers, professionals seeming to lack common sense or flexibility when it came to appointments or communication.

"Services do not appreciate how much stress I am under fulfilling my caring duties or realise how much more they create when they fail to fulfil promises they make or call me back with information or advice I have requested. My caring duties come first, which means I don't have time to think about my own health whilst I am chasing services."

2.2 Supporting the person you care for to look after their health and access services

Most carers said they would contact the GP if they were worried about the health of the person they care for. A smaller number said family and friends, 111, care staff (home or care home) or the district nurse. A few respondents said no one.

When asked about how well this usually works as a way of getting help, carers were far less positive about the experience of accessing health and care services for the person they care for than they were about accessing these services for themselves. In the main, this seems to reflect the challenges of accessing multiple health and care services more frequently for someone who has a complex health condition or disability.

Whilst some were positive, many respondents to our survey and participants in our focus groups spoke at length about the challenges and frustrations. These included:

Getting an appointment(s)

Many carers spoke about the amount of time and energy they spent trying to book health and care appointments for the person they care for. This was particularly difficult when carers need to engage with several different services and when carers are not online.

A key challenge was trying to rearrange automated health appointments and the lack of flexibility. Where carers need to take the person they care for to appointments, they may need to fit this around work responsibilities and the cared-for person's needs. Many carers felt that services were not accommodating of this.

"GP very difficult to get hold of, need to ring before 8am to get an appointment. 111 is rarely effective, although sometimes gets me an appointment with the GP Neighbourhood Team, very good for specific things."

"Systems are getting harder and harder to navigate. Appointments are automated, which usually needs a follow-up phone call to change it anyway, so it would have saved time to ring in the first place."

Communication

Carers spoke about some of the general challenges of communication with health services. In some cases, this was a lack of communication – not hearing the outcome of test results or different parts of the health service not talking to each other. Others spoke about inefficiencies in communication – receiving an email, a phone call and a letter cancelling the same appointment.

They also spoke specifically about how health services communicate (or rather, don't communicate) with carers. Many carers reported feeling invisible or ignored by health and care professionals at times. This experience could be threefold:

- Not valuing carer knowledge and insight on the health condition of the person they care for. For example, not taking carers' concerns about worsening symptoms seriously.
- Not seeing carers as partners in the delivery of health and care services. For example, not explaining changes to medication to carers, who were responsible for managing the person they care for's medication.
- Not asking about carers' own health and wellbeing, despite strong evidence that caring can have a negative impact on health and wellbeing.

"Speak to the carer, with permission, as well as the patient."

"It is a constant battle to get people in the health service to listen to you, you know the person you care for and their needs, but nobody will listen."

"It is a jungle out there and I feel lost in the middle of it. Communication is the key."

Co-ordination

Carers spoke about their frustrations about health services not being joined up and having to tell their story or the story of the person they care for repeatedly. This was exacerbated by not seeing the same doctor or health professional at each appointment and by professionals not always reviewing notes or health records before appointments. For example, one carer was asked to bring her husband to the surgery for an appointment when he is incredibly frail and bedridden.

A small number of carers had access to a care coordinator, a professional to help them navigate the health and care system. These roles were viewed as hugely positive, with carers highlighting the benefits of a single point of contact.



"I liaise with six different agencies and am never sure who to contact about what. Potluck. And then I have to repeat everything over and over every time because different systems cannot be accessed by different agencies and departments."

"I tend to avoid trying to contact anyone as much as I can due to past difficulties of getting passed on to other teams or signposted, as it's now referred to. It feels like no one really has any answers, so just pass us on elsewhere. We continually repeat the story of my son's mental health issues and his journey. It is often traumatic for us as parents to keep revisiting the extreme experiences our son had."

"Sometimes it is frustrating that services don't link together and deal with the whole person. Medical services are not joined up."

Lack of ongoing support

Some carers spoke about feeling 'left to their own devices' or 'fobbed off' when discharged from services after a diagnosis, operation or period of treatment for the person they care for. Carers said they would welcome ongoing support and check-ins following diagnoses and between medical appointments.



"A check in phone call, in between appointments, would be nice."

Many spoke about the challenges of getting the appropriate level of care and support for the person they care for, along with appropriate mobility equipment or home adaptations. Some said they would like home care staff trained to use certain equipment or perform health-related tasks, rather than having to wait for a health professional.

2.3 Carers and the person they care for accessing services together

Accessing online health and care services together

Most of the carers who responded to our survey had access to the internet every day (90%), and 65% already used online health and care services, particularly to make appointments, order prescriptions, get test results, check health records, or find local services. 26% were interested in accessing online health and care services (with a quarter of these respondents saying they would need help to do this). 9% of respondents said they were not interested in accessing online health and care services.

In contrast, most respondents said that the person they cared for couldn't access the internet every day (57%), and 69% of respondents said that the person they care for was not interested in accessing online care services. Only 16% said the person they care for was already accessing online health and care services, with 16% saying the person they care for would be interested but would need help to do this.

Many carers reported that they already accessed online services on behalf of the person they cared for. Or that they would need to provide help and support in the future if the person they cared for needed to use online health and care services.

Some of the barriers to people accessing online health and care services included English not being a first language, lack of digital skills, age (very young or very old), a health condition such as dementia, a visual impairment, lack of trust in digital platforms, not having a digital device or access to the internet.

"The person I am caring for is aged 71, does not read or write English and has no digital knowledge or skills. They are struggling to access information in their own language."

"They do this with my help, or I do it on their behalf."

"My father, whilst technically able to use online services, gets easily flummoxed and needs me to be involved re the timing of appointments and picking up prescriptions, so it is easier for me to do it all with his consent."

"This entirely depends on the fluctuation of their illness. When well, they can do most things online, when unwell, they couldn't."

Amongst those carers who do use online health platforms (e.g., the NHS app, PATCHES, or similar systems used by GPs), several spoke about the challenges of setting up and accessing two accounts (their own and the person they care for). Other carers said that this had put them off using online health platforms.

Most carers said that most online health platforms were relatively simple to use once set up and helped save time, particularly for repeat prescriptions and appointment requests. Others highlighted the benefit of being able 'to get all the information down in writing' when requesting advice or an appointment. One suggested improvement was to the mobile version of websites, carers described online forms as too long and complicated to complete on a smartphone (the most common device used).

Accessing local services together

When asked about how easy it was for them and the person they care for to get out of the house together, 55% of survey respondents said this was difficult or very difficult, with 24% describing this experience as neutral (not easy or difficult).

When asked about their use of local public spaces (such as libraries and community centres), 76% of carers said they rarely or never used these spaces with the person they cared for. When asked if they would feel comfortable having health appointments in these kinds of spaces, the survey responses were more mixed: 44% said yes, 25% said maybe, and 25% said no.

There was a lot of support for the idea of 'hubs' where services were co-located. Many carers could see the benefit of more health and care services being delivered from local venues, especially if it was easy to get to and there was a private room. As referenced earlier, an overriding concern for carers was the ease, flexibility and timeliness of appointments.

Of those who said no or maybe to feeling comfortable having health appointments in community venues, common worries related to the person they cared for, rather than their own concerns:

- Accessibility – getting to and getting into these venues (including parking). Clear signage outside and inside the building would be needed.
- Impact of the condition of the cared-for person – for example, people with autism or dementia not wanting to go to unfamiliar places or places which are not a recognised healthcare venue.
- Concerns about confidentiality in community venues and the need for quiet spaces (for appointments and for waiting).
- Person being housebound or needing care and support to leave the house – easier to have appointments at home.
- Venue staff knowing about any additional needs in advance and treating carers and the person they care for with understanding on arrival.

"As a person with dementia, they would not recognise a library or community centre as a place that offered healthcare (but a uniform might help). Their GP surgery is just as near as those venues and easier for parking."

"It would have to be accessible – wheelchair access and disabled facilities."

"It would need to be quiet and no waiting for my son."

"I have no worries, however, my parents, who I care for, are very traditional and may object to not going into an NHS facility. It would confuse mum, who has dementia, and dad would believe it was not secure, and his credentials would be at risk."

Conclusion and recommendations from carers

Many carers have their own health needs, either due to pre-existing conditions or because of their caring role. But caring can get in the way of carers prioritising their own health and access to health services. This can mean that, at times, carers are forgoing or delaying important medical treatment or access to services that could help improve their health.

As well as their own health needs, carers reported that supporting someone with complex or multiple health needs to look after their own health and access services can be hugely challenging. Whilst carers who took part in the survey and focus groups were generally positive about accessing health services for themselves, they were less positive when it came to supporting the person they care for. This illustrates some of the challenges faced by people with complex conditions who may need to access several health services regularly.

