



Consent to Organ and Tissue Donation for Research: Donor Family Survey Results

Background

The UK Organ Donation and Transplantation Research Network (UKODTRN) and the Donor Family Network have worked in collaboration to share a survey asking family members of organ and tissue donors about their views on donation for research.

We wanted to better understand the reasons why families may say yes or no to organ and tissue donation for research, and asked about their experiences, knowledge, attitudes, and suggestions on this topic.

The Donor Family Network shared the survey with their members between 27th June and 11th July 2025.

The survey received 202 responses.

Findings: Experience of Organ Donation

Consent to donation for transplantation and research

98% of respondents agreed to the donation of solid organs for transplantation, and 81% agreed to the donation of tissue for transplantation.

At the time of donation, 62% of people were asked about donation of solid organs or tissue for research, and 86% of those asked consented to it.

Reasons for non-consent to donation for research

We asked the 18 people who did not consent to the donation of solid organs or tissue for research to share the reasons why they did not. Some stated they were simply honouring the donors wishes or did not feel comfortable with this type of donation; others related to the ways in which donation for research is understood and perceived.

Some respondents mentioned a lack of understanding about the process:

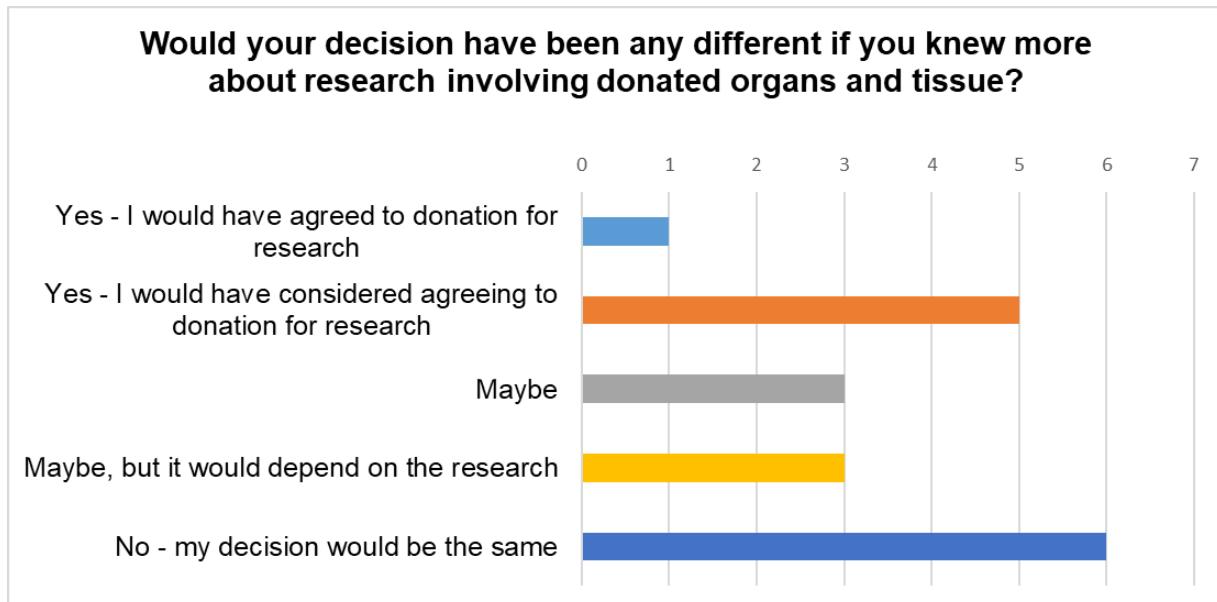
“I don't think I fully understood at that time”

Others suggested they saw less immediate personal benefit from research than transplantation:

“When they say research it sounds like science but with donation to a person it feels more personal”



Of those who did not consent to donation for research, 12 stated their decision would have- or might have- been different if they knew more about research involving donated organs and tissue.

