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Our Voice Citizens' Panel

Survey on the Scottish Ambulance Service, organ and tissue donation after death, and care provided by nurses and midwives

October 2019

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Foreword

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

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

The Panel was refreshed in early 2019, replacing Panel members who either did not want to continue being members or who had not responded to previous surveys. At the time of this survey in 2019 we have 1,168 Panel members from across all NHS Board, Integration Authority and local authority areas.

The report covers what the Scottish public think about the Scottish Ambulance Service, organ and tissue donation after death in Scotland and nursing and midwifery care.

The sponsor organisations that fed in the questions to this Citizens' Panel survey are committed to using the results to help develop services and improve healthcare in Scotland. We will report back to the Citizens' Panel members on these results as well as on the impact these have had more generally on health and social care services in Scotland.

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. I'd also like to thank our contractors, Research Resource, who helped to recruit new Panel members and conduct the survey. In addition, I'd also like to thank our topic sponsors the Scottish Ambulance Service, the Scottish Government Health and Social Care Analysis Team (organ and tissue donation after death topic) and the Excellence in Care Collaborative (nursing and midwifery care topic) for contributing to this Citizens' Panel survey.

I hope you enjoy reading this report.

Suzanne Dawson
Chair, the Scottish Health Council

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

The Panel was refreshed in early 2019. The refresh replaced Panel members who either did not want to continue being members or who had not responded to previous surveys. At the time of survey in 2019, we have 1,168 Panel members from across all 32 local authority areas.

This report details the findings from the fifth full Panel survey which included questions on three different topics:

- the Scottish Ambulance Service
- attitudes towards organ and tissue donation after death, and
- care provided by nurses and midwives.

A total of 636 responses (54% response rate) were received, either by post, email or by telephone. This level of return provides data accurate to +/-3.9%[1] at the overall Panel level. In this report we do not report results broken down into sub-categories (for example, gender or age) as they are not statistically significant. 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 2.

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

Key findings

The Scottish Ambulance Service

The Scottish Ambulance Service is beginning to develop its strategy for the future, focusing on the period 2021–2030. The Scottish Ambulance Service has changed significantly in recent years, moving away from primarily a means of transporting people to hospitals to becoming a key provider of healthcare in communities. The results from this survey will help influence the Scottish Ambulance Service's new strategy.

A fast or prompt response of service was most important to Panel members (85%) should they require the services of the Scottish Ambulance Service. This was followed by well trained, competent or knowledgeable staff (62%) and caring, understanding or empathetic staff (36%).

In terms of the qualities that Panel members believe contribute to a good ambulance professional, the top response was for knowledgeable, skilled, trained, professional or experienced staff (71%) followed by staff being caring, compassionate, understanding or sympathetic (57%).

Panel members were then asked about any situations where people may call for an ambulance, other than in a life-threatening emergency. Examples given included accidents such as broken bones or falls (14%), extreme situations requiring urgent help such as pain, blood loss, breathing issues, heart attacks and allergic reactions etc (11%) and for transport to appointments or hospital or where people don't have access to any other form of transport (10%).

More than 7 in 10 respondents (73%) felt either very or fairly comfortable knowing that they might have to wait a little longer for an ambulance response (outside of a life-threatening emergency), if it meant that they were more likely to receive a more appropriate response for their condition.

Eight in ten respondents (80%) felt either very or fairly comfortable discussing options for further care with ambulance professionals that may not result in a visit to a hospital emergency department.

Just under 7 in 10 respondents (68%) said they would feel comfortable if they were offered a consultation with an ambulance professional as part of the service offered by their GP practice.

In terms of what information Panel members believed would be most helpful for ambulance professionals to make decisions with them about their care, just under 9 in 10 respondents (89%) said their medical history would be helpful and 81% said key summary information about pre-existing medical conditions would be helpful.

Over 8 in 10 respondents (82%) felt either very or fairly comfortable with the Scottish Ambulance Service having access to this information (e.g. medical history, allergy information, community assistance etc).

Attitudes toward organ and tissue donation after death

In future, the law on organ and tissue donation after death in Scotland will be changing to an 'opt-out' system. To help the Scottish Government prepare for this

change, Panel members were asked for their opinions on a range of statements about organ and tissue donation after death.

The level of agreement ranged from 76% who agreed with the statement "I trust the organ and tissue donation system in Scotland" to 92% who agreed with the statement "I feel able to have a conversation with a family member or loved one about my organ and tissue donation".

Panel members were asked about their awareness and level of understanding in relation to organ and tissue donation after death.

- 88% understood that under the proposed 'opt-out' system they may be presumed to be willing to donate unless they have stated that they do not wish to do so.
- 86% were aware of the plans to move to an 'opt-out' system for organ and tissue donation in Scotland.
- 62% were aware how to register their organ and tissue donation decision.

Just under half of respondents have already registered their decision about organ and tissue donation after their death (46%) and just under half (49%) had not.

Around two thirds of those respondents (66%) said they were either very or somewhat likely to do this, 17% said they were somewhat likely and a further 17% were unsure. Over six in ten (61%) have had a conversation with a family member or loved one about their organ and tissue donation decision.

Nursing and midwifery care

The topic on nursing and midwifery care was included in the Citizens' Panel to inform and influence the Excellence in Care Programme which launched in April 2016. Excellence in Care aims to provide the Scottish public with confidence and assurance that nursing and midwifery care is high quality, safe, effective and person-centred.

When asked about the qualities of a 'caring nurse or midwife', the top response was for them to be compassionate, understanding or sympathetic (75%). This was followed by staff being knowledgeable, skilled, trained, professional or experienced (73%).

Over 3 in 10 survey respondents (31%) have had a recent care experience in the last 12 months with a nurse or midwife. Of these individuals, over half (55%) said they are always or frequently given the opportunity to share their preferences about their care with their nurse or midwife, 22% said they are sometimes given this opportunity, 21% said they are rarely or never given this opportunity and 2% were unsure.

Panel members were then asked how comfortable they would feel asking a nurse or midwife a range of questions about their care. This revealed that:

- 70% would feel comfortable asking for more information, explanation and options around their care
- 69% would feel comfortable asking when they would like aspects of care to be carried out
- 68% would feel comfortable asking how they would like to be cared for and how they can contribute to their plan of care, and
- 62% would feel comfortable asking how they can provide feedback about their experience.

Panel members were asked to select from a list of options, identifying which aspects of their care and treatment they would be happy discussing with their nurse or midwife. Over 9 in 10 respondents were happy to discuss each of these aspects, with respondents being most comfortable discussing the details of their current health condition (98%) and slightly less comfortable discussing the risks and benefits associated with the treatments available to them or doing nothing (92%) and details of likely future outcomes relating to their health condition (92%).

The majority of respondents (73%) said there was nothing that stops (or limits) them from being involved in decisions about their healthcare and treatment. On the other hand, 9% mentioned a lack of appointments or appointments being too short and 8% mentioned staff issues such as staff not listening to their concerns or a lack of consistency in terms of not seeing the same member of staff at their appointments.

Finally, when asked about what matters most to Panel members when thinking about the professional practice of nurses and midwives, 8 in 10 respondents (80%) said competence, knowledge and skill was most important. This was followed by being treated with dignity and respect (51%) and being cared for compassionately (32%).

Chapter 1: Introduction and context

Background and context

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

The Our Voice Citizens' Panel was established in 2016 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 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.

The Panel was refreshed with new members in early 2019. The refresh replaced Panel members who either did not want to continue being members or who had not responded to previous surveys. At the time of this survey in 2019, there are 1,168 Panel members spread across each and every Integration Authority and NHS territorial Board across Scotland.

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

Questionnaire design

The first section of the questionnaire focused on the **Scottish Ambulance Service** and in particular the questionnaire asked about what is important when requiring the services of the Scottish Ambulance Service and about the qualities that make a good ambulance professional. In addition to this, Panel members were asked about the types of situation where people may call for an ambulance (outwith life threatening emergencies).

The next section of the questionnaire asked Panel members about **their attitudes towards organ and tissue donation after death.** Panel members were asked about their awareness and support for moving to an 'opt-out'[2] system of donation and about trust in the donation system.

The survey concluded with a section on **nursing and midwifery care**, discussing what Panel members believe to be the qualities of a 'caring nurse or midwife', and about any recent experience with these health professionals.

A copy of the final questionnaire is available in a separate appendix.

[2] An 'opt-out' system works on the assumption that most adults can be a donor when they die unless they have specifically stated that they do not wish to donate.

Response rates and profile

At the time of writing this report, the Our Voice Citizens' Panel has a total of 1,168 members. The fifth Our Voice Citizens' Panel survey was sent by email on 18 June 2019 to all 988 Panel members for whom we have email addresses. On 21 June 2019 survey packs were sent to all Panel members for whom we have no email addresses and those from whom a bounce back email message was received. Reminder mailings were sent by email on the 25 June 2019 to those who had not yet responded by email. On 12 July 2019 additional postal surveys were delivered to Panel members who had not yet responded to the survey.

Postal responses continued to be accepted up until 26 July 2019. A detailed analysis of the response profile identified that the survey was under-represented in terms of younger Panel members (defined as younger members aged 44 and under) and females. It was decided that a targeted telephone boost be undertaken in an attempt to increase the response from these under-represented groups. A total of 51 telephone interviews were completed between 5 and 9 of August 2019. This took the final response up to 636, a 54% response rate. This level of return provides data accurate to +/-3.9% (based upon a 50% estimate at the 95% level of confidence) at the overall Panel level.

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

Full information on the response profile achieved and weighting, and further information about the Citizens' Panel can be found in Appendix 2.

Further information on Citizens' Panels can be found in Appendix 3.

Interpreting results

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

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

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

coding of open-ended responses, 10% of all responses are validated by a second person to check for any issues or errors.

Chapter 2: Scottish Ambulance Service

Introduction

The Scottish Ambulance Service is beginning to develop its strategy for the future, focusing on the period 2021–2030. The Scottish Ambulance Service has changed significantly in recent years, moving away from primarily a means of transporting people to hospitals to becoming a key provider of healthcare in communities.

The questionnaire asked Panel members what is important to people when they require the care of Scottish Ambulance Service, and what makes for a quality ambulance service in Scotland.

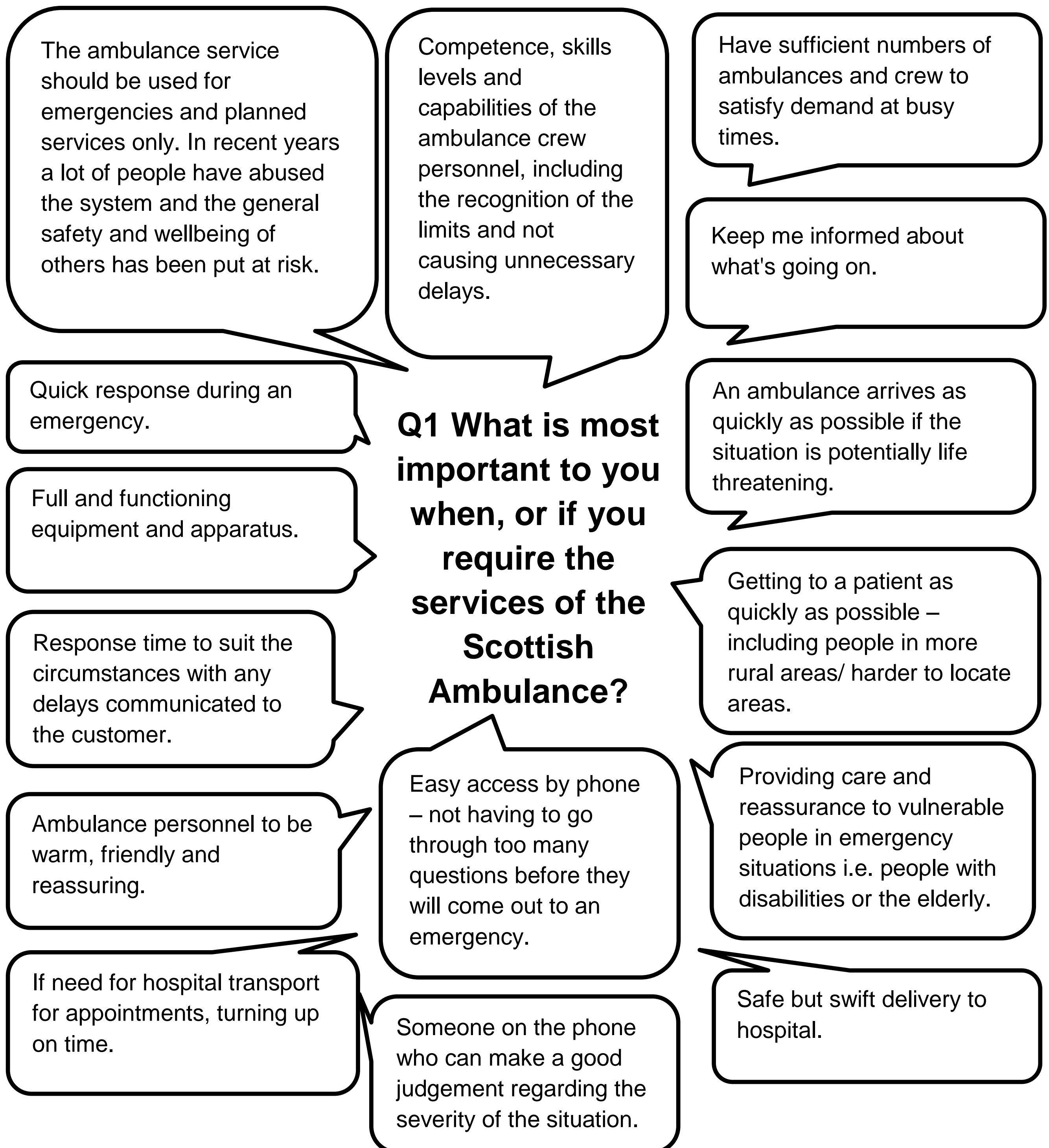
Scottish Ambulance Service priorities

The survey began by asking Panel members what was most important to them when, or if, they were to require the services of the Scottish Ambulance Service. This was asked as an open question with Panel members being asked to mention up to three things. For analysis purposes the open-ended responses have been coded into common themes and shown in the following table. This thematic analysis reveals that the vast majority of those who answered the question were of the opinion that a fast or prompt response and service was most important (85%). This was followed by well trained, competent and knowledgeable staff (62%) and for staff to be caring, understanding or empathetic (36%).

