

Appendix III

Survey looking at the publics' views on donating biological samples for medical research

This survey was originally conducted online in September 2012 and hosted by the market research company Research Now.

Q1. What age are you?

1. 18-24
2. 25-34
3. 35-44
4. 45-54
5. 55-64
6. 65+

Q2. Are you male or female?

1. Male
2. Female

Q3. What is the occupation of person who receives the highest income in your household?

1. Higher managerial/ professional/ administrative (e.g. established doctor, solicitor, board director in a large organisation (200+ employees, top level civil servant/public service employee)) **(A – Letters will be hidden)**
2. Intermediate managerial/ professional/ administrative (e.g. newly qualified (under 3 years) doctor, solicitor, board director small organisation, middle manager in large organisation, principle officer in civil service/local government) **(B)**
3. Supervisory or clerical level/ junior managerial/ professional/ administrative (e.g. office worker, student doctor, foreman with 25+ employees, salesperson, etc) **(C1)**
4. Student **(C1)**
5. Skilled manual worker (e.g. skilled bricklayer, carpenter, plumber, painter, bus/ ambulance driver, HGV driver, AA patrolman, pub/bar worker, etc) **(C2)**
6. Semi or unskilled manual work (e.g. manual workers, all apprentices to be skilled trades, caretaker, park keeper, non-HGV driver, shop assistant) **(D)**
7. Casual worker – not in permanent employment **(E)**
8. Housewife/househusband/ homemaker **(E)**
9. Retired and living on state pension **(E)**
10. Unemployed or not working due to long-term sickness **(E)**
11. Full-time carer of other household member **(E)**
98. Other (specify)

Q4. What region do you live in?

1. Channel Islands
2. East of England
3. East Midlands
4. London
5. North East
6. North West
7. Northern Ireland
8. Scotland
9. South East
10. South West
11. Wales
12. West Midlands
13. Yorkshire / Humberside
96. Not on Map

Q5. Please choose one option that best describes your ethnic group or background.

1. White or White British
2. Mixed race
3. Asian or Asian British (not Chinese)
4. Black or Black British
5. Chinese
6. Other ethnic group
96. Prefer not to say

Q6. Which religion do you most identify with?

1. Christianity
2. Islam
3. Hinduism
4. Sikhism
5. Judaism
6. Buddhism
7. Other religion
8. No religion
96. Prefer not to say

Q7. If you do have a religion you identify with, to what extent do you consider yourself religious?

1. Not at all religious
2. Moderately religious
3. Very religious
96. Prefer not to say

Q8. Please indicate which, if any, is the highest educational or professional qualification you have obtained.

1. No formal qualification
2. GCSE, O level, Scottish Standard Grade or equivalent
3. GCE, A-level, Scottish Higher or similar
4. Vocational (BTEC/NVQ/Diploma)
5. Degree level or above
96. Prefer not to say

Q9. How would you describe your own level of knowledge about the medical research process including the use of human tissue samples?

1. No knowledge
2. Some knowledge
3. Good knowledge

Q10. Are you or have you ever been affected by a long-standing illness, disability or infirmity which has required continuous or frequent medical attention (e.g. cancer, diabetes, heart disease, asthma, a genetic condition)?

1. Yes
2. No

Q11. Has a close family member ever been affected by a long-standing illness, disability or infirmity which has required continuous or frequent medical attention (e.g. cancer, diabetes, heart disease, asthma, a genetic condition)?

1. Yes
2. No

Q12. Have you ever had blood or tissue removed during a medical or surgical procedure?

1. Yes
2. No
97. Don't know

Q13. Have you ever been asked to donate any blood or tissue for medical research?

1. Yes
2. No
97. Don't know

ASK IF CODED 1 AT Q13.

Q14. Did you agree to donate?

1. Yes
2. No
97. Don't know

ASK IF CODED 2 AT Q14.

Q14a. Please tell us a little bit about your reasons for choosing not to donate.

There are no right or wrong answers – we're just interested in your honest opinion.

This survey is being done to help us understand public opinion about human tissue samples donated by people for medical research.

Medical research is essential to improve our understanding of what keeps us healthy and how diseases start and progress. It also means scientists can develop new and improved treatments. Body fluid such as blood, saliva and urine, and human tissue such as cells, skin, fat or even whole organs (in the event of someone's death), are often used in scientific and medical research. Usually these are referred to as samples.

Types of research that need samples include:

- Looking at how the body works to fight disease.
- Looking at why some people are more likely to develop certain diseases.
- Developing tests to diagnose conditions like cancer or dementia earlier on.
- Testing new treatments for conditions such as heart disease and diabetes.
- Researching how certain types of cells could be used to treat conditions like Parkinson's disease and Alzheimer's disease.

