

SDC, Table S1

Focus group composition (n=113)

Characteristics	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6	Group 7	Group 8	Group 9	Group 10	Group 11	Group 12
N	10	9	10	10	9	10	9	9	9	8	10	10
Age group (yrs)	18-30	31-50	≥51	18-30	18-30	≥51	≥51	18-30	31-50	31-50	≥51	31-50
Location - city	Adelaide	Adelaide	Adelaide	Sydney	Sydney	Sydney	Melbourne	Melbourne	Melbourne	Sydney	Sydney	Sydney
Gender n (%)												
Male	5 (50)	3 (33)	5 (50)	5 (50)	4 (44)	5 (50)	5 (56)	5 (56)	4 (44)	3 (38)	5 (50)	4 (40)
Female	5 (50)	6 (67)	5 (50)	5 (50)	5 (56)	5 (50)	4 (44)	4 (44)	5 (56)	5 (63)	5 (50)	6 (60)
Highest level of education n (%)												
Secondary	4 (40)	0 (0)	3 (30)	3 (30)	2 (22)	2 (20)	2 (22)	2 (22)	3 (33)	4 (50)	5 (50)	2 (20)
Tertiary	6 (60)	9 (100)	7 (70)	7 (70)	7 (78)	8 (80)	8 (89)	7 (78)	6 (67)	4 (50)	5 (50)	8 (80)
Marital Status n (%)												
Married/de facto	3 (30)	5 (56)	8 (80)	4 (40)	3 (33)	6 (60)	8 (89)	2 (22)	5 (56)	4 (50)	8 (80)	4 (40)
Divorced/ separated	0 (0)	1 (11)	2 (20)	0 (0)	0 (0)	3 (30)	1 (11)	0 (0)	0 (0)	0 (0)	2 (20)	0 (0)
Partner (not living with)	1 (10)	0 (0)	0 (0)	3 (30)	1 (11)	1 (10)	0 (0)	1 (11)	1 (11)	0 (0)	0 (0)	1 (10)
Single	6 (60)	3 (33)	0 (0)	3 (30)	5 (56)	0 (0)	0 (0)	6 (67)	3 (33)	4 (50)	0 (0)	5 (50)
Employment n (%)												
Full time	4 (40)	7 (78)	2 (20)	2 (20)	5 (56)	8 (80)	3 (33)	3 (33)	3 (33)	4 (50)	4 (40)	9 (90)
Part time	3 (30)	1 (11)	3 (30)	2 (20)	0 (0)	2 (20)	1 (11)	2 (22)	4 (44)	0 (0)	3 (30)	0 (0)
Not working	2 (20)	1 (11)	2 (20)	5 (50)	2 (22)	0 (0)	2 (22)	2 (22)	1 (11)	3 (38)	1 (10)	1 (10)
Student	1 (10)	0 (0)	0 (0)	1 (10)	2 (22)	0 (0)	0 (0)	2 (22)	1 (11)	1 (12)	0 (0)	0 (0)
Retired	0 (0)	0 (0)	3 (30)	0 (0)	0 (0)	0 (0)	3 (33)	0 (0)	0 (0)	0 (0)	2 (2)	0 (0)
Group dynamics												
Disposition	Humorous, confident, relaxed	Serious, sometimes cheerful	Serious, interested, focused	Contemplative and laid back	Subdued, some humour	Vibrant, humorous	Emotional	Subdued	Sombre, serious, then more dynamic	Serious, thoughtful, cohesive	Monotonous	Subdued, some listlessness
Group dynamic	All members contributed actively	All members contributed actively	Cohesive	Most members contributed actively	Respectful, relied heavily on facilitator	Lively discussion driven by all members	Dominated by four members	Collaborative discussion	Reflective	Most members contributed actively	All members contributed	Dominated by three members. some tension

