

Questionnaire and Data Key

Note – Below, the italics represent the name of the variable in the datafile

Demographic and Donation Information

We would like to know some information about you. Please answer the following questions.

Age

What is your age?

Sex

What is your sex?

- Male (1)
- Female (2)
- Other (please specify) (3) _____ - *Sex_other*
- Prefer not to say (4)

Donor_status

We would like to know about your decision to donate your organs after you die. Which of the following applies to you?

- I have registered a decision to donate my organs after I die (i.e., have opted in) (1)
- I have registered a decision **not to donate** my organs after I die (i.e., have opted out) (2)
- I have not registered a decision about what should happen to my organs when I die (3)

Donate_blood

Have you ever donated blood?

- No (1)
- Yes (2)
-

Wales_2015

Were you living in Wales before December 2015?

- No (1)
- Yes (2)
-

over18_2015

Where you 18 years or older in December 2015?

- No (1)
- Yes (2)
-

Donor_status_2015

Prior to December 2015, Wales used a different system for organ donation. In this system people could either a) register as an organ donor or b) not register as an organ donor. It was assumed that people who did not register did not want their organs to be used. Please state whether or not you registered a decision to be an organ donor prior to December 2015?

- I did not register as an organ donor (1)
- I had register as an organ donor (2)
-

Information about Organ Donation in Wales

First, we would like to let you know about organ donation in Wales.

In Wales, people can either:

- 1) Register they want to be a donor. These people are registered donors
- 2) Register they do not want to be a donor. These people are registered non-donors
- 3) Not register a decision. These people are assumed to agree with their organs being used. This is called 'deemed consent'

Organ transplantation can only happen in some situations.

Someone can be a donor if they died from a severe brain injury. This is called brain stem death.

Someone can also be a donor if they died from a loss of heart and lung function. This is called circulatory death.

After brain stem or circulatory death, the deceased's family are asked to think about organ transplantation. A specialist nurse will usually have a chat with the family. This nurse will tell them if the deceased has registered a decision.

The family can also discuss any chats they had with the deceased about donation. For example, the deceased may have registered as a donor. Later, they may have said to their family they changed their mind. In this chat, the family can tell this to the nurse.

The family and nurse then discuss whether the deceased's organs can be used. Organ transplantation only occurs if the family agree. This means family members have the final say.

Experimental Conditions Varying Deceased Donor Status

Text for participants in the registered donor condition

Next, please imagine the following scenario as vividly as possible.

Please imagine that a close family member has died after an accident. The death was caused by a severe brain injury. This means it was a brain stem death. This person lived and died in Wales. They had not discussed organ donation with you before they died.

This family member registered a decision. They registered as an organ donor. This means they wanted their organs to be used for transplantation after they died.

We would like you to consider whether or not you would support your family member's organs and tissues being used for transplantation.

It can be difficult to decide. Please think very carefully before making this decision.

Text for participants in the registered non-donor condition

Next, please imagine the following scenario as vividly as possible

Please imagine that a close family member has died after an accident. The death was caused by a severe brain injury. This means it was a brain stem death. This person lived and died in Wales. They had not discussed organ donation with you before they died.

This family member registered a decision. They registered as a non-donor. This means they did not want their organs to be used for transplantation after they died.

We would like you to consider whether or not you would support your family member's organs and tissues being used for transplantation.

It can be difficult to decide. Please think very carefully before making this decision.

Text for participants in the not registered condition

Next, please imagine the following scenario as vividly as possible.

Please imagine that a close family member has died after an accident. The death was caused by a severe brain injury. This means it was a brain stem death. This person lived and died in Wales. They had not discussed organ donation with you before they died.

This family member did not register a decision. Wales uses deemed consent. This means the person is assumed to have wanted their organs to be used for transplantation when they died.

We would like you to consider whether or not you would support your family member's organs and tissues being used for transplantation.

It can be difficult to decide. Please think very carefully before making this decision.

