

Ipsos MORI
Social Research Institute



HTA General Public Survey

Report prepared for the Human Tissue
Authority

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Contents

Summary	2
Background and Objectives	5
Background and Objectives	6
Methodology.....	7
Perceptions of the HTA and regulation	12
Perceptions of the HTA and regulation	13
Attitudes towards donating.....	17
Increasing the likelihood of donation	27
Consent	29
The role of the media	31
Use of the internet - media questions.....	38
Appendix 1 - Topline.....	39
Appendix 1 - Topline.....	40
Appendix 2: Internet usage of the sample	65
Appendix 3: Coverage in the media of people choosing, while they are alive, to donate their tissue or organs for transplantation while they are alive	67
Appendix 4: Coverage in the media of people choosing to donate their body (for medical education and training purposes) for use after their death.....	73

Summary

Summary

- Nearly three in five respondents (57%) have confidence in the way the donation, removal, storage and use of human tissue is regulated. This demonstrates a significant, rise in confidence levels since the 2007 general public survey (52%).
- Awareness of the Human Tissue Authority (HTA) itself is very low. About half of the general public (51%) do not know who regulates the donation, removal, storage and use of human tissue or organs in the UK. Only two per cent cite the HTA, which is typical for awareness of arms-length health bodies. Other suggestions include the NHS (21%), the Government (6%), the Department of Health (6%), British Medical Association (4%) and NHS Blood and Transplant (3%).
- The most widely perceived benefit of regulation (suggested spontaneously) is in preventing bad practice (32%) - and 10% specifically mention that *human tissue* is consequently not used at will or abused. However, over a quarter (28%) cannot think of any benefits, and 6% expressly say there are none.
- The perceived drawbacks of human tissue regulation are mainly restricted to 'too much red tape' (13%) and the potential restrictions placed on scientists - either in sourcing samples / bodies (8%) or more generally in losing ground to other countries' research (7%).
- Most individuals do not know of any (40%) or think there are no drawbacks to regulation (23%).
- Claimed donation levels (of material after death) are very high - although responses to all these questions are based on broad sentiment, and will not necessarily translate into actual donations. Two in five say they are certain (18%) or very likely (22%) to donate their tissue or organs after death for use in medical research - and a similar proportion say they are certain or very likely to donate after death for use in transplantation (21% and 22%, respectively).
- There is no predominant specific barrier to donation (other than 'I just don't want to' at 24% for a reason for not donating for medical research or 'I haven't thought about it' at 15%). Moral considerations and lack of information - each at 6% - are the top reasons specified for not donating for this purpose. Only one per cent mention 'lack of

regulation' as a reason - only two per cent mention this as reason for not donating for use in transplantation as well.

- 23% in total claim to be likely to donate their body for use in education or training of doctors - fewer than those likely to donate tissue or organs after death for medical research. The most common reason for not doing this is expected objections from relatives.
- Two in five respondents say they are likely to donate any of their tissue or organs while they are still alive for use in transplantation. Again, no one objection predominates - but concern about cutting open the body (7%) and lack of information (5%) are relatively common.
- However, half (49%) say that they are certain or very likely to consent to donate their tissue for use in medical research in the event that it is removed as part of their diagnosis or treatment. Lack of information is the top specific reason for not doing this (6%) - but again most often it is a case of people not having considered it (21%) or just not wanting to (20%).
- The groups with more confidence in the regulation of human tissue - and those generally more likely to donate in the various circumstances given - are those in full-time education (as opposed to those who do not work), those who have higher educational qualifications - such as a degree or A-levels - those of white ethnic origin, and often the more affluent AB and C1 social grades (rather than C2 and DE).
- Respondents who were not certain to donate claim to be more likely to if the donation helped a family member. Another common incentive was greater information: knowing the *specific use* of the donated material, and generally knowing more about the process.
- Regulation is also a factor in individuals' donating behaviour - about half of respondents agree they would be more confident to donate their tissue (49%), organs (52%) or body (43%) for transplants or medical research knowing that there is a regulator in place. 23% say that regulation would not make them more confident in doing so - against typically around one in six (16% or 17%) for tissue or organ donations.
- In common with the 2007 survey, consent is clearly an important concept to the general public. Nearly two thirds (64%) say it is *never* acceptable to use a person's tissue or organs for any purpose after their death unless that person or their family

has given prior consent. Only around 13% expressly disagree. In regard to family involvement, 56% think it is never acceptable for the family to override the donor's stated wishes after their death. 16% expressly disagree. However, half (50%) believe it *would* be acceptable for their family to give consent on their behalf.

- Similarly, half (50%) would be happy to give prior consent for their tissue or organs to be used for any purpose after their death. This figure is higher among those in full-time employment (55%), with A Levels / Degree (57%), of white ethnic origin (52% against 27% among non-whites), and aged between 35 and 54 (57%).
- Nearly half (46%) say they have seen or heard something in the media about people choosing while they are alive to donate their tissue or organs for transplantation while they are alive. The most common source - as usually cited for such questions - television (30%), particularly the news. This is followed by newspapers (19%) and radio (10%).
- Two in five (40%) have seen or heard something in the media about people choosing to donate their body for medical education and training purposes for use after their death. Again the most common means is through television (25%), then in newspapers (16%), whilst 7% have seen or heard something on the radio.
- Seeing something in the media about these issues does appear to influence individuals' claimed donation behaviour. About a quarter report being more likely to consider that form of donation (26% organ donation whilst alive; 24% body donation after their death). Many also say it made them more likely to want to find out more about donation (18% and 20%, respectively), discuss it with their family (21% and 18%) - and that it gave them more confidence that the correct regulatory processes are in place (19% and 24%, respectively). In both cases, only 16% say *none* of the above statements applied.

Introduction

Background and Objectives

Overview

The Human Tissue Authority (HTA) was established under the Human Tissue Act 2004 (HT Act) to regulate activities concerning the removal, storage, use and disposal of human tissue. Its role is to support public confidence by ensuring that the public's wishes are respected and that human bodies and tissue are treated ethically and safely. The HTA is an Executive Non-Departmental Public Body (ENDPB) sponsored by the Department of Health.

The HTA has several statutory functions:

- to inform the public, professionals and the Secretary of State for Health about issues within its remit. This is done (for professionals) by providing guidance - including codes of practice - to support good practice; and (for the public) by providing information to help people make informed decisions
- to regulate, through licensing organisations that store and use tissue for purposes such as research, patient treatment, post-mortem examination, teaching, and public exhibitions. (There are currently more than 850 licensed organisations)
- publish standards that licensed establishments must meet: on consent; governance and quality systems; premises; facilities and equipment; and disposal
- inspect organisations to check that they maintain good standards and follow appropriate procedures. Organisations considered to be highest risk are among the first to be inspected
- the regulation, through an independent assessment process, of the donation from living people of solid organs, bone marrow and peripheral blood stem cells for transplantation into others. The HTA also regulates living donation, in compliance with Scottish legislation, on behalf of the Scottish Government

As well as licensing under the HTAct, which covers England, Wales and Northern Ireland, the HTA is the Competent Authority in the UK responsible for ensuring the

safety of human tissue and cells used for patient treatment, in compliance with the European Union Tissue and Cells Directive (EUTCD).

The HTA also oversees the consent requirements of the HT Act for deceased organ donation.

HTA's overall goal is to create a regulatory system for the removal, storage, use and disposal of human tissue and organs that is clear, consistent and proportionate - and in which professionals, patients, families and members of the public have confidence.

Opinion Research

This report represents the findings of a survey conducted by Ipsos MORI on behalf of the HTA. The project builds on the HTA's public and professional evaluation work with Ipsos MORI in 2007, and evaluation of the research community with Opinion Leader in 2009.

The work is also related to the action in the Hampton Implementation Review of the HTA (July 2009) which states: "The HTA should monitor the effectiveness of its regulatory activity by commissioning surveys of public perception around handling of human tissue at regular intervals".

Throughout the report references are also made to the online component of this research - conducted in June 2010 - on professional stakeholders. This component on perceptions of the HTA and its regulation involved sending an online survey to all professional stakeholders listed on the HTA's database (to which 349 responded).

Methodology

General public evaluation

In order to track public perceptions of the HTA, a large-scale quantitative survey of adults aged 15+ across Great Britain was conducted using our **Omnibus Survey ('Capibus')**. This is a face-to-face survey conducted within people's homes using Computer Assisted Personal Interviewing (CAPI - laptops), on a sample of around 1,000 adults.

Two sets of questions were conducted: The first (Part 1) examined general attitudes to human material / organ donation and regulation, and were run on the Capibus between 13 and 19 August 2010. In total, 967 members of the general public aged 15+ participated. A second set of questions (Part 2) looking at information sources / the media in relation to human material / organ donation were put on the Capibus of 20-26 August 2010. In this case 1,019 people took part (an entirely different group to those answering the first set of questions - but with a matching [nationally representative] demographic and regional profile).

The second set of questions tested awareness of media coverage regarding people choosing to donate their tissue or organs for transplantation or their body for medical education or training purposes, thus these were separated from Part 1 so that the issues were not necessarily top of mind and awareness was more 'spontaneous'.

Questionnaire design

Both questionnaires were designed in close collaboration with the HTA. The key broad areas that the HTA originally identified for the questionnaire were:

- public confidence in regulation of human tissue
- public perceptions about what the HTA does
- whether the public has heard of the HTA plus a comparison question for awareness of other regulators
- hypothetical scenarios around willingness to donate
- awareness of relevant media coverage [and information sources]

In consultation with Ipsos MORI, a list of questions was then drawn up. In developing the questionnaire, the HTA and Ipsos MORI also used the 2007 survey for the HTA as a starting point, retaining some questions and replacing others with topic areas the HTA wanted to look into in greater depth. It is worth noting that although some similar questions were asked qualitatively in 2007 through focus groups, there was only one question that was asked in the quantitative survey in 2007 that is exactly the same in 2010. Therefore this question, of key interest to the HTA, on confidence in regulation, is the one we are able to formally trend.

Statistical Reliability

The samples provide robust overall findings and allow survey results from key social and demographic sub-groups to be considered in isolation (provided we have a minimum 'unweighted' sub-group size of 100). The sample tolerances for overall results and for a comparison of sub-groups are shown below.

Table 1 shows the possible variation that might be anticipated because a sample, rather than the entire population, is interviewed. As indicated, sampling tolerances vary with the size of the sample and the size of the percentage results. Those shown are based on the usual '95% confidence level'.

For example, on a question where 50% of the people in a sample of 1,000 respond with a particular answer, the chances are (95 times in 100) that this result would not vary by more than 3 percentage points, plus or minus, from a complete coverage of the entire population using the same procedures.

Table 1			
Approximate sampling tolerances applicable to percentages at or near these levels (95% confidence level)			
	10% or 90%	30% or 70%	50 %
<i>Base:</i>			
2,000	<u>+1</u>	<u>+2</u>	<u>+2</u>
1,000	+2	+3	+3
500	+3	+4	+4
300	<u>+3</u>	<u>+5</u>	<u>+6</u>
100	<u>+6</u>	<u>+9</u>	<u>+1</u> 0

Tolerances are also involved in the comparison of results from different surveys and sub-groups from the same survey. A difference, in other words, must be of at least a certain size to be considered statistically significant. Table 2 below gives a guide to the sampling tolerances applicable to various comparisons. So, where the 967 respondents in 2010 gave a result of 14%, the equivalent figure from the 2,058 respondents in 2007 must be at least +2 percentage points different from that (ie 12% or below, or 16% or above) to be statistically different and so indicate *genuine* change.

Table 2

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
500 and 500	4	6	6
100 and 1,000	6	9	10
500 and 1,000	3	5	5
967 (2010 sample) and 2,058 (2007 sample)	2	4	4

Weighting

This is the process whereby the statistical influence or 'weight' of each individual response is if necessary altered, to correct for any slight discrepancy between the survey sample profile and that of the 'universe'. (For example, general public survey samples comprising 50% men and 50% women are usually weighted to reflect that the *actual* proportions within the full GB population are closer to 49% men and 51% women. This then allows the survey to be considered precisely representative of the population as a whole).

The results from this survey were weighted using the Zelin and Capibus weighting scheme.

Deliverables

The following deliverables were provided to the HTA from the results of the General Public survey:

- A marked up 'topline' questionnaire showing the overall results and, where possible, making comparisons to the 2007 survey. (This is appended to this report)
-
- Data tables, including the aggregated data and any relevant sub-groups. These included significance testing at the 95% confidence level. (These are shown in a separate volume)

A review of the results in the form of a report - this document - and a combined summary, with the results of the quantitative online report of professional stakeholders and qualitative KOL stakeholder report.

Acknowledgements

We would like to thank Dr Shaun Griffin and Dr Laura Nelson at the HTA for their help with this project - and of course also the 1,986 members of the general public who took part.

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Main Findings

Perceptions of the HTA and regulation

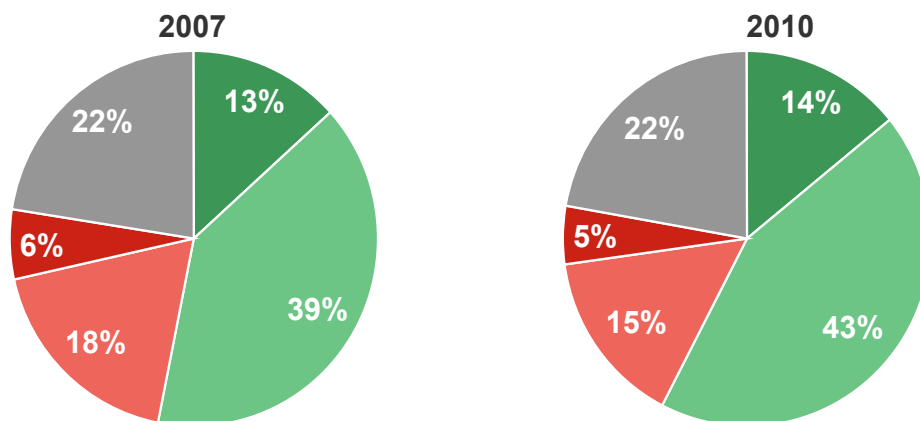
Confidence in regulation

Nearly three in five respondents (57%) now report having confidence in the way the donation, removal, storage and use of human tissue or organs is regulated - including 14% with 'a great deal' of confidence. Overall, this represents a statistically significant increase in confidence levels since 2007, when 52% of respondents had confidence.¹

Confidence in regulation

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

- A great deal
- A fair amount
- Don't know
- Not very much
- Not at all



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI
Ipsos

Groups more likely to voice confidence are those that work full time (63%, compared to 52% of those who are not working), and those of degree level or with A-levels (65% and 71%, compared to 52% of GCSE level respondents and 43% with no formal qualifications). White respondents are also more likely than non-white individuals to have confidence (58%, compared to 47% respectively).

