

# Citizens' Panel for health and social care

Survey on organ and tissue donation, and the regulation of independent healthcare

Report, November 2023

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# Foreword

Welcome to the twelfth Citizens' Panel report for health and social care in Scotland. This report details the findings from a Panel survey, which collected feedback between June and September 2023.

The questions were on two topics, organ and tissue donation and the regulation of independent healthcare.



## **Organ and tissue donation**

In 2019, we asked the Citizens' Panel for their views on deceased organ and tissue donation to help the Scottish Government prepare for the introduction of this opt-out system. Four years on, and after the introduction of the opt-out system in 2021, we have asked the Panel for their views on this topic again to explore how these may have changed since 2019.

## **Regulation of independent healthcare**

At times, the public may choose to seek healthcare outside of NHS Scotland. Independent healthcare services are regulated to ensure that the public are provided with high quality, safe healthcare that focuses on improvement. The findings from the Citizens' Panel, outlined in this report, will inform the future decisions made about the types of treatments and services that will require regulation and any changes required to ensure that regulatory work is helpful and meaningful to the public.

The Citizens' Panel has allowed us to seek the views of a cross-section of the Scottish public and topics are determined from priority areas in the Scottish Government Health & Social Care Directorate.

This twelfth survey received a 64% response rate, our second highest response to date. I would like to thank the individuals who have volunteered to be part of the Panel, who together make up a representative section of the population of Scotland. I would also like to thank our research partners, Research Resource, who conducted the survey and our partners in Scottish Government for their contribution, as well as all staff involved from Healthcare Improvement Scotland – Community Engagement and System Redesign Directorate.

I hope you enjoy reading this report and can use the findings to better understand the public's views on these two important topics.

**Suzanne Dawson**  
**Chair, the Scottish Health Council**

# Citizens' Panel for health and social care

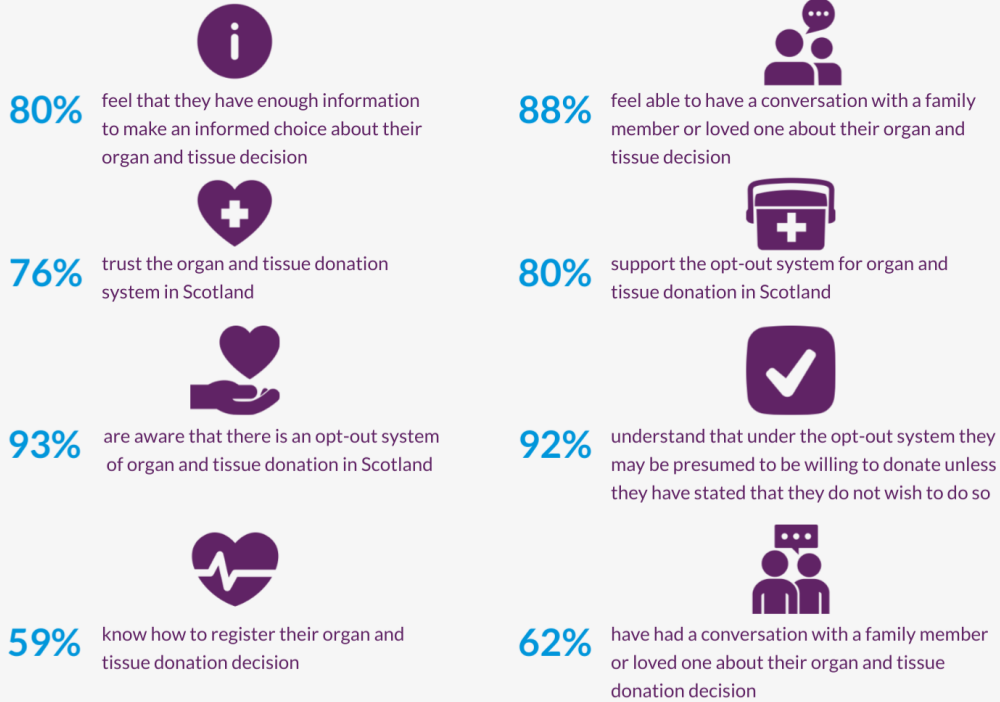
This infographic summarises the key findings from the twelfth survey. We asked questions about:

- Attitudes toward organ and tissue donation after death
- Independent healthcare regulation

In total **663** panel members responded to the survey by post, email or telephone, which represents a **64%** response rate.

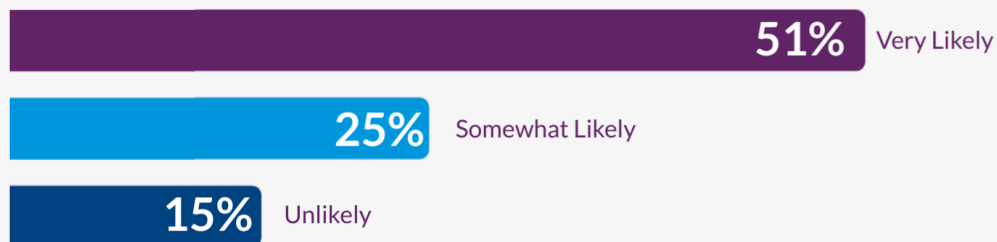
## Attitudes toward organ and tissue donation after death

### Statements on organ and tissue donation after death



### Registration of decision on organ and issue donation after death

How likely are you to register your organ and tissue donation decision?



### Opt-out decision on organ and issue donation after death

Have you decided to opt-out of organ and tissue donation after your death?



■ No 78%    ■ Yes 9%  
■ Unsure 13%

**80%**

of those who have opted-out have registered this decision with Organ Donation Scotland and/or informed family/friends

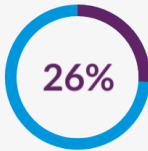


# Independent healthcare regulation

**51%** were aware of professional regulation

**40%** were aware of service regulation

## Awareness of what services are regulated



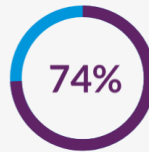
think beautician-led cosmetics **are** regulated



think private ambulance services **are** regulated

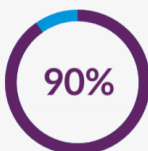


think that dentists that provide NHS and private dental care **are** regulated



think that dentists that only provide private dental care **are** regulated

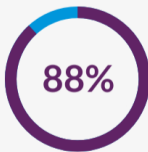
## Opinions on what services should be regulated



think beautician-led cosmetics **should** be regulated



think private ambulance services **should** be regulated



think that dentists that provide NHS and private dental care **should** be regulated



think that dentists that only provide private dental care **should** be regulated

## What is useful in choosing a service

**63%** said inspection reports by Healthcare Improvement Scotland



**62%** said recommendation from other healthcare professionals, for example GP



## Complaints about private healthcare services



**53%** would report any problem or complaint with a private healthcare service to the private healthcare provider

## What matters to you around private healthcare regulation

**25%** stated private healthcare services being independently regulated, having strict controls or being unbiased was most important



## Awareness of Healthcare Improvement Scotland role in regulation

**16%** were aware that Healthcare Improvement Scotland is the regulator for private healthcare services in Scotland



# 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 and is used by statutory agencies to identify priorities and consult the public on specific issues.

## Background and context

The Citizens' Panel for health and social care was established in 2016 to be nationally representative and allow statistically robust analysis of the views of the Panel members at a Scotland-wide level. Panel members were randomly selected from the general population and invited to join the Panel. Some targeted recruitment also took place to ensure that a representative Panel was created. Panel membership is monitored and refreshed as needed to remove less active Panel members and ensure continued representativeness. At the time of this survey in the summer 2023, there are 1030 Panel members from across all 32 local authority areas. You can find further information on our [Citizens' Panel webpage](#).

This report details the findings from the twelfth Panel survey which collected feedback between June 2023 and September 2023. The questions were on two topics:

- organ and tissue donation, and
- the regulation of independent healthcare, which is often called private healthcare.

A total of 663 responses (64% response rate) were received, either by post, email or by telephone. This level of return provides data accurate to  $\pm 3.8\%$ <sup>1</sup> at the overall Panel level. In this report, we do not report results broken down into sub-categories (for example, sex or age) as they are not statistically significant. All comparisons made in this report are statistically significant, unless otherwise stated.

This executive summary details the key findings from this research. Detailed information on the profile of responses is in Appendix 2.

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<sup>1</sup> Based upon a 50% estimate at the 95% level of confidence.

## Key findings

### Organ and tissue donation

#### Findings

In 2021, Scotland moved to an opt-out system of deceased organ and tissue donation. This means that if someone dies in circumstances where they potentially could become a donor, and they have not registered a donation decision, they would be presumed to be willing to donate, unless their family or friends provide information that the potential donor was unwilling to do so.

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 that they “trust the organ and tissue donation system in Scotland” to 88% who agreed that they “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:

- 93% were aware that there is an opt-out system for organ and tissue donation in Scotland.
- 92% understood that under the opt-out system they may be presumed to be willing to donate unless they have stated that they do not wish to do so.
- 59% were aware of how to register their organ and tissue donation decision.

More than three quarters of respondents said they were very likely or somewhat likely to register their organ and tissue donation decision (76%). Only 9% of respondents had decided to opt-out of organ and tissue donation after their death and of these individuals (56 respondents), over a third (34%) said they had registered their decision, 18% had informed family or friends of their decision and 28% said they had done both of these things.

The majority of respondents (88%) agreed they feel able to have a conversation with a family member or loved one about their organ and tissue donation decision and more than six in ten respondents (62%) have already had this conversation with a family member or loved one.

#### Recommendations

Healthcare Improvement Scotland (HIS) recommends that the Scottish Government considers the following when undertaking further awareness campaigns on organ and tissue donation:

1. Undertake work on understanding where the pockets of lack of awareness are and how to reach these people.



2. Determine how the campaign could increase trust in the system by:
  - a. reporting on the ethics involved and the difference the opt-out system has made to people's lives, and
  - b. including information about what happens at and after the donation point in campaigns. This should be very clear about how bodies are handled respectfully, which organs and tissue can be donated, and how donations only go to people on the waiting transplant list and are not used for other purposes nor in other contexts.
3. Aim to improve information on making an informed choice and highlight misconceptions about who can and cannot donate.
4. Continue to raise awareness of organ and tissue donation aspects such as the below, and consider how awareness-raising may achieve wider reach and increased impact:
  - a. how to register a donation decision
  - b. the benefits of registering organ and tissue donation decisions, specifically trying to encourage people who feel they don't need to register because it is an opt-out system. As in the recommendation above, this should include dispelling misconceptions about who can and cannot donate.
5. Focus on marginalised groups, including people with particular faiths and beliefs, and those who are less likely to register.
6. Continue to include a call to action in campaigns, such as having a conversation with family and friends regarding people's organ and tissue donation decision. Consider how this call to action may achieve wider reach and increased impact.
7. Integrate the awareness campaign into other processes, where appropriate, such as when giving blood.

## The regulation of independent healthcare

### Findings

The second half of the questionnaire was on the regulation of independent healthcare, also known as private healthcare services. The aim of this section was to find out the public's thoughts and awareness about private healthcare and its regulation, to inform future decisions made about the types of treatments and services that will require regulation and any changes required to ensure that regulatory work is helpful and meaningful to the public.

These statutory assurance duties sit with HIS as an organisation and HIS's Quality Assurance Directorate conducts this regulatory work. This Directorate is separate from HIS's Community Engagement & Systems Redesign Directorate that carried out the Citizens' Panel survey.

The private healthcare services that Panel members were most likely to think were regulated were dentists that provide NHS and private dental care (93%), followed by dentists that only provide private dental care (74%). On the other hand, respondents were least likely to think beautician-led cosmetics were regulated (26%). Private ambulance services, beautician-led

cosmetics, dentists that provide NHS and private dental care, slimming, nutritional and diet advice provided by dieticians, and internet-based GP and prescription services are not currently regulated. However, Panel members thought that these services are regulated, highlighting misconceptions around the scope of current regulation.

Private healthcare services that Panel members think should be regulated included beautician-led cosmetics (90%), followed by dentists that only provide private dental care (88%), dentists that provide NHS and private dental care (88%), internet-based GP and prescription services which operate only online and don't have clinics or premises (88%) and nurse or doctor-led cosmetics (87%).