Figure 1: Scottish Ambulance Service priorities (Open ended response themes)

What is important to you when, or if, you require the services of the Scottish Ambulance Service? (Please limit your answer to 3 things)	
Weighted base, n=616	**%**
Fast/ prompt response/ service	84.7%
Well trained staff/ competent/ knowledgeable	62.3%
Caring/ understanding/ empathetic staff	36.0%
Ambulance well equipped/ got the necessary equipment	11.1%
Call staff - helpful/ calm/ informative/ clear communication/ respectful	9.4%
Good communication/ explanation	7.8%
Reliability	6.9%
Availability of service	6.3%
Safe journey	3.8%
Immediate access to medical help/ treatment	3.5%
The level of care	3.2%
Appropriate response times based on urgency/ need	2.2%
Local service/ get to rural areas quickly/ know the routes well	2.2%
Appropriate treatment	1.8%
Ambulances clean/ good standard of repair	1.4%
Accurate diagnosis	1.0%
Ease of access/ quick response to call	1.0%
Being given an estimated time of arrival	0.6%
Other	9.8%
Don't know/ no opinion	1.2%

Some examples of the open-ended responses provided by Panel members to describe their priorities with regards to the services provided by the Scottish Ambulance service are shown below:



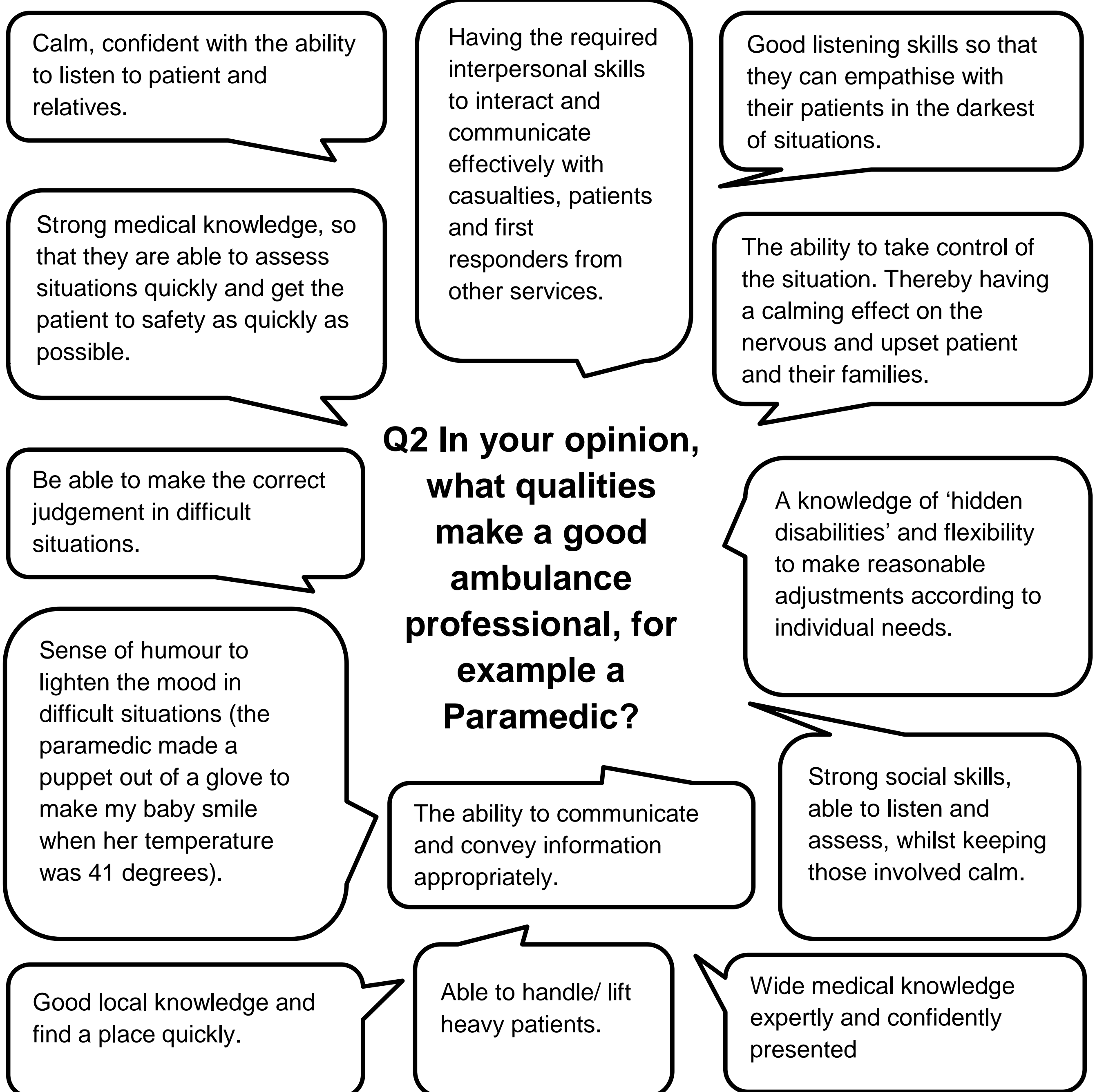
Qualities that make a good ambulance professional

Following on from this, the questionnaire asked Panel members about the qualities they believed contribute to a good ambulance professional. Again, this was asked as an open-ended question and Panel members were asked to limit their response to three things, with the responses being coded into generic themes for analysis purposes. Analysis of the open-ended responses revealed that the key priority was for ambulance staff to be knowledgeable, trained and professional (71%) and this was followed by staff being caring, compassionate and understanding (57%).

Figure 2: Qualities that make a good ambulance professional (Open ended response themes)

In your opinion, what qualities make a good ambulance professional, for example a Paramedic? (Please limit your answer to 3 things)	
Weighted base, n=607	**%**
Knowledgeable/ skilled/ trained/ professional/ experienced	70.6%
Caring/ compassionate/ understanding/ sympathetic	56.8%
Calm/ patient/ keeps cool under pressure	35.0%
Friendly/ good people skills	27.4%
Confidence/ ability to take control	16.5%
Good communicator	16.3%
Ability to assess the situation quickly and accurately/ make quick decisions	6.5%
Good listener	5.2%
Sense of humour	2.4%
Physically fit	1.3%
Other	10.1%
Don't know	0.2%

Some examples of the open-ended responses provided by Panel members to describe the qualities they believe make a good ambulance professional are shown below:



Prioritising response

When asked about any situations where people may call for an ambulance (other than life threatening emergencies), a range of examples were given by Panel members. Of the respondents who provided an open-ended response, 29% were unable to think of any other situations where they might require an ambulance, 14% said they may call for an ambulance regarding an accident that resulted in broken bones or where someone had a bad fall, 11% mentioned extreme situations which require urgent help such as blood loss, breathing issues, heart attacks, allergic reactions etc, and a further 10% mentioned transport for appointments or to attend hospital for those who had no other form of transport available to them.

Figure 3: Apart from a life-threatening emergency, other situations where people may call for an ambulance (Open ended response themes)

Apart from a life threatening emergency, are there other situations in which you think you may call for an ambulance?	
Weighted base, n=556	**%**
Can't think of any other situations/ don't know	28.8%
An accident such as broken bones or a fall	13.6%
Extreme situations requiring urgent help e.g. pain/ blood loss/ breathing issues/ heart attack/ allergic reaction etc	10.9%
Transport for appointment/ hospital/ no other form of transport available	10.2%
Issue with a child or older person	9.0%
Inability to walk/ move/ drive/ get to hospital	8.6%
Require specialist support and transport/ if unable to move patient safely	6.7%
I think ambulance service should be called for emergencies only	5.0%
Mental health issue	4.3%
Childbirth/ pregnancy related	4.0%
Road traffic accident	3.2%
If concerned/ unsure about the severity of the situation	2.6%
I would call NHS 24 (111)/ speak to GP/ other health professional first	0.9%
Epilepsy/ fits	0.7%
Minor injuries such as cuts, burns	0.5%
Other	5.7%

Some examples of the open-ended responses provided by Panel members to describe the qualities they believe make a good ambulance professional are shown below:

Q3 Apart from a life-threatening emergency, are there other situations in which you think you may call for an ambulance?

Ambulances should only be used for life threatening conditions. However, the majority of people do not have technical knowledge to identify these. Majority will be scared e.g. by sight of blood and will require reassurance.

In a situation that causes you to panic i.e. like a child choking or child unwell etc. At these times, you just want a qualified medical professional to look and help asap.

Whilst some instances are 'life threatening' there will be occasions when the patient may be in significant pain/discomfort that need a prompt response.

Certain situations for a pregnant mum.

Disabled people who need treatment and a disabled [accessible] taxi is not available.

Accident with unknown physical, spinal or orthopaedic injuries. Needing a more skilled assessment without moving or immobilising affected injury.

Transport for elderly/ infirm simply to get to hospital to keep appointments.

I believe the ambulance personnel are stretched to the limit with unnecessary calls so I would be loathed to call out unless in the case of an emergency.

A person with mental health issues who may be a danger to themselves or others.

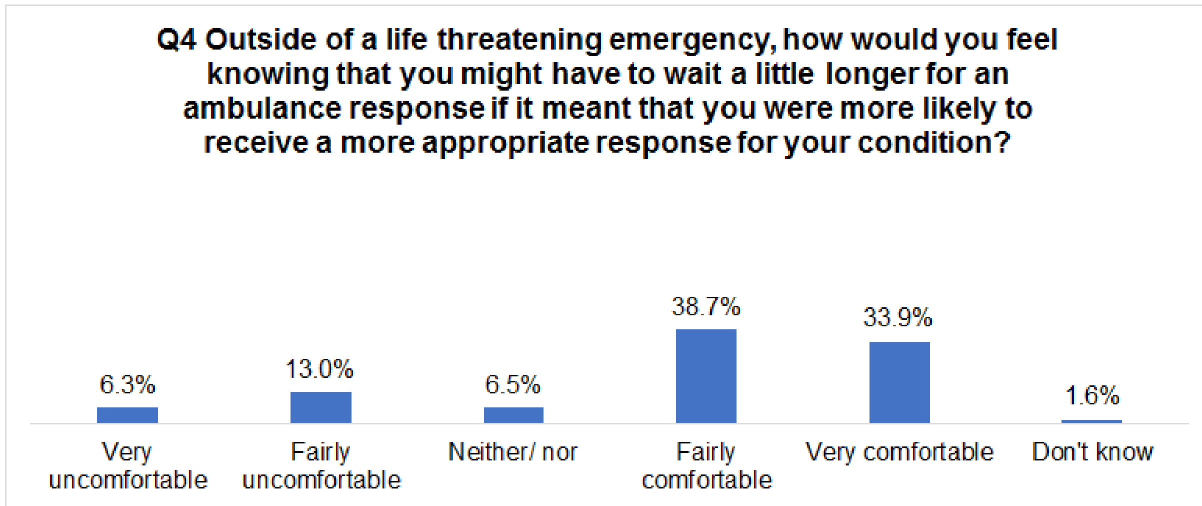
Before NHS phone line, I might have called if I was really worried about someone's health but now, I would go to the phone first so no other situations.

Concern over an elderly or baby's condition e.g. breathing, temperature, rash.

If someone had fallen at home and unable to get them up i.e. not immediately life threatening.

Following on from this, respondents were asked how comfortable they would feel knowing that they might have to wait a little longer for an ambulance response (outside of a life-threatening emergency), if it meant that they were more likely to receive a more appropriate response for their condition. Over 7 in 10 respondents (73%) felt either fairly or very comfortable in this respect compared to 19% who said they felt very or fairly uncomfortable, 7% who were neither comfortable nor uncomfortable and 2% who were unsure.