## SDC, Table S2

### Additional quotations

Theme	Illustrative quotations
<b>Expected benefits</b>	
Saving and improving life	[Case 2] Let them live out their retirement dreams, rather than just sitting in a hospital and watch your wife sit there on a machine and just watch her six hours a day. Risk [donating] or sit there and do nothing. (FG5, man, <20 yrs)
Societal gain	<p>So anonymous donations are needed to keep the ball rolling, so people can get off dialysis. (FG4, woman, 20s)</p> <p>The cost of surgery will be benefited by the reduction in the cost of dialysis, so from a financial perspective, there is a positive indication to actually undertaking the surgery. (FG7, man, 50s)</p>
Donor satisfaction/ gains	<p>It would be a positive thing for everyone involved, [non-directed donors] to be able to feel good about themselves and just generally thought I had made a difference in their community, in their country and in the world. (FG1, man, 20s)</p> <p>Yes, it's so intrinsic, from my point of view. I don't think there'd be any physical benefit of a donor doing it, aside from if you look at potential flow on effects of the donation, if you know you've given up a kidney, you might change your lifestyle for the better, because you know you need to be more aware of what you do and what you put through your body. So there could be some physical benefits, depending on the lifestyle they lived before the donation. (FG4, man, 20s)</p>
Reassurance and control	It's because I know that person, I know what's then going inside of me. (FG2, woman, 30s)
<b>Conscious of donor risks</b>	
Compromised health	<p>Because it is a risky operation, seizure, blood loss, anything could happen to [donors] on the operating table... then you sort of killed them leaving their family without their family member. (FG5, woman, 20s)</p> <p>Facilitator: What if they told you that the risk of death during the surgery is 0.03%? Man1 (30s): That's good news. Man2 (40s): That's favourable. (FG9)</p> <p>I was of the belief that you are given a pair for a reason. (FG7, man, 50s)</p> <p>If you give one of your kidneys and then that collapses, well, then you're basically liable to die. (FG7, woman, 50s)</p> <p>There'll always be the unknown, even with all the research you may do leading up to it, you still won't know how it affects you... (FG2, man, 40s)</p> <p>When you're young, you don't know if you're going to have high blood pressure or diabetes. Most of these things turn up when you've crossed your 30s or 40s. If I donate my kidney right now, I don't know if I'll have diabetes later on, and then I'm going to regret it. If I already know that I've got diabetes, and I might be putting myself in a lot of risk by donating a kidney, I probably wouldn't do it. (FG4, woman, 20s)</p>
Lifestyle limitations	<p>Our tolerance to things like alcohol would be a lot less. (FG1, man, 30s)</p> <p>If a father was to give away [unclear] and as they say you can't be physically capable as he was before that it could affect him on how he is being able to play around with his children if he had that and then, you know, it would influence them having to say, no every time the kids want their father to do something, saying, no, I can't, and he can't explain why, he'll just say, no, I can't and it will just affect them in the long run. (FG5, woman, &lt;20 yrs)</p> <p>The idea of cutting life shorter would worry me less than the idea of cutting the quality of life. If I thought, I'll cut ten years off my life, but I'm still going to get the quality for the time that I am around, that would be a really important thing for me. If I felt like I couldn't do the things that I want to do, I can't cope with the idea already. (FG8, woman, 20s)</p> <p>I'd be more worried about the quality of life. Does it affect you drinking socially two beers a night or three beers a night? I don't drink heavy, but I do drink two or three beers once a week. Am I banning alcohol for life? They're not the biggest issues, but you have to weigh it all up, for me, and I think yes, it'd be more quality of life. Does it stop you playing basketball, or surfing or, whatever you do? Will it stop those things? (FG8, man, 20s)</p> <p>There's a lot of pain to the donor, they suffer more than the recipient. (FG11, man, 60s)</p>
Financial consequences	<p>In the immediate time, I'm thinking that you're in a hospital so there's always a risk of infection. Downside would also be time off work, recovery time. (FG1, man, 20s)</p> <p>After-recovery can take a few weeks to recover, so maybe a financial situation maybe can be an issue, like what you'd do during the time that you were recovering. Like the</p>

