

Citizens' Panel for health and social care

Survey of public views on medicines safety, long term conditions and preconception health and care

Report, June 2025

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Foreword

Welcome to the fifteenth Citizens' Panel report for health and social care in Scotland. This report details findings from the full Panel survey which collected feedback between November 2024 and February 2025. The survey included questions on the topics below.



Public views on medicines safety

Medicines are the most common intervention in healthcare, helping Scotland's people live longer and healthier lives. However, medicines can cause harm, impacting on the sustainability of services and incurring significant costs for NHS Scotland. Health and care professionals, NHS Scotland and the Scottish Government are working to improve safety and reduce medicines-related harm. This work aimed to understand Panel members' views on medicines safety to inform priorities and shape relevant policies and services going forward.

Public views on long term conditions

Around half of the people across Scotland have a long term condition and, as people live longer, the number of people with long term conditions is growing, requiring support from services. Scottish Government is reviewing how it designs policy for long term conditions. Panel members' views will inform the development of a new policy for Scotland.

Public views on preconception health and care

Preconception health relates to people's health and wellbeing during childbearing years. It is shaped by the health behaviours and environment of women and men. Preconception health can influence fertility and early child development and can prevent harm to future generations. Panel members' views will be used to understand how to increase public awareness and understanding on this topic, as well as identifying areas for improvement.

The Citizens' Panel has allowed us to seek the views of a cross-section of the Scottish public on topics determined from priority areas for Scottish Government.

I would like to thank the individuals who have volunteered to be part of the Panel, who together make up a representative section of the Scottish population. I would also like to thank our research partners, Research Resource, and our partners in Scottish Government. I would like to thank those who contributed to user testing the survey questions, and staff involved from Healthcare Improvement Scotland. I hope you enjoy reading this report.

Suzanne Dawson
Chair, Scottish Health Council

Citizens' Panel for Health and Social Care

This infographic summarises the key findings from the fifteenth survey. We asked questions about:

- Medicines Safety
- Long Term Conditions
- Preconception Health and Care

In total 563 Panel members responded to the survey by post, email or phone, which represents a 57% response rate

Medicines Safety

A large majority of respondents (88%) said that NHS branding would help them feel confident that information about their medication from online sources is reliable and up to date

96% said they had a good understanding of how to take their medication



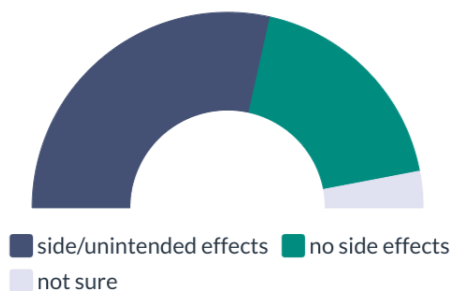
92% said they had a good understanding of the reason for taking their medication



73% said they had a good understanding of the side effects of their medication



Almost 6 out of 10 Panel members said they had experienced side-effects or unintended effects from a medicine, 37% had not experienced this and 6% were unsure



84% of those who had experienced unintended effects from medicines have spoken to a healthcare professional about this



99% agreed that it is important to understand the purpose, benefit and risk of the medication taken



95% agreed that they would be willing to report side effects from a medication to a healthcare professional



9 in 10 agreed that they are willing to be involved in discussions about medication they take (93%)



8 in 10 agreed that they have the support they need to understand the medicines they take (83%)



When asked, 98% of respondents agreed that they would expect NHS Scotland to collect and analyse data about medicines related harm to improve safety

Long Term Conditions

More than 9 out of 10 respondents had experience of a long term condition, either personally or because of someone they knew or cared for

76% said they had one or more long term conditions



60% said they had family members or friends with long term conditions



28% said they supported someone with a long term condition



Panel members' concerns about managing a long term conditions included

87% having access to healthcare, getting an appointment or seeing a specialist

68% having access to medication or equipment

64% having access to psychological or mental health support

63% having access to financial support

61% having support to self-manage conditions and symptoms

60% having enough time to manage a long term condition



Other than from a healthcare professional, Panel members were most likely to seek information about long term conditions through NHS websites (87%) or online searches (72%)

Panel members were most comfortable discussing their long term condition with

97%
a specialist healthcare professional



92%
a GP or nurse

83%
someone with lived experience

Asked how much they agreed or disagreed with the following statements, respondents said they

99% would expect a healthcare professional to discuss a long term condition with them

92% would change their lifestyle to prevent or manage a long term condition

63% knew enough to manage a long term condition relevant to them

54% knew enough about how to prevent a long term condition relevant to them

When asked what mattered most to them about long term conditions, a majority of Panel members identified ongoing support and access to healthcare professionals, and being able to manage their condition and look after themselves as their priorities

Preconception Health and Care

Other than from a healthcare professional, panel members were most likely to seek information about preconception health from NHS websites (74%), online searches (51%), friends and family (44%), or from third sector organisations (38%)

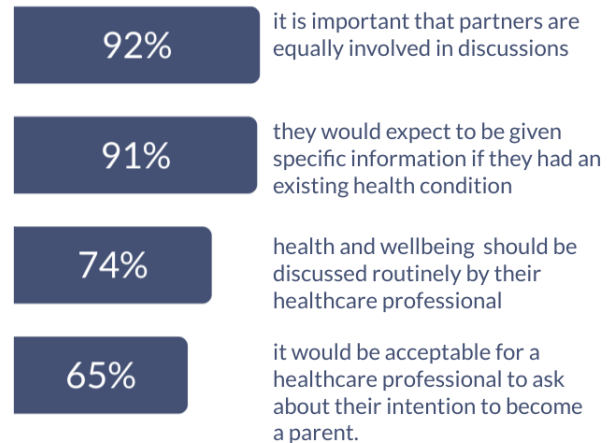
Respondents were most comfortable discussing preconception health with



Less respondents were comfortable discussing their preconception health with



Asked how much they agreed with the following statements in relation to preconception health, respondents said



Steps Panel members were likely to take in support of better preconception health included



One respondent said when asked what matters most thinking about preconception health, "The future health of a child/children and parents and having the best support from a range of people/organisations to achieve those outcomes."

Executive Summary

What is a Citizens' Panel?

A Citizens' Panel is a large, demographically representative group of citizens regularly used to assess public preferences and opinions. A Citizens' Panel aims to be a representative, consultative body of residents. They are typically used by statutory agencies, particularly local authorities and their partners, to identify local priorities and to consult the public on specific issues.

Background and context

The Citizens' Panel for Health and Social care was established in 2016 to be nationally representative. It has been developed at a size that allows statistically robust analysis of the views of the Panel members at a Scotland-wide level. This was the first time a national Citizens' Panel of this nature, focusing on health and social care issues, had been established in Scotland. Panel members were randomly selected from the general population and invited to join the Panel. Some targeted recruitment also took place to ensure that a representative Panel was created.

Since then, the Panel has been refreshed to ensure the representativeness of the Panel, including in spring and autumn 2024. The 2024 refresh activities focused on areas or demographics that were underrepresented in the Panel. At the time of this survey in the winter of 2024/25, there were 992 Panel members from across all 32 local authority areas. A profile of the Panel is provided in the appendixes of this report.

This report details the findings from the fifteenth Panel survey which collected feedback between November 2024 and February 2025. The questions explored public views on three topics:

- medicines safety
- long term conditions, and
- preconception health and care.

A total of 563 responses (57% response rate) were received, by post, email or telephone. This response rate provides data accurate to $\pm 4.13\%^1$ at the overall Panel level. In this report we do not report results broken down into sub-categories (for example, sex or age) as they are not statistically significant. All findings and comparisons stated in this report are statistically significant, unless otherwise stated.

This executive summary details key findings. More detailed information on the profile of responses can be found in [Appendix 2: Response profile](#).

¹ Based upon a 50% estimate at the 95% level of confidence.

Public views on medicines safety

Key findings

- Thinking about over-the-counter or prescribed medication respondents are currently taking or have taken recently:
 - 96% said they had a very good or good understanding of how to take the medication
 - 92% said they had a very good or good understanding of the reason for taking the medication, and
 - 73% said they had a very good or good understanding of the common side effects and risks related to the medication. 14% said they did not have much understanding, or had no understanding at all, of common side effects and risks related to the medication.
- Other than speaking to a healthcare professional, respondents were most likely to find information about a medicine by reading the information leaflet included in medication packaging (85%), visiting an NHS Scotland website (71%) or using an online search engine (61%). Some would ask others, such as family and friends (13%).
- If looking for more information about medicines online, the majority of respondents (88%) said that NHS branding, such as the NHS logo, would help them feel confident that the information is reliable and up-to-date. More than 6 in 10 said a recommendation from a healthcare professional to use the online source would give them this confidence (62%).
- Over half of the respondents said they had experienced side effects or unintended effects from a medicine (57%), 37% had not experienced any and 6% were unsure. This question relied on individuals' understanding of what may be a side effect, which could differ from a clinician's perspective. The question did not specify severity or whether these may have been known or expected side effects, for example, listed in the medicine leaflet.
- From those who had experienced side effects, most had spoken to a doctor, nurse or pharmacist about the side effects they experienced (84%, n= 313). 11% (n=313) had not talked about their side effects to anyone, mostly because they thought their side effects were minor or common (60%, n=33).
- The majority of respondents either agreed or strongly agreed with the statements provided:
 - 99% agreed it is important to understand the purpose, benefits and risks of any medications they are taking.
 - 98% agreed they would expect NHS Scotland to gather and analyse data on medicines-related harm to improve safety.
 - 95% agreed that if they realise they are experiencing side effects from a medication they take, they would be willing to tell a healthcare professional.
 - 93% agreed that they are willing to be involved in discussions about medication they take, including risks and potential harms.
 - 83% agreed they have the help and support they need to understand the medicines they take. 10% were neutral and 8% disagreed that they have the support they need.
- When asked what matters most about the safe use of medicines, around 3 in 10 respondents (30%) discussed side effects. They mentioned ensuring clear communication on the risks of side effects and what to do if they experience them. 20% said they wanted to know that any

medication they are taking is necessary and will be effective in treating their health condition. 19% said they would want to know that medicines are safe and have been rigorously tested². 18% wanted to know that information provided on medicines such as in the packaging is clear, accessible and accurate. Further aspects mentioned were: having clear instructions on how to take medication (11%); having confidence in the prescriber, being able to ask questions and have clear explanations (10%); knowing that benefits outweigh side effects (9%); and that the medicines are NHS approved (1%). 6% touched on multimorbidity and polypharmacy. They said that what matters most is knowing how medication will react with other medication and conditions.

Recommendations

Based on these findings Healthcare Improvement Scotland makes the following recommendations to Scottish Government and relevant stakeholders. Recommendations are outlined in further detail in the [Conclusions and recommendations for medicines safety](#) section.

1. Consider development of resources that support the public to understand the information, resources and processes that help people to take medicines safely and effectively. This should build upon the public's trust and willingness, seeking opportunities to engage with the public and patient representative groups in co-creating resources. This should also include work to encourage more widespread awareness and use of resources. It would be worthwhile considering how NHS branding is used in this area and whether its use could be further expanded where appropriate to support public confidence. Also consider how to obtain support from existing local arrangements and other partners, for example Community Pharmacy Scotland.
2. Ensure that information around medicines is available to the public in a range of formats, for example, in physical leaflets and online resources, and that it is provided to patients according to their preferences and accessibility needs, including through one-to-one discussion with healthcare staff. Ensure there are suitable avenues to ask questions and support understanding of medicines information. This could be for example about how medication may react with other medication or herbal remedies. Also consider how to address information needs where non-standard processes are in place. This could be where medicines are knowingly used outwith their product licence, for instance in treating some types of cancer, or in self-medication. In these cases, patients may not have all the information available to hand in the patient information leaflet.
3. Based on the prevalence of the public's use of digital tools to find medicines-related information, consider further work to explore in-depth how the public use Artificial Intelligence (AI) tools to find and understand healthcare information, and particularly information relating to medicines, aiming to help understand how to address potential risks of misinformation. Also consider the role of signposting from healthcare professionals to address risk posed by AI information sources.
4. Consider actions to support increased public understanding of why medicines are beneficial and necessary, as well as around side effects and risks related to medicines. This should build upon

² It is important to note that all medication prescribed through NHS Scotland has gone through a rigorous testing and approval process.

public trust in the NHS and healthcare staff. For example, this could be through using the BRAN questions³ and a realistic medicine approach, and increased signposting to relevant resources and information.

5. Take action to promote and support public awareness of the Yellow Card Scheme to improve under-reporting of medicines' side effects. Combined with this, improve how NHS Scotland draws learning from the data that are collected and analysed through the Yellow Card Scheme, and other data collected locally such as through Datix; and then uses this learning to identify and take specific actions to improve medicines safety across Scotland.
6. Consider work to further understand and identify where challenges relating to medicines safety may have more significant impact. This would include exploring potential barriers and enablers for particular groups. This could be for example around understanding side effects and risks, engaging in discussing medicines, and ensuring people have enough support to understand the medications they take.

Public views on long term conditions

Key findings

- Over 3 in 4 respondents (76%) said they personally have one or more long term conditions. Nearly 2 out of 3 (60%) said they have family members or friends with long term conditions. Just under 1 out of 3 (28%) said they provide care or support for someone with a long term condition. Less than 1 in 10 respondents (8%) answered none of the above to this question. It should be noted that the proportion of respondents who had a long term condition is higher for the survey than the data we hold on Panel members.
- Other than talking to a healthcare professional, Panel members were most likely to look for information about long term conditions on an NHS website, such as NHS Inform or local health board webpages (87%). They were also likely to do an online search (72%) or approach a third sector organisation or group (55%).
- Respondents were asked how comfortable they would feel discussing long term conditions with various people, including healthcare professionals. It was explained to Panel members that this could be for themselves now or in the future, a family member or someone they care for. Respondents were most likely to feel comfortable with a specialist healthcare professional (97%), primary care professional such as a GP or nurse (92%), someone with lived experience of the condition (83%) or pharmacist (80%). Panel members were most likely to say they would not be very comfortable or not at all comfortable discussing a long term condition with someone that practices alternative therapies (35%) or someone who knows the patient such as a coach or teacher (28%).
- The biggest concerns for Panel members about managing long term conditions included:
 - access to healthcare, for example getting an appointment or being able to see a specialist (87%)
 - access to medication and/or equipment (68%)

³ BRAN questions aim to help patients ask healthcare professionals the right questions. You can find more information about the BRAN questions on the [NHS Inform Realistic Medicine webpage](#) and the [Right Decision Service BRAN webpage](#).

