

Transplant Project

healthwatch
Liverpool

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Preface

The suggestion that Healthwatch Liverpool would undertake a Post-Transplant Recovery Project because of me and the difficulties I had experienced was both flattering and inspiring. Amongst other things it became a key factor to my recovery and overall well-being, I thank each member of the Team for their input and equally for the support and admiration they have always shown me.

Now, 2 years after transplant, I still feel it impossible to describe the before and the after. My core values remain the same however my vision and perception of everyday life has changed completely. I will medically always be considered as diabetic Type1 and a renal patient, I will always need to take anti-rejection medication (immunosuppressants) and I will always be afraid of rejection but now ... I do not live hooked up to a machine for 9 hours every day, I do not constantly measure sugar levels and I do not inject insulin 3 times a day. I do not need to do these things now because of an amazing young person that had expressed a wish to donate their organs. The family respected the wish and I received a pancreas and kidney. I have no way of ever expressing or showing gratitude large enough for such an act.

The road to recovery has been long and not always easy but that is where Healthwatch Liverpool have proven invaluable. This research has collated information from patients/participants and the difficulties they experienced post-transplant. Initially I was wary the research would prove pointless as I might have been the only person to feel I was not adequately supported after such a huge investment. Findings have shown my doubts to have very little justification.

In summary the findings, comments and common trends that arose are both in line with my feelings and experience.

We, as transplant patients, experience an overwhelming sense of change to circumstances and life in general. The loss of our identity proves to be an ongoing issue which we have not received any support around. The uncertainty of how to be normal and live a normal life persists and there is no orientation in 'how to start a life from scratch'.

In my experience, many medical staff and the general public are rather ignorant as to what a transplant and post-transplant life entails. Not many people are aware that the condition will always be considered chronic and healthcare and medication will forever be rigorously controlled.

For me, there was no clear and concise communication from the healthcare system as a post-transplant patient. There was no period of rehabilitation made available after surgery. After surgery focus is only on urine output and blood readings. For no matter how long a person has been seriously unwell, the idea is to "pull it together and get on with it".

The impact on a patient that does not receive emotional support can be damaging. Many patients, including myself, have been through a period of great despair where not much makes sense, where no-one understands and where there is little to turn to for answers.

Being a transplant patient is like suffering the death of your previous self. The shock, loss, period of grief and even the feelings of guilt are so intense and so lonely, yet there is no support available. At the same time being a transplant patient is like belonging to a very exclusive club and not many people are permitted entry ... so there is almost no support available.

The ultimate goal I would like this project to reach is, and has always been, making recovery and life easier and more enjoyable for transplant patients in the future. Allowing them to experience the magnitude and greatness of what they have received. Allowing them to not be as fearful and to know how to build a new sense of freedom and health.

Odette

Healthwatch Liverpool volunteer and kidney and pancreas transplant patient.

Introduction

What is the project and why are we doing it?

Rationale and aims:

This project arose from feedback we received from one of our volunteers who had gone through a transplant themselves, and told us about how difficult it had been for them to access appropriate help and support following their transplant. Anecdotally, they were aware of other kidney/SPK transplant patients who had found it difficult to access support, and wanted to see if other kidney/SPK transplant patients locally also had similar issues. We then conducted some desktop research and found that the majority of support services for people with kidney /kidney and pancreas issues were focused on people going through dialysis and pre-transplant rather than those post-transplant.

Although post-transplant patients receive ongoing medical reviews, it seemed that at a local level (Liverpool), more holistic support is lacking. However, no research has been conducted to explore this issue further. This is why we wanted to speak to adult kidney/simultaneous pancreas and kidney (SPK) transplant patients to achieve the following:

- + To give these patients an opportunity to tell their stories, and say what was helpful to them and what was lacking.
- + To identify the barriers patients face in moving forward with their lives post- transplant, and make recommendations that will support them to overcome these barriers.
- + To share the findings and recommendations from this project with Trusts, providers, and commissioners as to the needs of this patient group

Background information:

Kidney transplant is the process of transferring a healthy kidney into the body of someone who has little or no kidney function.

Loss of kidney function can have a number of causes but the most common is chronic kidney disease (CKD), a condition where kidney function is gradually lost over a period of years. The deterioration in kidney function is measured in stages. In the early stages the condition can generally be managed with medications and changes in lifestyle. However at stage 5, also known as end stage CKD, patients will generally require dialysis to take over some of the kidney's functions.

There are two types of dialysis: haemodialysis and peritoneal dialysis. Haemodialysis generally takes place in hospital and patients will usually require 3 sessions a week, each lasting about 4 hours. Peritoneal dialysis can be done at home and there are two types: continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). The CAPD process will typically be performed by patients about 4 times a day, whereas patients on APD connect themselves to a machine and receive dialysis for around 8 to 10 hours overnight.

Dialysis can be inconvenient and time-consuming. It can also have a negative impact on quality of life due to the side-effects of the treatment which can include pain, sleep disorder, nausea and depression. It can also significantly impact a patient's work, study and leisure activities. Although patients can survive for many years on dialysis, a kidney transplant generally offers the best quality of life for patients in the longer term.

The healthy kidney for the transplant can either come from a living donor or someone who has recently died and donated their organs. In either case, careful testing needs to be carried out beforehand to ensure that the donated organ will be suitable for the patient in terms of matching tissue and blood type.

In the UK in 2018/19, there were a total of 3344 kidney transplants carried out (2409 deceased donor and 935 living donor). As at the end of March 2019, there were a total of 4739 patients on the kidney transplant waiting list (NHS Blood and Transplant, 2019).

There are not enough donated kidneys available to meet demand, therefore patients will wait an average of two and a half to three years for a suitable kidney to become available (NHS, 2018). People from black, Asian and minority ethnic (BAME) backgrounds can often wait for longer than people from White backgrounds for a suitable transplant organ (NHS Blood and Transplant, 2018).

Kidney transplant is not a cure as kidneys from deceased donors last about 10-12 years and those from living donors about 12-15 years (Kidney Care UK, 2019). The donated kidneys will eventually begin to fail and the patient will then generally have to go back on the waiting list for another transplant.

Due to the chronic illnesses that can lead to kidney failure, it is not unusual for more organs to be affected. For example, Type 1 diabetes can severely affect both the kidneys and pancreas over time (National Kidney Foundation, 2019). As of March 2019 there were 212 people on the waiting list for a kidney and pancreas transplant and 156 transplants took place between April 2018 and March 2019 (NHS Blood and Transplant, 2019).

For those who need more than one transplant at the same time (e.g. kidney and pancreas) the procedure, treatment and waiting can be even more complicated and lengthy (National Kidney Foundation, 2019).

Therefore, going through a kidney/SPK transplant can be life changing and presents many challenges for the individual patient. For example, recipients of a transplant have to continually take anti-rejection medications (immunosuppressant drugs) for the rest of their lives, which have varied side-effects, such as digestive upset and poor wound healing. For some, the side effects of immunosuppressant drugs and other challenges faced post organ transplant have led to the deterioration of their mental health (Corbett et al., 2013) as well as physical health (Gordon et al., 20015).

Research has indicated that depression is more common in kidney transplant patients than compared to the general population (Veater & East, 2016) and that psychological issues such as depressive symptoms and anxiety lead to lower quality of life and also more hospitalisations, episodes of complication or transplant rejection/graft failure and mortality (Chilcot, Spencer, Maple & Mamode, 2014; Jana et al., 2014).

Research has shown mental wellbeing to impact physical aspects of health in transplant recipients as it can affect their medication adherence (for example, to anti-rejection medication) (Cukor, Newville & Jindal, 2008) and health behaviours such as diet and exercise (Gordon et al., 20015), all of which are important for maintaining the function of their organs and managing the health complications that can still exist even after transplants.

