Our Voice Citizens' Panel

Survey on relationships with health and social care professionals, shared decision making, how loneliness affects people in Scotland, and how well services are working locally

Second Survey Report, August 2017

Healthcare Improvement Scotland

www.scottishhealthcouncil.org

Contents

Foreword

Welcome to the report of the second Our Voice Citizens' Panel for Scotland.

The Our Voice Citizens' Panel is just one way that health and social care support services in Scotland can listen to the views of the Scottish public – and having listened, make improvements to the services they provide.

I would like to thank the individuals who have volunteered to be part of the panel, who together make up a representative 'slice' of the population of Scotland.

This survey has asked questions about the relationships people have with health and social care professionals. These questions are asked in the context of the Chief Medical Officer annual reports called "Realistic Medicine" and "Realising Realistic Medicine". In her reports, Catherine Calderwood the Chief Medical Officer for Scotland has asked challenging questions about doctors and how realistic they are in the decisions they make. Her report also challenges the variation in practice across Scotland and asks why doctors are likely to prescribe less and intervene less for themselves than they do for the public. Catherine Calderwood's report challenges everyone (both general public and professionals) to be more realistic in what 'medicine' i.e. doctors, healthcare interventions and all other health and care services can do for us.

Another area of the report builds on feedback from the Healthier Scotland national conversation. When asking the population 'what matters the most to keep you healthy?', an interesting theme emerged about how many people cited social isolation and loneliness as key issues to be addressed. The second Our Voice Citizens' Panel survey explores this theme further by asking Panel members questions about loneliness and perceptions of loneliness in Scotland.

This report sets out what Citizen Panel members have said in relation to questions about relationships with health and social care professionals, shared decision making, how loneliness affects people in Scotland, and how well services are working locally. There will be a follow on report providing feedback from the many people involved in developing these survey questions, detailing what they will now do in response to the views that have been expressed. Meanwhile, work is underway to refresh the Panel membership and to compile questions for the next Panel survey which will feature questions about Primary Care services and Digital Health Care.

I hope you enjoy reading this report.

Pam Whittle, CBE

Chair, Scottish Health Council

Acknowledgements

My thanks to all the Panel members who have taken the time to respond to the second Our Voice Citizens' Panel survey for Health and Social Care. We really value you sharing your views, opinions and experiences of a wide range of services, and your help to shape policies and future improvements to services.

Thanks to everyone involved in developing the Our Voice Citizens' Panel and in the work involved in developing questions, disseminating the survey and analysing the results as well as producing this report. This includes the Health and Social Care Alliance Scotland (The ALLIANCE), the Scottish Government Directorate for Healthcare Quality and Improvement, Chief Medical Officer, Age UK, Campaign To End Loneliness, Befriending Networks and COPE-Scotland.

Particular thanks are due to the Research Resource team and to the Social Researcher in Scottish Health Council, Wendy Brown, whose input has been immense.

Best wishes

Helen McFarlane
Our Voice Programme Director

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 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 1,258 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 recruited. 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 second full Panel survey which had questions on the relationships people have with health and social care professionals and about how loneliness affects people in Scotland and what people think could be done to tackle this issue.

A total of 551 responses (44% response rate) were achieved to the survey either by post, email or by telephone. This level of return provides data accurate to +/-4%[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

A good consultation

- The first section of the questionnaire asked Panel members about the different things that they feel provide the ingredients for a 'good doctor', and on a similar theme, what things combine to make a 'good consultation' with a doctor. The open-ended responses provided to this question were coded into common themes. Over 6 in 10 comments (64%) were where Panel members described a 'good doctor' as being knowledgeable or qualified. A further 59% of respondents commented they should be a 'good listener', 38% felt they should be friendly or approachable and 31% said a good doctor should be caring and show empathy.

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[1] based upon a 50% estimate at the 95% level of confidence

- As a follow up to this question, respondents were asked about the elements they think are most important for a 'good consultation' with a doctor. Again, the open-ended responses have been coded into common themes for analysis purposes. Two thirds of these individuals believed that it was important that a 'good consultation' with a doctor resulted in being provided with clear information (67%) and 76% felt it was important to feel that they have been listened to and were given sufficient time to speak to their doctor.

Making decisions together

- This section of the survey aimed to find out how Panel members currently make decisions about their health, care and treatment.

- All respondents were asked whether they have asked their doctor about a range of issues. Two thirds were in agreement that they have indeed asked their doctor about their treatment or care options (67%) and 64% have asked their doctor about the possible benefits and risks of their treatment or care options. Fewer respondents have asked their doctor about how likely the benefits and risks of each option are to happen to them (54%).

- Following on from this, all respondents were asked about how comfortable they would feel asking their doctor about a range of different things regarding their treatment or care options. Respondents were most likely to feel comfortable asking their doctor about their treatment or care options (92%), and about the possible benefits and risks of those options (91%).

- On the other hand, only 35% of survey respondents said they would feel comfortable asking to speak to another doctor compared to 41% who said they would feel uncomfortable.

- Only 13% of survey respondents said there were other questions they would like to ask their doctor to help them make decisions about their healthcare and treatment. The comments provided were of a varied and personal nature. However, the main themes emerging from these comments were where respondents were interested in alternative treatment options and regarding follow-up care and next steps.

Talking to a doctor

- This section of the questionnaire focused on understanding what is important to Panel members when talking to their doctor.

- Respondents were asked to describe any personal aspects of their life that they feel it is important to discuss when talking about their healthcare preferences with a doctor. The open-ended comments were coded into common themes and revealed that the top three factors perceived as being

most important for Panel members when talking about their healthcare preferences with a doctor were family circumstances (33%), general health (29%) and lifestyle or quality of life (30%).

- An open-ended question was included in the questionnaire which asked Panel members what information would help them make a decision about care and treatment when talking to a doctor. Just under half of respondents (48%) said that understanding the side effects or risks of their medication or treatment would be beneficial and 46% said that being properly informed to make decisions, being given a clear diagnosis or an honest opinion from their doctor would help them to make decisions.

- Only 15% of survey respondents were of the opinion that there are things that stop (or limit) them from being involved in decisions about their healthcare and treatment. The vast majority (74%) said this was not the case, 9% were unsure and 3% said this was not applicable.

- A total of 75 respondents (out of 79 who answered yes to the question above), provided details of the things that stop (or limit) them from being involved in decisions about their healthcare and treatment. The main themes emerging from these comments were:
    - not having sufficient time with doctor
    - having insufficient knowledge of treatment options to question anything
    - doctor knows best/don't like to question them
    - doctor doesn't listen to me/not approachable
    - lack of confidence in asking questions, and
    - mental health issues (e.g. depression, anxiety etc).

Talking to other Health and Care professionals

- The aim of this section was to understand how comfortable Panel members would feel talking to these other health and care professionals about their healthcare needs.

- In terms of other service professionals it was clear that people felt most comfortable asking a nurse (e.g. community nurse, midwife, GP practice nurse etc) about their treatment or care options with 91% stating they felt comfortable or very comfortable doing this. On the other hand, respondents felt less comfortable asking social care professionals (66%) and other service professionals such as counsellors or support staff (65%) about their treatment or care options.

- Following on from this, respondents were asked how comfortable people felt asking other service professionals about the benefits and risks of their

treatment and care options. Again, respondents felt most comfortable asking a nurse for this type of advice (90%). Respondents were least comfortable asking for this advice from a social care professional (66%) or other service professional such as a counsellor or support staff (66%).

- Just under 9 in 10 respondents (89%) said they would feel comfortable or very comfortable asking a nurse about how likely the benefits and risks of each option were. Respondents were less comfortable asking other service professionals such as counsellors or support staff (66%) and social care professionals (65%) about the likelihood of the benefits and risks happening to them.

Information delivery

- Panel members were asked about the forms of information they prefer to receive, to help them make decisions about their healthcare.

- Face-to-face consultations were by far and away the most preferred way of obtaining information about healthcare needs with 82% of respondents stating they would prefer a face-to-face consultation with a doctor and a further 46% preferring a face-to-face consultation with a nurse. Over 3 in 10 respondents preferred a phone consultation (31%) and 30% preferred information to be provided in leaflet form.

Social isolation and loneliness

- The aim of this section of the questionnaire was to find out how common feelings of loneliness are amongst the general public in Scotland and to seek views about ways to address loneliness.

- The questionnaire included an open-ended response which asked respondents what 'loneliness' means personally to them. The majority of these comments were where Panel members said that loneliness to them meant having no family or friends to talk to (61%) and a further 19% stated it was a lack of social interaction.

- All respondents were asked how often they have been feeling certain ways over the last month. These questions are from The UCLA 3-Item Loneliness Scale[2]. This scale is often provided in self-completion surveys and is an individualistic scale that allows us to measure the extent to which an individual feels lonely.

- The scores for each individual question can be added together to give a possible range of scores from 3 to 9 (using a scale where 1=never or hardly ever, 2=some of the time and 3=often). Scores between 3 and 7 can be identified as people who are "not lonely" and people with a score of 8 or 9 are

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[2] https://www.campaigntoendloneliness.org/wp-content/uploads/Loneliness-Measurement-Guidance1.pdf

identified as "often lonely". Using this scoring system for all respondents, 10% were identified as being often lonely and 90% not lonely.

- Following on from this, respondents were asked to what extent they agreed or disagreed with three statements about their relationships. The vast majority were in agreement that:
  - o they have enough people they feel comfortable asking for help at any time (76% either agreeing or agreeing strongly with this statement)
  - o they are content with friendships and relationships (73%)
  - o their relationships are as satisfying as they would want them to be (66%).

- An open-ended question was included in the questionnaire which asked respondents what they believed to be the main cause of loneliness. Over 4 in 10 of these comments were where respondents commented that the main cause of loneliness was due to a lack of social interactions or where people did not have someone to talk to (41%). A further 18% felt anxiety, depression and mental health issues was the main cause of loneliness, 16% said it was due to family and friends moving away or due to isolation and people being alone (16%).

- Respondents were then asked what they felt could be done to reduce loneliness in Scotland. The main themes were where respondents felt that more should be done to encourage people to socialise (22%), groups and activities should be available for people of all ages (22%) and strong community groups and support would help to reduce loneliness (21%).

What happens near you?

- The final section of the questionnaire asked Panel members, in relation to health and social care in Scotland, what they feel is being done well where they live and about anything which would benefit from improvements or changes to service delivery.

- In terms of what Panel members believe health and/or social care services are doing well in the area they live the top responses were good GP services (29%) and that health and social care services are doing everything well or the best they can (30%).

- When asked about the things that health and/or social care services could do better, one in four comments were regarding the availability of GP or nurse appointments (25%), 15% commented on staffing or resourcing issues and 11% mentioned improvements needed to mental health services.

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 1,258 people spread across each and every Integration Authority and NHS territorial Board across 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 recruited. 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 second full Panel survey which aimed to gather the views of the general public to help improve health care services and social care support.

Questionnaire design

The survey comprised 7 sections. The questionnaire opened by asking Panel members about the different things that they think provide the **ingredients for a 'good doctor'** and a **'good consultation'.**

The second section of the questionnaire asked Panel members about **how they currently make decisions about their health, care and treatment**. In February 2017, the Chief Medical Officer for Scotland released her Annual Report 2015/16 called 'Realising Realistic Medicine[3].' This builds on last year's report - her first in her role - called "Realistic Medicine[4]" which focused on establishing the outcomes that matter to people and applying knowledge and expertise to support them to achieve these outcomes. It focused on the following areas.

- Improving health
- Reducing patient harm from the over use of medicine
- Listening to patients – helping patients to reflect on, and express their preferences based on their individual circumstances, expectations, beliefs and values

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[3] The Chief Medical Officer for Scotland's Annual Report 2015/16: Realising Realistic Medicine. ISBN 9781786526731 http://www.gov.scot/Resource/0051/00514513.pdf

[4] Chief Medical Officer's Annual Report 2014-15: Realistic Medicine. ISBN 9781785449475 http://scotgov.publishingthefuture.info/publication/chief-medical-officers-annual-report-2014-15

- Informing patients – providing clear information about benefits/disadvantages to tests, treatments and medications as they apply to each individual
- Helping patients take a greater role in making decisions about their healthcare

The third section of the survey was designed to understand th**e factors that would make conversations with doctors about care and treatment easier, more meaningful and empowering**. For example, things like family, work or social responsibilities, money issues, medical technologies, and other issues can change over a lifetime, and this can influence care and treatment choices. In other studies, evidence of improved outcomes has been found when people are involved in healthcare decisions and their preferences taken into account.

In the next section, respondents were asked **how comfortable they would feel talking to other health and care professionals about their healthcare needs**. The Scottish Government has a vision that by 2020, everyone in Scotland will be able to live longer healthier lives at home or in a homely setting.

To help achieve this ambition, health and social care services are working together to provide integrated 'joined-up' care. This approach requires social care support staff and a wider range of healthcare professionals (which can include nurses, physiotherapists, pharmacists etc) to take on new roles. These new roles can help support patients and GPs where it is appropriate for them to do so. For example, a GP practice nurse may support people with minor conditions, or a local pharmacist may offer review of medications. Sometimes people may need social support in addition to - or even instead of - medical input to better meet their healthcare needs.

The next section of the questionnaire asked Panel members **about the forms of information Panel members prefer to receive about their healthcare needs**, to help them make decisions about their healthcare.

The Our Voice Citizens' Panel is set up to ask questions not only on health but on social care and support. Respondents were asked a number of questions on **the topic of loneliness**, to help understand how common feelings of loneliness are amongst the general public in Scotland. Lots of people feel lonely at some point in their life. Whilst studies have been conducted to find out how loneliness affects certain groups like elderly people, minority ethnic communities, and young people, we do not know how this issue impacts the general wider population.

The final section of the survey asked Panel members about **what health and social care services in Scotland are doing well locally and about anything that could be improved**.

A copy of the final questionnaire is available in Appendix 1. The infographic newsletter that was also provided to Panel members detailing the profile of the Panel can be found in Appendix 2.

Response rates and profile

The Our Voice Citizens' Panel at the time of writing this report has a total of 1,258 members. The second Our Voice Citizens' Panel survey was sent by email on 14 March 2017 to all 1,002 Panel members with email addresses. On 21 March 2017 survey packs were sent to all Panel members without email addresses and those from whom a bounce back email message was received. A reminder mailing was sent by email on the 21 March 2017 to those who had not yet responded by email. On the 29 March 2017 additional postal surveys were delivered to Panel members who had not responded to the email survey. A final email reminder was sent on the 7 April 2017 in an attempt to boost the response rate from those with email addresses.

Through a combination of these methods a total of 476 responses were received to the survey. Postal responses continued to be accepted up until the 8 May 2017. A detailed analysis of the response profile identified that the survey was underrepresented in terms of younger Panel members, defined as younger members aged 44 and under and males. This was consistent with the last Our Voice survey 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 underrepresented groups. A total of 75 telephone interviews were completed between the 18 April and the 8 May 2017. This took the final response up to 551, a 44% response rate. This level of return provides data accurate to +/-4% (based upon a 50% estimate at the 95% level of confidence) at the overall Panel level. It compares to a 48% response rate to the first full panel survey.

Despite the attempts of the telephone boost, younger respondents and males were still underrepresented. To ensure the data was representative by age and gender, weighting figures were used during the data analysis process to ensure that the data was reflective of the wider demographics of the Scottish population.

