



Version 1 | Internal Use Only

Human Tissue Authority stakeholder evaluation 2013

Report prepared by Ipsos MORI for the Human Tissue Authority

1. Introduction

- Background and objectives
- Methodology
- Interpretation of the findings

2. Key messages

3. Findings from the professional survey

- Profile of respondents
- Key performance measures
- Effectiveness and importance
- Communications
- Ease of compliance, taking views into account and feedback
- Views on changes within sector

4. Findings from the public survey

- Overall perceptions of regulation
- Attitudes towards donation

5. Conclusions and recommendations

6. Note on statistical reliability

Please click on the section title to scroll to the corresponding page.

1. Introduction



Background

- The Human Tissue Authority (HTA) was established under the Human Tissue Act 2004 to regulate activities concerning the removal, storage, use and disposal of human tissue. Since 2012 the HTA also holds the responsibility for establishing standards for the quality and safety of transplant organs across the United Kingdom, under the EU Organ Donation Directive.
- The HTA commissioned Ipsos MORI to carry out its 2013 stakeholder research programme. The 2013 study builds on a number of other pieces of work conducted with public and professional stakeholders, including the 2010 stakeholder research and 2007 general public survey also carried out by Ipsos MORI.
- Since the last survey, the HTA's remit has expanded to include licensing establishments in the organ donation and transplantation (ODT) sector. Stakeholders working as an ODT named contact or corporate licence holder are included in this survey, but were not included in the previous stakeholder evaluation.
- This particular iteration of study follows the announcement by the government in January 2013 that the HTA would be retained as a separate organisation, following a Department of Health consultation into the future of the HTA and a review of arm's-length bodies.
- In addition, an independent review by Justin McCracken, examining the way in which the HTA (along with the Human Fertilisation and Embryology Authority) undertake their functions and operations, was published in July 2013. This recognised the success of the HTA as a regulator and acknowledged the high levels of professional and public confidence in the HTA.
- Indeed, over this period of reflection, the Government and the HTA have received a large number of positive responses from key opinion leaders and stakeholders as part of the review process. They have, however, also been able to garner feedback on how the HTA could carry out its duties in an even more effective and efficient manner.

Background and objectives cont'd

- The HTA has used this feedback to develop its on-going strategy for communications and engagement with stakeholders, and its strategic and business plans. The strategic plan is focussed around four objectives, which can be summarised as follows.

HTA strategic aims 2013/14 – 2015/16

1. To improve further the effectiveness of our regulatory activity, and our advice and guidance;
2. To develop and consolidate productive stakeholder relationships with the public and professionals
3. To have a skilled, motivated and dedicated team equipped to do the job in a challenging operational environment; and
4. To ensure the HTA is effectively governed and is managed efficiently, providing value for money for licensed establishments and the tax payer.

Objectives

- The main objectives of this work were to carry out an evaluation of general public and stakeholder opinion in order to better understand:
 - Tracking of views, experiences and perceptions since the 2010 surveys;
 - Confidence in and attitudes towards the regulation and donation of human tissue for different purposes;
 - Views on issues related to and terminology of consent;
 - Stakeholder views on the effectiveness of HTA as a regulator and in their aim to reduce the burden of regulation;
 - Experiences of complying with HTA standards, and working with HTA in general, including gaining advice and training; and
 - Perceptions of value for money among stakeholders.
- Therefore, the findings from this evaluation programme will be used alongside the recommendations from the reviews to influence the future strategic direction, operational procedures and communications of the HTA.
- To meet these objectives, two quantitative surveys, one with professional stakeholders and one with the general public, were conducted by Ipsos MORI in July and August 2013.
- Unlike the HTA's 2010 stakeholder evaluation, key opinion leader research was not included in this work, due to the rich feedback received as part of the review of the Department of Health's arm's-length bodies (ALBs).

Professional survey

- Ipsos MORI interviewed 362 professional stakeholders between 15th July and 1st August 2013 via an online survey.
- This represents a response rate of 37%, with all 985 professional stakeholders receiving an email invitation to the survey.
- Data for 2010 are also based on an online survey of 349 HTA stakeholders, conducted between 14th June and 2nd July 2010.
- Data for 2013 are weighted to the sample profile (for professional type and sector) to account for non-response bias. Weighting was not required for the 2010 data.

Public survey

- Ipsos MORI interviewed a representative sample of 987 GB adults aged 15+ in a face-to-face survey between 2nd and 12th August 2013. An additional question was asked of 998 GB adults aged 15+ between 16th and 22nd August 2013. Both were carried out on the Ipsos MORI Capibus face-to-face omnibus survey.
- Data for 2010 is based on a face-to-face survey of 967 GB adults aged 15+ interviewed between 13th and 19th August 2010.
- Data for 2013 and 2010 are weighted to the known population profile.

Professional and Public surveys

- Questionnaires used for these surveys, and computer data tables are provided under separate cover.

Interpretation of the findings

- Throughout the report, where results do not sum to 100 this may be due to the effects of computer rounding or weighting.
- Results are presented for 2013, with change since 2010 (in percentage points) presented for tracking questions. Results from the 2007 general public survey are also presented where relevant.
- Changes and sub-group differences are only presented on the summary slides if they are statistically significant, but caution should be taken when looking at changes over time, especially in the professional survey where base sizes are sometimes very small.
- Please note that the question on public confidence in health sector regulation in general was carried out on a subsequent wave of the Ipsos MORI Capibus study, to avoid answers being influenced by the preceding questions on human tissue regulation.
- Small bases requiring caution are flagged throughout the report.
- A full note on statistical reliability can be found at the end of this report.

Structure of the report

- In this report we present the findings from the 2013 HTA Stakeholder survey. The report is structured thematically, dealing first with the findings from the professional survey, before discussing the findings from the general public survey.
- In each section, the main findings are summarised before data are presented for each question in graphic form.

2. Key messages



Overall professional stakeholders are very positive

- The HTA's professional stakeholders continue to be very positive about their relationship with the HTA, with improvement more or less across the board since 2010, including in the HTA's key performance indicators.
- Stakeholders have a **great deal of confidence** in the HTA, are **very favourable** towards the HTA, and are likely to be **strong advocates**.
- The HTA is thought to be performing **very effectively** in relation to many of the activities that stakeholders identify as being **very important**, such as, *giving advice and guidance; overseeing the consent requirements of the Human Tissue Act; ensuring dignity and respect for the deceased; and ensuring the safety and quality of human tissue, cells and organs used for patient treatment*.
- There are, however, three activities seen to be **very important** by stakeholders that the HTA is not viewed as being quite as effective at performing: *improving professional confidence; improving public confidence; and sharing best practice*.
- The HTA is seen to be performing better than other comparable organisations. Stakeholders feel that regulation by the HTA presents less of an obstacle to organisational success than health sector regulation in general.
- When benchmarked against other public sector organisations, the HTA comes out top in terms of **advocacy** and **keeping stakeholders informed**. Both of these are key measures of performance and the findings show that stakeholders who feel informed tend to be more positive about the HTA overall.
- Stakeholders are also very positive about their communications with the HTA. They use *telephone calls* and *email* frequently, and find them to be **very useful**. But the *HTA website*, *HTA online portal*, and *e-newsletter/bulletin*, do not perform quite as well, despite being used by high proportions of stakeholders. The HTA is already looking at improvements to these latter areas that may address these concerns.
- Fees are one of the areas where stakeholders feel **less well** informed, and are more uncertain about. The *'Fees and Stakeholder Group'* currently being established reflects initial steps by HTA to improve in this area.
- Across the sectors, stakeholders report that it is **easy** for them to know what they have to do to comply with standards, and are unlikely to see the HTA's regulation as an obstacle to success (performing better here than the health sector generally). The changes the HTA plans to make are on the whole seen to either have a positive, or no negative impact, on establishments.

Public confidence has declined, although fewer say they are unlikely to donate

- The level of overall public confidence in the donation, removal, storage and use of human tissue or organs has **declined since 2010**.
- However, it is important to consider this finding in the context of the wider health sector over this period, where recent scandals are likely to have **undermined public confidence**. This is highlighted by the findings of Ipsos MORI's Issues Index, where at the time of fieldwork (August 2013) the proportion of the public citing the state of the NHS as one of the most important issues facing Britain was at its highest since January 2008 at 29%, and up 11 percentage points compared to August 2010.
- Furthermore, the public are **more likely to lack confidence in health sector regulation in general** than specifically the regulatory functions carried out by the HTA. The public were asked separately about confidence in the regulation of the health sector in general and in the regulation of the donation, removal, storage and use of human tissue or organs. Around half for each are confident, but people are far more likely to state an active lack of confidence in the health sector generally. Perhaps reflecting the specific remit of the HTA, a higher proportion answer that they do not know how confident they feel in relation to the regulatory functions carried out by the HTA.
- While overall confidence is declining, of interest is how this relates to reported likelihood to donate. The proportion of the public who say they are **unlikely** to donate has generally decreased since 2010, for example the proportion of people who say they are **unlikely** to *donate any tissue or organs while alive for use in transplantation* has decreased significantly.
- While this has not yet led to a corresponding increase in the percentage of the public who say they are **likely** to donate, this is a positive message, and if the trend continues could potentially lead to future increases in reported likelihood to donate.
- Among those who remain **unlikely** to donate, many say that they simply do not want to. However, other reasons appear to be increasingly more about fundamental values, such as *religious considerations*, which will be harder to erode.

3. Findings from the professional survey

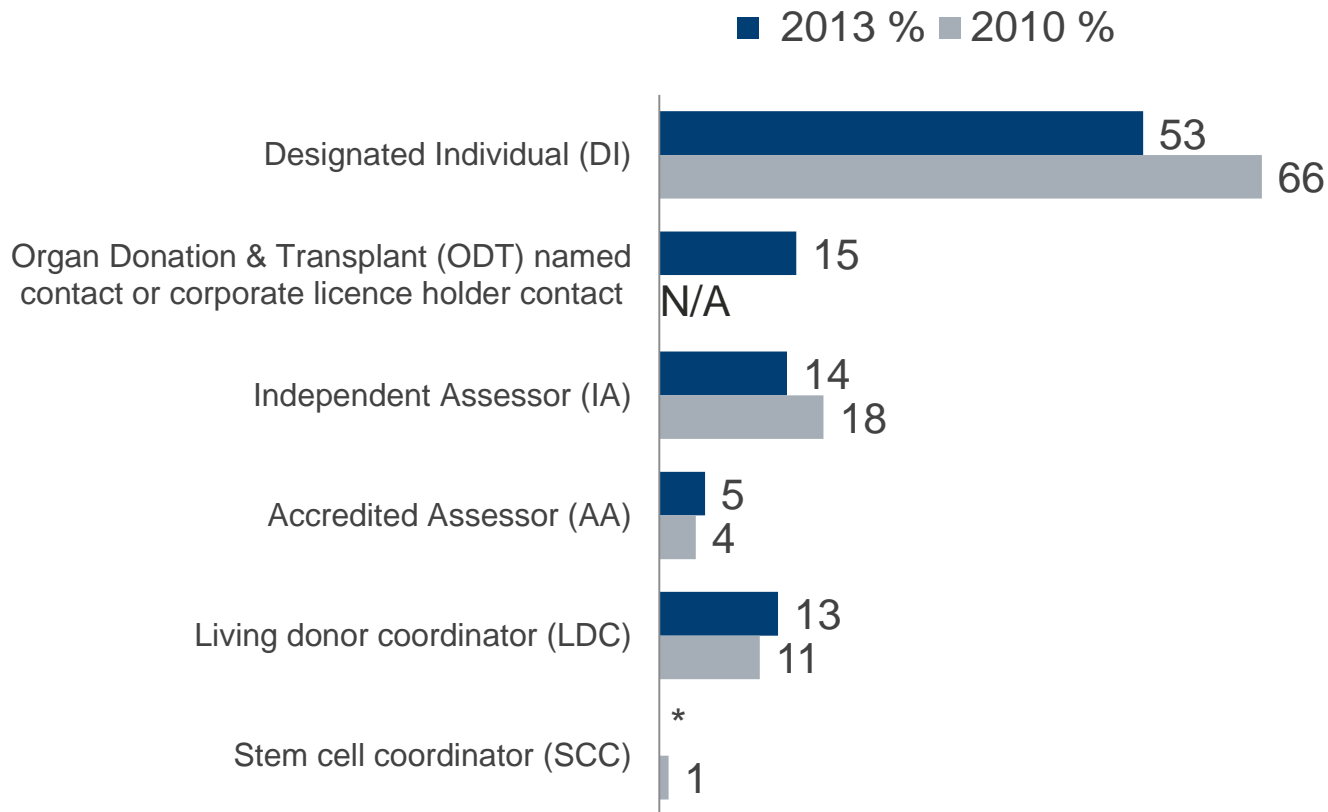


Profile of respondents

- As in 2010, the largest group of stakeholders, based on relationship with the HTA, is **Designated Individuals (DIs)**, who account for around half (53%) of stakeholders. While there have been some changes in profile compared to 2010, this can largely be attributed to the addition of a new role – that of **Organ Donation and Transplant (ODT) named contacts/corporate licence holder (15%)**. The other groups are Independent Assessors (IAs) (14%), Accredited Assessors (AAs) (5%), Living Donor Coordinators (LDCs) (13%) and Stem Cell Coordinators (SCCs) (<0.5%).
- As would be expected, given the time since the HTA was created in 2004, there is an increase in the proportion of stakeholders who have been working with the HTA for a longer period of time: 34% now say they have been in their role for **6-10 years**.
- The biggest sector is that of **Transplants – solid organ donation**, made up of stakeholders from various groups (primarily ODTs, IAs and LDCs), of which two fifths (40%) of stakeholders work in. The **post mortem sector**, comprised of DIs only, is the next largest, in which one in five (19%) of stakeholders work.
- The vast majority of respondents work in the **public sector** (88%).
- As was the case in 2010, the largest region is **London** (23% of stakeholders), with the second largest region the **North West** on 13%.

Relationship with HTA

Please specify your relationship with the HTA:



Absolute numbers		
	2013	2010
DI	191	230
ODT	54	N/A
IA	49	64
AA	19	14
LDC	47	38
SCC	1	3

*Indicates a percentage lower than 0.5% but greater than zero

Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

Source: Ipsos MORI

Length of time in role

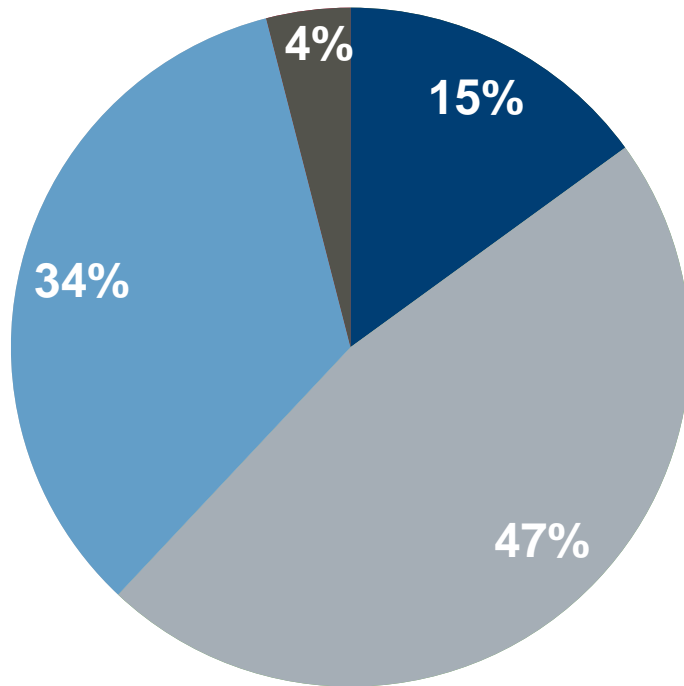
How long have you been working in this role?

Less than 1 year ■

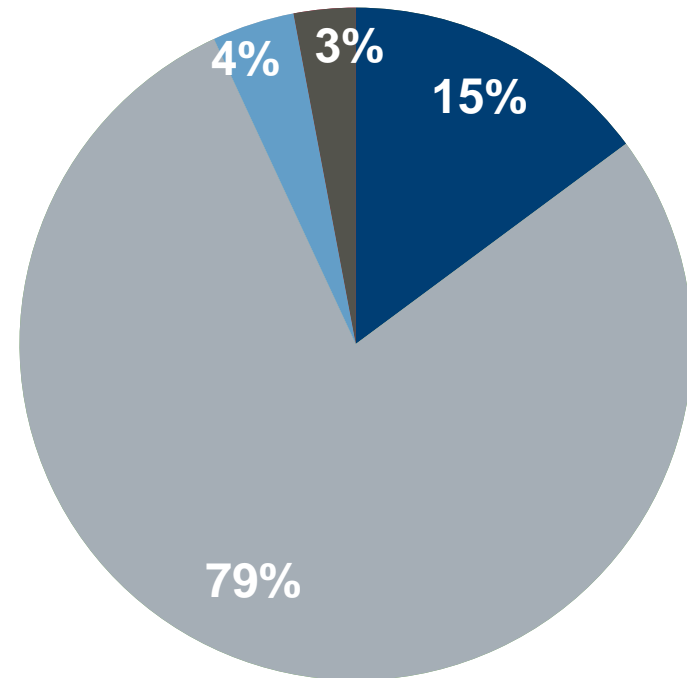
Between 1 and 5 years ■

Between 6 and 10 years ■

More than 10 years ■



2013

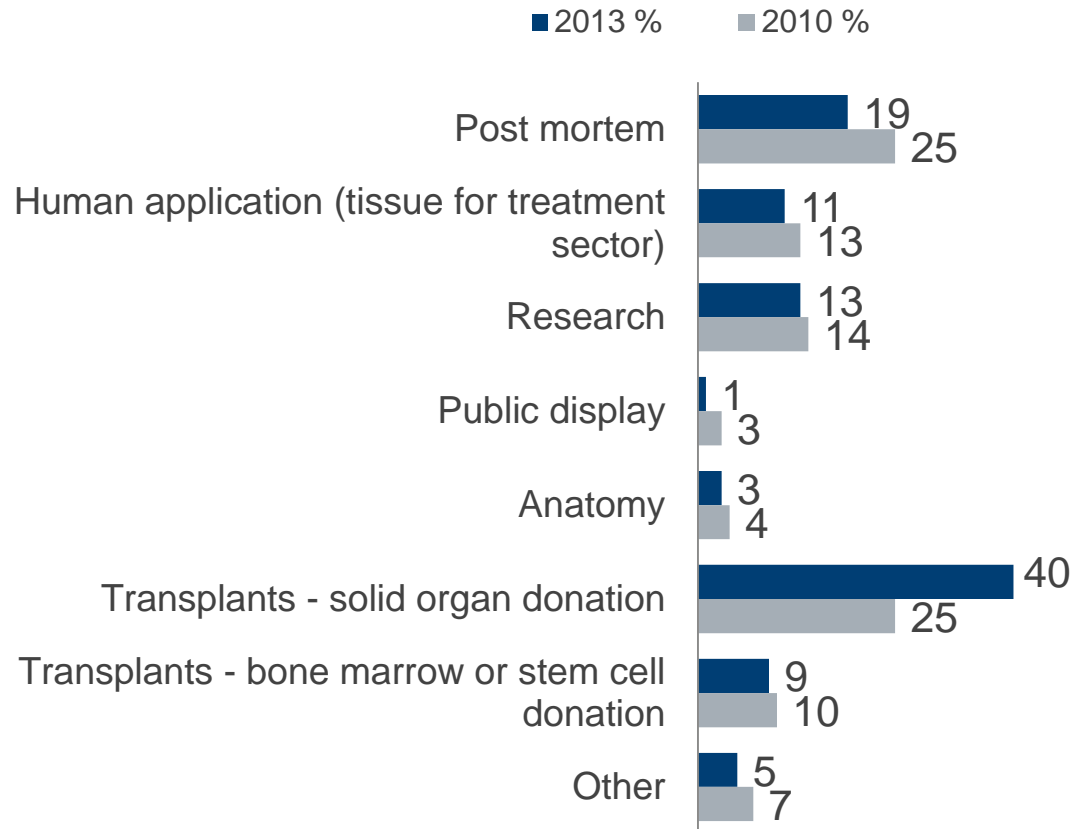


2010

Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

Source: Ipsos MORI

In which sector do you primarily work?

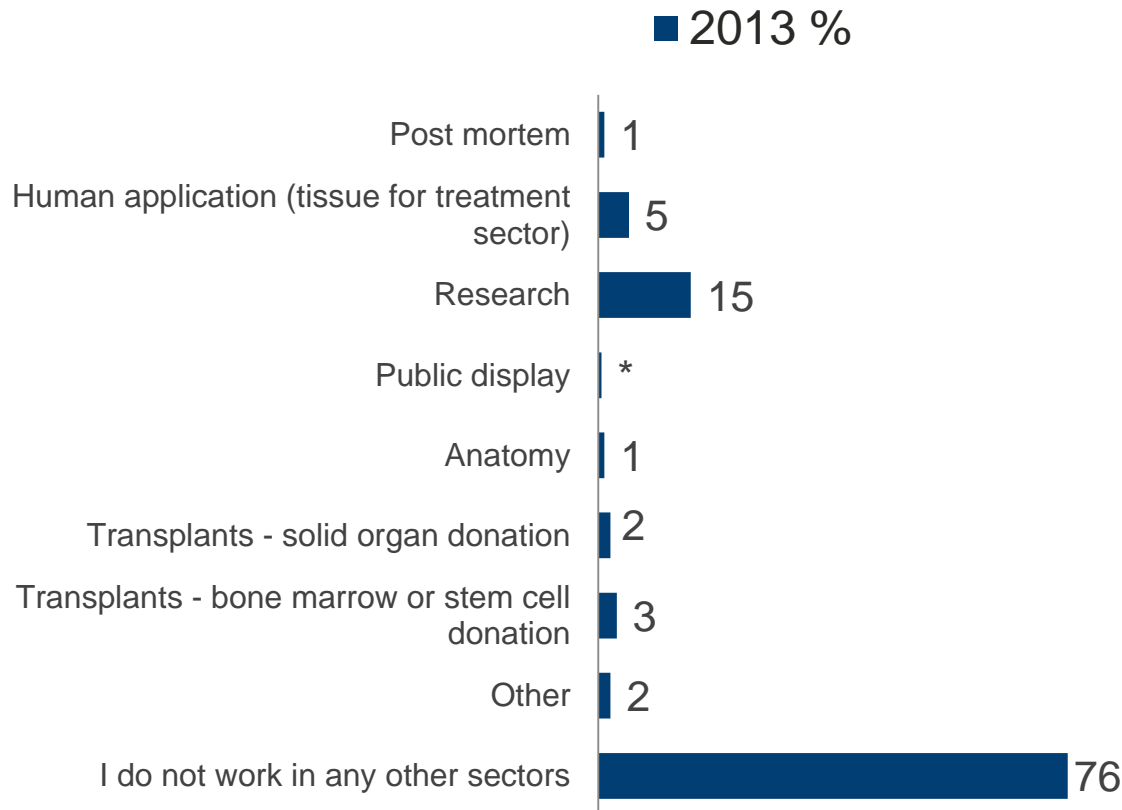


Absolute numbers		
Sector	2013	2010
Post mortem	69	86
Human application (tissue for treatment)	39	47
Research	47	49
Public display	3	9
Anatomy	12	13
Transplants – solid organ donation	144	88
Transplants – bone marrow or stem cell donation	32	34
Other	16	23

Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

Source: Ipsos MORI

Which other sectors, if any, do you work in?

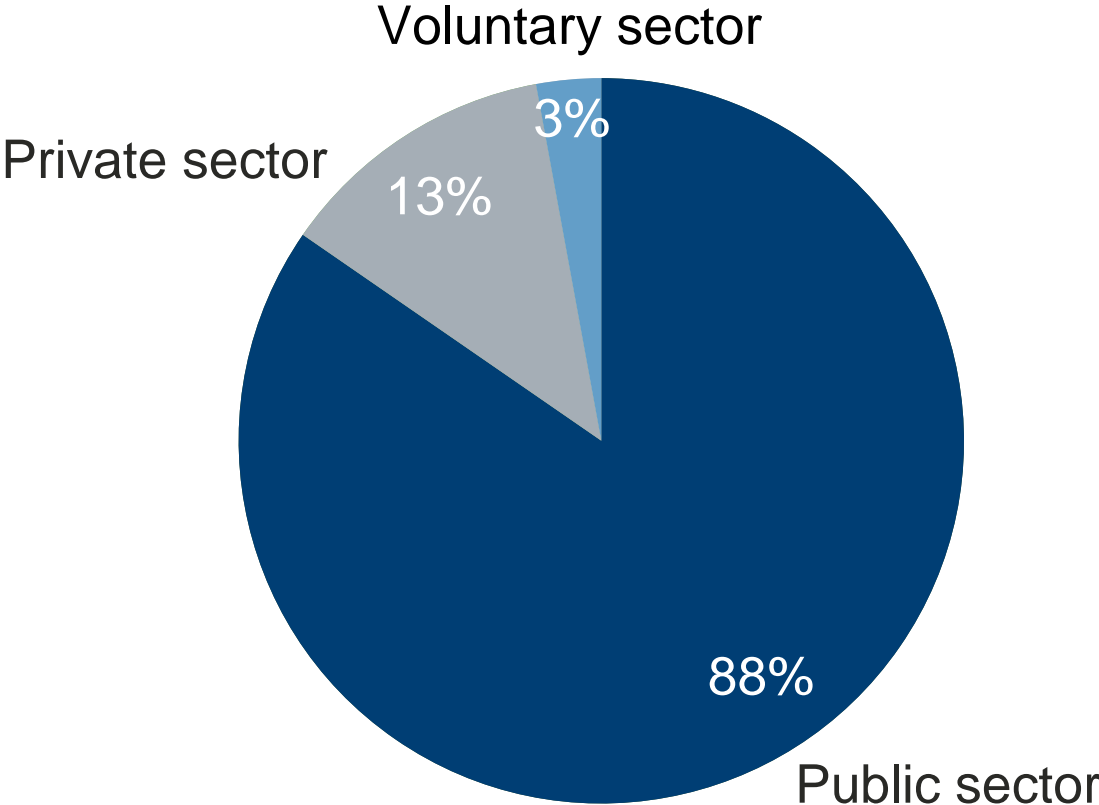


Absolute numbers	
Sector	2013
Post mortem	4
Human application	18
Research	55
Public display	2
Anatomy	5
Solid organ	8
Bone marrow	11
Other	8
No other sector	274

*Indicates a percentage lower than 0.5% but greater than zero

Public, private or voluntary sector

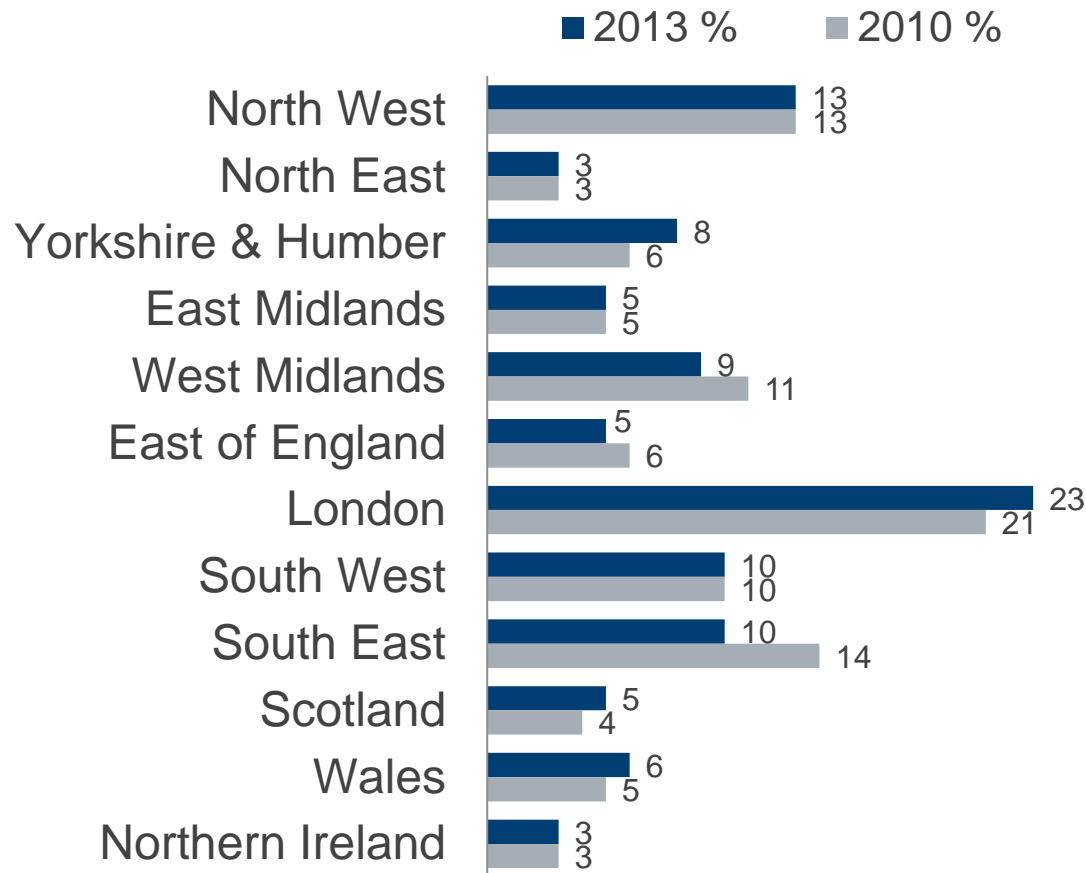
Do you work in the public, private or voluntary sector(s)?



Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI

In which of the following geographical areas are you mainly based?



Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

Source: Ipsos MORI

Key performance measures

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For all key performance measures covered in the professional survey, the HTA has shown considerable improvement since 2010.

Key Performance Indicators

- The proportion of stakeholders whose opinion is favourable (*mainly* or *very*) towards the HTA is up by 21 percentage points since 2010, while the proportion saying their opinion is **very favourable** has increased by 9 percentage points.
- Continuing the positive trend, overall advocacy of the HTA has risen by 15 percentage points to 73%, with those **speaking highly without being asked** having increased by 6 percentage points to 20%.
- This compares favourably with other public sector organisations, with the HTA now receiving a **higher level of advocacy than any similar organisation** in Ipsos MORI stakeholder evaluations over the past five years.
- Confidence in the HTA as a regulator has increased by 6 percentage points to 92%, with 49% now having **great deal of confidence** (an increase of 8 percentage points).
- Growth in these areas may reflect a number of things, including stakeholder engagement with the McCracken Review of the HTA (and HFEA). The period since 2010 in general has been one of change for the HTA, all of which could impact upon stakeholder perceptions.
- As would be expected among a group of professional stakeholders, knowledge of the HTA remains very high. Since 2010 knowledge has increased slightly, with 96% saying they know **very well or a fair amount** about what the HTA does, compared with 91% in 2010. Of these, the number who know the HTA **very well** has remained at the same level as 2010, however, at 39%.

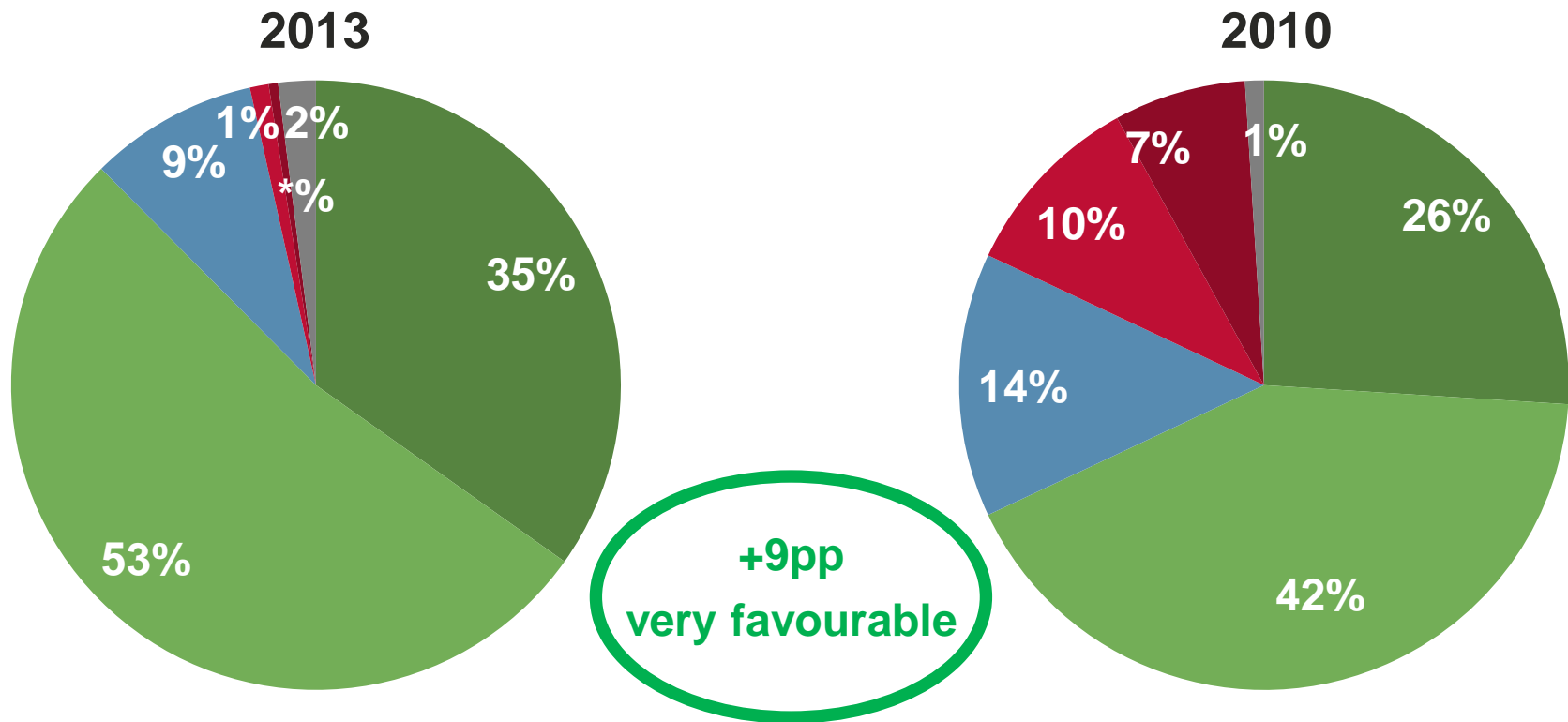
Summary: key performance measures

- There are some differences in opinion across sectors and roles for the key performance measures – although the small base sizes limit the degree of significance we can attribute to these changes:
 - DIs are most likely to claim to know **very well** what the HTA does at 46% (compared with 39% overall), while only one in five IAs say they know **very well** (21%).
 - IAs are more favourable than average towards the HTA, with half (51%) answering that they are **very favourable** (compared with 35% overall).
 - While propensity for unprompted advocacy is similar across the board, IAs are also more likely to say they would be **speak highly if asked** (65% say this, compared with 53% overall). Those in the research sector are also more likely to be advocates when prompted than average (70% compared with 53% overall).
 - Those in the research sector are also more likely than average to have a **great deal** of confidence in the HTA as a regulator – six in ten in this sector (61%) are **very confident**, compared to half (49%) overall.

Favourability towards the HTA has increased...

How favourable or unfavourable is your overall opinion of the HTA?

Very favourable Mainly favourable Neither Mainly unfavourable Very unfavourable No opinion/Don't know



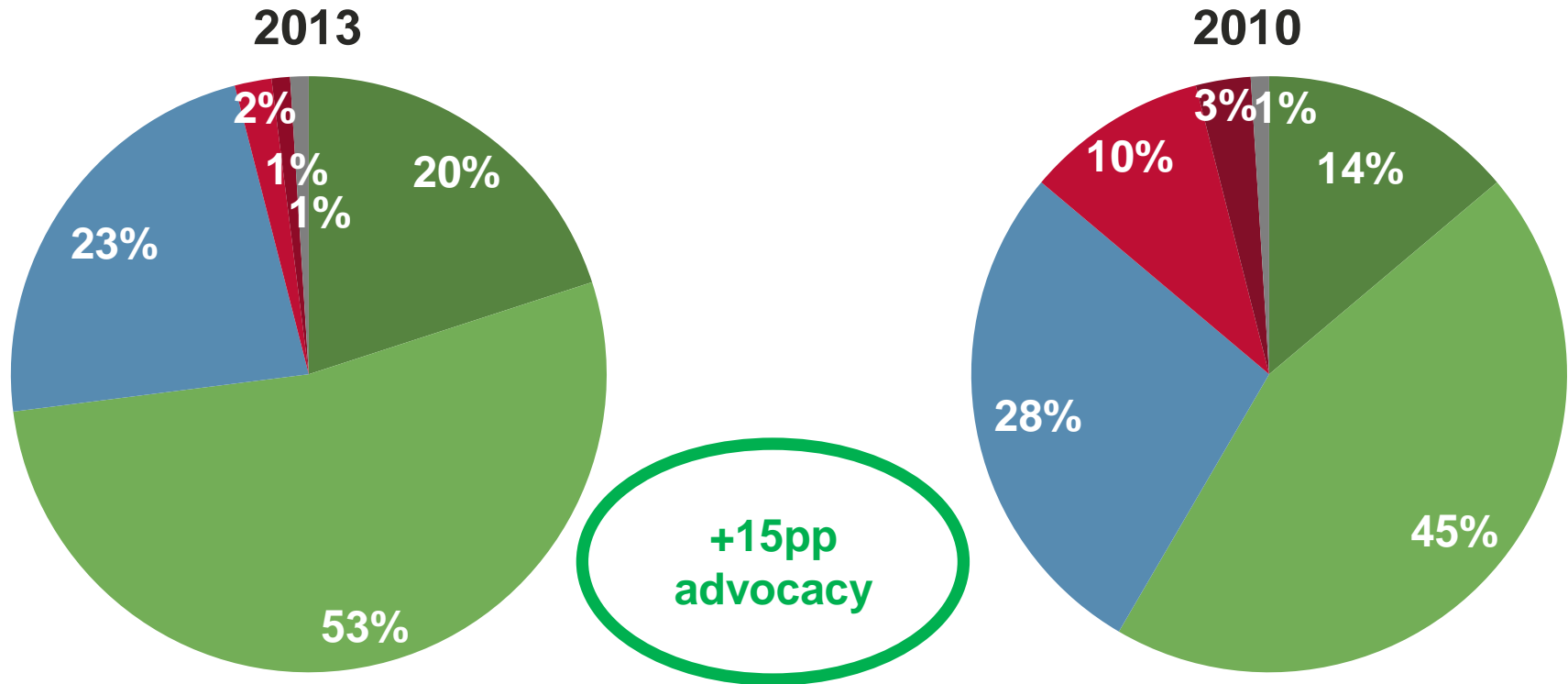
Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

Source: Ipsos MORI

...as has advocacy of the HTA

Which of these comes closest to describing how you would speak about the HTA? Would you...

- Speak highly without being asked
- Speak highly if asked
- Neutral
- Be critical if asked
- Be critical without being asked
- No opinion/Don't know

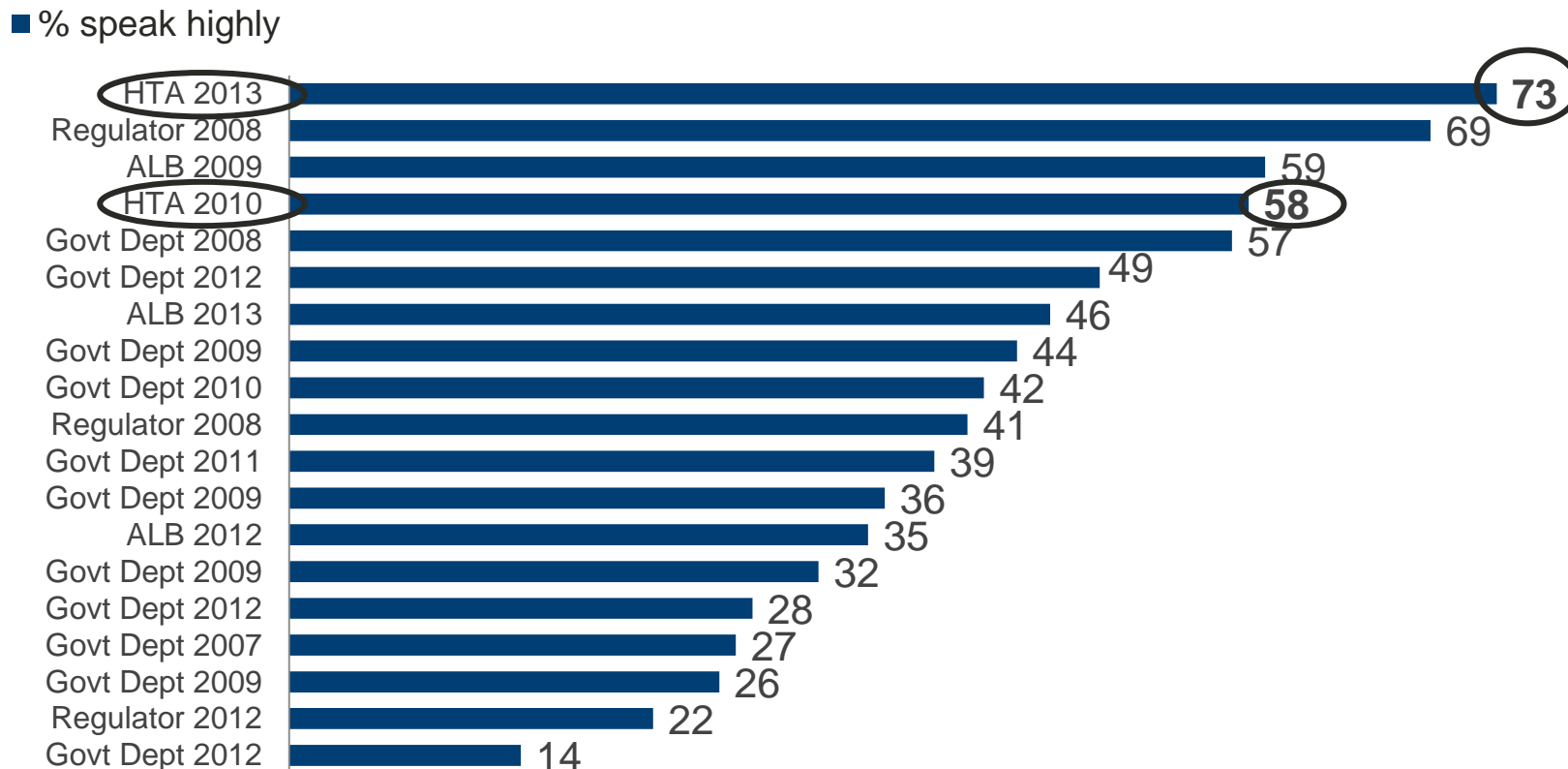


Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

Source: Ipsos MORI

Are the HTA's stakeholders more likely to be advocates than those in other organisations?

Which of these comes closest to describing how you would speak about the HTA?*



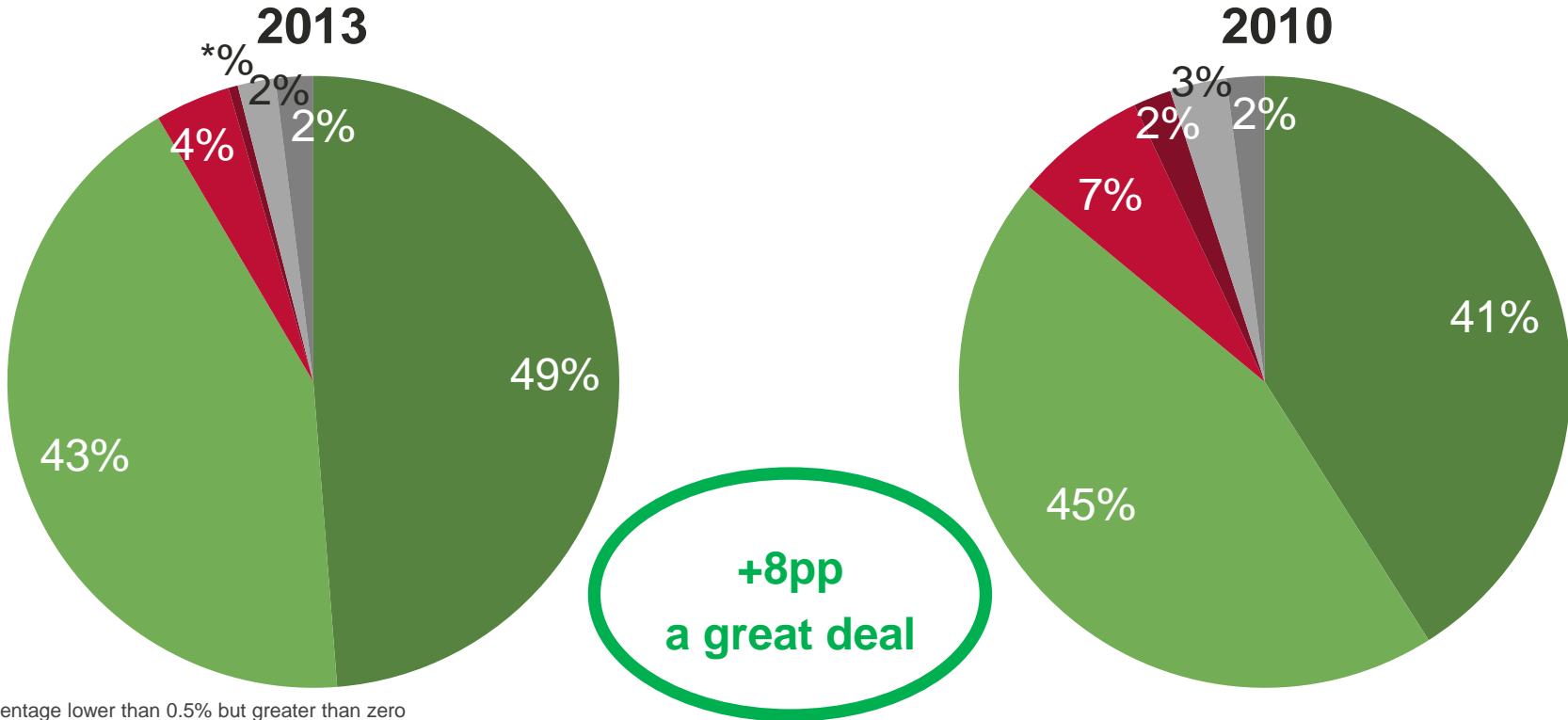
Base: Various user and stakeholder surveys of public sector organisations conducted between 2008 and 2013

Source: Ipsos MORI

Stakeholder confidence in the HTA has also increased since 2010...

To what extent, if at all, do you have confidence in the HTA as a regulator of the removal, storage, use and disposal of human tissue?

■ A great deal
 ■ A fair amount
 ■ Not very much
 ■ Not at all
 ■ No opinion
 ■ Don't know



*Indicates a percentage lower than 0.5% but greater than zero

Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

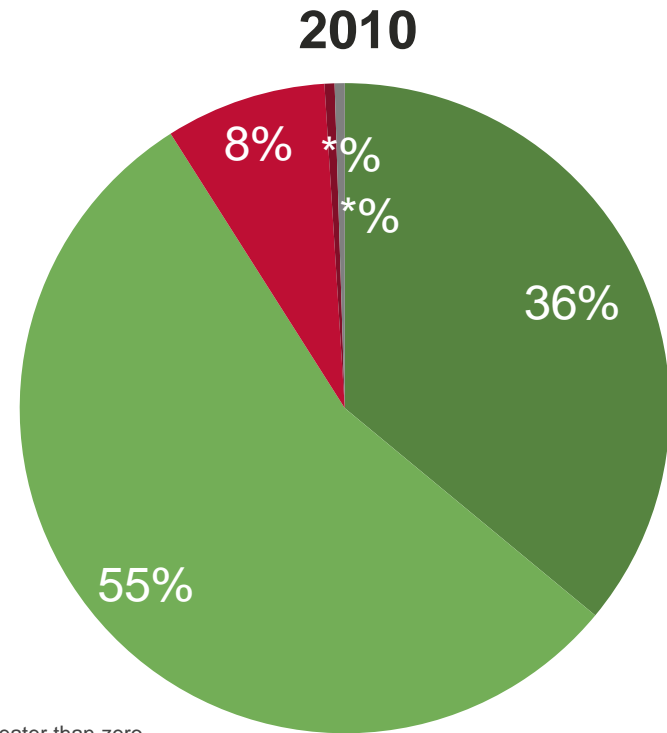
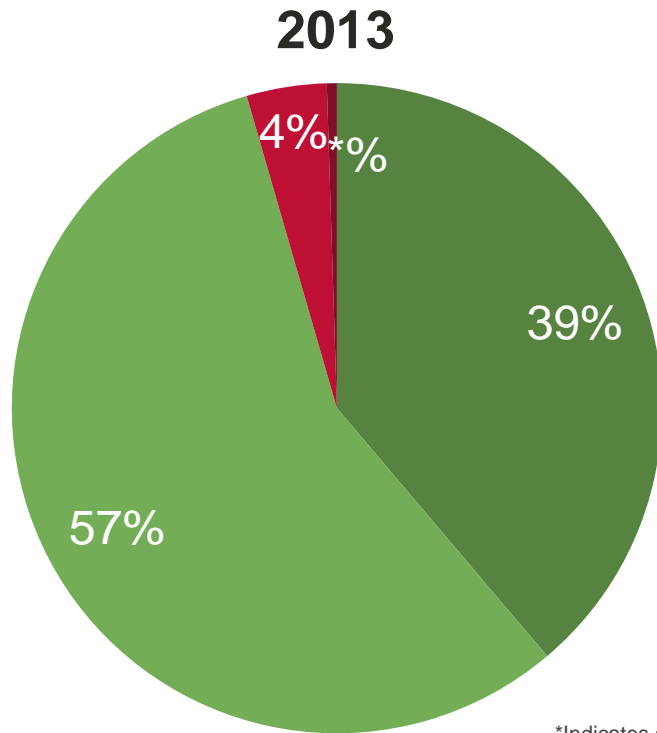
Source: Ipsos MORI



...and knowledge of the HTA is high

How well do you think you know what the HTA does?

■ Very well ■ A fair amount ■ Just a little ■ Not very well ■ Don't know



*Indicates a percentage lower than 0.5% but greater than zero

Base: All professional stakeholders, 2013: (362), 15th July - 1st August 2013; 2010: (349) 14th June and 2nd July 2010.

Source: Ipsos MORI

Effectiveness and importance

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Summary: effectiveness and importance

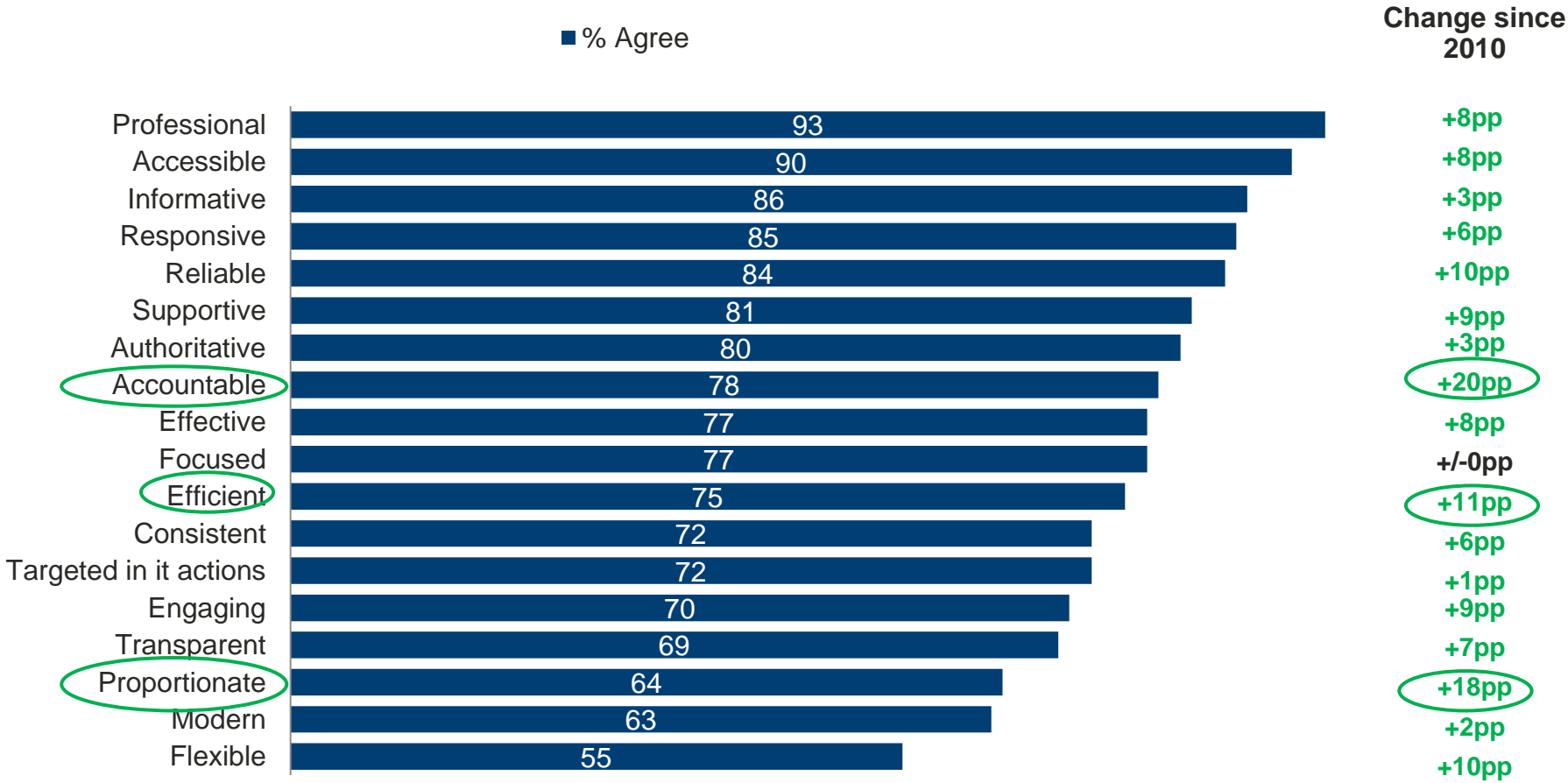
- As in 2010, professional stakeholders were asked to what extent they agreed with a number of descriptions of the HTA. Overall, the HTA is performing very well in regard to all of these, indeed more than half of respondents agree with each description. However, stakeholders think that some of the characteristics fit the HTA much more than others: around nine in ten agree that the HTA is **professional** and **accessible** (93% and 90% respectively).
- While there has been improvement more or less across the board since 2010, a number of characteristics stand out. In particular, there are significant increases in the proportion **agreeing** that the HTA is **accountable** (+20pp), **proportionate** (+18pp) and **efficient** (+11pp).
- The HTA is perceived differently across the sub-groups. For example, stakeholders who feel well informed by the HTA are more likely to agree with many of the descriptions of the HTA. Stakeholders with a newer relationship to the HTA (1-5 years) feel more strongly that the HTA is **focused** and **responsive**.
- Living Donor Coordinators (LDC) are more likely than stakeholders overall to **agree** that the HTA is **consistent**, **effective**, **efficient**, **reliable**, **responsive** and **transparent**. Those in the human application (tissue for treatment) sector are more likely than stakeholders overall to **strongly disagree** that the HTA is **proportionate**.
- Stakeholders think that *'ensuring the safety and quality of human tissue, cells and organs used for patient treatment'* (80% **very important**), *'improving public confidence'* (77% **very important**) and *'regulation to ensure that living donors are not coerced and understand the risks of organ donation or bone marrow donation'* (76% **very important**) are the top three most important activities for the HTA.
- Since 2010, there have been some significant shifts in the perceived importance of different activities. *'Improving professional confidence'* has **increased by 17 percentage points**, and *'Improving public confidence'* has **increased by 7 percentage points**. However, *'Working with Government and Europe to implement legislation'* has decreased in relative importance since 2010 (**down 9 percentage points**).

Summary: effectiveness and importance

- Looking at how the HTA is seen to be performing in relation to each of these activities, *'providing licences'*, *'overseeing the consent requirements of the Human Tissue Act'*, and *'producing codes of practice'* are seen to be the activities that the HTA performs the best, with more than half rating each of these as very effective. *'Inspecting organisations to ensure good standards and appropriate procedures'* sees the greatest increase in perceived performance (+13pp) since 2010, despite a decrease placed on the relative importance of this activity.
- Stakeholders who think that the HTA keeps them **well informed** are more likely to feel that the HTA is **effective** in relation to many of the activities mentioned. There are also several differences based on a stakeholder's relationship with the HTA, and the sector they work in, for example, DIs are more likely to feel that the HTA is **effective** at *'providing licences'*, and *'ensuring dignity and respect for the deceased'*, and more likely to feel the HTA is **not effective** at sharing best practice (as are those in the post mortem sector, which is made up entirely of DIs) compared to stakeholders overall.
- Comparing the importance and effectiveness scores for each activity adds further understanding.
 - **Areas HTA is performing well:** *'providing licences'*, *'producing codes of practice'*, *'inspecting organisations'*, *'giving advice and guidance'*, *'ensuring dignity and respect'*, *'overseeing the consent requirements of the Human Tissue Act'*, *'ensuring safety and quality'*, and *'regulation to ensure that living donors are not coerced'* are all seen both as being **very important** by stakeholders, and also being fulfilled **very effectively** by the HTA.
 - **Areas that may be in need of consideration:** *'Sharing best practice'*, *'improving professional confidence'* and *'improving public confidence'* are activities that stakeholders think are **very important**, but they **do not think** the HTA is **very effective** at performing. These represent areas to be looked at to continue the positive trend in overall favourability towards the HTA - although effectiveness is improving as regards *'improving professional confidence'* (30% say they are very effective in this area, up 8 percentage points since 2010).
- Professional stakeholders were also asked to consider the extent to which the level of regulation within the UK health sector in general, and by the HTA specifically, present an obstacle to their organisation's success. Overall, 28% of stakeholders **agree** that the level of regulation within the UK health sector is an obstacle to success. ODT named contacts or licence holders are more likely to **agree** (43%) than stakeholders overall. In contrast, just 14% of professional stakeholders **agree** that the level of regulation by the HTA is an obstacle, indeed, 26% **strongly disagree**.

The HTA is seen as professional and accessible

In your experience, please indicate the extent to which you agree or disagree with each of the following descriptions about the HTA.