There was a lot of support from carers for health and care services being closer to home, and the idea of 'hubs' where services were co-located. Many carers could see the benefit of more health and care services being delivered from local venues, especially if it was easy to get to and inclusive of the additional needs of carers and those they care for. The biggest concern for carers was the ease, flexibility and timeliness of appointments. Where there were concerns about the 'neighbourhood health service' idea, common worries related to the person they care for, rather than their own concerns.

The things that were most important to carers from neighbourhood health services were:

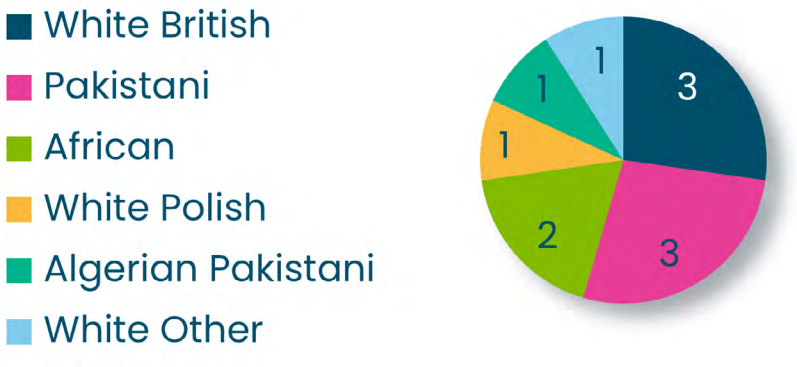
- Accessible and inclusive venue (getting there and getting into the venue).
- Good communication between professionals, the person and their carer.
- Co-ordinated services, so carers don't have to act as care co-ordinators.
- Recognition of carers, both of their own health needs and as a partner in the delivery of health and care services for the person they care for.
- Person-centred care, which includes the person who requires health and care support and their carer.
- Ongoing support and check-ins following diagnoses and between medical appointments.
- Online access and services could work well for some carers, helping to save time and energy.

Chapter 3: Children and young people

Demographics from the children and young people survey

We received 24 responses to our young people's survey. 11 provided demographic information. Ten were aged between 16 and 25 (one didn't tell us their age). Ten were female (one didn't tell us their gender). Our respondents described their ethnicity as follows:

Figure 59: Young people ethnicity

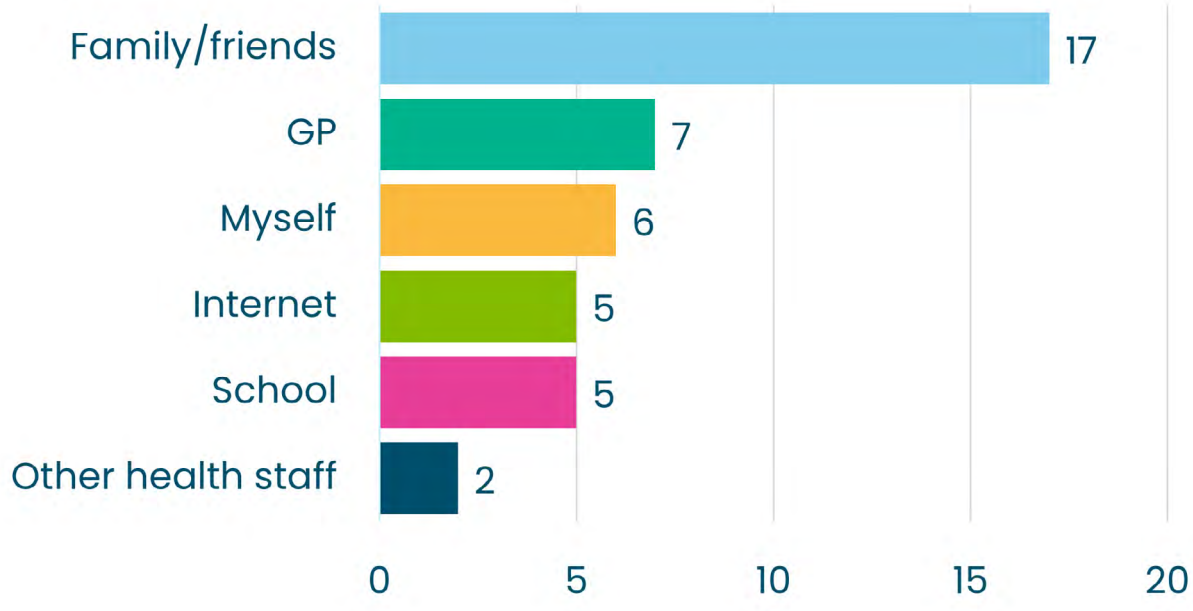






3.1 Learning about health

Figure 60: Who has taught you the most about your health and how to look after it?



3.2 Confidence in looking after your own health

Figure 61: On a scale of 1 to 5, how confident do you feel about looking after your own health right now? (1 is not confident at all, 5 is very confident)





Most of our respondents felt confident in their ability to look after their own health.

We asked children and young people, 'What would help you feel more confident (if anything)?' Many comments related to how they receive information. Their comments are as follows:

"If I can ask the Dr anytime whenever I need to."

"Less conflicting info, for example, there is so much information on social media, all saying different things."

“More healthcare websites apart from NHS.”

“Having available sexual health services to go to stay educated.”

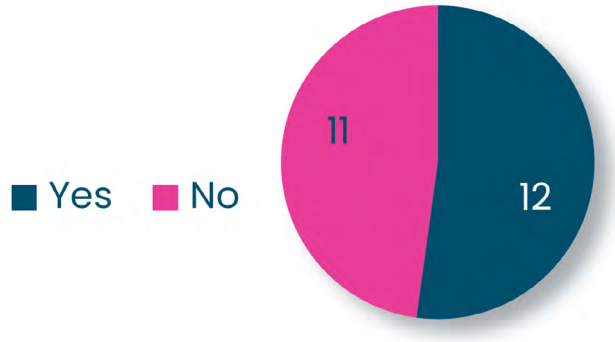
“Managing mental health better to help with physical.”

“Speaking to doctors who have had young people as patients (without parents present).”

“If there was more initiative to have frequent general health check-ups, e.g. every 2 months.”

3.3 Mental health

Figure 62: Has anyone given you advice about how to manage your mental health?



We asked, ‘Who gave you advice about how to manage your mental health?’ and ‘How helpful was their advice?’

Our respondents who had received advice about their mental health said it came from school and was helpful.

Tell us any worries you have about using your phone or computer to do things like book health appointments or speak to doctors.

"Long waiting lines when phoning the GP for an appointment."

"Sometimes unreliable. Sometimes GPs/others will not call/be late. Confirmation and reminders are sent too late around the appointment."

"Doctors may not take young people seriously when addressing healthcare concerns."

"Maybe technical issues from the website crashing or being slow. Privacy concerns, information being stolen, scams. How is data managed?"



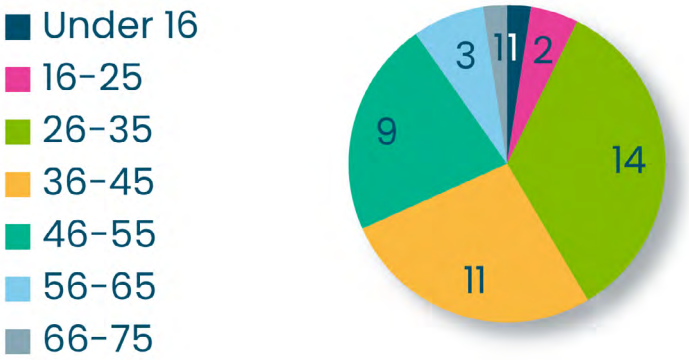
Chapter 4: Parents and carers

Demographics of parents and carers

We received 44 responses to our parents' and carers' survey.

Most of our respondents were aged between 26 and 55.