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

Citizens' Panels are used extensively across Local Authorities in Scotland, however, the Our Voice Citizen's Panel and Local Authority Citizens' Panels are not directly comparable due to different recruitment methods[5]. Although the Our Voice Citizens' Panel is similar to Citizens' Panels 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.

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

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% response[6]. A review of Citizens' Panels run by Local Authorities conducted by Rolfe, (2012)[7] 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. Thirty three Panel members have actively chosen to remove themselves from the panel between the first and second 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 Citizen' 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 as some of the 33 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.

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%. 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 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 they are not applicable. The percentages reported are weighted percentages.

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

[7] **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*

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.

Report structure

This report details the key findings from the second full Our Voice Survey. The report is structured as follows:

- Chapter 2: A good consultation
- Chapter 3: Making decisions together
- Chapter 4: Talking to a doctor
- Chapter 5: Talking to other Health and Care professionals
- Chapter 6: Information delivery
- Chapter 7: Social isolation and loneliness
- Chapter 8: What happens near you?

- Appendix 1: Questionnaire
- Appendix 2: Infographic newsletter
- Appendix 3: Response profile
- Appendix 4: Interpreting results

Chapter 2: A good consultation

Introduction

The first section of the questionnaire asked Panel members about the different things that they feel provide the ingredients for a 'good doctor', and on a similar theme, what things combine to make a 'good consultation' with a doctor.

What makes a 'good doctor'?

The survey opened by asking Panel members what they consider makes a 'good doctor'. Care was taken with this question to ensure that respondents could detail the skills, knowledge or personal characteristics that they considered imperative to the make-up of a good doctor. Respondents were limited to give three examples. A total of 529 respondents provided comments to this question. The open-ended responses received have been coded into common themes and are listed in the table below. This reveals that over 6 in 10 comments (64%) were where Panel members described a 'good doctor' as being knowledgeable or qualified. Just under 6 in 10 respondents (59%) commented they should be a 'good listener', 38% felt they should be friendly and 31% said a good doctor should be caring and show empathy.

Figure 1: **What makes a 'good doctor' (open-ended response themes)**

Q1 What makes a 'good doctor'? (Please limit your response to 3 things)	
Base: Unweighted, n=529; Weighted, n=529	%
Knowledge/ qualified	64%
Good listener	59%
Friendly/ approachable	38%
Caring/ shows empathy	31%
Patient/ willing to take time/ does not rush appointment	27%
Shows an interest in you/ your life	24%
Available/ easy to access	8%
Other	6%

Some examples of the open-ended responses provided by Panel members to describe what they consider to be a 'good doctor' are shown below:

A good all-round knowledge of medicine and particularly for health.

Knowledge of human body and remedies/ medicines so that problem can be diagnosed and appropriate treatment given.

Profound knowledge in medical science.

A good caring attitude.

The doctor conducts themselves well from the start, looks up from their desk when you enter the room smiles and welcomes you.

Someone who follows up e.g. blood tests, medications and informs patient/explains results.

Takes an interest in you as a person not just trying to get you out the door as quick as possible.

Listening to and engaging with patients, particularly giving eye contact during consultation.

Who listens to patients, finds out about patient's life context i.e. what they do, their circumstances, how they live, their beliefs and values.

Has a good knowledge of your medical history or has familiarised him/ herself with your medical records.

Q1 What makes a good doctor?

Someone with adequate communication skills, listening and explaining things in a way that the person can understand.

Prepared to listen with enough time available to make detailed explanations possible.

Takes time - the appointments are not long enough. You're not given enough time.

Knowledge on medical issues and different treatments. Such different aspects of diet and lifestyles can impact on health. For doctors to start making these suggestions - medication is not always the way forward.

Empathy and listening skills. Patience, to feel as if you're doctor really is listening to you.

Shows empathy with patient, whatever the ailment.

A doctor that doesn't feel rushed for time, squeezed for resources or unsupported by his or her employers.

Makes you feel relaxed the moment you meet him/her.

Competent but approachable personality, good 'bedside' manner.

Broad medical knowledge.

What are the most important elements of a 'good consultation' with a doctor?

As a follow up to this question, respondents were asked about the elements they think are most important for a 'good consultation' with a doctor. A total of 520 respondents chose to answer this question. Again, the open-ended responses have been coded into common themes for analysis purposes. Two thirds of these individuals believed that it was important that a 'good consultation' with a doctor resulted in being provided with clear information (67%) and 76% felt it was important to feel that they have been listened to and given sufficient time.

Figure 2: The most important elements of a 'good consultation' with a doctor (open-ended response themes)

Q2 What are the most important elements of a 'good consultation' with a doctor? (Please limit your response to 3 things)	
Base: Unweighted, n=520; Weighted, n=524	%
Feel you have been listened to/ not being rushed/ enough time	76%
Clarity/ clear information/ communication/ understanding	67%
Resolution/ diagnosis/ outcome	55%
Appointments/ availability/ punctuality	16%
Good/ thorough discussion	9%
Other	1%

Below are some of the comments made by Panel members to describe what they consider are the most important elements of a 'good consultation' with a doctor.

A feeling that doctor has time to listen and not trying to rush you to see the next person.

A friendly and reassuring demeanour. Patients are apprehensive when visiting surgeries and a friendly and welcoming atmosphere from reception and clinical staff is important.

Being listened to and having a treatment plan e.g. prescription or follow-up appointment referral.

Accessibility- availability of appointments within reasonable time.

Being offered enough time to cover what you want to say which may draw out important diagnostic details for the doctor.

Q2 What are the most important elements of a 'good consultation' with a doctor?

Careful communication of their assessment, findings, recommendations etc. And a clear, simple message about where/who to contact if the patient has further questions, or needs to talk through their worries.

When the doctor makes a decision to do something e.g. referral, treatment. Involves you in the decision process.

A good discussion of the problem/issue (knowledge, experience, good bedside manner and relaxed).

When both patient and doctor are satisfied they have been heard and are in agreement with prognosis or way forward.

Coming away having felt listened to.

Doctor being up to date with modern thinking and technology.

More time! It is so destructive to have so little time with a doctor and not be able to make your points or feel that you have been dismissed due to time constraints.

Good support, understanding and caring disposition.

Treating the cause not the symptom – being interested in wellbeing and overall health – seeking ways to prevent future issues.

Chapter 3: Making decisions together

Introduction

In February 2017, the Chief Medical Officer for Scotland released her Annual Report 2015/16 called 'Realising Realistic Medicine.' This builds on last year's report – her first in her role – called "Realistic Medicine" which focused on establishing the outcomes that matter to people and applying knowledge and expertise to support them to achieve these outcomes. It focused on the following areas.

- Improving health
- Reducing patient harm from the over use of medicine
- Listening to patients – helping patients to reflect on, and express their preferences based on their individual circumstances, expectations, beliefs and values
- Informing patients – providing clear information about benefits/disadvantages to tests, treatments and medications as they apply to each individual
- Helping patients take a greater role in making decisions about their healthcare

The aim of this section was to find out how Panel members currently make decisions about their health, care and treatment.

Asking your doctor about treatment/care options

All respondents were asked whether they have asked their doctor about a range of issues. Two thirds were in agreement that they have indeed asked their doctor about their treatment or care options (67%) and 64% have asked their doctor about the possible benefits and risks of their treatment or care options. Fewer respondents have asked their doctor about how likely the benefits and risks of each option are to happen to them (54%).

Figure 3: Asking your doctor about treatment or care options
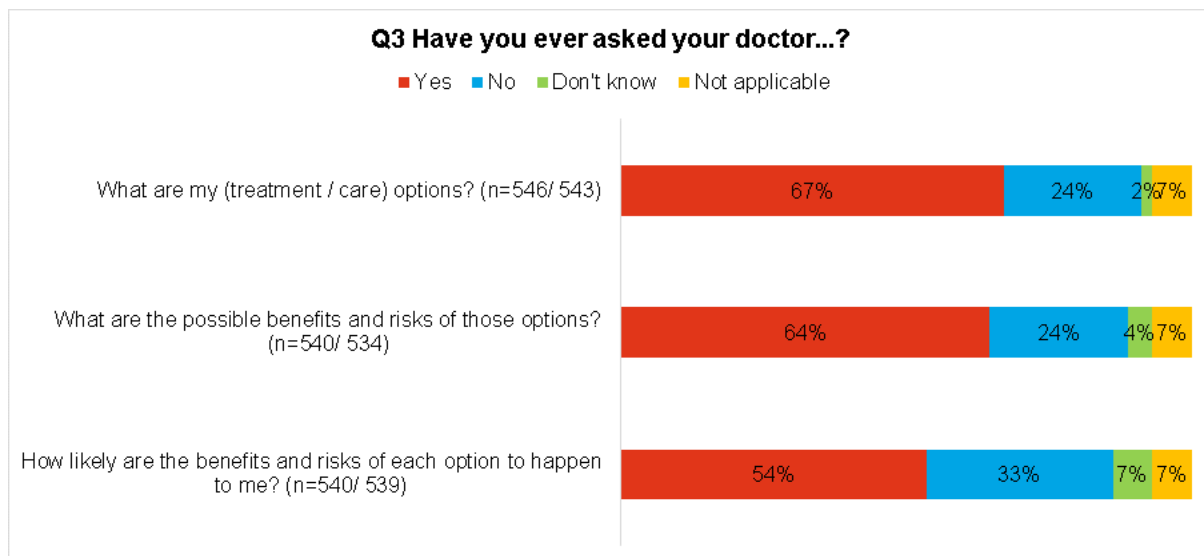
NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

How comfortable people feel asking doctors about their treatment/care options

Following on from this, all respondents were asked about how comfortable they would feel asking their doctor about a range of different things regarding their treatment or care options. Respondents were most likely to feel comfortable asking their doctor about their treatment or care options (92%), and about the possible benefits and risks of those options (91%).
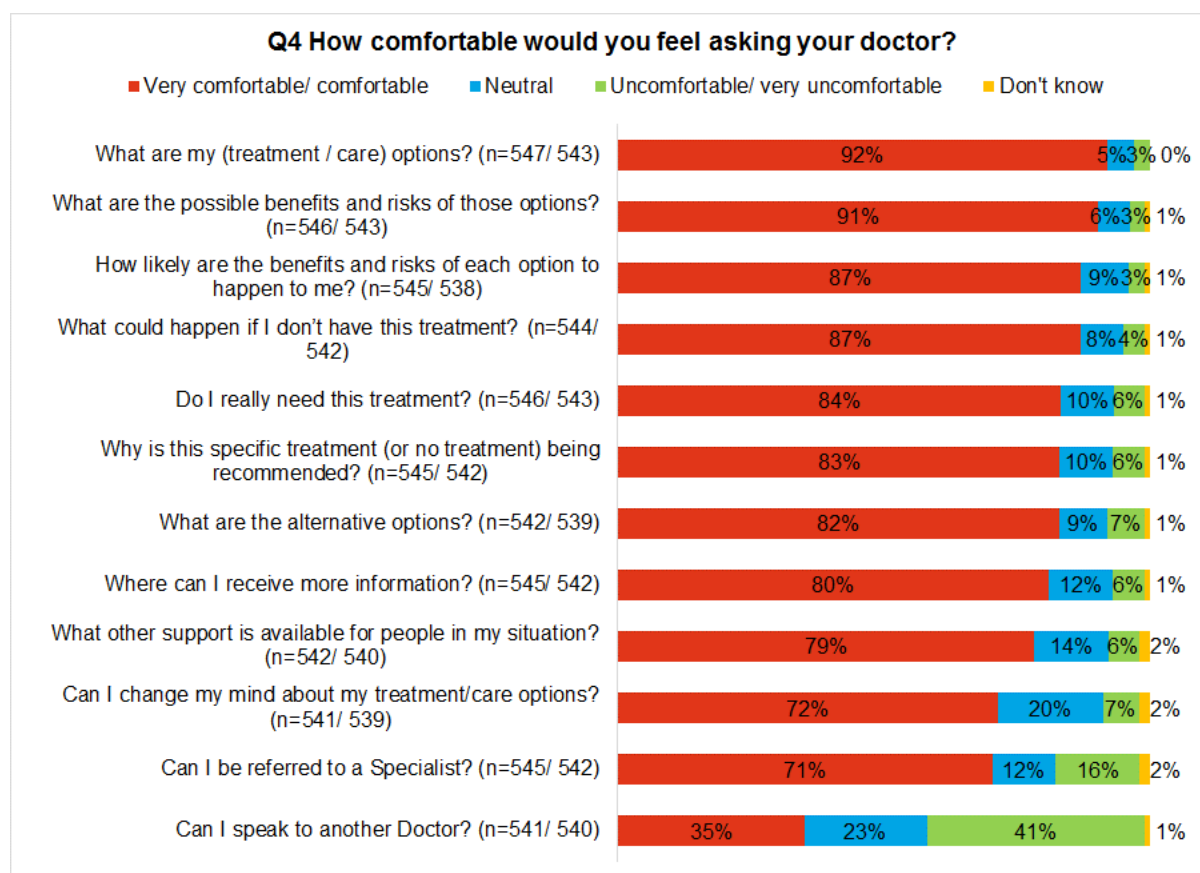
It is interesting to note that more respondents would feel comfortable asking to be referred to a specialist (71%) than asking to speak to another doctor (35%).

Figure 4: How comfortable people feel asking their doctor about their treatment and care options

Q4 How comfortable would you feel asking your doctor?

- Very comfortable/ comfortable
- Neutral
- Uncomfortable/ very uncomfortable
- Don't know

Question	Very comfortable/ comfortable	Neutral	Uncomfortable/ very uncomfortable	Don't know
What are my (treatment / care) options? (n=547/ 543)	92%	5%	3%	0%
What are the possible benefits and risks of those options? (n=546/ 543)	91%	6%	3%	1%
How likely are the benefits and risks of each option to happen to me? (n=545/ 538)	87%	9%	3%	1%
What could happen if I don't have this treatment? (n=544/ 542)	87%	8%	4%	1%
Do I really need this treatment? (n=546/ 543)	84%	10%	6%	1%
Why is this specific treatment (or no treatment) being recommended? (n=545/ 542)	83%	10%	6%	1%
What are the alternative options? (n=542/ 539)	82%	9%	7%	1%
Where can I receive more information? (n=545/ 542)	80%	12%	6%	1%
What other support is available for people in my situation? (n=542/ 540)	79%	14%	6%	2%
Can I change my mind about my treatment/care options? (n=541/ 539)	72%	20%	7%	2%
Can I be referred to a Specialist? (n=545/ 542)	71%	12%	16%	2%
Can I speak to another Doctor? (n=541/ 540)	35%	23%	41%	1%

NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

While 92% would feel comfortable asking their doctor about their treatment/care options, only 67% said they have actually asked their doctor this.

Over 9 in 10 respondents (91%) feel comfortable asking about the possible benefits and risks of those options, with only 64% stating they have asked their doctor this.

Similarly, 87% feel comfortable asking about the benefits and risks of each option to happen to them compared to 54% of respondents who have asked their doctor this.

These questions are the kinds of questions that the Chief Medical Officer is encouraging people to ask during any healthcare consultation.

Panel members were asked for any additional comments they had on their responses to these questions. A total of 117 Panel members provided additional comments. Some examples where Panel members feel comfortable asking their doctor questions are listed below. This includes where Panel members felt they had a good relationship with their doctor, had known them for many years and were able to have open conversations with them:

You must be comfortable with your doctor. I feel she is almost a friend.

We have a truly wonderful doctor's surgery, you could ask and feel confident in any one of them.