Panel members were asked about their awareness of professional and service regulation. Awareness of these was relatively low, and respondents were more likely to say they were aware of professional regulation (51%) than service regulation (40%).

Over half of respondents said that if they had a problem or complaint about a private healthcare service they would report their concern at first instance to the private healthcare provider (53%). A further 24% said they would report it to an NHS health board and 22% said they would report it to HIS.

Going online or conducting web searches (50%) was the most common way that respondents would look for inspection reports about a private healthcare service.

The information sources that respondents were most likely to find very useful when planning to use a private healthcare service were inspection reports by HIS (63%), followed by recommendations from other healthcare professionals such as GPs (62%).

Panel respondents' top three priorities as mattering most when thinking about the regulation of private healthcare were:

- 1) Independently regulated/strict controls/unbiased (25%)
- 2) Patient safety (19%)
- 3) Qualified/professional/well-trained staff (11%)

Over three quarters of survey respondents (76%) were unaware that HIS is the regulator for private healthcare services in Scotland.

## **Recommendations**

Based on these findings, we make the following recommendations to HIS, Scottish Government, and delivery partners:

1. Looking to the future of independent healthcare regulation, Scottish Government and HIS should consider the scope of regulation and ensure that public stakeholders are included in relevant processes so that public views and needs are met, including considering the current findings. When considering the broadening of regulation, these findings could help decide which areas to prioritise based on public views.

2. Work to increase public awareness and understanding around this topic. These activities should use a range of methods and platforms to ensure wide reach and should consider the sources of information mentioned by the Citizens' Panel as useful when planning and implementing awareness-raising activities. As this work would require significant resource, it could follow a gradual and staged approach, with certain aspects, services, or population groups prioritised. This work should look specifically at:
  - the scope of the regulation of private healthcare, what is and what is not regulated and why
  - the scope and differences between service regulation and professional regulation. Professional regulators, such as the General Medical Council (GMC), should be approached to be involved with this work
  - the complaints process, which aspects of care should be addressed and where. The complaints process needs to be clear on the role and responsibilities of HIS and other organisations. This should also include liaising with health boards to ensure they have the appropriate materials and information and can signpost accordingly. This could also include providing relevant information through NHS Inform
  - how and where the public can find regulation reports, and how to use this information to inform their decision-making, and
  - what the role of HIS is and what it is not, in terms of independent healthcare regulation.
3. Consider doing more engagement to further understand what the public want from regulation, and why people may prioritise some services over others.
4. Ensure that search engine optimisation for regulation reports on the HIS website is prioritised as part of website development work.
5. Consider making it a condition for services when registering that they signpost to the HIS regulation webpages and reports from their website, potentially using the HIS logo to increase visibility.

# Chapter 1: Introduction and context

## Questionnaire design

Healthcare Improvement Scotland's (HIS) Community Engagement & System Redesign Directorate designed the questions in partnership with the Scottish Government (organ and tissue donation) and HIS-Quality Assurance Directorate (regulation of independent healthcare). Members of the public tested the draft questions, which influenced the final question set. A copy of the final questionnaire is available in Appendix 1.

## Response rates and profile

At the time of writing this report, the Citizens' Panel for health and social care has 1030 members. The twelfth Citizens' Panel for health and social care survey was sent by email on the 9 June 2023 to all 945 Panel members for whom we have email addresses. Reminder emails were sent to those who had not yet responded by email on the 16 and 22 June 2023. On 7 July, survey packs were sent to all 664 Panel members for whom we have no email addresses and those from whom a bounce back email message was received, in addition to those who had not responded to the email surveys sent. Postal responses continued to be accepted up until 5 September 2023. Three respondents completed the survey online, via a link or QR Code from the postal survey pack.

A detailed analysis of the response profile identified that the survey was under-represented in terms of younger Panel members (defined as aged 54 and under). A targeted telephone boost was undertaken in an attempt to increase the response from younger Panel members. 94 telephone interviews were completed between the 10 August and 3 September 2023.

This took the final response up to 663, a 64% response rate. This level of return provides data accurate to +/-3.8% (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 were still under-represented. Furthermore, the response was under-represented in terms of those living in social housing and private rented accommodation. To ensure the data was representative by age and tenure, survey data was weighted to adjust for this imbalance.

Full information on the response profile achieved and weighting is in Appendix 2.

## Interpreting results

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

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.

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

# Chapter 2: Organ and tissue donation

## Introduction

The aim of this section of the questionnaire was to gain Panel members' views on organ and tissue donation.

In 2021, Scotland moved to an opt-out system of deceased organ and tissue donation. This means that if someone dies in circumstances where they potentially could become a donor, and they have not registered a donation decision, they are presumed to be willing to donate, unless their family or friends provide information that the potential donor was unwilling to do so. Whatever people decide, they should also tell family and friends about their donation decision to help ensure that it is honoured. Family and friends will be consulted about the deceased's latest views to ensure that donation does not proceed if they would not have wanted it to.

In 2019, we asked the Citizens' Panel for their views on deceased organ and tissue donation to help the Scottish Government prepare for the introduction of this opt-out system. These findings are published in our [fifth Citizens' Panel report](#). Four years on, and after the introduction of the opt-out system in 2021, we have asked the Panel for their views on this topic again. This is to explore public attitudes and awareness on this topic and how these may have changed since 2019. The information gathered will inform the evaluation and monitoring of the opt-out system for deceased organ and tissue donation and activities around it, for example, relevant marketing campaigns. All findings will be used for the five-year analysis report at the end of the monitoring and evaluation period in 2026.

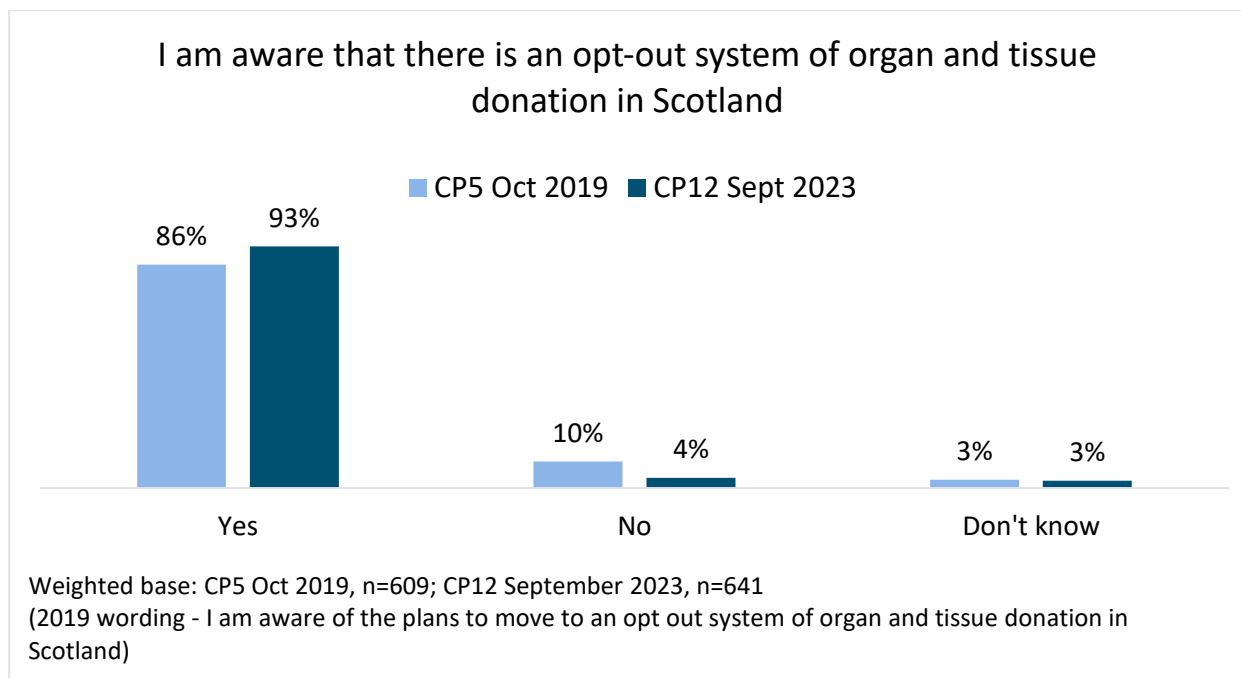
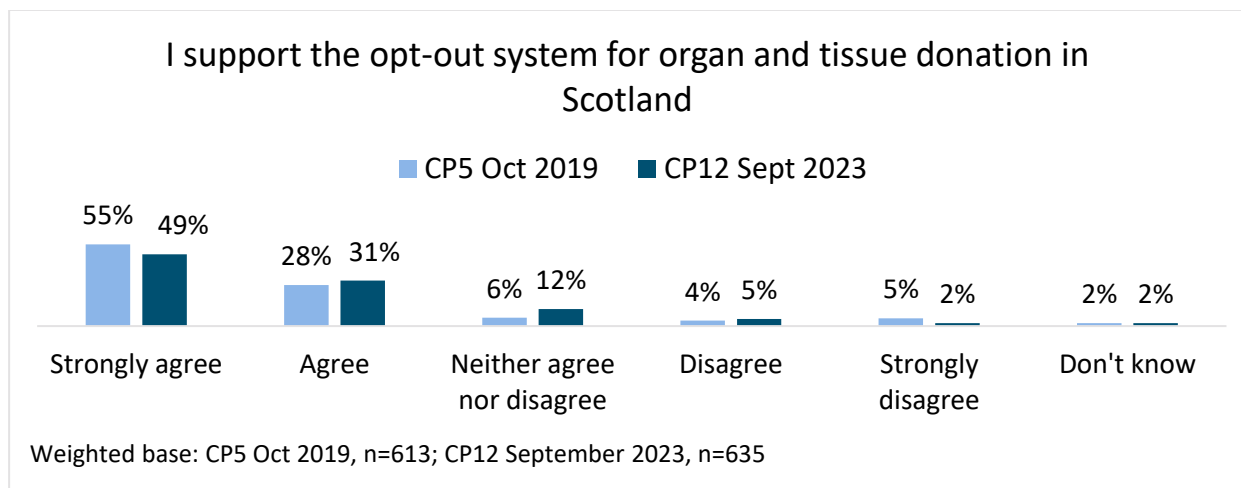
### **Methodological note:**

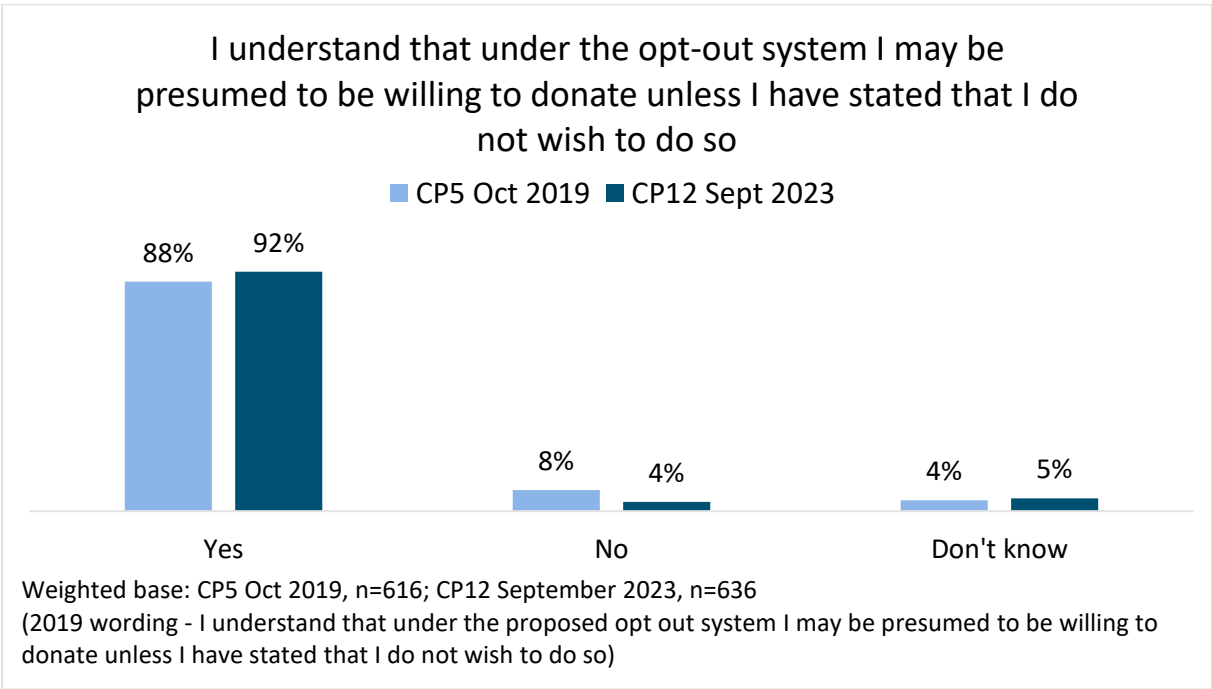
The questions asked on this topic were similar to those asked in 2019 in the fifth Citizens' Panel report and some comparisons have been made between the 2019 and 2023 results. In the main, there is little change between the results. There may appear to be some difference, but with the margin of error being + or - 3.8%, all results see little change with the exception of the findings on the level of awareness of the opt-out system which has increased slightly from 86% to 93%. In addition, just over half of the Citizens' Panel members who responded to the 2023 survey also responded to the 2019 survey. Given there are no large swings in difference between results we can assume that this has not made a significant difference in the results. This may have attributed to the slight increase in awareness although, given other results have largely remained the same, it is difficult to tell.

