Venter and Rodger

**Comfort King:** [00:00:00] Today we have the pleasure of having Bonnie Venter and Daniel Rodger, who will introduce themselves. And we will be talking today about the Affair Exchange, why liver, living, sorry, kidney donors in England should be financially compensated. And this was based off the article published in the Journal of Medical Ethics.

So at this point, I will hand it over.

**Bonnie Venter:** Hi, everyone. Thank you so much for joining us today. I'm Bonnie Venter. I am Daniel Rodger. Well, a final year PhD students in the final few weeks but I'm also a qualitative researcher at the University of Bristol with the medical school. So yes, welcome to join us.

I'm really excited to talk about this and really thank you for the opportunity as well. I'll hand over to Daniel first and then I'll introduce our topic.

**Daniel Rodger:** Hi, everyone. Yes. So I'm Daniel Roger. I'm a senior lecturer in operating department practice at London South Bank University, but I'm also a part time PhD student at Birkbeck as well, where my primary sort of focus is I'm doing sort of qualitative research around looking at key [00:01:00] stakeholders.

In xenotransplantation. So that's what I've been kind of been focusing on. But yeah, very much looking forward to exploring this topic with with Bonnie and yourselves.

**Bonnie Venter:** Yeah. So today we're kind of going to talk about, well, what started off as us just having a bit of a rant in Teams, then it developed into a paper, and now it developed to this idea, which we just continue thinking about.

And that is about whether we should reconsider compensating living kidney donors. Perhaps worth to say just a bit more in terms of that. Some of the arguments were based is also based within my PhD. Tell you a bit more about that when we get to there we go. I'm sorry, am I presently muted?

There we go. Okay, so I'll, I'll talk a bit more about how the data is embedded in my PhD as well. Just to say, to also start off, we're using the term compensation. We don't want to use remuneration because living donors are already remunerated with the reimbursement scheme. And when we talk about compensation, what we mean [00:02:00] is just kind of somebody receiving a predetermined amount for their kidney donation.

I should probably share the slides. I realize I forgot to do that. Okay, there we go. Okay. So we thought to start off, it would actually be great to just gauge how the audience is feeling. So we want to start off with a poll to just kind of ask about whether you are in favor of financially compensating living kidney donors.

As soon as I find the poll, we can get started. There we go. So the question should be on your screen now, and you can just think about that while I start to introduce the topic then. Okay. So firstly, when we hear the word painful kidneys, these are usually the kind of images that come to mind. So we, And it's rightly so that these images come to mind, because these are all examples of people that have been coerced and exploited in exchange for payment for their kidney.

But what if there was a model for receiving payment? That looks a bit different that didn't involve [00:03:00] cohesion and didn't involve exploitation during the next 40 minutes or so, maybe a bit less after the technological glitch Daniel and I will kind of talk about ideas about why we think compensation should be considered, especially in the system as sophisticated as the living kidney donation pathway in the NHS.

We'll start off, first start off with Daniel giving a bit of scene setting, we'll revisit some of the arguments and then also add some of our own ideas to why we think the time is right to talk about this now. So I'll hand over to Daniel for now. Yeah, thank you. So we'll just start a little bit about why is there a need for, for transplantable organs?

So at the moment you can see there's 700, 7, 485 people waiting for a transplant in the, in the UK. Average wait time said NHS is around two to three years for a deceased kidney from a deceased donor. And then roughly sort of three to six months for from, from a living kidney [00:04:00] donor.

We look at the activity data recently from uk the NHS Blood and Transplant from the last year, and, and the first sort of three quarters of, of 2224. By and large, they, they're quite disappointing compared to the, the figures from sort of 20 19, 20 20. So for instance, there's sort of, there's double the number of people who have opted out for organ donation on the organization register.

So it's gone up from two, two to 4%. And obviously there was a lot of hope associated with going to the deemed consent approach but so far those kind of significant improvement improvements that some people promised but by some, there's no kind of definitive evidence that you know, just adopting that system would result in, you know.

Significant improvements. If we look at data again over the last five years, except 2020 21 during COVID, the total number of patients on the active list has increased year on year over the last five years. So today, I just looked at it today, it's changed from when we last put this slide up, but there's [00:05:00] 7, 525.

And that's compared to 5, 685 from 2019, 20, and around roughly 5, 750 of those are patients who are, who are waiting for a, for, for a kidney. And obviously what, what we know, you know, there's so much evidence to support this is that a kidney transplant from a living patient you know, has better outcomes.

It's associated with fewer complications and. An overall longer functioning organ and again, we can see here the consequence of not having enough organs for transplantation is we look at the deaths there. So, 439 patients on the active. list died of which 250 are waiting for a kidney. And then we've got the the figure there with 239 removed from the list.

And often this is because they become too sick and end up being removed from from from the the live, the live register. Let me go on to my next slide. If you're able to do [00:06:00] that. We thought we'd just add a bit of context here. So he can see summary here, some comments from the human organ transplant bill from, from 1989.

Now in July, 1989, the human organ transplant act, 1989. Potter was passed. And, and, and it, we thought we'd It made it illegal to make or receive any payment for an organ that was intended for transplantation. Now the, the, the, the new legislation followed a quite well document documented scandal that occurred in England in 1989.

And it involved three three doctors a private London hospital. And it had been discovered that they had transplanted four kidneys that had been purchased from, from abroad, and in, in one case, a a 33-year-old printing worker. From Turkey sold his kidney for 2,500 pounds. And this was following, answering an advertisement that had been that had been paid put in a, a Turkish newspaper.

And after this Dr. Raymond Crockett, he was, he was eventually struck off [00:07:00] by the GMC after these events, and he was responsible for procuring the organs and arranging the. And he'd actually, he really, he failed to ensure that the four men that they actually understood the risks and possible complications associated with surgery.

And the, the, the, he did, there was, there was no valid informed consent really wasn't, wasn't established at all. So it's totally inappropriate, you know, and regardless of what you think of. Paid financial compensation. Everyone can agree that this was totally more unquestionable. One of the issues also, however, is that it was rushed through so quickly that no consideration was given to the potential benefits of of a kind of system of, again, we use financial compensation rather than payment.

whether it could be done more carefully in a way where valid consent could be given where proper follow up was given, where we weren't putting advertisements in foreign newspapers and things like that. And what we [00:08:00] saw, and I guess you can see here from the comments here from, from the human organ transplant bill, is that there were lots of preconceived ideas.