I have had excellent GPs all my life but have not needed them for 11 years.

I have recently undergone treatment for cancer and found the above very useful in decisions made.

My doctor is exceptionally good and always there. I feel I could talk to my doctor about anything.

I am very comfortable to ask any questions however I expect the doctor or consultant to know better than me. I would like to be advised. Very often now they say "what would you like me to do for you?"

As long as they are frank and listen well then it is usually ok.

The GPs etc I have seen so far have been open and communicative. Consultants sometimes need to be asked.

Very comfortable as I believe I am in charge of my health.

I have full confidence that my doctor gives me the best advice and refers me to a specialist if appropriate.

I can easily ask questions of my GP and he does listen.

Years of working in the NHS gives me the confidence to question.

Where Panel members felt uncomfortable asking questions about their health, care and treatment decisions this tended to be where Panel members had experienced barriers such as having limited time with their doctor, issues surrounding mental health issues, perceiving doctors to be unapproachable and where respondents would feel they were offending their doctor by asking questions or asking to see another doctor for a second opinion.

> It's uncomfortable as it's personal and I get depressed very easily and don't ask these questions.

> My present GP just wants to get you out as quickly as possible. Personally need longer. Sometimes you feel your problem like mental health, is insignificant to the doctor as he is under pressure to move to next patient.

> Asking some of the above questions would be very uncomfortable for me, because they could suggest that I do not trust my GPs opinion and I would very probably not ask them for fear that my GP would be offended.

> I am quite a confident person but I have many friends whom I know wouldn't be comfortable asking these questions because doctors make them feel inadequate.

> I don't think doctors are approachable, I feel that they are in charge and everything is so serious.

> It was difficult to get an appointment with a doctor and they have tunnel vision on the one problem. Say they don't have time to discuss other issues, and to make another appointment.

> I feel if you ask too many questions from GP, they get irritated and become unresponsive.

> I would feel uncomfortable with some of these questions because I would be worried the doctor would see it as a professional slight. This may influence his future responses and decisions about my care.

> I live in a small rural community where people know each other. I respect my GP but would feel very uncomfortable if I had to challenge his ability to have the last word – partially because it would feel like disrespect and partially because I would be wary of being seen a nuisance or time waster. In this place we can't easily change our doctor, if you don't get on with them you might have to suffer the consequences.

> I feel more uncomfortable about asking questions which question the doctor's decision or recommendation. If the options are introduced by the doctor, I feel much more comfortable asking about them.

Several Panel members commented that how comfortable they feel varies depending on the particular doctor that they see:

It would depend on the doctor I was dealing with. There are multiple GPs at my local practice and I feel more comfortable with some over others.

It all depends on your GP and if you can see the same one on a regular basis. Which is not always easy.

I can't answer this due to having lots of locum doctors. My surgery no longer has a full time doctor. Some locums are wonderful and others are awful. It completely depends on what locum has come in.

When I can get an appointment with one of the two doctors at my surgery that I am very familiar with. I would have ticked very comfortable for every question, however it is very difficult to get an appointment with a specific doctor and when seeing doctors I am unfamiliar with it makes me very uncomfortable asking many questions.

If I get the doctor I want to see I would be comfortable.

I think the degree of "comfort" around this is helped or depends on the approachability of the GP. I'm an articulate adult but if GP was resistant to my needs/views this could be very difficult.

Depends on what doctor as some better than others.

The willingness to ask some of these questions depends on the behaviour/style of the doctor and how busy they are/or are perceived to be.

Other Panel members commented that while they would feel comfortable asking their doctor questions about their health, care and treatment there were other barriers that prevented them from asking questions such as time constraints, or not knowing what questions to ask:

Not all GPs welcome questions when all you get is 10 minutes.

I would feel comfortable asking most of these questions if they occur to me. The main challenge is how to encourage myself to think of these questions in the first place. How will patients know what they need to ask and what they can ask? If information is always framed in a certain way it will never occur to me that I could ask these questions.

Although I would be very comfortable asking most of the above, the time available and nature of the doctor could inhibit this. If I felt rushed, as if GP was under time pressure I might not feel as comfortable asking all the right questions. Some more difficult questions I feel should almost be put forward or given as options by the doctor rather than relying purely on patients to ask.

I would feel largely comfortable asking these questions. Appointment times are so short that I would be unlikely to be able to ask all of them in one consultation or have my questions answered as thoroughly as possible.

For someone like me I would need to have the above options written down as it's easy to get flustered when visiting a doctor.

Other questions people would like to ask their doctor

Only 13% of survey respondents said there were other questions they would like to ask their doctor to help them make decisions about their healthcare and treatment.

Figure 5: Requirement to ask doctors other questions to help them make decisions about their healthcare and treatment
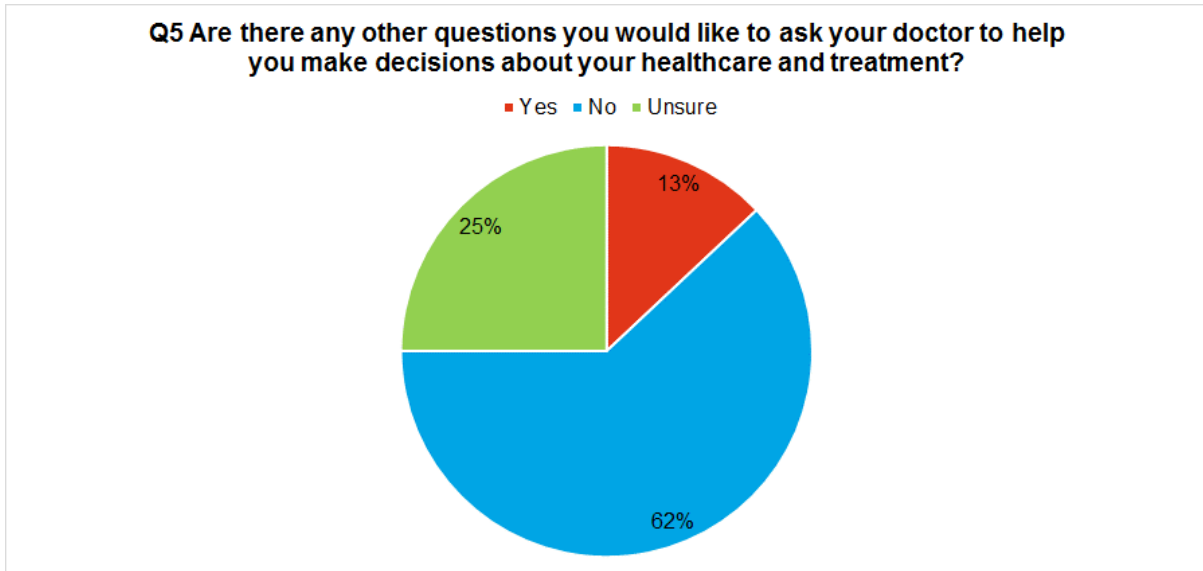
Base: Unweighted, n=527; Weighted, n=533

A total of 81 respondents provided examples of other questions they would like to ask their doctor to help them make decisions about their healthcare and treatment. The comments provided were of a varied and personal nature. However, the main themes emerging from these comments were as follows:

Figure 6: Other questions people would like to ask their doctor to help them make decisions about their healthcare and treatment (open-ended response themes)

Q5 Are there any other questions you would like to ask your doctor to help you make decisions about your healthcare and treatment? If yes, please state other questions.	
Base: Unweighted, n=81; Weighted, n=68	%
Are there any other treatments available overseas/ privately/ alternative treatments?	32%
Follow up care/ action/ what happens next	21%
What would you (the doctor) do in my situation?	17%
What is my chance of full recovery/ life expectancy?	12%
What will be the impact on my quality of life/ cost implications?	11%
What are the side effects from medication?	9%
Can I discuss options again once digested information/ can I refuse treatment?	5%
Anything that worries me	3%
Other	7%

Listed below are some examples of other questions Panel members would like to ask their doctor to help them make decisions about their healthcare and treatment:

If available, are there other alternatives such as homeopathic alternative medicine?

Can you direct me to sites which would give me more information to help me make an informed decision?

Side effects of mediation and what length of time it should be taken for everyone, repeat prescriptions too easy to obtain.

In event of a treatment not working I would ask what the next step is.

What happens if I change my mind half way through the treatment course?

For my children and me I often ask the doctor "what would you recommend if this were your child (or mother etc)"?

Are there any questions you would like to ask your doctor to help you make decisions about your healthcare and treatment?

What are the implications for my life expectancy and long-term health outlook given my condition?

Why are some conditions treated by postcode lottery and others not?

Are there further treatments available privately?

If there are cost implications to what has been suggested.

Anything that was worrying me.

What is the waiting time for hospital appointment?

Always want to know if there are further developments regarding my main problem in the medical field.

What alternative health options are available and for doctor to have same knowledge about different therapies. Also for the doctor to be open to this type of discussion and not just want to discuss the pharmaceutical options.

Chapter 4: Talking to a doctor

Introduction

The next section of the questionnaire was designed to understand what is important to Panel members when talking to their doctor.

Things like family, work or social responsibilities, money issues, medical technologies, and other issues can change over a lifetime, and this can influence care and treatment choices. Some studies[8] have found evidence of improved outcomes when people are involved in decisions and their preferences taken into account.

The survey asked Panel members about the things they think should factor into healthcare provision that would make their conversations with doctors about care and treatment easier, more meaningful and empowering.

Personal aspects that are important to discuss when talking about healthcare preferences

Respondents were asked to describe any personal aspects of their life that they feel it is important to discuss when talking about their healthcare preferences with a doctor. A total of 460 respondents chose to answer this question. Respondents could note up to three personal aspects they felt it was important to discuss. The open responses to this question have been coded into common themes and listed in the table below. Themes are created from the most commonly noted terms therefore some themes may be cross-cutting but are coded separately due to the volume of specific mentions of that theme. Please note that respondents could note more than one common theme therefore the percentages noted below sum to more than 100%. The top three factors perceived as being most important for Panel members when talking about their healthcare preferences with a doctor were family circumstances (33%), lifestyle and quality of life (30%) and general health (29%).

Figure 7: Personal aspects that are important to discuss when talking about healthcare preferences (open-ended response themes)

Q6 When you talk about your healthcare preferences with a doctor: What personal aspects of your life is it important to discuss? (Please limit your answer to no more than 3 items/ aspects).	
Base: Unweighted, n=460; Weighted, n=466	%
Family circumstances	33%
Lifestyle/ quality of life	30%
General health	29%
Work commitments/ impact on employment	20%
Diet	12%
Previous medical history/ medication	12%
Exercise	11%
Mental health issues	11%
Timescales/ outcomes	8%
Treatments - where/ when available	8%

[8] For example:
Health Foundation 2014. Person-centred care made simple. October 2014. ISBN 978-1-906461-56-0
http://www.health.org.uk/sites/health/files/PersonCentredCareMadeSimple.pdf

Caring responsibilities	7%
Money matters	5%
Relationships	5%
Age	4%
Support network/ social isolation	4%
Side/ long term effects	4%
All/ every aspect is important to discuss	3%
Other	5%
Don't know	1%

Below are some comments provided by Panel members which highlight some of the personal aspects of their life that they think it is important to discuss when talking about their healthcare preferences with a doctor:

If it involves issues of mental health, I don't think there should be anything held back.

Commitments to caring for relatives or others need to be openly discussed if treatments affect those responsibilities.

I suppose monetary status can impact your health and your ability to look after yourself properly. As it can impact the quality of food and 'over the counter' treatments you can afford to access.

The impacts of treatment options (including not treating) on my ability to work and earn a living.

Family relationships are important – how partner will be affected etc. Feel data protection does not always allow frank discussions.

Any effects that impact on my wife/family.

Q6 When you talk about your healthcare preferences with a doctor: What personal aspects of your life is it important to discuss?

Diet. How much alcohol, cigarettes, and drugs do you consume? Salt/ sugar intake. Do you eat mainly processed or fresh foods?

Family considerations and demands, e.g. children's needs and demands on my time and ability to do things.

Any lifestyle factors to be improved on – behavioural/ modifiable.

I suppose beliefs whether religious or otherwise can influence treatment you would be comfortable using, and can possibly affect your health. For example, as a vegetarian if I were to become anaemic I would not appreciate a doctor trying to tell me I should eat red meat to boost my Iron. Would prefer to be advised about for example eating more spinach, iron supplements etc. I am sure there are many other areas where personal beliefs impact on treatment options.

How are you coping with your prognosis? Is there anyone supporting you.

Long term treatment and timescale of illness.

Is there an alternative to taking this amount of medication? As I work full time and have a young child so it is not practical to take high doses of medicine early at night. Being given options and expected outcomes would help.

Knowing my medical history, what do you recommend?

Information that will help people make decisions about their care and treatment

A total of 470 respondents provided details of the kind of information they would find helpful when making decisions about their care and treatment. This question was an open-ended question with the responses being coded into common themes for analysis purposes. Just under half of respondents (48%) said that understanding the side effects or risks of their medication or treatment would be beneficial and 46% said being properly informed to make decisions, being given a clear diagnosis or an honest opinion from their doctor would help them to make decisions.

Figure 8: Information that will help people make decisions about their care and treatment (open-ended response themes)

Q7 When you talk with a Doctor: What information will help you make decisions about care and treatment?	
Base: Unweighted, n=470; Weighted, n=471	%
Side effects/ risks	48%
Being properly informed to make decisions/ clear diagnosis/ facts/ honesty of doctor	46%
Likelihood of success/ effectiveness/ outcomes	43%
Options/ alternatives	32%
Length of treatment	19%
Impact on personal life e.g. work, family	10%
Treatment - where/ when/ availability	6%
Other	4%
Cost	3%
After care	2%
Don't know	2%

The verbatim responses from a selection of Panel members on the information they believe would help them to make decisions about their care and treatment is shown below.

As much information about advantages and disadvantages of care or treatment as possible.

A full understanding of the treatment and what's needed from me.

Expected recovery time, or their best assessment of the degree of improvement I should expect.

Length of treatment and impact on my general health and activities.

Clear explanation of any possible side effects and what to do if side effects occur. Related to that is the alternative to the prescribed medication if side effects do occur. Often you are given the impression that the recommended or prescribed medication is the only one available to you so you put up with harmful side effects.

Effect on quality of life of any treatment.

Access to healthcare services locally. If you have to travel further and it is an ongoing treatment you are needing this may make it difficult to complete all of the treatment.

Q7 When you talk with a doctor: What information will help you make decisions about care and treatment?

What's the probability of a successful outcome?

I expect to be told the truth.

Availability on NHS or costs incurred in a treatment not available on NHS. I do however think that non-NHS funded treatments should also be discussed with you along with their pros and cons, availability and where possible costs involved. I don't think it is right to just assume that if it isn't covered on the NHS you simply won't be interested in a treatment.

A breakdown of all 'available' and 'not easily available' options for consideration.

Home care after hospital treatment.

Being provided leaflets is always helpful to me and being given time to think over treatment options.

Having time to digest the information and being offered a trial with the medication/treatment with a follow-up appointment.

Do I need all these medications?

Anything that stops/limits people being involved in decisions about their healthcare and treatment

Only 15% of survey respondents were of the opinion that there are things that stop (or limit) them from being involved in decisions about their healthcare and treatment. The vast majority (74%) said this was not the case, 9% were unsure and 3% said this was not applicable.