## Opinions on organ and tissue donation after death

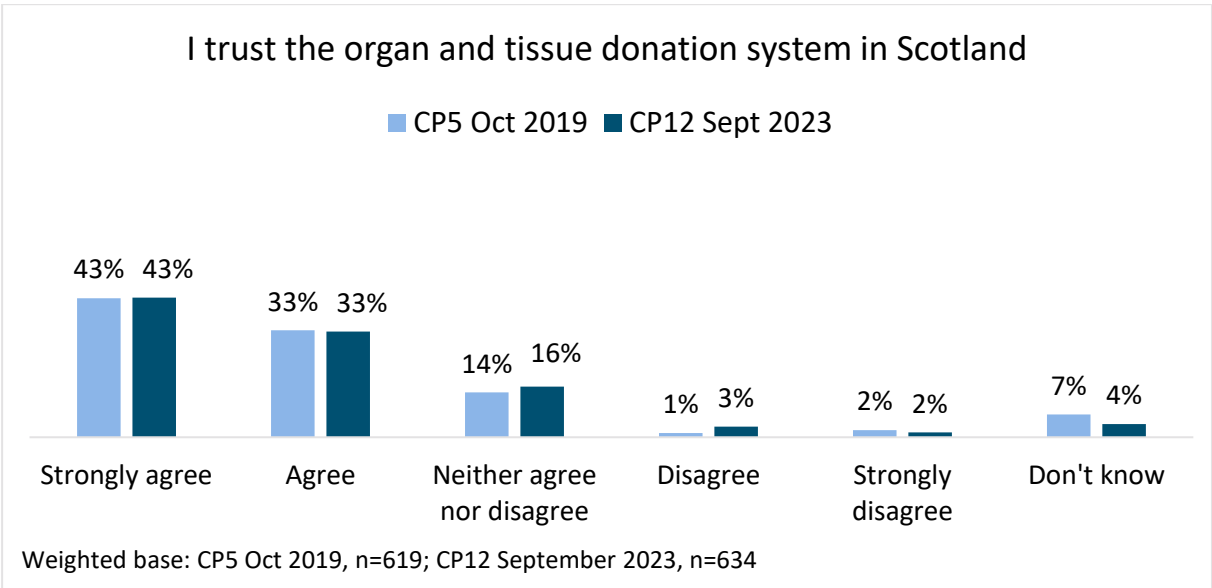
Panel members gave opinions on the opt-out system for organ and tissue donation in Scotland and, where there were similar questions in the fifth Citizens' Panel, we have compared them with public views collected in 2019. The main findings to emerge from these responses were:

- 80% of Panel members supported the opt-out system for organ and tissue donation in Scotland (83% supported its introduction in 2019)
- 93% were aware of the opt-out system for organ and tissue donation in Scotland (86% in 2019), which is a slight increase statistically, and
- 92% understood that under the opt-out system, they may be presumed to be willing to donate unless they have stated that they do not wish to do so (88% in 2019).





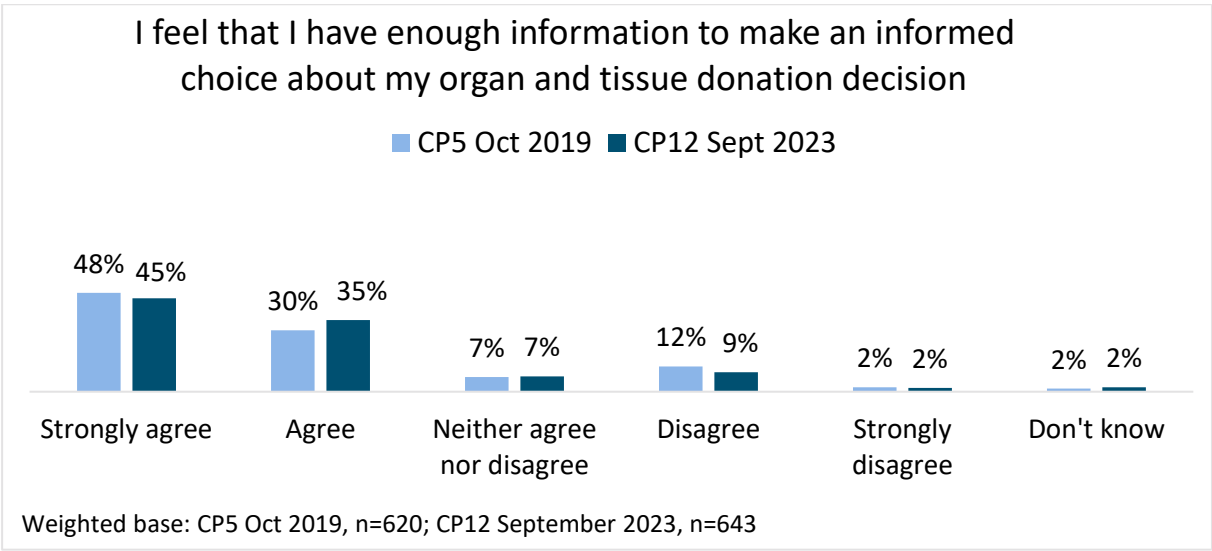
Concerning trust in the organ and tissue donation system, more than seven in ten Panel members (76%) agreed they held trust in the system, compared to 5% who disagreed. The level of agreement with this statement has not changed since 2019 (76%).



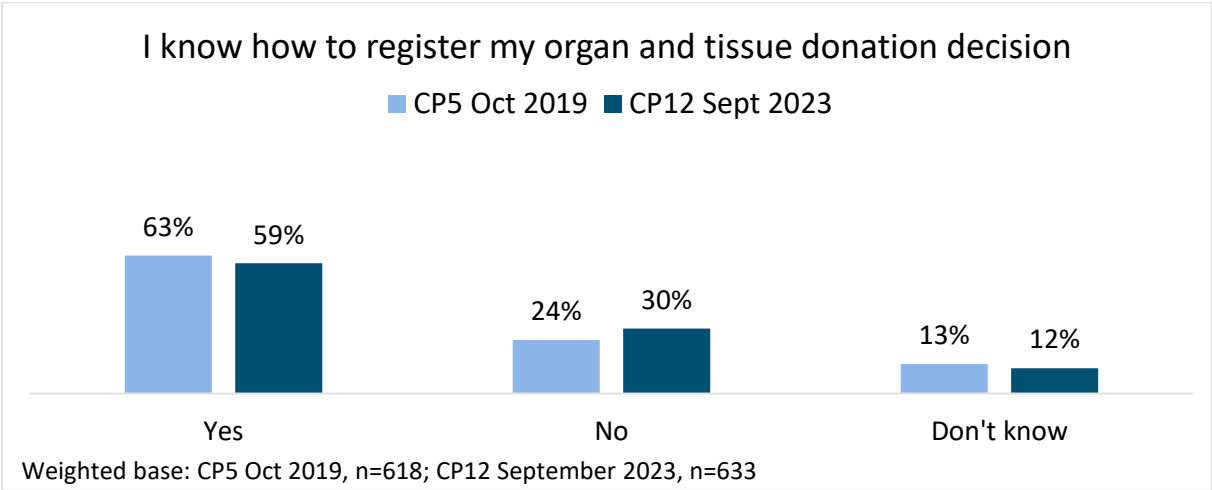
### Making and recording decisions

Eight in ten Panel members (80%) felt they have enough information to make an informed choice about organ and tissue donation, compared to 11% who did not. These findings are not significantly different from the 2019 results where 77% agreed and 14% disagreed.

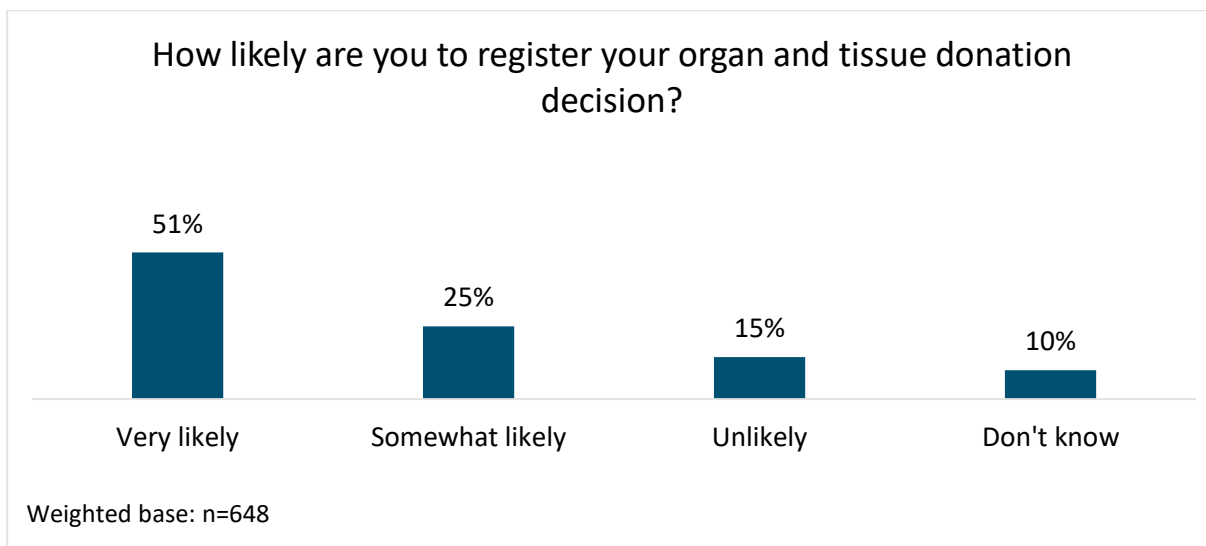




Just under 6 in 10 respondents (59%) knew how to register their organ and tissue donation decision (62% in 2019).



Just over half of the respondents (51%) said they were very likely to register their organ and tissue donation and 25% were somewhat likely. On the other hand, 15% said they were unlikely to do this and the remaining 10% were unsure.



