

SDC1. Interview guide

1) Context and participants' role and decision making in living kidney donation

- a) Can you please describe briefly the process for assessing living kidney donors? (*Who is involved and what is their role? – coordinator, social worker, general practitioner, psychiatrist, surgeon*)
- b) What are the legal restrictions in regards to living kidney donation? (*Paired exchange, non-directed donation*)
- c) What are the financial implications for living donors? (*Payment for health work up, insurance, reimbursement for out-of-pocket expenses*)
- d) What is your current position/s and how many years have you been working in that role?
- e) What sorts of decisions do you make regarding live kidney donation? (*Screening, follow up*)
- f) What are some of the most difficult or complex issues you face when making these decisions? (*considering benefits/risks to donor and recipient, psychosocial uncertainties, cultural considerations*)

2) Screening potential living kidney donors

- a) How do you decide whether to accept someone as a kidney donor? What factors do you take into account? (*medical, psychological, social*)
- b) What information do you think is important for donors to understand before donating a kidney? (*benefits, risks, harms*)
- c) There are various reasons why individual offer to donate, and in some cases may feel some "pressure" to donate. How do you identify and resolve this? (*family expectation*)
- d) Can you give me some examples of reasons as to why potential donors might have been "borderline" eligible? How did you come to a decision to accept/exclude the donor?

3) Follow up care of living kidney donors

- a) Can you describe any systems you have in place for the follow up kidney donors? If you had unlimited resources, what would you suggest should be done to provide short and long term follow up?
- b) What have you observed to be the main benefits of kidney donation for living donors?
- c) Have any donors experienced serious health or psychosocial outcomes after donation? (*death, health or surgical complications, psychosocial issues e.g. regret, unable to maintain a healthy lifestyle*) What happened, why do you think it happened, and what was done to resolve these issues? (*legal issues or lawsuits*)

4) Commercial transplantation

- a) Some professionals (policy makers, doctors, lawyers) believe that there are advantages in regulated markets for compensated donation. What are your thoughts on this?
- b) Are you aware of patients who have considered paid kidney transplantation overseas? How do you respond when they express a consideration or an intention to do so?
- c) How do you respond to patients who have undergone paid kidney transplant overseas?

5) New and emerging types of donation

- a) What are your experiences with paired/domino-paired exchange kidney donation? What do you believe are the benefits/risks/harms, or some of the contentious issues surrounding it?

- b) There are some debates and controversies around paired or domino-paired kidney exchange. What do you believe are these contentious issues? What is your perspective on this?
- c) Altruistic non-directed donation: What has been your experience with non-directed altruistic donors? In your opinion, is it appropriate to run a non-directed altruistic donation program? What problems might concern you?

SDC 2. Additional illustrative quotations

Theme	Illustrative quotations
Moral: vigilance against exploitation	
Mitigating the threat of commercialism	<p>The commercial activity which came into Pakistan brought about a lot of changes in transplantation. Everybody saw it as a commercial activity, so that harmed transplantation. ID52 PAKISTAN</p> <p>We at our institute are not allowed to do anything beyond family so its mother father brother sister, son daughter, and grandparents that is included in the family now. No friends. ID26 INDIA</p> <p>Rules get broken. If somebody feels that you can buy a kidney, then people will prefer to buy a kidney. Paid donation does happen. It may not be to a certain extent but it does happen. Once in a while we have scandal coming out. Not in my centre. It never happens in my centre because we are the government centre. So we are very strict, we should keep the standard. We don't let our standard go down. ID27 INDIA</p> <p>There is always scope for exploitation in a country like India, where there is a lot of disparity. There are people with very low income and people with very high income and people feel that they can get things done with money. We are a very corrupt society, I don't deny that. We have to be much more cautious. ID27 INDIA</p> <p>Maybe at first they want to be cautious so be more conservative. For living donation, their main concern is to prevent economical transactions, buying or selling organs. ID40 TAIWAN</p> <p>In developing countries the controlling system is not strong enough so you can do anything if you have money. It's very common, anywhere in developing world - not only in Vietnam. ID32 VIETNAM</p> <p>We couldn't accept anything because if not that will destroy the whole program in my hospital so anyone if unclear there is any relationships with the recipient, it's not accepted in [my hospital], very strict. ID33 VIETNAM</p> <p>Many Japanese now may marry foreign ladies and girls, say from Korean, the Philippines, and we are suspicious, in doubt of their marriage. ID31 JAPAN</p> <p>But I think in Thailand, we need to make a strict regulation, because the gap between the rich and the poor are very high. So some patients are very rich. So if we don't forbid them to make restriction, donation within the family, then I think that's a problem. ID53 THAILAND</p>
Combating disparities	<p>The other interesting thing that we noticed was that they used to always say, in the beginning of our program, that it's the sister that's going to donate to the brother, because the sisters are more caring. We discovered that we were doing more females as donors than should be. We got in a psychiatrist and a psychologist in our team and we</p>

started having interviews. Then it came out that it's not their wish. Again, in patriarchal society – 'so you sisters are more caring, you, why don't you go forward?' So by process of counselling we brought about that balance to change. ID52 PAKISTAN

