



Our Voice Citizens' Panel

Survey on HIV awareness, mental health and wellbeing and inclusive communication

Fourth Survey Report, May 2018





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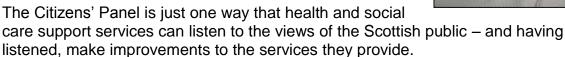
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Foreword

Welcome to the fourth report from the Our Voice Citizens' Panel for Scotland. This report covers what the Citizen Panel participants think about HIV and AIDS, mental health and wellbeing, and inclusive communication.

I would like to thank the individuals who continue to volunteer to be part of the Panel, who together make up a representative 'slice' of the population of Scotland.



The reports from the panel make interesting reading and can help make a difference.

Pam Whittle, CBE Chair, Scottish Health Council



Acknowledgements

Thanks to the Panel members who responded to the fourth Our Voice Citizens' Panel and to everyone involved in developing questions, disseminating the survey and analysing the results as well as producing this report. This includes:

- third sector organisations such as HIV Scotland, HIV Anti-Stigma Consortium, National AIDS Trust, See Me, Disability Equality Scotland
- the Royal College of Speech and Language Therapists
- NHS staff, and
- the Scottish Government's Mental Health and Protection of Rights Division, Health Protection Division, Care, Support and Rights Division, and the Directorate for Healthcare Quality and Improvement.

Thanks are also due to Helen McFarlane, who was Our Voice Programme Director from 2016-2018, Scottish Health Council Social Researcher Wendy Brown, who manages the Citizens' Panel Research, and consultants Research Resource.

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. 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 Our Voice Citizens' Panel was established to be nationally representative and has been developed at a size that will allow statistically robust analysis of the views of the Panel members at a Scotland-wide level. At present there are 1,185 Panel members from across all 32 local authority areas. Panel members were randomly selected from the general population and invited to join the Panel. Some targeted recruitment also took place in order to ensure that a representative Panel was established. This is the first time a national Citizens' Panel of this nature, focusing on health and social care issues, has been established in Scotland.

This report details the findings from the fourth full Panel survey which included questions on HIV awareness, mental health and inclusive communications.

A total of 516 responses (44% response rate) were received, either by post, email or by telephone. This level of return provides data accurate to +/-4.3%¹ at the overall Panel level. All comparisons that are made in this report are statistically significant, unless otherwise stated.

This executive summary details the key findings from the research. More detailed information on the profile of responses can be found in Appendix 3.

Key findings

HIV awareness and treatment

Seventy two per cent of respondents felt that HIV is an important issue in Scotland today. A similar number (77%) said that they were "well" or "moderately" informed about how HIV is passed on and how to prevent this. Only three per cent said that they "didn't know anything about it".

The majority of respondents believed that HIV could be transmitted via sharing needles or syringes (99%) or by unprotected sex (98%). They were least likely to believe that HIV could be passed from a public toilet seat (4%) or by sharing a glass, cup or cutlery (5%).

When asked about the extent to which they agree with various statements relating to HIV, respondents were particularly positive about working with a colleague who is living with HIV and being comfortable if their GP offered them an HIV test (85% strongly agreed or agreed with both these statements). They were least positive about knowing where to go for support with HIV (43% strongly disagreed or

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

disagreed with this statement) or being comfortable about starting a relationship with someone who is living with HIV (40% strongly disagreed or disagreed).

When asked to state whether they believed a number of statements relating to HIV treatment were true or false, 74% of respondents believed it to be true that 'someone taking effective HIV treatment will have a near normal life expectancy'. However, there was more uncertainty with other statements, most so with regard to the statement 'women on effective HIV treatment can have children without passing HIV on to them'; only 28% believed this statement to be true.

Mental health

One third of Panel members (34%) revealed that they care, or have previously cared for someone with a mental health problem. The same proportion of respondents (34%) stated that they have had or currently have a mental health problem.

Respondents indicated that they had witnessed (69%) and/or personally experienced (33%) differential or unfair treatment due to mental health problems. 29% of respondents reported experiencing different or unfair treatment because they know or care for someone who experiences mental health problems.

When asked how willing they would be to speak openly to a range of people about challenges to their own mental health, most respondents were willing or very willing to speak to healthcare professionals like GP's (94%), partner/spouse (89%), family (81%) and friends (77%). Willingness to speak openly to work colleagues (42%) managers (40%) or HR at work (41%) was less common.

When asked the extent to which they agree or disagree with a range of statements about mental health, respondents overwhelmingly agreed or strongly agreed with positive statements: 'It is possible to have a mental health problem and live a meaningful life (93%), and 'I would maintain a friendship with someone who has a mental health problem' (87%). Respondents overwhelmingly disagreed and disagreed strongly with negative statements around attitudes towards people who experience mental health problems, disagreeing that mental health problems are the fault of the individual (91%), and disagreeing that they would feel shame if a family member received a mental health problem diagnosis (89%).

Also of interest was a high neutral response (31%) to questions around relationships with people living with a mental health problem; not wanting someone with mental health problems looking after my child (42%), and not recommending a job to someone with mental health problems (38%).

90% of respondents agreed or strongly agreed that they were comfortable talking to friends who were worried about their mental health. Almost three quarters of respondents also agreed or strongly agreed that they knew where their friend could get support (69%) and information (73%) around mental health. 60% considered that they knew what they could do to help if a friend told them they were worried about their mental health.

Inclusive communication

In order to help them more easily understand what health and social care professionals are telling them, Panel members indicated it would be helpful if professionals used clear, day-to-day language when communicating with them (95%), checking back with them to ensure they have understood (93%). They also stated that it would be helpful to provide information at their pace, allowing them time to understand and ask and respond to questions (91%).

Written information would be most helpful in the form of a clear leaflet or letter before their appointment to help them prepare (90%) and a leaflet or letter after the appointment (87%).

Respondents were then asked what would help them express themselves more easily to health and social care services. The top 3 responses selected were:

- talking to someone face to face (94%)
- taking the time I need to get my message across (90%), and
- giving services information before my appointment to help them prepare for me (85%).

A majority of respondents agreed that they would find it helpful if health and social care services used recognisable symbols (for example: appointment time),

information opticians, pharmacy) on signs, to help people find their way around buildings (68%), in letters and leaflets (56%), and on websites and online communications (54%).

The top 3 communication supports respondents reported using, were glasses or contact lenses (73%), tablets or smartphones with apps or other functions to support communications (16%), and having a friend, family member or advocate to help them communicate (12%).

Chapter 1: Introduction and context

Background and context

Research Resource was commissioned by the Scottish Health Council as part of 'Our Voice' – a partnership involving Healthcare Improvement Scotland, public partners, the Health and Social Care Alliance Scotland (the ALLIANCE), the Convention of Scottish Local Authorities (COSLA) and the Scottish Government – to recruit a nationally representative Our Voice Citizens' Panel.

The Our Voice Citizens' Panel was established to be nationally representative and has been developed at a size that will allow statistically robust analysis of the views of the Panel members at a Scotland-wide level. The Panel is currently made up of 1,185 people spread across each and every Integration Authority and NHS territorial Board in Scotland. Panel members were randomly selected from the general population and invited to join the Panel. Some targeted recruitment also took place in order to ensure that a representative Panel was established. The Panel has been designed to be broadly representative of the Scottish population.

This is the first time a national Citizens' Panel of this nature, focusing on health and social care issues, has been established in Scotland.

This report details the findings from the fourth full Panel survey which aimed to gather the views of the general public to help improve health care services and social care services in Scotland.

Questionnaire design

The first two of eight sections of the questionnaire asked Panel members about their awareness of HIV and their understanding of how HIV is transmitted.

The next three sections of the questionnaire asked Panel members for their opinions on **mental health**, how they feel about **talking about mental health**, and how they feel about **responding to and supporting others in relation to their mental health**.

The survey concluded with three sections on **inclusive communication**, discussing **what would help Panel members better communicate** with health and social care professionals, their **experience of communicating with health and social care professionals** at appointments and finally their particular **communication needs**.

A copy of the final questionnaire is available in Appendix 1. The update for Panel members that was also provided to Panel members detailing the findings from the last survey can also be found in Appendix 2.

Response rates and profile

At the time of writing this report, the Our Voice Citizens' Panel has a total of 1,185 members. The fourth Our Voice Citizens' Panel survey was sent by email on 21 December 2017 to all 942 Panel members for whom we have email addresses. On 4 January 2018 survey packs were sent to all Panel members for whom we have no email addresses and those from whom a bounce back email message was received. Reminder mailings were sent by email on the 28 December 2017 and 24 January 2018 to those who had not yet responded by email. On 29 January 2018 additional postal surveys were delivered to Panel members who had not yet responded to the survey.

Postal responses continued to be accepted up until the 16 February 2018. A detailed analysis of the response profile identified that the survey was under-represented in terms of younger Panel members (defined as younger members aged 44 and under) and males. This was consistent with the last three Our Voice surveys and has also been the case in many local authority Citizens' Panels. It was decided that a targeted telephone boost be undertaken in an attempt to increase the response from these under-represented groups. A total of 75 telephone interviews were completed between the 20 February and 8 March. This took the final response up to 516, a 44% response rate. This level of return provides data accurate to +/-4.3% (based upon a 50% estimate at the 95% level of confidence) at the overall Panel level.