Those who were unlikely to register their organ and tissue donation decision were asked to provide their reasons for feeling this way, the main reasons were:

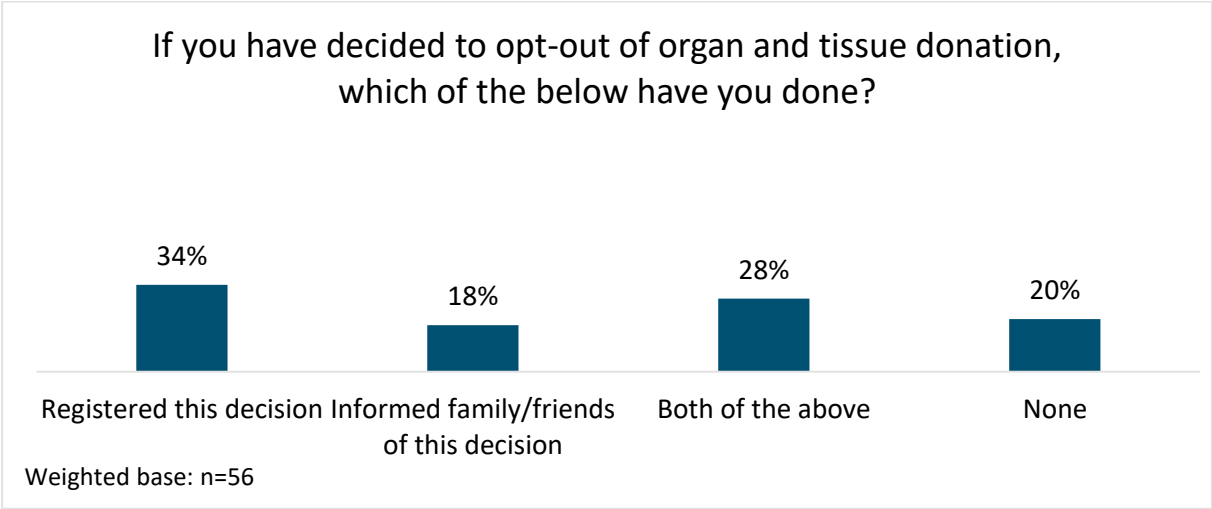
- it is an opt-out system and therefore they don't feel the need to register (19%)
- not interested in donating their organs or tissue (12%)
- unable to donate their organs due to a health condition (11%), and
- unaware of how to register or do not have enough information about the process (11%).

To note, the findings above highlight certain misconceptions. For example, there are very few conditions where organ and tissue donation is ruled out completely and there is no age limit for becoming an organ and tissue donor<sup>2</sup>.

If you are unlikely to register your organ and tissue donation decision, please tell us why?	
Base: unlikely to register organ and tissue donation decision, wn=73	%
Opt-out system in place therefore don't feel need to register	19%
Not for me/not interested	12%
Can't donate organs due to health condition	11%
Don't know how to register/not enough information about the process	11%
Happy to donate	10%
Too old to donate organs	7%
Have concerns that organs might be put to other use/concerns about how body would be treated	7%
Laziness/unlikely to get round to it	6%
Due to my beliefs	3%
Trust family to make the right decision	2%
Other	8%
Don't know/unsure	12%

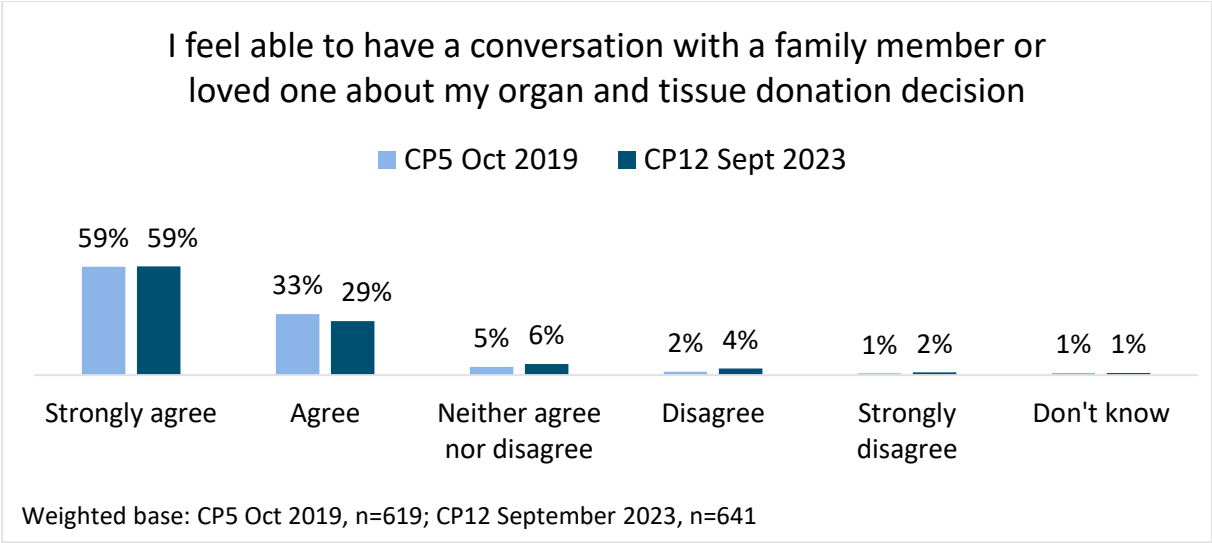
<sup>2</sup> Further information on organ donation and eligibility are available on the [Organ Donation Scotland website](#).

Just over three quarters of respondents (78%), said they had not decided to opt-out of organ and tissue donation, only 9% of respondents said they had decided to opt-out of organ and tissue donation and 13% were unsure. Of those who decided to opt-out (56 respondents), over a third (34%) said they had registered their decision, 18% had informed family or friends of their decision and 28% said they had done both things. 20% of those who have decided to opt-out of organ and tissue donation have taken no action on this.

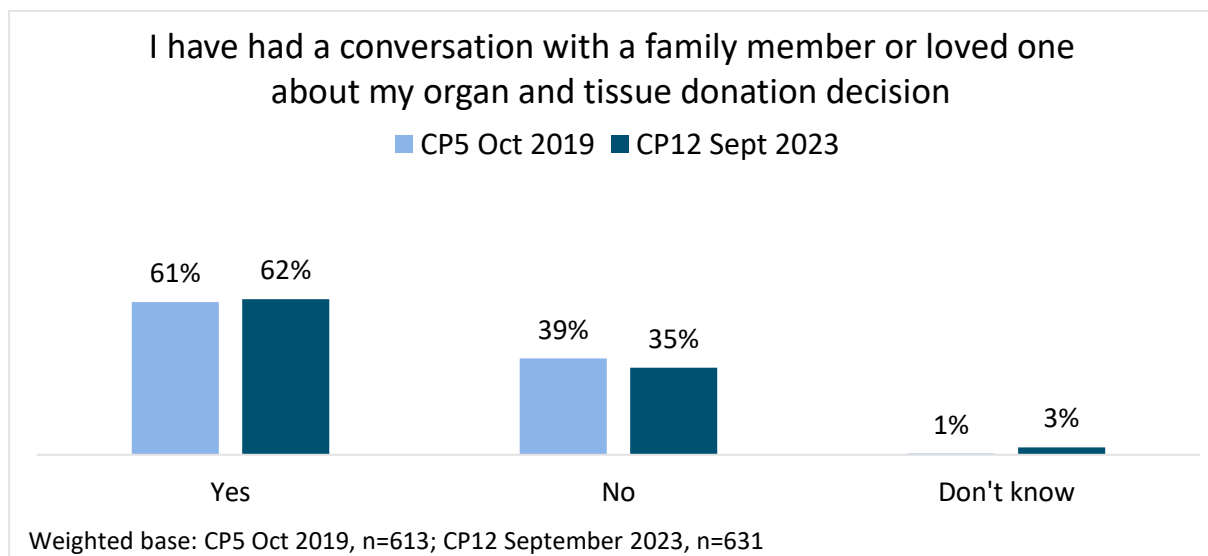


### Family conversations

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. Most respondents (88%) agreed they felt able to have this conversation, compared to 6% who did not. In 2019, 92% of respondents agreed with this statement and 3% disagreed.



More than six in ten respondents (62%) have already had this conversation with a family member or loved one (61% in 2019). Just 35% had not had this conversation with a family member or loved one (39% in 2019).



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, with the most common themes being where respondents agreed with organ donation and the opt-out scheme (33%) and where they would like more information on organ and tissue donation.

<b>Q4 If there is anything else you would like to say about organ and tissue donation after death, please use the space below:</b>	
<b>Base: respondents, wn=150</b>	<b>%</b>
In agreement with organ donation/opt-out scheme/happy to donate	33%
More information required on organ donation e.g. the process, the risks, who can donate, does it include being used for research purposes, how to opt-out etc.	21%
Don't agree with presumed consent/It should be a personal choice/should be opt-in	15%
I am an organ donor/on donor's register	9%
More promotion needed	9%
Don't want to think about it/difficult subject that needs to be discussed	6%
Too old/not in good health	4%
I have left/would like to leave my body to medical science	3%
Not sure yet/not made up mind	2%
Ensure family members are in agreement/can't refuse	2%
I am/family member is a recipient of organ donation	1%
Other	13%

Aside from general agreement with the opt-out system, the most common response 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 required are shown below:

*Is there any age limit or health condition factors that would prevent donations?*

*Does organ and tissue donation after death include the use of organ/tissue for educational and/or research purposes?*

*There should be greater clarity for those who are told they cannot donate for medical reasons...in my own case I know my body is valuable medically for testing but not everyone knows this is an option.*

*I would be interested in seeing some figures around this, made publicly available on a regular basis. I would be interested to see how donation changes over time, re frequency of donation, body parts, how many declined, case studies of those receiving a transplant (impact of donation).*

*I am Muslim, and I get buried within 24hours, how does that stand?*

*It is not easy to find out how to register your decision - particularly - if the Internet is the only avenue to do this.*

*I feel it would be helpful if loved ones are told just how the organs are removed and how long after the donation can the family members have a funeral for their loved one.*

## Conclusions and recommendations on organ and tissue donation

The levels of awareness of the opt-out system for organ and tissue donation in Scotland have increased slightly since 2019 to 93% (strongly agree or agree) which is a very high level of awareness. This compares favourably to Wales where 82% reported<sup>3</sup> they were aware of their opt-out organ donation system, two years after implementation. Whilst support for the opt-out system (80% strongly agree or agree) and understanding of the opt-out system (92% strongly agree or agree) has stayed largely the same, both are still at high levels.

Trust in the organ and tissue donation system has also stayed the same at 76%, but the findings suggest there may be the opportunity to increase this, as 16% stated neither agree nor disagree. Some respondents highlighted areas of mistrust. For instance, they raised concerns over what their organs would be used for and how their bodies would be treated.

It has been 4 years since the views of the Panel were first collected on organ and tissue donation, with there being little change in trust and understanding in that time despite the opt-out system being implemented in 2021. This could suggest that more work could be done to increase trust and understanding, while recognising that embedding and evaluating large-scale changes, such as this opt-out system, potentially requires a longer timescale than the 4 years within this work.

Again, there is no change in the proportion of respondents feeling that they have enough information to make an informed choice about their organ and tissue donation decision compared to 2019 findings, sitting at 80%. However, over 1 in 10 (11%) did not feel they had enough information. Feedback from some of the open questions about not having enough information also highlighted certain misconceptions about the system. These include Panel members thinking they are unable to donate due to health conditions or age, and not knowing how to register their decision.

These statements are untrue, as almost everyone is eligible to donate if they wish to, with very few exceptions. There are very few conditions where organ and tissue donation is ruled out completely<sup>4</sup>. Therefore, while most say they have enough information to make an informed choice, some may have incorrect information.

Just over half of the respondents (51%) stated that they were very likely to register their donation decision, 25% were likely to register and 15% said they were unlikely. The actual

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<sup>3</sup> Public attitudes to organ donation in Wales [Public attitudes to organ donation | GOV.WALES](#).

<sup>4</sup> You can find more information on the facts around the opt-out donation system, including around eligibility exceptions, on the relevant webpage: <https://www.organdonation.scot/about-donation/truth-about-organ-and-tissue-donation>

level of registration of donation decisions in 2022/23 was 56.2%<sup>5</sup> of the Scottish population (53% registering to opt-in and 3.2% registering to opt-out).

Despite the high support for the opt-out system from the Panel, around one third (30%) stated that they did not know how to register their decision. Elsewhere in the open text responses they provided reasons for not registering their decision, for example believing that they are too old to donate or because of personal beliefs. Some said that they wouldn't register their decision as it is an opt-out system. This suggests that there is misconception around registering a decision under the opt-out legislation. Therefore, public awareness on how to register a decision and who is eligible to donate could be improved.