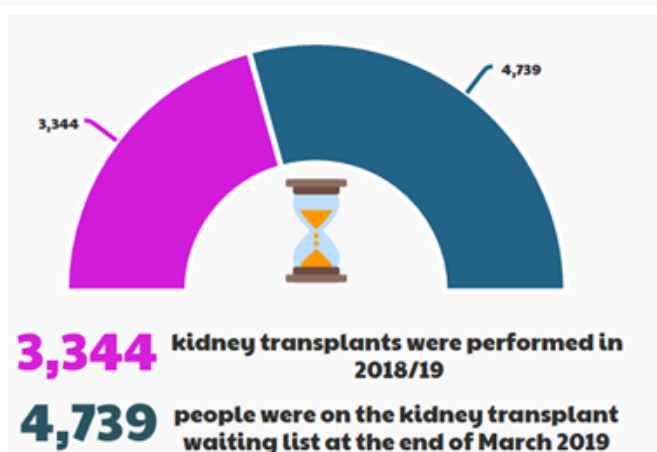
Research has also demonstrated that support, particularly psychosocial support (support for psychological or social problems usually provided by professionals), in the UK is lacking for renal patients generally (Seekles et al, 2018). Research among renal patients has highlighted a lack of support, particularly emotional support, as a key patient concern (British Renal Association and Kidney Care UK, 2018, 2019).

This evidence highlights the importance of taking a holistic approach to kidney transplant patients care that extends beyond the physical.

Kidney Transplants in the UK in 2018/19



28% living donors vs 72% deceased donors



How the data was collected and analysed:

Participants in the research:

To be a participant, the person was required to live in Liverpool/be registered with a Liverpool GP OR have had a transplant in Liverpool. This is because, as a Healthwatch, we are interested in finding out the experiences of people locally, and we know that simultaneous kidney and pancreas transplants are not currently performed in any Liverpool hospitals, and did not want to exclude any local residents with valuable input on this basis. We are also interested in evaluating the performance and patient experience at local hospitals.

A total of 6 people (5 female and 1 male) were interviewed, ages ranging from 31 to 67 years of age. Some patients were more recently transplanted than others. Three participants received their most recent transplant between 2010 and 2015. Three had received theirs between 2015 and 2019, when the interviews took place.

Data collection:

Healthwatch Liverpool volunteers were trained in research methods and assisted staff in designing the project and the recruitment of participants.

Participants were recruited through word of mouth as well as through posting a call for participants flyer on the Cheshire and Merseyside Kidney Information Network (CaMKIN) website.

Once a participant expressed an interest in taking part, we emailed or phoned them to arrange whether they wanted to do a telephone interview or if they wanted to come to the office, to do a face to face interview. We also conducted one interview in the participant's own home as this suited their needs best. We felt it was important to give people options depending on their circumstances.

We also asked them to fill in an initial questionnaire (see Appendix 1) before we arranged the interview. This gave us a chance to do some background reading if we were not familiar with their condition/initial diagnosis and enabled us to plan more tailored additional questions for the interview.

Participants were asked to sign a consent form before an interview was conducted (see Appendix 2). All interviews were recorded using a dictaphone. The interviews were semi-structured and all participants were asked the same core questions in the interview schedule (see Appendix 3). One of our volunteers shadowed some of the interviews to build their research experience. Interviews were uploaded from the dictaphone to a computer at Healthwatch Liverpool as soon as the interview had been conducted and then deleted from the dictaphone.

Interviews were transcribed (with the assistance of one of our volunteers) and then analysed using thematic analysis. The six stages of thematic analysis are described in the following table.

Step	Description of process
1. Researcher familiarises themselves with the data	Interviews are transcribed and re-read while simultaneously writing down the first few ideas relating to the research questions
2. Researcher generates initial codes	Initial themes of interest are noted across all transcripts and coded
3. Researcher searches for themes	Codes are collated into possible themes, first with individual transcripts and then across all data
4. Researcher reviews themes	Researcher makes sure themes relate to coded extracts across entire data set, a thematic map is produced
5. Final themes are defined	Salient themes and subthemes are narrowed down and named
6. Production of a report of the findings	Researcher selects the richest, most convincing examples of the extracts that supports the analysis and findings that related to the research questions

For reliability purposes, multiple people coded the data, and themes were reviewed by more than one individual to ensure that what was reported as a theme was truly reflected in the data. In addition, for triangulation purposes some of the participants were contacted and asked for their thoughts on our findings and whether they were representative of theirs or others' experiences.

How the data was collected and analysed:

While our sample size for this project was small, strong common trends did emerge across the conversations we had with participants. Our findings may not be representative of the experiences of every kidney/SPK transplant patient, but do provide a snapshot of what kidney/SPK patients who live and/or who have been under treatment locally have told us.

We were able to pull out four key themes from interviews we conducted from participants. These are:

1. Building and discovering a sense of identity, purpose, and lifestyle in the face of uncertainty and changes;
2. Lack of awareness and understanding from others, including the healthcare system, that exacerbates struggles and issues;
3. Lack of clear and compassionate communication from the healthcare system; and
4. Lack of appropriate emotional support & signposting.

Within each of these four themes, we were able to identify several other sub-themes. The following section discusses each theme in detail.

Theme 1: Building and discovering a sense of identity, purpose and lifestyle in the face of uncertainty and changes

Transitions and overwhelming changes

Each participant had their own unique journey as a transplant patient, with different experiences of pre-transplant life, dialysis, the transplant process itself, and recovery. However, all participants told us about how sudden, life-changing, and overwhelming various parts of their transplant journeys had been. Receiving a transplant was discussed as being an 'emotional rollercoaster.' Even when transplant was a generally positive experience, it could also be stressful and hard to cope with at times.

A number of participants lived with chronic illness and other co-morbid conditions for years before their transplant. Some had been diagnosed with kidney disease in their childhood, and began their transplant journey at a young age. Others lived with chronic conditions for many years of their adult life. The experiences of some participants in the run up to their transplant journeys were psychologically and physically taxing, and sometimes shaped that participant's attitude toward transplant.

I think I went through 20 something years of being diabetic and never admitting I was diabetic, never admitting I was ill, never willingly telling anybody I was diabetic. I hated it. I hated the idea of being dependent on something, it got to a point where there were days, I was injecting 6 times and I hated it, I hated absolutely every single moment of it. So, it had already been a psychological issue for me for 23, 24 years. Participant 5.

I was 16 when I first got diagnosed ... at the age of 16 I was supposed to take a load of medication but because I was completely asymptomatic, apart from the occasional headache, again I didn't bother ... I think I obviously was stubborn and did have a bad attitude. But yeah ... I was explained to as an adult and I probably wasn't mentally quite there yet. Participant 6.

All but one participant underwent some form of dialysis prior to transplant. The majority of participants had negative experiences with dialysis, even when they acknowledged it as a necessary treatment to maintain their kidney function, often describing it as an isolating, time-consuming, and tiring experience. A number of participants experienced problems and complications with their dialysis, which further impacted their negative view of the procedure.

Life on dialysis is very small. You don't go very far, you don't see very many people. Participant 1.

My first time on dialysis they blew the vein. And it was just a horrific experience because first of all I didn't know what to expect. Participant 6.

It kept me alive, but it was difficult because the bags would often not empty, and then I had liquid in my belly I couldn't get out. And I had two or three infections and, so it's not the nicest of things to do. And 9 hours on a machine every single day is a long time. It is really demanding, having your house full of equipment is....it just overtakes everything.

Participant 5.

However, even though dialysis had its impacts and limitations on their lives, it provided a sense of familiarity and routine, which some participants had developed coping mechanisms and even identities around. Following transplant, this was suddenly lost.

I think the psychology of survival on dialysis for years is kind of like the myth of Sisyphus, it is kind of like the rhythm of your life that you kind of like just keep going with, and then suddenly that stops and then you haven't got that structure, and you haven't got that group of people and then suddenly you just kind of like [...] for so many years being on dialysis was part of who I was but I kind of had a parallel life alongside it that was like just coping, coping .

Participant 4.

I liked the fact I had three set days, those three set times I just had blocked out both mentally and physically that I couldn't do anything else and that is what I was going to do.

Participant 6.

I mean it was very limiting as far as, you know, travel and all that sort of thing, but I was getting into a routine. I could have dealt with that.

Participant 3.