- psychological and mental health support (64%)
- financial support (63%), and
- support to self-manage conditions and symptoms (61%).
- Panel members were asked to state how much they agreed or disagreed with various statements about long term conditions. Most Panel members agreed with all statements:
 - 99% agreed if they were to have a long term condition, they would expect a healthcare professional to discuss with them how it might impact their life.
 - 92% agreed if they were advised to change something in their lifestyle to prevent or manage a long term condition, they would be motivated to do this.
 - 63% agreed they felt they knew enough about how to manage long term conditions that were relevant to them.
 - 54% agreed they knew enough about how to prevent long term conditions that were relevant to them.
- When asked what matters most about long term conditions, 26% spoke about ensuring a broad range of support being available. 19% mentioned having ongoing access to healthcare professionals and 17% spoke about being able to manage the condition or look after themselves. 16% mentioned the impact of their condition on quality of life and on family members, and 11% identified getting the right care or treatment.

Recommendations

Based on these findings Healthcare Improvement Scotland makes the following recommendations to the Scottish Government and relevant stakeholders. Recommendations are outlined in the Conclusions and recommendations on long term conditions section.

1. Consider that policy relating to long term conditions explicitly acknowledges that these impact on a great number of people, directly (as patients and carers) and indirectly (as members of the wider support networks). This should include acknowledgement of the very broad range of individual experiences shaped not just by the specific condition affecting the patient, but also by the individual's personal circumstances and their perceived support needs. In addition, these findings recognise that there is a range of overarching concerns which may be relevant to large numbers of people who are affected by different long term conditions. This supports the argument for an overarching framework for long term conditions addressing issues of common interest as a way forward.
2. Consider how long term conditions are approached across health and care, ensuring targeted support for healthcare professionals and the public. This might include:
 - offering appropriate training to healthcare professionals to support meaningful person-centred conversations with patients and carers. This would address their need for a holistic perspective (including medical and non-medical elements of their experience) and enhancing their understanding and ability to prevent and navigate conditions
 - considering how medical and non-medical support offers can be integrated with a focus on individual need, patient preferences and potential to self-manage their condition, and
 - reflecting on how to ensure inclusiveness across the framework so that individuals with specific needs have access to care in a way that is appropriate to their requirements.

3. Consider further work to explore how the public use AI-supported search engines and tools to find and understand healthcare information related to long term conditions and address potential risks of misinformation resulting from this. It could further include strengthening the NHS online brand as a guarantor for accessible, reliable and evidence-based information. Also consider information signposting by healthcare professionals to counter risks from AI-generated information sources.
4. Consider strengthening the case for patient and public engagement around long term conditions to support mutual learning. This should include the co-design and co-creation of local support networks incorporating and reaching beyond medical care.

Public views on preconception health and care

Key findings

- Other than a health care professional, to find out more information about preconception health respondents were most likely to turn to an NHS website (74%), or an online search engine (51%). They were also likely to speak to friends and family (44%) or a charity (38%). 2% said they would only speak to a healthcare professional.
- When asked whether they would be comfortable discussing preconception health with different people and roles, respondents selected all suggested options. However, all options also had some not being comfortable with them. Most were comfortable discussing preconception health with healthcare professionals such as in primary care (89%), a midwife (89%), or health visitor (83%). Further avenues that were comfortable to most included discussing preconception health with a friend (73%) or someone with lived experience (69%).
- Most agreed that it is important that partners are equally involved in conversations about preconception health (92%). Most also agreed that they would expect to be given specific information by a healthcare professional about preconception health if they had a pre-existing health condition (91%). Most thought that preconception health should be discussed routinely between people of childbearing age and healthcare professionals (74%). Over half said they would find it acceptable for a healthcare professional, such as a GP or nurse, to ask them about their intention to become a parent (65%). It is important to note, however, that more than 1 in 10 (13%) said they would not find it acceptable for a healthcare professional to ask them about their intention to become a parent.
- When asked if they would be willing to try a range of things to improve preconception health if they were to consider having a child, most respondents said they would be willing to try all actions included in this survey. For example, this could be discussing their long term condition(s) that could affect the pregnancy and child (94%), or to stop smoking cigarettes (93%). On the other hand, all actions had a small number of respondents saying that they would not be willing to do them.
- Respondents were asked about what matters most to them when thinking about preconception health. Over 4 in 10 respondents mentioned parents having good health (42%), and others mentioned access to information and advice (23%), and ensuring the baby's health and safety (15%).

Recommendations

Based on these findings Healthcare Improvement Scotland makes the following recommendations to the Scottish Government and relevant stakeholders. Recommendations are outlined in further detail in the [Conclusions and recommendations on preconception health](#) section.

1. Ensure that policy relating to preconception health acknowledges that preconception health is perceived as beyond being a “medical” issue, and as intersecting with a range of aspects in people’s lives and identities. Policy content should address and acknowledge this accordingly.
2. Consider how to increase awareness about the relevance and importance of preconception health at a population level. Include addressing sensitivities around preconception discussions, and the stigma attached to choosing not to have a child. This would also include increasing understanding of the benefits and risks of behaviours.
3. Consider how preconception health is approached across health and care, ensuring support for both healthcare professionals and the public. This could include training for healthcare professionals, considering how individuals can discuss preconception health routinely and the potential role of primary care professionals, community pharmacies, and midwives relating to preconception health. There should also be a way for individuals to opt-out from discussing preconception health. Also consider how to involve partners equally in preconception health discussions.
4. Consider development of further resources that support the public in understanding and engaging around preconception health. This should build upon the public’s interest and willingness to discuss, and adopt a culturally sensitive and person-centred approach, based on real-world needs.
5. Ensure that information around preconception health is available to the public in a range of formats, to enable discussions in different contexts and according to their preferences and accessibility needs, including through one-to-one discussion with healthcare staff.
6. Consider work to gain a further in-depth understanding of preconception aspects highlighted in these findings. This should include exploring information needs, the use of AI tools to find information, how to equally involve partners, barriers and enablers for particular groups, including regarding behaviour change.

Chapter 1: Introduction and context

Questionnaire design

The questions for this survey were designed by Healthcare Improvement Scotland in partnership with the Scottish Government. Draft questions were tested with members of the public, which influenced the final question set. A copy of the final questionnaire is available in [Appendix 1: Questionnaire](#).

Response rates and profile

When the survey discussed in this report was undertaken, the Citizens' Panel for health and social care had a total of 992 members. The fifteenth Citizens' Panel for health and social care survey was sent by email on 20 November 2024 to all 917 Panel members for whom we have email addresses. During the week commencing 2 December 2025 survey packs were sent to all Panel members for whom we did not have email addresses, those from whom a bounce back email message was received, and in addition to those who had not responded to the email surveys sent. This postal survey pack was sent to 727 Panel members. A reminder was sent on the 10th of January 2025 to all Panel members with email addresses who had not responded to either the postal or email survey. Postal and email responses continued to be accepted up until the 3rd of February 2025. A total of 100 respondents completed the survey online from a QR code in the postal survey. A further 100 telephone interviews were completed between 16 January and 3 February 2025.

This took the final response up to 563, a 57% response rate. This level of return provides data accurate to +/-4.13% (based upon a 50% estimate at the 95% level of confidence) at the overall Panel level. This survey is therefore statistically robust at the Scottish population level.

Despite the attempts of the telephone boost, younger respondents were still underrepresented. Furthermore, the response was underrepresented in terms of those living in social housing and private rented accommodation. To ensure the data was representative by age and tenure, survey data was weighted to adjust for this imbalance.

While the Citizens' Panel for health and social care was developed to be nationally representative at a Scotland-wide level, it is important to note that certain groups of the population may be less well-represented on the Panel, for example people who are experiencing homelessness or people with learning difficulties. Certain topics in Citizens' Panel surveys may affect these groups differently or more significantly, therefore it is important that Citizens' Panel findings are interpreted appropriately within this context.

Full information on the response profile achieved and weighting can be found in [Appendix 2: Response profile](#).

Interpreting results

When reporting the data in this document, in general, percentages in tables have been rounded to the nearest whole number. Columns may not add to 100% because of rounding or where multiple responses to a question are possible. The total number of respondents to each question is shown either as 'Base' or 'n=xxx' in the tables or charts. Where the base or 'n' is less than the total number of respondents, this is because respondents may be 'routed' past some questions if these were not applicable.

All tables have a descriptive and a numerical base, showing the population or population sub-group examined in it. Because of the self-completion nature of the survey, the base for each question varies slightly.

Open-ended responses have been coded into response categories in order that frequency analysis or cross-tabulations can be undertaken of these questions. The process of coding open-ended responses begins with reading through the responses to get a feel for potential response categories. A list of thematic response categories is then created. These are known as codes. The coding process then involves assigning each response to a code. Responses can be coded into multiple categories where more than one point is communicated. Response categories must be clear and easy for anyone reading the analysis to understand. To check the coding of open-ended responses, 10% of all responses are validated by a second person to check for any issues or errors.

The following chapters present the findings on each topic, followed by conclusions and recommendations at the end of each chapter.

Chapter 2: Public views on medicines safety

Introduction

The first section of the questionnaire explored public views around medicines safety.

It was explained to Panel members that medicines are the most common intervention in healthcare, helping Scotland's people live longer and healthier lives. However, medicines can cause harm to people, accounting for 1 in 10 hospital admissions worldwide. This harm also impacts the sustainability of services, and it's estimated that medication-related harm costs NHS Scotland up to £220 million each year.

Health and care professionals, NHS Scotland and the Scottish Government are working to improve safety and reduce medicines-related harm.

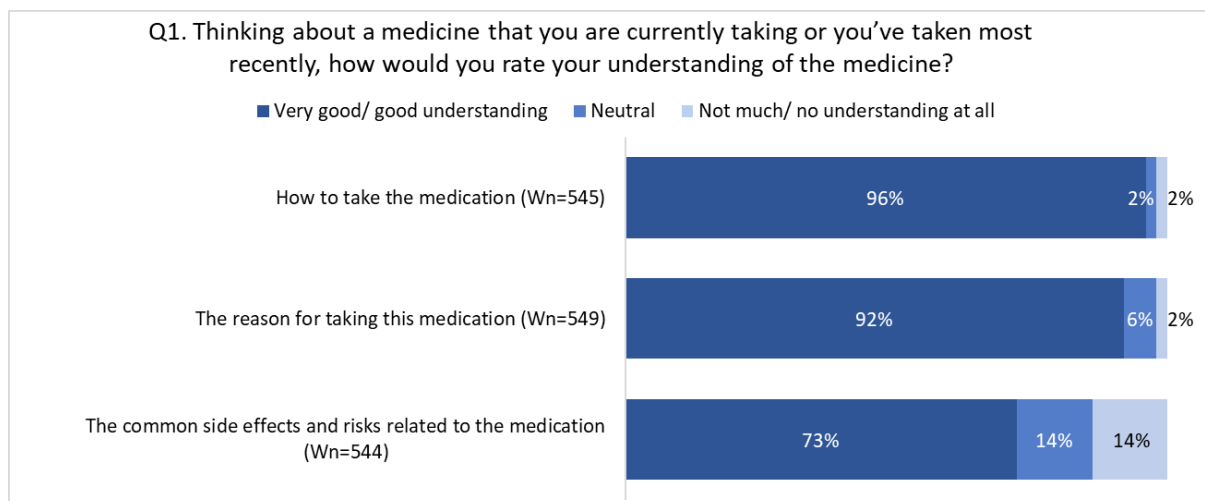
The aim of this section was to understand Panel members' opinions on medicines safety to inform priorities and shape relevant policies and services going forward.

This survey included questions touching on respondents' views and experiences of side effects, unintended effects, potential risks and medicines-related harm. It is important to note that we acknowledge the distinction and differences between these terms. However, these questions, and hence the findings, don't delve into these in great detail because of the scope and objectives of this work. The findings highlight public views which are based on public understanding of these terms, which may differ from clinicians' understanding.

Understanding of medicines taken recently

The survey opened by asking Panel members to think about a medicine they are currently taking or have taken most recently, which could be a one-off over-the-counter medicine or prescribed medication.

96% of respondents said they had a very good or good understanding of how to take the medication and 92% said they had a very good or good understanding of the reason for taking this medication. 73% said they had a very good or good understanding of the common side effects and risks related to the medication, which was lower than the previous two aspects in this question but remains relatively high. It is important to note, however, that 14% said they had not much understanding or no understanding at all of common side effects and risks.



Sources of information about medicines

Panel members were asked where they might look for information about a medicine other than asking a healthcare professional. The majority (85%) would look at an information leaflet about the medicine included in the medication packaging, and most would find information online, for example an NHS Scotland website (71%) or online search engine (61%). A smaller number of respondents said they would ask family and friends for this information (13%) or someone who has taken this medication (11%). Very few would ask a relevant third sector organisation (5%) or access the British National Formulary (2%).

4% emphasised that they would want to speak to a health professional for this purpose, implying they would prefer this to finding information about a medicine through other sources.

Q2. If you wanted to find information about a medicine, you might ask a healthcare professional. Where else might you look for more information? Please indicate up to 3 places you'd look for this information.	
Weighted base: n=550	%
An information leaflet about the medicine included in the medication packaging	85%
An NHS Scotland website	71%
An online search engine such as Google	61%
Family and friends	13%
Ask someone who has taken this medication, for example someone in a relevant support group	11%
A relevant third sector organisation such as a charity	5%
Would want to speak to a health professional e.g. doctor or pharmacist*	4%
BNF (British National Formulary)*	2%
Other	4%

* Additional codes added to existing list on questionnaire derived from "other" responses

Online information on medicines

Panel members were asked what would help them feel confident that information is reliable and up to date, if they were to look online for more information about medicine. 88% of respondents said that NHS branding, such as the NHS logo, would help them feel confident and 62% said a recommendation from a healthcare professional to use this specific online source. Other specific branding, for example

that of a charity, can also help with this for over half of the respondents (56%). Some drew confidence from getting online information from the medicine manufacturer (31%). 1% of respondents said they would not look for information online or did not have internet access.