¹ In 2007 this question was preceded by two questions (*What comes to mind, if anything, when I say 'human tissue'?* (unprompted) and *What do you think human tissue is used for?* (unprompted)), and therefore a comparison with 2010 should be treated with a little caution.

In terms of newspaper readership, it is broadsheet readers who have the most confidence (76%), as opposed to 54% of mid-market and 50% of tabloid readers.

However, express *lack* of confidence accounts for 20% overall - with another 22% saying they 'do not know'. This split is broadly reflected in most sub-groups, but with non-whites voicing *least* confidence (30% have 'not very much' or 'no' such confidence).

Members of the general public have less confidence in the regulation of human tissue and organs than do professional stakeholders. In the online survey conducted for the HTA by Ipsos MORI in August of this year, it was found that 86% of the professional stakeholders surveyed had a great deal or a fair amount of confidence in the HTA as a regulator.

Awareness of the HTA

Awareness of the HTA among the general public is very low. About half **do not know** who regulates the donation, removal, storage and/or use of human tissue or organs in the UK. Of those who were able to give an answer, one in five (21%) thinks the NHS who is responsible for such regulation - while only two per cent cite the HTA. (This question was unprompted - and so measures the *prominence* of organisations in people's minds as much as their basic awareness).

This is generally in line with the qualitative survey conducted among members of the public in 2007, where none of the in-depth interview participants had heard of the HTA.

In the 2010 statistical study, those aged between 55 and 64 are slightly more likely than younger respondents to name the HTA (7%, compared to 2% of those aged 25-54). Only 1% of those aged 65+ name it.

The Human Fertilisation and embryology Authority is named by 1% overall and the Medicines and Healthcare products Regulatory Agency by less than 1%.

Awareness of the HTA as a regulator

Q Who, or which organisation/s, if any, do you think regulates the donation, removal, storage and/or use of human tissue or organs in the UK? Who else?



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI

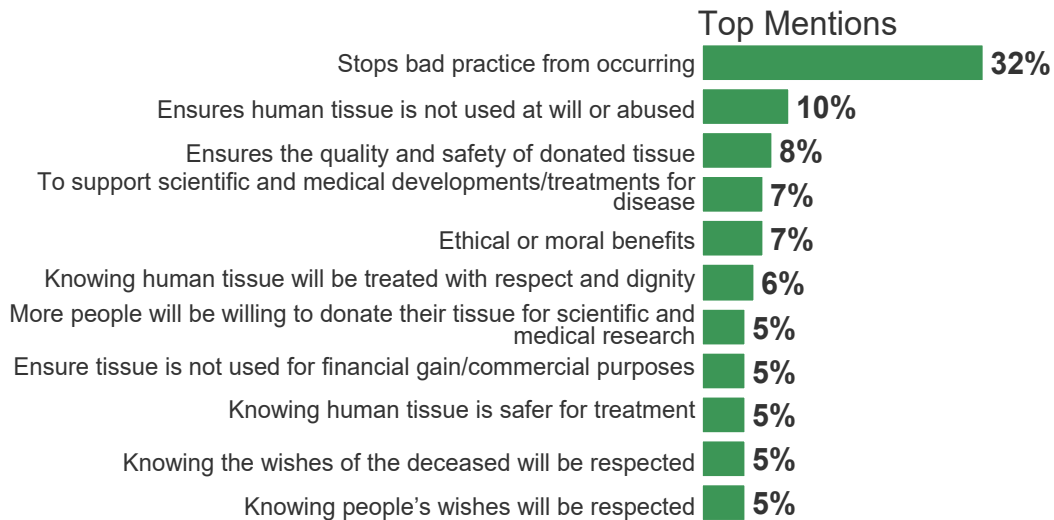


The perceived benefits and drawbacks to regulation


The most common perceived benefit of regulation is the prevention of bad practice: a third (32%) cite this, unprompted. Others say that regulation guards against human tissue being used at will or abused (10%) and that it ensures the quality and safety of human tissue (8%).

Perceived benefits of regulation

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



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

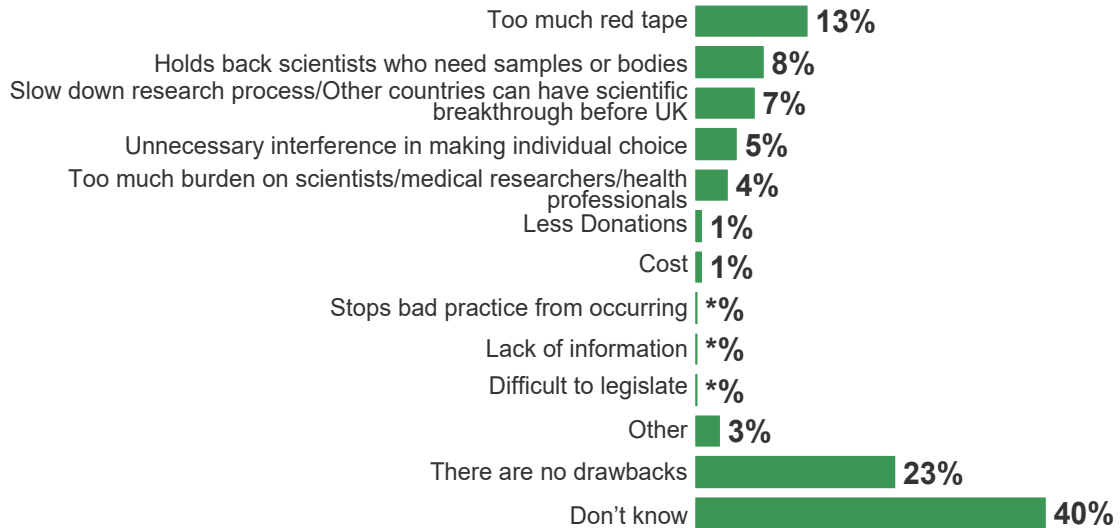
Source: Ipsos MORI


Positively, the majority of respondents cannot (unprompted) think of drawbacks to regulating human tissue. Two in five (40%) 'don't know' and nearly one in four (23%) expressly say that there are no drawbacks.


Too much 'red tape' is the most common answer (13%). Other concerns are that regulation holds back scientists who need samples or bodies (8%) and that it generally can slow down the research process, allowing other countries to move ahead (7%).

Perceived drawbacks of regulation

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



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI


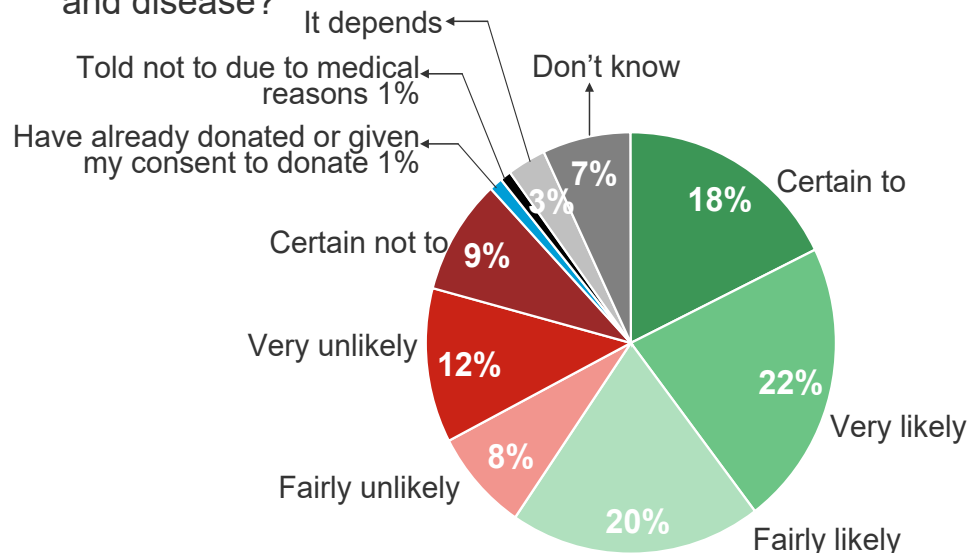
Attitudes towards donating

Donation of tissue or organs after death (for use in medical research into health and disease)

Three in five respondents (60%) say they are certain or likely to donate their tissue or organs after death for use in medical research into health and disease. Nearly one in five respondents (18%) say that they are 'certain to'. In contrast, about three in ten (29%) are certain not to or unlikely to (9% are 'certain not to' donate). However, it is worth noting that the questions reported on in this section record *what people say they do*, rather than their actual behaviour in reality.

Donation of tissue or organs after death for use in medical research into health and disease

Q 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: All on Version 2A adults aged 15+ (522), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI
Ipsos

Those in social grades AB and C1 are more likely than C2 and DE to be certain or likely to donate (63% and 74%, against 56% and 43% respectively), as are those that are in full-time employment (65%), compared to their non-working counterparts (52%). Likewise it seems that more educated respondents are more likely to donate for this reason (72% of degree level graduates and above and 69% of those with A-levels, compared to 56% of GCSE level students and 43% of those with no formal qualifications).

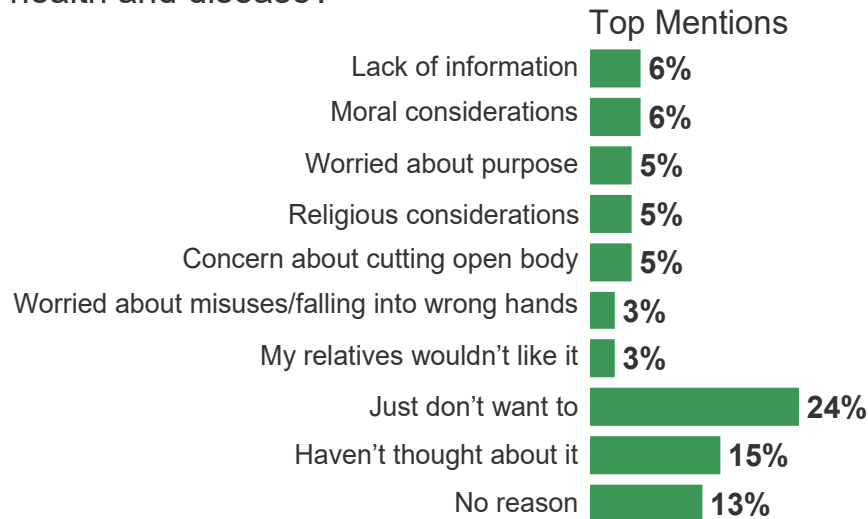
In terms of ethnic origin, whites appear more likely to donate on this basis (61%, against 47% of those from black and minority ethnic (BME) groups - though the latter is based on a small number answering).

The chart below shows the reasons given for not wanting to donate for medical research purposes after their death. The largest groups report that they 'just don't want to' (24%), that they 'haven't thought about it' (15%) or give no reason at all (13%). However, of those that do state a reason, the most common deterrents are 'lack of information' (6%) and moral considerations (6%). Only one per cent cite 'lack of regulation' as a reason.

For the fuller listing, please see the topline questionnaire appended.

Donation of tissue or organs after death for use in medical research into health and disease

Q 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?



Base: All 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 (155), fieldwork dates: 13th - 19th August 2010

Ipsos MORI

Source: Ipsos MORI



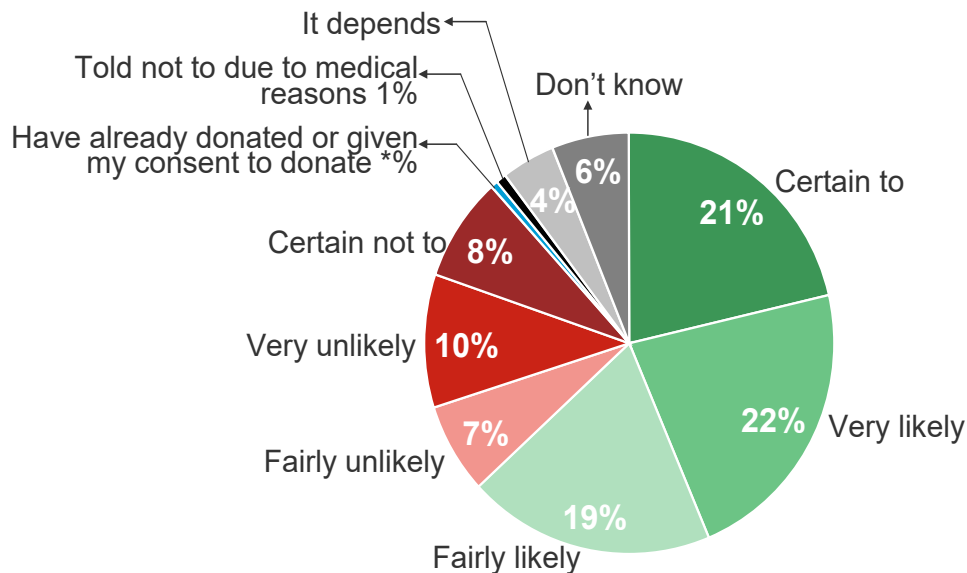
Donation of tissue or organs after death (for use in transplantation)

A similar proportion of respondents say they are likely or certain to donate their tissue or organs after death for use in transplantation (63%) as they are for use in medical research into health and disease. Again it is those working full-time and with higher qualifications who are more likely to - and BME groups (albeit small in number) again appearing least willing to, at 32%.

Those voicing confidence in the regulation of human tissue or organs are evidently far more likely to donate after death for both medical research and transplantation (74% and 78%, respectively, are likely or certain to).

Donation of tissue or organs after death for use in transplantation

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



Base: All on Version 2B adults aged 15+ (445), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI
Ipsos

Again nearly half of respondents either 'just don't want to' (26%), 'haven't thought about it' (15%) or give no reason (7%) for not donating. In a similar way to donating for medical research, 'moral considerations' and 'lack of information' are relatively the most common barriers (both 6%). Only two per cent believe that it is 'lack of regulation' that stops them from donating.

Reasons for not donating tissue or organs after death for use in transplantation

Q 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?