While a number of participants told us they had been aware that they would need to undergo dialysis or a transplant prior to starting this process, the timescales for this were unpredictable. For some, starting dialysis had been a sudden and urgent process.

From a lifetime of having poor functioning kidneys, which actually coped very well. Suddenly they just decided they'd had enough and started to go down and they went downhill very fast. So it was all systems go.

Participant 3.

I woke up with excruciating pain, had to go to A&E, they kept me there ... I was going to be admitted. Must have been in hospital for about two days, and one of the doctors came to me and said, basically, directly, 'Your kidneys have failed, you will have to start dialysis'. So that was like, terrifying, I sort of knew my kidneys were failing, but I never thought it would reach that point so quickly.

Participant 5.

For others, differences in opinion between different consultants led to uncertainty about when they would begin dialysis.

I had a period in 2012 where it was, we agreed I was going to start [dialysis]. I had a tube fitted, I started doing and I did do peritoneal at home ... I saw a different consultant who then said you look far too well to be doing dialysis. You're wasting your time, let's take it down and see how you get on ... at that point I didn't know how long it would be before I was back on dialysis and he'd said 'Don't know. Could be a month, could be a year, we'll see how you get on.' And that turned into 3 years.

Participant 1.



Uncertainty about the timescales for their transplant was a common factor that emerged from conversations with all participants. All participants spoke about the psychological and emotional toll that comes with waiting an unspecified amount of time for their transplants to occur.

It's an emotionally strange place to be. You know, you're waiting for something that may come tomorrow, next week, 10 years. Who knows? So, you're constantly balancing between making the most of what you can manage to do today against hoping that something better is coming in the future.

Participant 1.

The worst thing about dialysis is not knowing when you're going to get that transplant ... not knowing, it could be two years, one year, ten years, is the most frustrating thing.

Participant 6.

Even when participants received a call to say they could potentially be getting their transplant, it was not always certain that the procedure would go ahead. This was described as psychologically disorienting and dispiriting, particularly for patients who experienced multiple calls for their transplant before their transplant was successfully performed.

I was called late at night. They rang me back the next morning. Potentially there's a match. Can you come in? ... I tried very hard not to get too excited, because I'm a natural pragmatist. Right, until I'm actually on a trolley this isn't happening. So, the doctor had said, 'Kidney's on its way. I'm going to go and look at it and then we'll come back and let you know what the situation is. But if we're going, we're going to go quickly'. So, I was sat with a gown on by my bed waiting to find out, yeah, waiting to find out whether or not this was going to happen. And, and when he came back his answer was 'Ahh, it's not going to happen today because the kidney's not suitable quality'.

Participant 1.

I think those were probably my lowest point, those last two weeks before I actually got, before I actually had a transplant. Not forgetting that I had been called in 4 times previously to have a transplant done and they didn't go ahead. Participant 5.

All participants spoke about how their lives had changed rapidly after the transplant. Even those who had a positive post-transplant journey still found this transition overwhelming and stressful.

All kinds of things were totally different, there was not one aspect of my life that was the same. Picking that up from one day to the next is difficult. It is kind of almost being dropped on another planet. That is kind of what it felt like. It often feels as if you are sort of going through a bereavement where you have lost yourself and you are mourning your own death, which was a happy death, an extremely happy death. Participant 5.

I spent a lot of years gradually declining and adjusting slowly to those small changes ... and now suddenly it seems like a really big change ... So that was a bit overwhelming to start with. Participant 1.

For participants who underwent dialysis before their transplant, no longer having to dedicate a significant portion of their time to dialysis was a part of the reason that this transition was overwhelming. As mentioned above, even though most participants told us they did not enjoy dialysis, it was a significant feature of their pre-transplant lives.

A number of participants expressed a feeling of positivity following the transplant, where they felt they were 'on a high' and had the energy and opportunity to do new things and follow new opportunities. For some participants, this contributed to an inner pressure to 'make the most' of their life after transplant. This kind of internal pressure was sometimes a positive driver that helped them achieve goals that perhaps they would not have done in the past.

That's my mentality, I will just go out and do it. And that is because of the kidney, because prior to the kidney I wouldn't have done that. Participant 2.

It feels like that. It feels like a wasted opportunity if, for me, if you haven't done something that you wouldn't have been able to do otherwise. Participant 1.

For others this internal pressure led to actions that were detrimental to their health and recovery.

I first got my transplant, after a few weeks, when I was recovered, I went a bit wild. I went completely wild, I felt like I had a new lease on life ... I just really went back to not looking after myself. Which is stupid. Participant 6.

For some participants, the immediate recovery from transplant was slow and complicated. Participants discussed the difficulties of managing many different forms of medication and their side effects, along with the ongoing uncertainty about how long their transplanted kidney will continue to function well.

And like with the kidney, you're thinking, right I have had 6 good years now...how many more am I going to get? Participant 2.

The doctor said, 'Well, it will do. It can only get better now. You've got a sleeping kidney', or sleepy kidney. You know, it's starting to kick in type of thing. I thought, oh that's great and then when I went back last time he said 'Oh, your kidney function's 16%' ... And I said but last time it was at 23%. Participant 3.

Participants described a period (often still ongoing) of re-discovering themselves and their place and purpose in life. Although having a transplant offered a number of participants new opportunities and improved their overall health, the procedure also had its limitations. Going through transplant also meant that a number of participants had had to confront their own mortality which affected their mindset.

I think my mind set before was very...your mind set changes because...when it finally drops that you are having a transplant you become very black and white. I remember filling in the psych test, and they were like...it's the only question I remember, and it was 'Why do you need this transplant' and my answer was 'Well if I have it, I live, if I don't I die'. Participant 2.

Obviously starting [dialysis] at 22 and not taking care of myself and just thinking 'Right I just have to do this', I actually learnt to accept death pretty young. Participant 6.

This had also shaped their perceptions of themselves and the world. For some this new navigation of self and what their new life might mean was difficult.

There was a little bit of fear of doing too much. And there was a bit of a fear of I'd had, like an extended break from work and from career and that felt a bit odd to go back to trying to be professional and... I guess I had it in my mind that you could be one or the other. I hadn't really worked out how to be my whole self ... Because... are you disabled? Do you want to tell people? How long do you keep telling people? There's an element of 'well you should be normal now', or I thought I should be normal now. Participant 1.

I started refurbishing old furniture. Just to keep myself busy. And like I made a little money on the side from the furniture side. But its time consuming, to do it properly, it just, it takes over your life, and I didn't want something to take over my life, I wanted to rediscover me again. Participant 2.

It is important to note that in addition to the life changing experience of a transplant, participants still faced other challenges in their personal lives or careers, which when compounded with the experience of life after a transplant, had a significant psychological impact for some.

The best word is lost, because... the job side is affected by the kidney, so I have lost that side, but then I have lost the wife and the kid, and then you...you're trying to figure out who you are again. Like I still don't know now. Because you just...you carry on, if you don't carry on, you go backwards. Participant 2.

In a way you are kind of expected to deal with your illness and forget about your other problems. But it doesn't exactly work like that. Participant 5.

Always a transplant patient: unmet expectations and a barrier to 'moving on'

You never stop being a kidney patient ... it never stops being part of who you are. Participant 1

You are meant to have this freedom but it doesn't quite feel like that. Participant 4

I did get involved with CaMKIN and GMKIN ... and then realised that I couldn't. Because the longer I continued to be involved in dialysis, in kidney illness, the longer it was going to take me to move on. Participant 5

It was clear from our conversations with all participants that the psychological impact of having to deal with chronic illness, health-related anxieties and uncertainties in the run up to their transplants was still present during their recoveries.

Like at the moment I am alright, because everything is going the way I want it to go. Ah, but you have days where, you're just, you're just borderline depressed some days. Participant 2

For many, the reality of life after a transplant did not meet their hopes and expectations.

