Deep Dive Report

People who are seldom heard.

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Executive Summary

The new Healthwatch contract came into place in 2022. There were early discussions based on patient feedback of several possible areas for deeper investigation that were identified, of which Seldom Heard Groups was one. As we talked to individual patients, members of local patient participation groups, and carers groups, the theme of health inequalities was a concern.

We engaged through our intelligence network with wider members of Support Staffordshire including social prescribers.

Discussions also took place with commissioners at Staffordshire County Council, the councillors across the 8 districts of Staffordshire (through the Health and Wellbeing Board) and the Staffordshire Integrated Care Board.

"The term 'seldom-heard groups' refers to under-represented people who use or might potentially use health or social services and who are less likely to be heard by these service professionals and decision-makers. These groups used to be described as hard to reach – suggesting that there is something that prevents their engagement with services. Seldom heard emphasises the responsibility of agencies to reach out to excluded people…."

The three seldom heard groups what were identified for this Deep Dive were:

- **People undergoing Gender Affirmation** ('Gender affirmation is the process a transgender person goes through to change their physical sexual characteristics to match their gender identity. This typically involves a combination of surgical procedures and hormone treatment'.[1])
- **Rurality**
- **Co-occurring Needs (people who are neurodiverse).**

[1] https://www.cqc.org.uk/guidance-providers/healthcare/adult-trans-care-pathway

People undergoing Gender Affirmation

In June 2022 we spoke with people who had been waiting a long time to be seen by a Gender Dysphoria Clinic to undergo Gender Affirmation. As none of these clinics are based in Staffordshire, we could not influence the waiting times. However, we chose to look at people's experiences of local healthcare, related to their gender affirmation, whilst on the waiting list. This was because people told us about the negative effects of waiting such a long time for transition was having on their mental health.

We found that a lack of knowledge in Primary Care, combined with long waiting times to be seen by specialist care had a negative impact on people's health and wellbeing. We also found that more local support for individuals who were waiting to be seen was needed, as this would help prevent a deterioration in their wellbeing and mental health.

The recommendations from the report were –

- That further research needs be carried out with GP's to gain insight into their experiences of treating patients requiring gender reassignment.
- The development of a training package to support GP practices. This would need to be developed from people within the transgender community and at a local level. This would bring together their experiences and how best practice can be developed and shared. This training would include resources on where patients can be signposted to for health and wellbeing support whilst waiting for appointments at a Gender Dysphoria Clinic.
- The development of a specific care pathway, where patients are given details of information and resources locally to support them.

Rurality

When speaking with residents while undertaking our engagement work, we realised how difficult people who live away from the main areas find accessing health and social care. This seemed to apply mostly to the elderly and people who do not drive.

From the 59 people who answered the question asking how travelling more than 11 miles to access services affected them, 23 people cited poor public transport and being reliant on others to take them.

When we asked people which services, they would most like to have closer to where they live, the responses were divided equally between a local pharmacy and a local

dentist. In looking at this response Healthwatch are mindful of the general lack of dental provision. Other services which people said they would like closer, were public transport and a local hospital/more services at a local hospital.

The recommendations from the report are –

- Improved public transport so that people can access services that are further away.
- Better use of local Primary Care Centre/Hospitals.
- Pharmacies that open 6 days a week to be commissioned for villages that do not have this service.

Co-occurring Needs

When carrying out our engagement work, we found that carers and people with co-occurring needs, felt there was a general lack of understanding of their needs.

From the 86 respondents to our survey 73% were carers of people with co-occurring needs. People were asked which of seven different diagnosis' they/the person they cared for had. Out of a total of 163 answers (some people had multiple diagnosis') 72 people said Autistic Spectrum Disorder, and 36 ADHD. These were the top two diagnoses. In the survey we asked how going to various health and social care services affected people. For visiting a GP, hospital, dentist, social worker, and mental health services, people said their co-occurring need affected them 'a lot'. When asked why this was, common themes were that the professional they were seeing had a lack of knowledge about their diagnosis, that the patient struggled to express themselves, and they struggled with the waiting room/environment. Although the same reasons appeared in relation to opticians and district nurses, 32 people said that seeing an optician only affected them 'a little', and responses for district nurses were split evenly between 'not at all', 'a little', and 'a lot'.

When we asked what would improve services for people the top answers were, 'more education of professionals', 'staff who are patient with them and provide longer appointment times', 'being listened to/believed', 'easier to access, and 'alterations to the environment/waiting room'.

The recommendations from the report are –

- More education of all health and social care professional on neurological conditions.
- Separate areas or waiting rooms where people who find the traditional waiting place too overwhelming.

Introduction – who is seldom heard?

The quote on page 2 is taken from Healthwatch's 'A Guide on How to Work with Seldom Heard Groups'[2] it goes on to give examples of seldom heard groups as being:

'• Ethnic minority groups
• Carers
• Disabled people
• Lesbian, Gay, Bisexual, Transgender, and Queer people
• Refugees/asylum seekers
• People who are homeless
• Younger people
• People with language barriers.

To summarise, it is anyone who is under-served. These people may have particular needs when it comes to participating.'

In a second definition, Iriss[3] uses slightly different examples; 'Disability, Ethnicity, Sexuality, Communication impairments, Mental health problems, Homelessness, Geographical isolation'.

In this study, Healthwatch Staffordshire have focused on people who are undergoing gender reassignment, people who have co-occurring needs (disabled people), and those that live in rural areas (geographical isolation).

Why listening to the views of seldom heard people is important:

We all know that listening to the views of people from all backgrounds is important, but in this section, we evidence why it is essential that services listen to the views of those who are seldom heard.

[2]https://network.healthwatch.co.uk/sites/network.healthwatch.co.uk/files/20200727%20How%20to%20coproduce%20with%20seldom%20heard%20groups.pdf
[3] a Scottish charity 'that works with people, workers and organisations in social work and social care to help them use knowledge and innovation to make positive change happen'. https://www.iriss.org.uk/resources/insights/effectively-engaging-involving-seldom-heard-groups)

The Legal Framework

The Equality Act 2010 protects people from being discriminated against because of the following (called 'protected characteristics'): Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation[4]. The Act references 'Direct Discrimination'[5] and 'Indirect Discrimination'[6]. This reference to 'Indirect Discrimination' may be worth considering when we look at the findings from our rurality survey, as rurality itself is not a protected characteristic.

The Act also includes a 'Public Sector Equality Duty' [7] which states that public sector organisations must 'advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it [this] involves having due regard, in particular, to the need to—

(a)remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic.

(b)take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it…'.

We refer to this as it is relevant when looking at the results of our co-occurring needs survey, and the changes that would improve access to services for people who are neurodiverse.

Staffordshire & Stoke-on-Trent ICB do publish a Public Sector Equality Duty (PSED) Equality, Diversity and Inclusion Annual Report and the 2022/23 document can be accessed here: https://staffsstoke.icb.nhs.uk/your-nhs-integrated-care-board/our-publications/equality-diversity-inclusion-and-human-rights/ssot-icb-2022-23-final-psed-annual-report-proofed-002-rs-120523/?layout=default

[4] Equalities Act 2010, Part 2, Chapter 1
[5] Equalities Act 2010, Part 2, Chapter 2, Point 13
[6] Equalities Act 2010, Part 2, Chapter 2, Point 19
[7] Equalities Act 2010, Part 11, Chapter 1, Point 149, 3

Healthwatch England

In Healthwatch England's Our Strategy Explained, 2021-2026[8], the third of its six objectives for this time period are 'To seek the views of those who are seldom heard and reduce the barriers they face.' It says it will do this by 'Understand[ing] and address[ing] the barriers to participation in health and social care.' And 'Shar[ing] our evidence to bring about improvements.'[9]

The Care Quality Commission (CQC)

The Care Quality Commission says in its document 'Our Equality Objective 2021-2025'[10] that:

> **'We want to tackle inequality to make sure everyone has good quality care, as well as equal access, experience, and outcomes from health and social care services...We do not set the priorities for reducing inequalities and will work closely with other bodies who have these roles to align our work. But as an independent regulator, we will take appropriate regulatory action or speak up where care isn't good enough for any groups of people.'**

Examples given of 'groups of people' are 'people who face barriers in getting the care they need...'. It goes on to say that **'To reduce inequalities, we need to focus on the quality of care for those most likely to have a poorer experience. This does not mean that we are looking for poor care – it means we are looking for good care for these people.'**
The CQC explains that the first[11] of its 4 Equality Objectives, means that they will:

> **'Improve how we gather and act on the experiences of people most likely to have a poorer experience of care and those least likely to be able to access the care they need. We will expect health and care providers to actively seek out, listen and respond to people who are most likely to have difficulty accessing their care or a poorer experience or outcomes from care'.**

It goes on to say that 'We will develop a definition of the main groups. Over time, we will also develop our understanding of inequalities, as we have more evidence. The first two equality objectives set out activities that relate to some groups of people who are more

[8] Healthwatch England's Our Strategy Explained, 2021-2026, page 3.
[9] Healthwatch England's Our Strategy Explained, 2021-2016, page 6
[10] Our equality objectives 2021-2025 - Care Quality Commission (cqc.org.uk)
[11] CQC, Our Equality Objectives 2021-2015, Equality objective 1: Amplifying the voices of people most likely to have a poorer experience of care or have difficulty accessing care

likely to have difficulty accessing the right care or to have a poorer experience of care:...people with a learning disability and autistic people;...'

The NHS Nationally

In the NHS 2023/24 Priorities and Operational Planning Guidance[12] it refers to its Objectives and says that 'As we deliver on these objectives, we must continue to narrow health inequalities in access, outcomes, and experience...' The Staffordshire & Stoke-on-Trent Integrated Care System (ICS) also refers to National Objectives in its 2023/24 Operational Plan, the 29th National Objective being 'Continue to address health inequalities and deliver on the CORE20PLUS5 approach'.[13] (CORE20PLUS5 is not covered in this report).

Where are we locally?

The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) published its Joint Forward Plan (the Plan) 2023-2028 on 30th June 2023. This Plan [14] 'sets out how [the Integrated Care Board] will transform services and pathways to support delivery of the vision and ambitions outlined in the Integrated Care Partnership (ICP) Strategy to 'make Staffordshire and Stoke-on-Trent the healthiest places to live and work'.'
The Plan states that in the ICS' preparation of the Plan, they 'also had regard for the 'Triple Aim' established for NHS bodies that plan and commission services, requiring them to consider the effects of decisions on:

- The health and wellbeing of the people of England (including inequalities in health and wellbeing)
- The quality of services provided or arranged by both themselves and other relevant bodies (including inequalities in benefits from those services)
- The sustainable and efficient use of resources by both themselves and other relevant bodies.'[15]

The Foreword to the ICS' Joint Forward Plan states that 'Improving population health and tackling health inequalities is a complex task. Over the longer term we will continue our focus on prevention and proactively supporting people to stay well at home and arranging services so that people receive care from the right people in the most appropriate setting.'

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[12] https://www.england.nhs.uk/wp-content/uploads/2022/12/PRN00021-23-24-priorities-and-operational-planning-guidance-v1.1.pdf, page 3
[13] https://staffsstoke.icb.nhs.uk/your-nhs-integrated-care-board/our-publications/plans-and-strategies/acge-13414-ssot-ics-operational-plan-final/?layout=default, page 54
[14] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 6
[15] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 8

Further on in the forward it says 'Understanding the views of local people will help us to explore ideas such as…providing care in different settings closer to home and looking for new ways to reduce health inequalities. We have a solid foundation to build on, but we know we need to continually look for new ways to strengthen our networks and adapt our communications, engagement, and operational delivery – to enhance our understanding of the needs of our diverse population.'[16]

Improving health inequalities are also referred to in the ICB's Quality Strategy[17] and throughout the Integrated Care Partnership (ICP) Strategy[18]

What are 'Health Inequalities'?

The NHS states that –

'Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society. These include how long people are likely to live, the health conditions they may experience and the care that is available to them.

The conditions in which we are born, grow, live, work and age can impact our health and wellbeing. These are sometimes referred to as wider determinants of health. Wider determinants of health are often interlinked. For example, someone who is unemployed may be more likely to live in poorer quality housing with less access to green space and less access to fresh, healthy food. This means some groups and communities are more likely to experience poorer health than the general population. These groups are also more likely to experience challenges in accessing care.

The reasons for this are complex and may include:

- the availability of services in their local area
- service opening times
- access to transport
- access to childcare
- language (spoken and written)
- literacy
- poor experiences in the past

[16] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 4
[17] https://staffsstoke.icb.nhs.uk/your-nhs-integrated-care-board/our-publications/draft-icb-quality-strategy/?layout=default, page 4
[18] https://staffsstoke.icb.nhs.uk/your-nhs-integrated-care-board/our-publications/integrated-care-partnership/acge-13346-ssot-icp-strategy-design-v4-23-04-13-single-page/?layout=default

- misinformation
- fear'[19]

The Kings Fund states that:

'Health inequalities are ultimately about differences in the status of people's health. But the term is also used to refer to differences in the care that people receive and the opportunities that they need lead healthy lives – both of which can contribute to their health status. Health inequalities can therefore involve differences in:

- Health status, for example, life expectancy
- Access to care, for example, availability of given services
- Quality and experience of care, for example, levels of patient satisfaction
- Behavioural risks to health, for example, smoking rates
- Wider determinants of health, for example, quality of housing.'

The Kings Fund continues by asking 'Inequalities between who?

Differences in health status and the things that determine it can be experienced by people grouped by a range of factors. In England, health inequalities are often analysed and addressed by policy across four types of factors:

- Socio-economic factors, for example, income
- Geography, for example, region or whether urban or rural
- Specific characteristics including those protected in law, such as sex, ethnicity or disability
- Socially excluded groups, for example, people experiencing homelessness.'

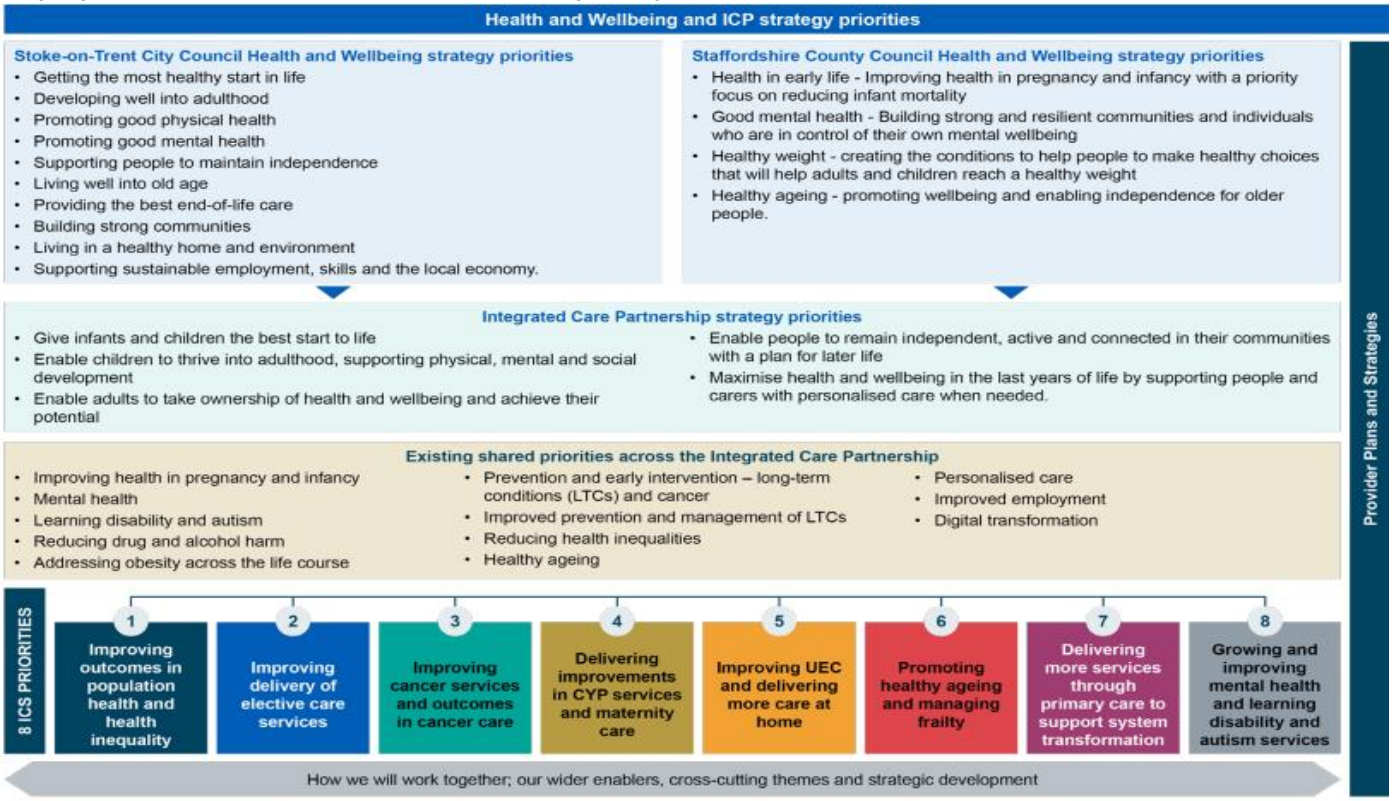
It continues, 'People experience different combinations of these factors, which has implications for the health inequalities that they are likely to experience. This means that people grouped according to one factor, such as disabled people or people from a particular ethnic background, will not be homogenous – there will be a variation in health profiles and risks within any given population group. The way these factors combine and interact with each other also influences the health inequalities people experience.'[20]

[19] https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/#:~:text=Health%20inequalities%20are%20unfair%20and,that%20is%20available%20to%20them.
[20] https://www.kingsfund.org.uk/publications/what-are-health-inequalities#what

The ICS' Joint Forward Plan, identifies 'Inclusion Health Groups (IHGs)' and says that this is a 'term used to describe people who are socially excluded and experience multiple overlapping risk factors resulting in health inequalities.' One IHG is people who have autism. And 'Our older population (prioritising those vulnerable or socially isolated)'.[21]

This last statement is particularly relevant when we look at the findings from our Rurality survey, as the older population (a protected characteristic under the Equality Act) appear to face greater difficulties in accessing health care than younger people.

As can be seen from the chart below, one of the 8 ICS Priorities is 'Improving outcomes in population health and health inequality'[22]

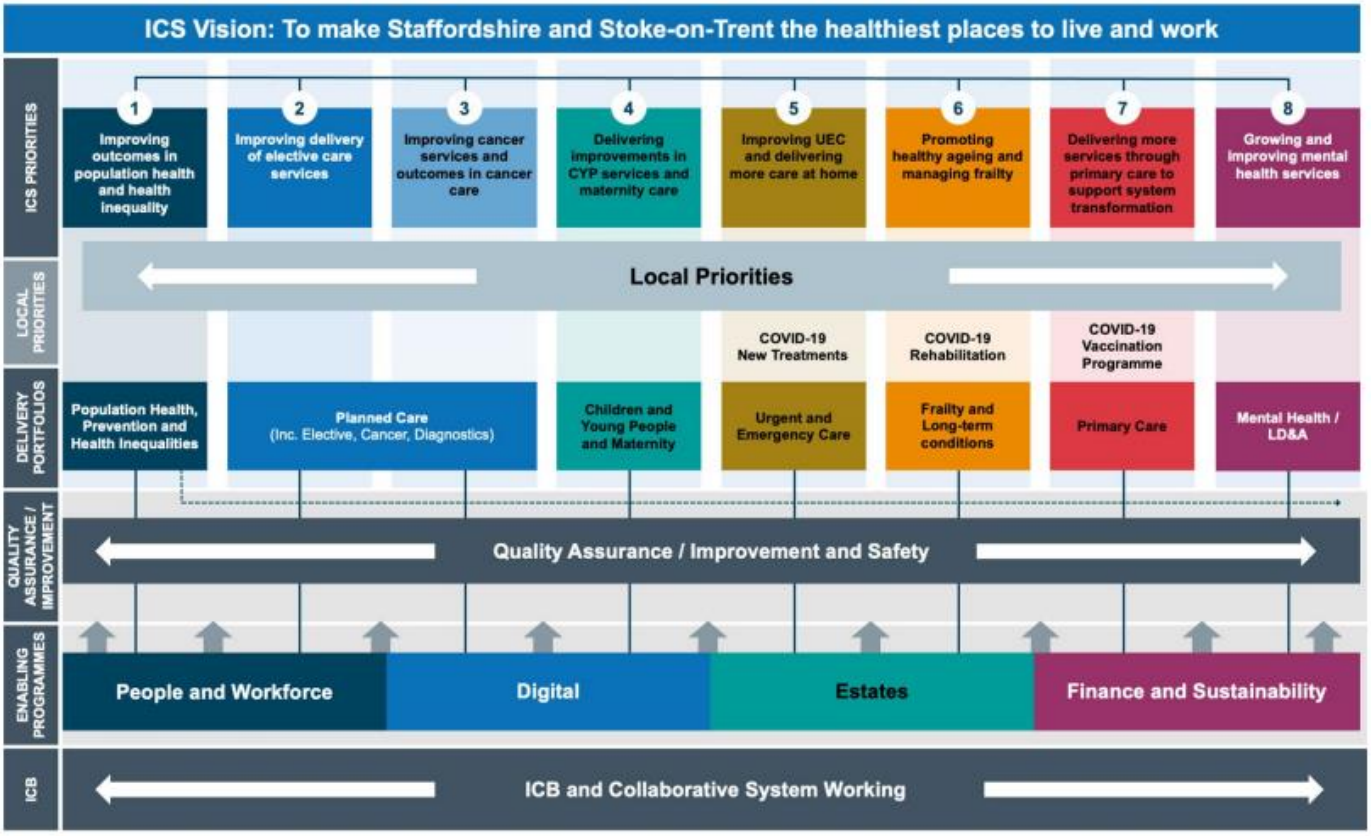


The Plan refers again to the ICP Strategy, stating that 'The four strategic ambitions outlined in the ICP strategy are to:

1. Improve population health and wellbeing outcomes
2. Address inequalities in access, experience and outcomes from health and social care services
3. Achieve a sustainable and resilient ICS
4. Work in partnership with communities to achieve social, economic, and environmental community development'[23]

[21] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 34
[22] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 11
[23] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 13

Addressing health inequalities, the Plan states that '…tackling health inequalities is a complex task but is key to the operational and financial sustainability of health and social care. Our main goals must include a focus on prevention, proactively supporting people to stay well at home, and arranging services so that people receive care from the right people in the most appropriate setting.'[24]



As you can see from the diagram above, one of the ICS' 'Delivery Portfolios' is 'Population Health, Prevention and Health Inequalities'.[25]

Theory of Change

Healthwatch Staffordshire reached out to Healthwatch England on their priority deep dives. Healthwatch England offered training to the Healthwatch Staffordshire team on using the **Theory of Change Model** to help us to focus our resources in the areas most needed.

Theory of Change is a comprehensive description and illustration of how and why a desired change is expected to happen in a particular context. It is focused in particular

[24] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 23
[25] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 24

on mapping out what has been described as the **"missing middle"** between what a program or change initiative does (its activities or interventions) and how these lead to desired goals being achieved. It does this by first identifying the desired long-term goals and then works back from these to identify all the conditions (outcomes) that must be in place (and how these related to one another causally) for the goals to occur. These are all mapped out in an Outcomes Framework. The Outcomes Framework then provides the basis for identifying what type of activity or intervention will lead to the outcomes identified as preconditions for achieving the long-term goal. Through this approach, the precise link between activities and the achievement of the long-term goals are more fully understood. This leads to better planning, in that activities are linked to a detailed understanding of how change actually happens. It also leads to better evaluation, as it is possible to measure progress towards the achievement of longer-term goals that goes beyond the identification of program outputs. The diagram below illustrates the toolkit provided by Healthwatch England.

We worked with Healthwatch England and used the **'Theory of Change Model'** to help us to focus our resources in the areas of the deep dive most needed. This helped Healthwatch Staffordshire to:

- Increase chances of successful outcomes.
- Identify what was working, and what was not, so we could adjust our approach and target resources.
- Measure and communicate the effectiveness of our work.
- Evidence the outcomes we achieved.

Methodology

We used a combination of approaches to collect feedback for our Deep Dive into Seldom Heard groups. Our report into the experiences of people undergoing Gender Reassignment began in June 2022 and was published in January 2023. Regards Rurality and Co-occurring Needs, we had collected some evidence from our work prior to the start of this part of the study in November 2022. In addition, over a period of 10 months, we:

- Spoke with people who had co-occurring needs (and their carers) and met with people who lived in rural areas.
- Met with health professionals.
- Met with Patient Participation Groups (PPGs)
- Devised and circulated surveys. These were sent directly to relevant groups and people, as well as being advertised on Healthwatch's social media channels.

People undergoing Gender Affirmation

In June 2022 we attended Stoke Pride. We were confident that this event would attract people from the Newcastle area and Staffordshire Moorlands as well as other parts of Staffordshire.

It was at this event that we spoke with a resident of Staffordshire who was experiencing difficulties with aspects of their health care as they were on the waiting list for gender reassignment. This was the starting point for our investigation as it was apparent that other people were having the same negative experiences.

We designed a short survey and distributed it via various social media platforms, placed it on our website, sent it to people within the LGBTQ community, and visited other events such as Chase Pride and Newcastle and Stafford College's Fresher's Fayres. We also sent it to large employers including, Staffordshire County Council, Midlands Partnership Foundation Trust (MPFT), Support Staffordshire, and Staffordshire Police's LGBTQ group. The survey was open for 4 months. A total of 31 people took part in the survey.

Issues that were raised were lack of knowledge in Primary Care, and long waiting times to be seen by specialist care and the impact this has on individuals' health and wellbeing.

At a local level we acknowledged that nothing can be done to reduce waiting times for Gender Dysphoria Clinics, however we said that more local support for individuals who are waiting to be seen was needed. An established process for supporting individuals waiting to be seen would help prevent a deterioration in their wellbeing and mental health.

The recommendations from the report were –
• that further research needs be carried out with GPs to gain insight into their experiences of treating patients requiring gender reassignment.
• the development of a training package to support GP practices. This would need to be developed from people within the transgender community and at a local level. This would bring together their experiences and how best practice can be developed and shared. This training would include resources on where patients can be signposted to for health and wellbeing support whilst waiting for appointments at a Gender Dysphoria Clinic.
• The development of a specific care pathway where patients are given details of resources locally to support them.

This Report was published in January 2023 and can be found by clicking this link: https://healthwatchstaffordshire.co.uk/wp-content/uploads/2023/01/Gender-Affirmation-Jan-2023.pdf

Following on from this Report, we then looked at further seldom heard groups we could engage with. The two that were chosen were –

- People who live in Rural areas.
- People with Co-occurring Needs (Neurodiverse Conditions).

People who live in Rural Areas

People who live in rural areas was a demographic we were hearing issues from during our regular engagement work.

Staffordshire consists of 8 districts - Newcastle-Under-Lyme, Staffordshire Moorlands, Stafford, East Staffordshire, Tamworth, Lichfield, Cannock Chase, and South Staffordshire. As of the 2021 Census there were 876,104 people who live in the County (excluding Stoke-on-Trent). [26]

In the Foreword to Staffordshire County Council's Rural Economic Strategy 2023-2030 (the Strategy), Councillor Philip White, Deputy Leader and Cabinet Member for Economy & Skills, states that[27] 'almost four-fifths of Staffordshire is rural…'. Further on in the Strategy it says that 'Staffordshire's rural area for the purpose of the Rural Economic Strategy have been defined by Lower Super Output areas based on DEFRA's 2015 urban/rural classification and also includes the urban areas associated with the 5 rural hub towns of Leek, Cheadle, Uttoxeter, Stone and Rugeley'.

The inclusion of these areas in the definition of rural, perhaps explains the difference in the ICB's statistics for the rural population of the County, when it states that '75% of Staffordshire residents live in areas that are classified as urban' [28], leading us to draw the conclusion that it classifies 25% of the population as living in rural areas.

'Hub Towns' are described as places that have populations of between 10,000 and 30,000, and 'have met statistical criteria to be considered hubs for services and businesses for a wider rural hinterland and their populations are therefore classified as effectively rural…'[29]

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[26] https://www.nomisweb.co.uk/sources/census_2021/report?compare=E10000028#section_4

[27] https://www.staffordshire.gov.uk/Business/Economic-and-Rural-Economic-Strategies/Rural-Economic-Strategy-2023-2030.aspx#:~:text=Almost%20four%2Dfifths%20of%20Staffordshire,of%20the%20county's%20economic%20activity.)

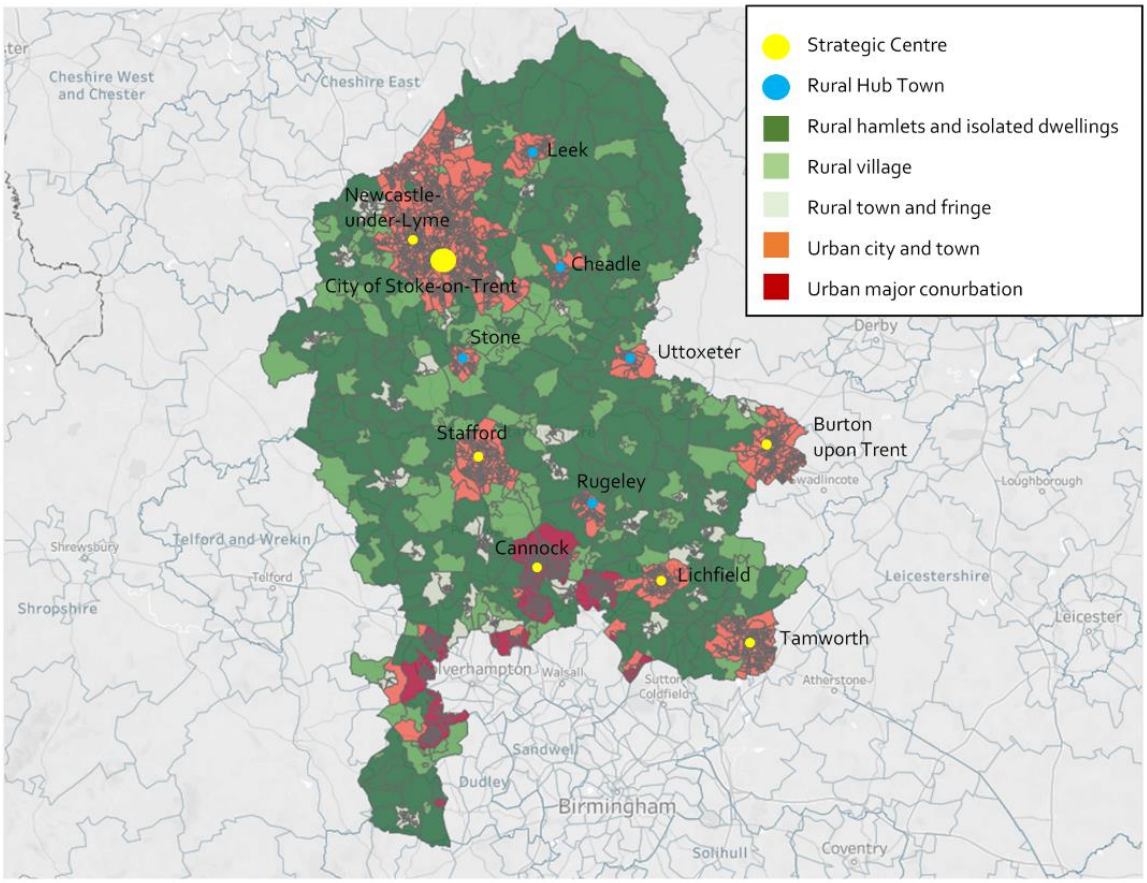
[28] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 10

[29]https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/597751/Defining_rural_areas__Mar_2017_.pdf

Strictly speaking, an area is classed as rural with a population of less than 10,000.[30] This figure will be referred to below when referring to the places where people who we spoke with, and who completed our rurality survey, lived. However, from speaking with people in Staffordshire, we would agree with the inclusion of the 'hub towns' in the definition of rural but would also include the town of Biddulph.

The following map shows where those Rural Hub Towns are situated, as well as the areas that are classified as rural and urban.

[31]Rural Staffordshire as defined by Lower-layer Super Output Areas



Source: DEFRA definitions

Our Research.

[30] https://www.gov.uk/government/statistics/2011-rural-urban-classification

[31] https://www.staffordshire.gov.uk/Business/Economic-and-Rural-Economic-Strategies/Rural-Economic-Strategy-2023-2030.aspx#:~:text=Almost%20four%2Dfifths%20of%20Staffordshire,of%20the%20county's%20economic%20activity

Healthwatch Staffordshire had been listening to the residents of Biddulph regarding the problem they were having in accessing health services that were not based in the Town. We then wanted to find out if this was something others who lived in the more rural areas of the County were experiencing.

To meet our objectives, we located and spoke with groups which met in rural areas. These groups were in Biddulph, Leek, Loggerheads, and Alton. Due to capacity, the groups we spoke with were all based in the North of the County. However, a survey was distributed throughout the whole of Staffordshire via Healthwatch Staffordshire's website and social media. We also sent the survey to GP practices in Newcastle and the Moorlands. We received 94 completed surveys.

Main findings

To find out how rural the place the people completed our survey were living, our survey asked **'What is your nearest village or town?'**

Responses were received from the following places:

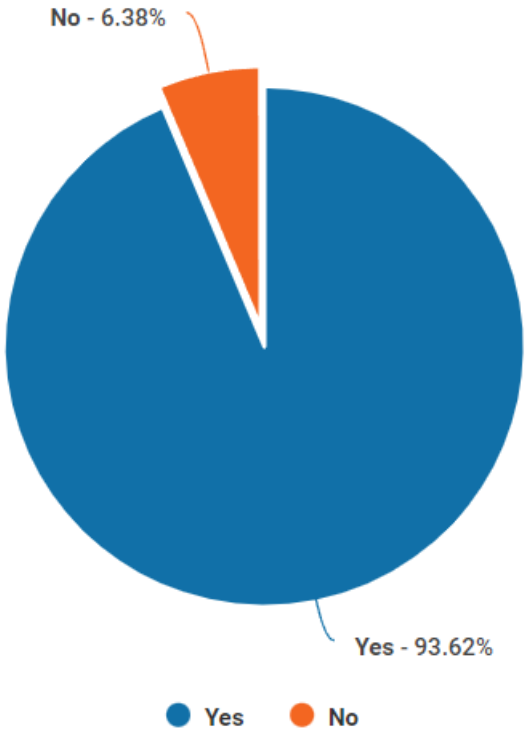
Leek (population 19,385)[32]	Biddulph (population 17,488)[33]	Alton (population 981)[34]	Loggerheads (population 2,522)[35]	Swynnerton (population 3,119)[36]	Horton (population 1,845)[37]
Fulford (population 654}[38]	Flash (population of Quarnford Parish 242)[39]	Barton-under-Needwood (population 5,019)[40]	Cheadle (population 11,406)[41]	Waterhouses (population 1,143)[42]	Maer (population 2,671 (this also includes Whitmore)}[43]

[32] https://www.citypopulation.de/en/uk/westmidlands/staffordshire/E63001792__leek/
[33] https://www.citypopulation.de/en/uk/westmidlands/staffordshire/E63001780__biddulph/
[34] https://www.citypopulation.de/en/uk/westmidlands/staffordshire/E63001980__alton/
[35] https://www.citypopulation.de/en/uk/westmidlands/staffordshire/E63002066__loggerheads/
[36] https://www.citypopulation.de/en/uk/westmidlands/admin/stafford/E04012927__swynnerton/
[37] https://www.citypopulation.de/en/uk/westmidlands/wards/staffordshire_moorlands/E05007058__horton/
[38] https://www.citypopulation.de/en/uk/westmidlands/staffordshire/E63002039__fulford/
[39] Flash is the main village in Quarnford parish, with the parish as a whole only being home to 242 people according to the 2011 Census. https://www.staffordshire-live.co.uk/news/local-news/what-its-like-live-staffordshires-6592947
[40]https://www.citypopulation.de/en/uk/westmidlands/admin/east_staffordshire/E04008879__barton_under_needwood/
[41] https://citypopulation.de/en/uk/westmidlands/staffordshire/E63001966__cheadle/
[42]https://www.citypopulation.de/en/uk/westmidlands/admin/staffordshire_moorlands/E04009061__waterhouses/
[43] https://citypopulation.de/en/uk/westmidlands/wards/E07000195__newcastle_under_lyme/

Haughton (population 1.071)[44]	Tean {population 3,241}[45]	Barlaston (population 2,811)[46]	Longsdon (population 562)[47]	Ipstones (population 1,751)[48]	Denstone (population 1,153)[49]
Gnosall (population 5,100)[50]	Cheddleton (population 6,133)[51]	Hollington (population 212)[52]	Meerbrook (population of Leekfrith Civic Parish 363)[53]	Burton-on-Trent (population 76,270)[54]	

Other responses received were from places outside of Staffordshire (Buxton, Hartington, Ashbourne, and Market Drayton).

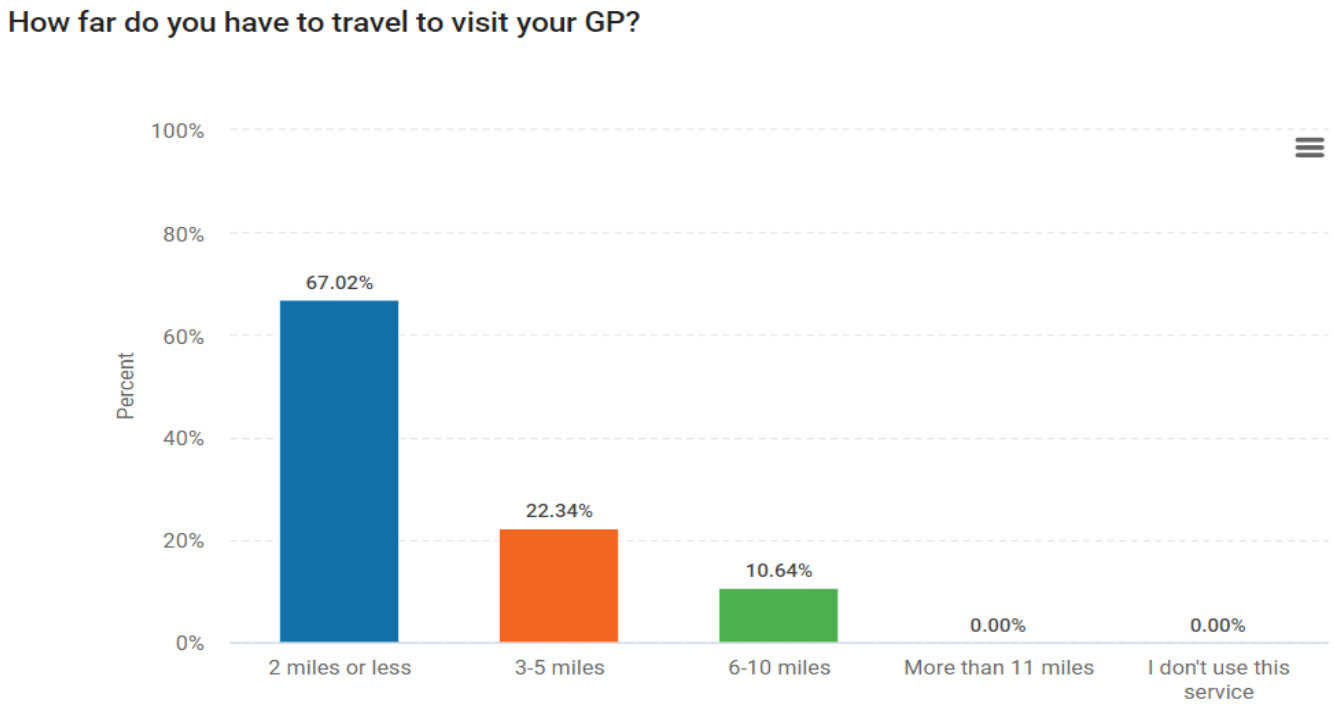
In our survey, people were asked to say, **'if they thought the area they lived in was rural?'**



[44] http://citypopulation.de/en/uk/westmidlands/admin/stafford/E04009000__haughton/
[45] https://www.citypopulation.de/en/uk/westmidlands/staffordshire/E63002013__upper_tean/
[46] http://citypopulation.de/en/uk/westmidlands/admin/stafford/E04008984__barlaston/
[47] http://citypopulation.de/en/uk/westmidlands/admin/staffordshire_moorlands/E04009053__longsdon/
[48] https://citypopulation.de/en/uk/westmidlands/wards/staffordshire_moorlands/E05007059__ipstones/
[49] https://citypopulation.de/en/uk/westmidlands/admin/east_staffordshire/E04008883__denstone/
[50] https://www.citypopulation.de/en/uk/westmidlands/admin/stafford/E04008999__gnosall/
[51] https://www.citypopulation.de/en/uk/westmidlands/admin/staffordshire_moorlands/E04009033__cheddleton/
[52] https://en.wikipedia.org/wiki/Hollington,_Staffordshire
[53] https://en.wikipedia.org/wiki/Meerbrook and https://en.wikipedia.org/wiki/Leekfrith
[54] https://www.citypopulation.de/en/uk/westmidlands/staffordshire/E63002256__burton_upon_trent/

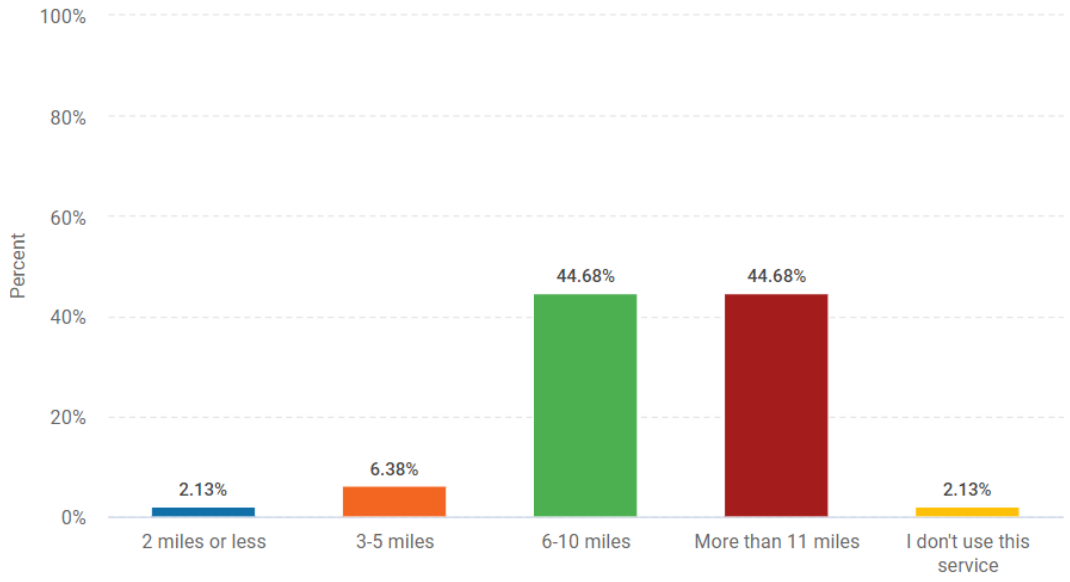
The places that people did not consider to be rural were Leek (2 people), Alton, and Biddulph (2 people). However, others who filled in the survey and lived in these areas did class them as rural. This data and feedback would indicate how 93.62% of respondents would class themselves as living in rural areas.

In order to find out how isolated from health services people who lived in these areas were, we asked the following questions: [55]

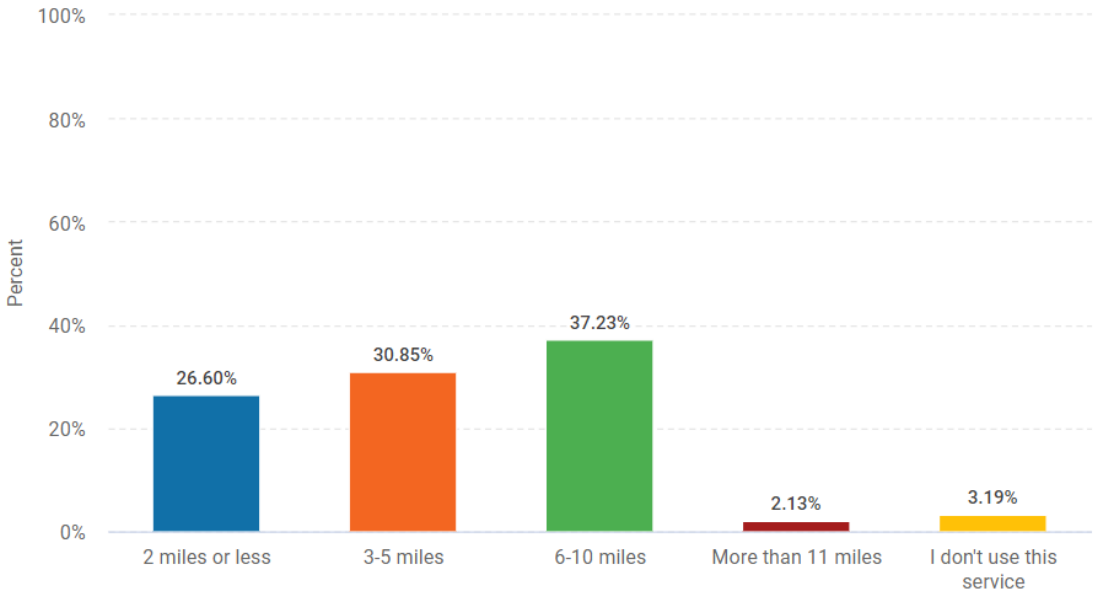


[55] All respondents answered the questions referred to in the bar charts below.

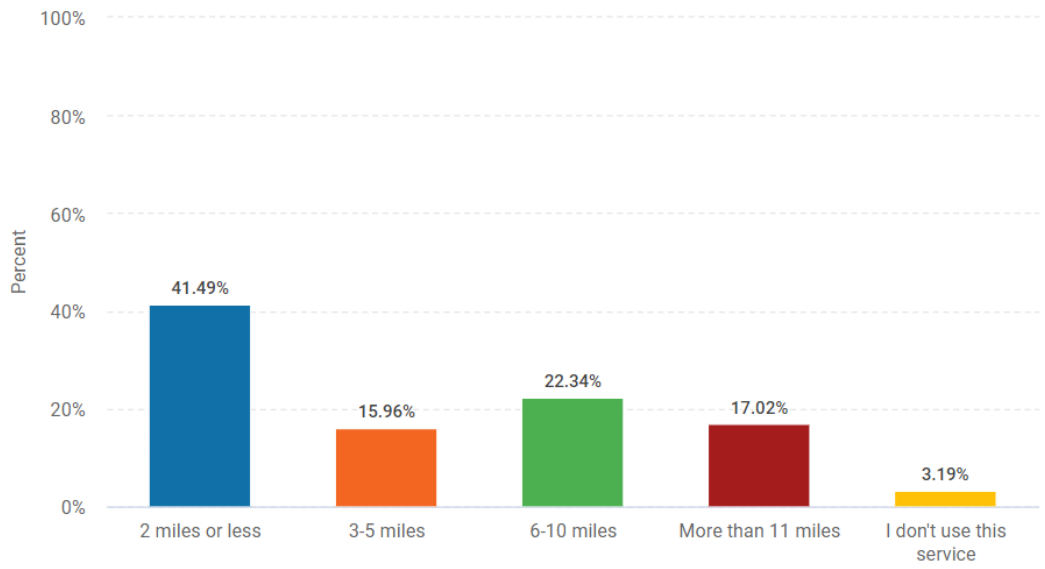
How far do you have to travel to visit a Hospital?



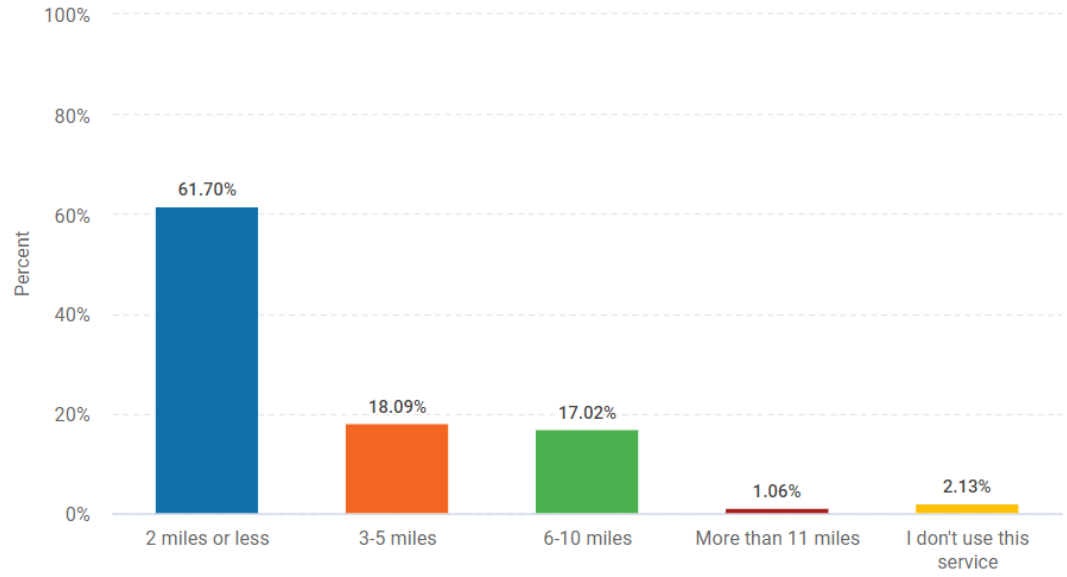
How far do you have to travel to visit an Optician?



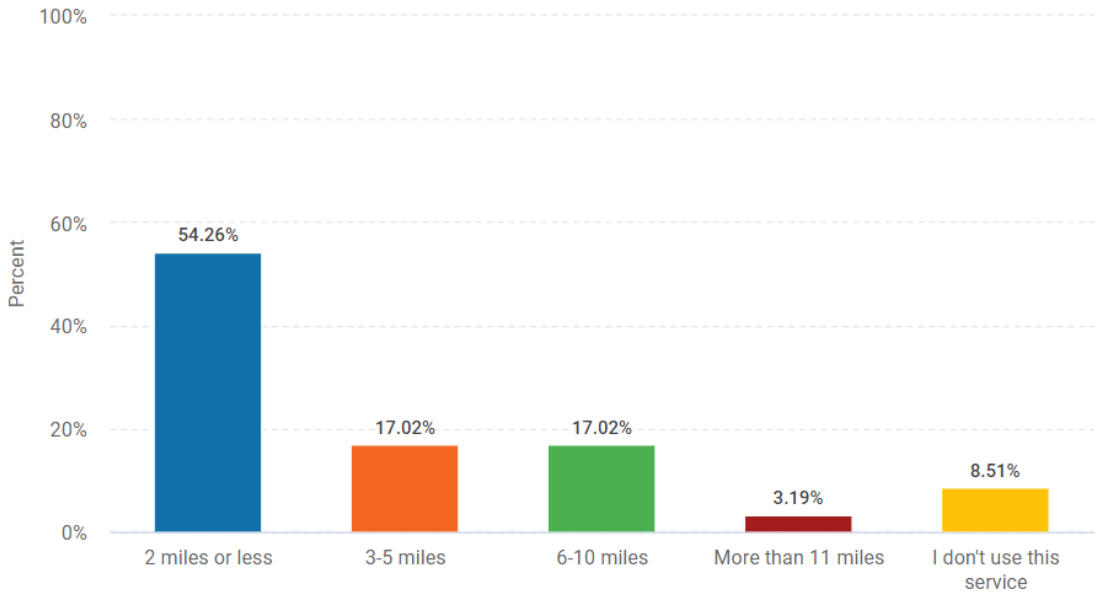
How far do you have to travel to visit an Dentist?



How far do you have to travel to visit a Pharmacy?



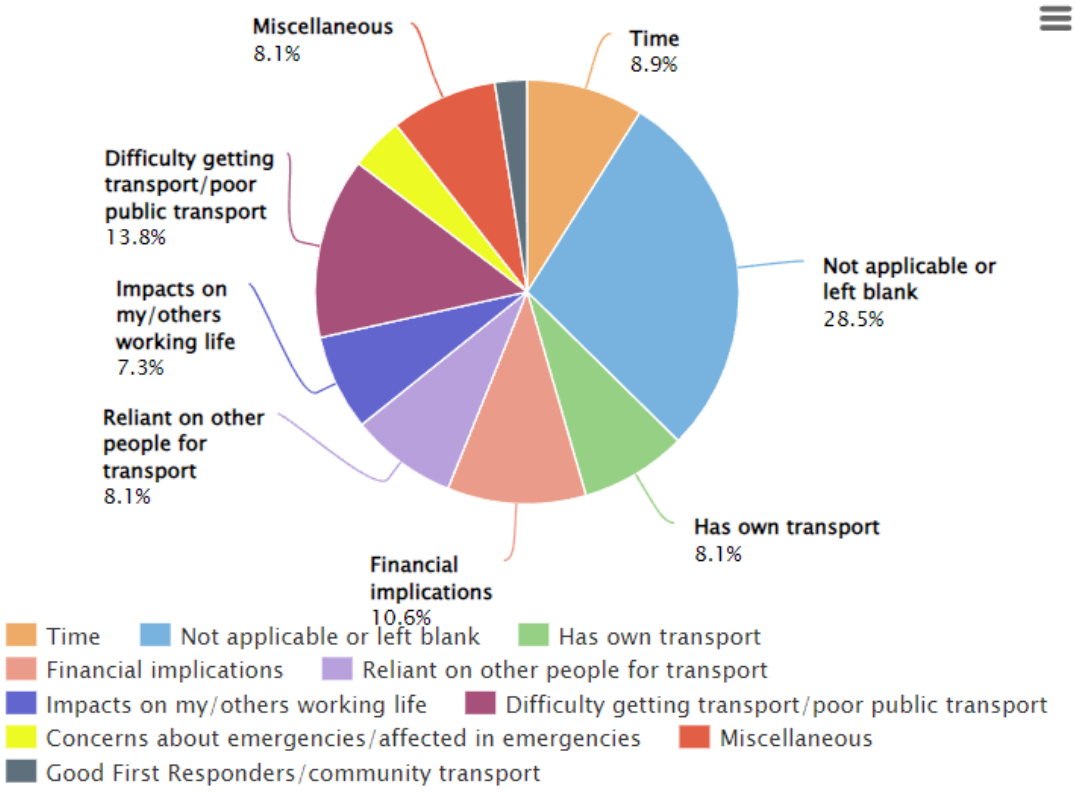
How far do you have to travel to visit a Health Centre?



From the above it can be seen that, except for hospitals and opticians, most people travelled less than two miles for a service.

The following questions in the survey were 'open questions' as we wanted to hear what people really thought. The charts that follow have therefore been analysed by grouping the same/similar answers together.

We then asked, 'How travelling more than 11 miles to a service affected people?'.[56]



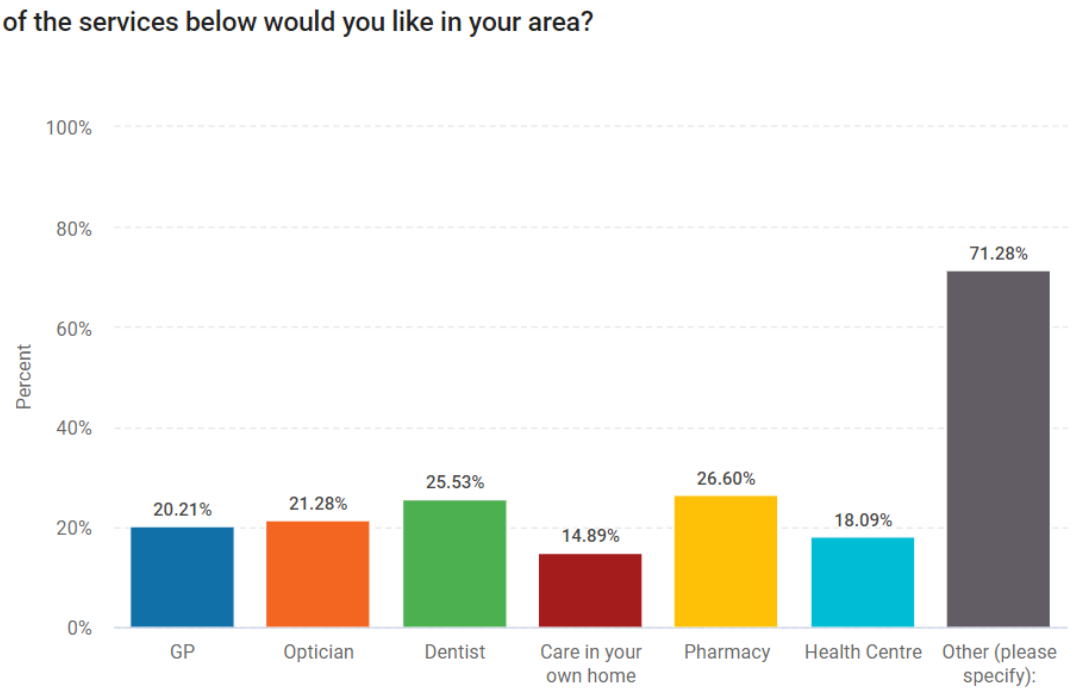
To add the missing figures to the table, 4.1% had concerns about emergencies/affected in emergencies, and 2.4% had Good First Responders/community transport.

The greatest number of people said that if affected them because of difficulty getting transport/poor public transport (13.8%) with a further portion saying they were reliant on others for transport (8.1%). As one person we spoke with said,

> **'...for my neighbours who have disabilities or poor mobility it is a struggle to get to the nearest bus stop. The bus stop is half a mile from the homes and only runs every hour, there is no direct route to GP/pharmacy which is up a very steep hill so again if you can't drive or have no family support it is very difficult to access.'**

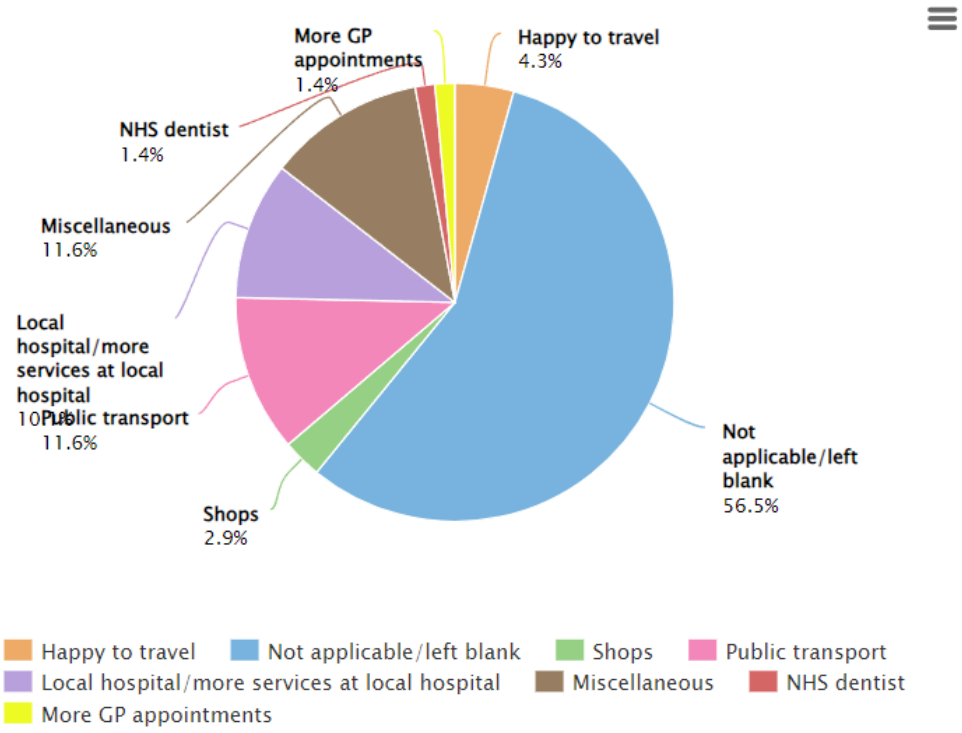
[56] To put the responses into perspective, out of 94 respondents, 35 said that this did not apply to them or left the response blank. Responses from the remaining 59 people contained more than one answer.

The miscellaneous responses included needing to plan journeys, not visiting a dentist due to the distance, and becoming stressed/anxious due to the situation (3 people).



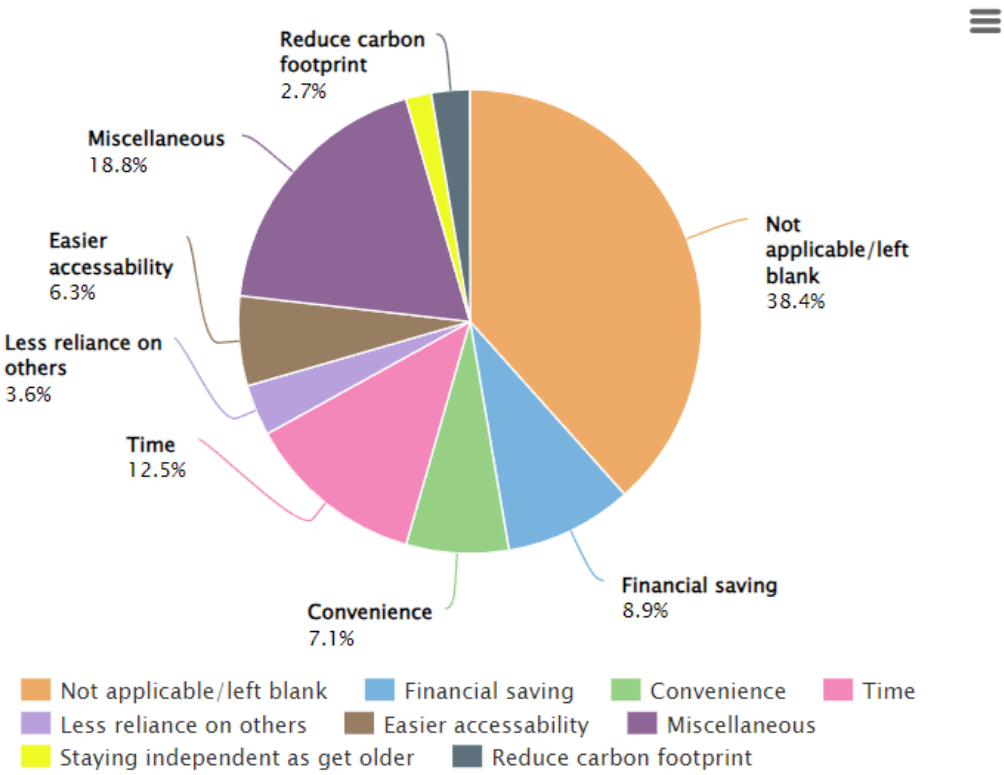
As can be seen, the services people would like was split quite evenly, with a local Pharmacy just ahead of a local dentist. When looking at the needs people have for dental services, Healthwatch Staffordshire are mindful of the national lack of dentistry and whether this may be a reason for this figure. The need for more pharmacies will be addressed in our recommendations.

The responses to 'Other' were –



So, of the other services that people would like, Public transport came out at 11.6%, and a local hospital/more services at local hospital was 10.1%. Amongst the miscellaneous responses was a Pharmacy that opens on a Saturday (2 responses), a First Responder (or ambulance) stationed in Leek, and a mental health group therapy hub (2 responses).

Please tell us what difference it would make having these services closer to you.



In this section, some of the miscellaneous answers are worthy of quoting –

'Safer/easier in winter'

'Peace of mind'

'I think that is quite obvious, less travel, care on our doorstep and a lot less pressure on our main hospitals, it's not rocket science.'

'They would be lifesaving.'

'Suggestion: Tailor services to the needs and demographic of the population, e.g., lots of people working on the land need chiropody.'

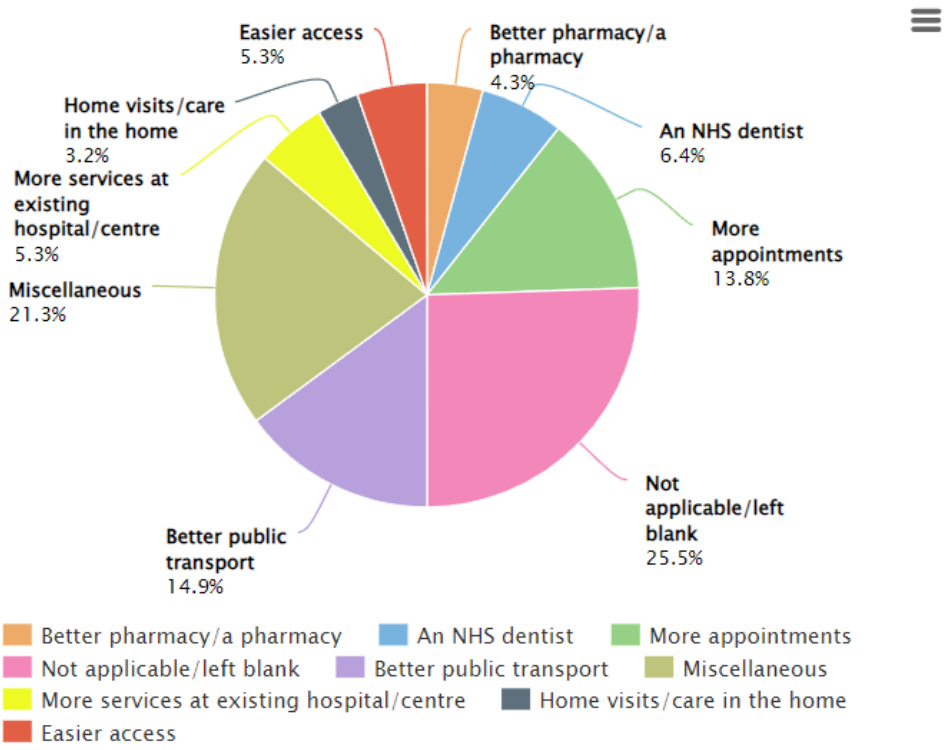
'...We are closer to services in Shropshire than Newcastle-under-Lyme but there is no local dentist. Our nearest GP is 5 miles away and public transport is limited so we have no choice but to drive...I rarely have reason to travel towards Newcastle for any other reason than to collect prescriptions or visit the dentist.'

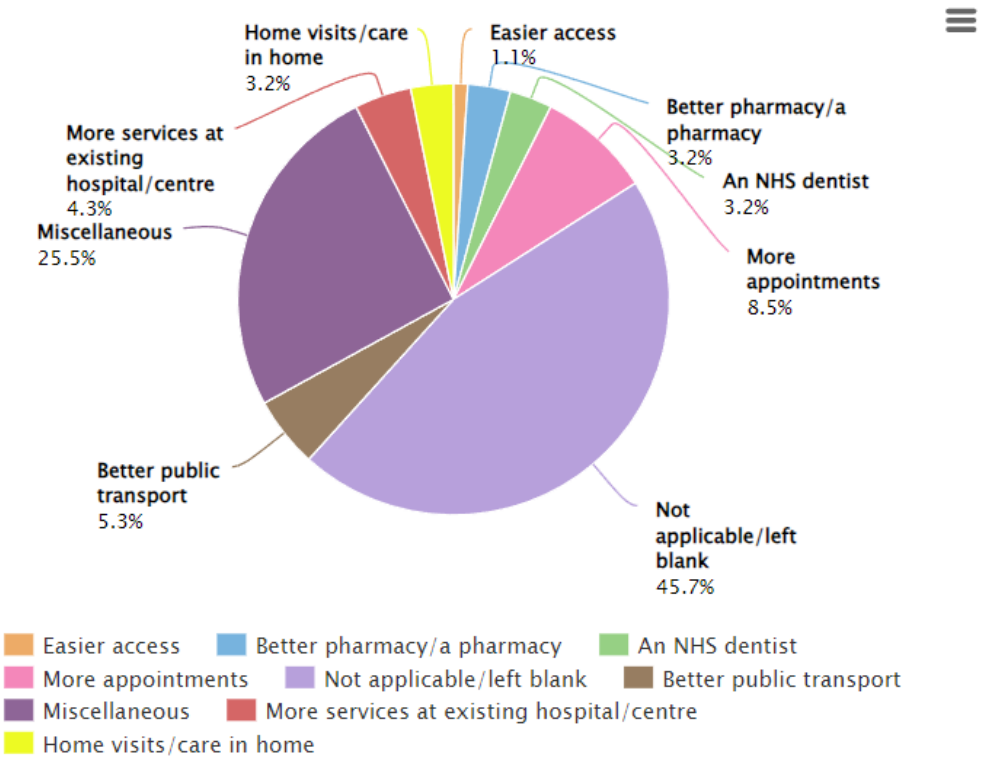
One pertinent comment was:

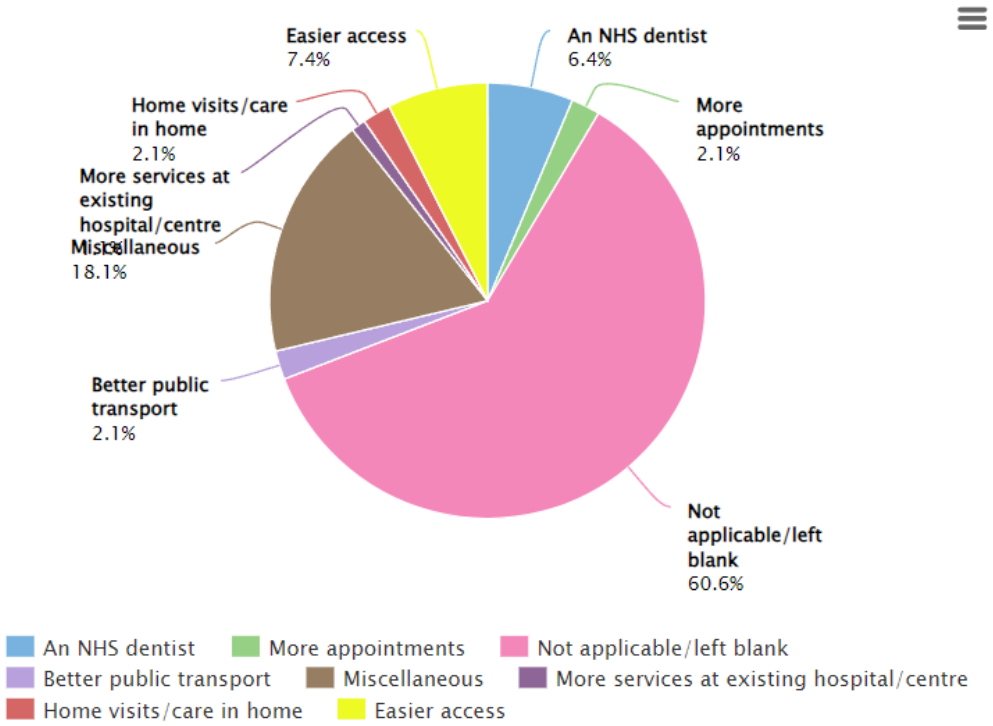
'I have chosen to live in such a remote area because I enjoy the fact that it does not have services close by. I love the seclusion we have here.'

What 3 things would improve your access to health and social care services

This question was split into three sections to enable people to write three different suggestions. The collated responses from the three pie charts are explained below.




Home visits/care in home 3.2%
Easier access 1.1%
Better pharmacy/a pharmacy 3.2%
An NHS dentist 3.2%
More services at existing hospital/centre 4.3%
Miscellaneous 25.5%
More appointments 8.5%
Better public transport 5.3%
Not applicable/left blank 45.7%
Easier access
Better pharmacy/a pharmacy
An NHS dentist
More appointments
Not applicable/left blank
Better public transport
Miscellaneous
More services at existing hospital/centre
Home visits/care in home


Easier access 7.4%
An NHS dentist 6.4%
Home visits/care in home 2.1%
More appointments 2.1%
More services at existing hospital/centre
Miscellaneous 18.1%
Better public transport 2.1%
Not applicable/left blank 60.6%
An NHS dentist
More appointments
Not applicable/left blank
Better public transport
Miscellaneous
More services at existing hospital/centre
Home visits/care in home
Easier access

Collating all 3 of the above pie charts together, we are left with the following percentages:

- Not applicable/left blank – 44%
- More appointments – 8.1%
- Better public transport – 7.4%
- An NHS Dentist – 5.3%
- Easier access – 4.6%
- More services at existing hospital/centre – 3.6%
- Home visits/care in home – 2.8%
- Better pharmacy/a pharmacy - 2.5%
- Miscellaneous – 21.6%

Miscellaneous answers included having a GP that was closer (7 people); longer opening hours/services at weekends (6 people); having a hospital/emergency service that was closer (11 people); better information/signposting regarding services (5 people); localised mental health services, physiotherapy, chiropody (2 people), podiatry, hearing tests; being contacted by services to check on their wellbeing (2 people); more home visits, access to reliable care at home, respite care.

One suggestion was to have '…a service that came to visit perhaps weekly – like a drop-in service.'

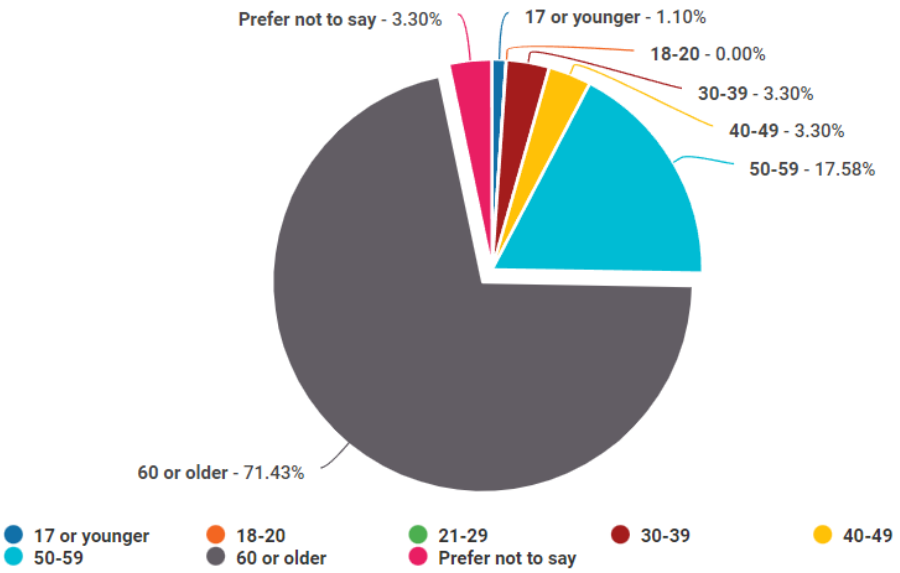
When looking at these figures Healthwatch Staffordshire are mindful of the fact that access to health services (needing more appointments) and dentistry is a national issue, so solutions will not be addressed in this report. However, a separate Deep Dive, on 'Access to Primary Care' is also being undertaken, which looks at these issues. Bearing this in mind, the top two wishes to come out of the survey are Better public transport (7.4%) and more services at existing hospital/centre (3.6%). These are the issues that will be addressed in our 'recommendations'.

Accessing services as we age

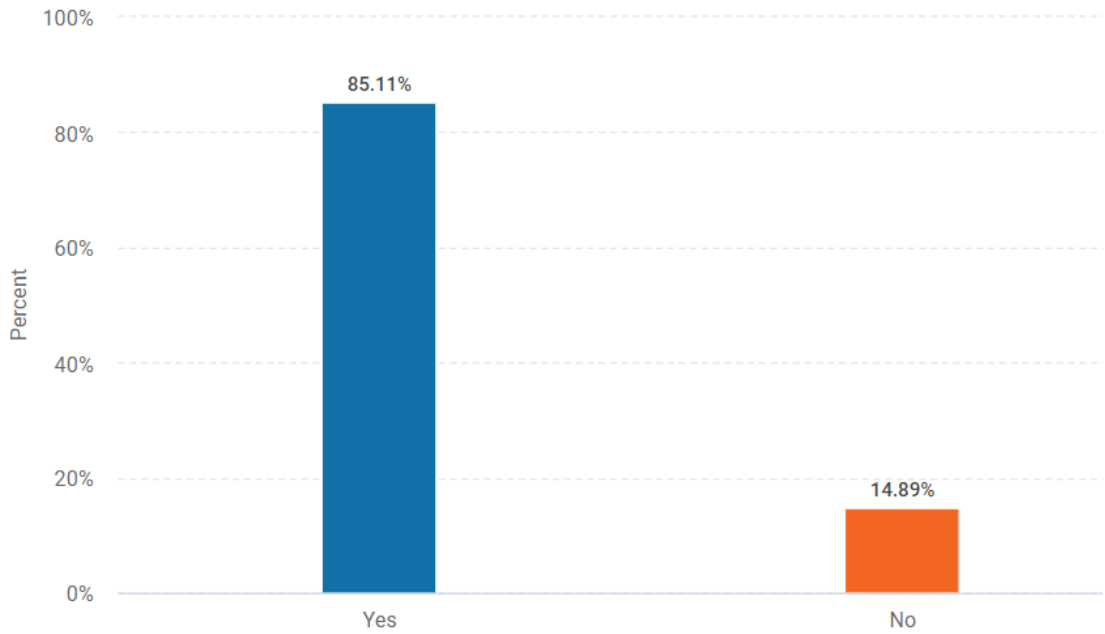
It is important to look at the ages of people who responded to our survey, and how many respondents had their own transport, as from the people who responded to this report we can see as people get older, they stop driving, making accessing health and care services more difficult. Several people also stated their reliance on family members when needing to attend services. On presenting these findings to our partners it was highlighted that deterorating health, plus a decrease in income, are

also factors which lead to a reduced ability to drive as we age. We also do recognise that these issues can affect younger people.

Please tell us your age.



Do you have access to your own transport?



As can be seen, many respondents still had their own transport, but as one person said:

As I get older, I am concerned that I will be able to drive and there are now no buses.

Recommendations

Improved Public Transport

The following statement is taken from the ICS' Joint Forward Plan[57]:

Improving population health

Our commitment – Dr Paul Edmondson-Jones, ICB Chief Medical Officer

We want to make sure that everyone in Staffordshire and Stoke-on-Trent (SSOT) has a fair opportunity to live a good life. Looking at some of the inequalities that we know still exist is simply not good enough and many of these can only be addressed by partners working together. Improved health and wellbeing will be achieved through better support and high-quality services, but also through preventing people from becoming unwell and supporting them to live well in their communities. We recognise that we need to look beyond health and care services to understand the barriers to living a healthier life and are committed to working with people and communities to address them. Working together is the fundamental principal behind the Staffordshire and Stoke-on-Trent Integrated Care Partnership (ICP), building on our collective resources and making better use of shared learning and experience. Our residents need to be an equal part of that partnership and we look forward to working with them to achieve our ambition of making Staffordshire and Stoke-on-Trent the healthiest place to live and work.

Further on in the Plan[58] it talks about the Population Health Management (PHM) programme which 'focuses on the wider determinants of health. These have a significant impact, as only 20% of a person's health outcomes are attributed to their ability to access good-quality health care.... PHM is a partnership approach across the NHS and other public services, including councils, schools, the fire service, the voluntary sector, housing associations, social services and the police.'

[57] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 29
[58] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 36

Indeed, Staffordshire County Council recognises that there is a lack of adequate provision of public transport in the County. In the Introduction to its Rural Economic Strategy:2023-2030 it is stated that '…Staffordshire also faces challenges typical of rural areas, including peripherality and isolation in some parts, with relatively weak internal transport…, and significant gaps in some locations.'[59] Indeed in the SWOT analysis the document states Weaknesses include: Weaknesses in internal transport connections, including public transport.'[60]

We would agree that the provision of a comprehensive bus service would have an impact on people's health and wellbeing, as it would not only make accessing health services easier but would also mean they were more able to travel to local towns.

We spoke with people from Biddulph who told us that there is 1 bus an hour to Hanley, and no bus service to Leek. To travel to Leek via bus involves 3 buses each way (Hanley-Leek-Leek Moorlands Hospital), which is a 34-mile round trip.

On speaking with people from Alton we were told that there is one bus a day from Alton to Cheadle, and a bus into Leek on a Wednesday.

One survey respondent told us:

> **…don't mind the cost of public transport, just how infrequent they are.**

More specifically related to attending health appointments, people did seem to be aware of the free ambulance transport service, we were told of someone who had to wait two hours for transport, so will not go to hospital in future. We were also told that a taxi from Alton to Royal Stoke costs £40-£50. If people do not have friends or family who can take them, this leads to a reliance on volunteers from within the village. Indeed, one respondent referred to volunteers directly saying we need 'More volunteer drivers for Moorlands community transport'.

[59] https://www.staffordshire.gov.uk/Business/Economic-and-Rural-Economic-Strategies/Rural-Economic-Strategy-2023-2030.aspx#:~:text=Almost%20four%2Dfifths%20of%20Staffordshire,of%20the%20county's%20economic%20activity. Introduction.
[60] https://www.staffordshire.gov.uk/Business/Economic-and-Rural-Economic-Strategies/Rural-Economic-Strategy-2023-2030.aspx#:~:text=Almost%20four%2Dfifths%20of%20Staffordshire,of%20the%20county's%20economic%20activity. Point 2.

We heard of a lack of public transport in certain areas which affects people accessing services, 'All services require transport by car, buses do not exist Swynnerton to Eccleshall'.

We were also told that from the beginning of July 2023, Wereton (an estate near to Audley) no longer have a bus which passes their GP in Audley. For people who have no transport this means an uphill walk, which people who are elderly or less mobile may find difficult.

When the people of Biddulph were advised nowhere in the Town would be providing Covid Booster Jabs, the people objected, and a building was sought. One resident emailed Healthwatch Staffordshire to say '…over 400 people attended the walk-in vaccination centre at the Fire Station in Biddulph…. What a result and I am told that people commented in the queue if it hadn't been in Biddulph they wouldn't have bothered as couldn't travel easily.'

Better use of local Primary Care Centres/Hospitals

From our conversations with people in Biddulph and Alton we know they would like more services provided in their local Primary Care Centres. Biddulph Primary Care Centre provides an ante-natal clinic, coronary heart disease clinic, diabetic clinic, family planning services, blood tests, minor surgery, respiratory clinic, spirometry clinic, has rooms available for Community Psychiatric Nurses (CCPNs) and Counsellors from the psychology or psychiatry departments of the North Staffordshire Hospitals, and hosts podiatrists, physiotherapists, district nurses and health visitors amongst other allied health professionals..[61] However, people from Biddulph told us that when the new Centre was first being planned they were promised an x-ray service and a couple of beds.

We were also told by the people of Alton that the Primary Care centre used to have district nurses and health visitors/midwifes working from there, and that they used to conduct minor surgeries and hold contraceptive clinics for coils & implants.

Referring again to the Joint Forward Plan, it says that 'The ICS's ability to maintain and improve people's health and wellbeing is essential. This means making sure that our health and care services are working in the most efficient ways possible and making the best use of funding and other resources like staff and buildings…'[62]

[61] Clinics and Services - Biddulph doctors

[62] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 20

Bringing more services into local Primary Care Centres and Hospitals, would also address an environmental issue. One pertinent comment from the surveys was the increase in the carbon footprint of people who live in villages and towns having to travel to appointments and services. Indeed, Climate Change is something that is referred to in the Joint Forward Plan 'The environmental changes taking place now and, in the future, will be the biggest global threat of the twenty-first century. We are committed to meeting the Net Zero Carbon targets set out, which means reaching Net Zero Carbon for…our indirect emissions (NHS Carbon Footprint Plus) by 2045 at the latest'.[63] It could be argued that people travelling to services is an 'indirect emission'.

Pharmacies

In the '2023/24 NHS Priorities and Operational Planning Guidance' 3 objectives are set, and the Guidance states that, 'Recovering productivity and improving whole system flow are critical to achieving these objectives. Essential actions include: …and increasing use of community pharmacies.'[64] This means people are being encouraged to visit their pharmacist for ailments that have previously been seen by GPs, hence easing pressure on this service. However, on speaking with the people of Alton, they have no Chemist in the village, the nearest ones being in Cheadle and Leek. There is a Pharmacist at Alton Primary Care, but as they are shared within the Primary Care Network (PCN) they are only with them for a maximum of one day per week.

One person from a different village (that does not have a Primary Care Centre or GP) made the following suggestion:

A pharmacy would be a great idea. I would love a 'pop up' service in our local village hall like they have with the Post Office – it is here for 2 hours on a Thursday, and I think a Monday as well.

[63] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 20
[64] https://www.england.nhs.uk/wp-content/uploads/2022/12/PRN00021-23-24-priorities-and-operational-planning-guidance-v1.1.pdf, page 3

Another person we spoke with did have a local pharmacy, but said:

> **The pharmacy tends not to have all the stock so you must attend a couple of times just to get your prescriptions and it doesn't open on a Saturday so if you were to rely on family support and they worked Monday to Friday this would be another issue.**

So we would recommend that pharmacists are commissioned for villages that have no seven day access to such services.

Digital access

Although not asked about in the survey, with the current push towards people accessing healthcare via digital technology, we feel that Digital access is worthy of a mention.

When speaking with people, the move towards digital access did concern many. When we spoke with a group of over 55's we were told that they were suspicious of smart phones and may struggle to view the screen.

We were also advised that people in rural areas cannot access the internet. Indeed, referring again to Staffordshire County Council's Rural Economic Strategy:2023-2030 it is stated that '…Staffordshire also faces challenges typical of rural areas, including peripherality and isolation in some parts, with relatively weak…, broadband and mobile phone connections, and significant gaps in some locations.'[65] Indeed in the SWOT analysis the document states Weaknesses include: 'Gaps in broadband coverage, particularly at higher connection speeds (>/=100Mbps), for commercial and residential properties'[66]

This therefore adds to the argument that services do still need to be made more local for some of Staffordshire's residents.

[65] https://www.staffordshire.gov.uk/Business/Economic-and-Rural-Economic-Strategies/Rural-Economic-Strategy-2023-2030.aspx#:~:text=Almost%20four%2Dfifths%20of%20Staffordshire,of%20the%20county's%20economic%20activity. Introduction.
[66] https://www.staffordshire.gov.uk/Business/Economic-and-Rural-Economic-Strategies/Rural-Economic-Strategy-2023-2030.aspx#:~:text=Almost%20four%2Dfifths%20of%20Staffordshire,of%20the%20county's%20economic%20activity. Point 2.

EXAMPLES OF GOOD PRACTICE

Abdominal Aortic Aneurysm (AAA) Screening Team

When researching rurality, we found out about the AAA Screening Team. This service is for men aged 65 and the team are peripatetic. As the website states 'The Staffordshire & South Cheshire AAA screening programme is run from Royal Stoke University Hospital and you will be invited to a local clinic for an ultra sound scan. Clinics are held in GP surgeries and other venues throughout the area.'

Werrington Community Library

We also spoke with Werrington Community Library. Although not as rural as some parts of Staffordshire (population 6,445[1]), it does have farms, and people have difficulty in travelling to Meir, Bentilee or Cobridge for a blood test if they don't drive. The community Library is run by volunteers, and they work closely with Werrington Surgery, which is located next door. The library has rooms which the Wellbeing Service, Family Health & Wellbeing Team, and an Independent Audiology Service use, amongst others. Although some charges may apply to the Audiology Services, the library is bringing a wide range of other health and wellbeing services closer to the community.

Local Community Transport

During this project we also learnt about community transport schemes including, volunteer drivers within Madeley and District Community Association, Moorlands Voluntary & Community Transport, and Newcastle Community Transport. Further details can be accessed via the following links -
https://madeleycentre.co.uk/services/madeley-and-district-community-association/
https://www.mvct.co.uk/voluntary-transport/
https://newcastlecommunitytransport.org.uk/booking/

Community First Responders

Two respondents to our survey mentioned the importance of their Community First Responders. Although we are referring to this as an example of good practice, we are mindful of the fact that this service is provided by volunteers.[67]

[67] Community First Responders – West Midlands Ambulance Service University NHS Foundation Trust (wmas.nhs.uk)

People with Co-occurring Needs (Neurodiversity)

Whilst carrying out our engagement work, we had heard from members of this community and so decided to focus on it as part of this project to delve deeper into the issues faced.

In addition to the Population Health, Prevention and Health Inequalities Portfolio, referred to earlier, Neurodiversity has the additional portfolio of Mental Health/LDSA. With regards to Learning disabilities and autism specifically, the Plan states that the ICS' ambition is 'To make learning disabilities and autism everyone's business, to ensure equal access and reasonable adjustments are considered across all services.'[68]

It also states that the ICS aims to 'Make sure that all NHS commissioned services are providing good quality healthcare and treatment to people with LDA and their families. We will make sure reasonable adjustments are made so that people with LDA get access to the support they need.'[69]

It is stated that the ICS' work is arranged around six workstreams for LDA, two of which are 'Universal services (dentists, opticians and the wider preventative services are accessible to all with reasonable adjustments)' and 'Community services (secondary mental health services for people with LDA).'[70]

The National Strategy for Autistic Children, Young People and Adults, 2021-26 has six key themes. Theme 1 is 'Improving understanding and acceptance of autism within society' and Theme 4 is 'Tackling health and care inequalities for autistic people.'[71]

The Staffordshire Autism Joint Implementation Plan 2020-2023 was produced to help achieve the vision of the previous Staffordshire Whole Life Disability Strategy[72] The Joint Staffordshire Disability and Neurodiversity Strategy (2023-2028) was being finalised when our research was being undertaken, so was not available for reference.[73]

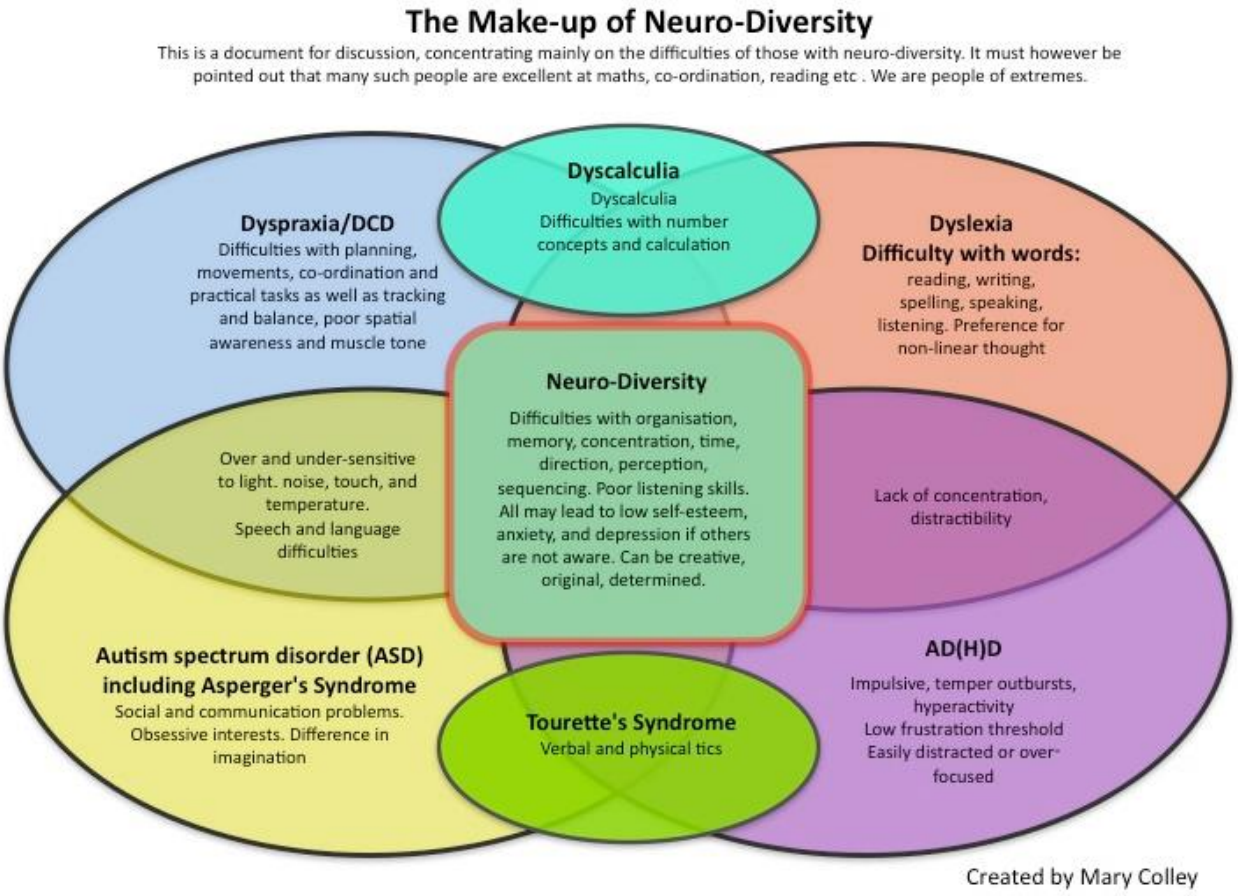
[68] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 82
[69] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 83
[70] The Staffordshire and Stoke-on-Trent Integrated Care System (ICS) Joint Forward Plan 2023-2028, page 83
[71] Living my Best Life with Autism, Stoke-on-Trent Strategy for Autistic Children, Young People and Adults, 2023-2026, page 16
[72] Staffordshire Autism Joint Implementation Plan 2020-2023, page 3
[73] https://www.staffordshire.gov.uk/Advice-support-and-care-for-adults/Information-resources/Whole-life-disability-strategy/Joint-Staffordshire-Disability-and-Neurodiversity-Strategy-2023-2028.aspx

Methodology

With these aims in mind, we wanted to find out how peoples' diagnoses affected them when visiting different health and care services, and why this was. To meet our aims, we spoke with carers for, and people who have, a neurodivergent diagnosis and asked them to complete our survey. The people we spoke with were from groups that worked with people who have co-occurring needs. We also distributed surveys to organisations who have a focus on working with people with co-occurring needs and asked them to send to their wider membership. The survey was also distributed via Healthwatch Staffordshire's social media channels and website. This led to a total of 86 responses to our survey.

What is Neurodiversity?

According to ADHD Aware 'Neurodiversity is a term that refers to the natural differences between people and was coined in the late 1990's by Australian sociologist Judy Singer…and is useful to describe people with varying characteristics and behaviours of neurodevelopmental conditions alongside the "neurotypical" majority in a non-prejudiced way…It is thought that up to 15% of the population are thought to be **neurodiverse.** The remaining majority are **neurotypical.**'



[74]

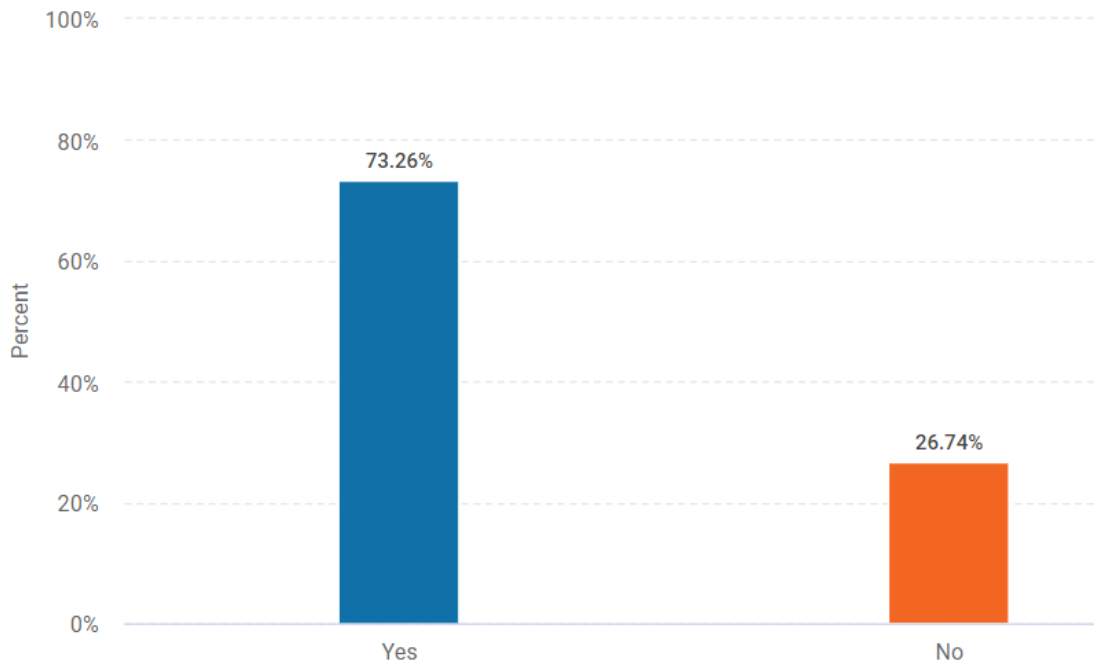
At this point we need to say that after speaking with people who are neurodiverse, they said they preferred the term 'co-occurring conditions' and so that it what this research became known as.

[74] Diagram created by Mary Colley & Joseph Aquilina, diagram and text from https://adhdaware.org.uk/what-is-adhd/neurodiversity-and-other-conditions/

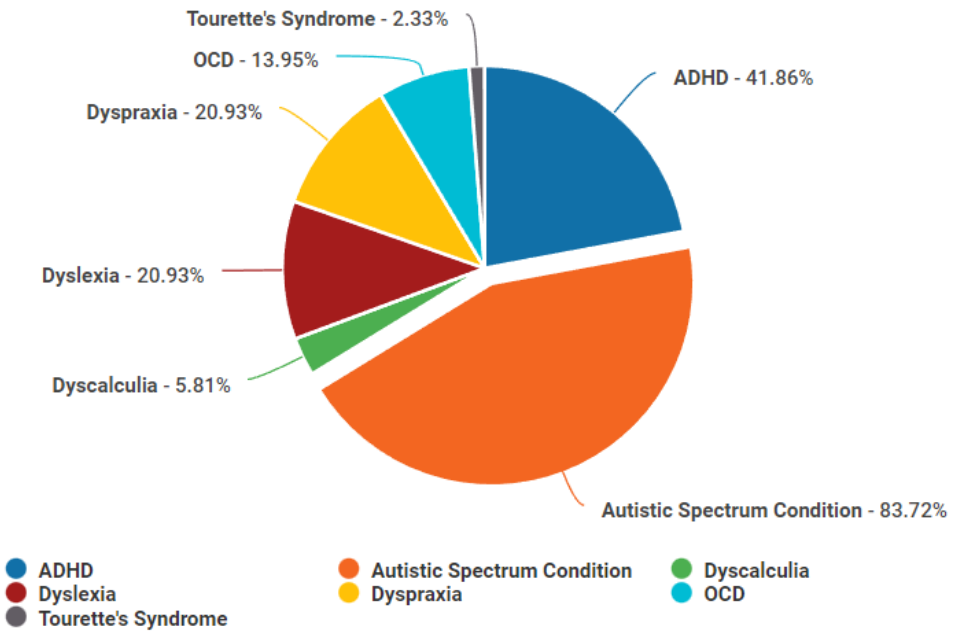
Main findings

The results from our surveys were as follows:

Are you answering this survey as a carer of someone with co-occurring conditions?

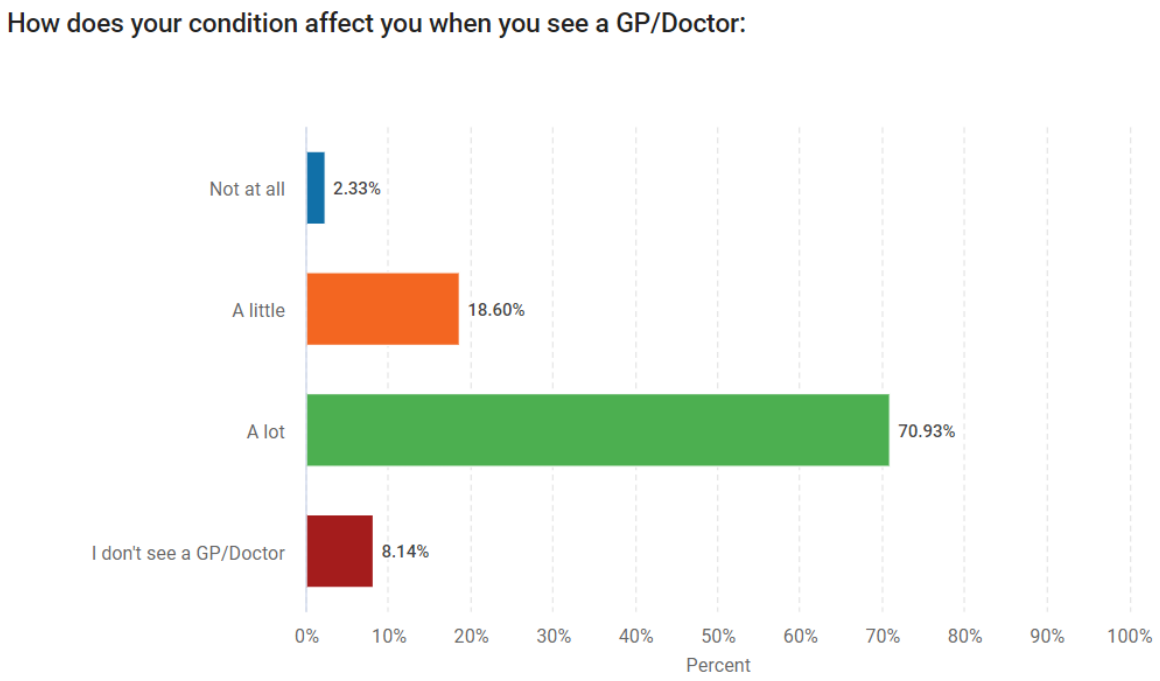


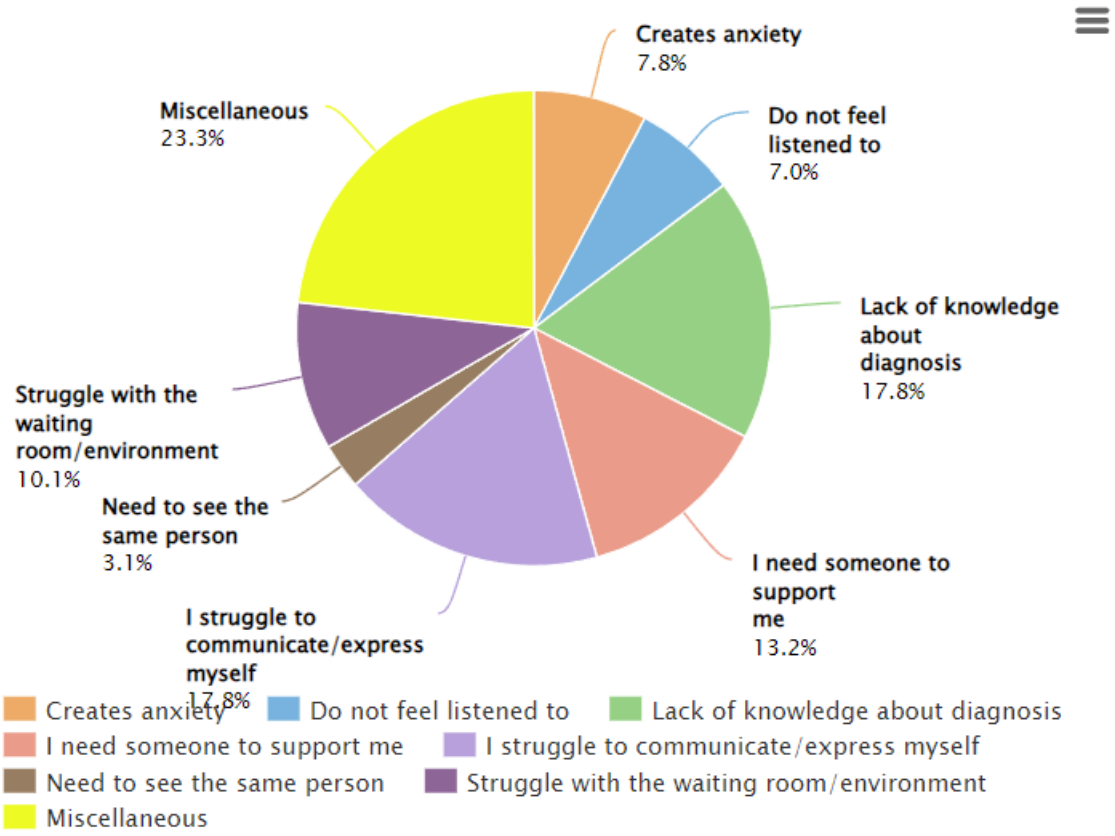
Which of the following conditions do you, or the person you care for, have?



As can be seen, most respondents were diagnosed with Autistic Spectrum Disorder (ASD) and ADHD. More than one condition could be chosen, hence the title of the survey being 'co-occurring needs'. This also is the reason the above pie chart adds up to more than 100%.

People were then asked how their diagnosis affected them when visiting various Health and Care services, and why this was. In asking the reasoning, we left the question open as we really wanted people to give their own thoughts. However, in the analysis we have grouped the responses, as many people said the same reasons. The results were as follows:





Except for the answers that did not fit into a category, 'Lack of knowledge about the diagnosis', 'I struggle to communicate/express myself', 'I need someone to support me', and 'Struggle with the waiting room/environment' were the top answers.

The miscellaneous answers included being forced onto medication and threatened with hospitalisation, being threatened with being removed from services, being unable to sit still (2 people), fear of being touched/examined (4 people), not liking new people/places (2 people). Two people mentioned unexpected changes and one of them explained:

> I have had unexpected things said to me at the beginning of a consultation which has left me unable to use the consultation properly because my mind cannot stop thinking about the unexpected thing'.

Time was also referred to by 3 respondents:

‘It takes him longer to make sure he has covered everything and he repeats things back to the Dr to make sure he’s understood correctly’

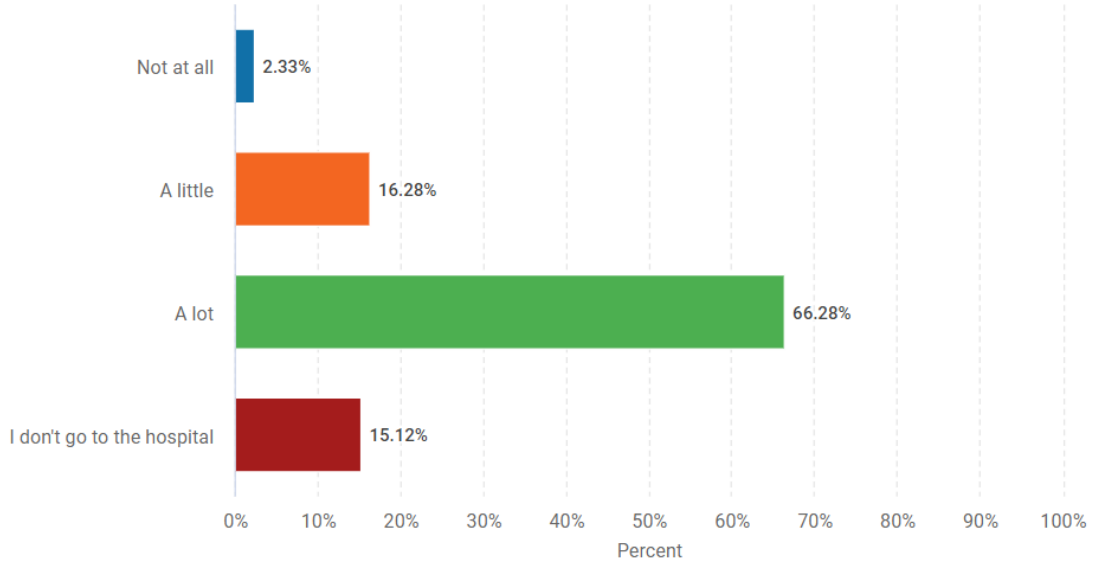
‘being rushed’

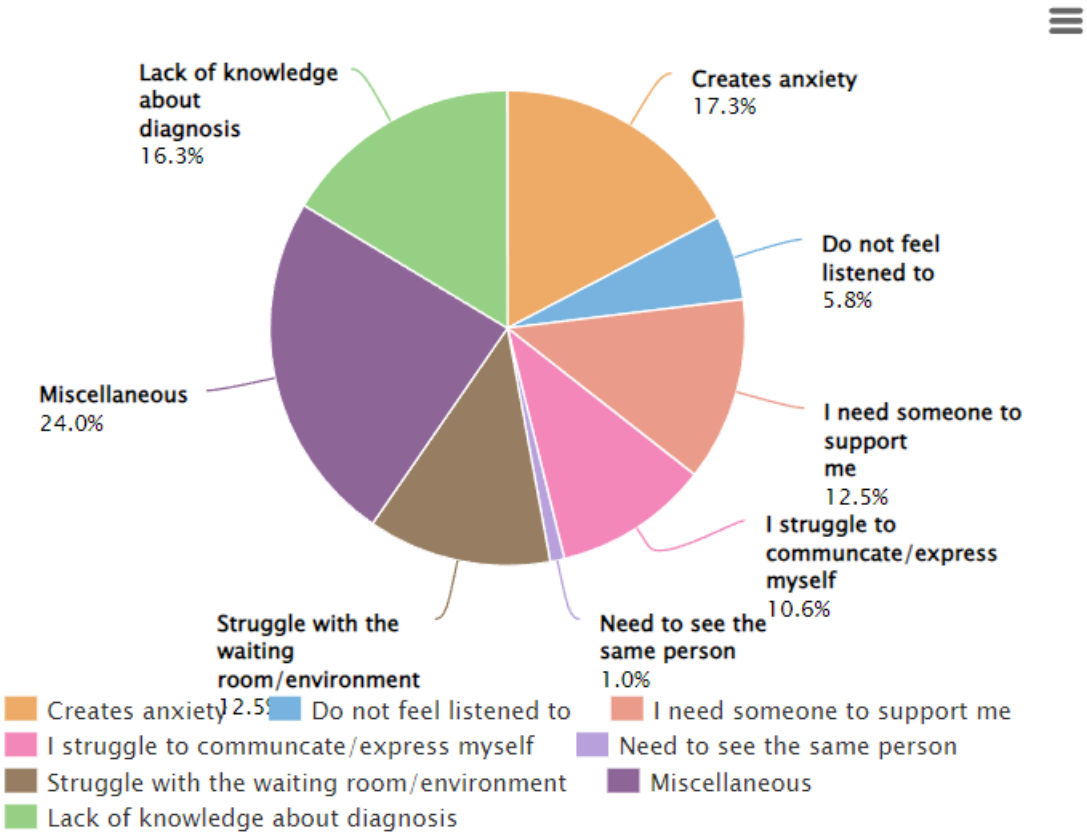
‘Has trouble explaining what’s wrong and needs extra time to process this and any answers.’

These last comments could have also been included in the category ‘I struggle to communicate/express myself’ and so will be considered in the recommendations.

Another comment related to getting an appointment, ‘Getting an appointment at all can be a challenge and it would help if some sort of priority was available for ASC…’.

How does your condition affect you when you go to a Hospital:





As you can see, as with visiting a GP, most people said that visiting the hospital affected them 'a lot'.

With the reasoning as to why this was, (with the exception of miscellaneous), 17.3% said it was because it creates anxiety, 16.3% said lack of knowledge about the diagnosis, 12.5% said they need someone to support them, 12.5% said they struggle with the waiting room/environment, 10.6% said they struggle to communicate/express themselves.

In analysing these figures further, it would have been useful to know why it created anxiety, was it because they struggle to communicate, or don't feel listened to, or because of the environment. Unfortunately, we were unable to ask this question.

Among the answers we classed as miscellaneous were again references to not like to be examined (2 people), struggles with new scenarios and strangers, not being able to sit still (2 people), feeling overwhelmed, difficulty reading letters and documents accurately, unpredictability and disrupting routines, and feeling rushed.

Further comments were:

‘Made to feel that I am misbehaving and put in a separate place or security come to tell me that I can’t behave or say things that I do! I have had to sit outside the accident unit waiting to be seen so that I don’t upset people with my condition! Even been told that it’s an excuse for bad behaviour!’

‘Autism is blamed for behaviour rather than looking for the medical reason for distress’.

As a Healthwatch we have heard from people who have been removed from GP’s lists due to inappropriate behaviour, and we are mindful that these actions could be related to neurodiverse conditions.

Another person said:

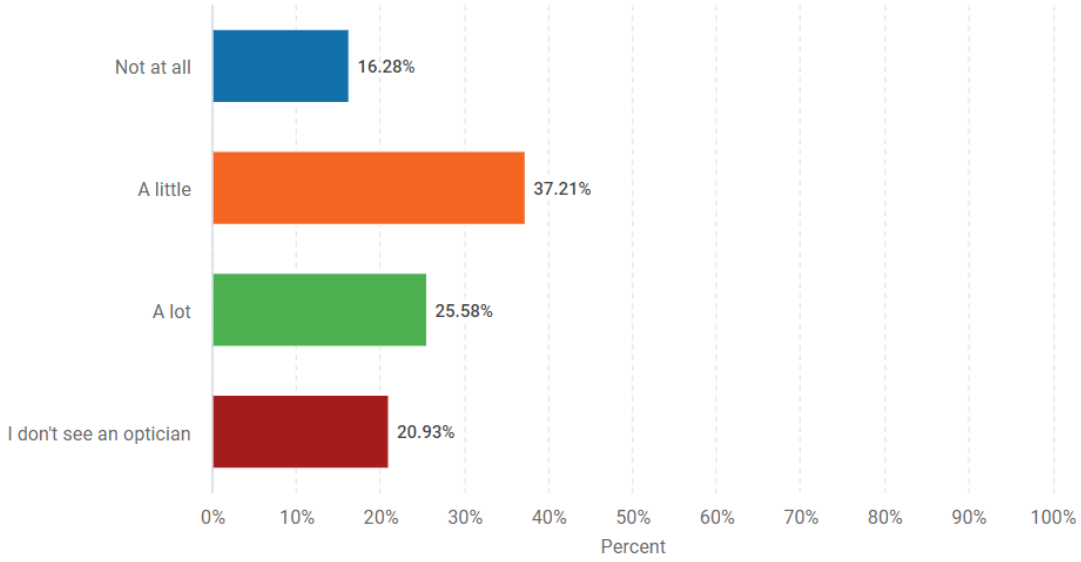
‘Wait times too long, too many noises going on, it smells funny and tends to have horrendous strip lighting.

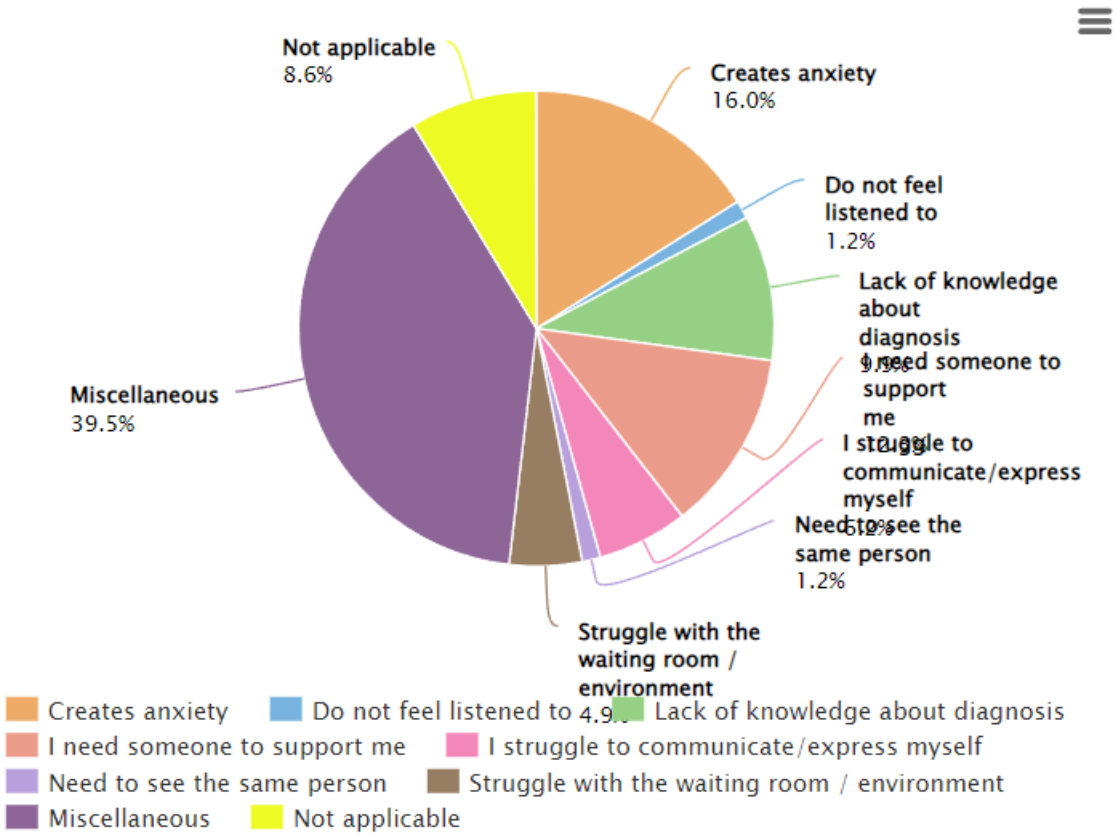
‘She gets restless and tired because she is so anxious but when I try and explain this to staff there is little that can be done to be seen quicker so we can leave the environment before she becomes completely overwhelmed and shuts down or cries. By the time she gets to see a doctor she is not able to communicate effectively and tell them what the problem is or if they are hurting her when she is examined. She can meltdown after we leave the hospital as the experience has been so overwhelming for her. Although staff are usually helpful there still isn’t the understanding of how difficult it can be for autistic children in a hospital environment and the anxiety it causes them. The experience needs to be in and out, not waiting around for hours becoming more and more anxious and overwhelmed.’

However, there were also comments about reasonable adjustments being made:

‘Hospital have been very good, on autism register and had recent surgery and put at the beginning of the list to help so not waiting.’

How does your condition affect you when you see an Optician:





As can be seen, most people said that their diagnosis only affected them ‘a little’ when seeing an optician. Again, the miscellaneous category had the highest percentage, but the following answers received these percentages, I need someone to support me 12.3%, Lack of knowledge about diagnosis 9.9%, I struggle to communicate/express myself 6.2%, Struggle with the waiting room/environment 4.9%, Need to see the same person 1.2%, Don’t feel listened to 1.2%.

Some of the answers that we couldn't categorise were, fidgeting, being uncomfortable wearing the glasses opticians use, being in unfamiliar surroundings, difficulties with strangers, 'Problems with direct eye contact for a period of time. Hard to keep asking them to repeat the words they use. Have ended up with bad prescriptions in the past due to what I believe as being ignored or patronised.', and difficulty concentrating.

However, we also received positive comments about opticians:

'My optician is very understanding of my daughter's condition. She explains everything to her. She checks it's okay before she touches her eyes and always takes in account her dyslexia.'

'They're better at taking their time and explaining things. Respectful of my conditions.'

'Have always informed opticians beforehand so they have been very accommodating.'

'I have explained to the optician about the issues with bright lights and separating head and eye movements, being a bit slower, not rushing, and they have been very accommodating and patient.'

'I have a brilliant optician who tells me exactly what's going on, all the time, answers my questions and allows me to move if I need to.'

'The optician makes some accommodations as they have known us for years.'

'May need reminders or confirmation about any issues from another person. In general, the environment is much better and consistently are able to see the same practitioner.'

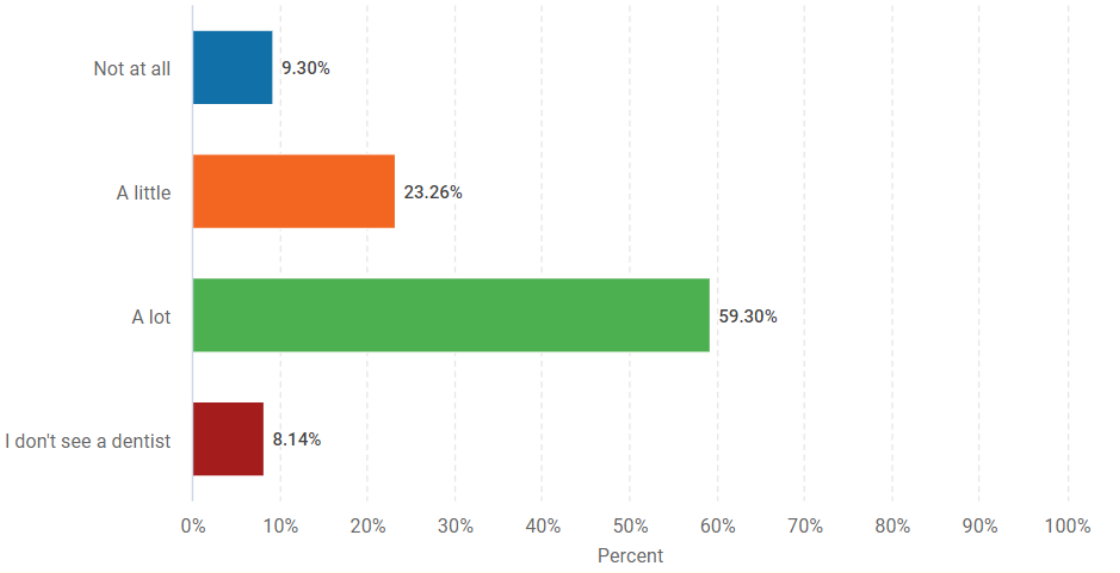
'Our optician knows how to communicate with ASD.'

‘Specsavers my daughter’s optician are very understanding and make special arrangements for my daughter to be seen during quieter times of the day. They will offer to turn off the music if the environment is too loud, so she isn’t sensory overwhelmed and offer her a drink of water. We are seen quickly so that she does not get restless waiting around. They are very calm with how they speak to my daughter to make her feel at ease and the optician takes her time when conduction the eye test so that she is less anxious. They leave us to take our time when choosing new glasses so that she doesn’t feel pressured.’

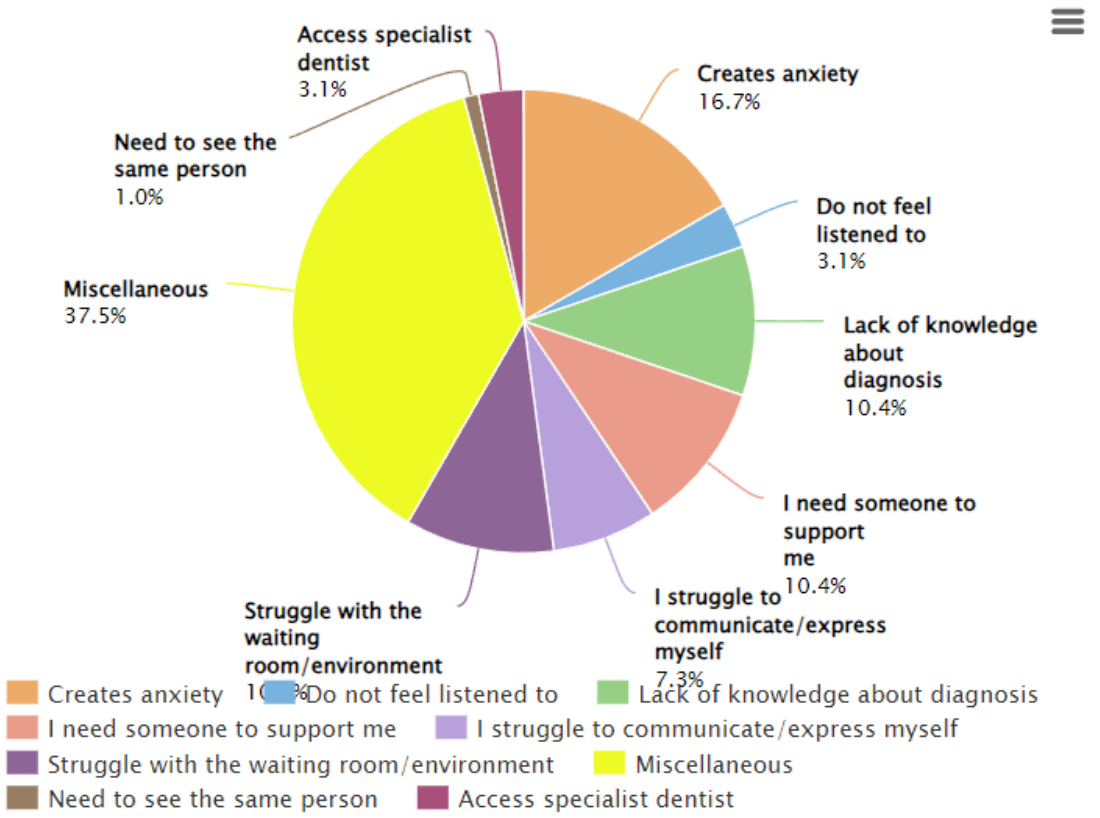
Someone else told us of the adaptions that are made when visiting the opticians,

‘High levels of anxiety with using the equipment & being close to the optician looking in my eyes, selective mutism (unable to talk in certain situations/with certain people). I use a text to speech app to say the letters I can read.’

How does your condition affect you when you see a Dentist:



As with GPs and hospitals, most people said that their diagnosis affects the 'a lot' when visiting a dentist. The reasons for this were categorised as follows:



Again, with the exception of the miscellaneous answers, the responses ranked as follows: creates anxiety 16.7%. lack of knowledge about diagnosis 10.4%, I need

someone to support me 10.4%, struggle with the waiting room/environment 10.4%, struggle to communicate/express myself 7.3%.

The answers we were unable to categorise included, sitting in the chair (2 people) and fidgeting (2 people).

As with opticians, we also received some positive comments regarding this service:

'My dentist understands my needs and adapts treatment to suit.'

'Dental phobia. Touching phobia. But after a lot of searching found 1 good dentist who is understanding.'

'However, our dentist tried his best to support our son he takes the whole family in and he lets our son choose who goes in which order.'

'I have explained to the dentist about slowing pace, one or two instructions at a time, and bright lights and they have been very accommodating.'

'My oral hygiene isn't great due to ADHD. I can't abide flossing. Since explaining this to my dentist, he has been much more accepting and kinder in the way he deals with me.'

'Although I have put 'a lot' I normally get on with my dentist who listens and understands my needs...I have had an issue recently where I had to see a different dentist...'

'In general, the environment is good and consistently are able to see the same dentist is a help.'

We also received positive responses about the Community Dentist:

'Things are better now that I'm being seen by the community dentist at Ryecroft. They work to adapt to my needs and are patient.'

'Must say the community dentist is great…'

However, some people were having issues accessing such a dentist:

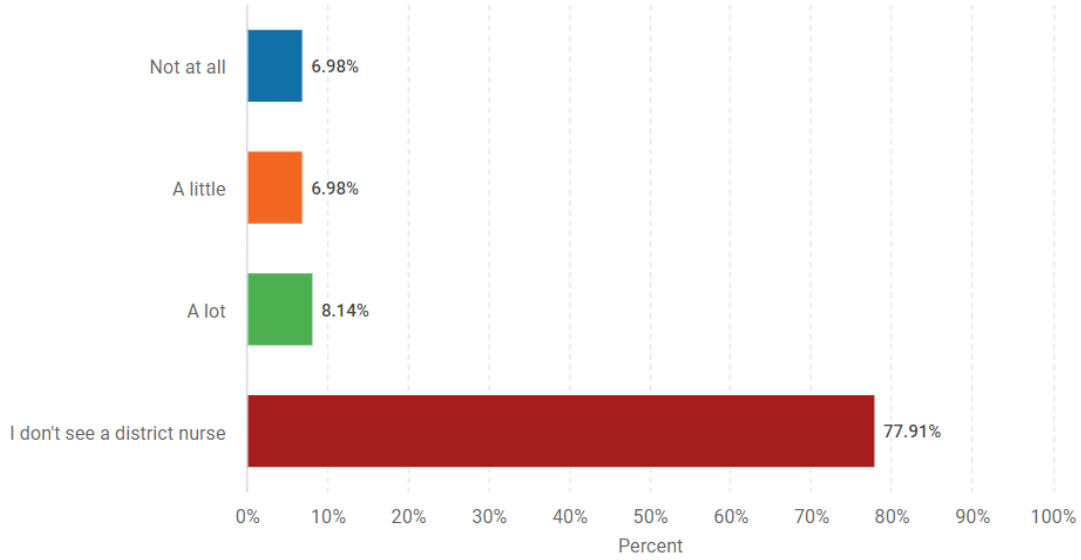
'Again, can't go because if I tick when having treatment, the dentist won't see me. I have tried to access Ryecroft special dental services, and I do not fit their criteria?'

'Our dentist cannot get to look in my child's mouth and we are having to take them every 3 months to keep trying. Our dentist tried to refer to the special needs dentist team however were told unless there is work to be done specifically, they cannot see my child.'

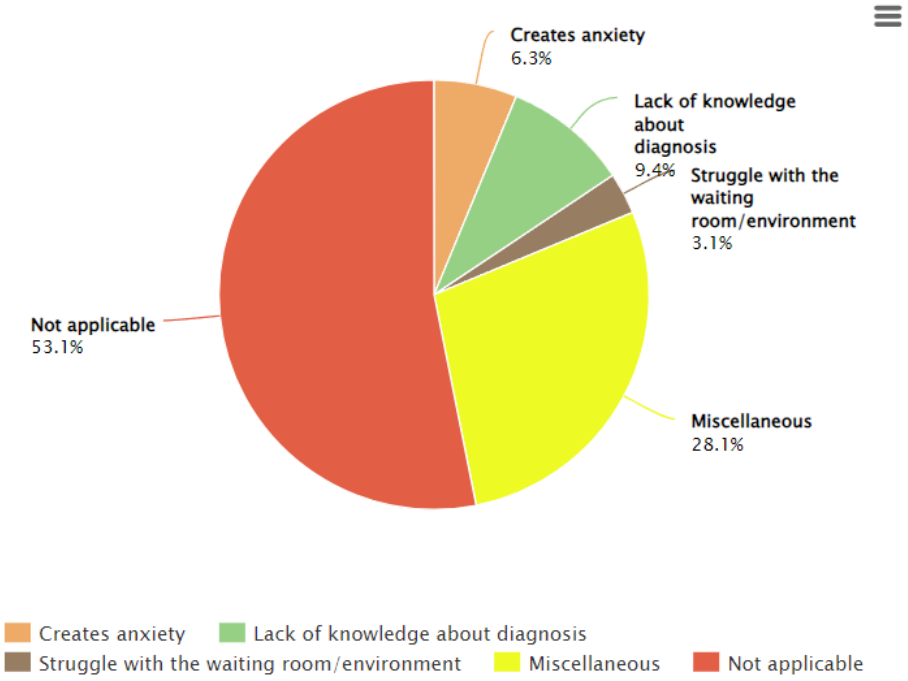
'Local one no longer NHS and so no autism friendly dentist nearby.'

'I asked to be referred to a specialist dentist and they said they won't do that.'

How does your condition affect you when you see a District Nurse:



As can be seen most people do not see a District Nurse, and of those that do, the responses were evenly matched. However, we again collated the reasons for the responses into the following categories:



The categories of response were fewer here, but, excluding 'not applicable' and 'miscellaneous', the responses were 'lack of knowledge about diagnosis 9.4%, creates anxiety 6.3%, and struggle with the waiting room/environment 3.1%. Again, it would have been useful if we could have found out exactly what was anxiety provoking about the situation.

The miscellaneous responses included not knowing what to expect and not knowing the person. One person said that:

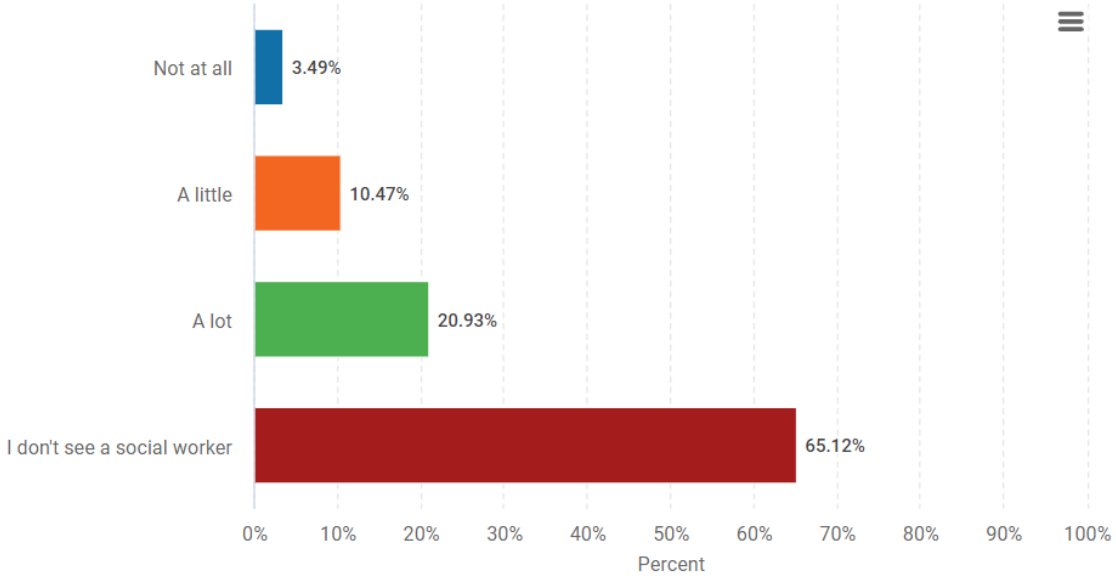
‘Don’t want to see anyone due to the judgement made about me. There is no understanding of Tourettes. People watch TV and see the ‘Undatables’ and assume we are all the same.’

However, two good comments related to visits in their home:

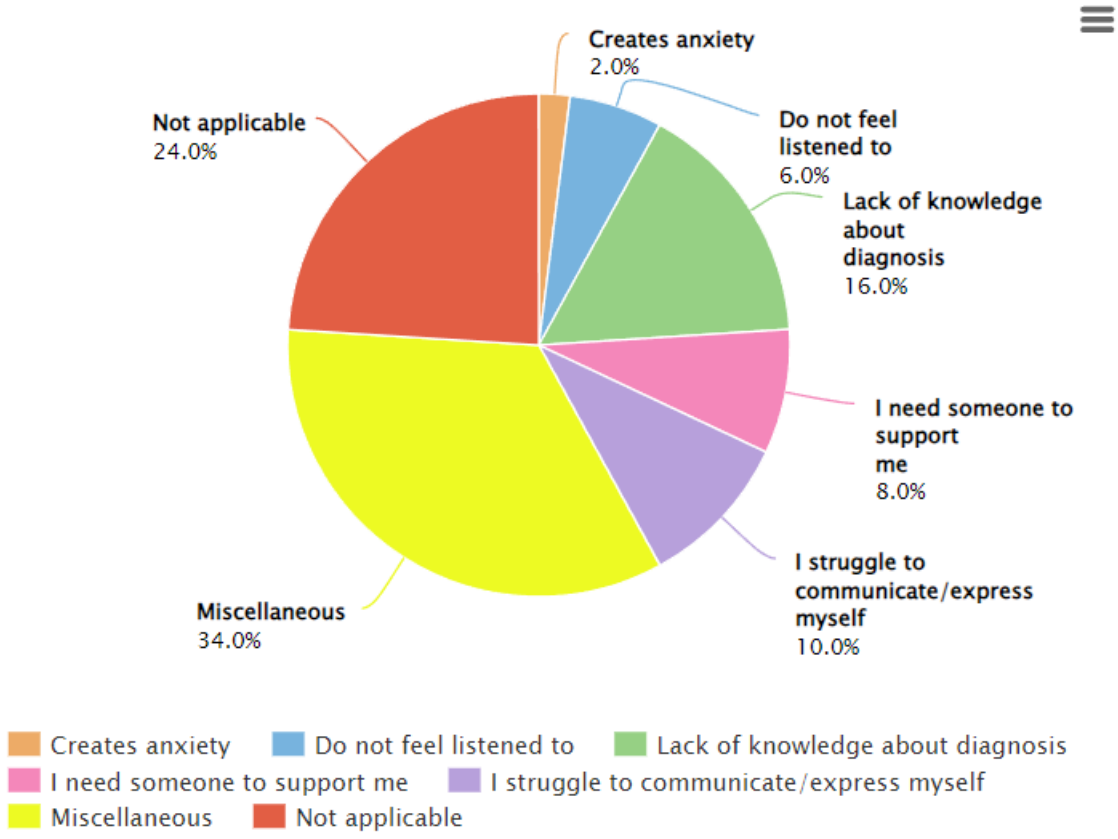
‘The paediatric district nurses have been brilliant with my child, and it works better him being able to be seen in his own home.’

‘In the past had this service for a period of time but the service came to the home and was generally very good.’

How does your condition affect you when you see a Social Worker?



As with a District Nurse, most people did not see a Social Worker. Of those that did, their condition affected them 'a lot'. The reasons are grouped as follows:



Again, lack of knowledge about the diagnosis (16%), struggle to communicate/express myself (10%) and I need someone to support me (8%) were high on people's reasoning. Of the responses we were unable to categorise, people said not knowing them (2 people), being anxious of unexpected changes/the unexpected (2 people), lack of

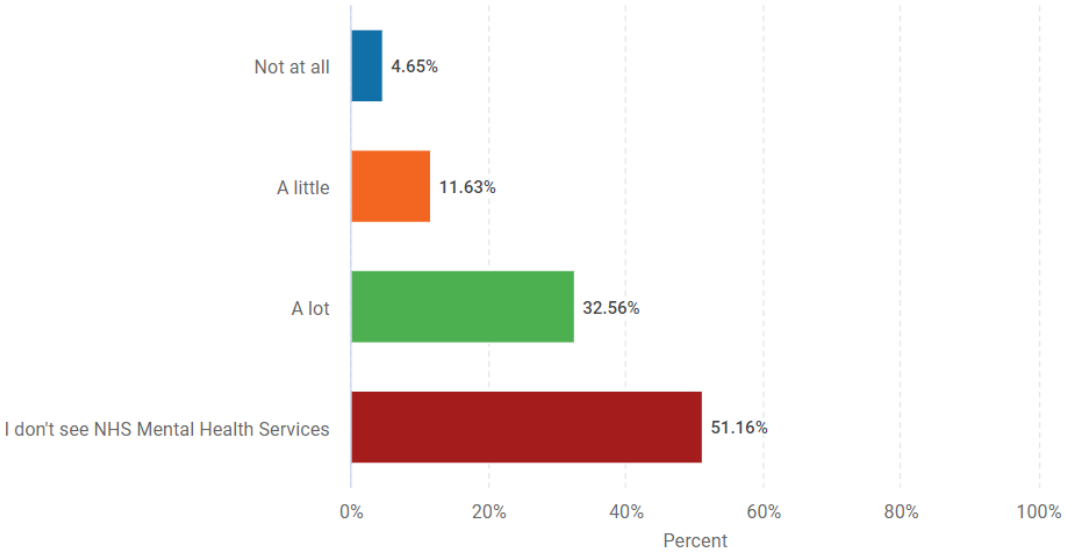
understanding (2 people). Three people also told us about the difficulties in obtaining a Social Worker:

'No real help or social workers available for level 1 ASC, we're just expected to mask and get on with it despite the negative effect it has on our mental health.'

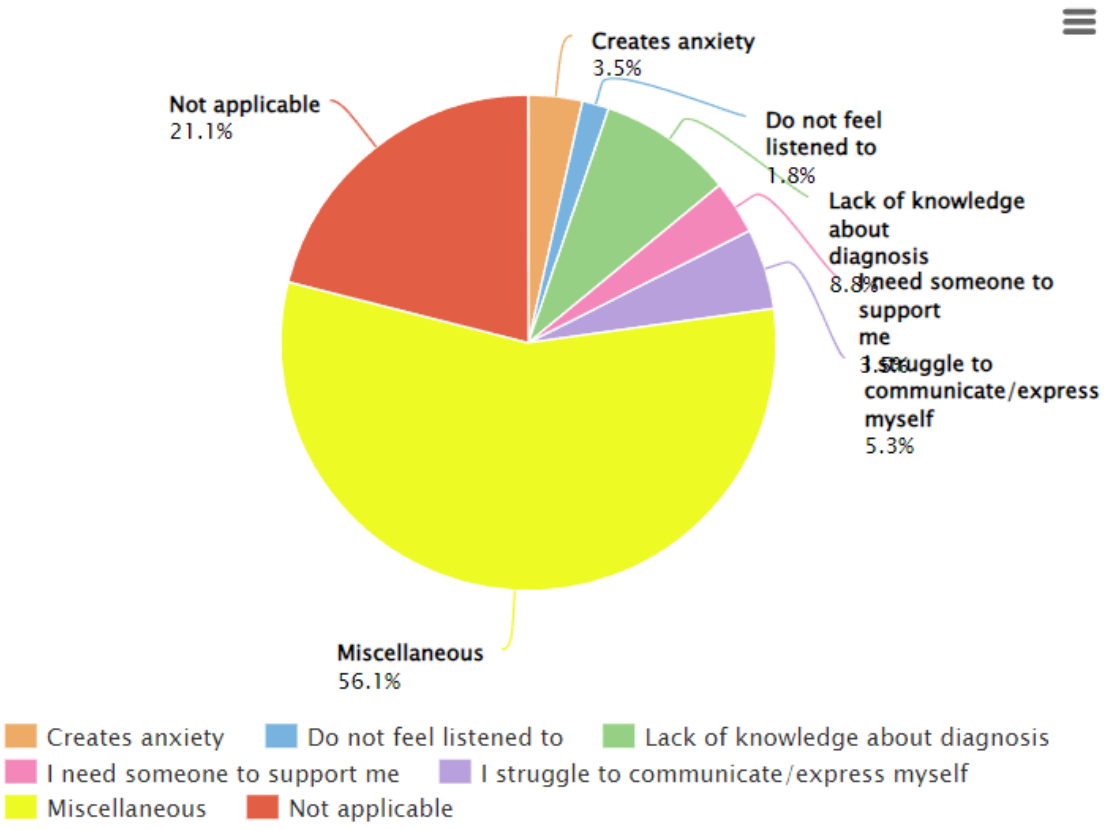
'Waiting the hear back from social worker but learning disabilities is not correct category for high functioning autism. There seems to be no category for high functioning autistic people with secondary conditions.'

'Not for want of trying to get a disability social worker.'

How does your condition affect you when you see NHS Mental Health Services, i.e. the Well-being Service or a Mental Health Resource Centre:



Although a majority of people did not access mental health services, those that did found their condition affected them 'a lot', and the reasons were as follows:



Once more, lack of knowledge about diagnosis (8.8%), struggle to communicate/express myself (5.3%), need someone to support me (3.5%), and creates anxiety (3.5%), were the most popular reasons.

Amongst the answers we felt didn't fit into a category, was the fact that it is difficult to be seen by mental health services, difficulty speaking with strangers, and being afraid of change.

There were also comments which points to the need for a specific mental health service for those with co-occurring needs:

'The problem is there are no specific services for ASC unlike learning disabilities, so you just fall down the gap. Their understanding of ASC is minimal and quite often they make you feel worse as they just don't get where you are coming from.'

'From past experiences they all seem a waste of time. Offer Cognitive Behavioural Therapy (CBT) which doesn't work, talking therapy which doesn't work when you don't speak the same as them and your alexithymia makes it difficult to word your emotions at the best of times, let alone when they insist on doing sessions over phone and my sensory issues and ADHD make it really difficult to focus.'

'I always feel I get discharged from these services just as I'm getting comfortable enough to make proper use of them.'

'Refuse to go. Useless and fail to understand me holistically. I'm just pathways! But I'm not. One condition affects another.'

'Mental health services are not autism friendly. Offering a psychologist appointment or occupational therapist every 8-12 weeks is not fit for purpose. Bit like offering an antibiotic to take every 8-12 weeks! Simply will never work!'

'Mental health services are unable to be flexible in working with my son's autism. Especially when he was unable to leave the house. Services are not accommodating at all in regard his autism.'

'Limited support for adults with ADHD. Not sure which service I fit into not a specialised service.'

We were also told that 'Secondary mental ill health is commonly present but Is not the primary condition and so services aimed at mental ill health mostly don't work as it doesn't treat the primary condition and to make a difference to these people's lives their primary conditions need to be treated so that their secondary conditions decrease…most can't do group sessions and a lot of the things they offer are aimed at people without their conditions and they find that they don't work for them.'

‘Their service don’t have much experience of my needs and I don’t qualify for the Adult LD service.’
‘Discharged not happy – had CPN but told he can’t have support as he has autism and no other conditions…secondary mental health are not fit for purpose for people with autism.’

The positive comments regarding mental health services were that:

‘Relieved got someone to talk to.’

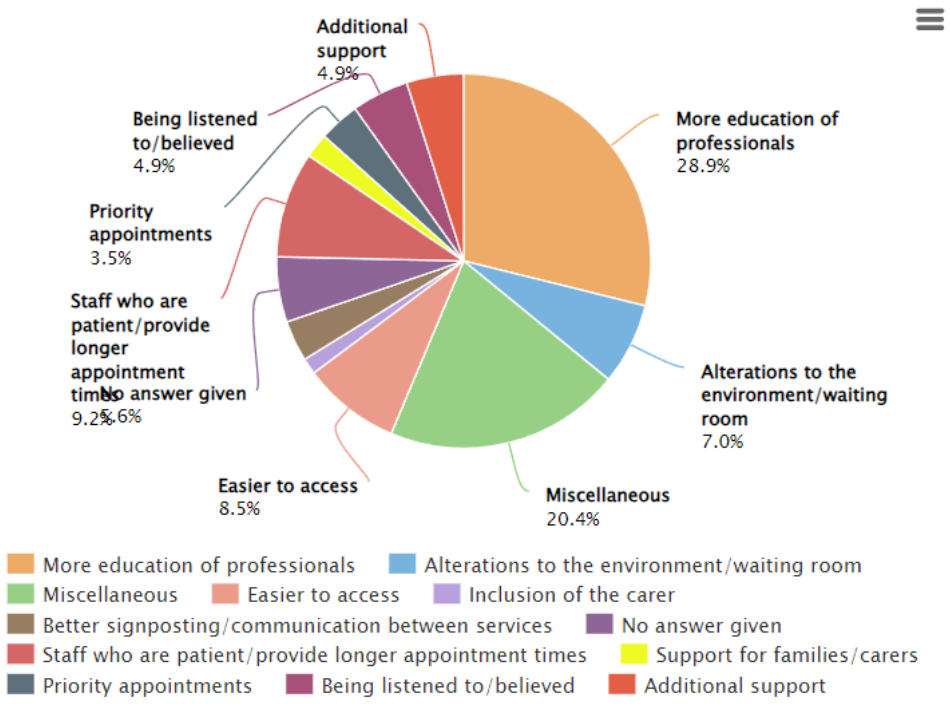
‘Not had to access them for years, but when I had CBT was very fortunate to have a supportive co-therapist.’

‘Initially it was a lot as it seriously affected my daughter as she did not want to go into the room or speak with the psychiatrist. Over time it has become easier as she sees the same psychiatrist at the same location, so it is more predictable. The psychiatrist had developed a better understanding of my daughter so doesn’t put her under pressure to speak about her difficulties as this just overwhelms her.’

‘Psychiatrist now does home visits as unable to cope with travel to clinic.’

‘The actual appointment with the Wellbeing Service seems to not be a problem as the counsellor seems to be perceptive of needs.’

We then asked people what would improve access to health and care services for them. As with previous questions, we wanted to know what people really thought, so the question was open ended. The responses have been grouped into categories by Healthwatch Staffordshire.



For ease of reading, the responses were as follows:

More education of professional 28.9%
Staff who are patient/provide longer appointment times 9.2%
Being listened to/believed 4.9%
Easier to access 8.5%
Alterations to the environment/waiting room 7%
Additional support 4.9%
Better signposting/communication between services 3.5%
Priority appointments 3.5%
Support for families/carers 2.1%
Inclusion of carer 1.4%

Again, amongst the miscellaneous answers were, shorter waiting times (2 people), seeing the same health professional (3 people), having someone ask at the start of the appointment what they can do to improve the consultation/complete a form asking

the same (2 people), being able to be seen by services for as long as the patient felt necessary, home visits, video and telephone appointment (3 people), professionals who will do what they have promised (2 people), a helpline, plus;

'Separate waiting rooms that are more sensory aware, other people are not always understanding and can be critical…'

'Having access to communication (AAC) devices like text to speech apps or similar available for those with communication difficulties would help people like me.'

'As a disabled and learning difficulties adult with an EHCP (Education Health Care Plan) I would prefer to be treated under children's services until 23. Or for there to be a young adult's service or hospital wards. To help with transition from children's services to adults. I would also like to have access to the community paediatrician until 23 and not signed off at 18.'

'I don't know that there's an answer to this question however it is often the same as it has always been – greater awareness, more patience and empathy, larger time slots for ADHD children/adults etc.'

'Better understanding of autism in girls and women. Understanding that stereotypes of autism are different in female presentation. Offering quiet waiting areas. Longer appointment and flexibility. For example, a dentist examining a child in a normal chair with no bright lights to build trust and confidence.'

'A quieter room and a slightly longer appointment.'

'I feel if you have high IQ with ASC you are discriminated against within services. If you have Learning Disability, the services know that you will always have LD so why isn't there something for ASC.'

‘To have a system when booking appointments that flags up this person may need support.’

‘A system where a red flag comes up on the medical file just like with an allergy. Where there is a red note such as ‘This child has autism, severe anxiety and sensory difficulties.’ Please use a calm manner with this patient and be aware that she may not be able to speak with you and tell you what the problem is or that you are hurting her when she is examined…’

‘Also, a red note that the child has difficulty with the environment due to anxiety and sensory issues so if possible, should be seen quicky and the waiting room environment can cause them to become overwhelmed and shut or meltdown.’

These comments regarding ‘red flags’ are pertinent as ‘NHS England commissioned NHS Digital to create a Reasonable Adjustment Flag…for the benefit of all patients covered by the definition of impairment under the Equality Act with the requirement that by 2023/24, a ‘digital flag’ in the patient record will ensure staff know a patient has…autism.’[75]

Fix the system and ensure guidelines are followed.