I take pride in three facts in my centre. One is that the male to female ratio for donors is about 60 per cent male in my centre so far since I've been here so I don't think there's coercion of females because we watch out for this very carefully in the Asian context. ID2 SINGAPORE

We are very conscious of protecting the vulnerable donor groups. For example, women. They might be vulnerable in the sense of being coerced by the families. We need to make sure, we need to probe and make sure that there is no coercion involved or if the person is not willing, then we give them an out for that. ID28 INDIA

There are more women donors. But this is quite hard in the Islamic environment. I think it's very hard to know whether the wife is subtly coerced or coerced or not coerced. ID8 SINGAPORE

There is still quite a strong preference for males. It's difficult. We cannot change the culture; we are just doing the role of the doctor. ID15 HONG KONG

Verifying volunteerism	I sit one on one with the donor and tell him if there is any coercion, family pressure, you are the younger brother or his the breadwinner and his asking for your kidney, any coercion give me a signal and I will find a medical reason to let you off the hook and I do that – one in 10. One in 20 donors will say "yes I really would like to give, my wife is not willing, but he is an elder brother I have to do it you know." And then we just find some excuse, medical, we say, "all right we let you off the hook, emotionally not trouble you, we'll say you have a medical reason." ID26 INDIA
	Sometimes we find that the potential donor, they may have certain type of pressure, maybe in their family the potential donor received the message that somebody want him to do the work-up but this is not actually what he wishes. ID16 HONG KONG
	The social worker will specifically define how is the family support, how is the relationship between the donor and recipient, and any they must ask any pressure, incentives, do you worry if you don't agree to donate, what will happen so they must do that skillfully to review if there is some coercion or force. ID40 TAIWAN
	Let them to have some honourable way out. I tell them "I will try my best to give you an honourable way out if you don't want to donate. I won't tell the recipient that you are not psychologically prepared." I will say that there is something wrong in terms of medical science. ID15 HONG KONG
	She didn't want to donate her kidney to her husband because he has some problems in his family. But she can't say. So I told them she had some renal problem so she cannot donate. ID29 JAPAN
	Live donation must be initiated by the donor. We can have the information spread widely to anybody in the country but I still maintain that I will not persuade any people to donate their organs to others. I think we have the most number of live donations in Taiwan and however I reject more patients, more donors than I did, our successful

donation rate was around 40%. And so far I don't promote live donation. ID48 TAIWAN

The top priority of my job is to establish the psychiatric diagnosis and to evaluate their competence to make the decision based on their own free will, free from psychosocial pressure from other sources. ID49 TAIWAN

The wife is the candidate to donate her kidney to her husband. She was very ambivalent about the donation. She had a very good excuse because the blood type is different. But in one day the surgeon told us the different blood type is ok for the transplantation, so the natural barrier disappeared and the wife should be face her inner conflict for whether she should donate the kidney to her husband. So the problem was brought about by the high tech development. Because just before the advancement of technique, she could tell herself, the blood type is different so I cannot donate my kidney to my husband, now the barrier is gone. So we offer her some session, psychotherapeutic interview or the session to make her more clear about the meaning or consequence about her decision. ID49 TAIWAN

Professional: Maintaining clarity of roles

**Relying on legal
safeguards**

We have very good laws in India. We have a screening committee, the authorization committee will see through the application and then they will interview and that's how every transplant has to go through the committee. ID27 INDIA

For other countries to not have that kind of restriction to 5th degree family donor? I think that the mostly they will they will find that issue is due to the organ trafficking – so [without this regulation] in your country how can you prevent these things happen? ID50 TAIWAN

I think the government does not want people to have trade. Because if it's a friend, I donate a kidney because you gave me some money. But if it's relative, then its love. I think it's because of money. It's better to be managed or to be ruled, it's also avoiding crimes. If its friends, maybe, I bought it, there are exchange conditions. ID43 TAIWAN

I am happy to have this kind of regulation of donation within the family. The relationship between friends or far distant relatives actually is complicated, actually it depends on many things so I would rather trust on the blood relationship and actually even if the donor and recipient are closely related there is always something we don't know. I would not be surprised. I can expect there are many factors to facilitate to put the donor come to me. I can expect and I will not be surprised but I do not want to have too many factors I don't like. ID48 TAIWAN