Figure 9: Anything that stops or limits people being involved in decisions about their healthcare and treatment
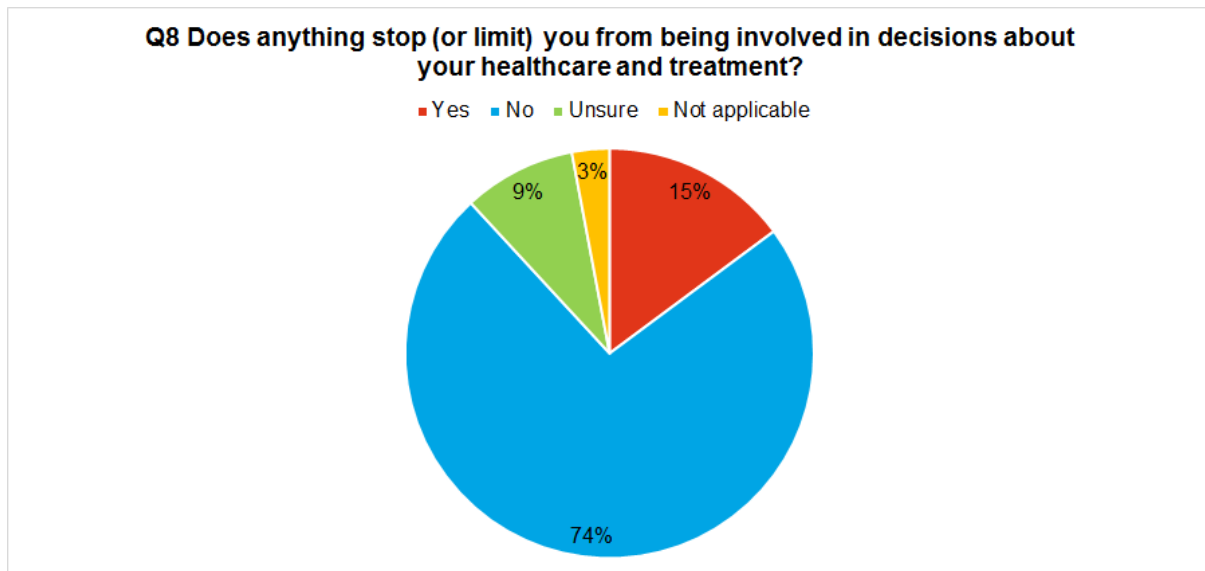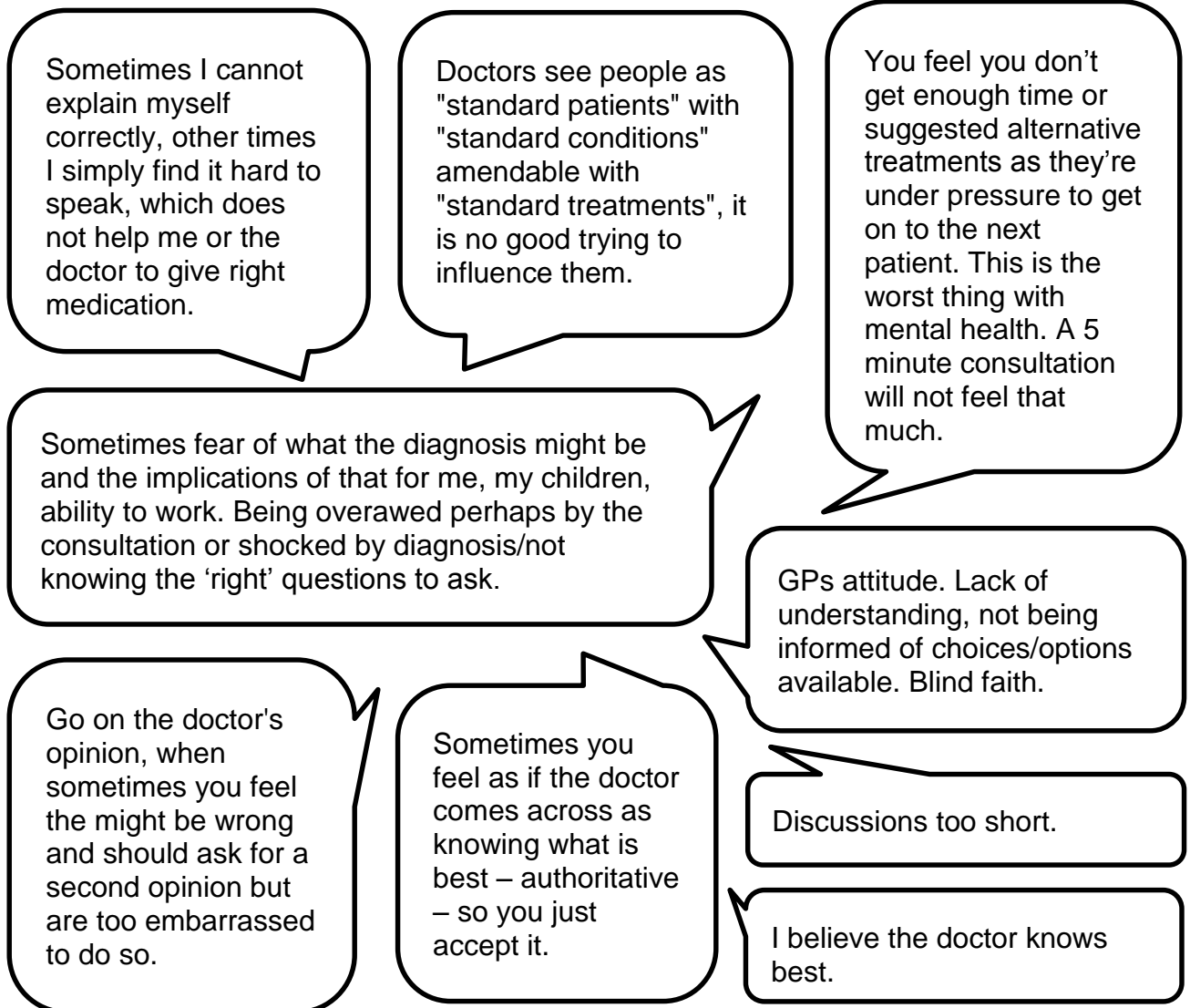

Base: Unweighted, n=517; Weighted, n=518

A total of 75 respondents (out of 79 who answered yes to the question above), provided details of things that stop (or limit) them from being involved in decisions about their healthcare and treatment. The main themes emerging from these comments were:

- not having sufficient time with doctor
- having insufficient knowledge of treatment options to question anything
- doctor knows best/don't like to question them
- doctor doesn't listen to me/not approachable
- lack of confidence in asking questions, and
- mental health issues (e.g. depression, anxiety etc).

Some examples of the comments made by Panel members to describe the types of things that stop or prevent them being involved in decisions about their healthcare and treatment are shown below:

Sometimes I cannot explain myself correctly, other times I simply find it hard to speak, which does not help me or the doctor to give right medication.

Doctors see people as "standard patients" with "standard conditions" amendable with "standard treatments", it is no good trying to influence them.

You feel you don't get enough time or suggested alternative treatments as they're under pressure to get on to the next patient. This is the worst thing with mental health. A 5 minute consultation will not feel that much.

Sometimes fear of what the diagnosis might be and the implications of that for me, my children, ability to work. Being overawed perhaps by the consultation or shocked by diagnosis/not knowing the 'right' questions to ask.

GPs attitude. Lack of understanding, not being informed of choices/options available. Blind faith.

Go on the doctor's opinion, when sometimes you feel the might be wrong and should ask for a second opinion but are too embarrassed to do so.

Sometimes you feel as if the doctor comes across as knowing what is best – authoritative – so you just accept it.

Discussions too short.

I believe the doctor knows best.

Chapter 5: Talking to other Health and Care professionals

Introduction

The Scottish Government has a vision that by 2020, everyone in Scotland will be able to live longer healthier lives at home or in a homely setting.

To help achieve this ambition, health and social care services are working together to provide integrated 'joined-up' care. This approach requires social care support staff and a wider range of healthcare professionals (which can include nurses, physiotherapists, pharmacists etc) to take on new roles. These new roles can help support patients and GPs where it is appropriate for them to do so. For example, a GP practice nurse may support people with minor conditions, or a local pharmacist may offer review of medications. Sometimes people may need social support in addition to – or even instead of – medical input to better meet their healthcare needs.

The aim of this section was to understand how comfortable Panel members would feel talking to these other health and care professionals about their healthcare needs.

How comfortable people feel asking other service professionals about their treatment and care options

In terms of other service professionals it was clear that people felt most comfortable asking a nurse (e.g. community nurse, midwife, GP practice nurse etc) about their treatment or care options with 91% stating they felt very comfortable or comfortable doing this. As reported earlier at figure 4, this response is similar to that of comfort asking doctors about treatment options (92%). On the other hand, respondents felt less comfortable asking social care professionals (66%) and other service professionals such as counsellors or support staff (65%) about their treatment or care options.

Figure 10: How comfortable people feel asking other service professionals about their treatment and care options

Q9 How comfortable would you feel asking other service professionals: What are my (treatment/ care) options.
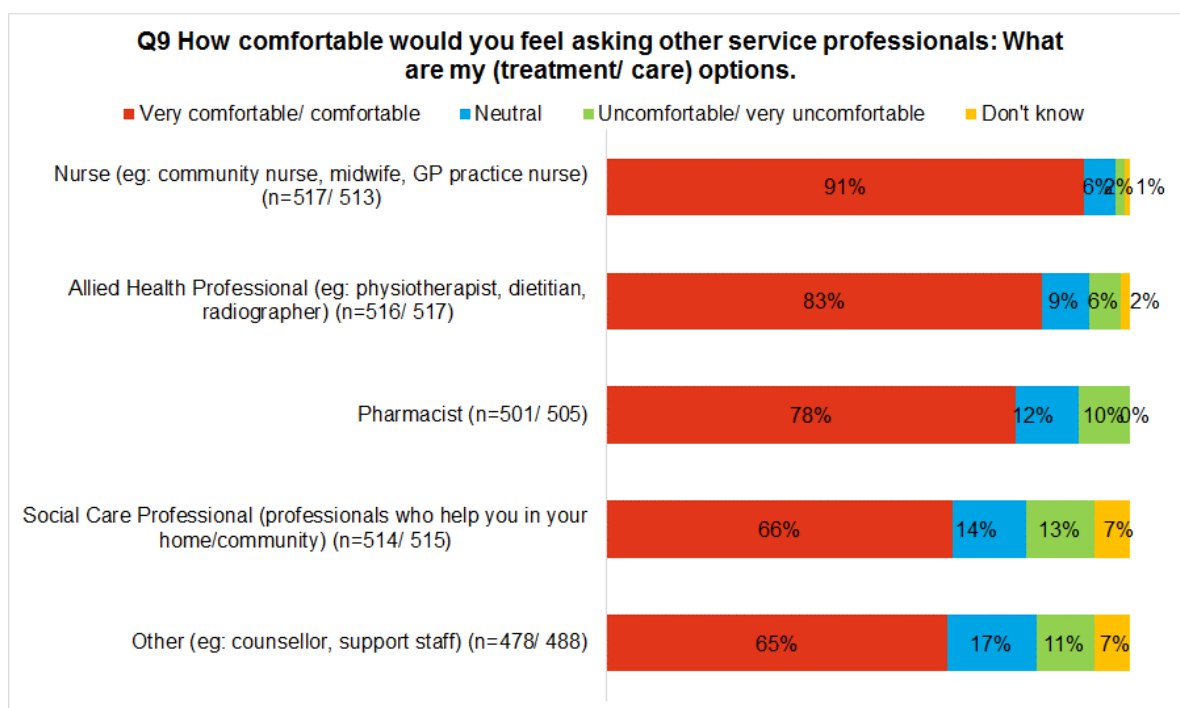
NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

Following on from this, respondents were asked for their reasons for their answers. The open-ended responses were coded into broad themes. The responses to this question were very varied, both positive and negative as we did not ask Panel members to differentiate this, and generally referred to individual circumstances. Broad codes were used to analyse some of the themes emerging from the additional comments and these are listed in the table below. Over half of respondents (52%) commented that these other service professionals were fully experienced and trained and should be able to answer their questions and a further 23% provided comments based on their personal experience or said they had did not have experience of all professions.

Figure 11: How comfortable people feel asking other service professionals what are my treatment/ care options: Reasons for answer given. (open-ended response themes)_

Q9 How comfortable would you feel asking other service professionals "what are my treatment/ care options"? Please provide reasons for your answers:	
Base: Unweighted, n=340; Weighted, n=321	%
They are the professionals/ fully experienced/ trained and should be able to answer questions	52%
Opinions based on personal experience/ have not had experience of all professions	23%
Feel certain professions not as knowledgeable as others	10%
Depends on their level knowledge/ experience	9%
Would depend on my issue	6%
Issues re confidentiality/ privacy issues	5%
Asking 'other' service professionals may help reduce doctors' workload	1%
Other	3%

Some examples of the comments made by respondents in response to how comfortable they would feel asking other service professionals "what are my treatment/ care options?" are listed below:

I trust that they'll be able to provide relevant advice depending on what's wrong. A **pharmacist** is often my first port of call before bothering the doctor.

Practice nurses are very good but normally give treatment better than diagnosis. **Radiographers** are not allowed to tell you anything, other health professionals should stay with their own practices.

I like to understand the expertise of the person I am dealing with. If I am unsure of a qualification or skill I would not be comfortable.

Depends on the situation e.g. whether these are replacing **doctors** to diagnose or decide on treatment or whether supporting what doctors have already diagnosed. Would also depend on the specific medical care required e.g. **midwife** would be a very good person to discuss care for a forthcoming birth.

Would worry **support staff** were not held to the same code of ethics.

These other **care professionals** tend to be more willing to listen and be more supportive to your decision.

I think this question entirely depends on the person treating me. I know my **doctor**, so I know how I feel about asking him questions. I can't make this assessment confidently about a range of strangers.

Practice nurses are part of the normal routine so easy to communicate with. No experience with other professionals - so no knowledge of how I might interact.

Privacy would be a main concern. The **Pharmacy** would be ok if it was confidential.

They are professionals and are sometimes easier to contact than a **doctor**.

How comfortable people feel asking other service professionals about the benefits and risks of their treatment and care options

A similar question was asked about how comfortable people felt asking other service professionals about the benefits and risks of their treatment and care options. Again, respondents felt most comfortable asking a nurse for this type of advice (90%). This figure is similar to the 91% of respondents who felt comfortable asking their doctor about the benefits and risks of their treatment (see question 4). Respondents were least comfortable asking for this advice from a social care professional (66%) or other service professional such as a counsellor or support staff (66%).