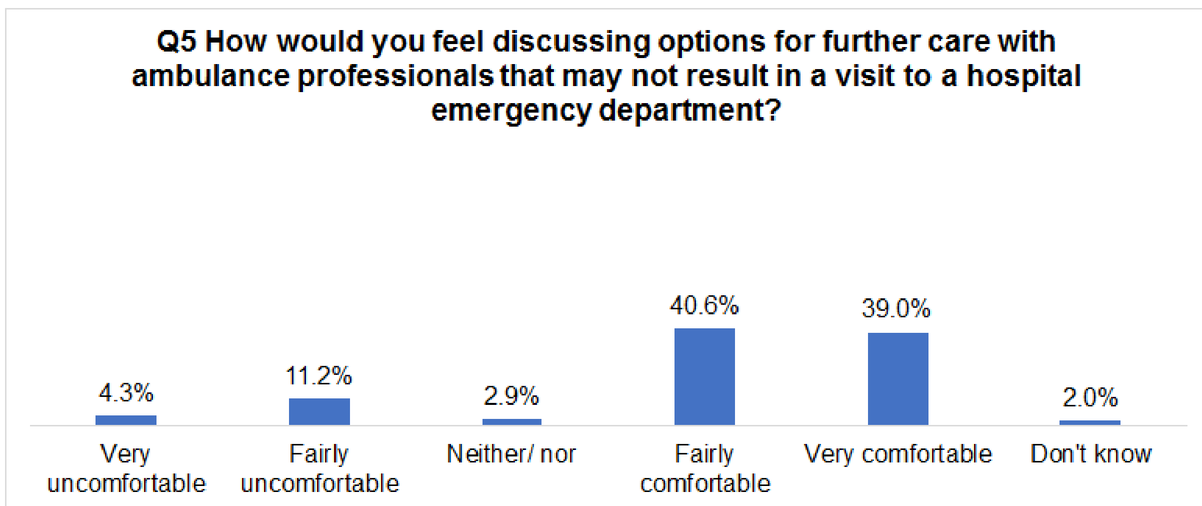
Figure 4: Opinions on waiting longer for an ambulance response (non-life threatening emergency), if it meant a more appropriate response for condition



Base: Weighted, n=621

Eight in ten respondents (80%) felt either very or fairly comfortable discussing options for further care with ambulance professionals that may not result in a visit to a hospital emergency department. On the other hand, 15% said they would feel uncomfortable with this.

Figure 5: Opinions on discussing options for further care with ambulance professionals that may not result in a visit to a hospital emergency department

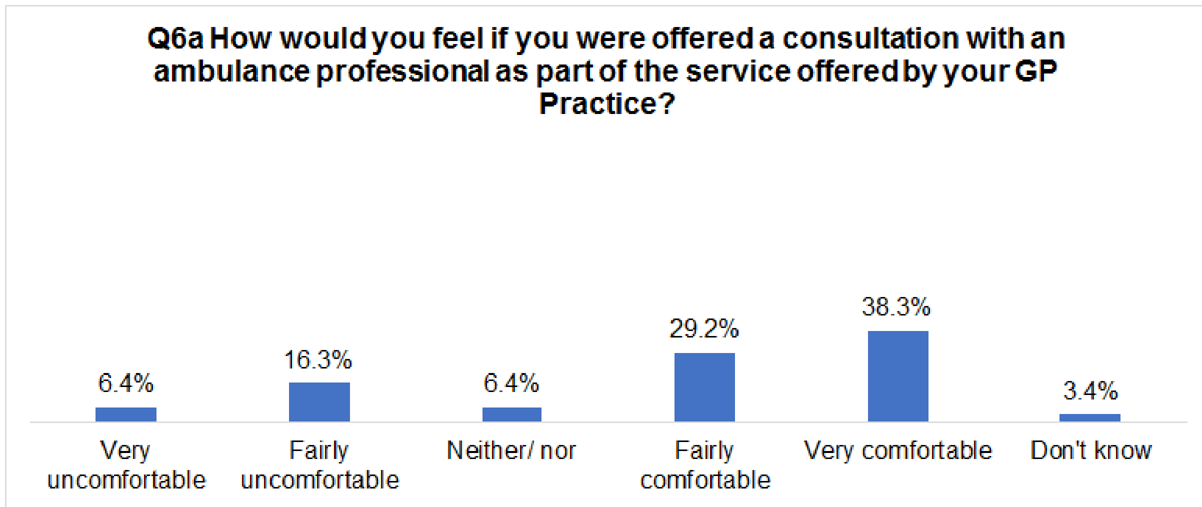


Base: Weighted, n=620

Working with other health services

Since 2018 there is a commitment that ambulance professionals will form part of primary care teams in GP practices. Panel members were asked for their opinions on the Scottish Ambulance Service working in GP practices. Just under 7 in 10 respondents (68%) said they would feel comfortable if they were offered a consultation with an ambulance professional as part of the service offered by their GP practice, compared to 23% who were of the opinion they would feel uncomfortable and 6% who would feel neither comfortable nor uncomfortable.

Figure 6: Opinions on being offered a consultation with an ambulance professional as part of the service offered by GP practice



Base: Weighted, n=625

As a follow up to this question, Panel members were asked to explain their response. A selection of some of the comments provided by those who would feel **comfortable** with being offered a consultation with an ambulance professional as part of the service offered by their GP practice are shown below:

It would depend on what symptoms I had and how severe they were. If it was just routine then I would be comfortable.

They are very well trained and in our surgery GP appointments are usually between 2-3 week wait.

We don't have enough GPs, but other professionals can deal with many medical conditions so we need to use them. They also cost less to employ.

The doctor's practice has highly trained nurses who often consult instead of the doctors. The system works well and so there is no reason why a suitably trained ambulance professional could not do a similar thing.

Ambulance professionals are used to dealing with emergencies and looking after people and probably see more different conditions than most doctors.

I believe all NHS staff are trained to a high level. Most visits to doctors are for minor concerns and I believe NHS paramedics are more than capable of dealing with these concerns.

Conversely, examples of the types of comments provided by Panel members who would feel **uncomfortable** with being offered a consultation with an ambulance professional as part of the service offered at their GP practice are provided below:

I would feel that the ambulance professional should be dealing with emergencies and therefore I would feel I was wasting their time.

Ambulance professionals are experts in emergency care and should not be used to alleviate the strain on GP services as it will stretch their resources and they will not be paid a GP's salary for providing the same service.

A doctor is bound by confidentiality on oath and it would be uncomfortable discussing a delicate medical problem with anyone other than a doctor.

I have complex, rare medical conditions which are hard to treat and a paramedic may not be familiar or have the training to recognise their seriousness.

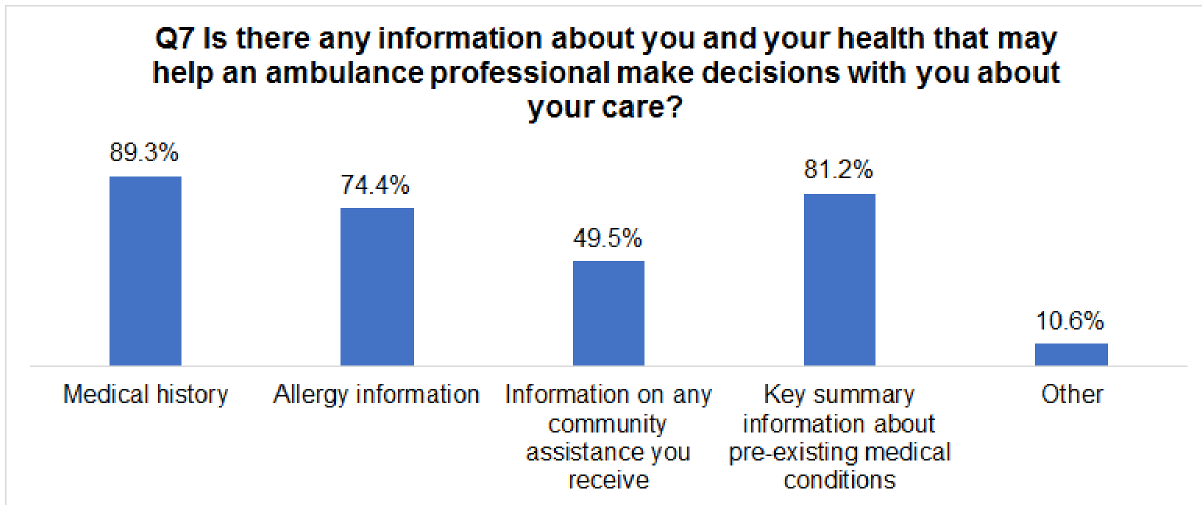
GPs are for long term care. Ambulance professionals are experts at short term care.

I would not have the same confidence in the knowledge and skills of the ambulance professional.

Panel members were asked to select topics from a list of options, identifying those where it would be helpful for ambulance professionals to make decisions with them about their care. Just under 9 in 10 respondents (89%) said knowing their 'medical history' would be useful and a further 81% selected 'key information about pre-existing medical conditions'. Those who selected 'other' were asked to specify any other types of information they believed would be helpful for ambulance professionals. The main themes emerging from these other responses were to provide information on:

- current medication
- mental health concerns
- special needs or disability needs
- family support/next of kin, and
- DNACPR (Do Not Attempt Cardiopulmonary Resuscitation).

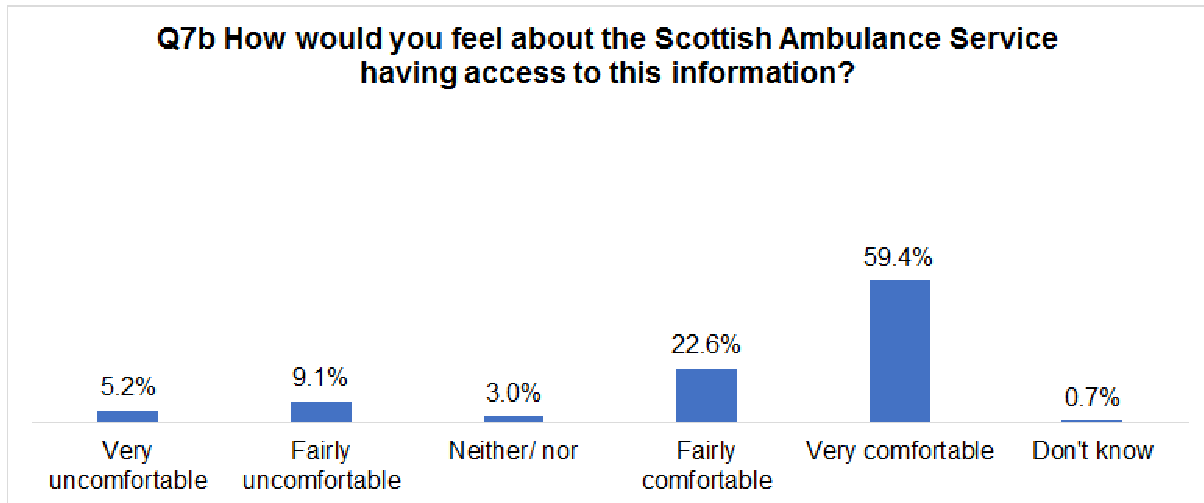
Figure 7: Information that may help an ambulance professional make decisions about care



Base: Weighted, n=598

Over 8 in 10 respondents (82%) felt either very or fairly comfortable with the Scottish Ambulance Service having access to this information (e.g. medical history, allergy information, community assistance etc.) On the other hand, 14% said they felt very or fairly uncomfortable in this respect.

Figure 8: Opinions on the Scottish Ambulance Service having access to this information



Base: Weighted, n=619

The following comments were made by Panel members who commented on the **benefits** of the Scottish Ambulance Service having access to their personal and medical history. These were generally where Panel members believed that having access to this information would result in easier, more accurate and more timely treatment and diagnosis:

It may help them to make quick decisions that could ultimately save a life.

Health professionals, local practice, hospitals and ambulance service should have access to those medical records.

It should be compulsory – all information should be readily available in an emergency situation.

I am confident of their understanding of patient confidentiality.

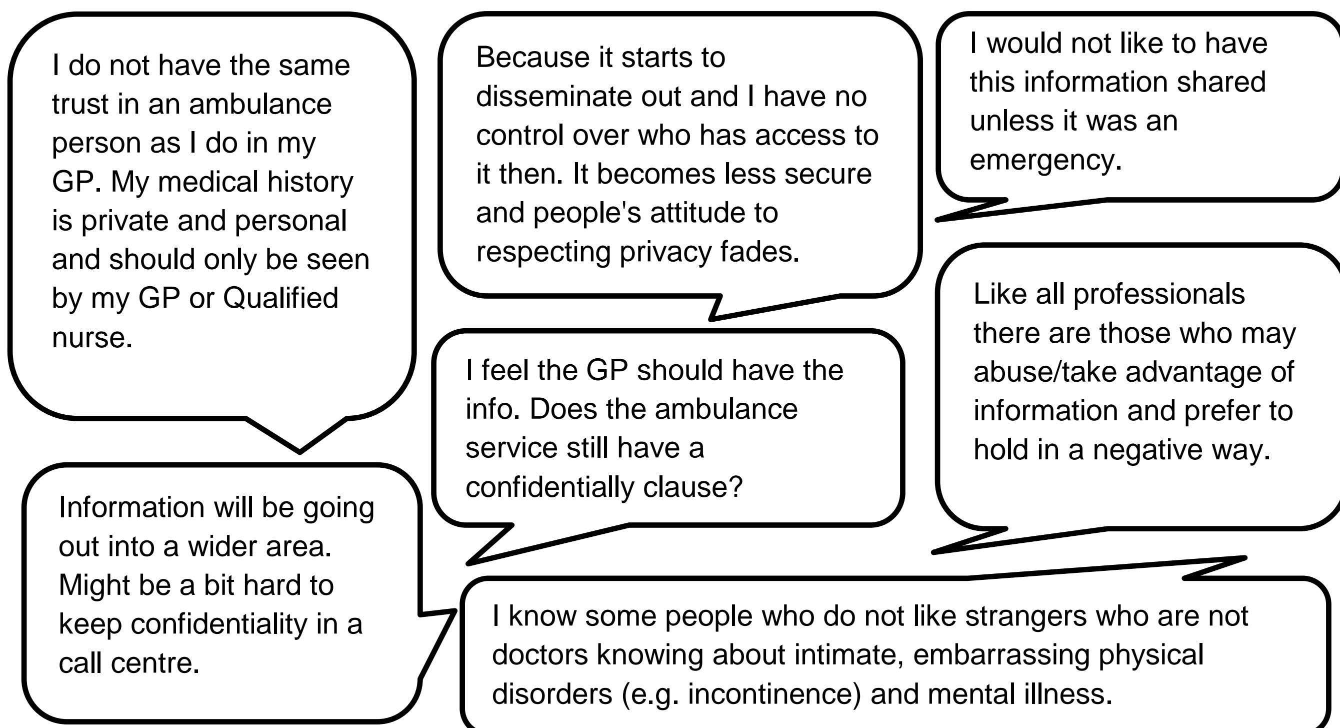
Makes accessing treatment and diagnosis easier.