	<p>money's can be a drama unless your partner can support you and stuff like that. (FG1, woman, 30s)</p> <p>What if a person doesn't have hospital cover or private insurance? Who takes on responsibility because I'm sure the medical staff are quite happy to perform the operation but not knowing if you can pay for it [overtalking]? (FG3, man, 60s)</p> <p>Financial impact is a huge aspect of it because some people haven't got sick leave, and if they offer to donate the kidney and they're going to have time off work. In this mean and nasty world we live in big companies don't give a continental whether you're donating your kidney. If you've used all your sick leave you're out, goodbye. (FG3, man, 60s)</p> <p>I don't think your insurance company is going to be paying you 75% of your wage on income protection if you voluntarily go off and give up a kidney; you have to give up six weeks' work. If the bank comes after you because you haven't paid your mortgage for six weeks, it's like, yes, but I donated a kidney. (FG10, man, 40s)</p>
Relationship tensions	<p>Your parents, your partner might not agree with you and you'll have some conflicts because they're worried for your safety and what can happen later in life. (FG1, woman, 30s)</p> <p>It's the old, blood is thicker than water. Friends are friends but plenty of things have happened with friendships over the time, whereas family's always family, even if a family dispute happens. Two brothers that haven't seen each other for 20 years, they're still family biologically. (FG2, man, 30s)</p>
Devastation	<p>Would you have a feeling of, is my body not good enough? (FG2, woman, 30s)</p> <p>It's like giving up your baby for adoption; would you always want to know, in back of your head, what happened to it and where a part of your body has gone? Would that haunt you? (FG2, woman, 30s)</p> <p>Resentment. You may think, at the time, that you're doing something beneficial, but five years down the track, if you start to get sick, that can lead to different emotions that you may experience towards the person you've donated to. (FG4, man, &lt;20 yrs)</p> <p>I don't think you really realise it until you're put in that position. I've got my tubes tied there's still a sense of loss because you can no longer have children. (FG7, woman, 50s)</p>
<b>Social precariousness</b>	
Fear of the unknown	<p>People are very frightened of what they don't know, if you don't know anything about it then you say, oh, I wouldn't go near it because I'm too scared, I don't know how my body would react. (FG2, woman, 30s)</p> <p>It's a fear of the unknown and the fear about your own individual health, and of the family's circumstances. It's just a fear of the unknown and we don't know what the future's going to predict. (FG4, man, 40s)</p>
Exploitative connotation	<p>I think you can donate to a close friend or relative because I've heard that in other countries, people selling organs. I don't think it would be possible to have a situation where people could donate to anybody, because then it would just open up the black market. (FG8, woman, 20s)</p> <p>If he ends up offering me a shipment of money for donating my kidney, I'd find a moral reason against it, just for the simple fact that I don't want body farming going on and I'd be promoting that. (FG10, man, 40s)</p>
Recipient deservingness	<p>There's people out there with lung transplants and they're still smoking so it has to go to someone who's worthy of it. (FG2, woman, 50s)</p> <p>I've always had it in my mind that if I was to donate any part, where would it be going to, the person it would be in? How did that person get in that situation? Did they take care of their body and they just happened to get sick, or did they abuse their body? That's what I would be thinking, so I wouldn't do it anonymously. (FG4, woman, 20s)</p> <p>If they're scoffing down Mars bars like air then they shouldn't have the opportunity to be a recipient. If their lifestyle is self-destructive then, you know, they're taking their own path aren't they? (FG6, man, 50s)</p> <p>I'm sure they sit back and look at people and say okay, you're a heavy smoker, you're a heavy drinker, and you're really not looking after yourself so we're not going to put you on the operating table and take someone's kidney and spend all that time trying. (FG6, man, 50s)</p> <p>My sister had very big problems with alcohol, and if she had have had kidney failure at that, and had not slowed down, I would be like, you understood what you were doing, and I don't feel comfortable unless you can prove that you've changed. What's the point in giving someone a second chance if they're just going to do the same as they had with the first chance? (FG8, woman, 20s)</p>
Protecting conscience	<p>If someone asked me for my kidney and if it wasn't my family, maybe I would feel like a massive guilt trip had been put on me and it would be very hard to say no, if I knew they're spending every second day on dialysis for half a day. It would be massive guilt trip. So, I'd rather put myself at the risk than risking something happening to them because I'm taking their kidney... I've got a conscience. (FG1, woman, 20s)</p> <p>I don't think I'd ask. I'd be waiting until somebody volunteered it. (FG3, woman, 60s)</p> <p>I couldn't do that I don't know why I just feel it's an obligation if anything to them. I couldn't do it, but then in the situation who knows how desperate you'll be. (FG5, woman, 20s)</p> <p>Like if you were to say it to your husband, if I was to go home and say John, I need a new kidney, that's putting him on the spot I can't say no because she's going to be so sick</p>