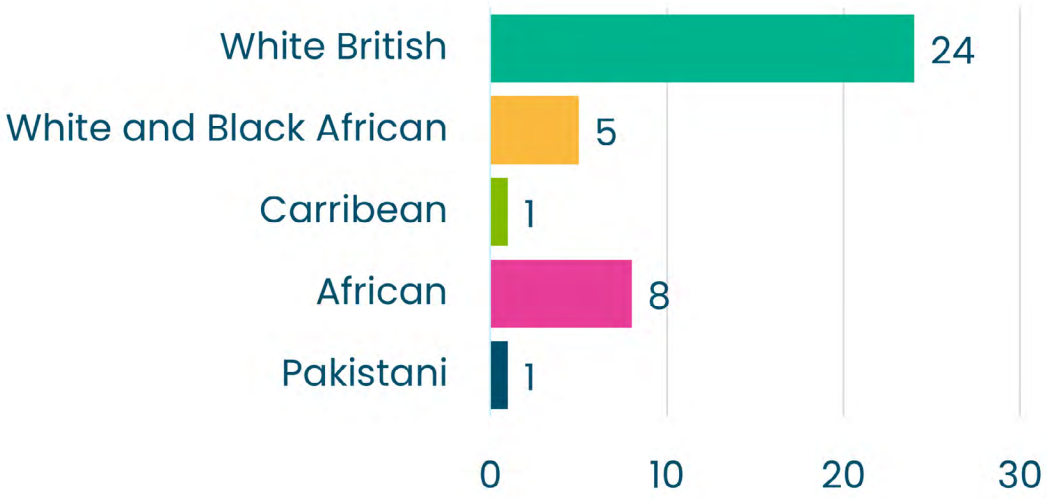
Figure 63: Our repondent's ages





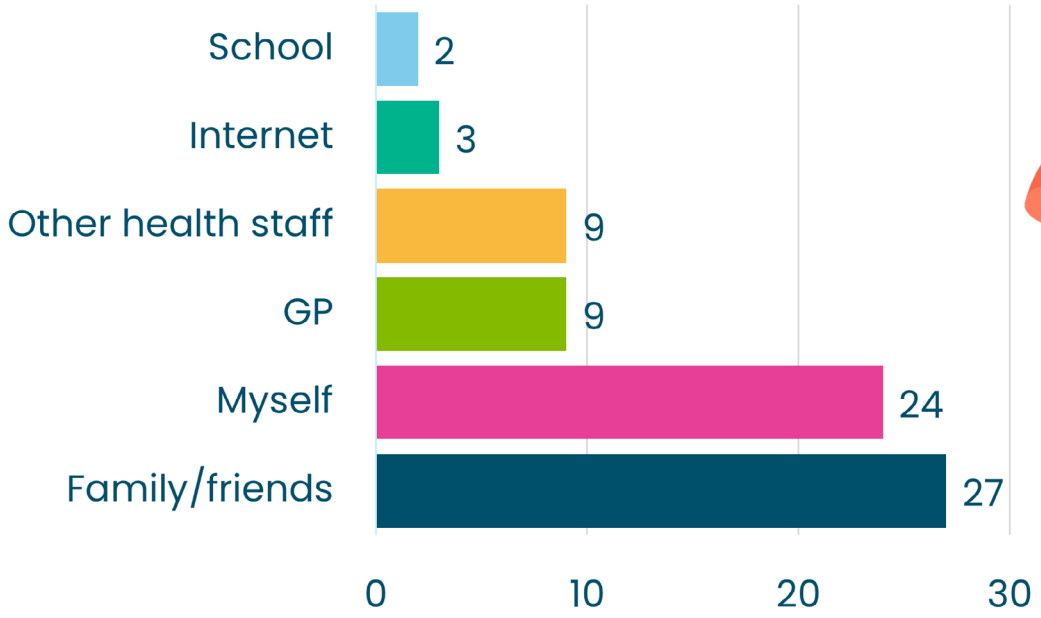
39 out of 44 respondents were female.

Figure 64: Our respondents' ethnicities



55% of respondents described their ethnicity as White British.

Figure 65: Who has taught you the most about your child's health and how to look after them?





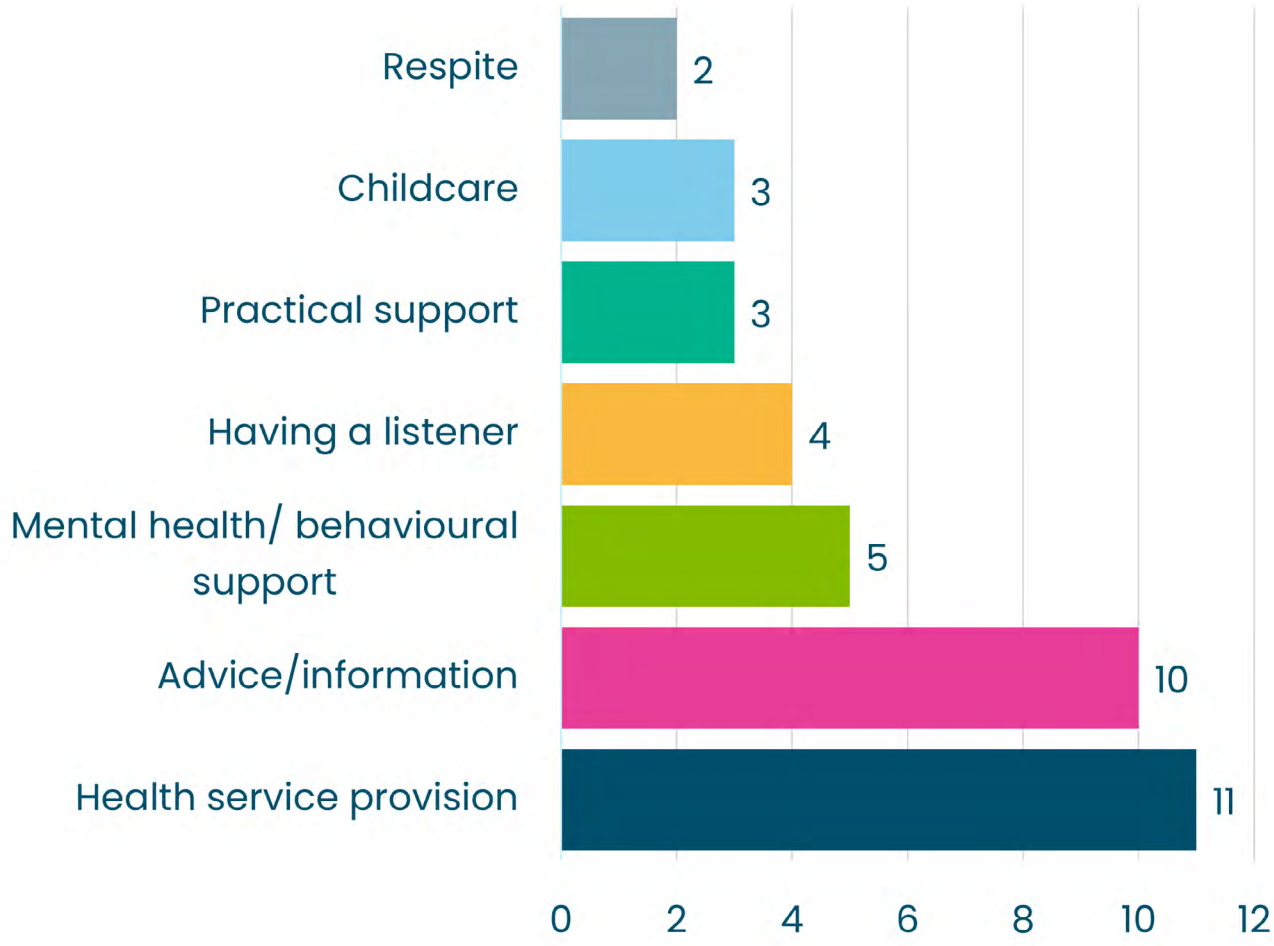
Our respondents saw their family and friends or themselves as their best teachers when it came to their children's health.

Figure 66: On a scale of 1 to 5, how confident do you feel about looking after your child's health? (1 is not confident at all, 5 is very confident)



Most of our respondents felt confident in their ability to look after their children's health.

Figure 67: What would help you feel more confident (if anything)?



The single largest group of people described how access to more (and quicker) support from services would help their confidence. Some said that services needed to listen more closely to their needs. Examples included the following:

> **"Health reviews."**



"Longer appointments when approaching services and faster results."

"The doctors can be quite dismissive in terms of information about constipation, just giving laxatives. Need people to take the time to provide more of a holistic explanation."

"If GPs listened more. I've had occasions where they have told me my child is fine, but they have actually [been] unwell."

Additionally, some parents/carers said they would have someone whose role was specifically to listen to them in a non-judgemental way.

Many parents felt that it would be helpful to have more information or advice, with some referring to guidance about children's mental health or emotional needs. For example:

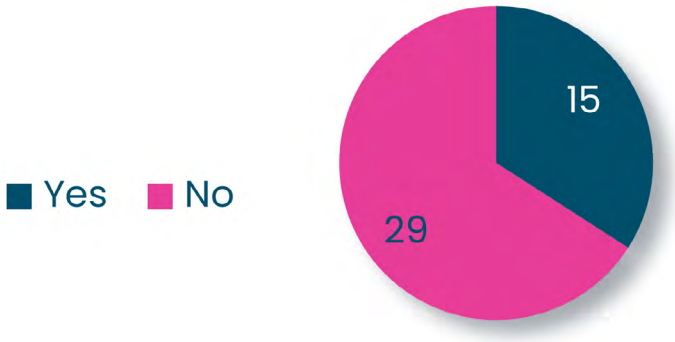
"Having more specialised information readily available. E.g. more details on NHS website."

"I would like more advice to help my child be more active."

"Parenting advice for emotional/mental health of small children, including anxiety, emotional regulation. Help with sleep."