About, about this whole notion of, of of exchanging finfin finances for, for, for for kidneys. You see it in comments around it being Mac carra about around it being abor abhorrent. And so because it went through so quickly in just a few months, no one was really able to think about it very carefully in a sort of rational lens, because what people are responding to is, is the very worst kind of version of this was and it was being treated as the norm without consideration given to, to how it, it, you know, it could potentially be done in a, in a more appropriate way.

Can we just go to the next slide, please. Thanks. So, what are we proposing? Well we're proposing something called a a monopsony system. Now, this is something we're, we're not the first to to, to suggest this not by any means. It was most popularized [00:09:00] by Harrison and Erin in 2000, 2002.

Now what a mono system is, is where there is one buyer. And in this case, we would propose that it would be the NHS. And so there wouldn't be any competitors in, in that case, say, buyer in, you know, in, in, in quotes. And what this means is that that, that someone with greater economic resources has at least, you know, I think more so, but in, in principle, no more advantage to procuring a kidney.

Than than they do in the current system. So in the system we're proposing, the way kidneys will be allocated remain exactly the same. It'll be based on clinical need as well as other factors in the existing scoring system that's used. What we would argue is the only significant difference would be that living kidney donors would have at least The option to receive some form of financial compensation if they opt in to receive it, it wouldn't be the default.

And the reason we favor an opt in approach is because we recognize that if it was [00:10:00] the default acceptance, if financial compensation was the default, I think it would probably be unlikely to be well received by those who do have moral qualms of it or, or, or strong, strongly oppose it. So whilst we acknowledge it, obviously, it's important for individuals to make informed decisions guided by their own moral values.

It shouldn't necessarily rule out other individuals making their own informed decisions based on their own moral values. Sort of. I, you know, those who believe that it is acceptable to accept financial compensation for donating their kidney. For example, you know, there are things that we, that are already morally contentious that are legal in the UK.

But because we live in a pluralistic, pluralistic society, you know, we recognize that moral disagreement doesn't always mean that that certain actions should be illegal. We also acknowledge that when we propose a a figure, that any figure has to be tested against public opinion [00:11:00] to be sure that it is actually fair, that it fairly compensates the risks that the individuals are undertaking, and that it isn't perceived as an undue inducement.

Something I something that people couldn't refuse or or and isn't in fact an undue inducement So we arrived at this figure of 35 000 pounds. As a kind of acceptable starting point So we're not wedded to the idea. We just use that as a As a, as a, as a starting point, the reason we chose it is because it's it's slightly above the median annual full time salary for someone in the UK.

And also it was lower than the figure tried to find some data, but it was from the US. It was it was below the figure that was perceived as an undue inducement. Some studies from from the U. S. It was lower for individuals who were considering being receiving compensation for donating to a family member, but it was significantly lower than the figure for donating to a to a stranger.

I think importantly, it's worth noting is that most [00:12:00] people agree that donating a kidney is a good thing to do. And but we, we know we have to, you know, we have good evidence support that there are, and we all know as well, that there are disincentives to doing that. There are common disincentives, but there are, there are distinct ones as well.

And we think that financial incentives could help to address those disincentives. You know, some of them include a lot of the data talks about post operative pain, discomfort, uncertainty about the long term health impact of donating a kidney, and concerns about whether that kidney that they donated might be needed by a loved one at some time in the future.

So, you know, our way of viewing it is that those that that financial compensation could act as that nudge that helps people do what they wanted to do, but we're worried about certain disincentives.

Next slide. So what I'm trying to do briefly here is just go through some of the objections. Obviously, I cannot in the [00:13:00] time allotted, we can't go through in detail. But I'll try and offer a sort of brief overview of some of the some of the common objections. Obviously, it's, it's It's true that some people find the idea of exchanging any money between a living donor.

No matter how it's framed, we'll find that some people will find it morally repugnant, kind of at the stronger end. And I think at the weaker end, some people find it morally uncomfortable and perhaps morally ambiguous. And I think I can sympathize you know, with that one level because I think when I started thinking about the art list idea It was very much framed by things i've seen in the media and again looking at those very worst examples of of of what of what can happen I think we all we all know the kinds of horror stories that come to mind and obviously reading some other accounts accounts as well.

I think even those who do feel strongly against financial exchange, with with living donors for example, something like leo cast will come come to mind even he would admit that That if we if [00:14:00] we did financially compensate donors, we would see an increase in the number of available kidneys And I think if that's the if that is the case then that would for me I would say that as that better respects the dignity of recipients.

Who would who would benefit from an organ that they wouldn't otherwise You know have received, and obviously that's better respects their interest in surviving by by receiving a life saving kidney. But as I've noticed I noted earlier is that believing that something is morally repugnant doesn't necessarily entail that it should be illegal or that that can't change.

And I think a good example would be the shift in opinions towards same sex marriage which I think example, exemplifies this we also have to think how we How we think, we think about how we frame the role of financial compensation can help address many of those intuitive reactions that people have towards our proposal.

Because we, we, we, how we, how we frame it, our rationale, it is that we base our [00:15:00] proposal on, on financial compensation being a fair response to the risks by physical, psychological and others that other things that are missed by the, the reimbursement scheme that a living donor must be willing to accept.

For example, we can often forget that undergoing invasive surgery where the patient themselves receives absolutely no therapeutic benefit is highly unusual. There aren't, there aren't many examples where someone undergoes invasive surgery for no, for no benefit to themselves. Because the benefits are primarily experienced by the recipient whilst the risks fall primarily on, on the donor themselves.

And so our kind of you know, theoretical position of this is, is we have to ask is, is it fair for an individual to absorb the burden of the risks, both short term and long term, without at least the option of receiving some compensation for doing so? And we, we would answer in the negative. You know some, some donors will donate just for the satisfaction of giving a loved one or a stranger, potentially, you know, decades, several years or a [00:16:00] decade or more of additional life.