	and if I say no she's absolutely going to kill me. And it's almost pressuring him into saying oh, okay. I think it's too much pressure. (FG6, woman, 50s)
Potential regret	<p>Donors might guilt them later on ... I gave you that kidney. (FG1, man, 20s)</p> <p>Or if you gave it to a friend and then your kid needed it. (FG1, woman, 20s)</p> <p>I was just going to say that, outside of the immediate family, I don't know that I could draw a straight line; it'd probably have to be on a case-by-case basis, to depend on how close I am to the person. I come from quite a large family, so there's a lot of potential people there, and I suppose if you give a kidney to someone else, in the future, if something were to happen, then there might be someone else who you would have, been more willing to give a kidney to. (FG4, man, 20s)</p> <p>It's probably a very small chance of happening, but if like the father gave their kidney to a brother or sister or something and then, you know, ten years down the track one of their children needed that, then they might feel like they can't help their children. (FG5, woman, 20s)</p>
Trauma of refusal	The subsequent perspective of how you feel about that individual or how that individual feels about the way that you might feel about them should they say no. (FG7, man, 50s)
<b>Upholding fairness</b>	
Equal access to transplantation	<p>It's kind of like being the last pitch for a football team or something like that. It's a popularity thing with Facebook. (FG1, woman, 20s)</p> <p>It sounds some people would be more deserving for a transplant than other people, and there would be some scumbag out there wanting a kidney or some scumbag gets it because he won it on Facebook. That's not really fair. I'd be pretty pissed off if that was me waiting for a transplant. (FG1, man, 20s)</p> <p>People advertise for egg donors, so what's the difference between someone putting an ad for a kidney? This is what they want to do. (FG2, woman, 30s)</p> <p>If the legal system and the registry system is in place, then there's a list of the people who need it the most. I think that they should get it first, instead of somebody who's jumping the queue and coming and asking for it through social media. I think it's wrong. (FG4, woman, 20s)</p>
Reciprocity	You have to be reassured. You give yours to someone that he will do it and not change their mind at the last second. (FG10, woman, 30s)
Prevent prejudice	<p>There must be laws in place, to make it anonymous, surely, partly to address the discrimination. If the person who was giving it was a racist, if it was a white person, they don't want to give it to a black person. (FG4, man, &lt;20 yrs)</p> <p>Let's say we've got an advertisement section in the paper now or on the internet and you've got all these people who need kidneys, they're saying there are going to be all sorts of racism and sexism and, you know, oh, I'll donate to them but I won't donate to them and somebody's going to get left out (man, 50s) But you're already doing that, discrimination. You're only donating to family (man, 50s) ( FG6).</p>
Donor safety net	<p>You don't know what happens in the future, if you're going to have kidney problems yourself, so if you knew you're going to get helped by the government or, you probably would consider it, but if you gave your kidney and then in a year's time you needed help and you're at the bottom of the list then you're like it's not an incentive to do it. (FG2, woman, 30s)</p> <p>So you should be able to get priority on the waiting list because you've given one. Even if I was someone that really wanted one, no worries, that person donated, they should be way above me in this list. (FG2, man, 30s)</p> <p>I think it should be an option. if you're a person that has given a kidney over anyway, you're probably the type of person who's going to think, well, if someone's been sick all their life, I'll wait behind them, but it should just be a choice. The government does everything they can to help you financially if that's the case. But, you know, still as an option. (FG2, woman, 30s)</p> <p>If I'm say, 40, 50, and there's an eight year old little boy or girl that needs a kidney, I may have donated but I'd like to think that I'd be strong enough to say I'd rather see little Sally or John with a kidney before me. (FG2, man, 40s)</p> <p>Because it's not their fault that they don't have someone that can donate to them as a living donor, it's sort of out of their hands even though you've had the opportunity to provide a donation yourself, it's all unbalanced. (FG2, woman, 30s)</p>
<b>Decisional autonomy</b>	
Body ownership	<p>It's totally over legislation, nanny state, big government stuff; people should have a choice to give a kidney. We shouldn't have all these regulations, people should be able to make their own choices in these matters. (FG1, man, 30s)</p> <p>I don't think other people have the right to judge the basis of your friendship and how you came to be friends. (FG2, woman, 30s)</p> <p>You're allowed to go to war at 18 and you're going to get killed there or you might be so what's the difference (man, 50s).. There's a difference though. It's just giving a part of you when you're so young, war is a different comparison; it's like you're going to defend your country (woman, 50s)... It's exactly the same situation. Young people are in a situation</p>