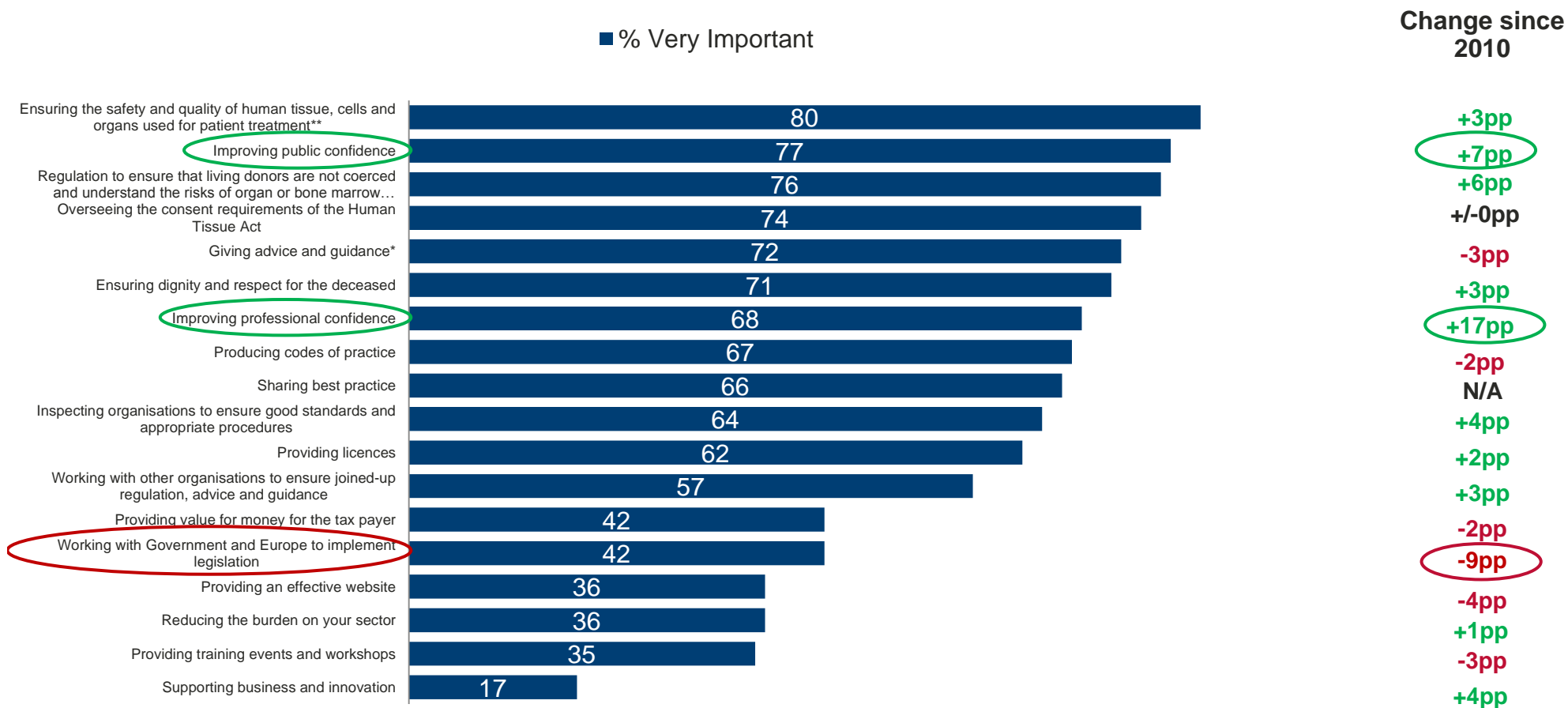
Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI



There is an increasing importance placed on improving public confidence...

How important, if at all, do you think each of the following activities are for the HTA?

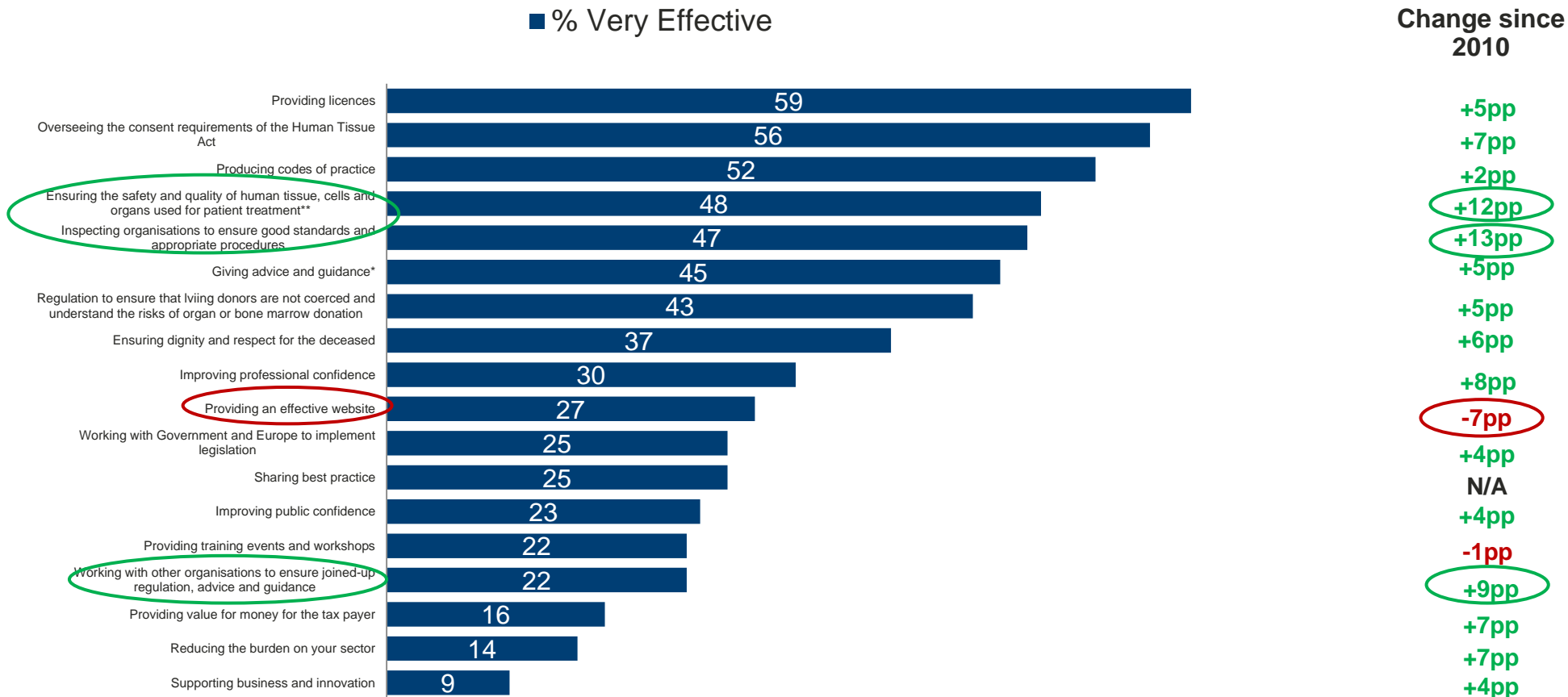


Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI

...But it is one area stakeholders feel could be more effective

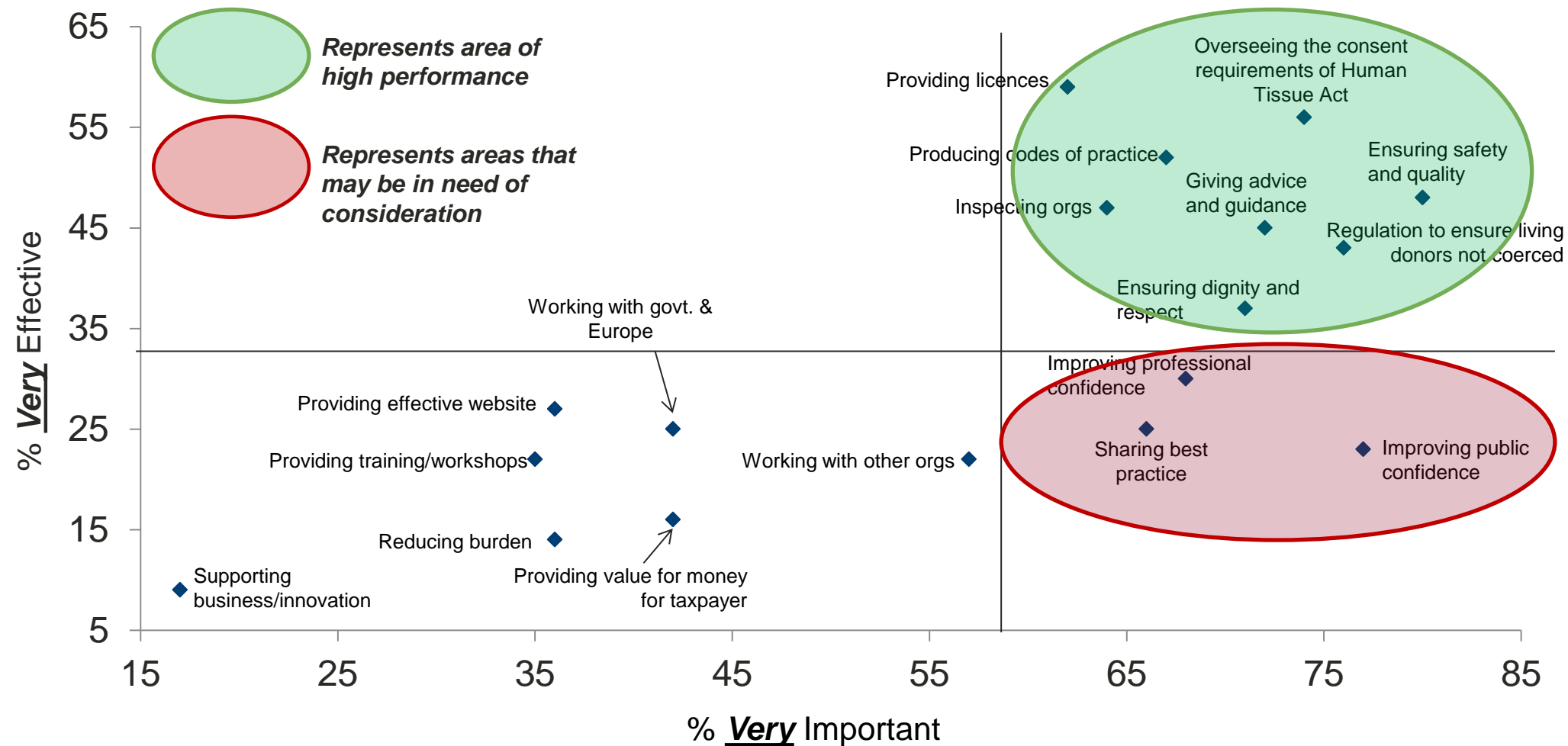
How effective if at all do you feel the HTA is in relation to each of these activities?



Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI

The HTA does lots of the important things very well, but there are some areas for consideration...



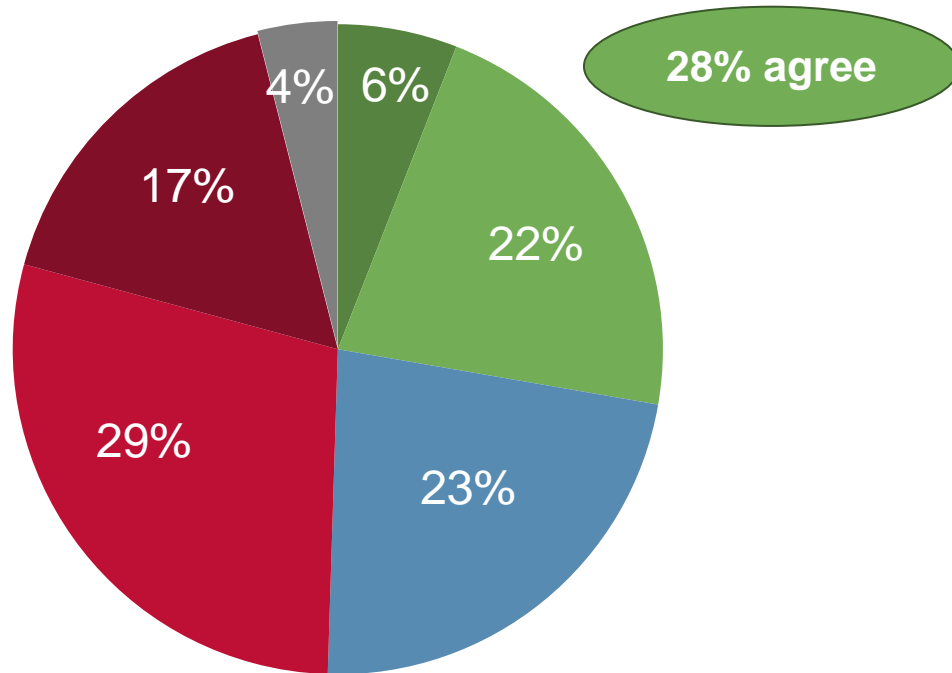
Base: All professional stakeholders (362), 15th July - 1st August 2013

For full wording of answer codes, please refer to previous charts.

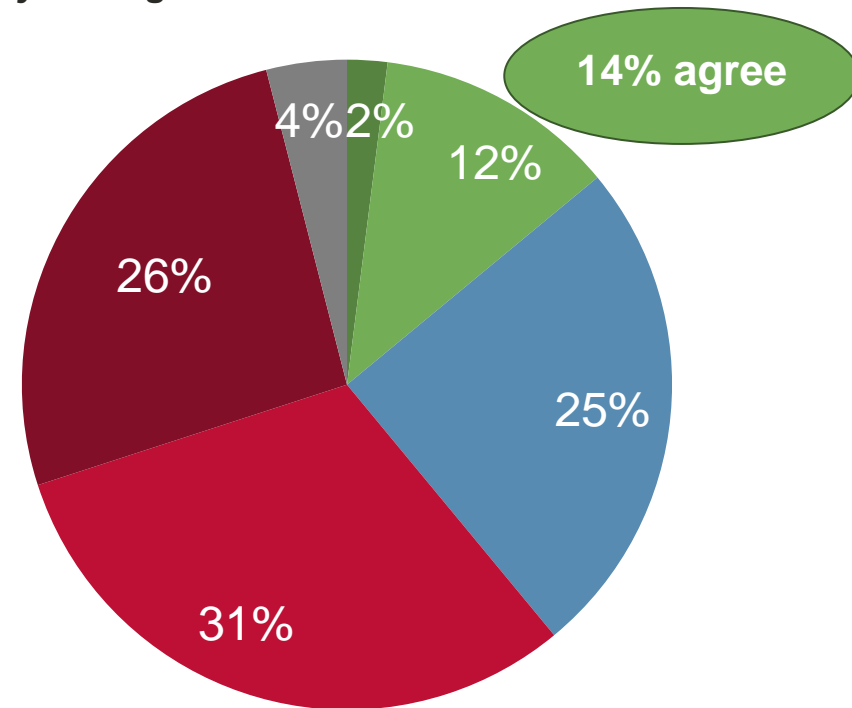
Source: Ipsos MORI

Regulation by HTA is less of a burden than health health sector regulation overall

To what extent do you agree or disagree that the overall level of regulation in the UK health sector is an obstacle to your organisation's success?



To what extent do you agree or disagree that the level of regulation by the Human Tissue Authority (HTA) is an obstacle to your organisation's success?



■ Strongly agree ■ Tend to agree ■ Neither/nor ■ Tend to disagree ■ Strongly disagree ■ Don't know

Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI

Communications

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Summary: communications

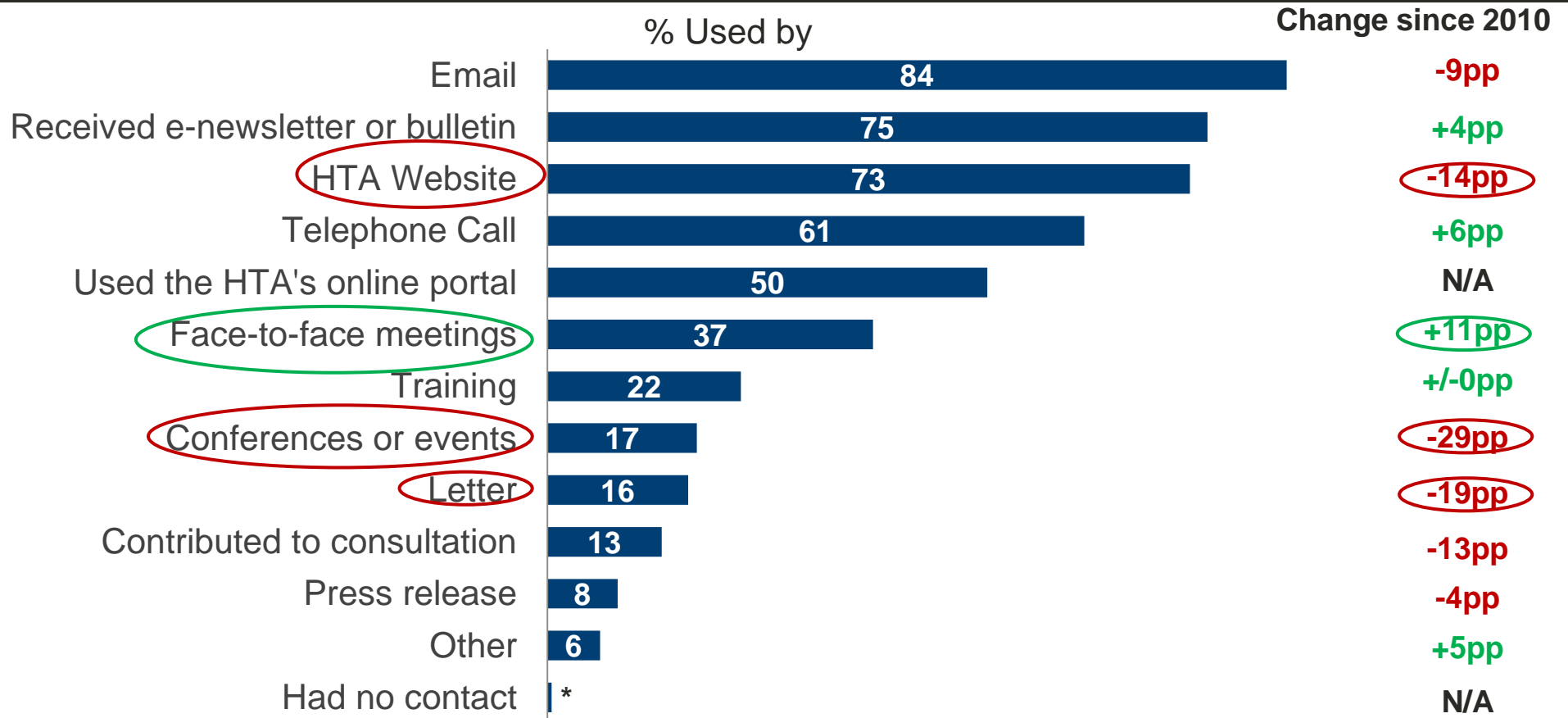
- The majority of stakeholders have communicated with the HTA via *email (84%), receipt of the e-newsletter or bulletin (75%)* and use of the *HTA website (73%)* in the last 12 months. Since the 2010 survey, the HTA online portal has been introduced, and 50% of professional stakeholders report having used this in the past 12 months. Use of *face-to-face meetings* has seen the biggest increase since the 2010 survey (+11pp). Whereas, attendance at *conferences or events (-29pp)*, use of *letters (-19pp)*, use of the *HTA website (-14pp)*, and *contributed to consultation (-13pp)* have all seen significant declines. These may reflect a lack of opportunity, rather than a lack of desire amongst stakeholders, particularly with regards to consultation.
- Stakeholders were also asked to rate the various modes of communication that they had used. As would perhaps be expected, the more personal modes of communication are found to be more useful. The majority of stakeholders who had spoken to the HTA over the *telephone (79%)* found this to be **very useful**, while 72% found *face-to-face meetings* to be **very useful**.
- The two best performing modes of communication are *telephone call* and *email*, which are used frequently, and high numbers of stakeholders find them to be **very useful**.
- The *HTA's online portal, HTA website, and e-newsletter/bulletin* are all used by a substantial proportion of stakeholders, but are not seen to be as useful as perhaps they could be. The HTA is currently making plans to improve its *website* and *e-newsletter*. The *online portal* is a new feature, and will not be a channel for all HTA stakeholders.
- For any membership organisation, or regulators, ensuring that stakeholders are well informed about its role, remit and activities is very important. Generally speaking, the HTA performs well in this regard. Between 70% and 87% of stakeholders feel **very/fairly well informed** about the *HTA's work generally (87%), why it takes specific decisions (70%)* and *forthcoming changes to regulation/legislation (78%)*. The last of these is the only aspect in which there has been a significant change since the 2010 survey, falling from 86%.
- This compares favourably with similar organisations, with **HTA stakeholders the best informed of any similar public sector organisation** to have asked this question in Ipsos MORI stakeholder evaluations in the past five years.

- Looking at the overall quality of communications with the HTA, the vast majority (88%) rate these as **good**, and less than 2% rate them as **poor**. When asked for possible improvements, a wide range of suggestions are given by small numbers of stakeholders, but the most frequent is *nothing in particular* (68%).
- This year, stakeholders were asked for the first time for their thoughts about fees, and the fee system employed by the HTA:
 - Compared to other measures, the HTA performs less well in this regard, although 54% still **feel very/fairly well informed** about '*fees charged and how to pay them*'.
 - Reflecting this significantly lower level of feeling informed, only a third (34%) agree that they have enough information about '*how the HTA's fees are calculated*' (25% don't know), a quarter (25%) **agree** that '*the fees charged are currently about right*' (31% don't know), and around one in six (17%) **disagree** that '*fees change too much from year to year*'. Half of stakeholders either have 'no opinion' or 'don't know' whether '*fees change too much from year to year*'.
 - Not all stakeholders pay fees, they apply only to licensed sectors. DIs, the main stakeholder group that is subject to HTA fees, feel better informed than stakeholders overall. The majority (83%) **feel very/fairly well informed** about '*fees charged and how to pay them*'. This is reflected throughout the other questions regarding fees. More than half of DIs (52%) agree that they have enough information about '*how the HTA's fees are calculated*', four in ten (42%) **agree** that '*the fees charged are currently about right*', and around three in ten (30%) **disagree** that '*fees change too much from year to year*'.

- Related to communications, and because of its importance in documents, guidance, and codes of practice produced by the HTA, the appropriateness of terminology related to the consent process was also explored this year.
- The majority of stakeholders (61%) feel that the term '**seeking consent**' is the most appropriate terminology to describe the actions of professionals when going through the process of informed consent with members of the public or their families. Looking at the impact of relationship with the HTA and sector, DI's favour '**seeking consent**' (66%), whilst LDCs favour '**obtaining consent**' (38%). Those working in the post mortem sector are also more likely to favour '**seeking consent**' (72%), compared with 61% overall. These differences may well reflect current differences in the terminology used in HTA codes of practices for the different sectors, and/or in advice and guidance from other organisations.

Email is the most common form of communication, with interaction through the website decreasing

Which, if any, of the following forms of communications with or from the HTA have you had in the past 12 months?

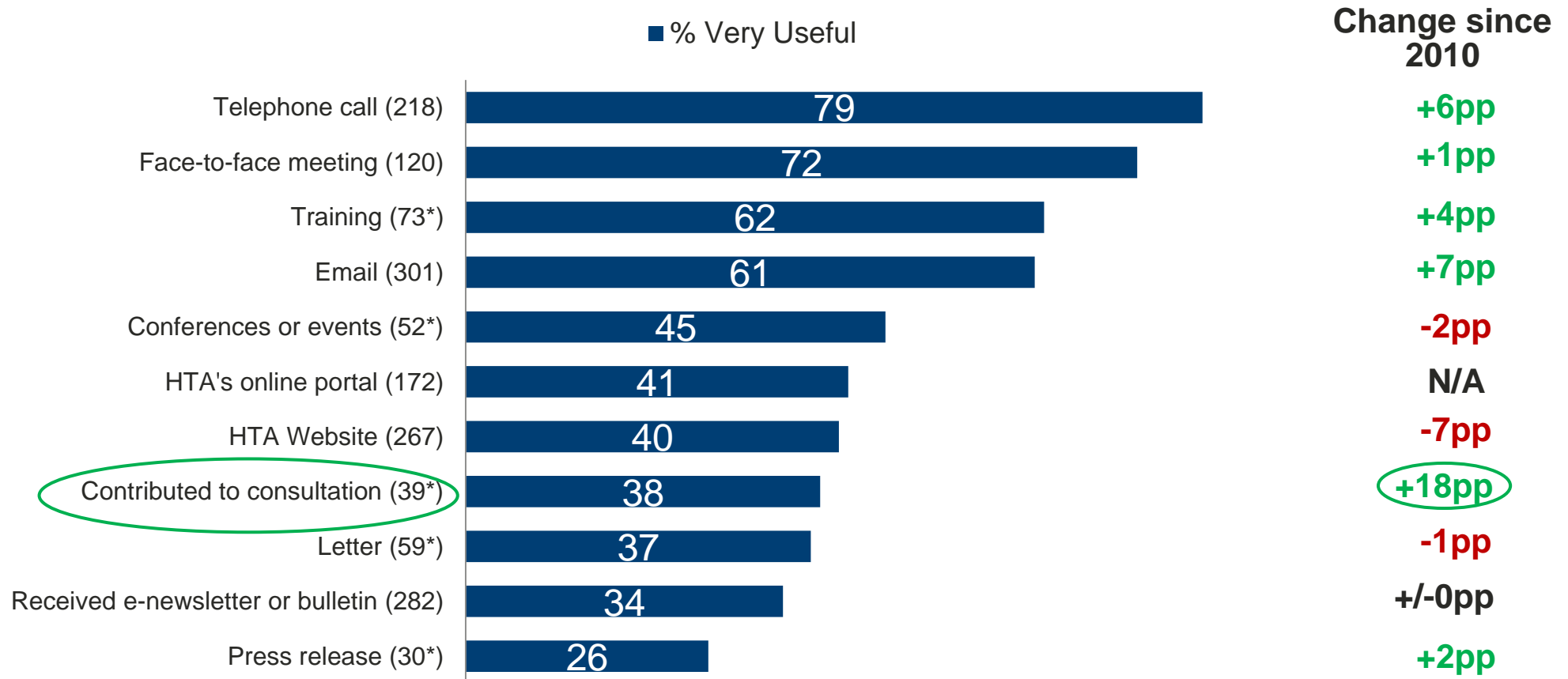


Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI

Personal modes of communication are seen as useful

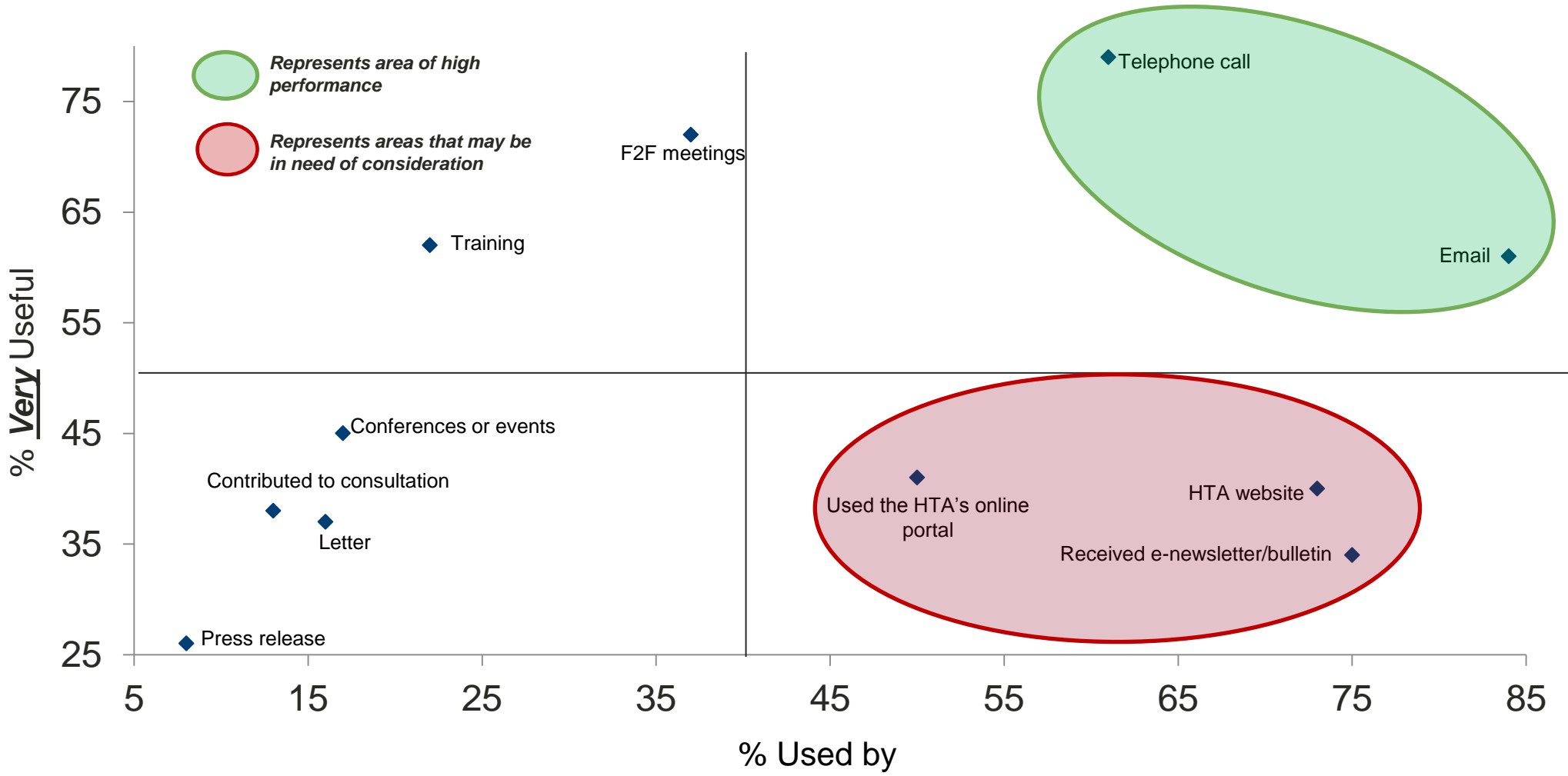
How useful, if at all, do you personally find the following forms of communication with the HTA?



