

**Staffordshire and  
Stoke-on-Trent  
Integrated Care Board**

# **PEOPLE'S PANEL SURVEY**

- 1. Repeat Prescriptions**
- 2. Learning Disability, Down's syndrome and Autism Awareness**



**September 2025**

**1**

# **Introduction**



# 1 Introduction

## 1.1 Background and objectives

This People's Panel survey invited members to share their thoughts on two important areas of healthcare and inclusion:

- experiences and views around Repeat Prescriptions
- awareness and understanding of Learning Disability, Down's syndrome, and Autism.

## 1.2 Approach

The survey was co-designed with the Staffordshire and Stoke-on-Trent Integrated Care Board (ICB) and shared to the People's Panel in August 2025.

Each questionnaire included a unique survey ID. This allowed us to:

- send reminders to people who had not yet responded
- link responses to demographic profiles for further analysis (e.g. age, location, or health condition).

### Technical testing of the survey

As part of the design process, the questionnaire was tested as follows:

1. a structured in-house testing plan was used to assess the survey's design, logic, and overall operability
2. piloting with five survey testers (non-panel members), who checked and reported on areas such as usability and complexity of wording
3. software to check that the survey had an acceptable fatigue and accessibility score.



### Fieldwork

The survey fieldwork period was as follows:

- 21<sup>st</sup> August 2025 – email invite to all panel members
- 27<sup>th</sup> August 2025 – email reminder to all panel members who had not completed the survey
- 3<sup>rd</sup> September 2025 – final email reminder to all panel members still to complete the survey
- 8<sup>th</sup> September 2025 – survey closed.

New members joining the panel during the fieldwork period were also given the opportunity to participate in the survey.

During the fieldwork period, ten members unsubscribed from the panel.



# Who we spoke to

Email invites



2,442  
Delivered

Responses



828  
Completed

Response Rate



34%  
Completion

**Prize draw**

As a thank you for taking part, all completed questionnaires were entered into a prize draw to win one of two £50 Love2shop vouchers. The draw was held in September 2025, and two lucky panel members received their £50 vouchers by email—ready to spend online or on the high street.

**Technical notes**

**Percentages** - Due to rounding, not all percentages shown may equal 100%.

**n=** When shown in this report, ‘n=XX’ is the number of responses received for a given question.

**Respondents’ comments**

Several questions gave the option for a respondent to explain further the reason for their answer. These comments are listed in full in this report.

Approximately 1,000 free-text comments were submitted as part of the survey. All responses have been lightly edited for spelling accuracy only; otherwise, they are presented verbatim to preserve the respondent’s original wording and intent.

Where a comment may potentially identify a respondent, these references have been omitted from the report.

# Net scores (Net promoter score)

Net Scores have been calculated by subtracting the total percentage of negative responses (‘Unlikely’ and ‘Very Unlikely’) from the total percentage of positive responses (‘Likely’ and ‘Very Likely’). Responses marked as ‘Neither Likely nor Unlikely’ have been excluded from this calculation to ensure a clearer representation of directional sentiment.

## The People's Panel

Staffordshire and Stoke-on-Trent People's Panel is a digital group of almost 2,500 local residents (as of August 2025) from across Staffordshire and Stoke-on-Trent.

Members share their views on health and care services through online surveys helping to shape decisions about health services that affect their community.

How it works:

- several times a year, members are sent surveys about local and national NHS topics
- a newsletter is sent twice a year, with updates on healthcare changes and actions taken as a result of panel feedback
- taking part is always voluntary. All responses are published anonymously on the Integrated Care Board (ICB) website and included in the report findings. These reports are shared with system partners, who can also access them via the ICB website.

Survey, data analysis and report production undertaken by Direct Data Analysis Ltd, who run the people's panel on behalf of the Integrated Care Board.

Direct Data Analysis Ltd  
Brampton Business Centre  
10 Queen Street  
Newcastle-under-Lyme  
ST5 1ED  
Email: [enquiries@direct-data-analysis.co.uk](mailto:enquiries@direct-data-analysis.co.uk)  
Web: [www.direct-data-analysis.co.uk](http://www.direct-data-analysis.co.uk)  
Tel: 0800 0996 422



**2**

## **Survey findings**



## Repeat Prescriptions

With over 800 responses to the Repeat Prescriptions survey, this offers a valuable snapshot of how local panel members manage their medication—how often they order, what influences their decisions, and how messaging might help reduce waste. These insights will help shape future communications, support carers, and improve repeat prescription processes across the system.

### Key findings from the Repeat Prescription section of the survey

#### High self-management of prescriptions

86% of respondents manage their own repeat prescriptions, indicating strong individual responsibility.

#### Responsible ordering habits

67% only request medication they currently need, and 94% report not ending up with excess due to over-ordering.

#### Minimal stockpiling

48% keep no extra medication in reserve, and 25% keep only up to one week's supply.

#### Timely reordering patterns

46% order repeat prescriptions 1–2 weeks before running out, aligning with safe and efficient medication management.

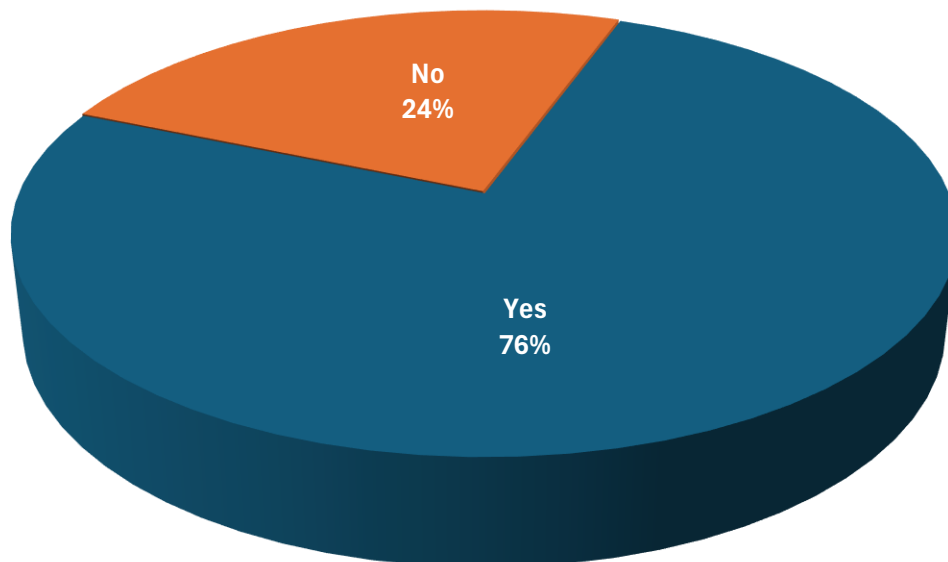
#### Limited carer involvement

Only 18% order prescriptions for someone else, and among them, 71% follow the same responsible ordering habits.

#### Messaging has potential impact

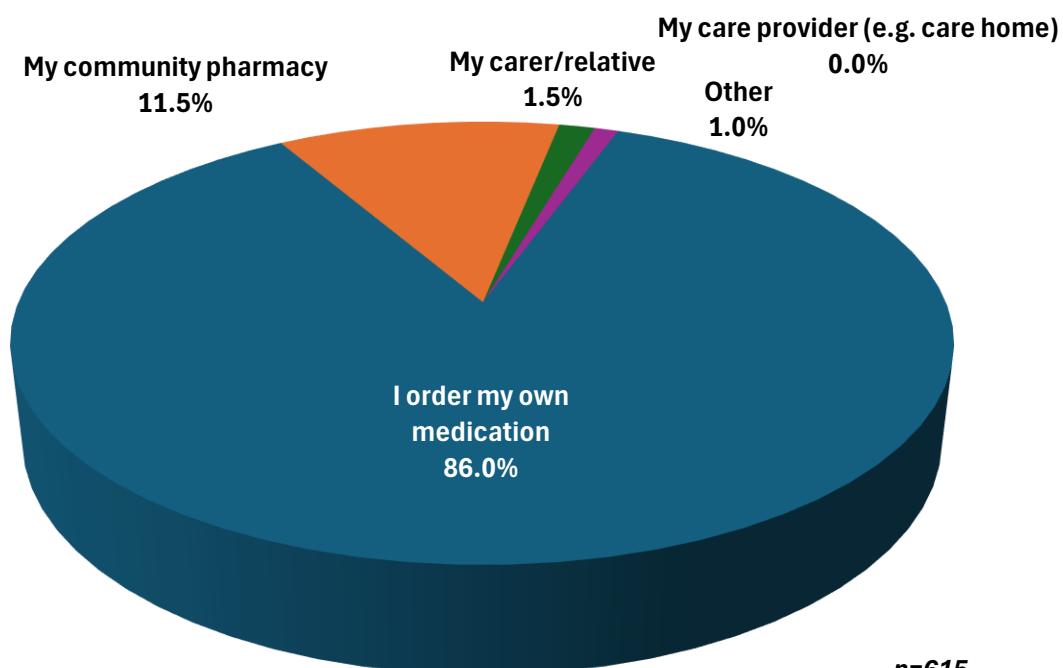
52% say reminder messages would encourage better ordering behaviour, and 73% would be prompted to return unused medication.

### Do you have any medicines prescribed on a repeat prescription?



*n*=821

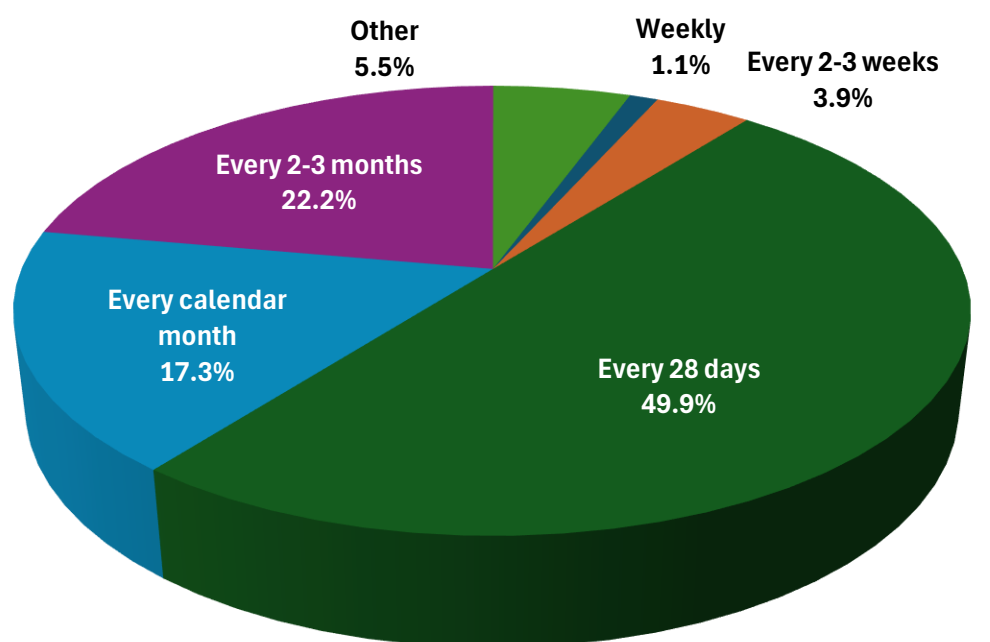
### Who has responsibility for ordering your medicines?



*n*=615

| Respondent Location         | Who has responsibility for ordering your medicines?<br>Responses to 'Other'                                      |
|-----------------------------|------------------------------------------------------------------------------------------------------------------|
| <b>East Staffordshire</b>   | I have to order part of my prescription every ten days at the surgery; the rest is done monthly via the pharmacy |
| <b>Lichfield</b>            | Specialist prescriber                                                                                            |
| <b>Newcastle-under-Lyme</b> | Via My GP Surgery                                                                                                |
| <b>Stafford</b>             | Doctor                                                                                                           |
| <b>Stoke-on-Trent</b>       | G.P. Practice                                                                                                    |
| <b>Stoke-on-Trent</b>       | Some dispensed by hospital, e.g. Cinacalcet                                                                      |

## How often do you usually request your repeat medication?

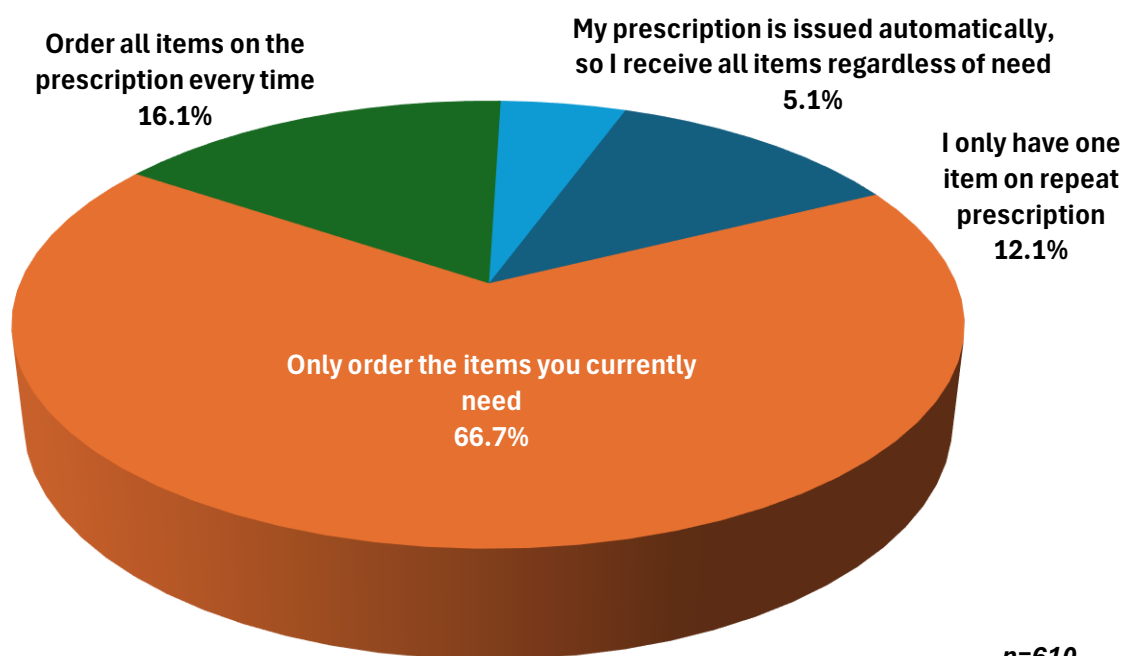


n=613

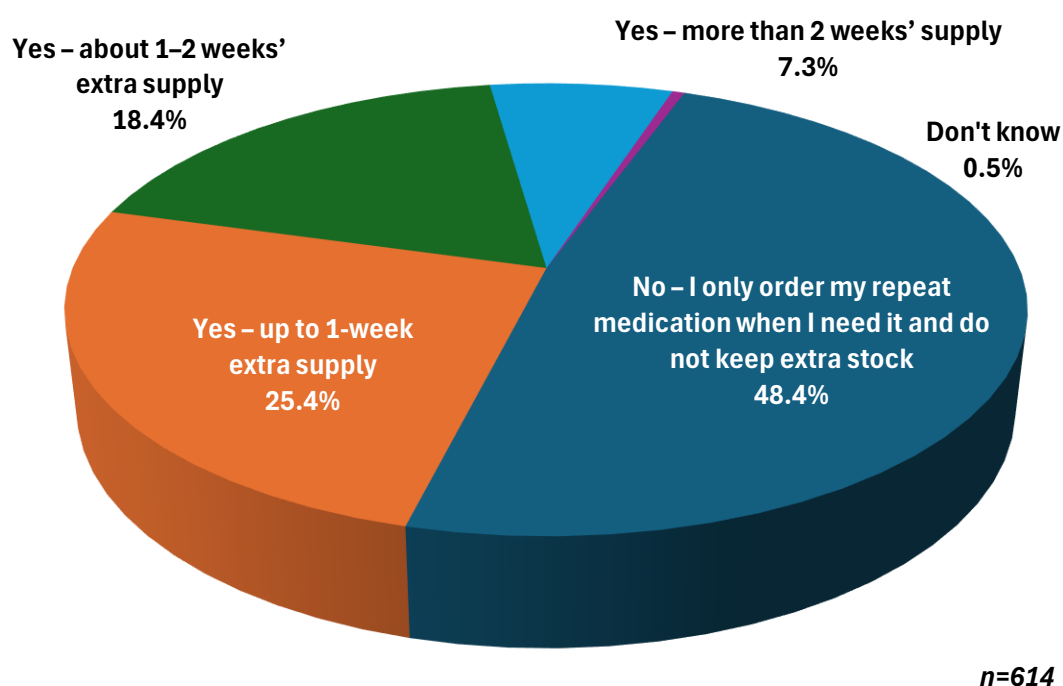
| Respondent Location  | How often do you usually request your repeat medication?<br>Responses to 'Other'                                                                                             |
|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cannock Chase        | 56 days                                                                                                                                                                      |
| East Staffordshire   | Every 56 days. I am prescribed 2x28 days for every repeat                                                                                                                    |
| East Staffordshire   | Every ten days                                                                                                                                                               |
| East Staffordshire   | I have some meds on 28 days and some on 3 months                                                                                                                             |
| East Staffordshire   | Never – the pharmacy orders them for me                                                                                                                                      |
| East Staffordshire   | Part of my prescription has to be requested every 10 days by myself at the surgery, the rest is done via the pharmacy                                                        |
| Lichfield            | 6 months                                                                                                                                                                     |
| Lichfield            | I don't request my medication; it is prescribed for me every month                                                                                                           |
| Lichfield            | I have a variety of medications on different schedules. I end up requesting at least one item every couple of weeks                                                          |
| Lichfield            | Most are monthly but 1 is 3 weekly.                                                                                                                                          |
| Lichfield            | Some items every 2 months                                                                                                                                                    |
| Newcastle-under-Lyme | My repeat prescriptions come automatically                                                                                                                                   |
| Newcastle-under-Lyme | Sometimes the chemist misses the order, about once a year                                                                                                                    |
| Newcastle-under-Lyme | When I open my last box                                                                                                                                                      |
| Newcastle-under-Lyme | When needed. Sometimes extra if going away for maybe 2 months                                                                                                                |
| Stafford             | Every other day as I have many. But they are different quantities, so sometimes I go weeks without ordering then I start running out so I will order a few days on the trot. |

|                                |                                                                                                                                                                                                                                                        |
|--------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stafford</b>                | I have prescribed medication for Ménière's disease. I take the medication according to my symptoms on any given day. Therefore, I do not take it daily. I only re-order when my supply is depleted.                                                    |
| <b>Stafford</b>                | I order Co-codamol in between my regular scripts due to limitations on amount dispensed                                                                                                                                                                |
| <b>Stafford</b>                | Only when I need them                                                                                                                                                                                                                                  |
| <b>Staffordshire Moorlands</b> | Every 12 days                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | Also, some medication I can only get directly from the hospital                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | As required – inform pharmacy and only order as I need                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | A week before my current prescription usually runs out                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | Every 56 days                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | Every 6 months or as required                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | Every 8 weeks                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | Mostly bi-monthly with extra if necessary (if a particular item doesn't last 2 months)                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | Some 2 weekly, some monthly and some every 3 months                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b>          | Usually, once every 6 months. The surgery recently changed this without any notification. The first thing I knew was when I went to the pharmacy to discover my medication was not there. If you are changing the system you <i>MUST</i> tell patients |
| <b>Stoke-on-Trent</b>          | When needed                                                                                                                                                                                                                                            |
| <b>Tamworth</b>                | 1 prescription monthly, one prescription bi-monthly                                                                                                                                                                                                    |

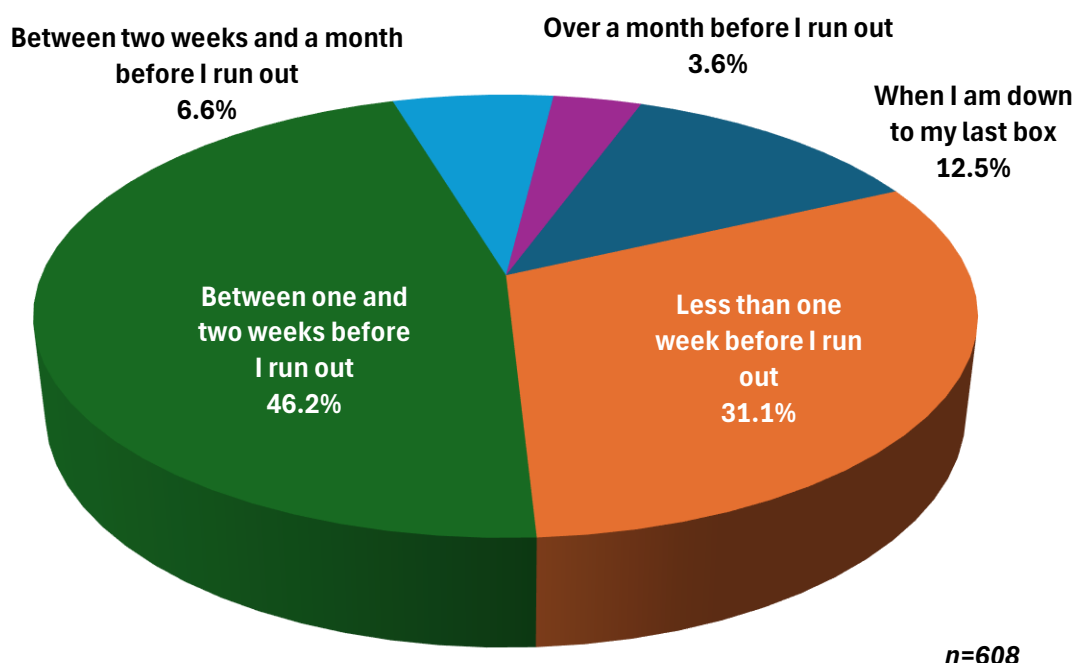
If you have more than one item on your repeat prescription, do you:



Do you usually keep a stock of your repeat medication at home?



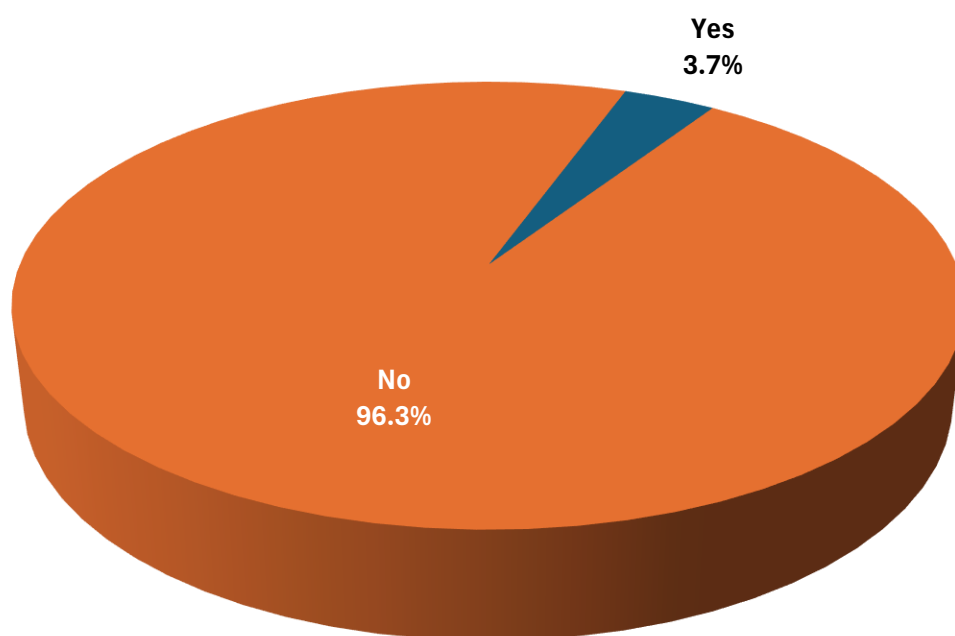
## When you need a repeat prescription, how far in advance do you usually order it?



| Respondent Location                          | When you need a repeat prescription, how far in advance do you order?                              |
|----------------------------------------------|----------------------------------------------------------------------------------------------------|
| Responses to 'Over a month before I run out' |                                                                                                    |
| Cannock Chase                                | My pharmacy keeps my prescription, so I get it on the same day every month                         |
| East Staffordshire                           | I don't order my medication                                                                        |
| Lichfield                                    | I order my next prescription one month in advance as I collect the current one                     |
| Newcastle-under-Lyme                         | Comes automatically via GP and pharmacy                                                            |
| Newcastle-under-Lyme                         | I do not order; my prescription is delivered automatically                                         |
| Newcastle-under-Lyme                         | I don't – the pharmacy and surgery sort it online                                                  |
| Newcastle-under-Lyme                         | Pharmacy orders it                                                                                 |
| Newcastle-under-Lyme                         | Prescription ordered for me                                                                        |
| Newcastle-under-Lyme                         | Repeats come automatically                                                                         |
| Newcastle-under-Lyme                         | When I pick up my prescription the chemist fills it in, and they text me when to pick it up        |
| Stafford                                     | 6 weeks                                                                                            |
| Stafford                                     | 7 days' supply then I reorder                                                                      |
| Stafford                                     | Tesco pharmacy takes 7–10 days to dispense my script. I'm lucky if I get it before that time frame |
| Staffordshire Moorlands                      | Ordered by pharmacy                                                                                |
| Staffordshire Moorlands                      | The pharmacist is supposed to order it                                                             |

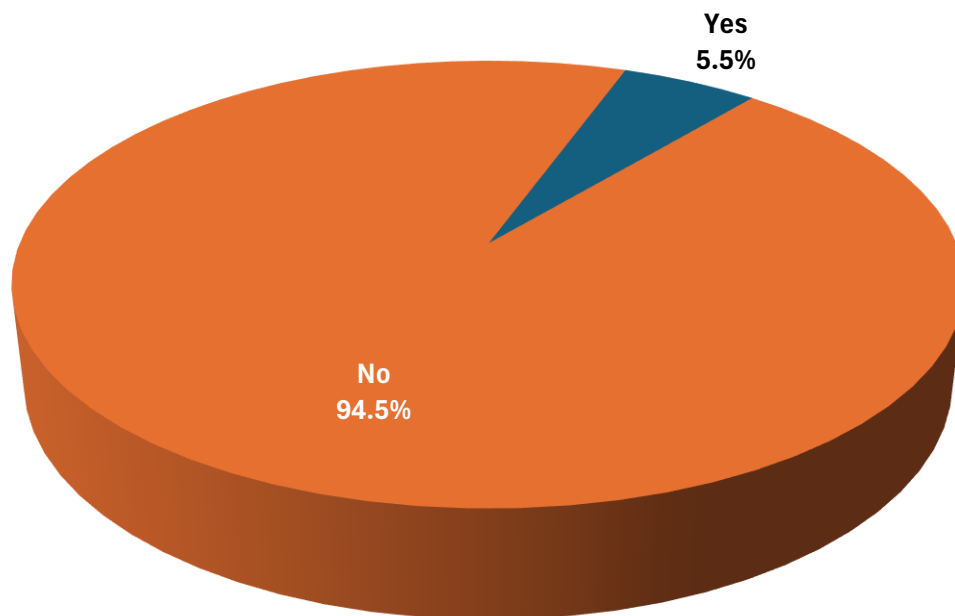
|                       |                                                                                                                                                            |
|-----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | It is automatic – the pharmacy requests it                                                                                                                 |
| <b>Stoke-on-Trent</b> | Pharmacy orders                                                                                                                                            |
| <b>Stoke-on-Trent</b> | Pharmacy puts it in for every 28 days i.e. antidepressants                                                                                                 |
| <b>Stoke-on-Trent</b> | Repeat prescriptions are generated automatically by my doctors to the local pharmacy                                                                       |
| <b>Stoke-on-Trent</b> | The chemist is terrible at filling scripts quickly, so you need at least 10 days in advance to order and receive meds, so 2 weeks supply needed in reserve |
| <b>Tamworth</b>       | Order when I collect                                                                                                                                       |

Are you often supplied with extra medication that you did not order:



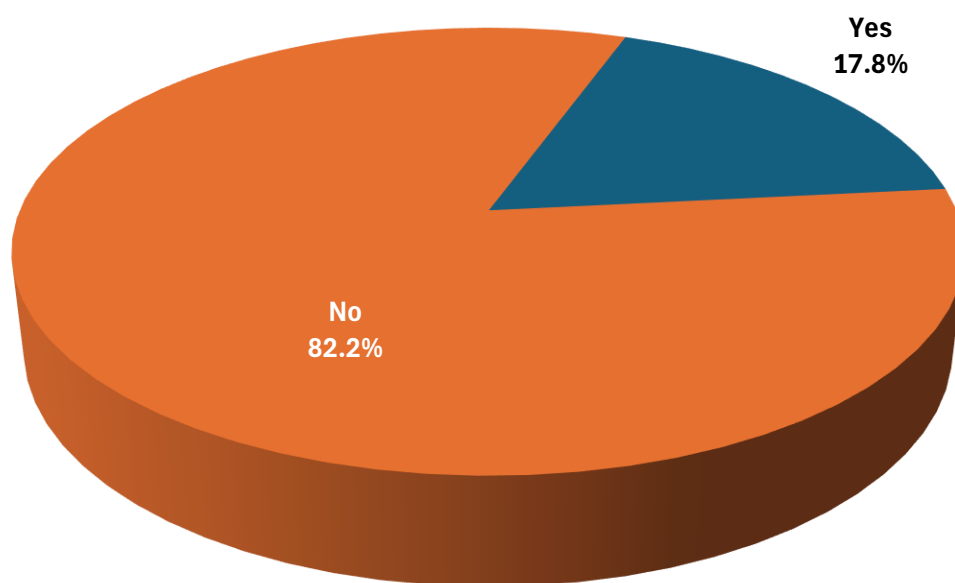
***n=614***

Are you often left with an excess of medicines due to over ordering?



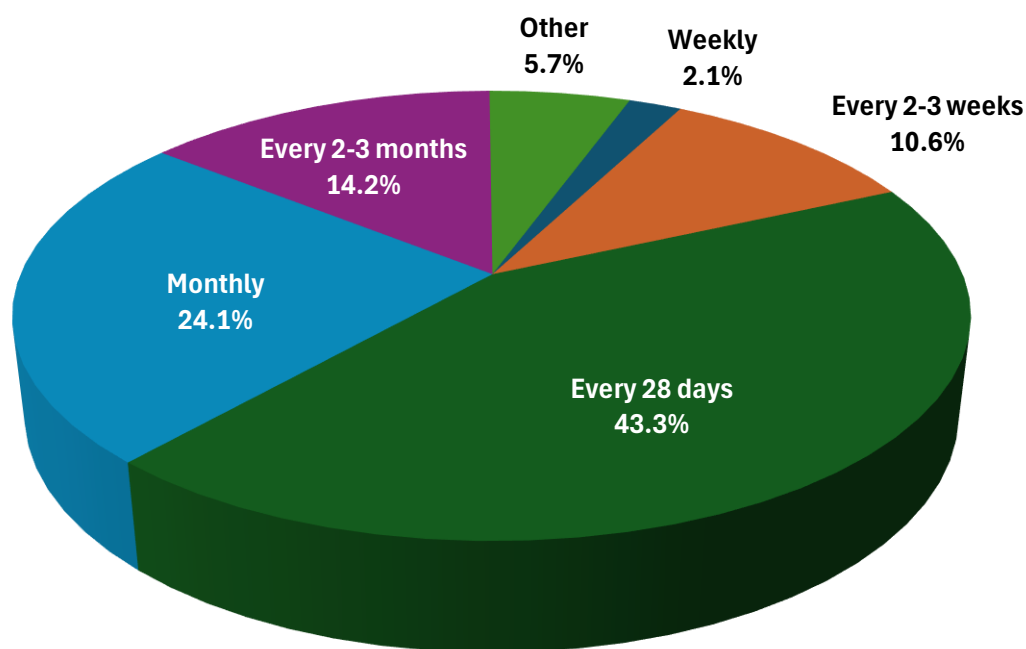
**n=613**

Do you order a repeat prescription for a friend or family member?