	<p>where they need a job, unemployment is high, it's so easy for them to be manipulated by nationalism to go and put themselves in harm's way. (man, 50s) (FG6)</p> <p>If they can do everything else, vote and smoke and drink, drive a vehicle, it's their body. If a 25-year-old wants to do that, then so be it. That's their choice. (FG4, man, 40s)</p> <p>[Case 3] Emotionally, I believe it's his choice. It's his mother. (FG4, woman, 40s)</p> <p>[Case 3] I'll always believe it's his choice, it's his kidney, but maybe he's too emotional to look at it too clearly. (FG11, man, 50s)</p>
Right to know	<p>But if the recipient say their donor wanted to know where if I wanted to know where my kidney went and then I got a letter back saying the recipient doesn't want to know you, I'd be devastated. (FG1, woman, 20s)</p> <p>It's the same as illegal sperm donation; it's becoming an absolute minefield, where donors are saying, I want it anonymous, I don't want all this legal hoo-ha; I won't donate. And doesn't that put the whole system at risk for people that want a legal, want the sperm? So... and that doesn't help people that can't conceive, for whatever reason. So I would think a live donation, for example, of a kidney, would be just the same minefield. If I want to do it, it's anonymous, end of story. The lawyers won't let it go; they think people have the right to know where you came from, where your kidney came from, so I don't like it. (FG7, man, 60s)</p>
Valid relationships	<p>The same safeguards should be in place whether it's people who've met two months ago, whether they met 45 years ago. But there is a greater chance, people who met two months ago, there's a greater chance for exploitation so maybe you have to be aware of that., I don't think it's the medical practitioner's role to dissect a friendship when two people present themselves as friends. (FG4, man, 20s)</p>
<b>Assumed duty of care</b>	
Facilitate informed decision making	<p>But at the same time I think I suppose the health practitioner or the surgeon will go through with you why you want to do it. Your health, your physical abilities and making some tests to see if you're healthy, if you can do it because you have some risks involved in doing it and you want to be sure that you get through it and going to be living. Is it a good life? (FG1, woman, 30s)</p> <p>I don't know if that falls under what having the same mutual risks that whether or not they've thought about their recovery or time afterwards, how it's gonna impact their life afterwards. You just want to be sure that they have thought about the whole process through and why can't we just say that they are genuine about it and that it's not just so off the cuff "Oh yeah you need some kidney, I've got two" (FG1, man, 20s)</p> <p>And there is a very extensive panel that she goes through to make sure that she's got all the information before the actual donation. (FG3, man, 50s)</p> <p>I don't think it's a case of letting her, I think it's a case of making sure that she's got all the information necessary to make that decision. (FG7, woman, 50s)</p> <p>You can have a doctor who can just peel off a whole lot of numbers, of percentages, and it can just not mean anything, because they're all just numbers. But when you have someone actually talking about, like, the possible scenarios, that's going to be a lot more real. (FG9, woman, 30s)</p> <p>I'm sure there's a process involved before you donate a kidney; there's a whole structure, I believe, an evaluation period and all that sort of thing, so the recipient will be quite well informed of the situation. It's quite a lengthy and detailed process from my understanding. (FG9, man, 40s)</p> <p>You've got to assess someone's maturity of whether or not they're fully cognizant of what kind of decision they're making. (FG9, woman, 30s)</p>
Safeguard against coercion	<p>Whilst I don't think you should preclude the person of being able to donate. I think there is a danger of like a power position, so like a daughter of someone or someone is employed by their family members. (FG1, man, 20s)</p> <p>You'd probably need to look out for people being pressured into it as well, family members feeling obligated. (FG2, woman, 30s)</p> <p>And also whether there was any coercion or force behind it, or any threat behind it. I think it's morally wrong if that's the case but if you're very close to your boss then I think it's up to the donor. (FG3, woman, 60s)</p> <p>You'd want to know why she would be willing to donate a kidney to someone that she maybe has never met and has only just conversed with online. (FG3, woman, 60s)</p> <p>I think that there should be some sort of a psychological assessment to ensure that a person isn't donating under duress, or under circumstances of unconscionability, because if a boss is requesting a kidney transplant from one of his employees, it may be innocent, because it might be a friendly situation, but it could be giving you a kidney, if you want a promotion (FG4, man, 20s)</p> <p>I'd ask for proof for friendship. Do you have pictures? Do you have anything to prove how strong your friendship is, or how old it is? Or you don't have any hidden agendas. (FG4, woman, 20s)</p> <p>Maybe, they can question the authenticity of the friendship over here, and if there is any blackmailing going on. (FG4, woman, 20s)</p>
Ensure psychological safety	<p>You would probably have to see if they're really of sane mind. (FG1, man, 30s)</p> <p>I would hope that the psychological portion where doctors go figure out whether or not the person was coerced. (FG1, man, 20s)</p>

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I have a problem with anonymous donation, like, me, personally, I just wouldn't give my kidney, so I guess there's a risk in any operation, I'm not going to risk my body for someone I don't know. If it's for a family, if it's one of my kids, or, you know, someone like that, no problems, but I'd be wanting to look at the mental state of someone who anonymously donates a kidney, personally, because I just think there's got to be something wrong with them, like, why would you give something away if you don't know what the reason is? (FG2, man, 40s)