Despite the attempts of the telephone boost, younger respondents and males were still under-represented. To ensure the data was representative by age and gender, survey data was weighted to adjust for this imbalance.

Full information on the response profile achieved and weighting can be found in Appendix 3.

Further information on Citizens' Panels can be found in Appendix 4.

Interpreting results

The results of the research are based upon a sample survey, therefore all figures quoted are estimates rather than precise percentages. The reader should interpret the data with statistical significance in mind. It should be noted that analysis is statistically robust at the overall Panel level to +/-4.3%. All comparisons that are made in this report are statistically significant, unless otherwise stated.

Analyses of subgroups of the survey population will be less robust and should be treated with caution.

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 answering 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' passed some questions if they are not applicable. The percentages reported are weighted percentages.

All tables have a descriptive and numerical base, showing the population or population subgroup examined in it. While all results have been calculated using weighted data, the bases shown give both the unweighted and weighted counts.

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.

Chapter 2: HIV awareness

Introduction

The survey began by asking questions which sought to understand public knowledge and public attitudes to HIV. Findings from this survey will be used to measure public knowledge and awareness about HIV, and will inform work on addressing HIV stigma in Scotland.

The questions were developed in collaboration with HIV Scotland and the HIV Anti-Stigma Consortium.

Perceptions of HIV

The survey opened by asking Panel members the extent to which they agree or disagree with the statement 'I think HIV is an important issue in Scotland today'. As shown below, almost three quarters of Panel members who responded (72%) said that they either strongly agree or agree with this statement, 21% neither agree nor disagree and 5% stated that they either disagree or strongly disagree.

Q1 Please rate the extent to which you agree or disagree with the following statement: I think HIV is an important issue in Scotland today

50%

22%

21%

Strongly agree Agree Neither agree nor disagree Dlsagree Strongly disagree Don't know

Figure 1: Agreement with the statement 'I think HIV is an important issue in Scotland today'

Base: Unweighted, n=503; Weighted, n=503

Knowledge of HIV

Following on from this, respondents were asked how they would rate their knowledge about how HIV is passed on and how to prevent this. 37% would rate their knowledge about how HIV is passed on and how to prevent this as 'well informed', 40% stated they felt 'moderately informed', 20% have 'a basic idea' and just 3% of respondents stated 'I don't know anything about it'.

Q2 How would you rate your knowledge about how HIV is passed on and how to prevent this?

40%

20%

Well informed Moderately informed I have a basic idea I don't know anything about it

Figure 2: Knowledge of how HIV is passed and how to prevent this

Base: Unweighted, n=502; Weighted, n=503

Attitudes towards HIV

All Panel members were asked to state the extent to which they agree or disagree with a number of statements about HIV.

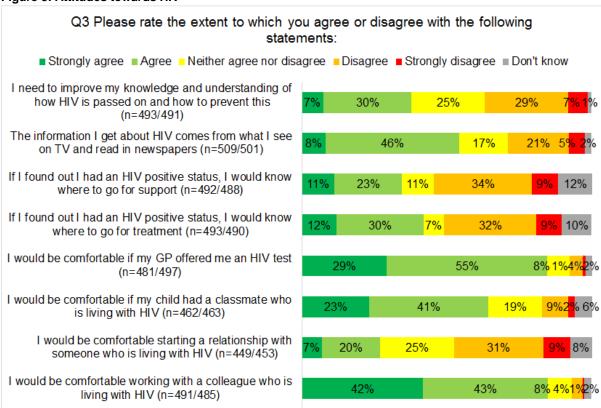


Figure 3: Attitudes towards HIV

Respondents were most likely to agree with the statements:

- I would be comfortable working with a colleague who is living with HIV (85% strongly agree or agree)
- I would be comfortable if my GP offered me an HIV test (85% strongly agree or agree)

Respondents were more likley to disagree with the statement:

- If I found out I had an HIV positive status, I would know where to go for support (43% disagree or strongly disagree)
- I would be comfortable starting a relationship with someone who is living with HIV (40% disagree or strongly disagree)

Similar proportions of respondents both agreed and disagreed with the statement:

 If I found out I had an HIV positive status, I would know where to go for treatment (42% strongly agree or agree and 41% disagree or strongly disagree).

Transmission of HIV

All Panel members were asked to respond to a number of statements about potential methods of HIV transmission, stating whether they thought these to be true or false methods of transmission. As shown below, the majority of respondents were correct in thinking that HIV could be transmitted via sharing needles or syringes (99%) or by unprotected sex (98%). The majority of respondents were also correct in thinking statements around transmission of HIV from shared cutlery (84%), toilet seats (87%), kissing (68%) and sneezing (73%) were false.

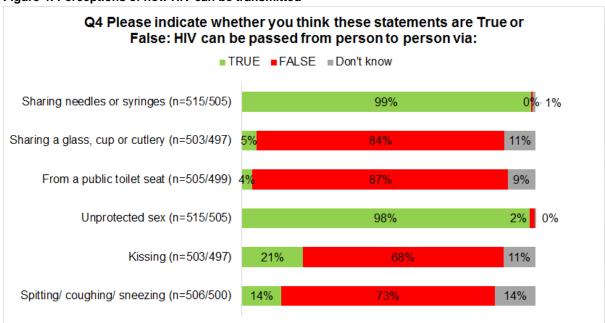


Figure 4: Perceptions of how HIV can be transmitted

Treatment of HIV

When asked to state whether they believed a number of statements relating to HIV treatment were true or false, it was found that 74% of respondents believed it to be true that 'someone taking effective HIV treatment will have a near normal life expectancy'. However, there was more uncertainty with other statements, most so with regard to the statement 'women on effective HIV treatment can have children without passing HIV on to them'. 28% believed this statement to be true, 23% false and 49% stated that they didn't know whether the statement was true or false.

There was also a higher degree of uncertainty around whether there is a pill that can be taken to prevent HIV infection (36% don't know) and whether someone taking effective HIV treatment does not pass on HIV (34% don't know). Similarly, large numbers of people did not believe there is a pill to prevent infection (47%) or prevent transmission of the disease (52%).

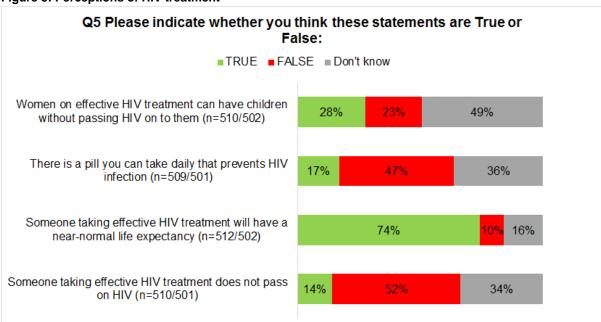


Figure 5: Perceptions of HIV treatment

HIV transmission and prevention

At the end of the survey, respondents were given the opportunity to find out more about HIV transmission and prevention. 20% of respondents (n=99) stated they would like to find out more.

These respondents were then directed to the following paragraph which told them more about HIV transmission and prevention.

In Scotland, HIV used to be considered a terminal illness but advances in treatments mean it is now possible to live a long and healthy life with HIV.

The most common ways HIV is transmitted are through sex without a condom and through sharing infected needles or syringes. It is passed on through infected bodily fluids.

You cannot get HIV through casual or day-to-day contact, or kissing, spitting or sharing a cup or plate. Very small amounts of the HIV virus can also technically be found in saliva but not in a sufficient quantity to cause transmission. There has never been a case of HIV transmission through saliva recorded in Scotland.

With new advancements in treatment, when a person living with HIV is on effective treatment for over 6 months and the virus becomes undetectable in the body (undetectable viral load), they cannot pass HIV on to anyone else, through any means of transmission. If a woman is on effective treatment for her HIV, it is extremely unlikely that she will pass HIV on to her baby in the womb, during childbirth or from breastfeeding. However, it is recommended that all HIV positive mothers use formula milk and bottle feeding instead of breastfeeding.

A pill called PrEP can be taken by people who are HIV negative to prevent them from acquiring HIV. PrEP is for HIV negative people who are at high risk of getting HIV (for example: partners of someone who is living with HIV). It is extremely effective at preventing HIV when taken as directed.

When asked if any of the above information surprised them, 74% of those who were interested in finding out more about HIV said 'yes'. 45 respondents made comment on what most surprised them about HIV transmission and prevention. This was an open question where respondents could answer freely in their own words. Responses have been coded thematically to allow for analysis and respondents' answers may have been coded under more than one theme.

Figure 6: Facts respondents found surprising about HIV

Q22. Please provide details of what surprised you				
Base: unweighted, n=45; weighted, n=34	%			
The pill called PrEP which can be taken by people who are HIV negative to prevent them from acquiring HIV	47%			
HIV cannot be passed by kissing or saliva	18%			
Did not know much about HIV at all	17%			
HIV is unlikely to be passed to babies through childbirth	16%			

Chapter 3: Mental Health

Introduction

The next section of the Panel survey was on the topic of Mental Health. Within this context, it was explained to Panel members that 'mental health problems' referred to a wide range of problems, including persistently low moods or levels of stress that affect how you think or feel, through to conditions which have been diagnosed (such as depression, anxiety, bipolar disorder, schizophrenia etc) by your GP or a mental health specialist (for example a psychiatrist).

The questions were developed in collaboration with See Me, Scotland's national programme to end mental health stigma and discrimination. See Me work mainly within the settings where people experience stigma and discrimination the most (i.e. within education, workplaces, communities, and health and social care environments).

See Me were interested in attitudes and behaviours around mental health. The information gathered from this survey will be used to inform See Me's ongoing programme of work and may also be used in their reports and published on their website.

Experience of mental health

The section of the survey on mental health began by asking respondents about their experience of mental health. This revealed that 34% of respondents had cared, or currently care, for someone who has a mental health problem. The same proportion of respondents (34%) stated that they have had, or currently have, a mental health problem.

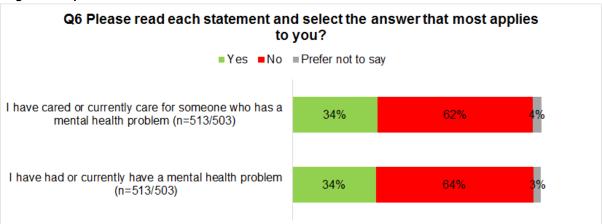


Figure 7: Experience of mental health

Analysis showed that 46% of those that currently have, or have had, a mental health problem themselves either cared or currently care for someone who has a mental health problem. 50% of those that do not have a mental health problem have cared or currently care for someone who has a mental health problem.

When asked to state 'yes' or 'no' to statements about the treatment of people with mental health problems, 69% of respondents stated 'yes' they have witnessed people being treated differently or unfairly because of their mental health problems, 29% have experienced being treated differently or unfairly because someone they know/ care for has a mental health problem and 33% have experienced being treated differently or unfairly because of their mental health problem.

Q7 Please read each statement and select the answer that most applies to you?

Prefer not to say

I have witnessed people being treated differently or unfairly because of their mental health problems (n=439/432)

I have experienced being treated differently or unfairly because someone I know / care for has a mental health problem (n=257/276)

I have experienced being treated differently or unfairly because of my mental health problem (n=200/212)

33%

66%

2%

Figure 8: Experience of treatment of people with mental health problems

NB Not applicable responses have been removed from this analysis

When asked if they had any further comment to make in this respect, 62% stated that they do feel that people are treated differently or that there is a stigma and 10% stated that they feel attitudes are changing/ improving. 28% made some other comment. Some examples of the comments made are noted below:

General public have no great understanding of mental health issues.

Further education needs to be done in schools to enable pupils to cope with the stress and pressure due to the changes in the education system. Also internet/ social media related problems.

People who don't know about mental health make a judgment that a person they meet with mental health is just too strange. They don't look deeper.

There is still a stigma. People still get talked down to if they have a mental health issue.

At work I didn't say I had a mental health problem so there was no chance "to be treated differently".

I have chosen to assume 'differently' as a positive having experienced periods of long term stress, my employer has been considerate and mindful of this.

Talking about mental health

Respondents were then asked how willing they would be to speak openly to a range of different people about existing or future challenges to their own mental health.

Respondents were most likely to be willing to speak to:

- a healthcare professional, for example GP (94% very willing or willing)
- partner (89% very willing or willing)
- family member (81% very willing or willing)
- friends (77% very willing or willing)

On the other hand, respondents were less likely to be willing to speak to:

- manager at work (40% very willing or willing)
- Human Resources department at work (41% very willing or willing)
- colleague at work (42% very willing or willing)

34% stated that they would be willing to speak to another person. Noted in this respect were counsellors, minister or priest, other healthcare professionals and neighbours. 23% would be unwilling to speak to 'anyone'.

Q8 How willing would you be to speak openly to the following people about existing or future challenges to your own mental health? ■Willing Neither willing nor unwilling Very willing Unwilling Other person (n=200/197) 20% 14% 43% 18% A social care professional (for example: Social Worker) 33% (n=458/451) A healthcare professional (for example: GP) (n=489/483) A member of staff at your place of study (n=254/281) 33% 24% 22% Human Resources department at work (n=348/354) 30% 26% Colleague at work (n=348/370) 30% 29% 24% Manager at work (n=344/365) 27% Partner (n=412/412) 58% 31% 6% 5% Friends (n=481/478) 41% <mark>10% 11% 2</mark>% Family member (n=481/478) 37% 11% 7% 1%

Figure 9: Willingness to speak openly about mental health

When asked the extent to which they agree or disagree with a range of statements about mental health, the responses given are illustrated in the chart below.

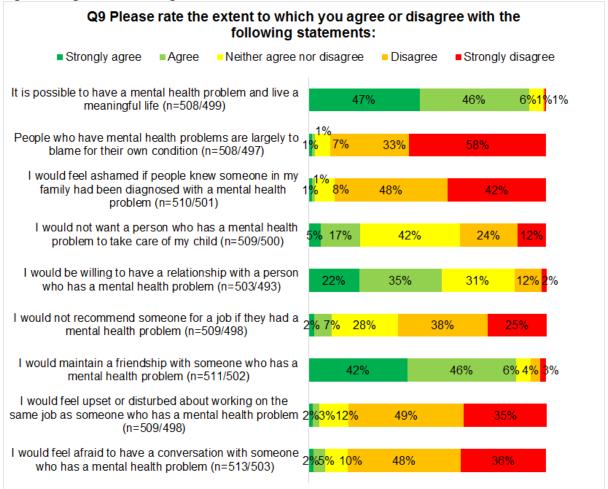


Figure 10: Agreement or disagreement with statements about mental health

Respondents were most likely to agree with the following statements:

- It is possible to have a mental health problem and live a meaningful life (93% strongly agree or agree)
- I would maintain a friendship with someone who has a mental health problem (87% strongly agree or agree)

Respondents were most likely to disagree with the following statements:

- People who have mental health problems are largely to blame for their own condition (91% disagree or strongly disagree)
- I would feel ashamed if people knew someone in my family had been diagnosed with a mental health problem (89% disagree or strongly disagree)
- I would feel afraid to have a conversation with someone who has a mental health problem (84% disagree or strongly disagree)
- I would feel upset or disturbed about working on the same job as someone who has a mental health problem (83% disagree or strongly disagree).

Also of interest was a high neutral response to the questions around having a relationship with a person who has a mental health problem (31%); not wanting someone with a mental health problem looking after my child (42%) and not recommending a job to someone who has a mental health problem (28%).

When asked if they wished to add comment on their answers, many gave the response that their answers would depend upon the circumstances. However, others took the opportunity to share personal experience of mental health, both positive and negative.

Some examples of the comments made are noted below:

I believe in giving everybody a chance but there has to be an understanding of risks involved.

Despite living with mental health issues since I was 14, at the age of 38 now I have successful career, completed a degree and have a well-rounded life. Sometimes it is harder than others but I think having a good support network, positive attitude and understanding of your condition are okay.

I would need to know the person well and their condition for a child to be in their care in a safe, happy environment. Also know their condition was managed well, what condition they had and there was no chance of any danger.

'Mental health problem' encompasses a wide range of mental health illnesses and issues. Each illness displays different symptoms and feelings. It is very difficult to give an opinion on a black and white statement when mental health itself is, by its nature, not black and white.

There are many mental health problems and it is impossible to answer such generically based questions on an issue where you would have to take individual circumstances into account each time.

People with a mental condition are ordinary people too. You may not be able to see their illness but they are entitled to same help and compassion as anyone with any other illness.

Responding to, and supporting others with regard to their mental health

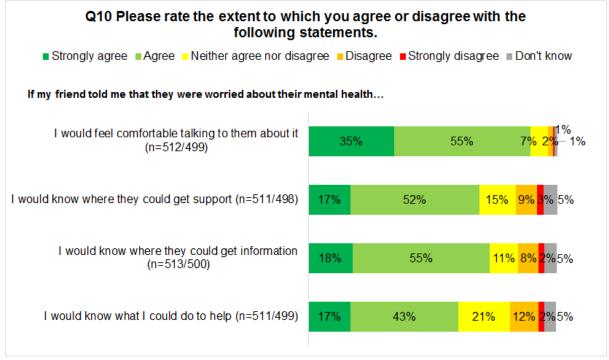
When asked the extent to which they agree or disagree with a range of statements beginning: 'If my friend told me that they were worried about their mental health....'. Respondents were most likely to agree that:

• I would feel comfortable talking to them about it (90% strongly agree or agree)

They were slightly less likely to agree, although still more likely to agree than disagree, with the following statements:

- I would know where they could get information (73% strongly agree or agree)
- I would know where they could get support (69% strongly agree or agree)
- I would know what I could do to help (60% strongly agree or agree).

Figure 11: If my friend told me they were worried about their mental health....



Chapter 4: Inclusive communication

Introduction

Communication is a two-way process. It is about both expressing ourselves (telling people things) and being able to understand what others are telling us. There are many ways of communicating and people have different communication strengths, preferences and needs.

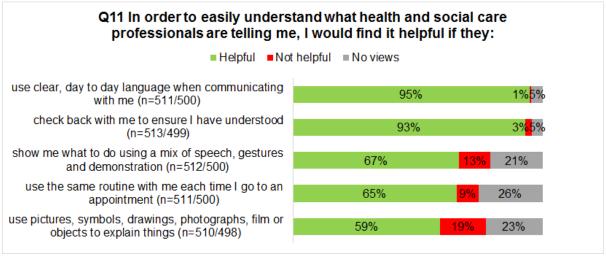
These questions were designed to unveil any particular communication needs that Panel members identified with. Questions also sought to understand Panel members' experience of communicating with professionals within health and social care services, and to find out what would help them communicate more easily with these professionals.

Helping people understand what health and social care professionals say

Respondents were presented with a range of communication steps/options and were asked to indicate whether they would find these helpful or not. To help them easily understand what health and social care professionals are telling them, Panel members indicated that it would be helpful if health and social care professionals:

- use clear, day-to-day language when communicating with them (95%)
- check back with them to ensure they have understood (93%)
- show them what to do using demonstration (67%)
- use predictable routines during appointments (65%), and
- use visual supports to explain things (59%).

Figure 12: What would help understanding what health and social care professionals say?

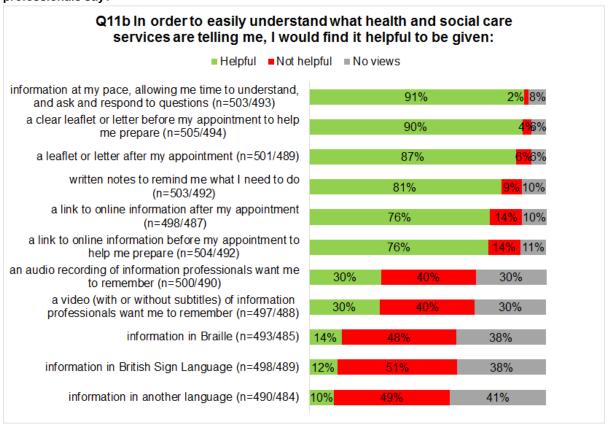


They were also provided with a list of items that could potentially aid understanding of what health and social care professionals say and were asked so state whether these would be helpful or not. To aid ease of understanding, respondents indicated it would be helpful to be given;

- information at my pace, allowing me time to understand and ask and respond to questions (91%)
- a clear leaflet or letter before my appointment to help me prepare (90%)
- a leaflet or letter after my appointment (87%)
- written notes to remind me what I need to do (81%)
- a link to online information after my appointment (76%), and
- a link to online information before my appointment to help me prepare (76%).

A substantial number of respondents (30%) agreed that recorded information (audio and/or video format) of what professionals want them to remember would help them understand what professionals are trying to communicate.

Figure 13: What could be given that would help understanding of what health and social care professionals say?



Respondents were then asked to think about other things that health and social care services and professionals working with them could do to help respondents understand the information professionals and services are trying to communicate. This was asked as an open question and coded thematically for analysis purposes. Where respondents made more than one suggestion or comment this has been coded under more than one theme. The percentages in the table below therefore round to more than 100%. One quarter of respondents who made a comment (25%) stated that all suggestions listed in Q11a would be useful. A further 22% of those who responded indicated providing clear and simple information would be useful, 17% suggested longer appointment times, 13% suggested talking clearly and slowly would help, and 11% stated writing down information would help them understand information being communicated. Many of these suggestions reflect the list provided in question 11a.

Figure 14: Suggestions for other things health and social care services/ professionals could do to help understanding

Q11b Please use this space to give details on other things health and social care services and professionals working in them could do to help you understand the information they are trying to communicate.				
Base: unweighted, n=57; weighted, n=64	%			
All of the suggestions would be useful	25%			
Provide clear/ simple information	22%			
Longer appointment times	17%			
Talk clearly and slowly	13%			
Write down information	11%			
Encouragement/ patience	8%			
Face to face communication	8%			
Do not need any help to understand information	6%			
Use methods other than online, as I don't have online access	4%			
Other	4%			

Expressing yourself to health and social care professionals

Respondents were then asked what would help them express themselves easily to health and social care services. They agreed the following would be helpful:

- talking to someone face to face (94%)
- taking the time I need to get my message across (90%)
- giving services information before my appointment to help them prepare for me (85%)
- bringing a friend, family member or advocate with me to help me get my message across (71%)
- showing a person what I mean using facial expression, body language or demonstration (61%)
- filling in a form (57%)
- writing a text or email (53%), and
- writing a letter (51%).

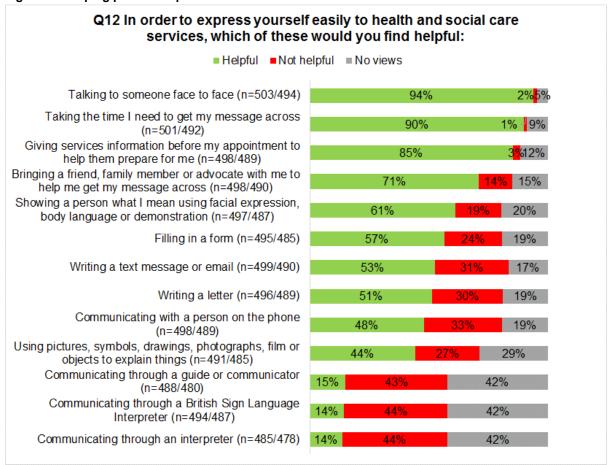


Figure 15: Helping patients express themselves to health and social care services

Respondents were provided with a space to give details on other things that health and social care services could do to help them express themselves and communicate their needs. Few respondents (n=47) made suggestions. The suggestions made have been grouped thematically for analysis and are listed below. The most common suggestion being face-to-face communication via Skype or video (25%).

Figure 16: What else could help you express yourself and communicate needs

Please use this space to give details on other things health and social care services could do to help you express yourself and communicate your needs.				
Base: unweighted, n=47; weighted, n=45	%			
Face-to-face communication via skype video	25%			
All the above are useful	14%			
Understand our circumstances/problems	12%			
Listen/give feedback	12%			
Help filling out forms	9%			
Not applicable to myself	8%			
Other	8%			
Give clear information/easy to understand	5%			
Friendlier staff	5%			
More time for appointments	4%			

Experience of communicating with health and social care professionals

The survey then went on to ask respondents about their experience of communicating with health and social care professionals. To set this in context, respondents were asked to think of the last time they had a health or social care appointment. When asked who this was with, the greatest proportion (57%) were with a GP, followed by a nurse (18%) and then a hospital consultant (10%).

Figure 17: Last appointment with a health or social care professional

Q13 Thinking of the last time you had a health or social care appointment, who was it with?				
Base: unweighted, n=425; weighted, n=433	%			
GP	57%			
Nurse	18%			
Hospital consultant	10%			
Optician	4%			
Doctor	3%			
Physiotherapist	2%			
Dentist	2%			
Psychology	1%			
Pharmacist	1%			
Social worker	1%			
Midwife	1%			
Other	7%			

Thinking of that last appointment, respondents were asked how 'easy to understand' a range of aspects were. The majority of respondents stated that all of the following aspects were easy to understand.

- The information you received on the place of your appointment (81%)
- The information you received on the time of your appointment (79%)
- The information given to you during your appointment (78%)
- The information you received on how to book an appointment (75%)
- The information given to you on what was to happen after your appointment (73%).

This is illustrated in the figure below.

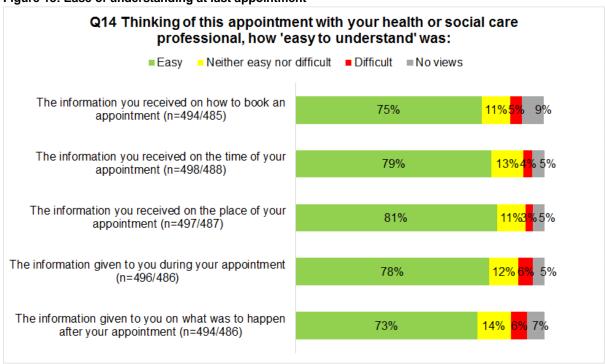


Figure 18: Ease of understanding at last appointment

Respondents were given the opportunity to provide an open response to the question 'how can health and social care services make it easier for people to understand the information which services communicate.' Responses have been coded thematically for analysis purposes. The most common suggestions were more time for appointments (31%), provide more information (26%), explain things fully (18%) and to use simple or plain language (13%).

Figure 19: How can services make it easier for people to understand the information they communicate?