But even in such cases, it's not obvious that receiving financial compensation would diminish the generosity of those, of that action. At least in a significant way that would warrant considering it morally, morally repugnant. Next, if we look at exploitation as well we would agree that any system that permitted or promoted exploitation of people would be concerning but we don't think our proposal is exploitative.

I think if we think of exploiting someone as, as wrongly taking advantage of someone we think that monopsony system helps to avoid exploitation that, that might occur. In the context of, say, in the legal market, how we're in balance between the buyer and vendor. Because as is already the case in England it would remain illegal for an individual to arrange or pay someone for their kidney and to take advantage of someone's vulnerable state.

So in our proposal, as we said, the buyer or the NHS already provide that established system for reimbursing costs to the donors. And I know, again, concerns have been raised about individuals of lower social [00:17:00] economic status as well being exploited, but again, we have to be careful not to be approach this from a paternalistic view, is that that those people are still capable of weighing up risks and benefits of their choices and making their own informed decisions.

And there's also some data available that's shown that the option of financial compensation actually increases the likelihood of becoming a living, of wanting to be a living kidney donor across all income levels, not just the lower ones. Again, if we are trying to speed up and taking a bit of time is it coercive as well?

Well coercive practices are usually those that involve some kind of threat or penalty. And we would say that the the option of receiving financial compensation. For those costs and risks they accept for donating kidney doesn't involve any kind of threat. And whilst we agree that a coercive kidney donation would be wrong merely having the option of receiving it is not sufficient for it to be coercive.

And so I think we would be skeptical of those claims. The, our system would increase [00:18:00] coercive donations because those same existing safeguards and processes remain in place where coerced donors already identified and not permitted to to deny if we look at crowding out as well, so this is based in the, and rooted in the work of Richard Titmuss in the context of blood donation.

And he argued that financial incentives would crowd out or they would reduce the number of altruistic donors. Now, he proposed that financial incentives would reduce altruistic motivation, lower pro social behavior, and lead to a smaller pool of willing donors. But if we actually look at the empirical data to support that it's increasingly showing that it's not necessarily the case, and it does depend on a number of factors.

For example, Luke Semaru has pointed out that this, what matters is the stakes and the size of the incentives. So you only see the upset the effects of crowding out when the stakes are low and the incentives are small. But the effect actually disappears when the incentive is increased. So given that kidney donation is a high stakes activity and the incentives are [00:19:00] high, it's highly unlikely that that will be subject to to crowd, to be crowd to crowding out.

We also try and mitigate that risk by making financial compensate by ensuring that financial compensation isn't the default. And there's also been some interesting work from recently from the economist Gary Becker, and he's shown that paradoxically, the payment makes crowding out of altruistic donors less likely rather than rather than more likely.

And again, I'm only going to mention Iran once just because I think it is interesting, even though we recognize problems with the system is that obviously they've had a state level level market since 1988. And although there are issues with that system, and we're not, we're not arguing to replicate that system.

And what it does show is that receiving payment for kidneys does increase the number of available kidneys. And there is one example of a state in Iran where the average wait for a kidney transplant is just over a year. It's 386 days. And as I said, studies today, as far as I'm aware haven't shown that the possibility of payment would reduce [00:20:00] the willingness of individuals to donate for altruistic reasons.

Thanks Bonnie, I'm done with that slide. Okay, I'll take over for a second, but you can have a breather. Okay, so why were we thinking about reopening this debate? So, as we said, we've been rethinking kind of previous debates, kind of looking at how is this work. I had a bit of a shock this morning when I realized it was 2003.

It feels like yesterday. But anyway, so why did we start to think about this? Part of it is rooted in my PhD research. So just to quickly give a bit of a background, what my PhD is doing is I'm kind of looking at this living kidney donor pathway that you see in front of you. So from the point where somebody indicates their interest in becoming a donor to where they donate, I was really interested in trying to understand.

I wanted to understand how the pathway works in the first place, but also I wanted to know about the experiences of the legal realities. So how [00:21:00] did the donors experience any kind of legal reality within the pathway? So as part of this, I interviewed 27 living kidney donors. I also spoke to healthcare professionals and policymakers.

Won't get into that now because it's not relevant to the kind of talk we're having today. for having me. What is relevant, though, is some parts of my data which is reflective of the system. Before I get that, let me quickly take you through the pathway and why it's important. So, this is one of the main reasons we thought it's time to reopen the debate, because all those kind of concerns that Daniel has gone through, especially the exploitation and the cohesion, is mitigated by this pathway.

It's an extremely rigorous assessment that Adrena goes through. Partly the system develops in the way that it did because of the Human Organ Transplant Act that Daniel was speaking about earlier. So the main aim of that act was to make sure the donors won't be rewarded and they won't be coerced. And we still see that as the main aims in the pathway [00:22:00] today.

Something that I just want to say about the pathway as well, before I go into how it actually works, is the fact that my research showed, and it is quite well documented in other research, That the pathway isn't very accessible for donors. Reason for that is your average donor that comes forward would be quite educated.

They're often highly educated. They can comprehend very complex health data. The most donors usually are from a middle income. So, All of those things are important when we think about how people access donation and why incentive or why disincentives would matter. Okay, so just to give you a brief view, I won't go into too much detail about the pathway.

But it starts off with the donor contacting their living donor coordinator or a living donor coordinator. And that's where the screening for acceptability comes in. Accessibility starts and from this point where the donor does that straight through all the assessments are going through the clinical testing, the consultations, [00:23:00] some donors might have a mental health assessment, depending on their category, through all those steps, it will be tested to make sure that the donor is not being coerced and they're not being rewarded.

The reason why this is so rigorous is because right at the end of the assessment, the donor will go for an interview with the Human Tissue Authority. That interview is done by an independent assessor, and they will once again reaffirm this idea of no cohesion and no reward attached to to the donation.

And that's in line with the current legislation guiding living donation, which is the Human Tissue Act. Okay, but there's other reasons why. There's other reasons embedded in my data, why we thought it was also time to reopen the debate. Something that I want to mention here, though, is I did not ask questions to my donors about whether they agree with payment.