**n=813**

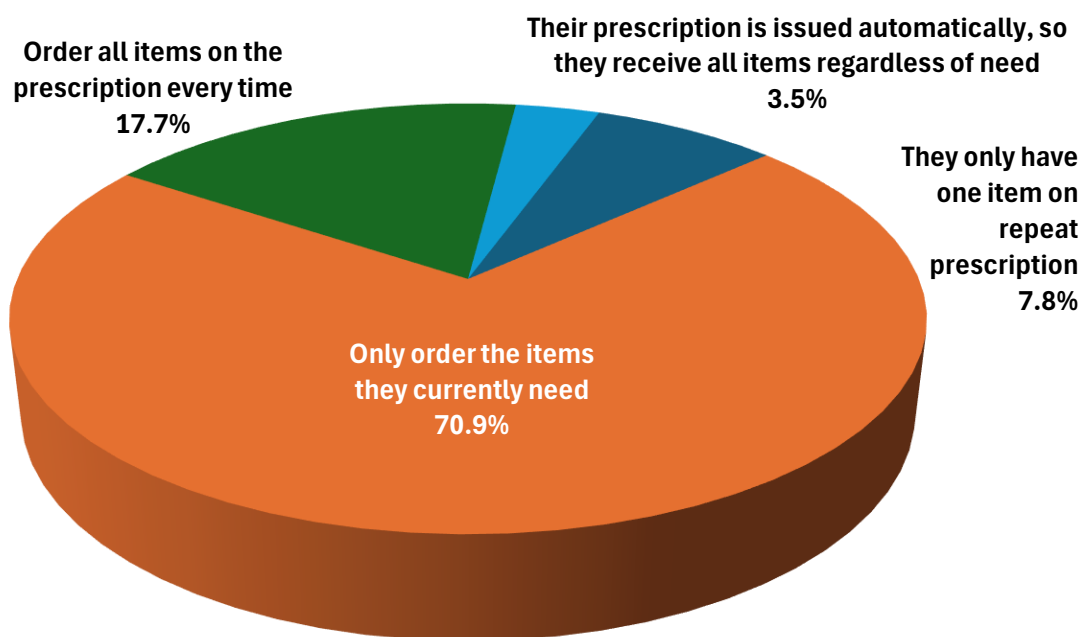
How often do you usually request a repeat prescription for a friend or family member?



*n=141*

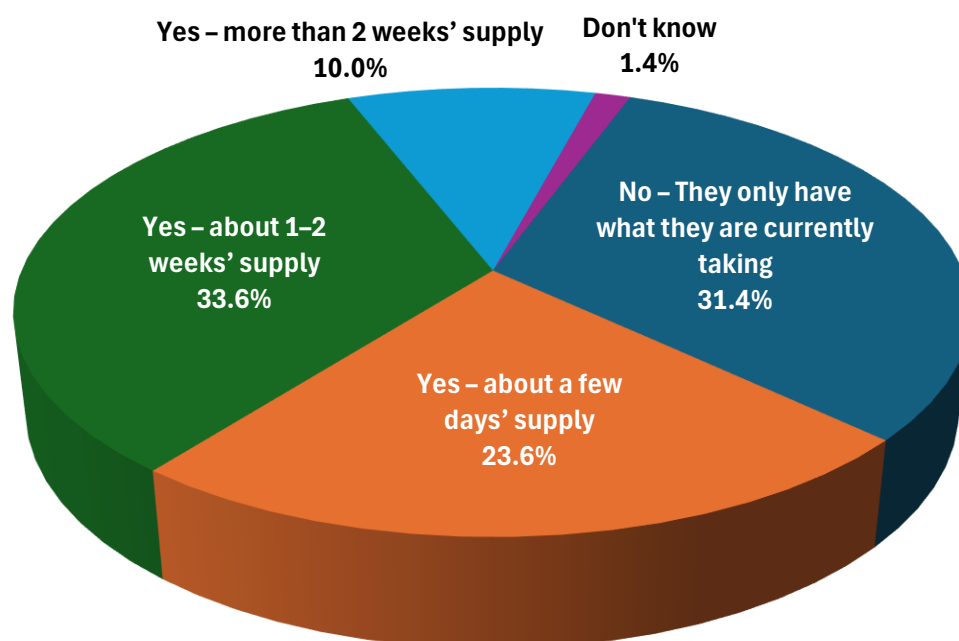
| Respondent Location     | How often do you usually request a repeat prescription for a friend or family member?<br>Responses to 'Other' |
|-------------------------|---------------------------------------------------------------------------------------------------------------|
| Stafford                | Irregular                                                                                                     |
| Stafford                | Whenever they ask me to re-order                                                                              |
| Stafford                | When they ask me to do so                                                                                     |
| Stafford                | When they can't do themselves                                                                                 |
| Staffordshire Moorlands | Again, pharmacist is supposed to do it                                                                        |
| Staffordshire Moorlands | Once requested, automatically done now by pharmacy                                                            |
| Stoke-on-Trent          | When needed – sometimes monthly, sometimes 3 months apart                                                     |
| Stoke-on-Trent          | When required                                                                                                 |

If your friend or family member has more than one item on their repeat prescription, do you:



*n=141*

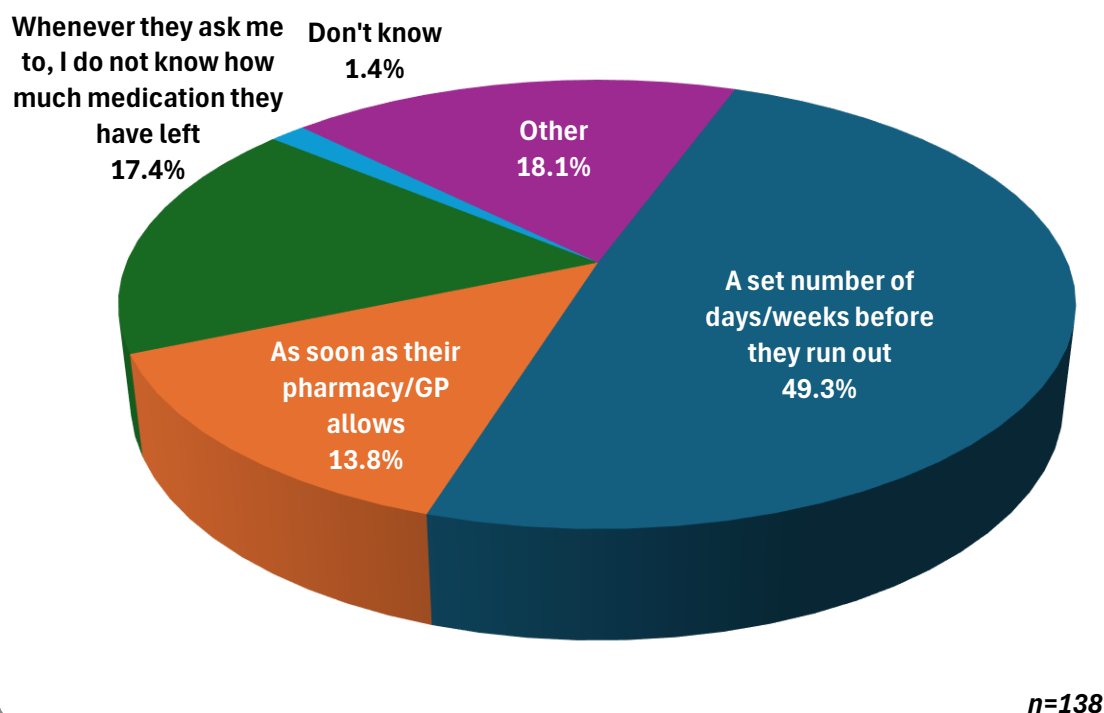
Does your friend or family member usually keep a stock of their repeat medication at home?



*n=140*

| Respondent Location            | Does your friend or family member usually keep a stock of their repeat medication at home?<br>Responses to 'Yes'<br>Grouped by Storage Location | Number of Responses |
|--------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|
| <b>Cannock Chase</b>           | Home / Kept at home                                                                                                                             | 4                   |
| <b>East Staffordshire</b>      | Home / Kept at home / at home                                                                                                                   | 3                   |
| <b>East Staffordshire</b>      | In dining room                                                                                                                                  | 1                   |
| <b>East Staffordshire</b>      | In the bathroom                                                                                                                                 | 1                   |
| <b>East Staffordshire</b>      | Reserved supply for son (epilepsy, LD, autism)                                                                                                  | 1                   |
| <b>Newcastle-under-Lyme</b>    | Home / Kept at home / At home                                                                                                                   | 7                   |
| <b>Newcastle-under-Lyme</b>    | Home and school                                                                                                                                 | 1                   |
| <b>Newcastle-under-Lyme</b>    | Kept at home due to supply issues                                                                                                               | 1                   |
| <b>South Staffordshire</b>     | Home / Kept at home                                                                                                                             | 3                   |
| <b>Stafford</b>                | Home / Kept at home / At home                                                                                                                   | 7                   |
| <b>Stafford</b>                | Bathroom cupboard                                                                                                                               | 1                   |
| <b>Stafford</b>                | In a cupboard                                                                                                                                   | 1                   |
| <b>Stafford</b>                | Overstocked / unused meds                                                                                                                       | 1                   |
| <b>Stafford</b>                | Meds keep arriving despite cancellation attempt                                                                                                 | 1                   |
| <b>Stafford</b>                | Needs 1–2 weeks supply due to month length mismatch                                                                                             | 1                   |
| <b>Staffordshire Moorlands</b> | Home / Kept at home / At home                                                                                                                   | 8                   |
| <b>Staffordshire Moorlands</b> | In bedroom cupboard                                                                                                                             | 1                   |
| <b>Staffordshire Moorlands</b> | Kitchen cabinet                                                                                                                                 | 1                   |
| <b>Stoke-on-Trent</b>          | Home / Kept at home / At home                                                                                                                   | 4                   |
| <b>Stoke-on-Trent</b>          | In home medicine drawer (with ibuprofen, cold & flu tablets etc.)                                                                               | 1                   |
| <b>Stoke-on-Trent</b>          | Emergency reserve due to pharmacy/illness risk                                                                                                  | 1                   |
| <b>Stoke-on-Trent</b>          | Kept at the house                                                                                                                               | 1                   |
| <b>Tamworth</b>                | Kept at home                                                                                                                                    | 1                   |
| <b>Tamworth</b>                | In a medical box                                                                                                                                | 1                   |

## When do you usually order the repeat medication for your friend or family member?



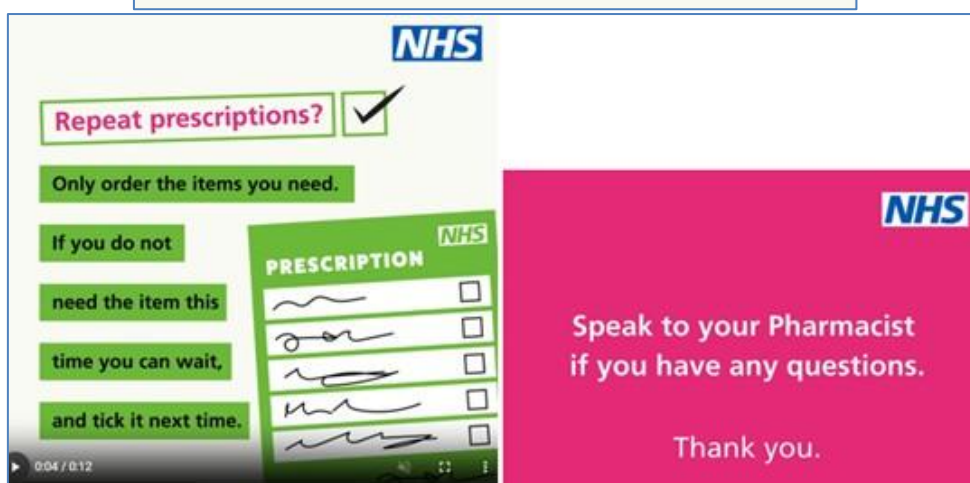
| Respondent Location     | When do you usually order the repeat medication for your friend or family member?<br>Responses to 'Other'            |
|-------------------------|----------------------------------------------------------------------------------------------------------------------|
| Lichfield               | 7 days                                                                                                               |
| Lichfield               | I order every 3 weeks                                                                                                |
| Newcastle-under-Lyme    | A week before running out                                                                                            |
| Newcastle-under-Lyme    | When they receive an email notification                                                                              |
| Stafford                | 1 week before                                                                                                        |
| Stafford                | A week                                                                                                               |
| Stafford                | A week or 2 weeks before meds run out                                                                                |
| Stafford                | I only do this sometimes                                                                                             |
| Stafford                | Normally 10 days' supply left (the Doctors do the prescriptions quickly, but the Chemist can take up to 5 or 6 days) |
| Stafford                | pharmacist requests meds                                                                                             |
| Stafford                | Whenever they ask me to, but I DO have an idea of how much medication they have approximately                        |
| Staffordshire Moorlands | 5 working days                                                                                                       |
| Staffordshire Moorlands | Chemists keep the repeat                                                                                             |
| Staffordshire Moorlands | I call the pharmacy to ask them only to dispense items needed                                                        |
| Staffordshire Moorlands | I order every 28 days                                                                                                |
| Staffordshire Moorlands | When I collect it from the pharmacy, I reorder for next time                                                         |
| Staffordshire Moorlands | Whenever carers ask me to                                                                                            |
| Stoke-on-Trent          | 1 week before                                                                                                        |

|                       |                                                                                                 |
|-----------------------|-------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | 5 days                                                                                          |
| <b>Stoke-on-Trent</b> | Every 28 days                                                                                   |
| <b>Stoke-on-Trent</b> | I usually wait until about 3 weeks supply before ordering.                                      |
| <b>Stoke-on-Trent</b> | My partner mainly keeps track of it but due to their blindness and stroke fatigue I also check. |
| <b>Stoke-on-Trent</b> | When picking up the medication I ordered the next one                                           |
| <b>Tamworth</b>       | 1 - 2 weeks before needed                                                                       |
| <b>Tamworth</b>       | I order them every 4 weeks                                                                      |

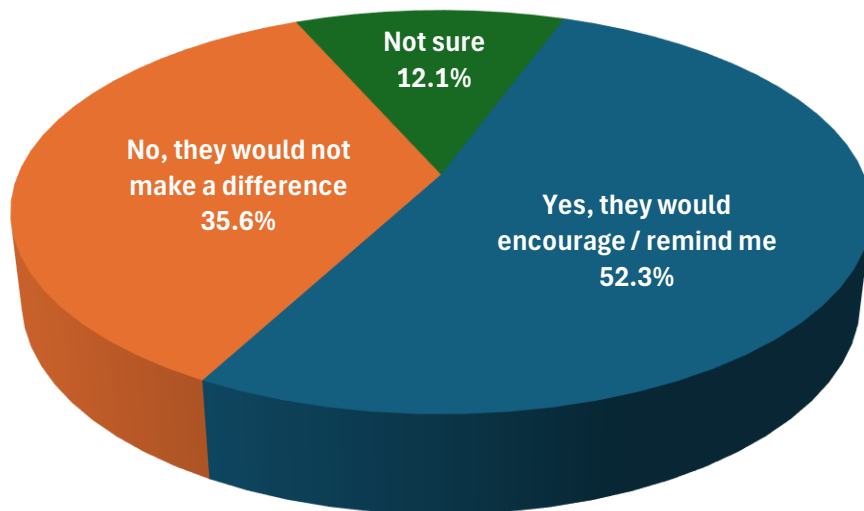
## Helping people order only what they need — and return what they don't need

Following a series of visual prompts, respondents were invited to reflect on the images and share their views. This section captures their immediate reactions, including how well the visuals conveyed key messages, whether they felt relevant or engaging, and any suggestions for improvement.

**Would these messages encourage / remind you to only order the medicines you need, when you need them?**



Would these messages encourage / remind you to only order the medicines you need, when you need them? (This question is for everyone, even if you don't have a repeat prescription.)



*n*=775

 **Key themes from respondents who answered 'No' or 'Not sure' when asked: "Would these messages encourage or remind you to only order the medicines you need, when you need them?"**

 **Confident self-management**

Many respondents already have structured routines for ordering medication — using calendars, apps, or personal judgement. They feel confident and do not need reminders.

"I diary date ordering my prescription and only order what I need." "I follow my own routine and know when I have 1–2 weeks left."

 **Message tone and fatigue**

The campaign messaging is often described as **patronising, cluttered, or ineffective**. Respondents prefer direct, respectful language and simpler visuals.

"Too much irrelevant information. The message is lost." "Patronising and simplistic — I do not need to be told what and when to order."

 **System-level frustrations**

Issues with **pharmacy delays, automatic repeats, and GP coordination** are common. These system-level barriers often lead to unintended overstocking or stress.

"Medications on automatic repeat should be stopped — it causes wastage." "The pharmacy regularly has issues getting in my prescriptions."

 **Digital tools and autonomy**

Patient Access, online pharmacies, and diary reminders are widely used. Respondents value autonomy and digital control, and often feel these tools are more effective than posters.

"I use Patient Access to order using the date it gives me." "I use an online pharmacy — they send me reminders."

 **Safety buffering and supply anxiety**

Some respondents intentionally keep a small buffer due to **supply chain concerns, travel, or health conditions**. They view this as responsible, not stockpiling.

"I prefer to have an extra week's supply in hand, so I always have enough." "I keep a couple of months buffer on most medications."

| Respondent Location | Would these messages encourage / remind you to only order the medicines you need, when you need them?<br>Responses to 'No' or 'Not sure'                                                                                                                                                                                                                                                               |
|---------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cannock Chase       | Because I only order what is necessary and bear in mind the pharmacy takes 7 days to provide the items and doesn't always have them even then.                                                                                                                                                                                                                                                         |
| Cannock Chase       | Because that is what I do anyway. Pharmacy cannot be relied upon to have meds ready when I need them, so I order early                                                                                                                                                                                                                                                                                 |
| Cannock Chase       | How do you know I have only ordered what I need?                                                                                                                                                                                                                                                                                                                                                       |
| Cannock Chase       | How do you know I have only ordered what I need? Would the message 'Please only order what you need' have a better impact. Also why not provide a sheet detailing all my repeat prescriptions and asking me to list how many of each medication I have at home, then ask me to bring into the pharmacy on my next visit. The pharmacist could then talk to me if they feel I am stockpiling any items. |
| Cannock Chase       | I already did my own checks to ensure I only have what I need                                                                                                                                                                                                                                                                                                                                          |
| Cannock Chase       | I already order only what is needed and do not need any reminder                                                                                                                                                                                                                                                                                                                                       |
| Cannock Chase       | I diary date ordering my prescription and only order what I need, having a buffer of one to two weeks.                                                                                                                                                                                                                                                                                                 |
| Cannock Chase       | I keep a regular record of my usage and order as necessary                                                                                                                                                                                                                                                                                                                                             |
| Cannock Chase       | I know when you order medicines however, they might need useful to help others                                                                                                                                                                                                                                                                                                                         |
| Cannock Chase       | I think there needs to be more emphasis on cost / waste and how precious the NHS resources are. Then waste medicines reduce the budget for other services.                                                                                                                                                                                                                                             |
| Cannock Chase       | I use an online pharmacy. They let me know when I should request my prescription. I think I order a little early as the post in my area isn't reliable.                                                                                                                                                                                                                                                |
| Cannock Chase       | I use Patient Access to order which gives you the next date you can order - but which unfortunately doesn't take account of 30/31 day months.                                                                                                                                                                                                                                                          |
| Cannock Chase       | If it was given to me just before I ordered my repeat prescription it would probably make me go and check I had not excess medication in storage. It would be pointless and make no difference if I received this when collecting my repeat prescription - I would probably have forgotten about the message by the time it came to re-order my next repeat prescription.                              |
| Cannock Chase       | If items are not included in repeat request, they can be removed from the list of repeats, and you need to see Dr to re add them?                                                                                                                                                                                                                                                                      |
| Cannock Chase       | It varies how long the delay between ordering the repeat prescription and the order being ready for collection as pharmacy sends out for some items, therefore need to have a stock at home just in case                                                                                                                                                                                               |
| Cannock Chase       | Not everyone has access to the internet                                                                                                                                                                                                                                                                                                                                                                |
| Cannock Chase       | Pharmacy orders on 2 monthly bases, I tell them when I collect if I don't need them and the keep them.                                                                                                                                                                                                                                                                                                 |

|                           |                                                                                                                                                                                                                                                                                                                                                                            |
|---------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Cannock Chase</b>      | The message does not really have any impact on stockpiling medication. Stay safe, stay well, stay green! So confusing and meaningless.                                                                                                                                                                                                                                     |
| <b>East Staffordshire</b> | Already only order what I need                                                                                                                                                                                                                                                                                                                                             |
| <b>East Staffordshire</b> | As its the chemist ordering for me and I do speak with them every month. But they are showing 12 months when I know I order every other month on some drugs                                                                                                                                                                                                                |
| <b>East Staffordshire</b> | Because I have a phone call from chemist and they take my order so only dispense what I need and the Dr's send everything so don't know if chemist still get paid. Did bring up with doctor pharmacy team . As could save you loads of money of over ordering I have the doser boxes week at a time .                                                                      |
| <b>East Staffordshire</b> | Because I have common sense and do not need reminders                                                                                                                                                                                                                                                                                                                      |
| <b>East Staffordshire</b> | Because none of them say only order what you need except the first one                                                                                                                                                                                                                                                                                                     |
| <b>East Staffordshire</b> | Confusing message. If you have assumed I have only ordered what I need, how does this encourage me not to stockpile medication?                                                                                                                                                                                                                                            |
| <b>East Staffordshire</b> | I already only order what I need, the leaflet is not giving me any information I do not already have and will not alter my behaviour                                                                                                                                                                                                                                       |
| <b>East Staffordshire</b> | I don't need reminders as only one order                                                                                                                                                                                                                                                                                                                                   |
| <b>East Staffordshire</b> | I don't generally overorder, though don't always remember to return unwanted medicines                                                                                                                                                                                                                                                                                     |
| <b>East Staffordshire</b> | I go to the to the chemists on my mobility scooter when I am down to my last 7 days and place my order as it takes 7 days to get it which has been the same for the last 5 years and if I get a exse of anyone of my prescription I ask the chemist not repeat it till the next time do not like to waste                                                                  |
| <b>East Staffordshire</b> | I know the reason for not over ordering or stockpiling. Not sure an advert would make me think about it more than I do.                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b> | I mark the calendar for date to order, so a reminder is unnecessary for me.                                                                                                                                                                                                                                                                                                |
| <b>East Staffordshire</b> | I order my repeats at a time to ensure that I have 1-2 weeks supply always available. There are constant supply problems either from manufacturers or wholesalers and I do not want to be left either without medication or without the time for my GP to issue an alternative. The messages shown suggest that I am not able to behave responsibly without this prompting |
| <b>East Staffordshire</b> | I suffer from migraines and the medication for that is issued monthly, but sometimes I need more than usual so I like to keep stock because not having them would leave me debilitated for 3 days.                                                                                                                                                                         |
| <b>East Staffordshire</b> | I'm already aware of the issue and order appropriately.                                                                                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b> | If someone is taking a medicine daily, they don't want to reorder every few days. I think that reordering once a month is reasonable provided it isn't a danger to children. I think sensible amounts should be suggested.                                                                                                                                                 |
| <b>East Staffordshire</b> | I'm already regimented in my approach to only ordering what I require.                                                                                                                                                                                                                                                                                                     |

|                           |                                                                                                                                                                                                                                                                                                                                                                                |
|---------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>East Staffordshire</b> | I'm not an idiot and do not need pictures to remind me. You should only order what you need.                                                                                                                                                                                                                                                                                   |
| <b>East Staffordshire</b> | It wouldn't help me, as I'm regimented in my ordering of repeat prescriptions, but I would imagine it would help some people.                                                                                                                                                                                                                                                  |
| <b>East Staffordshire</b> | It's a very busy poster, everything past the first bit is needlessly repeating the message and irrelevant. Keep it short and simple                                                                                                                                                                                                                                            |
| <b>East Staffordshire</b> | I've already said I only order what I need when I need it. I have 1 weeks extra in case the repeat is delayed.                                                                                                                                                                                                                                                                 |
| <b>East Staffordshire</b> | Need to make this advert with a little bit jealous subject. Like if you take more than you need, some may suffer from no treatment on time... Something like that                                                                                                                                                                                                              |
| <b>East Staffordshire</b> | Not clear what topic is or why                                                                                                                                                                                                                                                                                                                                                 |
| <b>East Staffordshire</b> | Not relevant                                                                                                                                                                                                                                                                                                                                                                   |
| <b>East Staffordshire</b> | Patronising and simplistic I do not need to be told what and when to order simple efficiencies by GP would help e.g. I am prescribed evorel patches these come in packs of 8 Utrogestan in a pack of 30 the latter lasts therefore slightly longer. My patch was increased recently, and I was prescribed a 3 month of that and the Utrogestan overlapping my existing supply. |
| <b>East Staffordshire</b> | Stay safe and stay green don't really have an impact on me when it comes to a message about not stockpiling medication.                                                                                                                                                                                                                                                        |
| <b>East Staffordshire</b> | The message should start 'please only order what you need', not thank you for only ordering what you need. What if I have ordered excess medication?                                                                                                                                                                                                                           |
| <b>East Staffordshire</b> | The only thing I would add is that the first poster is very busy and possibly provides too much information all at once as well as it's too small a print for people with altered eyesight. Small clear bursts of information would be a positive way to cascade the information you wish to share.                                                                            |
| <b>East Staffordshire</b> | They do not portray the message clearly.                                                                                                                                                                                                                                                                                                                                       |
| <b>East Staffordshire</b> | They wouldn't make any difference to me ordering repeat prescriptions, because I think of myself as a responsible adult, not a freeloader thinking the medication and doesn't cost me anything, so I'll go ahead and order it.                                                                                                                                                 |
| <b>East Staffordshire</b> | Too much irrelevant information. The message telling me to only order what I need is lost at the bottom of the poster                                                                                                                                                                                                                                                          |
| <b>Lichfield</b>          | A leaflet or a poster is a wasted exercise as they only work in small percentages. They are only useful as 'supplementary' marketing if used in conjunction with primary marketing campaigns.                                                                                                                                                                                  |
| <b>Lichfield</b>          | Confusing mix of messages.                                                                                                                                                                                                                                                                                                                                                     |
| <b>Lichfield</b>          | I am already aware of the issues. For anyone who isn't there is a lot of information if the poster isn't large. If its A4 it would be too much. I think the key headings don't get the message across and many people wouldn't read the smaller text giving more information. et the                                                                                           |
| <b>Lichfield</b>          | I check my medicine stock when I refill my weekly pill box and reorder them as required.                                                                                                                                                                                                                                                                                       |

|           |                                                                                                                                                                                                                                                                                                                              |
|-----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Lichfield | I check my medicine stocks weekly when I re-stock my "daily pill box". This prompts me to re-order. I am already aware of the need to keep medicine orders to what I need.                                                                                                                                                   |
| Lichfield | I consider that I have the cognitive ability to order medicines only when needed                                                                                                                                                                                                                                             |
| Lichfield | I follow these suggestions already                                                                                                                                                                                                                                                                                           |
| Lichfield | I have two batches of prescriptions two weeks apart; it would make sense to me to have them together to save travelling to pick them up. I have spoken to the pharmacist about this but no change!                                                                                                                           |
| Lichfield | I managed my own needs for assurance                                                                                                                                                                                                                                                                                         |
| Lichfield | I only order my meds a LITTLE in advance, so I don't run out if there's a supply problem.                                                                                                                                                                                                                                    |
| Lichfield | I only order what I need. I have a slight excess that I keep in my overnight bag as a backup when I am away from home, but I rotate this with new medication.                                                                                                                                                                |
| Lichfield | I order my prescription online and only tick the boxes that I need, I know this may be a reminder for some people but really, they should be intelligent enough to only order what they need                                                                                                                                 |
| Lichfield | I order via Patient Access online system. It is not possible for me to order more than I need. The system shows the amounts I need & when the next order is due. If I tried to order more or early, my order would be rejected by my GP. Could this sort of system be used more widely to prevent over ordering?             |
| Lichfield | I reorder HRT & the time frame of availability of meds & speed to process the request at the go varies greatly from request to request                                                                                                                                                                                       |
| Lichfield | Know what I need and when                                                                                                                                                                                                                                                                                                    |
| Lichfield | Most pharmacy's do not like to take back old medications now; in speaking to others, the biggest incentive would be to send left over medication to countries that need them instead of destroying them.                                                                                                                     |
| Lichfield | Only order what you need would have a far greater impact                                                                                                                                                                                                                                                                     |
| Lichfield | Stay safe, stay well, stay green is totally the wrong message to use to remind people to only order what medicines they need.                                                                                                                                                                                                |
| Lichfield | The font is tiny- much too small for older adults and those with visual challenges.                                                                                                                                                                                                                                          |
| Lichfield | The order is different across the top compared to down the side - doesn't make it flow properly. The graphics could be improved - looks more like a remote control.                                                                                                                                                          |
| Lichfield | The problem I have is having to order prescriptions at different times during the month meaning multiple trips to pharmacy. Also, with only one month's supply being allowed if I go away things get complicated and difficult. I never stockpile medicines but need to feel safe that my medications are available at home. |
| Lichfield | The speak to your pharmacist message has a far better impact. The first message makes no sense; it is not aimed at those stockpiling medication.                                                                                                                                                                             |
| Lichfield | Too many mixed messages in the poster. Stay green?                                                                                                                                                                                                                                                                           |