Many of the tests and treatments used today resulted from people donating samples for research previously. The removal of samples from a person is always done with the donor's permission. Samples that are donated for research are anonymised so that the researcher using the sample does not know who it came from. The types of research that are allowed to take place are highly regulated by both UK law and also by independent research ethics committees (usually made up of doctors, scientist, patients and the general public). These ensure any research allowed to be done is for the benefit of patients.

The next button will appear shortly. In the meantime take some time to read the information above as it relates to the remainder of the survey.

Q15. On a scale of 1 to 5 with 1 being Not At All Important and 5 being Extremely Important, how important do you think it is for people to donate samples for medical research?

SCALE:

1. Not at all important
- 2.

- 3.
- 4.
5. Extremely important
97. Don't know

Q16. Samples can be left over from surgery or a medical procedure, or they can be donated specifically for research. Left over samples that are not required for clinical diagnosis or donated for medical research are often destroyed.

In general, would you like to be asked to donate samples for medical research?

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

RANDOMISE STATEMENTS

Q17. You are having a medical procedure to treat a health issue. Would you donate the following types of samples for medical research if they were left over (after necessary medical tests had been done) following the procedure?

SCALE:

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

STATEMENTS:

1. Blood
2. Skin tissue
3. Fat
4. Cancerous tissue
5. Liver tissue
6. Bone or cartilage
7. Spare eggs not fertilised during IVF treatment (IVF is a process by which an egg is fertilised by a sperm outside the body and then transferred back into the body to establish a successful pregnancy) **ASK ONLY FEMALES**
8. Spare embryos (fertilised eggs) not transferred back into the body following IVF (IVF is a process by which an egg is fertilised by a sperm outside the body and then transferred back into the body to establish a successful pregnancy)

RANDOMISE STATEMENTS

Q18. You've gone to the hospital for an appointment and whilst you are in the waiting room the receptionist explains they are collecting samples for medical research. Would you agree to donate the following types of samples specifically for medical research, i.e. not as part of any medical procedure, but purely for the purposes of research?

Would you agree to donate the following types of samples specifically for medical research?
Below are some definitions you might need to know in order to answer the questions.

Local anaesthetic - "A type of painkilling medication that is used to numb areas of the body during surgical procedures. You stay awake when you have a local anaesthetic"

General anaesthetic - "A medication that causes loss of sensation. It is used to give pain relief during surgery. General anaesthetic makes you completely lose consciousness so that surgery can be carried out without causing any pain or discomfort. Most healthy people don't have any problems when having a general anaesthetic. However, as with most medical procedures, there is a small risk of long-term complications and, rarely, death."

SCALE:

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

STATEMENTS:

1. Saliva
2. Urine
3. Blood
4. Tissue collected requiring a local anaesthetic (e.g. a skin cell scraping)
5. Tissue collected requiring a general anaesthetic (e.g. a liver sample)
6. Sperm **ASK ONLY MALES**

Q19. In the event of your death, would you be willing to donate the following for medical research?

SCALE:

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

STATEMENTS:

1. A small sample of the liver
2. A small sample of the brain
3. A whole liver
4. A whole brain

Q20. You are having surgery for a health issue which requires a general anaesthetic. The surgeon asks you whether you would be willing to consent to any additional tissue (i.e. tissue not needing to be removed as part of the health issue) being taken during the surgery for medical research. He assures you that any additional tissue taken would have no impact for you or your health and that no extra tissue would be removed without your consent.

A decision to consent or not to consent would be equally respected and would have no impact on the care you receive.

Would you be willing to donate the following types of samples for medical research?

General anaesthetic - "A medication that causes loss of sensation. It is used to give pain relief during surgery. General anaesthetic makes you completely lose consciousness so that surgery can be carried out without causing any pain or discomfort. Most healthy people don't have any problems when having a general anaesthetic. However, as with most medical procedures, there is a small risk of long-term complications and, rarely, death."

SCALE:

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

STATEMENTS:

1. Samples taken from the same part of the body being operated on
2. Samples taken from an area close by
3. Samples involving an additional procedure e.g. taking bone marrow or a tissue sample whilst under the same general anaesthetic

RANDOMISE STATEMENTS

Q21. Samples may be used for lots of different types of research. The types of research that are allowed to take place are highly regulated by both UK law and also by research ethics committees. Would you be willing to donate samples for the following types of research?

Research ethics committee - "A committee usually made up of doctors, scientist, patients and the general public. These ensure any research allowed to be done is for the benefit of patients."

SCALE:

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

STATEMENTS:

1. Understanding how our body fights disease
2. Understanding how our genetic makeup influences whether or not we will be affected by certain conditions
3. Testing new treatments
4. Research which involves using cells that come from embryos (*fertilised eggs*)
5. Research involving animals
6. Research conducted outside of the UK

RANDOMISE ORDER OF STATEMENTS.