Note – The text that participants receive is indicated in the 'Cond' variable (0 = not registered, 1 = non-donor and 2 = donor)

Uncertainty about the Deceased's Wishes Measure

We would like to know your thoughts about the decision you made regarding donating your family member's organs. Please answer the following questions.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
I am unsure whether or not the deceased family member would support a decision to donate their organs (<i>uncertain1</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is clear what the deceased family member would want in this situation (<i>uncertain2</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not know what the deceased would want to happen to their organs (<i>uncertain3</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Anticipated Regret Measure

We would like to know your feelings about the decision you made regarding donating your deceased family member's organs. Please answer the following questions.

	Not at all (1)	A little (2)	Somewhat (3)	Moderately (4)	Very much so (5)
If I did not allow my family member's organs to be used for transplantation purposes I would regret it later (AR1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I did not allow my family member's organs to be used for transplantation purposes I would later wish that I had (AR2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Intention of Next-of-Kin to Approve of Organ Donation

Next, please think about the scenario we described earlier. We would like to know how likely or unlikely you are to donate your deceased family member's organs.

A number of organs can be transplanted after death. These include heart, lungs, kidneys, liver, corneas, pancreas, small bowel and tissue (e.g., skin, bone and tendons). We would like to know how likely or unlikely you are to allow each of these organs to be transplanted from your deceased family member. In this hypothetical scenario, how likely are you to donate your deceased family member's...

	No, not at all (1)	Very unlikely (2)	Neutral - cannot decide (3)	Very likely (4)	Yes, definitely (5)
Heart (<i>heart</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lungs (<i>lungs</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kidneys (<i>kidneys</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Liver (<i>liver</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Corneas (<i>corneas</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pancreas (<i>pancreas</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tissue (e.g., skin, bone and tendons) (<i>tissue</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Small bowel (<i>small_bowel</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Affective Attitudes Measure (O'Carroll et al., 2011)

Next, we would like to know your thoughts about organ donation. Please answer the following questions.

	Strongly disagree (1)	Moderately disagree (2)	Slightly disagree (3)	Neither agree nor disagree (4)	Slightly agree (5)	Moderately agree (6)	Strongly agree (7)
Removing organs from the body just isn't right (B1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The body should be kept whole for burial (B2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Organ donation allows something positive to come out of a person's death (PB1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Organ donation helps to bring meaning to the death of a loved one (PB2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospitals sometimes prescribe medication as a way of experimenting on people without their knowledge or consent (MM1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If I sign an organ donor card, doctors might take my organs before I'm actually dead (MM2)

Sometimes, medical procedures are done on people without their consent (MM3)

If I sign an organ donor card, doctors might not try so hard to save my life (MM4)

The idea of organ donation is somewhat disgusting (Ick1)

I wouldn't like the idea of having another person's organs inside of me, even if I needed an organ transplant (Ick2)

The thought of organ donation makes me uncomfortable (Ick3)

People who donate their organs risk displeasing God or nature
(*jinx1*)

The surest way to bring about my own death is to make plans for it like signing an organ donor card
(*jinx2*)

Organ donors may not be resurrected because they don't have all of their "parts"
(*jinx3*)

Organ donors are heroic because they save lives
(*PB3*)

Donating organs would allow part of me to live after I die
(*PB4*)

Risk Aversion Measure (Bibby & Ferguson, 2011)

Below are 10 hypothetical lotteries. Please indicate for each lottery whether you would 'accept' it (i.e., play this lottery) or 'reject' it and not receive anything.

	Reject (1)	Accept (2)
If a coin turns up heads, then you lose £2; if a coin turns up tails, you win £10 (<i>lott1</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £3; if a coin turns up tails, you win £10 (<i>lott2</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £4; if a coin turns up tails, you win £10 (<i>lott3</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £5; if a coin turns up tails, you win £10 (<i>lott4</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £6; if a coin turns up tails, you win £10 (<i>lott5</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £7; if a coin turns up tails, you win £10 (<i>lott6</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £8; if a coin turns up tails, you win £10 (<i>lott7</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £9; if a coin turns up tails, you win £10 (<i>lott8</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £10; if a coin turns up tails, you win £10 (<i>lott9</i>)	<input type="radio"/>	<input type="radio"/>
If a coin turns up heads, then you lose £11; if a coin turns up tails, you win £10 (<i>lott10</i>)	<input type="radio"/>	<input type="radio"/>