Base: All adults 15+ who are unlikely to donate any of their tissue or organs after they have died for use in transplantation (117), fieldwork dates: 13th - 19th August 2010

Ipsos MORI

Source: Ipsos MORI

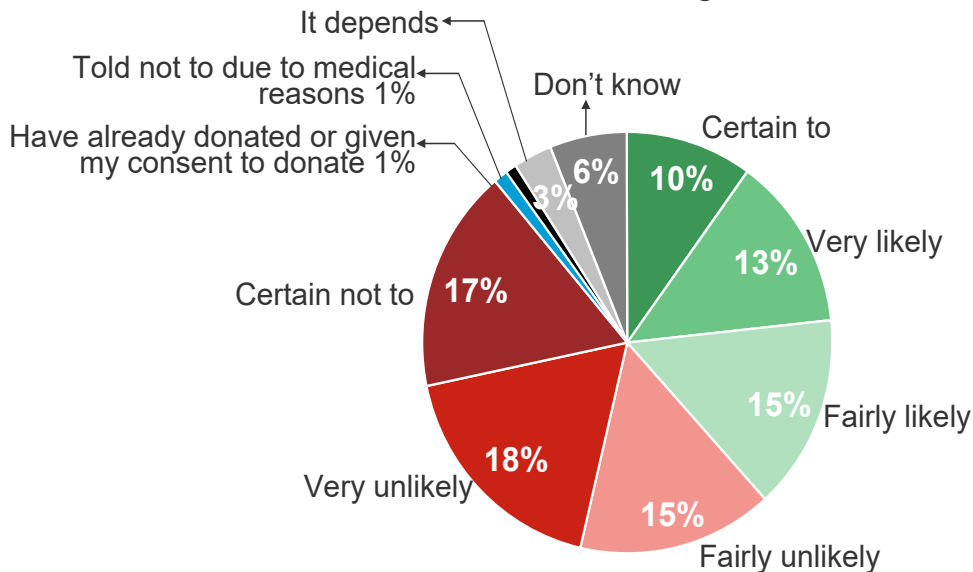


Donation of body after death (for use in education or training of doctors)

Fewer respondents say they would be likely to donate their body after death for education / training than for medical research or transplantation. Two in five would potentially donate for this reason (38%) - but only one in ten are 'certain to' donate, against 17% 'certain not to'. Those who have a great deal or a fair amount of confidence in the way human tissue or organs are regulated are more likely to be certain or likely to donate for this purpose (47%, compared to 21% who have not very much or no confidence at all).

Donation of body after death for use in education or training of doctors

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



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

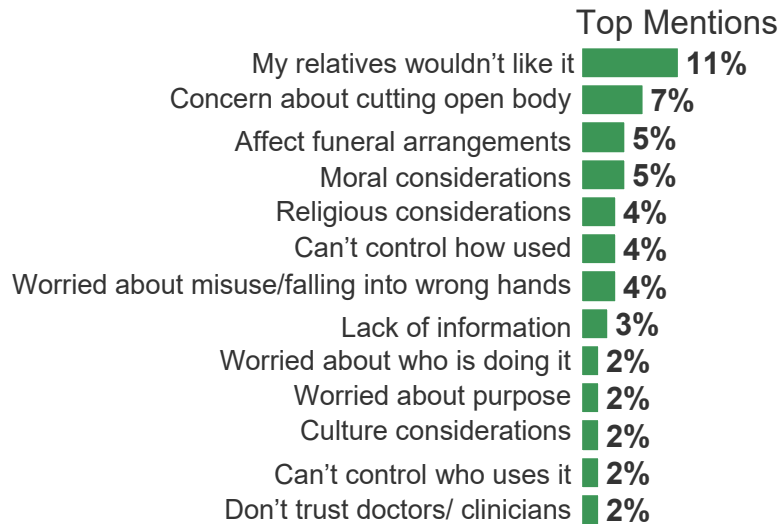
Source: Ipsos MORI
Ipsos

Once again, better educated (and so likely better informed) respondents voice greater willingness to donate: 44% of those with A-level qualifications, 43% with a degree - but 31% with no formal qualifications. Ethnicity is again an apparent factor: 39% of whites say they are likely to donate, against 25% of BME groups.

The concerns surrounding donation for training purposes are slightly different from those intended for transplant / research. With regard to training, people would most often not donate for fear of their relatives' views (11%), and 7% have concerns about cutting open the body. Moral considerations are slightly less prominent here (5% - on a par with fears around disrupted funeral arrangements). Again only one per cent state 'lack of regulation' as a reason.

Reasons for not donating body after death for use in education or training of doctors

Q 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?



Base: All adults 15+ who are unlikely to donate body after they have died for use in education or training of doctors (487), fieldwork dates: 13th - 19th August 2010

Ipsos MORI

Source: Ipsos MORI



Donation of tissue or organs while still alive (for use in transplantation)

Just over two in five respondents (42%) claim they are likely to donate their tissue or organs while they are still alive for use in transplantation.

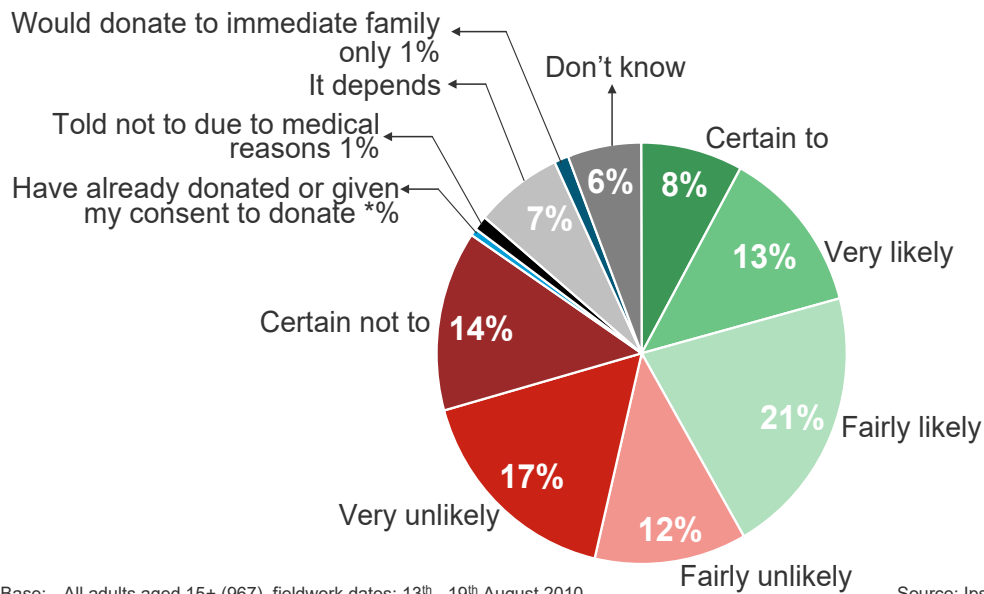
Eight per cent say they are certain to. This can be compared to 63% who are likely to donate their tissue or organs after they have died for use in transplantation (21% are certain to).

It is the older generation which is less likely to donate for this reason. While 10% of 15-24 year olds are certain *not* to, this rises to 22% of those aged 65+. Correspondingly, those with children in their household are *more* likely to donate (48%, compared to 39% of those without children in their household).

As has been the case with all types of donation, those in full-time employment and those with higher levels of education are more likely to donate.

Donation of tissue or organs while still alive for use in transplantation

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



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI

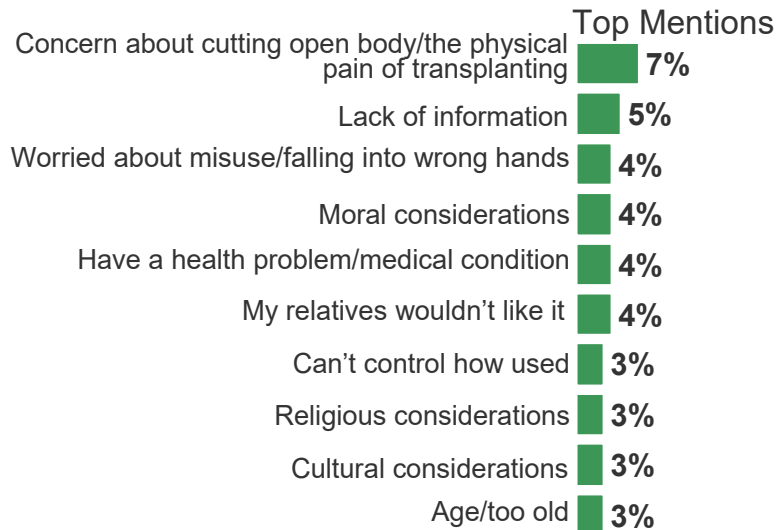


Nearly a quarter of respondents (23%) 'just don't want to' donate their tissue or organs while still alive and 16% 'haven't thought about it'. Further to this, as can be seen from the following chart, seven per cent have concerns about cutting open the body or the physical pain of transplanting - and five per cent feel they lack information. Only one per cent think that 'lack of regulation' is the reason for them not donating for this purpose.

Two per cent add the caveat that they would only consider donating to a family member. (Again, the question was unprompted.)

Reasons for not donating tissue or organs while still alive for use in transplantation

Q 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?



Base: All adults 15+ who are unlikely to personally donate any of their tissue or organs while they are still alive for use in transplantation (412), fieldwork dates: 13th - 19th August 2010

Ipsos MORI

Source: Ipsos MORI

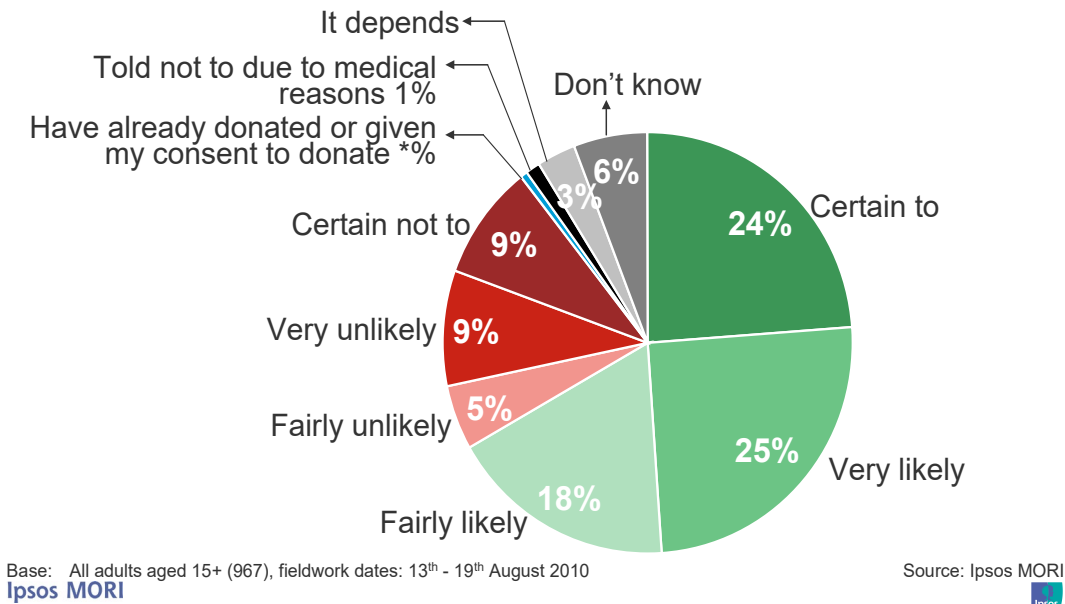


Consent to donating tissue while still alive (for use in medical research into health and disease - in the event of tissue being removed as part of diagnosis or treatment)

In this scenario, willingness to donate tissue for medical research into health and disease in the event of tissue being removed for diagnosis or treatment is relatively high. Two thirds (66%) say they would be certain (24%) or likely (42%) to do so.

Consent to donating tissue for use in medical research into health and disease in the event of tissue being removed as part of diagnosis or treatment while still alive

Q 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?



ABs are more likely to donate than are C2s and DEs (77%, compared to 66% and 55%). Those working full time and with higher qualifications are also more likely to donate.

There is a particularly marked ethnic divide here: among whites 69% voice willingness, as against 21% who reject the idea. Among the BME groups, the figures are 39% and 41% respectively.

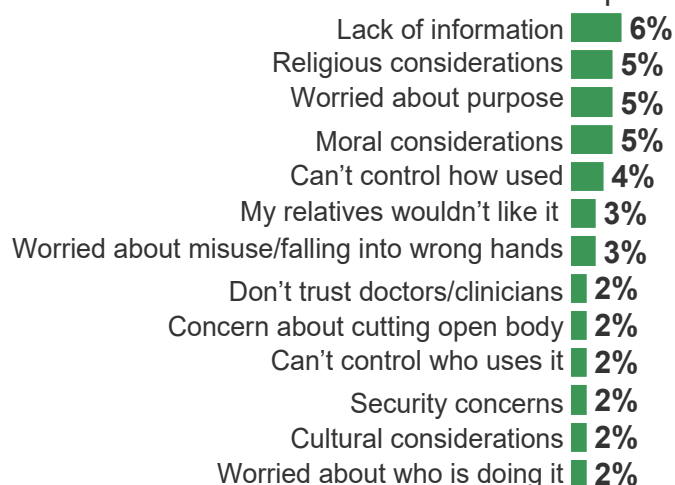
Overall, 20% 'just don't want to' donate in these circumstances, and a similar number 'haven't thought about it'. Lack of information is the most common specific barrier (6%), along with religious / moral considerations or concern about the purpose (5% each). Once again, only one per cent put 'lack of regulation' as a reason.

Numbers are too small to robustly identify any differences by ethnic group - though BME respondents do *appear* to be more concerned about religious factors.

Reasons for not donating tissue for use in medical research into health and disease in the event of tissue being removed as part of diagnosis or treatment while still alive

Q In the event 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?

Top Mentions



Base: All adults 15+ who are unlikely to also consent to donate any of their tissue for use in medical research into health and disease in the event of any of their tissue being removed as part of their diagnosis or treatment while they are still alive (232), fieldwork dates: 13th - 19th August 2010

Ipsos MORI

Source: Ipsos MORI



Increasing the likelihood of donation

Increasing the likelihood to donate body and organs or any tissue from the body for the purposes of medical research, education or transplants

Almost all the respondents (96%) voiced some degree of reservation about donating in one or more of the scenarios tested.

These people were asked what in general might make them *more* likely to donate their body / organs / tissue for medical research, education or transplant.

Most often, people would be spurred to act if a donation helped a family member (27%), while 17% said knowing the *purpose* of a procedure would help - and 16% if generally they *knew more* about the process.