Because not every, not every donation works, does it? So how're you going to feel about that, if it doesn't work? (FG2, man, 40s)

I think a psychological assessment would be really important as well as maybe some advocacy. (FG2, woman, 40s)

But if John is told by the doctors we're rejecting your offer here, psychologically what is that going to do to John if his mother then dies and he feels like he could have saved her. (FG3, woman, 60s)

It's not just a... I think, as you say, it's not just the valuation, the suitability evaluation, from a medical perspective, but also from the emotional or physiological perspective, but also the management of that subsequently. I think there needs to be, whether people think that they'll be okay or will not, that this affects people, traumatic circumstances affect people in so many different ways, and those are ways that you may not be able to identify or be able to manage. So it's not just a case of coming out of hospital, the wound is repaired, that's it, get on life. I think it needs to be managed, managed properly, that the post... it's a traumatic circumstance [overtalking]. (FG7, man, 50s)

With any sort of transplant there must be a psychological assessment. The first thing to sort out is the family dynamics. (FG7, woman, 50s)

Having [the psychological assessment] for everyone will catch the crazies, hopefully. (man, 20s) ... Psychologists are fallible in just the same way as doctors are (man, 20s). Maybe if there's criteria that might indicate if somebody's being pressured into doing it. Or maybe the surgeon would just see the signs, that this person perhaps is doing it for another motive. Or they're being pressured into it by a family member. This guy in China who donated a kidney for an iPhone, obviously he did it for the money, but the same thing could happen in between family members. It could be a lot more money, or could be, like, the Will. (woman, 20s). (FG8)

Well, it can't be someone you're stalking. You have to do a psychology test: so, why do you want to give her a kidney? Because I enjoy watching her through the window. (FG10, man, 30s)

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Justifiable risk	<p>If he's got a, even a small increase in the risk of death, you would perhaps look at other options before you then get to this? (woman, 40s) ...I thought if it was a good surgeon it was okay (man, 30s). (FG2)</p> <p>[Case 2] The risk here is death so I probably wouldn't want to go with that and considering his age I might say maybe, I don't know, as a doctor I would probably be inclined not to recommend it as much just because of his age and because there's a small increase in the risk of death I would be a bit reluctant to say, you know, it's going to be fine for you to go ahead. (FG5, woman, 20s)</p> <p>I guess it could be a risk to your own life if you donate it and the doctor would advise against doing it. (FG6, woman, 50s)</p>
Objectivity	<p>It also raises the question, if you're saying that legally you're not allowed to do it until you're 18, it doesn't make sense when they won't accept a donor in their 20s, then what's the point of having a young donation age of 18, why not make the minimum 25, just to overcome that moral grey area ... you're actually not dealing with pen and paper here, you're actually dealing with the surgeon that gets to decide, well, that's ridiculous. It depends on who you're seeing, the story you put on, there's no law there, then, is there? It's just a personal opinion of that surgeon. (FG2, man, 30s)</p>
Warranted disclosure	<p>I think it's important to tell the father, that needs to be transparent (woman, 30s)... But is it the doctors responsibility overall? He's got nothing to do with the family. He doesn't know them at all. All he sees in front of him is this information that tells him that hey that's not his son. So do I make the choice to tell him. (man, 40s) (FG9)</p> <p>I do believe every child deserves to know who their parent is. (FG7, woman, 50s)</p> <p>Yes, but a doctor hasn't been contracted to find out that fact (man1, 20s)... Well, I'd be pretty annoyed if they found cancer, and later said oh, we weren't contracted to find the cancer (man2, 20s). (FG8)</p> <p>If you told the donor that the recipient has HIV, are they going to turn around and say, okay, I'm not going to donate, anymore? Then you've just lost a kidney. But if that donor would say, okay, then I'd like to give my kidney to a recipient who's going to get more benefit from it, then that kidney can go to someone who's healthier, who doesn't have HIV. (FG8, woman, 20s)</p> <p>You'd need the waiver from the recipient, to actually say anything., I would love for the recipient to have meetings with a counsellor to discuss whether they would feel comfortable with that, because in an ideal situation, I think they should tell, because it is an important factor. If that person has the potential for that to develop into AIDS their life quality is going to be so greatly diminished as it is, that it would be such a hard balancing act. And I think it would be better if both people understood what was going on, but I don't think you should be able to tell without actually getting approval from the recipient. (FG8, woman, 20s)</p> <p>Morally I don't know, but I think the doctors should just say that they're not compatible, and then if he does want to proceed, if the father does want to know why isn't he compatible, I think the doctor is obliged to tell him straight out (woman, 40s) ... But then why would you want to ruin somebody else's life? (woman, 30s) (FG10)</p> <p>I know this is only related to the kidney transplant, look, is it any different that I could be doing tests for cholesterol, heart and they find I've got cancer and they say well we didn't</p>