Base: All professional stakeholders who have received one of forms of communication in the past 12 months (bases in brackets), 15th July - 1st August 2013 *Indicates small base to be treated with caution.

Source: Ipsos MORI

The HTA uses some channels of communication very effectively, but others could be improved or may be overused...



Base: All professional stakeholders (362), 15th July - 1st August 2013

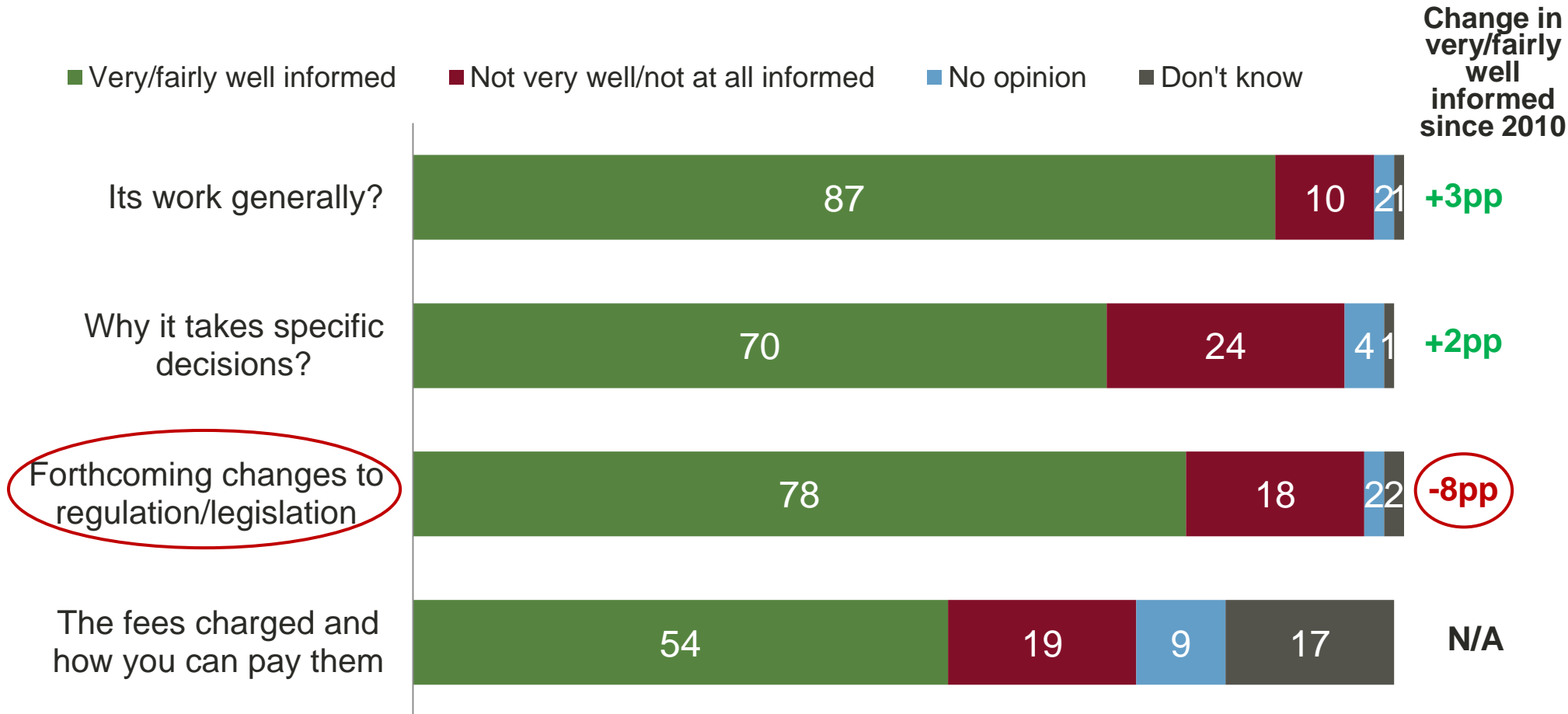
For full wording of answer codes, please refer to previous charts.

Source: Ipsos MORI



Stakeholders generally feel well informed

How well informed, if at all, do you feel HTA keeps you about

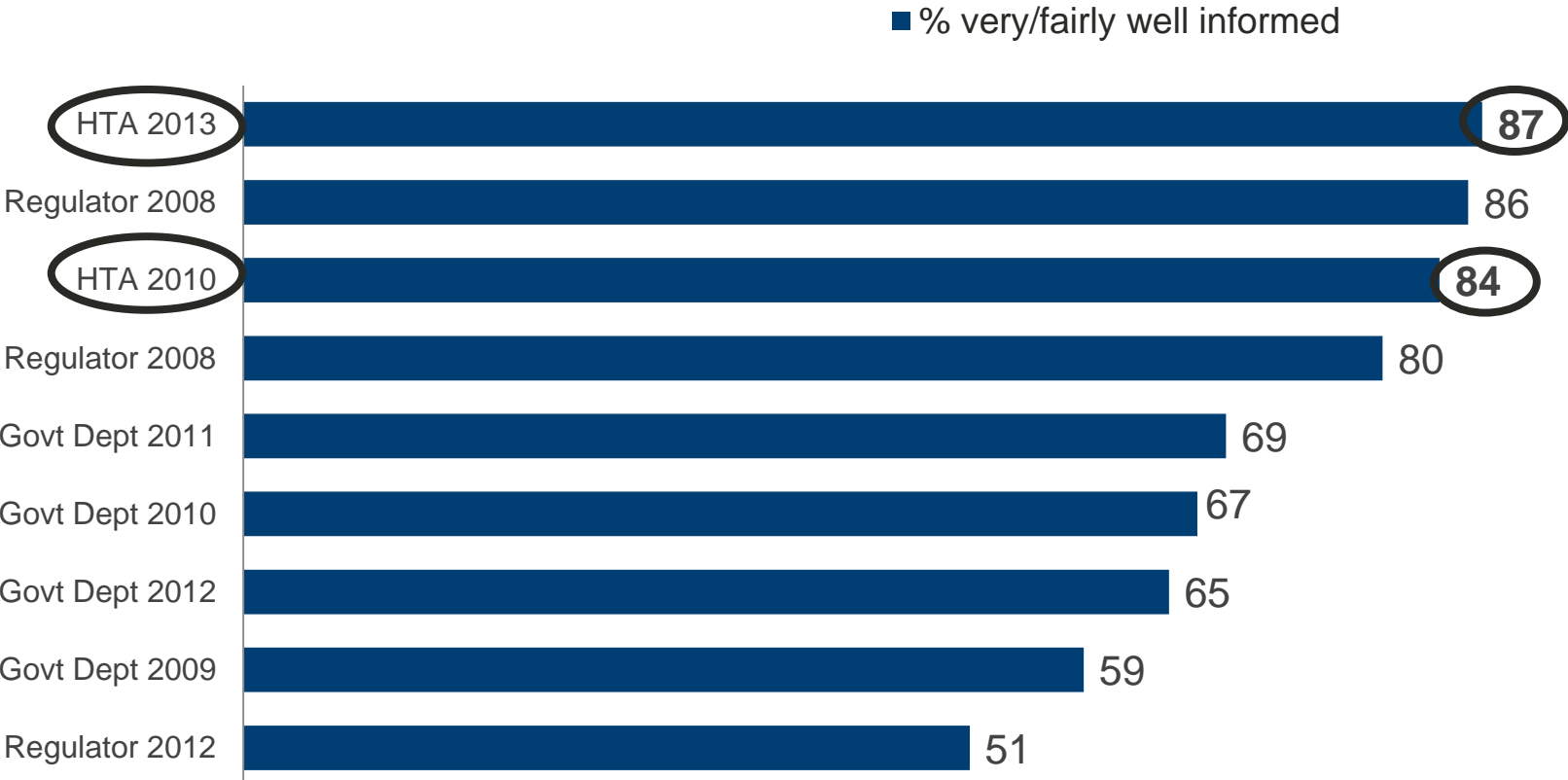


Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI

The HTA compares well against other organisations

How well informed, if at all, do you feel HTA keeps you about its work generally?

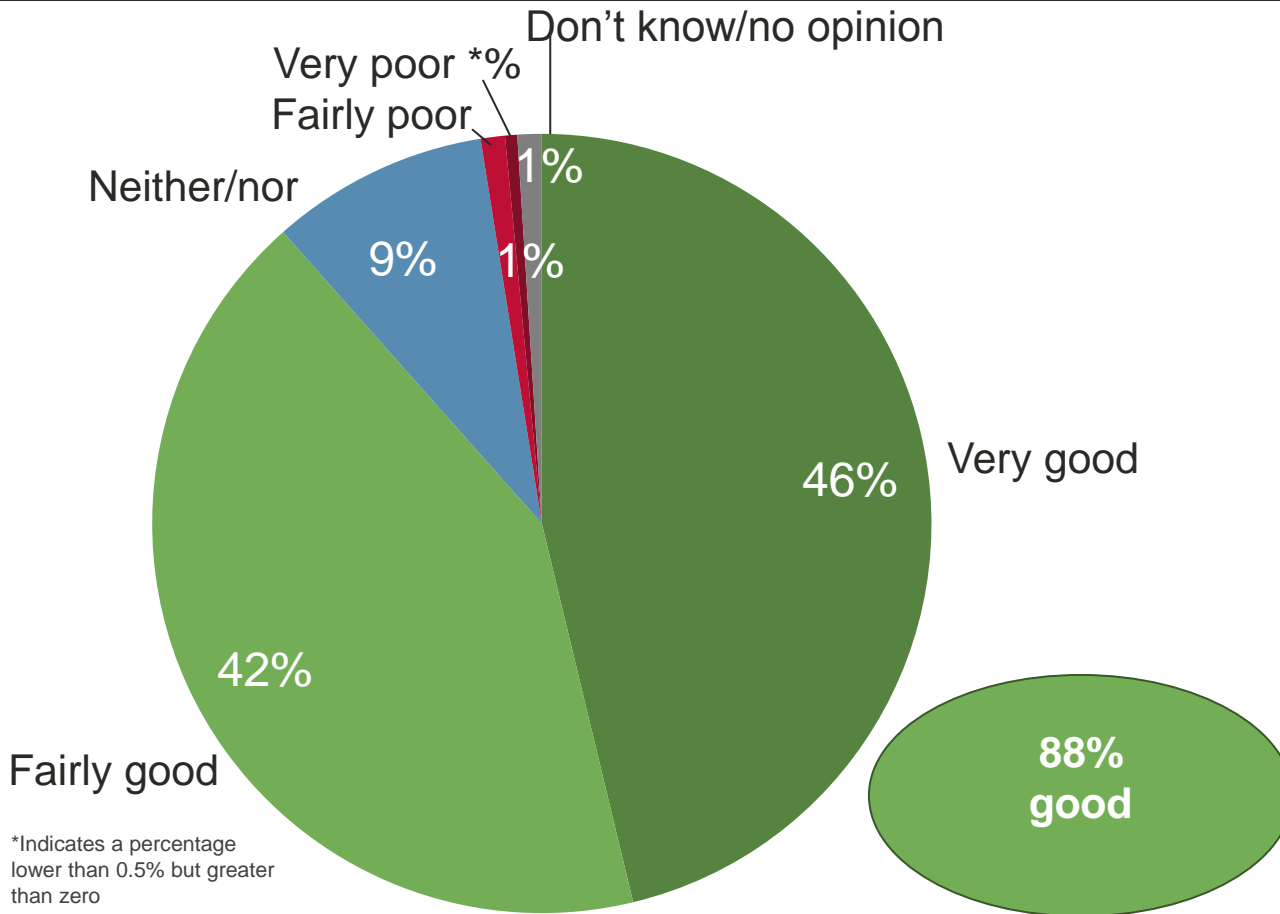


Base: Various user and stakeholder surveys of public sector organisations conducted between 2008 and 2013

Source: Ipsos MORI

Stakeholders are very positive about communications

And overall, how would you rate your communications with the HTA? Would you say they are ...



How could communications be improved?

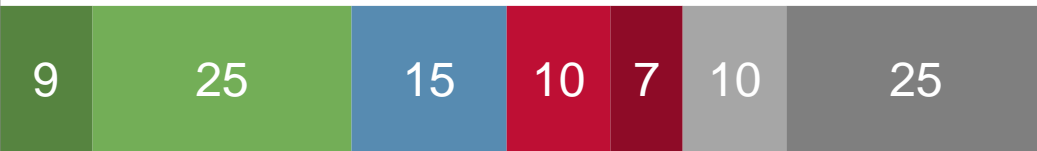
- 4% quicker response time to emailed/written queries
- 4% able to contact a specific person/telephone contact
- 68% nothing in particular
- 9% don't know

Only a third have enough information on how fees are calculated

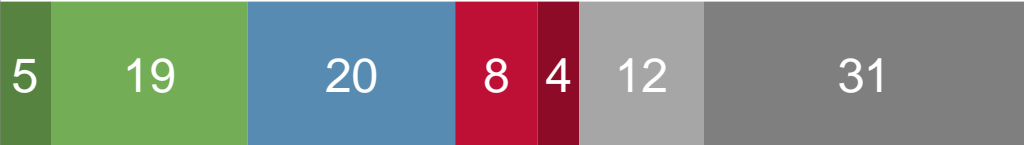
To what extent, if at all, do you agree or disagree with each of the following descriptions about the HTA's fees and payments?

■ Strongly agree
 ■ Tend to agree
 ■ Neither/nor
 ■ Tend to disagree
 ■ Strongly disagree
 ■ No opinion
 ■ Don't know

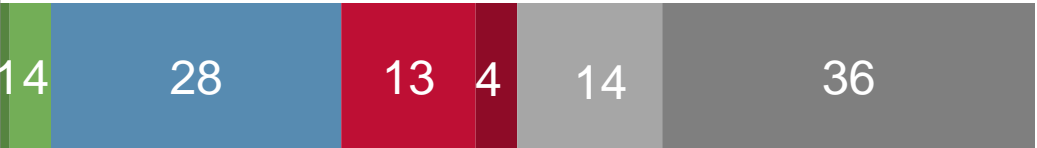
I have enough information about how the HTA's fees are calculated



The fees charged are currently about right



Fees change too much from year to year



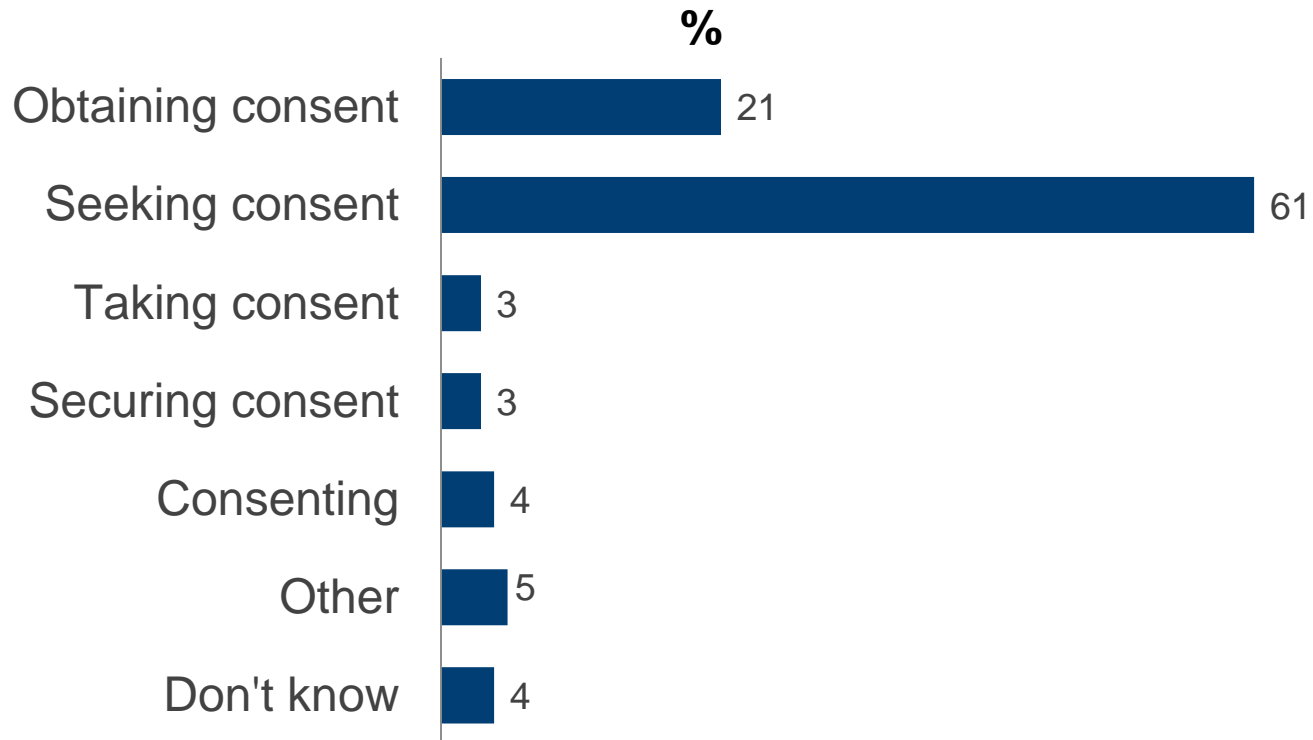
Base: All professional stakeholders (362), 15th July - 1st August 2013

Source: Ipsos MORI



'Seeking consent' is the preferred terminology

Members of the public or their families have to give informed consent for organs and tissue to be donated for scheduled purposes under the Human Tissue Act. When a professional is talking to a member of the public, what do you consider the most appropriate terminology to describe what the professional is doing in that conversation?



Ease of compliance, taking views into account and feedback

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Summary: ease of knowing how to comply with standards, taking views into account and feedback

Members of every sector* were asked the three questions covering how easy it is to comply with HTA standards in their sector; the extent to which they think the HTA takes into account the views of their sector in decision making; and to what extent the HTA takes action following feedback from their sector.

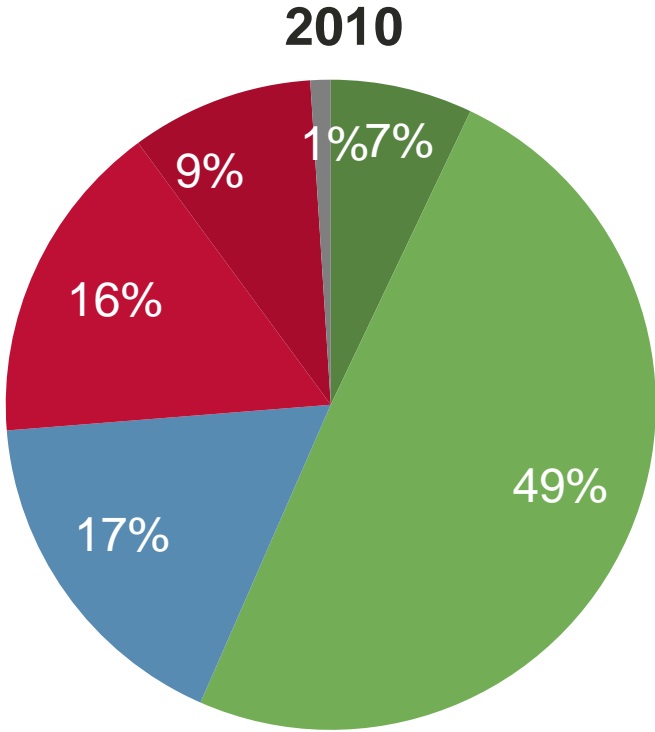
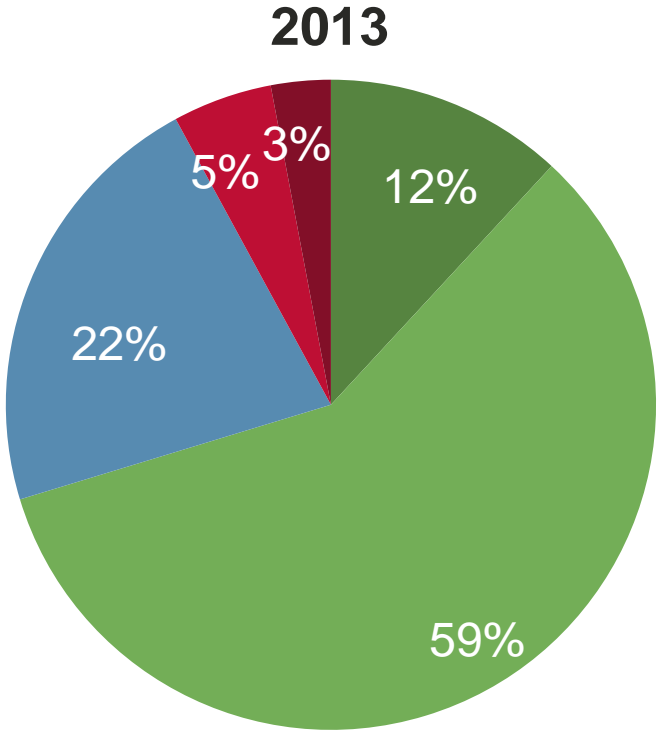
- The majority in all sectors think that it is either **very or fairly easy** to know what to do to comply with HTA standards. This is lowest among ODT contacts in the solid organ donation sector at 63%, but highest among non-ODT contacts (a combination of IAs, DIs, AAs, and LDCs) in this same sector at 85%.
- Views vary more widely across the sectors on whether their views are taken into account and acted upon by the HTA. Nearly three quarters (73%) of ODT contacts in the solid organ donation sector and two thirds (63%) in the bone marrow and stem cell donation sector feel **their views are taken into account**, compared with four in ten (40%) in the post mortem sector and under half (46%) of non-ODT contacts in the solid organ donation sector (a combination of IAs, DIs, AAs, and LDCs).
- Belief that the HTA take action following feedback from their sector is broadly in line with the proportion who believe the HTA takes account of their views. ODT contacts in the solid organ donation sector again are most positive with 63% agreeing that the HTA take action following feedback, with 61% of respondents in the human application sector saying this. The **least positive** again were non-ODT contacts in the solid organ donation sector (a combination of IAs, DIs, AAs, and LDCs) on 37%.

*Separate questions were asked of across the eight different sectors, with responses as follows: post mortem (78 responses), human application (38), anatomy (18), public display (3), research (59), ODT contacts in solid organ donation (30), non-ODT contacts in solid organ donation (89), and bone marrow and peripheral blood stem cell sectors (30). No individual sector had number of respondents over 100, and therefore results should be viewed as indicative only. The findings for the anatomy and public display sector are presented in the topline documents under separate cover, as there were fewer than 30 responses.

Those in the post mortem sector find it easy to know what to do to comply with standards

How easy, if at all, is it to know what you have to do to comply with the HTA's standards in the post mortem sector?

Very easy Fairly easy Neither/nor Fairly difficult Very difficult No opinion/Don't know



Base: All in the post mortem sector (78), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

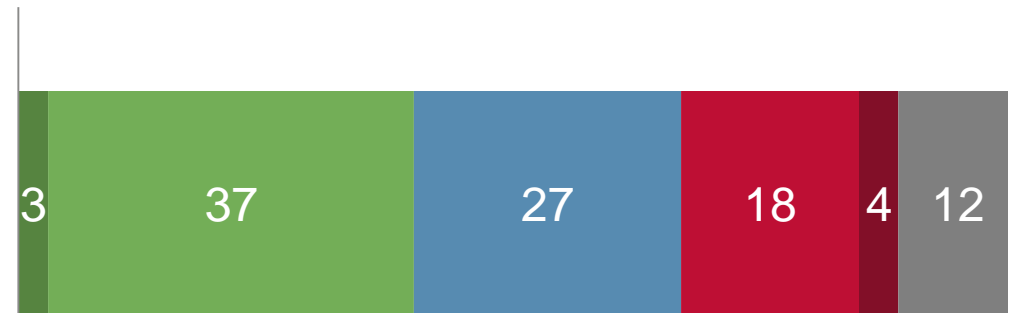
Source: Ipsos MORI

And they generally feel listened to

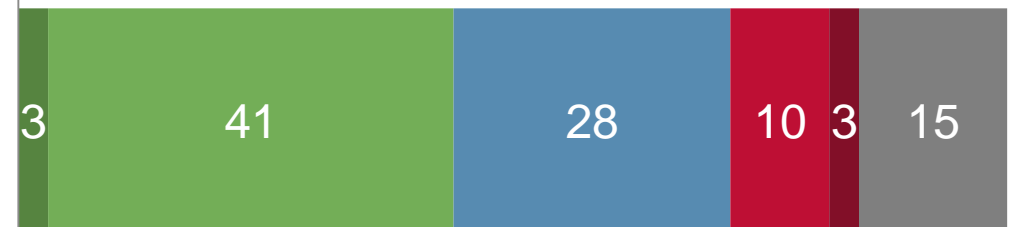
To what extent do you agree or disagree that the HTA . . .

■ Strongly agree ■ Tend to agree ■ Neither/nor ■ Tend to disagree ■ Strongly disagree ■ Don't know

. . . takes into account the views of the post mortem sector when making decisions that might affect the sector?



. . . takes action following feedback from the post mortem sector?

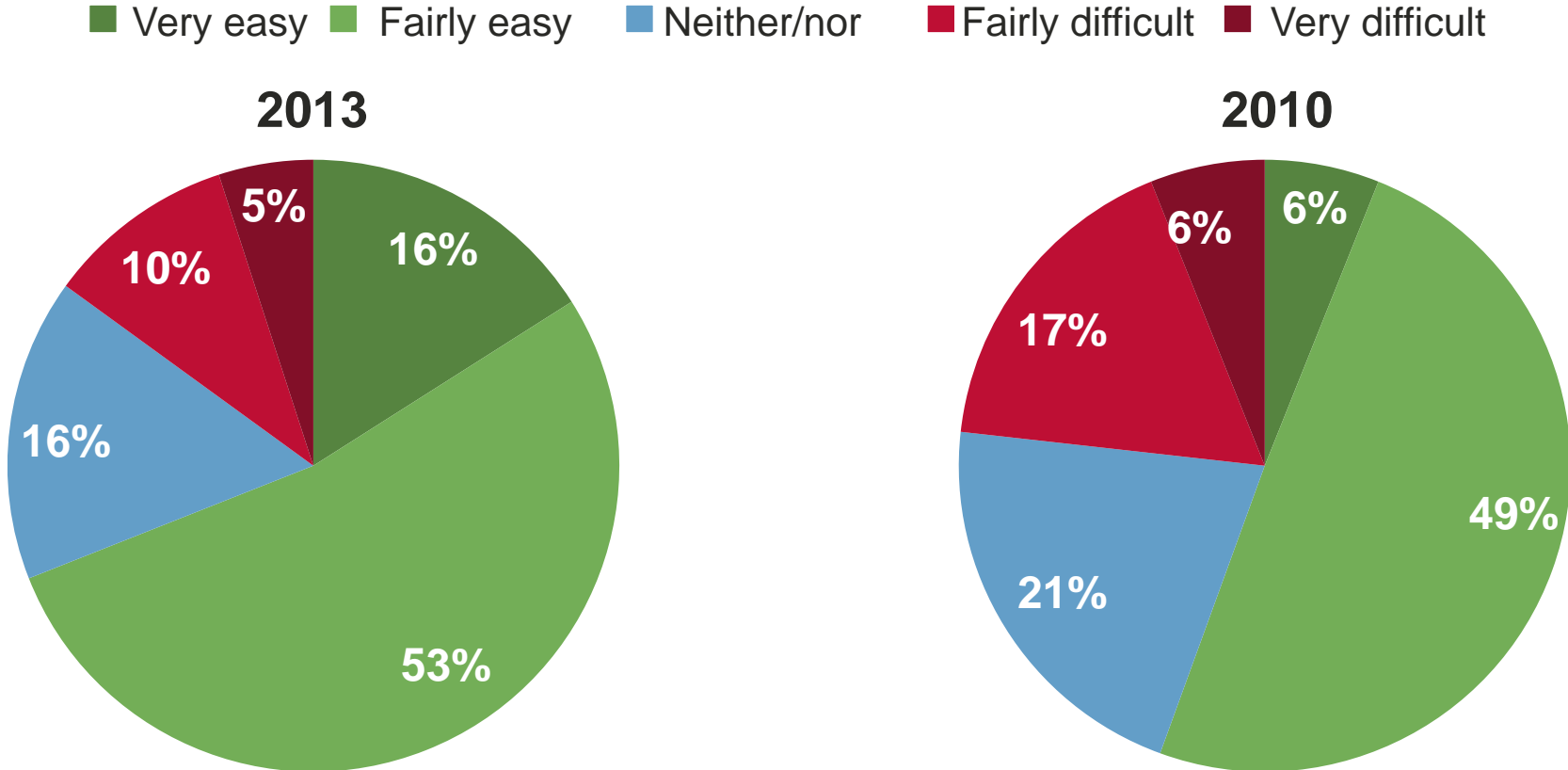


Base: All in the post mortem sector (78), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

Source: Ipsos MORI

Similarly, the human application sector find it easy to know what to do to comply with standards

How easy, if at all, is it to know what you have to do to comply with the HTA's standards in the human application (tissue for treatment) sector?