Four per cent (spontaneously) say the presence of a regulator / watchdog might be an incentive. Although a small percentage figure, this does potentially extrapolate to significant numbers of people. The impact is explored in more detail below.

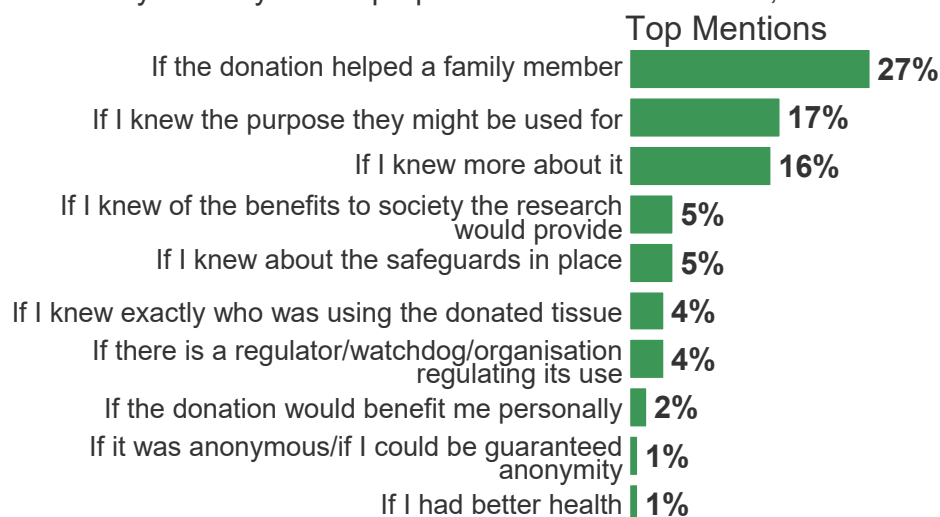
Among sub-groups, ABC1s are more likely to want more information on the process than are C2DEs (despite probably already having a better insight), while the 25-34 year

olds are particularly focussed on the potential to help a family member: this perhaps being an age group that could potentially be donating to benefit either a child or a parent. (In isolation, those with children are no more likely to cite this reason than are other groups).

Ethnically, the relative incentives are very similar between whites and BME groups - with the one exception that BME groups place far *less* emphasis on knowing the purpose of the donation.

Increasing the likelihood to donate body and organs or any tissue from the body for the purposes of medical research, education or transplants

Q You mentioned earlier that you would not be certain to donate your tissue, organ or body for one or more of the purposes we discussed. What, if anything might make you more inclined to donate your body, and organs or any tissue from your body for the purposes of medical research, education or transplants?



Base: All adults aged 15+ who are not certain to donate any of their tissue or organs/body for all the reasons mentioned (924), fieldwork dates: 13th - 19th August 2010

Ipsos MORI

Source: Ipsos MORI



When *prompted* on the potential impact of a regulator, people are generally positive.

By knowing there was a regulator for the donation, storage, use and disposal of human tissue:

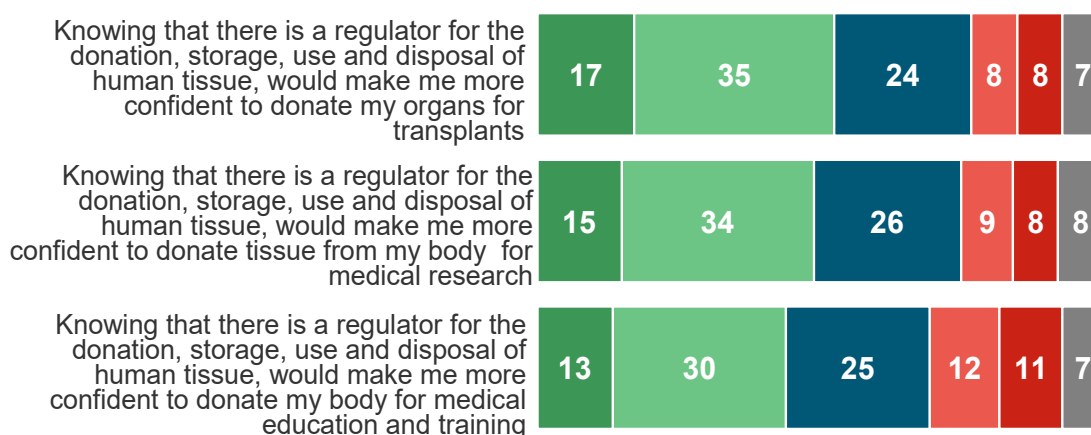
- 49% would be more confident to donate tissue from their body for medical research
- 52% would be more confident to donate their organ/s for transplant
- 43% would be more confident to donate their body for medical education / training

Having a regulator in place is generally more important to full time workers rather than those who are not working, those of white ethnic origin, and those with higher educational qualifications. These groups were more likely to agree with each of the three statements.

The effect of having a regulator on the propensity to donate

Q 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 / nor
■ % Tend to disagree ■ % Strongly disagree ■ % Don't know



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI
Ipsos

Consent

Consent is clearly an important concept to the general public; nearly two thirds (64%) believe it is *never* acceptable to use a person's tissue or organs for any purpose after their death unless that person or their family has given prior consent. This also emerged in the focus groups in the 2007 project.

This advocacy of consent is most important to married individuals (68% of those that are married agree - compared to 57% of people who are single or widowed / separated) and to those with children (70% of people with children in the household, compared to 61% of those without). In line with this, those aged between 35 and 44 - who are perhaps most likely to be married and have children - also place the most importance on consent (74%, compared to 55% of 15-24 year olds and 60% of those aged 65 and over).

White respondents also place more importance on consent (66%, compared to just 42% of non-white respondents). The latter is the lowest such sub-group figure recorded, along with the 44% in Britain's most ethnically diverse area: London).

Half (50%) of all respondents say that they would be happy to give prior consent for their tissue or organs to be used for any purpose after their death. As has generally been the case, these individuals are more likely to be in full-time employment (55%, compared to 44% who are not working), have educational qualifications (54%, compared to 34% with no formal qualifications) and be of white ethnic origin (52%, compared to 27% of BMEs). Those aged 35-54 are also the most likely to give this consent to donate (57%, compared to only 39% of those aged 65+).

There are slightly more mixed views on *family involvement* in consent. Fifty five per cent say it is never acceptable for their family to override their wishes after they have given consent for their tissue or organs to be used for any purpose after death. However, only 30% *strongly* hold this view - against the 40% who strongly believe that donation without prior consent is unacceptable.

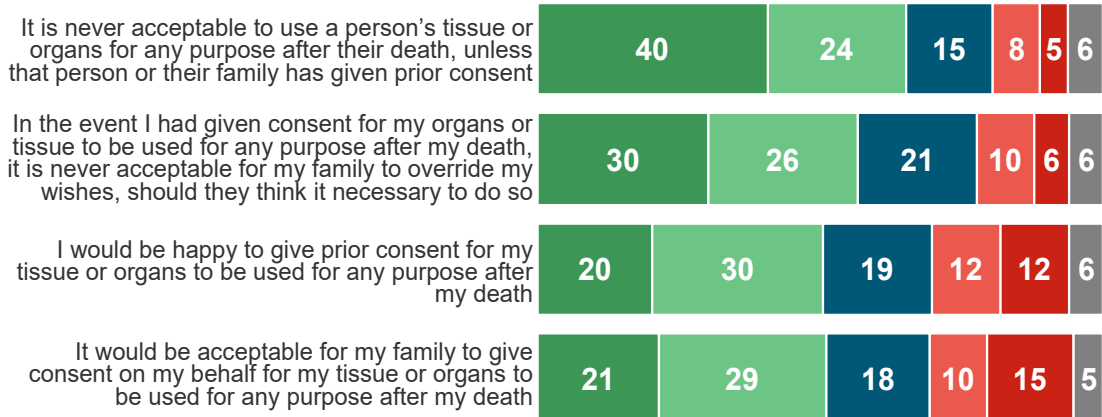
Half (50%) believe it would be acceptable for their family to give consent *on their behalf* to be used for any purpose after death - but 25% expressly disagree, rendering this relatively the most divisive of the four family-related scenarios tested.

BME groups are more equivocal on the question of families overriding a deceased's wishes. Just one in ten (11%) *strongly* object to this - against 32% of whites - while 37% neither agree nor disagree (vs 19% of whites).

Views on consent

Q To what extent, if at all, do you agree or disagree with each of the following statements?

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



Base: All adults aged 15+ (967), fieldwork dates: 13th - 19th August 2010
Ipsos MORI

Source: Ipsos MORI
Ipsos

The role of the media

Awareness of coverage: People choosing, while they are alive, to donate their tissue or organs for transplantation while they are alive

1,019 respondents were surveyed (between 20 and 26 August 2010) about the media's impact on their knowledge of / attitudes to transplant regulation.

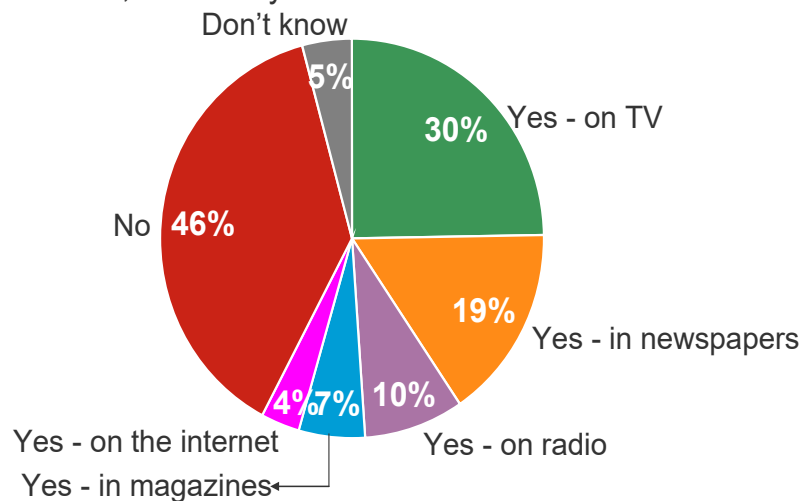
Of those, almost half (46%) claim to have read or heard something in the media - eg in newspapers, magazines, on television, on radio, or on the internet - about **'people choosing, while they are alive, to donate their tissue or organs for transplantation while they are alive'**.

The most common source cited (as is typical in such surveys) is through television: three in ten (30%) cite it here. About one in five (19%) have seen something in newspapers and one in ten (10%) heard something on the radio.

Exposure by age is fairly consistent (with the exception of 25-34 year olds, at just 34%), while ABC1s report more awareness than do DEs. Those of white ethnic origin are more widely exposed than are BME groups (48% and 29% respectively).

Exposure to media coverage of people choosing, while they are alive, to donate their tissue or organs for transplantation while they are alive

Q Have you read or heard anything in the media – eg in newspapers, magazines, on television, on radio, or on the internet about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive?



Base: All adults aged 15+ (1,019), fieldwork dates: 20th - 26th August 2010
Ipsos MORI

Source: Ipsos MORI
Ipsos

Appendix 3 shows the range of television programmes, newspapers, magazines, radio stations and internet sites respondents have seen or heard this coverage on.

Impact of media coverage

It does appear that the media has some effect on individuals' propensity to donate and their behaviour with regards to donation. A quarter (26%) feel that what they have seen about this form of donation makes them more likely to consider donating their tissue or organs while they are alive for transplantation *after* their death.

One in five (21%) say it made them want to discuss with their family the use of their tissue or organs after their death - and a similar number (19%) feel more confident that

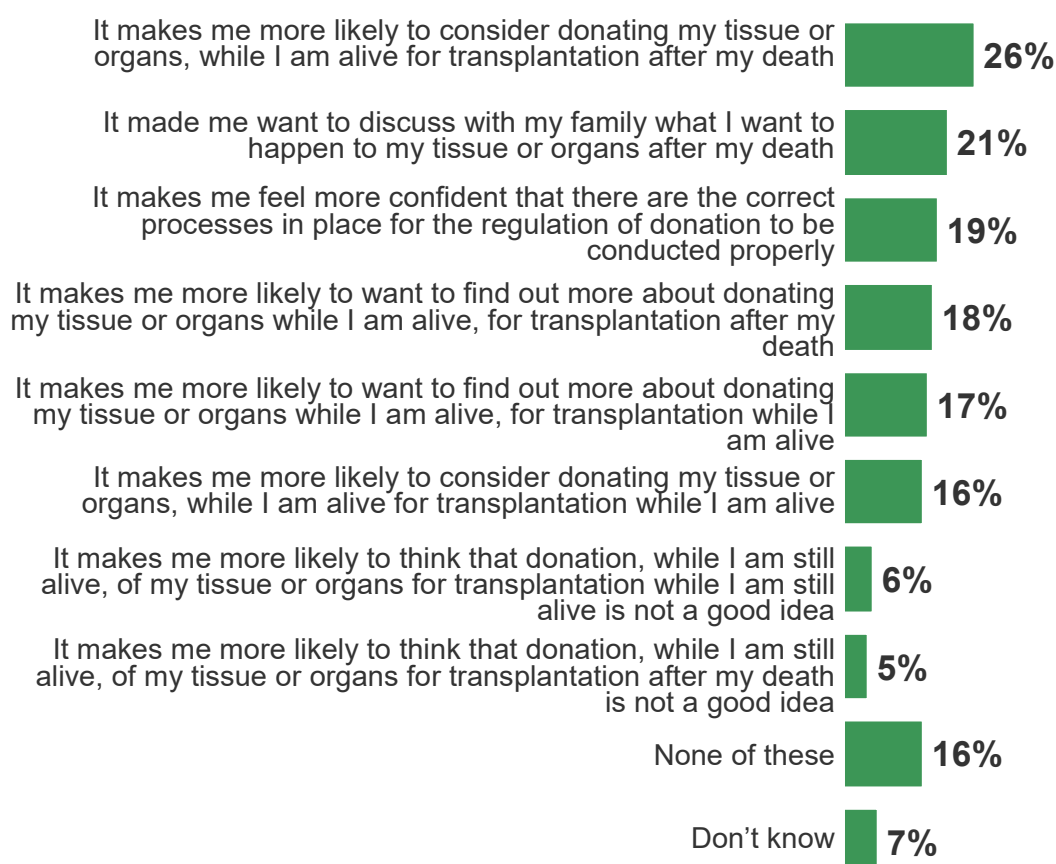
there are correct processes in place for the regulation of donation to be conducted properly.