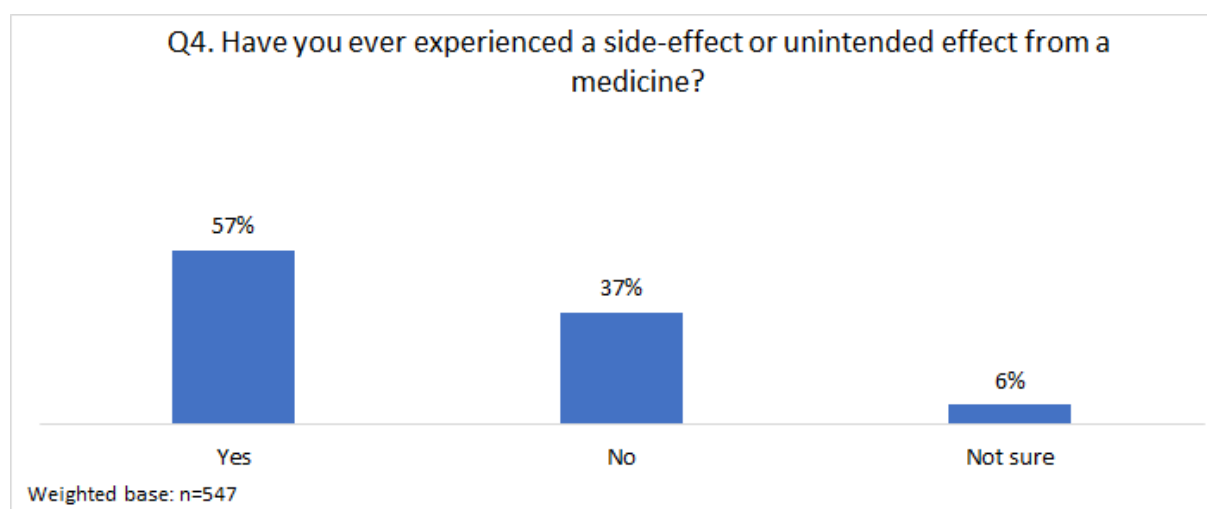
Q3 If you were to look online for more information about a medicine, what would help you feel confident that the information is reliable and up-to-date? Please tick all that apply.	
Weighted base: n=546	%
NHS branding, such as the NHS logo	88%
Recommendation from a healthcare professional to use this online source	62%
Other specific branding, for example from the Royal College of Physicians or a charity such as Parkinson's UK	56%
Online information from the medicine manufacturer	31%
I wouldn't go online/no internet access*	1%
Other	6%

* Additional code added to existing list on questionnaire derived from "other" responses

Experiences around side effects

Panel members were asked whether they have experienced a side effect or unintended effect from a medicine. Over half of the respondents had experienced a side effect or unintended effect from a medicine (57%), though it is important to note that the side effects or unintended effects experienced may have ranged in severity, as this question did not specify severity or whether these may have been known or expected side effects, for example, listed in the medicine leaflet. This question also relied on individuals' understanding of what may be a side effect, and this could differ from a clinician's perspective.

37% said they had not experienced any side effects or unintended effects from a medicine, and 6% were unsure.



Those who had experienced side effects were then asked if they had spoken to anyone about the side effect they experienced. Over 8 in 10 (84%) had spoken to a doctor, nurse or pharmacist about the side effects, 29% had spoken to family and friends and 10% had reported this through the Yellow Card Scheme run by the Medicines and Healthcare products Regulatory Agency (MHRA).

In contrast, just over 1 in 10 respondents (11%) did not talk to anyone about the side effects they experienced.

Q5. Who did you talk to about the side effect(s) you experienced? Please tick all that apply.	
Weighted base: n=313	%
Doctor, nurse or pharmacist	84%
Family and friends	29%
Did not talk to anyone about this	11%
Reported this through the Yellow Card Scheme run by the Medicines and Healthcare products Regulatory Agency (MHRA)	10%
Other	1%

From those who experienced side effects and said they did not talk to anyone about them, most said it was because they felt the side effect was minor or common and they didn't feel the need to speak to anyone about it (60%, n=33). However, 15% said they did not discuss side effects with someone because they dealt with it at the time or changed medication themselves⁴. For 10% this was because the medication was not something that was prescribed, or they were self-medicating. 6% said they didn't discuss their side effect because they did not want to bother anyone about this.

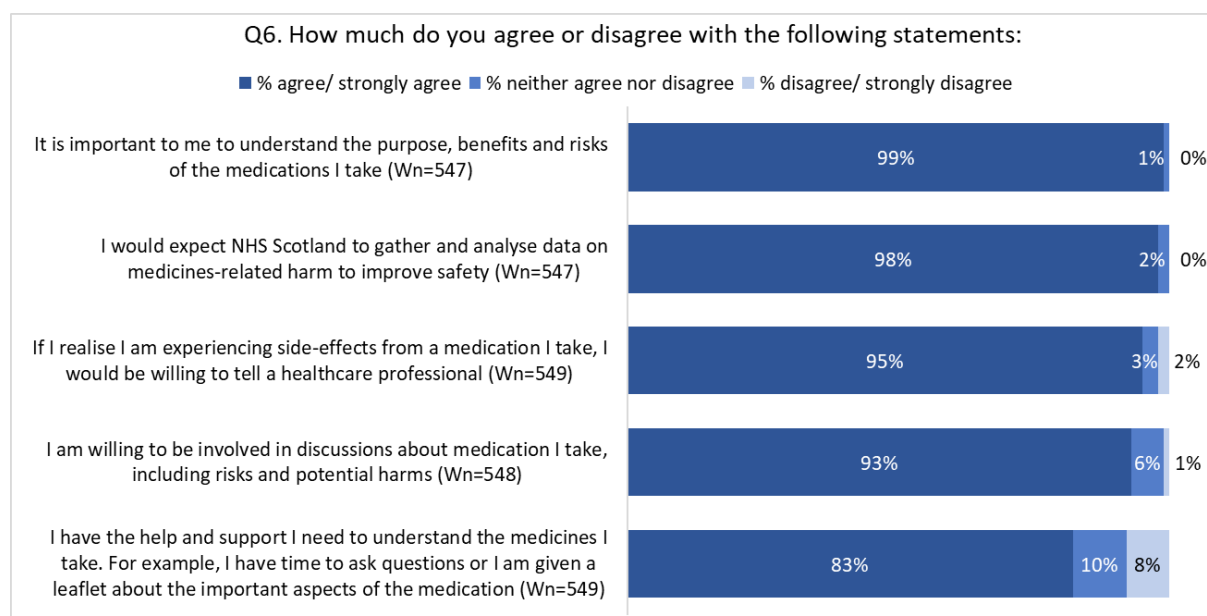
Please tell us why you didn't feel you wanted to talk about this with someone.	
Weighted base: n=33	%
Was a minor/common side effect, didn't feel the need to talk to anyone about it	60%
Dealt with at time/changed medication myself	15%
It wasn't something that was prescribed/self-medicated	10%
Didn't want to talk to anyone/bother anyone	6%
Other	15%

Opinions on medicine safety

Panel members were asked whether they agree or disagree with a range of statements linked to medicines safety. The majority of respondents agreed or strongly agreed with all statements in this question.

Nearly all agreed that it is important to them to understand the purpose, benefits and risks of the medications they take (99%). Nearly all also agreed that they would expect NHS Scotland to gather and analyse data on medicines-related harm to improve safety (98%). The majority also said they would be willing to tell a healthcare professional if they realise they are experiencing side effects from a medication (95%). 93% said they are willing to be involved in discussions about medication they take, including risks and potential harms. Just over 8 in 10 said that they have the help and support they need to understand the medicines they take (83%), with 10% neutral and 8% disagreeing that they have the support they need.

⁴ It is important to note that changing medication, especially when prescribed medication, should be discussed with a healthcare professional.



What matters most about the safe use of medicines

Lastly in this section, participants were asked what matters most to them when thinking about the safe use of medicines in a free text question. Around 3 in 10 respondents (30%) discussed side effects and mentioned ensuring clear communication on the risks of side effects and what to do if they experience them. 20% said they wanted to know that any medication they are taking is necessary and will be effective in treating their health condition. 19% said they would want to know that medicines are safe and have been rigorously tested⁵, and 18% that information provided on medicines such as in the packaging is clear, accessible and accurate. Further aspects mentioned were: having clear instructions on how to take medication (11%); having confidence in the prescriber, being able to ask questions and have clear explanations (10%); knowing that benefits outweigh side effects (9%); and that the medicines are NHS approved (1%). 6% touched on multimorbidity and polypharmacy, saying that what matters most is knowing how medication will react with other medication and conditions.

Q7. What matters most to you when thinking about the safe use of medicines? (free text question)	
Weighted base: n=471	%
Comments about side effects e.g. minimal side effects/risks clearly communicated/what to do if experience side effects	30%
That they are necessary/effective/will be of benefit/not overprescribed/told about the benefits	20%
That they are safe/been tested	19%
Accurate/accessible information/clear packaging	18%
Clear instructions on how to take medication/dosage etc.	11%
Having confidence in health professional prescribing them/being able to ask questions/clear explanations	10%
That the benefits outweigh the side effects	9%
How medication will react with other medications currently taking/other conditions	6%
NHS Approved	1%
Other	7%
Don't know	4%

⁵ It is important to note that all medication prescribed through NHS Scotland has gone through a rigorous testing and approval process.

Examples of the responses provided by Panel members about what matters most to them when thinking about the safe use of medicines are shown below:

**What matters
most to you when
thinking about the
safe use of
medications?**

That there are developments in new treatments and progression towards improving the condition, treatment, science and all of that.

That appropriate support is available and accessible within a reasonably short timescale, particularly where timeous medical interventions are necessary to prevent the condition becoming intractable.

Having specialist doctor input ongoing and short waiting times. Access to GP, physio, etc. as required. Effective medicines.

Access to information, support and advice to enable me to respond to any long-term conditions effectively.

Getting the best treatment that enables me to be pain-free and live the best life I can under the circumstances.

The effect someone's condition has on the rest of the family. Quite often some me time is required for those caring. A chance for short term alternative involvement to recharge!

Availability of treatment should not be years or even months once the specific solution has been identified e.g. hip operation necessary.

To have full information that looks at all the conditions someone has, rather than insisting on only looking at one thing in isolation. E.g. I think everyone's prescription combo should be assessed annually by the GP practice, not only when someone e.g. locum comes in blind, sees the patient and thinks "hang on, this combination is not safe or has risks".

What the long term implications are.

Quality of life. Some medications designed to prevent catastrophic ailments/injury have side effects that ruin quality of life. I don't want to feel awful all the time just to stay alive. Support for this choice may be controversial but it's more compassionate than 'do all we suggest or else' approach.

Knowing what I/we can do to self-manage and improve our situation/s.

Conclusions and recommendations for medicines safety

Conclusions

The following conclusions can be drawn from the results of the survey.

Discussing and understanding medicines safety

Respondents reported high levels of understanding on how to take medication and the reason for taking medication, which is a positive finding, though this could be about prescribed medicine for a long term complex condition or less complex over-the-counter medication. It is important to note, however, that a small number of respondents said they had little or no understanding at all, suggesting they may be taking medication without understanding how they should take it or why they're taking it. While these are small numbers, this is important to consider when thinking about medicines safety and scaled up numbers across the Scottish population.

When looking at respondents' understanding of common side effects and risks related to medication, this was still high but 14% said they had not much understanding or no understanding at all, and a further 14% had neutral feelings about this. This finding suggests that 28% of respondents, over a quarter, could be taking medication without feeling that they have a good understanding of common side effects and risks. This could pose risk in terms of medicines safety, as lack of this understanding could lead to less engagement in relevant discussions and reporting of side effects. This suggests that there is scope to improve the public's understanding on side effects and risks.

All participants agreed that it is important to understand the purpose, benefits and risks of the medication they take, and most said they are willing to be involved in discussions about medication they take, including risks and potential harms. This aligns with [Citizens' Panel 14](#) findings, where nearly all respondents supported getting involved in shared decision making with healthcare professionals. The findings reflect a strong public interest in being active participants in their care, which can be built upon further to support NHS Renewal priorities, such as shifting the balance of care and prevention.

While the findings from these questions are positive overall, it is important to acknowledge that there is still a small number of respondents who are not willing to be involved in discussions about the medication they take, and some who say they do not have the help and support they need to understand the medicines they take, highlighting that there is a part of the public who need further support to engage and understand medications. This could be more likely in groups that are less well-represented on our Panel, and support needs in this area will vary.

Finding information about medicines

These findings highlight the importance of both traditional information sources and digital formats. All dispensed medicines, including over-the-counter medication, require having a patient information leaflet included in packaging. Given that most find medicines information through reading this information leaflet, it would be important to encourage patients to continue to utilise this source and encourage them to ask questions of their healthcare professionals too. This would also be important for repeat prescriptions, where patients may be less likely to re-read information and notice any changes or updates if they have already read the information leaflet before, thinking they know all relevant information already. There are some instances where medicines are knowingly used outwith

their product licence, so called off-label⁶ prescription, for instance in treating some types of cancer, and patients may not have all the information available to hand in the patient information leaflet. Therefore, communication with a healthcare professional should be considered a priority in these situations.

The prevalence of using online search engines to find information about a medicine, highlights the importance of ensuring information related to medicines found via this route is reliable and evidence-based. This is particularly important since certain search engines use Artificial Intelligence (AI) to provide a summary of search results, without clarity in terms of what sources are included and their reliability. This can pose potential risk to people using online search engines to find information about medications. This is also important to consider with the increasing rise of the use of AI, with individuals potentially using AI tools to find medicines information. For example, a [nationally representative study in Australia](#)⁷ estimated that 9.9% of Australian adults (about 1.9 million people) asked ChatGPT health-related questions during the six months preceding their 2024 survey, for example to find out what symptoms mean or for help to understand medical terms, and 38.8% (n=2034) of this study's participants who had not used ChatGPT for health-related questions were considering doing so within six months. Their findings suggest that this may be a conservative estimate of the use of generative AI services for obtaining health-related information and that the number of users is likely to grow. They also found that 2 out of 3 people in their study (61%) who use ChatGPT for medical advice ask questions that usually require clinical advice, and that groups who face barriers to healthcare access were more likely to use ChatGPT for health information, for example those whose health literacy is limited or who have language barriers. This highlights the importance of reiterating messaging that is evidence-based and reliable, as well as the value of expertise from healthcare professionals.

When considering information sources, it is important to note that a small number of respondents said they would want to speak to a health professional about medicines, so this avenue must remain accessible, and a small number of participants noted in this survey that they don't use digital tools or the internet, again highlighting the importance of considering digital exclusion and ensuring appropriate options are available for those who cannot or choose not to use digital tools. Opportunity to engage with community pharmacy and healthcare professionals would be a priority.

These findings indicate high levels of confidence in information provided by the NHS and highlight the importance of NHS branding in helping the public feel confident that the information is reliable and up to date, as well as signposting from healthcare professionals. This suggests there could be scope to build on the use of NHS branding further in this area. These findings take on further importance in the context discussed above, where information found online may be of questionable reliability, highlighting a potential role for the NHS and healthcare professionals to play in signposting the public to reliable online information sources and supporting them in assessing the reliability of information.

⁶ Prescribing off-label means that the person prescribing the medicine wants to use it in a different way than that stated in its licence. This could mean using the medicine for a different condition or a different group of patients, or it could mean a change in the dose or that the medicine is taken in a different way. You can find more information on this on the [National Institute for Health and Care Excellence \(NICE\) website](#).