Over three quarters (78%) of respondents stated that they have decided not to opt-out of organ and tissue donation. This finding mirrors the high support for the opt-out system (80%). There were also 58 respondents (9%) who had decided to opt-out. The majority of these respondents have either registered their decision to opt-out, informed family or friends or done both. This suggests they understand how the opt-out system works and have actioned this appropriately based on their preference. Furthermore, the right of people to not wish to donate is acknowledged, and that this may sometimes be linked to religious beliefs, so it is important that no pressure is applied on people to insist on donation.

Whilst most respondents (88%) agreed they felt able to have a conversation with a family member or loved one about their organ and tissue donation decision, only 62% have done so, with some comments in the open questions around it being a difficult subject to discuss. These findings suggest that there may be a gap between views and actions, such as feeling able to have family conversations versus actually having a conversation, and the likelihood of registering a decision compared to knowing how to do so as well as actually registering a decision. However, given that the opt-out system has been running for 4 years, the lack of change in people who have had a conversation about this with families or loved ones compared to 2019 suggests that more could be done to support people in doing so.

## **Recommendations**

HIS recommends that the Scottish Government considers the following when undertaking further awareness campaigns on organ and tissue donation:

1. Undertake work on understanding where the pockets of lack of awareness are and how to reach these people.
2. Determine how the campaign could increase trust in the system by:
  - a. reporting on the ethics involved and the difference the opt-out system has made to people's lives, and
  - b. including information about what happens at and after the donation point in campaigns. This should be very clear about how bodies are handled

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<sup>5</sup> Organ Donation Annual Activity report - [Annual Activity Report - ODT Clinical - NHS Blood and Transplant.](#)

respectfully, which organs and tissue can be donated, and how donations only go to people on the waiting transplant list and are not used for other purposes nor in other contexts.

3. Aim to improve information on making an informed choice and highlight misconceptions about who can and cannot donate.
4. Continue to raise awareness of organ and tissue donation aspects such as the below, and consider how awareness-raising may achieve wider reach and increased impact:
  - a. how to register a donation decision
  - b. the benefits of registering organ and tissue donation decisions, specifically trying to encourage people who feel they don't need to register because it is an opt-out system. As in the recommendation above, this should include dispelling misconceptions about who can and cannot donate.
5. Focus on marginalised groups, including people with particular faiths and beliefs, and those who are less likely to register.
6. Continue to include a call to action in campaigns, such as having a conversation with family and friends regarding people's organ and tissue donation decision. Consider how this call to action may achieve wider reach and increased impact.
7. Integrate the awareness campaign into other processes, where appropriate, such as when giving blood.



# Chapter 3: Independent healthcare regulation

## Introduction

The survey went on to ask a series of questions on the regulation of independent healthcare, also known as private healthcare.

At times, the public may choose to seek healthcare outside of NHS Scotland. In many cases, these will be services that the patient has to pay for, or provided by a charity, such as a hospice. Independent healthcare services are regulated to ensure that the public are provided with high quality, safe healthcare that focuses on improvement.

These statutory assurance duties sit with HIS as an organisation and HIS's Quality Assurance Directorate conducts this regulatory work. This Directorate is separate from HIS's Community Engagement & Systems Redesign Directorate that carried out the Citizens' Panel survey.

These findings will inform future decisions made about the types of treatments and services that will require regulation and any changes required to ensure that regulatory work is helpful and meaningful to the public.

## Awareness of and opinions on the regulation of private healthcare services

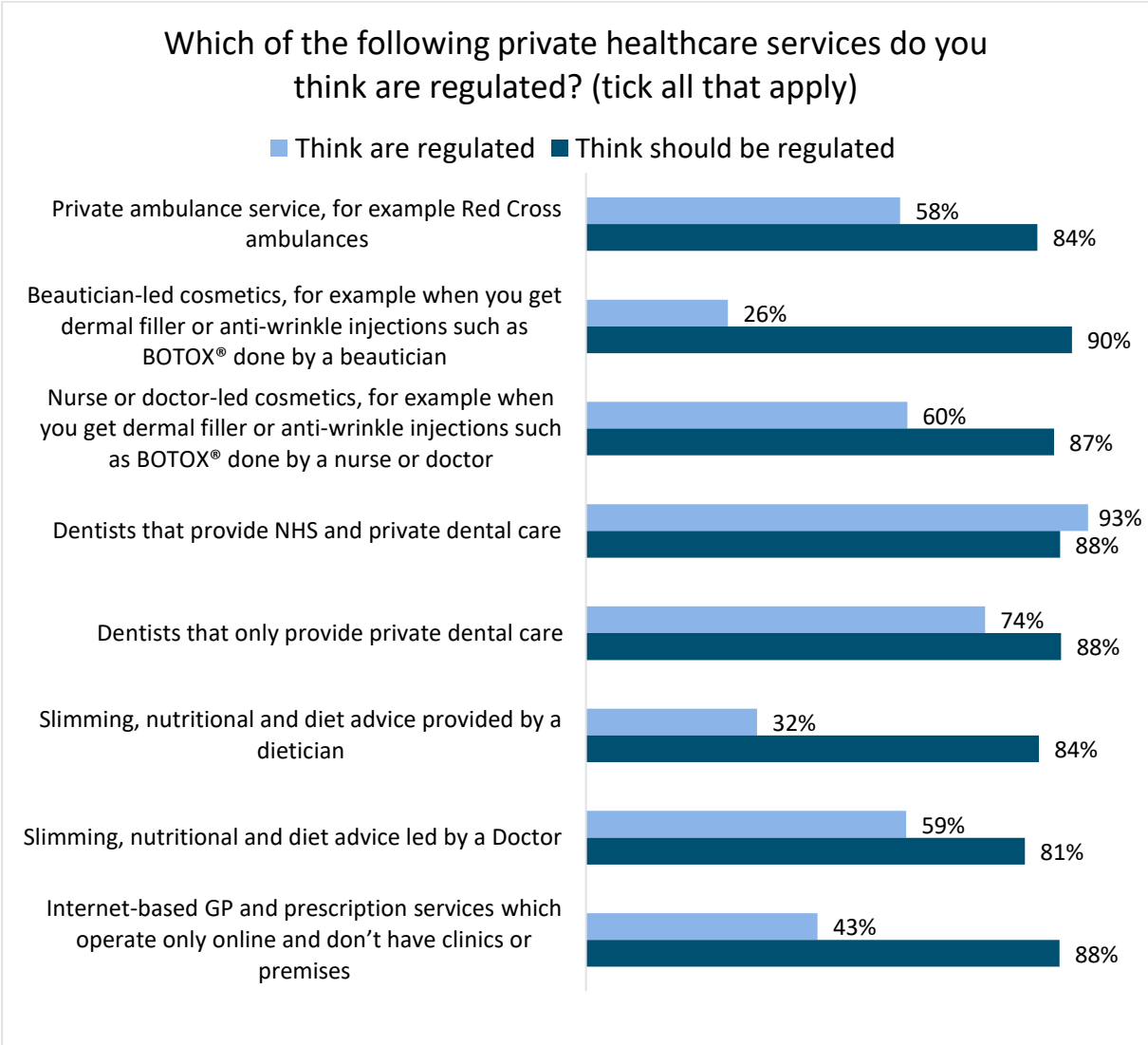
The section began by asking respondents to select, from a range of private healthcare services, which they think *are* regulated and which they think *should* be regulated. For all service options provided there were Panel members who thought they *are* regulated. First in terms of the services which respondents think *are* regulated, were dentists that provide NHS and private dental care (93%), followed by dentists that only provide private dental care (74%). On the other hand, respondents were least likely to think beautician-led cosmetics were regulated (26%). These findings highlight misconceptions around what services are currently regulated, as, in contrast to public beliefs, private ambulance services, beautician-led cosmetics, dentists that provide NHS and private dental care, slimming, nutritional and diet advice provided by dieticians, and internet-based GP and prescription services are not currently regulated<sup>6</sup>. Nurse or doctor-led cosmetics, dentists that only provide private dental care, and slimming, nutritional and diet advice led by a doctor are regulated.

In terms of what services *should* be regulated, again for all options provided there were Panel members who thought they should be regulated. Private healthcare services that most Panel members think *should* be regulated included beautician-led cosmetics (90%), followed

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<sup>6</sup> Further information on what services are currently regulated and the processes around this is available on the [Healthcare Improvement Scotland webpage](#).

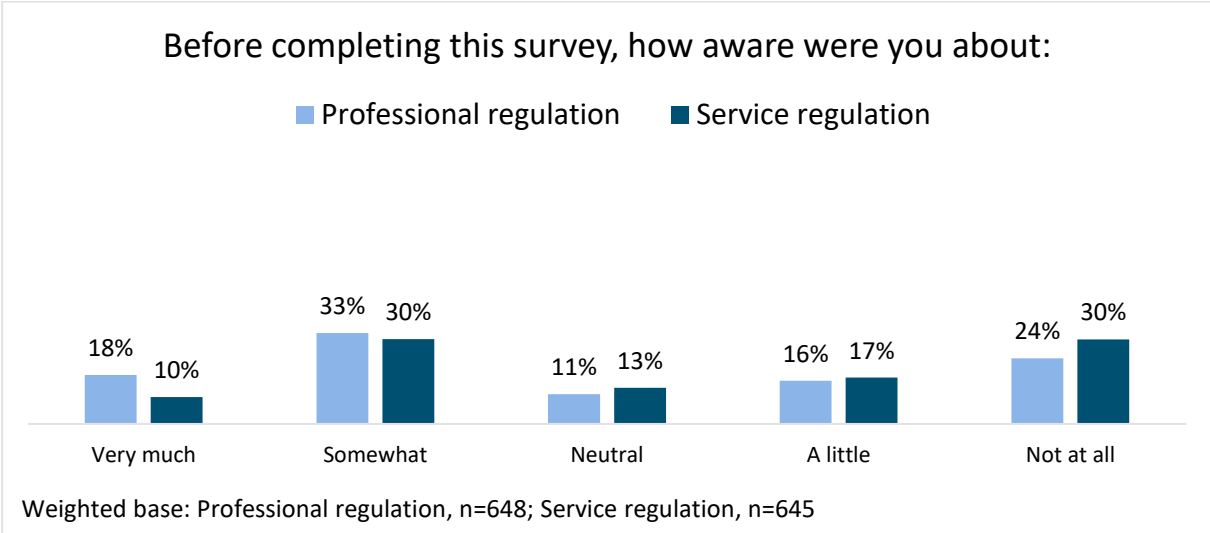
by dentists that only provide private dental care (88%), dentists that provide NHS and private dental care (88%), internet-based GP and prescription services which operate only online and don't have clinics or premises (88%), and nurse or doctor-led cosmetics (87%).



## Awareness of professional and service regulation

There are two types of healthcare regulation: professional regulation and service regulation. The overall aim of both types of regulation is to protect the public. Professional regulators set standards of education, training, practice, and conduct expected of healthcare professionals in the UK. They register qualified professionals who meet these standards and monitor their practice to ensure they continue to meet them. These regulators will also investigate any concerns raised with them about a registered professional's fitness to practice. Concerns can be raised by members of the public, employers, colleagues, third parties, or through self-referral. Service regulators set the standards of operation for the organisations that provide care, and the premises which care is delivered from. This regulator may also be able to investigate complaints about the quality of the service.

Panel members were asked how aware they were about professional and service regulation before completing the survey. Respondents were more likely to say they were very much aware or somewhat aware of professional regulation (51%) than service regulation (40%). Three in ten Panel members were not aware at all of service regulation (30%), and 24% were not aware at all of professional regulation.