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-----------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Lichfield</b>            | Where are the signs to be placed to make an impact? My doctor's surgery has walls covered with messages and reminders. How does anyone prioritise this information. The only way to control overprescribing is at point of issue. I remember discussing this at a CCG meeting years ago. Some patients need regular monitoring on medications and usage. Who should do this?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | Able to order my own medication                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Newcastle-under-Lyme</b> | Answering not sure so I can reply. The first 2 may encourage people not to over order. But returning medication to the pharmacy when you know it will be destroyed is not green, it is wasteful to most people.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Newcastle-under-Lyme</b> | How do you know I have only ordered what I need?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Newcastle-under-Lyme</b> | I already do it!                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Newcastle-under-Lyme</b> | I already only order the medication I need.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Newcastle-under-Lyme</b> | I already order only items needed.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Newcastle-under-Lyme</b> | I am organised. I diary date when I need to reorder and check what I have before reordering.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | I can at times be a bit scatty in remembering things- having run out of pain relief once I'm now a bit paranoid around not having medication- don't like being in pain                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | I can only answer this question for myself, as I am not the one who is on a repeat prescription. I would only order the drugs I need but have the confidence to manage drugs safely and effectively due to my professional background. These posters would therefore not make any difference to the way I carry this out for myself. However, when ordering drugs for someone else, and attempting to assist them with managing their prescriptions I, like many other people who do this, am not the one who is concerned about their supply and can only attempt to encourage them to follow good practice. I am not sure how effective these posters would be for other people, but they might help with this task. Of course, if they are in surgeries and pharmacies, then anyone who requires assistance managing their medication might not be exposed to them, unless some process for circulating them more widely is adopted. |
| <b>Newcastle-under-Lyme</b> | I didn't realise that you could order extra. My GP only allows me to order after a specific date each month.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | I do not order more than I need. However, the information should be more about the cost of unused meds and how many hospitals appts could be provided instead                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | I don't need reminding                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | I don't over order anyway                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Newcastle-under-Lyme</b> | I don't need a reminder as I only order what is required. But I could! Some people would perhaps benefit from a reminder. I do feel though in a lot of cases, you could stamp the messages on people's foreheads, and it still wouldn't make any difference.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | I only ever order what is needed.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |

|                      |                                                                                                                                                                                                                                                                                                                                                                  |
|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Newcastle-under-Lyme | I only order a week before prescription finishes this gives times for Dr to prescribe and pharmacy to make up the order                                                                                                                                                                                                                                          |
| Newcastle-under-Lyme | I only order what I need already                                                                                                                                                                                                                                                                                                                                 |
| Newcastle-under-Lyme | I only order what I need anyway                                                                                                                                                                                                                                                                                                                                  |
| Newcastle-under-Lyme | I only order what I need in any case                                                                                                                                                                                                                                                                                                                             |
| Newcastle-under-Lyme | I order my medication online and have it delivered to my door. Perhaps if the leaflet is posted with medication it would help. Any reminders at chemists like the poster would be helpful                                                                                                                                                                        |
| Newcastle-under-Lyme | I order what I need with a small overlap, to avoid running out or if a prescription is missed or I'm away and can't pre-order at the right time. A small fail-safe is important for critical medications.                                                                                                                                                        |
| Newcastle-under-Lyme | I sometimes go on holiday away from home so order extra for then, if my reordering date lands whilst I'm away                                                                                                                                                                                                                                                    |
| Newcastle-under-Lyme | I think I've been frightened by Covid! I am petrified I won't be able to get what I need, but that said, I don't over order.                                                                                                                                                                                                                                     |
| Newcastle-under-Lyme | I use a note in my diary to remind me. It works for me!                                                                                                                                                                                                                                                                                                          |
| Newcastle-under-Lyme | I would wish to have a reserve of tablets to cover holidays. Often not easy to get extra tabs for last minute holiday                                                                                                                                                                                                                                            |
| Newcastle-under-Lyme | I'm pretty good at remembering when to reorder It depends where you display the posters                                                                                                                                                                                                                                                                          |
| Newcastle-under-Lyme | If you are dependent on a drug, i.e. it is life maintaining medicine , you are likely to want to keep a small number of drugs in your home rather than run out. Drugs are not always readily available at pharmacists, they can be out of stock, so a small number of tablets at home is a wise thing to do. This advert would not dissuade me from this belief. |
| Newcastle-under-Lyme | In the past I have found that there was no availability of one medication...ezetimibe.                                                                                                                                                                                                                                                                           |
| Newcastle-under-Lyme | In theory, I now have to order my prescription even earlier to allow 7 days for the pharmacy to process and prepare it as well as a couple of days for the GP to raise and process the prescription. These are not my choice but rather reflect the notice posted on the counter at the pharmacy.                                                                |
| Newcastle-under-Lyme | It would have a far better impact saying, 'Please only order what you need' It is confusing. You say at the top 'thank you for only ordering what you need', but at the footer of the poster you say, 'only order what you need'. The message is confusing and has no impact as far as I am concerned.                                                           |
| Newcastle-under-Lyme | I've been having repeat prescriptions for years and always use the same system                                                                                                                                                                                                                                                                                   |
| Newcastle-under-Lyme | Looks like nursery/ preschool poster                                                                                                                                                                                                                                                                                                                             |
| Newcastle-under-Lyme | Only answered not sure as we don't over order on medication and only get what we need                                                                                                                                                                                                                                                                            |
| Newcastle-under-Lyme | Pharmacy orders for me and I use all my tablets                                                                                                                                                                                                                                                                                                                  |
| Newcastle-under-Lyme | Say I had a surplus one month of antihistamine, so didn't order that, the next month my gp might have removed my ability to reorder the Medicines                                                                                                                                                                                                                |

|                      |                                                                                                                                                                                                                                                                                                                                                                                                                              |
|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Newcastle-under-Lyme | The last image has the greatest impact.                                                                                                                                                                                                                                                                                                                                                                                      |
| Newcastle-under-Lyme | The main campaign doesn't really get the message across. The red and green image has a far greater impact in my opinion.                                                                                                                                                                                                                                                                                                     |
| Newcastle-under-Lyme | The pharmacy and surgery deal with it but sometimes my order seems to be earlier than needed so I end up with a stock!!                                                                                                                                                                                                                                                                                                      |
| Newcastle-under-Lyme | The pharmacy looks after my repeat prescriptions, I collect every month, I never have more than a week's supply left over, usually 3/4 days. They are issued by them when the surgery releases the prescription.                                                                                                                                                                                                             |
| Newcastle-under-Lyme | The poster is too 'busy' - needs to have less words and pictures. Just highlight strap lines!                                                                                                                                                                                                                                                                                                                                |
| Newcastle-under-Lyme | The speak to your pharmacist has the most impact. Stay green!!! that doesn't have much on an impact.                                                                                                                                                                                                                                                                                                                         |
| Newcastle-under-Lyme | They do not have the Wow factor. There is nothing striking about them.                                                                                                                                                                                                                                                                                                                                                       |
| Newcastle-under-Lyme | Too confusing                                                                                                                                                                                                                                                                                                                                                                                                                |
| Newcastle-under-Lyme | Too much information with same size text and would give up after a time                                                                                                                                                                                                                                                                                                                                                      |
| Newcastle-under-Lyme | We only ever have a few days extra to cover if we can't collect on time or at Christmas                                                                                                                                                                                                                                                                                                                                      |
| Newcastle-under-Lyme | You are assuming I have only ordered what I need. How do you know I have not ordered a repeat prescription when I have several months of supply at home? Why not send a list of current medication which each patient has to return say every 6 months with their repeat prescription detailing how much medication they have stockpiled at home. That way the pharmacist could decide what needs to be ordered.             |
| South Staffordshire  | Because I am responsible enough at present to know what I need, my problem is I have to keep checking that my medication has not been reduced, I have complex co-morbidities and are on several medications. Some have been reduced and I manage but I do not manage without their being some consequence, it is too stressful to order here there and everywhere or actually get through to the surgery to speak to someone |
| South Staffordshire  | Do people actually take any notice?                                                                                                                                                                                                                                                                                                                                                                                          |
| South Staffordshire  | I do not need the reminder                                                                                                                                                                                                                                                                                                                                                                                                   |
| South Staffordshire  | I only order what I need I do not want to keep being badgered with unnecessary messages.                                                                                                                                                                                                                                                                                                                                     |
| South Staffordshire  | Message needs to be more direct.                                                                                                                                                                                                                                                                                                                                                                                             |
| South Staffordshire  | No because I only order prescriptions when I need them.                                                                                                                                                                                                                                                                                                                                                                      |
| Stafford             | Although colourful the images and words are not very impactful. "Beautiful rivers and sea" the first part of the sentence is impactful, the words "and sea" is a bit of an add on as of you couldn't progress any further without adding a few more characters.                                                                                                                                                              |
| Stafford             | Confusing. Stay green, stay safe???                                                                                                                                                                                                                                                                                                                                                                                          |
| Stafford             | Don't think advertising would influence me                                                                                                                                                                                                                                                                                                                                                                                   |

|                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stafford</b> | For people whose medication is critical, if any med should be in short supply, it is a worry that they may not have medication, eg my husband who has epilepsy, heart condition.                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stafford</b> | Have been doing it for so long it is now automatic                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stafford</b> | I already only order what I need, and do not dispose of them at home.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stafford</b> | I already order what I need as sometimes stock is a problem but also if my script changes, then I have meds to dispose of which is wasteful                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stafford</b> | I am very careful and always order what is required                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stafford</b> | I don't like wastage so don't have surplus stock of medication. The poster would not change my mind on how I order                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stafford</b> | I don't over order so it's not applicable                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stafford</b> | I don't watch adverts                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stafford</b> | I feel that I am usually on top of my supply of medication. A poster wouldn't influence me unless I had an issue.                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stafford</b> | I follow my own routine and know when I have 1-2 weeks left and only order what I need.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stafford</b> | I get my medication sent to my address via Royal Mail from Pharmacy2U but there can be some holds up from time to time, where I have to chase then because the DATES are not always kept to. So, I have to chase them to see what the holdup is to get my MEDS sent and delivered so that I don't run short. It is not good when you are waiting for the MEDS, and they don't come. I changed to Pharmacy2u because my local chemist could only deliver me half or not the full prescription. So, I had to wait sometimes over a week to get my full quota of very vital MEDS to me. |
| <b>Stafford</b> | I have been left without because of the timings for my medications. So, I would love to not over order but needs must.                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Stafford</b> | I only order what I need when I need it                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stafford</b> | I only request what I need                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stafford</b> | I probably wouldn't relate the slogans with a repeat prescription order.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stafford</b> | I rely on myself to re-order without prompting. The message would need to be more specific for me to need it.                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stafford</b> | I stick to my 28-day routine                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stafford</b> | I think people already know they should only order what is needed so already ignore advice on wastage and over ordering.                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stafford</b> | I'm Just seeing worse colour shade                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stafford</b> | I'm already ethically aware of this risks and costs to the public and environment. But aimed at other people I'm not sure the 'safe' phrase is helpful. Also need to think about where this would be seen                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stafford</b> | I'm not sure because I don't need convincing; I'm already on board with this message.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stafford</b> | In the past, family members have accumulated unwanted and unused medication due to the ordering process being in the hands of the pharmacy. If any alteration is made to the repeat prescription, items become out of sync and don't appear when they should. It was such a hassle trying to bring them back into line. Therefore, it was easier to                                                                                                                                                                                                                                  |

|                 |                                                                                                                                                                                                                                                                                                                      |
|-----------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                 | re-order everything on the list. I have always been frustrated by the waste of medication. In addition, I have known people receive the wrong items and tried to return them to the pharmacy and have been told that medications cannot be returned once they have left the pharmacy premises, even if still sealed. |
| <b>Stafford</b> | It's up to the GP to keep an eye on his patients and keep a note on what's been issued                                                                                                                                                                                                                               |
| <b>Stafford</b> | Medications on automatic repeat should be stopped as this causes wastage of meds and NHS money people should have to request medication                                                                                                                                                                              |
| <b>Stafford</b> | Multiple tablets are easier to manage if ordered at the same time especially if you are ordering many different medicines.                                                                                                                                                                                           |
| <b>Stafford</b> | My pharmacy order and receive my repeat prescriptions - I leave it to them unless there are any changes.                                                                                                                                                                                                             |
| <b>Stafford</b> | Only order what I need anyway                                                                                                                                                                                                                                                                                        |
| <b>Stafford</b> | Only order what I need, I do not stockpile.                                                                                                                                                                                                                                                                          |
| <b>Stafford</b> | Over detailed and fussy                                                                                                                                                                                                                                                                                              |
| <b>Stafford</b> | Part of the problem is that the Pharmacy do not always have the items which I need so I usually try for having at least one week's worth of the medication so that I don't get left without it. No campaign will change my view on that.                                                                             |
| <b>Stafford</b> | People tend to have a routine for prescriptions and could overstock because fearful of running out. Not sure a poster would make them think otherwise                                                                                                                                                                |
| <b>Stafford</b> | People who use the Chemist's repeat service would not pay attention as they do not think it is their problem.                                                                                                                                                                                                        |
| <b>Stafford</b> | Prescribe myself over counter meds when needed                                                                                                                                                                                                                                                                       |
| <b>Stafford</b> | Since Brexit some meds are taking longer to arrive supply shortage, they are extinct at last minute so then it gives time to go back n ask to go to prescribe something similar med. Giving 1 to 2 weeks' notice also gives leeway to gp surgery mistakes                                                            |
| <b>Stafford</b> | Some meds come as 28 days others monthly or 30 or 31 days, so sometimes discrepancy with days. Pharmacy order for a month, get 28 days but realistically need 31 for the actual month .                                                                                                                              |
| <b>Stafford</b> | The pharmacy regularly has issues getting in my prescriptions and I can also have problems collecting them (due to health condition). If I was only to order with 1 week's supply left, I would run out before I have the items ordered.                                                                             |
| <b>Stafford</b> | The picture of the hands holding medicine don't have any meaning, other than what I see                                                                                                                                                                                                                              |
| <b>Stafford</b> | The signs should read in bold letters. "Please just order what you need" Too much on any poster gets missed. It's got to hit the reader right away. Those posters are nice, but I don't think people would read them and actually take the point of the poster in.                                                   |
| <b>Stafford</b> | The system is unwieldy, very difficult to synchronise repeats for a range of meds Drs not too helpful or even over concerned with over                                                                                                                                                                               |

|                                |                                                                                                                                                                                                                                                                             |
|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                | prescribing, pharmacy tries to help but in end says sort out with your surgery.                                                                                                                                                                                             |
| <b>Stafford</b>                | The time it can take for a prescription to be processed and the frequency with which they are "mislaidd" means I'd always make sure I and my relatives have sufficient supply in hand to mitigate the risk of running out                                                   |
| <b>Staffordshire Moorlands</b> | Because I cannot order before they are due, therefore I cannot build any stock.                                                                                                                                                                                             |
| <b>Staffordshire Moorlands</b> | Common sense                                                                                                                                                                                                                                                                |
| <b>Staffordshire Moorlands</b> | Do it anyway                                                                                                                                                                                                                                                                |
| <b>Staffordshire Moorlands</b> | Don't know how many people actually take note of this type of thing - usually the responsible ones that are ordering correctly in the first place.                                                                                                                          |
| <b>Staffordshire Moorlands</b> | Don't usually bother to read notices like this. But I think people may tend to like to have a bit of extra stock in case the supply chain fails. There are sometimes shortages of medicines, and this could cause serious problems for some people if they have none spare. |
| <b>Staffordshire Moorlands</b> | I already know to order what I need                                                                                                                                                                                                                                         |
| <b>Staffordshire Moorlands</b> | I am already aware of the cost to the NHS of medicines and try to manage my own accordingly                                                                                                                                                                                 |
| <b>Staffordshire Moorlands</b> | I am already doing these things                                                                                                                                                                                                                                             |
| <b>Staffordshire Moorlands</b> | I am conscious about ordering medication and consider anyway whether I need to order it or not.                                                                                                                                                                             |
| <b>Staffordshire Moorlands</b> | I am conscious of not overordering as I think it should be addressed in general as it costs the NHS millions.                                                                                                                                                               |
| <b>Staffordshire Moorlands</b> | I am in strict control personally of my medications.                                                                                                                                                                                                                        |
| <b>Staffordshire Moorlands</b> | I can only order every 28 days anyway                                                                                                                                                                                                                                       |
| <b>Staffordshire Moorlands</b> | I don't forget now                                                                                                                                                                                                                                                          |
| <b>Staffordshire Moorlands</b> | I feel that I already follow the advice                                                                                                                                                                                                                                     |
| <b>Staffordshire Moorlands</b> | I have to get in touch every month so restricted drugs can be included in my prescription.                                                                                                                                                                                  |
| <b>Staffordshire Moorlands</b> | I know what I need and when I need it.                                                                                                                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | I live alone and take essential medication to maintain my wellbeing. My approach to essential supplies is to ensure I have sufficient to weather periods of illness or shortages in the supply chain. I keep a couple of months buffer on most medications.                 |
| <b>Staffordshire Moorlands</b> | I only order what I need, and it is used up well before any expiry date                                                                                                                                                                                                     |
| <b>Staffordshire Moorlands</b> | I only order what I need anyway.                                                                                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | I only order what I need. I assume the practice will tell me if I need to alter the prescription                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | I only order what I need. I know people who have multiple items on prescription and just repeat them every 4 weeks as there is no cost to them. This is a waste of NHS money and resources.                                                                                 |
| <b>Staffordshire Moorlands</b> | I only order what is needed now so not sure these would make a difference to me but I'm sure they might help some people                                                                                                                                                    |
| <b>Staffordshire Moorlands</b> | I order responsibly as and when I need, I would think about doing anything else                                                                                                                                                                                             |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|--------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Staffordshire Moorlands</b> | I think the worry is that might run out and have forgotten to order so poster wouldn't make a difference.                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | I would only order what needed anyway                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Staffordshire Moorlands</b> | I'm competent to order correctly                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Staffordshire Moorlands</b> | It took too much scrolling to see the complete message. At first it was not obvious what the stay safe stay well stay green logo was all about. To make it more effective for me I would need to see everything on that first image with the short statements below the pictures. Something like "Stay well, expired medicine isn't effective" "Stay safe - Know your stock and keep it away from children" "Stay green - Over-ordering creates waste. Take unused medicines back to your pharmacy." |
| <b>Staffordshire Moorlands</b> | Keep my medication under review.                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Staffordshire Moorlands</b> | My sister-in-law had repeats, she would only tick what she needed, however quite often the chemist would repeat the whole prescription. When she passed away, she had many boxes of unused meds which had to be destroyed what a complete waste of money. This also happened to a friend when she cleared out her mum's house, she had a bin bag full of pills.                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | Not aware of the campaign.                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Staffordshire Moorlands</b> | Not everyone on repeat prescriptions has children or pets so the stay safe message may not chime with all                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | Poster too cluttered, too much information and rather annoying. A simpler poster would be more effective.                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | Repeat process (time from order to collecting or delivery from pharmacy) takes two weeks. Carers usually tell me WHEN mum has run out.                                                                                                                                                                                                                                                                                                                                                               |
| <b>Staffordshire Moorlands</b> | The issue is my GP surgery do not always respond to requests I make to reduce or remove items from my repeat prescription list.                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | The issue is with the chemist not the ordering. Long delays, some items missed off order, often leaves elderly mum running very low and chasing with the chemist causing stress and going without meds                                                                                                                                                                                                                                                                                               |
| <b>Staffordshire Moorlands</b> | There is a need to order early due to shortages of certain drugs . We try not to waste items and use each one up in order                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | While I try not to over order and when I find I have a full month extra now and again, I won't order on that occasion. The biggest issue is that some of my prescriptions are 28 some 30 some come as 2 months' supply. It would be really confusing to order each prescription as and when I got down to a weeks' worth.                                                                                                                                                                            |
| <b>Stoke-on-Trent</b>          | At present I do not require a reminder however they may work for some people.                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | Because I know exactly when I need to order and I do not over order I deploy waste of any kind and especially to the NHS                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b>          | Because I no longer trust the system. For over a decade, I ordered my repeat medication once every 6 months. The system changed without notifying either me as the patient or the pharmacist. I had requested my medication as usual & went to the pharmacy to collect it to                                                                                                                                                                                                                         |

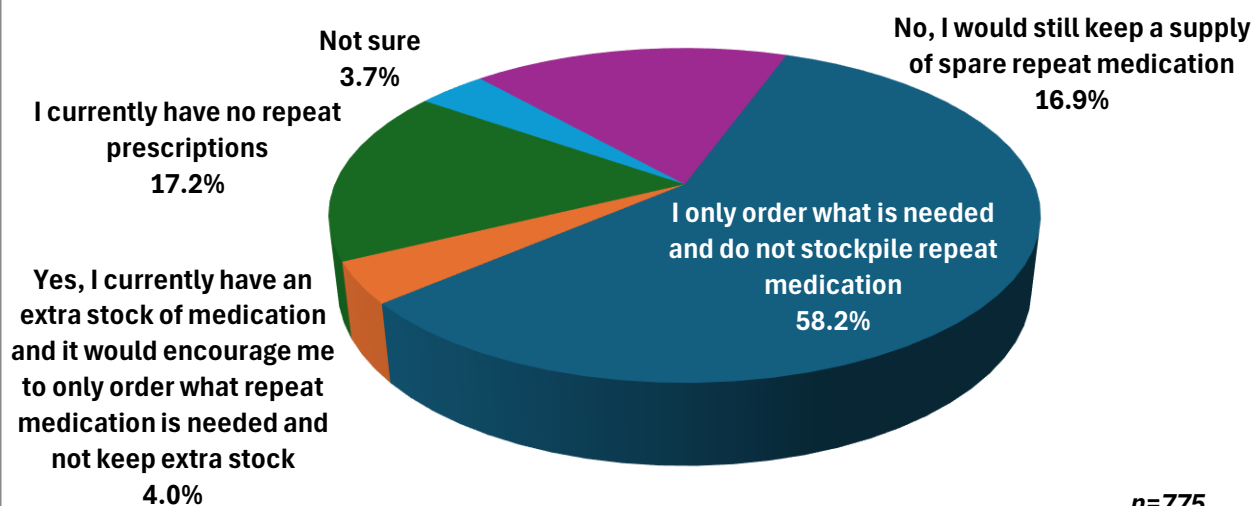
|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                       | discover it had not been prescribed. Since I only order my medication when about to run out, this left me panicking because I did not have the tablet that I am required to take daily. Patients will only listen to campaigns like this, if they trust that their medication will be there when needed. You cannot change systems without notifying patients. Your campaign needs to reassure patients that they will get their medication when needed. I now order my medication much further in advance than I previously did, so that I will have time to sort out any problems. |
| <b>Stoke-on-Trent</b> | Because I only do order what I need anyway. If I do ever find I have a few more doses than I would need, which occasionally can happen they are then used up, and I reorder that particular medication at later date than usual once I have used any spare. However, if I did need to be prompted, it would help.                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | Because I only order what is needed 1 week in advance as requested by my pharmacy                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | Because I've only ever ordered what I need.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b> | Because I already wouldn't order something I didn't need as I know it's wasteful.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | Can the posters be translated as well                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | Don't know                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | For the majority of users, I am not sure the message is clear or strong                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | How would you know I have only ordered what I needed? The 'speak to your pharmacist' image has a far better impact in my opinion.                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | I try not to over order but as been on some for a while and varying amounts some recently increased or reduced so I inform pharmacy which I am running low on and only order as needed                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Stoke-on-Trent</b> | I already do it                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | I already do this                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | I already follow this, so seeing the message wouldn't change my practice                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b> | I am responsible, find this type of messaging patronising. For example, by using 'Green' and 'helping the environment' feels like it is aimed at primary school children. My GP only prescribes if a medicine is due for ordering unless there is a reason to order early-e.g. holiday. If all GPs did this -this would be a more efficient and effective way of saving money.                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b> | I am aware if medicine waste and only order what is needed                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | I am aware of costs involved in my medications. So, try to be sensible as a point and only order as needed. I don't like waste.                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | I am capable of managing myself                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | I am capable of remembering when to order                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | I am only prescribed my exact needs for 30 days. The system seems to work very well for me.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b> | I automatically order on time just what I need when I need it                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b> | I do that anyway.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | I don't feel that I need encouraging or reminding                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |

|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|-----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | I don't over order. My experience is that people rarely pay much attention to posters they are set in their ways and ignore printed materials,                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | I don't overstock— when the pharmacist ordered I often ended up with things I didn't need. Hence, I order and only what is required                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | I generally am aware of the need to just order what I need                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | I keep all together, arranged for the 3 of them to be collected together. I am eighty-four, if I reached a stage when I might get forgetful, I would gladly allow someone else to take responsibility for ordering.                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | I know when I need to order my medication.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | I need all of my medication and creams every day                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | I only order what I am running out of prescription wise, I do not order extra or over order as I don't see the need.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b> | I only order what I need                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | I only order what I need anyway                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Stoke-on-Trent</b> | I only order what I need anyway so wouldn't take much notice of it                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | I only order when needed, so do not need advertising campaigns to remind me.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b> | I only reorder my meds when I have 7 days left. I only order earlier if I would be on holiday when next due. Once returned from holiday would only reorder when back down to 7 days' supply left.                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b> | I think the main issue is people are worried about not having any medication. Illnesses, especially long term can be quite anxiety inducing. Add to that that the system seems dysfunctional where you don't often get prescriptions on time or sometimes it takes a while for them to get approved, then people are more anxious about getting their medication. Thus, want to stockpile to make sure they are not without. This poster does not really address that. I think people would feel safer ordering and keeping just what they need if they felt they could trust the system to provide for them. |
| <b>Stoke-on-Trent</b> | I use an online pharmacy, and they will send me reminders. But I don't usually need reminding.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | I worked for the NHS for over 21 years and understand the importance of managing medication. As a former Hospital Supplies Manager, I saw the consequences of poor rotation and the waste of expired goods. I worked closely with pharmacy and witnessed similar issues. I have got into a routine of repeat ordering when I start my last box of medication.                                                                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b> | I would only order when I need anyway                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | If you stop ordering a particular prescription because you have more than you need it can disappear off your repeat prescription, so you then have the hassle of explaining to the GP surgery, yes, you do still take it etc                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b> | I'm clear in my own thoughts and actions to receive the medication when I need them. Don't waste money                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |

|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | It would not make any difference because I already order only what I need. I receive either a 1- or 2-month supply of medication and all have an expiry date well beyond 2 months so there is no wastage.                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | Medicines can change. During the prescribed time                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | My prescriptions are automatically requested by the pharmacy                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | No, as I keep a check on the amount of medication I have left.                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b> | Quite wordy but otherwise informative and useful.                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | Some tablets take time to be delivered to the chemists.                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | Sometimes prescriptions get delayed, so you need extra to make sure you have enough in case this happens.                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | Surplus of medication due to poor compliance in the past due to unsocial working hours.                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | The chemist has handed over meds that aren't even mine and some I haven't ordered, yet they refuse to take them back. I have refused some meds as not ordered - they can be pushy about giving you unwanted meds but slow and difficult to obtain meds you do want, often giving you half of one brand and a note for the remaining script which when collected is a different brand                                                                                                                                 |
| <b>Stoke-on-Trent</b> | The first one is by far the best at catching attention and highlights overordering. The others are non-descript at first glance                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | The people who over order are in my opinion elderly or automatic orders from chemists. As my own son who cannot manage his own prescriptions has his done via a chemist and they just order it all. They never ask which results in sometimes him having extra tubes of a cream he uses. We found if we contact the chemist to say pls don't order this next month they usually either ignore it or forget to order the entire script. I have friends in their 60s who order even when it's not needed just in case. |
| <b>Stoke-on-Trent</b> | There are too many users to read.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | They have too many images                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | They make no difference as I am well aware that over ordering is unnecessary                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | They're awful representations                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b> | Too many irrelevant messages. Why not just say 'please make sure you only order what medication you need'                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | We only order what we need                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Tamworth</b>       | Any right-minded person would and should only order medications that they need. I am not aware of anyone stockpiling medications?                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Tamworth</b>       | However, I prefer to have an extra week's supply in hand so that I always have enough for going away. As my medicine is essential to take daily, I dare not risk being without.                                                                                                                                                                                                                                                                                                                                      |
| <b>Tamworth</b>       | I do it myself and wouldn't need any help                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Tamworth</b>       | I hope that I can manage my wife's and my prescription - don't trust local pharmacy to order automatically                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Tamworth</b>       | I just order for a relative once a month. It is up to them to tell me if there is anything they do not require.                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Tamworth</b>       | I only order what I need.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |

|                 |                                                                                                                                   |
|-----------------|-----------------------------------------------------------------------------------------------------------------------------------|
| <b>Tamworth</b> | I take full responsibility for my health needs, so additional awareness would make no difference to me.                           |
| <b>Tamworth</b> | I'm pretty organised at repeat orders                                                                                             |
| <b>Tamworth</b> | It doesn't stand out enough.                                                                                                      |
| <b>Tamworth</b> | It would be better a phone call asking me how much of each item I have left then leaving it to the pharmacy to decide.            |
| <b>Tamworth</b> | Most chemist do not have the required medications which means it is difficult to get them. I cannot keep going down there to see. |
| <b>Tamworth</b> | My meds are important for me to take. I do not need reminding to do so.                                                           |
| <b>Tamworth</b> | My pharmacy ordered my medication for me                                                                                          |
| <b>Tamworth</b> | That is because I only order when I need to but if I wasn't as well organised it could help people                                |
| <b>Tamworth</b> | The only order what you need message needs to go at the top and needs to be given as a reminder before ordering.                  |
| <b>Tamworth</b> | Too many irrelevant messages in the poster.                                                                                       |
| <b>Tamworth</b> | Why would they make a difference?                                                                                                 |

If you keep an extra stock of repeat medicines at home (more than you need right now), would these messages encourage you to reduce your stock and only order what you need for your next prescription?



## **Key themes from respondents answering 'No' or 'Not sure' when asked if the messages would encourage them to reduce stock**

### **Supply chain anxiety**

Respondents frequently mention **delays in GP approval, pharmacy stock issues, and postal disruptions**. These concerns lead many to keep a buffer of medication to avoid running out.

"I have been 'caught out' in the past when prescription requests have not been processed promptly." "Pharmacy takes 1–2 weeks to dispense — I keep a week's supply in hand."

### **Responsible buffering**

Many respondents describe keeping **1–2 weeks of surplus** as a **safety net**, not stockpiling.

"I keep a couple of weeks in hand to allow for a possible supply issue." "I only have a two-week surplus just in case I'm not able to collect it when it's due."

### **System-level frustrations**

Issues with **automatic repeats, lack of coordination, and inflexible GP policies** are common. These system flaws often result in unintended surplus or missed prescriptions.

"My husband has lots of spare meds as they keep coming automatically even though he asked for it to stop." "I've had to chase the pharmacy multiple times — it's stressful."

### **Messaging impact and suggestions**

While some respondents say the campaign visuals are helpful, many find them **confusing, too busy, or not impactful enough**. Suggestions include clearer language and stronger calls to action.

"Too many irrelevant messages — just say 'please only order what you need.'" "The last image had the greatest impact. The main poster didn't get the message across."

### **Medication importance and risk**

Respondents with **critical conditions** (e.g. Addison's, asthma, epilepsy) express a need to **never run out**, even for a day. For them, surplus is essential, not optional.