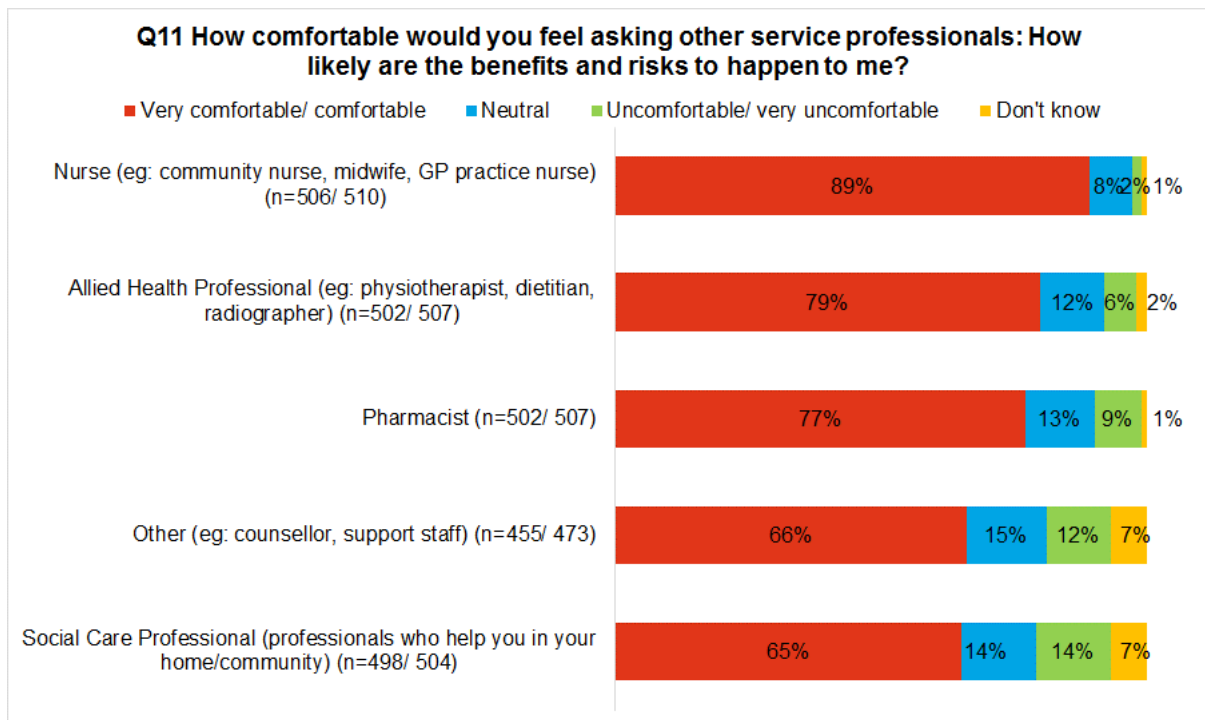**Figure 12: How comfortable people feel asking other service professionals about the benefits and risks of their treatment and care options[9]**
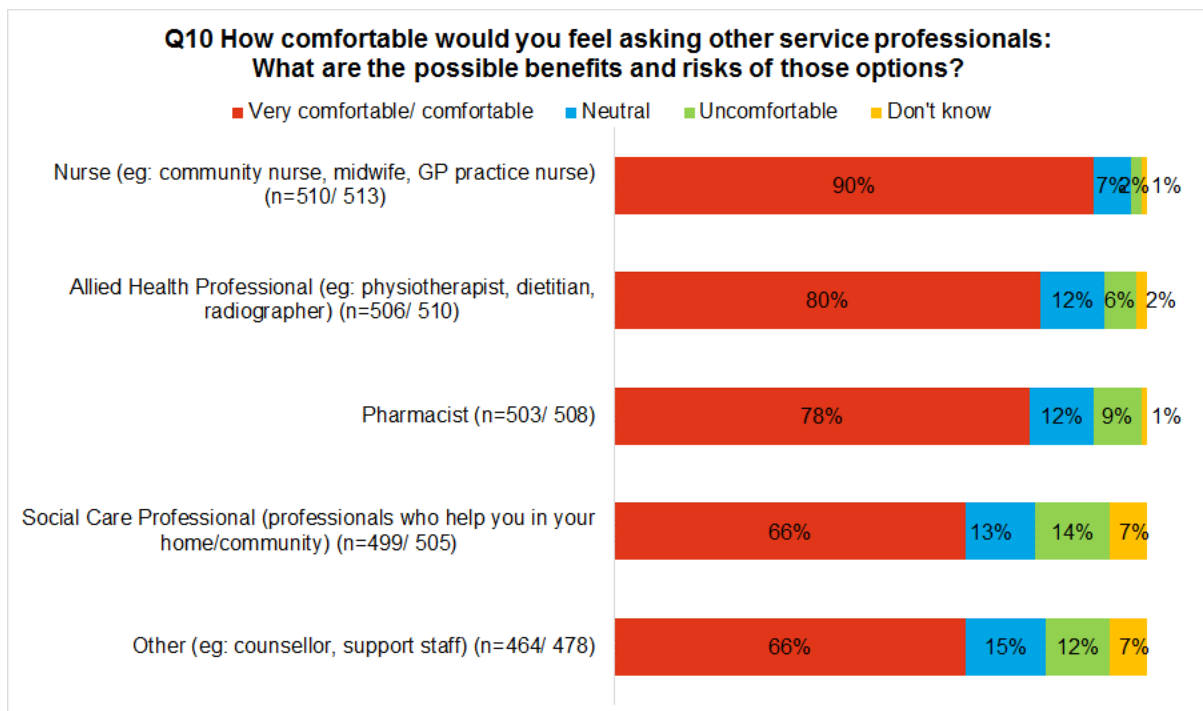
NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

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[9] Information collected when recruiting Panel members indicates that Panel members are less likely to have experience of using social care professionals than using pharmacists or GPs.

Again, respondents were asked for any further comments they had on their responses to how comfortable they would feel asking other service professionals "what are the possible benefits and risks of those options?". The responses given were similar to those reported at the previous question with over half of respondents (55%) commenting that other service professionals have the experience and training to be able to answer these questions and 15% providing comments based on their personal experience or said they have not had contact with all of these professionals.

Figure 13: How comfortable people feel asking other service professionals what are the possible benefits and risks of their treatment and care options: Reasons for answer given. (open-ended response themes)

Q10 How comfortable would you feel asking other service professionals "what are the possible benefits and risks of those options"? Please provide reasons for your answers:	
Base: Unweighted, n=302; Weighted, n=293	%
They are the professionals/ fully experienced/ trained and should be able to answer questions	55%
Opinions based on personal experience/ have not had experience of all professions	15%
Would depend on my issue	12%
Depends on their level knowledge/ experience	12%
Feel certain professions not as knowledgeable as others	10%
Asking 'other' service professionals may help reduce doctors' workload	1%
Other	2%

How comfortable people feel asking other service professionals about how likely the benefits and risks of each option are

Just under 9 in 10 respondents (89%) said they would feel very comfortable or comfortable asking a nurse about how likely the benefits and risks of each option were. Similar to the previous questions, respondents were less comfortable asking other service professionals such as counsellors or support staff (66%) and social care professionals (65%) about the likelihood of the benefits and risks happening to them.

Figure 14: How comfortable people feel asking other service professionals about how likely the benefits and risks of each option are

NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

Following on from this, respondents were asked for any further comments they had on their responses to how comfortable they would feel asking other service professionals "how likely are the benefits and risks of each option?". The responses given were similar to those reported at previous questions with over half of respondents (54%) commenting that other service professionals have the experience and training to be able to answer these questions. A further 16% said how comfortable they would feel would depend on their issue and 15% said their opinions were based on their personal experience or that they had not had experience of all professions.

Figure 15: How comfortable people feel asking other service professionals how likely are the benefits and risks of each option: Reasons for answer given. (open-ended response themes)

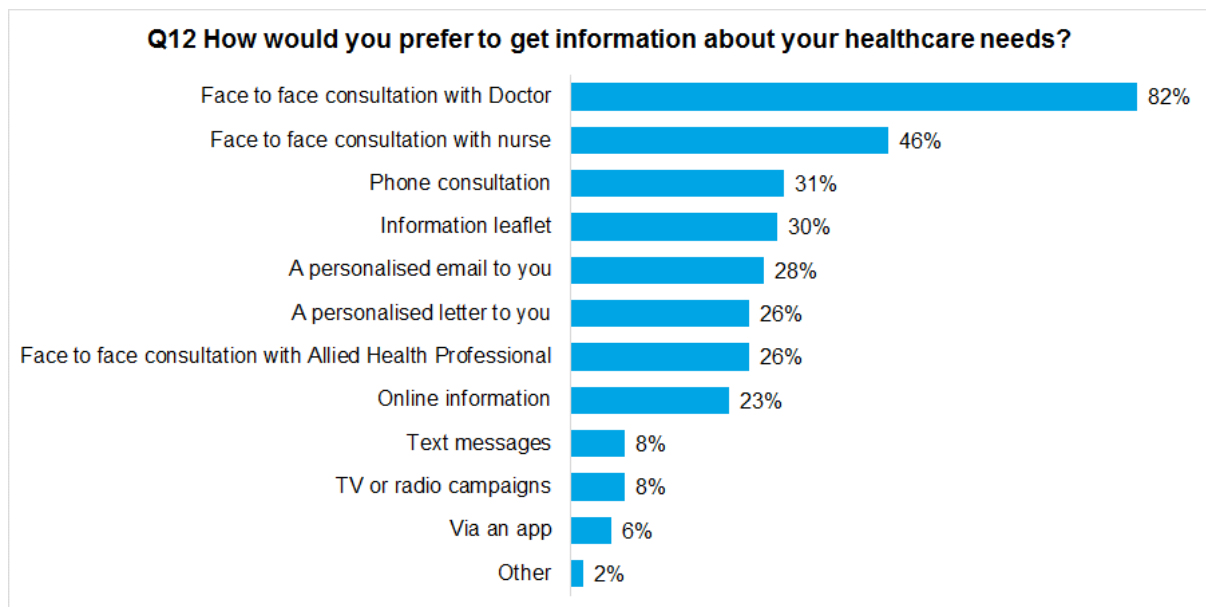| Q11 How comfortable would you feel asking other service professionals "how likely are the benefits and risks of each option"? Please provide reasons for your answers:	
Base: Unweighted, n=267; Weighted, n=259	%
They are the professionals/ fully experienced/ trained and should be able to answer questions	54%
Would depend on my issue	16%
Opinions based on personal experience/ have not had experience of all professions	15%
Depends on their level knowledge/ experience	10%
Feel certain professions not as knowledgeable as others	6%
Asking 'other' service professionals may help reduce doctors' workload	1%
Other	2%

Chapter 6: Information delivery

Introduction

In our last survey, Panel members were asked questions around their preferences for receiving information about social care support and medicines that they may be prescribed. As a follow up to this, Panel members were asked about the forms of information they prefer to receive, to help them make decisions about their healthcare.

Preferences for obtaining information about healthcare needs

Panel members were asked to rank their top three preferred methods for obtaining information about healthcare needs from a list of 11 options. Face-to-face consultations were by far and away the most preferred way of obtaining information about healthcare needs with 82% of respondents stating they would prefer a face-to-face consultation with a doctor and a further 46% preferring a face-to-face consultation with a nurse. Over three in 10 respondents preferred a phone consultation (31%) and 30% preferred information to be provided in leaflet form.

Figure 16: Preferences for obtaining information about healthcare needs (multiple response)

Q12 How would you prefer to get information about your healthcare needs?

Face to face consultation with Doctor	82%
Face to face consultation with nurse	46%
Phone consultation	31%
Information leaflet	30%
A personalised email to you	28%
A personalised letter to you	26%
Face to face consultation with Allied Health Professional	26%
Online information	23%
Text messages	8%
TV or radio campaigns	8%
Via an app	6%
Other	2%

Base: Unweighted, n=511; Weighted, n=517

Chapter 7: Social isolation and loneliness

Introduction

Lots of people feel lonely at some point in their life. Whilst studies have been conducted to find out how loneliness affects certain groups like elderly people, minority ethnic communities, and young people, we do not know how this issue impacts the general wider population. The aim of this section of the questionnaire was to find out how common feelings of loneliness are amongst the general public in Scotland and to seek views about ways to address loneliness.

What does 'loneliness' mean to you?

The questionnaire included an open-ended response which asked respondents what 'loneliness' means personally to them. A total of 497 respondents answered this question. The majority of these comments were where Panel members said that loneliness to them meant having no family or friends to talk to (61%) and a further 19% stated it was a lack of social interaction.

Figure 17: What does 'loneliness' mean to you? (open-ended response themes)

Q13 What does 'loneliness' mean to you?	
Base: Unweighted, n=491; Weighted, n=495	%
Having no one to talk to/ no friends/ family/ relationship	61%
Lack of social interaction	19%
Depression/ unhappy/ sadness	17%
Feeling of isolation	15%
Being alone	11%
Prolonged periods of being alone	4%
Other	1%
Don't know	2%
Nothing/ not experienced	2%

How people have been feeling over the last month

All respondents were asked how often they have been feeling certain ways over the last month. These questions are from The UCLA 3-Item Loneliness Scale[10]. This scale is often provided in self-completion surveys and is an individualistic scale that allows us to measure the extent to which an individual feels lonely.

The chart below shows the percentage responses achieved for each of the three questions. Firstly, in terms of feeling left out, 30% said they had never felt this way compared to 13% who felt this way often. With regards to lacking companionship, 37% had never felt this way in the last month compared to just 8% who felt this way often. Finally, in terms of feeling isolated from others, 38% of respondents had never felt this way in the last month compared to 11% who had felt like this often.

Figure 18: How people have been feeling over the last month (The UCLA 3-Item Loneliness Scale)
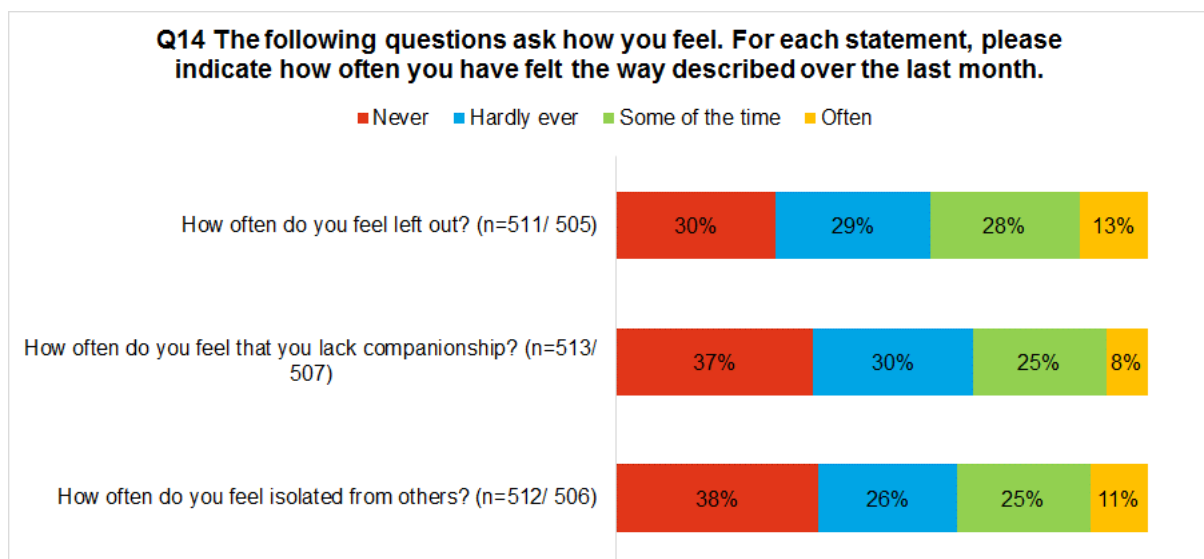
NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

The UCLA Loneliness Scale typically uses three response categories "hardly ever"/ "some of the time" and "often". The Our Voice Citizens' Panel Survey also included a "never" option. For analysis purposes, those who answered "never" have been combined with those who answered "hardly ever". Only respondents who have answered all three questions are included in this analysis. To interpret the results, each respondent's answers have been coded as follows:

Response	Score
Never/hardly ever	1
Some of the time	2
Often	3

The scores for each individual question can be added together to give a possible range of scores from 3 to 9. Scores between 3 and 7 can be identified as people who are "not lonely" and people with a score of 8 to 9 are identified as "often lonely".