I specifically tell them, or my team will specifically tell the donor, that if they do receive anything it's against the law and they can be prosecuted and I make it very explicit, they can be prosecuted and put to jail. We're the only country in the world that has actually put somebody to jail. ID2 SINGAPORE

So we asked how many years she married, she said just one year. Then we asked them to have the certificates to prove their marriage but she cannot take any proof. Two questions or two things we ask her to do, the first is to get the certificate to prove their marriage is - prove that its okay, it's legal. The other thing is we ask her to wait for two

years, because we have a recommendation in Hong Kong for the wife and husband or the spouse we have to make sure that they're married for over two years to avoid any money or any illegal thing or unethical thing in that. ID16 HONG KONG

Sometimes it's difficult to go to prove that there are no financial issues behind. In Hong Kong I think that every hospital in the case of a situation like friends comes out that sometimes they may be from the same Church. In that situation we would just ask the donor and also the recipient to try to get all the documents, and then we will submit all those documents to the [Human Organ Transplant] HOT board and pending the reply from the HOT board we will see whether we can propose it or not. ID24 HONG KONG

The next pitfall is getting over the legal problems. The government insists that we have to identify genetically that this is a real brother because people masquerade. So besides taking the birth certificate, marriage certificate if the wife is donating, the wife is counted as related although she is not genetically related we need the certificates we need both their ID cards, passports, and certain legal consent documents on legal paper and then we go ahead and put the case before the ethical committee of the hospital which doesn't include anyone of us. There is a lawyer, social worker, a medical director of the hospital and a physician and for each there are 3 or 4 options, so one administrator, and that committee sits every 2 weeks and all the cases that are up for transplant are put forward and so we have to then interview, they interview on their own, the donor, the recipient and the next of kin of the donor so if the wife is donating then we call her father. ID26 INDIA

Ensuring informed consent	Initially I do have some reservations, but as long as this is informed consent - they know what they're putting themselves through. ID4 SINGAPORE
	We have to talk with the sister or brother-in-law - the wives or husbands of these people, and then some of them are quite scared, but after talking with us, they understand the things, and we did everything very carefully and our standards for selection - the criteria are - I think are a little bit higher than in other countries, to make sure that everything is fine and then to ensure the safety for donors, because the donor is our priority - the top priority. So if they see that, they understand and we just explain to them so they are quite happy and everything is fine. ID32 VIETNAM
	I would very much still want the recipient and donor to be the one making the decision. I mean it's really depending on the priority of the person's life. ID6 SINGAPORE
	There's a high risk of surgery, living with one kidney is not possible to remain healthy - so, there's a lot of these misperceptions. They think that, after donating one kidney, they need to take medicine. ID3 SINGAPORE
	We are using Western data, which may not be applicable to Singapore. Because, in Singapore, diabetes is now the number one cause of endocrinal failure. So, what is the risk for obese donors donating? In 10 years' time, will he get diabetes? So we need to look at our outcomes now. In Asia, there's hardly any data on living kidney donation, very few data. I feel that we need to have a living kidney donor registry, an Asian living kidney donor registry. ID3 SINGAPORE
	As a doctor, sometimes we like to paint a rosy picture that kidney donation is safe, we investigate you with all the blood tests, urine tests, CT scan. We tend to tell them that, in fact, after screening you may be - found that you are actually better than the general population so we give them a lot of encouragement and reasons to donate and things

	<p>like that but sometimes when they're not simply the best sometimes you think otherwise. ID2 SINGAPORE</p> <p>I think if the donor has enough information and they know - he or she may not know everything about the complications of the process and even know the pros and cons and they're willing, I think it will be okay. ID18 HONG KONG</p>
Demarcating responsibilities	<p>I don't want to make my job too complicated. I don't want to have to be in a position to decide whether this is suitable. Whether there is any financial arrangement between the parties, because in the current system that we have there are people whose role is to decide on that, as it is. I don't want to add another layer to that, another filter for the system. ID4 SINGAPORE</p> <p>It's very difficult to say because we are medical team. So we look only at the medical aspect. We look at the health problems. We look at the kidney function. We look at the safety for donors and for recipients. It's many, many other things that we don't understand and we don't know, but we try to keep everything correctly if we know that they have like a good relationship. ID32 TAIWAN</p> <p>I'm a surgeon, we are doctors, we just focus on the health of the patients and the health of the donors. ID22 HONG KONG</p> <p>This should have been screened out because we work as a team, we're involved very, very late in the process of the transplant. So the system in Hong Kong is the patient and his family have the idea of kidney transplant, will be offered to see the psychologist, clinical psychologist, for an assessment referred by the nephrologist and if they think that this patient is mentally prepared or stable, all these kinds of things, and allow them to proceed with the process of living kidney transplant. We're involved very late in the process, so most of the time we would just see the imaging and then we say okay the anatomy for the kidney is okay so I don't have any surgical contraindication for a kidney transplant. ID13 HONG KONG</p> <p>For these patients, sometimes we do not be involved in the life of the patient so much so that we start this topic of living related transplantation [with their family]. It's still some struggle for the doctor because I'm not involved in their life, so should I at this moment say "you can be a candidate donor for your wife?" I'm involved in their life so I cannot give such recommendation. But we will deliver some information in some open, public health, educational situation for the health promotion, not for my individual patient. ID42 TAIWAN</p> <p>We just have to do our job, and say no, the compatibility isn't that good, but the social aspect – I don't think we should interfere but we have to allow or give them time to sort these problems out. ID10 SINGAPORE</p>
Minimizing conflict of	<p>I think it's a good idea to have separate teams in regards to donor as well as the donor surgery and recipient surgery, so there is no conflict of interest in regards to what you do for a donor, and as well as the recipient surgery. It's not a bad idea, but as per any surgeon, you want to do as much things as possible. ID4 SINGAPORE</p>