Q22. There are many places where research is performed, such as universities, the NHS, medical research charities such as Cancer Research UK and Arthritis Research UK, pharmaceutical companies and diagnostic companies. These organisations work individually, and often in collaboration, to carry out research, to understand disease, develop tests for diseases and develop and test new treatments.

Would you be willing to donate samples to the following organisations to carry out approved medical research?

Diagnostic companies - "A company which develops and manufactures medical tests to diagnose diseases"

SCALE:

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

STATEMENTS

1. NHS hospitals
2. Universities
3. Medical research charities
4. Pharmaceutical companies
5. Diagnostic companies

Q23. Samples left over following surgery and once any necessary tests have been done, can be anonymised and used for medical research. On a scale of 1 to 5 with 1 being Not At All Important and 5 being Extremely Important, how important do you think it is that you are first asked for your permission (often known as 'consent') for any left over samples to be used for medical research?
Anonymised - i.e. identifying features such as names and addresses are removed

SCALE:

1. Not at all important
- 2.
- 3.
- 4.
5. Extremely important

Q24. There are a number of different ways that a person could give consent for their left over samples to be used for medical research.

- a) One way is an 'opt-in' system. Opt-in means that a person must specifically be asked for their permission before any leftover samples can be used in medical research.
- b) The other way is an 'opt-out' system. In this system, it is assumed that a person is happy, after they turn 18 years old, for any leftover samples to be used for medical research unless they specifically say otherwise.

Which of the two systems to donating leftover samples do you prefer?

1. Opt-in
2. Opt-out
3. No preference
97. Don't know

Q25. The current system in the UK is an opt-in system. That means you have to say whether you want any leftover samples to be donated for medical research. If you were going to be asked to donate any leftover samples for medical research there are three ways this could be done.

- a) You could be asked to give consent for left over samples to be used for research **every time** you have samples removed, or
- b) you could be asked just **once for life** for any future left over samples to be used for medical research (with the option of withdrawing your permission at any later point if you wanted to),
- c) you could be **asked at certain points** during your life, for example every 10 years by your GP, or at the start of treatment for a particular condition or health issue.

Which of these three approaches do you prefer?

1. Consent every time
2. Consent once for life
3. Consent at certain points
4. No preference
97. Don't know

Q26. If you were going to be asked to donate left over samples for medical research every time you had a medical procedure, would you rather this was discussed with you by a health professional before the medical procedure or afterwards?

1. Before
2. After
3. No preference
97. Don't know

Q27. If we adopted a consent once for life system in the UK for adults (i.e. aged 18 years and over), when would you prefer to be asked about consenting left over samples for medical research? *Choose up to 3 options.*

1. When registering at a GP surgery
2. During a routine GP appointment
3. When applying for a driving license
4. When applying for a passport
5. The first time I visit the hospital
6. The first time I have a medical procedure (e.g. blood test or surgery)
98. Other (please specify)

Q28. What would be your preferred way to register your consent to donate left over samples for medical research?

1. Face to face with a health professional
2. Letter
3. Email
4. Telephone
5. Via a website
6. Completing a form (from a GP surgery, post office, library or other community centre) and returning it by post
98. Other (please specify)
97. Don't know

Q29. If you later decided you didn't want your samples to be used for medical research, what would be your preferred way to withdraw that consent?

1. Face to face with a health professional
2. Letter
3. Email
4. Telephone
5. Via a website
6. Completing a form (from a GP surgery, post office, library or other community centre) and returning it by post
98. Other (please specify)
97. Don't know

Q30. Imagine you have agreed to donate a sample for medical research. There are a number of ways you can give consent for that particular sample to be used:

STATEMENTS

1. You can give consent once for your sample to be used in any future research that has been approved by a research ethics committee. This type of consent is called Generic Consent.

Thinking about Generic Consent, if this was the type of consent you were asked to give, how likely would you be to donate samples for medical research?

Research ethics committee. "A committee usually made up of doctors, scientist, patients and the general public. These ensure any research allowed to be done is for the benefit of patients."

2. You can give consent once for your sample to be used in any future research that has been approved by a research ethics committee but with the option of saying whether there are certain types of research you don't want your sample to be used for. This type of consent is called Tiered Consent.

Thinking about Tiered Consent, if this was the type of consent you were asked to give, how likely would you be to donate samples for medical research?

Research ethics committee. "A committee usually made up of doctors, scientist, patients and the general public. These ensure any research allowed to be done is for the benefit of patients."

3. You can give consent once for the sample to be used for a specific study that you have been told about, which has been approved by a research ethics committee. The sample will not be used for any other research other than the particular study you have given consent for. Any leftover tissue at the end of the study may be destroyed. This type of consent is called Specific Consent – once only.