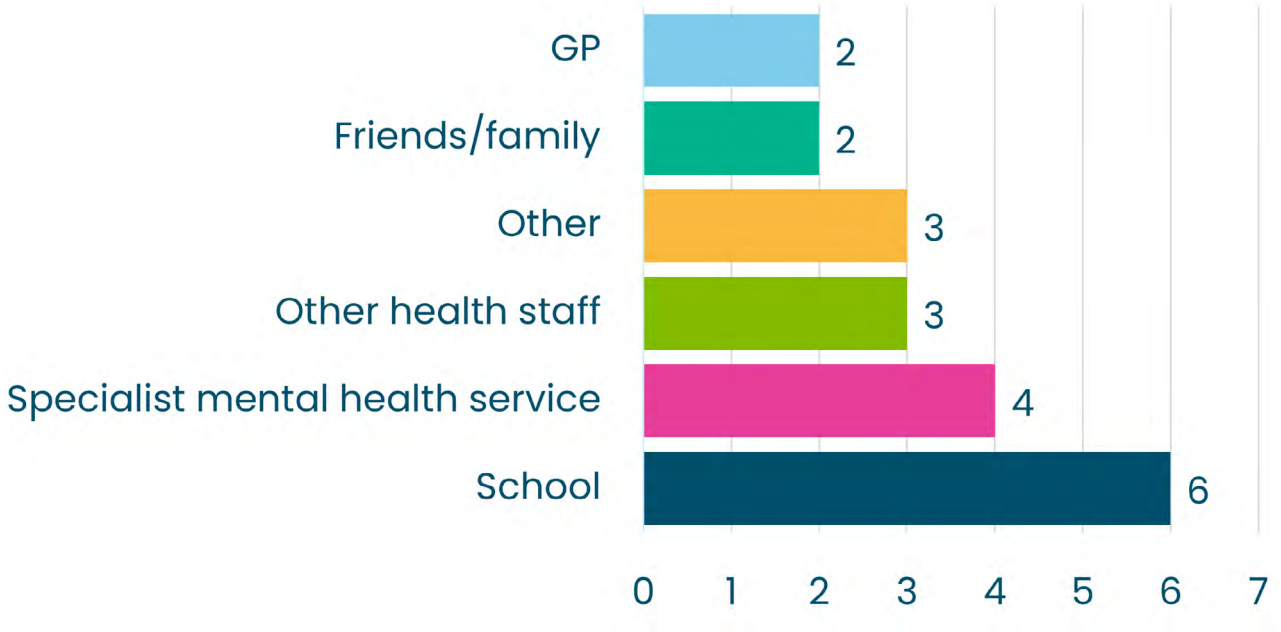
"Having a drop-in/helpline to ask questions, gain advice."

Figure 68: Has anyone given you advice about how to manage your child's mental health?



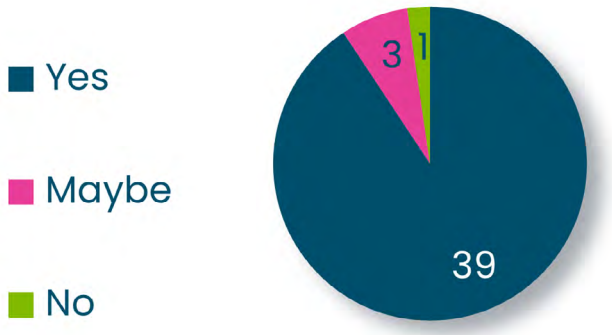
Most of the parents/carers who spoke to us hadn't been given information about supporting their child's mental health.

Figure 69: Who gave you advice about how to manage your child's mental health?



Among parents/carers who had been given advice about their child's mental health, the single largest group cited school as the source.

Figure 70: Would you feel comfortable bringing your child to appointments with a health professional in public places (like libraries, community centres, and others) if they could offer a private room?



Our parents/carers said overwhelmingly that they would be comfortable attending an appointment in a public space with their child.

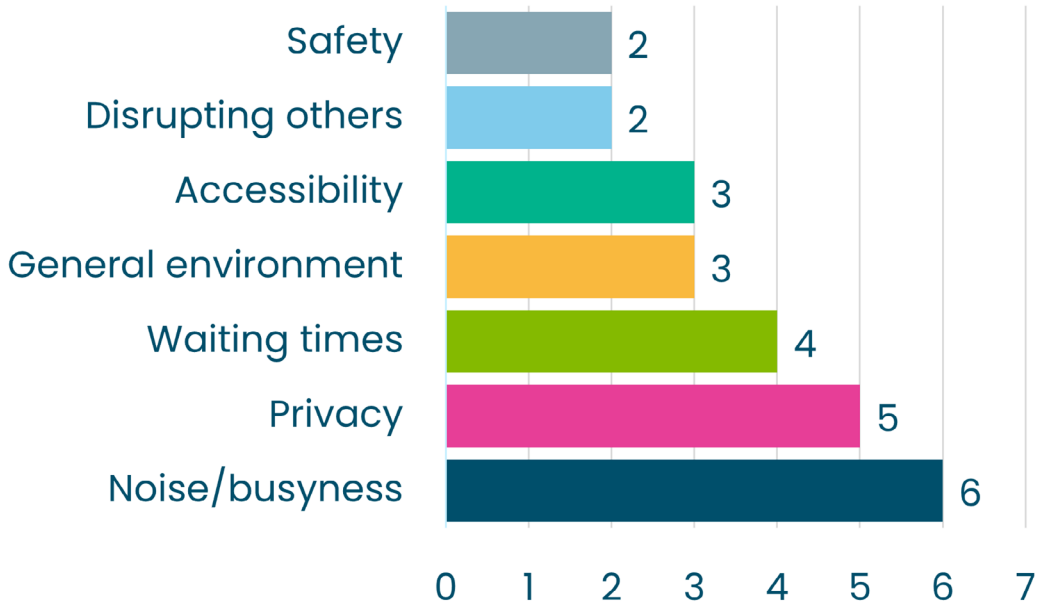
We received two comments from those who said they wouldn't feel confident, or would maybe feel confident:

"[I would worry about] How busy it is, and my child's safety."

"It may be crowdy. May not feel confident about the environment. May meet someone who we don't want them to know about our child's health."



Figure 71: Please tell us any worries you might have about bringing your child to a health appointment in a public place like a library or community centre.



The biggest concern our parents/carers had about attending appointments in public spaces was that they would be too noisy or too busy for their children. A small number also talked about the environment more generally, such as harsh lighting (which could be particularly disruptive for autistic children). A few parents/carers were also worried that their children might disrupt other activities in the space.

Privacy was also a concern for some parents. Example comments included:

"[I would worry about] The reason for visit being obvious to people - would need to be off a corridor rather than straight from a public area - and no one calling out their name."

Some parents also commented that they thought using community spaces for children's appointments was a good idea.

We asked parents and carers, 'tell us any worries you have about using your phone or computer to do things like book health appointments or speak to doctors'. Our respondents' concerns were divided into two categories: technical issues with online systems and accessibility issues related to their own personal needs.

Technical issues often centred around login details, in particular the difficulty of managing several login details for multiple people:

"[I have] Lots of worries because it is not easy to always remember to sign in and accept the appointment with 3 kids. Sometimes [I] receive message about child app [but] without [a] name and age means we don't know which child it is for"

"Forgetting passwords, trying to reset the password, taking too long to get to the right appointment screen, [I] Hate using phone so much."

"[I] Would still call up. I don't do computers, don't get what you want when you use a computer. Log on details or email details are confusing."

"The use of PATCH's when it gets to after lunch and there are no appointments left with GP."

"Not got access, can't do multiple [online accesses] across other surgeries."

Personal difficulties included language barriers and a lack of confidence with their own computer skills:

"At times [I have] language barriers."

"I need to speak to someone [otherwise there is] Confusion."

"I am not very good with computers. It will waste time."

"I am not very good with computers."

"Always will ring up still – [I'm] dyslexic, so will always. Always made adjustment, not had a problem just calling up - GP, dentist, health visitor."

"I struggle online as I have bipolar and [online] sends me manic."

"Lack of time to learn how to use the NHS app."



Chapter 5: Third Sector

Reporting by Volition, a partner in Forum Central. The following reporting is based on a survey carried out among Forum Central members. Please get in touch to see organisations' responses in full.

5.1 About the Third Sector

The Third Sector in Leeds, encompassing voluntary, community, and social enterprise organisations, plays a pivotal role in supporting health and care delivery within neighbourhoods and communities. Sometimes this is referred to as VCS or VCSE. There are approximately 3,500 Third Sector organisations in Leeds, and just over 1,500 of these are registered organisations. Of the registered organisations, 1,180 are reported to contribute to people's wider determinants of health, with 170 delivering physical or mental health services.