Base: All in the human application sector, 2013: (38), 15th July - 1st August 2013; 2010: (47) 14th June and 2nd July 2010. N.B. Small base to be treated with caution.

Source: Ipsos MORI

And the majority feel the HTA take their views into account

To what extent do you agree or disagree that the HTA takes . . .

■ Strongly agree ■ Tend to agree ■ Neither/nor ■ Tend to disagree ■ Strongly disagree ■ Don't know

. . . into account the views of the human application (tissue for treatment) sector when making decisions that might affect the sector?



. . . action following feedback from the human application (tissue for treatment) sector?



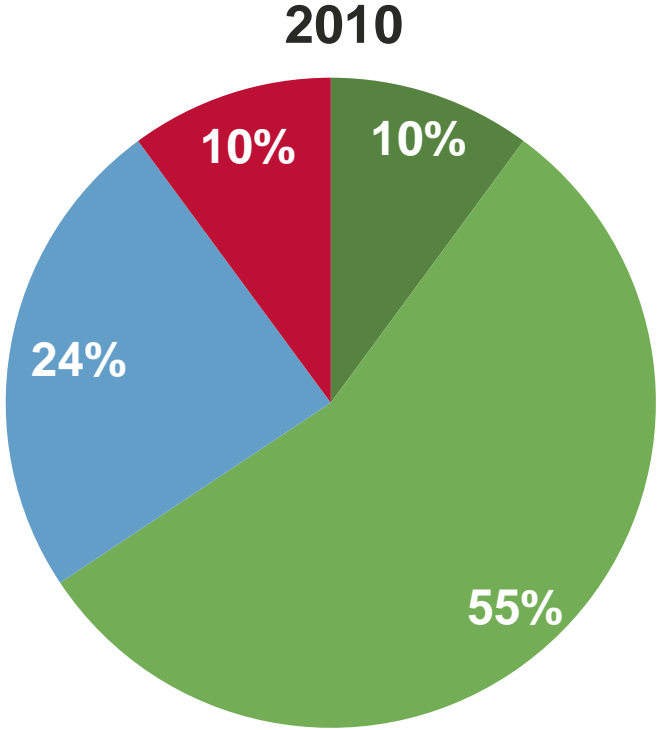
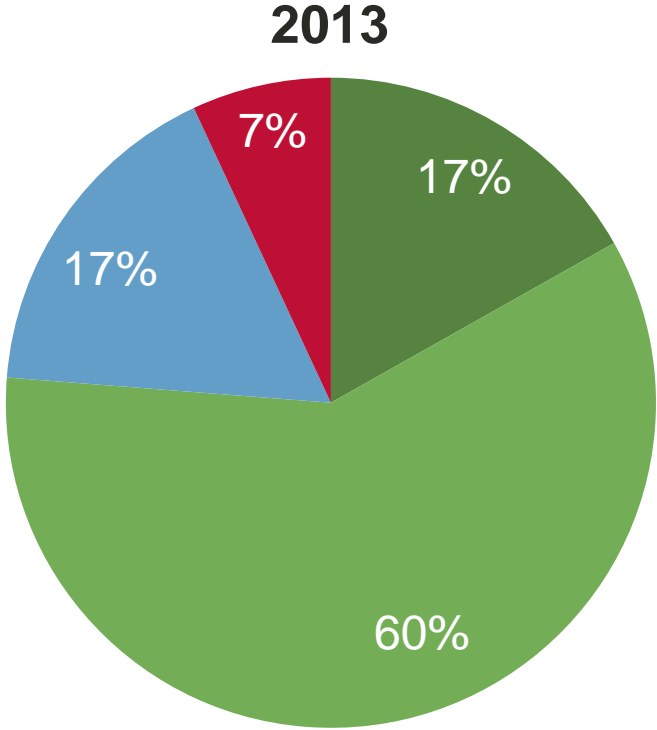
Base: All in the human application sector (38), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

Source: Ipsos MORI

In line with 2010, nobody in the research sector thinks it is very difficult to know what to do to comply with standards

How easy, if at all, is it to know what you have to do to comply with the HTA's standards in the research sector?

■ Very easy ■ Fairly easy ■ Neither/nor ■ Fairly difficult

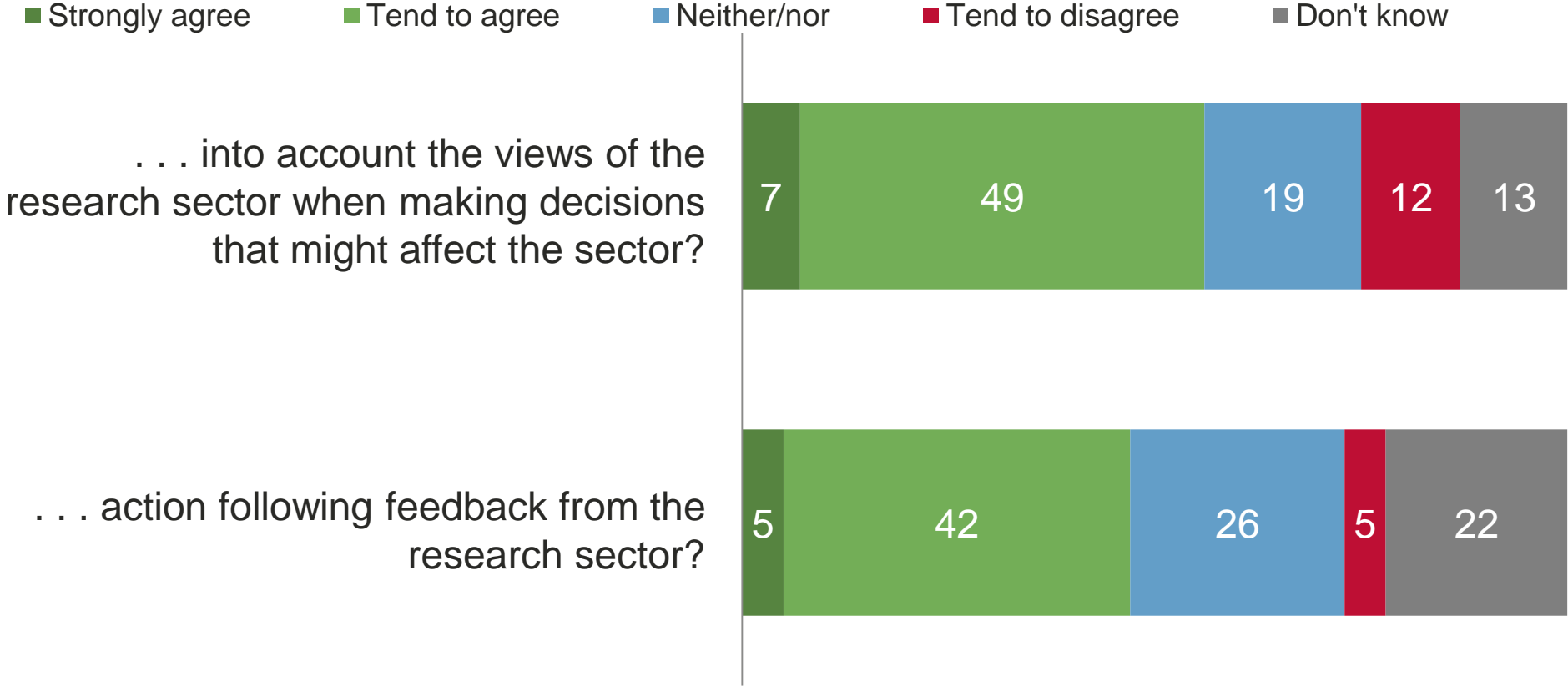


Base: All in the research sector 2013 (59), 15th July - 1st August 2013; 2010 (49) 14th June and 2nd July 2010. N.B. Small base to be treated with caution.

Source: Ipsos MORI

They also feel listened to – although two fifths don't know if the HTA takes action following feedback

To what extent do you agree or disagree that the HTA takes . . .

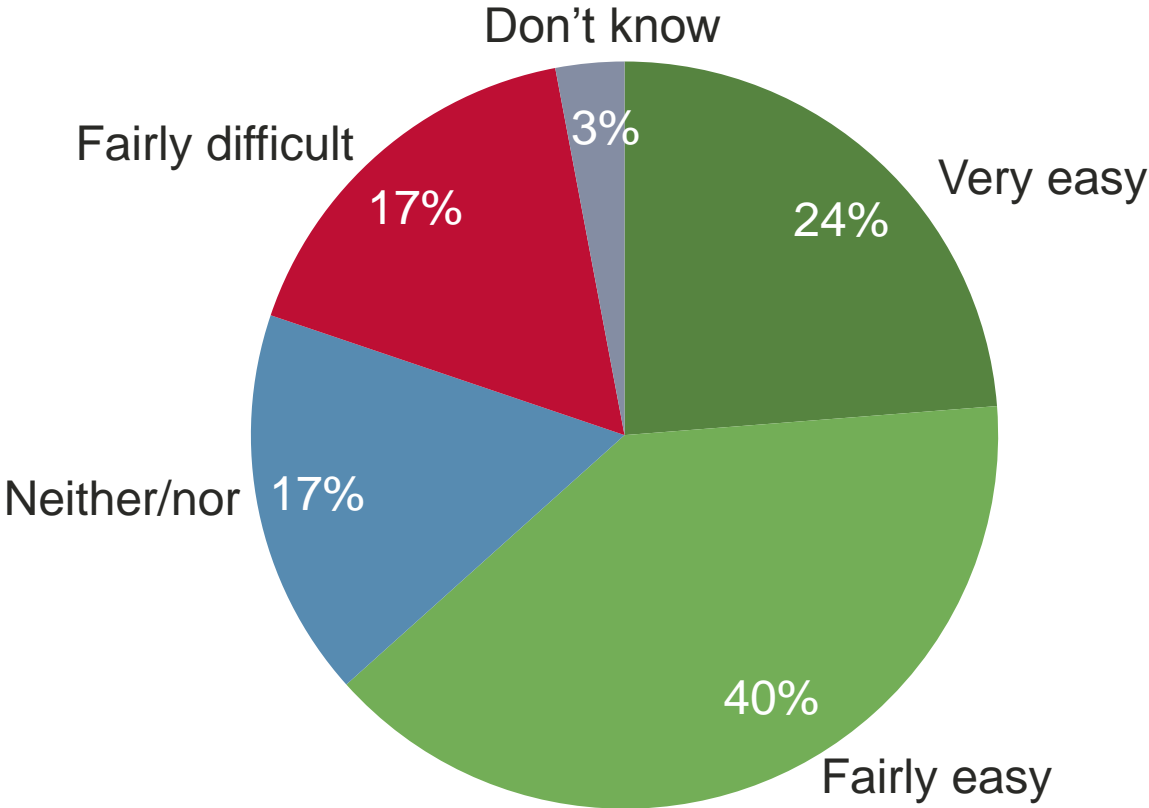


Base: All in the research sector (59), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

Source: Ipsos MORI

Over three fifths of ODTs in the solid organ donation sector think it is fairly/very easy to know what to do to comply with standards

How easy, if at all, is it to know what you have to do to comply with the HTA's standards for ODT named contacts and corporate licence holder contacts in the solid organ donation sector?



Base: All named contacts and corporate licence holder contacts in the solid organ donor sector (30), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

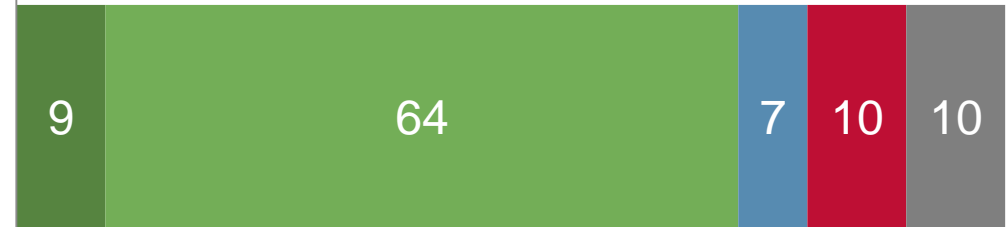
Source: Ipsos MORI

And they feel their views make a difference

To what extent do you agree or disagree that the HTA takes . . .

■ Strongly agree ■ Tend to agree ■ Neither/nor ■ Tend to disagree ■ Don't know

. . . into account the views of ODT named contacts and corporate licence holder contacts in the solid organ donation sector when making decisions that might affect the sector?



. . . action following feedback from ODT named contacts and corporate licence holder contacts in the solid organ donation sector?

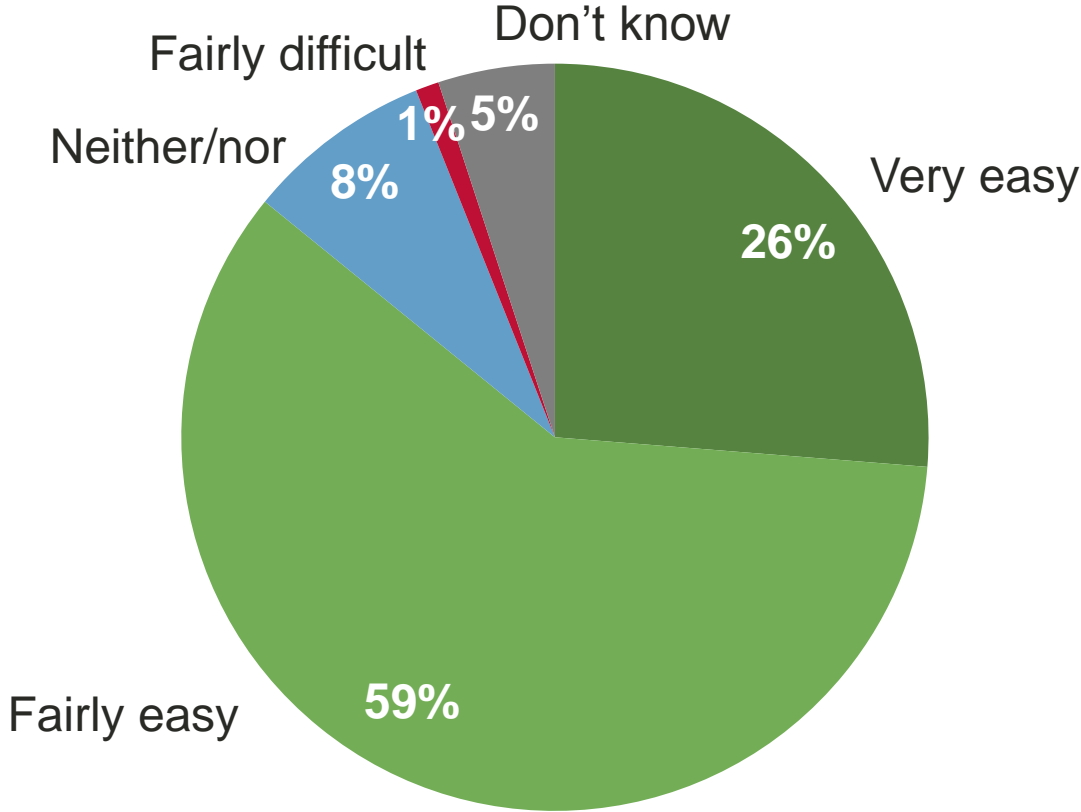


Base: All named contacts and corporate licence holder contacts in the solid organ donor sector (30), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

Source: Ipsos MORI

The majority of non-ODT contacts* in the solid organ donation sector find it fairly or very easy to know what to do to comply with standards

How easy, if at all, is it to know what you have to do to meet the HTA's requirements for solid organ donation?



Base: All in the solid organ donation sector other than named contacts and corporate licence holder contacts (89), 15th July - 1st August 2013. N.B. Small base to be treated with caution Source: Ipsos MORI

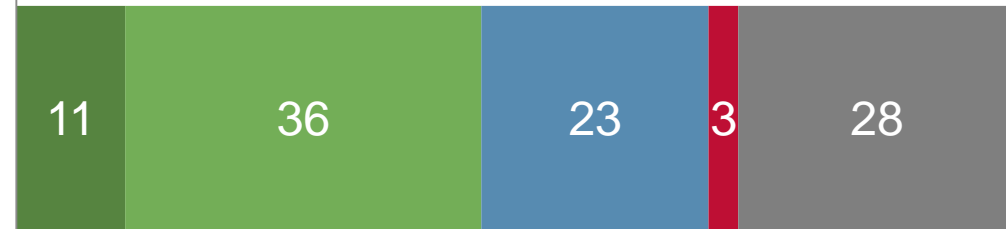
* non-ODT contacts are a combination of IAs, DIs, AAs, and LDCs.

There is room to improve on informing non-ODT* contacts about action taken

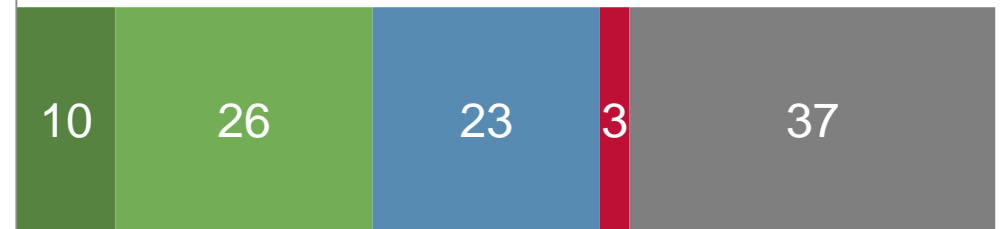
To what extent do you agree or disagree that the HTA takes . . .

■ Strongly agree ■ Tend to agree ■ Neither/nor ■ Tend to disagree ■ Strongly disagree ■ Don't know

. . . into account the views of the solid organ donation sector when making decisions that might affect the sector?



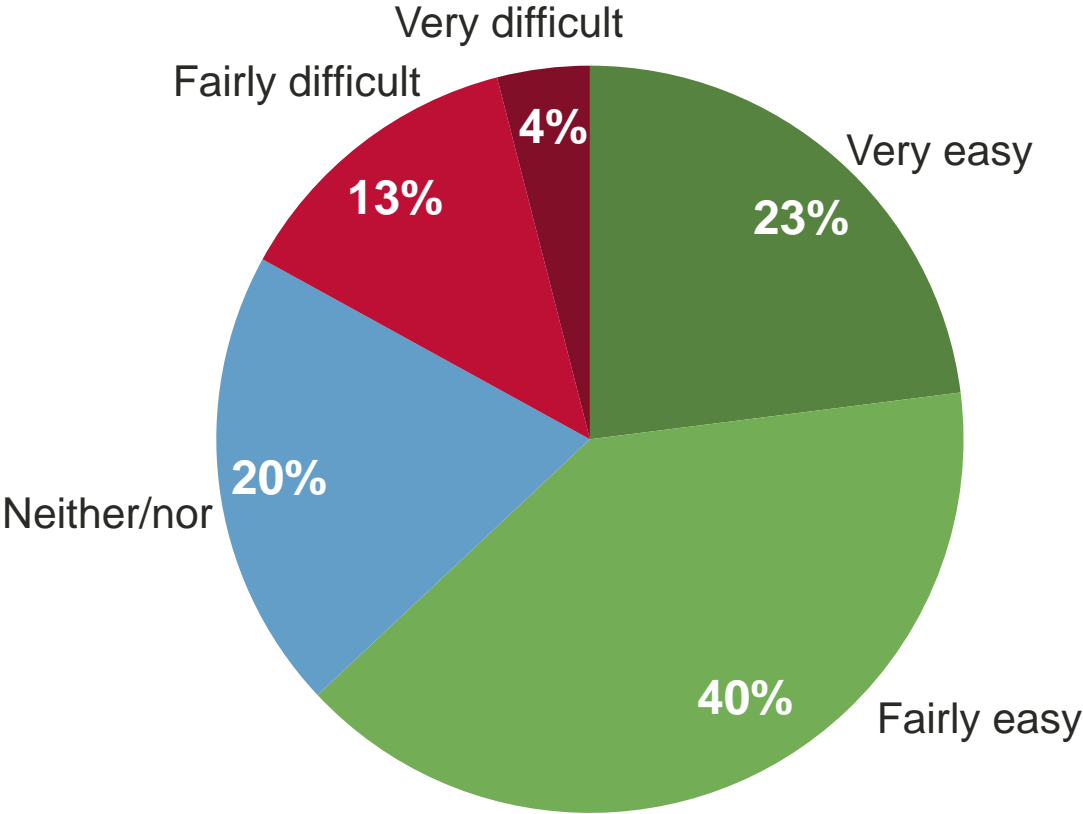
. . . action following feedback from the solid organ donation sector?



Base: All in the solid organ donation sector other than named contacts and corporate licence holder contacts (89), 15th July - 1st August 2013. N.B. Small base to be treated with caution. Source: Ipsos MORI

The majority of those in the bone marrow and stem cell donation sector find it easy to know what to do to comply with standards

How easy, if at all, is it to know what you have to do to meet HTA's requirements for bone marrow and stem cell donation?

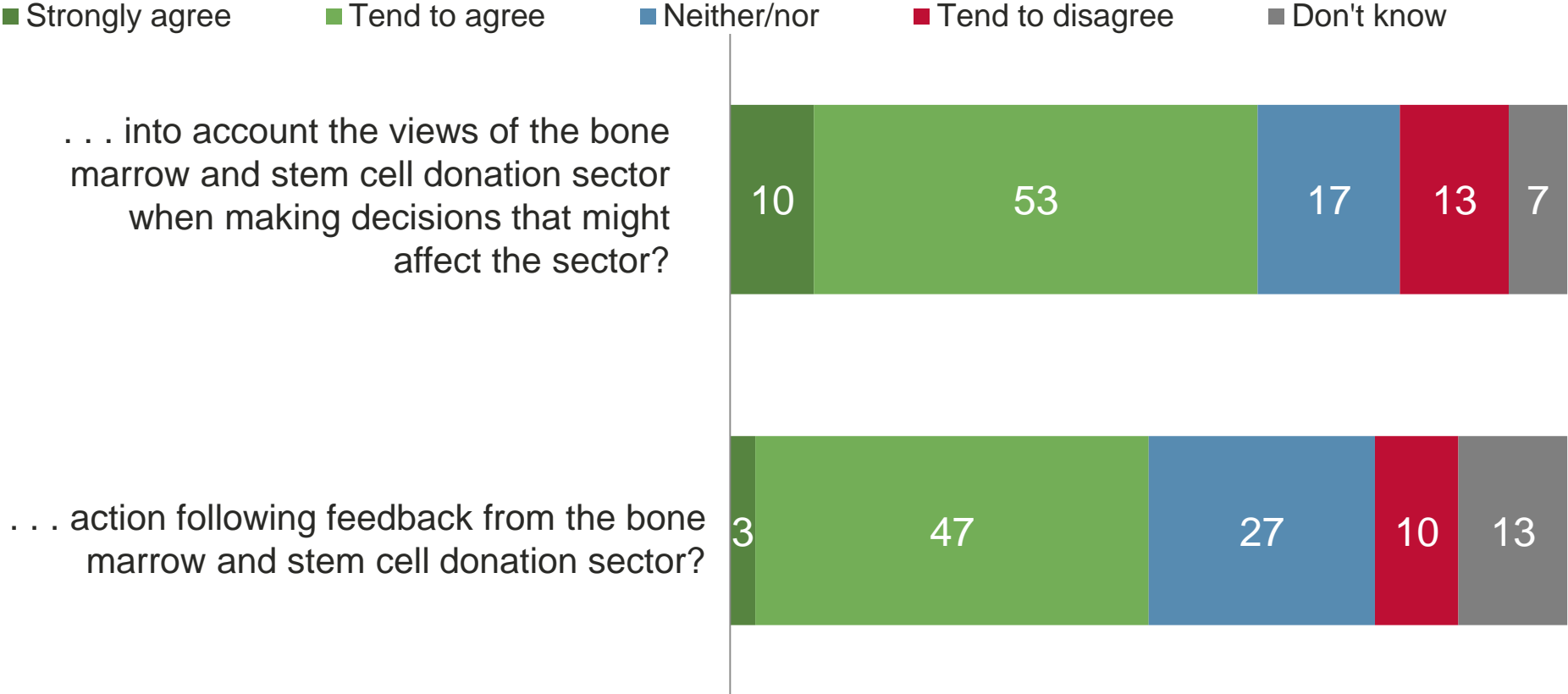


Base: All in bone marrow and stem cell donation sector (30), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

Source: Ipsos MORI

And views are generally positive about feeding back to the HTA

To what extent do you agree or disagree that the HTA takes . . .



Base: All in bone marrow and stem cell donation sector (30), 15th July - 1st August 2013. N.B. Small base to be treated with caution.

Source: Ipsos MORI

Views on changes within sector

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Post mortem sector changes

- A number of changes have recently been made, or are in the process of being made, by the HTA, that will affect those stakeholders working in the post mortem sector. Overall, it is thought among stakeholders in this sector that they will have at worst no impact either way, with very few reporting possible negative impacts. Stakeholders are most positive about the *creation of the adult post mortem information leaflet and the perinatal Sands information* in this sector, and a *more proportionate approach to the regulation of microscope slides*. A majority (67% and 66% respectively) think these will have a **positive impact**. *Changing the name of Serious Untoward Incidents (SUIs) to HTA Reportable Incidents* is the change that is thought by the largest proportion (60%) to have **no impact either way**.
- Half (50%) of stakeholders working in the post mortem sector think that *the ACPO report on the retention of tissue holdings for the police* has had neither a positive or negative impact on their practice, and just one in ten (10%) report that it has had a **minor or significant positive impact**.

Human application (tissue for treatment) sector changes

- Stakeholders working in the human application sector were asked to think about the impact of the following changes on their establishment: *Themed inspections, joint inspections with the MHRA in the regenerative medicine sector, and joint advice and guidance produced with other regulators or agencies*. Of these, *themed inspections* is thought to have the greatest potential positive impact: 44% think it will have a **significant positive impact**. One in ten (10%) of those in the sector think that *joint inspections* will have a **significant negative impact**.
- Overall, four in ten (39%) stakeholders in the human application sector feel that they understand the Preparation Process Dossier (PPD) procedure **very or fairly well**. A similar proportion feel that they **do not understand it very well or not well at all** (36%). Among those who it is applicable to, two fifths (42%) **strongly or tend to agree** that the HTA's approach to implementing this improves the quality and safety of their processes.

Research sector changes

- Among stakeholders in the research sector, nearly three fifths (57%) think that *collaborative work with other regulators or agencies* will have a **positive impact** on their establishment, and only one in fourteen (7%) think this will have any kind of *negative impact*. *Increased licensing options for the removal of tissue from deceased donors* is considered by 29% to have a **positive impact**, while a further 29% think this change will have no impact either way.

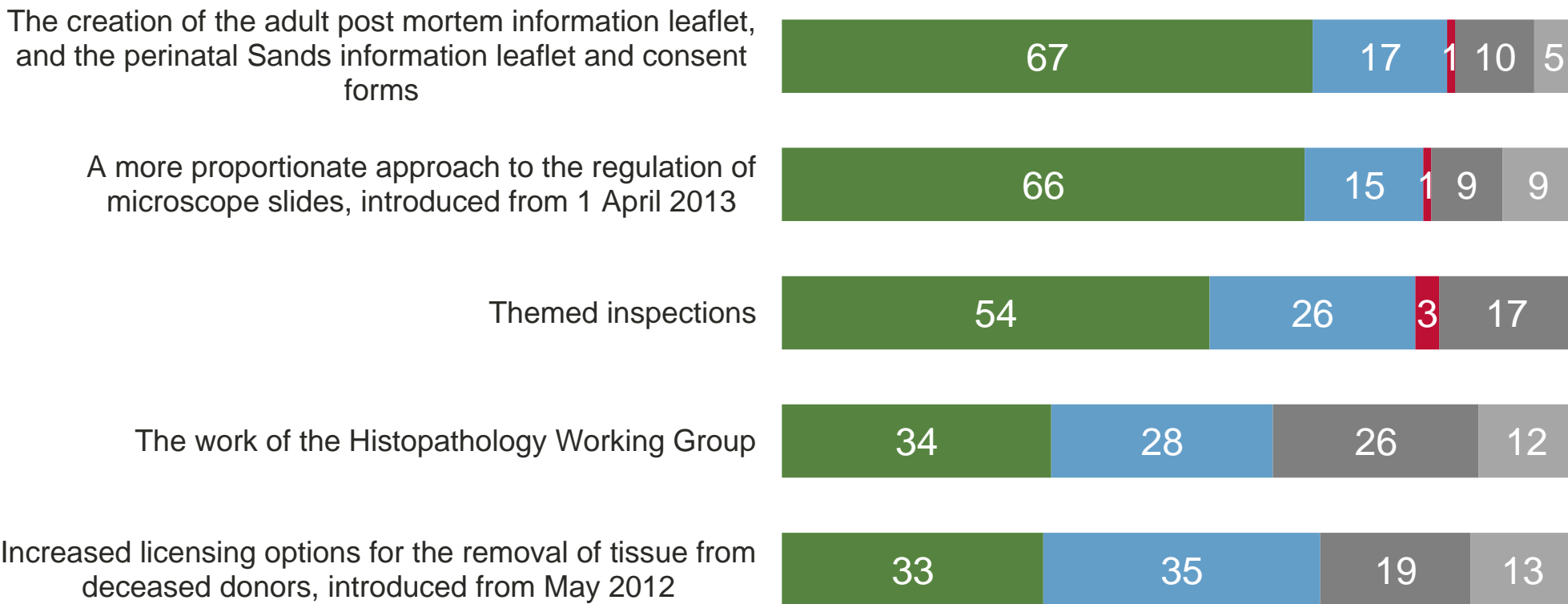
Solid organ donation sector changes

- The majority of ODT contacts working in the solid organ donation sector (70%) think that the *new documentary framework for the quality and safety of organs intended for transplantation* will have a **positive impact**.