⁷ Ayre J, Cvejic E, McCaffery KJ. Use of ChatGPT to obtain health information in Australia, 2024: insights from a nationally representative survey. *Med J Aust*. 2025; 222(4):210-212. Available from: <https://doi.org/10.5694/mja2.52598>

Side effects and medicines-related harm

With over half of respondents reporting that they have experienced a side effect or unintended effect from a medicine, this seems to be relatively common⁸. Most of these respondents had spoken to someone about the side effects they experienced, mostly to a doctor, nurse or pharmacist, highlighting the public's willingness to discuss side effects and the importance of having access to clinicians for this purpose. Personal communication with a clinician seems to be important for this purpose, in comparison for example to finding information about medicines, where most did this by reading a leaflet or using online sources. The low proportion of respondents reporting side effects through the Yellow Card Scheme may be because the side effects were not seen at the time as significant enough to report, though it could potentially indicate that there is opportunity to further increase public awareness of the Yellow Card Scheme.

Some who had experienced side effects did not talk to anyone about this, mainly because they didn't feel the need to as it was a minor or common side effect. A small number did, however, say that they changed medication themselves, or mentioned self-medication and not wanting to bother anyone, which could pose a risk when thinking about medicines safety at a population level. Speaking with a healthcare professional should be the priority in these cases. Some respondents were unsure whether they had experienced a side effect, potentially suggesting a degree of uncertainty around what a side effect may feel like and scope to support better public understanding.

There were high levels of public expectation in terms of NHS Scotland collecting and analysing medicines-related harm data, as well as this leading to improvement in safety. Given the function of the Yellow Card Scheme to collect medicines-related harm data across the UK, this suggests there is further opportunity to promote and support public awareness of the Scheme, with NHS Scotland drawing learning from the data collected and analysed. The high willingness of respondents to tell healthcare professionals about experiencing side effects is encouraging in terms of discussing side effects in general, and it would be important to also support reporting side effects to the Yellow Card Scheme, given its role in data collection and analysis.

What matters most to people around medicines safety

Nearly one third of respondents said that what matters most is in relation to side effects. This highlights how important concerns around side effects are to the public, and the need to address these. 2 in 10 respondents said that what is most important is knowing that medicines are necessary, effective and not overprescribed, echoing findings from [Citizens' Panel 14](#) where some respondents said that what matters most to them about NHS Scotland reducing waste is the need to tackle unnecessary prescriptions and overprescribing (18%, n=404). A priority for nearly 2 in 10 was knowing that medicines are safe and tested, and similar numbers highlighted the importance of accurate, accessible information and clear packaging. Considering this alongside findings that respondents feel confident in relying on NHS Scotland branding and signposting by healthcare staff, this suggests that

⁸ It is important to note that this doesn't mean that all these respondents experienced severe side effects and harm. The side effects or unintended effects experienced may have ranged in severity, as this question did not specify severity or whether these may have been known/expected side effects, e.g. listed in the medicine leaflet. This question also relied on individuals' understanding of what may be a side effect, and this could differ from a clinician's perspective.

there could be scope to further build on this to improve the public's confidence in the safety, necessity, and benefits of medication.

Looking at these findings overall, having accurate and appropriate information and understanding around aspects related to medicines was a priority for many respondents. This highlights the importance of patients having access to the information they need, in the format they need it in, and support to understand it. For some it was important to have confidence in the prescriber and the ability to ask questions, suggesting that this could be an avenue to increase understanding.

Some highlighted the importance of knowing how medication will potentially react with other medication and conditions, which acts as a reminder of the complexity of polypharmacy and multimorbidity, and the potential impacts on people's lives.

Recommendations

Based on these findings Healthcare Improvement Scotland makes the following recommendations to Scottish Government and relevant stakeholders:

1. Consider development of resources that support the public to understand the information, resources and processes that help people to take medicines safely and effectively. This should build upon the public's trust and willingness, seeking opportunities to engage with the public and patient representative groups in co-creating resources. This should also include work to encourage more widespread awareness and use of resources. It would be worthwhile considering how NHS branding is used in this area and whether its use could be further expanded where appropriate to support public confidence. Also consider how to obtain support from existing local arrangements and other partners, for example Community Pharmacy Scotland. Further resources could be potentially hosted by NHS Inform and build upon existing resources such as the [Manage my meds - for patients and carers toolkit](#) by the Right Decision Service. Consideration should be given to including information which:
 - outlines what patients should understand and know about medicines they are taking and suggests questions for patients to ask their medical team about medicines they are taking, to support increased understanding and shared decision making. This should acknowledge that patients have different information and access needs
 - explains common terminology used when discussing why and how to take medication and side effects and risks for example, what taking medication twice daily means in practice, or how "common" a common side effect may be, including guidance on how to read and interpret medication leaflets
 - explains clearly the medicines approval processes and safety protocols, and what it means for medicines to be NHS approved, to support public confidence in these processes
 - explains what might lead to a change in medication or brand of medication, the different factors that lead to such a decision and what it means for patients, addressing perceived overprescription or that change can be based solely on financial factors
 - explains side effects, what they are, what patients should do if experiencing side effects and why it may be important to report/discuss them. This could include a decision-tree tool that outlines avenues to support with side effects, for example, the Yellow Card Scheme or 111. This should also include information on what processes NHS Scotland has in place to learn and improve relating to medicines-related harm, and

- supports patients to assess the reliability of information sources, including Artificial Intelligence (AI) tools.
2. Ensure that information around medicines is available to the public in a range of formats, for example, in physical leaflets and online resources, and that it is provided to patients according to their preferences and accessibility needs, including through one-to-one discussion with healthcare staff. Ensure there are suitable avenues to ask questions and support understanding of medicines information. This could be, for example, about how medication may react with other medication or herbal remedies. Also consider how to address information needs where non-standard processes are in place. This could be where medicines are knowingly used outwith their product licence, so called off-label⁹ prescription, for instance in treating some types of cancer, or in self-medication. In these cases patients may not have all the information available to hand in the patient information leaflet.
 3. Based on the prevalence of the public's use of digital tools to find medicines-related information, consider further work to explore in-depth how the public use Artificial Intelligence (AI) tools to find and understand healthcare information, and particularly information relating to medicines, aiming to help understand how to address potential risks of misinformation. Also consider the role of signposting from healthcare professionals to address risk posed by AI information sources.
 4. Consider actions to support increased public understanding of why medicines are beneficial and necessary, as well as around side effects and risks related to medicines. This should build upon public trust in the NHS and healthcare staff. For example, this could be through using the BRAN questions¹⁰ and a realistic medicine approach, as well as increased signposting to relevant resources and information.
 5. Take action to promote and support public awareness of the Yellow Card Scheme to improve under-reporting of medicines' side effects. Combined with this, improve how NHS Scotland draws learning from the data that are collected and analysed through the Yellow Card Scheme, and other data collected locally such as through Datix; and then uses this learning to identify and take specific actions to improve medicines safety across Scotland.
 6. Consider work to further understand and identify where challenges relating to medicines safety may have more significant impact. This would include exploring potential barriers and enablers for particular groups. This could be for example around understanding side effects and risks, engaging in discussing medicines, and ensuring people have enough support to understand the medications they take.

⁹ Prescribing off-label means that the person prescribing the medicine wants to use it in a different way than that stated in its licence. This could mean using the medicine for a different condition or a different group of patients, or it could mean a change in the dose or that the medicine is taken in a different way. You can find more information on this on the [National Institute for Health and Care Excellence \(NICE\) website](#).

¹⁰ BRAN questions aim to help patients ask healthcare professionals the right questions. You can find more information about the BRAN questions on the [NHS Inform Realistic Medicine webpage](#) and the [Right Decision Service BRAN webpage](#).

Chapter 3: Public views on long term conditions

Introduction

In this part of the survey the aim was to gain a better understanding of people's experiences and awareness of long term health conditions.

Over a third of the people across Scotland have a long term condition.¹¹ A long term condition is a physical or mental health condition that lasts a year or longer, which impacts on a person's daily life and may require ongoing care and support. This includes conditions such as asthma, diabetes, heart disease and bipolar disorder. Long term conditions are important because as people live longer, the number of people with long term conditions is also growing, putting additional pressure on the NHS.

Until recently, Scottish Government's approach to formulating national policy in relation to long term conditions was primarily addressed at individual conditions. A renewed focus on population health, prevention and early intervention now provides an opportunity to develop a cross-cutting policy framework for long term conditions. In support of this work Scottish Government wanted to hear the views of people from across Scotland. This survey was one of the steps in finding out what matters to people about long term conditions, as the new framework will aim to build on existing achievements and learning by integrating common themes from previous work.

The findings from this Citizens' Panel will be used alongside the [Scottish Government consultation on long term conditions](#) and will help to inform the consultation findings for the development of the Long Term Conditions Framework.

To answer the questions in this survey, Panel members were asked to think of themselves if they have a long term condition, or of someone else they might know or are helping to care for who has a long term condition. Alternatively, they were asked to think of what they might say if they were to have a long term condition in the future.

Experience of long term conditions

In the first question respondents were asked about their experience of long term conditions. Over 3 in 4 respondents (76%) said they personally have one or more long term conditions, 6 in 10 (60%) said they have family members or friends with a long term condition and just less than 1 out of 3 (28%) said they provide care or support for someone with a long term condition. Less than 1 in 10 (8%) participants answered that none of the above applied to them.

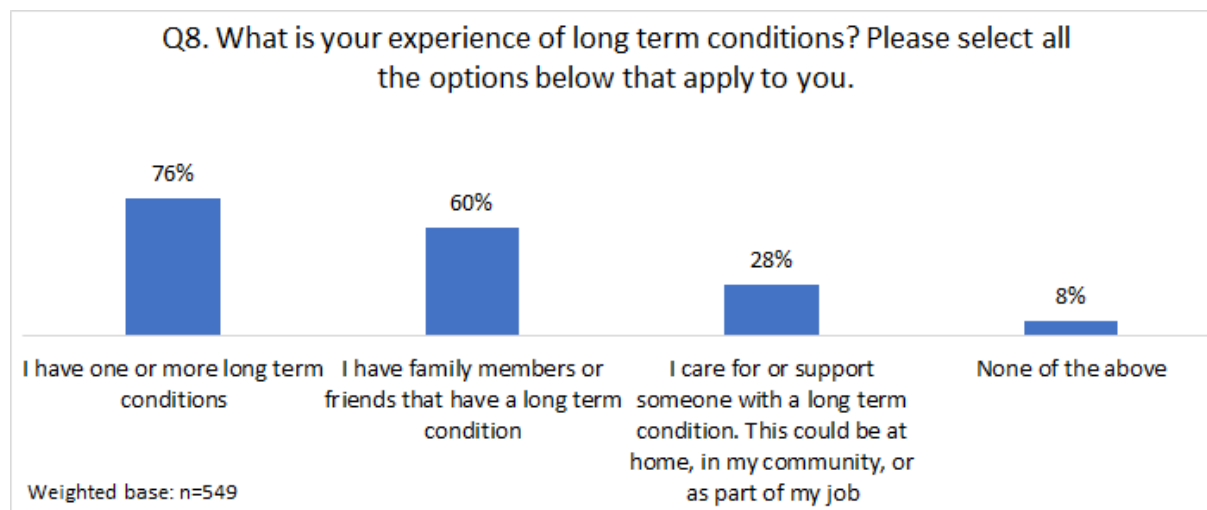
It should be noted that the proportion of respondents who stated that they have one or more long term conditions is higher in this survey than according to the information we hold on Citizens' Panel members. Different figures again are stated elsewhere.¹² This may be because of subtle differences in

¹¹ In the Citizens' Panel 15 survey text we noted that around half of the people across Scotland have a long term condition. The numbers provided here differ and are based on the more recent [Scottish Government consultation](#).

¹² <https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-paper/2025/04/long-term-conditions-framework-consultation-paper/documents/long-term-conditions-strategy-consultation/long-term-conditions->

the interpretation of the questions by respondents or in the way long term conditions are defined elsewhere, including by Panel members themselves. In addition, members of the Citizens' Panel who have direct experience of a long term condition may have been more likely to complete this survey since the topic was of personal interest to them, whereas those without lived experience might have opted not to take part. This response pattern is sometimes called *non-response bias* and is an inevitable feature of self-completion surveys where respondents are required to opt in to participate.

However, since it is the purpose of the survey to inform the development of an overarching national framework for long term conditions, greater participation from people with lived experience is of benefit.



Information on long term conditions

When asked where they might look for more information about long term conditions other than speaking to a healthcare professional, most respondents (87%) said they would look on an NHS website, such as NHS Inform or a local health board webpage, and 72% said they would do an online search.

Just over 1 in 2 respondents (55%) stated that they would seek information from a relevant third sector organisation and 3 in 10 respondents (30%) said that they would seek information from family or friends.

Significantly smaller numbers identified social media as an information source they would use, just under 1 in 7 (14%), whereas 6% would include local services such as libraries among their information sources. A small number of respondents (2%) said they would only speak to a healthcare professional, underpinning the central role medical professionals continue to occupy for some. A further 3% stated they would use other sources of information. Despite the figures at the lower end of the table appearing small in comparison, scaled up to population level they represent real need and an opportunity for emphasising the value of a broad and diverse approach to information provision.

Q9. If you were looking for information about long term conditions, you may speak to a healthcare professional. Where else would you go to find more information? Select all the places you think you would look.	
Weighted base: n=548	%
NHS website, for example NHS Inform or local health board webpages	87%
Online search, for example Google	72%
Charity or third sector organisation, such as Maggie's, MacMillan, Alzheimer's UK or Diabetes UK	55%
Family or friends	30%
Social media, for example Facebook, X, TikTok, Instagram, Reddit	14%
Local services, for example library	6%
I would only speak to a healthcare professional*	2%
This isn't something I would look for	0%
Other	3%

* Additional code added to existing list on questionnaire derived from "other" responses

Willingness to discuss long term conditions

Panel members were asked how comfortable they would feel discussing long term conditions with a range of people including healthcare professionals. A large majority of participants reported feeling either very or somewhat comfortable discussing long term conditions with specialist healthcare professionals (97%), primary care professionals (92%), or pharmacists (80%). Notably, 83% also expressed comfort in speaking with someone who has lived experience of the condition, highlighting the value placed on peer insight alongside professional expertise.