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do tests for that, but we found something else, by the way. I just think if you're looking for something and you find something else, maybe they'll want to know that. (FG11, man, 50s)

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## **SDC, Materials and Methods**

### **Interview guide**

#### **1) Knowledge about organ donation**

- a) Which organs can be transplanted? What organs can a person donate while they are still alive?
- b) What benefits/risks or harms might a donor/recipient experience?

We have prepared an information sheet about kidneys and kidney transplantation to help with the discussion. We'll take 2 minutes to review this. [Supplementary File 2]

#### **2) Support for living kidney donation**

- a) Who do you think you should be able to donate a kidney too?
  - i. *a family member - Why/why not? (genetic/close emotional relationship - child, spouse, sibling)*
  - ii. *an unrelated person with whom the donor has a pre-existing relationship - why/why not? (friend, social group – sport club, church, employer/employee)*
  - iii. *an anonymous recipient - In some transplant centres, a few people have donated a kidney anonymously to a suitable recipient next on the waiting list. What are your thoughts about “altruistic anonymous donors” and do you think they should be able to donate - why/why not? Do you think they should be kept anonymous – why/why not?*
  - iv. *Someone who has appealed on the media/internet*
- b) [Supplementary File 2] In paired kidney exchange, donor organs are exchanged between incompatible donor-recipient pairs. This can happen between transplant centres across different states in Australia. What do you believe are the potential benefits and risks? Do you think the donor-recipient pairs should be kept anonymous – why/why not?

What are some reasons that people might have for not wanting to be kidney donor while they are still alive? *(lack of knowledge about donation, surgical and health risks, financial impact, distrust in hospitals, impact on relationship with the recipient, socio-cultural considerations)*

#### **3) Willingness to receive/donate a kidney**

- a) If you had kidney failure, would you be willing to accept a kidney transplant? Would you prefer a living kidney transplant or a transplant from someone who has died – why?
- b) Who would you ask to be a donor/how would you feel about asking them?
- c) Hypothetically would you consider being a living kidney donor? Who would you be willing to donate to – why? (family member, unrelated person, anonymous recipient)
- d) If you were considering becoming a living kidney donor, what information would you want to know to help you make a decision about living donation? *(risk of death, surgical complications, physical impact, psychosocial impact, financial impact)*

What sorts of risks might you be willing to take? *(death, surgical complications, graft survival in recipient)*

#### **4) Donor safety and autonomy**

- a) Imagine that you were a healthcare provider assessing a potential living kidney donor, what sorts of questions would you ask the potential donor? (*medical issues, motivations, psychosocial circumstances*)
- b) For the following scenarios which are based on or adapted from clinical experience, what would you advise?

**i) CASE 1**

**Tina** is in her late 20s and has not started a family. She wants to donate a kidney to her mum. Research suggests that women who donate may have a very small risk of pregnancy outcomes such as premature births (babies born less than the 37 weeks), gestational diabetes, and preeclampsia (high blood pressure, swelling, reduces flow of blood to the placenta so it can restrict the baby's growth because not enough oxygen or nutrients get through). However, she has really wants to donate and says she will feel upset and guilty if she is unable to donate.

Would your opinion change if:

- (1) She wanted to donate to her partner, brother/sister, close friend, an anonymous recipient?
- (2) She had an 8 year old daughter/son and wanted to donate to her child?

**ii) CASE 2**

60 year old **Bill** offers to donate a kidney to his wife who has been going to hospital three times a week for dialysis for the past 5 years. If the kidney transplant works well, they will be able to live a near-normal life and travel. However, he is considered medically borderline. His kidney function is slightly below normal and he has mild high blood pressure. There is a little bit of research to suggest that there will be no significant (major/considerable) increase in the risk of death but it is unknown whether there is a "small" increase in the risk of death.

Would your opinion change if:

- (1) His wife had been waiting for less than one year for a transplant?
- (2) There was research to indicate that the donation may reduce his life expectancy by approximately 6 months? By 2 years?