I have ongoing health problems and in my experience the paramedics have been excellent and very understanding to my situation.

If you require the appropriate treatment, you need to share relevant information i.e. your health status. Ambulance personnel are professionally trained; adhere to set standards of practice.

They would be trained to deal with this and provide appropriate treatment.

Conversely, examples of the comments made by Panel members who had **concerns** about the Scottish Ambulance Service having access to their personal and medical history are shown below. These included concerns about confidentiality and data security:



Respondents were then asked if they would like to expand on any of their answers covered in this section of the questionnaire. Themes to emerge from these responses included:

- an acknowledgement of and admiration for the service ambulance professionals provide
- an awareness of limited resources and funding, meaning healthcare professionals are stretched to capacity
- a requirement for more healthcare professionals, rather than modifying the role of existing staff members
- additional confirmation that respondents would be happy to share their medical history with ambulance professionals
- concerns regarding confidentiality and consent when sharing medical information and history with ambulance professionals, and
- concerns about the Scottish Ambulance Service being adversely affected if paramedics had to substitute the GP service.

Chapter 3: Attitudes toward organ and tissue donation after death

Introduction

Organ and tissue donation means giving part of your body to someone else who needs it, after your death. Organs which are routinely transplanted include the kidneys, liver, heart, lungs, pancreas and small bowel. Tissue which is routinely transplanted includes the eyes, tendons, heart valves, bone and skin.

In future, the law on organ and tissue donation after death in Scotland will be changing to an 'opt-out' system'[3]. To help the Scottish Government prepare for this change, Panel members were asked for their views on organ and tissue donation (after death) at the present time.

Moving to an 'opt-out' system and trust in the system

Panel members were asked for their opinions on the 'opt-out' system that will be implemented in Scotland. The main findings to emerge from these responses were:

- 83% of Panel members supported the introduction of an 'opt-out' system for organ and tissue donation
- 86% of were aware of the decision to move to an 'opt-out' system in Scotland
- 88% understood that under the proposed 'opt-out' system, they may be presumed to be willing to donate unless they have stated that they do not wish to do so, and
- 76% agreed they held trust in the system, compared to 3% who disagreed.

[3] The law around organ and tissue donation in Scotland is due to change in Autumn 2020.

Figure 9: Opinions on moving to an 'opt-out' system

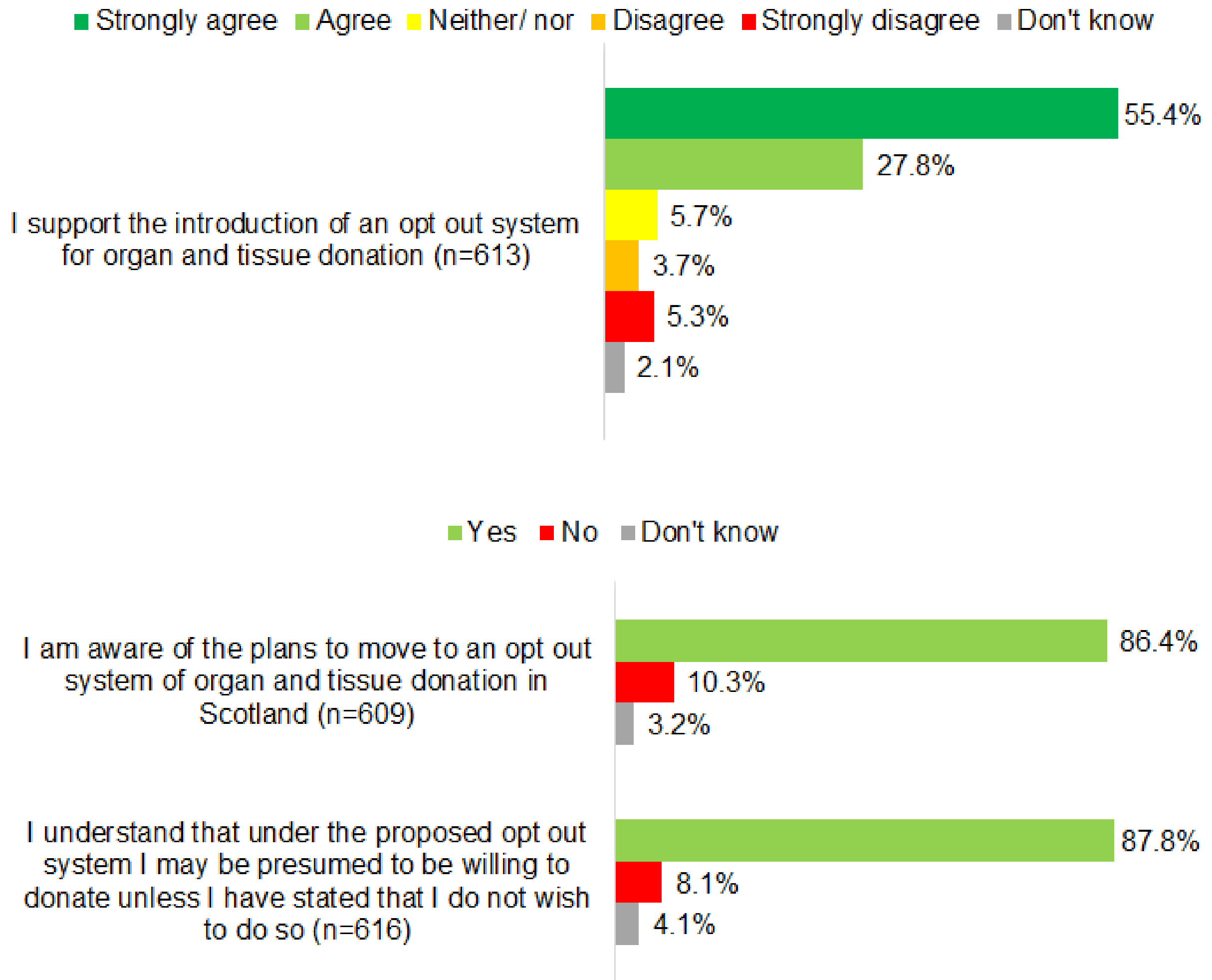
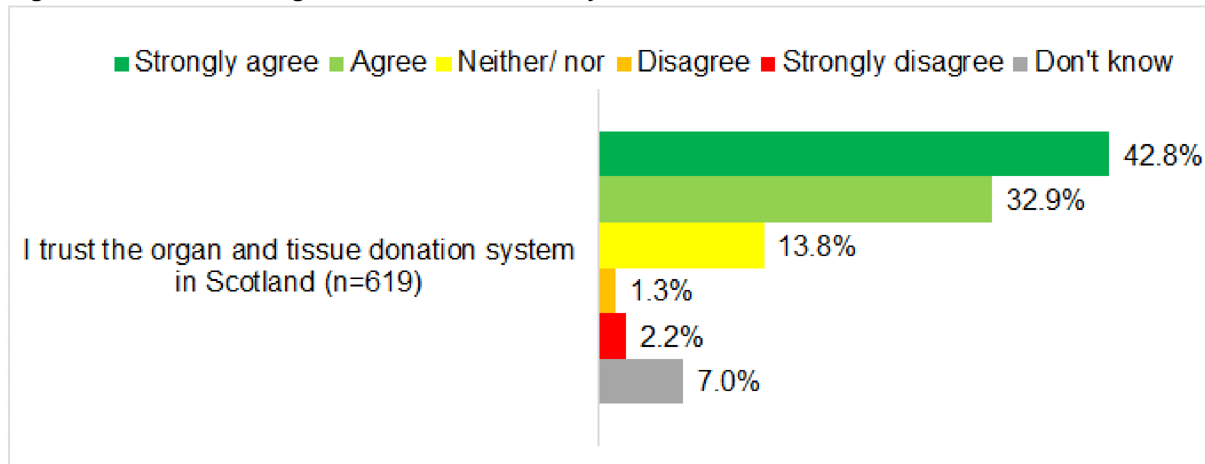


Figure 10: Trust in the organ and tissue donation system

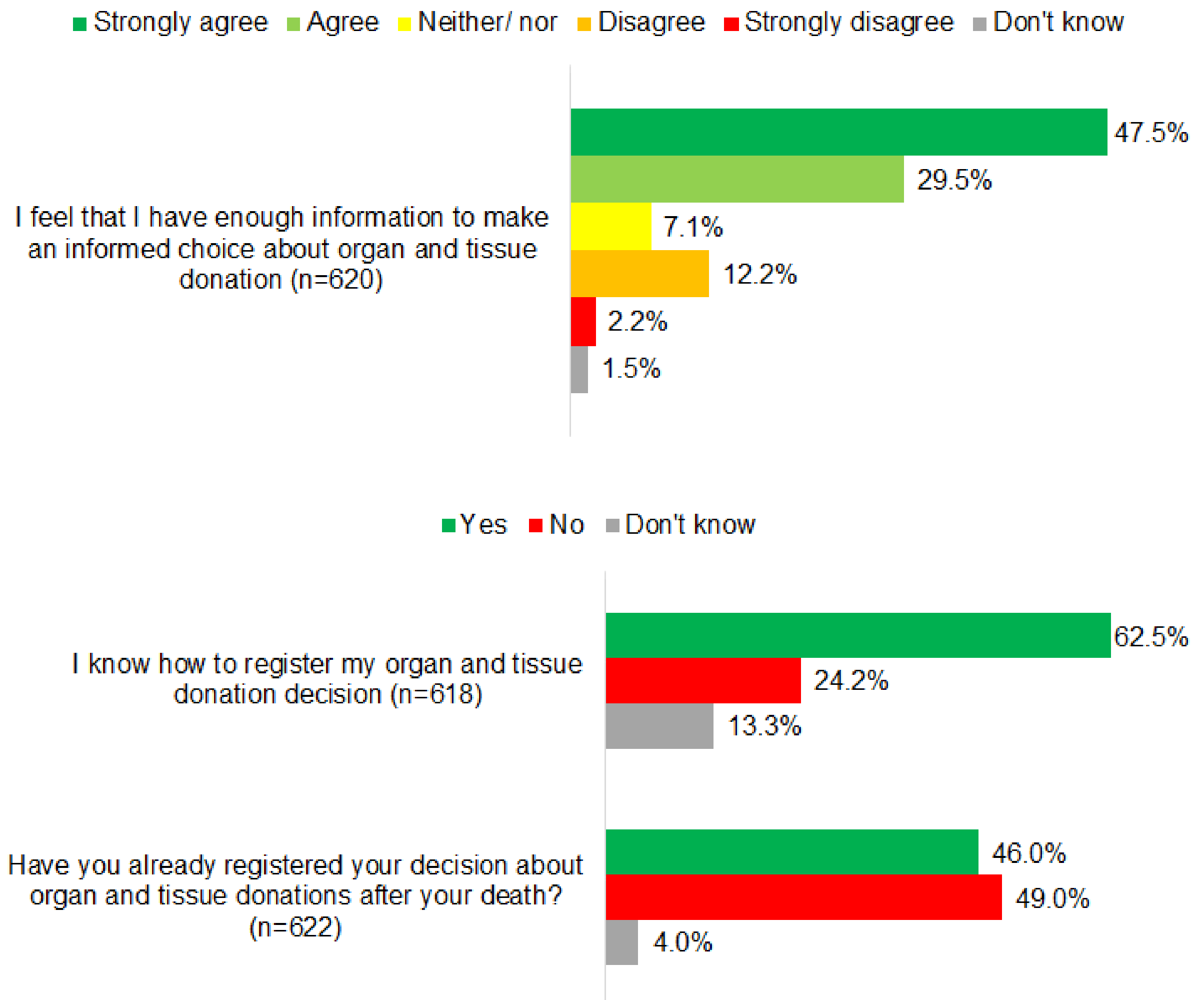


Making and recording decisions

Just under eight in ten Panel members (78%) felt they have enough information to make an informed choice about organ and tissue donation, compared to 14% who did not.

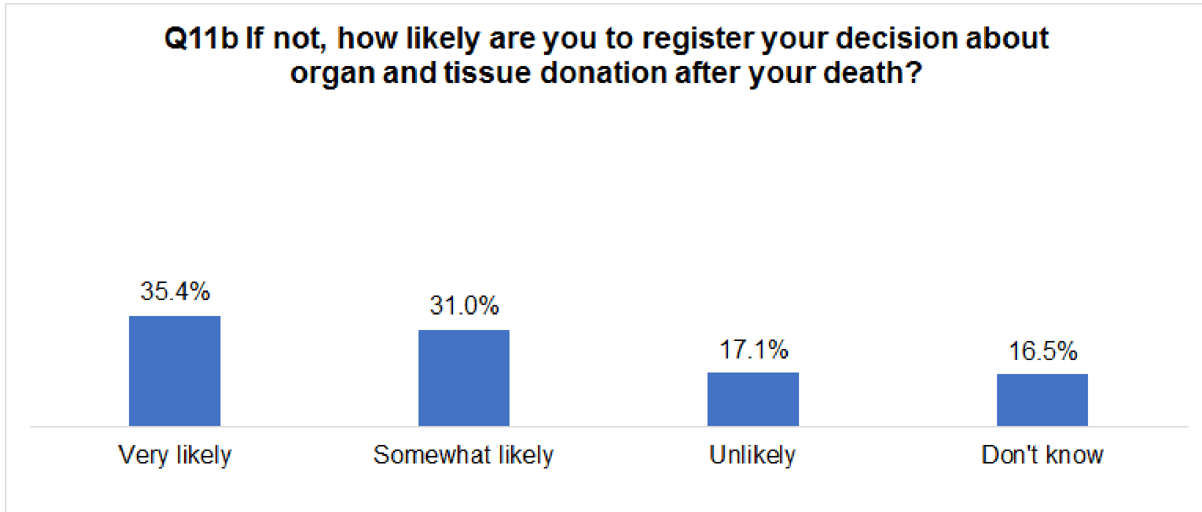
Nearly two thirds of respondents (62%) knew how to register their organ and tissue donation decision, with just under half of respondents (46%) stating they had already registered their decision, compared to 49% who had not and 4% who were unsure.

Figure 11: Making and recording decisions regarding organ and tissue donation



Respondents who had not registered their decision were asked how likely or unlikely they would be to register their decision about organ and tissue donation after their death. Around two thirds of these respondents (66%) said they were either very or somewhat likely to do this, 17% said they were unlikely and a further 17% were unsure.

Figure 10: Likelihood of registering decision about organ and tissue donation after death

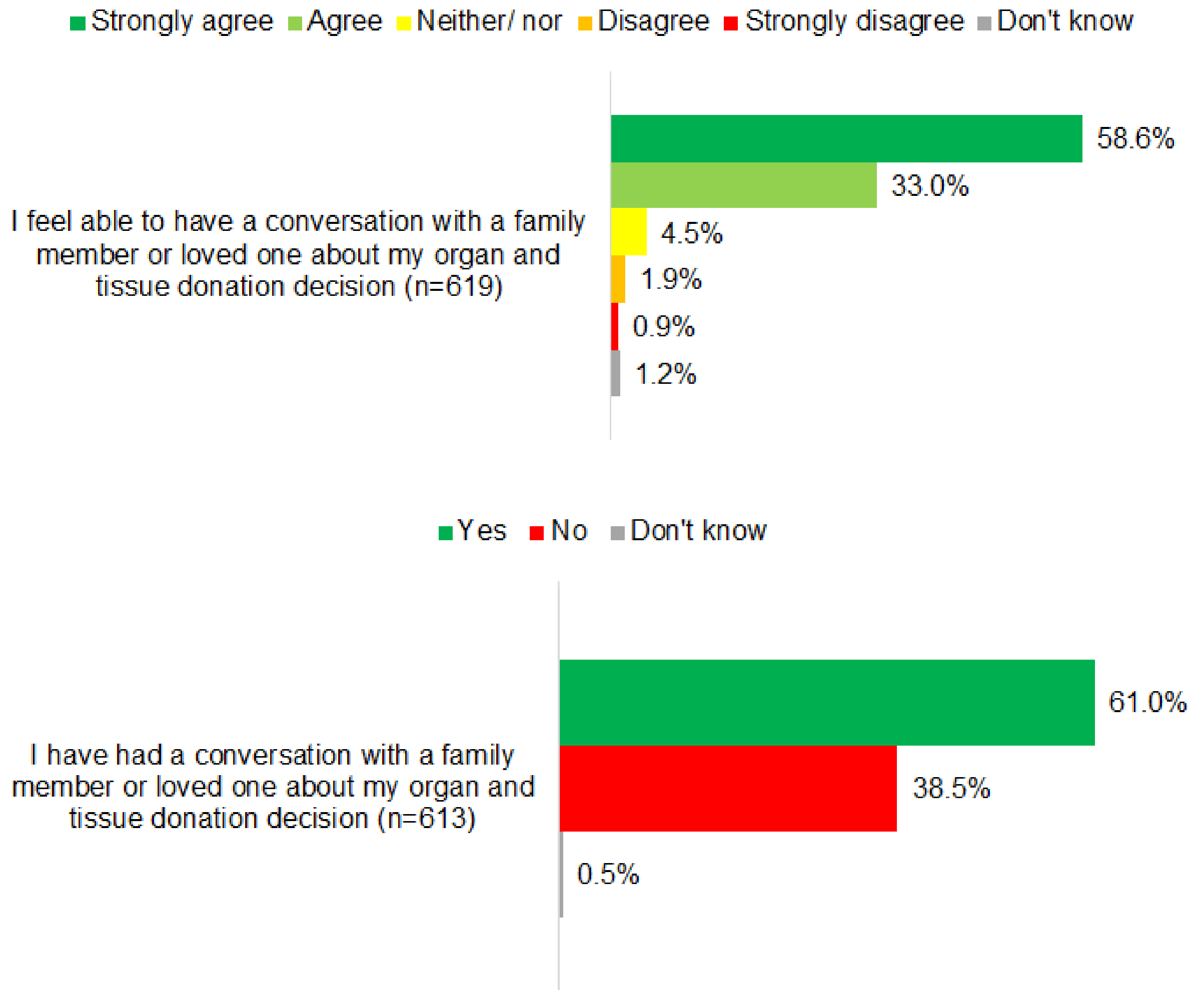


Base: Weighted, n=302

Family Conversations

Organ and tissue donation can be a very sensitive topic of discussion. Panel members were asked if they felt able to have a conversation with a family member or loved one about their organ and tissue donation decision. The majority of respondents (92%) said they felt able to have this conversation, compared to 3% who did not. More than six in ten respondents (61%) have already had this conversation with a family member or loved one, while 39% said they have not.

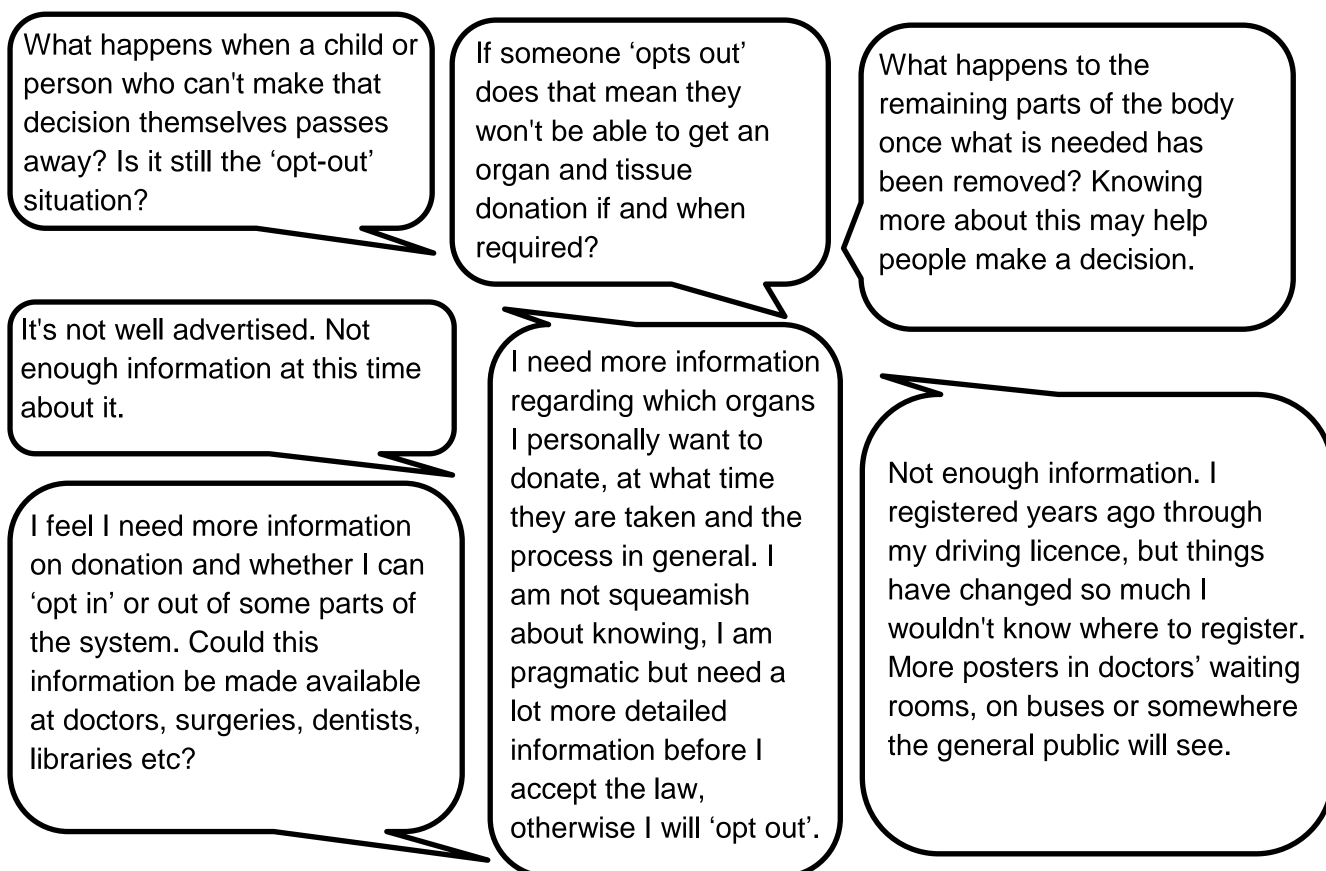
Figure 13: Proportion of respondents able to discuss organ and tissue donation with family or loved ones



The questionnaire included an open-ended question asking respondents to record any other comments they had about organ and tissue donation after death. The responses to this question were quite varied, but included a number of broad themes listed below.

- Respondents felt more information about organ and tissue donation should be made available.
- Agreement with the new 'opt-out' system.
- Uncertainty regarding the condition of organs suitable for donation, e.g. deterioration due to age or ill health.
- A positive perception of organ and tissue donation.
- A sentiment that the state should not presume consent and therefore disagreement with the adoption of the 'opt-out' system.
- Reservation regarding family members' ability to negate the deceased's personal decision on organ and tissue donation.
- A belief that organ and tissue donation is something that everyone should consider and think about.
- A negative view of organ and tissue donation.
- Concerns regarding potential impact on family members.

The most common response from Panel members when asked if they had anything else they would like to say about organ and tissue donation after death was the need for more information. Some examples of the types of information Panel members felt were needed are highlighted below:



Chapter 4: Nursing and Midwifery Care

Introduction

Excellence in Care is a national approach to develop and implement a world-class, evidence-based, national method to assuring nursing and midwifery care across all hospital and community settings in Scotland.

The approach seeks to improve, integrate and co-ordinate the way nursing and midwifery services are delivered across Scotland to ensure that everyone receives a consistent standard and quality of service.

A good care experience

When asked about the qualities of a 'caring nurse or midwife', the top response from Panel members was for them to be compassionate, understanding or sympathetic (75%). This was followed by staff being knowledgeable, skilled, trained, professional or experienced (73%). This question was open-ended and reported by the following themes in the table below.

Figure 11: Qualities of a 'caring nurse or midwife' (Open ended response themes)

Q13 What do you feel are the qualities of a 'caring nurse or midwife'?	
Weighted base, n=575	**%**
Compassionate/ understanding/ sympathetic	74.9%
Knowledgeable/ skilled/ trained/ professional/ experienced	72.5%
Good listener/ Having sufficient time for patients	21.7%
Friendly/ good people skills	21.6%
Calm/ patient	15.7%
Good communicator	11.1%
Ability to assess the situation quickly and accurately/ make quick decisions	5.1%
Confidence/ ability to take control	4.1%
Hygienic/ appearance	1.3%
Sense of humour	1.2%
Enjoy/ love their job	0.8%
Physically fit	0.6%
Other	9.4%
Don't know	0.8%

Some examples of the open-ended responses provided by Panel members to describe the qualities they believe make a caring nurse or midwife are shown below:

Q13 What do you feel are the qualities of a 'caring nurse or midwife'?

Even when they were busy, they make time to just see how you are.

To explain medical terms or treatment that can be understood by the patient and to answer any queries that they may have.

Kind, listens to what I want and need and acts in a calm and professional manner.

Strong social skills, ability to listen and manage frightening situations calmly.

Excellent clinical skills, and commitment to ongoing learning and skills development.

Someone who takes time with each patient to reassure and give time to listen to concerns.

The ability to exude confidence in the patient that he/she is being cared for by a competent professional.

One that knows as much as possible about their patient and their needs and requirements.

Someone who is compassionate and who can remain impartial and not judge people.

With regards to a midwife, that they have full background information about the patient to enable them to respond to any given situation before during and after the birth.

Not under pressure because of shortages of staff.

There is currently a high level of training, but there should be compulsory continuous development of skills at all levels.

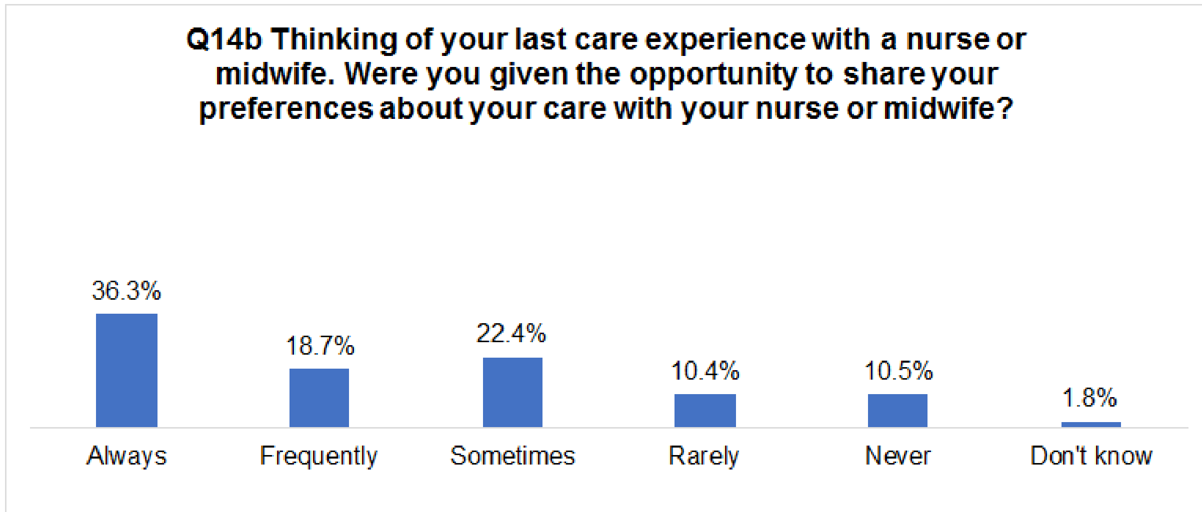
A wee bit of humour goes a long way and being able to listen.

Knowledge, experience, well-trained, and highly skilled.

Person-centred care

Over 3 in 10 survey respondents (31%) have had a recent care experience in the last 12 months with a nurse or midwife. Of these individuals, over half (55%) said they are always or frequently given the opportunity to share their preferences about their care with their nurse or midwife, 22% said they are sometimes given this opportunity, 21% said they are rarely or never given this opportunity and 2% were unsure.

Figure 12: Being given the opportunity to share care preferences with nurse or midwife



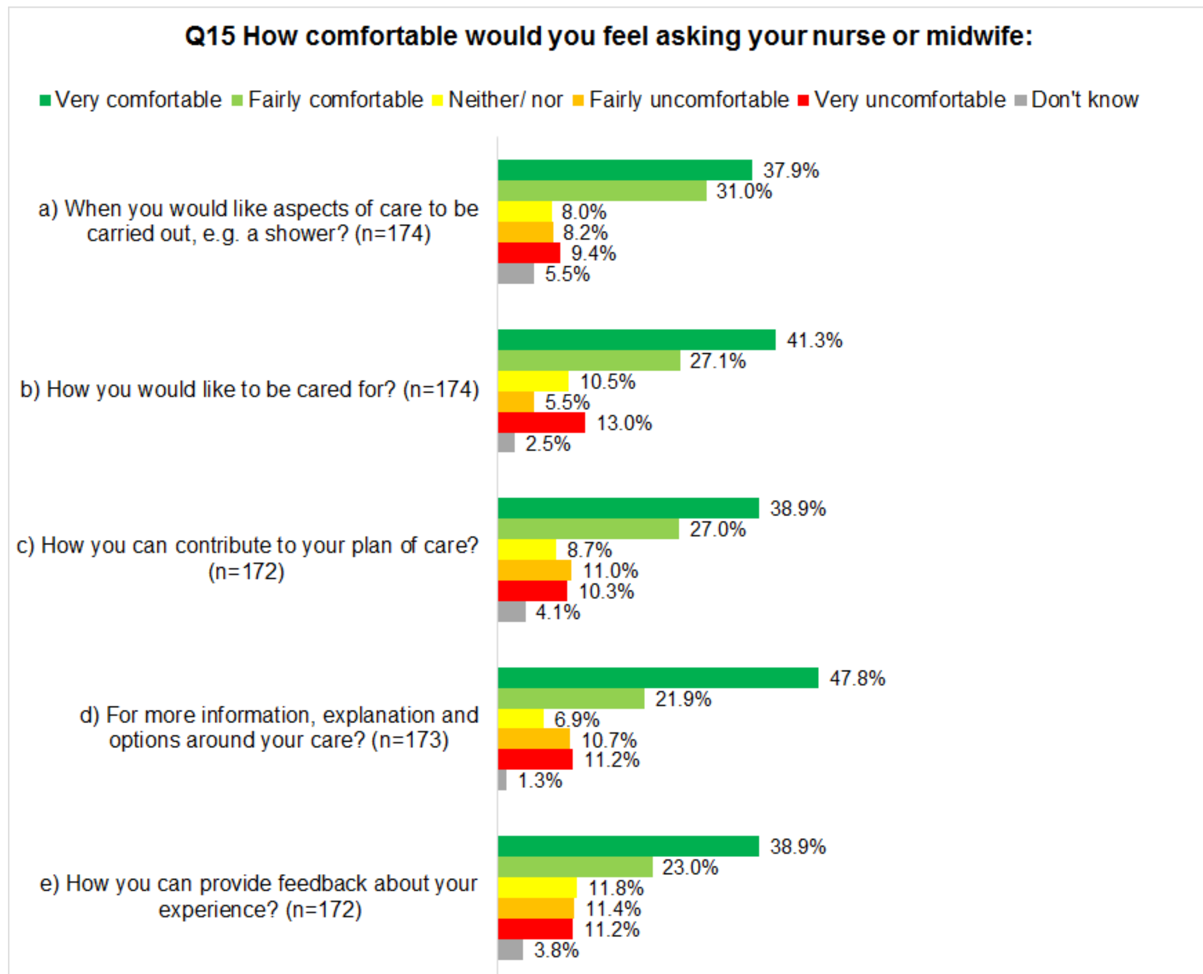
Base: Weighted, n=173

Following on from this, respondents were asked how comfortable or uncomfortable they would feel asking a nurse or midwife a range of questions about their care. Seven in ten respondents felt comfortable asking their nurse or midwife the following:

- For more information, explanation and options around their care (70%)
- When they would like aspects of care to be carried out (69%)
- How they would like to be cared for (68%)
- How they can contribute to their plan of care (66%)

Fewer respondents (62%) felt comfortable asking their nurse or midwife how they could provide feedback about their experience.

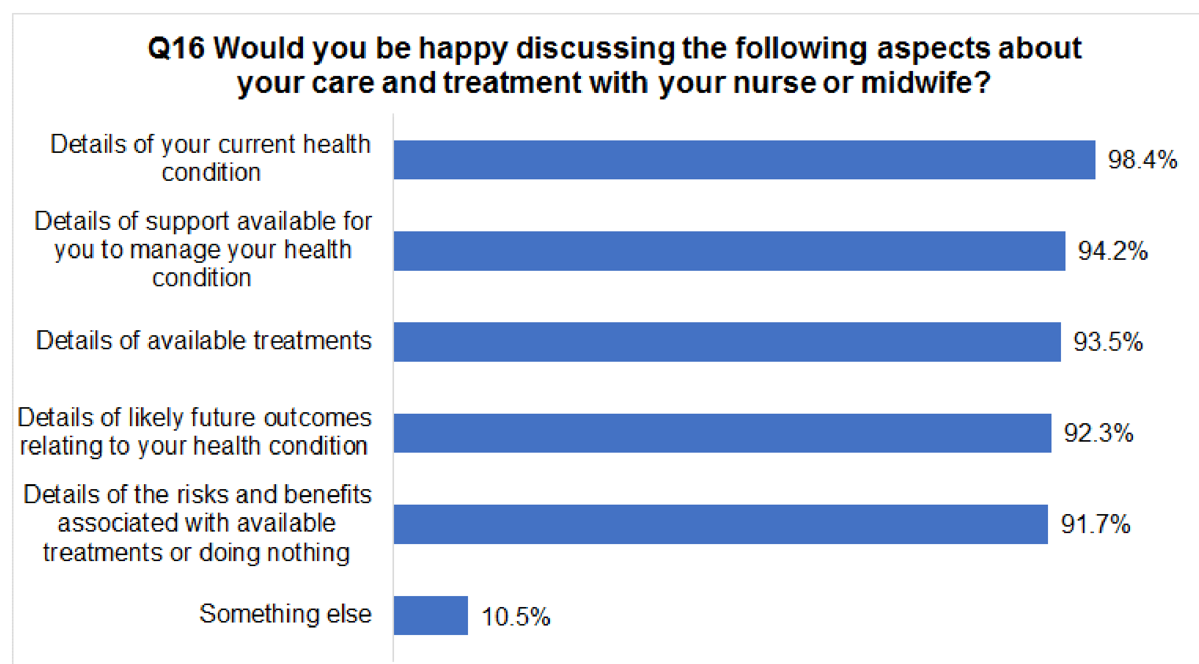
Figure 13: How comfortable people feel asking nurse or midwife a range of questions about their care



Reponses varied when asked if there was any other kind of information Panel members would like to share with nurses or midwives due to personal circumstances. Some examples were medical history, mental health concerns and the effects of previously prescribed medication.

Panel members were asked to select from a list of options, identifying which aspects of their care and treatment they would be happy discussing with their nurse or midwife. Over 9 in 10 respondents were happy to discuss each of these aspects with respondents being most comfortable discussing the details of their current health condition (98%) and slightly less comfortable discussing the risks and benefits associated with the treatments available to them or doing nothing (92%) and details of likely future outcomes relating to their health condition (92%).

Figure 14: Aspects of care and treatment Panel members would be happy to discuss with their nurse or midwife



Base: Weighted, n=588

When asked if there was anything that stops Panel members or limits them from being involved in decisions about their healthcare and treatment, more than 7 in 10 respondents said there was nothing to stop them being involved (73%). Where respondents feel limited from becoming involved, 9% said this was due to a lack of available appointments or appointments being too short with health professionals while 8% said they did not feel comfortable due to staff issues.

Figure 15: Anything that stops (or limits) Panel members from being involved in decisions about their healthcare and treatment (Open ended response themes)

Does anything stop (or limit) you from being involved in decisions about your healthcare and treatment?	
Weighted base, n=267	**%**
Nothing, I feel comfortable	72.5%
Lack of appointments/ apps too short/ time	8.8%
Staff issues e.g. staff not listening/ not seeing the same staff member	8.0%
Something else	7.2%
Fear/ embarrassment/ lack of confidence	2.1%
Limited knowledge	2.0%
Mental health/ anxiety/ developmental disorder/disability	1.7%