I suppose I've been quite disappointed really. That it hasn't worked as well as I hoped it would. As well as I thought it would really [...] Well, it was pretty bad before, but then on because I thought after I'd had the transplant it would be fine, but it just continued really. Participant 3

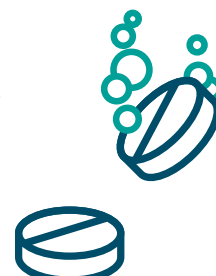
There's nothing...like when you go on holiday it is expensive, insurance is expensive. Participant 2

Recovery from transplant was far from straightforward for the majority of participants, and included difficulties such as: managing an (often considerable) daily medication regime; coping with medication side effects; needing to remain vigilant about their health, due to being on immunosuppressant drugs; and regularly attending medical check-ups to monitor their kidney function. This meant that, for many participants, a considerable portion of their lives was still closely linked to their kidney health, and they were unable to 'move on' from being a transplant patient. This feeling seemed to be stronger in participants who had more difficult recoveries.

Even little things like when you...when somebody's got a cold you're more cautious.

Participant 2

The drugs for transplant make you more anxious and drain your energy, and those things make it sort of like harder just to keep going, especially as I thought 'Oh I will travel the world with my transplant, I will do all these things after my transplant' and when I got my transplant, the anxiety about getting infection went through the roof. Because I did get it, and then I had more hospital, and so I actually didn't do any of the things I thought I'd do when I got it. Participant 4



The all-encompassing nature of it. It's sort of my whole life has changed to fit around this taking tablets and dealing with the side effects. Cause I used to have a very, well I still have quite an active lifestyle, but, well it's constantly there really. Participant 3

The need to continually be aware of their health and attend frequent medical check-ups was another barrier to moving on. It was also a source of considerable stress and anxiety for some, being aware that fluctuations in blood tests could possibly be indicative of a serious problem with their transplanted kidney.

It's just keeping your head busy, because like, the minute you start, because I have had bloods taken today and I am thinking of okay I will have to be back in two weeks, I know from 4 months ago my creatinine had gone up, so what's my creatinine going to be like? And then you start thinking like what...you start thinking three steps ahead. Participant 2.

You can go [online] and get your readings and get your bloods and stuff, and I just don't want to know all of that, until my appointment because if something is bad, ignorance is bliss for me ... [my doctor] was like, you should log into this, you should do this, and I was just like I don't want to, but you will have access 24/7, I don't want to! I do not want to, and I think while it is obviously really good for people to be able to keep an eye on stuff like that, I also think it is going to cause quite a bit of upset and panic for people. Participant 6.

Trying to retain or regain a sense of control, autonomy and normality

I'm a bit of a control freak and a lot of this is out of my control. I like to be able, you know, if they said to me, well, if you stop eating this you'll feel better, or if you did this or you did that. But the fact that, it doesn't matter what I do, it doesn't seem to make a lot of difference. Participant 3.

I must have spent a lot of years knowing that it was coming but trying my very hardest not to let it affect me until I needed to. And, I think I probably over-compensated for a lot of years and worked very hard to say, 'No! I'm the same as everybody else'. Participant 1.

For many participants, maintaining a sense of control and autonomy over their lives was a struggle, both before and after their transplants. Before the transplant, this was influenced by not wanting to be seen as 'ill' by others, or other factors such as having their routines and lives determined by the need to undergo dialysis, or making changes to their lifestyles and diet to maintain the kidney function they had.

I basically didn't make it part of my life and so my friends at work, nobody knew that I was on dialysis or anything like that, I'd just turn up for work every day and just crack on.

Participant 6.

When my kidney was only around 20% ... that's when I really started bulking down and cutting salt out, cutting drink out, cutting everything out just to try and make the kidney last.

Participant 2.

After their transplants, this was influenced by needing to attend numerous medical appointments, managing side effects of medication, and a feeling of pressure to get back to a 'normal' level of physical health and strength.

*When you're well you don't want to be reminded of it every 5 minutes. When you're well and active and being part of and I think it's the identity of it. I don't want to be different, I want to be able to do the same as everybody else or otherwise what was the point? **Participant 1.***

*The pressure I have comes from me. I am one of them that if somebody said to me 'You can't do that' I will go out and do it to prove to them I can. Like the 10k, my dad said a while ago that oh I will never do that, and that has been my goal this year, just to run a 10k ... I would always push to prove a point that just because you had a kidney transplant it doesn't mean you can't do it. **Participant 2.***

This was also strongly linked to a desire to appear 'normal' or maintain a sense of normalcy which was voiced by all participants. This desire for normalcy was linked to a number of motivations, including not wanting to be judged by others on the basis of their health or medical history.

*Like in the work place ... I don't want to be the one they go 'Oh he's had a kidney transplant'. **Participant 2.***

When people hear that you have had a transplant, it is not that people don't know how to deal with it, they congratulate you and they make it seem as if you have done this massive great thing, and I don't think you have, I don't think that I have personally done a damn thing.

Participant 5.

For some participants, a desire for normality was linked to a desire to distract themselves from their health problems and complications. They spoke about 'throwing' themselves into normal life, and in particular their work, as ways to distance themselves from previous or current poor health. For some participants, this internal drive to get 'back to normal' had a positive impact. For others, it meant they pushed themselves physically to an extent that had a negative impact on their health.

*Getting back into work has had less of an impact than what I thought ... I think it has helped distract me in a way ... [it's] something else besides illness or recovery. **Participant 5.***

I think my response to that was becoming a workaholic as soon as I could. I started work part-time within three weeks of leaving the hospital and then that became a fulltime job.

Participant 4.

*I went back to work too quickly, and I have learnt from that, because I was just so determined to be normal, that I just went back and actually sometimes I cried, I would just start crying at work for no reason ... I just wasn't really emotionally ready to go back, even though I could physically do the job, I just kind of maybe pushed myself a bit too hard. **Participant 6.***

A desire to push themselves physically was also sometimes connected to anxieties and uncertainties around their health and the functionality of their kidneys. Participants expressed a desire to live a fulfilling life, in case their health deteriorated significantly, or out of a feeling that focusing too much on their health or limitations would be detrimental to them.

*I tried to cram as much in, while I was well enough, as I could. And again after transplant. I'm well! I need to live 100 miles an hour. I need to do as much as I can now! Because then when I'm not well I've got, at least I've got memories to look back on and it wasn't just ... I don't know. **Participant 1.***

I think I have got a bit of an idea that you don't in general, the more you talk about illness the worse it becomes. That has always kind of been my ethos, stupid but yeah. But the more you talk about it, the more you convince yourself that you are not okay, the less okay you are going to be. Participant 5.

The process of going through transplant itself was seen by some participants as a barrier to regaining a sense of normalcy. Participants told us about how their transplant journeys had changed their perceptions, and made it difficult to connect with others over insignificant problems.

Coming into contact with other people, or 'normal' people, is very difficult. Trying to see the world through somebody else's eyes, with day to day things is difficult, it just blows my mind. I think that's...it is difficult to understand, how something like, I don't know, a flat tyre, or a child that is crying, or a cold cup of coffee, or waiting for the bus is difficult. And sometimes it is quite complicated to, almost to keep quiet and to not, not let that affect me. Participant 5.

Whenever someone is moaning about pain, I tell them to shut up. Because they don't know what pain is ... Because you get this appreciation after a transplant where, it puts everything into perspective, that little cough, that little sore throat that you used to go 'Oh I won't go in today', nah you just go in. Because you can. Participant 2.

There were various other ways in which participants found this pressure to be 'normal' isolating. Some bottled up their worries and feelings about their health, so as not to burden others, although this had a detrimental effect on them. Other participants talked about the impact of their health on their long-term relationships with friends and family, and how their experiences with their health could lead to a gulf in understanding with loved ones.

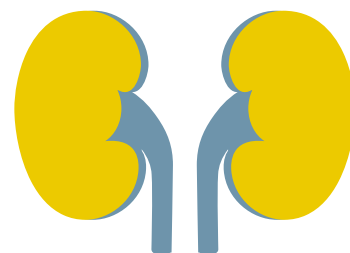
I became quite withdrawn to start with. Umm, being a small family unit I think there's a tendency to not share umm, all of your worries, particularly with a teenager. You don't want to create more worries than they would normally have ... I guess, I kind of thought I was protecting people from that but actually just isolated myself. Participant 1

I sometimes feel [my friends] must be bored with it by now. You know, they've had nearly a year of me going on about this, that and the other. I mean, I'm sure they aren't, but I think they expect, you know, that next time they speak to me I'm going to say 'I'm great now, I'm better'. Participant 3.