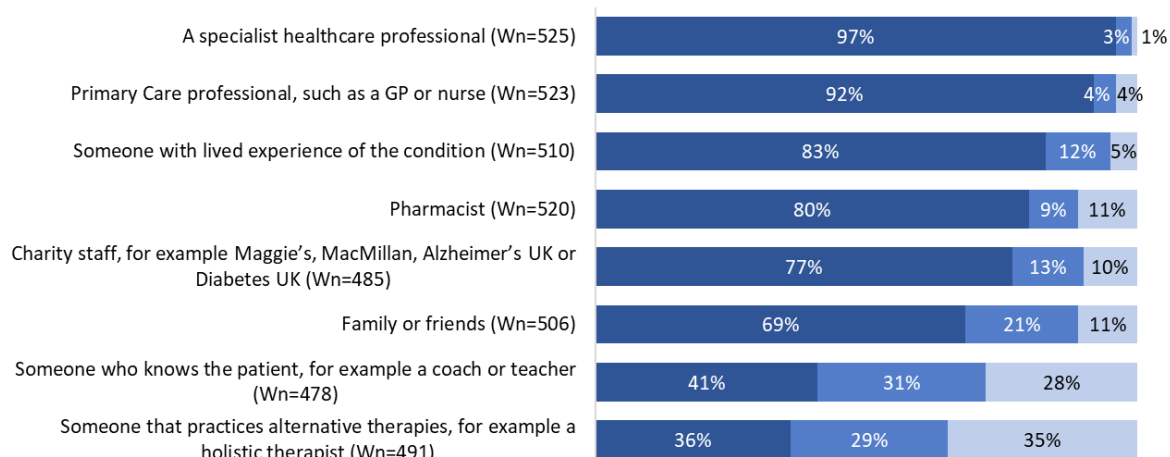
The comfort level extended to relevant third sector staff, with 77% of respondents indicating they would be willing to discuss a long term condition with them. Family and friends were also seen as viable conversation partners by 69% of participants. In contrast, only about 1 in 10 respondents reported feeling not very comfortable or not comfortable at all discussing such matters with these groups (across pharmacists (11%), third sector staff (10%), and family/friends (11%)).

The two categories that were least favoured as discussion partners included practitioners of alternative therapies and individuals who knew the person in a non-medical capacity, such as a coach or teacher. Here, discomfort also was significantly higher, 35% and 28% respectively, suggesting a marked decline in perceived credibility or appropriateness for these roles in health-related conversations.

A small number of participants identified additional contacts as potential discussion partners beyond the suggestions provided in the survey. This included faith leaders, workplace roles like Human Resources (HR) staff or managers, and members of support groups. A few noted that their choice would depend on the specific condition or the willingness of the other person to listen, underscoring the elements of relationality and trust underlying interactions of this kind.

Q10 How comfortable would you feel to discuss long term conditions with any of the below? This could be for yourself now or in the future, a family member, or someone you care for.

■ % very/ somewhat comfortable ■ % neutral ■ % not very/ not at all comfortable



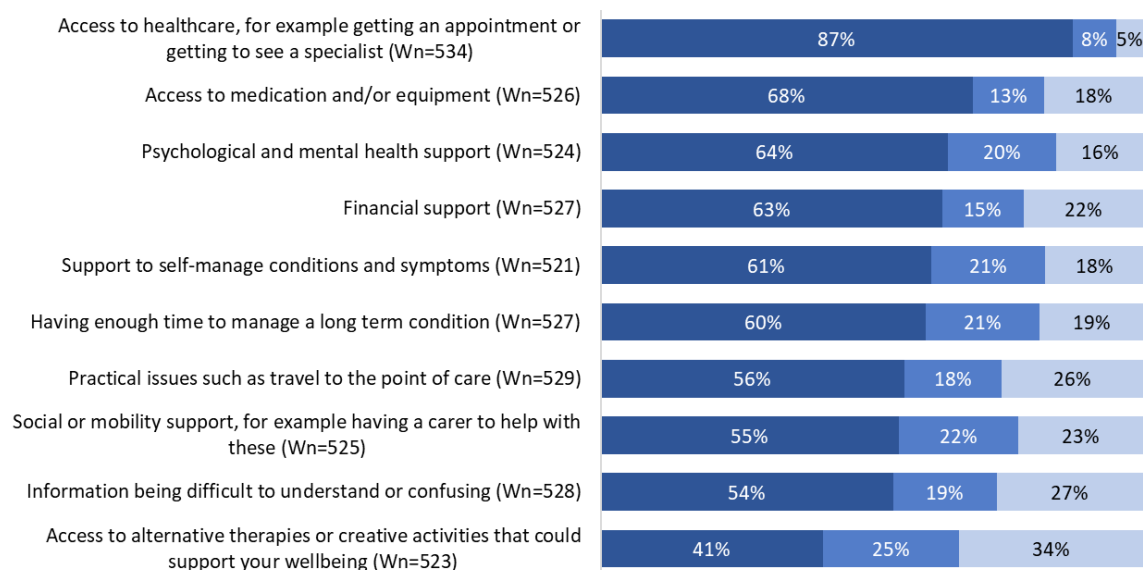
Concerns about managing long term conditions

Panel members were asked to think about managing a long term condition, either for themselves, a family member or a friend, now or in the future, and how concerned they were with various aspects of this.

Respondents were most likely to be concerned about access to healthcare, for example, getting an appointment or being able to see a specialist (87%). This was followed by access to medication and/or equipment (68%), psychological and mental health support (64%), and financial support (63%). Meanwhile, 6 out of 10 Panel members were concerned about getting support toward self-managing their conditions and symptoms (61%) and a similar number about having enough time to manage a long term condition (60%). This was followed by 56% of respondents sharing concerns about practical issues such as travel to the point of care, and 55% being concerned about social or mobility support. About the same number identified information being difficult to understand or confusing as a concern (54%), with having access to alternative therapies and wellbeing support bringing the list of options to a close with 41% or 2 out of 5 respondents. Notably respondents most shared concerns centred on healthcare access themes.

Q11 Thinking about managing a long term condition, how concerned might you be about the below? This could be about yourself, family and friends, or thinking about what may happen in future.

■ % very concerned/ somewhat concerned ■ % neutral ■ % not very/ not at all concerned



Panel members were asked if there was anything else they would be concerned about. Of those that responded to this question (about one fifth of overall respondents), 6 out of 10 indicated that there was nothing else they would have concerns about (61%). 17% provided further comments on the options already provided, and a small number of individuals respectively suggested additional points (6%).

Is there anything else you would be concerned about (please specify):	
Weighted base, n=111	%
Nothing else	61%
Other comment on existing list of concerns	17%
Public awareness/more understanding for condition/less stigma	4%
Waiting times for treatment/receiving treatment straight away if needed	4%
Other comment about personal situation/condition	3%
Comments about declining health/being a burden/not having support	3%
Concerns about employment	2%
Lack of support for carers/availability of carers	2%
Other comment	6%

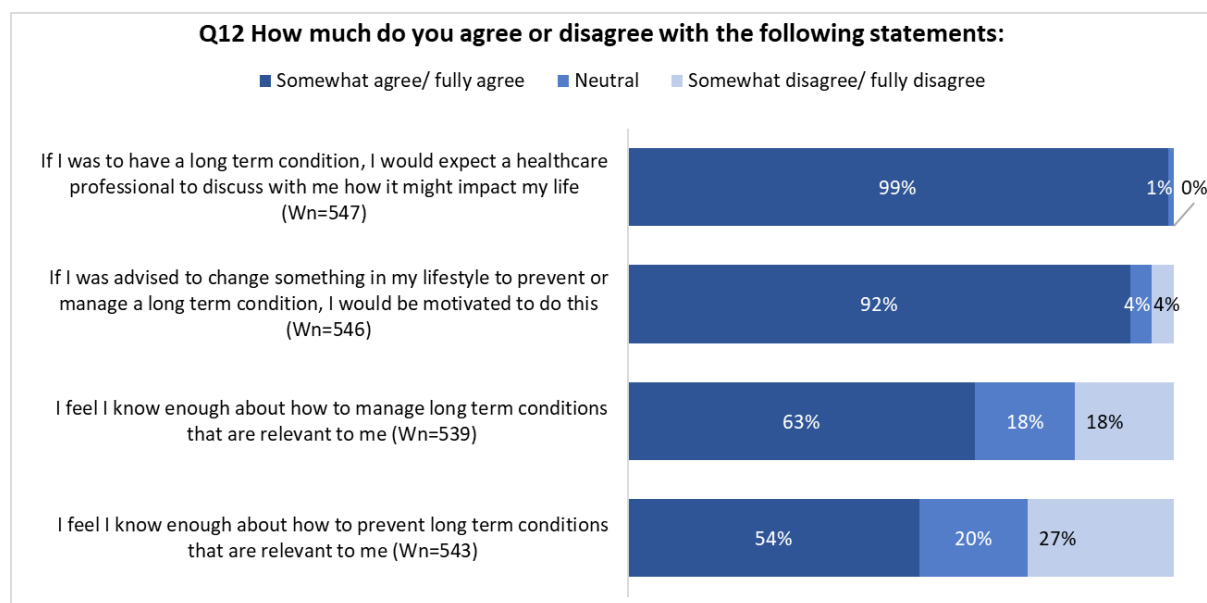
Opinions on long term conditions

When asked about their attitudes toward managing long term conditions, nearly all respondents (99%) agreed that if they were to develop a long term condition, they would expect a healthcare professional to discuss how it might affect their life. This broad consensus highlights the importance people place on person-centred care that goes beyond clinical treatment.

In addition, participants showed a high level of personal motivation to follow advice aimed at prevention and self-management. A significant 92% said they would be willing to make lifestyle

changes if advised to do so by a healthcare professional. This suggests respondents are asking for support but also are ready to contribute when given the right information and encouragement from a trusted source.

When enquiring about personal knowledge and confidence, the picture becomes more nuanced. While 63% felt they knew enough about managing long term conditions relevant to them, a notable 36% either felt unsure or disagreed. The gap widened further when stating their knowledge about prevention, where only 54% felt confident and over a quarter (27%) felt they did not know enough about prevention.



What matters most about long term conditions

When asked what matters most to them about long term conditions, respondents identified a range of factors. Just over a quarter (26%) commented that ensuring support was available to them was most important. This included comments about general and specific support, for example from individuals and groups such as friends and family. Other than by identifying specific individuals, the need for support was tied to areas of concern such as personal finances and mobility. A further 1 in 5 (19%) respondents indicated that ongoing and regular access to healthcare professionals and support were most important to them. For 17% this meant being able to manage conditions and look after themselves was most important. Just over 1 in 6, fed back that quality of life and impact of the condition on themselves and on their family were most important (16%). Getting the right care and quality of care mattered most to just over 1 in 10 (11%) and ranked lowest among the categories that attracted double figures. In addition, there was a broad range of responses which were collected into nine further categories (not including other or no comment and not sure).

Overall, the emphasis respondents put on having access to medical professionals and services in combination with access to non-medical support offers, suggests a holistic perspective on their own needs and a call for a person-centred approach.

Q13. What matters most to you and your family when thinking about long term conditions? (free text question)	
Weighted base, n=404	%
Ensuring support is available e.g. support network, financial, travel, care at home etc.	26%
Access to healthcare professionals/ongoing access/regular and consistent contact	19%
Being able to manage condition/look after myself	17%
Quality of life/impact on daily life/impact on family members	16%
Getting the right/quality care/treatment	11%
Access to medication and/or equipment	7%
Easy to understand/accessible/accurate information	6%
No long waiting times/timely access to services	6%
Being listened to/understood/treated well	6%
Mental wellbeing	4%
To try and prevent health conditions/deteriorating health/healthy lifestyles	3%
Long term side effects of medication	1%
How long will the illness last? How long do I have left in my life?	1%
Prolonging life expectancy/survival	0.3%
Other	4%
No comment/not sure	7%

Examples of the responses provided by Panel members about what matters most to them and their family when thinking about long term conditions are shown below:



Conclusions and recommendations on long term conditions

Conclusions

Experience of long term conditions

Over 3 in 4 survey respondents (76%) stated that they had one or more long term conditions. This reflects the growing number of people experiencing long term conditions themselves or supporting someone who does, and the increasing impact of this on people's lives. It also highlights public interest in the topic and opportunities for the integration of current activities into a coordinated national approach across long term conditions.

Information on long term conditions

A large majority of people (87%) stated that they would look at an NHS website when seeking information on long term conditions other than from speaking to a healthcare professional. In conjunction with over 7 in 10 people stating that they would use an online search engine, it reflects that the public by and large would look to seeking health information from digital sources. Despite this, more traditional information sources are still valued and widely accessed, notably through relevant third sector agencies, underpinning the importance of maintaining a broad and inclusive approach to information provision. This extends to the provision of non-digital formats and face to face contact to ensure equal access.

Willingness to discuss long term conditions

When asked who they were comfortable with discussing a long term condition, respondents demonstrated they were comfortable with involving a broad range of people in discussions without giving any one of the category 100% comfort. Not unexpectedly categories including medical professionals ranked highest. However, people clearly also valued peer support from others with lived experience, with support networks including third sector staff and family and friends following a close third. A lower level of comfort was indicated in relation to non-medical staff; the data also reveals a more nuanced picture. Despite lower comfort levels, up to 7 in 10 respondents were neutral or somewhat comfortable discussing long term conditions with the less favoured contacts. This suggests a broader openness among participants to engage in conversations about their long term condition beyond the more likely and favoured groups in the list.

Overall, this demonstrates a willingness to engage with a wide range of people over a long term condition, with medical expertise, lived experience in others and relational ties representing good foundations for being comfortable.

Concerns about managing long term conditions

Panel members' most prominent concern was continuing access to health care, including getting appointments and seeing specialists. Whereas this ranked high among concerns, there was a broad spectrum of additional worries including emotional, financial and logistical. Despite some concerns being less prominent, most were still shared by a significant number of respondents. Given the option to point out concerns not listed as response options, most respondents had no additional concerns reflecting that the main concerns were captured by the options provided. Some participants, however, took the opportunity to refine concerns they had already stated, sometimes adding a personal

perspective or experience. Based on feedback from relatively few participants (percentage in single digits), a list of themes emerged which spanned the breadth of individual and sometimes shared experiences of how long term conditions can limit personal choice and increase the need to rely on others. Overall numbers suggest that despite respondents' individual experiences of their respective long term conditions, the options given in question 11 are mostly relevant across conditions and personal circumstances. This supports the argument for an overarching framework for long term conditions addressing issues of common interest as a way forward.

Opinions on long term conditions

Almost all respondents demonstrated a notable preference for healthcare professionals helping them to navigate the illness. This was paired with expectations of high quality, holistically orientated care which recognises and considers the impact on individual patients' circumstances. Participants' expectations of support were matched by a willingness to act and contribute when guided. With reference to self-management and prevention, this suggests a timely opportunity to further develop and build health literacy around long term conditions.

What matters most about long term conditions

Respondents prioritised practical and emotional support, access to care, and personal autonomy. There was also emphasis on relational aspects and quality of care such as regular and consistent contact with healthcare professionals, and being listened to, understood and treated well. A diverse range of individual concerns also emerged, reflecting the lived and living experience with long term conditions.