"I cannot afford to suddenly stop taking Prednisolone." "My partner's sleep medication is crucial — we keep 7 days spare in case of delays."

| Respondent Location | If you keep an extra stock of repeat medicines at home, would these messages encourage you to reduce your stock and only order what you need for your next prescription?<br>Responses to 'No' or 'Not sure'                                                                                         |
|---------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cannock Chase       | Anxiety over running out outweighs desire to be responsible                                                                                                                                                                                                                                         |
| Cannock Chase       | As above                                                                                                                                                                                                                                                                                            |
| Cannock Chase       | As question above.                                                                                                                                                                                                                                                                                  |
| Cannock Chase       | I am elderly and occasionally miss something off my prescription, the surplus is a buffer for sorting it out.                                                                                                                                                                                       |
| Cannock Chase       | I have a regular record                                                                                                                                                                                                                                                                             |
| Cannock Chase       | I only have a two-week supply surplus just in case I am not able to collect it when it's due.                                                                                                                                                                                                       |
| Cannock Chase       | I sometimes go on holiday. In case of bad weather etc.                                                                                                                                                                                                                                              |
| Cannock Chase       | Incase of medicines shortage from the pharmacy at any time. My mum has had numerous occasions where part of her repeat prescription was not available and had to be delivered at a later date.                                                                                                      |
| Cannock Chase       | The anxiety of running out of medication due to shortages, public holidays etc far outweighs one's desire to save resources in my experience                                                                                                                                                        |
| Cannock Chase       | They may be a delay in GP authorisation or for the pharmacy to dispense which for the latter can be up to a week                                                                                                                                                                                    |
| East Staffordshire  | As above                                                                                                                                                                                                                                                                                            |
| East Staffordshire  | As above also delays and lack of availability of medication causes people to be anxious                                                                                                                                                                                                             |
| East Staffordshire  | As chemist orders not me                                                                                                                                                                                                                                                                            |
| East Staffordshire  | As its the chemist ordering not me, only found out this was going on when I got a copy of my repeat and it said I had 12 times, yet I had only had 6 months'                                                                                                                                        |
| East Staffordshire  | Because of repeated problems with GP and pharmacy in past meaning I have run out so when I did have repeats I did try and keep 2 weeks supply to mitigate this                                                                                                                                      |
| East Staffordshire  | Delays in prescription availability or not being able to collect my prescription for several days.                                                                                                                                                                                                  |
| East Staffordshire  | I am always concerned about supply issues with some medications and therefore like to keep a little ahead of my ordering to ensure I do not run out of any.                                                                                                                                         |
| East Staffordshire  | I have a couple weeks extra medication stocked, the rest I have no extra stocked, so I have to rely on it being there at the pharmacy                                                                                                                                                               |
| East Staffordshire  | I have had previous problems with medications not being ready/available                                                                                                                                                                                                                             |
| East Staffordshire  | I have Rescue Packs of medication for my repeated chest infections                                                                                                                                                                                                                                  |
| East Staffordshire  | I keep a week spare in case of delays                                                                                                                                                                                                                                                               |
| East Staffordshire  | I'm a relapsed ALL (leukaemia) patient, so I absolutely cannot risk running out of medication, and as some of it is prescribed by my treating hospital (which is a 100-mile round trip away), I'm always prescribed more than I need at any given time to save me having to travel to the hospital. |
| East Staffordshire  | Maybe the last image, but not the main poster.                                                                                                                                                                                                                                                      |

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>East Staffordshire</b>   | My reason is given in my previous answer                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>East Staffordshire</b>   | Some medications for me and my family are in short supply, and the pharmacy often has trouble getting supplies so to avoid going without (which is not an option) we keep a small amount of spare supplies of certain medications to avoid running out.                                                                                                                                                                                                                                                                                                                                            |
| <b>East Staffordshire</b>   | The images do not portray the need to waste less medicines!                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Lichfield</b>            | As previous answer                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Lichfield</b>            | Because often I get messages 'we have not been able to complete your prescription due to low stock, or unable to get stock , this is all too often                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Lichfield</b>            | For reasons stated above                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Lichfield</b>            | I have previously not been allowed to request medication before a specific repeat date, and it meant on several occasions (especially at weekends or holidays) I ran out of medication and/or required an emergency prescription. I try to keep a week or two extra to ensure that I am covered for delays, medicine shortages, and potential holidays. However, this may stop me from having a bigger supply. I also think the key headlines (stay [blank]) do not get the relevant message across. And, as a comms professional, people will likely not read the subtext if it is printed small. |
| <b>Lichfield</b>            | I keep a spare supply for Eczema treatment as can flare up at short notice and takes 6 days or more from ordering a repeat prescription to being supplied by the pharmacy. I do not keep a supply of medications for other conditions.                                                                                                                                                                                                                                                                                                                                                             |
| <b>Lichfield</b>            | I managed my own needs                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Lichfield</b>            | I think the challenges are knowing requests will be approved on time. It's taken a week for some family members prescriptions to be processed.                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Lichfield</b>            | I would only if I could guarantee to have my medication when I am week off ordering, but this is not the case                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Lichfield</b>            | Just incase there is a delay in receiving my repeat prescription.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Lichfield</b>            | One of my blood pressure medications is regularly out of stock with my pharmacy. My two-week buffer has covered me so far. Stock outages or delayed orders are a worry for some patients.                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Lichfield</b>            | People I know worry about getting repeat scripts due to delays as the doctors, so tend to ask for extra, just in case                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Newcastle-under-Lyme</b> | A variety of reasons. Sometimes I forget something, I am arthritic and can drop tablets, and because there are rumours that there can be shortages, I like to have a few extra.                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Newcastle-under-Lyme</b> | Because in the past the pharmacy has had to 'owe me' some of the heart medication                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | Because it is sometimes difficult to get the extra meds on time. If I forget to order I will be short as it takes 3 to 5 days to be delivered so I keep a week of meds spare now. Also, for some people they do not receive their repeat meds and then they have to try and get it from GP which is nigh on impossible and end up calling 111                                                                                                                                                                                                                                                      |
| <b>Newcastle-under-Lyme</b> | Because the pharmacy and surgery take charge                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Newcastle-under-Lyme</b> | For the reasons stated above. I do not have confidence I could get the drug as I needed in a timely manner                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |

1. Repeat Prescriptions. 2. Learning Disability, Down's syndrome, and Autism Awareness

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Newcastle-under-Lyme</b> | I don't want to be down to my last couple of days' worth of tablets and then find there is some problem collecting my repeat prescription.                                                                                                                                                                                                                                                                                                         |
| <b>Newcastle-under-Lyme</b> | I have medication that I cannot run out of - steroid dependent due to Addison's disease                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | I have two types of repeat medication:- Colostomy consumables - I have to keep a small surplus stock of these as my usage of the various items can vary dependent on my stoma output each day. Blood Pressure, Statin etc type medicine - This usage is easier to predict as the dose is the same every day, so I have a much smaller stock of these (Just a few days). This also helps if my dosage changes or if the pharmacy runs out of stock. |
| <b>Newcastle-under-Lyme</b> | I need to keep a couple of weeks spare incase I am ill and cannot get to the pharmacy for several days.                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | I only order what I need but have at least 2 weeks back up as it takes a week all so to process (GP straight away but chemist can take a week)                                                                                                                                                                                                                                                                                                     |
| <b>Newcastle-under-Lyme</b> | If they were life affecting medication, I would like to keep a very small number in case I forgot to order and ran out. It would be better if there was a reminder to reorder, which was automatically set when I ordered to be sent a week before I was due to run out.                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | In the past my medication has not been available                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Newcastle-under-Lyme</b> | In the past the pharmacy has not always had my medication in stock when I have ordered my repeat prescription, and I have had to collect at a later date. Since this, I have always kept a few weeks spare supply of my medication.                                                                                                                                                                                                                |
| <b>Newcastle-under-Lyme</b> | Only order what I need.                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | See above response. Only a small overlap otherwise meds could go out of date.                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Newcastle-under-Lyme</b> | There are sometimes supply issues, and medication I take cannot be stopped suddenly. Therefore, I believe keeping only 1 week in reserve allows time for the GP to be contacted if problems arise. I also ensure my stock is rotated. Suddenly stopping if there were supply issues would certainly cause more serious problems.                                                                                                                   |
| <b>Newcastle-under-Lyme</b> | Too complex advert                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Newcastle-under-Lyme</b> | Too often there has been a problem sourcing the medication needed and it is vital that there is no break in the medication being given. Without at least a week in hand we could be left without enough medication to control the condition.                                                                                                                                                                                                       |
| <b>Newcastle-under-Lyme</b> | We are told by the government to stockpile essentials such as bottled water, tinned food, candles etc, in case of a national emergency. Surely stockpiling medication should be included within this.                                                                                                                                                                                                                                              |
| <b>South Staffordshire</b>  | I have repeat medication via the post. as the postal system is currently erratic (some post is delayed over 10 days) it would be unwise to not have a couple of weeks spare medication at home. My medication doesn't change or on short expiry dates.                                                                                                                                                                                             |
| <b>South Staffordshire</b>  | I have spare inhaler for asthma so if I need one at work etc I have it. I think certain meds you might want a bit of spare capacity People who are working sometimes find it difficult to get to pharmacy and don't want                                                                                                                                                                                                                           |

|                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                            | to run out of essential meds, e.g. my husband has levothyroxine tablets, daughter had carbimazole                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>South Staffordshire</b> | If away for a holiday of 3 or more weeks I do not want the risk of running out of my medication                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>South Staffordshire</b> | Just in case I dropped them on the floor... or lost them during travelling                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stafford</b>            | Also, quite frequently now pharmacy can't get hold of meds and have to order in .so need emergency supply                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stafford</b>            | Because the pharmacy is constantly running out of medication, and I have to make repeated visits, so I would rather keep surplus so that I know I have some                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stafford</b>            | Condition varies and consequently so does usage.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stafford</b>            | For some of my medications I just have enough to last the month, and this makes me quite anxious.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stafford</b>            | I have been 'caught out' in the past when prescription requests have not been processed promptly and I have been on the verge of running out. One of my meds is Prednisolone, which I cannot afford to suddenly stop taking. Hence, I keep a couple of weeks in hand to allow for a possible supply issue.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stafford</b>            | I keep a week's supply because my pharmacy takes 1-2 weeks to dispense my prescription and I end up running out because they don't dispense in a timely manner                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Stafford</b>            | I only order what I need because there are only 28 tablets in some of the boxes.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stafford</b>            | I'm conscious of wastage of medicines                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stafford</b>            | My doctors would not allow me to over order. The member of staff who issues the prescription is very thorough and checks every prescription to make sure she does not over issue.! Chemists' assistants can also see if a prescription is due - If they pay attention to detail.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stafford</b>            | My husband has lots of spare med as it keeps coming automatically even thou he has asked for it to stop .This must be happening all over the county                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stafford</b>            | PLEASE NOTE MISSED THIS OUT IN ORIGINAL SURVEY! I have to "gauge" how long my repeat prescriptions will take to be ready at the Pharmacy before I total run out of medications. So, I submit a request online for repeat prescriptions & wait for GP approval. This is not always the same day & could take two days for approval. I then after waiting for the Pharmacy to receive my requests and make up my prescriptions. This is not a "same day" service and could take up to 72 hours before ready for collection. I am now messaged by the Pharmacy to say my meds are ready for collection. So, the whole process could take as long as 5 days from start to finish! Plus, my Pharmacy is not open Saturdays! so this could add to the wait! This is why I usually have a week's supply of meds left over to cater for this delay otherwise I could end up with no essential meds left, so hence a temporary stockpile of meds to cater for this. So, in some instances I can see levels of prescriptions building up due to this uncertainty in how long the process will take, which must vary a lot from |

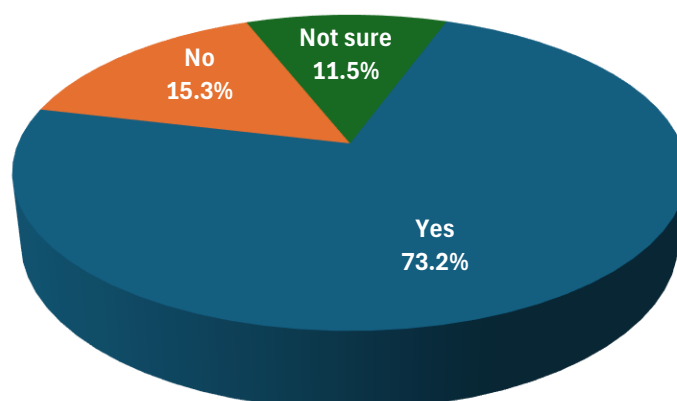
|                                |                                                                                                                                                                                                                                                                                    |  |  |
|--------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|
|                                | each GP? Unsure how this process could be simplified? In built pill tracker linked to repeat orders?                                                                                                                                                                               |  |  |
| <b>Stafford</b>                | Processing of prescriptions at GP and/or pharmacy is frequently delayed. Medication is frequently out of stock                                                                                                                                                                     |  |  |
| <b>Stafford</b>                | Repeat orders can take 1 to 2 weeks to be collected                                                                                                                                                                                                                                |  |  |
| <b>Stafford</b>                | See above.                                                                                                                                                                                                                                                                         |  |  |
| <b>Stafford</b>                | The time it can take for a prescription to be processed and the frequency with which they are "mislaidd" means I'd always make sure I and my relatives have sufficient supply in hand to mitigate the risk of running out                                                          |  |  |
| <b>Stafford</b>                | There are certain drugs that I do not need to stockpile but please see my answer above.                                                                                                                                                                                            |  |  |
| <b>Stafford</b>                | These msgs visual msgs do not encourage bcz of practicalities on ground delays or mistake from gp surgery , supply issues since Brexit, control drugs are harder to get at times and when we get them, they are short, expired dates eg paraldehyde given had 4-month expiry date. |  |  |
| <b>Stafford</b>                | While I understand this, timings between ordering or receiving my order has left me without and that is worrying                                                                                                                                                                   |  |  |
| <b>Stafford</b>                | Worrying about running out and not being able to get a prescription in time, if pharmacy cannot get the item which I've had happen several times                                                                                                                                   |  |  |
| <b>Staffordshire Moorlands</b> | Because pharmacies have been unable to get vital items that absolutely essential for me to take daily and I have been without drugs for over 2 months and have become extremely unwell as a result. Consequently, I do not ever want to be in that situation again.                |  |  |
| <b>Staffordshire Moorlands</b> | Delays in prescribing by pharmacist means that I have to keep one week's medication in hand so that I don't run out.                                                                                                                                                               |  |  |
| <b>Staffordshire Moorlands</b> | Hard to get certain items and have to wait 2 weeks sometimes before prescription is filled                                                                                                                                                                                         |  |  |
| <b>Staffordshire Moorlands</b> | I don't keep extra                                                                                                                                                                                                                                                                 |  |  |
| <b>Staffordshire Moorlands</b> | I have often not received all the items I ordered on repeat and would have been short of medicines as I have to order them again.                                                                                                                                                  |  |  |
| <b>Staffordshire Moorlands</b> | I only keep a one- or two-week extra supply. I do not hoard a load of medicine I don't need.                                                                                                                                                                                       |  |  |
| <b>Staffordshire Moorlands</b> | I take some of my meds 'as needed' not regularly and I need a small supply in hand just in case I need to take it.                                                                                                                                                                 |  |  |
| <b>Staffordshire Moorlands</b> | I think if there was a possibility to return to pharmacist more easily it would do                                                                                                                                                                                                 |  |  |
| <b>Staffordshire Moorlands</b> | I travel quite a bit and leave medication there - so I am keeping medication in two places, which is why I keep spare. Plus, I use salbutamol and a couple of the new the inhalers haven't worked properly - so ordered medication before due.                                     |  |  |
| <b>Staffordshire Moorlands</b> | I try not to keep too many in stock but equally I can't rely on that my tablets will be delivered in time as there are often delays in them being authorised by the surgery and deliveries are not made every day.                                                                 |  |  |
| <b>Staffordshire Moorlands</b> | See above                                                                                                                                                                                                                                                                          |  |  |

|                                |                                                                                                                                                                                                                                                                                                                                            |
|--------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Staffordshire Moorlands</b> | These other people would not continually reorder medication they no longer use if they had to pay for it...in my opinion GP surgeries need to review repeat prescriptions every 6 months and remove anything no longer being used. I've taken carrier bags full of unused medication back to pharmacies and consider it a widespread issue |
| <b>Staffordshire Moorlands</b> | We collect our medicines from the surgery, which is twenty minutes in the car, so I need a small stock in case the weather is bad, I'm not well or the car breaks                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | Again, as I don't trust the system to always be able to get me medication on time. 28 days also isn't a lot of meds so being able to have 2 months' worth would make me feel better about being able to manage if there were a problem or crises.                                                                                          |
| <b>Stoke-on-Trent</b>          | As explained above.                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | Because of medication shortages. All my repeat items have problematic supply issues. If I didn't have spares I would quite often run out.                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b>          | I feel more comfortable having a spare supply of medication at home. If I am not feeling too well then I do not have to make an effort to go to the pharmacy to pick up my prescription and can go another day when I am feeling better.                                                                                                   |
| <b>Stoke-on-Trent</b>          | I like to keep a small over stock in case of pharmacy supply issues as I have had this issue previously so gives me some grace if I need to request an alternative brand or if the pharmacy takes time to order items in                                                                                                                   |
| <b>Stoke-on-Trent</b>          | I order when needed now as the chemist is unreliable                                                                                                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b>          | In the past some medication was in short supply, and you had to wait for the stock to come back in.                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | It's becoming increasingly common for pharmacies to experience delays in obtaining some drugs. I think keeping a small extra amount makes practical sense                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b>          | See answer above. Patients need to trust the system                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | Sometimes I go abroad and it's so much fuss for the GP practice to be given more than the standard 28 days - so it's so much easier to have a small buffer stock                                                                                                                                                                           |
| <b>Stoke-on-Trent</b>          | Sometimes takes longer for prescription to arrive. Also sometimes need to order early for going on holiday.                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b>          | Sometimes there is a surplus because of the calendar dates I. E. 28 tablets issued per month but more days in a month than 28 so they never run perfectly.                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | Takes too long sometimes to receive and don't want to be left without                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b>          | The medication my partner is taking is crucial to his sleep and wellbeing, and we cannot risk him going without even if it's only for 1 day. We keep the extra stock reasonable (about 7days worth) in case of post or GP delays which have happened before                                                                                |
| <b>Stoke-on-Trent</b>          | Things can go wrong with supply so, a backup is sensible                                                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | Why do pharmacies not receive any back, e.g. when you change a medication or stop that surely is wasteful told in the past to throw them away, I can understand running out of date, but some are more than 6                                                                                                                              |

|                 |                                                                                                                                                                                                 |
|-----------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                 | months left on them. That is wasteful! so long as they are unopened and still on date sealed if in bottle! Always thought that stupid but as been the rule all the time I've been on medication |
| <b>Tamworth</b> | Due to the chemist not always having the required medications.                                                                                                                                  |
| <b>Tamworth</b> | I do not order more than I need so not applicable to me                                                                                                                                         |
| <b>Tamworth</b> | I keep extra in case of emergency.                                                                                                                                                              |
| <b>Tamworth</b> | I only have 2 or 3 tablets in case I don't get my repeat in time                                                                                                                                |
| <b>Tamworth</b> | Sometimes takes ages for gp to issue prescription. Also, meds out of stock occasionally                                                                                                         |

Below are three messages to encourage people to take unused medicines back to their pharmacy.

Would these messages encourage you to take unused medicines back to your pharmacy?



n=764



Three messages to encourage people to take unused medicines back to their pharmacy

## **Key themes from respondents answering 'No' or 'Not sure' when asked "Would these messages encourage you to take unused medicines back to your pharmacy?"**

### **Barriers to returning medication**

Many respondents tried to return unused medication but were refused by pharmacies.

- reasons include: not being the original dispenser, lack of space, or unclear policies
- this leads to frustration, confusion, and sometimes inappropriate disposal.

### **Clarity and visibility of messaging**

The phrase "Take them to your pharmacy" is often seen as too small, vague, or passive.

- suggestions include using bold fonts, red crosses on incorrect disposal methods, and clearer positive framing
- visual hierarchy and message placement are critical—many want the "correct action" to be the dominant message.

### **Need for education and explanation**

Respondents want to understand *why* proper disposal matters.

- lack of information about what happens to returned medication leads to scepticism and disengagement
- requests for statistics, environmental impact, or NHS cost implications were common.

### **Accessibility and convenience**

Housebound individuals, those with disabilities, or people using online pharmacies face logistical challenges.

- suggestions include drop-off boxes, supermarket collection points, or simplified return processes
- some feel embarrassed returning large quantities or medication for deceased relatives.

### **Existing responsible behaviors**

A significant portion already returns medication properly and sees the messaging as redundant.

- however, many acknowledge that others may benefit from reminders or clearer guidance
- there's a call for standardization across pharmacies to reduce confusion and improve uptake.

| Respondent Location       | Would these messages encourage you to take unused medicines back to your pharmacy?<br>Responses to 'No' or 'Not sure'                                                                                                                                                                                               |
|---------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Cannock Chase</b>      | I already know the correct disposal method - a pharmacy                                                                                                                                                                                                                                                             |
| <b>Cannock Chase</b>      | I do that anyway, but pharmacy refuses to dispose of them                                                                                                                                                                                                                                                           |
| <b>Cannock Chase</b>      | I do this already if I find I have extra building up.                                                                                                                                                                                                                                                               |
| <b>Cannock Chase</b>      | I return what I no longer need anyway. Don't like to waste medicine.                                                                                                                                                                                                                                                |
| <b>Cannock Chase</b>      | I take them already                                                                                                                                                                                                                                                                                                 |
| <b>Cannock Chase</b>      | I would feel embarrassed taking several months of stockpiled medication back to a pharmacy. When an elderly relative died, I found a large stockpile of medication, but due to the amount, was too embarrassed to return to the pharmacy.                                                                           |
| <b>Cannock Chase</b>      | I wouldn't get rid of medicines inappropriately                                                                                                                                                                                                                                                                     |
| <b>Cannock Chase</b>      | It would be better to know what happens to medication when returned to the pharmacy. Perhaps a poster stating how much unused medication has been returned locally and what has been done with that medication. That would have a far greater impact.                                                               |
| <b>Cannock Chase</b>      | It would encourage me to return unused medication, but I would like to know what happens to returned medication.                                                                                                                                                                                                    |
| <b>Cannock Chase</b>      | There isn't enough of a "why" - tell people about the impact of not doing so or the benefits of doing so                                                                                                                                                                                                            |
| <b>East Staffordshire</b> | Because Chemist's are reluctant to take back unused medication. Tried to take back medication to County Hospital Pharmacy that they had dispensed, they would not take it back as they said they had no means of disposal. Tried to take it to another pharmacy who would not take it as they had not dispensed it. |
| <b>East Staffordshire</b> | Because I am housebound and can't take unused medication anywhere                                                                                                                                                                                                                                                   |
| <b>East Staffordshire</b> | Clear to not throw away but not to take to pharmacy instead                                                                                                                                                                                                                                                         |
| <b>East Staffordshire</b> | Everyone knows they can't be reissued which is unfortunate really. I don't end up with any unused medication                                                                                                                                                                                                        |
| <b>East Staffordshire</b> | I always return unused medications to the pharmacy (and veterinary pharmacy). The posters would remind others to do this though.                                                                                                                                                                                    |
| <b>East Staffordshire</b> | I am regimented in my approach to sorting out and disposing of old or unsuitable medications to the pharmacy. I would say they are a good reminder to some people though.                                                                                                                                           |
| <b>East Staffordshire</b> | I do already or to boots                                                                                                                                                                                                                                                                                            |
| <b>East Staffordshire</b> | I do it automatically                                                                                                                                                                                                                                                                                               |
| <b>East Staffordshire</b> | I don't tend to have unused medication                                                                                                                                                                                                                                                                              |
| <b>East Staffordshire</b> | I don't have any unused medication                                                                                                                                                                                                                                                                                  |
| <b>East Staffordshire</b> | I don't need to be told this. If I have anything that will NEVER be used again then I take it back to the pharmacy.                                                                                                                                                                                                 |
| <b>East Staffordshire</b> | I have great difficulty disposing of unused EpiPens and have to go the hospital as my pharmacy won't take them.                                                                                                                                                                                                     |
| <b>East Staffordshire</b> | I never bin unwanted medicines nor chuck them down the sink/toilet. Though some may lurk in drawers!                                                                                                                                                                                                                |
| <b>East Staffordshire</b> | I never knew I could take unused medicine back to pharmacy                                                                                                                                                                                                                                                          |

|                           |                                                                                                                                                                                                                                                                                                  |
|---------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>East Staffordshire</b> | I'd like to know what happens to unused medication when returned.                                                                                                                                                                                                                                |
| <b>East Staffordshire</b> | I'm regimented in my sorting and disposing of old or unsuitable medications to a pharmacy, but I'd imagine that they would prove a good idea to remind people.                                                                                                                                   |
| <b>East Staffordshire</b> | Images will not make much difference in my opinion                                                                                                                                                                                                                                               |
| <b>East Staffordshire</b> | Needs to explain why                                                                                                                                                                                                                                                                             |
| <b>East Staffordshire</b> | Nothing mentioned regarding bringing this back                                                                                                                                                                                                                                                   |
| <b>East Staffordshire</b> | People of a certain age tend to get, forgetful they forget why they went upstairs, where their glasses are etc, these images may make them think about disposing of excess medication responsibly, but they may not remember to do it.                                                           |
| <b>East Staffordshire</b> | The one time I returned medication (reaction to antibiotic) the overreaction of the pharmacist caused me embarrassment                                                                                                                                                                           |
| <b>East Staffordshire</b> | What happens when I return unused medication? That would have a greater impact in deciding whether to return or bin unused medication.                                                                                                                                                           |
| <b>East Staffordshire</b> | You need a big Red Cross through each image to show people what not to do.                                                                                                                                                                                                                       |
| <b>Lichfield</b>          | Do not help neurodivergent people                                                                                                                                                                                                                                                                |
| <b>Lichfield</b>          | Don't know what happens to them when you take them back e.g. can they be used for someone else etc                                                                                                                                                                                               |
| <b>Lichfield</b>          | I already do                                                                                                                                                                                                                                                                                     |
| <b>Lichfield</b>          | I already take unused medicines to my pharmacy.                                                                                                                                                                                                                                                  |
| <b>Lichfield</b>          | I always take unused medicines back to the pharmacy anyway.                                                                                                                                                                                                                                      |
| <b>Lichfield</b>          | I am already aware that I should only dispose of medicines via the pharmacy and always do so.                                                                                                                                                                                                    |
| <b>Lichfield</b>          | I think there should be a last picture saying drop your unused medication back to the pharmacy                                                                                                                                                                                                   |
| <b>Lichfield</b>          | I would do it anyway, but I know that they are thrown away- what a waste                                                                                                                                                                                                                         |
| <b>Lichfield</b>          | I would feel embarrassed taking unused medication back to the pharmacy.                                                                                                                                                                                                                          |
| <b>Lichfield</b>          | I'm not sure why people would put medication down the toilet - feels random                                                                                                                                                                                                                      |
| <b>Lichfield</b>          | I'd like to know what happens when I return unused medication. Is it reused, thrown in the bin, etc?                                                                                                                                                                                             |
| <b>Lichfield</b>          | It would be interesting to know what happens to unused medication that is returned. If the pharmacy is just going to dispose of the medication and not reuse them, I may as well just throw in the bin rather than making a trip to the pharmacy.                                                |
| <b>Lichfield</b>          | Pharmacy's not always willing to take back used medicines. Eg our bin is full. Come back in a couple of weeks. Some won't take some hospital issued products. We need a very clear instruction and guide from the NHS on disposal routes AND the folly of disposing in the bin or down the sink. |
| <b>Lichfield</b>          | Should say take all medicines to pharmacists clearly                                                                                                                                                                                                                                             |
| <b>Lichfield</b>          | They would work on only small percentages due to the lower impact these marketing strategies have.                                                                                                                                                                                               |

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Lichfield</b>            | Tricky as more convenient to throw in through bin                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Lichfield</b>            | Very effective clear simple message.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Lichfield</b>            | What happens when someone returns unused medication, is it reused or just thrown out by the pharmacy.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Newcastle-under-Lyme</b> | Again, I don't need reminding to take unused medicines back, but again some people would benefit from reminders. Sadly, with the government's lack of progress in controlling drug taking a lot of people would try to sell any excess drugs.                                                                                                                                                                                                                                                                                                                                                                |
| <b>Newcastle-under-Lyme</b> | As before, my professional background means that I would always return unused medication to the pharmacy for disposal. One element of these messages which is missing, is an explanation of why these three things shouldn't be done, and as such they come over as being very directive. A far more effective strategy is to educate and encourage, thus allowing people to take ownership of the decision to act in a responsible way.                                                                                                                                                                     |
| <b>Newcastle-under-Lyme</b> | Because I do always take unused medication and empty inhalers back to the pharmacy... sometimes they won't take it as they have too much.                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Newcastle-under-Lyme</b> | Don't have spare tablets                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Newcastle-under-Lyme</b> | Don't stockpile                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Newcastle-under-Lyme</b> | FYI, I have seen folks take medicines back to two different pharmacies ....<br>1. one just accepted the bag of item 2. and the other, required every item to be listed and paperwork to be completed regarding what it was, who it belonged to, when it was issued, when it was last used, etc. In the latter case, the drugs used to be taken by someone who had died which made the whole process even harder. It might encourage folks to return old drugs if the process was standardised and simple and did not assume that the person returning the drugs was the person to whom they were prescribed. |
| <b>Newcastle-under-Lyme</b> | Have return unused medicine to the pharmacy after I checked with the GP Surgery it was ok to do so                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | I already know to return to the pharmacy It could be clearer if the consequences were explained                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Newcastle-under-Lyme</b> | I already take unused meds to the pharmacy. I think the ad should explain simply why ppl should not dispose of them in other ways                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | I do not keep extra meds                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Newcastle-under-Lyme</b> | I do that anyway.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | I don't have unused medicines                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Newcastle-under-Lyme</b> | I don't have unused medication, but if I did, I would take it back to the pharmacy anyway, as I am aware of how they should be disposed of.                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | I think the main message should be bolder and at the top 'take meds back to pharmacy' then the image telling you what not to do                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Newcastle-under-Lyme</b> | I think the writing telling me to take them to pharmacy should be bigger and bolder not smaller than the writing telling me what I shouldn't do.                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Newcastle-under-Lyme</b> | I tried that before and the pharmacy would not accept them                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Newcastle-under-Lyme</b> | I would return unused medication without being reminded                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Newcastle-under-Lyme</b> | If there were my own medication, I would probably keep them just in case I needed them in the future.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |

|                             |                                                                                                                                                                                                                                                                                                     |
|-----------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Newcastle-under-Lyme</b> | It would be good to know what happens to unused medication once returned.                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | No, because I always do anyway.                                                                                                                                                                                                                                                                     |
| <b>Newcastle-under-Lyme</b> | Not seen any of these in my pharmacy.                                                                                                                                                                                                                                                               |
| <b>Newcastle-under-Lyme</b> | People that do have them, have them as a buffer. Drugs can go out of supply without warning. That's what others say. I suppose, I risk it, because I don't have a reserve. Perhaps they are sensible n I'm not                                                                                      |
| <b>Newcastle-under-Lyme</b> | People would feel guilty about amassing medication and put in bin                                                                                                                                                                                                                                   |
| <b>Newcastle-under-Lyme</b> | Sounds awful but life is busy, I wouldn't go out of my way to a pharmacy, I order my medication online, I'd want to be able to drop any unused medication if I had any at a more convenient location e.g. a supermarket                                                                             |
| <b>Newcastle-under-Lyme</b> | They need a message underneath to say what happens to the medicines once returned. If they are reused, then I would be far more likely to return unused medicines.                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | They're good but 'take them to your pharmacy' needs to be much bolder because it's very easy to miss it.                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | Would only see them when picking up script                                                                                                                                                                                                                                                          |
| <b>South Staffordshire</b>  | Again, does anyone take any notice                                                                                                                                                                                                                                                                  |
| <b>South Staffordshire</b>  | I feel safer and at ease to keep a spare pack of medicine                                                                                                                                                                                                                                           |
| <b>South Staffordshire</b>  | No, because I already take unwanted medicines to the pharmacy. However, what could be promoted is that they will only take the medications not the box they come in if it contains personal information.                                                                                            |
| <b>Stafford</b>             | 'Take them to your pharmacy' is not clear enough - needs to be said once and in large bold font                                                                                                                                                                                                     |
| <b>Stafford</b>             | Again, a simple message would be better.!!! Black and White sign. "URGENT Please take unwanted / unused medications back to your chemist " Simple but effective if you make it bold. Possibly use  sign.       |
| <b>Stafford</b>             | Do it anyway                                                                                                                                                                                                                                                                                        |
| <b>Stafford</b>             | I already do so, although even if unopened or refused at point of delivery, they are destroyed. Total waste of NHS money.                                                                                                                                                                           |
| <b>Stafford</b>             | I do this anyway with basic medicine cabinet items such as paracetamol, or if one of my prescription items is changed and I have unused tablets. There's no advantage in cluttering storage places with unnecessary items.                                                                          |
| <b>Stafford</b>             | I don't have enough unused medicines to make this worthwhile.                                                                                                                                                                                                                                       |
| <b>Stafford</b>             | I don't really have any to dispose of                                                                                                                                                                                                                                                               |
| <b>Stafford</b>             | I have tried to take tablets back to the pharmacy, but they won't take open boxes.                                                                                                                                                                                                                  |
| <b>Stafford</b>             | I like the advert, but I fetch from the chemist and may forget the old ones                                                                                                                                                                                                                         |
| <b>Stafford</b>             | I think that these PICTURES speak louder than words, And HELP those who are nonverbal to understand instructions better and can try to incorporate them into their routines, like people who are the AUTISTIC Spectrum or have Hidden Disabilities like Brain Damage or ABBI Acquired Brain Injury. |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stafford</b>                | I think the message needs to be clearer that medicines should be returned to the pharmacy that issued them as others may not accept them.                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stafford</b>                | I willingly take unused medication back                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stafford</b>                | I would feel embarrassed to hand it over at the counter. A secure anonymous drop off box would be more welcoming.                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stafford</b>                | I would only dispose of meds no longer required by returning them for safe disposal. You never know who might be rooting round your bin, at the recycling/disposal centre etc and some meds are dangerous to the wrong person.                                                                                                                                                                                                                                                                                              |
| <b>Stafford</b>                | It would be good to know why in the pictures                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stafford</b>                | Needs an explanation of why I should take back to the pharmacy, what's the impact if I did flush them or pour them away?                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stafford</b>                | None of them tell you to return unused medication to the Pharmacist                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stafford</b>                | On the rare occasion I might have any I always return them to my pharmacy                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stafford</b>                | People are not aware of correct disposal and will just throw in the bin as they feel the medication is of no use for anyone                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stafford</b>                | People need a reason why they shouldn't. A shocking statistic and something to induce guilt and to motivate people to drop medication back to the pharmacy.                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stafford</b>                | Take medication back anyway                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stafford</b>                | The pictures would suggest to me to do the opposite to that intended!                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Stafford</b>                | When I have tried, they have refused to take them as "they are full at the moment and have no room for them"                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Staffordshire Moorlands</b> | Already aware of disposal via pharmacy.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Staffordshire Moorlands</b> | Already returned unwanted items                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Staffordshire Moorlands</b> | As above                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Staffordshire Moorlands</b> | Because the pharmacy just throws them away even though they have not been opened. Indeed, once I came out of the pharmacy with a prescription, opened the bag it was in to check it, realised I had been given a wrong prescription, took it back. They said they would have to throw it away as it had been taken out of the pharmacy. This is an appalling waste. I know that if you take medicines back because you no longer need them, they just get thrown away. It is shocking. No wonder the NHS is in such a state |
| <b>Staffordshire Moorlands</b> | But the last time I did that the pharmacy said that they couldn't take them as they had too many already.                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Staffordshire Moorlands</b> | Don't stockpile                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Staffordshire Moorlands</b> | I already return any to the pharmacist.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Staffordshire Moorlands</b> | I already take any unused medicines back to the pharmacy                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Staffordshire Moorlands</b> | I always return unwanted items to the pharmacy.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Staffordshire Moorlands</b> | I have taken medicines back in the past that have been wrongly prescribed and been told they would have to go in the bin even though packets unopened and need no special storage - this does not inspire one to return medicines!                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Staffordshire Moorlands</b> | I think some people aren't aware that you can return medication                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Staffordshire Moorlands</b> | I think they might encourage me but what I see at first glance is the image of a bin, sink and toilet. The images of medications are not at all clear so at a first glance I might not realise what you are trying to tell me. Also, so that the message is more clear could you place a big X on them to show visually that these three places are NOT where medications should go. As it stands, for those not reading the words the images may be mistaken for permission to get rid of old medications in these places. I also think that the message about where to take the medicines should be at least equal in size to the images of what not to do. I've read somewhere that our brains don't process negative messages effectively so rather than starting with "don't do this" which is a negative message why not say "Take your unused medicines to the pharmacy" in big text (positive message). then in smaller text Never put them in your bin, or flush down the sink or toilet" |
| <b>Staffordshire Moorlands</b> | I would hope so but I'm not sure my pharmacy would take them back                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Staffordshire Moorlands</b> | It may prompt me to make sure I don't have too many in stock.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | It would be good if you also mention returning used inhalers to the pharmacy                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Staffordshire Moorlands</b> | Maybe 'Don't put unused medicines anywhere apart from the pharmacy' with images of each of the above with a Red Cross against them                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Staffordshire Moorlands</b> | Message tells you three do nots but the message to indicate what you should do is too small and insignificant. I would reverse the message, with take extra medications to your pharmacy bold/ main message, then smaller don't flush them down the toilet.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Staffordshire Moorlands</b> | My pharmacy doesn't take medication back                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Staffordshire Moorlands</b> | Never have unused medication.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | Not me people I know.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Staffordshire Moorlands</b> | Pharmacy has refused to take unused meds back previously as not dispensed by them.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Staffordshire Moorlands</b> | Those messages are negatives; the brain and person will react better if the message is... Take your unused medicines to your pharmacist in LARGE letters, not small and put red x's across the graphics i.e. the picture. Much more user friendly to the brain. Show a pharmacy sign with a tick too.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