Eighteen per cent feel it makes them more likely to find out more about donating their tissue or organs while they are alive for transplantation after their death. Seventeen per cent say that it makes them more likely to consider donating their tissue or organs while they are alive for transplantation *while they are alive*.

By contrast, few say the media coverage acted as a deterrent - whether in terms of donating before (6%) or after death (5%).

Effects of media coverage on the propensity to donate

Q Thinking now about this media coverage, which, if any of the following statements applies to you about people choosing while they are alive, to donate their tissue or organs for transplantation while they are alive?



Base: All adults aged 15+ who have read or heard anything in the media about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (472), fieldwork dates: 20th - 26th August 2010

Ipsos MORI



People choosing to donate their body (for medical education and training purposes) for use after their death

Slightly fewer respondents have seen something in the media about people choosing to donate their body, for medical education and training purposes, for use after their death.

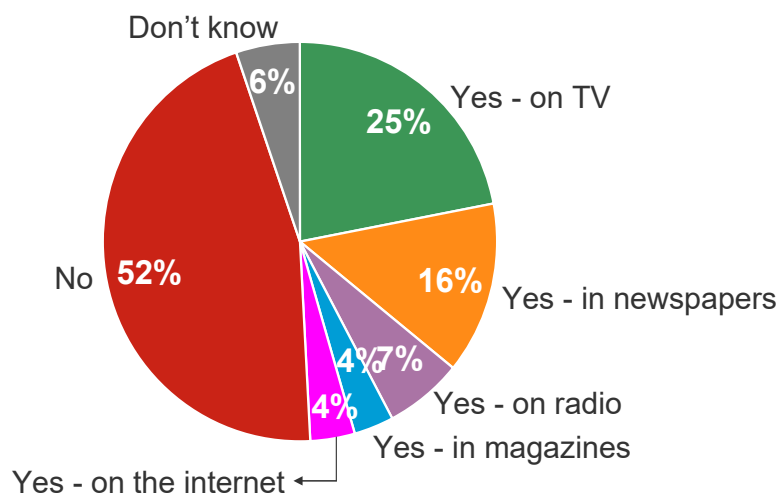
Two in five (40%) report having seen such coverage, while half (52%) do not. A quarter have seen something on television, sixteen per cent in newspapers and seven per cent on the radio.

For this form of donation, it is more likely to be men who have seen or heard something in the media (44%, compared to 35% of women), those aged between 55 and 64 (47%, compared to 35% of 25-34 and 65+ year olds). As well as those in the more affluent social grades (45% of ABC1s, 34% of C2DEs).

Again, reported exposure is much lower among BME groups, at 25%.

Media exposure to people choosing to donate their body, for medical education and training purposes, for use after their death

Q Have you read or heard anything in the media – eg in newspapers, magazines, on television, on radio, or on the internet about people choosing to donate their body, for medical education and training purposes, for use after their death?



Base: All adults aged 15+ (1,019), fieldwork dates: 20th - 26th August 2010

Ipsos MORI

Source: Ipsos MORI

Appendix 4 shows the range of television programmes, newspapers, magazines, radio stations and internet sites respondents have seen or heard this coverage on.

A very similar pattern emerges as that observed for with living donations, when it comes to the effect the media has on people's intending *post-death* donating behaviour.

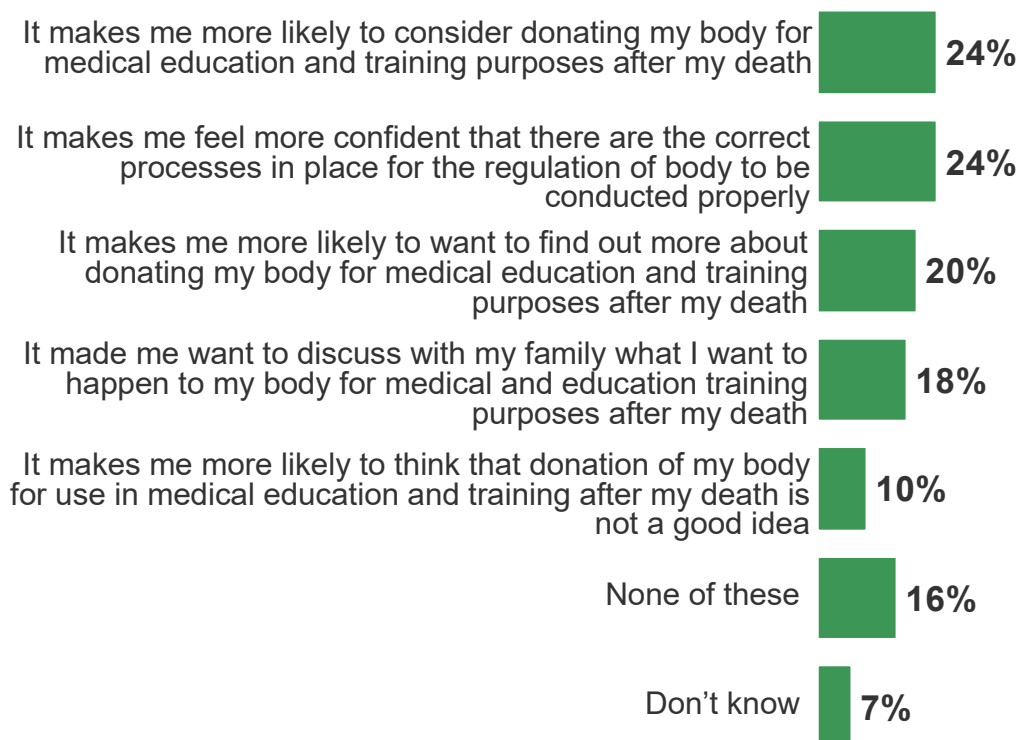
About a quarter of respondents (24%) say they would be more likely to consider donating their body for medical education and training purposes after their death - having seen something about this in the media. The same proportion also feels it makes them more confident that correct regulatory processes are in place.

One in five (20%) say that media coverage has made them want to find out more about donating their body for medical education and training purposes after their death - and eighteen per cent feel it has made them want to discuss the implications with their family. Only sixteen per cent think that the media has not had any effect on any of the statements mentioned in the chart overleaf.

Meanwhile, 10% say the coverage has tended to deter them from donation of this kind (a view particularly evident among DEs).

Effects of media coverage on the propensity to donate

Q Thinking now about this media coverage, which, if any of the following statements applies to you about people choosing to donate their body, for medical education and training purposes, for use after their death?



Base: All adults aged 15+ who read or heard anything in the media about people choosing to donate their body, for medical education and training purposes, for use after their death (399), fieldwork dates: 20th - 26th August 2010

Ipsos MORI



Use of the internet - media questions

The frequency of internet usage questions were repeated in the media-related questions - primarily to allow sub-group analysis for this latter set of measures in the full computer tables. These questions were bespoke to the HTA.

The results are similar to those for the first phase: around half use 'Facebook' and nearly two in five 'YouTube'. Facebook is also the most frequently used site / activity of those listed.

Appendices

Appendix 1 - Topline

HTA General Public Questionnaire Topline Results 25/08/10

- Ipsos MORI interviewed a representative quota sample of 967 adults aged 15+.
- Interviews were carried out face-to-face with the aid of CAPI (Computer Assisted Personal Interviewing) terminals in Great Britain.
- Fieldwork took place between 13 and 19 August 2010.
- Data have been weighted to the known population profile.
- Where results do not sum to 100, this may be due to multiple responses, computer rounding or the exclusion of don't knows/not stated.
- Results are based on all respondents unless otherwise stated. Base sizes are in brackets.
- An asterisk (*) represents a value of less than half a per cent, but not zero.
- A double asterisk (**) represents a very low base size - these findings should be treated as indicative only.
- Where results are based on a very low number of interviews actual numbers of respondents, rather than percentages, are given.
- Results for 2007 are based on a representative quota sample of 2,058 GB adults aged 16+ interviewed between 17 and 22 May 2007.

Q1. SHOWCARD Using this card how much confidence, if any, do you have in the way the donation, removal, storage and use of human tissue or organs is regulated? SINGLE CODE

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

Q2. Who, or which organisation/s, if any, do you think regulates the donation, removal, storage and/or use of human tissue or organs in the UK? Who else? PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

	%
The NHS	21
The Government/Government quango/Govt department/agency	6
The Department of Health (DH)	6
BMA (The British Medical Association)	4
NHSBT (NHS Blood and Transplant)	3
MRC (Medical Research Council)	3
GMC (The General Medical Council)	2
NICE (National Institute for Health and Clinical Excellence)	2
HTA (The Human Tissue Authority)	2
Charities	2
Private medical sector e.g. BUPA	1
No-one/ No organisation	1
HFEA (The Human Fertilisation and Embryology Authority)	1
Campaign groups	1
The Healthcare Ombudsman	*
Research Council (general)	*
The Royal College of Surgeons (RCS)	*
The Royal College of Physicians (RCP)	*
The EU/ Brussels	*
The Citizen's Advice Bureau	*

² In 2007 this question was preceded by two questions (*What comes to mind, if anything, when I say 'human tissue'?* (unprompted) and *What do you think human tissue is used for?* (unprompted)), and therefore a comparison with 2010 should be treated with a little caution.

(CAB)	
Shareholders	*
Pharmaceutical companies	*
NPSA (National Patient Safety Agency)	*
MHRA (The Medicines & Healthcare products Regulatory Agency)	*
CQC (The Care Quality Commission)	-
The police	-
Other	2
No-one/ no organisation	1
Don't know	51
Refused	*

Q3. **What, if anything, do you feel are the benefits of regulating the way in which human tissue is used in the UK? What else?** PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

	%
Stops bad practice from occurring	32
Ensures human tissue is not used at will or abused	10
Ensure the quality and safety of donated tissue	8
Ethical or moral benefits	7
To support scientific and medical developments / treatments for disease	7
Knowing human tissue will be treated with respect and dignity	6
Knowing human tissue is safer for treatment	5
More people will be willing to donate their tissue for scientific and medical research	5
Knowing the wishes of the deceased will be respected	5
Knowing people's wishes will be respected	5
Ensure tissue is not used for financial gain / commercial purposes	5
More people will be willing to donate their organs and/or tissues for transplants	4
Ensures consistency across the country/across medical units etc	4
Prevents another Alder Hey / Bristol Royal Infirmary / same type of situation	3
Ensuring human tissue is of high	3

quality for research and other purposes	
More people will be willing to donate their bodies for medical education and training	2
Saves lives/helps others	1
Other	2
There are no benefits	6
Don't know	28

Q4. **What, if anything, do you feel are the drawbacks of regulating the way in which human tissue is used in the UK? What else?** PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

	%
Too much red tape	13
Holds back scientists who need samples or bodies	8
Slows down research process/Other countries can have scientific breakthrough before UK	7
Unnecessary interference in making individual choice	5
Too much burden on scientists/medical researchers/health professionals	4
Less Donations	1
Costs	1
Stops bad practice from occurring	*
Difficult to legislate	*
Lack of information	*
Other	3
There are no drawbacks	23
Don't know	40
Refused	*

SPLIT SAMPLE. V1 GET Q5 AND V2 GET Q6
 ROTATE ORDER OF Q5/6-8a/b. Q8a ALWAYS PRECEDES Q8b

Q5. SHOWCARD **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?**
 SINGLE CODE ONLY

Base: Split sample - all adults aged 15+ on Version 2A (522)

	%
Certain to	18
Very likely	22
Fairly likely	20
Fairly unlikely	8
Very unlikely	12
Certain not to	9
Have already donated or given my consent to donate my tissue or organs or body (i.e. one or more of these) for this purpose	1
Would want to but have been told I cannot due to medical reasons	1
It depends	3
Don't know	7
Refused	*

Q6. SHOWCARD **How likely or unlikely would you be to donate any of your tissue or organs after you have died for use in transplantation?** SINGLE CODE ONLY

Base: Split sample - all adults aged 15+ on Version 2B (445)

	%
Certain to	21
Very likely	22
Fairly likely	19
Fairly unlikely	7
Very unlikely	10
Certain not to	8
Have already donated or given my consent to donate my tissue or organs or body (i.e. one or more of these) for this purpose	*
Would want to but have been told I cannot due to medical reasons	1
It depends	4
Don't know	6
Refused	1

Q7. SHOWCARD **How likely or unlikely would you be to donate your body after you have died for use of education or training of doctors?** SINGLE CODE ONLY

	%
Certain to	10
Very likely	13
Fairly likely	15
Fairly unlikely	15
Very unlikely	18
Certain not to	17
Have already donated or given my consent to donate my tissue or organs or body (i.e. one or more of these) for this purpose	1
Would want to but have been told I cannot due to medical reasons	1
It depends	3
Don't know	6
Refused	1

Q8a SHOWCARD **How likely or unlikely would you be to donate any of your tissue or organs while you are still alive for use in transplantation?** SINGLE CODE ONLY

	%
Certain to	8
Very likely	13
Fairly likely	21
Fairly unlikely	12
Very unlikely	17
Certain not to	14
Have already donated or given my consent to donate my tissue or organs or body (i.e. one or more of these) for this purpose	*
Would want to but have been told I cannot due to medical reasons	1
It depends	7
Would donate to immediate family only	1
Don't know	8

Q8b SHOWCARD **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?** SINGLE CODE ONLY

	%
Certain to	24
Very likely	25
Fairly likely	18
Fairly unlikely	5
Very unlikely	9
Certain not to	9

Have already donated or given my consent to donate my tissue or organs or body (i.e. one or more of these) for this purpose	*
Would want to but have been told I cannot due to medical reasons	1
It depends	3
Don't know	6
Refused	1

Q9A 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? PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

Base All 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 at Q5 (155)

	%
Lack of information	6
Moral considerations	6
Religious considerations	5
Worried about purpose	5
Concern about cutting open body	5
My relatives wouldn't like it	3
Worried about misuse/falling into wrong hands	3
Worried about who is doing it	2
Ethical implications	2
Organisations may share donations for commercial purposes gain	2
Scandals	2
Can't control how used	2
Can't control who uses it	2
Age/too old	2
Have a health problem/medical condition	2
Worried about disclosure to family, friends or acquaintances	2
Don't trust doctors/clinicians	2
Worried about whether donation is anonymised/linked to individuals	1
Cultural considerations	1
Lack of regulation	1
Concern about profit motives	1
Medical researchers use animals for experiments	1
Affect funeral arrangements	*

Alder hey/Bristol Royal Infirmary	*
Would not be of any use	*
I am against medical research	-
Data Protection Act	-
Doctors/clinicians have poor communications skills	-
Lack of transparency	-
Certain types of tissue are not acceptable to share	-
Northwick Park	-
Cardiff/Wales mortuary being shut down	-
Read/heard something worrying in the media	-
Scandals/cases in the media	-
Security concerns	-
Other	2
Just don't want to	24
Haven't thought about it	15
No reason	13
Don't know	6
Refused	1

Q9B 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? PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

Base: All adults aged 15+ who are unlikely to donate any of their tissue or organs after they have died for use in transplantation at Q6 (117)

	%
Moral considerations	6
Lack of information	6
Concern about cutting open body	5
Religious considerations	5
Worried about purpose	5
Can't control how used	4
My relatives wouldn't like it	4
Age/too old	3
Don't trust doctors/ clinicians	3
Cultural considerations	3
Ethical implications	2
Can't control who uses it	2
Security concerns	2
Worried about misuse/falling into wrong hands	2
Alder Hey / Bristol Royal Infirmary	2

Lack of regulation	2
Affect funeral arrangements	2
Certain types of tissue are not acceptable to share	1
Concern about profit motives	1
Have a health problem/medical condition	1
Data Protection Act	1
Doctors/ clinicians have poor communication skills	1
Would not be of any use	1
Scandals (unspecific)	1
Worried about whether donation is anonymised/linked to individuals	1
Scandals/ cases in the media	1
Organisations may share donations for commercial purposes/gain	*
Worried about disclosure to family, friends or acquaintances	*
Worried about who is doing it	*
I am against medical research	-
Lack of transparency	-
Medical researchers use animals for experiments	-
Northwick Park	-
Cardiff / Wales mortuary being shut down	-
Read/Heard something worrying in the media	-
Other	-
Just don't want to	28
Haven't thought about it	15
No reason	7
Don't know	6

Q9C 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? PROBE FULLY. DO NOT PROMPT.
MULTICODE OK.