So the kind of arguments I'm making here is not based on my donors views at all. It's based on how the system is rather set up. I just want to [00:24:00] make clear. That quite clear. Okay. So the first thing is about the reimbursement scheme. So when we think about living kidney donation, it is universally accepted and there's various international documents in place that say that we want to make sure that living kidney donation is cost usual.

A donor should never be left out of pocket to achieve this. What often happens is they introduce reimbursement schemes. So The UK is a great example of a reimbursement scheme. I was really interested in this because there's not anything documented about how donors kind of experience this scheme.

So just to give you an idea, the scheme was enacted in 2013, and the main purpose, and this is stipulated in the policy, is actually, that is to make sure that the there's no financial impact on a living, on a living kidney donor. Okay, so what can donors be reimbursed for? They have a few kind of claims they can or expenses they can claim.

Some examples are accommodation, so you might be a donor that's [00:25:00] living far away from a transplant center, so you would have to travel for all those tests I just showed you. You can be reimbursed for your travel, you can get reimbursement for loss of earnings for up to 12 weeks, and then there are some additional costs that are allowed.

An example that's given is, for instance, for child care. But what my data showed from the 27 donors that I spoke to. Is that unfortunately the scheme is not working and I know some people said they'd be like, oh, it's only 27 donors. I absolutely acknowledge that as well. But even if it's just one donor that says the scheme isn't working, it's something we should be paying attention to.

Okay. So what were some of the issues? The issues was that there was a lack of awareness. Some donors thought that there should be other kind of expenses they can claim for, and then just the experience of claiming. So to give you a few examples, I'll actually show you what the donors told me. So just on the awareness side, donor 17, for instance, said, Loads of donors didn't know that you could get the money back.

They didn't know you could have your salary paid, and some donors have had to fight for that. So this donor is [00:26:00] saying, not only is there this fact that donors weren't aware, It's also a thing that once they claim, it's quite a difficult process, and they have to fight to get this money back. You'll see she goes on and she talks about this fact as well, and it's things like, for instance, claiming for your car parking.

People don't keep those receipts, and when you have to claim, they don't have it, and then they can't claim for those funds. And you'll also see she talks about the fact that You know, you only get paid after and this is stipulated in the policy. Actually, it says you can only claim reimbursement after you've donated.

And she says, well, you know, sometimes this takes a year and a half and people are left out of pocket. That's just a bit of an example to start showing the problems. Then another one is about what you can actually claim. And don't worry, I'm not going to read this whole quote. But I do want to point some things out.

So this is Dona 44. And she kind of said to me when I asked about the reimbursement scheme, she was quite passionate about this. She said the bit on the NHS website where it says you won't be, you won't be paid, but you won't be out of pocket. It's just [00:27:00] nonsense. And then she kind of goes on to explain to me that.

Her partner wanted to attend on the day of her surgery, but he was traveling up separate from her, and they weren't able to claim those expenses for him to be there to support her on the day of donation, unless he was traveling up with her. That's the only way they could claim it. And she says, you know, this is quite a legitimate thing to want to have somebody there.

And in her case, this is somebody highly educated, definitely middle income. And she kind of says, you know what, it doesn't really matter for me, but for some people this might make the difference about a partner being able to come or not. The expensive stuff was horrible. Apart from this kind of claimable expense, loads of donors I spoke to, and this is especially donors that donated to family members, they went on to have counselling after donation.

Not necessarily about the donation, but often they will be living with a family member, they will Who has a chronic illness, and they go to therapy to cope with that, actually. And those are kind of expenses that they have to pay out of their pocket as well. Okay, what [00:28:00] else? So it's also the experience of actually claiming.

So donor 18 to once again just give you a bit of context of her background. This is a donor, this is a donor that is in a very senior position in a very well established publishing house. She just said to me, I couldn't complete this form. It was too difficult. She says, I was aware there was a scheme, but there was no way I could fill in that form.

And this is with some guidance that donors actually get to complete the form as well. Apart from that, and this is where kind of altruism starts to come in. So the entire living kiddie donation pathway is built around this idea of altruism. We associate that when people are donors, they have to be altruistic, or they just naturally are altruistic.

This kind of implicates the system in some ways, because Here's quotes from two donors, and you'll see I've indicated the non directed donors, so that just basically means that they've donated to a stranger. So, yeah, Donor 87 said to me, You know, it's a [00:29:00] very hiss and miss ramshackle arrangement, because I remember I would speak about it, And he's referring to the reimbursement scheme.

He says, I'm going to speak about it a little. Otherwise, it just sounds like you're there. You're just there for the money. As a donor also donated to a stranger. She kind of says because she got the expenses knocked back. And this is that donor that I showed you earlier with the partner. So that, that expense was knocked back.

And she says, it just makes you feel like you're trying to extort money out of the system. Okay, so those are only a few examples of how the reimbursement scheme isn't really working. So we have this to make sure it's supposed to be cost neutral, but my data clearly shows that at the moment, Living Kidney Donation unfortunately isn't cost neutral.

Okay, but then on to the next argument and This is something that only came together at the end of my PhD and was, oh, I can honestly say I sat there hating every moment of thinking through it and that was my favorite bit of it. But anyway, so this is about this idea of altruism and that living kidney donors should be altruistic.

So you heard Daniel [00:30:00] speaking about the fact about crowding out people. So, and he referred to Titmus and this is all embedded in Titmus's idea of altruism. of donation, which comes from 1970 when he was thinking about what he would want in a good society. And to him, he said, we want people to be altruistic because that kind of bonds societies together.

And he kind of raised the argument. The moment we introduce payments, people will become less altruistic or any kind of compensation. But the question is, and this is something I was really interested in, in my PhD only came around later. So Might be useful for anybody that's interested in like the method side of it.

I didn't actually include a question on what motivates the donors. This is data that organically kind of generated. So the kind of question is, is everybody coming forward altruistic? Why is this important? Because if everybody is coming forward altruistic, then we know if we're going to introduce compensation and people will really be crowded out, that would be a problem.