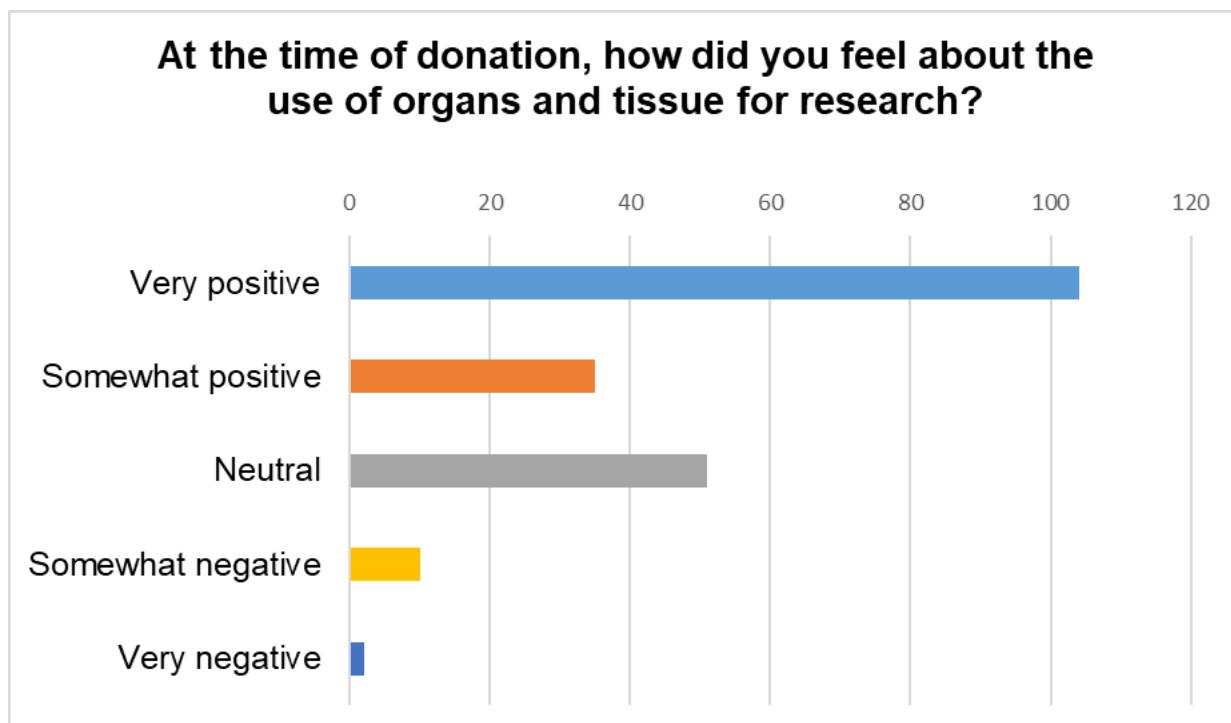


Those who listed a lack of understanding as the reason they did not consent answered 'Yes – I would have considered agreeing to donation for research' to this question.

Findings: Knowledge and Attitudes

Knowledge and attitudes towards donation for research

Most respondents felt 'Very positive' (51%) about the use of organs and tissue for research, with only 6% feeling either 'Somewhat negative' or 'Very negative'.