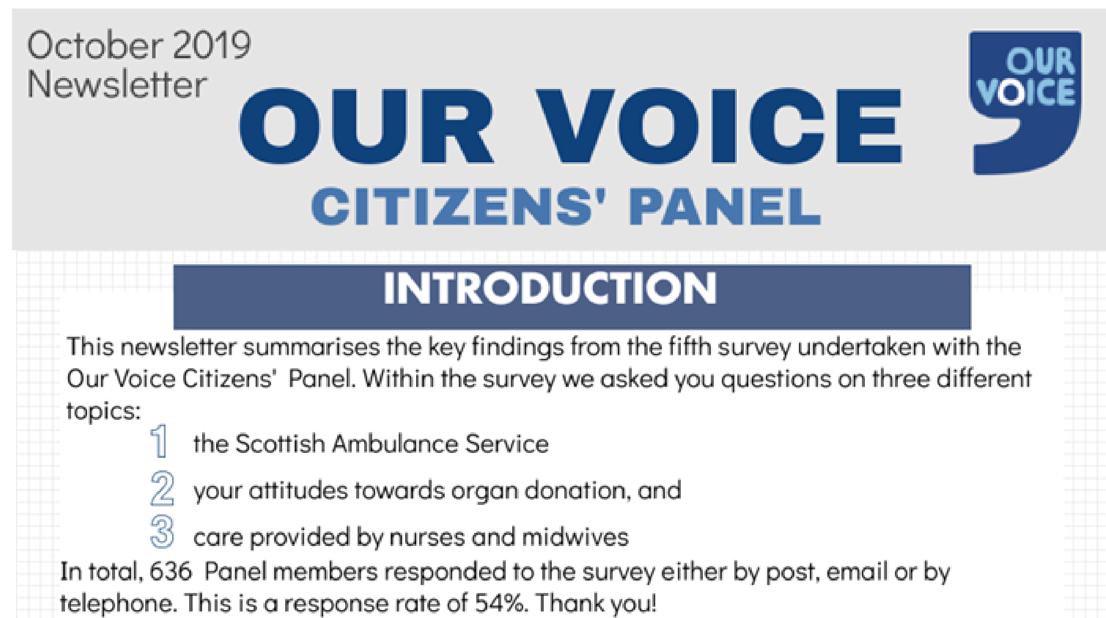
Professionalism

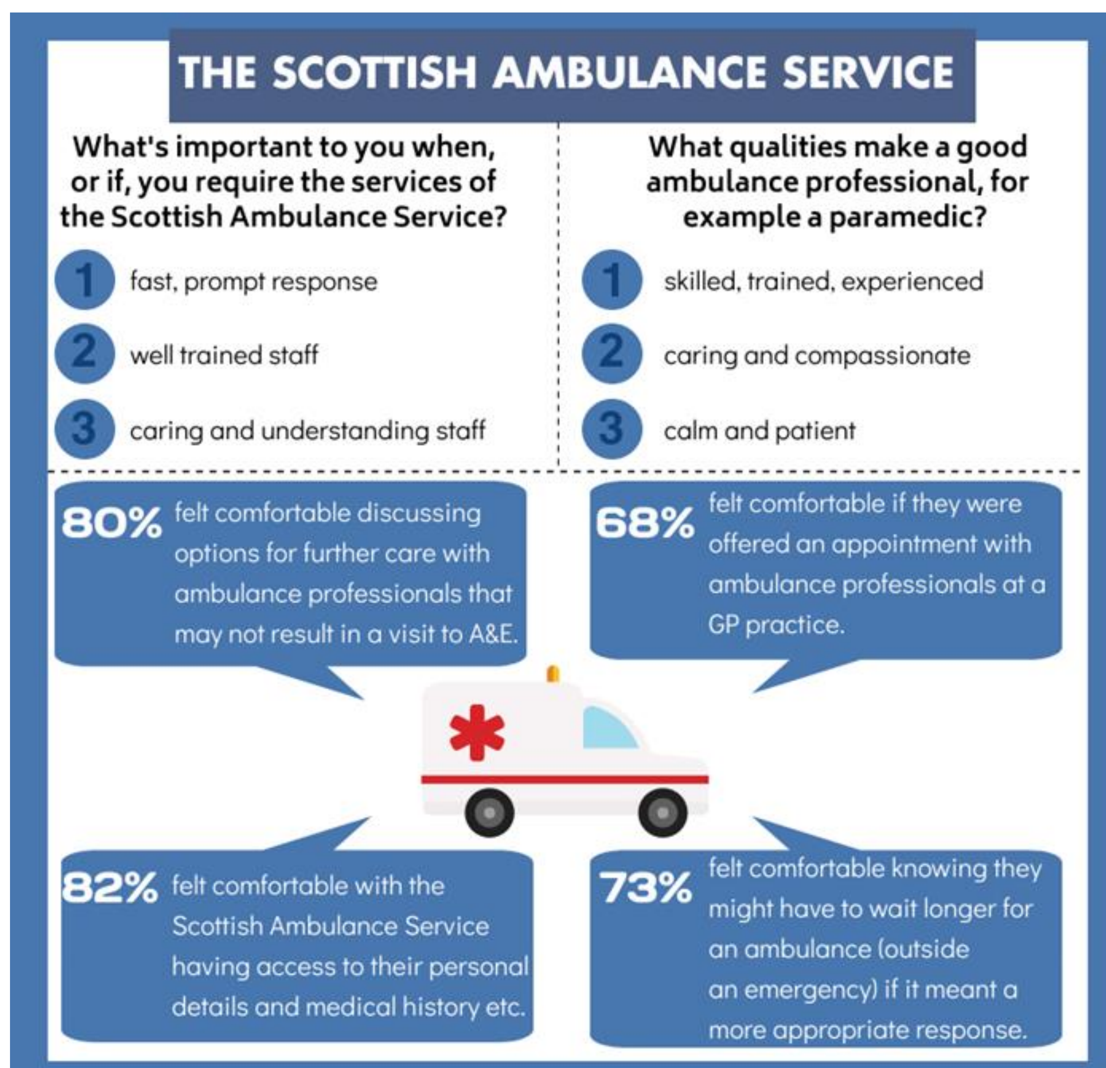
Finally, respondents were asked to select, from a list of options, which three things matter most to them when they think about the professional practice of nurses and midwives. The top response was the 'competence, knowledge and skill' of nurses and midwives (80%), followed by being treated with dignity and respect (51%) and being cared for compassionately (32%).

Figure 16: Priorities for the professional practice of nurses and midwives

What matters to you most when you think about the professional practice of nurses and midwives? (Please tick the three most important to you)	
Weighted base, n=614	
Competence, knowledge and skill	79.5%
Being treated with dignity and respect	51.0%
Being cared for compassionately	31.5%
Honesty and integrity	25.1%
Being treated as an individual with your preferences recognised	24.5%
Being encouraged and enabled to be involved in decisions about your care	22.8%
Inspiring trust and confidence	17.2%
A sense of safety	16.8%
Putting your interests first	16.2%
Maintaining privacy and confidentiality	12.0%
Something else	0.9%

Appendix 1: Our Voice Citizens' Panel newsletter





ORGAN AND TISSUE DONATION

46%
of respondents had already registered their decision about organ and tissue donation after their death.

66%
of respondents who had not registered their decision said they would be likely to do this

88%
understood that under the proposed opt out system they may be presumed to be willing to donate unless they have stated that they do not wish to do so.

86%
were aware of the plans to move to an opt out system or organ and tissue donation in Scotland.

62%
were aware how to register their organ and tissue donation decision.

61%
have had a conversation with a family member or loved one about their organ and tissue donation decision.

NURSING & MIDWIFERY CARE

What do you feel are the qualities of a 'caring nurse or midwife'?

1. caring and understanding
2. well trained
3. good listener/ having sufficient time for patients

What matters to you most when thinking about the professional practice of nurses and midwives?

1. competence, knowledge and skill
2. being treated with dignity & respect
3. being cared for compassionately

55% of respondents who have had a recent care experience said they always or frequently are given the opportunity to share their preferences about their care.

70% felt comfortable asking their nurse or midwife for more information, explanation and options around their care and how they can contribute to their plan of care.

69% felt comfortable asking their nurse or midwife when they would like to be cared for.

62% felt comfortable asking their nurse or midwife how they can provide feedback about their experience.

Appendix 2: Questionnaire

1. Welcome to the Our Voice Citizens' Panel

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

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

In this Our Voice Citizens' Panel survey there are questions on three different topics, they are:

- the Scottish Ambulance Service
- your attitudes towards organ donation, and
- care provided by nurses and midwives.

There are no wrong answers to these questions - this is not a test. We are interested in your personal responses, thoughts and experiences of these issues and how they apply to you. Your answers are confidential and all views will be made anonymous.

Please answer the questionnaire as fully as you are willing, and able. It should take about 15-20 minutes to complete. If there is anything you do not wish to answer please just move on to the next question.

Please do not use Google to answer these questions.

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

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

Thank you.

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

Please complete and return this survey by 26th July 2019

2. Scottish Ambulance Service

The Scottish Ambulance Service is beginning to develop its strategy for the future, focusing on the period 2021 – 2030. The Ambulance Service has changed a lot in recent years, moving away from primarily a means of transporting people to hospitals to becoming a key provider in healthcare in communities'.

The Scottish Ambulance Service would like to know what is important to people when they require the care of Scottish Ambulance Service, and what makes for a quality ambulance service in Scotland.

1. What is important to you when, or if, you require the services of the Scottish Ambulance Service? (Please limit your answer to 3 things)

1

2

3

2. In your opinion, what qualities make a good ambulance professional, for example a Paramedic? (Please limit your answer to 3 things)

1

2

3

<u>Prioritising Response</u>

We have recently made improvements to how the Scottish Ambulance Service identifies and prioritises its response to its sickest patients. In order to ensure these people receive the fastest response, and that patients with more complex needs are directed to the most appropriate response for their condition, those with complex needs might spend a little longer on the phone discussing their needs.

In order to continue to improve the Scottish Ambulance Service response and care that people receive, it is important for it to understand how and why people might access its services, and what they expect to happen when they do.

3. Apart from a life threatening emergency, are there other situations in which you think you may call for an ambulance?

4. Outside of a life threatening emergency, how would you feel knowing that you might have to wait a little longer for an ambulance response if it meant that you were more likely to receive a more appropriate response for your condition?

Very uncomfortable	Fairly uncomfortable	Neither nor	Fairly comfortable	Very comfortable	Don't know
☐	☐	☐	☐	☐	☐

5. How would you feel discussing options for further care with ambulance professionals that may not result in a visit to a hospital emergency department?

Very uncomfortable	Fairly uncomfortable	Neither nor	Fairly comfortable	Very comfortable	Don't know
☐	☐	☐	☐	☐	☐

Working with other health services

Since 2018 there is a commitment that ambulance professionals will form part of primary care teams in GP practices. The Scottish Ambulance Service would like to better understand how people feel about it working in GP practices.

6. a) How would you feel if you were offered a consultation with an ambulance professional as part of the service offered by your GP Practice?

Very uncomfortable	Fairly uncomfortable	Neither nor	Fairly comfortable	Very comfortable	Don't know
☐	☐	☐	☐	☐	☐

6 b) Can you explain why you say this?

7. a) Is there any information about you and your health that may help an ambulance professional make decisions with you about your care?

Please tick all that apply or specify other information you think appropriate.

Medical history	☐
Allergy information	☐
Information on any community assistance you receive	☐
Key summary information about pre-existing medical conditions	☐
Other (please specify)	☐

7 b) How would you feel about the Scottish Ambulance Service having access to this information?

Very uncomfortable	Fairly uncomfortable	Neither nor	Fairly comfortable	Very comfortable	Don't know
☐	☐	☐	☐	☐	☐

7 c) Can you explain why you say this?

8. Are there any of your answers in this section of the questionnaire you would like to expand on?

3. Attitudes toward organ and tissue donation after death

Organ and tissue donation means giving part of your body to someone else who needs it, after your death. Organs which are routinely transplanted include the kidneys, liver, heart, lungs, pancreas and small bowel. Tissue which is routinely transplanted includes the eyes, tendons, heart valves, bone and skin.

In future, the law on organ and tissue donation after death in Scotland will be changing to an 'opt-out' system. To help the Scottish Government prepare for this change, we are interested to hear about people's views on organ and tissue donation (after death) at the present time.

Please select one answer on each row. ☒

9. To what extent do you agree or disagree with the following statements about organ and tissue donation after death?

	Strongly agree	Agree	Neither nor	Disagree	Strongly disagree	Don't know
a) I feel that I have enough information to make an informed choice about organ and tissue donation	☐	☐	☐	☐	☐	☐
b) I feel able to have a conversation with a family member or loved one about my organ and tissue donation decision	☐	☐	☐	☐	☐	☐
c) I trust the organ and tissue donation system in Scotland	☐	☐	☐	☐	☐	☐
d)I support the introduction of an opt out system for organ and tissue donation	☐	☐	☐	☐	☐	☐

10. Please select the answer that best applies to you with the following statements about organ and tissue donation after death.

	Yes	**No**	**Don't Know**
a) I know how to register my organ and tissue donation decision	☐	☐	☐
b) I have had a conversation with a family member or loved one about my organ and tissue donation decision	☐	☐	☐
c) I am aware of the plans to move to an opt out system of organ and tissue donation in Scotland	☐	☐	☐

d) I understand that under the proposed opt out system I may be presumed to be willing to donate unless I have stated that I do not wish to do so	☐	☐	☐

11 a) Have you already registered your decision about organ and tissue donation after your death?

Yes	No	Don't Know
☐	☐	☐

11 b) If not, how likely are you to register your decision about organ and tissue donation after your death?

Very Likely	Somewhat Likely	Unlikely	Don't Know
☐	☐	☐	☐

12 If there is anything else you would like to say about organ and tissue donation after death, please use the space below:

4. Nursing & Midwifery Care

Excellence in Care is a national approach to develop and implement a world-class, evidence-based, national method to assuring nursing and midwifery care across all hospital and community settings in Scotland.

The approach seeks to improve, integrate and co-ordinate the way nursing and midwifery services are delivered across Scotland to ensure that everyone receives a consistent standard and quality of service.

A Good Care Experience

We want to find out about the things that are important to you as well as explore what a positive experience of healthcare would look like to you.

13 What do you feel are the qualities of a 'caring nurse or midwife'?
(please limit your response to 3 items):

1	
2	
3	

Person Centred Care

It is generally agreed that person-centred care is delivered when health and social care professionals work together with people who use services, tailoring them to the needs of the individual and what matters to them.

We would like to find out about your experiences of person-centred care relating to your experience of nursing or midwifery care.

14a Have you had a recent care experience in the last 12 months with a nurse or midwife?

Yes	☐	Go to Q14b
No	☐	Go to Q16

14b Thinking of your last care experience with a nurse or midwife. Were you given the opportunity to share your preferences about your care with your nurse or midwife?

Always	Frequently	Sometimes	Rarely	Never	Don't know
☐	☐	☐	☐	☐	☐

15 How comfortable would you feel asking your nurse or midwife:

	Very uncomfortable	Fairly uncomfortable	Neither nor	Fairly comfortable	Very comfortable	Don't know
a) When you would like aspects of care to be carried out, e.g. a shower?	☐	☐	☐	☐	☐	☐
b) How you would like to be cared for?	☐	☐	☐	☐	☐	☐
c) How you can contribute to your plan of care?	☐	☐	☐	☐	☐	☐
d) For more information, explanation and options around your care?	☐	☐	☐	☐	☐	☐
e) How you can provide feedback about your experience?	☐	☐	☐	☐	☐	☐

Is there any other kind of information about you and/ or your care that you would like to share with a nurse or midwife?

Talking to your Nurse or Midwife, Understanding What Matters to You

We would like you to tell us about the things you think would make your conversations with nurses or midwives about care and treatment easier, more 'doing with you' rather than 'doing to you'.

16 Would you be happy discussing the following aspects about your care and treatment with your nurse or midwife? **Please tick all that apply**

Details of your current health condition	☐	Details of likely future outcomes relating to your health condition	☐
Details of available treatments	☐	Details of the risks and benefits associated with available treatments or doing nothing	☐
Details of support available for you to manage your health condition	☐	Something else	☐

If something else, please tell us:

17 **Does anything stop (or limit) you from being involved in decisions about your healthcare and treatment? If yes, please indicate here:**

Professionalism

The Nursing and Midwifery Council (NMC) is the regulator for nurses and midwives in the UK and has identified that 'Good health and care outcomes are highly dependent on the professional practice and behaviours of nurses and midwives.'