We'll see less But let's see what the data said. Just [00:31:00] quickly, before I jump into the data though, apart from Titmiss, that was in 1970, we still kind of see this expectation that donors should be altruistically motivated. It's all over the media, it's all over the news just to give you an example, these headlines that I take out of the media, Is that's in one week where we see four different headlines that use words like altruistic that talk about gifts Altruism and gift language are kind of embedded in each other So let's talk about this gift of life and this beautiful gift even a recent post This is more for deceased donation, but a recent post on saint patrick's day from The NHS spoke about kind of like receiving this gift, but apart from being in the media and this kind of societal expectation, expectation that people should be altruistic.

We also see it on the professional side. So the main professional body in living kidney donation is the British transplantation society. And they use these guidelines for living kidney donors. And [00:32:00] within these guidelines, they say that altruism is the basis of organ donation. And you'll see, if you look at the definition down here, they use a very narrow definition, which is by the way, taken from.

So they say it should be a selfless gift to others without any expectation of remuneration. But what did my data say about donor motivations? So, surprise, surprise, donor motivations are complex. People come forward to donate for an array of reasons. Something I want to caveat, though, is I'm not saying at all that people are not altruistic.

I absolutely agree. Donors show signs of altruism, and that's why I have the, like, I'm altruism right in the middle of this Venn diagram, because yes, part of why people come forward is altruism, but that's not the only reason. There's a lot going on why donors come forward. So from my data, I kind of created this Venn diagram, and I don't unfortunately have time to go through this today, but I just want to highlight some like four big reasons why donors come forward.

So one big [00:33:00] reason is no decision, a donor feels that they have no decision and this shouldn't be seen at all as they're being coerced. This is rather example of where somebody is donating to their child and they feel like, you know, there's no other option. They need to do this. I'm going to show you some quotes in a moment just to support this.

I just want to quickly take you through the reason before I get into the quotes. Another reason is because donors find it rewarding. If you think about a spouse donating to another spouse, they get to see how their spouse's health improves. But there's other reasons why people find it rewarding as well.

Spoke to a donor who was somebody who donated to a stranger, and they said to me, you know what I got from this? I got a confidence boost. I feel so much better about myself as a human. Another reason people donate is often due to life experiences. Most of the time, with some examples I saw, for instance, was around bereavement.

People that have been bereaved decided to become living donors. And often this had nothing to do with any kind of renal disease. And then another reason, it's a main one we see with the non directed [00:34:00] altruistic donors. They just see it as an act anyone would do. They, don't necessarily relate to this idea of, once again, that we often see in the media that there's this big year row or anything like that.

They just think, you know, this is something anybody would do. Once again, quickly just to show you a few quotes why I came up with these reasons. Unfortunately, won't have too much time to go into the, like, smaller reasons where they overlap, but to give you an example of this no decision one. So this was a dad I spoke to, he donated to his son, and he said to me, right at the start of the interview, when I started asking him about the donation, he kind of directly said to me, well, you know, this wasn't something I thought about.

He says, the reason I mentioned this is because all of my decision around donating was never really a decision. It was just something as a dad, I thought had to be done. All those steps that I had to go through, the legal steps, I just treated it as a bit of a tick box exercise to get to the ultimate goal, which was getting Which was getting him a kidney.

So you already see this kind of, there's something [00:35:00] else coming forward apart from just pure altruism, or the kind of ideas we have about how pure altruism should work. Another example is this kind of idea of reward, and this is actually a spouse, and she speaks about the fact, she says, I would say it's a very rewarding thing, and she then kind of, she spoke to me later in the interview about seeing her husband regain his life, but then she says, I cannot honestly say whether I would have ever considered doing it altruistically if it hadn't come into our life.

I don't know if I would have been that person. Once again, we're seeing this thing about where it's all, or everything is aimed around altruism, but there are just some people that come forward that, It's not necessarily just about altruism for them. Then, as I kind of said, if you think back over here about an act anyone would do with the stranger donors, here one of the donors spoke to me and they said, it just always seemed to be, to me, sensible.

People are altruistic donors. People who are altruistic donors, it's just a really weird question to ask because it's, you know, why wouldn't you? [00:36:00] And then I had a very good example of somebody that overlapped all three of these categories. So, the donor I was speaking to was 35. He explained to me, you know what, at this age, it's the right time to do it.

I won't have to worry about my wife having to take care of me in the future. It can just be me that's doing it right now. He also resonated with this idea of it's an act that, you know, just anyone would do. Like, why wouldn't you be doing this? And then just for a bit of light humor this afternoon, he kind of also said to me, you know, why is another reason I'm doing this?

is because of The Simpsons. He said, I'm a massive fan of The Simpsons and there's an old episode where Grandpa Simpson needs a kidney and Homer ends up donating it. And then he saw it on Family Guy and he was like, well, you know, this got me thinking about maybe I should be a donor. So that kind of gives us this idea of, well, maybe it is an altruism doing all the work and maybe Kind of worry ideas about worrying about hurting altruism shouldn't be at the front of our mind But apart from just me saying this comes out of my data This is within the [00:37:00] last month and this is related to the xenotransplantation or the successful xenotransplantation that recently happened in the u.

s These were two pieces that appeared in in the u. s And the reason why I want to show them is because Because they're from two different perspectives. One is from a donor and he kind of says, well, I absolutely think donors should be paid. So he uses the argument, which, if some of you are familiar with the literature Janet Radcliffe Richards talks about, it's that everybody else is receiving compensation.

The doctors are receiving compensation. The hospital is receiving compensation. This donor either goes so far to say, well, you know, even the person that transplanted my, transported my kidney got paid, so did the social workers. He says, but it enrages me because kidney donors are doing something important.

And I think if you're doing important work, you deserve to be compensated for it in some way. And it truly pisses me off when opponents of compensation are like, that's like a beautiful, selfless, altruistic, like shut up. pay people for their work, like your gratitude is not going to save these people's [00:38:00] lives.

So this is a very direct view from a donor. And something I always wonder about with this is the fact that we don't have recipient's views, right? We don't know how a recipient is going to feel about receiving a kidney that they know was compensated. And of course, this is just one view, but I found it really interesting that at the same time, a piece appeared in the New York Times from A recipient him and his brother both received kidneys, and he says it so succinctly, he kind of talks about the problem.