Only very few in the post mortem sector think changes will have a negative impact

Thinking about the following changes implemented by the HTA, what level of impact, if any, do you think they will have on your establishment?

- Significant/minor positive impact
- No impact either way
- Minor/significant negative impact
- Don't know
- Not applicable to my establishment

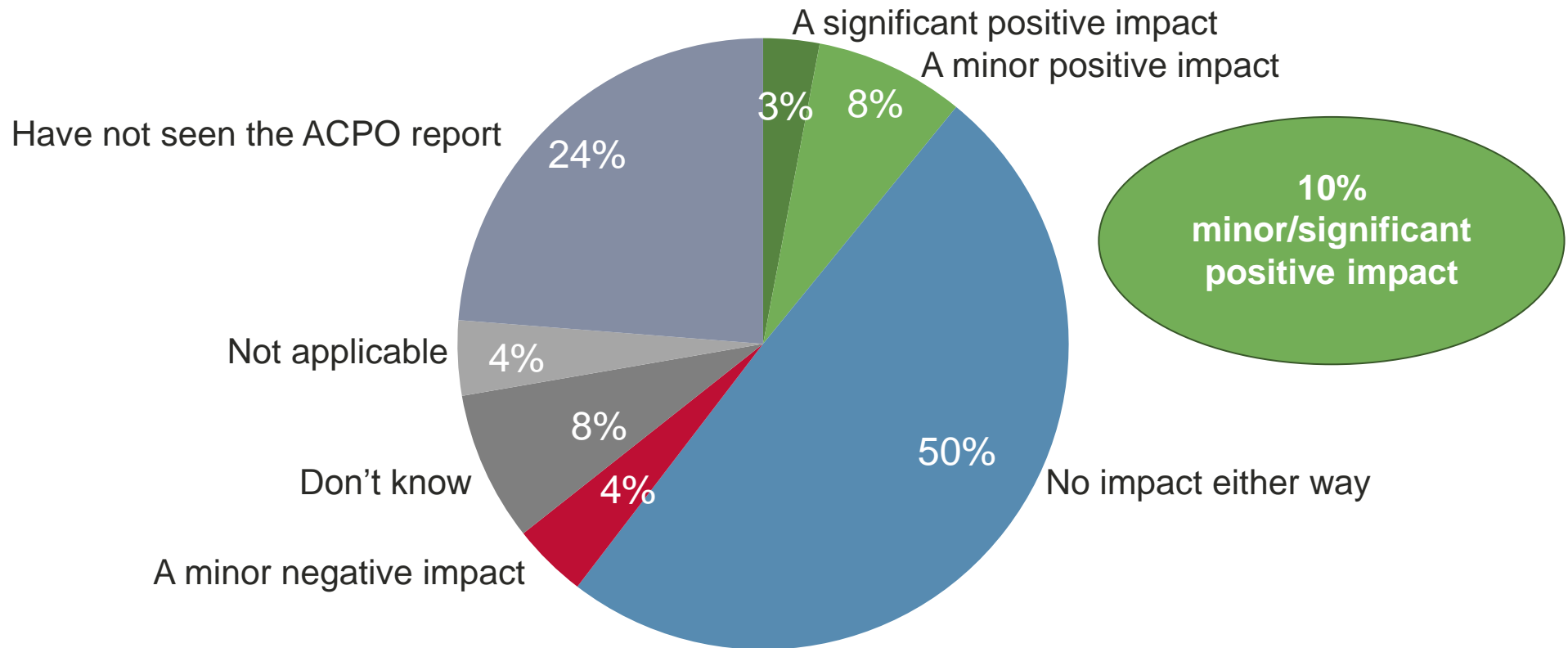


Base: All working in the post mortem sector (78), 15th July - 1st August 2013

Source: Ipsos MORI

Half think the ACPO report will have no impact either way

What level of impact, if any, has the Association of Chief Police Officers (ACPO) report on the retention of tissue holdings for the police had on your practice?



Base: All working in the post mortem sector (78), 15th July - 1st August 2013

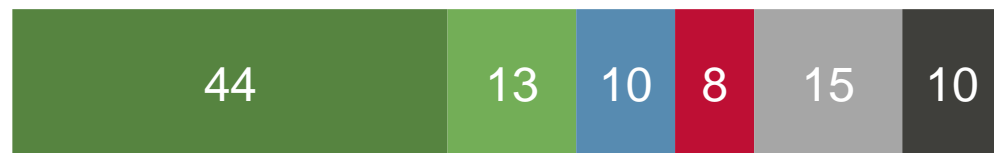
Source: Ipsos MORI

Themed inspections are thought to have the most positive possible impact in the human application sector

Thinking about the following changes implemented by the HTA, what level of impact, if any, do you think they will have on your establishment?

- Significant positive impact
- Minor positive impact
- No impact either way
- Minor negative impact
- Significant negative impact
- Don't know
- Not applicable to my establishment

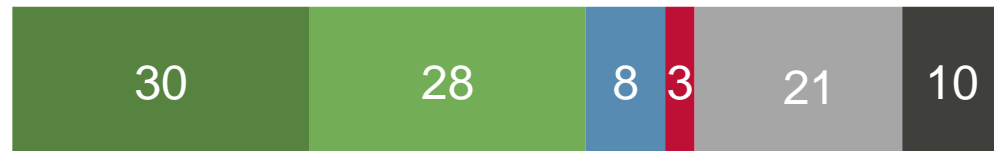
Themed inspections



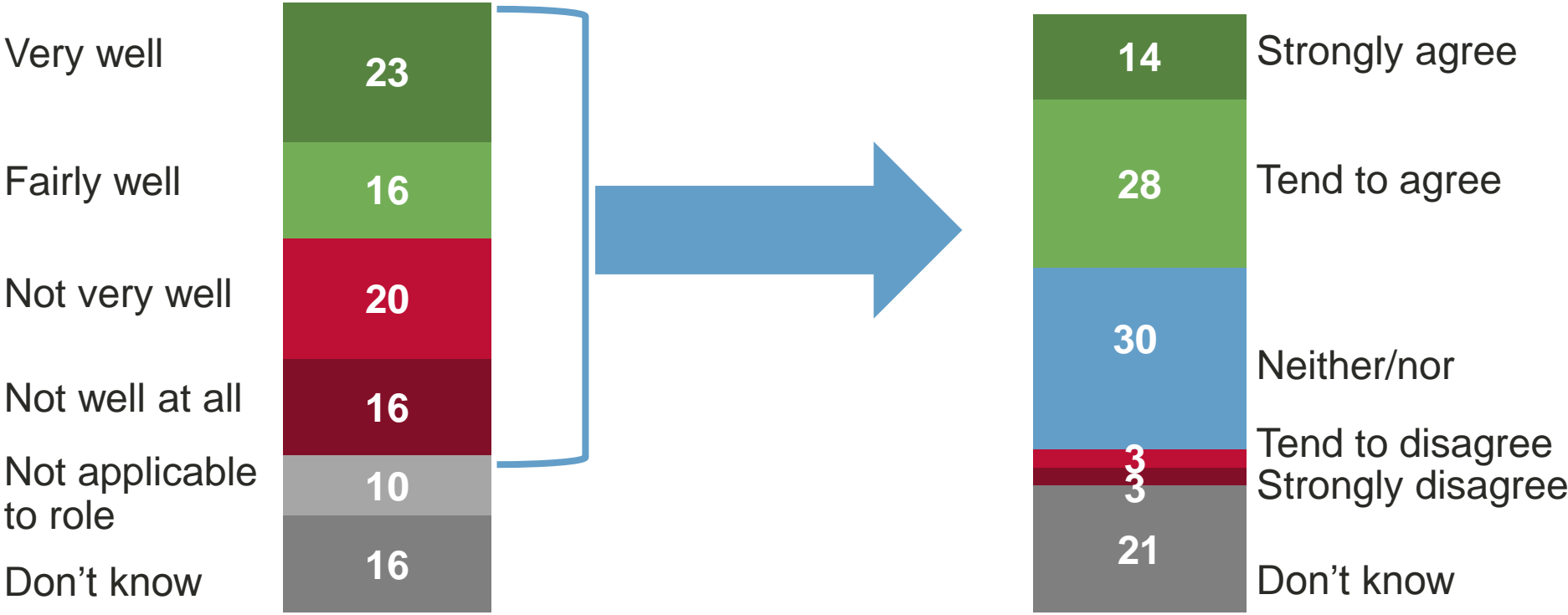
Joint inspections with Medicines and Healthcare products Regulatory Agency in the regenerative medicine sector



Joint advice and guidance produced with other regulators or agencies



The human application sector is split on how well it knows the PPD



How well would you say that you understand the Preparation Process Dossier (PPD) procedure?

To what extent do you agree or disagree that the HTA's approach to implementing the PPD procedure improves the quality and safety of your processes?

Base: All working in the human application sector (38) 15th July - 1st August 2013

Base: All working in the human application sector to whose role the PPD is applicable (28) 15th July - 1st August 2013 N.B. Small base to be treated with caution.

Source: Ipsos MORI

Nearly three fifths in the research sector think collaborative working will have a positive impact

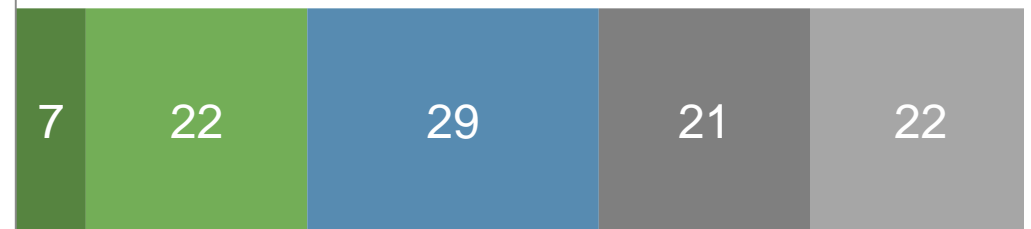
Thinking about the following changes implemented by the HTA, what level of impact, if any, do you think they will have on your establishment?

- Significant positive impact
- Minor positive impact
- No impact
- Minor negative impact
- Significant negative impact
- Don't know
- Not applicable

Collaborative work with other regulators or agencies (e.g. consolidated guidance and/or information sharing)

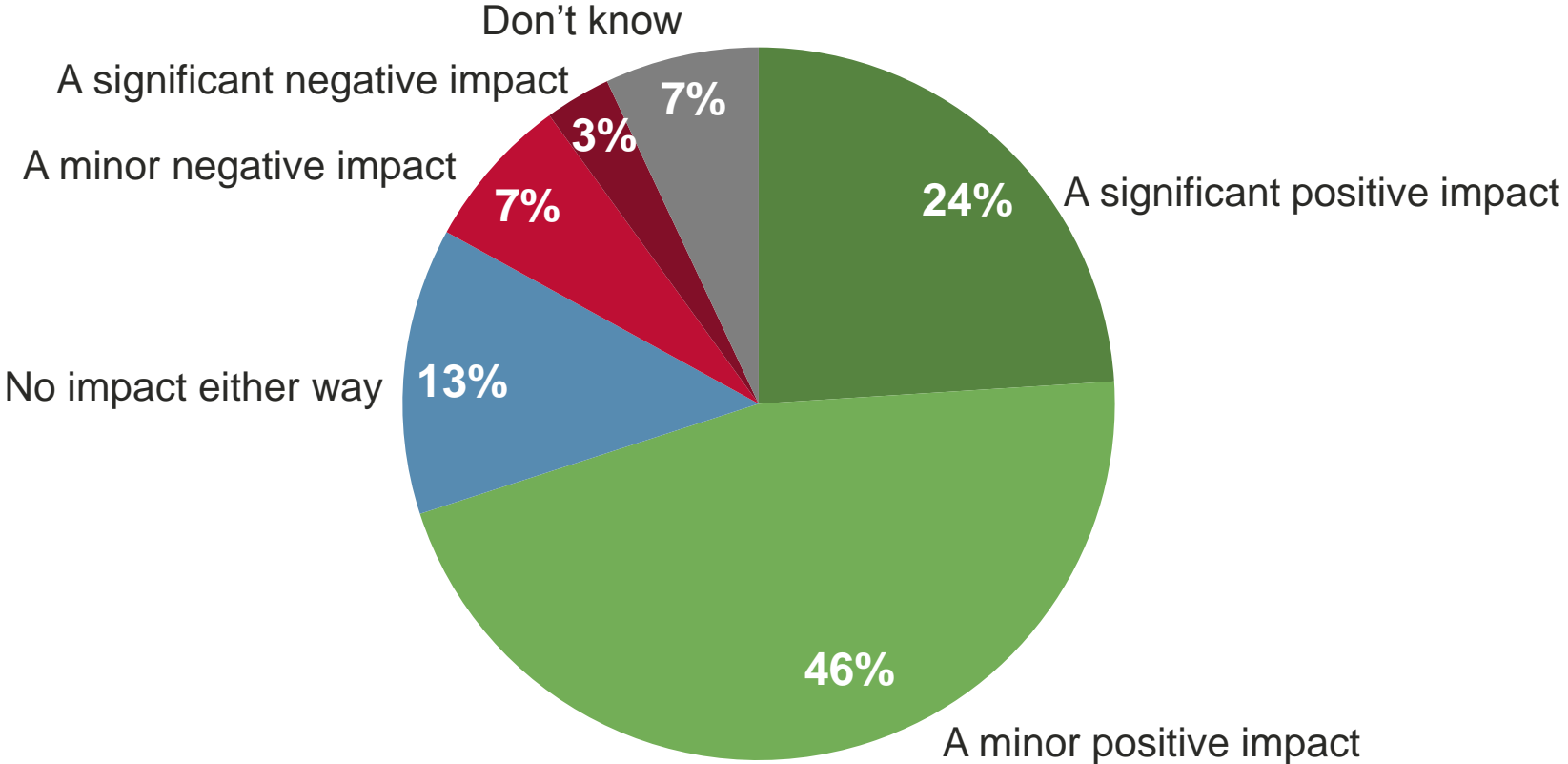


Increased licensing options for the removal of tissue from deceased donors, introduced from May 2012



The new documentary framework: a positive likely impact

Thinking about the new documentary framework for the quality and safety of organs intended for transplantation, what level of impact, if any, do you think it will have on your working practices?



Base: All ODT contacts working in the solid organ donation sector (30), 15th July - 1st August 2013 N.B. Small base to be treated with caution.

Source: Ipsos MORI

4. Findings from the public survey



Overall perceptions of regulation

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Summary: overall perceptions of regulation

- The public were asked how much confidence, if any, they have in the way that the donation, removal, storage and use of human tissue or organs is regulated. Overall, half (49%) have a **fair amount/great deal** of confidence. This represents a decline in confidence of 8 percentage points since 2010. There has also been a slight but significant increase in the proportion reporting **no confidence at all** (8% compared with 5%) and don't know (27% compared with 22%). These findings relate to those in the professional survey, where *improving public confidence* is identified as an activity that is seen as **very important** to HTA stakeholders, but for which the HTA is not seen as being as effective.
- This decrease in confidence is important to understand, as it can be seen to influence propensity to donate any of the organs or tissue. By way of broad comparison, a question was asked of a separate sample of the general public, to measure confidence in health sector regulation **in general**. While overall confidence is very similar (52%), the proportion of people reporting **a lack of confidence** is much higher (40%) when the public are asked about the regulation of the health sector in general. The much smaller proportion of 'don't know' answers indicates that the public feel much better placed to comment on general health sector regulation, than they do to comment on human tissue regulation. For both, levels of confidence are lower in the West Midlands than overall.
- Furthermore, the decline in reported confidence in the HTA is likely to reflect general concern among the public in relation to the NHS, especially in the light of recent scandals.
- Respondents were also asked to identify the benefits and drawbacks of regulating human tissue use. In line with the 2010 survey, the most frequently cited benefit was *stops bad practice from occurring* (32%). *Ensuring human tissue is not used at will or abused* (11%), *knowing human tissue is safer for treatment* (11%), *knowing people's wishes will be respected* (14%), *ensure tissue is not used for financial gain/commercial purposes* (10%) and *more people will be willing to donate their organs and/or tissues for transplants* (12%) were others receiving top mentions, with the final four all showing significant increases since 2010.
- As for the perceived drawbacks to regulation, the top mention was again *too much red tape*, although a smaller proportion mentioned it (13% in 2010 and 9% in 2013), while a fifth (19%) suggested that *there are no drawbacks*.

Summary: overall perceptions of regulation

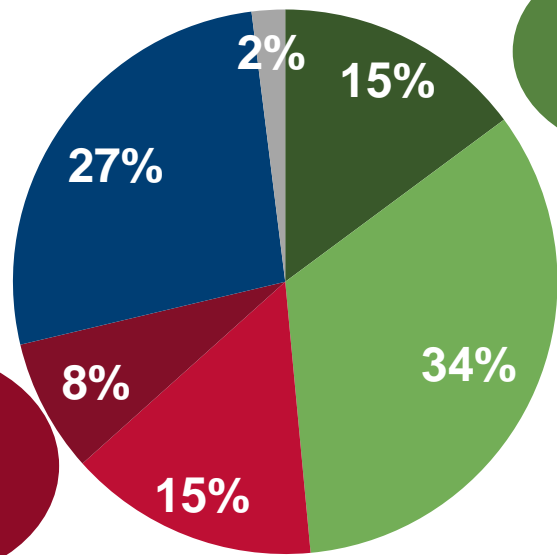
In order to try and measure the impact of knowledge of a regulator on confidence in donating, respondents were informed of the existence of the HTA, and of its role. They were then asked to what extent knowing that there is a regulator would make them more confident to donate for various purposes.

- Overall this is positive with between 43% and 54% agreeing that it would make them **more confident**. The proportion disagreeing varies from one in ten (10%) *tissue from their body for the treatment of patients* to nearly one in five (18%) for *brain for use in research*. The proportion saying that they would not donate under any circumstances is relatively similar across all types of donation (ranging from 7% to 11%).
- By looking at some of the demographic differences, we can try and further understand these findings. Throughout the responses to these statements, we can see the impact of ethnicity, education and region.
 - Indeed, for all types of donation, White respondents are more likely to agree than Black and Asian respondents that knowing would make them more confident to donate. Similarly, level of education makes a difference. For example, respondents educated to degree/master's/PhD level are more likely to agree than those with no formal qualifications across all types of donation.
 - Those respondents in the West Midlands are more likely than average to report *I would not consider donating under any circumstances*, and for *donation of tissue from their body for medical research*, *donation of their body for medical education or training* and *donation of brain for use in research* so too are those in the South West. This perhaps reflects events such as the Staffordshire Hospital scandal, the Birmingham Children's Hospital organ donation scandal, and the Bristol heart scandal. There is, however, no impact of the Alder Hey scandal to be seen amongst respondents from the North West.

A decline in public confidence from 2010

How much confidence, if any, do you have in the way the donation, removal, storage and use of human tissue or organs is regulated?

2013



49% great deal/fair amount

22% not very much/none at all

- A great deal ■ A fair amount
- Not very much ■ None at all
- Don't know ■ Refused

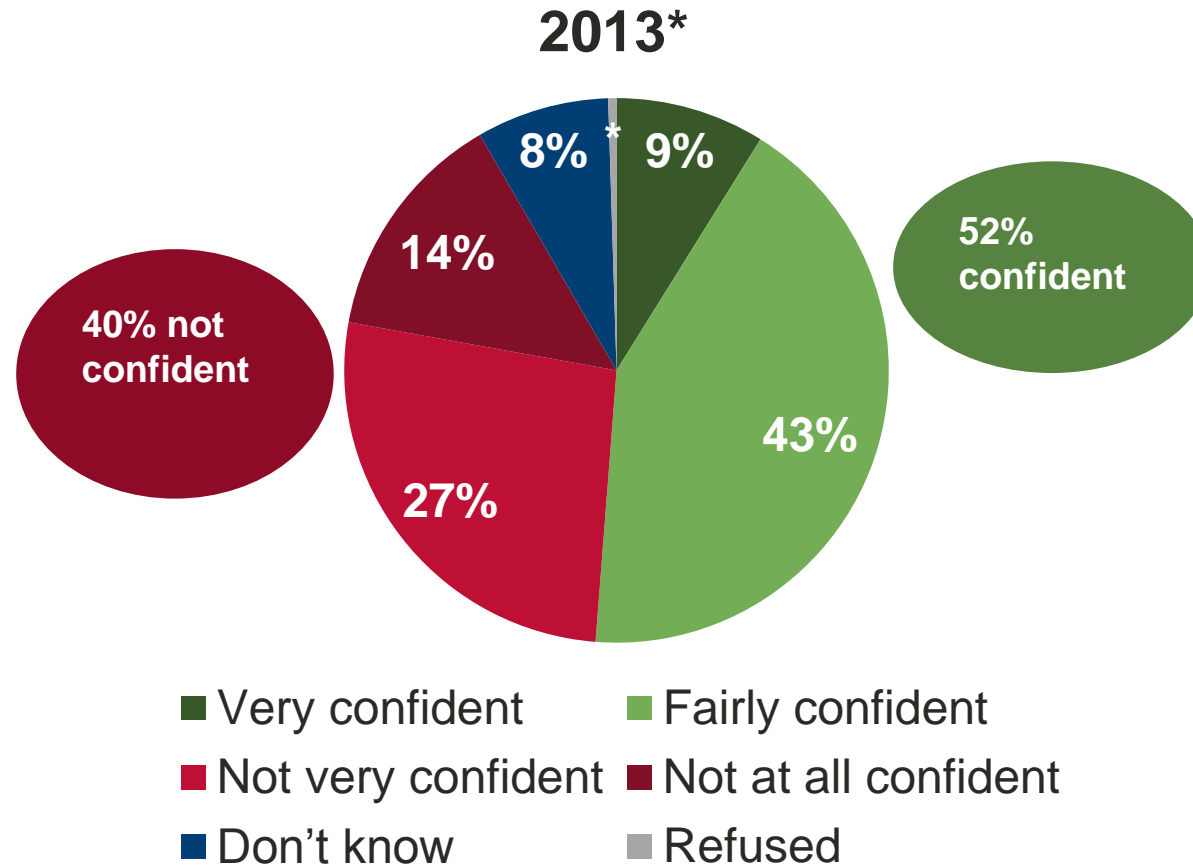
	2007 %	2010 %	2013 %
A great deal	13	14	15
A fair amount	39	43	34
Not very much	18	15	15
None at all	6	5	8
Don't know	22	22	27
Refused	2	1	2

Base: All GB adults 15+, 2013: (987); 2nd – 12th August 2013; 2010: (967) 13th - 19th August 2010; 2007 (2058) GB adults aged 16+ 17th-22nd May 2007.

Source: Ipsos MORI

But two fifths of the public lack confidence in health sector regulation in general

Using this card, how confident, if at all, are you that the health sector in general is regulated effectively?



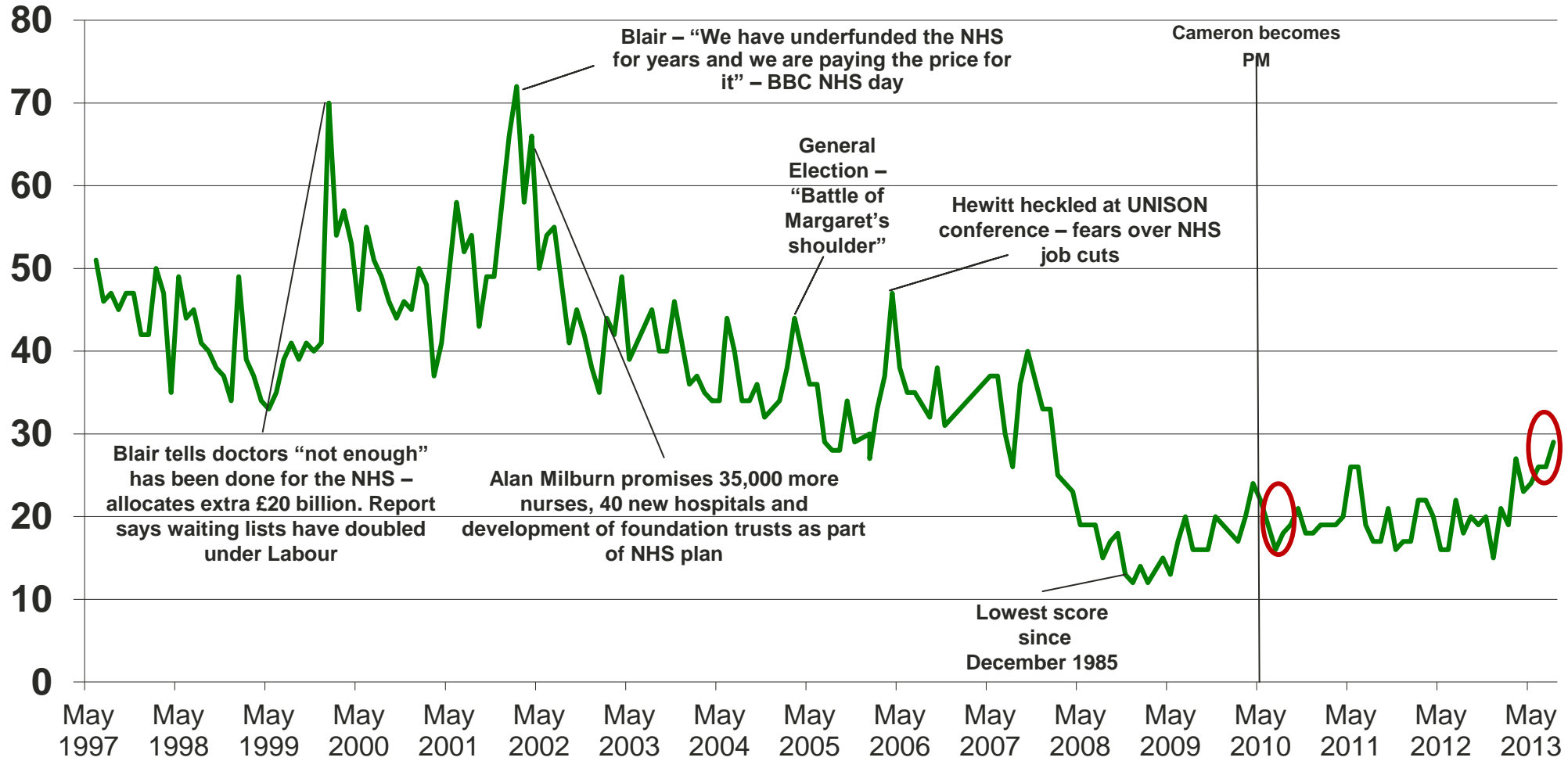
Base: All GB adults 15+ (998); 16nd – 22nd August 2013

Source: Ipsos MORI

*N.B. this question was asked of a different Capibus sample

And concern about the NHS/hospitals/healthcare is on the rise

What do you see as the most/other important issues facing Britain today?



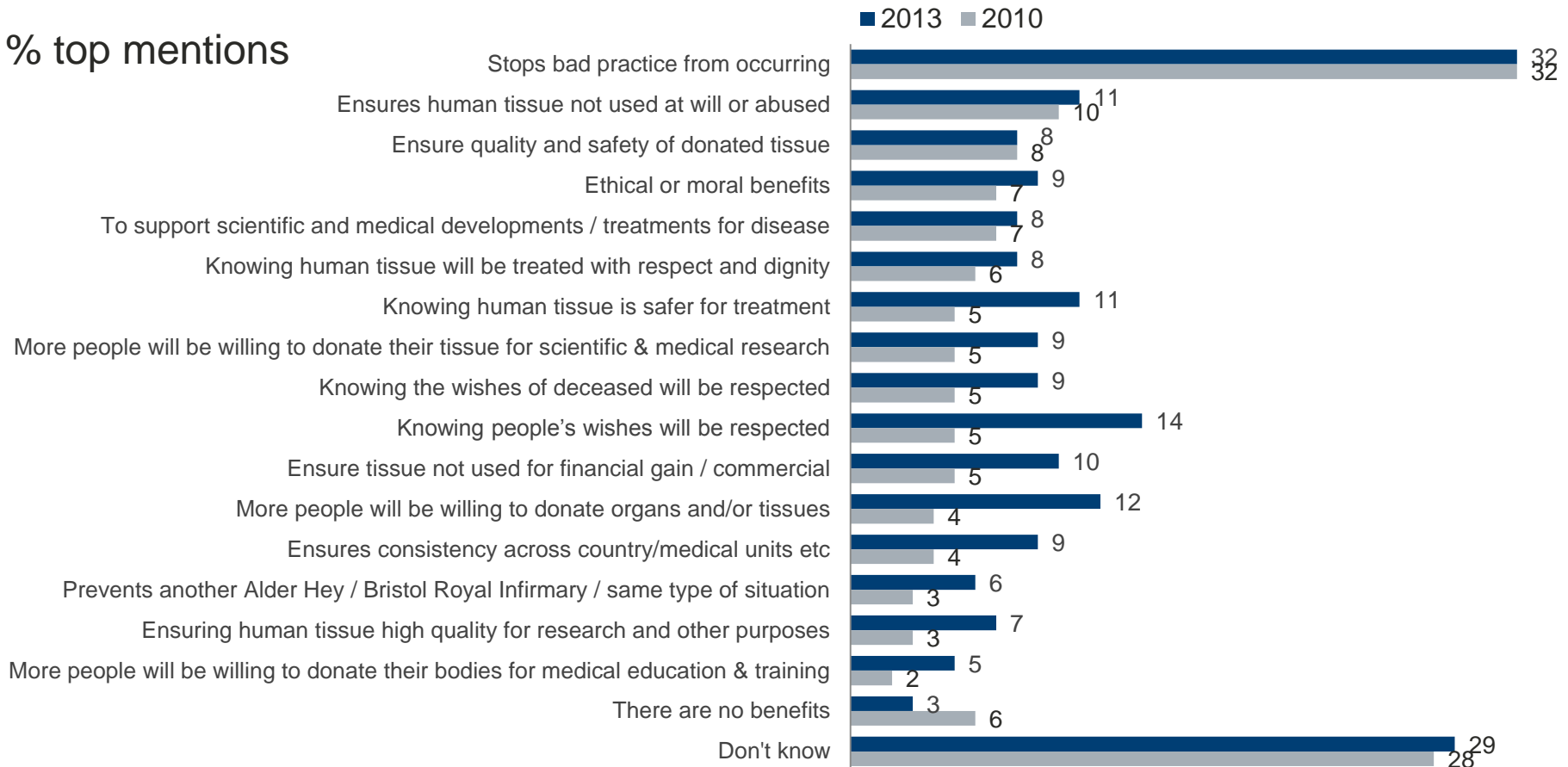
Base: representative sample of c.1,000 British adults age 18+ each month, interviewed face-to-face in home

Source: Ipsos MORI Issues Index

People feel that regulation helps to stop bad practice

What, if anything, do you feel are the benefits of regulating the way in which human tissue is used in the UK? What else?

% top mentions

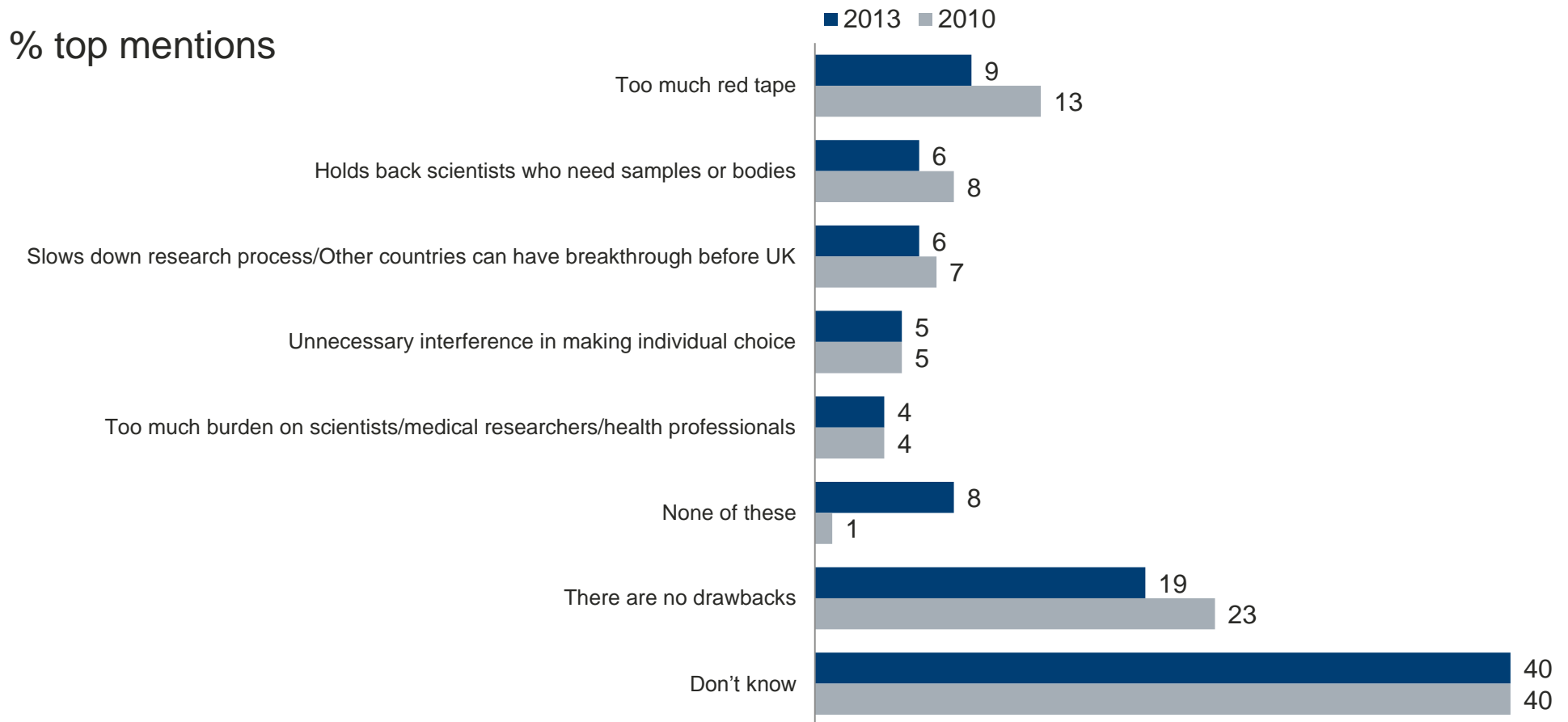


Base: All GB adults 15+, 2013: (987); 2nd – 12th August 2013; 2010: (967) 13th - 19th August 2010

Source: Ipsos MORI

But there are some concerns about red tape

What, if anything, do you feel are the drawbacks of regulating the way in which human tissue is used in the UK? What else?



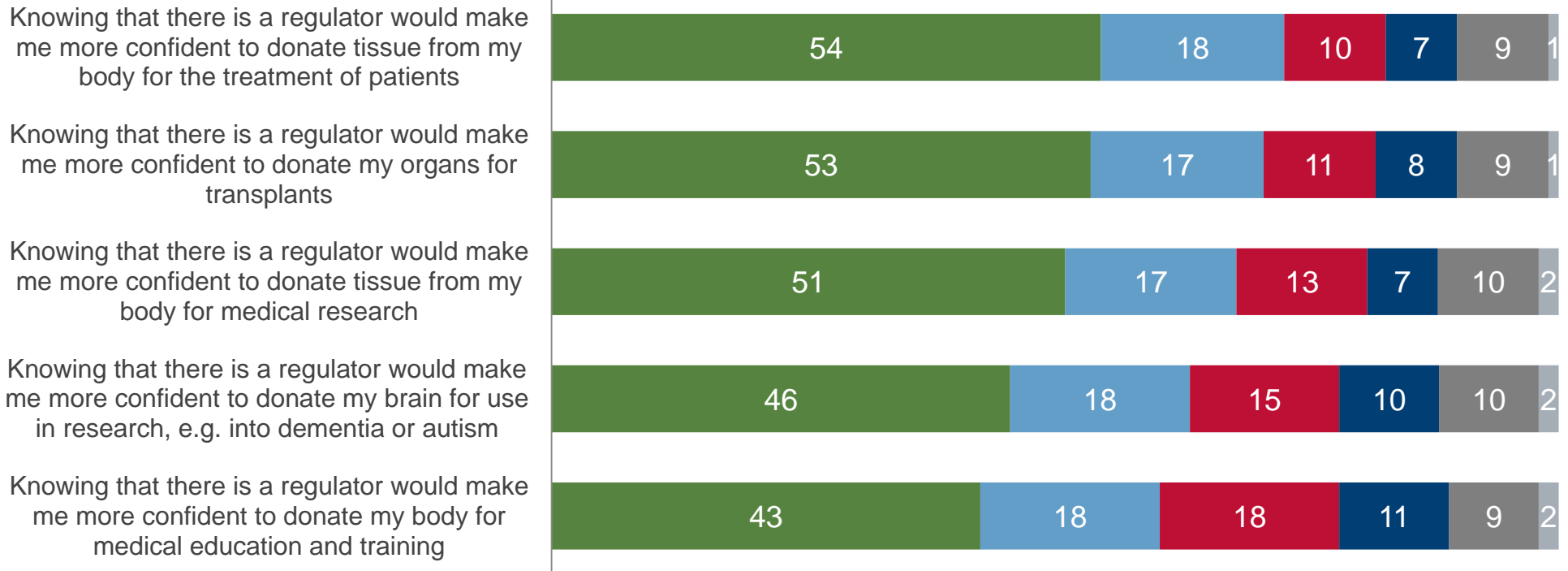
Base: All GB adults 15+, 2013: (987); 2nd – 12th August 2013; 2010: (967) 13th - 19th August 2010

Source: Ipsos MORI

Knowing there is a regulator, generally makes people confident to donate

As you may or may not be aware, the donation, storage, use and disposal of human tissue and organs is regulated by a body called the Human Tissue Authority (the HTA). Please tell me to what extent, if at all, you agree or disagree with each of the following statements?

- % Strongly agree/ Tend to agree
- % Neither agree nor disagree
- % Tend to disagree/ Strongly disagree
- % I would not consider donating under any circumstances
- % No opinion/Don't know
- % Refused



Base: All GB adults 15+ (987), 2nd – 12th August 2013

Source: Ipsos MORI



Attitudes towards donation

Version 1 | Internal Use Only

Summary: attitudes towards donation

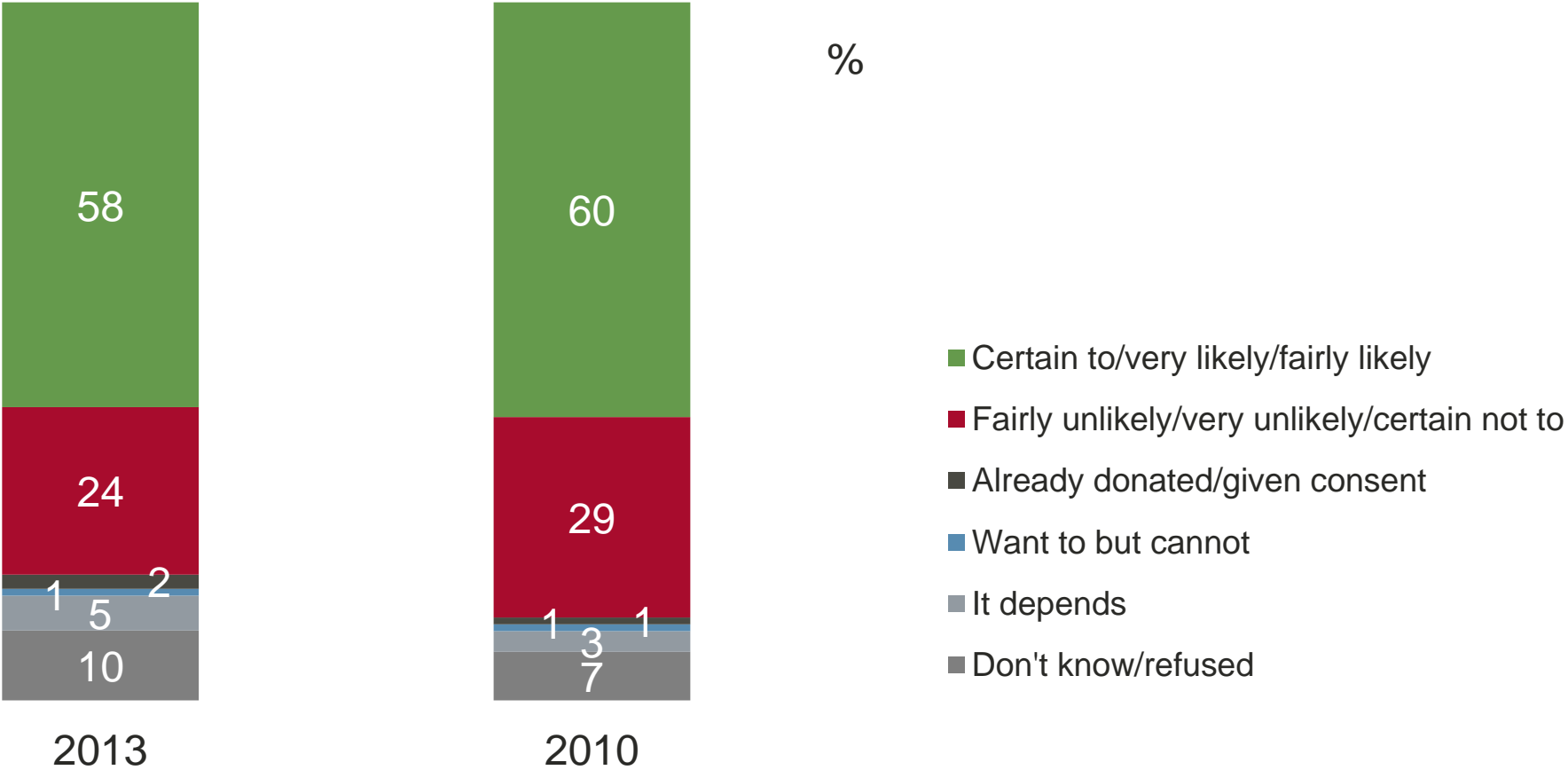
- For most types of donation, the public express a **similar likelihood to donate** as in 2010. However, the increase in the proportions answering 'don't know' and 'it depends' is reflected in a decline in those saying they are unlikely to donate across most types. For example, the proportion saying they are **unlikely** to donate any of their tissue or *organs while they are still alive for use in transplantation* has fallen from 42% to 33% (-9pp), and **it depends** has increased from 7% to 15% (+8pp).
- People are most likely to simply reiterate that they **just don't want to** as a reason for being unlikely to donate. Beyond this, other reasons include strongly held beliefs or unavoidable problems – e.g. religious considerations, health problems/medical conditions.
- Indeed, there has been an increase since 2010 in people mentioning *religious considerations* across several types of donation. *Religious considerations* can be thought of as a 'value', that is very difficult or not desirable to shift. This is also likely to be linked to concerns about *cutting open the body*. Therefore, if the proportion of people reporting being unlikely to donate falls over time (as it has since 2010), then we would expect to see an increase in the proportion of people giving reasons based on 'values' increasing, as these are the most difficult to counteract.
- For donation to medical research in particular there has also been an increase in those answering that they are worried about their lack of control over who their tissue or organs are used by (increasing from 2% to 9%) how they are used, and concerns about misuse.

Summary: attitudes towards donation

- Likelihood to donate varies by certain demographic groups. It is higher among those with a higher level of education. For example, four in ten people (41%) with no formal qualifications are likely to donate for transplantation after death, compared with nearly three-fifths (57%) overall. This is particularly the case for the example of brain donation where over half of people with a degree or higher qualification (55%) or with A-Levels or equivalent (54%) were likely to donate, compared with four in ten (42%) of those with GCSE or equivalent and just over a third (36%) of those with no qualifications.
- Relatedly, those in higher social grades are more likely to donate, with, for example, 56% of ABs likely to donate their brain compared with 39% of DEs (and 48% overall).
- Donation is also more likely than average among those who read broadsheets, and less likely among tabloid readers. For example, two thirds of broadsheet readers (65%) would be likely to donate, as opposed to half (49%) of tabloid readers. This compares with an overall rate of 58%.

As in 2010, around two thirds say they are likely to donate tissue or organs after they have died for use in medical research

How likely or unlikely would you be to donate any of your tissue or organs after you have died for use in medical research into health and disease?



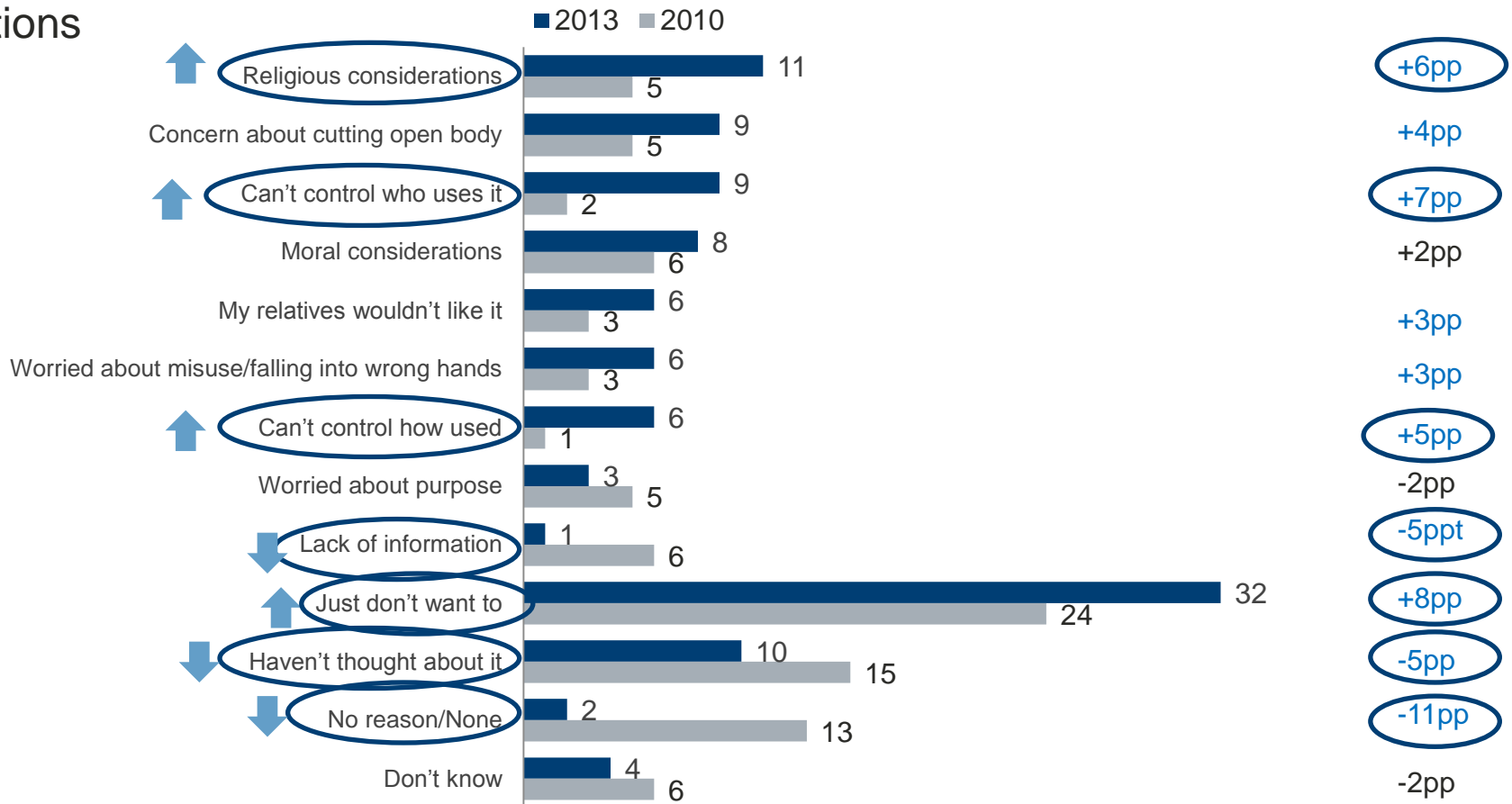
Base: Split Sample - All GB adults 15+ Version 2A, 2013: (495); 2nd – 12th August 2013; 2010: (522) 13th - 19th August 2010

Source: Ipsos MORI

Among those unlikely, religious considerations have become more prominent, as have issues of control

Why do you say that you are not likely to donate any of your tissue or organs after you have died for use in medical research into health and disease?

% top mentions

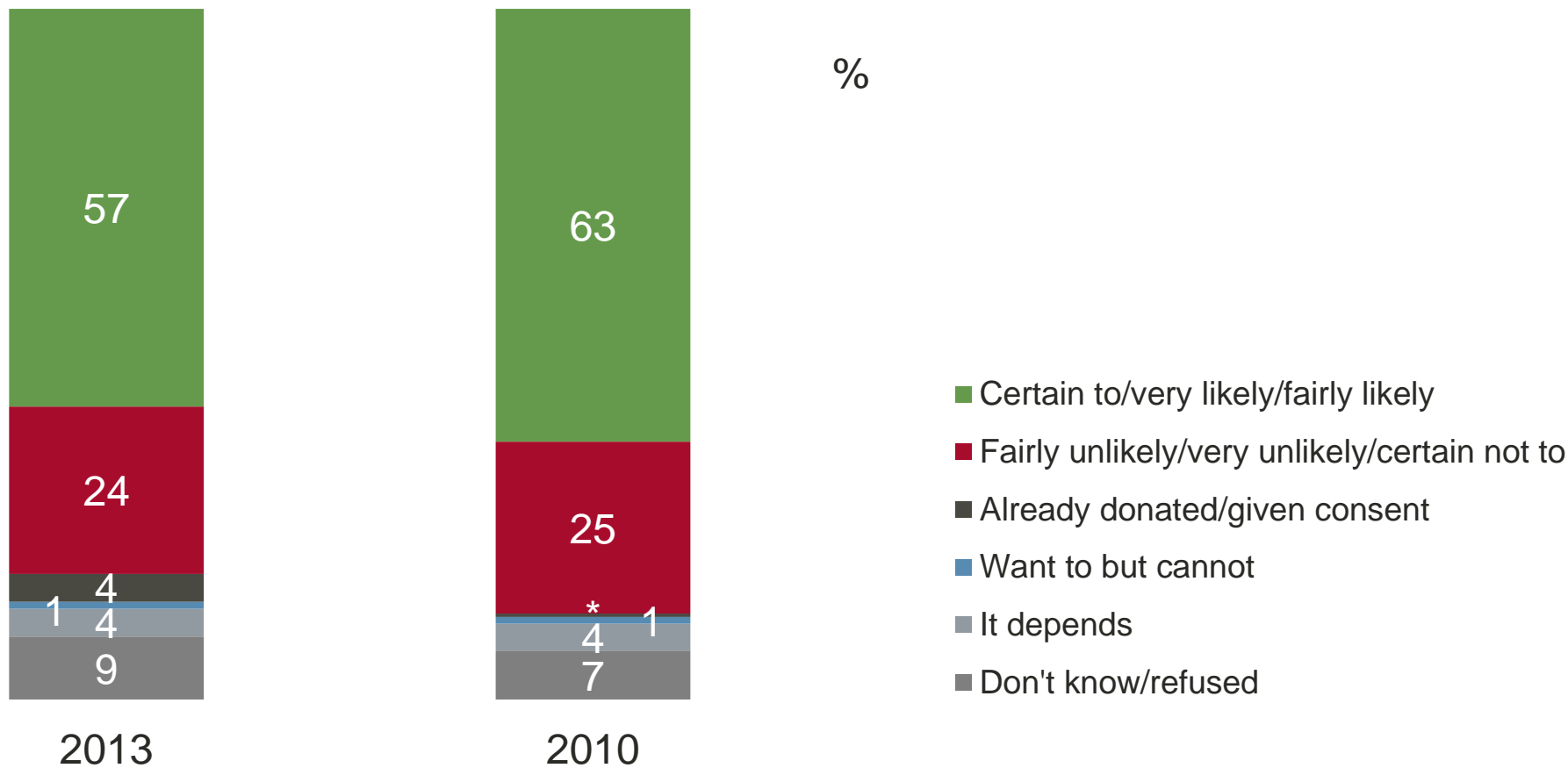


Base: All GB adults 15+ who are unlikely to donate any of their tissue or organs after they have died for use in medical research into health and disease, 2013: (127); 2nd – 12th August 2013; 2010: (155) 13th - 19th August 2010

Source: Ipsos MORI

Similarly, the majority say they are likely to donate after they have died for use in transplantation

How likely or unlikely would you be to donate any of your tissue or organs after you have died for use in transplantation?



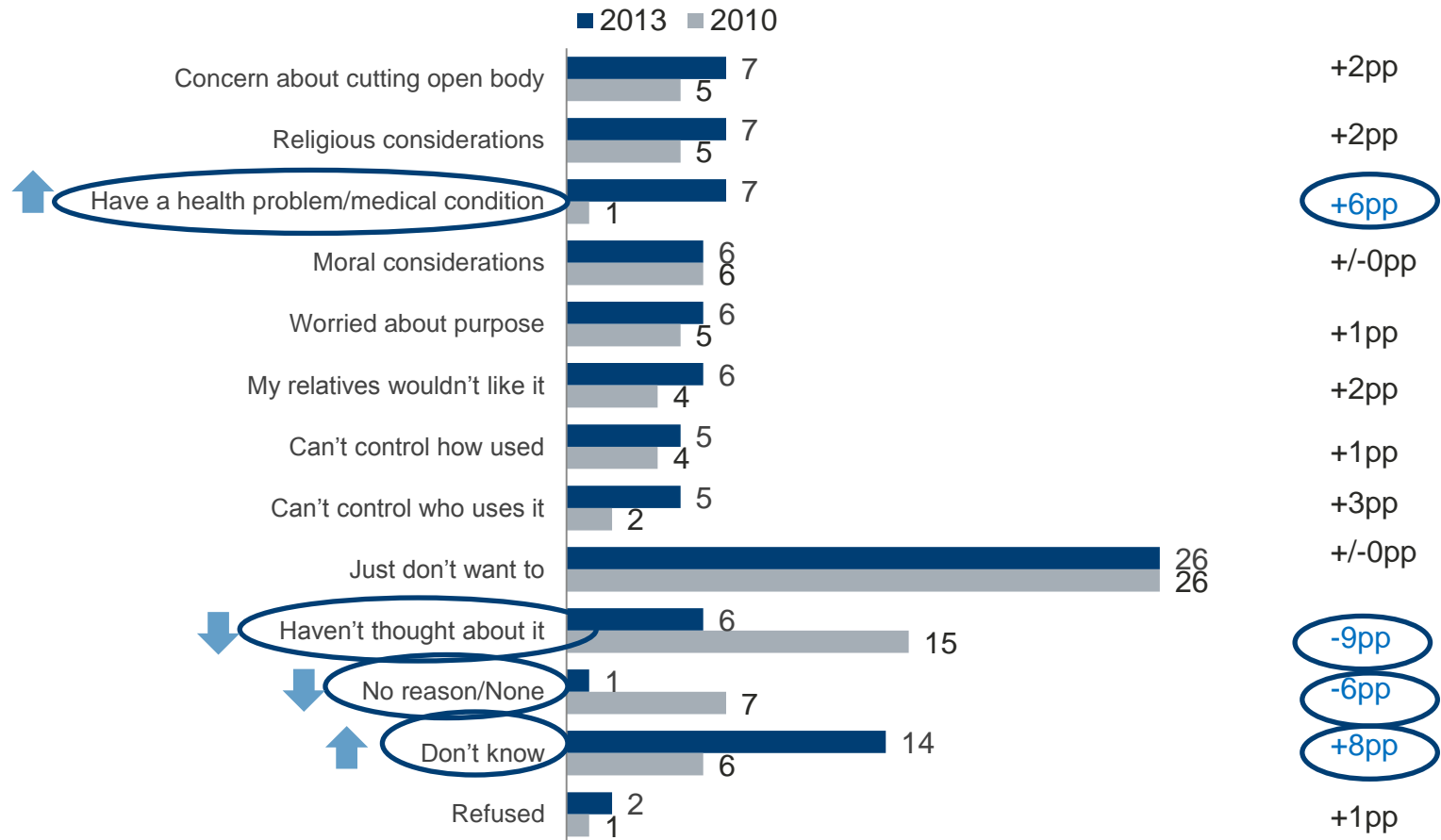
Base: Split Sample - All GB adults 15+ Version 2B, 2013: (492); 2nd – 12th August 2013; 2010: (445) 13th - 19th August 2010

Source: Ipsos MORI

Among those who are unlikely to donate a quarter simply say they just do not want to as a reason why

Why do you say that you are not likely to donate any of your tissue or organs after you have died for use in transplantation? Why else?

% top mentions

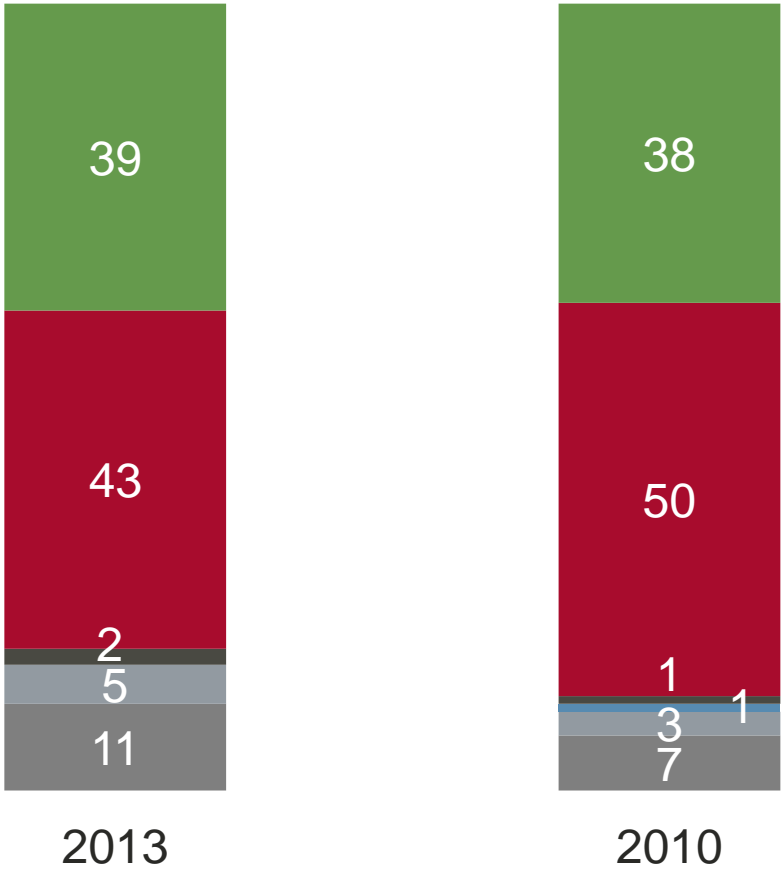


Base: All GB adults 15+ who are unlikely to donate any of their tissue or organs after they have died for use in transplantation, 2013: (119); 2nd – 12th August 2013; 2010: (117) 13th - 19th August 2010

Source: Ipsos MORI

Two fifths say they are likely to donate their body after they have died for use in education or training

How likely or unlikely would you be to donate your body after you have died for use of education or training of doctors?



%

+4pp
Don't know/
refused

-7pp unlikely

- Certain to/very likely/fairly likely
- Fairly unlikely/very unlikely/certain not to
- Already donated/given consent
- Want to but cannot
- It depends
- Don't know/refused

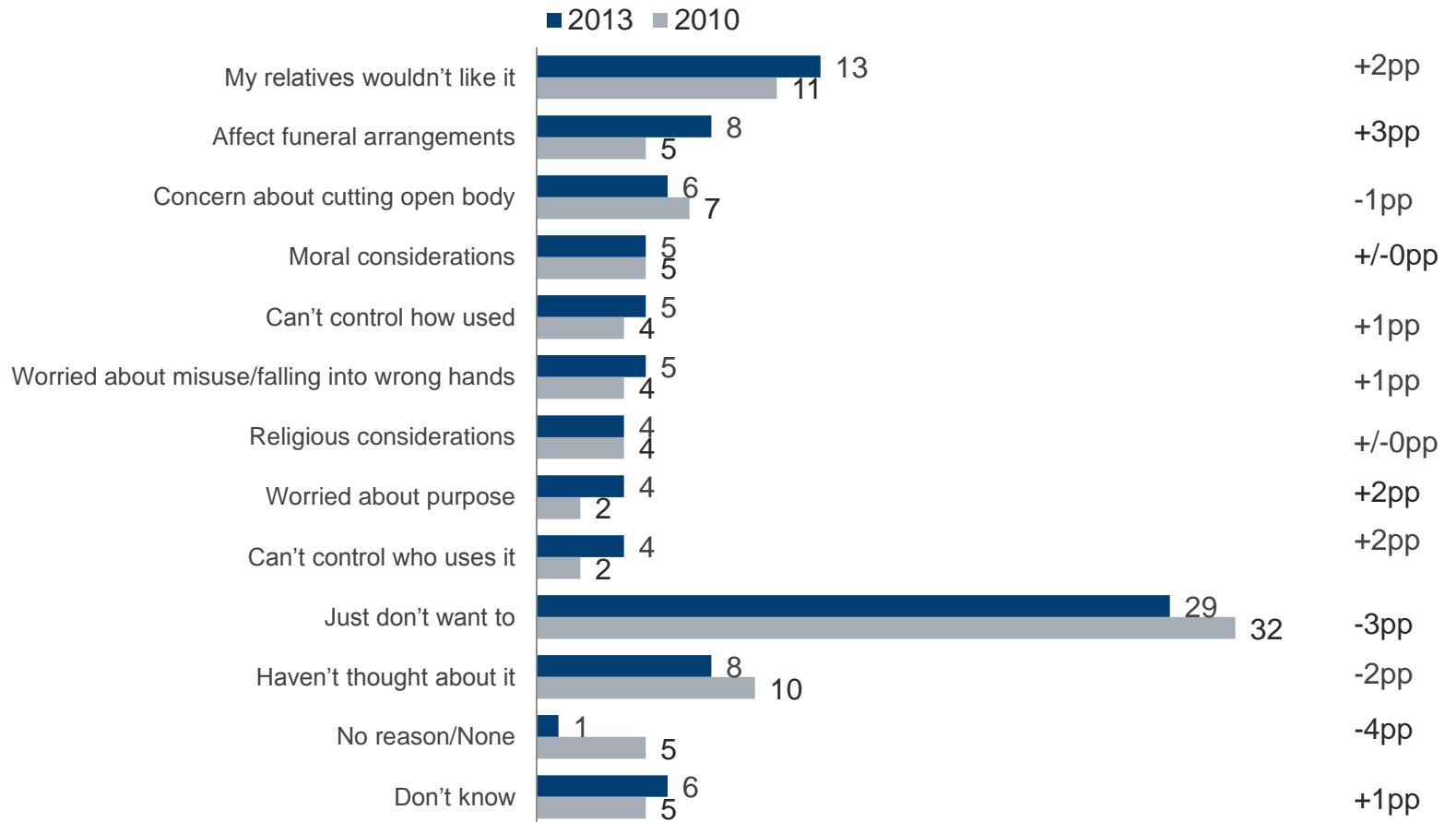
Base: All GB adults 15+, 2013: (987); 2nd – 12th August 2013; 2010: (967) 13th - 19th August 2010

Source: Ipsos MORI

With concern about the reaction of relatives being important for around one in eight

Why do you say that you are not likely to donate your body after you have died for use in education or training of doctors? Why else?

% top mentions



Base: All GB adults 15+ who are unlikely to donate their body after they have died for use in education or training of doctors, 2013: (433); 2nd – 12th August 2013; 2010: (487) 13th - 19th August 2010

Source: Ipsos MORI

Around half say they are likely to donate their brain for use in research

How likely or unlikely would you be to donate your brain after you have died for use in research, for example into dementia or autism?



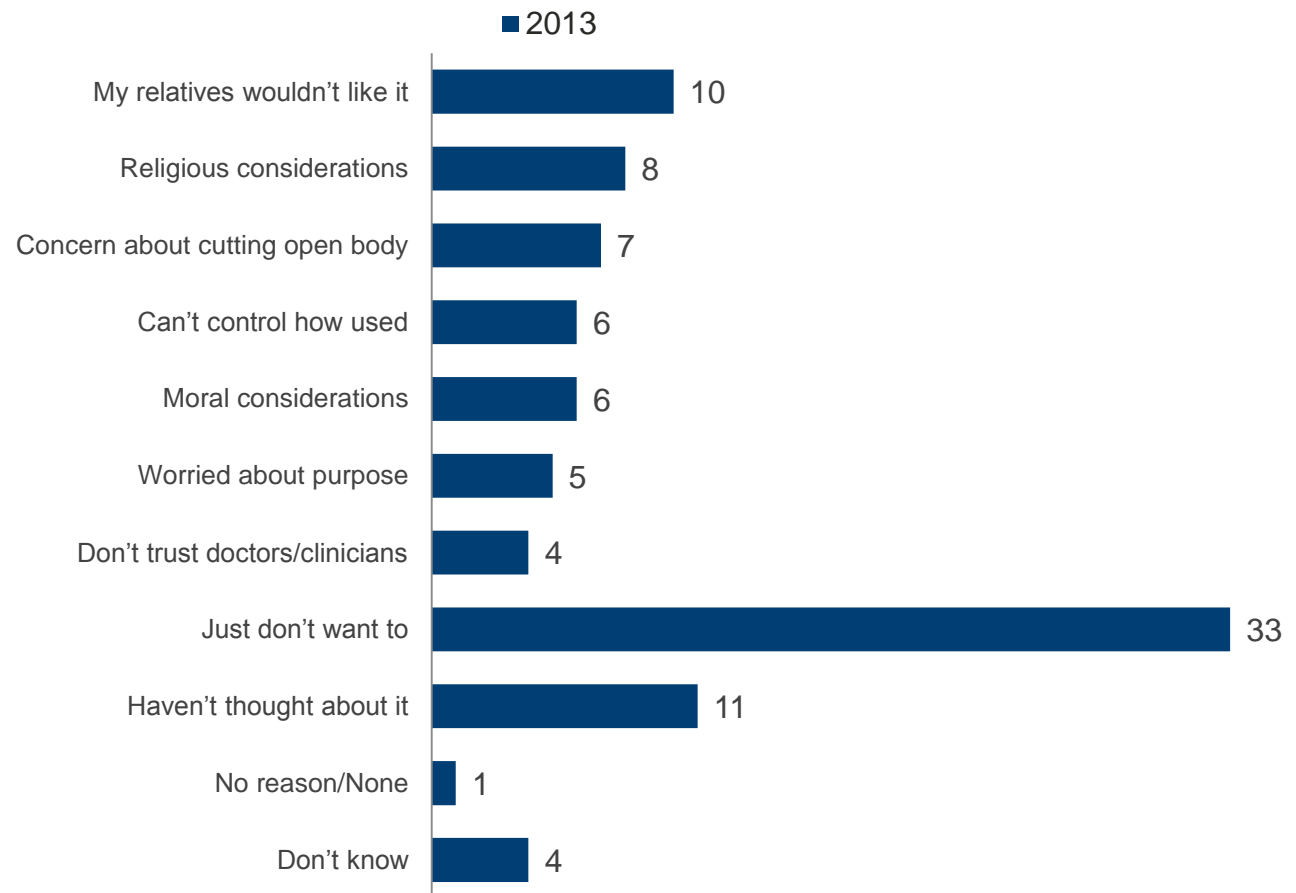
Base: All GB adults 15+, (987); 2nd – 12th August 2013;

Source: Ipsos MORI

Again, a third of those who are unlikely just don't want to donate their brain for this purpose

Why do you say that you are not likely to donate your brain after you have died for use in research, for example, into dementia or autism? Why else?

% top mentions

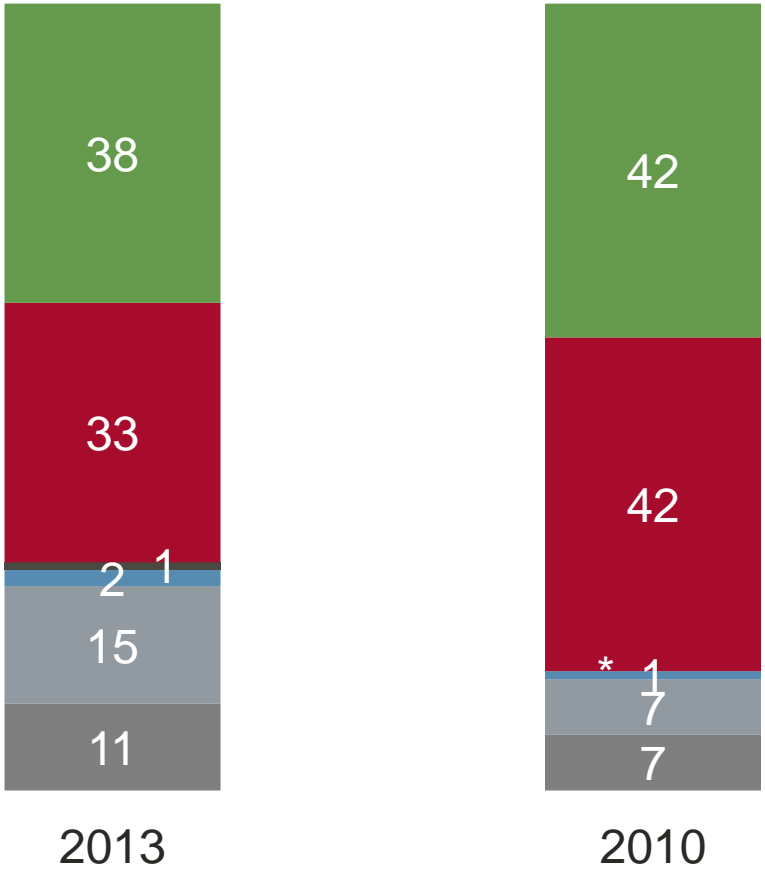


Base: All GB adults 15+ who are unlikely to donate their brain after they have died for use in research, (338); 2nd – 12th August 2013;

Source: Ipsos MORI

Fewer say they are unlikely to donate while still alive for transplantation than in 2010

How likely or unlikely would you be to donate any of your tissue or organs while you are still alive for use in transplantation?



- Certain to/very likely/fairly likely
- Fairly unlikely/very unlikely/certain not to
- Already donated/given consent
- Want to but cannot
- It depends
- Don't know/refused

Base: All GB adults 15+, 2013: (987); 2nd – 12th August 2013; 2010: (967) 13th - 19th August 2010

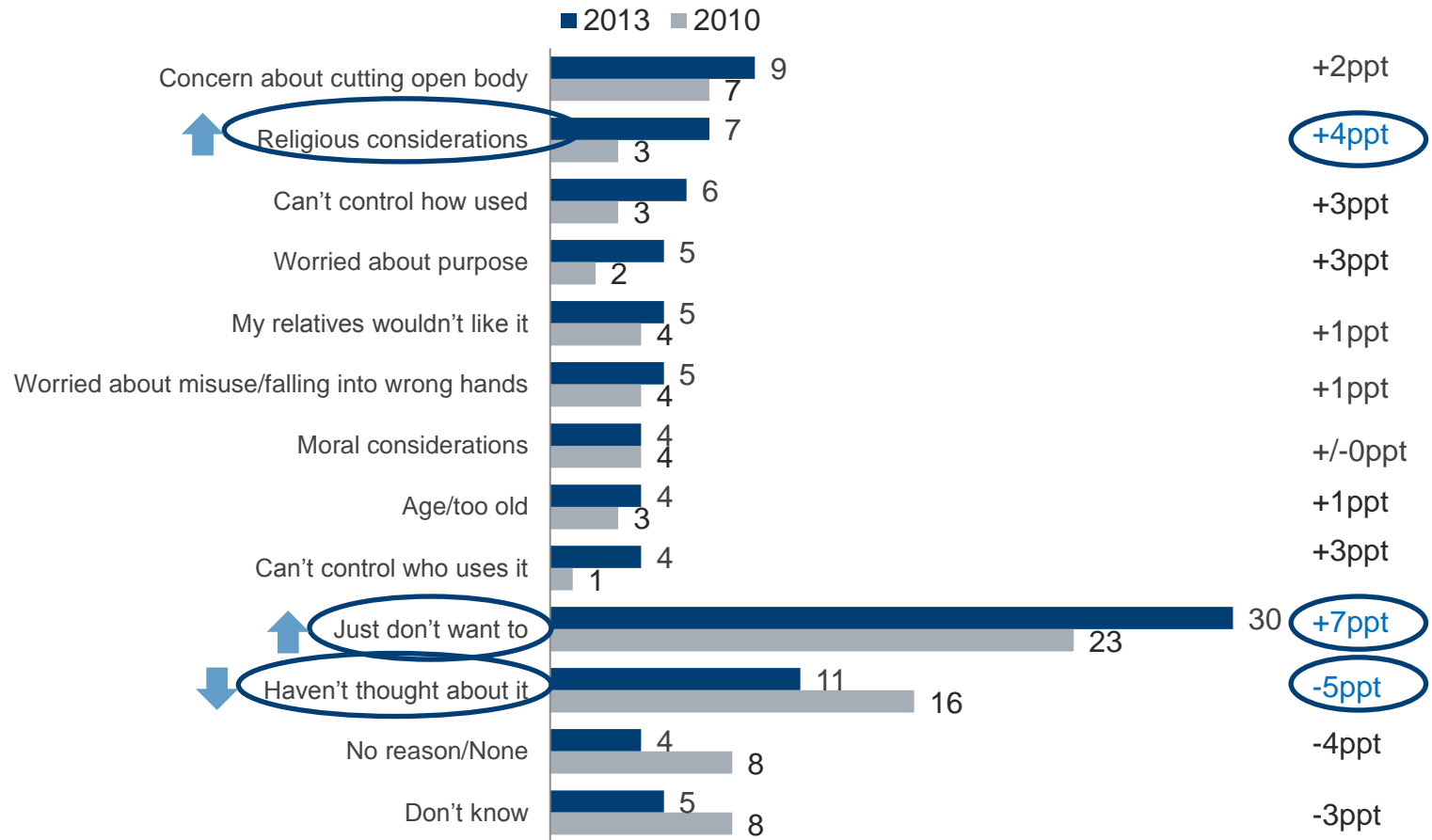
Source: Ipsos MORI

*In 2010, 1% of respondents reported that they 'donate to immediate family only'

With a notable increase, again, in those saying they are unlikely because they just don't want to

Why do you say that you are not likely to donate any of your tissue or organs while you are still alive for use in transplantation? Why else?

% top mentions

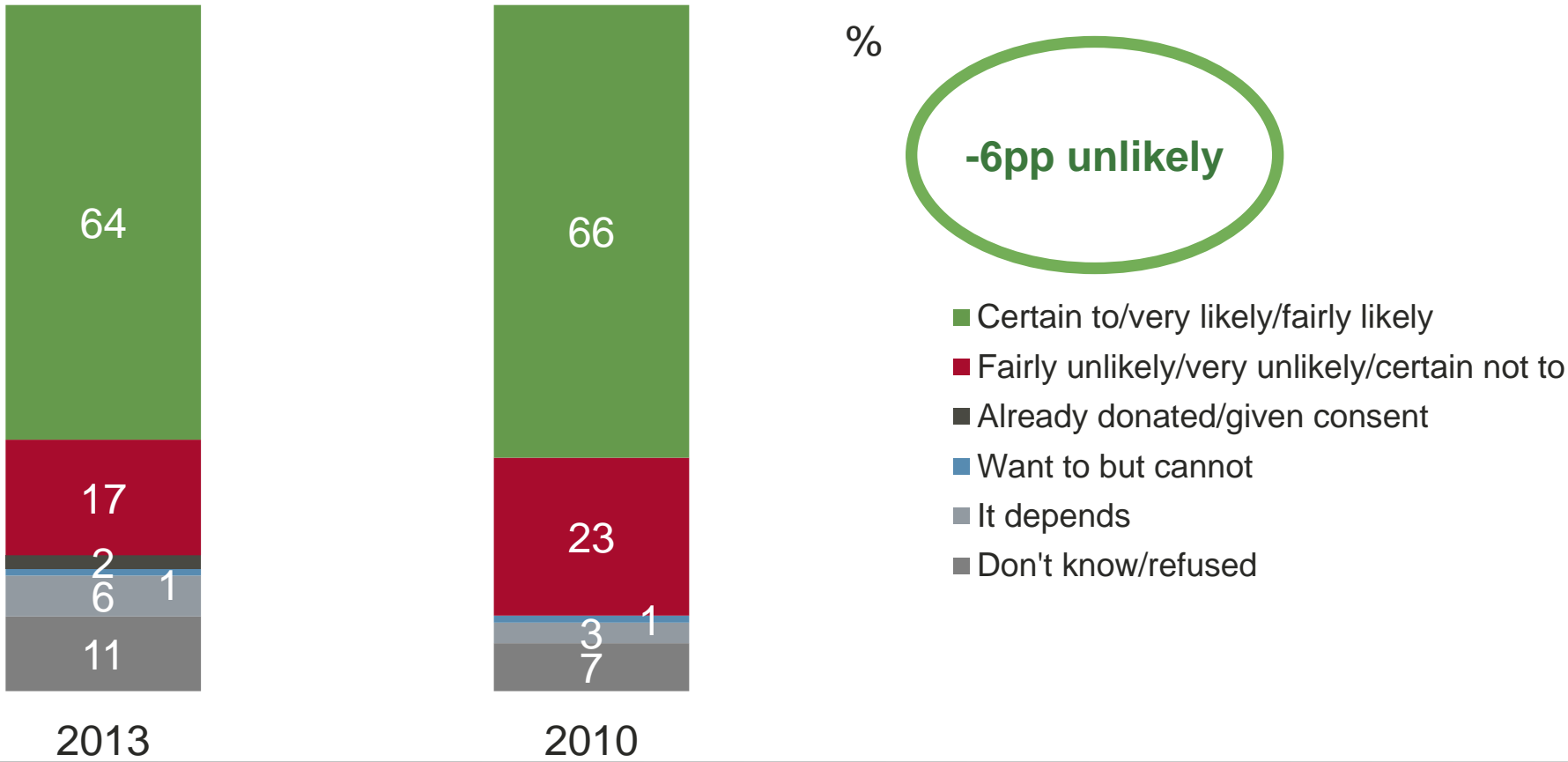


Base: All GB adults 15+ who are unlikely to donate any of their tissue or organs while they are still alive for use in transplantation, 2013: (337); 2nd – 12th August 2013; 2010: (412) 13th - 19th August 2010

Source: Ipsos MORI

As in 2010, around two thirds are likely to donate tissue while alive for medical research

In the event of any of your tissue being removed as part of your diagnosis or treatment while you are still alive, how likely or unlikely would you be to also consent to donate it for use in medical research into health and disease?



Base: All GB adults 15+, 2013: (987); 2nd – 12th August 2013; 2010: (967) 13th - 19th August 2010

Source: Ipsos MORI

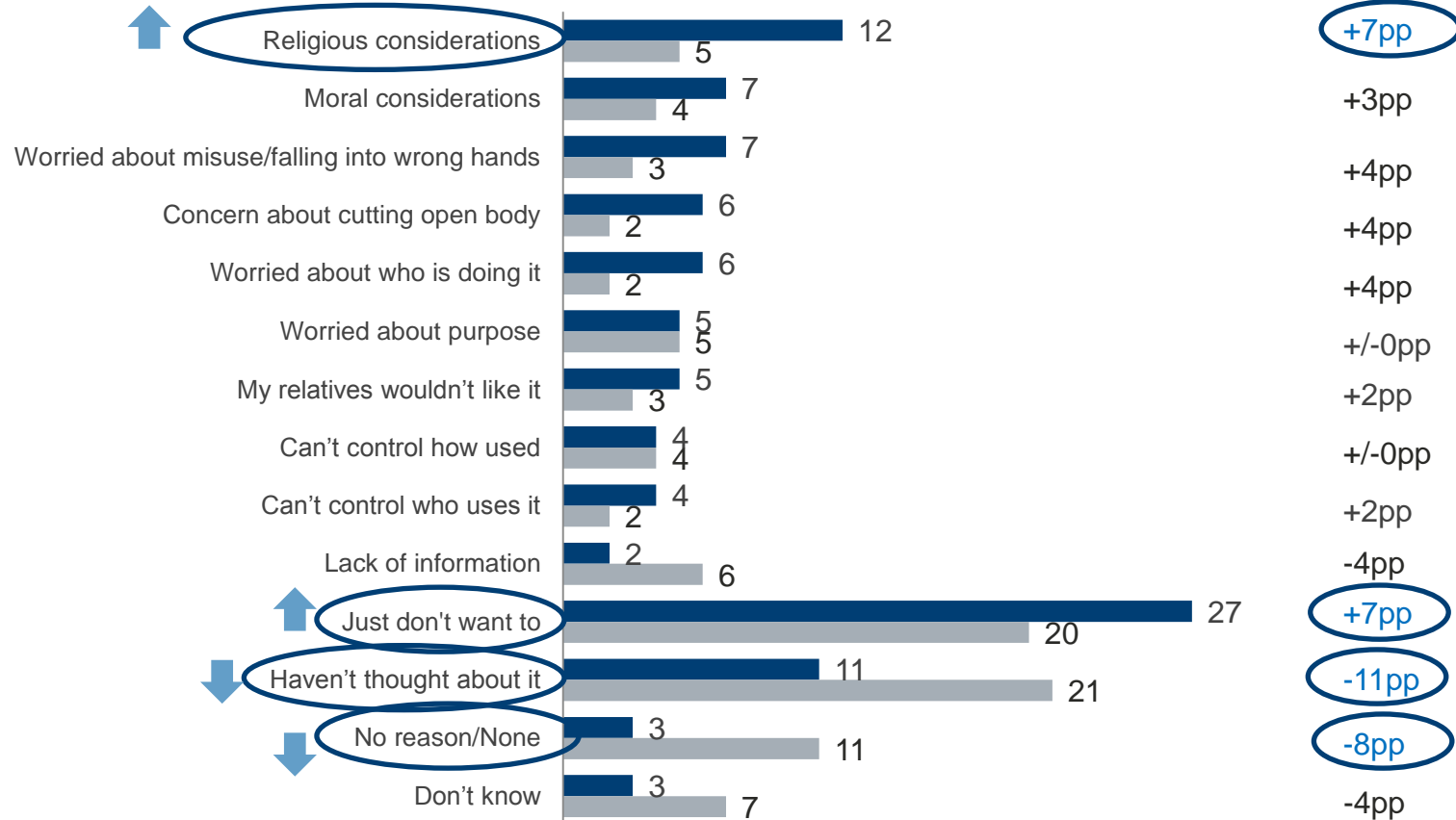


With an increase in religious considerations as a reason for being unlikely to donate for this purpose

In the event of any of your tissue being removed as part of your diagnosis or treatment while you are still alive, why do you say that you are not likely to donate any of your tissue for use in medical research into health and disease? Why else?

% top mentions

■ 2013 ■ 2010



Base: All GB adults 15+ who are unlikely to donate any of their tissue or organs for use in medical research into health and disease in the event of any tissue being removed as part of their diagnosis or treatment while they are still alive, 2013: (175); 2nd – 12th August 2013; 2010: (232) 13th - 19th August 2010

Source: Ipsos MORI

5. Conclusions and recommendations



- The results from the professional stakeholder survey show that ***the HTA is performing very well in many areas***. Favourability towards the HTA, advocacy for the HTA and confidence in the HTA are all high and growing, as is knowledge about what the HTA does.
- ***Successful communication*** appears to be at the heart of this. Professional stakeholders are very positive about their communications with the HTA, generally feel well-informed and have few suggested improvements for this area when asked.
- This may be built on an ***increased use of communication channels which are found useful*** by stakeholders; face-to-face and telephone are among the channels found most useful, and have increased significantly in use since 2010. Continuing this policy and expanding on the use of training, another highly-rated communication channel, may perpetuate this success.
- There is still room for further consideration here, however. ***Many people use the HTA portal, website and e-newsletter but each are comparatively poorly-rated.***
- Areas perceived as important but where stakeholders believe the HTA could improve their performance include ***sharing best practice and improving public and professional confidence***. Continuing to improve communication channels will be key to each of these.

- While the context of perceptions of the wider health sector and health regulators is important, **public confidence** in the regulation of tissue and organ donation **could certainly be improved**, with the public evenly split between those confident and not confident. In every area of donation, an **awareness of a regulator would increase the likelihood of donation** among a large proportion of the general public.
- The greatest perceived benefit of regulation is stopping bad practice, so **greater levels of engagement with the public** demonstrating the HTA's work in this area may be beneficial.
- The greatest perceived drawback of regulation among the public is an increase in red tape, as it was in 2010. The majority of stakeholders in all sectors regard knowing what they need to do in order to comply with HTA standards as easy, so **communicating the HTA's effectiveness** in this regard may again garner further public trust in the regulation of organ donation.
- Stakeholders have mixed feelings regarding the HTA's fees system, with large numbers answering that they 'don't know' or have 'no opinion' about their knowledge of how they're calculated, the fee levels and how often they change. The newly established **Fees and Stakeholder Group** may boost knowledge and engagement among stakeholders in this area.

6. Note on statistical reliability



A1: Statistical reliability of results I

- The respondents who took part in our survey are only a sample of the total "population" (either of the general public or the professional stakeholders) , so we cannot be certain that the figures obtained are exactly those we would have if everybody had responded (the "true" values). We can, however, predict the variation between the sample results and the "true" values from knowledge of the size of the samples on which the results are based and the number of times a particular answer is given. The confidence with which we can make this prediction is usually chosen to be 95% - that is, the chances are 95 in 100 that the "true" value will fall within a specified range. The table below illustrates the predicted ranges for different sample sizes and percentage results at the "95% confidence interval":

Size of sample on which survey result is based	Approximate sampling tolerances applicable to percentages at or near these levels		
	10% or 90%	30% or 70%	50%
	\pm	\pm	\pm
100 responses	6	9	10
200 responses	4	6	7
300 responses	3	5	6
362 responses (professional survey)	3	5	5
500 responses	3	4	4
800 responses	2	3	4
1,000 responses (public survey)	2	3	3
1,500 responses	2	2	3
2,000 responses	1	2	2
2,500 responses	1	2	2

- For example, with a sample size of 1,000 where 30% give a particular answer, the chances are, 19 in 20, the "true" value (which would have been obtained if the whole population had been interviewed) will fall within the range of ± 3 percentage points from the survey result (i.e. between 27% and 33%).

A1: Statistical reliability of results II

- When results are compared between separate groups within a sample, different results may be obtained. The difference may be "real," or it may occur by chance (because not everyone in the population has been surveyed). To test if the difference is a real one - i.e. if it is "statistically significant" - we again have to know the size of the samples, the percentage giving a certain answer and the degree of confidence chosen. If we assume a "95% confidence interval", the differences between the results of two separate groups must be greater than the values given in the table below*:

Differences Required for Significance At or Near These Percentages			
	10% or 90%	30% or 70%	50%
100 and 100	8	13	14
250 and 250	6	9	10
349 (2010 professional survey) and 362 (2010 professional survey)	4	6	7
500 and 500	4	6	6
100 and 1,000	6	9	10
500 and 1,000	3	5	5
967 (2010 public survey) and 987 (2013 public survey)	3	4	4

*N.B. this assumes a random probability survey, and therefore actual confidence intervals may be wider than those detailed above, but this still serves as a good predictor of likely confidence intervals for interpreting results.

Thank you

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