[10] https://www.campaigntoendloneliness.org/wp-content/uploads/Loneliness-Measurement-Guidance1.pdf

Using the scoring system mentioned earlier where scores of 3 to 7 are identified as "not lonely" and scores of 8 and 9 are "often lonely". For all respondents, 10% were identified as being often lonely and 90% not lonely.

The results to this question do not vary significantly by gender. However, younger respondents were more likely to be often lonely (14%) than respondents aged 45-64 (7%) or aged 65 and over (5%). Please note that while these findings are interesting, the results are not statistically robust and therefore should be treated with caution.

Figure 19: The UCLA 3-Item Loneliness Scale analysed by age and gender (loneliness category)
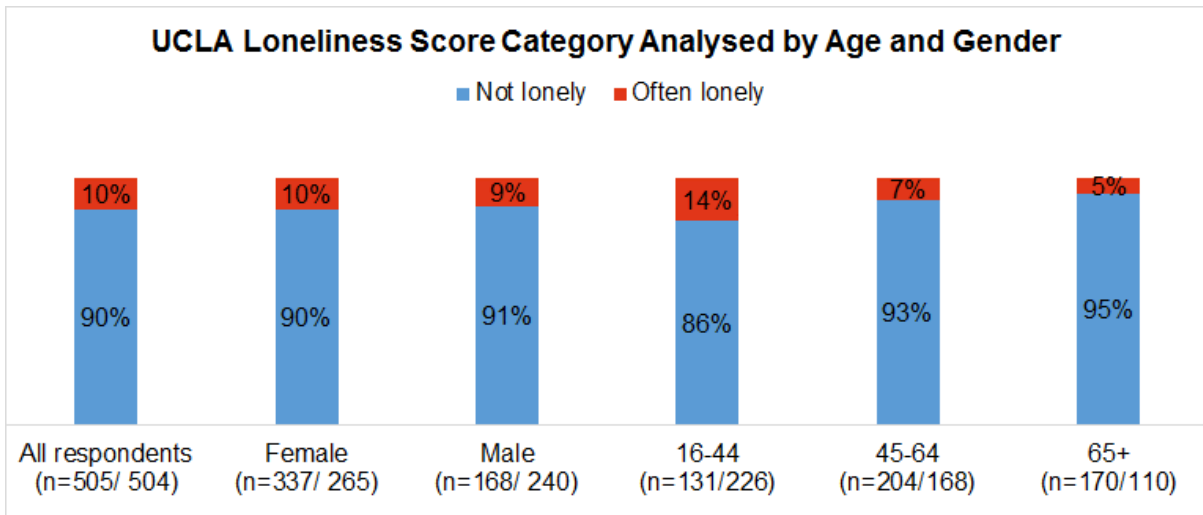
NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

Following on from this, respondents were asked to what extent they agreed or disagreed with three statements about their relationships. These questions were derived from the Campaign to End Loneliness Measurement Tool[11].

Firstly, in terms of the percentage responses, the vast majority were in agreement that:

- they have enough people they feel comfortable asking for help at any time (76% either agreeing or agreeing strongly with this statement)
- they are content with friendships and relationships (73%)
- their relationships are as satisfying as they would want them to be (66%).

Figure 20: Level of agreement with statements regarding how people have been feeling in the last month
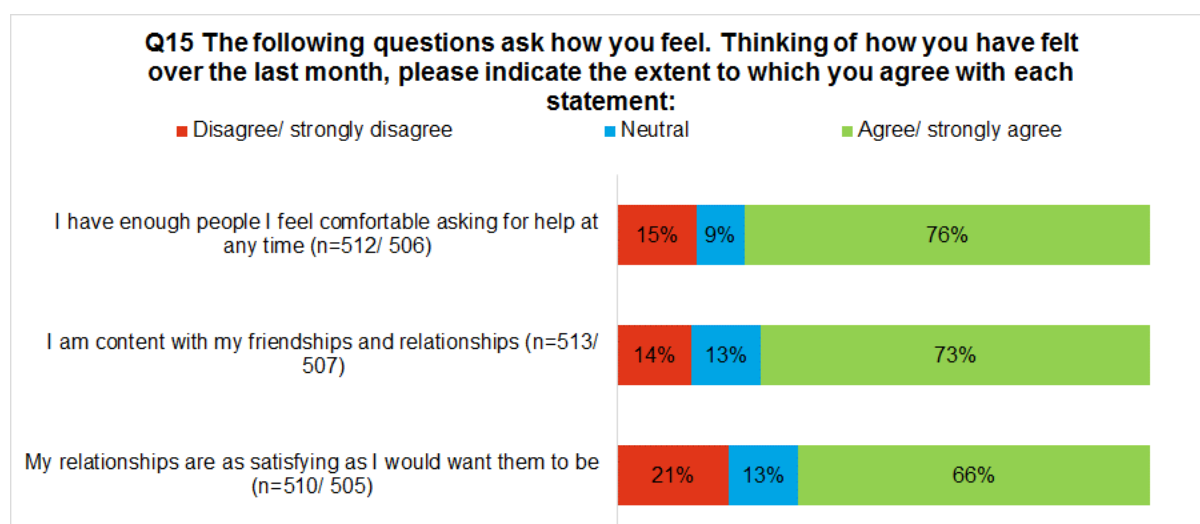
NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

The analysis guidance describes the scoring system to be used to interpret the responses to these questions as shown below:

Response	Score
Strongly disagree	4
Disagree	3
Neutral	2
Agree	1
Strongly agree	0

The scores for each individual question can be added together to give a possible range of scores from 0 to 12. So someone with a score of 0 to 3 can be said to be unlikely to be experiencing any sense of loneliness, whereas anyone with a score of 10 to 12 is likely to be experiencing the most intense degree of loneliness. Scores in-between these two extremes are on a spectrum of feelings of loneliness; however, it
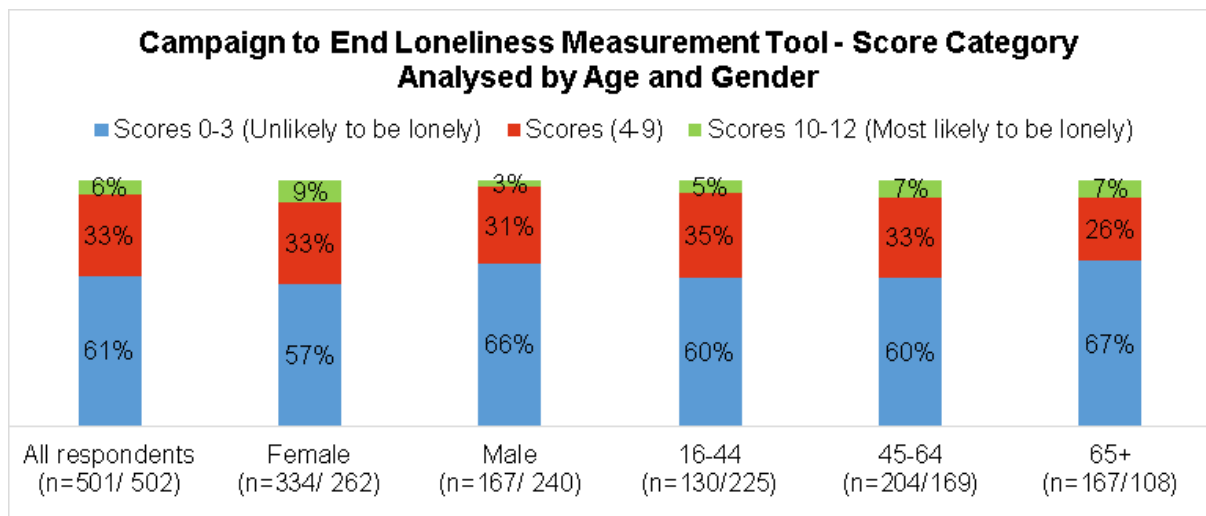
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[11] https://www.campaigntoendloneliness.org/wp-content/uploads/Loneliness-Measurement-Guidance1.pdf

is not possible to say that each point on the scale represents an equal increase or decrease in the degree of loneliness someone might be feeling.

Unlikely to
be lonely

Likely to
be lonely

**Least
lonely**

0 1 2 3 4 5 6 7 8 9 10 11 12

**Most
lonely**

Using the classifications mentioned earlier where scores 0-3 are those who were least likely to be lonely and scores of 10-12 were those most likely to be lonely, overall 61% of all respondents were categorised as being 'unlikely to be lonely' and 6% were 'most likely to be lonely'. Analysis by age and gender reveals that males (66%) and those aged 65 and over (67%) had the highest percentage of respondents in the category 'unlikely to be lonely'. Females had the highest proportion of respondents being 'most likely to be lonely' (9%). Again, please note that while gender and age-related findings are interesting, the results are not statistically robust and should be treated with caution.

Figure 21: Campaign to End Loneliness Measurement Tool analysed by age and gender (loneliness category)

Campaign to End Loneliness Measurement Tool - Score Category Analysed by Age and Gender

■ Scores 0-3 (Unlikely to be lonely) ■ Scores (4-9) ■ Scores 10-12 (Most likely to be lonely)

	All respondents (n=501/ 502)	Female (n=334/ 262)	Male (n=167/ 240)	16-44 (n=130/225)	45-64 (n=204/169)	65+ (n=167/108)
Scores 10-12	6%	9%	3%	5%	7%	7%
Scores 4-9	33%	33%	31%	35%	33%	26%
Scores 0-3	61%	57%	66%	60%	60%	67%

NB The first base figure provided in the chart above is the unweighted base, and this is followed by the weighted base.

The main cause of loneliness

An open-ended question was included in the questionnaire which asked respondents what they believed to be the main cause of loneliness. A total of 476 respondents provided a response to this question. Over 4 in 10 of these comments were where respondents commented that the main cause of loneliness was due to a lack of social interactions or where people did not have someone to talk to (41%). A further 18% felt anxiety, depression and mental health issues was the main cause of loneliness, 16% said it was due to family and friends moving away or due to isolation and people being alone (16%).

Figure 22: The main cause of loneliness (open-ended response themes)

Q16 Thinking of yourself or others that you know, what do you think could be the main cause of loneliness?	
Base: Unweighted, n=476; Weighted, n=478	%
Lack of social interactions/ not having someone to talk to	41%
Anxiety/ depression/ mental illness	18%
Family/ friends moved away/ moving away	16%
Isolation/ being alone	16%
Old age/ disability/ ill health	12%
Bereavement	10%
Lack of confidence	10%
Divorce/ separation	3%
Financial constraints	2%
Work commitments	2%
Lack of transport	1%
Other	2%
Don't know	1%

Lack of social interactions or not having someone to talk to was the top response across all age groups and gender. However, anxiety, depression and mental illness was cited by more males (22%) than females (14%). On the other hand, more females (19%) than males said that isolation or being alone was the main cause of loneliness.

Analysis by age reveals that younger respondents aged 16-44 were most likely to have said mental health issues was the main cause of loneliness (26%). Bereavement was cited most by older respondents aged 65 and over (17%). Family or friends moving away was mentioned by more respondents aged 45-54 (19%) or aged 65 and over (21%) than younger respondents aged 16-44 (11%). Old age, disability and ill health perhaps unsurprisingly was mentioned by more respondents in the older age category (18% of respondents aged 65 and over).

Please note that while this analysis by age and gender is interesting, the results are not statistically robust and should be treated with caution.

Below are some examples of the comments provided by Panel members on what they believe is the main cause of loneliness:

Loss of a long-term partner and the unwillingness to engage with new acquaintances or organisations.

For me, being away from family, being from an ethnic minority who migrated to UK some years ago. Lack of close friends who can be relied upon and asked for help without hesitation.

Everyone is different but for me I feel I can't always go to my friends or family because they'll think 'here we go again'. I don't want to burden others, I often feel embarrassed.

Isolation both physically and mentally. People who can't go out or travel due to illness or mobility problems. Not having friends to drop in for a cuppa and a chat.

Death of a spouse, partner or close friend can leave a gap that no one else can fill. All your plans for the future are torn up and thrown to the wind, and there's no one who can step in and accompany you on your journey through the rest of life.

Q16 Thinking of yourself or others that you know, what do you think could be the main cause of loneliness?

The fact that people are too busy for time to be spent on relationships. Social media, instead of face-to-face contact, much prefer face to face.

Poverty, the pace at which the world moves due to technological advancements in many areas and other factors such as demands of work, pressure from various sources to be the perfect mum, employee, friend, partner etc. Social media, consumerism and individualism.

My ill health means I had to medically retire from my job, which I really enjoyed. Having chronic health problems which impact daily on my/a person's life is the main cause of loneliness. I lost many friends due to illness as I cannot commit to attending social events and I am limited in the type of social activity I can take part in.

Money to socialise, to get out and about.

I have chronic depression. I have periods of time when I do not like to be around others. This isolates me from people. My close friends understand this and involve me when I feel up to things again.

For some it is being physically on their own e.g. at home. For others it is feeling they don't fit in or feel people don't understand them.

What could be done to reduce loneliness in Scotland?

Following on from this, respondents were asked what they felt could be done to reduce loneliness in Scotland. A total of 458 respondents chose to answer this question. The main themes were where respondents felt that more should be done to encourage people to socialise (22%), groups and activities should be available for people of all ages (22%) and strong community groups and support would help to reduce loneliness (21%).

Figure 23: What could be done to reduce loneliness in Scotland (open-ended response themes)

Q17 What do you think could be done to reduce loneliness in Scotland?	
Base: Unweighted, n=457; Weighted, n=456	%
Encourage people to socialise	22%
Group/ activities for people of all ages	22%
Strong community/ community groups/ community support	21%
Visiting vulnerable people/ volunteering	14%
Befriending/ buddy networks	10%
Increased advertising/ campaign on activities available	9%
Increased access to community activities	8%
More social care	6%
More funding	4%
Other	2%
Don't know	8%

Below are some examples of the comments provided by Panel members on what they believe would help to reduce loneliness in Scotland:

It's a cultural thing, I guess. British people are generally pretty reserved with strangers. Since moving here from the South East of England I've noticed a difference in the culture where people are more prepared to chat with strangers. The village where I live is a great example, you can't walk along the street without people saying hello. In an ideal world that would be the same in all communities across Scotland. It's that sense of community that makes a difference I think.

Provide more accessible facilities and improve public transport.

Provide more services that train volunteers to visit people who are lonely and link them into services available to their needs.

More local information to let people know what is available to them. Clubs for all ages. Local services need to be more structured to accommodate all ages' not just young people or elderly. Buddy friends, befriending service, home visits and social media sites.

Lunch clubs to get people together. Activities for old and young, get people out and meeting others.

Encourage churches, social groups and local Councils to provide meeting places during the day for people, especially the elderly to gather together. Try to encourage schools to become involved.

Q17 What do you think could be done to reduce loneliness in Scotland?

Go and see if elderly people are all right. They love a chat. Look in on people. Have a sense of community.

Visiting vulnerable people in their home. More groups for people to go to with activities/ food available.

Access to information, located in doctor surgery's, libraries, supermarket "memo" boards, community centres about meeting places, coffees and chat together, walking groups - not everyone likes/or are good at chatting to strangers. Especially elderly, the majority would appreciate and benefit from a befriending service, people from their local area.

Befriending support for all ages.

Communities we used to have could help people. A sense of community has to come back where people are friendlier with one another. I feel over the years this has changed a lot. People don't visit each other, people are afraid. It's all changed.

People first have to talk about being lonely and hopefully find the confidence to get out and back into the community to make new friends.

Chapter 8: What happens near you?

Introduction

The final section of the questionnaire asked Panel members, in relation to health and social care in Scotland, what they feel is being done well where they live and about anything which would benefit from improvements or changes to service delivery.

What are health and/or social care services doing well?

All respondents were asked, thinking about where they live, what they believed health and/or social care services are doing well. The open-ended responses have been coded into common themes and are listed in the table below. Three in ten (30%) of the 356 individuals who provided comments said that health and social care services are doing everything well or doing the best they can and 29% expressed satisfaction with GP services.

Figure 24: What are health and/ or social care services doing well? (open-ended response themes)

Q18 Where you live, what are health and/ or social care services doing well?	
Base: Unweighted, n=356; Weighted, n=330	%
Doing everything well/ do the best they can	30%
Good GP services	29%
Social care services/ personal care/ care at home for elderly/ those living alone and services for disabled people	18%
Emergency/ same day appointments/ can see doctor quickly/ availability of GP appointments	18%
Practice nurse services	7%
Not a lot/ going downhill	5%
Clean hospitals[12]	0%
Other	4%
No issues	5%

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[12] The response for 'clean hospitals' has been rounded down to 0%

Below are some examples provided by Panel members on what they believe local health and social care services are doing well:

Home care seems to be successful in this area allowing people to stay in their own homes as long as possible.

I get an appointment when I need it. The hospital gave excellent care, they are dedicated and lovely people.

My local GP surgery is a great example of somewhere where I've never felt rushed. You always get the sense that there is time to discuss issues and concerns in detail.

Hospitals are much cleaner. They provide healthier food, skilled staff, less waiting times.

My local surgery is very proactive and often contacts me to invite me for health check-ups. They also offer early and late appointments.

Staff are friendly and approachable.

I can get a GP appointment when I need one.

Q16 Where you live, what are health and/or social care services doing well?

Good district nurse services.

Plenty of leaflets explaining possible ailments or leaflets for those with ailments diagnosed.

Social services are doing a good job with people with mental health problems.

A nurse practitioner is appointed at my local surgery, whom I have on two occasions had consultations with and found them very supportive and able to help greatly with my illness. Also an online appointment booking or rearranging system is due to commence.

There is good communication between GPs, nurses and social care.

Excellent practice with good emergency appointment system.

GPs are just managing by implementing new phone consultations before offering an appointment. Nurse practitioners are running more and more clinics and are able to triage and prescribe therefore freeing up GP time.

It is relatively easy to get a doctor's appointment and services are well advertised. Partnership working is popular.

What could health and/or social care services do better?

A total of 351 respondents provided suggestions on what they feel health and/or social care services could be doing better. Please note any responses of 'don't know' have been excluded from this analysis. The table below shows the main themes occurring from these responses. One in four comments (25%) were regarding the availability of GP or nurse appointments, 15% commented on staffing or resourcing issues and 11% mentioned improvements needed to mental health services.

Figure 25: What could health and/ or social care be doing better? (open-ended response themes)

Q19 Where you live, what could health and/or social care services do better?	
Base: Unweighted, n=351; Weighted, n=342	%
Availability of GP/ nurse appointments/ opening times outwith normal working hours	25%
More staff/ resources	15%
Improved mental health services	11%
Support for elderly/ disabled people/ vulnerable people	10%
Spending more time with patients	10%
Satisfied with services/ what is available/ nothing needs improved	7%
Home visits/ home care	6%
Staff (doctors/ receptionists etc) to be more understanding/ listen/ compassionate	6%
Shortening consultant/ hospital waiting lists	5%
Better communication between departments/ organisations e.g. charities	5%
More funding required/ budget constraints	4%
Social activities/ support groups/ community activities	4%
Public transport/ travel issues to health facilities/ living in rural locations	4%
Improved promotion of services available/ about services	3%
Dental services	1%
Online services e.g. for appointments/ test results/ email correspondence	1%
More activities[13]	0%
Other	12%

---

[13] The percentage of respondents whose comments were coded under 'more activities' has been rounded down to 0%.

Below are some of the things Panel members consider health and/or social care services could be doing better where they live:

Promote services more to the public, many people do not know about the Integration Joint Boards and what their remits are. I think they need to promote their plans by visiting various community groups, clubs in the local area. Health services in some areas need to improve communication between staff and departments.

Change the procedures to see the relevant people and treatment. There are too many people and procedures to get through to get advice/ service. This wastes a lot of money and resources. Too many people expecting a treatment/medicine for very minor ailments.

Access to doctors/ health centre is terrible as phones to health centre continually engaged. Having to wait at least a fortnight for a face-to-face with a doctor, receptionists who think they know everything regarding medical conditions.

Q19 Where you live, what could health and/or social care services do better?

We have an excellent surgery but this awful procedure of having to call at 9am on the day to get an appointment is very difficult. It has taken me sixteen attempts to get through. They say urgent cases will always be seen but many people are told the appointments are full, they will just go away and not ask.

More joined-up accessible services for elderly/disabled. Experience has been if vulnerable people don't have someone to advocate strongly for them, they can be forgotten about and denied the help they need.

Doctors should have more time with patients.

More modern ways of booking appointments e.g. if you are sent an appointment which isn't suitable. Typically you need to wait for another to be sent out in writing which can take weeks.

Not visiting vulnerable people in their own homes. As always a shortage of staff, resources and underfunding is the main problem.

Listen – be compassionate, educate and care.

For mental health there's a waiting list and really the person can't wait. Organisations have to communicate with each other so that you can be referred quicker. There was a charity group who helped me and the healthcare professionals didn't tell me about it. I found it myself.

Support with transport to and from venues. Raising awareness of services.

Home helps to spend 1 hour with a client instead of 5 mins as it gives a purpose for older people to look forward just for a chat.

Chapter 9: Next steps

This report will be published and shared widely, but this is only the first step in our improvement process. 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. Our Voice will then offer support to services to make improvement plans including how improvement can be described and measured. A further report will then be produced by the Our Voice Project Team to share how the feedback from the Our Voice Citizens' Panel has been considered and led to improvements to Scottish health and social care services. These findings will be shared with Panel members and shared more widely with health and social care organisations and professionals.

Appendix 1: Questionnaire

Citizens' Panel 2nd Survey

1. Welcome

Welcome again to the Our Voice Citizens' Panel.

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

Enclosed with this survey is a summary of the key findings of the first Citizens' Panel survey. In this first survey, we asked you to suggest areas of health and social care you would like us to investigate in future Panel surveys. You suggested that we look at issues around mental health, care of our elderly population, and issues around GP services. We hope to ask you questions about these issues in future surveys.

This is the second Our Voice Citizens' Panel survey on Health and Social Care. In this survey:
- we will ask you questions about your relationships with health and social care professionals to find out if there are any ways we can make communicating with them more meaningful for you.
- we will also ask you some questions about loneliness in order to find out how this issue affects people in Scotland, and to find out your views on how we could tackle this issue.

As usual, there are no wrong answers to these questions. Please do not use Google. We are interested in your own experiences of these issues and how they apply to you.

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

Thank you.

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

2. A Good Consultation

We want to find out about the different things that you think provide the ingredients for a 'good doctor', and on a similar theme, what things combine to make a 'good consultation' with your doctor?

1. What makes a 'good doctor'? (please limit your response to 3 things)

1

2

3

2. What are the most important elements of a 'good consultation' with a doctor? (Please limit your response to 3 things)

1

2

3

2

3. Making Decisions Together

In February 2017, the Chief Medical Officer for Scotland released her Annual Report 2015/16 called 'Realising Realistic Medicine.' This builds on last year's report - her first in her role - called "Realistic Medicine" which described a personalised approach to providing healthcare services that focus on listening to what patients want in order to provide the best person centred treatments. It focused on:

- Improving health.
- Reducing patient harm from the over use of medicine.
- Listening to patients - helping patients to reflect on, and express their preferences based on their individual circumstances, expectations, beliefs and values.
- Informing patients - providing clear information about benefits/disadvantages to tests, treatments and medications as they apply to each individual.
- Helping patients take a greater role in making decisions about their healthcare.

We would like to find out how you currently make decisions about your health, care and treatment.

3. Have you ever asked your doctor:

	Yes	No	Don't Know	Not Applicable
What are my (treatment / care) options?	☐	☐	☐	☐
What are the possible benefits and risks of those options?	☐	☐	☐	☐
How likely are the benefits and risks of each option to happen to me?	☐	☐	☐	☐

4. How comfortable would you feel asking your doctor:

	Very comfortable	Comfortable	Neutral	Uncomfortable	Very uncomfortable	Don't Know
What are my (treatment / care) options?	☐	☐	☐	☐	☐	☐
What are the possible benefits and risks of those options?	☐	☐	☐	☐	☐	☐
How likely are the benefits and risks of each option to happen to me?	☐	☐	☐	☐	☐	☐
Why is this specific treatment (or no treatment) being recommended?	☐	☐	☐	☐	☐	☐
Do I really need this treatment?	☐	☐	☐	☐	☐	☐
What are the alternative options?	☐	☐	☐	☐	☐	☐
Can I speak to another Doctor?	☐	☐	☐	☐	☐	☐
Can I be referred to a Specialist?	☐	☐	☐	☐	☐	☐

3

	Very comfortable	Comfortable	Neutral	Uncomfortable	Very uncomfortable	Don't Know
Where can I receive more information?	☐	☐	☐	☐	☐	☐
What other support is available for people in my situation?	☐	☐	☐	☐	☐	☐
Can I change my mind about my treatment/care options?	☐	☐	☐	☐	☐	☐
What could happen if I don't have this treatment?	☐	☐	☐	☐	☐	☐

Please provide further detail here (if you wish)

5. Are there any other questions you would like to ask your doctor to help you make decisions about your healthcare and treatment?

☐ Yes   ☐ No   ☐ Unsure

If Yes, please state other questions here:

4. Talking to a Doctor
We would like to understand what matters to you!

Things like family, work or social responsibilities, money issues, medical technologies, and other issues can change over your lifetime, and this can influence care and treatment choices. Some studies have found that patients are more likely to stick to their treatments when their life circumstances are taken into account during treatment discussions.

We would like you to tell us about the things you think we should factor into healthcare provision that would make your conversations with Doctors about care and treatment easier, more meaningful and empowering.

4

6. When you talk about your healthcare preferences with a doctor: What personal aspects of your life is it important to discuss? (please limit your answer to no more than 3 items/aspects)

1

2

3

Doctors need to make sure that their patients are aware of the risks involved in recommended treatments and alternative treatment options. Some studies have found that well-informed patients chose to be prescribed less medicine, also, patients are more likely to stick to their treatments when they are involved in making decisions about their care. We would like to know what sort of information would help you to make decisions about your healthcare?

7. When you talk with a Doctor: What information will help you make decisions about care and treatment? (please limit your answer to no more than 3 things)

1

2

3

8. Does anything stop (or limit) you from being involved in decisions about your healthcare and treatment?

☐ Yes   ☐ No   ☐ Unsure   ☐ Not Applicable

If Yes, please indicate what stops (or limits) you from being involved in decisions about your healthcare and treatment?

5

5. Talking to other Health and Care Professionals

The Scottish Government has a vision that by 2020, everyone in Scotland will be able to live longer healthier lives at home or in a homely setting.

To help achieve this ambition, health and social care services are working together to provide integrated 'joined-up' care. This approach requires a wider range of health professionals (which can include nurses, physiotherapists, pharmacists etc) to take on new roles to help support patients and GP's where it is appropriate for them to do so. For example, a GP practice nurse may offer to manage minor ailments for patients, or a local Pharmacist may offer review of medications.

We would like to know how comfortable you would feel talking to these other health and care professionals about your healthcare needs.

9. How comfortable would you feel asking other service professionals (listed below): **What are my (treatment / care) options?**

	Very comfortable	Comfortable	Neutral	Uncomfortable	Very uncomfortable	Don't Know
Social Care Professional (professionals who help you in your home/community)	☐	☐	☐	☐	☐	☐
Nurse (eg: community nurse, midwife, GP practice nurse)	☐	☐	☐	☐	☐	☐
Allied Health Professional (eg: physiotherapist, dietitian, radiographer)	☐	☐	☐	☐	☐	☐
Pharmacist	☐	☐	☐	☐	☐	☐
Other (eg: counsellor, support staff)	☐	☐	☐	☐	☐	☐

Please provide reasons for your answers:

6

10. How comfortable would you feel asking other service professionals (listed below): **What are the possible benefits and risks of those options?**

	Very comfortable	Comfortable	Neutral	Uncomfortable	Very uncomfortable	Don't Know
Social Care Professional (professionals who help you in your home/community)	☐	☐	☐	☐	☐	☐
Nurse (eg: community nurse, midwife, GP practice nurse)	☐	☐	☐	☐	☐	☐
Allied Health Professional (eg: physiotherapist, dietitian, radiographer)	☐	☐	☐	☐	☐	☐
Pharmacist	☐	☐	☐	☐	☐	☐
Other (eg: counsellor, support staff)	☐	☐	☐	☐	☐	☐

Please provide reasons for your answers:

11. How comfortable would you feel asking other service professionals (listed below): How likely are the benefits and risks of each option to happen to me?

	Very comfortable	Comfortable	Neutral	Uncomfortable	Very uncomfortable	Don't Know
Social Care Professional (professionals who help you in your home/community)	☐	☐	☐	☐	☐	☐
Nurse (eg: community nurse, midwife, GP practice nurse)	☐	☐	☐	☐	☐	☐
Allied Health Professional (eg: physiotherapist, dietitian, radiographer)	☐	☐	☐	☐	☐	☐
Pharmacist	☐	☐	☐	☐	☐	☐
Other (eg: counsellor, support staff)	☐	☐	☐	☐	☐	☐

Please provide reasons for your answers:

7

6. Information delivery

In our last survey, we asked you questions around your preferences for receiving information about social care support and medicines that you may be prescribed. We would now like to know more about what forms of information you prefer to receive, to help you make decisions about your healthcare.

12. How would you prefer to get information about your healthcare needs? Please indicate your top three preferences, selecting one in each column.

	Top preference	2nd preference	3rd preference
Information leaflet	☐	☐	☐
Online information	☐	☐	☐
Phone consultation	☐	☐	☐
Via an app	☐	☐	☐
Text messages	☐	☐	☐
A personalised email to you	☐	☐	☐
A personalised letter to you	☐	☐	☐
TV or radio campaigns	☐	☐	☐
Face to face consultation with nurse	☐	☐	☐
Face to face consultation with Doctor	☐	☐	☐
Face to face consultation with Allied Health Professional	☐	☐	☐
Other (please specify):	☐	☐	☐

7. Social Isolation and Loneliness

Lots of people feel lonely at some point in their life. Whilst studies have been conducted to find out how loneliness affects certain groups like elderly people, minority ethnic communities, and young people, we do not know how this issue impacts the general wider population. We would like to use Scotland's Our Voice Citizens' Panel to find out how common feelings of loneliness are amongst the general public in Scotland.