He says about the fact that we can now transplant from pigs. And then he says, there's a simpler and long overdue answer, pay people for their kidneys. And then I'm going to hand over to Daniel to do one of our last kind of arguments around, around this debate. Wait, if we just go to the next slide, is that right?

So yeah, so the question there frames is, does a good app become bad because of, because of pavement? And we would argue that the answer is is no, not, not [00:39:00] necessarily. So there may be cases where this could occur, but we just don't think that this is, this is one of them. So, It's undoubtedly a good thing to donate your kidney and expect nothing in return.

Some people might even think it's desirable. I know we've talked about, you know, the different organizations that think it's desirable that people donate with no expectation and purely altruistically. But when we think about this, there's no, there's no overriding kind of ethical reason why this ought to be a requirement of donating.

So even in cases we said were described as altruistic, they're often more complicated and nuanced and can be motivated by what could be described as at least a kind of self interest. Is it you want to preserve the life of a loved one? And there's a potential penalty or cost if you don't donate. Is the potentially the loss of their life or continued suffering, et cetera, and wait on the [00:40:00] on the wait list.

But even irrespective of that you know, such donations are good. They are, you know, they're generous, they're brave, and they provide you know, societal, societal good. Receiving some kind of financial compensation it might be considered less good than that, but it doesn't, it doesn't make that bad.

Could be less good, but it doesn't make it less bad. And so, our, you know, one of our points is, is that something good and generous doesn't necessarily become bad because financial compensation is involved. And I think that the underlying principle is generally considered uncontroversial, just depends on the context, is that if we, if we pay people or compensate people to do good things and for accepting some kind of risk for doing so it doesn't necessarily diminish the good of that act or make any payment involved immoral.

So lots of people will receive payment compensation for doing good things. That they do without anything [00:41:00] like the risks that are associated. I know the risks are small, very safe surgery and things like that, but not anything like the risk associated with invasive surgery that a living kidney donor will accepts.

And we're generally unconcerned about that. So what we would, what we would say is that you know, providing A living kidney donor understands what they're doing and that they can provide informed consent which is what the current system already ensures, then financial compensation doesn't diminish the good that, that, that, that, that does.

That would be our point. Bonnie, I think it's you for the next one. Yeah, perfect. And basic Ooh, gosh, now I'm going all over the thing. Yeah, last one, then, just actually to kind of summarize our arguments. So the reasons we're putting this forward is because, as I kind of spoke from the data, donors are left out of pocket.

Previous concerns we had about crowding out or hurting altruism is not true. Kind of less of a concern at the moment, because our understanding of reasons [00:42:00] why people donate has evolved, as Daniel kind of explained, the good of the act is not diminished if we introduce payments. The fact that there are moral views about this, and we both respect the fact that people might not agree with us, but that could be circumvented by the fact that we're giving people the option to be compensated.

And then the last and the biggest reason is that going back to how that pathway look is looked is. We have a perfect example within the NHS of a rigorous pathway, which will limit exploitation and cohesion to look at this example. I see we're a bit over time. So Daniel, should I maybe just go over to the poll?

Yeah. Okay. So kind of to stop there, actually, we just want to redo the poll. I'm just going to stop screen sharing because I've been talking at my screen the whole time and I can't see anybody. There we go. So I'm just going to reopen the poll again. So this is the results from the first one. I'm just going to screenshot this quickly.

So there we go. That's from the first one. [00:43:00] And then I'm just going to share. So let's stop sharing that one and then just open the second question because we're kind of interested to see if we changed anybody's views today. Yes. And so much for having us.

Thank you so much. I'll give everyone a few minutes to put in their answers. I just want to express my gratitude again for this session. It's been really informative and I love the interplay with so many ethical principles as well. Just seeing that come to light. I don't know if you want to share the poll answers if everyone's finished up on that.

Oh, sorry, you're on mute. Of course, I do that this evening as well. Okay, I should be able to share that now. That's really interesting. You've managed to move some people towards, yes, I don't know. Gosh, hopefully we don't get anybody to go now. That's really interesting. I think [00:44:00] the unsure has increased as well.

I'll just now open it up to questions. I don't know if anyone wants to quickly jump in. I think Paola has a question. Yeah. Hi. Thanks very much for, for the very interesting presentation. And my question is about terminology language. So I understand you might have theoretical reason for that, but you know, financially to the, to the everyday mind, you know, financially compensating a donor.

Means buying and, you know, a donor who's financially compensating is a seller. Right? So I know you have, as I was saying, you may have theoretical reasons to keep using the word donor and financial compensation. But do you think it's. It's just, you know, it's appropriate to keep talking about donors if we accept financial compensation.

Is it something that, for example, the public would understand? Should we say seller or donor [00:45:00] buyer or financial compensation? Thank you. Yeah, really good question. This is something we, we're, we're, we still think about because the terms that we use are, like I said, so important but they are Morally loaded.

They have baggage culturally, morally. And I'll, I'll, I'll be honest. It's someone raised this when I first, when we first started talking about it. And I'm still, I I'll just admit, I'm still uncertain about what terms to use because I can see it from both, from both sides. The reason we opt for the language that we've chosen is because at least in terms of financial compensation, rather than payment, you know, is, is, you know, it's.

You know, it's rooted in how those terms could be misunderstood because they can, they're so often appropriated by abuses, you know, you know and that would be our concern. So there's sort of psychological reasons as, as, as, as well. And, and you're right in the sense of again, but it comes down to, to motivations, which you can't always know, is that if someone who [00:46:00] wants to donate yeah, it gets really, you know, I'm, I'm, I'm, I'm still, it's one of those things, the argument I'm still really thinking about is terminology, because it's so important, because I think if, if we get it wrong it has, it has quite serious implications for how people will weigh up the arguments that we make and you're right, you know, maybe donor is not the right word, but then, you know, You know, seller and, and I'm not sure seller and buyer are totally appropriate either.

