

## Summary of Results for Research Participants

# Organ Donation and Mechanisms of Trust in the Medical System

Thank you very much for participating in our research. This research was conducted for Amie Brook's Honours thesis in Psychology at The University of Queensland.

### Brief background

Transplantation requires compatible blood and tissue types between donors and recipients, which most often occurs between people with the same race/ethnicity. Due to organ shortages globally, patients – particularly people from ethnic minority groups – are left on waiting lists indefinitely or die before receiving a transplant. Organ donation rates need to increase. Currently, some campaigns are directed at ethnic minority groups and promote the idea that if more people from these communities sign up to be organ donors, the chances of organs being given to people from the same background (ingroup) will increase. For example, a recent National Health Service Blood and Transplant (UK) campaign included the following:

*“While some people with a Black or Asian background go on to donate when they die each year, this is not enough to meet the needs of all patients waiting for a transplant from those communities [...] **You could help improve the chances of black, Asian and other minority ethnic community patients getting the transplant they need by signing up to the NHS Organ Donor Register.**”*

National Health Service Blood and Transplant. (2019). Organ donation and ethnicity. Retrieved from <https://www.organdonation.nhs.uk/helping-you-to-decide/organ-donation-and-ethnicity/>

However, allocation of organs is not solely limited to compatibility of blood and tissue types, there are other criteria that also determine who receives an organ transplant. These campaigns promote unrealistic expectations about organ donation that may not be met (breached) and could worsen mistrust. Medical mistrust already contributes to lower consent rates and greater organ shortages amongst these populations.

According to Psychological Contract Breach (PCB) theory, “breached expectations” often result in people losing trust and performing fewer behaviours that support the other party (e.g., medical systems). We applied PCB theory in the context of organ donation, amongst disadvantaged and advantaged groups. Queensland residents (students and Prolific online panel users) were given real data presenting Queensland's organ donation system as disadvantaged or advantaged compared to New South Wales.

We then explored whether there was any effect of breaching people's organ donation expectations when they belonged to and identified with a disadvantaged or advantaged group (advantaged or disadvantaged in terms of how many organ donations their group receives). We indicated to participants (gave them expectations) that the organs of their close relative would be donated to an ingroup member. We then explored the effect of these expectations being **met** (the recipient of the organs belongs to the ingroup) or **breached** (the recipient belongs to the outgroup), on participants' attitudes towards organ donation/medical systems, as well as their behavioural intentions related to organ donation (e.g., willingness to donate, joining the organ donor register).

We hypothesised that disadvantaged participants would show greater levels of trust in medical/organ donation systems, and stronger behavioural intentions related to organ donation, when their expectations were **met** (i.e., they believed their close relative's organ donation would be received by an ingroup member, and this occurred) compared to disadvantaged participants who had their expectations **breached** (i.e., they believe their close relative's organ donation would be received by an ingroup member, and this did not occur).

## Research Participant Characteristics

A total of 414 Queensland residents provided complete data for this research program which included three studies (Pilot study, Study 1, Study 2). The Queensland participants were of Australian nationality, aged 18 years or older, and only participated in one of the three studies. Specific participant characteristics for each study are listed below.

### Pilot Study

#### 'Identity and organ donation attitudes'

This study tested materials that would be used for Study 1 and 2.

Survey Participant Characteristics:

- Surveys completed May to June 2020
- 73 participants
- Aged 18-79 years (average age 35 years)
- Mostly female (64%)
- 45% reported being a registered organ donor

Participants wrote about what it means to be a Queenslander for three minutes. They were then provided with information sheets that presented Queensland's organ donation system as either disadvantaged or advantaged compared to New South Wales.

Research Questions:

- RQ1: Does writing about what it means to be a Queenslander increase the salience of one's Queensland identity?  
Answer: Yes.
- RQ2: When participants read information sheets that present Queensland's organ donation system as either advantaged or disadvantaged compared to New South Wales, do participants then identify Queensland's organ donation system as advantaged or disadvantaged?  
Answer: Yes.

The two manipulations were effective and therefore used for Study 1 and 2 below.

### Study 1

#### 'Organ donation and allocation for Queensland residents: Study 1'

Survey Participant Characteristics:

- Surveys completed June to July 2020
- 157 participants
- Aged 18-82 years (average age 34 years)
- Mostly male (56%)

- 43% reported being a registered organ donor

Participants were provided with information sheets that presented Queensland's organ donation system as disadvantaged compared to New South Wales. Additionally, participants were asked to imagine their close relative's organ donation was expected to increase the chances of an organ transplant for a Queensland recipient (i.e., an ingroup member). Participants were then told the recipient would actually be from either Queensland (ingroup, i.e., expectations were **met**) or New South Wales (outgroup, i.e., expectations were **breached**).

Research Questions and Summary of Results:

RQ3: Compared to disadvantaged participants who have their expectations about organ donation **breached**, do disadvantaged participants who have their expectations about organ donation **met** demonstrate...