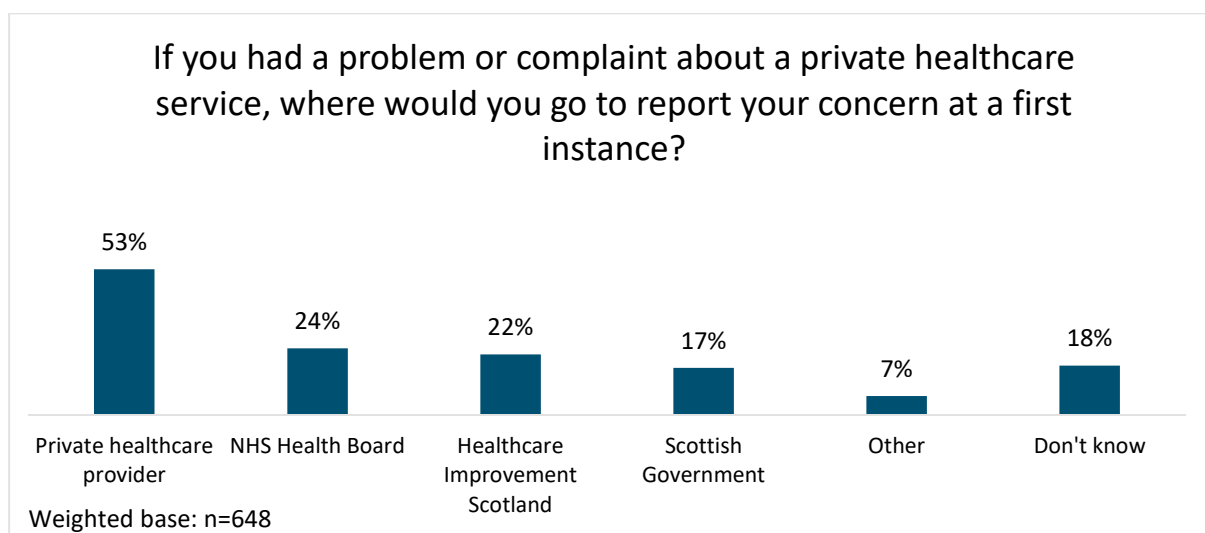


The questionnaire included an open-ended question which asked respondents what they think would be the best way to raise awareness around the regulation of private healthcare. Social media and online campaigns were the top response from Panel members (23%), followed by using leaflets, flyers or posters in public places (16%).

Q7b. What would be the best way in your opinion to raise awareness around the regulation of private healthcare?	
Base: respondents, wn=466	%
Social media/online campaign	23%
Leaflets/flyers/posters in public places	16%
Advertising in general/media	14%
TV advertising	12%
Certification mark or information on regulation on publications/website/premises/must state registration status in any publicity	8%
More information available on regulation etc.	7%
Private healthcare providers should ensure users aware of how they are regulated/regulation status/information provided before "signing up"	6%
Health board websites/healthcare provider website/websites	5%
All healthcare providers should be regulated the same way/same as NHS/should be compulsory/enforced	4%
Newspaper articles	3%
Inspection reports/regulation status available to the public	3%
Letters	2%
Radio advertising	2%
Other	8%
Don't know	17%

## Making a complaint about a private healthcare service

Over half of the respondents said that if they had a problem or complaint about a private healthcare service they would report their concern at a first instance to the private healthcare provider (53%). A further 24% said they would report it to a NHS health board and 22% said they would report it to HIS.



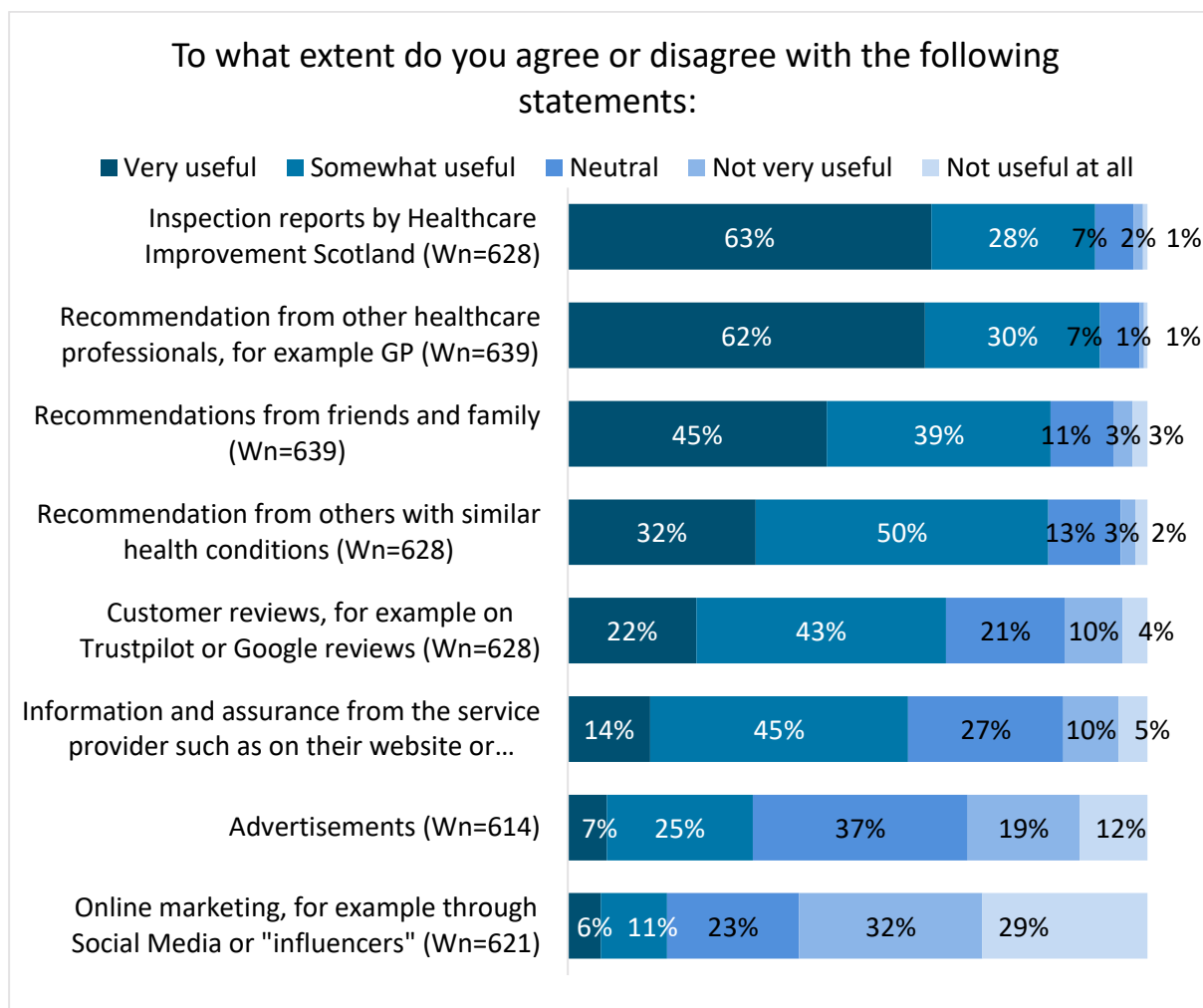
## Inspection reports

Panel members were asked how they would find inspection reports about a private healthcare service. Just under 3 in 10 Panel members who responded to the open-ended question were unsure where to obtain this information. On the other hand, half (50%) said they would go online or carry out a web search.

<b>Q9. If you wanted to find an inspection report about a private healthcare service, how would you find it? The report would include information about what the service is doing well and areas for improvement</b>	
<b>Base: respondents, wn==528</b>	<b>%</b>
Online/web search	50%
Service provider website/directly from the service provider	6%
Care Inspectorate/Care Quality Commission	5%
Scottish Government	5%
Healthcare Improvement Scotland	4%
NHS/NHS Scotland	3%
Inspection reports	2%
Ask GP/medical professional	1%
Local health board	0%
MP	0%
Other	4%
Don't know	29%

## Information sources when planning to use private healthcare services

All respondents were asked how useful various sources of information and advice would be in helping them choose a private healthcare service, if they were planning to use one. Over 6 in 10 respondents (63%) said they would find inspection reports by HIS very useful and 62% said they would find recommendations from other healthcare professionals such as GPs very useful. On the other hand, a significant proportion of respondents felt that online marketing via social media or “influencers” would not be useful at all (29%).

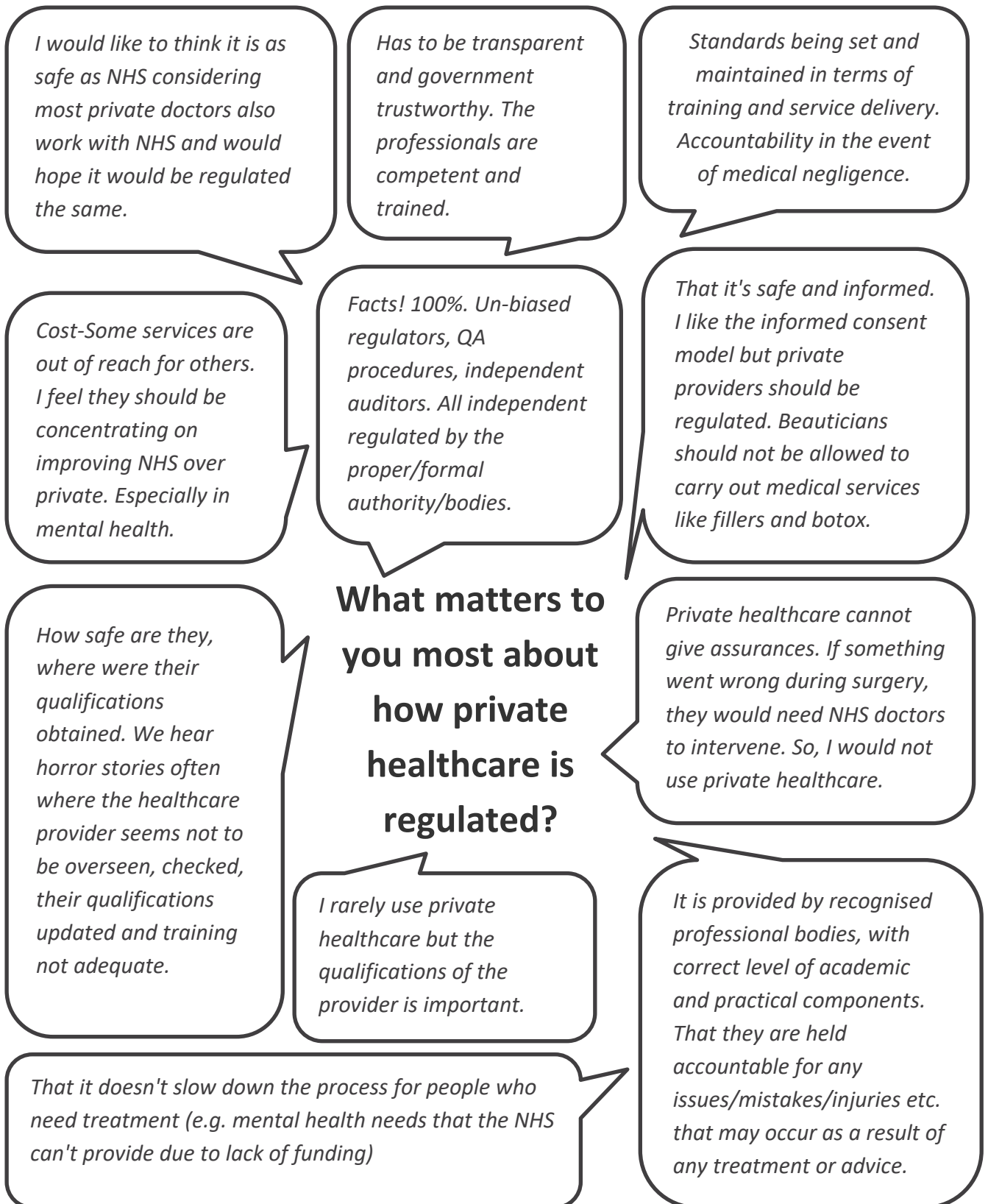


## Priorities for private healthcare regulation

Respondents were asked via an open-ended question about what matters most to them in terms of how private healthcare is regulated. A quarter of respondents (25%) stated it is most important to them that private healthcare services are independently regulated, have strict controls and are being unbiased, followed by mentions of patient safety (19%) and having qualified or well-trained staff (11%).

