

From donation to transplantation: organ procurement and allocation experiences and challenges

Call for volunteers for in-depth interviews

Who is implementing the research?

The research investigator is Marie Le Clainche - Piel, PhD. I am a sociologist, permanent research fellow at the French National Centre for Scientific Research (CNRS) and attached to the Cermes3 laboratory specialized in the study of health and science.

Who can volunteer?

I invite anyone willing to share their experience of organ donation, transplantation and allocation: donor, recipient, relative of donor or recipient, activist, etc. As much as possible, I come wherever it is best for you across the UK and the USA (NYC, Boston) to meet you. When this is not possible, I propose a meeting by videoconference.

What is the aim of this research project?

This research project funded by the CNRS (2022-2027) looks at the plurality of practices and experiences of organ procurement and transplantation, and the logic for organ allocation in the United Kingdom, France and the United States. In a global context where not every patient on the waiting lists will receive an organ, how do institutions and professionals organise their procurement, allocation and transplantation? How do they tackle the challenges of health disparities? How do living donors, relatives of deceased donors and patients experience the procurement and allocation processes?

There are two principal research orientations. One is to shed light on the logic and practices of procurement and allocation thought to be fair, effective and acceptable in each country since the 1980s. The second one is to study the concrete tools (scores, algorithms, lists, campaigns, etc.), medical categories and legal frameworks that are developed to organise and optimise this activity, as well as the everyday challenges faced in this process by institutions, professionals, donors and recipients nowadays.

This research contributes to deepening the socio-anthropological understanding of organ donation, allocation and transplantation, and promotes reflexive dynamics.

What questions do I ask?

We will talk about your personal or activist trajectory and experience in the field of organ donation, allocation and transplant. The in-depth interview methodology allows space to share experiences, ideas, practices and feelings.

The items that can be discussed include:

- Body history and illness experience.
- Waiting list and waiting times.
- The steps of your journey as a donor or recipient of an organ.
- Donor-recipient relationships and challenges.
- Organ procurement legal framework and its impact on your personal history.
- Activism, awareness activities, involvement in charities or collective events.
- Personal background: potential personal history related to organ donation and transplantation prior to your involvement, and any element you want to share or feel pertinent.

How does an interview work?

If you agree to contribute to this sociological research, our in-depth interview will take as much time as you are comfortable with – usually between 1 and 2 hours but there is no standard. I don't anticipate that there are any risks associated with your participation, but you have the right to stop the interview or withdraw from the research at any time.

Per ethical standards for academic social science research:

- With your consent, the interview can be recorded to facilitate the active listening from the interviewer.
- You will have the opportunity to request the transcript and to comment, erase or complete any element we discussed.
- Summary interview content or direct quotations from the interview that would be made available through an academic publication will be anonymised.

How do we get in touch?

If you are willing to be interviewed or if you have any question about this research, please contact me. Thank you very much for your precious time and consideration.

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