This year and a half, my family relationships have massively suffered ... with my sister it has been almost impossible because, she has got three kids, so I just feel like she doesn't have any empathy... I just feel like, her life and her choices are just so miles apart from mine. Participant 4.

You just end up keeping everything bottled. And it is something that...like I...as much as I blame a lot of things for myself and my wife's splitting, it is the bottling up which has caused the rupture so to speak. But you bottle up because you don't want to appear weaker so to speak because of the kidney. Participant 2.

Each participant's transplant journey therefore had a significant impact on their sense of self and identity, and what they felt was important to them in their lives. Coming to terms with their own mortality, sometimes at a young age, and having to live with a chronic illness which affected their health and energy were additional factors that influenced participants' lifestyles and identities. Some participants struggled with the influence that being a kidney transplant patient had on their lives, and others were more able to accept that as a facet of their identity.



Theme 2: Lack of awareness and understanding from others, including the healthcare system, that exacerbates struggles and issues

Transplant is a treatment not a cure

Overall the benefits way outweigh the risks because potentially you've got a functioning kidney. It might not be doing 100% of the kidney's job but it's doing more than dialysis is. So from that perspective it has to be worth trying. If you can, it's the best treatment we've got. It's not a cure but it's a treatment and it's the best chance we've got at the moment.

Participant 1.

As discussed previously, many participants spoke about the pressure they felt to 'be normal' or 'get back to normal' after the transplant. Whilst, for a number of participants, this was an internalised pressure, other participants also felt this pressure from others. They spoke about the general misconception that transplant was a 'cure' and that surgery would fully resolve their health issues.

The expectation of everybody around you is that you've had a transplantation, therefore you're fixed. And you're fit and well and you could be doing 40 hours a week and if everyone else can manage to get to there, so can you. **Participant 1.**

People have said to me, Oh, did you feel better straight away? ... They think, 'oh a new kidney'. Well actually I felt better before, than at the moment. **Participant 3.**

This sense of lack of understanding from others also made some the participants feel that they could not connect or talk to others about their experience, which can be isolating, as discussed above.

Additionally, some participants discussed feeling a sense of guilt that their transplant had not been an effective treatment and that their donor kidney was not functioning as well as they had hoped.

I mean, there's this issue you were saying about contacting your donor, at the moment I don't feel up to doing that because I don't want to say to them 'Actually the kidney I got from your relative hasn't been much good to me, yet'. **Participant 3.**

Another issue that impacted participants' long-term health and wellbeing following their transplant was their medication burden, and managing the side-effects of various medications they needed to take. Participants spoke about the difficulty in finding a balance of medication that worked well for them, and figuring out the kinds of side-effects that they would be able to cope with in their day to day life and how to eliminate or reduce others that were having a more detrimental effect on them. All participants spoke about the difficulty of managing their medication burden and medication side-effects.

Because obviously you have got your immunosuppressants, but then you have every other drug to counteract that drug. It's like the woman who ate the spider or swallowed the spider to catch the fly or whatever. **Participant 6.**

I always knew it was going to be a trade off with drugs, and I think the drugs have had an effect on my mental health because I do think that the things around sleeplessness and anxiety are affected by the big immunosuppressant drugs. **Participant 4.**

But they seem to be saying, well we can't, we don't wanna mess around with medication at the moment. So, I'm just gonna have to go with the flow and get them to sort ... at least the feeling faint thing's gone. The next thing to tackle is the muscle thing, which could be salt, it could be I'm on statins as well. So, it might be statins. It might be a different blood pressure tablet. It could be any number of things really. **Participant 3.**

Participants also expressed frustration at the lack of understanding within the benefits system regarding transplants. Those who were in receipt of disability benefits pre-transplant spoke about how their benefits were stopped after they received their transplant, and how frustrating this was. Participants who chose to apply for Personal Independence Payments (PIP) also spoke about their frustrations with this process. Numerous changes to the benefits system in recent years added to the

complexity for participants trying to navigate this process. There was a general perception that the benefits system did not take into account that their recovery from transplant would not be immediate, and that fluctuations in their physical and mental health during their recovery were also not considered.

And in my case for example I was two months after surgery and they cut my personal independence payment, they cut everything else because the idea was, you had had a transplant ... then I had to go through a period of almost a year and a half in tribunal, so I had no financial income during that period whatsoever ... I wanted to go back to work but obviously I wasn't well enough. Participant 5.

Yeah PIP really frustrates me ... a couple of months back I applied and I think I missed it by one or two points. And it just comes down to my fitness. Because I am physically able to do it. But it doesn't take into account the mental side, the highs the lows, or the fact that you have to keep coming back and to. Participant 2.

When I was on dialysis, I was entitled to disability living allowance. And as soon as I got a transplant I wasn't. Participant 6.

This is particularly worrying as, regardless of their physical fitness to work, a number of transplant recipients may live with chronic health conditions that may require ongoing care or support following their transplant. Depending on their professions prior to transplant, patients may also need to switch to less manual and physically demanding roles following their transplants. Many may therefore need additional support to re-enter the work environment, and would benefit from a less rigid assessment system for benefits.

Participants also voiced their frustration at a lack of understanding from employers, who also did not understand that the health of a transplant recipient may not be the same as other people, or appreciate the time commitment many participants needed to give to medical appointments.

Like I am off this week, but if I wasn't off I'd have to switch my days around because like my new job, so next year ... if I see Liverpool every 4 months, 6 days of my holidays are going to be for Liverpool, already predetermined. Participant 2.

Physically I could turn up and do what anybody else can do. How that would affect my work, life balance and my overall wellness - probably not great. Participant 1.

Complications of immunosuppressant medication: need for alternative pathways to care

As well as possible other side-effects, the immunosuppressant medication that participants need to take to ensure their transplanted organs are not rejected puts them at higher risk of infection and illness, which could in turn put their wider health and kidney function at risk. This was a source of anxiety and fear which participants would need to manage for the rest of their lives. It manifested in various ways, and in some cases kept them from participating in certain activities or seeing unwell friends or family.

I remember pre transplant I got told once you have a transplant don't get a tattoo, chance of bacteria, don't bother. Participant 2.

I'd love to go swimming again, but I think like ...do I really want to go swimming again? ... It sounds stupid, it sounds totally ridiculous, but am I going to be in a pool of water with what? Participant 5.

Worryingly, however, a number of participants expressed concern that healthcare professions outside of specialist consultants and their renal team lacked an understanding of the dangers and risks they faced due to being immunosuppressed.

What I found is that people who, not just people, nurses and doctors, people in the health profession, who don't know about post-transplant care won't take you seriously. So I had an ingrown toenail, and I kept going, and I kept saying its infected and I was told that it wasn't, I was told that I didn't need antibiotics ... [my GP] wouldn't give me any antibiotics, and one of the reasons was that he was scared to give me it because I was a post-transplant patient ... and one night I just woke up and I was shivering and I just cold, I ended up crawling around the floor trying to find some paracetamol or something, and I ended up in hospital and it was sepsis. Well it was some form of blood poisoning from my infection. Participant 6.

I need a tooth taken out and the dentist won't take it out. And I am now waiting for a referral to the hospital. I need it done in the hospital, because they scared of bleeding, they scared of anti-rejection ... something that is a normal, simple [procedure] for anybody else can become quite complicated. Participant 5.

GPs are absolutely lovely but they're a bit clueless in terms of transplant. Participant 3.

Some participants expressed a particular concern around staff in A&E being unaware of the specific needs of transplant patients. This is a key issue, as participants also told us that A&E is an area that they are frequently signposted to, even when they may not need urgent or emergency care.