|                                |                                                                                                                                                                                                                                                                                                     |
|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Staffordshire Moorlands</b> | Unused medication is returned to practice pharmacy.                                                                                                                                                                                                                                                 |
| <b>Staffordshire Moorlands</b> | When a relative who was on a lot of medications died, the pharmacy was not pleased to accept them                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | A lot of pharmacies won't have them back -tell you flush them down the loo. Is that still the relevant practice.                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b>          | Already follow that advice.                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | Because its already do this.                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | But they can be reluctant                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b>          | Do really think about it, or have time                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | Don't have any to dispose of                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | Don't think, they high mark, I know to take unwanted medicines back to the pharmacy                                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | I already aim to return unused medication provided in error.                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | I already know that information                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b>          | I already take unwanted medication back to the pharmacy                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b>          | I am already aware of how to safely dispose of medicines                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b>          | I am capable of dealing with medications and, I do not overstock to a large amount                                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b>          | I don't have unused medication                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b>          | I have experienced this and am I intelligent process of carrying out return of the medicine                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | I know already the correct way to dispose of medication is via the chemist                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | I know to take any unused medication to the chemist's.                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | I like to have spare medication in case there's a shortage.                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | I never have any unused medication to get rid of.                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | I never have unused medication                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b>          | I return medication to the pharmacy e.g. controlled medication patches when I need to.                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | I think I would do this anyway but there is no incentive. It doesn't make it any easier for disabled or those with additional needs to drop of extra medication. Those who often can't get to the pharmacies in the first place. It doesn't make the process any easier it just tells you to do it. |
| <b>Stoke-on-Trent</b>          | I tried taking unused medicines (belonging to a deceased relative) to a pharmacy and I received the impression they weren't happy about it. What would really help would be notices displayed in pharmacies saying 'Return unused medicines here, we're happy to help' or something on those lines. |
| <b>Stoke-on-Trent</b>          | I would always take back unused medication for disposal. Cared for a friend for years and was shocked that there seemed little interest in the fact he was often believed of medication he did not need despite my repeatedly reporting it.                                                         |
| <b>Stoke-on-Trent</b>          | I would do this anyway                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | I would normally take them back if I had any                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | I'm told if I take them back, they are not re-used they are simply disposed of                                                                                                                                                                                                                      |

|                       |                                                                                                                                                                          |
|-----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | It would make me think twice about medication disposal but type not bold enough to take it to a pharmacy                                                                 |
| <b>Stoke-on-Trent</b> | I've tried to take unused medicines back to a pharmacy, but they refuse to take them                                                                                     |
| <b>Stoke-on-Trent</b> | Not me personally, but I think the message needs to say WHY medications MUST be returned to a pharmacy.                                                                  |
| <b>Stoke-on-Trent</b> | Not me personally. I have a background in healthcare, and I am aware that any unused medications can be disposed of by returning to the pharmacy.                        |
| <b>Stoke-on-Trent</b> | Not sure if I would take any notice, it's common sense, maybe.                                                                                                           |
| <b>Stoke-on-Trent</b> | Pharmacy returns are just disposed of and un re-useable                                                                                                                  |
| <b>Stoke-on-Trent</b> | Pharmacy will not accept any issued back they only put them in bin                                                                                                       |
| <b>Stoke-on-Trent</b> | The words Take them to your Pharmacy should be more prominent and Pharmacy replaced with the word Chemist.                                                               |
| <b>Stoke-on-Trent</b> | There needs to be a reason why, which none of the posters have.                                                                                                          |
| <b>Stoke-on-Trent</b> | These images would need to be on large billboards to have an impact as unless you go the pharmacy or gp surgery they would not be seen by the people you need to target. |
| <b>Stoke-on-Trent</b> | They tell me that they won't accept unused Medicine once it has left the premises.                                                                                       |
| <b>Tamworth</b>       | Already taken unused meds back to chemist.                                                                                                                               |
| <b>Tamworth</b>       | Because I always return to pharmacy and never put down toilet sink or in refuse.                                                                                         |
| <b>Tamworth</b>       | Easier to dispose. What would be better would be a deposit system that you get back if you return them.                                                                  |
| <b>Tamworth</b>       | Have attempted to return medication to pharmacy to be told they were unable to take it.                                                                                  |
| <b>Tamworth</b>       | I don't over order                                                                                                                                                       |
| <b>Tamworth</b>       | We don't have any unused medicines                                                                                                                                       |
| <b>Tamworth</b>       | Why would they make a difference?                                                                                                                                        |

## Which of the text messages about repeat prescriptions do you prefer?

### Text message A

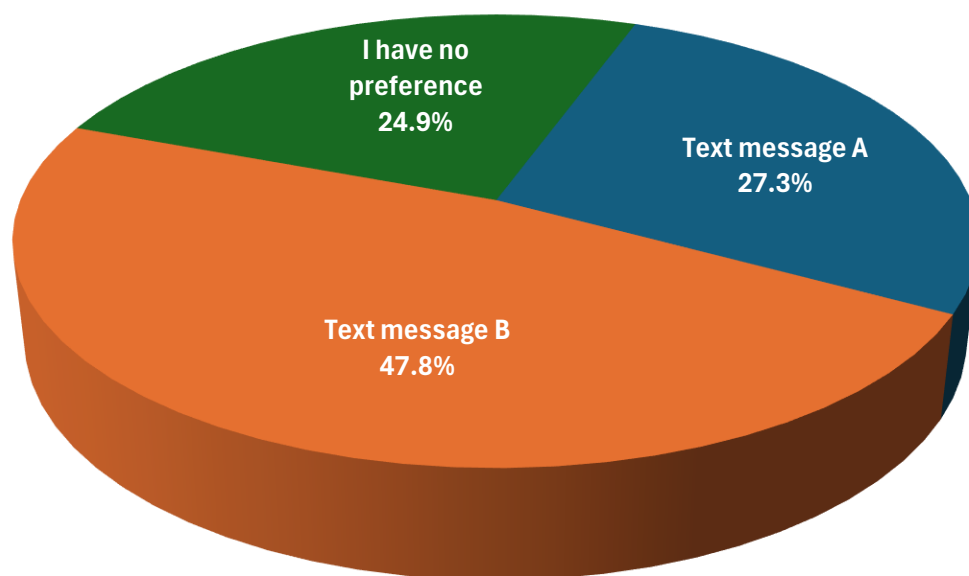
📱 By only ordering what you need on your repeat prescription, you're helping the NHS reduce medicine waste and protect the environment.  
Find out more at [staffsstokeics.org.uk/only-order-what-you-need](https://staffsstokeics.org.uk/only-order-what-you-need).

### Text message B

📱 Did you know you can help your local NHS to reduce medicines waste by only ordering what you need on your repeat prescription?  
Thank you for your support.

For more information, please visit [staffsstokeics.org.uk/only-order-what-you-need](https://staffsstokeics.org.uk/only-order-what-you-need).

## Which of the text messages about repeat prescriptions do you prefer?



n=768

## Learning Disability, Down's syndrome or Autism Awareness

Over the past 12 months, the Integrated Care Board (ICB) has been working with partners across the system to make Staffordshire and Stoke-on-Trent as open and inclusive as possible for people with Learning Disabilities or Down's syndrome, and Autistic people.

This summary presents key insights from the 2024 and 2025 experience data, highlighting year-on-year changes in communication, safety, accessibility, and public sentiment across health, social care, and community services. The findings reflect the voices of individuals and carers across Staffordshire and Stoke-on-Trent, and offer a clear view of where services are improving — and where further attention is needed.

The data informs the ICB's ongoing commitment to inclusive design, responsive communication, and equitable treatment. It supports strategic planning across NHS and partner organisations, helping us shape services that are not only effective, but trusted and accessible to all.

The following set of questions could be answered by either a person with a Learning Disability, Down's syndrome, Autistic people, or a friend, relative or carer, based on their observations or experiences.

**This section of the survey was answered by 185 respondents.**

### **Making services more inclusive: What people told us**

The 2025 Learning Disability, Down's Syndrome and Autism Awareness Survey highlights measurable progress across key public services, with improvements in communication, staff awareness, and perceptions of safety.

Compared to 2024, respondents reported greater confidence in raising concerns and accessing support, particularly within social care, education, and local authority settings. However, the findings also reveal persistent challenges in public space safety and equitable treatment across NHS and benefits services.

These insights provide a clear direction for targeted action, reinforcing the importance of inclusive practice, cross-sector collaboration, and continued investment in staff training and public engagement.

## **Summary of key changes: 2025 vs 2024 awareness survey**

### **Communication improved**

 Local Authority,  Police, and  Schools made the biggest gains in meeting communication needs — reflecting more inclusive, accessible messaging.

▲ Local Authority (+15.9%) ▲ Police (+10.9%) ▲ Schools (+11.0%)

### **Awareness of disabilities increased**

Staff understanding of autism, learning disabilities, and Down's syndrome improved across  Housing,  Local Authority, and  Hospital Services — supporting more inclusive service delivery.

▲ Housing (+22) ▲ Local Authority (+18) ▲ Hospital Services (+14)

### **Safety perceptions strengthened**

Care environments feel safer, but public spaces still raise concern.

 Social Care (+14),  Educational Settings (+12), and  Home Environments (+18) saw notable improvements. 🌙 Public spaces after dark remain a concern (–8).

### **Feedback channels more accessible**

 Ambulance Service,  Police, and  Local Authority improved ease of raising concerns — empowering users to speak up and be heard.

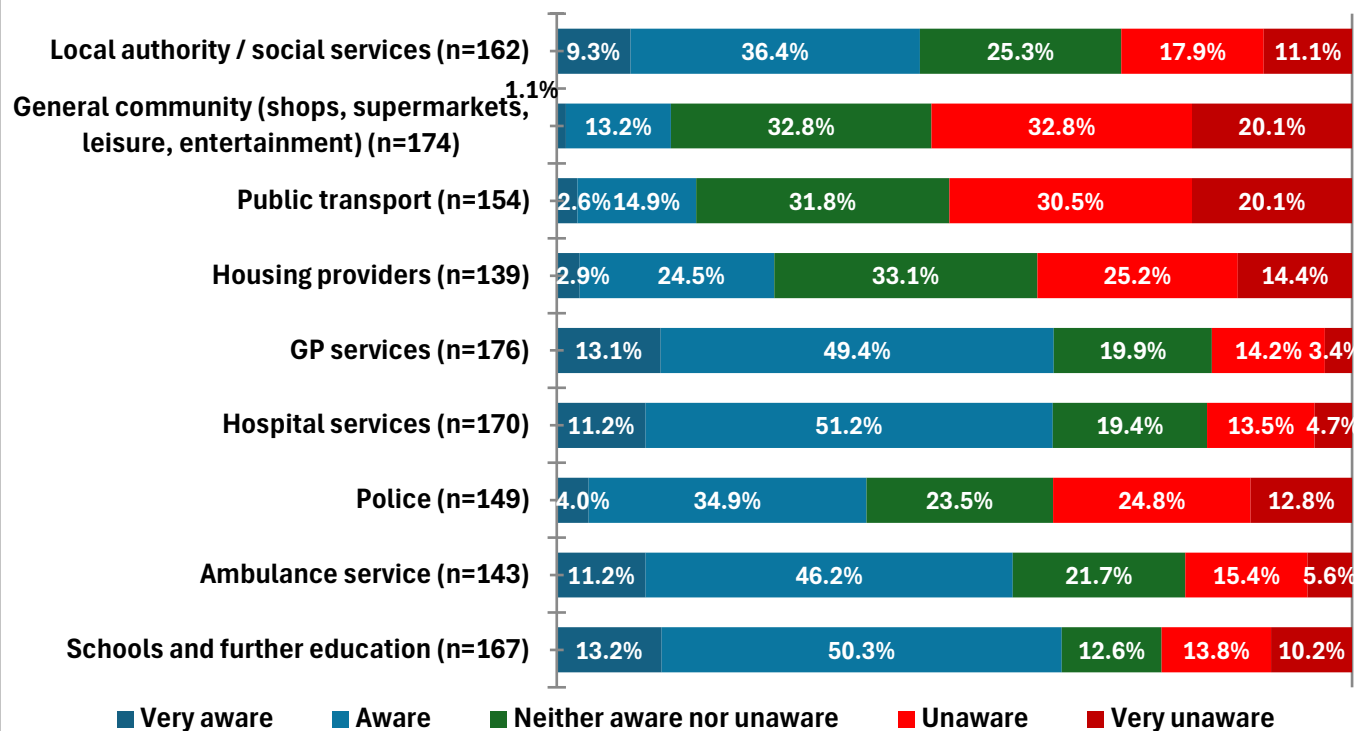
▲ Ambulance (+15) ▲ Police (+13) ▲ Local Authority (+13)

### **Equality of treatment remains mixed**

 Social Care and  Housing improved slightly, but  Benefit Departments and  NHS services showed uneven or declining scores — highlighting areas for targeted improvement.

▲ Social Care (+2) ▼ NHS (–1) ▼ Benefit Departments (–2)

### How aware do you feel the following organisations are in supporting a person with a Learning Disability, Down's Syndrome or Autism?



Figures exclude respondents who answered "Not applicable" or "Don't know".

### How aware do you feel the following organisations are in supporting a person with a Learning Disability, Down's syndrome or Autism?

| Sector / Service                                   | NPS 2024 | NPS 2025 | Change |
|----------------------------------------------------|----------|----------|--------|
| Schools & Further Education                        | 28       | 40       | ▲ +12  |
| Ambulance Service                                  | 33       | 36       | ▲ +3   |
| Police                                             | 0        | 1        | ▲ +1   |
| Hospital Services                                  | 30       | 44       | ▲ +14  |
| GP Services                                        | 33       | 45       | ▲ +12  |
| Housing Providers                                  | -34      | -12      | ▲ +22  |
| Public Transport                                   | -41      | -33      | ▲ +8   |
| General Community (Retail, Leisure, Entertainment) | -26      | -39      | ▼ -13  |
| Local Authority / Social Services                  | -1       | 17       | ▲ +18  |

Net Promoter Scores (NPS) for 2024 vs 2025 across key public service sectors

## **Key themes from respondents answering 'Unaware' or 'Very unaware' to organisations supporting a person with a Learning Disability, Down's syndrome or Autism**



### **Lack of neurodiversity awareness across services**

- many respondents describe poor understanding of autism, ADHD, and learning disabilities in schools, hospitals, police, and social services
- staff often rely on stereotypes or dismiss symptoms as part of a diagnosis, leading to miscommunication and inadequate care
- hidden disabilities frequently overlooked, especially when individuals mask.



### **Inconsistent and inappropriate treatment in healthcare settings**

- hospitals and GP surgeries are repeatedly cited for failing to adjust communication styles or environments for neurodivergent patients
- examples include ignoring sensory needs, dismissing symptoms, or failing to read visible indicators like lanyards
- e-learning and box-ticking approaches to training are seen as insufficient.



### **Education system failing to support individual needs**

- schools are described as lacking inclusive practice, relying on generic strategies, and failing to recognize or accommodate specific challenges
- late diagnoses and mislabelling of students as "lazy" or "naughty" are common
- respondents call for mandatory training and better recognition of hidden disabilities.



### **Social isolation and stigma**

- individuals and families report feeling misunderstood, judged, or excluded in public spaces
- there's a strong emotional undertone of frustration, embarrassment, and exhaustion from repeated negative experiences
- some respondents advocate for public education campaigns and visible symbols of inclusion.



### **Need for practical adjustments in everyday environments**

- suggestions include quiet hours in shops, sensory-friendly transport options, and clearer signage
- lack of legal requirements or enforcement around accessibility is noted
- respondents want more visible, proactive efforts to make public spaces inclusive and welcoming.

| Respondent Location       | How aware do you feel the following organisations are in supporting a person with a Learning Disability, Down's syndrome or Autism?<br>Responses to 'Unaware' or 'Very unaware'                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|---------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Cannock Chase</b>      | Haven't had any need to make enquiries                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Cannock Chase</b>      | I feel like the systems are all overloaded and the help is just not there because there's not enough people to provide it. People are also unaware of the effects of many disabilities and don't realise how much people are suffering                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Cannock Chase</b>      | People hold stereotypical views unless they have personal experience of the conditions                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Cannock Chase</b>      | People hold stereotypical views until they have direct experience of knowing or caring for a person or child with these conditions                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Cannock Chase</b>      | Some groups don't encounter autistic people regularly enough                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>East Staffordshire</b> | I am a late diagnosed autistic woman in my 50s. I struggle with communication; however, I mask and feel that people would not realise that I am autistic as I have no learning disabilities. I find hospitals/GP surgeries a place where I am bombarded with information and instructions that I am not able to fully take on board due to processing disorder. As health is vitally important, I feel that the NHS has an enormous amount of work to do to understand issues facing autistic people. Have you ever sat in a waiting room in a hospital and looked at the huge amount of signs and posters over every wall and door and then varying members of staff appearing and giving you instructions when the only piece of information you've been able to process is 'take a seat'. Unless you are autistic it is impossible to understand day to day issues which is why it's so important to seek opinions from autistic people by carrying out surveys such as this.                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>East Staffordshire</b> | I am a massive advocate for Autism Awareness. Generally, when out in public we have a mixed response from people. Some people we meet almost shun or shy away from people with disability even those that are hidden, like autism. My own son is very outgoing and loves to meet and engage with everyone he meets and whilst this was a problem to manage when he was younger we now at the age of 20 rejoice in him meeting and interacting with new people and places, at the same time being aware that he is a vulnerable with no sense of stranger danger. Responses to his personality vary extremely from him being ignored completely to being welcomed with open arms in certain places. As Secretary of a parents/family support group (The Autism Pyramid Group) I often award self-produced certificates to establishments who are Autism Aware and welcoming to my son and will often confront people who have no awareness of people with a disability, especially when they criticize his behaviours and quirks. I fully embrace Autism / LD / Downs acceptance as some members of the public forget they are people who have feelings. I find particularly that schools deal terribly in general with any student who doesn't fit in - they should all be made to study the recognition and how to manage students with SEND as in my experience this is where all the problems stem from - failure to |

|                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|---------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                           | recognise and acknowledge a condition (especially hidden disability) can soon snowball and actually ruin that person's life - I can give examples from my experiences since 2009 Educate, make people aware and celebrate the differences of these incredible people is my motto and mission.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>East Staffordshire</b> | I am autistic, and my previous experiences with the police have been terrible. They treat me like I don't have a clue about anything when I am highly intelligent.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b> | I think a lot more education (and acceptance) in the public sector is needed towards those with additional needs                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>East Staffordshire</b> | Ignorance is bliss in their eyes! Too much work and paperwork                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>East Staffordshire</b> | Intolerant attitudes.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>East Staffordshire</b> | It is hit and miss in community who is aware and often reflects personal experiences they have had rather than workplace training                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>East Staffordshire</b> | Lack of support in hospitals for LD is frightening, especially inpatient services                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>East Staffordshire</b> | Little empathy on buses etc                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>East Staffordshire</b> | More awareness and education is needed in many areas. Especially around late diagnosed adults with Autism and ADHD                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b> | People often are not aware of what a learning disability can entail or how autism can present. People can mistakenly think that because an individual makes eye contact or speaks reasonably well that they may be more capable than they actually are. They do not understand such concepts as impaired executive functioning.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>East Staffordshire</b> | Since the functional ability of these people can vary day to day, many people do not realise this and tend to think of the extremes in each and if a person does not fit the extreme end of disability/difficulty functioning, they do not realise the impact                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>East Staffordshire</b> | Some people are kind but little actual support available                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>East Staffordshire</b> | That sort of information not available widely, such like bus stops or little adverts in a supermarket. No info at all                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Lichfield</b>          | Do shops have any legal requirement to assist special needs people?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Lichfield</b>          | Don't have anything to do with housing providers                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Lichfield</b>          | I asked a consultant that I had to see last week, did he understand what Autism and ADHD is, after some pushing he admitted he did not. This is all too often the case. I had a nurse tap my arm at Goodhope Hospital when I was having a melt down due to the noise and pain, to calm down dear its ok. Burton Hospital, I was stimming and a dr said stop doing that. When I said what, he said moving! Derby Hospital told me to calm down and act my age, when I was triggered, bus driver have no clue. Social services have sent carers time and time again who have no idea about how to be with someone who has complex needs with AUDHD, my own GP and psychiatrist even wrote to them and said they were providing inappropriate care, it didn't stop social services and my mental health deteriorated to the point of needing medical intervention. Social services now say they cannot provide carers for me! Police have no idea, and recently when I tumbled out of my |

1. Repeat Prescriptions. 2. Learning Disability, Down's syndrome, and Autism Awareness

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                             | ambulance, the paramedics kept telling me to calm down, I went mute, and then they kept telling me to talk, I was wearing my lanyard that tells people I have AUDHD and also my disabilities, but they declined to read them. E learning is not good enough.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Lichfield</b>            | Some services I'm do not use or have any contact with                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Newcastle-under-Lyme</b> | Do not have contact with anyone with tee difficulties                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Newcastle-under-Lyme</b> | I think some services are not aware of learning disabilities, but I worked with learning disabilities for 35 years and I notice people around me do not realise someone has a disability or because they have no obvious signs are unaware                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | It all varies so much based on individual background and experiences. Services can be great when you get the right person but not knowing how it's going to be is really hard.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Newcastle-under-Lyme</b> | Lack of understanding                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Newcastle-under-Lyme</b> | My Autistic family member does not have any interaction with these organisations                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Newcastle-under-Lyme</b> | My daughter has autism, and I can say with confidence, people are absolutely clueless. We profess to be inclusive, we are not.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Newcastle-under-Lyme</b> | Schools I have answered unaware/very unaware because in my experience schools often lack a real understanding of autism beyond the most obvious traits. Staff tend to rely on stereotypes or general strategies rather than recognising the individual needs of autistic children. Awareness is often limited to ticking boxes for policies or training rather than embedding inclusive practice. This leads to difficulties being dismissed, support not being put in place, and autistic children being misunderstood or seen as "difficult" rather than needing adjustments. Social Services I have answered unaware/very unaware because I have found that social services often have little knowledge of how autism affects day-to-day life for families. They may not recognise the challenges autistic children face in education, relationships, or accessing services, and they often underestimate the impact on families. Their lack of awareness can result in inappropriate advice, signposting to unsuitable services, or families being blamed rather than supported. |
| <b>Newcastle-under-Lyme</b> | The police do not seem aware that people with LD or autism will react differently to commands or even uniforms that someone without those characteristics                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Newcastle-under-Lyme</b> | There is insufficient training given for persons to know how to communicate and help people with learning disabilities etc. From experience a person without any communication is not understood by anyone, including hospital staff, police, ambulance and other services. School which is purposely trained in special education needs can learn to communicate. Only family members and close friends and carers learn to recognise what is wanted by those with learning disabilities etc.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Newcastle-under-Lyme</b> | These conditions are not always obvious                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

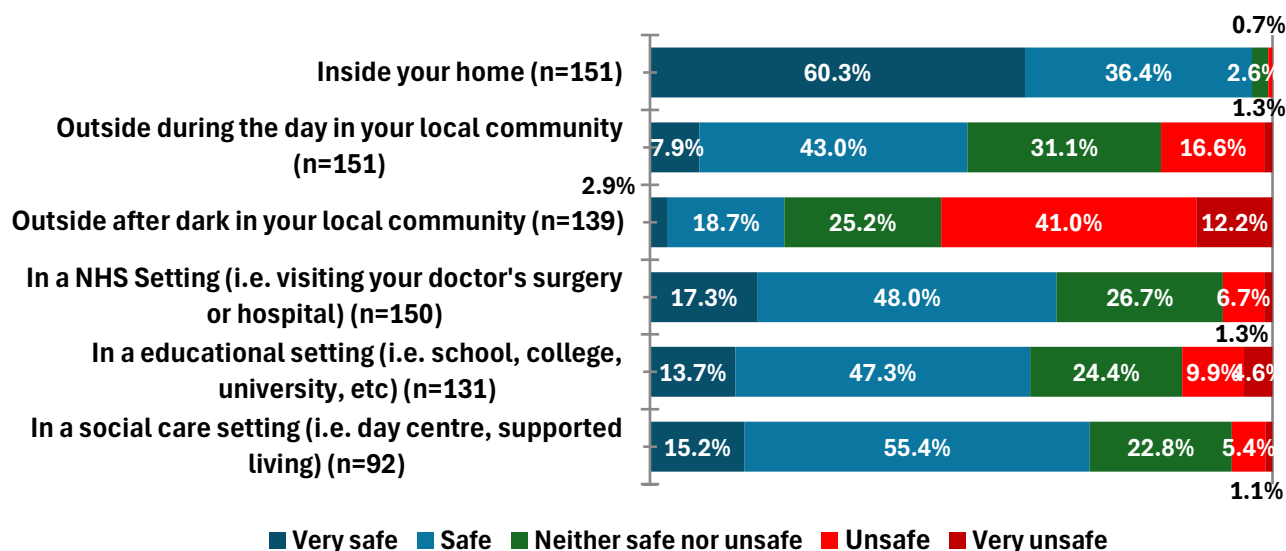
|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Newcastle-under-Lyme</b> | They do not display their awareness. The police in particular are bad at dealing with disability                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Newcastle-under-Lyme</b> | Unfortunately, hospital teams and policing have little time to consider diversity in their day-to-day roles                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stafford</b>             | Because I am a person with the lived experience and I am one of those people who were treated very different in the late 70s and early 80s were we were treated very different, we were treated more like freaks. And like the saying OUT OF SIGHT OUT OF MIND. We were always in detention because we could not understand the subject matter, I left school with no formal Qualifications so when onto a government training program called a YTS Scheme. So, I am now showing my age, I always wanted Continuity of Employment, but this never happen to me I have more jobs than some people have hot dinners. It took me to have a BREAK DOWN in 2012 and then get STATEMENTED with AUTISTIC traits or MILD AUTISM for me to start to get the HELP and Support I had been wanting for so many years. But without an understanding or diagnosis there was little or no understanding of people with complexed brain issues or hidden Disabilities or Difficulties to finally be heard. It is now time that organisations both Public and Private have to make Reasonable Adjustments to enable us to be part of society. And The Two Tick Symbol is not worth its meaning or implementation. |
| <b>Stafford</b>             | GP and paediatric Dr for autism not working on same hymn sheet for benefit of patient Community speech dietician not communicating with each other over needs None put child first but put more pressure on parent. School and NHS do not work together for the child. No cohesion in welfare or support                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stafford</b>             | I think all organisations are aware but how individuals are thin the organisation act on the information varies. This is particularly the case with hidden disabilities.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stafford</b>             | In Most ordinary situations people are not able to tell if someone is autistic or deaf or has mental health issues and doses do not give time or extra care                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stafford</b>             | I've not received adequate support from any of these sectors.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stafford</b>             | Local schools failed my son badly - he has dyslexia, and they refused to help in any way saying he was lazy. We had to send him to a private school that helped him to read properly, write legibly and have some confidence that he actually could achieve without being made to think he was stupid/lazy or disruptive. This is not that long ago ( 10 to 15 years) and my understanding is that this has not changed in any way in the county of Staffordshire. Public transport is simply down to the bus driver; some care some don't.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stafford</b>             | Not come across any instances of these and actually not given it much thought (sorry)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stafford</b>             | The time it is taking to get a diagnosis is so long that people affected are not treated early enough & the general public, in particular schools, are not aware of how to treat people early enough                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|--------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Staffordshire Moorlands</b> | I gave a family member that's disabled. Ji safe space posted. Not always a disabled toilet, loud music, rude GP staff                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Staffordshire Moorlands</b> | I would like to think people are aware, but I think there is a way to go still yet and being aware doesn't necessarily mean able to be positive I that awareness                                                                                                                                                                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | It seems under advertised what these services can offer.                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Staffordshire Moorlands</b> | Lack of awareness by both providers and users.                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Staffordshire Moorlands</b> | Police - they often assume drugs with certain conditions, not blaming but still more awareness needed Housing - it's hard to get on the list yet alone push the reasoning for it through Public transport - there is no isolated sections for sensory overloaded people. General community - sometimes announcements make me jump yet alone a sensory sensitive person, lighting is way too bright and no quick service or prioritised self-service for people who may struggle with crowds |
| <b>Staffordshire Moorlands</b> | They can only do so much innit...                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Staffordshire Moorlands</b> | They either do not have the time, resources or the knowledge to properly support autism. It varies from provider to provider, so the answer is a generalisation.                                                                                                                                                                                                                                                                                                                            |
| <b>Staffordshire Moorlands</b> | Unless you are actively involved with social services , they are oblivious to you. Schools can't cope with a child that doesn't fit in to the 'normal' box. Supermarkets and shops may now have quiet hours for autism but their awareness of which customers are autistic is zero unless they have a family member who displays the same behaviours.                                                                                                                                       |
| <b>Stoke-on-Trent</b>          | Difficulty in getting Dyslexia assessments                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b>          | Do they really care                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | Due to the nature of autism, it is unlikely someone who is not aware of the condition can understand it at face value. "You can't tell he's autistic" is often said.                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | For autism my experience is that the services I said unaware' who should have extensive training have only limited knowledge. Mainstream schools fail these children and young people, and social services provide little support. General public have limited knowledge therefore many who come into contact with this group do not interact appropriately with them.                                                                                                                      |
| <b>Stoke-on-Trent</b>          | Have no information about how these organisations make adjustments for the people/children the survey is focussed upon. Also, seen badly managed situations.                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b>          | Housing providers are unaware as they take so long to do essential adaptations off families and also do not pricing suitable housing for the families. Public transport does not do enough to support people with learning difficulties to use their services and need training on this.                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b>          | I can. For any of the above places, there will always be somebody who is not as aware as they could be. The ones which are unaware, can often be very narrow in their thinking, or not as educated about these                                                                                                                                                                                                                                                                              |