So yeah, I'm, I'm open to persuasion and that's probably not the best answer, but it's just to admit I'm, I'm, I, that's one of the areas that I'm most uncertain about. Yeah, I absolutely agree with Daniel. I do think it's a really good question. I also just wanted to point out, I think there's quite a lot of dialogue going on at the moment with recipients also talking about not feeling always, or the recipients that don't agree with the organ being seen as a gift, not feeling comfortable with the language of using donor.

So I think there's a [00:47:00] lot to talk about actually about the language we use about organ donation in general, more broader than just within this debate as well. Thank you. Thank you, Paolo. Let's just go to Matthew, who's next. Great talk, both. I think I'm starting a bad habit of just asking Bonnie if anything's been published instead of actually reading anything about it myself, but you touched briefly on the idea that some people don't want to donate because they're sort of saving their kidneys in case their loved ones ever need one, and I wondered if anyone ever thought about Rather than compensating financially compensating with the promise of sort of having being further up the list if you or maybe a loved one ever wanted donation.

I don't know if that's ever been discussed. Yeah, so actually, sorry, I'm getting extremely excited because it's also part of my PhD research. The NHS has a prioritization scheme. So donors, there's a policy that basically allows them to be prioritized if they've donated now in future, if they need a kidney, they go up, but they don't go above people who are on urgent need.

There's a very good [00:48:00] system of where they get prioritized and donors also have kind of the option of deciding whether they want to opt into the scheme, which is also very interesting to see how ideas about altruism influences that scheme, because loads of people will, when I ask them about the prior, Prioritization scheme say, no, no, no, I don't want anything back.

I did this because I'm completely altruistic. So those kind of use definitely influence as well. So, yes, there is that scheme. It's very recent though, Matthew. It came in 2016 and I don't think it's very widely known that it's implemented as well. Awareness is another issue. Yeah, definitely. Okay. Thanks. A good question as always.

I think I'll jump to David. Hi great talk. Thoroughly enjoyed it. My question, well, my, my surgeon, when he did my donation he struggled with it because as he said, he became a surgeon to do no harm. And when I went in, I was perfectly healthy, and he took apart a major organ to give to somebody else.

Now, I would wonder how he would struggle knowing that I'd been paid to [00:49:00] do that. And Also, the psych assessment as an altruistic donor, it was really quite heavy. All of the questions that I was asked, and I had to prove myself to be whether you've been a a non directed altruistic donor, would be null mute in respect of just answering and doing it for the money.

Any, any input on that? Bonnie, do you want to go first? Yeah, yeah, that's a brilliant question. I David and I know each other from talking about his donations. I was quite nervous about hearing his views about this talk. But very, very good. It's such a good point. I haven't thought about, you know, the healthcare professional side of it and you're completely right.

And I think we like to think, well, surgeons have moved away from the do no harm kind of argument, but that's not, that, that would be incorrect. There's still so many transplant surgeons have subscribed to that view. So it's not something I thought about, you've caught me [00:50:00] absolutely unaware. It's something to think about and definitely to test.

No, it's brilliant. And definitely to test. I don't know if Daniel has any thoughts on it. Yeah, no, no, it's interesting. I think the, the, the questions obviously would need to be tailored. And this is something we thought about as well. It's obviously a lot of people will raise objection around motivations.

It's like, well, are we saying, is it okay to just do it for the money? And I have a lot of, yeah, I have to spend a while going into that. I mean and people will push me for it. Push, push back on that and people doing it for the money. I think as long as people provide their informed, informed consent.

If someone wants it, this is, this is the reality. If you, if you push us right to the end of it, what we're saying is, is it is acceptable to people to do it just for the money, providing that they know what they under know what they're doing. They meet all the requirements of informed consent. What people do with that is up to them.

Now it might be that people can think about the worst case scenario of someone will just do it, well not worst case, but someone do it for a deposit for a house or a holiday and a new [00:51:00] car. But there was, so there's other things. I mean, if it's someone who is an altruistic donor, let's say if they're effective altruist, they might want to do it to get the money to donate the money.

So there's a whole, there's a whole range of motivations, how people would use the money. And I think, you know, if we're, we have to be careful about being paternalistic again, is that we don't, we don't You know, people earn all sorts of money and get, receive money for lots of, for lots of different reasons, and we can't decide what they do with that money.

Now, some of them might do things that we wouldn't do and and, and, and would not do things that otherwise we would do with, with, with money. With that with that compensation, but but yeah, that that's the implications of the system And it's really interesting to hear your thoughts about the interview as well because yeah, I mean that would take some some some tweaking because like you said it's trying to avoid because it's focused on on on the payment but I think there are there are other areas we should be concerned about as well in terms of exploitation and coercion that that fall outside that and something we didn't talk about as well that we didn't [00:52:00] briefly mention is that You A lot of the worst kinds of exploitation and coercion, you know would be reduced because one of the issues that forces people to do these extreme things and it makes them so desperate is that need, the fact that there isn't a kidney for a loved one of themselves.

But actually, if there are more kidneys available, we disinvent, we disincentivize people doing crazy things like illegal and immoral things if there are more kidneys available. You know, potentially, you know, recent cases with the politician in Nigeria and things like that is that if there are more kidneys, there's less incentive to do things that are coercive and exploitative.

But then, you know, I can imagine what you're saying. There are other things that then become potential problems that we'd have to to ensure that that that interview would mitigate.

I've got two more questions. I'll go to Joanne first and then Trevor. Hi, thank you for that. It was really interesting. I'm on the fence and for remuneration. I [00:53:00] can see the scheme doesn't work, obviously. And I agree that you have to try and avoid paternalism. You know, people who aren't well off can make decisions, but my concern is that actually the poorest in society will, will be drawn to this option.

And it's like being paid for research. Sometimes it's, you know, poor students who are drawn into this, and maybe they're not really, the consent process, it might not be valid. But my point, my question was, do you think that the quality of organs will be reduced? Because the WHO say in relation to blood donors, I know blood is slightly different to kidneys, but actually the three types, so voluntary, unpaid, family or paid, and the voluntary unpaid donors are the safest group.

with the lowest prevalence of bloodborne infections. So considering blood goes through the kidneys, et cetera, do you think that that might be the case [00:54:00] if compensation happened, was offered? And then if that was the case, would a lot of resources be put into this to actually try and filter out maybe disease, diseases, et cetera, et cetera.