Q15 How can health and social care services make it easier for people to understand the information which services communicate?				
Base: unweighted, n=159; weighted, n=156 %				
More time for appointments/don't feel rushed	31%			
Provide information e.g. leaflet/written/online	26%			
Explain things fully	18%			
Simple/plain language	13%			
Consider the individual - needs/issues	6%			
Listen to what we say	5%			
Polite/friendly staff	5%			
Other	3%			
More face-to-face communication	3%			
Already explained in detail	3%			
Don't know	2%			
Look at the patient	1%			

Again, thinking about this appointment, respondents were asked how easy it was to express themselves. The majority of respondents stated that they had found this easy.

- 78% found it easy to express themselves when they arrived for their appointment
- 78% found it easy to express themselves during their appointment
- 77% found it easy to express themselves when making an appointment
- 75% found it easy to ask questions about what was to happen after the appointment.

Q16 Thinking of this appointment with your health or social care professional, how easy was it to: ■ Easy Neither easy nor difficult Difficult No views Express yourself (communicate your views or needs) 77% when making an appointment (n=495/483) Express yourself (communicate your views or needs) 78% when you arrived for your appointment (n=495/483) Express yourself (communicate your views or needs) 78% during your appointment (n=494/483) Ask questions about what was to happen after the 75% appointment (n=495/483)

Figure 20: Ease of expressing yourself at appointments with health and social care professionals

Respondents were asked to provide their own views on 'how can health and social care services make it easier for people to express themselves and communicate their needs.' Respondents most commonly suggested that health and social care services could take time to listen (43%), and have approachable/friendly staff (20%).

Figure 21: How can services make it easier for people to communicate their needs?

Q17 How can health and social care services make it easier for people to express themselves and communicate their needs?				
Base: unweighted, n=146; weighted, n=131	%			
Take time to listen	43%			
Approachable/friendly staff	20%			
Easy to understand information/provide more information	14%			
Longer/easier appointments	12%			
Non-jargon language/simple	8%			
Improve receptionist attitude/manner	6%			
No problems/doing a good job	5%			
Other	4%			
Don't know	3%			
Face-to-face communication	2%			

Respondents' Communication

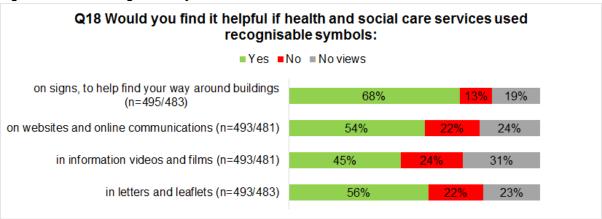
Respondents were asked about their individual communication needs and what would help them communicate well.

Firstly, respondents were asked if they would find it helpful if health and social care services used recognisable symbols, for example:

Respondents were most likely to agree that the use of recognisable symbols would be helpful:

- on signs to help find your way around buildings (68%)
- in letters and leaflets (56%)
- on websites and online communications (54%).

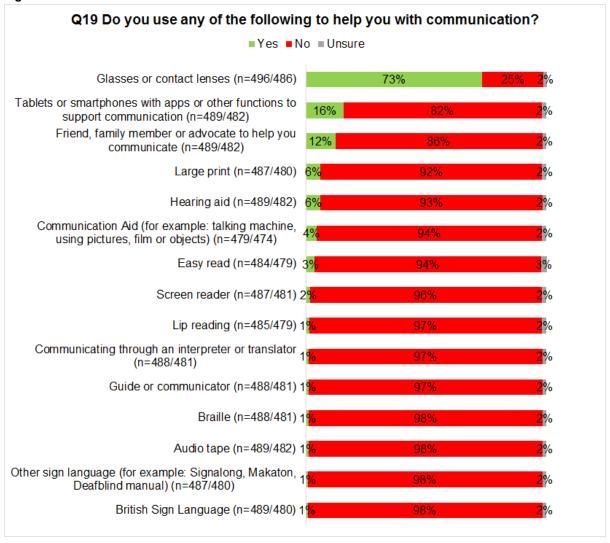
Figure 22: Use of recognisable symbols



Respondents were presented with a list of communication aids and supports. They were asked which of these supports (if any) they use. Respondents used:

- glasses or contact lenses (73%)
- tablets or smartphones with apps or other functions to support communication (16%), and
- friend, family member or advocate to help you communicate (12%).

Figure 23: Communications aids



Improving communication; Additional comments

Finally, respondents were asked for any other comments they wished to make on how services could improve the way they communicate with them. Most commonly noted were being considerate of or listening to views (34%), longer appointment times/spending more time with patients (28%), better communication (24%), and providing more information (21%).

Figure 24: Ease of understanding at last appointment

If you have any other comments on how services can improve the way they communicate with you (help you express yourself and understand information), please use this space to provide detail.				
Base: unweighted, n=69; weighted, n=53	%			
Listen to our views/be considerate	34%			
Longer appointment times/more time with patients	28%			
Better communication e.g. face-to-face/ email/ txt	24%			
Provide more information	21%			
Improved/trained staff	9%			
Simple/clear language	8%			
Already receive a good service	6%			
Other 3%				

Chapter 5: Next steps

This report will be published and shared widely, but this is only the first step in using the feedback to improve services. The sponsors of each set of questions will be asked how they intend to use the feedback to make improvements to health and social care services.

Below is an example of how Panel members' responses from previous Citizens' Panel reports are being used. From this, it is evident that the views and experiences provided by Panel members are welcomed and are being considered by policy makers and others involved in delivering health and social care services in Scotland.

Our Voice Citizens' Panel 2nd survey

The second Our Voice Citizens' Panel survey explored Panel members' opinions about and experiences of what makes a good doctor and what makes a good consultation with a doctor. This survey also questioned how comfortable Panel members would feel asking doctors a range of questions about care and treatment. The findings from this survey were published in August 2017 and have subsequently been used to inform ongoing work by the Chief Medical Officer around shared decision making. Findings from this survey have featured in the newest Chief Medical Officer report Practising Realistic Medicine, which was published on 20 April 2018: http://www.gov.scot/Resource/0053/00534374.pdf

In the same second Panel survey, Panel members were asked questions around loneliness and social isolation. Findings from this survey were included in "A Connected Scotland", the Scottish Government's vision for tackling social isolation and loneliness and building stronger communities: http://www.gov.scot/Publications/2018/01/2761/349573

Our Voice Citizens' Panel 3rd survey

The third Our Voice Citizens' Panel survey investigated public attitudes towards and experiences of using Digital Technologies for healthcare improvement, and using and sharing personal health and social care information. Findings from this survey have been used to inform the Digital Health and Care Strategy, launched April 2018: http://www.gov.scot/Publications/2018/04/3526

Findings from other Citizens' Panel reports are being used to improve and inform services throughout Scotland. The longer term impact of findings will be monitored and reported back to Panel members in due course.

Appendix 1: Questionnaire

1. Welcome again to the Our Voice Citizens' Panel

Thank you for volunteering to be part of the national Our Voice Citizens' Panel for health and social care.

As a member of this panel, you are one of a group of volunteers who provide public opinions on a range of health and social care issues. When taken together, the views of Panel members provide can reflect the views of the Scottish population.

Enclosed with this survey is a summary of the key findings from the third Citizens' Panel survey which asked questions around the use of Digital Technologies for healthcare improvement; using and sharing personal health and social care information; and accessing healthcare professionals other than doctors.

In this, our fourth Our Voice Citizens' Panel survey, we will ask you questions on:

- HIV awareness
- mental health and wellbeing, and
- inclusive communication.

As usual, 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. Again, we confirm that your answers are confidential and all views will be made anonymous.

Please do not use Google to answer these questions.

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.

BSL users can contact us via Contact Scotland BSL http://contactscotland-bsl.org/

Thank you

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

Please complete and return this survey by Friday 9th February 2018.

2. HIV awareness

The HIV Anti-Stigma Consortium is a group of experts in HIV-related stigma that have come together to determine how to eliminate HIV-related stigma in Scotland. The Consortium is made up of people living with and affected by HIV, and professionals working in relevant fields. Over the past year, the Consortium has collaboratively drafted the HIV Anti-Stigma Strategy, an action plan for eliminating stigma.

Public knowledge and public attitudes to HIV are a good indicator of how well we as a society are responding to changes in HIV prevention, treatment and technology. Findings from this survey will be used to measure public knowledge and awareness about HIV, and will form part of the monitoring and evaluation of the HIV Anti-Stigma Strategy.