|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|-----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                       | things in general, but the people who are aware are generally very helpful, and very good at being able to support us in the way that we find most helpful. You will find that some neurodiverse individuals, particularly if high functioning, will also help people to learn if they find a service which is needing this help. In all areas, I'm afraid I don't see a huge difference often enough in some places to be sure that neurodiversity is better understood. Maybe you could consider finding a neurodiversity education bus from somewhere to come over to stoke and help with this. It will definitely help to get the message across in an interactive way as a great and thought providing experience for everyone who uses it. |
| <b>Stoke-on-Trent</b> | I don't see much information relating to it.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | I feel some places don't understand how to support these disabilities                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | I have seen no change in treatment of people with Autism or any awareness of it. Noone has asked, no one has put anything in place, no one has checked my notes to see if I am. It's exactly the same in that the awareness does not exist.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | I think most services struggle to recognise and respond to neurodivergent needs in the most appropriate way and have little time for the individual. In my experience schools in particular are very poor in supporting neurodiverse children and meeting the needs of the individual child often seeing the child as "naughty" rather than recognising the need and appropriately supporting them to achieve the best that they can                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b> | I work with students that have a wide range of disabilities and with working in this environment I feel a lot of the students are forgotten about in mainstream day to day. Many people do not know how to engage with the students outside of the college I work within. Hospital environments are particularly bad when engaging with people with disabilities, as most have no experience and have no knowledge of how to converse with patients with any disabilities.                                                                                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b> | It depends on who you get/ speak with. Some are rude and ignorant- others helpful                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | It's down to the individual even with some knowledge people can appear patronising and others are ignorant of needs, and some professionals don't care.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b> | Just don't think places are aware of disabilities especially certain types of autism that are not visible                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b> | Just feel there is little awareness in some agencies                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b> | Lack of knowledge and understanding of a person with learning disabilities and their associated needs. Often a lack of compassion or as basic as giving the person time to express themselves or being given time to understand what is being asked of them.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | My answers are based mainly on Autism as my experience through my daughter (a physics teacher) and my grandson (Very Autistic) my daughter was only recently diagnosed though in her 40s She now talks to various groups explaining Autism as she was until very                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |

|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|-----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                       | recently teaching at a school for Autistic ADHD Tourette's and other disabilities. She was surprised how many in positions of power e.g. Managing Directors Heads of schools etc who have no idea of the problems connected with Severe autism. e.g. anything that throws out their normal routine e.g. something as a bus not turning up - a train cancelled can cause them to have a severe meltdown! Years ago, they were called difficult, or even worse "naughty" Autistic people still suffer a certain amount of abuse and misunderstanding. usually by so called intelligent people who should know better especially people in a place of responsibility dealing with others. I only feel able to respond on the Autism spectrum as that is the one I've had varying experience of.                                                                                                                                                                   |
| <b>Stoke-on-Trent</b> | My son has autism and he finds interaction with services very challenging due to their lack of understanding and awareness of his difficulties.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | My son has autism is very clever but there aren't any local NHS services that can help him                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | No significant changes seen with support or advice from these agencies                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | Not enough training                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | People are not given enough education to understand these disabilities                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | The reasons for my answers are due to my son is autistic and the experience we have had in schools and colleges are not good. Also, hospitals they either understand, or don't so sometime a consultant will talk to me instead of my son who is in his 20s. He is perfectly able to listen and respond to them if it's a day he cannot he uses txt to give the answers, but they don't seem to like this. One consultant even said to him can you look at me when I'm talking. Excuse me that's part of his autism no eye contact. He had medical notes that say he continued to play on his phone during the consultation again that helps his stress. He does listen and just because he has autism it doesn't mean he's been rude. The GPs again either understand or don't. They tend to dismiss everything like his anxiety, stress and depression to his autism when giving them his symptoms he got dismissed as it's your autism. It was in fact POTs |
| <b>Stoke-on-Trent</b> | The way my nephew has been treated. As for NHS services they should be aware as the completion of the Alistair McGowan in mandatory (well it is for MPFT)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | These are questions I don't have information for, so I can't comment.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b> | They don't see the person if they have a hidden disability.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Tamworth</b>       | As I don't know anyone with these disabilities, it isn't something I would be aware of.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Tamworth</b>       | I have a husband with dementia and a grandson with autism and neither seem to receive any help or advice from anyone unless they can be bothered. I guess this is the way we're going.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Tamworth</b>       | People still treat individuals with these conditions as odd, dangerous, figures of fun unless they have experience of the conditions in their own families, community or workplaces.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |

### How safe do you or the person you are answering on behalf of feel in the following settings?



Figures exclude respondents who answered "Not applicable" or "Don't know".

| How safe do you or the person you are answering on behalf of feel in the following settings? |          |          |        |
|----------------------------------------------------------------------------------------------|----------|----------|--------|
| Setting                                                                                      | NPS 2024 | NPS 2025 | Change |
| Inside your home                                                                             | 78       | 96       | ▲ +18  |
| Outside during the day in your local community                                               | 31       | 33       | ▲ +2   |
| Outside after dark in your local community                                                   | -24      | -32      | ▼ -8   |
| In an NHS setting (doctor's surgery or hospital)                                             | 52       | 57       | ▲ +5   |
| In an educational setting (school, college, university)                                      | 35       | 47       | ▲ +12  |
| In a social care setting (day centre, supported living)                                      | 50       | 64       | ▲ +14  |

Net Promoter Scores (NPS) for 2024 vs 2025 across different settings

## **Key themes from respondents answering 'Unsafe' or 'Very unsafe' in selected settings**

### **Public spaces and crime**

Many feel vulnerable in parks, streets, and town centres—especially after dark—due to antisocial behaviour, drug use, and lack of visible policing.

### **Lack of neurodiversity awareness**

Neurodivergent individuals often face misunderstanding or dismissal in public and professional settings, leading to anxiety and fear of confrontation.

### **Unsafe educational environments**

Bullying, exclusion, and lack of support in schools and universities leave students feeling unprotected and emotionally unsafe.

### **Healthcare settings**

Overstimulating environments, poor communication, and lack of trauma-informed care in NHS services contribute to distress and avoidance.

### **Social isolation and stigma**

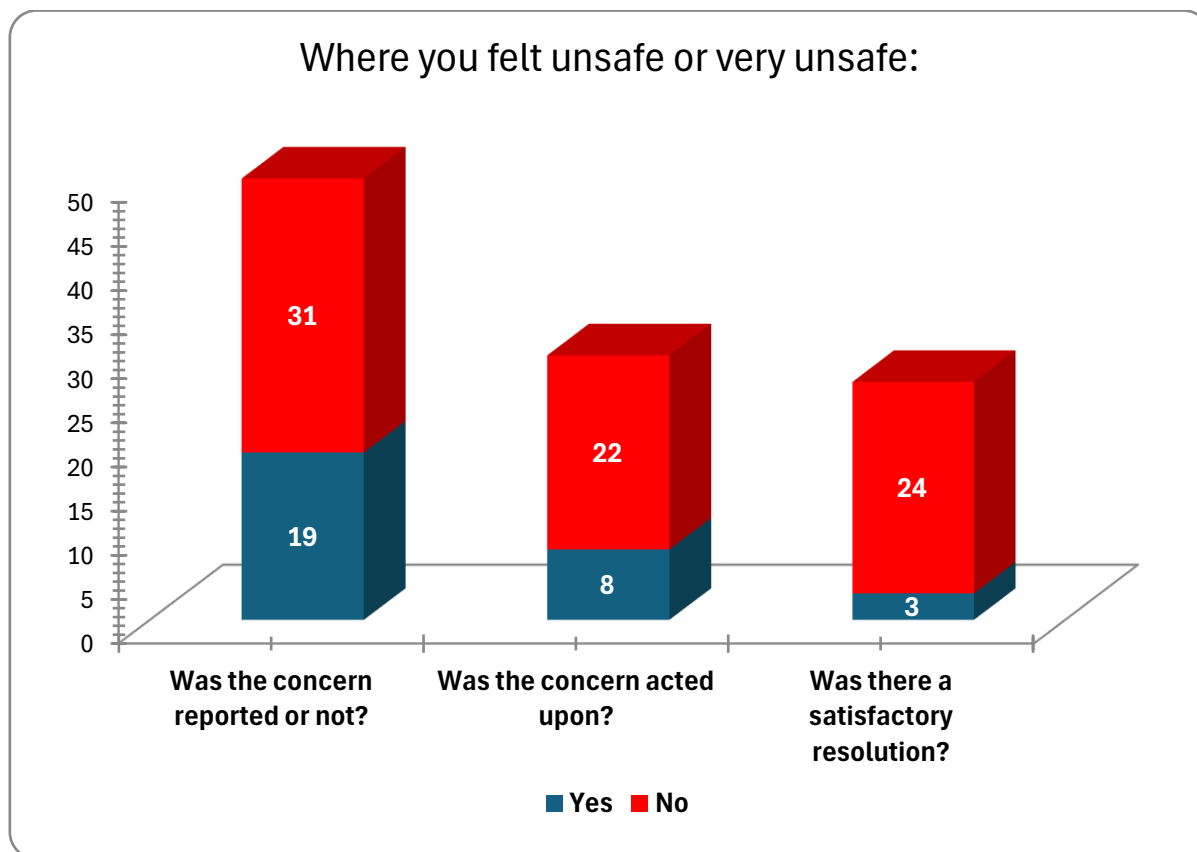
Many feel judged or excluded due to hidden disabilities, leading to emotional harm and reluctance to engage with community services.

| Respondent Location       | How safe do you or the person you are answering on behalf of feel in the following settings?<br>Responses to 'Unsafe' or 'Very unsafe'                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|---------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Cannock Chase</b>      | Answering on behalf of a child                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Cannock Chase</b>      | I feel like nobody feels safe going out on their own after dark - there's too many bad people in the world and crime is just rising each year. I definitely won't be letting my kids play out any time soon!                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Cannock Chase</b>      | My daughter had to de role from school due to lack of understanding of her autism.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b> | I just never feel safe outside in the dark                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>East Staffordshire</b> | My son was placed in day support at 18 years old with a company who claimed to understand and accept clients with Autism, SLD and communication issues but this was clearly not the case. Thankfully he is now placed with an incredible provider and the experience with the first provider is in the past but still triggers memories for my son as we pass it often in our hometown, I made an official complaint to the Management of the company but received an unsatisfactory response. I haven't taken it further as I was told that they did not fall within the remit of the CQC and quite shockingly appear to be unregulated. I realise I should have reported it as a Safeguarding Issue but being a busy parent fighting for my own son |

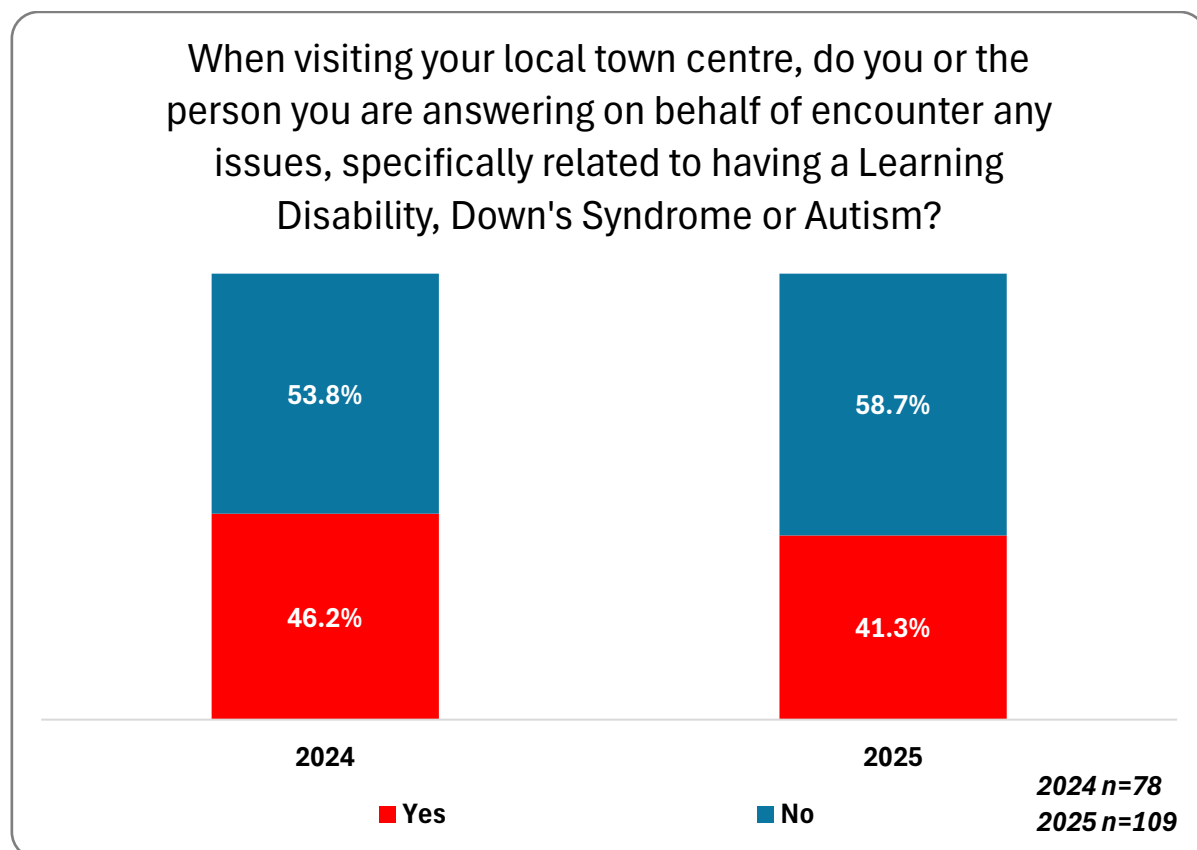
|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                             | an others became a priority I would be very happy to discuss our experience further with anyone who is interested as I still feel that some vulnerable people may be at risk                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>East Staffordshire</b>   | Plenty of local neighbours acting very unsafe and unsocial behaviour used for communication Lots of verbal abuse around streets, so save way to show your point of view. No freedom of speech anymore.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>East Staffordshire</b>   | School have attempted to support but have insufficient resource, so support is not sustained and not consistent.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>East Staffordshire</b>   | Schooling situation - child ended up switching schools                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>East Staffordshire</b>   | Some were reported, some weren't the answers given were not acceptable. Outside after dark in my community, most people feel unsafe, and so my reporting it would make no difference. NHS Settings, my autism is frequently ignored, people keep trying to make telephone calls and ask me to call back or have been known to end my treatment if I don't answer when they know I cannot use the telephone. I've also had services gaslight me, causing me to have autistic meltdowns, forcing me to never go near their buildings again. I was even put on the violent patient scheme because of one meltdown. While I was at Staffs University, I frequently tried to get reasonable adjustments for my Autism, but my course leader refused the support I required, and the disability support team told me they couldn't tell her that my support needs were reasonable adjustments under the Equality Act 2010 because they would have all other students coming to them demanding their rights. If the disability department isn't there to support students in accessing their rights, then what on earth is it supposed to be for? |
| <b>Lichfield</b>            | I have answered unsafe to 2 questions one was resolved the other not, you also need to ask the question how safe do you feel with carers/support workers, and social workers                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Lichfield</b>            | My autistic child lost their brother to hospital negligence so is consistently anxious and worried about needing medical treatment in a hospital setting.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | Being out in the dark is not always safe for those without any learning disabilities etc. so for those people with disabilities it would not be safe.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Newcastle-under-Lyme</b> | I have been attacked in the past                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | I think you might need to provide your definition of safe/ unsafe! We're not at risk, but feeling unsafe is out everyday life in settings that are not inclusive/ particularly friendly!                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Newcastle-under-Lyme</b> | Levels of crime in the community                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | My daughter was physically, verbally, and cyber bullied at her previous school. The incidents were reported both to the police and the school. While the police acted appropriately, the school failed to take meaningful action. My daughter was expected to attend lessons alongside the pupil who physically assaulted her, and the school appeared to want the incidents to be minimised or ignored. Despite submitting an official complaint and meeting with the headteacher and governors, no changes were made. As a result, I felt I had no choice but to remove my daughter from the school. This demonstrates a lack of awareness and understanding                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|--------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                | of both safeguarding responsibilities and the impact of bullying on autistic children.                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stafford</b>                | As a disabled individual I feel vulnerable in the community. Especially at night.                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stafford</b>                | Because until recently been accepted into Society We have not had recognition or a voice that society would accept us as group of people we have to do a lot of speaking to groups like our local Police Authority, and through Mencap were we hold group sessions to try to work with the Police. And like most recently the OLIVER MCGOWAN Program where I am a Co Trainer delivering the program and getting the course and understanding of People with Learning Disabilities or Autism which is being delivered Country wide. |
| <b>Stafford</b>                | Deafness and old age mean insecurity in unfamiliar surroundings                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stafford</b>                | Own personal mobility issues making me feel unsafe & increase in antisocial behaviour at nighttime making me not venturing out during these times                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Staffordshire Moorlands</b> | I answered unsafe because my son has PTSD from his school days which were horrendous. Any educational establishment would trigger those memories.                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Staffordshire Moorlands</b> | I wrote a letter to the hp practice explaining what a receptionist did across my mum with dementia, I received a letter to say it would not happen again and 2 weeks later the same receptionist did the same thing again                                                                                                                                                                                                                                                                                                          |
| <b>Staffordshire Moorlands</b> | My step sone has very complex need and recently required hospital admission. He acquired a pressure sore on his heel whilst in hospital which resulted in him needing additional nursing and care which he found very difficult to understand                                                                                                                                                                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | School -even that school has acted upon issues and tried their best to provide adaptations my daughter still faced bullying and lack of understanding                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | Bullying in the school. Not believed. Autism not acted upon.                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b>          | Feels unsafe because of their anxiety in settings rather than actually being unsafe. Won't go out on their own                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b>          | I don't feel my needs as an autistic person will be considered, discussed with me or even acknowledged in these scenarios so I'd feel unsafe just because it's not understood, and don't trust people around to respond appropriately. The onus feels like it is on me to mask and fit in, not those around me to make allowances.                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | I'm told social services are too busy and any support needed e.g. out in the community i.e. an advocate or PA has to be found and paid for by the person.                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | In regard to school situation I have been made out to be a neurotic aren't for highlighting concerns later to be proven accurate for my child, I have had to move my child to another school as my child was unsafe in the setting. I have been told my child needs to develop more resilience to get through life rather than the school support his needs to help him grow and develop                                                                                                                                           |

|                       |                                                                                                                                                                                                                                                                                                                                                                                        |
|-----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | Most places visited by people with disabilities feel very unsafe due to the fact that staff in these places do not know how to deal with people with disabilities at all. Only schools or colleges that have experience of students with disabilities, make students feel safe and feel excepted. Mainstream schools or colleges often exclude students and make them feel a burden    |
| <b>Stoke-on-Trent</b> | My son often doesn't get the help he needs and finds it a challenge to access any social settings due to this leaving him very isolated.                                                                                                                                                                                                                                               |
| <b>Stoke-on-Trent</b> | No need for action. Just a general comment                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b> | Only my observations otherwise not applicable.                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | Please see response above                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | Relatives I have in mind are children supported by caring adult and avoid unsafe environments.                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | Schools just say that they cannot meet needs after issues were raised                                                                                                                                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b> | The person feels safe if all normal very often it is when the abnormal happens e.g. sudden changes to routine that he (grandson) can feel unsafe or any similar severely Autistic person it can stress them out.                                                                                                                                                                       |
| <b>Stoke-on-Trent</b> | There are some crimes and especially hate crimes that are not properly investigated by policing services.                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | There's confusing and/or insufficient signage in NHS settings, like GP or hospital. There are no designated quiet/less busy areas to reduce overwhelm while waiting. The area we live in (Blurton) is very unsafe after dark, with groups of people wandering the streets, and lots of dangerous and antisocial driving (reported to police multiple times, which made no difference). |
| <b>Stoke-on-Trent</b> | University of Staffordshire don't care about learning support agreements, they are often just a tick box, nor do they know anything about the legislation around assistance dogs.                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | Vulnerable people are not safe on their own.                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | Yes, I took control of the situation                                                                                                                                                                                                                                                                                                                                                   |
| <b>Tamworth</b>       | Our child with autism is very scared of dogs. Unfortunately, places have become more and more dog friendly, and so it gets very difficult for our son to feel safe. Why does everywhere now have to allow dogs, why can't we have dog free places? There has been an increase in dog attacks, and I'm not surprised unfortunately.                                                     |



Number of respondents – 2025 results only



Figures exclude respondents who answered "Not applicable" or "Don't know".

## **Key themes from respondents who identified issues visiting a local town centre**

### **Sensory overload & environmental stressors**

- loud noises, bright lights, strong smells, and crowded spaces are repeatedly mentioned as overwhelming
- unexpected stimuli like music, hand dryers, and flashing lights contribute to anxiety and shutdowns
- lack of quiet zones or calm areas makes it hard to regulate when overstimulated.

### **Public perception & social stigma**

- many respondents describe being stared at, judged, or misunderstood—especially during meltdowns or moments of distress
- there is a strong fear of being seen as “naughty,” “dramatic,” or even being mistaken for a threat
- comments reflect a need for greater public awareness of hidden disabilities and neurodiverse behaviours.

### **Accessibility & physical barriers**

- issues with navigating cluttered aisles, steps, and inaccessible toilets are common
- disability parking and safe spaces are inconsistently available or poorly marked
- some mention needing a carer or PA at all times due to safety and mobility concerns.

### **Staff training & empathy**

- staff are often described as impatient, dismissive, or lacking understanding
- requests for autism-friendly hours, clearer signage, and more compassionate service are frequent
- there is a call for better training in communication, sensory needs, and inclusive practices.

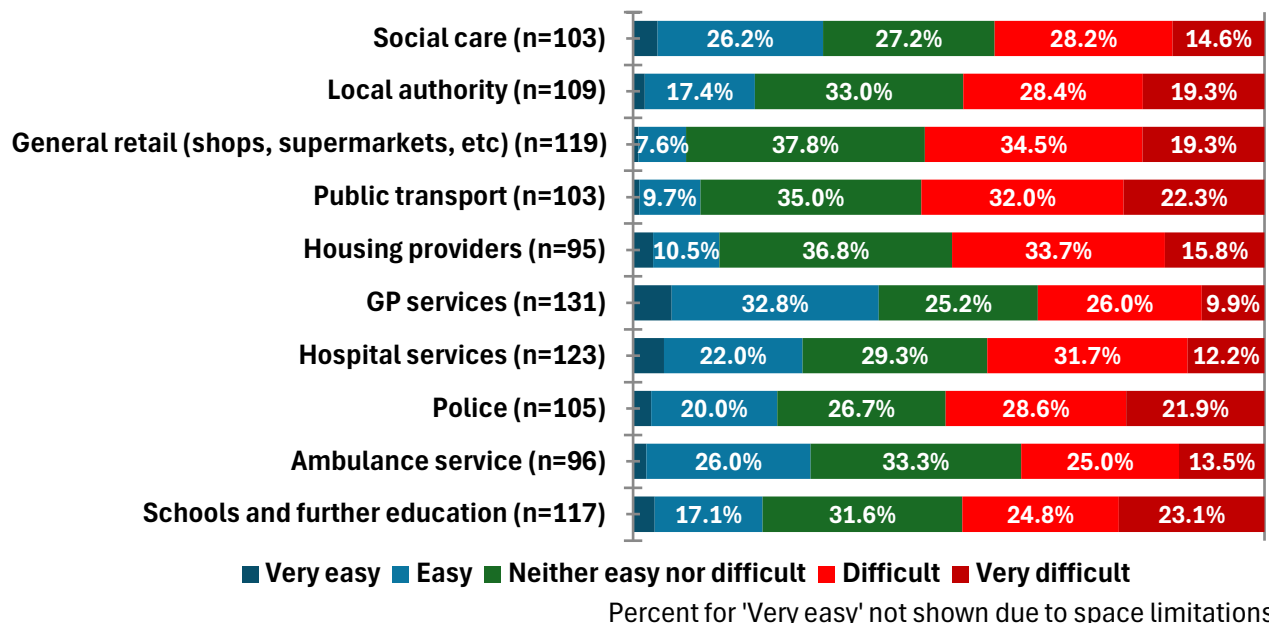
### **Planning & coping strategies**

- several respondents describe detailed routines to manage anxiety—planning routes, writing lists, or preparing the night before
- these strategies highlight how taxing a simple trip into town can be
- the need for predictability and control is a recurring theme.

| Respondent Location  | When visiting your local town centre, do you or the person you are answering on behalf of encounter any issues, specifically related to having a Learning Disability, Down's Syndrome or Autism?<br>Issues Identified                                                                                                                                                                                                                       |
|----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cannock Chase        | Most places are too bright and too loud. Shops have no patience.                                                                                                                                                                                                                                                                                                                                                                            |
| Cannock Chase        | People confuse meltdowns with being a naughty child. In an adult you are dismissed as a drama queen. Sometimes the pain and frustration become overwhelming, and you have to let the pressure out                                                                                                                                                                                                                                           |
| Cannock Chase        | People looking when son experiencing overwhelm and sensory issues                                                                                                                                                                                                                                                                                                                                                                           |
| Cannock Chase        | People think meltdowns are temper tantrums                                                                                                                                                                                                                                                                                                                                                                                                  |
| East Staffordshire   | Every aspect of being autistic is a challenge in every setting which is why I spend a large proportion of my time either in my own home or with my husband when outside.                                                                                                                                                                                                                                                                    |
| East Staffordshire   | Generally my son is well accepted in our home town and in many others but there are still people who are unaware of hidden disabilities and will either shy away from interaction with my son or voice their ignorant opinions - of which I will always defend and explain but I fear for what would happen if he was ever to find himself alone Again I try to promote Awareness , Acceptance and Inclusivity wherever we go               |
| East Staffordshire   | Lots of requests for donations or help worries re transport                                                                                                                                                                                                                                                                                                                                                                                 |
| East Staffordshire   | Music in shops can be way too much and flashing lights etc.                                                                                                                                                                                                                                                                                                                                                                                 |
| East Staffordshire   | My son has autism and on some days, he might manage other people but on other days he may be mute and becomes extremely avoidant due to anxiety - sometimes his behaviour can look bizarre due to anxiety, and we fear people calling the police on him when this happens                                                                                                                                                                   |
| East Staffordshire   | Not paid attention to it really                                                                                                                                                                                                                                                                                                                                                                                                             |
| East Staffordshire   | She gets overwhelmed easily, and struggles with aspects of daily living, so a trip into town adds a lot of pressure on her                                                                                                                                                                                                                                                                                                                  |
| Lichfield            | People not understanding trigger, noise, fear and how to make people feel safer,                                                                                                                                                                                                                                                                                                                                                            |
| Newcastle-under-Lyme | Access to some establishments is prohibited either by steps or cluttered aisles that are obstacles that many with learning difficulties etc cannot cope with. Should the person in question have mobility issues then this compounds on the accessibility.                                                                                                                                                                                  |
| Newcastle-under-Lyme | Disability parking spaces                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Newcastle-under-Lyme | Lack of inclusion, empathy, adjustment                                                                                                                                                                                                                                                                                                                                                                                                      |
| Newcastle-under-Lyme | People staring                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Newcastle-under-Lyme | Unexpected music, noisy hand dryers in toilets, general public staring , asking insensitive questions and eye rolling staff when you ask for assistance                                                                                                                                                                                                                                                                                     |
| South Staffordshire  | When I visit the town centre, I sometimes find it hard because it can be noisy, crowded, and confusing. Waiting in long queues is difficult, and signs or instructions aren't always easy to understand. There are not many quiet spaces if I feel overwhelmed, and staff aren't always trained or patient. It would help if there were autism-friendly hours, clearer signs, more understanding staff, and quiet areas to use when needed. |
| Stafford             | Few public toilets or calm/private places to re-regulate in privacy                                                                                                                                                                                                                                                                                                                                                                         |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|--------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stafford</b>                | General unawareness of social anxieties and 'odd' behaviours IE stimming. People generally stare, point, speak about and that's unpleasant.                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Stafford</b>                | Generally, people with autism are not treated properly                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stafford</b>                | People not understanding have no knowledge of difficulty.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stafford</b>                | People not willing to talk to you like other people we are somewhat rushed, and assistance is very reluctant to assist you, because everyone is so rushed and trying to meet Targets so it can be an experience. I write a list before I enter into town and plan my journey before I leave the house even down to which bus stop I pick my bus home. I always start the evening before, so I don't have an anxiety attack, so I normally fall asleep when I get home. So that is how I deal with my mild autism and Learning Disability. |
| <b>Staffordshire Moorlands</b> | Being overstimulated in crowded, noisy environments with a lot of visual input. Lacking awareness of road safety.                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Staffordshire Moorlands</b> | Difficulty in using public toilets. Very difficult with neurodiverse children when they need to be accompanied and helped.                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Staffordshire Moorlands</b> | Many places have lighting that is too strong.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Staffordshire Moorlands</b> | My stepson has complex needs but always requires 1 to 1 care 24 hours a day                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Staffordshire Moorlands</b> | No shops displaying safe space posters                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b>          | Beggars and groups of men                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | Can be overwhelmed by crowds and noise                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b>          | Can't cope if someone approaches or asks something of them                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b>          | Communication usually. Need time to respond and a well-known support person with them.                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b>          | Looks stares comments                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b>          | Loud noises, lots of people who have varying degrees of anti-social behaviour. Those who pick up on the lack of eye contact and see vulnerability. Going to a town centre is a very overwhelming sensory experience and it doesn't feel like anyone cares to do anything about it.                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | Name calling, unwanted offers of help and support                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | No access and also spaces are small so often to close for people with autism as it gets crowded in certain areas.                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | People not always being kind                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | People will stare and make comments and generally make the whole experience very uncomfortable                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b>          | Shops do not allow time for them to pay for their items                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | So many people are so impatient, pushing past, sighing etc.                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Stoke-on-Trent</b>          | To may loud noises in shops to many street singers. He is worried about being attacked for looking different                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | Too loud, too busy, too many bright colours and too many strange smells                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | Unable to visit regular settings alone due to feeling unsafe.                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Tamworth</b>                | The person I am answering on behalf of always has a PA/carers with them to keep them safe and advocate in their behalf.                                                                                                                                                                                                                                                                                                                                                                                                                   |

How easy do you feel it is for a person with a Learning Disability, Down's Syndrome or Autism to raise any issues they may have with the following?



Figures exclude respondents who answered "Not applicable" or "Don't know".

| How easy do you feel it is for a person with a Learning Disability, Down's Syndrome or Autism to raise any issues they may have with the following? |          |          |        |
|-----------------------------------------------------------------------------------------------------------------------------------------------------|----------|----------|--------|
| Sector / Service                                                                                                                                    | NPS 2024 | NPS 2025 | CHANGE |
| Schools & Further Education                                                                                                                         | -29      | -27      | ▲ +2   |
| Ambulance Service                                                                                                                                   | -25      | -10      | ▲ +15  |
| Police                                                                                                                                              | -41      | -28      | ▲ +13  |
| Hospital Services                                                                                                                                   | -11      | -17      | ▼ -6   |
| GP Services                                                                                                                                         | 0        | 3        | ▲ +3   |
| Housing Providers                                                                                                                                   | -41      | -36      | ▲ +5   |
| Public Transport                                                                                                                                    | -53      | -44      | ▲ +9   |
| General Retail (Shops, Supermarkets, etc)                                                                                                           | -41      | -45      | ▼ -4   |
| Local Authority                                                                                                                                     | -41      | -28      | ▲ +13  |
| Social Care                                                                                                                                         | -22      | -13      | ▲ +9   |

Net Promoter Scores (NPS) for 2024 vs 2025 across key public service sectors

## **Key themes from respondents who found it 'Difficult' or 'Very difficult' to raise issues**

### **Communication barriers and self-advocacy**

Individuals with learning disabilities, Down's syndrome, or autism often face challenges expressing concerns due to anxiety, fear of conflict, or inaccessible systems. **Common issues:** telephone-only contact, complex forms, lack of confidence, and previous negative experiences.