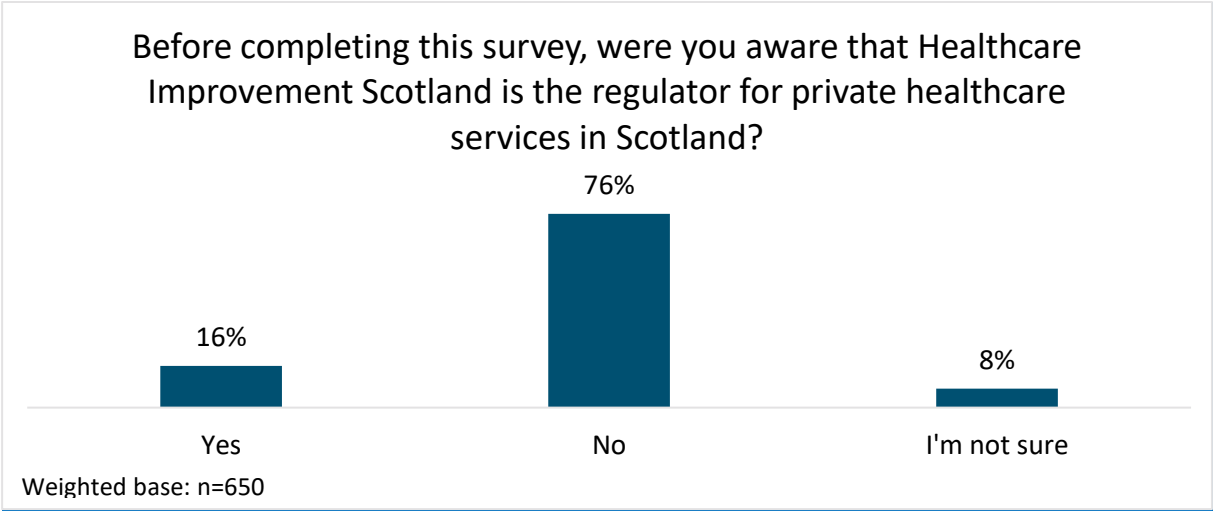
<b>Q11. What matters to you most about how private healthcare is regulated?</b>	
<b>Base: respondents, wn=529</b>	<b>%</b>
Independently regulated/strict controls/unbiased	25%
Patient safety	19%
Qualified/professional/well-trained staff	11%
Standard of care/high standard	9%
Similar regulations/standards to NHS	9%
That they are transparent	6%
I would always use the NHS/not use private healthcare/NHS should not be impacted	6%
Cost/fair pricing	6%
That they take accountability when things go wrong	5%
Accessible/speed of access to service	4%
Access to information	3%
Trust/peace of mind	2%
Other	11%
Don't know/no comment/no opinion	15%

Examples of the open-ended responses provided by Panel members to describe what matters most to them in terms of how private healthcare is regulated are shown below:



# Awareness of the role of HIS in the regulation of private healthcare services

Over three quarters of survey respondents (76%) said they were unaware that HIS is the regulator for private healthcare services in Scotland. On the other hand, 16% were aware and 8% were unsure.



# Conclusions and recommendations on the regulation of independent healthcare

These findings highlight that the public think that more private healthcare services both are and should be regulated compared to current practice. Independent healthcare is regulated when provided within premises by nurses and clinicians<sup>7</sup>, therefore services such as private ambulances, beautician-led cosmetics, private dentistry provided alongside or integrated with NHS dentistry, slimming services by dieticians, and online GPs are not currently regulated. These findings show misconceptions around this, for example with 93% believing that dentists that provide both NHS and private dental care are regulated, even though they currently are not. This may also suggest that the public think that all provision of NHS services is regulated, which is not currently the case.

Furthermore, it seems that the public wish for the regulation of independent healthcare to have a broader scope and include more services than it currently does. Over 80% of respondents said that there should be regulation, and this was the case for all services listed. The service which most thought should be regulated was beautician-led cosmetics (93%). This suggests that the public endorse and value the regulatory work of HIS and think regulation is positive and important, but they do not fully understand the scope and limitations of the current arrangements for the regulation of independent healthcare. This could also highlight the need to consider public views when thinking about what should be

<sup>7</sup> Information on what private services are regulated can be found on the HIS webpage [The regulation of independent healthcare in Scotland](#).



regulated and why, given the difference between current practice and public wishes, especially in the context of the potential change or expansion of scope for the regulation of independent healthcare in future. We recognise, however, that the scope of this must also consider practical requirements and limitations.

On the other hand, the findings make clear that public awareness of professional regulation and service regulation is relatively low, with respondents more likely to be aware of professional regulation than service regulation. When asked how to best raise awareness of private healthcare regulation, the Panel highlighted the need for a range of activities and use of different methods and platforms, such as social media, leaflets, and TV ads, to ensure wide reach.

Most respondents correctly identified that the first point of call if they had a problem with a private healthcare service is the provider (53%). However, many said they would go to the NHS health board (24%) or HIS (22%) with their complaint. While HIS can indeed progress complaints around independent healthcare, they can only address complaints around the quality of service and not clinical decisions or fitness to practice, therefore not all complaints are suitable to take to HIS, as outlined in the complaints process guidance. This could suggest, therefore, that further clarity would be helpful to the public around what complaints can and should be addressed via HIS and which complaints should be resolved through the private healthcare providers or other routes.

Many were unsure how to find an inspection report (29%) and most said that they would search for this online (50%). While searching online may be helpful, this also highlights the need for regulation reports to be clearly signposted to and easy to find via web search.

These findings confirm the importance of HIS inspection reports, with 91% saying that they are useful when planning to use a service. Recommendations from other healthcare professionals, from friends and family, and from others with similar conditions, were also noted as useful by most. This highlights the importance of signposting, both formally by clinicians, but also informally through word of mouth. These sources of information could also prove helpful when working to increase awareness of regulation.

Public priorities for independent healthcare regulation focused for most on the regulation being independent, strict and unbiased (25%). Another aspect noted was the importance of patient safety (19%). This finding links in well with the high level of trust and importance in regulation noted by the respondents in previous questions, for example, when saying that all services should be regulated and that HIS regulation reports are useful when selecting a service to use. But this also shows that this importance and trust relies on the processes being independent, strict and unbiased and focusing on patient safety, emphasising that the public want what they think is the right kind of regulation, and moving away from these priorities may mean that regulation loses the public's trust.

The findings also highlight a lack of awareness of the role of HIS in independent healthcare regulation, with only 16% being aware of this beforehand. It is important to note that

Citizens' Panel members may be somewhat more aware of the functions and roles of HIS overall, therefore this level of awareness may even be slightly higher than what could be expected outside the Citizens' Panel. The importance of regulation and regulation reports for the public based on these findings emphasises the need for further clarity and awareness of the HIS role.

## **Recommendations**

Based on these findings, we make the following recommendations to HIS, Scottish Government, and delivery partners:

1. Looking to the future of independent healthcare regulation, Scottish Government and HIS should consider the scope of regulation and ensure that public stakeholders are included in relevant processes so that public views and needs are met, including considering the current findings. When considering the broadening of regulation, these findings could help decide which areas to prioritise based on public views.
2. Work to increase public awareness and understanding around this topic. These activities should use a range of methods and platforms to ensure wide reach and should consider the sources of information mentioned by the Citizens' Panel as useful when planning and implementing awareness-raising activities. As this work would require significant resource, it could follow a gradual and staged approach, with certain aspects, services, or population groups prioritised. This work should look specifically at:
  - the scope of the regulation of private healthcare, what is and what is not regulated and why
  - the scope and differences between service regulation and professional regulation. Professional regulators, such as GMC, should be approached to be involved with this work
  - the complaints process, which aspects of care should be addressed and where. The complaints process needs to be clear on the role and responsibilities of HIS and other organisations. This should also include liaising with health boards to ensure they have the appropriate materials and information and can signpost accordingly. This could also include providing relevant information through NHS Inform
  - how and where the public can find regulation reports, and how to use this information to inform their decision-making, and
  - what the role of HIS is and what it is not, in terms of independent healthcare regulation.
3. Consider doing more engagement work to further understand what the public want from regulation, and why people may prioritise some services over others e.g. beautician-led cosmetics over dentistry.
4. Ensure that search engine optimisation for regulation reports is prioritised as part of website development work.

5. Consider making it a condition for services when registering that they signpost to the HIS regulation webpages and reports from their website, potentially using the HIS logo to increase visibility.

# Appendix 1: Questionnaire

## Citizens' Panel 12

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

- organ and tissue donation, and
- the regulation of independent healthcare, which is often called private healthcare.

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 to. If there is anything you do not wish to answer please just move on to the next question.

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

[www.researchresource.co.uk/CitizensPanelSurvey12.html](http://www.researchresource.co.uk/CitizensPanelSurvey12.html)

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](mailto: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 Panel surveys online, please provide your email address:

# 1. Attitudes toward organ and tissue donation after death

Organ and tissue donation means giving part of your body, after your death, to help someone who needs a transplant. Some living donor organ transplantation takes place but the focus of this work is donation after death. Organs which are routinely transplanted include the kidneys, liver, heart, lungs, pancreas and small bowel. Tissue which is routinely transplanted includes parts of the eyes, such as the cornea, tendons and heart valves.

In 2021, Scotland moved to an 'opt-out system' of deceased organ and tissue donation. This means that if someone dies in circumstances where they potentially could become a donor, and they have not registered a donation decision, they would be presumed to be willing to donate, unless their family or friends provide information that the potential donor was unwilling to do so.

To opt-out of donation (say no to donation) you can register your decision. If you support donation, you can still choose to actively register your decision to be a donor.

Whatever you decide, you should also tell family and friends about your donation decision to help ensure that it is honoured. Your family and friends will always be consulted about your latest views to ensure that donation does not proceed if you would not have wanted it to.

In 2019, we asked the Citizens' Panel for their views on deceased organ and tissue donation to help the Scottish Government prepare for the introduction of this opt-out system.

Four years after the 5th Citizens' Panel report, and the introduction of the opt-out system in 2021, we are asking the Panel for your views on this topic again. This is to explore public attitudes and awareness on this topic and how these may have changed since 2019. The information gathered will inform the evaluation and monitoring of the opt-out system for deceased organ and tissue donation and activities around it, for example relevant marketing campaigns. All findings will be used for the five year analysis report at the end of the monitoring and evaluation period in 2026.

**Q1 To what extent do you agree or disagree with the following statements about organ and tissue donation after death? Please select one answer on each row.**

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

**Q2 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 am aware that there is an opt-out system of organ and tissue donation in Scotland	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I understand that under the opt-out system I may be presumed to be willing to donate unless I have stated that I do not wish to do so	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I know how to register my organ and tissue donation decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I have had a conversation with a family member or loved one about my organ and tissue donation decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q3 a) How likely are you to register your organ and tissue donation decision?**

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

**If you are unlikely to register your organ and tissue donation decision, please tell us why?**

**Q3 b) Have you decided to opt-out of organ and tissue donation after your death?**

- Yes – Go to 3c
- No - Go to 4
- Don't know – Go to 4

**Q3 c If you have decided to opt-out of organ tissue donation, which of the below have you done? Please select one answer.**

- Registered this decision
- Informed family/friends of this decision
- Both of the above
- None

**Q4 If there is anything else you would like to say about organ and tissue donation after death, please use the space below:**

## 2. Independent healthcare regulation

At times, the public may choose to seek healthcare outside of NHS Scotland. Independent healthcare services are often called private healthcare services, and this is how we refer to them in this survey. In many cases these will be services that the patient has to pay for, or may be provided by a charity, such as a hospice. Independent healthcare services are regulated to ensure that the public are provided with high quality, safe healthcare which focuses on improvement.

We are asking these questions to find out your thoughts and awareness about private healthcare and its regulation. We understand that you may not have used, or not be planning to use, private healthcare. However, we are still interested in your views on this topic. Please answer these questions based on what you already know and would do, rather than what you think you should know or do.

We are keen to make sure that information we provide about private healthcare services is helpful and relevant, and we want to understand if regulation needs to be extended. These findings will inform the future decisions we make about the types of treatments and services that will require regulation and changes we want to make to ensure our regulatory work is helpful and meaningful to the public.