Anu-Sugma S	strategy	•						
1. Please rate I think HIV is a					ee with the	efollowing	stateme	ent:
Strongly	Agr	ee Ne	either agre	e nor Di	sagree	Strongly	D	on't
agree	7 (9100		disagree			disagree	kı	now
			uisagiee					
2. How would this?	_	-		out how HI	V is passed	d on and ho	w to pr	event
Well inform	ned	Moderately	informed	I have a	basic idea		know an	ything
						6	about it	
3. Please rate	the exte	ent to whic	h you agr	_	ree with th	e following	statem	ents:
		Strongly	Agree	Neither	Disagree	Strongly	Don't	Not
		agree		agree nor disagree		disagree	know	applicable
I would be con working with a colleague who with HIV	a							
I would be constarting a relawith someone	tionship who is							
I would be con if my child had classmate wh with HIV	d a							

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	Not applicable
I would be comfortable if my GP offered me an HIV test							
If I found out I had an HIV positive status, I would know where to go for treatment							
If I found out I had an HIV positive status, I would know where to go for support							
The information I get about HIV comes from what I see on TV and read in newspapers							
I need to improve my knowledge and understanding of how HIV is passed on and how to prevent this							

3. Transmission of HIV

4. Please indicate whether you think these statements are True or False:

HIV can be passed from person to person via:

	True	False	Don't
			know
Spitting / coughing / sneezing			
Kissing			
Unprotected sex			
From a public toilet seat			
Sharing a glass, cup or cutlery			
Sharing needles or syringes			

5. Please indicate whether	you think these statements are	True or False:
----------------------------	--------------------------------	----------------

	True	False	Don't
			know
Someone taking effective HIV treatment does not pass on HIV			
Someone taking effective HIV treatment will have a near-normal life expectancy			
There is a pill you can take daily that prevents HIV infection			
Women on effective HIV treatment can have children without passing HIV on to them			

You will have the opportunity to find out more about how HIV is passed on and how to prevent this at the end of this survey.

4. Mental health

See Me is Scotland's national programme to end mental health stigma and discrimination. They work mainly within the settings where people experience stigma and discrimination the most: within education, workplaces, communities, and health and social care environments.

See Me are interested in attitudes and behaviours around mental health. The information we gather from this survey will be used to inform See Me's ongoing programme of work and may also be used in their reports and published on their website.

Within these questions, we talk about "mental health problems". When we talk about this, we are referring to a wide range of problems, including persistently low moods or levels of stress that affect how you think or feel, through to conditions which have been diagnosed (such as depression, anxiety, bi-polar disorder, schizophrenia, and so on) by your GP or a mental health specialist (for example: a psychiatrist).

It is extremely important to be honest in your answers, and select the answer that feels most true to you – your answers will always be anonymous.

6. Please read each statement and select the answer that most applies to you.

	Yes	No	Prefer not
			to say
I have had or currently have a mental health problem			
I have cared or currently care for someone who has a mental health problem			

			Yes	No	Not applicable	Prefer not to say
have experienced being treat unfairly because of my mental		•				
have experienced being treat unfairly because someone I kn mental health problem		•				
have witnessed people being unfairly because of their menta		-	or			
you would like to add furthe	er comme	ent, pleas	e use this sp	pace to do	so:	
Talleina Alaassi	Menta	al Hea	alth			
I AIKINA ANAIIT I			AILII			
Please select one answer on ow willing would you be to s	each row	/. enly to th		people ab	out existing	g or future
Please select one answer on ow willing would you be to s	each row speak ope al health?	/. enly to th	e following p	people ab	g Very	Not
Please select one answer on ow willing would you be to shallenges to your own mental	each row speak ope al health?	/. enly to th ?	e following _l	-		Not
Please select one answer on ow willing would you be to s	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to stallenges to your own mental	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to stallenges to your own mental family member	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to stallenges to your own mental amily member friends	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to stallenges to your own mental family member friends Partner Manager at work	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to stallenges to your own mental family member Friends Partner Manager at work Colleague at work Human Resources	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to stallenges to your own mental family member Friends Partner Manager at work Colleague at work Human Resources Jepartment at work The member of staff at your	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to stallenges to your own mental family member friends Partner Manager at work Colleague at work Ituman Resources epartment at work member of staff at your lace of study healthcare professional (for	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not
Please select one answer on ow willing would you be to shallenges to your own mental family member	each row speak ope al health?	/. enly to th ?	e following position of the following positions willing nor	-	g Very	Not

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a. I would feel afraid to have a conversation with someone who has a mental health problem					
b. I would feel upset or disturbed about working on the same job as someone who has a mental health problem					
c. I would maintain a friendship with someone who has a mental health problem					
d. I would not recommend someone for a job if they had a mental health problem					
e. I would be willing to have a relationship with a person who has a mental health problem					
f. I would not want a person who has a mental health problem to take care of my child					
g. I would feel ashamed if people knew someone in my family had been diagnosed with a mental health problem					
h. People who have mental health problems are largely to blame for their own condition					
i. It is possible to have a mental health problem and live a meaningful life					
If you would like to add comment to any of y the statement(s) in question (by labelling a,		-		-	-

6. Responding to, and Supporting Others

10. Please rate the extent to which you agree or disagree with the following statements.

If my friend told me that they were worried about their mental health:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	Not applicable
I would know what I could do to help							
I would know where they could get information							
I would know where they could get support							
I would feel comfortable talking to them about it							

7. Inclusive Communication

Communication is a two way process. It is about both expressing ourselves (telling people things) and being able to understand what others are telling us. There are many ways of communicating and people have different communication strengths, preferences and needs.

Please answer these questions so that we can find out what you find helpful when communicating with health and social care services.

11. Please select one answer on each row.

In order to easily understand what health and social care professionals are telling me, I would find it helpful if they:

	Helpful	Not	No
		helpful	views
wrote down important things for me to remember			
use clear, day to day language when communicating with me			
check back with me to ensure I have understood			
use the same routine with me each time I go to an appointment			
show me what to do using a mix of speech, gestures and demonstration			
use pictures, symbols, drawings, photographs, film or objects to explain things			

11b. In order to easily understand what health and social care services are telling me, I would find it helpful to be given:

	Helpful	Not	No
		helpful	views
a clear leaflet or letter before my appointment to help me prepare			
a link to online information before my appointment to help me prepare			
information at my pace, allowing me time to understand, and ask and respond to questions			
information in another language			
information in British Sign Language			
information in Braille			
written notes to remind me what I need to do			
a leaflet or letter after my appointment			
an audio recording of information professionals want me to remember			
a video (with or without subtitles) of information professionals want me to remember			
a link to online information after my appointment			
Please use this space to give details on other things health and s professionals working in them could do to help you understand t trying to communicate.			

12. Please select one answer on each row.

In order to express yourself easily to health and social care services, which of these would you find helpful:

	Helpful	Not	No
		Helpful	views
Giving services information before my appointment to help them prepare for me			
Talking to someone face to face			
Showing a person what I mean using facial expression, body language or demonstration			
Using pictures, symbols, drawings, photographs, film or objects to explain things			
Taking the time I need to get my message across			
Bringing a friend, family member or advocate with me to help me get my message across			
Communicating through an interpreter			
Communicating through a British Sign Language Interpreter			
Communicating through a guide or communicator			
Communicating with a person on the phone			
Writing a text message or email			
Writing a letter			
Filling in a form			
Please use this space to give details on other things health and s do to help you express yourself and communicate your needs.	social car	e service	s could

8. Communication in practice

				r,
I. Thinking of this appointment with your health or socia	l care pro	ofessional:		
ow 'easy to understand' was:				
	Easy	Neither	Difficult	No
		easy nor difficult		views
The information you received on how to book an				
appointment				
The information you received on the time of your				
appointment The information you received on the place of your				
appointment				
The information given to you during your appointment				
The information given to you on what was to happen				
The information given to you on what was to happen after your appointment				
inter your appointment				
	easier fo	r people to	understan	d the
5. How can health and social care services make it e				
5. How can health and social care services make it e formation which services communicate?				

16. Thinking of this appointment with your health or socia	ı care pro	oressiona	1:	
How <i>easy</i> was it to:	Easy	Neither easy no difficult	r	No views
Express yourself (communicate your views or needs) when making an appointment				
Express yourself (communicate your views or needs) when you arrived for your appointment				
Express yourself (communicate your views or needs) during your appointment				
Ask questions about what was to happen after the appointment				
9. Your communication	_			
18.Would you find it helpful if health and social care (for example: appointment time), information , opti			_	symbols
ror example: appointment time 😏, information 😎 , opti	Yes	, pnarm No	No views	
in letters and leaflets			VICVO	
in information videos and films				
on websites and online communications				

on signs, to help find your way around buildings

19. Do you use any of the following to help you with communication?

	Yes	No	Unsure
Hearing aid			
Lip reading			
Glasses or contact lenses			
Large print			
Screen reader			
Audio tape			
Braille			
Easy read			
Tablets or smartphones with apps or other functions to support communication			
British Sign Language			
Other sign language (for example: Signalong, Makaton, Deafblind manual)			
Friend, family member or advocate to help you communicate			
Communicating through an interpreter or translator			
Guide or communicator			
Communication Aid (for example: talking machine, using pictures, symbols, drawings, photographs, film or objects)			
If you use any other communication support, please detail here			
20. If you have any other comments on how services can improve to communicate with you (help you express yourself and understand inforthis space to provide detail.			se use

10. Further Information

21. If you would like	to find out more	e about HIV ti	ransmission and	וd prevention, ן	please
select "Find out mor	e"				

Find out more	Skip, finish survey

11. HIV transmission & prevention

In Scotland, HIV used to be considered a terminal illness but advances in treatments mean it is now possible to live a long and healthy life with HIV.

The most common ways HIV is transmitted are through sex without a condom and through sharing infected needles or syringes. It is passed on through infected bodily fluids.