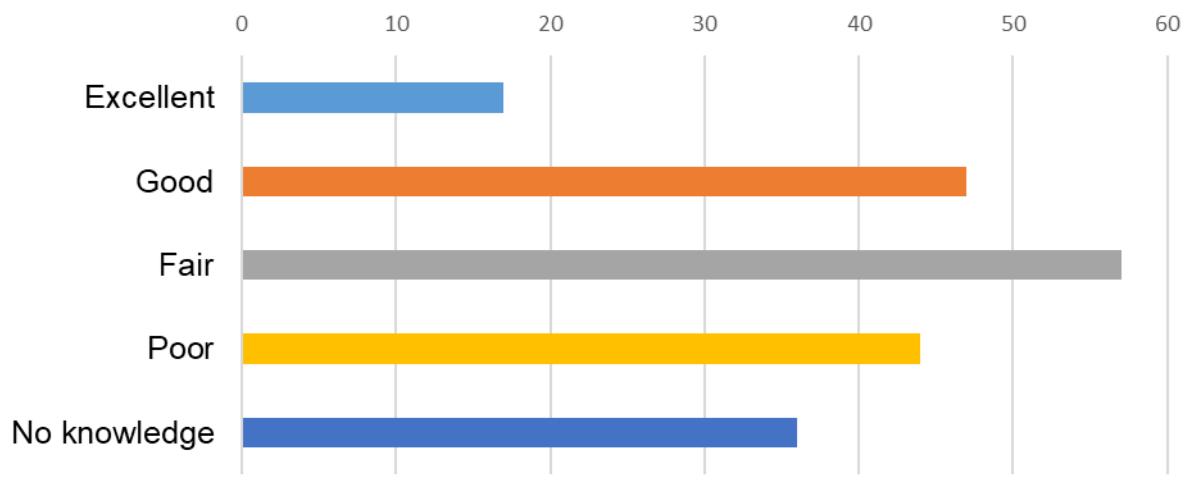




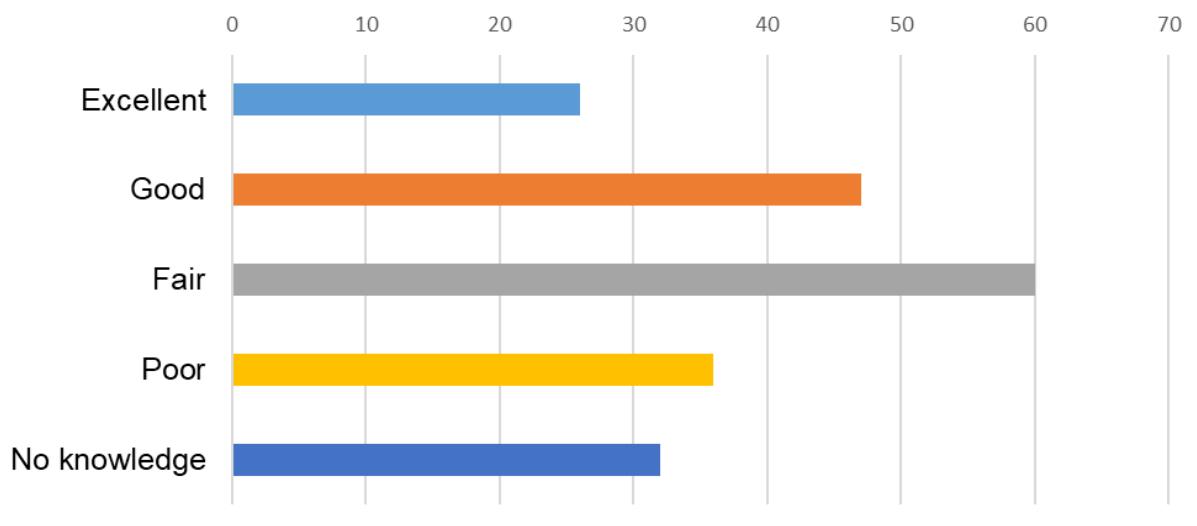
Despite many reporting positive attitudes towards this type of research, knowledge about how donated organs and tissues are used in research and the potential benefits of such research was weaker.

The most frequent answer from respondents when asked to rate their knowledge of the ways in which donated organs or tissues may be used in research and the potential benefits of such research was 'Fair' (approximately 30% in both cases).

At the time of donation, how would you rate your knowledge of the ways in which donated organs or tissues may be used in research?



At the time of donation, how would you rate your knowledge of the potential benefits of using donated organs or tissues in research?



Findings: Suggestions



90% of respondents believed that the public should receive more information about the potential use of human organs and tissues in research.

We asked respondents for suggestions about how donation for research could be better communicated with families of potential donors. This question received 95 responses, of which 65 could be sorted into two categories:

1. Information at the point of donation
2. Public awareness and education

1: Information at the point of donation

17 respondents suggested that research could be better communicated with families of potential donors by referencing examples of specific studies that have used donated organs or tissue and discussing the potential benefits of such research. One answer stated:

“it needs humanising somewhat maybe with specific examples of how research thus far has improved methods of survival rates from some diseases or case studies that show someone who has directly benefitted from something that came out of research”

9 respondents suggested alternative ways of presenting information to families of potential donors; these included providing leaflets, showing a video, and creating a specialist informative app. It was also stated that all information should be provided in plain language.

“Maybe a simple leaflet - with just a few of recent success stories”

3 people suggested that families should be told more specific information about what will happen to the donor's organs and how they will be used. However, some specified this level of detail should only be provided to those who want to know more, and others suggested families may be less likely to agree to donation if they feel “pushed” into it.

2: Public awareness and education

26 respondents suggested there should be more public awareness and education about the benefits of organ or tissue donation for research, so families are already aware of the topic when faced with the decision. One answer stated:

“we were aware of organ donation... but we had no knowledge at all about donation for research... Organ donation should be promoted much more to people. I think it still feels like a taboo subject that people don't understand so they don't think about it or discuss it. Education is the way forward”



Another suggested:

“awareness before you are in that situation would be beneficial so it's not new when you are dealing with the death of a loved one”

Proposed means of education included social media campaigns, school or university curriculum, documentaries, advertising, and GP surgeries and hospitals.