[75] Living my Best Life with Autism, Stoke-on-Trent Strategy for Autistic Children, Young People and Adults, 2023-2026, page 26

Recommendations

Considering all the reasons people find accessing the different services difficult, together with the suggestions people made for improving services, we make the following recommendations:

Education of Professionals

In the last pie chart, we believe that the tops three needs (more education of professionals 28.9%, staff who are patient/provide longer appointment times 9.2% and, being listened to/believed 4.9%) would all be improved if staff were educated about what it is like to have a co-occurring need. 'Lack of knowledge' was also the top or second most common reason for people's diagnosis' affecting them when attending all services.

In July 2022, the Health & Social Care Act made it mandatory for '...all registered health and social care providers [to be] required to provide training for their staff in learning disability and autism, including how to interact appropriately with autistic people and people who have a learning disability. This should be at a level appropriate to their role'[76] With reference to this, the Staffordshire & Stoke-on-Trent Integrated Care Board (ICB) is now rolling out Oliver McGowan Training[77] to all its staff. We understand that it is early days in providing this staff training, so would need to ask people if staff are more understanding once all professionals have been trained. We are also mindful that this training only applies to autism and learning disabilities, so would recommend that training for a wider range of neurodiverse conditions be provided.

Separate waiting rooms/areas

The environment and waiting area was something that many respondents said caused them difficulty. When researching this topic, Healthwatch Staffordshire were able to view a Patient Experience film produced by University Hospital Derby (UHDB). This included someone speaking about their experience of having autism and being in A & E. In the film, the patient speaks about having a 'safe space' where people with autism can go and gives the example of places having separate rooms for breastfeeding mothers.

[76] Training staff to support autistic people and people with a learning disability - Care Quality Commission (cqc.org.uk)
[77] The Oliver McGowan Mandatory Training on Learning Disability and Autism - elearning for healthcare (e-lfh.org.uk)

Good Practice

Health Passport

The Health Passport was a result of LeDeR Reviews. These Reviews are carried out when people who have a learning disability and/or autism die and looks at the care they received 2 years prior to their death. As Staffordshire and Stoke-on-Trent Integrated Care System's (ICS) website explains, 'The Staffordshire and Stoke-on-Trent NHS Health Passport is for anyone with a learning disability, learning difficulty or autism. It is an important document which tells NHS staff about a person's needs such as, medication, personal details and how they like to communicate.[78]

The Health Passport can be downloaded from here - https://staffsstokeics.org.uk/your-health-and-care/learning-disability/health-passport/

Although the Health Passport is a good idea, we did hear one note of caution from one professional, sometimes 'hospital passports are ignored are we find adjustments are not made particularly in hospitals…e.g. not waiting for family to be present before explaining procedures/actions to client. Not allowing family to remain with them, not adhering to hospital passport guidance on communication or wishes.' Perhaps this explains why many people said that having someone to support them and struggling to communicate/express themselves were still high on the reasons why people found attending services difficult.

Bluebell & Tulip Cards

The Bluebell card was the concept of Dr Catherine Harris from Furlong Medical Centre in Stoke-on-Trent, and is referred to in the LeDeR Annual Report 2022/23, which describes it as '(a card which is provided to individuals registered at the practice/PCN that have an LD diagnosis, this easily helps staff identify that reasonable adjustments are required to be made when booking an appointment, communicating etc)…a simple but effective way of informing staff that a person has a learning disability or is an autistic person.'[79]

[78] https://staffsstokeics.org.uk/your-health-and-care/learning-disability/health-passport/

[79] Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR) programme, Annual Report 2022/23, page 14

The Tulip Card is used for the same purpose within Newcastle North Primary Care Network (PCN) and can be seen below.

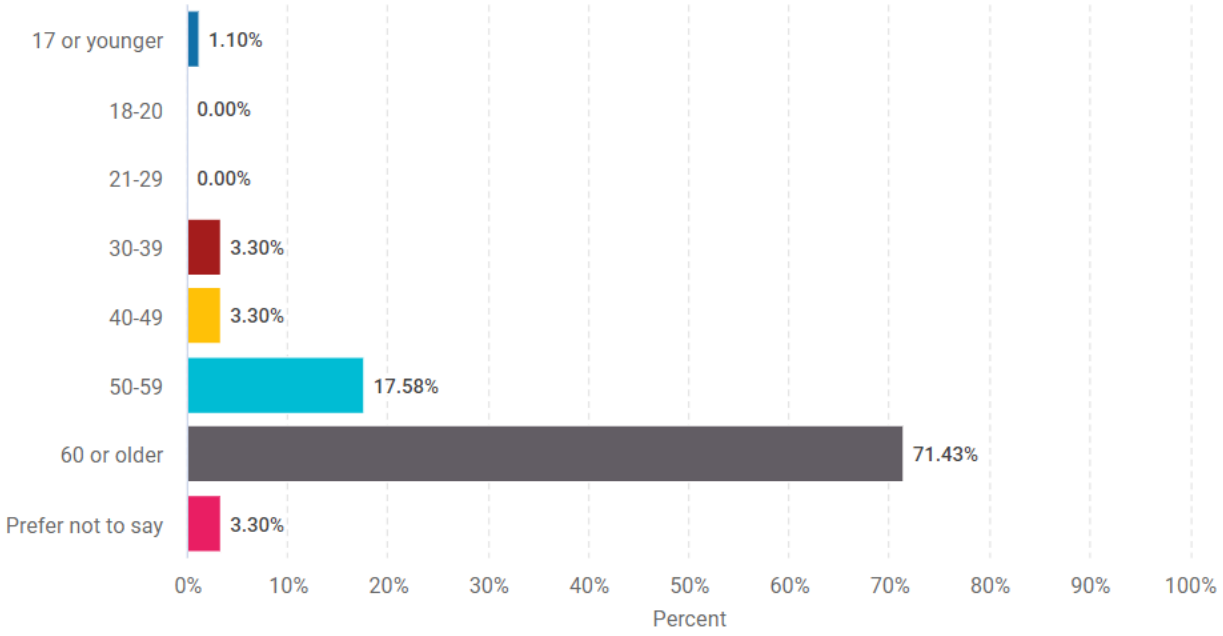
University of North Midland's Visiting Policy

'...we are committed to continue supporting compassionate visiting, allowing more individualised visiting arrangements where required, for example a patient may...Require assistance with their communication or to meet their health, emotional, religious or spiritual care needs...'[80]

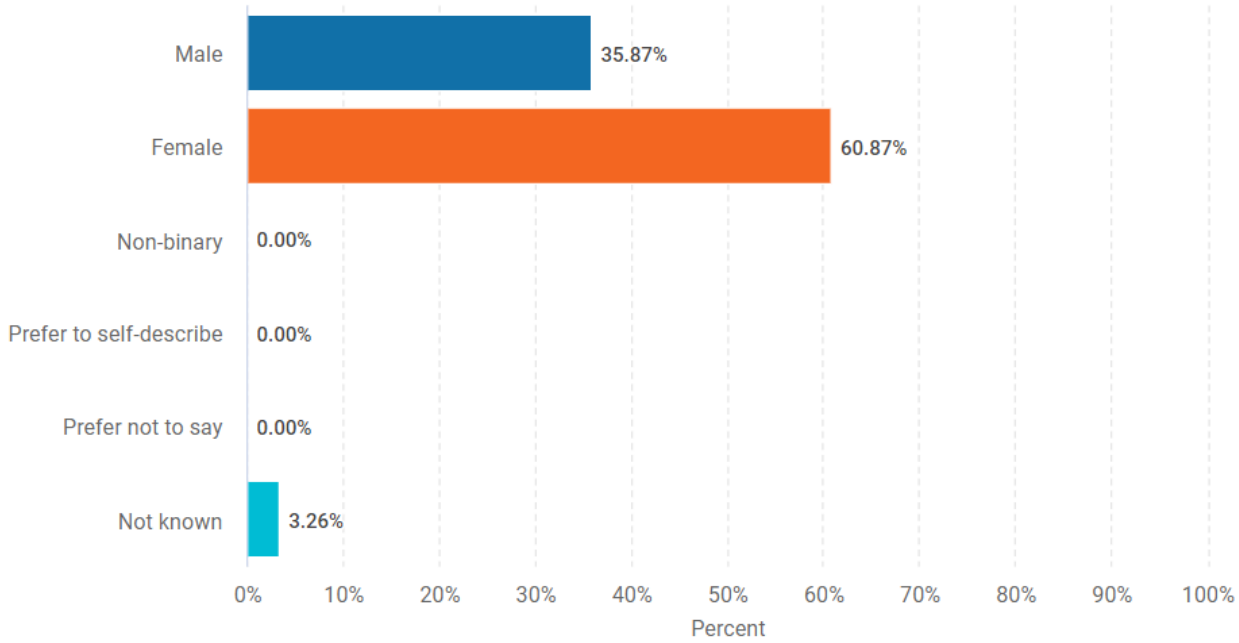
[80] Visiting at UHNM

Appendix A: Demographics of Rurality Respondents

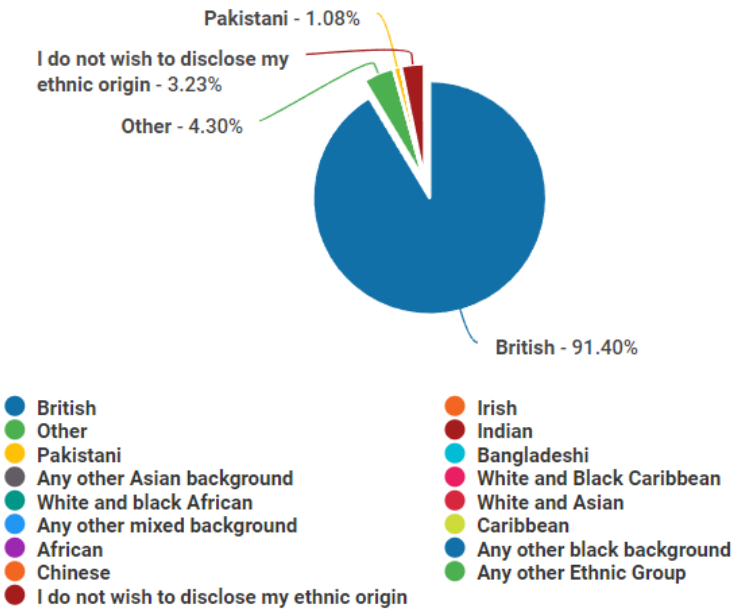
Please tell us your age.



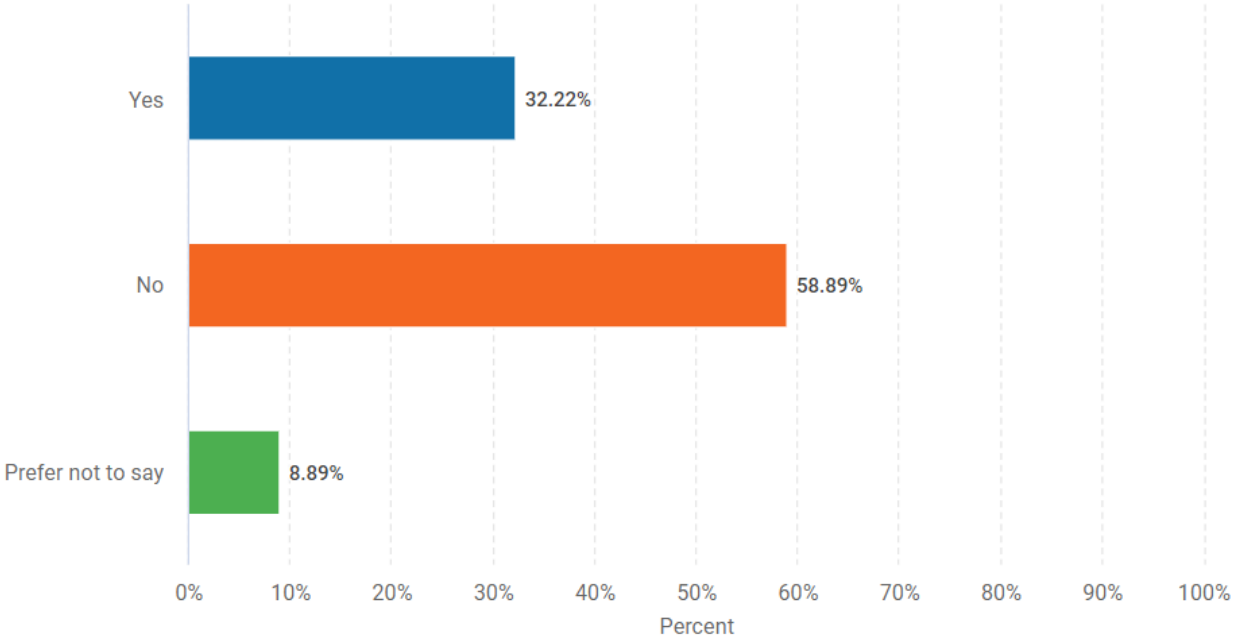
Please tell us your gender.



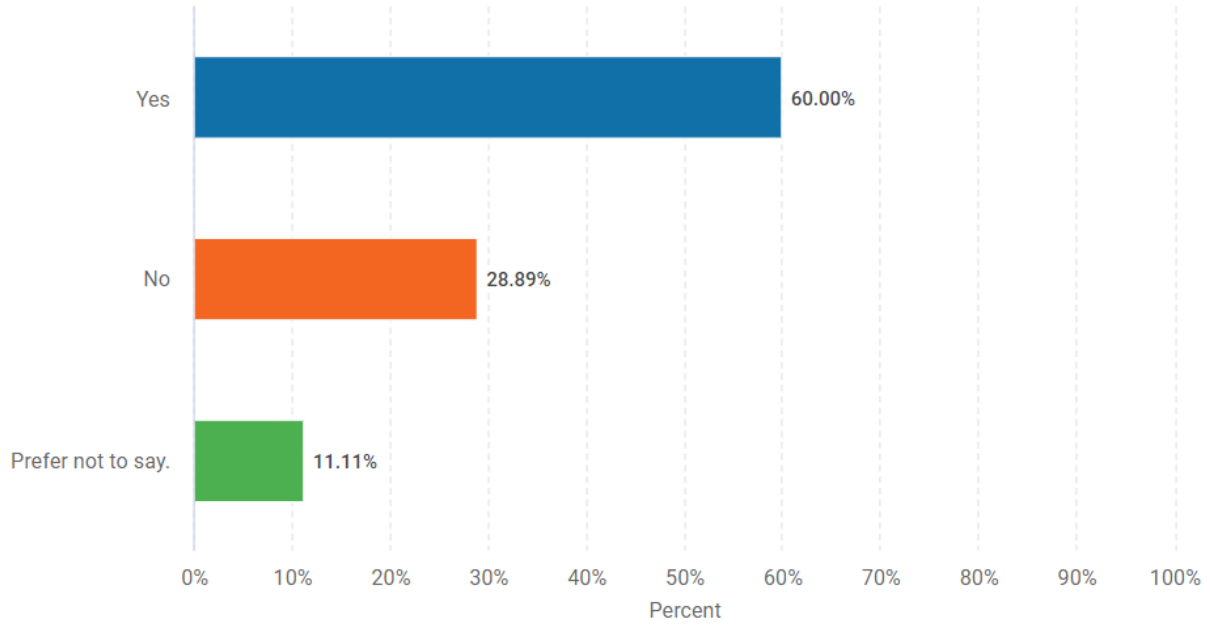
Please tell us your ethnicity.



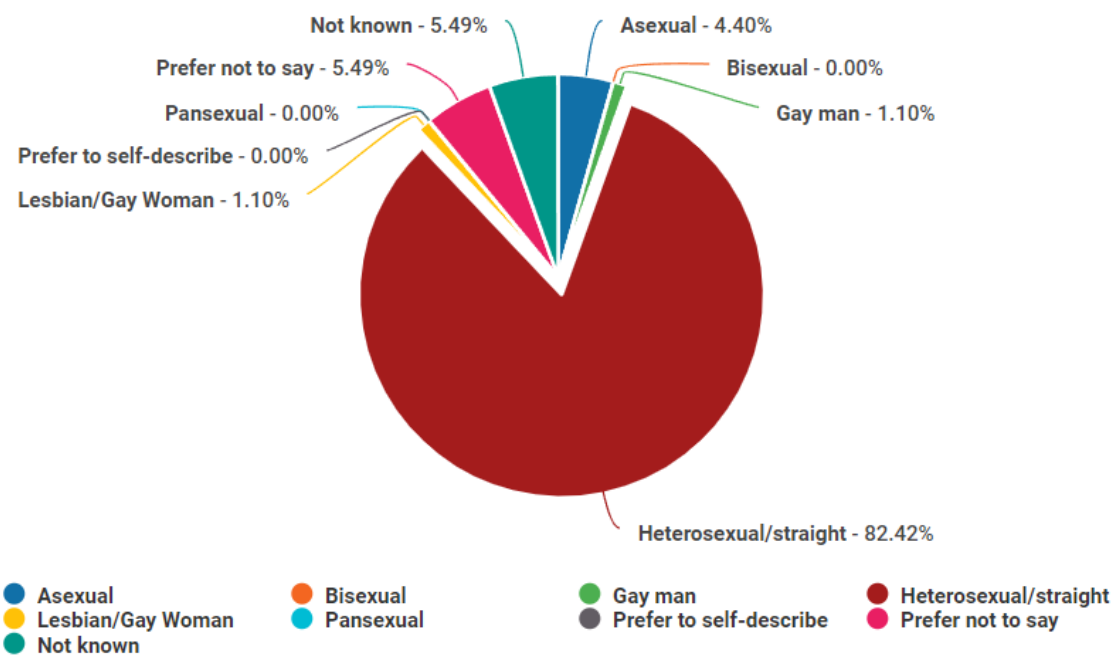
Please tell us if you regard yourself as having a disability.



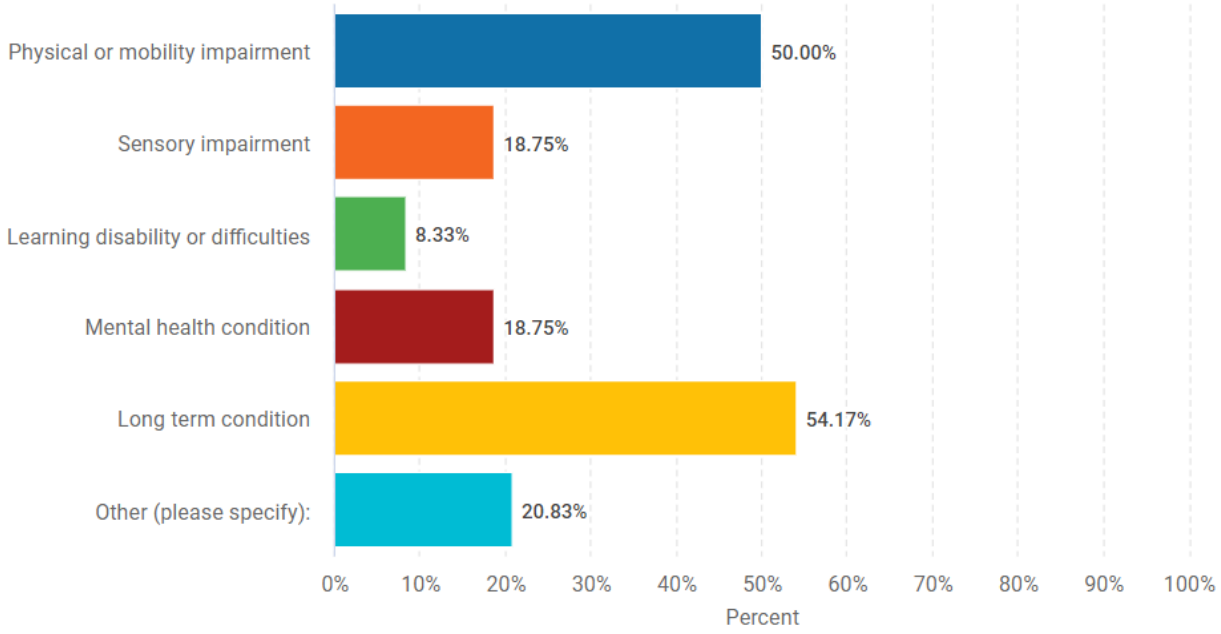
Do you consider yourself to have a long term condition?



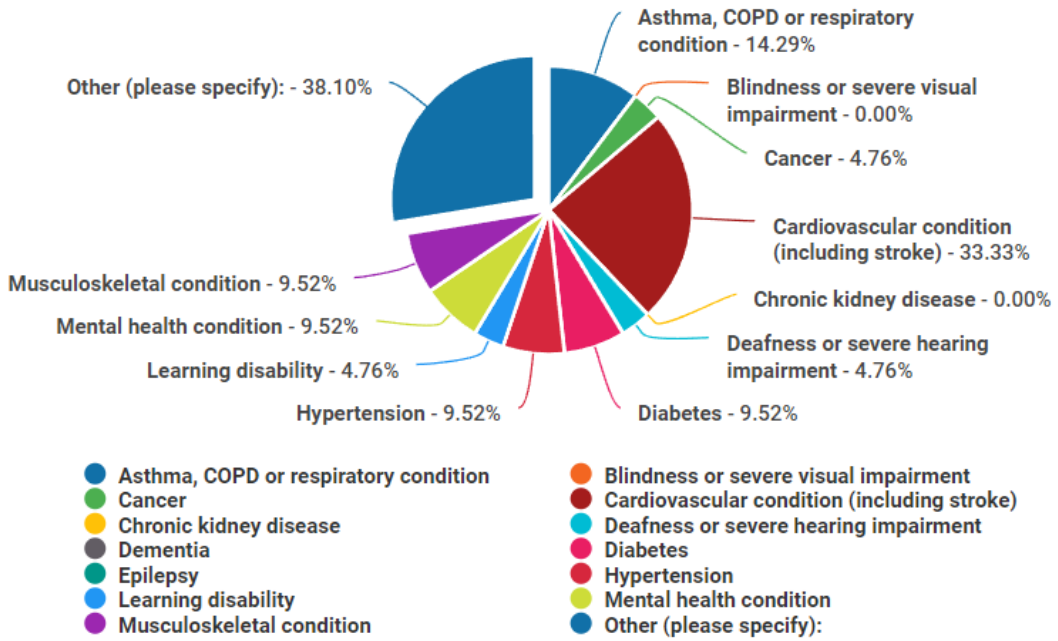
How would you describe your sexual orentation?