You cannot get HIV through casual or day-to-day contact, or kissing, spitting or sharing a cup or plate. Very small amounts of the HIV virus can also technically be found in saliva but not in a sufficient quantity to cause transmission. There has never been a case of HIV transmission through saliva recorded in Scotland.

With new advancements in treatment, when a person living with HIV is on effective treatment for over 6 months and the virus becomes undetectable in the body (undetectable viral load), they cannot pass HIV on to anyone else, through any means of transmission. If a woman is on effective treatment for her HIV, it is extremely unlikely that she will pass HIV on to her baby in the womb, during childbirth or from breastfeeding. However, it is recommended that all HIV positive mothers use formula milk and bottle feeding instead of breastfeeding.

A pill called PrEP can be taken by people who are HIV negative to prevent them from acquiring HIV. PrEP is for HIV negative people who are at high risk of getting HIV (for example: partners of someone who is living with HIV). It is extremely effective at preventing HIV when taken as directed.

22. Did any of the above information surprise you?

	-	
Yes	No	
If yes,		provide details of what surprised you and why you are surprised

THANK YOU FOR COMPLETING THIS SURVEY. ©

Appendix 2: Update for Panel members on previous Panel survey

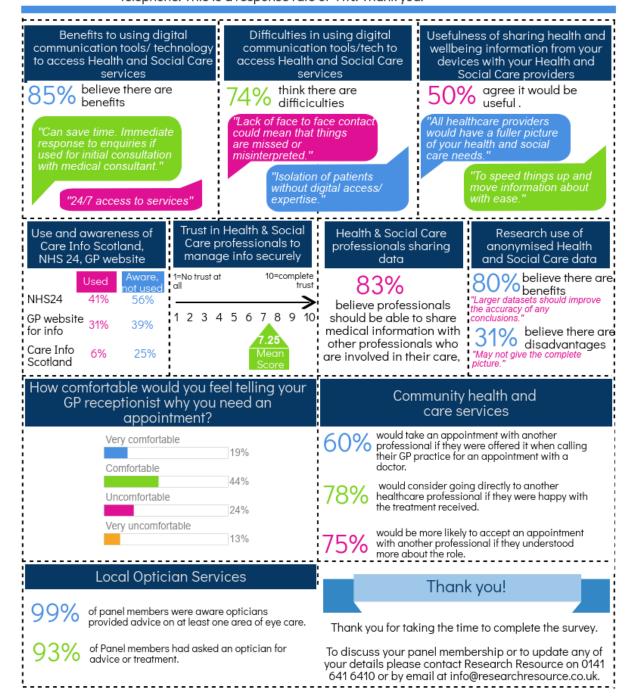
December 2017

Our Voice Citizens' Panel Third Survey Results



This newsletter summarises the key findings from the third survey undertaken with the Our Voice Citizens' Panel. Within the survey we asked you about your use of Digital Technologies for healthcare improvement, using and sharing personal health and social care information and about accessing healthcare professionals other than your doctor. In addition to these questions we also asked you a few personal background questions, to make sure our information remains up to date and representative of the Scottish population at large.

Scottish population at large. In total, 496 Panel members responded to the survey either by post, email or by telephone. This is a response rate of 41%. Thank you!



Appendix 3: Response profile

Our Voice Citizens' Panel - Fourth Survey Response Analysis and Profile

Date	Activity	Description	Number
21 st	First	Distributed	942
December	email	Bounce back	82
	Citian	Total emails delivered	860
28 th	First email	Number sent	754
December	reminder	Number Bounce back	0
		Total emails delivered	754
4 th January		Number sent to Panel members without email addresses	274
2018	First postal survey	Number sent to bounce back Panel members and those who had not responded	706
		Total number sent	980
24 th January 2018	Second email reminder	Number sent	671
29 th January 2018	Postal survey reminder	Number sent	848
8 th March 2018	Telephone boost		75

SURVEY OUTCOMES AS AT 09/03/2018

Emails sent	860
Number of email responses	202
Email response rate	23%
Number of postal sent	980
Number of postal returned	239
Postal response rate	24%
Telephone surveys	75
OVERALL RESPONSE RATE	
Current response	516
Current number on panel	1185
Overall response rate	44%

Gender[1]	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.	Difference
Male	179	35%	48%	374	32%	49%	-17%
Female	336	65%	42%	804	68%	51%	17%
Prefer not to answer	1	0%		5	0%		
Total	516	100%	44%	1183	100%		

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

Source: National Records Scotland - Population Estimates 2014. Table 1. Retrieved from: http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2014/list-of-tables 07/11/2016

Tenure	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.	Difference
Own	381	74%	53%	716	61%	62%	-2%
Rent from Council/ HA	75	15%	27%	273	23%	24%	-1%
Private Rent	37	7%	31%	118	10%	14%	-4%
Other	19	4%	28%	67	6%		6%
Total	512	100%	44%	1174	98%	100%	

Source: Scotland's Census 2011. Table DC4427SC - Accommodation type by tenure - Households. (2014). National Records of Scotland, Crown copyright. Retrieved from: http://www.scotlandscensus.gov.uk/ods-anlyser/jsf/tableView/tableView.xhtml 26/10/2016

Age	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.	Difference
16-24	19	4%	18%	104	9%	14%	-5%
25-44	93	18%	28%	333	28%	31%	-3%
45-64	223	44%	50%	449	38%	33%	5%
65+	174	34%	61%	283	24%	22%	2%
Total	509	100%	44%	1169	100%	100%	

Source: National Records Scotland - Population Estimates 2014. Table 2. Retrieved from: http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2014/list-of-tables 07/11/2016

Ethnic group	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.[2]	Difference
White British/ Irish	415	98%	37%	1127	96%	96%	0%
Other	10	2%	24%	42	4%	4%	0%
Total	425	100%	36%	1169	100%	100%	

Source: Scotland's Census 2011. Table DC2101SC - Ethnic group by sex by age. (2014). National Records of Scotland, Crown copyright. Retrieved from: http://www.scotlandscensus.gov.uk/ods-analyser/jsf/tableView/tableView.xhtml 26/10/2016

SIMD Quintile (2012)	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.	Difference
1	66	13%	28%	239	21%	20%	1%
2	96	19%	39%	247	21%	20%	1%
3	97	19%	42%	232	20%	20%	0%
4	133	26%	54%	247	21%	20%	1%
5	116	23%	59%	196	17%	20%	-3%
Total	508	100%	44%	1161	100%	100%	

Sexual Orientation	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.	Difference
Bi / Bisexual	2	0%		5	1%	1%	0%
Gay / Lesbian	7	2%		9	1%	1%	0%
Other		0%		1	0%	0%	0%
Heterosexual / Straight	400	94%		575	94%	95%	-1%
Prefer not to answer	16	4%		21	3%	3%	1%
Total	425	100%		611	100%	100%	

Source: Scottish Survey Core Questions 2015 Data. Sourced from: https://beta.gov.scot/publications/sexual-orientation-scotland-2017-summary-evidence-base/pages/1/ (11/01/2018)

Religion	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.	Difference
Buddhist	3	1%		4	1%	0%	0%
Church of Scotland	147	34%		206	34%	32%	2%
Hindu	1	0%		1	0%	0%	0%
Muslim	3	1%		4	1%	1%	-1%
None	138	32%		194	32%	37%	-5%
Other Christian	45	11%		71	12%	6%	6%
Other religion	12	3%		19	3%	0%	3%
Prefer not to answer	23	5%		32	5%	7%	-2%
Roman Catholic	55	13%		82	13%	16%	-3%
Total	427	100%		613	100%	100%	

Source: Scotland' Census 2011, Release 2A Table 7. Sourced from:

http://www.gov.scot/Topics/People/Equality/Equalities/DataGrid/Religion/RelPopMig (11/01/2015)

Physical or mental health condition or illness	Response to date OV4	% of respondents	Response rate	No on Panel	% of Panel	Scottish popn.	Difference
Yes	229	44%	51%	449	38%	40%	-2%
No	264	51%	38%	686	58%	60%	-2%
Prefer not to say/ Don't know	23	4%	46%	50	4%		
Total	516	100%	44%	1185	100%	100%	

Source: Long term conditions. (December 23, 2015). The Scottish Government. Retrieved from http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions 26/10/2016

	No. on panel	No. of returns	Response rate	
Aberdeen City	43	12	28%	
Aberdeenshire	45	20	44%	
Angus	26	13	50%	
Argyll & Bute	31	16	52%	
Clackmannanshire	8	7	88%	
Dumfries &		,		
Galloway	36	16	44%	
Dundee City	29	9	31%	
East Ayrshire	32	14	44%	
East	27		52%	
Dunbartonshire		14		
East Lothian	21	12	57%	
East Renfrewshire	43	11	26%	
Edinburgh, City of	86	37	43%	
Eilean Siar	19	14	74%	
Falkirk	27	15	56%	
Fife	64	20	31%	
Glasgow City	104	41	39%	
Highland	53	21	40%	
Inverclyde	27	10	37%	
Midlothian	27	13	48%	
Moray	27	14	52%	
North Ayrshire	32	13	41%	
North Lanarkshire	67	25	37%	
Orkney Islands	15	7	47%	
Perth & Kinross	29	13	45%	
Renfrewshire	26	12	46%	
Scottish Borders	31	17	55%	
Shetland Islands	33	24	73%	
South Ayrshire	33	18	55%	
South Lanarkshire	57	20	35%	
Stirling	19	11	58%	
West	28		57%	
Dunbartonshire		16		
West Lothian	39	11	28%	
#N/A	1	0	0%	
Total	1185	516	44%	

	No. on panel	No. of returns	Response rate	
Ayrshire & Arran	97	45	46%	
Borders	31	17	55%	
Dumfries & Galloway	36	16	44%	
Fife	64	20	31%	
Forth Valley	53	32	60%	
Grampian	115	46	40%	
Greater Glasgow & Clyde	268	109	41%	
Highland	84	37	44%	
Lanarkshire	112	41	37%	
Lothian	173	73	42%	
Orkney	15	7	47%	
Shetland	33	24	73%	
Tayside	84	35	42%	
Western Isles	19	14	74%	
#N/A	1		0%	
Total	1185	516	44%	

Weighting survey data

As can be seen in the analysis of the response profile to this survey, different response rates have been achieved for different groups of respondents. For this survey, we received a greater response from females than males and also from older respondents than younger respondents.

