**Supplemental Digital Content (SDC): Appendix A**

**Focus/nominal Group - Community**

Welcome and thank you for coming along to today’s discussion group about organ donation and organ allocation. My name is Michelle Irving, I’m a researcher at the University of Sydney and I will be facilitating this group discussion. Allison Tong is also from the University of Sydney and are also involved in this research.

In the next 2 hours, we would like to get an idea of what your thoughts are on organ donation. Also, as you may or may not be aware, there are many people waiting for a transplant and there is a real shortage of organs in Australia. During this discussion, we would like to hear about how you think organs should be allocated in Australia. Many of decisions on organ donation are made by Health professional and we believe it’s important to learn and understand the perspectives and thoughts of the general public on this topic.

We will have some breaks. Please feel free to ask any questions. I also need to remind you that participation is voluntary. You are free to leave at any time without any reason or explanation. Everything we discuss will be kept confidential. Nothing you say will be traced back to you as everything will be reported as a “group” finding. We would also appreciate it if you could please keep this discussion confidential also.

**This will be recorded** so that I can transcribe and analyse the data later on.

Begin questions

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|  | **Topic** | **Question guides** | **Time (mins)** |
| **1** | **Introduction** | As members of the general public you are here to share your own views on organ donation.  During this discussion you are free to agree or disagree with one another. It is likely that others may not share the same opinion or views as you; please do listen to each other considerately and respectfully. | **5**  **6:35pm** |
| **2** | **Ice breaker** | Could you introduce yourself to the group *and* as this group is about organ donation: Could you tell us what is the first thing that comes to mind when I say organ donation? | **10**  **6:45** |
| **3** | **Focus Group Questions** | Today we are going to focus on deceased donation – where organs are donated after death. Not living donation – such as donating a kidney to a family member.  (spend some time discussing this if not already discussed in ice breaker)  **Organ donation**  - Would you be an organ donor?  Why/Why not?  - Is there anything that would make you NOT want to be an organ donor?  Why/Why not?  Have you heard of the organ donor register? (Drivers licence/ organ donation registry- National register – on-line. State register – drivers licence)  Would you (have you?) register to be an organ donor?  Why/Why not?  What would make you want to register?  If you had a family member that was admitted to hospital after a car accident and you were told that they had passed away.  - Would you give consent to donate their organs?  - Is there anything that would make you not want to donate their organs?  Australia has one of the lowest organ donation rates in the developed world, with a donor rate of 9.4 donors per million population (dpmp) compared with, for example, Spain (36.6dpmp) and the United States (25.5dpmp)   1. Why do you think Australia has such low organ donation rates? 2. What sorts of things do you think would make you personally (or others) more likely to donate your organs? | **25**  **7:10** |
| **4.** | **Nominal group technique – Organ donation** | Now, we are going to do a couple of exercise that will require you to rank some issues around organ donation and organ allocation, in order of what you think is most important to least important.  **“What sorts of things do you think are important to people when they are deciding to donate their organs?” eg -**  What are the things you would consider when deciding whether to be an organ donor or not?  Please write down three things you think are important to either yourself or to others that influence a person’s decision to become/or not to become an organ donor. Please do this on your own. After a few minutes, I will ask you to share your ideas with everyone else.  Now, we will go around. Can you suggest one thing that you think is important for people when making a decision about whether or not they wish to be an organ donor. Tell us about your idea – try to give me an idea that has not been mentioned by anyone else.  **[Write responses on the flipchart]**  Is there anything else that you think is important that we have not included on the board?  [5 min Break: The facilitator will add to the board additional items identified from the literature and print off a copy for each participant)  **Prompts list**   * 1. availability of incentives   financial vs non-financial   * + - payment to family,     - donation to charity,     - coverage of medical expenses,     - discounted health insurance if you are a registered donor,     - ??maybe tax incentives?     - preferred recipient status for donors, or donors family  1. Control over recipient - directed vs non-directed donation 2. Consent systems    1. Opt-in – specific registration, or just talk to anyone about their wishes    2. opt-out / presumed/implied consent – unless specific opt-out, it is assumed that there is consent       1. ‘hard’ – only way to prevent organ removal is be registered as a non-donor       2. ‘soft’ – families consulted about whether deceased objected to organ donation – families can object if they know of an unregistered objection    3. mandated choice (where everyone has to make an explicit  choice to be registered as a donor, or as a non-donor, rather than just choosing to be registered as a donor, with Opt-in) 3. whether family is able to over-rule potential donor wishes eg levels might be:    1. Yes, only if  registered as a non-donor family can over-rule and make donation    2. Yes, if not explicitly registered as donor or non-donor    3. Yes, family can always over-rule potential donor wishes, even if they are registered as donor (is this the current system in Australia as far as I'm aware)    4. no, family can never over-rule potential donor wishes    5. No, family cannot over-rule if person is registered as a donor    6. Any others?, 4. Hospital Staff approach to donor family 5. support of religious/cultural leaders in your community – yes, no   Now, we’ll just go through each on to discuss or clarify each idea.  Have a look at all the items on the board. Now, I’m going to ask you to rank each item in order of importance. 1 being the most important, to x being the least important. Just put a number on the side of each item.  General discussion about ranking – similarities and differences.  What did people think was the most important? Etc. | **25**  **7:35** |
| **5** | **Close** | **Thank you again for your time.** | **8:30** |