### **Variable staff understanding and empathy**

Experiences vary widely depending on staff training and attitude. **Positive examples** include inclusive schools and GP practices; **negative examples** highlight dismissiveness or lack of awareness in retail and public services.

### **System complexity and bureaucratic hurdles**

Processes for raising concerns are often unclear, repetitive, or fragmented. Families frequently act as advocates, navigating multiple departments and repeating information across services.

### **Fear of discrimination and social stigma**

Respondents report feeling judged or dismissed, especially when disabilities are hidden or misunderstood. This leads to reluctance in seeking help or reporting issues, particularly in public-facing environments.

### **Need for personalised support and advocacy**

There's a strong call for trusted carers, tailored support, and flexible systems. One-size-fits-all approaches are seen as ineffective; person-centred care is essential for meaningful engagement.

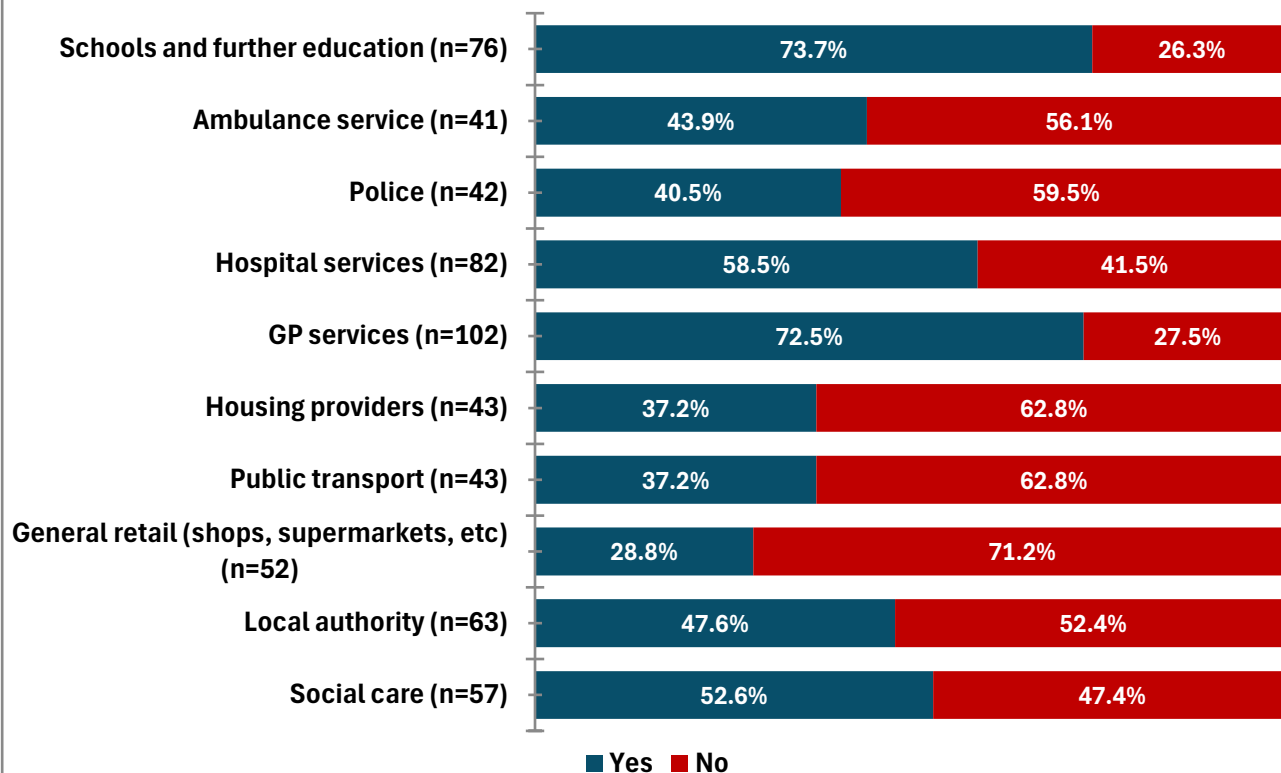
| Respondent Location  | How easy do you feel it is for a person with a Learning Disability, Down's Syndrome or Autism to raise any issues they may have with the services shown?<br>Responses to 'Difficult' or 'Very difficult'                                                                                                                                                                 |
|----------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cannock Chase        | Depends totally on individual persons encountered when trying to problem solve and their level of education, experience and empathy                                                                                                                                                                                                                                      |
| Cannock Chase        | My daughter has been ignored and belittled in the past. She would be way too anxious to raise anything.                                                                                                                                                                                                                                                                  |
| Cannock Chase        | Often need to call people which is difficult to do                                                                                                                                                                                                                                                                                                                       |
| Cannock Chase        | Understanding about these conditions remains patchy despite some media coverage and people have varying levels of education and acceptance.                                                                                                                                                                                                                              |
| East Staffordshire   | Attitude of shop assistants etc.                                                                                                                                                                                                                                                                                                                                         |
| East Staffordshire   | Health services are very busy, and it seems difficult to raise issues, easily. Retail makes it embarrassing to highlight issues                                                                                                                                                                                                                                          |
| East Staffordshire   | I tend to not raise issues as I feel like they would be seen as trivial. However, if I was to mention my issues to other autistic people, they would also have the same issues. I feel like an unheard voice.                                                                                                                                                            |
| East Staffordshire   | It is really difficult to access support, especially over the age of 18, but the individual themselves still isn't in a position to advocate for themselves                                                                                                                                                                                                              |
| East Staffordshire   | My housing association doesn't care about anything but rent.                                                                                                                                                                                                                                                                                                             |
| East Staffordshire   | People often just don't understand the issues.                                                                                                                                                                                                                                                                                                                           |
| East Staffordshire   | Responses from agencies and organisations whether public or private vary immensely depending mostly on the person you are actually dealing with                                                                                                                                                                                                                          |
| East Staffordshire   | When my autistic daughter was in hospital and the GP surgery recently, she found it very difficult to cope and some staff were very dismissive of her and did not act in the way I would expect someone in the caring profession to behave.                                                                                                                              |
| East Staffordshire   | Where I have answered difficult or very difficult it is often because communication is expected to happen over the telephone, which I cannot do. Alternatively, it is because I have found a way to complain via an alternative route, but I feel my complaints have been ignored or deemed inappropriate as the organisation sees nothing wrong in what they have done. |
| East Staffordshire   | While do we complain to, and we need to have the executive skills to do this                                                                                                                                                                                                                                                                                             |
| Lichfield            | I have a friend with a learning disability, and he finds all services very difficult he doesn't understand how to ask for help                                                                                                                                                                                                                                           |
| Lichfield            | If undiagnosed GPs/hospitals ignore problems with neurodiversity                                                                                                                                                                                                                                                                                                         |
| Lichfield            | The don't listen, or reply inappropriately, trigger, tell you to ring, I don't speak on phone unless I know who is ringing, why they are ringing, and when they ringing. They get E learning , which you can cheat at, learning should be a combination of E learning and practical experience                                                                           |
| Lichfield            | Very difficult as lost their brother to hospital medical negligence                                                                                                                                                                                                                                                                                                      |
| Newcastle-under-Lyme | Autism, selective mutism, anxiety, none of which lend themselves to raise issues!                                                                                                                                                                                                                                                                                        |
| Newcastle-under-Lyme | Because I have seen how learning disabilities are treated in the community some people are afraid of behaviours they don't understand.                                                                                                                                                                                                                                   |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|--------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Newcastle-under-Lyme</b>    | From personal experience, autism in children has been very difficult to obtain help and advice Again it is not easy to recognise all these conditions and they do vary in severity and presentation                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Newcastle-under-Lyme</b>    | I don't think they care                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Newcastle-under-Lyme</b>    | Most people in many work scenarios will accept persons with disabilities but often do not know how to relate to them. Being unable to explain or even communicate is a barrier to most even if they are in an occupation that would suggest that they should have the skills.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Newcastle-under-Lyme</b>    | No interactions with them                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b>    | Schools It is very difficult for an autistic child to raise issues in school. They are often not listened to, their experiences are minimised, or they are blamed for behaviours that are actually linked to their needs. Even when families raise concerns on their behalf, schools can be defensive, dismissive, or focus on protecting their reputation rather than safeguarding the child. Local Authority It is also very difficult to raise issues with the local authority. Processes are often complex and not accessible, with a lot of bureaucracy, delays, and "passing the buck" between departments. Families often have to repeat themselves multiple times, fight to be heard, and escalate complaints just to get basic support. For someone with a learning disability, these barriers make it extremely challenging to raise issues independently |
| <b>Stafford</b>                | Communication, time allowances and presumption not treating as individual or with respect                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stafford</b>                | I can only speak about my own experiences because I look normal and are very hard on myself and structured because there was no Help there for my generation we had to sink or swim. I am one of the generations that are in our fifties, so we were treated very different and treated like freak because I have a HIDDEN DISABILITY. And with not having a diagnosis did not Help we were very much isolated as a group of people.                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stafford</b>                | Insufficient information for the general public to help them understand the issues faced                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stafford</b>                | People generally don't have time - too many complaints have forced a defensive culture. Empathy is a rare gift often. Ignorance is common.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stafford</b>                | Raising issues requires confidence and also the knowledge that by raising issues you won't be discriminated against. This can be challenging not least if a person experienced challenges with language skills and processing. Many organisations now do not have a direct telephone line and therefore service users are required to email concerns. This assumes access to IT, skills in writing and being able to articulate the issues.                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Staffordshire Moorlands</b> | It can be difficult to raise concerns for fear of conflict.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Staffordshire Moorlands</b> | It seems difficult to navigate these processes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | Most of the staff are ignorant to ppl with disabilities                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Staffordshire Moorlands</b> | No                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Staffordshire Moorlands</b> | People are so busy doing their jobs they don't spare the time to listen.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Staffordshire Moorlands</b> | Everywhere you have to make sure you state your issues in writing as often reports are being noted. There are only advice lines after which you are being guided but after 2 hours on the phone you are just an inch further than before. Finally, being Polish and calling DLA I felt discriminated hearing only option in English and Punjabi (taking Polish community is vast it is against British Values of Equality and Inclusion... more like favouriting to me - sorry but that's how I felt).                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b>          | A lot of these are difficult as you can't actually speak to a human who can help and its often online or automated which doesn't help the situation                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | Alot of people with disabilities will not want to raise issues they are having so as not to draw attention to themselves. They may not feel confident enough to speak up either, or may feel speaking up may lead to bullying etc                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b>          | Ambulance services are diabolical. My son was having a Pots issue phoned 111 who put him through to ambulance who in turn said one was being dispatched. Then 2 hrs later they told him go to hospital yourself. Easy when he doesn't drive had no money and was having heart palpitations. GPS the dismiss everything as either part of your autism or oh it's one of your other conditions.                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | As a parent and carer, I would raise any issued on their behalf.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b>          | Because of his behaviour he sees issues with anyone or anything in 'authority', therefore would be reluctant to raise any concerns.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | Depending on how well known on a person is to the provider. The understanding and need for implementation being recognised and managed correctly by organisation.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b>          | Expressing how he feels is often misunderstood as being difficult which prevents raising any complaints and creates further frustration and isolation.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b>          | For the reasons I have explained they could react abnormally (in our eyes) to a situation Make a rude comment about someone (if say I did it I would be called tactless and have to apologise) With Autism they can't see that. They say it as it seems to them! Fortunately, my daughter (his Mum ) had to fight tooth and nail to get him the funding and into a special school specialising in Autism etc I dread to think what would have happened if he had had to continue in a mainstream school as there is very little help for any of the disabilities you mention. We can give Billions of pounds in Foreign Aid and pointless Crusades but when it comes to helping our own - suddenly the Well is dry!!! |
| <b>Stoke-on-Trent</b>          | I have to say from my own experience that sometimes it can be very difficult to raise a complaint about something or express what some people see as a problem. We are often unable to stand up for ourselves all of the time , rarely feel as if making a fuss would help, and often lack the self-confidence to stand up for ourselves and therefore are often inadvertently misunderstood when we do, or can be completely ignored or it can just be very anxiety providing as we are concerned that we might be dismissed or not taken as seriously. Having a disability doesn't mean we are unable, it                                                                                                           |

|                       |                                                                                                                                                                                                                                                                                                                                                                                               |
|-----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                       | just means that we are differently abled or wired up and just need people sometimes to give us the time and space, and encouragement that it's okay to stand up for yourself and to speak up if there's a problem so that it can easily be fixed. That is all we usually need.                                                                                                                |
| <b>Stoke-on-Trent</b> | It is just a difficult thing.                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b> | It's difficult to communicate most people will understand and frustration can become an issue.                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | Lack of continuity within social care. Lack of training and understanding that everyone is unique and one size does not fit all                                                                                                                                                                                                                                                               |
| <b>Stoke-on-Trent</b> | Lack of resources or support available. Preconceived ideas that the person is lying so makes the person less likely to speak up.                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | Many with downs do not like to complain or raise issues. They just accept                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | Only see observations.                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b> | People today need a voice to be heard and a lot of special needs that don't have the ability to explain or ask for help or what they need are overlooked and ignored. Colleges can help but again someone else has to explain the need as also in a hospital environment where sympathy and time is not available                                                                             |
| <b>Stoke-on-Trent</b> | Schools not acting upon bullying and not doing anything about autism                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b> | Schools say you are just a naughty child and others say you are just making up an excuse and others just listen but do not hear you                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | Schools sometime don't listen, understand or act appropriately. Not enough investment in SEND provision in schools for either staff or physical items.                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b> | Their anxiety makes it very difficult to deal with any services and needs me his carer to deal with them on his behalf                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b> | There is no place to go specifically that's centralised to talk about concerns and often nobody would understand anyway. I'm not sure local shops would care let alone entertain the idea of talking about it.                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | They do not have the confidence to speak up and/or nervous of authority figures. They think there's a wrong/right answer. Need support from trusted carer. They have experienced bad service/reactions in the past.                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | Unclear routes for where to report which issue, and if you do find them, the forms to report something are wordy and long.                                                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b> | University of Staffordshire is just ticking boxes at times, without the actual care.                                                                                                                                                                                                                                                                                                          |
| <b>Tamworth</b>       | My husband has dementia and trying to find suitable support and advice is a challenge. Shops have no recognisable help for people with dementia. As far as I can see the government would rather we weren't here anymore. Trying to see my GP is a challenge and I have to ask my son to beg for an appointment. Considering I worked for the NHS it is an insult the way we are treated now. |
| <b>Tamworth</b>       | The person I'm answering on behalf of would need someone to advocate on her behalf. Her previous advocates have found making complaints challenging.                                                                                                                                                                                                                                          |

Do the following organisations provide communications to you or the person you are answering on behalf of in a way that you need them?



Figures exclude respondents who answered "Not applicable" or "Don't know".

| Do the following organisations provide communications to you or the person you are answering on behalf of in a way that you need them? |            |            |          |
|----------------------------------------------------------------------------------------------------------------------------------------|------------|------------|----------|
| Organisation                                                                                                                           | ☑ Yes 2024 | ☑ Yes 2025 | 📈 Change |
| 🎓 Schools & Further Education                                                                                                          | 62.7%      | 73.7%      | ▲ 11.0%  |
| 🚑 Ambulance Service                                                                                                                    | 45.8%      | 43.9%      | ▼ -1.9%  |
| 👮 Police                                                                                                                               | 29.6%      | 40.5%      | ▲ 10.9%  |
| 🏥 Hospital Services                                                                                                                    | 58.1%      | 58.5%      | ▲ 0.4%   |
| 👨‍⚕️ GP Services                                                                                                                       | 72.0%      | 72.5%      | ▲ 0.5%   |
| 🏠 Housing Providers                                                                                                                    | 33.3%      | 37.2%      | ▲ 3.9%   |
| 🚌 Public Transport                                                                                                                     | 30.3%      | 34.8%      | ▲ 4.5%   |
| 🛒 General Retail                                                                                                                       | 41.9%      | 28.8%      | ▼ -13.1% |
| 🏛️ Local Authority                                                                                                                     | 36.7%      | 52.6%      | ▲ 15.9%  |
| 🤝 Social Care                                                                                                                          | 52.2%      | 52.6%      | ▲ 0.4%   |

Percentage comparison for 2024 vs 2025 across key public service sectors

## **Key themes from respondents who stated organisations did not provide communications in a way that they need them?**

### **Communication gaps and accessibility**

Respondents frequently highlight issues with how services communicate—especially for individuals with sensory impairments, neurodivergent traits, or learning disabilities:

- letters and verbal-only formats often exclude those with visual impairments or non-verbal communication styles
- overuse of jargon, inconsistent messaging, and inaccessible formats (e.g. phone-only systems) create barriers
- there's a strong call for simplified, personalised, and multi-format communication—especially email, SMS, and clear written materials.

### **Lack of individualised understanding**

Many services are described as treating everyone the same, without recognising the unique needs of people with autism, ADHD, or learning disabilities:

- respondents report being dismissed, patronised, or spoken over—especially in schools, GP practices, and housing services
- there's a clear need for staff training on hidden disabilities, sensory triggers, and respectful interaction
- families often act as advocates because services fail to engage directly with the person affected.

### **Need for staff education and consistency**

A recurring theme is the variability in staff knowledge, empathy, and responsiveness:

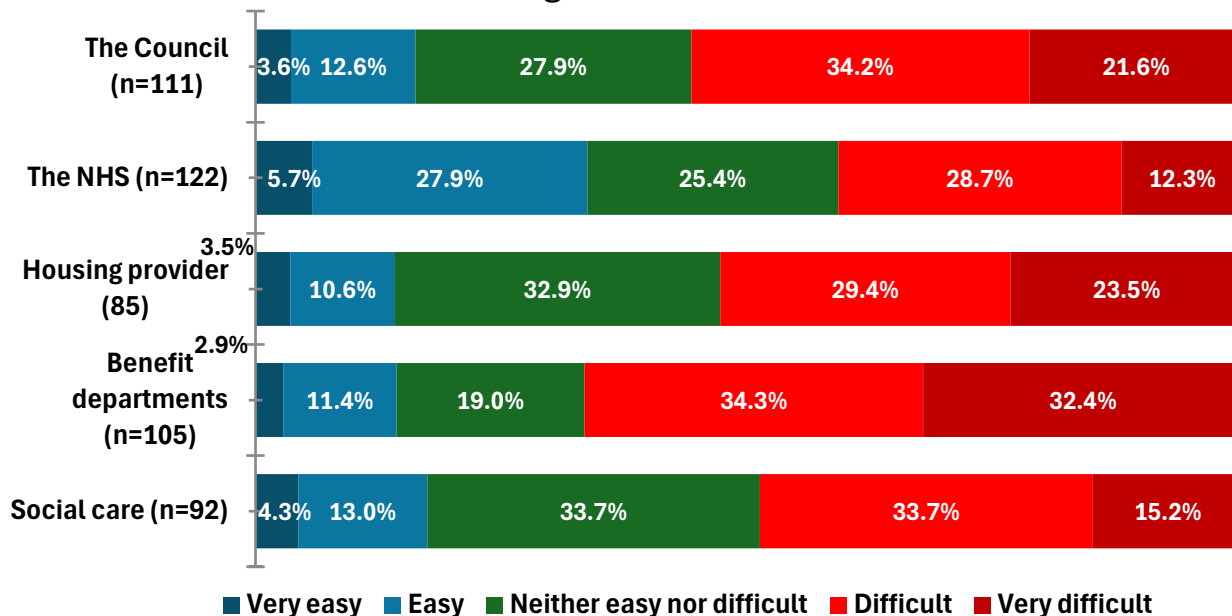
- positive experiences are often tied to individual staff members rather than systemic practice
- respondents call for consistent training across sectors—especially in schools, hospitals, and local authorities
- there's a desire for staff to “listen with their head as well as their ears,” and to avoid assumptions or dismissive behaviour.

| Respondent Location         | Do the organisations listed provide communications to you or the person you are answering on behalf of in a way that you need them?<br>Responses to 'No'                                                                                                                                                                                                                                                                                                                                   |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Cannock Chase</b>        | Answering for child                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Cannock Chase</b>        | Most of the time my daughter is treated as difficult.                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>East Staffordshire</b>   | Be more readily available for a start, particularly by email                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>East Staffordshire</b>   | I do not have any personal involvement with anyone who is a Downes or other type of, shall I say, mental difficulty or disorder, though I do see them with their carers. When I am out in town shopping sometimes, I wave to them.                                                                                                                                                                                                                                                         |
| <b>East Staffordshire</b>   | I would like to not be overloaded with information. I would like information to be clear and to the point as I struggle with ambiguity. I would like information to not be contradictory, for example I have received several letters in the post all on the same day for the same hospital appointment but on different days.                                                                                                                                                             |
| <b>East Staffordshire</b>   | In general my son has a positive experience in most cases but as I have said before it depends on the situation and circumstances and the person he is interacting with services need to be aware of the differences in our children , educate or have guidance on how to interact and how to make them feel welcome and an integrated part of society as a parent you soon learn the good places , the bad places and even the ugly !!                                                    |
| <b>East Staffordshire</b>   | Many of the ones I've answered no to expect information to be given over the telephone, and I just cannot do this.                                                                                                                                                                                                                                                                                                                                                                         |
| <b>East Staffordshire</b>   | There is no sometimes, which would be more accurate for all that have been answered yes                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b>   | To have my LONG TERM diagnosed conditions logged on my file so I don't have to explain it EVERY time I ring them                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Lichfield</b>            | Because he doesn't want anyone to know he has a learning disability Although it is clearly obvious, I encourage him to tell organisations so he can get more understanding                                                                                                                                                                                                                                                                                                                 |
| <b>Lichfield</b>            | They just need to have an understanding of how to respond , if the person triggered, or stimming , watching for reactions, listening to responses, DO NOT PATRONISE, do not dismiss, talk to the person not the friend relative or carers if the client /patient has capacity. if they trigger someone, understand the responses, and LEARN MAKATON.                                                                                                                                       |
| <b>Newcastle-under-Lyme</b> | Do not have contacts                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Newcastle-under-Lyme</b> | Having put yes to most responses this is only because the communication would be between myself and the organisations mentioned.                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | No experience with them. Shops have no staff with any awareness, avoid shops mostly                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Newcastle-under-Lyme</b> | School Communication has not always met our needs. Information is often delayed, inconsistent, or withheld. Concerns are not properly acknowledged, and when we have raised serious issues (such as bullying), responses have been dismissive rather than supportive. GP The GP is usually responsive but tends to refer us on to CAMHS rather than addressing issues directly. As CAMHS communication and support are very poor, this leaves us without the help we need. Local Authority |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                | Communication is poor. It is often complicated, full of jargon, and not adapted for families or children with additional needs. The local authority frequently passes us between departments rather than giving clear, direct answers. This makes it very difficult for my daughter's needs and voice to be recognised.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b>    | To talk to in person and to talk to me as an intelligent person                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Newcastle-under-Lyme</b>    | What an oddly phrased question! Not sure I fully comprehend it! But, communications and interactions (including treatments) tend to be verbal, we're non-verbal and therefore largely excluded                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stafford</b>                | As a person at my age, we have not had it easy because if you don't speak up then they are not going to get any HELP, so we are very much written of when you fall into these certain groups. And it takes a lot to be heard and listened to as a person with a Diagnosis of either Autistic or having a Learning Disability or Difficulty.                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stafford</b>                | Providers often 'speak over' the person with difficulties without trying to speak AT or TO that person even if someone else has to answer                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Staffordshire Moorlands</b> | After being at A&E for 12 hours just for an x-ray it would be nice to get a discharge letter stating the diagnosis... maybe it was available if I'd ask but after 12 hours on metal chairs in filthy waiting area and having weakened immunity, I just wanted to get out ASAP. Verbal communication wasn't pleasant either as everyone was just finishing their night shift I guess. With my housing agency I kept reporting mold, loose bricks in the garden wall and there is never record of it, and I admit it's not hard to do it through e-mail nevertheless it is a private agency that same as many businesses seems to not care about trading standards and consumer rights as there is less and less public support and strength to go through legal proceedings just to prove our own rights. |
| <b>Staffordshire Moorlands</b> | Again ignorant.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Staffordshire Moorlands</b> | For the person to take the time to listen, not try to rush the person with autism.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Staffordshire Moorlands</b> | More publicity                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b>          | Again, an advocate with intelligence of the situation and a voice is needed.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b>          | Again, continuity education and training as applicable to meet the needs of the person                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b>          | Anything would have been different                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b>          | Better communication from school prior to changes being introduced for an autistic person                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b>          | Better education for staff working in hospitals would be a good idea, so that they are better educated on the various disabilities their patients may present.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b>          | Communication in the form of letters isn't of use to my partner who is blind. NHS ones could be sent by email or text format so her phones accessible technology would read it out to her. But it's not set up across the board to do this. We have to ask, time and time again when on her records it says she's severely sight impaired.                                                                                                                                                                                                                                                                                                                                                                                                                                                               |

|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|-----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | Easy to understand but not treated like an idiot. Clear, open communication, understanding of someone with autism more direct approach. Taking care to understand and help eliminate the extra anxiety and sensory overwhelm that autistic people have. Most importantly, make me and others like me feel seen, not an afterthought or indeed, no thought.                                                                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b> | I would like more written communication and feel more regular feedback but in addition to this, the information shared with school to be communicated to all relevant staff as this clearly does not happen                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | More clear letters without all the clutter as autistic people tend to get confused when too much writing.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b> | Most the above need education on dealing with people with disabilities especially with the not so visible disabilities such as Autism ADHD etc as until something out of the normal happens it is then they get stressed and suffer a meltdown which can come without warning Eg my grandson terrified of wasps and seeing one can cause one During Covid my daughter took him to the Supermarket shopping Following the arrows when people perhaps forgetting something retraced their steps they were going against the direction and he suffered a meltdown - my daughter had to abandon her shopping!! |
| <b>Stoke-on-Trent</b> | People don't tend to listen to an autistic person, and it increases their anxiety. Services expect to deal with everyone the same and that is difficult when dealing with autism                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b> | Simplified, less jargon, less overwhelming, with contact numbers to call if we have questions (and for the phones to be answered when called!)                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b> | The mental age of the adult is generally not taken into consideration.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | To listen to significant carer. Not to give tasks that are unachievable.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stoke-on-Trent</b> | To listen with their head as well as their ears                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | With compassion and understating                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Tamworth</b>       | Communications are delivered in several different ways - email, post, SMS, encrypted messages, apps. Sometimes addressed to the person I'm answering on behalf of, sometimes to her PAs/Carers, sometimes to me as her appointee.                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Tamworth</b>       | We need more acknowledgement that not everyone is the same. People are not always in the best of health both physically and mentally. Nobody wants to acknowledge that. They just expect everyone to be the same.                                                                                                                                                                                                                                                                                                                                                                                          |

How easy do you feel it is for a person with a Learning Disability, Down's Syndrome or Autism to obtain information, advice, or guidance from the following organisations?



Figures exclude respondents who answered "Not applicable" or "Don't know".

| How easy do you feel it is for a person with a Learning Disability, Down's Syndrome or Autism to obtain information, advice, or guidance from the following organisations? |          |          |         |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|----------|---------|
| Organisation                                                                                                                                                               | NPS 2024 | NPS 2025 | Change  |
|  The Council                                                                            | -51.1    | -39.6    | ▲ +11.5 |
|  The NHS                                                                                | -17.3    | -7.4     | ▲ +9.9  |
|  Housing Provider                                                                       | -56.7    | -38.8    | ▲ +17.9 |
|  Benefit Departments                                                                    | -60.0    | -52.4    | ▲ +7.6  |
|  Social Care                                                                            | -40.3    | -31.5    | ▲ +8.8  |

Net Promoter Scores (NPS) for 2024 vs 2025 across key organisations

## **Key themes from respondents who found it 'Difficult' or 'Very difficult' to obtain information, advice, or guidance**

### **Communication barriers**

Many respondents describe difficulty accessing services due to reliance on phone calls, online forms, and jargon-heavy materials:

- non-verbal individuals and those with sensory or cognitive challenges struggle with standard contact methods
- lack of Easy Read formats and inconsistent messaging across departments adds to confusion.

### **Lack of continuity and personalisation**

Support is often fragmented, with frequent staff changes and generic approaches that overlook individual needs:

- respondents report having to repeat their story multiple times
- the absence of named contacts or consistent care plans undermines trust and efficiency.

### **Limited staff awareness and training**

Frontline staff in benefits, housing, and healthcare settings are often perceived as lacking understanding of neurodivergent conditions:

- respondents highlight dismissive attitudes, poor listening, and assumptions about capability
- there's a strong call for practical, experience-based training—not just e-learning modules.