In most surveys it will be the case that some **groups are over-represented** in the raw data and **others under-represented**. These misrepresentations are usually dealt with by weighting the data.

The idea behind weighting is that:

- Members of subgroups that are thought to be over or under-represented in the survey data are each given a weight
- Over-represented groups are given a weight of less than one
- Under-represented groups are given a weight of greater than one

The weight being calculated in such a way that the weighted frequency of groups matches the population.

All survey estimates are calculated using these weights, so that averages become weighted averages, and percentages become weighted percentages, and so on.

Appendix 4: Citizens' Panels

Citizens' Panels are used extensively across local authorities in Scotland, however, the Our Voice Citizens' Panel and Local Authority Citizens' Panels are not directly comparable due to different recruitment methods². Although the Our Voice Citizens' Panel is similar to those conducted by local authorities across Scotland, it varies in one significant methodological aspect – that Panel members cannot actively volunteer or petition to 'sign up' to the Our Voice Citizens' Panel. Although a mixed methodology of recruitment practice exists across local authorities, using for example electoral rolls, face-to-face recruitment, issue-based recruitment and, door-to-door recruitment, most local authorities allow Panel members to actively volunteer or 'sign up' rather than be reactively recruited. It is possible that this active interest rather than reactive interest may provide one reason why the Our Voice Citizens' Panel experiences lower completion rates than some local authority Citizens' Panels.

Of the 24 local authorities that had Citizens' Panels in 2013, 43% of participants are recruited as volunteers. Although response rate varies widely across these panels from a high of 82% to a low of 28%, 44% of panels retrieve an average 40-60% response³. A review of Citizens' Panels run by local authorities conducted by Rolfe, (2012)⁴ noted that the majority of Panels have proportionately fewer younger people than the wider population. The Our Voice Panel, has experienced similar difficulties in recruiting and encouraging response of younger Panel members. More surprisingly, over half of the local authority Panels reported in Rolfe's review also had lower than proportional representation of older people, suggesting that a truly representative Panel is difficult to achieve and sustain.

It is usual to experience attrition of Panel members. One hundred and fifteen Panel members have actively chosen to remove themselves from the Panel between the first and fourth survey cycle. It has been argued that citizens are only interested in participating in Panels when their views have a tangible impact on service delivery. To this end, it has been noted that local authority Citizens' Panels have to continually demonstrate the impact that Panel members have on service delivery. Due to the high level and national nature of the Our Voice Citizens' Panel, the process of demonstrating the impact of Panel members' views on local service change and delivery is often slow. It is possible that this has contributed to attrition rates. Some of the Panel members who have requested to be removed from the Panel have fed back that the Panel is not what they thought it was and without the opportunity to provide feedback on their own local health and social care services, they do not wish to participate in the Panel on an ongoing basis.

Discussion is underway to address these challenges, in the meantime, the Our Voice Citizens' Panel remains robust with statistically significant findings at national level.

² http://www.improvementservice.org.uk/documents/research/Consultation%20Report%20Aug%2014.pdf

 $^{^3\ \}underline{\text{http://www.improvementservice.org.uk/documents/research/Consultation\%20Report\%20Aug\%2014.pdf}$

⁴ **Steve Rolfe. 2012.** More than ticking boxes. An exploration of the representativeness of Citizens Panels in Scotland. *MSc in Applied Social Research. University of Stirling, 2012*

Appendix 5: Interpreting results

The results of the research are based upon a sample survey therefore all figures quoted are estimates rather than precise percentages. The reader should interpret the data with statistical significance in mind.

All tables have a descriptive and numerical base, showing the population or population subgroup examined in it. While all results have been calculated using weighted data, the bases shown give both the unweighted and weighted counts.

In some tables and charts, differences between subgroups have been noted because they are interesting, however, not all differences are statistically significant. Where the unweighted base on which percentages are calculated is less than 50 or close to 50, they should be treated with caution, as even though these estimates have been published, they are subject to high levels of volatility and have a high degree of uncertainty around them.

All proportions produced in a survey have a degree of error associated with them because they are generated from a sample of the population rather than the population as a whole. Any proportion measured in the survey has an associated confidence interval (within which the 'true' proportion of the whole population is likely to lie), usually expressed as ±x%. It is possible with any survey that the sample achieved produces estimates that are outside this range. The number of times out of 100 surveys when the result achieved would lie within the confidence interval is also quoted; conventionally the level set is 95 out of 100, or 95%. Technically, all results should be quoted in this way. However, it is less cumbersome to simply report the percentage as a single percentage, the convention adopted in this report.

Where sample sizes are small or comparisons are made between subgroups of the sample, the sampling error needs to be taken into account. There are formulae to calculate whether differences are statistically significant (i.e. they are unlikely to have occurred by chance) and the table below provides a simple way to estimate if differences are significant.

		Sub-group Size									
		50	75	100	150	200	250	300	400	500	617
le of	5%	6.9%	5.7%	4.9%	4.0%	3.5%	3.1%	2.8%	2.1%	2.2%	1.7
	10%	9.6%	7.8%	6.8%	5.5%	4.8%	4.3%	3.9%	2.9%	3.0%	2.4
multiple	15%	11.4%	9.3%	8.0%	6.6%	5.7%	5.1%	4.6%	3.5%	3.6%	2.8
<u> </u>	20%	12.8%	10.4%	9.0%	7.4%	6.4%	5.7%	5.2%	3.9%	4.0%	3.2
	25%	13.8%	11.3%	9.8%	8.0%	6.9%	6.2%	5.6%	4.2%	4.4%	3.4
es	30%	14.6%	11.9%	10.3%	8.4%	7.3%	6.5%	6.0%	4.5%	4.6%	3.6
nearest	35%	15.2%	12.4%	10.8%	8.8%	7.6%	6.8%	6.2%	4.7%	4.8%	3.8
	40%	15.6%	12.8%	11.0%	9.0%	7.8%	7.0%	6.4%	4.8%	4.9%	3.9
b (45%	15.9%	12.9%	11.2%	9.2%	7.9%	7.1%	6.5%	4.9%	5.0%	3.9
kup 5%)	50%	15.9%	13.0%	11.3%	9.2%	8.0%	7.1%	6.5%	4.9%	5.0%	4.0%
(lookup 5%)	55%	15.9%	12.9%	11.2%	9.2%	7.9%	7.1%	6.5%	4.9%	5.0%	3.9
≗	60%	15.6%	12.8%	11.0%	9.0%	7.8%	7.0%	6.4%	4.8%	4.9%	3.9
te	65%	15.2%	12.4%	10.8%	8.8%	7.6%	6.8%	6.2%	4.7%	4.8%	3.8
l e	70%	14.6%	11.9%	10.3%	8.4%	7.3%	6.5%	6.0%	4.5%	4.6%	3.6
Estimate	75%	13.8%	11.3%	9.8%	8.0%	6.9%	6.2%	5.6%	4.2%	4.4%	3.4
	80%	12.8%	10.4%	9.0%	7.4%	6.4%	5.7%	5.2%	3.4%	4.0%	3.2
þ	85%	11.4%	9.3%	8.0%	6.6%	5.7%	5.1%	4.6%	3.5%	3.6%	2.8
Sample	90%	9.6%	7.8%	6.8%	5.5%	4.8%	4.3%	3.9%	2.9%	3.0%	2.4
Ϋ́	95%	6.9%	5.7%	4.9%	4.0%	3.5%	3.1%	2.8%	2.1%	2.2%	1.7

Below is a worked example which explains how to interpret results presented in the analysis of the survey.

The percentage of respondents who stated that they have witnessed people being treated differently or unfairly because of their mental health problems was 69%, with a base of 439.

Using the statistical significance table above to find the 95% confidence intervals for each value, we can see that a base of 400 the lower limit of the 95% confidence interval is (69%-4.5%) 64.5% and the upper limit is (69%+4.5%) 73.5%.

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