Base: All who are unlikely to donate any of their body after they have died for use in education or training of doctors at Q7 (487)

	%
My relatives wouldn't like it	11
Concern about cutting open body	7
Affect funeral arrangements	5
Moral considerations	5

Religious considerations	4
Can't control how used	4
Worried about misuse/falling into wrong hands	4
Lack of information	3
Worried about purpose	2
Worried about who is doing it	2
Can't control who uses it	2
Cultural considerations	2
Don't trust doctors/clinicians	2
Ethical implications	1
Age/too old	1
I am against medical research	1
Worried about disclosure to family, friends or acquaintances	1
Scandals (unspecific)	1
Lack of regulation	1
Spiritual reasons	1
Concerns about profit motives	*
Organisations may share donations or commercial purposes/gain	*
Alder Hey/Bristol Royal Infirmary	*
Worried about whether donation is anonymised/Linked to individuals	*
Doctors/clinicians have poor communication skills	*
Have a health problem/medical condition	*
Certain types of tissue are not acceptable to share	*
Read/heard something worrying in the media	*
Scandals/cases in the media (non-specific)	*
Security concerns	*
Cardiff/Wales Mortuary being shut down	*
Lack of transparency	*
Medical researchers use animals for experiments	*
Would not be of any use	*
Northwick Park	-
Data Protection Act	-
Other	3

Just don't want to	32
Haven't thought about it	10
No reason	5
Don't know	5
Refused	*

Q9D 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? PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

Base: All who are unlikely to personally donate any of their tissue or organs while they are still alive for use in transplantation at Q8a (412)

	%
Concern about cutting open body/the physical pain of transplanting	7
Lack of information	5
Have a health problem/medical condition	4
Can't control how used	4
Worried about misuse/falling into wrong hands	4
My relatives wouldn't like it	4
Moral considerations	4
Religious considerations	3
Age/too old	3
Cultural considerations	3
Worried about purpose	2
Would only consider a family member	2
Don't trust doctors/clinicians	2
Worried about who is doing it	2
Scandals (unspecific)	1
Risks to own health	1
Security concerns	1
Can't control who uses it	1
Lack of regulation	1
Ethical implications	1
Concern about profit motives	1
Alder Hey/Bristol Royal Infirmary	1
Worried about whether donation is anonymised/linked to individuals	1
Lack of transparency	1
Organisations may share donations for commercial purposes/gain	1
Spiritual reasons	1
Would not be of any use	*
Certain types of tissue are not acceptable to share	*
Cardiff/Wales Mortuary being shut down	*

Doctors/clinicians have poor communication skills	*
Northwick Park	*
Worried about disclosure to family, friends or acquaintances	*
Scandals/cases in the media (non-specific)	*
I am again medical research	-
Data Protection Act	-
Affect funeral arrangements	-
Read/heard something worrying in the media	-
Medical researchers use animals for experiments	-
Other	1
Just don't want to	23
Haven't thought about it	17
No reason	7
Don't know	7
Refused	*
No answer	*

Q9E 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? PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

Base: All who are unlikely to also consent to donate any of their tissue for use in medical research into health and disease in the event of any of their tissue being removed as part of their diagnosis or treatment while they are still alive at Q8b (232)

	%
Lack of information	6
Religious considerations	5
Worried about purpose	5
Can't control how used	4
Moral considerations	4
Worried about misuse/falling into wrong hands	3
My relatives wouldn't like it	3
Concern about cutting open body	2
Can't control who uses it	2
Cultural considerations	2
Don't trust doctors/clinicians	2
Security concerns	2
Worried about who is doing it	2
Worried about disclosure to family, friends or acquaintances	1

Concern about profit motives	1
Ethical implications	1
Scandals (unspecific)	1
Cardiff/Wales mortuary being shut down	1
Age/too old	1
Lack of transparency	1
Lack of regulation	1
Have a health problem/medical condition	1
Read/ heard something worrying in the media	1
Northwick Park	*
Certain types of tissue are not acceptable to share	*
Doctors/ clinicians have poor communication skills	*
I am against medical research	*
Medical researchers use animals for experiments	*
Risks to own health	*
Would not be of any use	*
Other	-
Just don't want to	20
Haven't thought about it	21
No reason	11
Don't know	7
Refused	*

Q10 What, if anything might make you more inclined to donate your body, any organs or any tissue from your body for the purposes of medical research, education or transplants? What else? PROBE FULLY. DO NOT PROMPT. MULTICODE OK.

Base: All who are not certain to donate any of their tissue or organs/ body for all the reasons mentioned (924)

	%
If the donation helped a family member	27
If I knew the purpose they might be used for	17
If I knew more about it	16
If I knew of the benefits to society the research would provide	5
If I knew about the safeguards in place	5
If there is a regulator/ watchdog/ organisation regulating its use	4
If I knew exactly who was	4

using the donated tissue	
If the donation would benefit me personally	2
If it was anonymous/if I could be guaranteed anonymity	1
If I had better health	1
If I had rare blood group/rare condition	*
Financial reward	*
Other	2
Nothing would	21
Don't know	13
Refused	1

Q11 SHOWCARD Please tell me to what extent, if at all, you agree or disagree with each of the following statements? SINGLE CODE FOR EACH. ROTATE ORDER

	Strongly agree %	Tend to agree %	Neither agree nor disagree %	Tend to disagree %	Strongly disagree %	No opinion/ Don't know %	Refused %
Knowing that there is a regulator for the donation, storage, use and disposal of human tissue would make me more confident to donate tissue from my body for medical research	15	34	26	9	8	8	1
Knowing that there is a regulator for the donation, storage, use and disposal of human tissue would make me more confident to donate my organs for transplants	17	35	24	8	8	7	1
Knowing that there is a regulator for the donation, storage, use and disposal of human tissue would make me more confident to donate my body for medical education and training	13	30	25	12	11	7	2

Q12 SHOWCARD Please tell me to what extent, if at all, you agree or disagree with each of the following statements? SINGLE CODE FOR EACH. ROTATE ORDER

	Strongly agree %	Tend to agree %	Neither agree nor disagree %	Tend to disagree %	Strongly disagree %	No opinion/ Don't know %	Refused %
It would be acceptable for my family to give consent on my behalf for my tissue or organs to be used for <u>any</u> purpose after my death	21	29	18	10	15	5	1
I would be happy to give prior consent for my tissue or organs to be used for <u>any</u> purpose after my death	20	30	19	12	12	6	1
It is never acceptable to use a person's tissue or organs for <u>any</u> purpose after their death, unless that person or their family has given prior consent	40	24	15	8	5	6	1
In the event that I had given consent for my organs or tissue to be used for <u>any</u> purpose after my death, it is never acceptable for my family to override my wishes, should they think it necessary to do so.	30	26	21	10	6	6	2

Q13 SHOWCARD For which, if any, of the following purposes do you use the Internet? MULTICODE OK.

Base: All adults aged 15+ who use the internet (710)

	%
Facebook	56
YouTube	43
Posting a comment on a site	16
Contributing to an online discussion board	7
Maintaining a personal website	7
Twitter	6
Participating in chat rooms	5
Linkedin	5

Myspace	4
Writing a blog	4
Flickr	3
Bebo	2
Contributing to a WIKI	2
Other	15
None of These	23
Don't know	2

Q14 SHOWCARD How often do you use internet for? SINGLE CODE FOR EACH. ROTATE ORDER

Base: All adults aged 15+ who use/engage in each internet activity

		Bases	Several times a day	About once a day	Every few days	Once a week or less often	Don't know
Facebook	%	(371)	29	32	20	19	-
Twitter	%	(39)	15	21	32	31	1
Linkedin	N	(25**)	1	7	2	26	-
Myspace	N	(28**)	1	5	7	14	1
Bebo	N	(19**)	-	1	1	15	2
Youtube	%	(294)	11	19	26	43	*
Flickr	N	(20**)	-	3	10	13	-
Contributing to a wiki	N	(13**)	-	1	-	11	1
Contributing to an online discussion board	%	(46)	12	20	22	46	-
Posting a comment on a site	%	(103)	12	19	20	49	-
Writing a blog	N	(21**)	-	4	1	16	-
Maintaining a personal website	%	(47)	16	15	23	41	6
Participating in chat rooms	%	(40)	15	15	14	56	-

**Where the overall number of respondents (N) is 30 or less the absolute number of respondents is stated

Media Questions 31/08/10

- For these questions, Ipsos MORI interviewed a representative quota sample of 1,019 adults aged 15+.
- Interviews were carried out face-to-face with the aid of CAPI (Computer Assisted Personal Interviewing) terminals in Great Britain.
- Fieldwork took place between 20 and 26 August 2010.
- Data have been weighted to the known population profile.
- Where results do not sum to 100, this may be due to multiple responses, computer rounding or the exclusion of don't knows/not stated.
- Results are based on all respondents unless otherwise stated. Base sizes are in brackets.
- An asterisk (*) represents a value of less than half a per cent, but not zero.
- A double asterisk (**) represents a very low base size - these findings should be treated as indicative.
- Where results are based on a very low number of interviews actual numbers of respondents, rather than percentages, are given.

ALTERNATE (Q1/Q2) WITH (Q3/Q4)

Q1. SHOWCARD **Have you read or heard anything in the media - e.g. in newspapers, magazines, on television, on radio, or on the internet about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive?** MULTICODE OK

	%
Yes - on TV	30
Yes - in newspapers	19
Yes - on radio	10
Yes - in magazines	7
Yes - on the internet	4
All yes	46
No	46
Don't know	5
Refused	3

Q1A. Please tell me in which newspaper(s) did you read this? OPEN ENDED

Base: All adults aged 15+ who have read anything in newspapers about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (196)

	%
Daily Mail	20
The Sun	15
The Times	10
Daily Telegraph	9
Daily Express	6
The Guardian	5
Local papers	5
Other Sunday papers	5
Daily Mirror	5
Daily Record	3
The Independent	1
Metro	1
Mail on Sunday	1
News of the World	1
Evening papers	1
The Observer	1
Other	7
Don't know	16

Q1B Please tell me in which magazine(s) did you read this? OPEN ENDED

Base: All adults aged 15+ who have read anything in magazines about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (65)

	%
Take A Break	7
Chat	5
Supplements	4
New Scientist	4
OK	4
Woman	1
Closer	1
Other	26
Don't know	50

Q1C. Please tell me on which TV programme did you see this? OPEN ENDED

Base: All adults aged 15+ who have seen anything on TV about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (313)

	%
News (not specified)	24
BBC News	7
Adverts	7
Hospital programmes	5
Panorama	4
Documentaries	3
GMTV	3
This Morning	2
BBC	2
Debates/ Discussions	2
ITV News	1
The One Show	1
Newsnight	1
Autopsy programme	1
BBC1	1
Stephen Fry in America	1
Channel 4	*
Other	7
Don't know	33

Q1D. Please tell me on which radio programme/ station did you hear this? OPEN ENDED

Base: All adults aged 15+ who have heard anything on radio about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (90)

	%
Radio 4	28
Radio 2	13
Radio 5	7
Today	7
Local radio stations	6
Adverts (not specified)	3
BBC	2
Radio 1	1
Capital Radio	1
Other	6
Don't know	29

Q1E. Please tell me on which website did you see this? OPEN ENDED

Base: All adults aged 15+ who have read or heard anything on the internet about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (43)

	%
BBC	16
NHS	9
New Scientist	4
Google	3
Facebook	2
Other	40
Don't know	31

Q2. SHOWCARD Thinking now about this media coverage, which, if any of the following statements applies to you about people choosing while they are alive, to donate their tissue or organs for transplantation while they are alive? You may choose as many or as few as apply.

MULTICODE OK

Base: All adults aged 15+ who have read or heard anything in the media about people choosing, while they are alive, to donate their tissue or organs for transplantation, while they are alive (472)

	%
It makes me more likely to consider donating my tissue or organs, while I am alive for transplantation after my death	26
It made me want to discuss with my family what I want to happen to my tissue or organs after my death	21
It makes me feel more confident that there are the correct processes in place for the regulation of donation to be conducted properly	19
It makes me more likely to want to find out more about donating my tissue or organs while I am alive, for transplantation after my death	18
It makes me more likely to want to find out more about donating my tissue or organs while I am alive, for transplantation while I am alive	17
It makes me more likely to consider donating my tissue or	16

organs, while I am alive for transplantation while I am alive	
It makes me more likely to think that donation, while I am still alive, of my tissue or organs for transplantation while I am still alive is NOT a good idea	6
It makes me more likely to think that donation, while I am still alive, of my tissue or organs for transplantation after my death is NOT a good idea	5
None of these	16
Don't know	7
Refused	*

- Q3. SHOWCARD **Have you read or heard anything in the media - e.g. in newspapers, magazines, on television, on radio or on the internet, about people choosing to donate their body, for medical education and training purposes, for use after their death?**
MULTICODE OK

	%
Yes - on TV	25
Yes - in newspapers	16
Yes - on radio	7
Yes - in magazines	4
Yes - on the internet	4
All yes	40
No	52
Don't know	6
Refused	3

- Q3A. **Please tell me in which newspaper(s) did you read this?** OPEN ENDED

Base: All adults aged 15+ who have read anything in newspapers about people choosing to donate their body, for medical education and training purposes, for use after death (164)

	%
Daily Mail	17
The Sun	13
The Guardian	9
The Times	8
Daily Telegraph	6
Daily Express	6
Local papers	4
Daily Mirror	4
Daily Record	3

Other Sunday papers	2
The Independent	2
Metro	2
News of the World	2
Evening papers	2
The Observer	2
Mail on Sunday	1
Other	7
Don't know	22

Q3B Please tell me in which magazine(s) did you read this? OPEN ENDED

Base: All adults aged 15+ who have read anything in magazines about people choosing to donate their body, for medical education and training purposes, for use after death (44)

	%
Closer	9
Take A Break	4
New Scientist	4
Supplements	3
Woman	2
Other	21
Don't know	56

Q3C. Please tell me on which TV programme did you see this? OPEN ENDED

Base: All adults aged 15+ who have seen anything on TV about people choosing to donate their body, for medical education and training purposes, for use after death (254)

	%
News (not specified)	22
BBC	6
BBC News	4
Adverts	3
Panorama	3
Documentaries	3
Channel 4	3
Hospital programmes	2
GMTV	2
This Morning	2
The One Show	2
Debates/ Discussions	1
ITV News	1
Autopsy programme	1
BBC1	1
Stephen Fry in America	1

Newsnight	*
Other	7
Don't know	38

Q3D. Please tell me on which radio programme/ station did you hear this?
OPEN ENDED

Base: All adults aged 15+ who have heard anything on radio about people choosing to donate their body, for medical education and training purposes, for use after death (66)

	%
Radio 4	25
Radio 2	11
Radio 5	9
Local radio stations	8
Radio 1	5
Adverts (not specified)	2
BBC	2
Capital Radio	1
Other	9
Don't know	28

Q3E. Please tell me on which website did you see this? OPEN ENDED

Base: All adults aged 15+ who have read or heard anything on the internet about people choosing to donate their body, for medical education and training purposes, for use after death (33)

	%
BBC	20
New Scientist	4
NHS	2
Google	1
Facebook	1
Other	28
Don't know	48

- Q4. SHOWCARD Thinking now about this media coverage, which, if any of the following statements applies to you about people choosing to donate their body, for medical education and training purposes, for use after their death? You may choose as many or as few as apply. MULTICODE OK.

Base: All adults aged 15+ who read or heard anything in the media about people choosing to donate their body, for medical education and training purposes, for use after their death (399)

	%
It makes me more likely to consider donating my body for medical education and training purposes after my death	24
It makes me feel more confident that there are the correct processes in place for the regulation of body donation to be conducted properly	24
It makes me more likely to want to find out more about donating my body for medical education and training purposes after my death	20
It made me want to discuss donating my body for medical and education training purposes after my death with my family	18
It makes me more likely to think that donation of my body for use in medical education and training after my death is NOT a good idea	10
None of these	16
Don't know	7

- Q5. SHOWCARD For which, if any, of the following purposes do you use the Internet? MULTICODE OK.

Base: All adults aged 15+ who use the internet (747)

	%
Facebook	50
YouTube	38
Posting a comment on a site	10
Twitter	8
Contributing to an online discussion board	6

Maintaining a personal website	5
LinkedIn	4
Participating in chat rooms	3
MySpace	3
Writing a blog	3
Flickr	3
Bebo	2
Contributing to a WIKI	2
Other	16
None of These	24
Don't know	3

Q6 SHOWCARD **How often do you use internet for?** SINGLE CODE FOR EACH. ROTATE ORDER

Base: All adults aged 15+ who use/engage in each internet activity

			Several times a day	About once a day	Every few days	Once a week or less often	Don't know
Facebook	% (361)		31	36	17	17	-
Twitter	% (51)		12	33	32	21	1
LinkedIn	N (22**)		3	3	10	12	-
Myspace	N (26**)		1	1	10	13	1
Bebo	N (17**)		1	4	4	9	-
Youtube	% (271)		13	19	26	41	-
Flickr	N (18**)		-	2	3	18	-
Contributing to a wiki	N (14**)		-	-	6	11	-
Contributing to an online discussion board	% (39)		2	14	27	56	-
Posting a comment on a site	% (62)		10	16	34	40	-
Writing a blog	N (21**)		1	3	6	14	-
Maintaining a personal website	% (33)		19	18	23	35	5
Participating in chat rooms	N (24**)		2	3	9	13	-

Appendix 2: Internet usage of the sample

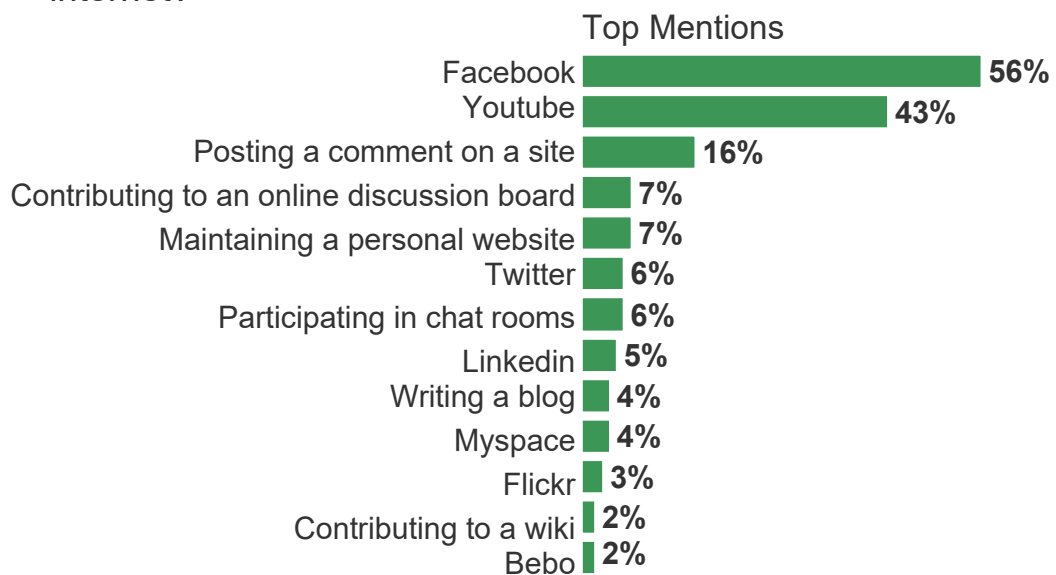
Respondents were asked about their use of the internet.³ Of the sites / activities shown to respondents (all relating to online interaction) the most commonly-used is 'Facebook' (56%). 'YouTube' is also popular - two in five use the internet for this. Sixteen per cent use it for posting comments on sites.

A quarter (23%) report undertaking none of these. As is typical, this varies hugely by age - ranging from 2% non-users among 15-24 year olds to 60% among the 65+ group. Respective figures among the white and BME groups are 24% and 12%, with the latter particularly active on YouTube.

The chart below outlines some of the other uses.

Use of the internet

Q For which, if any, of the following purposes do you use the internet?



Base: All adults aged 15+ who use the internet (710), fieldwork dates: 13th - 19th August 2010

Ipsos MORI

Source: Ipsos MORI



The majority of internet users who use each of the sites above use them on an irregular basis (once every few days at most). Facebook, however, is used daily by over three in five of its users - and a further three in ten use it several times a day.

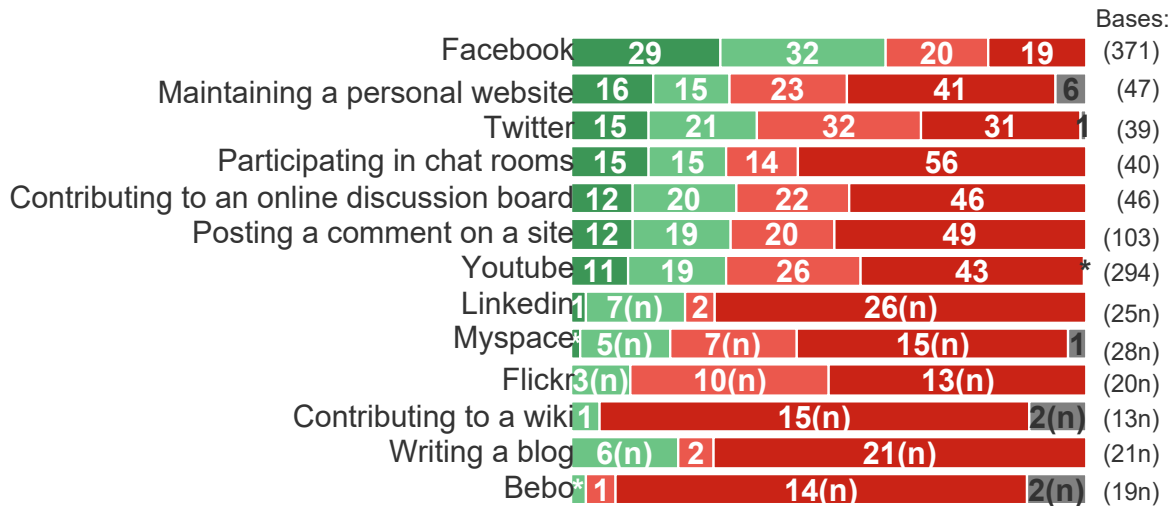
³ The questions on internet usage were bespoke to the HTA.


Approximately three in ten users in each case report daily use of Twitter, personal websites, chat rooms, online discussion boards, YouTube and posting comments on sites.

Frequency of internet use

Q How often do you use the internet for?

■ % Several times a day ■ % About once a day ■ % Don't know
■ % Every few days ■ % Once a week or less often



Base: All adults aged 15+ who use/engage in each internet activity, fieldwork dates: 13th - 19th August 2010 Source: Ipsos MORI
 Ipsos MORI 

Use of the internet - media questions

The frequency of internet usage questions were repeated in the media-related questions - primarily to allow sub-group analysis for this latter set of measures in the full computer tables.

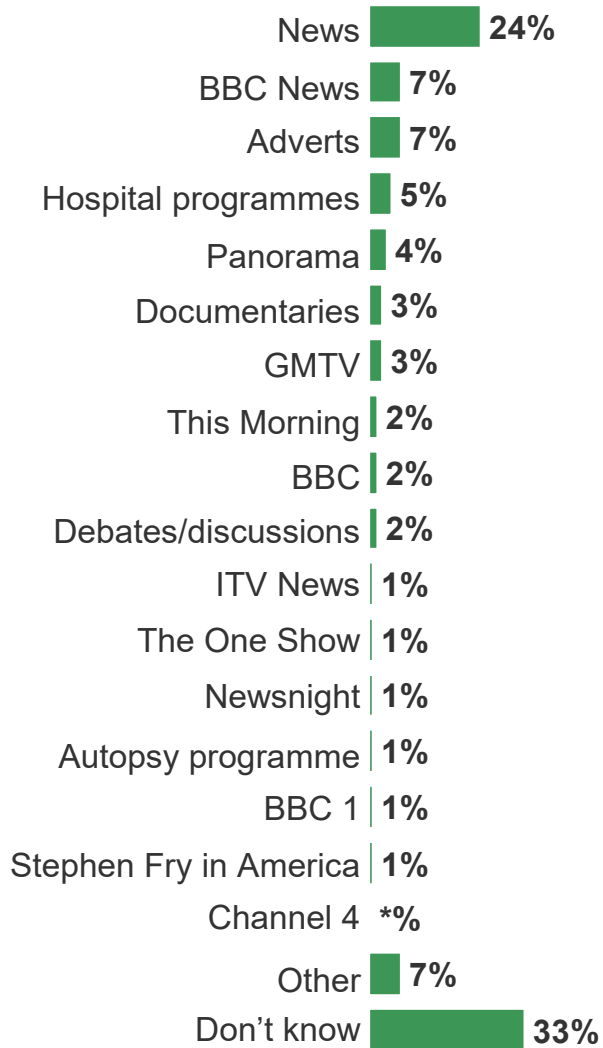
The results are similar to those for the first phase: around half use 'Facebook' and nearly two in five 'YouTube'. Facebook is also the most frequently used site / activity of those listed.

Appendix 3: Coverage in the media of people choosing, while they are alive, to donate their tissue or organs for transplantation while they are alive

A wide range of television programmes were cited (unprompted) – most often the news, by 24%.

Coverage on television

Q Please tell me on which TV programme did you see this?



Base: All adults aged 15+ who have seen anything on TV about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (313), fieldwork dates: 20th - 26th August 2010

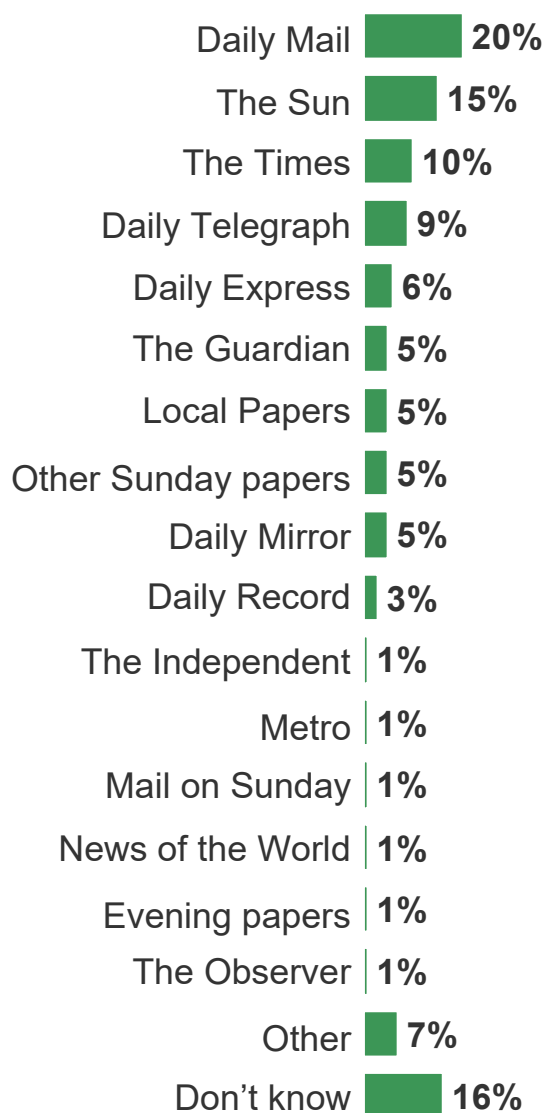
Ipsos MORI



Those who have seen something in newspapers most often cite the Daily Mail (20%), The Sun (15%) and The Times (10%).

Coverage in newspapers

Q Please tell me in which newspaper(s) did you read this?

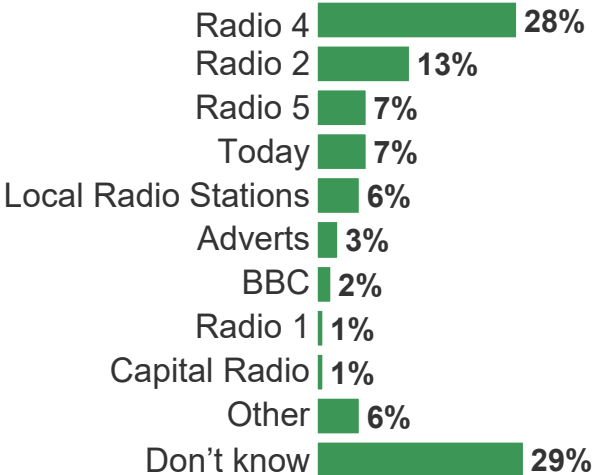


Base: All adults aged 15+ who have read anything in newspapers about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (196), fieldwork dates: 20th - 26th August 2010

Radio 4 is the most commonly-mentioned radio station: nearly three in ten of those hearing something about donations etc on the radio heard it on Radio 4. Thirteen per cent mention Radio 2 and 7% each mention Radio 5 and The Today Programme. (Again, these responses are unprompted).

Coverage on the radio

Q Please tell me on which radio programme/station did you hear this?

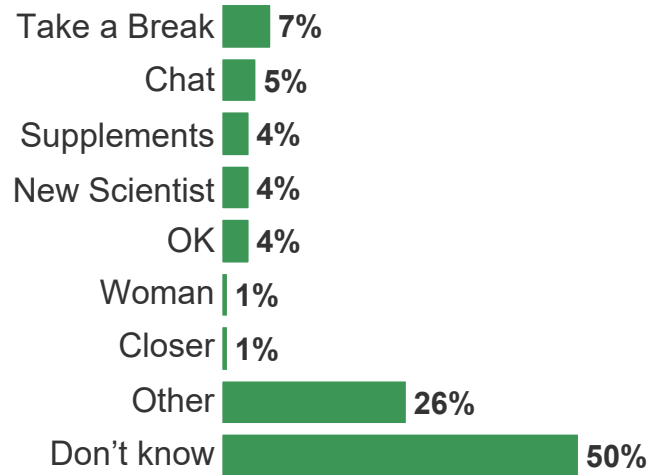


Base: All adults aged 15+ who have heard anything on radio about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (90), fieldwork dates: 20th - 26th August 2010
Source: Ipsos MORI

Respondents were not as clear when it came to recalling which magazines they had seen something in. Half of those citing magazines as a source do not know which publication they had seen it in. Seven per cent mention 'Take a Break' and five per cent 'Chat'.

Coverage in magazines

Q Please tell me in which magazine(s) did you read this?



Base: All adults aged 15+ who have read anything in magazines about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (65), fieldwork dates: 20th - 26th August 2010

Source: Ipsos MORI

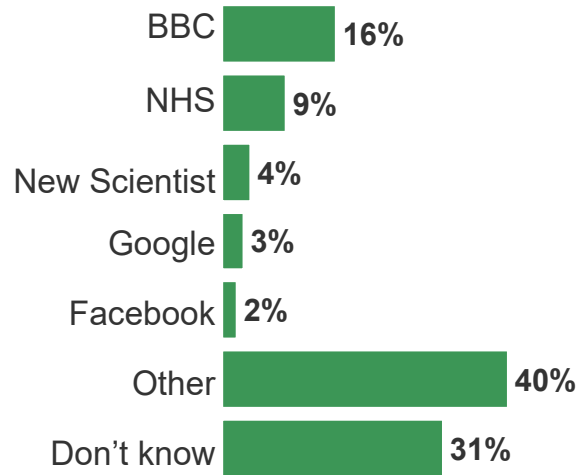
Ipsos MORI



In terms of websites, the most widely-referenced is the BBC, accounting for 16% of reported online sightings. About one in ten (9%) mention the NHS website. Three in ten do not recall the specific site, and two in five gave a range of 'other' responses.

Coverage on the internet

Q Please tell me on which website did you see this?



Base: All adults aged 15+ who have read or heard anything on the internet about people choosing, while they are alive to donate their tissue or organs for transplantation, while they are alive (43), fieldwork dates: 20th - 26th August 2010

Ipsos MORI

Source: Ipsos MORI



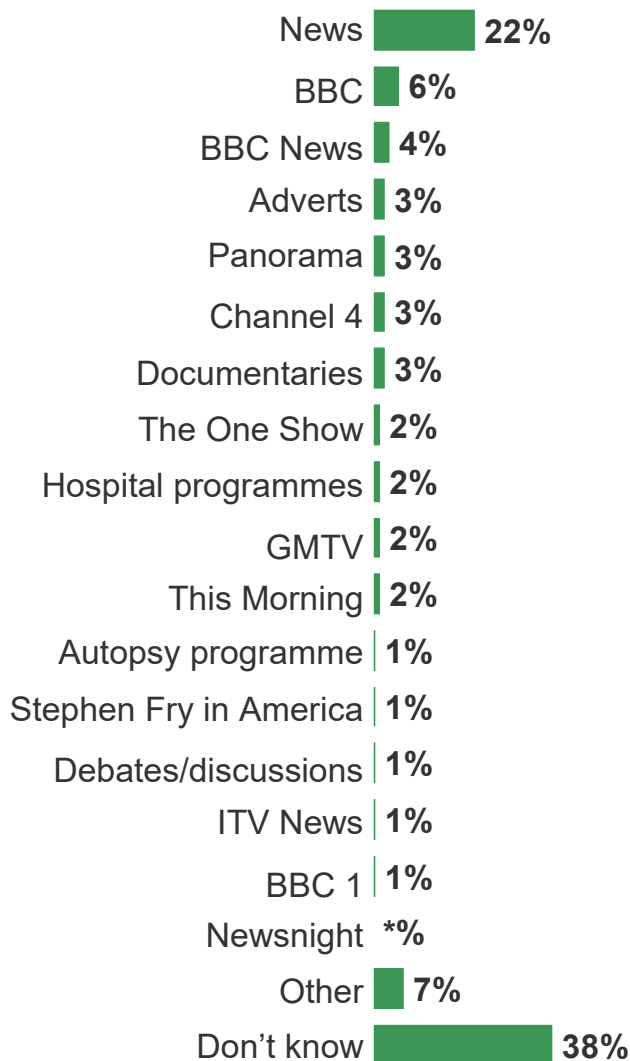
Appendix 4: Coverage in the media of People choosing to donate their body (for medical education and training purposes) for use after their death

A wide range of television programmes are cited as featuring post-death donations.

The chart overleaf shows the range of responses. Over one in five mention the News – four per cent specifically the BBC News – and six per cent the BBC generally.

Coverage on television

Q Please tell me on which TV programme did you see this?



Base: All adults aged 15+ who seen anything on TV about choosing to donate their body, for medical education and training purposes, for use after their death (254), fieldwork dates: 20th - 26th August 2010

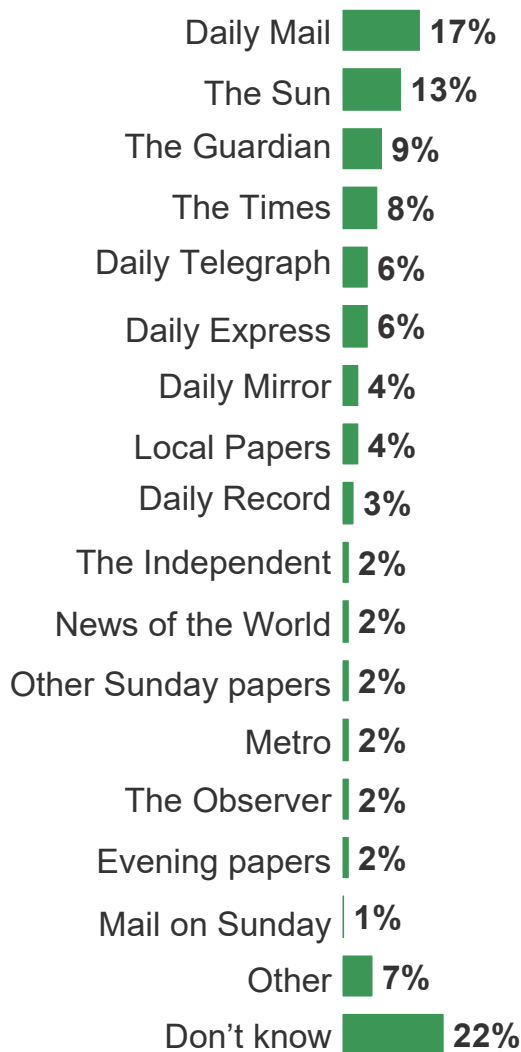
Ipsos MORI



Again, The Daily Mail (17%) and The Sun (13%) are the most commonly-named newspapers. Nearly one in ten each mentions The Guardian and The Times.

Coverage in newspapers

Q Please tell me in which newspaper(s) did you read this?



Base: All adults aged 15+ who have read anything in newspapers about people choosing to donate their body, for medical education and Training purposes, for use after their death (164), fieldwork dates: 20th - 26th August 2010

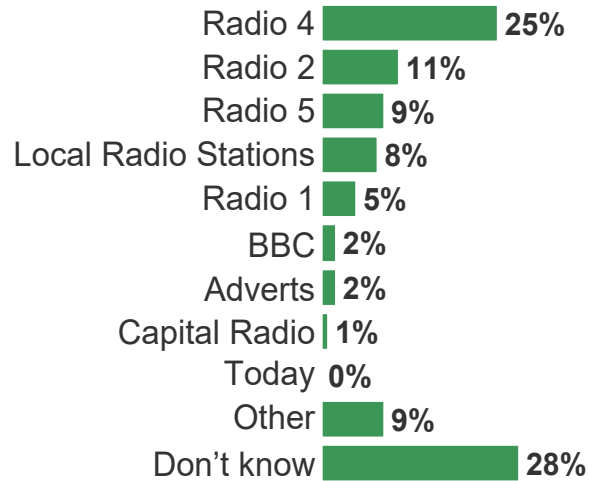
Ipsos MORI



As before, Radio 4 predominates among radio stations - accounting for a quarter of all reported radio coverage. Just over one in ten cite Radio 2 and nine per cent Radio 5. Local stations are also an important source - but nearly three in ten do not recall where they heard it.

Coverage on the radio

Q Please tell me on which radio programme/station did you hear this?



Base: All adults aged 15+ who heard anything on radio about people choosing to donate their body, for medical education and training purposes, for use after their death (66), fieldwork dates: 20th - 26th August 2010

Ipsos MORI

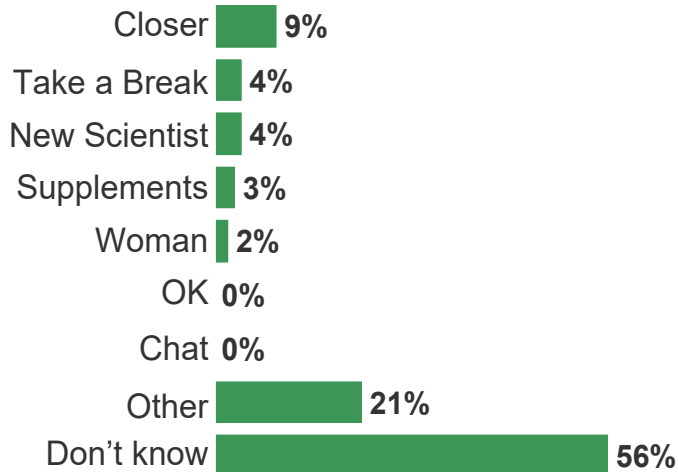
Source: Ipsos MORI



There is again a lack of clarity as to which magazine respondents have seen something in - with well over half of those citing magazines as a source not recalling the specific title. Of those who do, nearly ten per cent mention 'Closer' and four per cent each 'Take a Break' and 'New Scientist'.

Coverage in magazines

Q Please tell me in which magazine(s) did you read this?



Base: All adults aged 15+ who read anything in magazines about people choosing to donate their body, for medical education and training purposes, for use after their death (44), fieldwork dates: 20th - 26th August 2010

Ipsos MORI

Source: Ipsos MORI

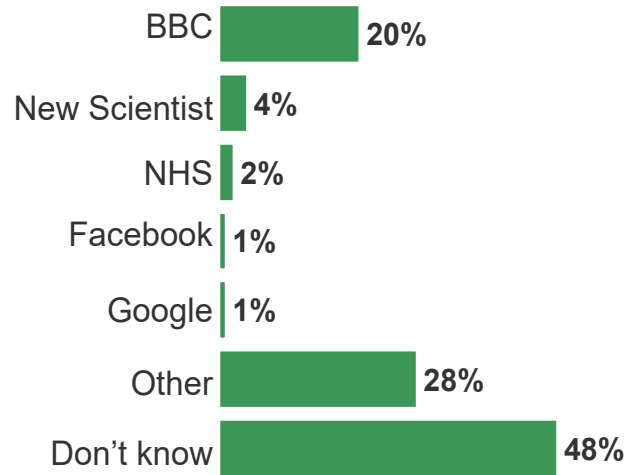


Again the most common website is the BBC: one in five of those with online sources mention it (unprompted). However, nearly half do not know which online source they used.

On the evidence of the very small numbers citing online sources, the BBC's spread *appears* reasonably wide by age - while mentions of New Scientist are confined exclusively to young ABs. Both are solely mentioned by white respondents.

Coverage on the internet

Q Please tell me on which website did you see this?



Base: All adults aged 15+ who read or heard anything on the internet about people choosing to donate their body, for medical education and training purposes, for use after their death (33), fieldwork dates: 20th - 26th August 2010

Ipsos MORI

Source: Ipsos MORI