interest	<p>Well I do think that's a little bit of a conflict but the practical difficulty is that we are a small team. ID19 HONG KONG</p> <p>So all these are independently held from the recipient. We don't allow the recipient's relatives to be there. We don't allow anybody - even if we need an interpreter it is a completely independent interpreter. So then they sign a document. They sign the risk acknowledgement form which is all the risks that they've been told about for the donation of the kidney. Then in addition we have an official MOH document which they have to sign off in which they categorically state four things. one is that they have not been coerced and that there is no contract that they're entering into, that they're not receiving anything in return for this donation and that they have not gone through another ethics committee elsewhere in the country and that they fully understand what it is that they're doing and all the risks that have been described. ID2 SINGAPORE</p>
Meeting	Controlled hypertension we accept. We are not really liberal with the extended donors, we don't do such extended donor program and the surgeon is very conservative
community	because he doesn't want a bad result so he doesn't take an old person, not more than 60. ID27 INDIA
expectations	<p>I think [countries starting a transplant program] need to start with good successful initial transplants. They need to choose the recipient and donor carefully, a very fit recipient and fit donors medically and then immunologically suitable and have successful transplantations. Then it will start the program. If we have a complication in the beginning the rest would be difficult. ID34 INDONESIA</p> <p>Global results, 80% is quite good, but I think it depends on many kinds of factors. In Taiwan we are a we are closely related society, in terms of genetic, cultural, quite the same, so we expect our outcomes to be very good, as compared to the US. US is a multi-racial nation. I don't expect their outcome to be as good as ours. ID48 TAIWAN</p> <p>So far our live donor renal transplantation program has 10 year survival of 80%. That's now our standard. So if we are thinking about this kind of standard. Previously we did successfully, we might think now we be unsatisfied in terms of so high standard. So we are still struggling but we are getting more conservative. ID48 TAIWAN</p> <p>Society in developing societies. India is a country with a mix - there are a variety of reasons people might be different from each other. It could be religion. Religions. Hindus, Muslims, Christians, Sikhs. There are so many religions in India. We don't know but some people have strong feelings about the exchanges not being across religions. Who knows? I can't make that judgment for a given person. Socioeconomic status. India has been typically a divided society in terms of castes and so on. Caste religions, so because of this, we need to make sure that all these sensitivities are basically addressed and which will happen if the donor recipient, the two pairs or more than two pairs that get to know each other and make sure that things are. That is in my centre. That is the approach that we take. But thinking about what has been done in other centres, they will keep it anonymous to prevent so-called prejudice. You know? We have to be sensitive to the society. The niche of the society and how the society sees it. We don't want to do something which will create a negative impact. Because if we do something and then if we create a - if we do anonymous exchange, I understand completely the rationale behind it and if at a later date, if either recipient or donor family comes up with something which they find distasteful, it might create a negative publicity for the entire program, which we don't want. ID28 INDIA</p>

Resolving ambivalence	<p data-bbox="296 180 2022 365">Everybody wants a certain part of a person's body. So what does that mean to a person to be a donor? Will it come to a point one day when it becomes a norm to be a donor to any part of our body just for the sake of medicine? Should it be? That raises the issue of cultural sensitivity. I know people laughed about it. I see transplant medicine as actually having a bit of impact on that because of the way we start to take all these things. Then, we start to de-emphasize the importance of human body. I see it as that way but people may not see it as that. You see? To me, the other aspect is when do we decide enough is enough? ID7 SINGAPORE</p> <p data-bbox="296 391 2022 524">Actually, the law says if someone is over 18 years old, but 18 years old for me is too young. I would prefer the people over 30, because in Vietnam the system for insurance is not working very well, and sometimes if you are still too young and you don't have a good job, so sometimes you cannot have enough living expenses too. It's very difficult to earn your living, and if you become ill or quite with some kidney problems it could be catastrophic for them. ID32 VIETNAM</p> <p data-bbox="296 550 2022 631">The safety of the donor is the priority because I am a nephrologist I don't want to see another chronic kidney disease patient after they donate the kidney and the second is how to provide the healthcare for them, secondly I like to make sure that no financial problem, make sure that its fair. ID33 VIETNAM</p> <p data-bbox="296 657 2022 842">I would focus on the deceased organ donations, yes so living donors we keep them because we don't have many deceased donors. I expect if we have enough deceased donors the number of living donor would decrease. There was data presented in the last meeting that the mortality of the living donors is eight times higher. It is very serious data so we usually say that the donor is okay and this still has a - but even though the percentage is very small but the risk is eight times higher, this is a significant increase. ID51 KOREA</p> <p data-bbox="296 868 2022 1002">Japan is a very special country because basically the number of deceased donors is limited. Besides that in this situation we try to perform many living transplantations so we developed the ABO incompatible transplantation. But our transplant surgeons believe the transplantation should be done from the deceased donor. Basically living donation is not so good because all the Japanese population wanted to increase the deceased donors so we need not perform the living transplantation. ID29 JAPAN</p> <p data-bbox="296 1027 2022 1109">Basically it's not so good because before the operation for the donor we have some stress. The donor is completely healthy and so but we have to cut the donor. ID51 KOREA</p> <p data-bbox="296 1135 2022 1268">We cannot promise that when we take a kidney we really will not hurt their health. But in most of the time because we do in our process of investigation to screen up to the donor we have five processes of investigation. After the five processes of investigation I think at least at the time we take the kidney from the donor we believe that the patient is in a perfect health. ID14 HONG KONG</p> <p data-bbox="296 1294 2022 1429">Younger donors, we do have a couple of young children to a parent donation. They are very happy to donate. I think at that point of time usually the discomfort is for me rather than for the patient. The patient is really keen to donate, you can tell, the donor is really I'm going to give it. But personally I felt a little bit uncomfortable but after weighing all the pros and cons and all that we proceeded. ID10 SINGAPORE</p>
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The system to take good care of these patients both in short term and long term are not well established. I think even in the US, it's not well established. You can say oh, long term it's safe, long term it's safe according to the medical literature. You may not have premature death. ID53 THAILAND

I think we should be concerned, because they have to live another 50 years or more. There should be a system to ensure that early detection of any illness. ID53 THAILAND

The long-term data on donation is limited to at best about maybe 20 years. So good data and bad data exists for 37 years I know but bad data is really horrible data. ID2 SINGAPORE

Yeah right, he was quite young. I was very uncomfortable with that, I think it's because of the lack of evidence. I think any of us would feel very comfortable with allowing offspring to parent donation if the age gap wasn't all that much or if the donor wasn't too young but I do favour taking from an older donor rather than a younger donor. As an Asian nephrologist I do that, mainly because of lack of evidence but having said that it doesn't mean I wouldn't allow an offspring to parent donation. It happens every once in a while. Every tenth transplant we do is an offspring to parent so it happens at least once to two times a year. ID2 SINGAPORE

Societal: plight driving caution

**Poverty and
desperation**

This is very common problem in developing countries to see for people in the poor place and they sell the organ. ID33 VIETNAM

It's the vulnerable people who are poor. If you are paying the debt of your father's generation before because of a feudal setup, you've taken money for some small needs, and you can't so it keeps on multiplying. The next generation is then supposed to pay, until they become free. They have their own private policing, so they don't run away and so on and so forth. They're only given dry ration, not giving any salary as such, very informal. But you can't escape that, that's the tragedy. So these are the people who are the vendors because these big hospitals used to send in their - first it was a middle man, but then they dispensed with that. It was their own people employed by the hospitals to go into these villages convincing them that if you sell your kidney, you will get 100,000 rupees which for Pakistani standards is quite high because our GDP per capita was then only \$1000. They used to fall for this a bit. After the surgery was done they were all literally kicked out after seven days, and never to return to that hospital, there was no follow-up. ID52 PAKISTAN

**Higher risk of
disease**

We have more than 200 prevalence hemodialysis patients in our centre and almost near 400 maintenance peritoneal dialysis patients so its 200, more than 200 hemodialysis patients and 400 peritoneal dialysis patients. All these patients are potential candidates for renal transplant. ID42 TAIWAN

The good thing is that most of the families here they have a lot of siblings so you very easy find the huge family but the barrier is that a lot of them have infectious disease, they have TB, they have hepatitis, and you couldn't get the kidney from hepatitis B or C. ID33 VIETNAM

I don't quite know the reason why they make the limitation about 55 years perhaps sometimes we know that the incidence of end-stage kidney disease is top 1 or top 2 in the

world. ID41 TAIWAN

There's a very high incidence of diabetes in Singapore among the Asians which I think we need to pay particular attention to and most of the medical failures are because of abnormal glucose tolerance stats. So I would probably use that almost as my screening test so I think we need to be more watchful about diabetes from the social cultural medical lifestyle kind of an issue. ID2 SINGAPORE

The second big fallout is the high incidence of diabetes or glucose intolerance. I am very strict. Fasting glycemia, two strikes they're out. The only circumstance that I think I'm a bit more liberal for a marginal donor is if the donor is hypertensive, age less than 50 but he's donating to his kid or her kid. I tend to bend my rules a little bit about the age limit but otherwise we're very, very robust and very, very rigorous and I'm sure you can tell. ID2 SINGAPORE

**Lack of social
security**

It is extreme in India because of poverty. There is no social dole or social security. I pay tonnes of taxes but if I'm sick the government gives me nothing so you see there's no social security so people are not wealthy and they want to live long so mainly, so if I were to ask for modification of the law, and I don't believe that a country which cannot promise two square meals, has any right to tell me what to do with my body as long as nobody takes advantage of me, that is the bottom line. Living donation should not take advantage of me. I should get what I want. I am the boss of my body. ID26 INDIA

The challenging aspects are when we have only one potential - superficially suitable potential donor available. If that donor is because of some reason medically not suitable, that becomes a big challenge for us to break the news to the recipient and to the family, because they have pinned a lot that that particular donor will be suitable and will donate a kidney. When that cannot take place, then that becomes a challenging issue. The most challenging issue in terms of it applies to a larger number of individuals, is to explain to them the need to raise finances and the amount of money which might be required for the transplantation. Because a large proportion of Indians don't have health insurance. ID28 INDIA

If something happens to you, you have to be responsible to yourself, to your family and everything else. So sometimes I'm not sure this kind of altruism is, maybe a bit lacking especially for major decisions like organ donation and things. ID11 SINGAPORE.

Although we have a public but there's always a co-pay, it's not totally free, sometimes to a certain individual or certain socio-economic classes there's still much of a financial burden. ID11 SINGAPORE

Sociocultural: navigating barriers

**Centrality of
family**

Every day when we have this three to five family visiting hours, the number of people who come and visit a patient is extraordinary. It applies to India, Bangladesh, Sri Lanka, Nepal, Bhutan and I would think the same applies to eastern part of Asia as well, Thailand, Burma ... The modern area with industrialization and everything else kind of

loosened those bonds, but they are still to us very relevant; to them they may be less. But in our ethical concerns also it matters how the family sees it. It's the family which is important, central to decisions. ID52 PAKISTAN

The Indian family system is very cohesive. So mother is the first option that will invariably come forward. Second is the sister, very often, but then married sisters have their husbands and their in-laws, they are very joint family society and husband of the donor and mother in law of the donor are very important people who if they say no that's it. ID26 INDIA

The culture because relationships between the family, so when the donor donates their kidney, he sees the recipient get healthy, and did not receive the dialysis, the donor will feel satisfied. ID39 TAIWAN

When you are living in Indonesia you are a close community, closely related, not only to your first degree family but also to your society. ID34 INDONESIA

I'm happy to have the regulation on the relationship because sometimes the son may have the autonomy to donate the organ to the father or mother, but the son's wife may not agree. And in our regulation, the donation would not be performed. You have to get agreement from the wife. I'm happy to have this regulation. Because the autonomy may come from complicated factors. I'm not sure what kind of agreement or arrangement will be set up between the son and the father, but I think the wife will think a lot for her husband. So I would not accept the donation by law. It's quite common. Sometimes I have to isolate the wife to because she won't say. It's quite common. I will give the family a different reason.. ID48 TAIWAN

Sometimes the potential donor, will be influenced by their spouse, especially the female donors, and when they get married, and she wishes to donate one of her kidneys to her relatives, the decision of her husband is very important. Most of the time her husband will refuse the donation. Because they have to take their own kids, to take care of her mother-in-law, her father-in-law. ID41 TAIWAN

They're actually very united as a family and their community's actually very strong, so somehow the sense of duty to one's child or parent seems to override what people would typically conceive Muslims to think that they wouldn't want to donate because this is part of their religious belief. But interestingly the family duties actually or sense of responsibility overrides that and yeah quite a lot of spouses, fathers, parents, are coming forward to donate to their loved one. ID5 SINGAPORE

But the family, under the Taiwanese or Chinese Culture, we are very family bonded so the family, the family bonded plus we have very small families, maybe just 5 or 6 members, core family, nuclear family, very small, so family members will, I think they don't have to say about it but you can feel they give the hope on you. The hope is on the family member to donate. ID39 TAIWAN

If the husband needs the kidney, maybe they have 4 kids, but the whole family prefers the wife to donate, they don't want to affect the children's body. So, the spouse will, not under other people's opinion, the spouse will say I want to be the donor. ID39 TAIWAN

I guess it's more or less the same in probably Asia - not to say Korea or Japan, which has really different culture. The same mindset is still around. They don't want the family member to suffer, they worry that it will affect the fertility. Usually, for the parents, they are not so keen for their daughter to donate. Some will be for the daughter, some will be for the son, because the son is the sole breadwinner, he hasn't got married. The daughter, same thing - not the sole breadwinner, but haven't got married, still haven't delivered any babies before. So they don't want it to affect, no matter how much we have told them that it shouldn't affect. But they still don't want to take the risk. ID1 SINGAPORE

A lot of them are middle-aged people, our patients. Of course, our potential donors are also either their children, who are just starting out in their career, or also middle-aged, trying to look after their family. So, they also have their own issues, which prevent them from readily agreeing to donate. ID3 SINGAPORE

For living donors, I think if it's a man, it's a husband then usually the parents will not agree with the son donating a kidney to the wife. If the husband is the son of the parents. Maybe because usually people think the son is more important to earn money, he's the, he has the most important role in the family. So usually they will encourage, they will not oppose to the wife, the daughter in law given a kidney to their son but I think they will oppose the son giving a kidney to a daughter in law. For example one of my patients is only, 20 years old or 25, his mother is going to donate a kidney to him so they will have the operation next month. The mother will donate usually it's the women who will donate a kidney. So mother want to donate, because of the great love of the mother, they will not let the husband donate, they will donate so for women I can just say in the oriental countries, or at least in Chinese, I think the mother's love is very great, the mother will donate a kidney to their son, I mean the wife to the husband. ID43 TAIWAN

For living donor I think because of education and because of love it's easier. For example the husband does not want the wife to donate the kidney because the wife can take care of him. They have to decide by themselves. For the new generation I'm not sure. For the older generation, usually the love is very strong between couples. For younger generation I don't know because there are many divorces. I think love makes the man or women wants to donate a kidney. I can see love between brothers and sisters. ID43 TAIWAN

Interestingly, the older they are, the recipients decline consideration of donation or transplant. They don't want to trouble their own family members. The older they are they seem to feel that they don't want to be troubling their relatives so there's this concept, I'm old. That seems to be a little bit more prominent in Asia than you would perceive in the west. ID2 SINGAPORE

Economic priorities	<p>The economic resource of a family is from the male patient, so I think this is why females such as the daughter, or wife, are willing to donate their kidney. ID47 TAIWAN</p> <p>Some of them are the main person who get money for the whole family, and they have big family too, they have 4 or 5 kids and then, here if one parent want, if one parent works it's not enough for the family to support the life, both of them have to work, both of them have to work so you see now it's enough money to grow up two kids if they have more than that it's really hard for them, so the life and the quality of life is you know it's not high enough, people have to work very hard and for them if they, they don't</p>
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have enough of energy or strength to continue to support for the whole family and sometimes I can see the single person offer the kidney more than the married, because for a single they said oh I'm single, it doesn't matter, its ok, and I'm not, I don't have to take care of anyone so I don't have to worry about the future. ID39 TAIWAN

So cost is a big concern in regards to, not just for the surgery per se, subsequent follow-up and the need for medical care, there's implication in regards to insurance cover as well, and of course the implication on work. ID4 SINGAPORE

I don't know whether this is the culture of the Chinese people but we have seen quite a number of times that it is more the wife who donates to the husband but not vice versa. In Chinese culture the male is still the boss. So in the whole family the father is the breadwinner and everybody has to listen to him. That's why it is more common for the wife to donate to the husband but not the other way around, much less common. ID15 HONG KONG

Especially in some families their husband or their father has to take care of the family in economic level so they have to keep the family, economically it's a problem. So I think money is more important than other relationship. But I think in some families, they have to earn their money by their labour. Male gender is important. But in higher level, my wife is doctor and I am doctor, if she has to go dialysis, maybe I will donate a kidney for her because in my job one kidney is ok. So there is difference. In some families there is no difference in gender. Gender difference is different and different level. In some families gender differences in not so prominent but in lower class it's prominent. ID44 TAIWAN

Some will be for the son, because the son is the sole breadwinner, he hasn't got married. The daughter, same thing - not the sole breadwinner, but haven't got married, still haven't delivered any babies before. So they don't want it to affect, no matter how much we have told them that it shouldn't affect. But they still don't want to take the risk. ID1 SINGAPORE

Because over here, it's - once you are sick, your employers tend not to be very forgiving. ID3 SINGAPORE

The donors also have to take leave to see a doctor. They have to consume their own leave. They don't take MC, because they feel that the MC will penalise them. ID3 SINGAPORE

If he is 35, I think his parents should be 50 something or 60, depends how old his parents are because if the patient donates a kidney and it affects his life or his work I think it's not cost effective. I mean you donate a kidney to your parents who are not working, and you are the donor, is young and reproductive not just in, in children but also reproductive in work, he still has a work so I think it's not absolutely contraindicated but not the best. ID43 TAIWAN

For living donors, I think if it's a man, it's a husband then usually the parents will not agree with, agree to the son donating a kidney to the wife. If the husband is the son of the parents. Maybe because usually people think the son is more important to earn money, he's the, he has the most important role in the family. So usually they will encourage, they will not oppose to the wife, the daughter in law given a kidney to their son but I think they will oppose the son giving a kidney to a daughter in law. ID3 SINGAPORE

	<p>I'm not sure, like in Hong Kong you live in an environment that is very competitive and things like that. You always want to win, you always want to benefit. You want to [win] and Singapore is very crowded. You always want to be the one to survive and then you do have these things that you have enough, that you do have this sense that you have enough, that you want to do something for society. Now in Singapore everything is very expensive. My first priority, to get a house, get a car, get a wife and children, get condominiums and send the kids to school. People are working and so their environment is working towards economic gains rather than do I help people and things so I'm not sure whether that is the thing. ID11 SINGAPORE</p>
Distrust in modern medicine	<p>I believe that there are still some misunderstandings from the general population that the donation of one kidney will interfere or affect their future life, life expectancy. But I don't think so. If the donor is very healthy, then there is not effect on their life expectancy at all so I believe we can do, we should do some education to the public about organ donation, especially the kidney, it's a safer procedure to them but a very helpful procedure to them, helping their relatives, the education is very important. ID41 TAIWAN</p> <p>Most of the family who cannot or do not have potential living donor, they are fear of the operation. They fear the loss of one kidney. ID53 THAILAND</p> <p>In terms of religious barriers to donation, I suppose it's a little bit more than in the western world though none of the religions actually say there's anything wrong with living donation, I still think that there's a general disbelief in modern health and modern science at least among the older generation. ID2 SINGAPORE</p> <p>Just correct the misconception that this living donation is unsafe. In regard to the publicity, we can do a better job in getting more of these recipients coming forward and showing how much kidney transplantation has changed a life. That would help a lot locally. At least when in the UK, the altruistic donors that come forward that are screened, when I ask them why they're coming forward, most of them are telling me they've heard good stories from their friends or relatives who's undergone a kidney transplantation and they're inspired by it to donate a kidney. ID4 SINGAPORE</p> <p>There's still a lack of awareness and a culture to think that donation is normal and common, so that is probably another issue. ID5 SINGAPORE</p> <p>The second most important one is to do more education try to change the culture in the society. In our culture in Hong Kong kidney donation both deceased donor donation and living kidney donation is not very common. Most of the families still have the traditional Chinese culture that is that if my family have a sick member we will help them. But we do not want to have another member also have the disease. So actually the culture in Hong Kong it is better in recent years but it is still a lot to improve. Especially try to change their belief of donating a kidney you will not hurt their health.ID14 HONG KONG</p>
Generational traditions	<p>The challenges; maybe in our Chinese culture, you see is a bit difficult for the family members or for them to donate the kidney, but over these years, because of the young generation, they are more willing to donate.ID20 HONG KONG</p> <p>I mean the youngsters now they may not have these kinds of thinking, but the more traditional Chinese culture is like that. ID13 HONG KONG</p>

	<p>I think the questions that we tend to raise to them, to make them think twice, is the same for both younger and older. But I think that, in their minds, the thought process is a bit different. So, for the middle-aged, I think they tend to decide based on a need or necessity. For example, a father would donate because he wants his child to get on with his career or get on with schooling. So, that motive - whereas, for the younger one, they just want - I mean, it's the same. I don't think - I think the motivation to donate is the same, but the intensity of the motivation is... ID3 SINGAPORE</p>
Emotional opacity	<p>Chinese people are less explicit and sometimes we do encounter someone who will be more enthusiastic and just volunteer and if it is so the situation will be better. ID12 HONG KONG</p>