The Third Sector in Leeds has always played a crucial role in supporting people to stay well, embedded within our strong relationship with communities. Recognising this, we sought to capture the thoughts and opinions of colleagues working in the Third Sector as part of our review. The primary tool to capture information was a brief online survey.

We received responses from 47 Third Sector organisations, all worked with at least one health and care service, formally or informally. Collectively, they reported being involved with many aspects of health and care delivery, from community services to primary and secondary care and mental health services.

5.2 Readiness to deliver care

We asked Third Sector organisations, 'How ready is your organisation right now to work with the NHS to deliver more care to people in your community?'

Many organisations expressed willingness to work collaboratively with the NHS, and some have already done so. Some organisations reported feeling considerably more ready than others. Organisational strengths that came up regularly included the following:

- Good, long-standing relationships with people and communities.
- Positive experiences of collaborative working with NHS organisations.
- Collaborative models that simplify contracts and processes between the voluntary community sector (VCS) and the NHS.

Reported issues and barriers to working with the NHS included:

- Not having the data collection and sharing systems required for compliance with NHS standards.
- A lack of capacity, resources and appropriate funding for sustaining programmes of work.
- The uncertainty of short-term contracts that VCS organisations take on.
- Formalised referral and signposting systems into NHS services are not always in place, and conversely, NHS partners do not have robust systems to understand and refer people to local VCS services.
- NHS workers were sometimes seen as being uncertain about working with outside organisations.

5.3 NHS support for the Third Sector communities

We asked Third Sector organisations, 'What are the main things the NHS could do to support you to help people keep well in your community?'

Ideas that repeatedly came up included the following:

- Giving community organisations access to NHS estates, and the NHS using existing community spaces as a base for greater outreach into communities.
- Offering VCS workers training.
- Improving the process for referring people into NHS services and giving NHS staff the knowledge and tools they need to signpost and refer people into organisations.
- Better sharing of information and data with VCS organisations.
- Recognising the value of smaller, more niche organisations which work with marginalised communities, including in decision-making forums.
- Keeping VCS organisations informed about changes to NHS services ahead of time.
- Retaining non-digital options for accessing NHS services, which would particularly benefit older people and enable them to keep well.

Chapter 6: Desktop Review of Engagements Focussing on Community Services

This desktop review aims to give readers a sense of the issues that come up time and again in insight and engagement work focused on services based in communities. By taking a broad look at its subject, it seeks to identify some overarching principles about "what good looks like" for people navigating health and care. Eight principles have been identified. Readers should note that each of the eight can be explored in much greater detail than this review allows – for instance, they may be interested in how the principles relate to specific services - and some ideas of where to start are given at the end of each section.

The principles are relevant to people of all ages, although engagements with children and young people have sometimes described them in slightly different ways.

This review will be presented as part of a 2025 engagement commissioned by Leeds Community Healthcare, focussing on "what good looks like" for community services and the ways in which this can be applied to the Three Shifts set out by the national government. The engagement will build on the pre-existing knowledge that this review aims to present.



6.1 What is insight and what can it do?

Insight work aims to capture how people experience health and care services at a point in time, in a specific place. People's experiences can range from the highly personal and subjective to more objective hows, wheres and whens. Insight work aims to focus on the aspects of care that feel most important to people, which are not always the same as services' priorities.

Leeds is fortunate to have a thriving insight scene which encompasses its statutory organisations, the voluntary and community sector (VCS) and a local Healthwatch. It's possible to garner local insight from people of all ages, identities and backgrounds.

The basic purpose of insight work is to enable services to continuously improve by matching what they offer ever-more closely to people's needs. That said, a lot of insight work doesn't offer neat, easy answers – in fact, it reveals just how complex and varied our communities are. Insight work isn't the same as research, and neither is it democratic or an opinion poll: it's extremely rare that insight enables a majority of people to have their say on what they want from their health and care providers. So, while it's rarely able to give services specific directives, it can provide a bedrock of principles upon which services can make decisions.

6.2 Three Cs: communication, compassion, coordination



"The Three Cs" are a well-established part of Leeds' health and care world and will be familiar to anyone interested in people's experience of services. This slogan represents a movement which aims to improve experience based on what we've learnt as a city through the 'How Does It Feel For Me?' programme and engagement more generally.

'How Does It Feel For Me?' is an initiative led by the People's Voices Partnership. It was born out of the observation that there was a gap in our collective understanding of people's experiences as they moved across the Leeds health and care system. Having worked to fill that gap for a number of years, this multi-pronged programme then sought to summarise its key learning. The partnership found that good health and care were always characterised by three things: communication, coordination and compassion.

The Three Cs come up time and time again in engagement in Leeds and beyond (albeit under different names at times – for instance, "coordination" might be described as "joined-up working", while "communication" is sometimes discussed in terms of "being involved" in one's own care). They are as much a part of children's experience as they are of adults'.

Communication

Good communication means that people are always informed about the "what", "where", "when" and "why" of their care. They know who to contact when they have questions and can do so when they need to.

Some engagements have found that good communication is particularly important to people when they feel less able to manage their health independently (for example, people living with frailty) and that short appointment times can sometimes feel like a barrier to this. One way clinicians can communicate reassuringly with people is by not making assumptions that they already know a lot about their care or treatment.

Recent engagements on waiting times have revealed how people value (or would value) contact from services while they wait for treatment, to reassure them they haven't been forgotten and to signpost them to any support.

We have also heard how changes to services need to be accompanied by timely and ongoing communication. (One example of a service change was the introduction of PATCHs in primary care).

For people for whom English is a second language (including British Sign Language users), interpreting can be important for effective communication. It should also be borne in mind that some native English speakers have low levels of literacy. Communication needs are explored further in this review in the sections entitled "Good community services are geared up for complexity" and "Good community services adhere to the Accessible Information Standard".

Compassion

Compassion means that people are cared for in a way that recognises that they are a person, rather than a name on a list. The staff who care for them understand that the way people present is sometimes affected by past experiences: this is known as a trauma-informed approach.

Good community services support people's dignity and independence (which becomes paramount when service users' health makes them more vulnerable, such as when frailty becomes an issue).

Compassion comes up in any engagement exercise which touches on interaction between staff and people, although when care is tied to particularly emotional events – such as births and deaths – compassion can feature more prominently. It should be noted that people often praise the compassion of staff working in Leeds.

One area in which the compassion of staff tends to be discussed less positively is in engagements about mental health and mental health crisis. A lack of compassion is also sometimes mirrored in the way mental health services are structured, which can make them feel remote or unwelcoming when people are at their most vulnerable.

Coordination

Coordination means services are joined up, ensuring continuity of care and enabling people to move seamlessly from one service to the next. When people have multiple health conditions, each service providing care is aware of and appropriately informed about the involvement of other services. People don't have to tell their story every time they speak to a new member of staff because shared care records are in action. Other terms commonly used in insight work to describe coordination are "joined-up" or "holistic" care.

It is worth noting that some definitions of "holistic" care take a much broader perspective to include people's wider circumstances, such as cultural needs, housing, employment status and more; in this review, we will consider these in the section entitled "Good community services are geared up for complexity".

Thresholds to care and treatment can sometimes present an issue to people navigating systems. Engagements have at times revealed that people fall between the gaps from service to service, particularly when they are seeking mental health care. They might be told that they are too sick for one service but not sick enough for another, leaving them without any care as a result. Historically, some people have also found that they had nowhere to go once their course of mental health treatment was completed, even when they felt continued contact would be helpful. Staff's ability to signpost and refer to other services is important to a well-coordinated system.

Coordination is a major feature of much of the insight into end-of-life care, home care, and frailty. It is also notably important for unpaid carers and people living in border areas who may receive some support from one trust and other elements from another. The importance of staff reading people's medical notes is a cross-cutting theme too.

The Three Cs: where to start

The following documents are a good place to start learning about the Three Cs. Additionally, bear in mind that any insight report is likely to refer to one, if not all, of the three.

- How Does It Feel for Me?: healthwatchleeds.co.uk/our-work/how-does-it-feel-for-me/
- ICB Leeds Insight Reviews: healthandcareleeds.org/have-your-say/get-involved/insight-reviews/
- About the People's Voices Partnership: healthwatchleeds.co.uk/our-work/pvp/



6.3 Timely community services

Good community services are timely. People's dissatisfaction with long waits for care is a national issue and one that has been well documented (and well publicised in the media and political campaigns). People's experience of long waits for secondary care has been particularly well documented since the COVID-19 pandemic.

However, the problem isn't limited to hospital-based services. Waiting times for primary care remain a significant issue for people in Leeds and beyond. The King's Fund writes in its report on Public Satisfaction with the NHS and Social Care in 2024 that "62% of all respondents were dissatisfied with the time it takes to get a GP appointment. 23% were satisfied", while the Health Foundation noted in February 2025 that "For the first time in our polling series, the public's top priority for the NHS is making it easier to get appointments at GP practices (38%)". Repeated engagements on primary care access by Healthwatch Leeds and others have mirrored these levels of dissatisfaction. People have told us that waiting to get primary care has impacted their mental wellbeing and meant they have had to live with symptoms as they deteriorate.