Happy to take it. Yeah, I think that's a great question. Thanks, Joanne. I'm happy to hear you on the fence. It's always good to hear why people are actually on the fence as well. So to answer your question, I think that relates back. Oh, hello. I'm sorry. Don't worry. It's fine. You can join. I think it relates back to TITMAS as well.

So one of the reasons TITMAS was also against introducing payment was the argument of it will you know, increase. Unsafe blood products at that time. I don't know too much to actually give you a concrete answer on this, but what I would say though is I think it does go back to the rigorous nature of the system.

kidney donation is that is it's so heavily regulated and also not just from the donor side but from the [00:55:00] quality and safety product side. I don't and the reason or so I don't think that would necessarily be a major concern of course can't completely say that. And in terms of the resources that goes into the process, I think once again, the pathway is already set up in a way that is so good that it would already, before it gets to that point, filter out the people that would have those concerns.

I think they're very good at taking medical history straight from the start. So that first kind of assessment I shared with the Living Kidney Donor coordinator checks your entire medical history. They follow up with your GP as well. So I think any of those concerns might be mitigated right from the start and even if not So by the time gets the donation everything gets checked again, but that's just going on the little bit I do know about the system.

I don't have a clinical background. By the way, I'm a lawyer.

I don't have anything to add to that. That's a really good point though. And then for the last question to Trevor. Thanks very much. That was a fascinating session. I've, I've been pretty opposed to [00:56:00] this in the past, but I'm now at fence sitting and I think one of my remaining issues relates to what you were saying, Daniel, about you didn't think that the Nigerian couple would do what you called a desperate thing if this game came into being.

And I think this blurring between a legal scheme and what those Nigerians did, which was a deliberate trafficking of another human being, which is a heinous crime. I'm not sure a compensation system would. affect that? And I wonder if it were to be introduced, how it would affect the definitions of organ trafficking.

You mentioned yourself about the Human Tissue Act saying it was wrong to make payments and the Declaration of Istanbul and so on has the giving of financial compensation or sums as, as part of the definition of trafficking. So how do you see that [00:57:00] side of things panning out? If this is introduced.

Yeah, I think how it would be legislated again is we I think we've, we've primarily focused on the, the ethical issues associated, at least I, I, I have, and I'm still, I would say, myself. Still a fence sitter in terms of implementation. And what, what that would look like. I mean, certainly there, there would have to be changes to ensure that, you know, people can't just come from abroad and come over and be subject and be subject to to receiving compensation.

So, perhaps, I know, obviously, they're quite rigorous in terms of who Who's eligible for the opt out system at the moment. So it could be something similar to that, that, that legislation in terms of who's eligible in terms of ages and things and things like that. Now yeah, so I, I, I, I'm, I'm, I think the point about the the issue with the Nigerian politician, I think my, my, my point in [00:58:00] that is that if we have evidence, I think from.

Iran, and I think in principle that if we do, if we do, if, if financially compensating living donors does significantly increase the number of kidneys available. At least my thinking I'm open to being wrong. I think the implications of that is that there will be far fewer people who will be incentivized to do things that are illegal, you know, bring people over from other countries and try and gain the system.

Now, I appreciate that every, every system. Is, is open to, to abuse and I, and I don't think I have thought about every possible way that, that, that could occur. And and I think that would be for, for legislators to think more about. I know that sounds like I'm dodging that a bit, but I haven't, I really, my, my emphasis is more, is it ethically acceptable?

Because they're this, that's the way I sort of think about, but you're absolutely right to be concerned. You know, it's quite possible that it could be ethically accessible, [00:59:00] acceptable, but actually, it, it couldn't actually be legislated. That, that's certainly a possibility. I'm not, I'm not saying that it, that it is.

I'm saying that it's something that should be put back on the table. It should be reconsidered and people more informed than myself and more able may be able to think about ways how it could be, it could be legislated in a way that could mitigate some of the legitimate concerns you've raised. And it definitely has implications because it's going to be, Like you said, talking about Istanbul, you know, the whole, this is why language is so important as well, because it has implications for all the same, all the things that you have that you, that you've raised.

So that's not much of an answer, that's more of a dodging, but just because I, I don't know, yeah, I don't know how we would, I don't know what that would look like, I haven't got to that bit yet but I think it's, I think there's, there's enough evidence there to, to warrant exploring it in further.

I don't know if Bonnie probably has something more insightful to add. Definitely not more insightful. I do think it's a really good comment. Thank you so much for that, Trevor. [01:00:00] And especially I think with the recent changes to the Human Seizure Act in terms of organ trafficking, that we now even see the Human Seizure Authority having, you know, extra jurisdiction kind of powers as well.

So I do think that's important. I think this is a very step by step by step approach. So I think the next natural step for us is first to see how people really feel about this. When I say people, donors, recipients, health care professionals, that kind of first building that acceptance, building acceptance from the public as well.

And then moving on to thinking about how I guess the bigger system might change. This is not something that I think will be happening very soon, but it's good to get people to think a bit and speak about as we're looking at other kind of solutions for the organ. Because that's why we're here, right?

We're here because there are people waiting on waiting lists and dying every day, so we're trying to find ways through that, but it's a very good question, and it's definitely something that's going to keep me up at night now about the how do we basically think about this within organ trafficking as well.

Thank you so much for that. Lovely. Thanks. Thank you Trevor. [01:01:00] Thank you again to everyone for attending and thank you again to Daniel and Bunny. That was fantastic and the recording will be on the website because I'm sure there's a lot of aspects where everyone would want to digest and process everything again and a lot of arguments can be raised and yeah, very interesting.

Yeah, I'm sure if anyone wants to keep in touch then I can pass on your details if you're interested in finding out a bit more as well. Sorry for overrunning a little bit but I'm sure you'd agree we could talk for more hours about this as well. So I wish you all a very good evening and thank you again to the both of you for that session.

Thanks Comfort, thanks everyone. Thank you so much everyone. Take care, bye. bye.