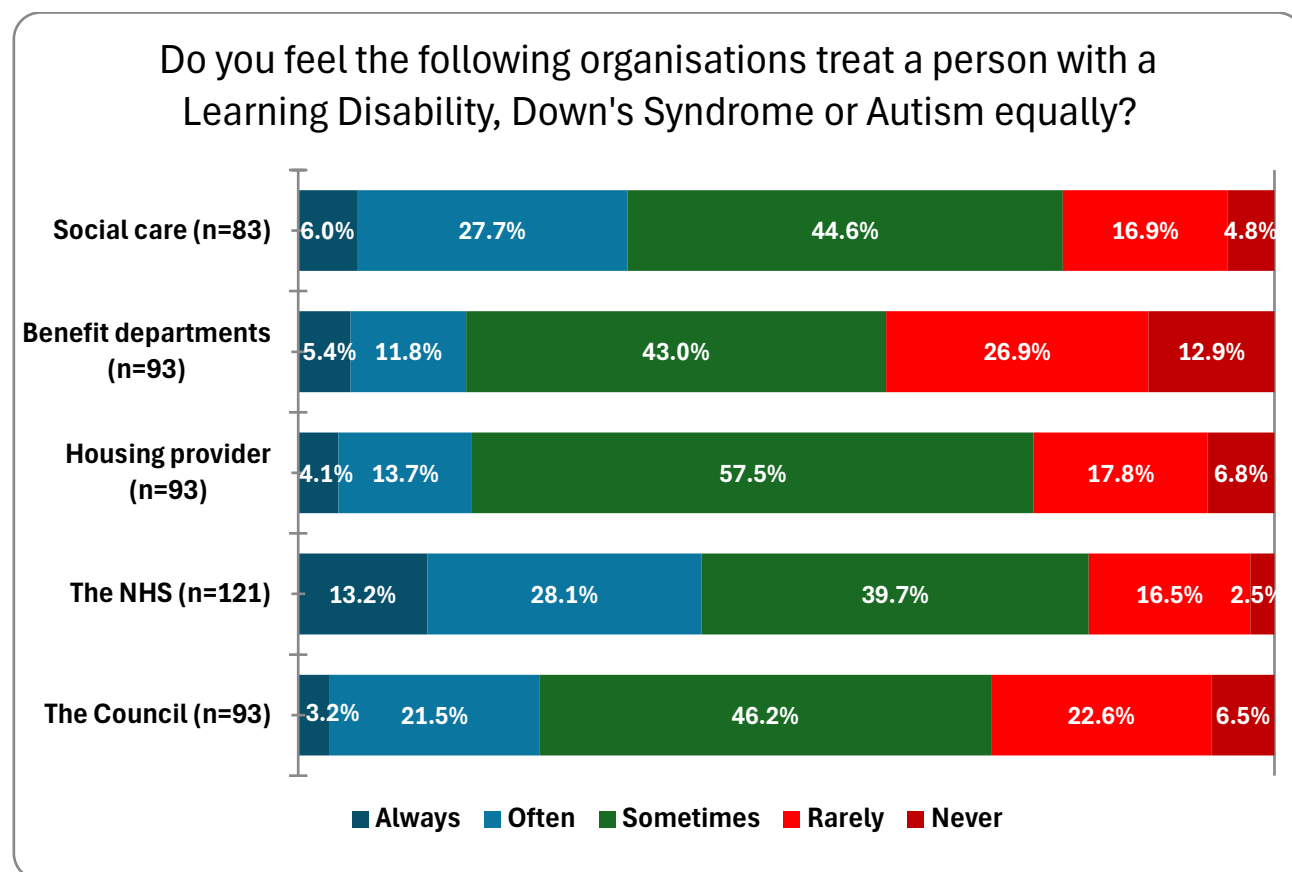
| Respondent Location                                 | How easy do you feel it is for a person with a Learning Disability, Down's Syndrome or Autism to obtain information, advice, or guidance from the organisations listed?                                                                        |
|-----------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Responses to 'Difficult' or 'Very difficult'</b> |                                                                                                                                                                                                                                                |
| <b>Cannock Chase</b>                                | Again, depends on different organisations and areas some put money into providing easy read formats etc                                                                                                                                        |
| <b>Cannock Chase</b>                                | The world is not set up for those who find communication difficulties. Technology is not always easy.                                                                                                                                          |
| <b>East Staffordshire</b>                           | A lot of information is online and not always in an easy read format. 'As a neurotypical person I can often find it difficult to navigate the websites to find the information I am looking for. My son would not have an idea where to start. |
| <b>East Staffordshire</b>                           | Again, this is all down to people being expected to use the telephone for specific advice.                                                                                                                                                     |

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-----------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>East Staffordshire</b>   | Benefits are complex and there's not enough face to face help. Too much reliance on online forms.                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>East Staffordshire</b>   | Benefits departments and the information they provide are complicated for an able-bodied neuro typical person - so it would be unimaginable how a person with a Learning Disability, Down's Syndrome or Autism cope trying to access support and help.                                                                                                                                                                                                                                                                  |
| <b>East Staffordshire</b>   | Most issues are addressed by phone calls, which I have problems with                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b>   | Need to know what to ask for, can know to ask for help if don't know it's a possibility                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>East Staffordshire</b>   | Nothing is accessible and recently you are treated like you are the bottom of society since the government have put a huge effort to make disabled people the issue with the country                                                                                                                                                                                                                                                                                                                                    |
| <b>East Staffordshire</b>   | Once over the age of 18 it is incredibly difficult to access support and accurate information                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>East Staffordshire</b>   | They don't have enough empathy or awareness of how adults are affected by Autism                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>East Staffordshire</b>   | We ( his parents) the full time advocate and representatives for our son - we are lucky to currently have a fabulous support network from Carers and Social Services but our biggest fear as we get older is how he would navigate the world in general without our support We have experienced good , bad and downright awful responses during since 2009 when we adopted our son and his younger sibling from SCC                                                                                                     |
| <b>Lichfield</b>            | Because they presume he can understand He gets angry and frustrated                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Lichfield</b>            | They just don't understand why I won't talk on phone, why I react as I do, lack of training , understanding, and often saying , 'yes I know about Autism' when they obviously don't just because your aunt, uncle, sister, brother, cousin, Mrs Smith child down the road, you went to school with someone with Autism, does not give you any understanding of all ranges of Autism/ADHD. There is no continuity in the above groups of people, so no understanding, just the thought of the above groups is triggering |
| <b>Lichfield</b>            | You need to be intelligent to interact with most departments effectively                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Newcastle-under-Lyme</b> | Benefits service don't inform you of what support is available                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Newcastle-under-Lyme</b> | Communication between those with medical conditions as mentioned, would either not know what to ask or understand the responses given and that the person they are speaking to may not know what they are being asked.                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | I'm not sure how much info is available to these organisations or how much importance they place on these conditions                                                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Newcastle-under-Lyme</b> | In most circumstances they wouldn't know who to ask or what questions to ask but they should have a care worker to help them.                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | No interaction                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Newcastle-under-Lyme</b> | Non-verbal, autistic, anxious                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Newcastle-under-Lyme</b> | The information available online is generally good but it can be hard to find the right bit, and there's no one to ask questions to if you can't. Phone calls are hard and often phone queues are long which is difficult. It's even harder when people say they'll call you back as you don't know when and can't do anything else until they do.                                                                                                                                                                      |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Newcastle-under-Lyme</b>    | The staff do not understand my needs and act as if I'm being difficult                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stafford</b>                | Information is difficult as an adult advocating for disability Lack of information the presumption we all know what or how to fill some forms in . No support                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Stafford</b>                | It's about identifying the need and then communicating it. Not enough people understand alternative communication styles or how to behave with specific groups but if the barrier is language, an interpreter is arranged. Funny really.                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stafford</b>                | Obtaining information from organisations is challenging and bureaucratic for people without additional needs so I would assume it is even more difficult if you had needs.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stafford</b>                | This because people out there still have a very narrow view of people with any Disability or Difficulty, because we are treated very different and we are judged because of having a Disability or Difficulty. So, we are trying to get Society to treat us better than we ever have.                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Staffordshire Moorlands</b> | Although the local council has a help desk Its main function seems to be to refer people to its website instead of providing the information themselves.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Staffordshire Moorlands</b> | Everyone is in such a rush to meet targets they d9nt have the time to spare to take things at a pace for the person with autism to understand.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Staffordshire Moorlands</b> | I feel I have to search for the info.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Staffordshire Moorlands</b> | Ignorance about disabilities, belittle ppl                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Staffordshire Moorlands</b> | It would be nice to design some kind of benefit map/blueprint explaining what comes before, what after, what affects what, with ALL the phone numbers and links to those supports available as now it is a very tangled and messy system that after very long process involving CAMHS to get right treatment and being a single parent makes this process sometimes beyond overwhelming and it takes so long that financial pressure often causes an individual deteriorating due to overall pressure on the household. Also as mentioned before Having just one "random" foreign language through which you can communicate with "the most generous" part of the Benefit Department - that's just disgraceful. |
| <b>Staffordshire Moorlands</b> | No                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b>          | Anxiety of dealing with any services and communication difficulties for people with autism makes contacting or getting their point over very difficult unless they have an advocate present                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b>          | As the carer it is down to me to pass on any information in a way my son can understand.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b>          | Because we are often not understood ways that help us enough whether that's because we are unable to use a telephone or find it harder sometimes to communicate with others, particularly if non-verbal! It's virtually impossible to get help from any service if you cannot actually verbally speak to somebody. There are not enough non-verbal ways for us                                                                                                                                                                                                                                                                                                                                                  |

|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                       | to communicate with others when we are ill and need urgent care or medical support. That is so hard to do.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | Benefit departments are often not medical qualified                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | Camhs don't help with solutions and do not do diagnosis so you can get the right help and support. Benefits do not make it easy to fill out forms without help as questions can be confusing                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | Depending on disabilities and personal support available                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | DWP and GP services seem to be my sons hardest challenge and he finds it difficult to speak or find someone who understands autism.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b> | My observations                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b> | Often do not have the independence skills or are misunderstood by person dealing with them. Technology and telephone communication too difficult. Need assistance to access and with face to face.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b> | One example this week - appointment needed at Gp. Rang on Monday morning wanting an appointment for the person - offered Friday appointment... But they cannot ring themselves or answer stupid questions from receptionists or challenge the appointment offered                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b> | Overload of information, long wait on the phone to be connected, professionals using complicated language, when you ask for clarification, you're made to feel like a problem and that you're causing a nuisance but not understanding what's being said. I marked NHS as „easy” as online information is great, but when it comes to in person contact like phone or f2f it's not as easy unfortunately                                                                                                                                                                                                                                                                                                                                                |
| <b>Stoke-on-Trent</b> | Please see previous answers.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | Some people are so impatient and in such a hurry.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <b>Stoke-on-Trent</b> | The Council is useless for people that aren't disabled never mind Autism Learning difficulties Downs syndrome etc You can be on the telephone a good twenty minutes and then put through to the wrong departments. 2 With regard to the local hospital I'd say the switchboard is ok but once they put you through to a department or ward and no one answers. They don't look if you've got an answer, so you have to ring the switchboard back (that happens a lot!) Anyone with any of those disabilities would have trouble dealing with that ! When I worked a switchboard in the 60s (the old peg and wire system) you knew before you put them through the person they were after had answered! Progress lol That definitely needs looking into! |
| <b>Stoke-on-Trent</b> | The UC claim is horrendous. I've had a friend with a 19yr old daughter who cannot speak having to take her to the job centre ever two weeks and give in sick notes until she is assessed. The action plan was she would need to look for work till that happened. Seriously she can't speak is in nappies and uses a wheelchair but still needs assessing. Thats a big stress for the family                                                                                                                                                                                                                                                                                                                                                            |
| <b>Stoke-on-Trent</b> | There is a lack of clear information written in appropriate ways for this group of individuals and it's hard enough to get this information for neurotypical people let alone neurodiverse                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Stoke-on-Trent</b> | They are all difficult due to the lack of communication from them and the lack of contact information available for the order departments.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

|                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|-----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Stoke-on-Trent</b> | To me it's all about better education of the staff in these establishments that would help people with disabilities greatly.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>Stoke-on-Trent</b> | Too many forms, not enough communication between all agencies. CAHMS is rejecting so many children rather than put them on a waiting list. When a child does make it into the waiting list, the wait time is ridiculously long. They are failing our children.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Tamworth</b>       | Council workers housing officers and benefits staff have little or no training on dealing with neurodivergent conditions                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Tamworth</b>       | Most communications are now being done online. The person I'm answering on behalf of can't use technology. Regarding social care / local authority - she doesn't have a named social worker so communication is done with duty officer who passes the message onto a social worker who won't know her or her support needs and will have to read about her in her case file. She rarely has the same social worker - a different one every visit. It's so important for people with these conditions to have continuity and it's a waste of resources for a new SW every time to have to read through case files before reviews etc. it's one of the most frustrating issues in social care which families have been complaining about for decades. |
| <b>Tamworth</b>       | Try phoning them                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |



Figures exclude respondents who answered "Not applicable" or "Don't know".

| Do you feel the following organisations treat a person with a Learning Disability, Down's Syndrome or Autism equally? |          |          |        |
|-----------------------------------------------------------------------------------------------------------------------|----------|----------|--------|
| Organisation                                                                                                          | NPS 2024 | NPS 2025 | Change |
| The Council                                                                                                           | -17      | -4       | ▲ +13  |
| The NHS                                                                                                               | +23      | +22      | ▼ -1   |
| Housing Provider                                                                                                      | -11      | -7       | ▲ +4   |
| Benefit Departments                                                                                                   | -21      | -23      | ▼ -2   |
| Social Care                                                                                                           | +10      | +12      | ▲ +2   |

Net Promoter Scores (NPS) for 2024 vs 2025 across key organisations

 **Key themes from respondents who felt organisations ‘Rarely’ or ‘Never’ treat a person with a Learning Disability, Down's syndrome or Autism equally.**

 **Lack of understanding and empathy**

Many respondents describe feeling dismissed, judged, or misunderstood—especially when interacting with benefits departments, councils, and healthcare services:

- staff often lack awareness of neurodivergent conditions and hidden disabilities
- requests for reasonable adjustments are frequently ignored or met with resistance.

 **Complex systems and bureaucratic barriers**

Navigating support services is described as overwhelming, confusing, and emotionally draining:

- long forms, unclear processes, and inconsistent communication create stress
- families often act as advocates, but fear what will happen when that support is no longer available.

 **Equality vs equity misunderstood**

Respondents highlight that “equal treatment” often fails to meet their needs:

- there’s a strong call for **equity**—tailored support based on individual circumstances
- standardised approaches and tick-box systems are seen as harmful, especially in benefits and employment settings.

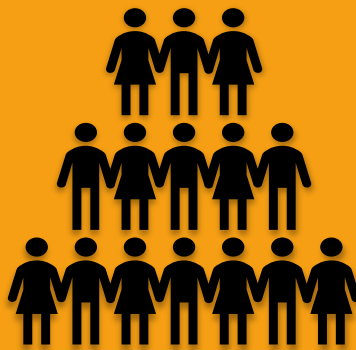
| Respondent Location | Do you feel the organisations listed treat a person with a Learning Disability, Down's Syndrome or Autism equally?<br>Responses to ‘Rarely’ or ‘Never’                                                                                                                                                                                                                                                                                                |
|---------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Cannock Chase       | Can't always speak to the right person. No time for people who struggle. Not accepting that someone can't speak for themselves                                                                                                                                                                                                                                                                                                                        |
| East Staffordshire  | Always dismissive                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| East Staffordshire  | Equity and equality are not the same                                                                                                                                                                                                                                                                                                                                                                                                                  |
| East Staffordshire  | Generally our son has been looked after well in all aspects of his 20 years on earth so far but only with the never ending support of ourselves and the agencies we have in our network Without this I believe he would not survive alone - that may sound dramatic but it is truly how we feel and have little confidence for his future without his current support network through my involvement with the Autism Pyramid Group I have encountered |

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|-----------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                             | families who are in a much worse position but my priority is and always will be our son                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <b>East Staffordshire</b>   | I have either been told tough I need to use the telephone for something and have had alternative communication methods refused, meaning my ability to communicate with organisations quickly is seriously impaired. Even 999 texts are not dealt with as quickly as 999 calls. When I do manage to communicate with organisations, they treat me like I'm 7 years old instead of a highly intelligent adult.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>East Staffordshire</b>   | Ironically I think that the NHS is the organisation that least understands the issues faced by autistic people. Autism can be a hidden disability, and the NHS needs to change their perception.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>East Staffordshire</b>   | My autistic daughter is currently applying for PIP and her autism means she doesn't cope well with interviews and questions - and when I have tried to answer on her behalf they don't take me seriously.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>East Staffordshire</b>   | Our son's experience of going onto universal credit and the Burton Job centre was positive, we took lots of evidence e.g. EHCP, diagnosis letters, etc. and they were quick to recognise and support him through the journey of application and assessment for the limited capacity for work-related activities. Equally he has found GPs understanding and helpful. When younger and supported via the Early Help team of the council, the worker while pleasant and good at pulling service providers together, she kept suggesting she knew very little about Autism and we were teaching her. The SENDIAS service of the local authority was also extremely supportive when we had issues with the high school. In contrast, the local authority team and key workers responsible for EHC Needs Assessments, EHCPs and annual reviews of EHCPs have all been extremely stressful to communicate with, related to attitudes, and the frequent turnover of staff, the lack of accountability and not following legally prescribed processes. |
| <b>Lichfield</b>            | Because he doesn't disclose his learning disability                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Lichfield</b>            | For all the same reasons I have given in the previous answers                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | I don't think it's reasonable to be treated equally, we need to be treated differently because we are different, to ensure equity                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Newcastle-under-Lyme</b> | No experience                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Newcastle-under-Lyme</b> | Not being able to understand the complexity of someone's learning disability etc. compounds the needs of the person from being given equality with someone without any disabilities of learning.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Newcastle-under-Lyme</b> | The staff act as if they have had no training                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stafford</b>             | Again, presumption the advocate knows the system and all the answers. Knows which forms etc. Navigating support entitlement is made very hard. Getting organisations to work together whether individual NHS dept or benefits is almost impossible putting added pressure on family.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stafford</b>             | This is because we are being treated so differently because it is hard to go against the NORM, so we are treated more like Second Class citizens, and we are then thrown onto the Benefits Scrap Heap. So, it is very hard to get into employment because organisations don't want to Baby Sit people with Disabilities or Difficulties.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Staffordshire Moorlands</b> | I am answering in relation to my step son who is in full time care so many of the questions are not actually appropriate                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <b>Staffordshire Moorlands</b> | Not understanding of people needs i.e. longer time to be in apt9                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Staffordshire Moorlands</b> | This form is too long, fed up now                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Staffordshire Moorlands</b> | Too busy meeting targets.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Stoke-on-Trent</b>          | Again, it all comes down to a lack of understanding about various disabilities and how to interact with patients with disabilities. Education of staff                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Stoke-on-Trent</b>          | As previous questions answer that will cover this question                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | CAHMS dismisses children out of hand.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Stoke-on-Trent</b>          | DWP don't recognise the suicide risk with autism and how their process can increase risk to life.                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | No. If you ask for clarification, extra information, or anything else that is out of the „standard“ you're made to feel like you have to justify yourself, or that you're a nuisance. It puts you off asking for help that supports neurodivergence, so you just try your best to fit and end up struggling.                                                                                                                                                                                                                                                               |
| <b>Stoke-on-Trent</b>          | Please see previous answers. I'd just be repeating myself.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| <b>Stoke-on-Trent</b>          | The benefit system is a minefield for anyone and having autism and trying to explain difficulties is even worse if the person doesn't understand                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stoke-on-Trent</b>          | These groups of people are often not given all the information they need due to preconceived opinions about what they understand rather than adapting the communication method to suit the needs of the individual                                                                                                                                                                                                                                                                                                                                                         |
| <b>Stoke-on-Trent</b>          | They should be treated as individuals. Equally sounds like they/we are all the same or fit into their tick boxes.                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Stoke-on-Trent</b>          | Treating them equally is virtually impossible as they would require an excessive amount of time spent on an individual. In an ideal world this would be great.                                                                                                                                                                                                                                                                                                                                                                                                             |
| <b>Stoke-on-Trent</b>          | When he has had to interact with benefits it has caused a lot of anger which has been taken out on family members. He has recently been moved to JSA from PIP so I am expecting all hell to break loose if they try and put him on any form of employability program because he would not cope, and neither would his family and carers                                                                                                                                                                                                                                    |
| <b>Stoke-on-Trent</b>          | With the council it's the difficulty getting through and finding the relevant person department!) who understands their problems whether in person or on the phone benefit departments Those two I'd say are the worst culprits It would be a simple solution to have a delegated person or persons and perhaps make it easier for them to contact and find the information. Disability is or supposed to be a priority in law now you wouldn't think so with the Benefits office and local councils (Being fair some are better than others, but it's a bit of a lottery) |
| <b>Tamworth</b>                | Everything is a challenge, and it shouldn't be.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Tamworth</b>                | They often make you feel like you are trying to get something for nothing, lying about your capabilities, and do not treat you as an individual / you are just one of a group of people who are different and therefore not entitled to the same rights and respects as the rest of the population.                                                                                                                                                                                                                                                                        |

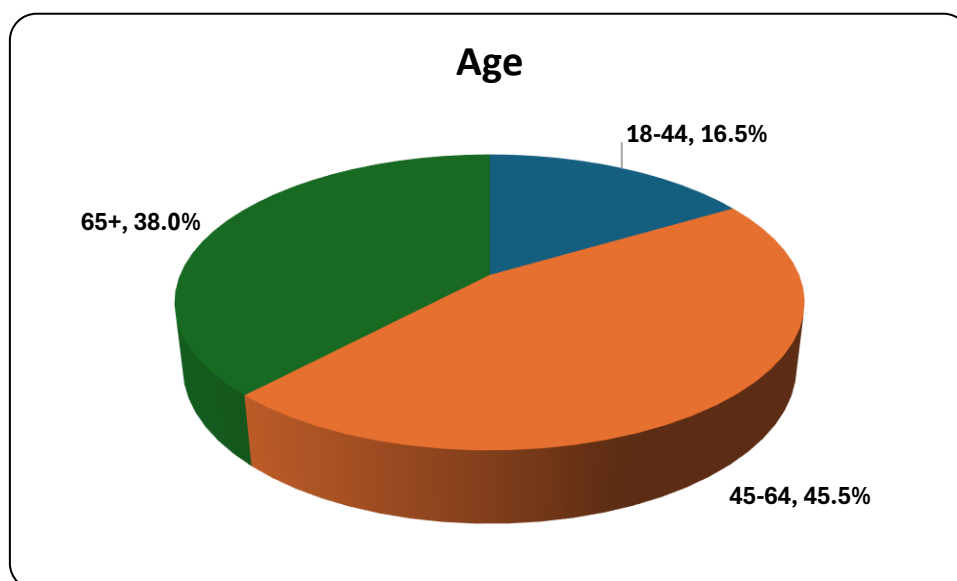
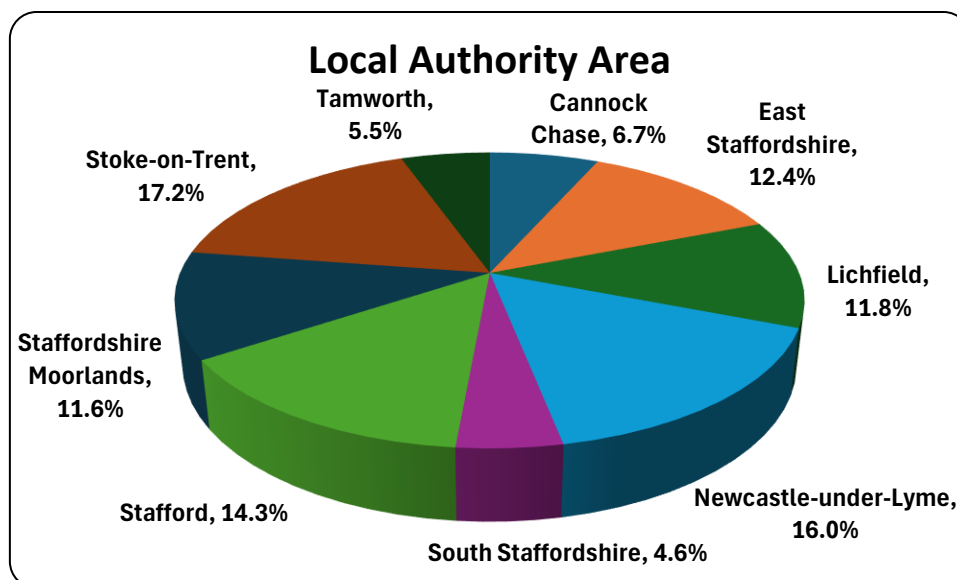
**3**

## **Respondent profiles**

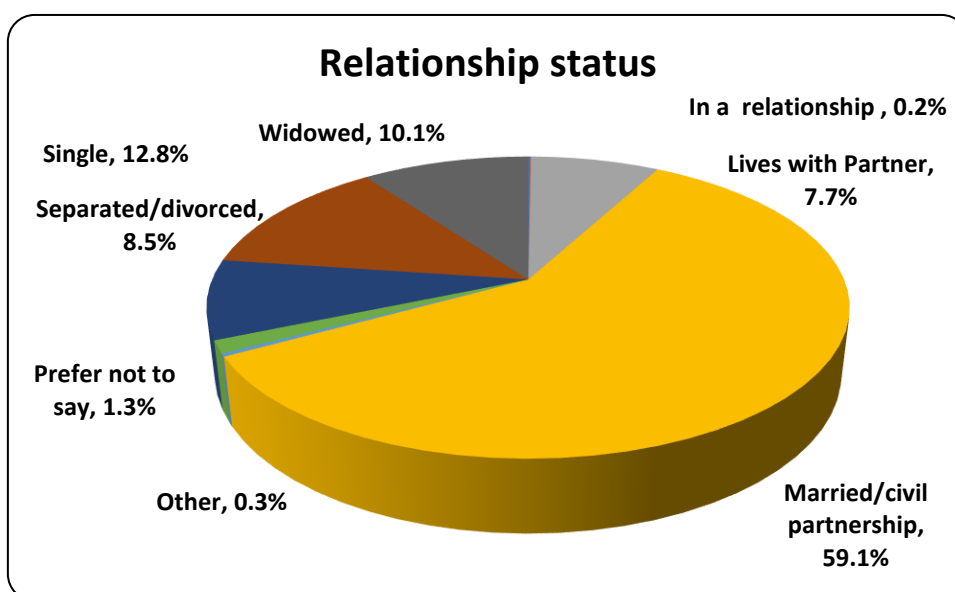
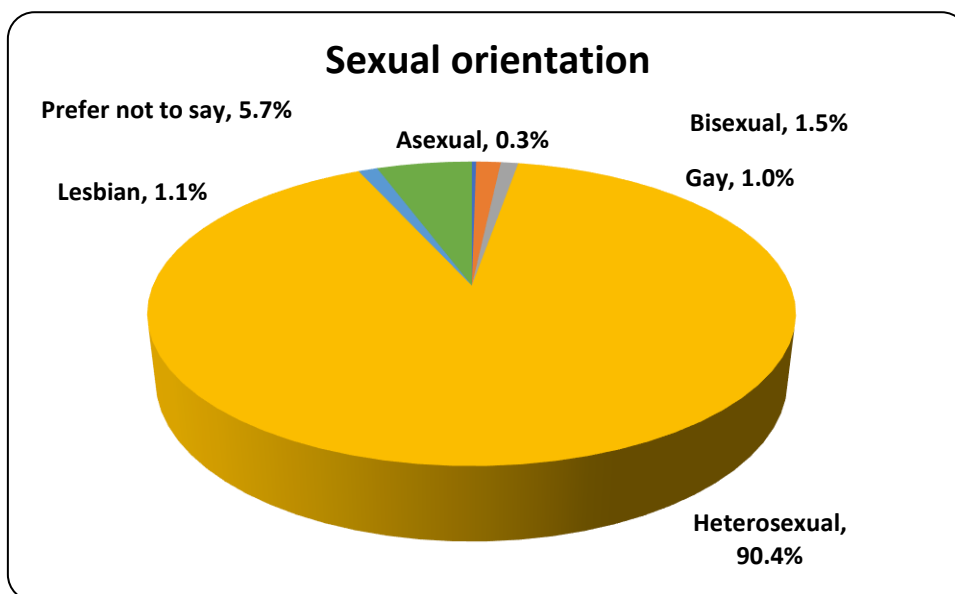
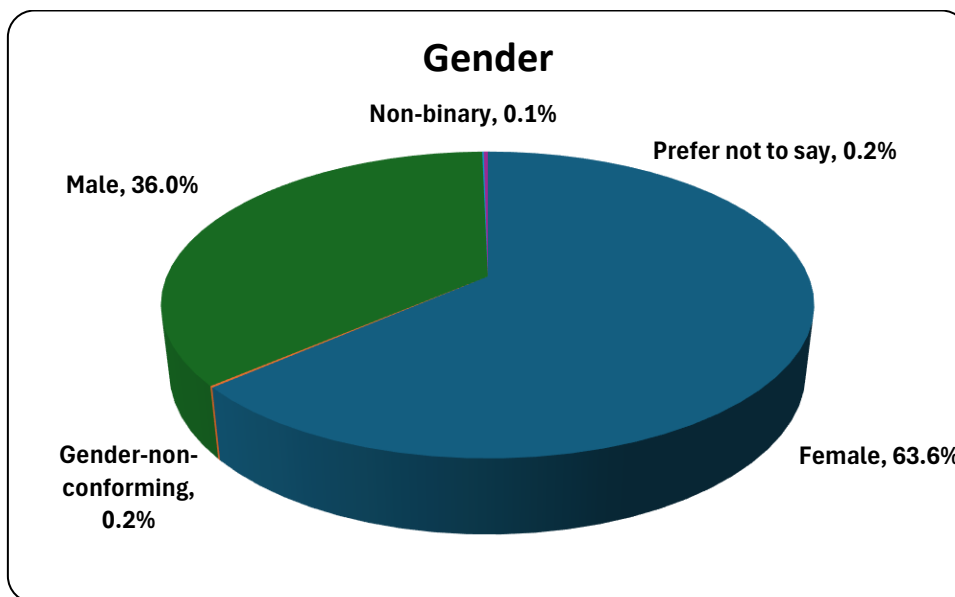


Demographics of the People's Panel are broadly representative of the profile for Staffordshire and Stoke on Trent (ONS 2021 Census data for Staffordshire and Stoke on Trent). <sup>1</sup>

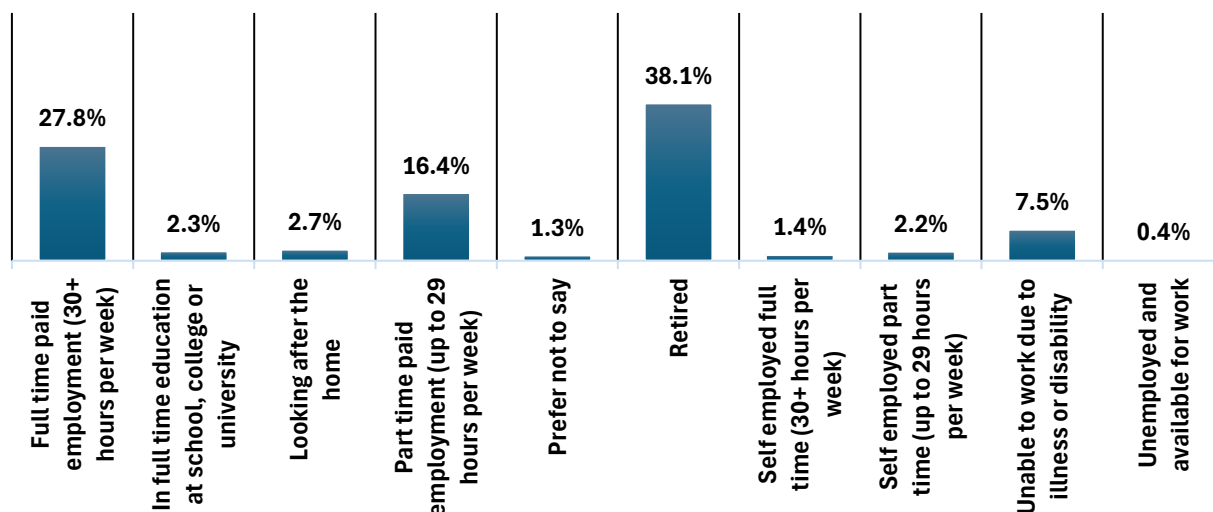
Breakdown of the 828 panel members who responded to the survey.



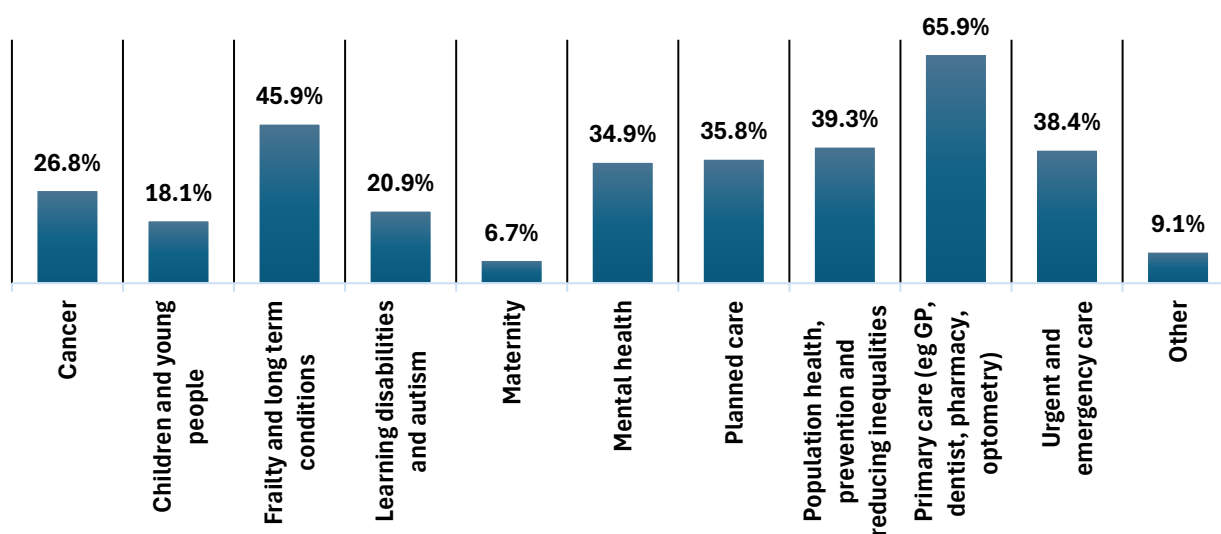
<sup>1</sup> Staffordshire and Stoke on Trent have separate ONS Census data  
September 2025 (V3.1)



### Employment status



### Do you have a special interest in any of the following areas of healthcare?



Special interest data is for members signing up to the panel from June 2023. Respondents could select more than one area of interest