**iii) CASE 3**

Young healthy 30 year old **John** wants to donate to his mother. His mother, aged 55, suffers from depression and had attempted to take her own life twice in the past 5 years. Some other doctors believe that she may try to take her own life again or may not be able to cope with the medications after the transplant and lose the kidney. But her son says the decision should be his choice and that he is mature enough to make an informed decision about donating.

Would your opinion change if:

- The donor was her husband?
- The mother was the donor who wanted to donate to her son?

**iv) CASE 4**

**Gail** is in her 50s and wants to donate to her 45 year-old brother who has been on dialysis for 3 years. She is the only person among family and friends who can donate. She has 3 children. Her husband is worried and tells her that he does not want her to donate.

Would your opinion change if:

- (1) Her brother was not yet on dialysis (pre-emptive transplant) and her husband was ok with her decision.

**v) CASE 5**

**Mark** is a father wants to donate to his 17-year old daughter who has been on dialysis for one year. She does not take her medications. Once in a while, she will go out with her friends to a party and smokes and takes drugs. The doctors are worried that after the transplant, she will not take her immunosuppressive medications which help to keep the new kidney working in her body.

Would your opinion change if:

- The donor was her 25 year old brother?

**vi) CASE 6**

**Carla** who has just turned 45 wants to donate to her best friend Cathy since childhood.

Would your opinion change if:

- (1) Carla and Cathy had become friends via "facebook" 5 years ago?
- (2) Cathy was Carla's boss at work? Or vice versa?

## Participant materials

### Item A. Information about kidneys

Adapted from

<http://www.kidney.org.au/LinkClick.aspx?fileticket=s0rM4P9aX1Q%3d&tabid=618&mid=854>

#### What do kidneys do?

- Remove waste fluid from the body
- Help to control blood pressure
- Help to make red blood cells
- Help to keep bones strong

Kidney disease can progress to kidney failure. If the kidneys are working at less than 10% of their normal rate, dialysis or kidney transplant is the only option.

#### What is dialysis?

Dialysis means that the kidney's role is replaced with a "machine." The type of dialysis used depend on different factors e.g. age, resources, health, lifestyle.

- *Haemodialysis*: the blood is removed from the body, cleaned by an "artificial kidney" and returned to the body. Each treatment lasts 4-6 hours and is required three to four times a week for life or until a transplant donor is found.
- *Peritoneal dialysis*: a tube is inserted into the abdomen and the waste removing and blood cleansing happens inside the body. Clean solution enters the abdomen and leaves the abdominal cavity, removing waste products. Treatment usually takes place four times a day, seven days a week.

#### What is a kidney transplant?

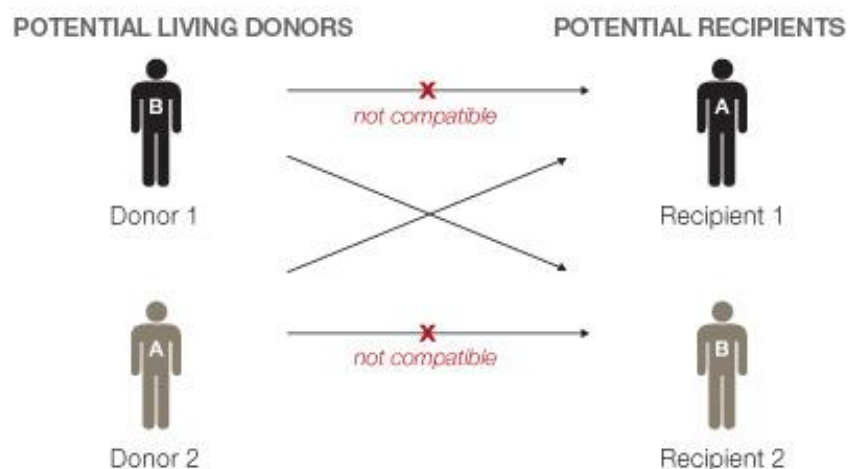
Donated kidneys can come from either deceased donors or from live donors. Live donors are usually close relatives, but spouses, distant relatives and close friends may be able to donate. Kidney transplantation can give people with kidney failure a chance to be free from dialysis. However, it is not a cure. A new kidney requires a lifetime of care, including taking daily anti-rejection medication.

#### Who can be a live donor?

In living kidney donation, one kidney is removed from the donor and transplanted into the recipient. A donor needs to be:

- Healthy
- Blood compatible
- Pass the cross match test
- Compatible in terms of age, size etc.

### Item B. Paired kidney exchange



From

<http://stanfordhospital.org/clinicsmedServices/COE/transplant/kidney/overview/living/paired.html>