Recommendations

Based on these findings Healthcare Improvement Scotland makes the following recommendations to the Scottish Government and relevant stakeholders:

1. Consider that policy relating to long term conditions explicitly acknowledges that these impact on a great number of people, directly (as patients and carers) and indirectly (as members of the wider support networks). This should include acknowledgement of the very broad range of individual experiences shaped not just by the specific condition affecting the patient, but also by the individual's personal circumstances and their perceived support needs.
In addition, these findings recognise that there is a range of overarching concerns which may be relevant to large numbers of people who are affected by different long term conditions. This supports the argument for an overarching framework for long term conditions addressing issues of common interest as a way forward.
2. Consider how long term conditions are approached across health and care, ensuring targeted support for healthcare professionals and the public. This might include:
 - offering appropriate training to healthcare professionals to support meaningful person-centred conversations with patients and carers. This would address their need for a holistic perspective (including medical and non-medical elements of their experience) and enhance their understanding and ability to prevent and navigate conditions
 - considering how medical and non-medical support offers can be integrated with a focus on individual need, patient preferences and potential to self-manage their condition

- reflecting on how to ensure inclusiveness across the framework so that individuals with specific needs have access to care in a way that is appropriate to their requirements.
3. Consider further work to explore how the public use AI-supported search engines and tools to find and understand healthcare information related to long term conditions and address potential risks of misinformation resulting from this. It could further include strengthening the NHS online brand as a guarantor for accessible, reliable and evidence-based information. Also consider information signposting by healthcare professionals to counter risks from AI-generated information sources.
 4. Consider strengthening the case for patient and public engagement around long term conditions to support mutual learning. This should include the co-design and co-creation of local support networks incorporating and reaching beyond medical care.

Chapter 4: Public views on preconception health and care

Introduction

The survey went on to explore public views around preconception health and care.

Preconception health relates to the health and wellbeing of people during their childbearing years. It is shaped by the health behaviours and environment of both women and men. Preconception health is an important topic because it can influence fertility, early child development, and can prevent harm to future generations. We recognise that the area of preconception health is closely related to fields such as reproductive health and population health, hence these findings may be relevant to inform thinking in further fields.

The responses to these questions will be used to help increase public awareness and understanding on this topic, as well as helping to identify any areas for improvement.

Panel members were told that their views on this topic were important even if they are not currently considering pregnancy or having children. To answer the survey questions, members were asked to think about themselves currently, or in the past or future, and they could also think about a partner or family member.

Finding information about preconception health

This section of the questionnaire started by asking respondents about sources they might turn to if they were looking for information on preconception health and care, other than healthcare professionals. The most common source of information for respondents were NHS websites, such as NHS Inform or local health board webpages (74%), and this was followed by using online search engines (51%). Respondents also said they would ask friends and family (44%) and/or find information through charity or third sector organisations such as Tommy's¹³ (38%). While not as common, 18% said they would find this information through social media and online forums, and 9% would do so through local services, for example a library.

It is important to note that 2% would only speak to a healthcare professional about this, and 14% said that this isn't something they would look for, 2% saying that this is not applicable to them.

¹³ Tommy's is a UK pregnancy and baby loss charity. Further information can be found on their website at <https://www.tommys.org/>

Q14. If you were looking for information about health and wellbeing during preconception, you might speak to a healthcare professional. Where else would you go to find more information? Select all that apply.	
Weighted base, n=537	%
NHS website, for example NHS Inform or local health board webpages	74%
An online search engine, for example Google	51%
Friends and family	44%
Charity or third sector organisation, such as Tommy's (charity focusing on pregnancy and baby loss)	38%
Social media and online forums, for example TikTok, Instagram, Facebook, Reddit, X, NetMums Forum	18%
This isn't something I would look for	14%
Local services, for example library	9%
No other sources/would only speak to healthcare professional*	2%
Other	2%
Not applicable to me*	2%
Don't know*	0.4%

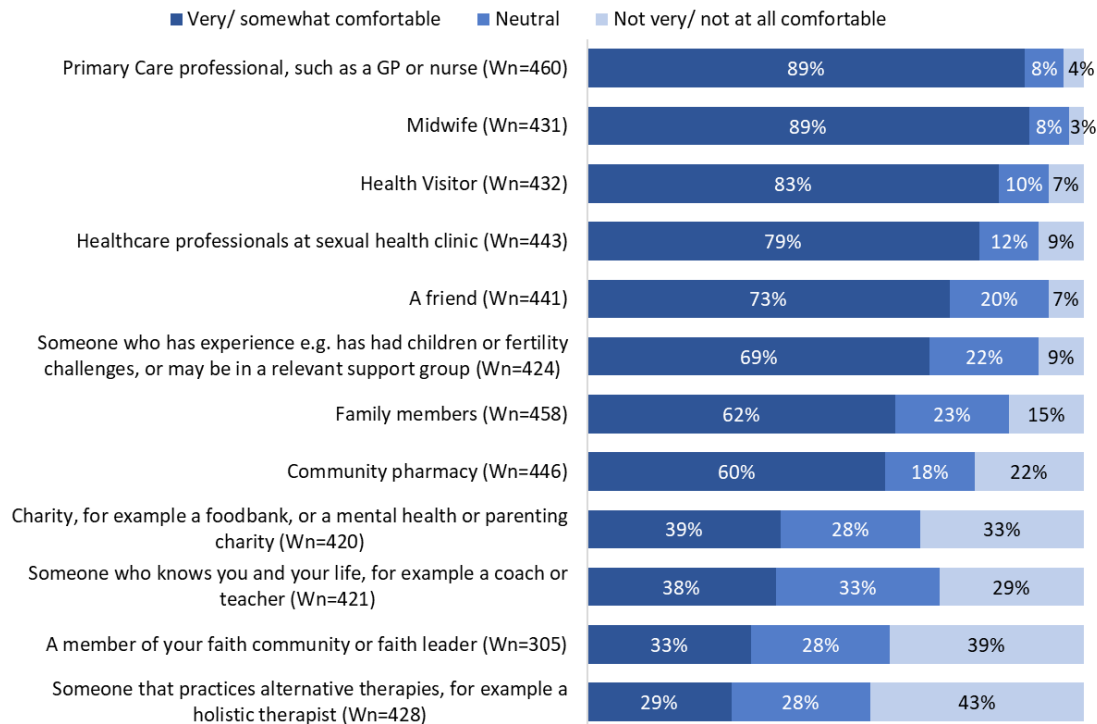
*Additional codes added to existing list on questionnaire derived from "other" responses

Discussing preconception health

When asked how comfortable they would feel to discuss health and wellbeing during preconception with a range of people and roles, all options provided in the survey were selected by respondents as feeling comfortable. Most respondents felt comfortable to discuss health and wellbeing during preconception with health and care professionals. This included primary care professionals, such as a GP or nurse (89%), a midwife (89%), a health visitor (83%), healthcare professionals at a sexual health clinic (79%), or at a community pharmacy (60%). It is important to note that there is currently no role for midwives in preconception before pregnancy. It is possible that this option received high responses because of midwives being seen as "pregnancy experts", however this suggests there is scope to consider which healthcare professionals should be thought of as having this important role regarding preconception. While the numbers of people comfortable with this varied, respondents were also comfortable discussing preconception health with a friend (73%), someone with lived experience (69%), family members (62%), charity staff (39%), someone who knows them and their life (38%), a member of their faith community (33%), or someone who practices alternative therapies (29%).

On the other hand, the options that most respondents said they would not feel comfortable discussing preconception health with were someone that practices alternative therapies (43%), member of their faith community or faith leader (39%), or a charity (33%). It is important to note though, that all options also had some respondents say they would not be comfortable discussing preconception health with them, including healthcare professionals. For example, 4% said they would be uncomfortable discussing preconception health with a primary care professional. The small proportion of those who said they would be uncomfortable having these discussions with medical professionals, however, may be because some respondents felt that this topic was not relevant to them, hence they may not feel comfortable discussing it with anyone.

Q15. How comfortable would you feel to discuss health and wellbeing during preconception with any of the below?

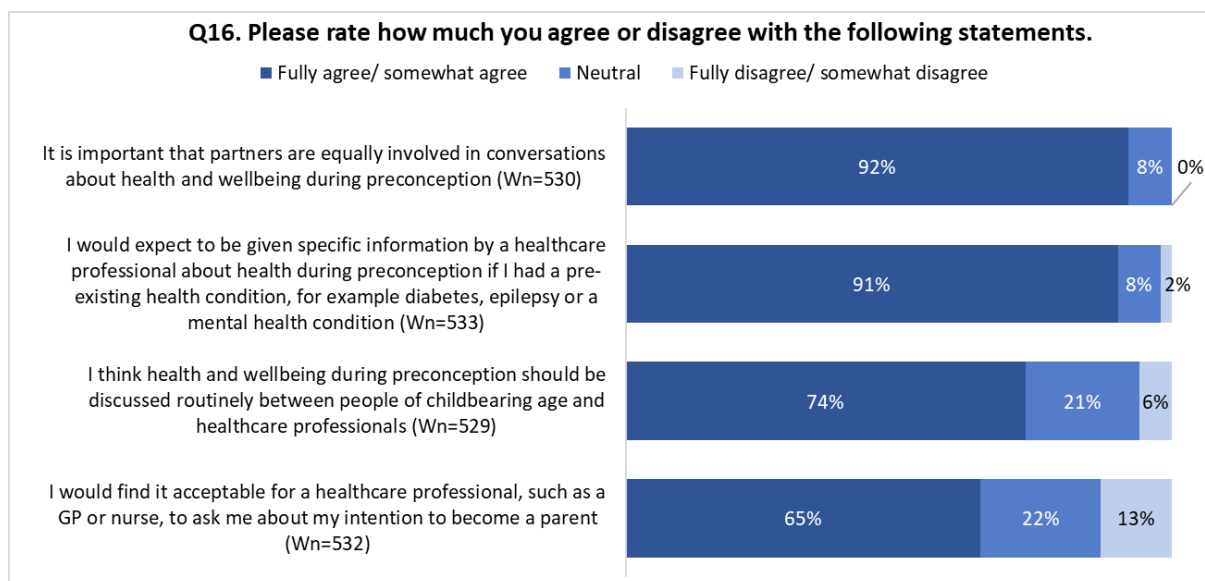


Opinions on preconception health aspects

Following on from this, respondents were asked to what extent they agree or disagree with a range of statements about health and wellbeing during preconception. Most participants agreed with the four statements provided in this question.

- The majority of respondents agreed that it is important that partners are equally involved in conversations about health and wellbeing during preconception (92%), and a few were neutral on this (8%), with no one disagreeing with this statement.
- The majority also agreed that they would expect to be given specific information by a healthcare professional about health during preconception if they had a pre-existing health condition (91%).
- Most thought that health and wellbeing during preconception should be discussed routinely between people of childbearing age and healthcare professionals (74%).
- Over half said they would find it acceptable for a healthcare professional, such as a GP or nurse, to ask them about their intention to become a parent (65%).

It is important to note, however, that more than 1 in 10 (13%) said they would not find it acceptable for a healthcare professional, such as a GP or nurse, to ask them about their intention to become a parent, and 6% did not agree that health and wellbeing during preconception should be discussed routinely between people of childbearing age and healthcare professionals. This highlights that while discussing preconception health and their intentions to become a parent may be acceptable to most, this is not the case for everyone.



Willingness for actions to improve preconception health

Panel members were asked to put themselves in the shoes of someone who is considering having a child and were asked about their willingness to do a range of things. Respondents showed high levels of willingness for action to improve preconception health, as all actions listed in the survey were selected by the majority of respondents as willing to do them. The majority of respondents were willing to:

- discuss their long term condition that could affect the pregnancy and child (94%)
- stop smoking cigarettes (93%)
- discuss prescription medication that could affect the pregnancy and child (93%)
- stop vaping (92%)
- stop taking recreational drugs (92%)
- try to improve their diet (90%)
- stop drinking alcohol (87%)
- take vitamin/mineral supplements (84%)
- take folic acid (81%), and
- do more physical activity and exercise (78%)

It is important to note, however, that even though the majority of respondents said they would do these actions, all actions had some respondents say they would not do this or that they weren't sure. For example 5% said that they would not be willing to do more physical activity and exercise, and 3% said they would not be willing to take folic acid or vitamin/mineral supplements. A very small number of respondents said they would not stop smoking cigarettes (1%), vaping (2%), taking recreational drugs (1%), nor drinking alcohol (3%). While small numbers in this survey, it would be important to consider what this may look like at a population scale.



What matters most around preconception health

Respondents were asked what matters most to them when thinking about health and wellbeing during preconception in a free text question. Over 4 in 10 respondents (42%) said that what matters most is parents being in good health or having a healthy lifestyle. 23% said having access to information and advice on health and wellbeing during preconception. 15% said ensuring a healthy baby or safety for the baby was most important. Respondents highlighted the importance of access to health and care services and support (6%) and having a support network and mental wellbeing (10%). 6% highlighted the stigma and assumptions associated with the choice not to have children, suggesting that discussions on preconception health may benefit from taking a sensitive and person-centred approach.

It is important to note that over 1 in 10 said that this topic is not relevant to them (11%), and 7% did not know what to answer.

Q18. What matters most to you when you think about health and wellbeing during preconception? (free text question)	
Weighted base, n=339	%
Parents being in good health/healthy lifestyle e.g. no smoking/active/eating well	42%
Information/advice	23%
Healthy baby/safety for baby	15%
Not relevant/doesn't apply to me	11%
Support network/mental wellbeing	10%
Access to health professionals/relevant care and support	6%
Assumption that people should have children/it is a choice/should not be stigmatised	6%
Other	11%
Don't know	7%

Examples of the responses provided by Panel members about what matters most to them in terms of health and wellbeing during preconception are shown below:

The future health of a child/children and parents and having the best support from a range of people/organisations to achieve those outcomes.

For those who are young and have chosen not to have children to not be stigmatised, not believed or patronised "you'll change your mind". Discussions about the choice to not have children should be treated with the same sincerity as the choice to have children.

Cutting out harmful habits and changing your lifestyle for the better but not just for preconception and pregnancy but for the child growing up as well.

My long term condition has affected my ability to have children. This has never been something I have been supported with even though it was clear in my very early 20's. I was lucky to have a good support system to help me with this at home. New professional being aware of this (e.g. when I had surgery) would help avoid the potentially damaging questions of "Could you be pregnant?" Just because you are of that age.

What matters most to you when you think about health and wellbeing during preconception?

We need to deliver this message at the earliest possible opportunity e.g. PSE in school etc. I think industry partners could and should be involved e.g. women's/men's healthcare product suppliers etc.

Speaking to someone before getting pregnant about how to be as healthy as possible - generally wouldn't even talk about it until first midwife appointment.

That both parents are healthy, strong and aware of any risks. Both parents have all the information to hand and know what to do and what not to do.

Having seen the physical, mental and financial cost of conceiving that family and friends have endured, I would like to see more discussion around the fact that desire to conceive does not equate to an absolute right.

Giving good contraceptive advice and access to contraception plus giving information around how to recognise ovulation and peak conception time during a woman's menstrual cycle. Educating young people more about how their bodies work and the impact of various drugs on conception.