I found that hard during this transplant because it is like all the nurses are trained to say it as well, so if you ring the dialysis ward even after the transplant and say look I am really worried about this, they are like 'Ah right, A&E'. And you are like really? Participant 4.

Participants who voiced a concern around knowledge of how to deal with immunosuppressed patients in A&E were particularly concerned about the triage system, and having to be in a waiting room with people who potentially had serious infectious illnesses. All of the participants who voiced such concerns shared with us their personal experiences of using A&E as a transplant patient.

I got a tiny blister on my toe, on Easter Sunday morning, by Easter Sunday night the whole toe was infected, in a complete open sore in probably less than 24 hours. And I went to A&E and I sat in A&E for another 24 hours. Whereby, I sat in A&E and then they came to me and said there was a risk of losing my toe, of amputation. So that was terrifying ... I knew about the risk, the possibilities of infections spreading very quickly because you have got not immune system. But I never thought it could happen in that period of time ... they probably do make you aware of that, if anything strange does happen, consult your doctor. Okay, what they don't say is when you go to A&E is that A&E don't know what to do with you. ... I went in on Easter Monday morning, about 9 o'clock, it got to 4 o'clock the next morning, and I still hadn't been seen ... I kept saying to them please speak to the renal department, please speak to the renal department, they eventually sent somebody down from orthopaedic ... I am not sure that they understood the extent of the seriousness there. Although I did tell them various times and that was my first point of contact was, recently transplanted I am terrified of infection. Participant 5.

One participant who shared their concerns about A&E spoke to us about how they felt emergency care for transplant patients has shifted more into A&E, to the detriment of patients.

Because I have got something that is triggered by infection ... when that happens, when you know that that's happening, and your only way into the system is A&E that is really hard, because you can't...you're not an A&E case. So, and... I have had some quite traumatic experiences in A&E which mean I will avoid A&E at all costs. Normally I will have been waiting between 5 and 6 hours sometimes longer, and then you are put in the acute medical ward, then you are transferred, but normally it is not to the kidney ward immediately ... I don't think it's right that there's not a - like throughout my 20s if something went wrong after that traumatic transplant, I was straight in the renal ward. And there was always a consultant who could make decisions at any time of the day or night, and you just had to wait two hours maybe until you were seen. Now, normally they don't come down from the renal ward to A&E for quite a long time. Participant 4.

This participant expressed a particular worry about spending time in A&E, as they had previously lost a transplant after contracting pneumonia during a hospital stay where they were in contact with someone with the illness.

I think it was about three days after I had had the IV steroids for the treatment for the rejection, I was, I had plasma exchange opposite somebody with acute pneumonia who was spiking a temperature that day ... I got pneumonia straight off within 48 hours and, I don't even know if its pneumonia that caused the function to go down so dramatically or the IV antibiotics, but that was when the transplant really dived. Participant 4.

This underlines how important it is for transplant patients to feel they are being listened to and that their needs and concerns are taken into account by the healthcare system. Incidents such as the one that happened to the above participant may be rare overall across the healthcare system but are incredibly stressful and traumatic for those who are affected by them.

However, not every participant had a negative experience of receiving care from other health professionals or care at A&E. This shows that when patient concerns are listened to and dealt with, seeking urgent care does not need to be a source of additional stress for transplant patients.

I had Norovirus. They were very quick on that. I came in umm, I came in through A&E ... when I explained I was just transplanted then I was taken through. On a corridor they gave me anti-sickness and I did end up in the infectious diseases ward. Not because I was infectious but because I was immune suppressed. So they couldn't put me on a renal ward because everybody else would be immune suppressed. So the safest place to put me was in a barrier nursing room. Participant 1.

Participants who spoke to us about their A&E concerns had similar suggestions for how their patient experience in hospitals could be improved. Participants suggested having a protocol for dealing with transplant and other immunocompromised patients coming in to the healthcare system through A&E, or having an additional point of contact for transplant patients, who could be contacted when patients had concerns but did not feel like A&E was an appropriate avenue.

People who have illnesses that go beyond that six months, that make the transplant more vulnerable, they need a different level of intermediary care that is not A&E ... in a way the home dialysis nurses for somebody on dialysis were more of that function, of that connection into the hospital, but when you have got transplant you lose that, you don't have that person who...if you want to get an extra blood test done because you have got a concern ... it's like, if you have got a traffic system like red, yellow, green ... you have got nowhere to go in the yellow zone, you have only got A&E which is a red zone. So, in that yellow zone, when you have got transplant and somebody who is high risk, because of your transplant, you need some place to go. And I feel like that's what's missing for me. Because even if I had a registrar which wasn't necessarily a consultant, I could, just flag up when I am in that yellow zone, something to. And that would make a really big difference. Participant 4.

If there were a kind of protocol, a transplant patient comes in, don't allow them near anyone else, isolate them, call in their specific department. Don't take it further than that or less than that, just do that. Don't take them through triage or anything else, just. Something as simple as that whereby I could have had a nephrologist come downstairs look at me and say 'Okay fine, your kidneys are alright, but...lets go from here'. Participant 5.



Comparisons made between transplants and other conditions

Participants expressed a feeling that post-transplant care and the transplant pathway was not equal to other pathways and treatment routes for other long term conditions. One issue that was picked up was the lack of a rehabilitation period for patients following their transplant. One participant, who had also undergone open heart surgery (due to complications linked to impaired kidney function), recounted how their cardiac team did not understand why they had not had any rehab after their kidney transplant.

There is no rehab after transplant ... cardiac rehab couldn't understand how I'd had a kidney transplant and not had a period of physical activity. Participant 1.

The majority of other things that exist, other illnesses or other accidents or whatever it is, there is always a period of rehab, everybody goes through a period of rehabilitation. Whether it be... I don't know, whatever. However, there doesn't seem to be for transplant, there is absolutely no kind of period where...you are allowed to get stronger. It's kind of 'Ok discharge, here is a four-page booklet get on with it' Participant 5.

Cancer was another long term condition mentioned, particularly in reference to the co-design of care plans and patient involvement in their treatment.

I just don't feel there is a culture of co-designing the care plan. I just don't feel there is a culture of like listening, it is not like in cancer care where like they agree a care plan with the patient. I just feel like the culture is like, this is it, this is what is happening now. Participant 4.

There were even comparisons made to the kind of support received while on dialysis. For some, having a transplant also meant that they no longer had access to the renal nurses who they felt were empathetic and supportive of them while they were on dialysis, which transplant patients did not have a substitute for.

If you could have an equivalent of a home dialysis nurse who just went and kept an eye on transplant patients every now and then that would be a great thing. Participant 4.

A number of participants expressed their frustration that they had to pay for their own medication, particularly for immunosuppressant drugs, which they would need to take indefinitely to ensure their transplanted kidneys were not rejected. This was seen as unfair in comparison for some other long-term conditions, medication for which is covered on the NHS.

The outcome of not having our immunosuppressants would be we would be back on dialysis and cost the NHS even more. So, I think there is a disconnect there, as I say I can pay for them ... but for the people that can't I think it is really unfair. Participant 6.

Me and my mum, we were trying to get the prescriptions for free, because my brother gets them because he has epilepsy ... he gets them for free, whereas I don't. And that's...like I paid for the pre-payments and that's £110 or whatever for the year. But, it's strange how they work that out, how if I didn't take mine, the tablets are lifesaving. Participant 2.

Theme 3: Lack of clear and compassionate communication from the healthcare system

Focus on kidney function: other issues not formally acknowledged or handled well

[My kidneys] are, I have to accept, a part of me and the medics are interested in that particular part... but you lose the whole of you which is why that rebuilding afterwards ...maybe is a bit more difficult. Because you spend that period very intensely being scrutinized as a patient, and a kidney. Participant 1.

Following their transplant surgery, participants spoke about the intensive monitoring of their kidney function by specialists. Many participants talked about needing to return to the hospital where they had their transplant for frequent tests. Several participants mentioned the difficulties of attending frequent hospital appointments whilst they were still healing from intense and invasive surgery, or the financial difficulties of such frequent travel.