Repeated engagements on children's and adults' mental health services have, over many years, revealed people's dissatisfaction with waiting times for therapeutic treatments. There is also a growing issue with waits for neurodiversity assessments.

In his Independent Investigation of the National Health Service in England, Lord Darzi notes that "High quality community services are essential to create a sustainable NHS and have been highlighted by national strategies to shift care closer to home for decades. Yet properly assessing access in NHS community services is hampered by the lack of data."

Timely services: where to start

- Public Satisfaction with the NHS and Social Care in 2024: Results from the British Social Attitudes Survey (The King's Fund and Nuffield Trust; April 2025) www.kingsfund.org.uk/insight-and-analysis/reports/public-satisfaction-nhs-social-care-in-2024-bsa
- Independent Investigation of the National Health Service in England (Lord Darzi; September 2024) www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england
- Things Can Only Get Better?: Public Perceptions of Health And Care Under the New Government (The Health Foundation; February 2025) www.health.org.uk/reports-and-analysis/analysis/things-can-only-get-better
- People's Experience of Accessing Primary Care in West Yorkshire (Healthwatch West Yorkshire; November 2023) healthwatchleeds.co.uk/reports-recommendations/2024/primary-care-briefing/
- Living with Chronic Pain (Healthwatch Leeds, 2025) healthwatchleeds.co.uk/reports-recommendations/2025/pain-management-videos/
- Health Inequalities - Children and Young People (Healthwatch West Yorkshire, September 2024) healthwatchleeds.co.uk/reports-recommendations/2024/health-inequalities-cyp/

- Life on Hold - Neurodivergent People and Healthcare Experiences (Healthwatch West Yorkshire; November 2023) healthwatchleeds.co.uk/reports-recommendations/2024/life-on-hold/
- Insight Report: Waiting Lists (Leeds Health and Care Partnership; May 2024) www.healthandcareleeds.org/wp-content/uploads/2024/11/2024_05_Insight_Rep_waiting-lists.pdf
- Insight Report: Mental Health (Leeds Health and Care Partnership; January 2023) www.healthandcareleeds.org/have-your-say/get-involved/populations/mental-health/#insight-review

6.4 Service availability

A good service is a service that continues to exist, which is a statement of the obvious. Yet it is important to bring this to attention, given the diminishment of NHS dentistry over the past several years.

The phenomenon of "dental deserts" – areas of the country where no or very few dentists are accepting new NHS patients – has been well documented in the press and recognised by the government. The impact on people has also been widely publicised and includes reports of people living with pain, attempting to self-treat, and seeing their mental wellbeing affected by shame about their oral health issues, amongst other issues. Inevitably, people who can't afford private treatment are the worst affected.

Healthwatch Leeds regularly receives requests for help from the public with finding an NHS dentist in our city. Unfortunately, it has been many years since we've been able to signpost people towards dental surgeries that regularly accept new NHS patients.

It is true that, as of 2006, people don't have the right to register with an NHS dentist in the same way they have the right to other NHS care. Nonetheless, the dentistry problem illustrates how services can be worn away over time until they effectively no longer exist for large parts of the population. This is despite patients having fed back over many years that NHS dentistry was becoming increasingly scarce. That feedback wasn't acted on in time, leading to the situation we are now in.

Service availability: where to start

- People's Experience of NHS Dental Services (Healthwatch West Yorkshire; May 2023) healthwatchleeds.co.uk/reports-recommendations/2023/west-yorkshire-nhs-dentistry/
- Access to NHS Dentistry: New Polling Findings, 2024 (Healthwatch England; 2024) www.healthwatch.co.uk/report/2024-11-20/access-nhs-dentistry-2024-findings
- Investigation into the NHS Dental Recovery Plan (National Audit Office; November 2024) www.nao.org.uk/wp-content/uploads/2024/11/Investigation-into-the-NHS-dental-recovery-plan-HC-308-1.pdf



6.5 Geared up for complexity

Every individual's relationship with health and care services is shaped by an array of factors. Broadly speaking, these can be divided into two interrelated categories:

- Protected characteristics.
- Wider determinants of health.

The characteristics protected under the Equality Act 2010 are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. A popularly used way of describing the wider determinants of health is the Dahlgren and Whitehead model, which encapsulates the following:

- Age, sex and constitutional factors.
- Individual lifestyle factors.
- Social and community networks.
- Living and working conditions.
- General socioeconomic, cultural and environmental conditions.

A few examples of ways in which protected characteristics and wider determinants of health come out in insight are as follows:

- People might have one or several caring responsibilities; they might be in temporary or unsuitable accommodation; they might work unsocial hours; or they might need advice and support with debt and money worries.

- People might have specific cultural needs (which are sometimes linked to religious needs). Dietary requirements are among the more common examples of this, but cultural needs can also come into play, particularly when health services coincide with events such as births and deaths.
- People have varying levels of reading comprehension, familiarity with English, regional accents, and abilities to speak English with an expected level of formality, all of which can affect how they interact with services and, in some cases, their self-confidence and readiness to self-advocate.
- Some people will live further away from health services and / or be less independently mobile.
- Some people will feel less safe than others while moving around their local area.
- Some people's interactions with services are shaped by their need to protect themselves from domestic abuse.
- Some people have had traumatic experiences. These might stem from previous interactions with public services, or they might be related to something else entirely. This trauma might shape their willingness to seek help, their confidence in their own ability to do so, their trust in others, and so on.

This is a handful of examples, but there are many more, and they can all intersect with one another in a person's life. What's more, individuals may not even be fully conscious of these factors and their impact or be able to verbalise them.

In addition to the above examples drawn from insight work, there is a very well-established evidence base that uses data over time to make the link between poverty and poor health outcomes. An example of this is the Marmot Review 10 Years On, which describes in detail how health inequalities "widened" across the UK between 2010 and 2020. Some factors which currently (but not inevitably) generate health inequalities will always be present because they are part of being human – for example, the needs of neurodiverse people. Some factors wouldn't need to be addressed if our society prioritised their eradication, such as poverty, low levels of literacy or domestic abuse.

In addition to having a dedicated health inequalities insight organisation in Healthwatch Leeds, Leeds has a diverse voluntary and community sector, with organisations that support and advocate for people of all kinds of identities and circumstances. Some feed insight about the people they work with into health and care experience networks, such as the People's Voices Partnership. There are also initiatives specifically targeted at gathering insights from marginalised communities, including Healthy Communities Together and Synergy. Nationally and locally, there is an array of insight focussing on different communities, experiences, characteristics, conditions and more.

So how can community services hope to navigate the complex picture that insight and experience paints for us here? If such a task didn't sound difficult enough, we should add that occasionally accommodations made to improve health access for one group can conflict with the needs of another. There are no simple answers, no one set of instructions to follow, but there are all ways of building flexibility into services so that they can accommodate individuals' and communities' enormous complexities. A few examples of how this is currently done include health inclusion programmes within services (such as LCH's Inclusion team focussing on homelessness and Gypsy and Traveller communities); community champions programmes; staff training in subjects such as trauma and cultural competence; and the use of mobile units to get clinical staff closer to people's homes and workplaces.

Gearing up services for complexity: where to start

- Contact Healthwatch Leeds for information and access to a variety of reports focussing on different aspects of health inequality. healthwatchleeds.co.uk/get-in-touch/
- The Marmot Review 10 Years On (Institute of Health Equity, 2020) www.instituteofhealthequity.org/resources-reports/marmot-review-10-years-on

6.6 Understanding the role of the unpaid carer

There are thousands of unpaid carers in Leeds providing essential support to people who use health and care services. Carers can be children or adults. It is important to hear unpaid carers' perspectives in order to understand:

- How being a carer impacts an individual's health, wellbeing and ability to access health, care and other services.
- The role of the unpaid carer in interactions between services and their patients, and how services either support or hinder carers in their efforts to provide the most effective unpaid care they can.
- How effectively health and care services are meeting the needs of cared-for people, especially when cared-for people are less able to advocate for themselves.

This section will focus on the first two of these bullet points.

Insights collected locally and nationally over time include the following:

- Some unpaid carers do not get enough support with their caring responsibilities, which impacts negatively on their own health, wellbeing and ability to tend to their own needs. (This is compounded when unpaid carers have their own pre-existing health issues or frailties.) Caring for a person can be a 24/7 role and is very often tiring and physically and emotionally demanding. Family dynamics are often altered when caring becomes a factor.