- RQ3a: Greater trust in medical systems?
- RQ3b: Greater trust in organ donation systems?
- RQ3c: More intentions to donate their own organs, donate a close relative's organs, or join the Australian Organ Donor Register?
- RQ3d: A greater likelihood of visiting the Australian Organ Donor Register website?
- Answers for RQ3a to RQ3d: No. Contrary to expectations, there were no differences between participants who had their expectations about organ donation breached or met.

## Study 2

### 'Organ donation and allocation for Queensland residents: Study 2'

Following the unexpected results of Study 1, we hypothesised that **advantaged** group members would be more reactive to met/breached expectations than **disadvantaged** group members. We also hypothesised there would be greater levels of trust in medical/organ donation systems, and stronger behavioural intentions related to organ donation, amongst **advantaged** group members who had their expectations **met** (i.e., they believed their close relative's organ donation would be received by an ingroup member, and this occurred), compared to **disadvantaged** group members who had their expectations **breached** (i.e., they believe their close relative's organ donation would be received by an ingroup member, and this did not occur).

Survey Participant Characteristics:

- Surveys completed August to November 2020
- 184 participants
- Aged 18-68 years (average age 23 years)
- Mostly female (66%)
- 31% reported being a registered organ donor

Research Questions and Summary of Results:

RQ4: Are **advantaged** participants more *reactive* than **disadvantaged** participants about organ donation expectations being met/breached? (i.e., will differences in trust levels and behavioural intentions when expectations are **met** vs **breached** be *greater* amongst **advantaged** participants

than **disadvantaged** participants?)

Answer: No.

**RQ5:** Compared to **disadvantaged** participants who have their expectations about organ donation **breached**, do **advantaged** participants who have their expectations about organ donation **met** demonstrate...

- **RQ5a:** Greater trust in medical systems?  
Answer: Regardless of belonging to an **advantaged/disadvantaged** group, participants who experienced **breached** expectations showed greater medical mistrust based on their Queensland identity.
- **RQ5b:** Greater trust in organ donation systems?  
Answer: Regardless of belonging to an **advantaged/disadvantaged** group, participants who experienced **breached** expectations were more likely to report other Queenslanders as having low levels of trust in Australia's organ donation system.
- **RQ5c:** More intentions to donate their own organs, donate a close relative's organs, or join the Australian Organ Donor Register?  
Answer: No.
- **RQ5d:** A greater likelihood of visiting the Australian Organ Donor Register website?  
Answer: No.


## Take Home Message

The purpose of this research was to explore the effect of organ donation expectations being breached when people belong to a group that is disadvantaged in terms of how many organ transplants their group receives. We wanted to determine whether people in a disadvantaged group would show less trust in medical/organ donation systems, and weaker behavioural intentions related to organ donation, when their expectations about organ donation were not met. Further, we also examined if this effect was strongest when compared to advantaged groups whose expectations were met.

Evidence was mixed. In Study 1, breached expectations did *not* lead to disadvantaged groups having less trust in medical/organ donation systems, nor weaker behavioural intentions related to organ donation. In Study 2, however, breached expectations *did* lead to participants (both disadvantaged AND advantaged) reporting greater levels of medical mistrust based on their Queensland identity, as well as perceiving other Queenslanders as having lower trust in Australia's organ donation system. In summary, evidence that breached expectations have a negative impact on trust/behavioural intentions in the context of organ donation, particularly amongst disadvantaged groups, was partial and incomplete.

## Limitations of the study

This research included effective manipulations of group status and social identity; however, it was limited by our use of 'Queensland' identity, in place of the more central identity of interest such as ethnicity. Being a Queenslander may have been too weak as a social identity to detect PCB effects when PBC was based on ingroup/outgroup outcomes.



In addition, participants were also recruited through different systems (Prolific online panel, students) and average age of participants differed, with age known to impact PCB effects (Study 2 participants were younger). Given time constraints, this thesis also did not manipulate expectations (expectations for an ingroup recipient were held constant), only group status and outcomes.

### **Future directions for research**

Future research may find stronger effects of PCB, if studies better reflect the strength of feelings and identities involved. Specifically, future research would benefit from using more central identities (e.g., ethnic group) and providing materials that felt “real” (e.g., articles about organ donation systems meeting or breaching expectations). It is recommended that this research also controls for age. Future research should also expand upon the variables manipulated in this thesis to include expectations that are varied (ingroup/outgroup recipient).

### **Practical implications of the research**

Organ donation campaigns should provide clear information about the allocation process to avoid confusion or inadvertently communicating expectations that may not be met. Similarly, organ donor focused organisations should investigate how audiences perceive its messages from their campaigns. If campaigns successfully avoid any unintended miscommunication about expectations, then the risk of PCB will be low.

### **Ethical Approval**

This study received Human Research Ethics Approval from The University of Queensland (Approval number 2020000807).

### **Citation**

Brook A, Hyde MK. (2021). Summary of results for research participants: Organ donation and mechanisms of trust in the medical system. Donor Research Network, The University of Queensland.