I think there's a period of physical recovery when actually what you need the most is peace and quiet. And be allowed to sleep and wake as suits you ... discharge from hospital is - can you get to the toilet yourself, can you wash yourself, can you dress yourself ... umm ... and at that stage you're then deemed well enough to go home, aren't you? Because if you don't need nursing they don't want you in a bed. That's not helping you get any better. But there's a period between that and being well enough to actually take part in any kind of activity. Participant 1.

I was overwhelmed with everything that had to do with the medical part of it. I actually probably had too much care, as I still do, they are extremely observant ... in the beginning I was at clinic ... every second day. For about the first three weeks. Then it dwindled down to about every fourth day. Then it moved to every week. Then he pushed me onto about every ten days. So, it took a long period, so it took at least 6 months before, no I am lying...it took at least 9 months, before I passed onto a two-month stage. And at the moment I still go in every third month. So, you are still very very very carefully watched. Participant 5.

I missed a load of appointments ... I couldn't afford to get over to Liverpool, I didn't have the toll fair, or the petrol or the parking because it cost me a fortune every time I went. Participant 6.

All participants said that the focus of clinical appointments post-transplant were overwhelmingly medical, and followed a 'by the book' format. This was frustrating and unhelpful both for participants who had experienced a smooth recovery, and for those whose recoveries were more difficult. For participants who experienced smooth recoveries, the appointments were time-consuming, routine and predictable. For patients who had experienced or were experiencing difficulties with their transplant and kidney function, the format of post-transplant appointments meant that patients felt there was not enough time or opportunity to discuss specific concerns. Regardless of how well their recovery went, for the majority of participants, clinical appointments did not offer patient-centred or flexible care.

I go for my check-ups every 3 or 4 months and I will be honest it is a waste of time. It is just a waste of time ... you get there, you get weighted ... they do your blood pressure, they dip your urine, sometimes they will take your blood pressure, sometimes they won't. They will ask how you are feeling. You will be 'Yeah I am alright'. Participant 2.

You've got like your 10 minutes. So really what you need to do, what I focus in on, is the physical stuff cause I want this taste thing sorted. I want this blood pressure business sorted. So all the other stuff once I started it, I'd be there for hours. So I just don't and I don't really, I don't know if they'd have much of a clue about it really. Participant 3.

After those six months, when things were going wrong, over that period, I was having clinic every two to three weeks, they would be doing bloods in-between, but they still weren't listening and giving me the treatment that I wanted. So it wasn't like I wasn't seeing the clinicians, I just felt like I wasn't being listened to even when the creatine went up.

Participant 4.

A number of participants we spoke to did not raise concerns or problems with medication and side effects, even serious ones, at their post-transplant check-ups. They told us that they did not seek advice from their renal team about possible medication side-effects, or that they tried to manage their medication outside of their renal team, as they did not really view this as something the renal team would be able to help with.

Prior to the transplant I'd had this strange episode of something called PRES, which is Posterior Reversible Encephalopathy Syndrome and there are things I couldn't do. It lasted about 48 hours. I couldn't work out how the loo worked. I went to the hospital with my friend, I couldn't remember where the dialysis was. I couldn't find my way to the 3rd floor ... it was this weird thing which is connected with kidneys and high-blood pressure ... I started to think, oh, maybe that's coming back ... I didn't really think about [talking to the renal team about it], I don't really think about it being their sort of area of expertise. **Participant 3.**

I had changed the tablets. Because I got [the pharmacist] ... I got him to do it for me. I didn't go through the doctors themselves. Like he had a chat with them, but it was all done through the pharmacist. **Participant 2.**

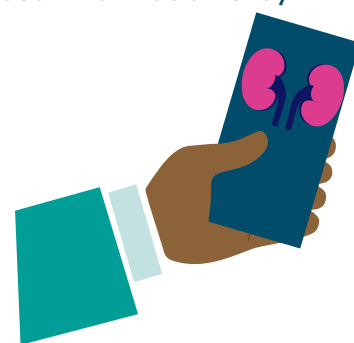
All participants told us that their check-ups with their renal team were overwhelmingly focused on kidney function, and that specialists did not ask about the participant's general physical health, mental health, or emotional wellbeing. It is possible that the narrow focus of such appointments contributed to participants' reluctance to raise other issues at their appointments.

Lack of information and follow-up

Participants also expressed that they had a lack of adequate information on post-transplant care and looking after their own health following their surgery. Some participants described being given a very brief amount of general information about transplant aftercare. Others discussed information they knew they were not provided with, such as information on diet and nutrition.

I was discharged with a book to tell me what I needed to do after transplant and it's not a very big one to be fair. It's not like there was a lot of information ... it's a pamphlet. **Participant 1.**

Like when I got discharged I remember they were meant to give me a leaflet about foods to avoid and everything, and I never got that, it's something...I was aware of because I had seen them do it, but when I got discharged I never had it. **Participant 2.**



Some participants also discussed a lack of follow-up from professionals for transplant-related care. In some cases, this was a lack of follow-up for specific requests for advice, information and consultation that participants had been told they could have access to following their transplant. In other cases, it was a general lack of follow-up when regular check-ups and appointments had been missed.

I got something from the Royal. These, this list of things not to do and not to eat ... I emailed a dietician at the Royal and she never responded to me. No reply to that email. I've kept it and I just feel really angry that she didn't even bother to reply to my email. Because it said on the leaflet, any questions, any queries, this is our email address blah, blah, blah. **Participant 3.**

I missed a load of appointments, completely my own fault ... and there was never any follow up on that apart from I would get a letter saying 'You missed your appointment here is another one' ... what if there is a vulnerable person out there that is genuinely missing these appointments and no one is checking up on them? **Participant 6.**

Responsibility of patient to self-advocate

It just seems like...the patient has to fill in a lot of gaps. And if you are feeling weak and you are not feeling like, self-confidence because you're feeling vulnerable for whatever reason, it is a lot to do to fill in those gaps. It is a lot of management around it you know. Participant 4.

All participants spoke to us about feeling the need to self-advocate for appropriate medical care as a kidney transplant patient. This was linked to experiences of poor communication pathways between primary and secondary or specialist care providers, perceptions that healthcare professionals working in other areas had a lack of knowledge or awareness about transplant care, and a poor quality of information provided to transplant patients about their medication regime or aftercare.

There is always an element of whoever you deal with, if it's not renal, I have, this is where I advocate for myself and say 'I am a transplant patient, this is important. You need to let them know before you give me medication, before you do scans'. So, I had an angiogram before the heart surgery and I'm ringing renal and saying, 'Is this OK? Can you make sure that they know what they need to do?' Participant 1.

It's about being listened to and you know I can stand up for myself, but there are going to be people who can't stand up for themselves ... and there's things like medication and stuff, knowing your dose, because you are just like given your medications and just left to get on with it. Participant 6.

And when I, they discharged me from the Royal they didn't write to the GP immediately to say I'd had a transplant. So when I ran out of medication I traipsed down to the GP, communication between them was pretty awful. So they wouldn't accept any of my accountable medication I was on. For obvious reasons, really. Cause they'd not had a letter, so they didn't know I'd had a transplant even. So the discharge letter I think might have taken even a month to get to the GP. Participant 3.

As previously mentioned, participants did not always mention issues with medication and side-effects to their renal team, even when side-effects had a negative impact on their day to day life. In order to get these problems with medication resolved, participants had to raise this issue with healthcare professionals themselves, rather than having their medical team check in with them to see what side-effects they might be experiencing and whether they were happy to manage these in their daily lives.

There was one [medication] ... that affected my periods. I bled very heavily for longer than I would normally. Umm, didn't realize that was related, then made the connection, then said to the doctors 'This, I think this is causing this. Is it very likely?'. 'Yeah, oh yeah! That could be. We'll stop that and swap that instead'. Because again they are looking at the medical benefit of you having it and if you don't have side effects than it is working. And if you do have side effects, it's up, the burden is on you to say. Participant 1.