Thinking about Specific Consent – once only, if this was the type of consent you were asked to give, how likely would you be to donate samples for medical research?

Research ethics committee. "A committee usually made up of doctors, scientist, patients and the general public. These ensure any research allowed to be done is for the benefit of patients."

4. **Lastly**, you can give consent every time for the sample to be used for a specific study that you have been told about, which has been approved by a research ethics committee. With this type of consent you would then be contacted and asked for your consent for every new study in which your sample might be used. This type of consent is called Consent for every new study.

Thinking about Consent for every new study if this was the type of consent you were asked to give, how likely would you be to donate samples for medical research?

Research ethics committee. "A committee usually made up of doctors, scientist, patients and the general public. These ensure any research allowed to be done is for the benefit of patients."

SCALE:

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

Q31. Which of these four types of consent do you prefer? Please rank them in order of preference. Put 1 for your first preference; 2 for your second; 3 for your third preference and 4 for your last preference. If you don't have any preference, and like all 4 equally, tick the 'No preference' you don't know then tick 'Don't know'

1. Generic consent
2. Tiered consent
3. Specific consent – once only
4. Consent for every new study
5. No preference
97. Don't know

ASK TO THOSE PEOPLE WHO DID NOT RANK GENERIC CONSENT AS FIRST CHOICE

Q32. Generic consent is the most practical type of consent as it is the least costly to put in place. Researchers try their very best to honour donors' wishes, but in some cases where it is too costly to put Tiered or Specific Consent in place, instead of risking using a sample for something the donor feels strongly against, it won't be used at all. If Tiered or Specific consent was not available, what would you do?

1. I would agree to give generic consent
2. I would rather my sample was not used at all
97. Don't know

Q33. Some people feel there are certain types of samples that are more sensitive to donate, for example sperm or left over eggs. If there was a sample that you considered to be sensitive, but were still willing to donate for medical research, which of the four types of consent would you prefer to give?

1. Generic consent
2. Tiered consent
3. Specific consent – once only
4. Consent for every new study
5. No preference
97. Don't know

Q34. Researchers often need to have access to the donor's medical records to be able to interpret the results of their scientific research. However, information such as names or addresses are always removed and are not included with the sample. This is so that the person who donated the sample cannot be identified by the scientist conducting the research or anyone analysing the results of the research. However, the sample may have a code so that someone not involved in the research can identify the individual if necessary, for example, if there was a serious health issue the donor should be aware of.

Would you be willing to have your anonymised medical records linked to your sample?

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

Q35. Sometimes it can also be helpful for the researcher to have certain information about the lifestyle of the person who donated the sample, for example whether they smoke, drink alcohol, how often they exercise etc. This information might help them to better understand the particular

condition they are investigating. Would you be willing to have your anonymised lifestyle information linked to your sample?

1. Definitely yes
2. Probably yes
3. Probably not
4. Definitely not
97. Don't know

Q36. For some people, it would be interesting to find out what type of medical research is going on. How would you like to get information on medical research including research on a particular condition that might use your sample?

1. Website
2. Newsletter
3. Email
4. Letter
5. Would not be interested in additional information

Q37. If you were considering donating whole organs for medical research in the event of your death, are there any particular organs you would **not** feel comfortable donating?

Please choose all that apply.

1. Brain
 2. Eyes
 3. Heart
 4. Kidneys
 5. Liver
 6. Lungs
 7. I would not donate any of my organs for medical research
 8. None of the above apply as I would be happy to donate either all my organs or whole body for research
98. Other organs I would not donate (please state)

Q38. Sometimes, organs donated for transplant can't be transplanted because for some reason they are not suitable. However, these organs can still be very useful to researchers. Would you be willing to donate organs you had intended for transplant for medical research instead if the organ was not suitable?

1. Yes, I would donate an organ for research if it was not suitable for transplant
2. No, if they can't be used for transplant I would prefer they were not used at all
3. I would not agree to donate an organ for transplant

97. Don't know

Q39. If someone wanted to donate their tissue or organs for medical research in the event of their death, how do you think they should be able to provide their consent to do this?

1. It should be obtained at the same time as consent for organ transplantation and recorded on the organ donor register
 2. It should be discussed at a GP appointment and recorded in the patients' notes
 3. It should be discussed at a hospital and recorded in the patients' notes
98. Other (please specify)
97. Don't know

Q40. Someone has indicated in writing that they are willing to donate tissue or organs for medical research in the event of their death. After the donor's death the relatives decide they disagree with the donor's wishes. Do you think the relatives should be allowed to override the donor's wishes?

1. Yes
 2. No
97. Don't know

Q41. If you have any particular views you would like to share with us about the topics raised in this questionnaire please feel free to write them here: