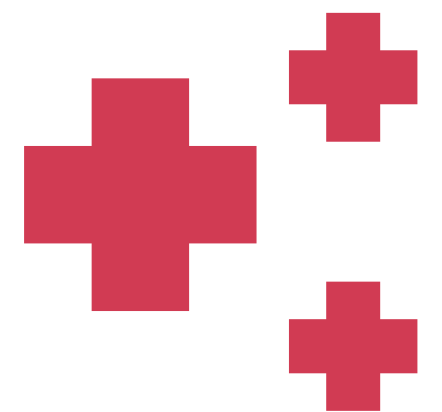


# Data Versus Human Factors in Decision Making: the Heart or the Head?



# The Transplant Process



Organ Donation



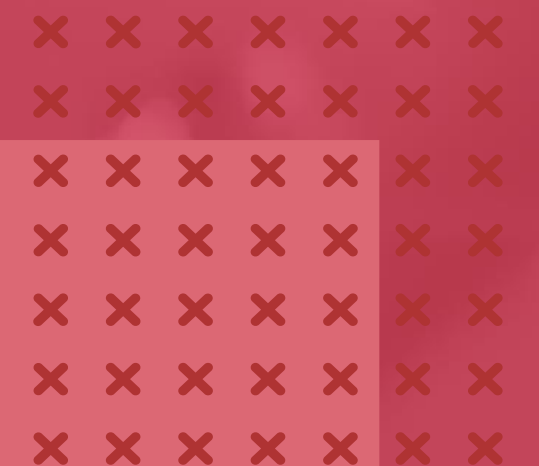
Healthcare Professionals

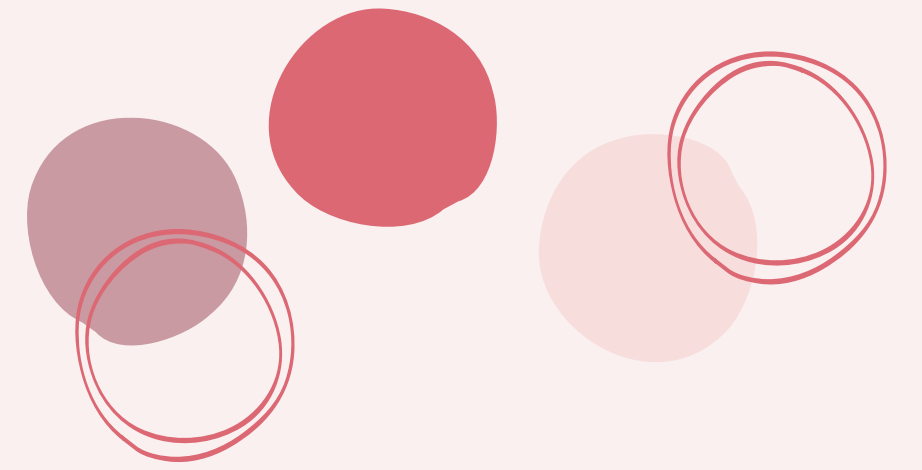


Kidney Transplant Patients



Decision-making





# Transplant Choices

## 3 Questions

I asked:

How do you, as a patient, make decisions around whether or not to accept an offered organ



# Views

A. I will have to make a rational and emotional decision. I will like to know the historical health status of the donor and the medical practitioner's opinion on the medical suitability. Where the donor is not a perfect match, i will like to know what the more likely risks and benefits of going ahead with accepting the organ.

B. My views as to how I made decisions around offered organs stems from my whole experience with kidney disease and dialysis and their overall attendant effects on my life.

One major factor was the fact that it seemed your whole life was placed in prison controlled by this disease and it's treatment. How you feel, what you eat, where you go , everything became secondary. So in taking the decision I had to think deep what I wanted to claw back to get some semblance of normalcy.






# Views



A. My first was at age 3 so it wasn't my choice or decision that fell on my parents. My second was from my dad so it logically seemed the best option as it was a live donor. Third transplant I wanted my life back my childhood and 20s were basically put on hold and I needed to get some stability in my life, it was also during the pandemic so it all felt a little crazy but I thought I'm probably not going to get many offers being my third and antibodies so I said yes.

B. I will have to make a rational and emotional decision. I will like to know the historical health status of the donor and the medical practitioner's opinion on the medical suitability. Where the donor is not a perfect match, i will like to know what the more likely risks and benefits of going ahead with accepting the organ.

C. I make my decision based on the information I am given by the medical team on the day. There's no prior research to be done on the donor's health history, so I would go with what the team would relay to me.





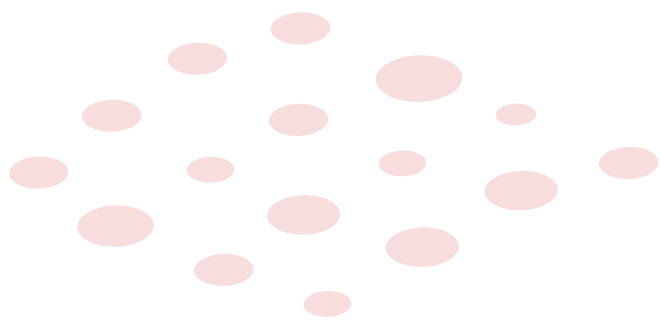
# Views



A. When I accepted my first kidney for transplant, I was so eager and excited that I didn't fully grasp the implications of the situation. The kidney had been out of the donor's body for 23 hours before the surgery. In hindsight, I believe that the extended time the kidney spent outside the body had a significant impact on its viability and, ultimately, my recovery. I struggled with complications after the transplant, spending 20 days in the hospital, and that kidney continued to give me problems until it was removed three years later. For my second kidney transplant, I approached things differently. This time, I was determined to receive a kidney that was fresher. The kidney had only been out of the donor's body for three hours, and I believe this made all the difference in my recovery. After the second surgery, I was out of the hospital in just six days, and the recovery was smoother. Looking back, I realize how important it is to consider the condition and preservation of the organ before accepting a transplant.

B. I made a decision to reject the offer based on the information from others patients experience. I did few research and weighted advantages vs disadvantages and all that made me make my own decisions





# Views



A. When I had my conversation with my consultant about my operation. I wasn't expecting to receive an organ quite quickly. The answer was yes cos the prospect of waiting so long, then he did say I could decline and I said I would only decline if it was in a really poor condition. That's the only thing that would stop me from accepting an organ. I won't say no if there was a chance of my condition coming back which is a chance I have taken.

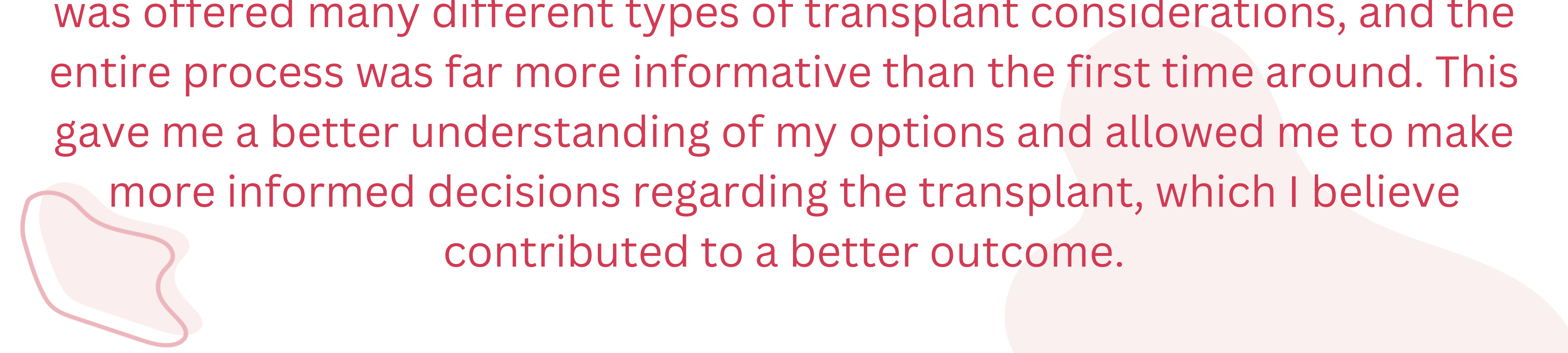
B. Myself and my family members will discuss it thoroughly with my consultant. 1b) I will ask necessary and relevant questions, I will research the success rates of kidney transplants and ask questions about the surgeon, his or her surgery success, and after care offered to the patient. I will also request a pre-op counselling and talk to renal patients who have received transplants.





2. Is this purely an objective decision, or are there more subjective factors involved?

A. The workup for my second kidney transplant felt significantly more thorough compared to my first. The doctor asked me a wide range of questions about the type of kidney I would prefer, including whether I would consider a double transplant or accept a kidney from a younger or older donor, or even one from a donor with certain health conditions. I was offered many different types of transplant considerations, and the entire process was far more informative than the first time around. This gave me a better understanding of my options and allowed me to make more informed decisions regarding the transplant, which I believe contributed to a better outcome.





2. Is this purely an objective decision, or are there more subjective factors involved?

B. No, for me I understood from the consultation, the decision to make was based purely on knowledge gained from waiting and the wait list must be longer for me cos of my ethnicity, and the chance of finding a match within that ethnicity. I did my research for that and understood that it would be a lot more longer to wait. It was purely knowing that, I would take the chance no matter what. Specifically, only things that would stop me only if there were a lot of things wrong with it rather than say no straightaway. I would definitely look at those subjective factors whether it carried something my body isn't used to, or it could give me something. Before if I knew what I know now, I would probably question it a bit now, things to know before hand.

2. Is this purely an objective decision, or are there more subjective factors involved?

C. I think generally they were objective it's only really the third transplant where it felt like a choice for me, and as explained I just wanted stability and my life back. I guess when it came to my second transplant from my father there were factors like religious factors and what society may say, but after talking and researching as a family (mainly my father to be honest) we felt it was acceptable to do as a family but for me there was backlash on me in school and also the relationship with my father did change too.

## 2. Is this purely an objective decision, or are there more subjective factors involved?

D. On the subject of whether it was objective or had factors that helped predetermined my choice, airforce would say it was a bit of both because my sole reason was to get back to living a normal life as much as possible

But there were various secondary factors that influenced this .. a. Overall well being , age, dependence on dialysis , ability to choose what to do and eat .. quite a few things. Even wanting to keep a relationship/ family because kidney disease and dialysis does influence both a great deal.

E. The average patient solely depends on their medics to take care of their health and trusts all the information given them. The Doctor knows best, if he or she jump they will do that. They entrust their care to the medical professionals. They rarely feel empowered to share the care or take an active interest. Who I am told would greatly influence my decision, then again in this scenario, time is of the essence.

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3. How are you as a patient influenced by what your transplant team tells you about an organ and the risks or benefits that might come with that organ offer?

A. Because I trust the team, I accept what am told by them. Note you are always given the chance to ask questions concerning the transplant and the organ on areas you are either not sure of or comfortable with. The team tries to the best of their ability to explain and make you comfortable concerning everything to do with the organ and the transplant.



3. How are you as a patient influenced by what your transplant team tells you about an organ and the risks or benefits that might come with that organ offer?


B. This is big for me cos I've suffered quite a lot after my transplant. There were a lot of things not discussed, I did get a brief overview of the risks and benefits. I tried to not take all onboard because I didn't want anything negative in my head. The recovery time, we could talk about this for ages how the recovery would look like for a patient, what they should watch out for, what they should have to hand, what they should know for sure are the little things that would make their healing process and mental health a lot better, it's not just about the risks and benefits that it covers but it should cover your well being afterwards, and how to access those parts of your transplant journey.



3. How are you as a patient influenced by what your transplant team tells you about an organ and the risks or benefits that might come with that organ offer?

C. I think by the time I got to a third transplant I already understood the risks and benefits, I didn't get told a great deal apart from it's a suitable match. And again there may be other people who could be a better match so be aware that you may not even get the organ so I guess I tried to stay calm as this was my first call in my life and I have had that feeling of not being the best match so I knew it was a possibility.

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D. Objectively it is the patient's right to make a decision based on the information they might have gathered regarding 'transplants'. And it will have to be a choice they will not regret making in the future. Furthermore, Subjectively, they would be in need of the input of other medical practitioners and their immediate family members, but should not be enforced if the patient is not 100% sure of what choice to make. They should be given enough for mediation and counselling. They should feel safe and confident enough to go ahead with the surgery. Due to all the pros and cons involved. So yes, for me, I believe it would have to be both objective and subjective. We have heard of patients who didn't survive surgeries or their bodies rejecting the kidneys



# Other views

I believe it's crucial for a patient to fully understand not just the kidney they are receiving, but the entire transplant process. This includes the importance of maintaining overall health and being aware of the medical interventions required after a transplant. Patients need to know about the medications they will need, how these drugs can affect their body, and how they might need to be adjusted over time. It's vital to be well-informed so that you can work closely with your medical team, manage your health more effectively, and ensure the best possible outcome after the transplant.

I think personally the information I got from my transplant team about the risks and benefits helped quite a lot and ofcourse coming from my own experience where I had to think of having a double transplant (kidney and pancreas) I would say yes the information went a long way to helping me decide what options to take.



**Thankyou!**