We want to live in a Scotland where people feel they have someone to talk to or share experiences with. Sharing your views with us can help us find out how we can make people feel more connected and less isolated - so please tell us what you really think.

13. What does 'loneliness' mean to you?

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14. The following questions ask how you feel. For each statement, please indicate how often you have felt the way described over the last month

	Never	Hardly ever	Some of the time	Often
How often do you feel that you lack companionship?	☐	☐	☐	☐
How often do you feel left out?	☐	☐	☐	☐
How often do you feel isolated from others?	☐	☐	☐	☐

15. The following statements describe how people feel. Thinking of how you have felt over the last month, please indicate the extent to which you agree with each statement:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am content with my friendships and relationships	☐	☐	☐	☐	☐
I have enough people I feel comfortable asking for help at any time	☐	☐	☐	☐	☐
My relationships are as satisfying as I would want them to be	☐	☐	☐	☐	☐

16. Lots of people say they feel lonely from time to time. Thinking of yourself or others that you know, what do you think could be the main cause of loneliness?

17. What do you think could be done to reduce loneliness in Scotland?

If you are affected by loneliness, there are several organisations such as:
- Befriending Networks (www.befriending.co.uk)
- Campaign To End Loneliness (www.campaigntoendloneliness.org)
- Wavelength (www.wavelength.org.uk)

who exist to provide opportunities to lessen its impact on your life.
Age Scotland (www.ageuk.org.uk/scotland) also provide information on this issue.

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8. Final Questions: What's happening near you?

Finally, in relation to health and social care in Scotland, we want to hear about what we are doing well where you live, to see how we can learn from this, and to hear about what we could do better.

18. Where you live, what are health and/or social care services doing well?

19. Where you live, what could health and/or social care services do better?

Thank You

You have completed this survey!

Thank you for taking the time to answer this survey.
By providing feedback in this survey, you have helped us to consider these issues and will help inform future health and social care services delivery in Scotland.

The information you provide will be used by Our Voice, the Scottish Health Council and our partners for the purposes stated. The views you express in this questionnaire will remain anonymous, and no personal data that identifies you will be published or shared with third parties. This survey is being conducted by Research Resource on behalf of Our Voice and the Scottish Health Council.

Research Resource adhere to the SRA Ethical Guidelines and all work is undertaken in accordance with the Data Protection Act, under which Research Resource are registered.

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Appendix 2: Infographic newsletter

August 2017

Our Voice Citizens' Panel Second Survey Results

This newsletter summarises the key findings from the second survey undertaken with the Our Voice Citizen's Panel. Within the questionnaire we asked you about your relationships with health and social care professionals to find out if there are ways we can make communicating with them more meaningful for you. We also asked you some questions about loneliness in order to find out how this issue affects people in Scotland and to find out your views on how we could tackle this issue.

In total, 551 Panel members responded to the survey either by post, email or by telephone. This is a response rate of 44%. Thank you!

A good consultation

What makes a 'good doctor'?

1. Knowledge/ qualifications
2. Good listener
3. Friendly/ approachable

What are the most important elements of a 'good consultation' with a doctor?

1. Feel listened to/ not being rushed
2. Clear communication
3. Resolution/ diagnosis/ outcome

Making decisions together

How comfortable do you feel asking a doctor...

...what are my treatment options? (92% feel comfortable)

...what are the risks/ benefits of my treatment options? (91% feel comfortable)

...how likely are these to happen to me? (87% feel comfortable)

Communication preferences

How would you prefer to get information about your healthcare needs?

Face to face consultation with doctor (82%)

Face to face consultation with nurse (46%)

Phone consultation (31%)

Social isolation and Loneliness

Feelings of loneliness

One in 10 often feel lonely.

Main cause of loneliness

Lack of social interactions or having no one to talk to (41%)

Anxiety/ depression/ mental health (18%)

What could be done to reduce loneliness?

Encourage people to socialise (22%)

Groups activities for all ages (22%)

Strong community groups (21%)

What are health/ social care services good at?

1. Doing the best they can (30%)
2. Good GP services (29%)
3. Availability of appointments (18%)

What could health/ social services do better?

1. Availability of appointments (25%)
2. More staff/ resources (15%)
3. Improved mental health services (11%)

Thank you!

Thank you for taking the time to complete the survey.

To discuss your panel membership or to update any of your details please contact Research Resource on 0141 641 6410 or by email at info@researchresource.co.uk.

Appendix 3: Response profile

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

16th May 2017

Date	Activity	Description	Number
14th March	First email	Distributed	1002
		Bounce back	103
		Total emails delivered	899
21st March	First postal survey	Number sent to Panel members without email addresses	285
		Number sent to bounce back Panel members	103
		Total number sent	388
21st March	First email reminder	Number sent	754
		Number Bounce back	1
		Total emails delivered	753
29th March	Additional postal surveys delivered	Number sent to those with email addresses who had not responded	717
7th April	Final email reminder	Number sent	682
		Number Bounce back	0
		Total emails delivered	682

SURVEY OUTCOMES AS AT 16/05/2017

Emails sent	898
Number of email responses	248[14]
Email response rate	**28%**

Number of postal sent	1105
Number of postal returned	228
Postal response rate	**21%**

Telephone surveys	**75**

OVERALL RESPONSE RATE	
Current response	551
Current number on Panel	1258[15]
Overall response rate	**44%**

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[14] This includes 33 partial email responses (2 completed the survey then opted out of future surveys).
[15] 33 Panel members have requested to be removed from the Panel (30 via email opt out and 3 contacting Research Resource directly)

Gender	No on Panel	Response	Response rate	% of response	Scottish popn.[16]	Difference	Panel	% of Panel	Scottish popn.	Difference
				Second Survey				Original Panel		
Male	406	183	45%	33%	49%	-16%	414	32%	49%	-17%
Female	851	368	43%	67%	51%	16%	877	68%	51%	17%
Prefer not to answer	6	0	0%	0%			5	0%		
Total	1263	551	44%	100%			1296	100%		

Physical or mental health condition or illness	No on Panel	Response	Response rate	% of response	Scottish popn.[17]	Difference	Panel	% of Panel	Scottish popn.	Difference
				Second Survey				Original Panel		
Yes	449	222	49%	40%	40%	0%	462	36%	40%	-4%
No	757	308	41%	56%	60%	-4%	782	60%	60%	0%
Prefer not to say	56	21	38%	4%			50	4%		
Total	1262	551	44%	100%	100%		1294	100%		

Tenure	No on Panel	Response	Response rate	% of response	Scottish popn.[18]	Difference	Panel	% of Panel	Scottish popn.	Difference
				Second Survey				Original Panel		
Own	766	397	52%	73%	62%	11%	787	62%	62%	0%
Rent from Council/ HA	290	94	32%	17%	24%	-7%	295	23%	24%	-1%
Private Rent	125	35	28%	6%	14%	-8%	127	10%	14%	-4%
Other	68	20	29%	4%		4%	68	5%		
Total	1249	546	44%	100%	100%		1277	100%	100%	

[16]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
[17]Long term conditions. (December 23, 2015). The Scottish Government. Retrieved from http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions 26/10/2016
[18]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	Second survey						Original Panel			
	No on Panel	Response	Response rate	% of response	Scottish popn.[19]	Difference	Panel	% of Panel	Scottish popn.	Difference
16-24	108	21	19%	4%	14%	-10%	113	9%	14%	-5%
25-44	347	119	34%	22%	31%	-9%	357	28%	31%	-3%
45-64	473	222	47%	41%	33%	8%	486	38%	33%	5%
65+	315	184	58%	34%	22%	12%	330	25%	22%	3%
Total	1243	546	44%	100%	100%		1286	100%	100%	0%

Ethnic group	Second survey						Original Panel			
	No on Panel	Response	Response rate	% of response	Scottish popn.[20]	Difference	Panel	% of Panel	Scottish popn.	Difference
White British	1199	525	44%	96%	96%	0%	1240	97%	96%	1%
Other	46	20	43%	4%	4%	0%	43	3%	4%	-1%
Total	**1245**	**545**	**44%**	**100%**	**100%**	**0%**	**1283**	**100%**		

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[19]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
[20]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

Local authority	No on Panel	Responses	Response rate
Aberdeen City	45	13	29%
Aberdeenshire	48	18	38%
Angus	27	20	74%
Argyll & Bute	31	18	58%
Clackmannanshire	9	6	67%
Dumfries & Galloway	38	16	42%
Dundee City	30	10	33%
East Ayrshire	34	15	44%
East Dunbartonshire	29	13	45%
East Lothian	25	11	44%
East Renfrewshire	45	19	42%
Edinburgh, City of	90	35	39%
Eilean Siar	21	16	76%
Falkirk	29	14	48%
Fife	70	21	30%
Glasgow City	111	46	41%
Highland	56	22	39%
Inverclyde	30	13	43%
Midlothian	28	16	57%
Moray	31	9	29%
North Ayrshire	33	16	48%
North Lanarkshire	73	23	32%
Orkney Islands	18	9	50%
Perth & Kinross	30	14	47%
Renfrewshire	26	13	50%
Scottish Borders	32	17	53%
Shetland Islands	33	24	73%
South Ayrshire	34	18	53%
South Lanarkshire	60	22	37%
Stirling	20	13	65%
West Dunbartonshire	28	14	50%
West Lothian	43	17	40%
Total	**1257**	**551**	**44%**

NHS Board			
	No on Panel	**Response**	**Response Rate**
Ayrshire & Arran	101	49	49%
Borders	32	17	53%
Dumfries & Galloway	38	16	42%
Fife	70	21	30%
Forth Valley	57	32	56%
Grampian	124	40	32%
Greater Glasgow & Clyde	282	126	45%
Highland	87	40	46%
Lanarkshire	121	38	31%
Lothian	186	79	42%
Orkney	18	9	50%
Shetland	33	24	73%
Tayside	87	44	51%
Western Isles	21	16	76%
#N/A	1	0	0%
Total	1258	551	44%

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.

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
Sample Estimate (lookup to nearest multiple of 5%)	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
	15%	11.4%	9.3%	8.0%	6.6%	5.7%	5.1%	4.6%	3.5%	3.6%	2.8
	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
	30%	14.6%	11.9%	10.3%	8.4%	7.3%	6.5%	6.0%	4.5%	4.6%	3.6
	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
	45%	15.9%	12.9%	11.2%	9.2%	7.9%	7.1%	6.5%	4.9%	5.0%	3.9
	50%	**15.9%**	**13.0%**	**11.3%**	**9.2%**	**8.0%**	**7.1%**	**6.5%**	**4.9%**	**5.0%**	**4.0%**
	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
	65%	15.2%	12.4%	10.8%	8.8%	7.6%	6.8%	6.2%	4.7%	4.8%	3.8
	70%	14.6%	11.9%	10.3%	8.4%	7.3%	6.5%	6.0%	4.5%	4.6%	3.6
	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
	85%	11.4%	9.3%	8.0%	6.6%	5.7%	5.1%	4.6%	3.5%	3.6%	2.8
	90%	9.6%	7.8%	6.8%	5.5%	4.8%	4.3%	3.9%	2.9%	3.0%	2.4
	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 gender analysis tables.

The percentage of respondents who were identified as being lonely was 31% for female respondents and 22% for male respondents. At face value, these values seem to differ significantly. However, because this figure is based upon a sample we need to calculate confidence intervals to determine where the true value of the population lies.

Using the statistical significance table above to find the 95% confidence intervals for each value, we can see that for females (with a base of 337) the lower limit of the 95% confidence interval is 25% and the upper limit is 37%. For males (with a base of 168) the lower limit is 14.6% and the upper limit is 29.6%.

Looking at the intervals for the two together we can see that the upper limit for males does overlap with the lower limit for females. This means that the difference observed between these two groups for this variable is not statistically significant and, therefore, should be read with caution.

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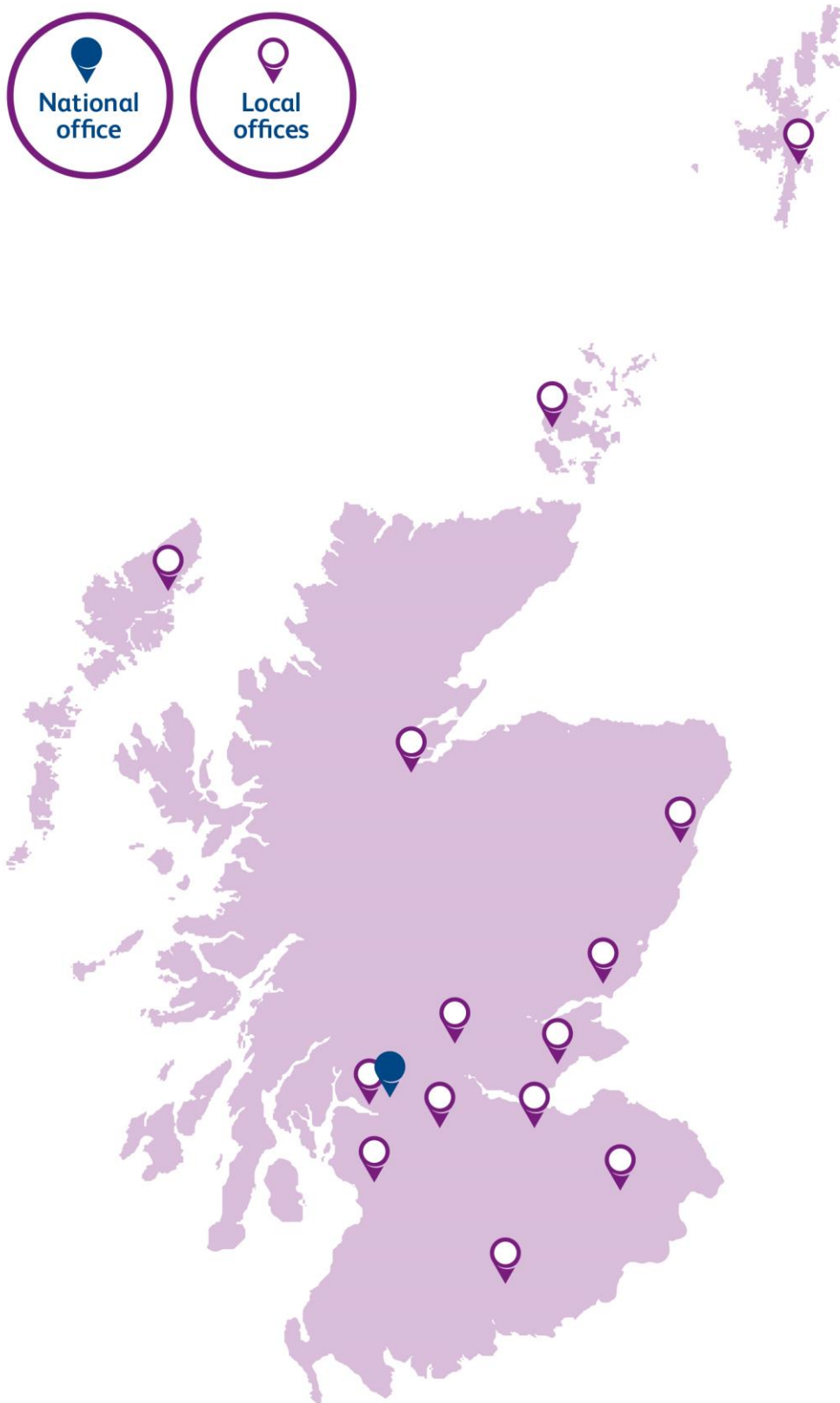
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