Conclusions and recommendations on preconception health

Conclusions

Finding preconception health and care information

Respondents' information-seeking preferences suggest an interest in information related to preconception health. These findings highlight the importance of online information sources, as well as the range of further information sources used for this purpose, such as charities or asking family members. Preconception health information is accessed via clinical routes as well as through people with lived experience and what might be considered general passed-on societal knowledge.

On seeking information online, in the same way as other findings in this report, these findings highlight the importance of ensuring online information related to preconception health is reliable and evidence-based. This includes considering implications relating to the use of Artificial Intelligence (AI) tools to find healthcare information, as discussed in more detail in the Conclusions and recommendations for medicines safety section of this report. Online misinformation and disinformation can pose potential risk to the public when using online tools and AI to find and understand information relating to preconception health, and may have stronger impact on groups already facing barriers and inequalities.

When considering information sources, it is important to note that a small number of respondents said they would only speak to a healthcare professional about preconception health, so this avenue must remain accessible for all. A small number of participants noted that this isn't something they would look for and it is not applicable to them. This highlights that, while preconception health is linked to population health and should feel relevant to all, this is not the case in practice, hence it should be possible for individuals to opt-out of messaging or discussions on this topic. This also suggests that there is scope for increased public awareness on why preconception health is relevant across the population independently of individual characteristics and intentions.

Discussing preconception health

These findings suggest that the public is comfortable discussing preconception health with a wide range of individuals and roles, but this will differ between individuals and comfort should not be assumed. It is also interesting to note that fewer respondents were comfortable discussing preconception health compared to previous questions on long term conditions, suggesting that preconception health may be a more sensitive or difficult topic to discuss. Most were comfortable discussing preconception health with healthcare professionals, such as a GP, nurse, midwife or health visitor, highlighting the important role of primary care and that healthcare professionals may be more widely trusted and perceived as comfortable to discuss preconception health with. Individuals may choose or prefer to discuss preconception health with a wide range of people and outwith clinical settings, in many cases with people who they have a trusting or familial relationship with, such as a family member or someone with experience in this. This could suggest that preconception health may be understood by the public as being broader than healthcare, touching on wider aspects of people's lives. In this context, it is important to work towards ensuring that discussions and information on preconception health obtained via different sources are not significantly misaligned.

Opinions on preconception health aspects

These findings suggest an overall positive public approach towards preconception health. With the majority agreeing that partners should be equally involved in conversations about preconception health, this suggests public willingness and expectation to be engaged in these conversations, alongside partners. The majority also said they would expect to be given specific information by a healthcare professional about preconception health if they had a pre-existing condition. Again, this shows public expectation for healthcare staff to consider preconception health aspects and how particular conditions may impact this, when providing this information to patients. This is in line with the majority saying that preconception health should be discussed routinely with healthcare professionals; the public expect preconception health to be discussed and for them to be informed of any aspects of their life and broader health that might impact their preconception health. While it is important to consider how these expectations can be met, this public willingness can be a resource to build upon.

It is interesting to see, however, that a slightly lower proportion of respondents would find it acceptable for a healthcare professional to ask them about their intention to become a parent, and more than 1 in 10 said they would not find this acceptable. This shows that the topic of preconception health can be perceived as sensitive or taboo, and this finding is in line with results above that emphasise how individuals may feel differently and strongly about discussing preconception health, with whom and how. Therefore, how and when discussions around preconception take place should be considered and agreed with individuals, with the required sensitivity and person-centredness. To note, this should also be the case as much as possible in situations where discussions on this topic are mandatory, for example when there are risks related to medicines.

Willingness for actions to improve preconception health

The high levels of willingness for action to improve preconception health and broad preparedness to abstain from behaviours that are perceived as detrimental to good preconception health in these findings are positive. This also matches the high public expectation to be involved in discussions on this topic; the public expect healthcare professionals to discuss preconception health, and they in turn are willing to make the changes needed to their lifestyle.

Indeed, all actions were agreed upon by over 7 in 10. It could be worthwhile building upon this general willingness, to increase certain aspects that were lower compared to others, for example taking folic acid or doing more physical activity. This could be because of awareness around certain aspects being a more recent focus, for example awareness about the importance of folic acid and supplements for preconception being a focus since the 1990s, therefore older respondents may have less awareness of this.

It is important to see, however, that all actions had a small number of respondents who said they would not make these changes, for example stop smoking, taking recreational drugs or drinking alcohol. While small numbers in this survey, it would be important to consider what numbers may look like at a population level and the rationale behind this, also considering that this may be more likely to affect groups that are less well-represented in the Panel, for example relating to substance misuse. These findings suggest that there may be scope to further increase public awareness around the

benefits and risks of certain behaviours related to preconception health, as understanding and willingness to change behaviours should not be taken as a given.

What matters most around preconception health

When thinking about what matters most on preconception health, 4 in 10 mentioned the health of parents, suggesting understanding of the importance of parental health and potential intention to support this, aligning with previous responses on willingness to act towards increased preconception health. Others noted the importance of access to information and advice, aligning with previous responses showing public expectation to get information and guidance on preconception health from healthcare professionals and discuss this routinely. Health and safety of the baby was most important to some, and others highlighted further related aspects such as access to services and support, having a support network and mental wellbeing, and the stigma and assumptions associated with people choosing not to have children. Just over 1 in 10 said that preconception health is not relevant to them. This could be associated with the number of respondents that are over 65 years old, also aligning with similar responses to previous questions in this section, highlighting that there is scope to increase public awareness about why preconception health is relevant.

Recommendations

Based on these findings Healthcare Improvement Scotland makes the following recommendations to the Scottish Government and relevant stakeholders:

1. Ensure that policy relating to preconception health acknowledges that preconception health is perceived as beyond being a “medical” issue, and as intersecting with a range of aspects in people’s lives and identities. Policy content should address and acknowledge this accordingly.
2. Consider how to increase awareness about the relevance and importance of preconception health at a population level, across generations and for all. Include addressing sensitivities around preconception discussions, and the stigma attached to choosing not to have a child. This would also include increasing understanding of the benefits and risks of behaviours, with targeted interventions focusing on aspects that need increased buy-in from the public, for example taking folic acid and vitamin supplements.
3. Consider how preconception health is approached across health and care, ensuring support for both healthcare professionals and the public. This could include:
 - ensuring appropriate training and information is provided to healthcare professionals, to support comfortable and meaningful discussions on preconception health, meeting the public’s expectation for routine discussion. This work should take into account the deeply personal nature of views and feelings around preconception health, and equalities aspects that might be relevant, including potential taboo and stigma. Focus should be on adopting a sensitive and person-centred approach. Training and information must be developed focusing on the realities of the Scottish population, rather than following an idealistic approach, potentially drawing on real case studies. For example, recognising that pregnancies are often unplanned, what the implications of this may be. This should also include information on how long term conditions may affect preconception health, as well as discussing benefits and risks linked to certain behaviours

- considering how individuals can discuss preconception health routinely and with which healthcare professionals or services, in a sensitive and person-centred manner and making every contact count
 - considering the potential role of primary care professionals, community pharmacies, and midwives relating to preconception health and how it may help address public needs and expectations
 - ensuring there is a way for individuals to opt-out from discussing preconception health and being asked their intentions to become parents, with this noted and passed on to further services appropriately, and
 - considering how to involve partners equally in preconception health discussions.
4. Consider development of further resources that support the public in understanding and engaging around preconception health. This should build upon the public's interest and willingness to discuss, adopting a culturally sensitive and person-centred approach. This should also include work to encourage more widespread awareness and use of resources, considering the role of other stakeholders that can support this, for example third sector organisations. Resources should be co-created, culturally sensitive, person-centred and supporting to alleviate taboo and stigma relating to this topic. They should be based on real-world needs, for example recognising that pregnancies are often not planned. This information could include:
- acknowledging the holistic nature of this topic and further aspects beyond medical factors in this area, signposting for example to peer support networks and mental health resources
 - helping individuals know what questions to ask healthcare professionals around preconception health
 - supporting individuals to understand the benefits and risks of certain behaviours, signposting to support for change. This should be supporting informed decision-making in terms of lifestyle changes for preconception, encouraging reproductive autonomy and not reinforcing stigma, with sensitivity around fertility
 - supporting partners to be equally involved in considering and discussing preconception health
 - focusing on particular groups and communities, in a culturally sensitive manner, and
 - supporting patients to assess the reliability of preconception health information, including Artificial Intelligence (AI) tools, signposting to further reliable sources.
5. Ensure that information around preconception health is available to the public in a range of formats, and accessible by a range of audiences, to enable discussions in different contexts. Information should be provided to individuals according to their preferences and accessibility needs, including through one-to-one discussion with healthcare staff. This should also include ensuring there are suitable avenues to ask questions and support understanding, for example discussing the benefits and risks of certain behaviours. Provision of information on preconception health should allow individuals to opt-out from receiving this information, if they aren't comfortable with this. To support clarity around the reliability of information, a trusted single source could be developed, for example hosted by NHS Inform or a specific preconception health and care information toolkit.

6. Consider work to gain a further in-depth understanding of preconception aspects highlighted in these findings. For example, this should include exploring:
- what kind of further information on preconception health the public would find helpful, and in what forms
 - how the public use Artificial Intelligence (AI) tools to find and understand information about preconception health and care, aiming to help understand how to address potential risks of misinformation
 - how to best equally involve partners in preconception health conversations, considering this in different contexts and for different people, including same-sex parents, single parents and potentially unwanted or traumatic situations relating to preconception
 - challenges, barriers and enablers for particular groups and how these may be addressed towards increased understanding and buy-in. This should consider which parts of the population may be more likely to be impacted from issues relating to preconception health, and
 - which individuals and groups are least likely to make changes in behaviours despite impacts on preconception health. This could then explore the rationale, enablers and barriers , with sensitivity and using a person-centred approach, aiming to understand people's realities and co-create meaningful change.

Appendix 1: Questionnaire

RRID:

Citizens' Panel 15



In this Citizens' Panel survey we will ask you questions relating to:

- Medicines safety,
- Long term conditions, and
- Preconception health and care

There are no wrong answers to these questions - this is not a test. We are interested in your personal responses, thoughts and experiences of these issues and how they apply to you. Your answers are confidential and all views will be made anonymous. If you wish to find out more about how we use your data, please visit www.researchresource.co.uk/privacy-notice

Please answer the questionnaire as fully as you are willing and able to. If there is anything you do not wish to answer **please just move on to the next question.**

If you would prefer to complete the survey online, please visit the following link. You will need your ID above to access the survey:

We are very grateful to you for taking the time to complete this survey, to help us gain a better picture of the opinions of the Scottish public on issues of health and social care. If you need help to answer the questions please call Research Resource on FREEPHONE 0800 121 8987 or email info@researchresource.co.uk.

If you would prefer to complete the survey online, please visit the following link or the QR code. You will need your respondent identification number noted at the top of the page to access the survey.

www.researchresource.co.uk/citizenspanel15.html



BSL users can contact us via Contact Scotland bsl.org/

BSL <http://contactscotland->

Thank you.

If you would like to complete future surveys online, please provide your email address:

Medicines Safety

Medicines are the most common intervention in healthcare, helping Scotland's people live longer and healthier lives.

However, medicines can cause harm to people, accounting for 1-in-10 hospital admissions worldwide. This harm also impacts the sustainability of our services, and it's estimated that medication-related harm costs NHS Scotland up to £220 million each year.

Health and care professionals, NHS Scotland and the Scottish Government are working to improve safety and reduce medicines-related harm.

Your views will inform priorities and shape relevant policies and services going forward.

1. Thinking about a medicine that you are currently taking or you've taken most recently, how would you rate your understanding of the medicine? This could be about a one-off over-the-counter medicine or prescribed medication. Please tick one response for each point below.

	Very good understanding	Good understanding	Neutral	Not much understanding	No understanding at all
The reason for taking this medication	☐	☐	☐	☐	☐
How to take the medication	☐	☐	☐	☐	☐
The common side effects and risks related to the medication	☐	☐	☐	☐	☐

2. If you wanted to find information about a medicine, you might ask a healthcare professional. Where else might you look for more information? Please indicate up to 3 places you'd look for this information.

- ☐ An information leaflet about the medicine included in the medication packaging
- ☐ An NHS Scotland website
- ☐ Family and friends
- ☐ A relevant third sector organisation such as a charity
- ☐ An online search engine such as Google
- ☐ Ask someone who has taken this medication, for example someone in a relevant support group
- ☐ Other (please specify):

3. If you were to look online for more information about a medicine, what would help you feel confident that the information is reliable and up-to-date? Please tick all that apply.

- ☐ NHS branding, such as the NHS logo
- ☐ Other specific branding, for example from the Royal College of Physicians or a charity such as Parkinson's UK
- ☐ Recommendation from a healthcare professional to use this online source
- ☐ Online information from the medicine manufacturer
- ☐ Other (please specify):

4. Have you ever experienced a side-effect or unintended effect from a medicine?

- ☐ Yes Go to Q5
- ☐ No Go to Q6
- ☐ Not sure Go to Q6

5. Who did you talk to about the side-effect(s) you experienced? Please tick all that apply.

- ☐ Doctor, nurse or pharmacist
- ☐ Family and friends
- ☐ Reported this through the Yellow Card Scheme run by the Medicines and Healthcare products Regulatory Agency (MHRA)
- ☐ Can't remember
- ☐ Did not talk to anyone about this. Please tell us why you didn't feel you wanted to talk about this with someone.

Other (please specify):

6. How much do you agree or disagree with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
It is important to me to understand the purpose, benefits and risks of the medications I take	☐	☐	☐	☐	☐
I have the help and support I need to understand the medicines I take. For example, I have time to ask questions or I am given a leaflet about the important aspects of the medication	☐	☐	☐	☐	☐
I am willing to be involved in discussions about medication I take, including risks and potential harms	☐	☐	☐	☐	☐
If I realise I am experiencing side-effects from a medication I take, I would be willing to tell a healthcare professional	☐	☐	☐	☐	☐
I would expect NHS Scotland to gather and analyse data on medicines-related harm to improve safety	☐	☐	☐	☐	☐

7. What matters most to you when thinking about the safe use of medicines?

Long term conditions

Around half of the people across Scotland have a long term condition. A long term condition is a physical or mental health condition that lasts a year or longer, which impacts on a person’s daily life and may require ongoing care and support. This includes things like asthma, diabetes, heart disease and Bipolar disorder. Long term conditions are very important because as people live longer, the number of people with long term conditions is also growing.

Scottish Government are reviewing how they design policy for long term conditions, and want to hear the views of people across Scotland. This is the first step in finding out what matters to people about long term conditions.

These findings will be used to inform a consultation paper which will be available for comment in early 2025, leading to the development of a new long term conditions policy for Scotland. You can find more information about this work in 2025 on the [Scottish Government consultation webpage \(consult.gov.scot\)](https://consult.gov.scot).

When answering these questions, please think of yourself if you have a long term condition, or someone else you might know or are helping care for that has a long term condition. Alternatively, you can think of what you might say if you were to have a long term condition in the future.