**Q5 Which of the following private healthcare services do you think are regulated?  
(Tick all that apply) Please don't worry if you aren't sure or don't know the answer to this.  
We are trying to understand general public awareness.**

- Private ambulance service, for example Red Cross ambulances
- Beautician-led cosmetics, for example when you get dermal filler or anti-wrinkle injections such as BOTOX® done by a beautician
- Nurse or doctor-led cosmetics, for example when you get dermal filler or anti-wrinkle injections such as BOTOX® done by a nurse or doctor
- Dentists that provide NHS and private dental care
- Dentists that only provide private dental care
- Slimming, nutritional and diet advice provided by a dietician
- Slimming , nutritional and diet advice led by a Doctor
- Internet-based GP and prescription services which operate only online and don't have clinics or premises



**Q6 Which of the following private healthcare services do you think should be regulated? (Tick all that apply)**

- Private ambulance service, for example Red Cross ambulances
- Beautician-led cosmetics, for example when you get dermal filler or anti-wrinkle injections such as BOTOX® done by a beautician
- Nurse or doctor-led cosmetics, for example when you get dermal filler or anti-wrinkle injections such as BOTOX® done by a nurse or doctor
- Dentists that provide NHS and private dental care
- Dentists that only provide private dental care
- Slimming, nutritional and diet advice provided by a dietician
- Slimming , nutritional and diet advice led by a Doctor
- Internet-based GP and prescription services which operate only online and don't have clinics or premises

**Q7 There are two types of healthcare regulation: professional regulation and service regulation.**

The overall aim of both types of regulation is to protect the public.

Professional regulators set standards of education, training, practice and conduct expected of healthcare professionals in the UK. They register qualified professionals who meet these standards, and monitor their practice to ensure they continue to meet them. These regulators will also investigate any concerns raised with them about a registered professional's fitness to practice. Concerns can be raised by members of the public, employers, colleagues, a third party, or through self-referral.

Service regulators set the standards of operation for the organisations that provide care and the premises care is delivered from. This regulator may also be able to investigate complaints about the quality of the service.

a) Before completing this survey, how aware were you about:

	Very much	Somewhat	Neutral	A little	Not at all
Professional regulation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Service regulation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**B) What would be the best way in your opinion to raise awareness around the regulation of private healthcare?**

**Q8 If you had a problem or complaint about a private healthcare service, where would you go to report your concern at a first instance? Please select all that apply.**

**Don't worry if you're not sure or don't know how to answer this. We want to know where you think you might go at a first instance if needed.**

- NHS Health Board
- Healthcare Improvement Scotland
- Scottish Government
- Private healthcare provider
- Other (please specify):
- Don't Know

**Q9 If you wanted to find an inspection report about a private healthcare service, how would you find it? The report would include information about what the service is doing well and areas for improvement.**

**Q10 If you were planning to use a private healthcare service, how useful would the below be to help you choose that service?**

	Very useful	Somewhat useful	Neutral	Not very useful	Not useful at all
Recommendations from friends and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advertisements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information and assurance from the service provider such as on their website or leaflet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Customer reviews, for example on Trustpilot or Google reviews	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inspection reports by Healthcare Improvement Scotland	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online marketing, for example through Social Media or "influencers"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recommendation from others with similar health conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recommendation from other healthcare professionals, for example GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other, please describe:

**Q11 What matters to you most about how private healthcare is regulated?**

**Q12 Before completing this survey, were you aware that Healthcare Improvement Scotland is the regulator for private healthcare services in Scotland?**

- Yes
- No
- I'm not sure

**Q13 In order to allow us to make sure we are obtaining a response from the right person, please record your month and year of birth below. (MM/YYYY).**

Thank you for completing these questions around the regulation of independent healthcare.

Healthcare Improvement Scotland is currently responsible for regulating independent hospitals, voluntary hospices, private psychiatric hospitals and independent clinics.

You can find more on this topic on the Healthcare Improvement Scotland website:

[https://www.healthcareimprovementscotland.org/our\\_work/inspecting\\_and\\_regulating\\_care/independent\\_healthcare.aspx](https://www.healthcareimprovementscotland.org/our_work/inspecting_and_regulating_care/independent_healthcare.aspx)

Our website also provides a service search tool to find inspection reports and information on the services and clinics we regulate:

[https://www.healthcareimprovementscotland.org/our\\_work/inspecting\\_and\\_regulating\\_care/independent\\_healthcare/find\\_a\\_provider\\_or\\_service.aspx](https://www.healthcareimprovementscotland.org/our_work/inspecting_and_regulating_care/independent_healthcare/find_a_provider_or_service.aspx)

## Appendix 2: Response profile

### Response profile

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

Emails sent	945
Number of email responses	405
Email response rate	43%
Number of postal sent	664
Number of postal returned	161
Postal response rate	24%
Telephone surveys	94
Online survey	3
<b>OVERALL RESPONSE RATE</b>	
Response	663
Current number on Panel	1030
Overall response rate	64%

Age	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
16-24	12%	56	5.48%	17	3%	30%	-9%
25-44	32%	204	19.98%	106	16%	52%	-16%
45-64	33%	375	36.73%	258	39%	69%	6%
65+	24%	386	37.81%	276	42%	72%	18%
<b>Total</b>	<b>101%</b>	<b>1021</b>	<b>100%</b>	<b>657</b>	<b>100%</b>	<b>64%</b>	

Source: National Records Scotland - Population Estimates 2021. Table 1. Retrieved from: <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2021> Data - table 1 05/08/22

Sex	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
Male	48%	469	46%	329	50%	70%	2%
Female	52%	556	54%	330	50%	59%	-2%
Other		1	0%		0%	0%	0%
Prefer not to answer		2	0%	0	0%	0%	0%
<b>Total</b>	<b>100%</b>	<b>1028</b>	<b>100%</b>	<b>659</b>	<b>100%</b>	<b>64%</b>	

[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 2021. Table 1. Retrieved from: <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2021> - Data - Table 1 05/08/22

Tenure	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
Own	58%	722	70.30%	505	77%	70%	19%
Rent from Council/HA	23%	167	16.26%	86	13%	51%	-10%
Private Rent	15%	70	6.82%	40	6%	57%	-9%
Other	4%	68	6.62%	26	4%	38%	0%
<b>Total</b>	<b>100%</b>	<b>1027</b>	<b>100%</b>	<b>657</b>	<b>100%</b>	<b>64%</b>	<b>0%</b>

Source: <https://www.gov.scot/publications/housing-statistics-stock-by-tenure/> 19/08/22

Physical or mental health condition or illness	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
Yes	47%	334	33%	228	36%	68%	-11%
No	53%	665	67%	412	64%	62%	11%
<b>Total</b>	<b>100%</b>	<b>999</b>	<b>100%</b>	<b>640</b>	<b>100%</b>	<b>64%</b>	

Source: Scottish Health Survey – telephone survey – August/September 2020: main report: Chapter 1 General Health, Long Term Conditions and Caring. Retrieved from <https://www.gov.scot/publications/scottish-health-survey-telephone-survey-august-september-2020-main-report/pages/5/> 05/08/22

Religion	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
Church of Scotland	32%	300	32%	209	33%	70%	1%
Roman Catholic	16%	103	11%	66	11%	64%	-5%
Other Christian	6%	65	7%	48	8%	74%	2%
Buddhist	0.20%	9	1%	6	1%	67%	1%
Hindu	0.30%	2	0%	0	0%	0%	0%
Jewish	0.10%	2	0%	2	0%	100%	0%
Muslim	1.40%	26	3%	12	2%	46%	1%
Sikh	0.20%	3	0%	3	0%	100%	0%
Other religion	0.30%	25	3%	12	2%	48%	2%
None	37%	396	42%	253	41%	64%	4%
Prefer not to answer	7%	17	2%	13	2%	76%	-5%
<b>Total</b>	<b>101%</b>	<b>948</b>	<b>100%</b>	<b>624</b>	<b>100%</b>	<b>66%</b>	

Source: Scotland's Census 2011 - National Records of Scotland. Table KS209SCb - Religion. Retrieved from: <https://www.scotlandscensus.gov.uk/ods-analyser/jsf/tableView/tableView.xhtml> NB - No data for 340 Panel members

Sexual orientation	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
Heterosexual or straight	95%	862	90%	568	90%	66%	-5%
Gay or lesbian	1%	42	4%	31	5%	74%	4%
Bisexual	0.60%	20	2%	8	0%	40%	-1%
Other	0.40%	8	1%	5	0%	63%	0%
Prefer not to say	3%	21	2%	16	3%	76%	0%
<b>Total</b>	<b>100%</b>	<b>953</b>	<b>100%</b>	<b>628</b>	<b>98%</b>	<b>66%</b>	

Source: Scottish Government. Sexual orientation in Scotland 2017: summary of evidence base. Figure 4: Sexual Identity in the UK compared with Scotland -2015. Retrieved from: <https://www.gov.scot/publications/sexual-orientation-scotland-2017-summary-evidence-base/pages/3/>

SIMD Quintile (2020)	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
1	20%	208	20%	117	18%	56%	-2%
2	20%	205	20%	123	19%	60%	-1%
3	20%	204	20%	131	20%	64%	0%
4	20%	198	19%	142	22%	72%	2%
5	20%	204	20%	146	22%	72%	2%
<b>Total</b>	<b>100%</b>	<b>1019</b>	<b>100%</b>	<b>659</b>	<b>100%</b>	<b>65%</b>	

Urban Rural Classification	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
Accessible Rural	11%	111	11%	65	11%	59%	0%
Accessible Small Towns	8%	91	9%	52	9%	57%	1%
Large Urban Areas	38%	324	32%	186	33%	57%	-5%
Other Urban Areas	33%	357	35%	179	32%	50%	-1%
Remote Rural	6%	86	8%	51	9%	59%	3%
Remote Small Towns	3%	52	5%	35	6%	67%	3%
<b>Total</b>	<b>99%</b>	<b>1021</b>	<b>100%</b>	<b>568</b>	<b>100%</b>	<b>56%</b>	

Source: National Records Scotland - Household Estimates 2021.

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/households/household-estimates/other-geographies-2011-data-zone-based/household-and-dwelling-estimates-by-urban-rural-classification> 05/08/22



Local Authority	Scottish Popn. %	No on Panel	% of Panel	No of respondents	% of respondents	Response rate	Difference response v popn
Aberdeen City	4%	35	3%	27	4%	77%	0%
Aberdeenshire	5%	51	5%	37	6%	73%	1%
Angus	2%	41	4%	28	4%	68%	2%
Argyll and Bute	2%	13	1%	9	1%	69%	-1%
City of Edinburgh	10%	93	9%	70	11%	75%	1%
Clackmannanshire	1%	9	1%	5	3%	56%	2%
Dumfries and Galloway	3%	35	3%	26	4%	74%	1%
Dundee City	3%	30	3%	17	3%	57%	0%
East Ayrshire	2%	26	3%	10	2%	38%	0%
East Dunbartonshire	2%	14	1%	9	1%	64%	-1%
East Lothian	2%	18	2%	13	2%	72%	0%
East Renfrewshire	2%	15	1%	11	2%	73%	0%
Falkirk	3%	27	3%	23	3%	85%	0%
Fife	7%	25	2%	15	2%	60%	-5%
Glasgow City	12%	100	10%	64	10%	64%	-2%
Highland	4%	47	5%	33	5%	70%	1%
Inverclyde	1%	6	1%	2	0%	33%	-1%
Midlothian	2%	27	3%	16	2%	59%	0%
Moray	2%	20	2%	17	3%	85%	1%
Na h-Eileanan Siar	0%	13	1%	8	1%	62%	1%
North Ayrshire	2%	31	3%	14	2%	45%	0%
North Lanarkshire	6%	81	8%	37	6%	46%	0%
Orkney Islands	0%	7	1%	4	1%	57%	1%
Perth and Kinross	3%	32	3%	21	3%	66%	0%
Renfrewshire	3%	28	3%	18	3%	64%	0%
Scottish Borders	2%	21	2%	14	2%	67%	0%
Shetland Islands	0%	17	2%	12	2%	71%	2%
South Ayrshire	2%	22	2%	11	2%	50%	0%
South Lanarkshire	6%	80	8%	43	7%	54%	1%
Stirling	2%	18	2%	12	2%	67%	0%
West Dunbartonshire	2%	15	1%	9	1%	60%	-1%
West Lothian	3%	28	3%	25	4%	89%	1%
<b>Total</b>	<b>100%</b>	<b>1025</b>	<b>100%</b>	<b>660</b>	<b>102%</b>	<b>64%</b>	

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