If you have a disability please tell us what it is (choose all that apply)

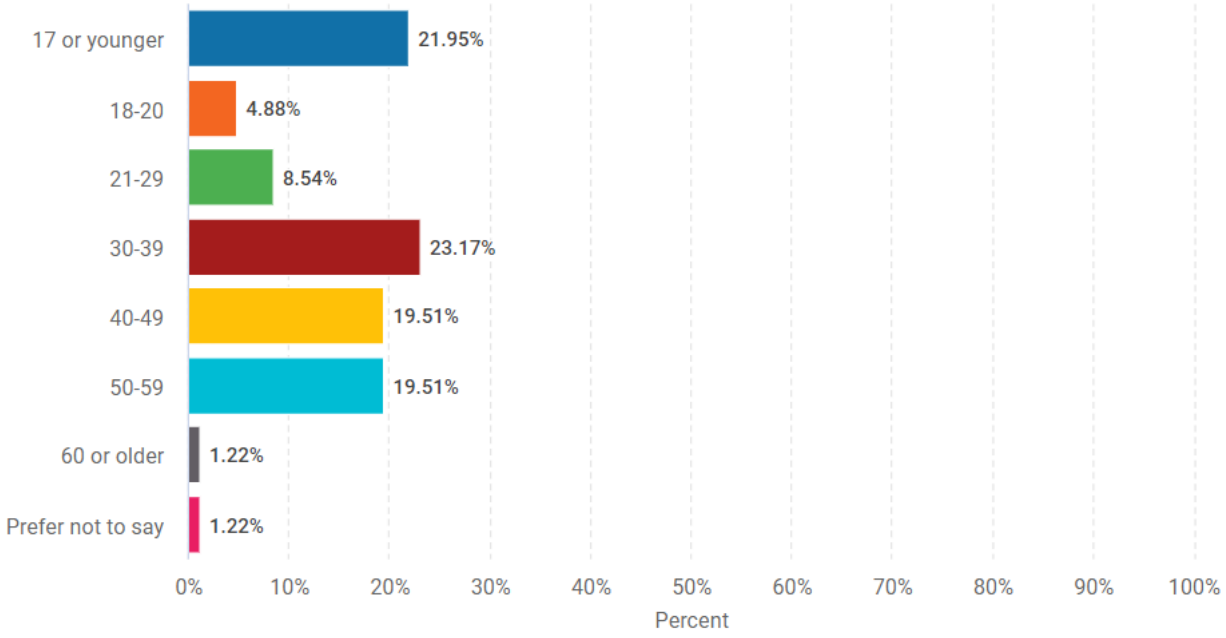


If you have a long term condition, please tell us what it is (please select all that apply)

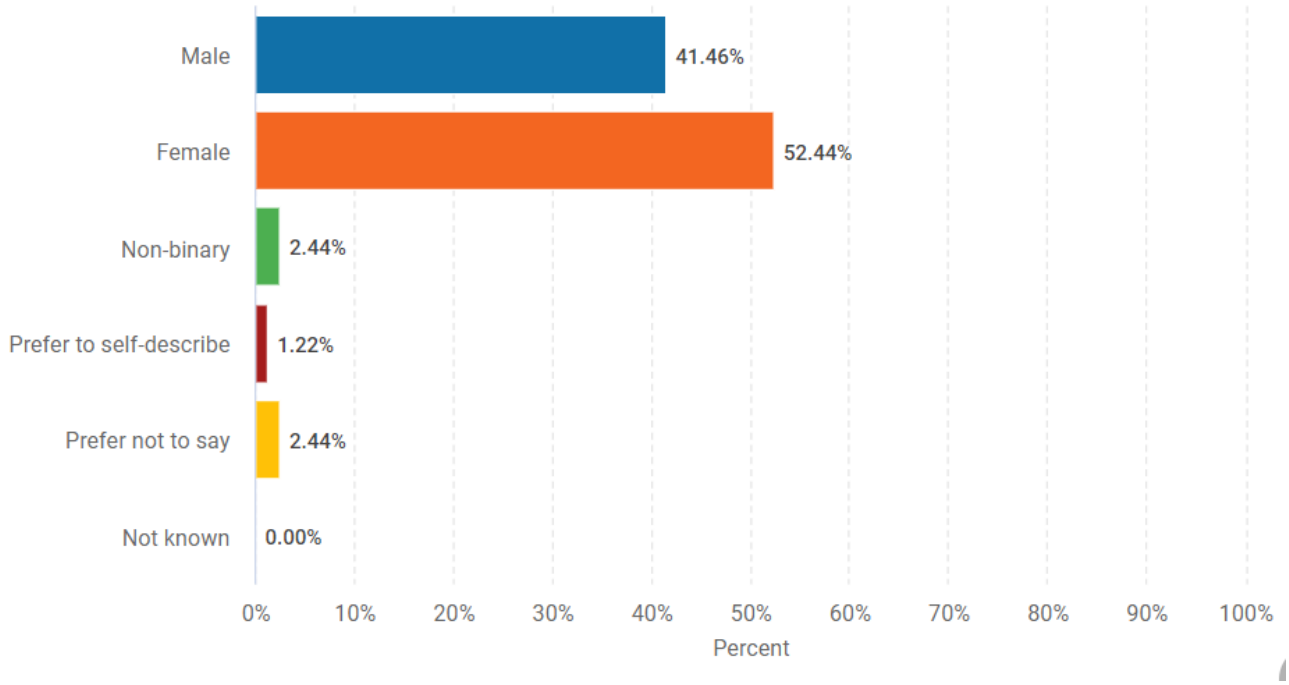


Appendix B: Demographics of Co-occurring Needs Respondents

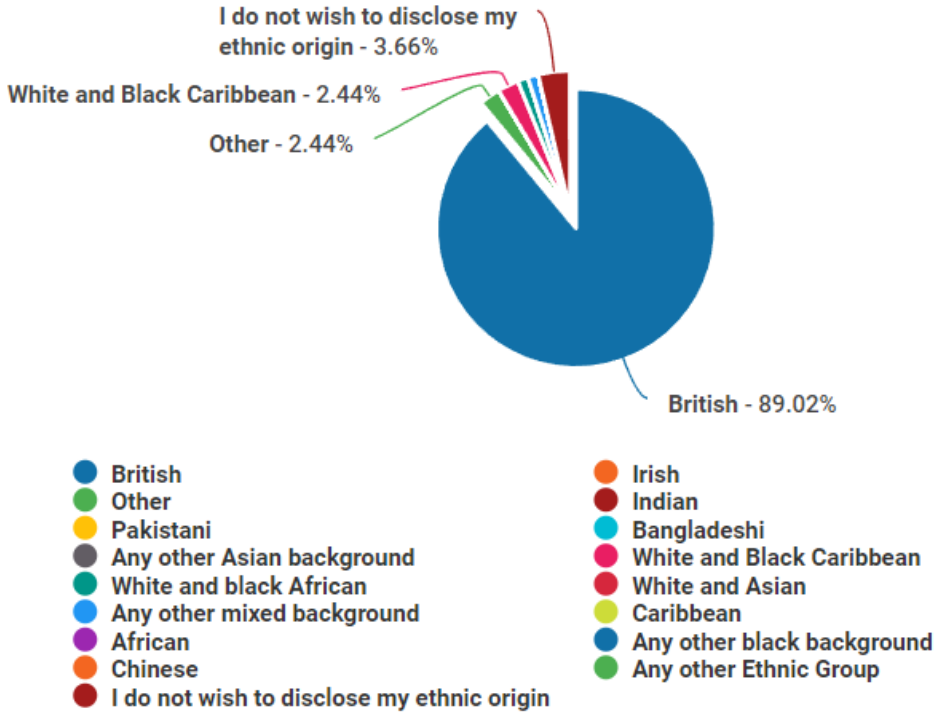
Please tell us your age.



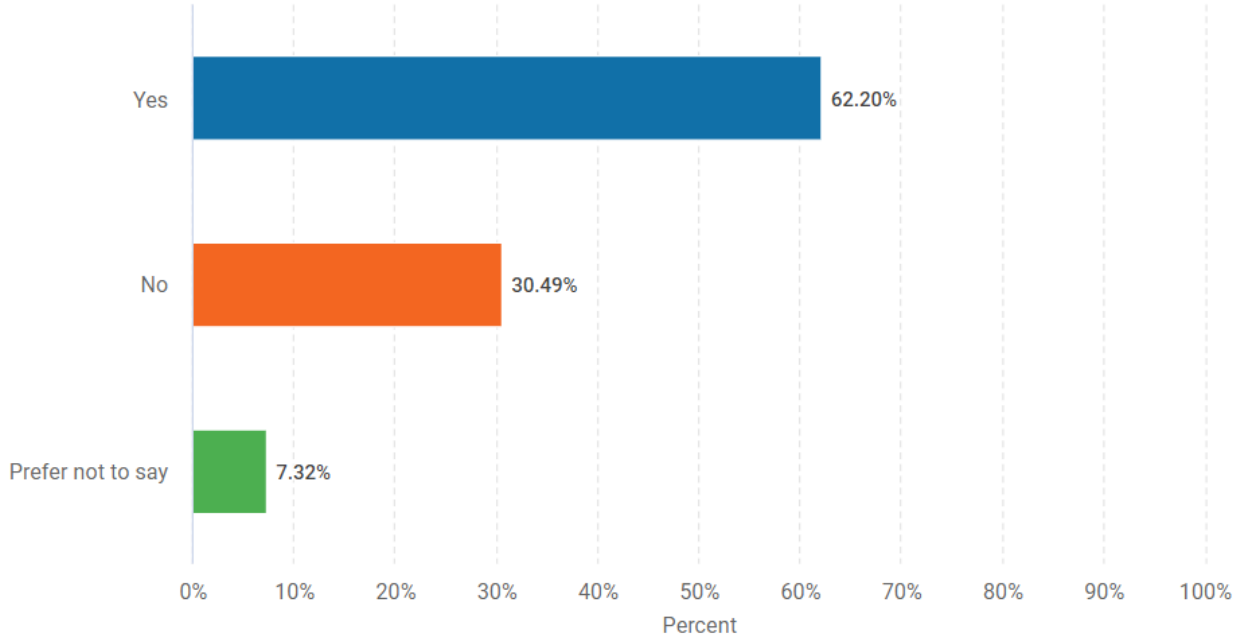
Please tell us your gender.



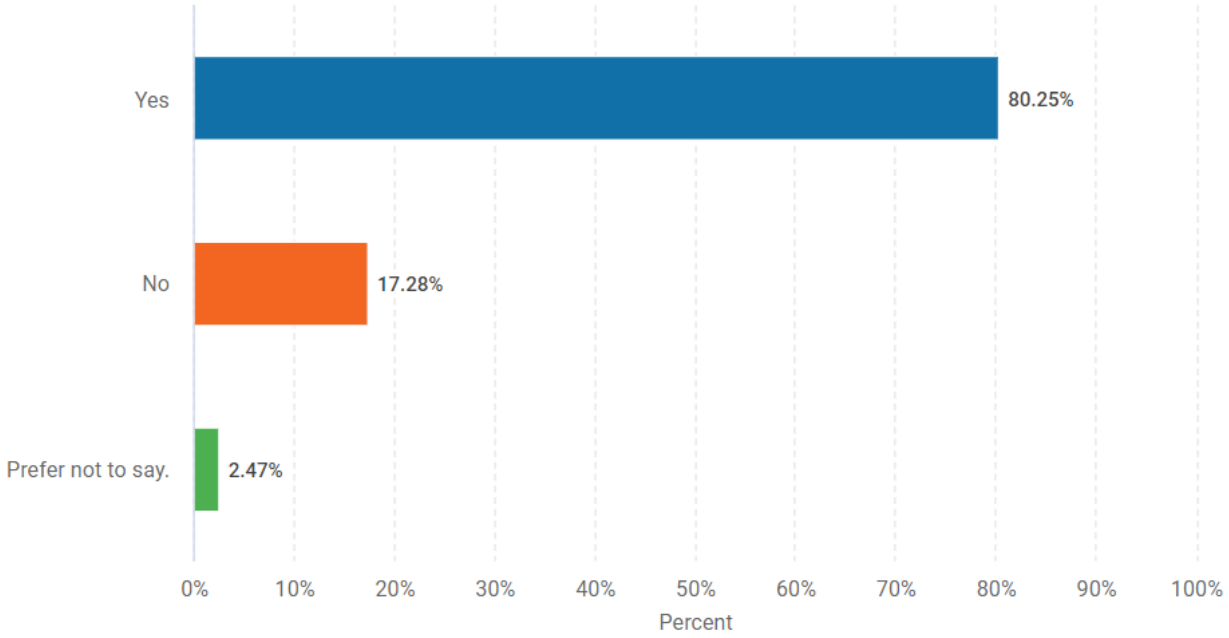
Please tell us your ethnicity.



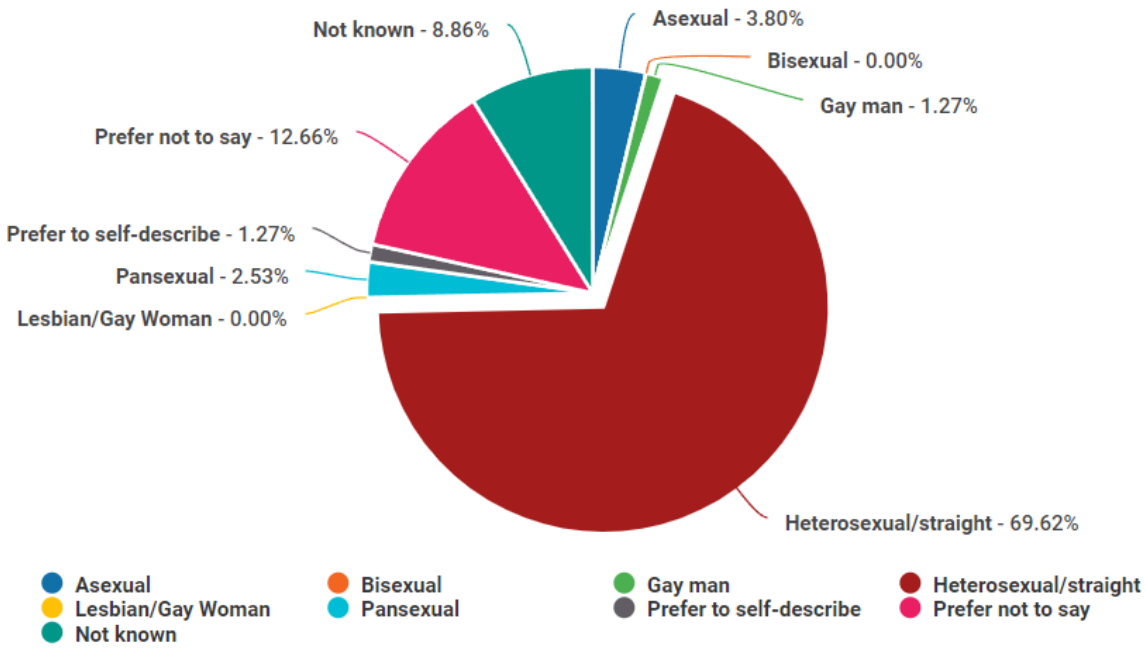
Please tell us if you regard yourself as having a disability.



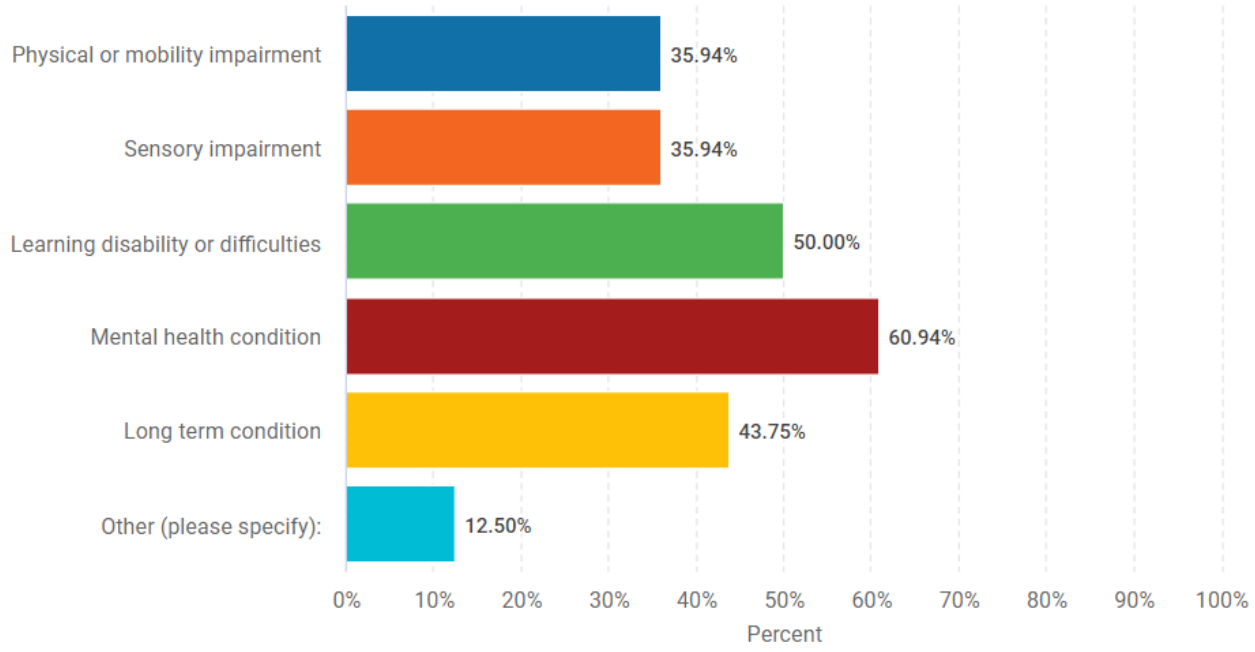
Do you consider yourself to have a long term condition?



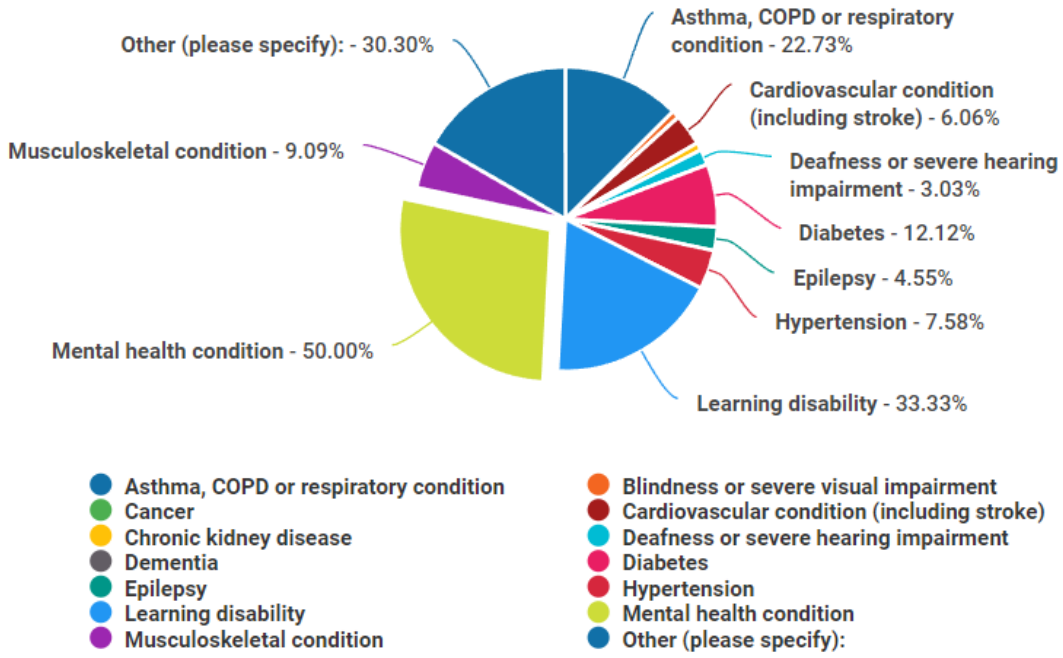
How would you describe your sexual orentation?



If you have a disability please tell us what it is (choose all that apply)



If you have a long term condition, please tell us what it is (please select all that apply)



Appendix C: Rurality Survey

Healthwatch Staffordshire is looking into how living in a rural area can affect a person's access to health and social care services. We would like to invite you to take our survey.

You may answer the survey anonymously, or you can give us your contact details at the end if you would like to discuss anything further. We will not use your details for any other purposes.

The views collected by the survey collated into a report which will be published at the end of 2023. Your name will not be attached to specific comments in our reporting unless you ask us to do so. Please send your responses to us before the end of 31st August 2023.

1. What is your nearest village or town? *
2. Do you consider this a rural area? *
   - Yes
   - No
3. How far do you have to travel to visit your GP? *

2 miles or less3-5 miles6-10 milesMore than 11 milesI don't use this service

4. How far do you have to travel to visit a Hospital? *

2 miles or less3-5 miles6-10 milesMore than 11 milesI don't use this service

5. How far do you have to travel to visit an Optician? *

2 miles or less3-5 miles6-10 milesMore than 11 milesI don't use this service

6. How far do you have to travel to visit an Dentist? *

2 miles or less3-5 miles6-10 milesMore than 11 milesI don't use this service

7. How far do you have to travel to visit a Pharmacy? *

2 miles or less3-5 miles6-10 milesMore than 11 milesI don't use this service

8. How far do you have to travel to visit a Health Centre? *

2 miles or less3-5 miles6-10 milesMore than 11 milesI don't use this service

9. If you travel more than 11 miles for a service, how does this affect you? *
10. Which of the services below would you like in your area? *
    - GP
    - Optician
    - Dentist
    - Care in your own home
    - Pharmacy
    - Health Centre
    - Other (please specify):
11. Please tell us what difference it would make having these services closer to you: *
12. Do you have access to your own transport? *
    - Yes
    - No
13. What three things would improve your access to health and social care services (please state). *

1 *

2 *

3 *

If you would like to talk to us in more detail about your answers, please provide your name and preferred contact details below.

14. Please tell us your age.

- 17 or younger
- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older
- Prefer not to say

15. Please tell us your gender.

- Male
- Female
- Non-binary
- Prefer to self-describe
- Prefer not to say
- Not known

16. Please tell us your ethnicity.

- **White**
- British
- Irish
- Other
- **Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background
- **Mixed**
- White and Black Caribbean
- White and black African
- White and Asian
- Any other mixed background
- **Black or Black British**
- Caribbean
- African
- Any other black background
- **Other Ethnic Group**
- Chinese
- Any other Ethnic Group
- I do not wish to disclose my ethnic origin

17. Please tell us if you regard yourself as having a disability.

- Yes
- No

- Prefer not to say

18. Do you consider yourself to have a long-term condition?

- Yes
- No
- Prefer not to say.

19. How would you describe your sexual orientation?

- Asexual
- Bisexual
- Gay man
- Heterosexual/straight
- Lesbian/Gay Woman
- Pansexual
- Prefer to self-describe
- Prefer not to say
- Not known

20. If you have a disability, please tell us what it is (choose all that apply)

- Physical or mobility impairment
- Sensory impairment
- Learning disability or difficulties
- Mental health condition
- Long term condition
- Other (please specify):

21. If you have a long-term condition, please tell us what it is (please select all that apply)

- Asthma, COPD, or respiratory condition
- Blindness or severe visual impairment
- Cancer
- Cardiovascular condition (including stroke)
- Chronic kidney disease
- Deafness or severe hearing impairment
- Dementia
- Diabetes
- Epilepsy
- Hypertension
- Learning disability
- Mental health condition
- Musculoskeletal condition
- Other (please specify):

You can contact Healthwatch independently of this survey if you would like to give us any feedback on your experience of Health and Social Care Services in Staffordshire. Our freephone number is 0800 051 8371 and our email address is enquiries@healthwatchstaffordshire.co.uk.

If you are completing a paper questionnaire you can return it by post to Healthwatch Staffordshire, c/o Support Staffordshire, Floor 3, Civic Centre, Riverside, Stafford ST16 3AQ.

Appendix D: Co-occurring Conditions Survey

Healthwatch Staffordshire is looking into how having a Co-occurring Condition can affect a person's access to health and social care services. We would like to invite you to take our survey.

You may answer the survey anonymously, or you can give us your contact details at the end if you would like to discuss anything further. We will not use your details for any other purposes.

The views collected by the survey collated into a report which will be published at the end of 2023. Your name will not be attached to specific comments in our reporting unless you ask us to do so.

Please send your responses to us before the end of 31st August 2023.

1. Are you answering this survey as a carer of someone with co-occurring conditions? *
   - Yes
   - No
2. Which of the following conditions do you, or the person you care for, have? *
   - ADHD
   - Autistic Spectrum Condition
   - Dyscalculia
   - Dyslexia
   - Dyspraxia
   - OCD
   - Tourette's Syndrome

If you have selected more than one condition, tell us about how one condition affects you on this survey. Complete separate surveys for any other conditions. Which condition are you telling us about in this survey?

3. How does your condition affect you when you see a GP/Doctor: *
   - Not at all
   - A little
   - A lot
   - I don't see a GP/Doctor

Why have you chosen this answer

4. How does your condition affect you when you go to a Hospital: *
   - Not at all
   - A little
   - A lot
   - I don't go to the hospital

Why have you chosen this answer

5. How does your condition affect you when you see an Optician: *
   - Not at all
   - A little
   - A lot
   - I don't see an optician

Why have you chosen this answer

6. How does your condition affect you when you see a Dentist: *
   - Not at all
   - A little

- A lot
- I don't see a dentist

Why have you chosen this answer

7. How does your condition affect you when you see a District Nurse: *
   - Not at all
   - A little
   - A lot
   - I don't see a district nurse

Why have you chosen this answer

8. How does your condition affect you when you see a Social Worker: *
   - Not at all
   - A little
   - A lot
   - I don't see a social worker

Why have you chosen this answer

9. How does your condition affect you when you see NHS Mental Health Services, i.e. the Well-being Service or a Mental Health Resource Centre: *
   - Not at all
   - A little
   - A lot
   - I don't see NHS Mental Health Services

Why have you chosen this answer

10. What would help improve access to health and social care services for you? *

If you would like to talk to us in more detail about your answers, please provide your name and preferred contact details below.

11. Please tell us your age.

- 17 or younger
- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older
- Prefer not to say

12. Please tell us your gender.

- Male
- Female
- Non-binary
- Prefer to self-describe
- Prefer not to say
- Not known

13. Please tell us your ethnicity.

- **White**
- British
- Irish
- Other

- **Asian or Asian British**
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background
- **Mixed**
- White and Black Caribbean
- White and black African
- White and Asian
- Any other mixed background
- **Black or Black British**
- Caribbean
- African
- Any other black background
- **Other Ethnic Group**
- Chinese
- Any other Ethnic Group
- I do not wish to disclose my ethnic origin

14. Please tell us if you regard yourself as having a disability.

- Yes
- No
- Prefer not to say

15. Do you consider yourself to have a long term condition?

- Yes
- No
- Prefer not to say.

16. How would you describe your sexual orientation?

- Asexual
- Bisexual
- Gay man
- Heterosexual/straight
- Lesbian/Gay Woman
- Pansexual
- Prefer to self-describe
- Prefer not to say
- Not known

17. If you have a disability please tell us what it is (choose all that apply)

- Physical or mobility impairment
- Sensory impairment
- Learning disability or difficulties
- Mental health condition
- Long term condition
- Other (please specify):

18. If you have a long-term condition, please tell us what it is (please select all that apply)

- Asthma, COPD or respiratory condition
- Blindness or severe visual impairment
- Cancer
- Cardiovascular condition (including stroke)
- Chronic kidney disease
- Deafness or severe hearing impairment
- Dementia
- Diabetes
- Epilepsy
- Hypertension
- Learning disability
- Mental health condition
- Musculoskeletal condition
- Other (please specify):

You can contact Healthwatch independently of this survey if you would like to give us any feedback on your experience of Health and Social Care Services in Staffordshire. Our freephone number is 0800 051 8371 and our email address is enquiries@healthwatchstaffordshire.co.uk.

If you are completing a paper questionnaire you can return it by post to Healthwatch Staffordshire, c/o Support Staffordshire, Floor 3, Civic Centre, Riverside, Stafford ST16 3AQ

Healthwatch Staffordshire

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Stafford

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www.healthwatchstaffordshire.co.uk