- Some unpaid carers live in poverty. Some carers are reliant on state benefits and /or cannot work, while others work in addition to providing unpaid care.
- Unpaid carers sometimes report being left in a coordinating role when the person they care for is in contact with multiple services. This can be time-consuming and stressful, and lead to feelings of isolation.
- Sometimes carers have had difficulties accessing the records of the person they care for or acting on their behalf due to data protection issues (Bear in mind that sometimes the unpaid carer is a child).
- Sometimes carers have voiced concerns that if they were to complain about the services received by the person they care for that person would then be treated less well by staff. Such concerns tend to be especially acute when the cared-for person lives in a residential facility.
- When a cared-for person doesn't meet thresholds for treatment, the unpaid carer can be left to cope with them alone. This issue has often come up in engagements about mental health.
- Sometimes the cared-for person has been bypassed in conversations with clinicians, with the staff member focussing on the carer instead. The risk of this is particularly high when the cared-for person doesn't speak English. Similarly, carers have sometimes had to offer impromptu interpreting services.
- Unpaid carers have to cope with the impact of seeing a loved one decline and perhaps die. Emotional support, including bereavement counselling, is not routinely offered (with exceptions including hospice care).

When community services work well with carers, the impact is doubly positive: the carer is enabled to offer the best support they can for the cared-for person, and the carer's own health and wellbeing is maintained.

Services' support for carers: where to start

- The State of Unpaid Caring in Leeds (Carers Leeds, 2023) www.carersleeds.org.uk/news/the-state-of-unpaid-caring-in-leeds/
- End of Life Care in West Yorkshire (Healthwatch West Yorkshire, 2023) healthwatchleeds.co.uk/reports-recommendations/2024/end-of-life-care/
- Bereaved Carers (Healthwatch Leeds 2023) healthwatchleeds.co.uk/reports-recommendations/2023/bereaved-carers-2023/
- Caring in a Complex World: Perspectives from Unpaid Carers and the Organisations that Support Them (The King's Fund, May 2023) www.kingsfund.org.uk/insight-and-analysis/reports/unpaid-carers-caring-complex-world

6.7 Digital technology

While interest in how digital technology can be utilised in health and care predates the pandemic, it amped up as repeated lockdowns made remote services a necessity. It has been the subject of an increasing number of consultations over the past five years, creating a strong pool of insight to work from.

One of the subjects that has been a concern - and therefore among the most studied by engagement workers - is digital exclusion. Nationally and locally, we know what the drivers of digital exclusion are, and which communities are most likely to be affected. While the former are described in varying terms across different pieces of work, it is widely agreed that some key factors that drive exclusion are:

- A lack of access to devices and data,
- A lack of skills,
- A lack of trust in one's own abilities and in the safety of digital systems.

People who are more likely to be digitally excluded are, in many cases, at risk of exposure to wider health inequalities. They include (but aren't limited to):

- People living in poverty.
- People whose disabilities or health conditions make the use of standard devices difficult or impossible.
- People with communication or language needs.

- Older people, but also other groups who have often been less exposed to digital technology, such as people who work or have worked in manual labour, and some children and young people.
- People from health inclusion communities, due to often complex wider circumstances.

It is also worth bearing in mind that a person's level of digital exclusion or inclusion isn't necessarily static. When people's circumstances are precarious or liable to change, the same can be said for their access to digital technology. Simply giving digitally excluded people access to technology and skills is unlikely to be the only answer to the problems of digitalisation.

Moreover, insight work has shown us that a person's level of digital inclusion does not always correlate with their willingness to use it in every circumstance. People have told us that there are occasions when they would prefer to interact with health services in person. They have explained that the act of connecting with a clinician – the natural back-and-forth of conversation aided by eye contact and body language – is in itself a valued part of their care. Examples of when people are more likely to value face-to-face interactions include interventions that involve describing or showing symptoms, or receiving a diagnosis (especially when that diagnosis is worrying).

On the other hand, insight has also confirmed that people have had positive experiences with digital services. They are welcomed when they offer a level of convenience that isn't outweighed by other factors, which might make people more comfortable having at least the option to speak in person. As suggested in the paragraph above, these factors are often emotional or relational–emotional when the issue at hand is likely to cause a lot of worry, or relational when there is a heightened need for articulacy on the part of the patient and clinician.

Mental health care offers us a good illustration of just how complex a single group of people's needs can be when it comes to digital services. Engagements with people living with mental health conditions have revealed that, for some, digital services offer a very welcome sense of distance and relieve them of the stress of having to get out of the house, travel and so on. Others, however, feel that the extra interpersonal interaction they get from speaking to clinical staff face-to-face is vital to the effectiveness of their treatment.

Insight into the digitalisation that has taken place over the past five years has also highlighted the importance of keeping people informed in advance of changes, and keeping communication channels open when people have questions about how to use new systems.

Insight work and other research have demonstrated that digital exclusion remains a serious threat to the effectiveness of digitalised services; that some groups are more at risk of this; and that there are occasions when people are more or less willing to use digital technology in their interactions with services. Again, however, the picture is not only highly complex, but it is in continual flux. Insight doesn't give many easy answers about digitalisation, but it does suggest that giving patients different options whenever possible is likely to be important for the time being at least.

Services and digital technology: where to start

- Digitising Leeds: Risks and Opportunities for Reducing Health Inequalities in Leeds (Healthwatch Leeds, July 2020) healthwatchleeds.co.uk/wp-content/uploads/2020/07/Digitising-Leeds-Risks-and-Opportunities-For-Reducing-Health-Inequalities-in-Leeds.pdf
- Digitising Inclusion in Leeds: How Does it Feel for Me? (Healthwatch Leeds; November 2020) healthwatchleeds.co.uk/wp-content/uploads/2020/11/Digital-inclusion-report-October-2020.pdf
- Communicating Change Briefing Paper (Healthwatch Leeds, September 2024) healthwatchleeds.co.uk/reports-recommendations/2024/communicating-change/
- Repeat Prescriptions Check-In (Healthwatch Leeds, July 2024) healthwatchleeds.co.uk/reports-recommendations/2024/repeat-prescriptions/

- Inclusive Digital Healthcare: A Framework for NHS Action on Digital Inclusion (NHS England; May 2023) www.england.nhs.uk/long-read/inclusive-digital-healthcare-a-framework-for-nhs-action-on-digital-inclusion/
- Mitigating Risks of Digital Exclusion in Health Systems (Good Things Foundation; July 2024) www.goodthingsfoundation.org/policy-and-research/research-and-evidence/research-2024/health-inequalities-digital-exclusion
- Community Mental Health Transformation: What Matters to People in Inner West and South Leeds (Healthwatch Leeds; October to December 2023) healthwatchleeds.co.uk/reports-recommendations/2024/community-mental-health-transformation-phase-2/

6.8 Understanding how other public services contribute to health and wellbeing

As discussed in earlier sections of this review, people's health is intimately connected to other aspects of their lives. This, in turn, means other services have a role to play in supporting them in staying well.

Conversations held for the Big Leeds Chat 2021 often turned towards this subject. In fact, seven of the ten statements that came out of the engagement touched upon the importance of wider services to people's health and wellbeing. They were:

- Make Leeds a city where children and young people's lives are filled with positive things to do.
- Make Leeds a city where there are plentiful activities in every local area to support everyone's wellbeing.
- Make Leeds a city where each individual community has the local facilities, services and amenities they need.
- Make Leeds a city where fears about crime and antisocial behaviour are no barrier to enjoying everything the community has to offer.
- Make Leeds a city where there are affordable activities that enable everyone to stay healthy.
- Make Leeds a city where green spaces are kept tidy and welcoming, because services understand the vital role they play in keeping people well.

- Make Leeds a city where everyone can get around easily on public transport, no matter their location or mobility needs.

There is clearly public recognition in Leeds that activities, services and facilities that bring people of all ages together are essential to our collective wellbeing, and that they need to be accessible within local neighbourhoods and affordable. Parks need to look welcoming, public transport needs to be reliable and accessible to all, and public spaces need to feel safe.

Two years later, the Phase 2 engagement work for the Community Mental Health Transformation explored these issues further. This project focussed on the inner west and south areas of the city and asked people to what extent where they lived impacted their mental health. Most respondents agreed that where they lived did have at least some bearing on their mental wellbeing. One way in which an area could impact negatively on people's mental health was if it was felt to be blighted by crime and antisocial behaviour. This issue was more often reported in areas with higher levels of deprivation (and in some, respondents drew a direct link between antisocial behaviour and a local preponderance of drug use). Issues with neighbours represented another way in which local areas were frequently said to be impacting negatively on people's health. Some of the people who said that crime and antisocial behaviour impacted their mental health had complained to services such as the police, but hadn't felt supported.

Conversely, when people's neighbourhoods felt safe and welcoming and offered pleasant green spaces, it could have the opposite effect and positively boost people's wellbeing.