8. What is your experience of long term conditions? Please select all the options below that apply to you.

A long term condition is a physical or mental health condition that lasts a year or longer, which impacts on daily life.

- ☐ I have one or more long term conditions
- ☐ I have family members or friends that have a long term condition
- ☐ I care for or support someone with a long term condition. This could be at home, in my community, or as part of my job
- ☐ None of the above

9. If you were looking for information about long term conditions, you may speak to a healthcare professional. Where else would you go to find more information? Select all the places you think you would look.

- ☐ Online search, for example Google
- ☐ Local services, for example library
- ☐ Social media, for example Facebook, X, TikTok, Instagram, Reddit
- ☐ NHS website, for example NHS Inform or local health board webpages
- ☐ Family or friends
- ☐ Charity or third sector organisation, such as Maggie's, MacMillan, Alzheimer's UK or Diabetes UK
- ☐ This isn't something I would look for. Please tell us why:

Other (please specify):

10. How comfortable would you feel to discuss long term conditions with any of the below? This could be for yourself now or in the future, a family member, or someone you care for.

	Very comfortable	Somewhat comfortable	Neutral	Not very comfortable	Not comfortable at all	Not relevant to me
Primary Care professional, such as a GP or nurse	☐	☐	☐	☐	☐	☐
A specialist healthcare professional	☐	☐	☐	☐	☐	☐
Pharmacist	☐	☐	☐	☐	☐	☐
Charity staff, for example Maggie's, MacMillan, Alzheimer's UK or Diabetes UK	☐	☐	☐	☐	☐	☐
Someone that practices alternative therapies, for example a holistic therapist	☐	☐	☐	☐	☐	☐
Someone who knows the patient, for example a coach or teacher	☐	☐	☐	☐	☐	☐
Family or friends	☐	☐	☐	☐	☐	☐
Someone with lived experience of the condition	☐	☐	☐	☐	☐	☐

Other (please specify):

11. Thinking about managing a long term condition, how concerned might you be about the below? This could be about yourself, family and friends, or thinking about what may happen in future.

	Very concerned	Somewhat concerned	Neutral	Not very concerned	Not concerned at all
Access to healthcare, for example getting an appointment or getting to see a specialist	☐	☐	☐	☐	☐
Practical issues such as travel to the point of care	☐	☐	☐	☐	☐
Information being difficult to understand or confusing	☐	☐	☐	☐	☐
Having enough time to manage a long term condition	☐	☐	☐	☐	☐
Social or mobility support, for example having a carer to help with these	☐	☐	☐	☐	☐
Financial support	☐	☐	☐	☐	☐
Psychological and mental health support	☐	☐	☐	☐	☐
Access to medication and/or equipment	☐	☐	☐	☐	☐
Access to alternative therapies or creative activities that could support your wellbeing	☐	☐	☐	☐	☐
Support to self-manage conditions and symptoms	☐	☐	☐	☐	☐

Other (please specify):

12. How much do you agree or disagree with the following statements:

	Fully agree	Somewhat agree	Neutral	Somewhat disagree	Fully disagree
If I was to have a long term condition, I would expect a healthcare professional to discuss with me how it might impact my life	☐	☐	☐	☐	☐
I feel I know enough about how to <u>prevent</u> long term conditions that are relevant to me	☐	☐	☐	☐	☐
I feel I know enough about how to <u>manage</u> long term conditions that are relevant to me	☐	☐	☐	☐	☐
If I was advised to change something in my lifestyle to prevent or manage a long term condition, I would be motivated to do this	☐	☐	☐	☐	☐

13. What matters most to you and your family when thinking about long term conditions?

Preconception health and care

Your views on this topic are important to us even if you are not currently considering pregnancy or having a child.

What is preconception health and why it is important

Preconception health has to do with the health and wellbeing of people during their childbearing years. It is shaped by the health behaviours and environment of both women and men.

Preconception health is an important topic because it can influence fertility, early child development, and can prevent harm to future generations.

How to answer the questions

When answering these questions, it may be helpful to think about yourself in the past or future, or about a partner or family member.

Your answers will help understand public awareness and understanding on this topic, helping to identify areas for improvement.

14. If you were looking for information about health and wellbeing during preconception, you might speak to a healthcare professional. Where else would you go to find more information? Select all that apply.

☐ NHS website, for example NHS Inform or local health board webpages

☐ An online search engine, for example Google

- ☐ Friends and family
- ☐ Social media and online forums, for example TikTok, Instagram, Facebook, Reddit, X, NetMums Forum
- ☐ Charity or third sector organisation, such as Tommy's (charity focusing on pregnancy and baby loss)
- ☐ Local services, for example library
- ☐ This isn't something I would look for
- ☐ Other (please specify):

15. How comfortable would you feel to discuss health and wellbeing during preconception with any of the below? This could be about having a child, or choosing not to have a child. This could be for yourself, a partner, or family and friends, in the past or future.

[illegible]

	Very comfortable	Somewhat comfortable	Neutral	Not very comfortable	Not comfortable at all	Not relevant to me
Someone who knows you and your life, for example a coach or teacher	☐	☐	☐	☐	☐	☐
Family members	☐	☐	☐	☐	☐	☐
A friend	☐	☐	☐	☐	☐	☐
A member of your faith community or faith leader	☐	☐	☐	☐	☐	☐
Someone who has experience, for example has had children or fertility challenges, or may be in a relevant support group	☐	☐	☐	☐	☐	☐

Other (please specify):

16. Please rate how much you agree or disagree with the following statements.

	Fully agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Fully disagree
It is important that partners are equally involved in conversations about health and wellbeing during preconception	☐	☐	☐	☐	☐
I think health and wellbeing during preconception should be discussed routinely between people of childbearing age and healthcare professionals	☐	☐	☐	☐	☐
I would find it acceptable for a healthcare professional, such as a GP or nurse, to ask me about my intention to become a parent. If you don't feel this applies to you currently, answer this based on your views if this applied to	☐	☐	☐	☐	☐

	Fully agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Fully disagree
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you, for example what you might have thought in the past.

I would expect to be given specific information by a healthcare professional about health during preconception if I had a pre-existing health condition, for example diabetes, epilepsy or a mental health condition

☐	☐	☐	☐	☐
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17. Please try to put yourself in the shoes of someone who is considering having a child. Would you be willing to do any of the things listed below?

Yes, I would do this	No, I would not do this	Not sure
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Stop smoking cigarettes	☐	☐	☐
Stop vaping	☐	☐	☐
Stop taking recreational drugs	☐	☐	☐
Stop drinking alcohol	☐	☐	☐
Discuss my long term condition(s) that could affect the pregnancy and child	☐	☐	☐
Discuss prescription medication(s) that could affect the pregnancy and child	☐	☐	☐
Do more physical activity and exercise	☐	☐	☐
Try to improve my diet	☐	☐	☐
Take vitamin or mineral supplements, for example multivitamins, fertility vitamins, Vit D, or Iron	☐	☐	☐
Take folic acid	☐	☐	☐

18. What matters most to you when you think about health and wellbeing during preconception?

In order to allow us to make sure we are obtaining a response from the right person, please record your month and year of birth below. (MM/YYYY)

Appendix 2: Response profile

Response profile

Citizens' Panel for health and social care - Fifteenth survey response analysis and profile

Emails sent	917
Number of email responses	291
Email response rate	32%
Number of postal sent	727
Number of postal returned	162
Postal response rate	22%
Telephone surveys	100
Online survey	10
OVERALL RESPONSE RATE	
Response	563
Current number on Panel	992
Overall response rate	57%

Age	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
16-24	13%	32	3.3%	-9.7%	5	0.9%
25-44	30%	178	18.2%	-11.8%	67	12.1%
45-64	33%	354	36.1%	3.1%	195	35.3%
65+	24%	416	42.4%	18.4%	285	51.6%
Total	100%	980	100.0%		552	100.0%

Source: Scotland's Census 2022 - National Records of Scotland Table UV103 - Age by single year All people

Sex	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
Male	48%	472	47.7%	-0.3%	291	52.2%
Female	52%	514	52.0%	0.0%	263	47.2%
Other		1	0.1%		1	
Prefer not to answer		2	0.2%		2	
Total	100%	989	100%		557	

[1] Panel members could also describe their sex using any other terms. No Panel members took the opportunity to do so.

Source: Scotland's Census 2022 - National Records of Scotland Table UV102b - Age by sex (16+ population)

Tenure	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
Own	63%	706	71.4%	8.4%	433	77.9%
Rent from Council/HA	23%	148	15.0%	-8.0%	65	11.7%
Private Rent	13%	66	6.7%	-6.3%	26	4.7%
Other	1%	63	6.4%	5.4%	28	5.0%
Prefer not to answer		6	0.6%		4	0.7%
Total	100%	989	100%		556	

Physical or mental health condition or illness	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
Yes	48%	385	38.8%	-9.2%	232	41.6%
No	52%	576	58.1%	6.1%	311	55.7%
Prefer not to say/don't know		30	3.0%		15	2.7%
Total	100%	991	100%		558	

Ethnic group	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
White British/Scottish	87%	902	92%	4.7%	515	92.8%
Other	13%	82	8%	-4.6%	40	7.2%
Total	100%	984	100%		555	

Source: Scotland's Census 2022 - <https://www.scotlandscensus.gov.uk/documents/scotland-s-census-2022-ethnic-group-national-identity-language-and-religion-chart-data/> Figure 4

Please note that since the refresh this has been reclassified as Irish is categorised in minority ethnic background in the Census

Religion	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
Church of Scotland	20%	293	32%	11.5%	181	34.6%
Roman Catholic	13%	99	11%	-2.5%	50	9.6%
Other Christian	5%	70	8%	2.5%	42	8.0%
Buddhist	0.28%	8	1%	0.6%	8	1.5%
Hindu	0.55%	2	0%	-0.3%		0.0%
Jewish	0.11%	2	0%	0.1%	1	0.2%
Muslim	2.20%	25	3%	0.5%	9	1.7%
Sikh	0.20%	3	0%	0.1%	2	0.4%
Other religion	0.23%	21	2%	2.1%	8	1.5%
None	51%	379	41%	-9.9%	211	40.3%
Prefer not to answer	6%	17	2%	-4.3%	11	2.1%
Total	100%	919	100%		523	100%

Source: Scotland's Census 2022 - <https://www.scotlandscensus.gov.uk/documents/scotland-s-census-2022-ethnic-group-national-identity-language-and-religion-chart-data/> Figure 2

Sexual orientation	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
Heterosexual or straight	88%	834	90%	2.4%	476	90.5%
Gay or lesbian	2%	41	4%	2.4%	24	4.6%
Bisexual	2%	18	2%	0.2%	7	1.3%
Other	1%	8	1%	0.4%	6	1.1%
Prefer not to say	8%	22	2%	-5.6%	13	2.5%
Total	100%	923	100%		526	100.0%

Source: Scotland's Census 2022 - <https://www.scotlandscensus.gov.uk/search-the-census#/topics/list?topic=Sexual%20orientation%20and%20trans%20status%20or%20history&categoryId=5> Table UV904

SIMD Quintile (2020)	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response -Counts	CP15 response -%
1	20%	185	19%	-1.2%	77	13.9%
2	20%	191	19%	-0.6%	102	18.4%
3	20%	196	20%	-0.1%	112	20.2%
4	20%	204	21%	0.8%	123	22.2%
5	20%	207	21%	1.1%	140	25.3%
Total	100%	983	100%		554	100.0%

Local Authority	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
Aberdeen City	4%	32	3%	-0.9%	20	3.6%
Aberdeenshire	5%	49	5%	0.3%	34	6.1%
Angus	2%	41	4%	2.1%	22	3.9%
Argyll and Bute	2%	16	2%	0.0%	12	2.2%
City of Edinburgh	10%	109	11%	1.4%	63	11.3%
Clackmannanshire	1%	12	1%	0.3%	9	1.6%
Dumfries and Galloway	3%	35	4%	0.9%	24	4.3%
Dundee City	3%	23	2%	-0.4%	11	2.0%
East Ayrshire	2%	20	2%	-0.1%	6	1.1%
East Dunbartonshire	2%	16	2%	-0.3%	9	1.6%
East Lothian	2%	18	2%	-0.2%	14	2.5%
East Renfrewshire	2%	16	2%	-0.1%	11	2.0%
Falkirk	3%	26	3%	-0.2%	17	3.1%
Fife	7%	33	3%	-3.4%	17	3.1%
Glasgow City	12%	105	11%	-0.9%	56	10.1%
Highland	4%	44	5%	0.2%	25	4.5%
Inverclyde	1%	10	1%	-0.4%	3	0.5%
Midlothian	2%	26	3%	0.9%	12	2.2%
Moray	2%	18	2%	0.1%	11	2.0%
Na h-Eileanan Siar	0%	12	1%	0.7%	5	0.9%
North Ayrshire	2%	25	3%	0.1%	12	2.2%
North Lanarkshire	6%	57	6%	-0.3%	25	4.5%
Orkney Islands	0%	6	1%	0.2%	6	1.1%
Perth and Kinross	3%	29	3%	0.2%	20	3.6%
Renfrewshire	3%	26	3%	-0.7%	13	2.3%
Scottish Borders	2%	20	2%	-0.1%	14	2.5%
Shetland Islands	0%	16	2%	1.2%	9	1.6%
South Ayrshire	2%	18	2%	-0.2%	8	1.4%
South Lanarkshire	6%	63	6%	0.5%	29	5.2%
Stirling	2%	18	2%	0.1%	12	2.2%
West Dunbartonshire	2%	22	2%	0.6%	10	1.8%
West Lothian	3%	28	3%	-0.4%	18	3.2%
Total	100%	989	101%		557	

Source: National Records Scotland – Mid-year population estimates, Scotland, mid 2023.
<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2023-31/10/2024> (16+ population)

Urban Rural Classification	Scottish Popn. %	Panel profile Counts	Panel profile %	Difference (Panel versus population)	CP15 response Counts	CP15 response %
Accessible Rural	12%	106	11%	-1.2%	66	11.9%
Accessible Small Towns	8%	91	9%	1.2%	60	10.8%
Large Urban Areas	38%	333	34%	-4.2%	187	33.6%
Other Urban Areas	33%	322	33%	-0.3%	169	30.4%
Remote Rural	6%	81	8%	2.2%	39	7.0%
Remote Small Towns	3%	52	5%	2.3%	35	6.3%
Total	100%	985	100%		556	

Source: National Records Scotland - Household Estimates 2023. <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/households/household-estimates/other-geographies-2011-data-zone-based/household-and-dwelling-estimates-by-urban-rural-classification> 31/10/2024

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Healthcare Improvement Scotland

Edinburgh Office
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

Glasgow Office
Delta House
50 West Nile Street
Glasgow
G1 2NP

0141 225 6999

www.healthcareimprovementscotland.scot