18 What matters to you most when you think about the professional practice of nurses and midwives? (Please tick the <u>three</u> most important to you).

Putting your interests first	☐	Competence, knowledge and skill	☐
A sense of safety	☐	Honesty and integrity	☐
Being treated with dignity and Respect	☐	Inspiring trust and confidence	☐
Being treated as an individual with your preferences recognised	☐	Being encouraged and enabled to be involved in decisions about your care	☐
Being cared for compassionately	☐	Maintaining privacy and confidentiality	☐
Something else	☐		☐

If something else, please state:

Thank you for taking the time to complete the survey.

Appendix 3: Response profile

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

Date	Activity	Description	Number
18th June 2019	First email	Distributed Bounce back Total emails delivered	988 125 863
25th June 2019	First email reminder	Number sent	707
		Number Bounce back	0
		Total emails delivered	707
21st June 2019	First postal survey	Number sent to Panel members without email addresses Number sent to bounce back Panel members Total number sent	183 125 311
12th July 2019	Postal survey reminder	Number sent	841
5th August 2019	Telephone boost		51

SURVEY OUTCOMES AS AT 19/08/2019

Emails sent	863
Number of email responses	254
Email response rate	29%

Number of postal sent	841
Number of postal returned	331
Postal response rate	39%

Telephone surveys	51

OVERALL RESPONSE RATE	
Current response	636[4]
Current number on Panel	1168
Overall response rate	54%

[4] Two surveys were returned without an ID attached and were therefore unable to be included in the weighting process as they were unidentifiable in terms of age and gender.

Gender	No on Panel	% of Panel	Scottish popn.	Difference	OV 2019 First Survey Profile	% of first survey response	Response rate
Male	626	53.6%	49%	4%	373	59%	60%
Female	538	46.1%	51%	-5%	259	41%	48%
Prefer not to answer	4	0.3%			2	0%	50%
Total	**1168**	**100%**	**100%**		**634**	**100%**	**54%**

[1] Panel members could also describe their gender using any other terms. No Panel members took the opportunity to do so.
Source: National Records Scotland - Population Estimates 2018. Figure 1.3. Retrieved from: https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2018

Tenure	No on Panel	% of Panel	Scottish popn.	Difference	OV 2019 First Survey Profile	% of first survey response profile	Response rate
Own	836	71.6%	62%	10%	495	78.1%	59%
Rent from Council/ HA	195	16.7%	22%	-5%	75	11.8%	38%
Private Rent	70	6.0%	15%	-9%	34	5.4%	49%
Other	55	4.7%	1%	4%	25	3.9%	45%
Prefer not to answer	12	1.0%			5	0.8%	42%
Total	**1168**	**100%**	**100%**		**634**	**100%**	**54%**

Source: Scotland's Household Survey 2017. Figure 1.3 – Tenure of household by year- (2017). National Records of Scotland, Crown copyright. Retrieved from: https://www.gov.scot/publications/scotlands-people-annual-report-results-2017-scottish-household-survey/

Age	No on Panel	% of Panel	Scottish popn.	Difference	)V 2019 First survey profile	% of first survey response profile	Response rate
16-24	27	2.3%	11%	-8%	9	1.4%	33%
25-44	211	18.1%	26%	-7%	88	13.9%	42%
45-64	432	37.0%	28%	9%	232	36.6%	54%
65+	487	41.7%	19%	22%	300	47.3%	62%
Prefer not to answer	11	0.9%			5	0.8%	45%
Total	**1168**	**100%**	**100%**		**634**	**100%**	**54%**

Source: National Records Scotland - Population Estimates 2018. Figure 1.3 – Population of Scotland by age and sex. Retrieved from: https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2018

Ethnic group	No on Panel	% of Panel	Scottish popn.	Difference	OV 2019 First survey profile	% of first survey response profile	Response rate
White Scottish/ Other White British	1120	95.97%	89%	9%	613	96.7%	55%
Other	34	2.91%	11%	-9%	14	2.2%	41%
Prefer not to answer	13	1.11%			7	1.1%	54%
Total	**1168**	**100%**	**100%**		**634**	**100%**	**54%**

Source: Scottish Surveys Core Questions 2017. Table 2. – Age profile of ethnic groups, SSCQ. (2017). National Records of Scotland, Crown copyright. Retrieved from: https://www.gov.scot/publications/scottish-surveys-core-questions-2017/pages/5/

SIMD Quintile (2012)	No on Panel	% of Panel	Scottish popn.	Difference	OV 2019 First survey profile	% of first survey response profile	Response rate
1	195	16.7%	20%	-3%	81	12.8%	42%
2	236	20.2%	20%	0%	128	20.2%	54%
3	239	20.5%	20%	1%	135	21.3%	56%
4	249	21.3%	20%	1%	146	23.0%	59%
5	247	21.1%	20%	1%	143	22.6%	58%
Prefer not to answer	2	0.2%			1	0.2%	50%
Total	**1168**	**100%**	**100%**		**634**	**100%**	**54%**

Physical or mental health condition or illness	No on Panel	% of Panel	Scottish popn.	Difference	OV 2019 First Survey Profile	% of first survey response profile	Response rate
Yes	456	39.0%	45%	-6%	256	40.4%	56%
No	667	57.1%	55%	2%	356	56.2%	53%
Prefer not to say/ Don't know	45	3.9%		3%	22	3.5%	49%
Total	**1168**	**100%**	**100%**		**634**	**100%**	**54%**

Source: The Scottish Health Survey 2017: Key findings. Page 2. Retrieved from https://www.gov.scot/publications/scottish-health-survey-2017-summary-key-findings/

Local Authority	Estimated population 2018	Scottish Area by population %	No on Panel	% of Panel	OV 2019 First Survey Profile	% of first survey response profile	Response rate
Aberdeen City	227,560	4.2%	41	3.5%	18	2.8%	44%
Aberdeenshire	261,470	4.8%	69	5.9%	38	6.0%	55%
Angus	116,040	2.1%	40	3.4%	29	4.6%	73%
Argyll and Bute	86,260	1.6%	21	1.8%	11	1.7%	52%
City of Edinburgh	518,500	9.5%	93	8.0%	51	8.0%	55%
Clackmannanshire	145,730	2.7%	11	0.9%	7	1.1%	64%
Stirling			24	2.1%	18	2.8%	75%
Dumfries and Galloway	148,790	2.7%	49	4.2%	28	4.4%	57%
Dundee City	148,750	2.7%	29	2.5%	12	1.9%	41%
East Ayrshire	121,840	2.2%	29	2.5%	16	2.5%	55%
East Dunbartonshire	108,330	2.0%	21	1.8%	9	1.4%	43%
East Lothian	105,790	1.9%	26	2.2%	15	2.4%	58%
East Renfrewshire	95,170	1.8%	24	2.1%	13	2.1%	54%
Falkirk	160,340	2.9%	33	2.8%	21	3.3%	64%
Fife	371,910	6.8%	35	3.0%	10	1.6%	29%
Glasgow City	626,410	11.5%	98	8.4%	53	8.4%	54%
Highland	235,540	4.3%	70	6.0%	44	6.9%	63%
Inverclyde	78,150	1.4%	16	1.4%	7	1.1%	44%
Midlothian	91,340	1.7%	28	2.4%	15	2.4%	54%
Moray	95,520	1.8%	19	1.6%	11	1.7%	58%
Na h-Eileanan an Iar	26,830	0.5%	15	1.3%	12	1.9%	80%
North Ayrshire	135,280	2.5%	24	2.1%	9	1.4%	38%
North Lanarkshire	340,180	6.3%	68	5.8%	33	5.2%	49%
Orkney Islands	22,190	0.4%	8	0.7%	7	1.1%	88%
Perth and Kinross	151,290	2.8%	39	3.3%	24	3.8%	62%
Renfrewshire	177,790	3.3%	22	1.9%	9	1.4%	41%
Scottish Borders	115,270	2.1%	30	2.6%	17	2.7%	57%
Shetland Islands	22,990	0.4%	27	2.3%	12	1.9%	44%
South Ayrshire	112,550	2.1%	19	1.6%	8	1.3%	42%
South Lanarkshire	319,020	5.9%	74	6.3%	45	7.1%	61%
West Dunbartonshire	89,130	1.6%	21	1.8%	6	0.9%	29%
West Lothian	182,140	3.3%	43	3.7%	25	3.9%	58%
No response			2	0.2%	1	0.2%	50%
Total	**5,438,100**	**100.0%**	**1168**	**100.0%**	**634**	**100.0%**	**54%**

Health Board Area	Estimated population 30 June 2017	Scottish Area by population %	No of Panel members	% of Panel members	OV 2019 First Survey Profile	% of first survey response profile	Response rate
Ayrshire and Arran	369,670	6.8%	72	6.2%	33	5.2%	46%
Borders	115,270	2.1%	30	2.6%	17	2.7%	57%
Dumfries and Galloway	148,790	2.7%	49	4.2%	28	4.4%	57%
Fife	371,910	6.8%	35	3.0%	10	1.6%	29%
Forth Valley	306,070	5.6%	68	5.8%	46	7.3%	68%
Grampian	584,550	10.7%	129	11.0%	67	10.6%	52%
Greater Glasgow and Clyde	1,174,980	21.6%	202	17.3%	98	15.5%	49%
Highland	321,800	5.9%	91	7.8%	55	8.7%	60%
Lanarkshire	659,200	12.1%	142	12.2%	77	12.1%	54%
Lothian	897,770	16.5%	190	16.3%	106	16.7%	56%
Orkney	22,190	0.4%	8	0.7%	7	1.1%	88%
Shetland	22,990	0.4%	27	2.3%	12	1.9%	44%
Tayside	416,080	7.7%	108	9.2%	65	10.3%	60%
Western Isles	26,830	0.5%	15	1.3%	12	1.9%	80%
No response			2	0.2%	1	0.2%	50%
Total	**5,438,100**	**100.0%**	**1168**	**100.0%**	**634**	**100.0%**	**54%**

Planning Region[5]	Estimated population 30 June 2017	Scottish Area by population %	No of Panel members	% of Panel members	OV 2019 First Survey Profile	% of first survey response profile	Response rate
West	2,658,710	48.9%	533	45.6%	282	44.5%	53%
North	1,394,440	25.6%	378	32.4%	218	34.4%	58%
South	1,384,950	25.5%	255	21.8%	133	21.0%	52%
No Response			2	0.2%	1	0.2%	50%
Total	**5,438,100**	**100.0%**	**1168**	**100.0%**	**634**	**100.0%**	**54%**

[5] The West planning region consists of NHS Ayrshire and Arran, Dumfries and Galloway, Forth Valley, Greater Glasgow and Clyde and Lanarkshire. The North consists of Grampian, Highland, Orkney, Shetland, Tayside and Western Isles. The South consists of the Borders, Fife and Lothian.

Weighting survey data

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

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

The idea behind weighting is that:

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

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

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

Appendix 4: Citizens' Panels

Citizens' Panels are used extensively across local authorities in Scotland, however, the Our Voice Citizens' Panel and local authority Citizens' Panels are not directly comparable due to different recruitment methods[6]. Although the Our Voice Citizens' Panel is similar to those conducted by local authorities across Scotland, it varies in one significant methodological aspect – that Panel members cannot actively volunteer or petition to 'sign up' to the Our Voice Citizens' Panel. Although a mixed methodology of recruitment practice exists across local authorities, using for example electoral rolls, face-to-face recruitment, issue-based recruitment and, door-to-door recruitment, most local authorities allow Panel members to actively volunteer or 'sign up' rather than be reactively recruited. It is possible that this active interest rather than reactive interest may provide one reason why the Our Voice Citizens' Panel experiences lower completion rates than some local authority Citizens' Panels.

Of the 24 local authorities that had Citizens' Panels in 2013, 43% of participants are recruited as volunteers. Although response rate varies widely across these Panels from a high of 82% to a low of 28%, 44% of Panels retrieve an average 40-60% response. 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 (drop out) of Panel members. Two hundred and fifty two Panel members have actively chosen to remove themselves from the Panel between the first and fifth survey cycle. It has been argued that citizens are only interested in participating in Panels when their views have a tangible impact on service delivery. To this end, it has been noted that local authority Citizens' Panels have to continually demonstrate the impact that Panel members have on service delivery. Due to the high level and national nature of the Our Voice Citizens' Panel, the process of demonstrating the impact of Panel members' views on local service change and delivery is often slow. It is possible that this has contributed to attrition rates. Some of the Panel members who have requested to be removed from the Panel have fed back that the Panel is not what they thought it was and without the opportunity to provide feedback on their own local health and social care services, they do not wish to participate in the Panel on an ongoing basis.

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

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

Appendix 5: Interpreting results

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

All tables have a descriptive and numerical base, showing the population examined in it.

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.

Sample Estimate (lookup to nearest multiple of 5%)		Sub-group Size									
		50	75	100	150	200	250	300	400	500	636
	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%	2.3
	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%	3.1
	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%	3.7
	40%	15.6%	12.8%	11.0%	9.0%	7.8%	7.0%	6.4%	4.8%	4.9%	3.8
	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%	3.9%
	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%	3.8
	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%	3.1
	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 analysis of the survey.

The percentage of respondents who had not already registered their decision about organ and tissue donation after death but said they were 'very likely' to do this was 35%, with a base of 311.

Using the statistical significance table above to find the 95% confidence intervals for each value, we can see that a base of 300 the lower limit of the 95% confidence interval is (35%-6.2%) 28.8% and the upper limit is (35%+6.2%) 41.2%.

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