The issues people have raised during engagement exercises are wide-ranging, deep-rooted and, on the face of it, too much for a single service to solve. Yet initiatives by services based in Leeds and elsewhere have suggested that the link between poorer health outcomes and wider social unease can be mitigated at least in part. Research has demonstrated that partnership working between statutory services and voluntary and community organisations can improve the lives of people with a specific health need. Two examples of this are the Enhance and Neighbourhood Network programmes. Evaluations of both these initiatives have revealed real improvements in service users' health and wellbeing.

Local Neighbourhood Networks (LNNs) are commissioned by Leeds City Council and aim to "support people in later life to live independently and participate in their communities by providing a range of activities and services at a neighbourhood level". They have been assessed as contributing to "healthy ageing" in the following ways:

"Range: LNNs provide people in later life with a range of activities and other opportunities tailored to their needs, which enables holistic and personalised care.
Relationships: LNNs build meaningful, trust-based relationships with and between members and volunteers (and their families), as well as with other organisations and groups within communities.
Responsiveness: LNNs are responsive to their members' needs and contexts and sensitive to when these change. In-depth knowledge of members enables LNNs to respond in highly personalised ways.
Reassurance: Being part of an LNN provides members and their families with a sense of reassurance and security through knowing that the LNN is there for them whenever needed."

How Community Organisations Contribute to Healthy Ageing, Centre for Better Ageing (2022)

The Enhance programme is funded by LCH and is managed by Leeds Older People's Forum on behalf of Forum Central. It is delivered by 13 VCS partners and aims to provide "person-centred, community-based support to individuals to help avoid delayed hospital discharges and readmissions, and to enhance capacity throughout the health system". A Summary of the Enhance Evaluation Findings for Year Two (May 2024) (Dr Sarah Alden, 2024) evaluated its achievements as follows:

- Improved physical health.
- Reduced loneliness and social isolation and improved mental wellbeing.
- Promoted inclusion and reduced financial inequality.
- Reduced pressure on LCH Neighbourhood Teams by complementing service provision.

In addition to the above, LCH contributes to several services run as partnerships between multiple organisations. Examples include the Leeds Mental Wellbeing Service and Leeds Sexual Health. LCH also runs stroke rehabilitation services in coordination with community settings via the Community Neurological Rehabilitation service, as well as working in close coordination with the Stroke Association's Leeds Stroke Recovery Service. LCH provides the Stroke Association with clinical oversight, enabling service users to be referred back to clinical services if necessary.

Finally, looking to potential future developments, the CMHT Phase 2 engagement also asked people how comfortable they might be about attending health and care appointments in public spaces such as community centres and libraries. Overall, about half of the respondents said they would be comfortable, while the other half preferred more traditional NHS settings. Privacy was flagged up as a key concern.

Services and wider public wellbeing: where to start

- Enhance Programme Learning and Evaluation Findings for Year Two: March 2024 (Dr Sarah Alden, 2024) www.opforum.org.uk/wp-content/uploads/2024/07/Enhance-programme-learning-evaluation-findings-for-year-2-full-report-DIGITAL.pdf
- How Community Organisations Contribute to Healthy Ageing (Centre for Better Ageing, 2022) www.shu.ac.uk/centre-regional-economic-social-research/publications/how-community-organisations-contribute-to-healthy-ageing
- Community-Centred Public Health: Taking a Whole System Approach (Public Health England, 2020) www.gov.uk/government/publications/community-centred-public-health-taking-a-whole-system-approach
- Community Mental Health Transformation: What Matters to People in Inner West and South Leeds (Healthwatch Leeds, 2023) healthwatchleeds.co.uk/reports-recommendations/2024/community-mental-health-transformation-phase-2/
- What Did We Learn at the Big Leeds Chat 2021? (People's Voices Partnership, 2022) healthwatchleeds.co.uk/wp-content/uploads/2022/06/big-chat-leeds-2022-RevC.pdf

- The 'Gold Dust' Report Supporting Adults with Complex Mental Health Needs in our Communities: What Have We Learnt? (Forum Central, 2025) forumcentral.org.uk/learning-from-2-years-of-transforming-mental-health-grants-the-gold-dust-report/
- Creative Health in Leeds Report (Leeds Arts Health and Wellbeing Network, 2025) lahwn.co.uk/wp-content/uploads/sites/157/2025/05/Creative-health-report-090525-1.pdf

6.9 Adhering to the Accessible Information Standard

People with specific communication needs have long reported facing barriers when trying to access and receive health and care services. The Accessible Information Standard (AIS) (2016) was intended to force services to make changes that would alleviate these barriers.

Leeds has taken an insight-driven approach to implementing the AIS through the Inclusion for All initiative. Inclusion for All brought together staff from Leeds' health, care, and VCS organisations who could influence the implementation of AIS. It was driven by two factors: the weight of insight about people's continuing difficulties when communicating with services, and the new impulsion that the AIS lent to the work of solving such problems.

Leeds has been recognised for its insight-driven willingness to grapple with the implementation of the AIS. This was why it was one of two localities chosen to test an AIS self-assessment framework with people with lived experience.

It should be noted, however, that people with communication needs still report barriers in their interactions with services, and work to overcome them is ongoing.

Services and AIS: where to start

- Inclusion for All Action Hub (Healthwatch Leeds website) healthwatchleeds.co.uk/our-work/inclusion-for-all/
- Accessible Information Standard Self-Assessment Framework Pilot (Healthwatch Leeds, March 2025) healthwatchleeds.co.uk/reports-recommendations/2025/ais-saf-pilot/



Service provider response

In response as a result of Healthwatch Leeds desk top review and final report, Leeds Community Healthcare NHS Trust has agreed to take the following actions.

Raise LCH staff awareness about the findings

We are embedding the 8 Key Principles set out in the Desk Top Review and providing a link to the reports in:

- information provided to all LCH new staff.
- LCH Patient Involvement intranet.
- LCH change methodology including the Equity and Quality Impact Assessment process.

Preventing ill health

We will review the accessibility of LCH services' self-management information and share learning across services.

Children's services

Enabling access to information and advice about children and young people's physical and mental health and emotional needs: LCH Youth Board to:

- explore further information to include on LCH website (January – March 2026).
- promote health to young people, parents and carers in Youth Board members' schools and colleges.
- explore what support young people may be accessing from sources such as internet searches and social media as may have a negative impact on their health and signposting to appropriate support is important.

Assurance about how health information is stored: to explore if a statement for children and young people and information about how their information is stored should be written in a child friendly format.

Enable access to services: raise with service Involvement champions potential for establishing parent / carer groups and drop – ins.

Carers and the person / children and young people they care for being able to book appointments together: this isn't possible currently, but commitment given to try and enable this in the future.

Carers

Findings will be brought to the LCH Carers Steering Group which is being re-established. Carers Leeds and Family Action.

Partnership working with the Third Sector

Keep 3rd sector organisations informed about changes to NHS services ahead of time: we are discussing with Forum Central and LCH service leadership and corporate teams how to ensure we consistently do this.

Offering third sector workers training: we will link with Leeds Health Care Academy and Forum Central about a system approach to understand and meet the 3rd sector's priority training requirements.

Giving NHS staff the knowledge and tools they need to signpost and refer people into organisations: to link with Forum Central and LCH services to identify gaps in knowledge and tools for signposting and referring people to the 3rd sector.

Next Steps

This report has been reviewed by the LCH Community Services Engagement Reference Group and will be shared within LCH and in the Leeds health and care system more widely.

Thematic leads at LCH have produced action plans based on the report's findings. The plans cover key insights and learning, and how these relate to current priorities and work planned or underway, and short- and long-term actions.

LCH and Healthwatch Leeds will work together to feed back to the general public, including the people who shared their thoughts with us for this project, on the actions taken as a result of the findings.

Acknowledgements

We would like to thank all the members of the LCH Community Services Engagement Reference Group for their guidance and support with this project. The Group is led by Caroline Schonrock and Dan Barnett and supported by Kirsty McKeegan. We are particularly grateful to everyone at LCH for their help with sharing the survey via their engagement channels.

Thank you to all the decision-makers who attended the engagements for their support and insight.

We are very grateful to all the third-sector and other organisations which hosted engagements. Their contribution was essential to the project's success.

On behalf of Healthwatch Leeds, we would like to thank the volunteers who supported the engagements. They are Paulina Nehrebecka, Muthu Kumar, Denise Wall, Matty Burchell, Jane Mischenko, Wumi Obi, Hannah Gray, Janet Onslow, Simran Kanani, Philip Xiu, Dameisha Choudhary, Dianne Parker and Meg Polese.

Finally, we would like to thank everyone who shared their views with us. We hope this report does some justice to you.

This project was led by Healthwatch Leeds and partnered with Carers Leeds and Forum Central. The engagements were led by Parveen Ayub and supported by Tatum Yip, except for those managed by Carers Leeds. Except where stated otherwise, the report was written by Anna Giles.

Report designed by Gemma O'Connell, illustrations by Musbila.

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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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