They changed tablets, from Prograf to Adoport. And some people the Adoport, they are fine on. With me, it just wrecked me. It wrecked my stomach ... they did investigations and put me down as chronic colitis or Crohns ... I rang up the pharmacist, at Liverpool Royal, and said 'Look something has got to change', I said 'All my issues started when I changed tablets, can you put me back on my old ones, just to try them'. And within two weeks I was back to normal. Participant 2.

Participants also often found themselves having to self-advocate, particularly around medication, during hospital stays.

One of the things that really frustrated me in the hospital was if I'd go back in sick, I'd get my medicine at random times, so it wouldn't be the 12 hours it was supposed to be ... and then I had some phosphate binders, I would have them half an hour before dinner or half an hour after, and they were giving me them like two hours before any food, and I'd leave them on the side and they'd be like 'You haven't had them' and I would be like - they are meant to bind the phosphate to the food that I eat, so if I am not eating anything, there is no point, and I felt like the nurses didn't quite understand the medication side of things. Participant 6.

Need for sensitive communication and respectful dialogue with medical professionals

Participants' need to self-advocate was often linked to a feeling of not being heard or listened to by medical professionals, whether this was their own renal teams or healthcare professionals across the NHS. Participants spoke about how their knowledge of their own conditions and needs was not respected by medical professionals.

Even when I was in the hospital ... I asked them to get someone to look at my [infected] toe, and they refused, and luckily for me there was a diabetic girl in the bed next to me, who needed her toes looking at and as the guy was in there she said 'She needs her toe looking at you know, she has been asking the nurses for days' and he was like 'Oh you are not on my list' and I said 'Well can you please have a look' and when he did he was like 'Oh my God, how have you been coping with this?'. Because my nail had grown like right round to the side of me foot, it wasn't a normal nail. So, he ended up packing it and doing whatever he could to relieve the pressure ... I wasn't even his patient. But the nurses hadn't told him, and I was saying that's why I am in here, that's the issue, just...but nothing happened. Participant 6.

I have known what I needed and in A&E they don't trust you they treat you like you could be any kind of drug addict or any other kind of people they deal with, they won't listen to you as a patient who knows their body first, chronically ill, because they are not used to that, they are used to like dealing with all kinds of crisis. Participant 4.

Participants spoke about different approaches between different doctors and the impact this had on them and their trust with healthcare professionals both within and across medical departments and specialisms. This was often linked to the manner of medical professionals, and their ability to communicate information both clearly and sensitively when required. An inability of staff to do this, or to arrange appropriate follow-up with patients, had a detrimental effect on participants' levels of trust in their medical team and the healthcare system overall.

And then also when you see the doctors, they're totally different. You see, they're all very nice, but you see a different one. And then one new one said, 'Well of course 16%, if it goes down to 15% you'll be back on the transplant list'. And I said, 'What!!' ... And then another one, the other one who I really like, that's always very up-beat and positive, he said 'Oh no! no! no! No, this one will last you for a decade or two, even'. So they have a totally different approach ... so you just think, they just sort of don't really know these doctors, they just sort of, it's a bit trial and error. Participant 3.



There is a very, very big difference between the diabetic department and the renal department ... I feel in the diabetic department they do not care, simply. As I said I was accused more than once of over-eating, of being too fat, of kinds of things like that, ridiculous things ... More than once they have had cancelled appointments, not rebooked them. I haven't had follow ups. Participant 5.

The tone of communication with medical professionals also had an impact on participants' relationships and trust with healthcare professionals. It is important for healthcare professionals to be aware of the tone in which they are talking to patients, along with the content of what they are saying, and how appropriate this is. This is particularly important for transplant patients, where the unpredictability and uncertainty of transplant mean that good kidney function and health cannot be taken for granted. As well as tone in conveying medical information, it is important that healthcare professionals always use an appropriate tone in general communication with patients.

I always get nervous going to them still, even though every time it's always the same. There was one time when I turned up and he said 'I have got some really bad news' and I was like 'Oh God what is it?' and he is like 'Um, your blood sample, we lost it' and I was like 'Jesus Christ that is really good news, don't ever start with I have got really bad news!' Participant 6.

I always remember there was somebody ... I never liked him. He was a specialist kidney nurse and he said to me 'I know for the Christmas period you need to be getting onto your potential donors and really get them to commit to donating'. Participant 3.

Continuity of care with a trusted professional can have a significant impact on patients. Participants who had this kind of relationship with specialists expressed a stronger feeling that they could speak to their medical team about any issues they were facing and have their questions answered.

I know I have been extremely lucky because I have seen the same nephrologist...I kind of don't get to clinic and see whoever is there. I always see the same person and I do have that continuity of care. And I know that he has not time but he does listen and he does ask and he does run things up and if I call him his secretary will always help. Participant 5.

Participants often discussed a difference in their interactions with nurses and with doctors or specialists. Nurses were often seen as having a more understanding and empathetic approach.

I mean before I had to go on dialysis [there was] a really good nurse, whose husband she'd met actually on the transplant ward and she was a dialysis nurse, so she knew about, she knew what it was like because she lived through it. They're all much, much more tuned into that, I think. Because they were nurses, maybe as well. Participant 3.

There's nurses that really do understand ... the nurses are your day to day link support. And I think some of them do incredible jobs, really incredible jobs, and certainly my life going on dialysis and going back on home dialysis has been really supported by them. Participant 4.

Good communication and a two-way trusting relationship with healthcare professionals was something that was, understandably, a high priority for people who'd had more difficult experiences.

I think the main thing I am trying to think about is the next transplant and how it can be different. And how I can somehow feel like I have got a care plan. Because I have had 26 years of being chronically ill, diagnosed 27, and I have never had a care plan you know ... I don't think that they will have factored in my lived experience. Because I think they will say, this is pathway for this illness, this is what we offer. And yet a lot of that hasn't worked for me. So, I have to kind of like...I have to kind of navigate that and write it down the care plan like. Almost like you would write it down if you were having a baby you know like, you would say well 'I want to make these choices at this point. And I want to be listened to here, and this is what I want'. Participant 4.

Theme 4: Lack of appropriate emotional support & signposting

I am not sure anybody can really prepare you for [transplant]. You do need support, you definitely do need somebody there, and I probably still do. Participant 5.

Inappropriate support

A consistent theme across interviews was the lack of emotional and psychological support offered to participants throughout a very stressful and overwhelming period of their lives. All participants said they were not asked about their mental and emotional wellbeing during check-ups with medical specialists, and no one was actively signposted to a support organization by any medical professionals. One participant told us they noticed an advertisement for a generalized support group in a waiting room, but they were not actively signposted to the group and did not attend a meeting out of an assumption they would not find it useful at that point in their transplant journey.

In the little waiting room, there's a notice up about Women on Wirral who had transplants or something like that. But actually at the time I thought I don't want to be sitting in a group like Alcoholics Anonymous and talking about my symptoms. Participant 3.

Three participants were aware of external charities like Kidney Care UK, who provide support for people with kidney disease, but all had discovered these organisations themselves. Of the three that knew of them, only two had used their services and one was aware through work they had done with another charity but was not aware of all the services they offered.

I specifically joined Facebook so that I could join the Kidney UK Facebook group ... because it was a charity the Kidney Care UK, was then able to start sort of popping up with 'We have counsellors. Did you know that that's available to you?' So I then was aware of it. Participant 1.

A number of participants told us they had, at some point, attempted to seek support to help them cope with the difficulties of dialysis, transplant, and kidney disease, but had ended up receiving support they felt was inappropriate for someone in their situation.

The truth is that I did go to the GP at one point and he brought me through to Talk Liverpool. ... it wasn't convenient for me, it wasn't what I needed ... basically they put me on a 6 week 8 week online course which I had obviously done a hundred and fifty times before so I went through in half an hour, and it meant nothing for me but at that point I was told that I was not participative so I didn't have right to face-to face counselling, which ok good and well, it wouldn't have been worth my while going to face to face counselling anyway because they wouldn't have been adequately trained or prepared to help me at that point because it was like, almost maybe 6 or 7 months after surgery. Participant 5.

They sent a counsellor to see me on dialysis, she was rubbish. She basically just kept going 'so tell me what happened in your childhood that has made you so sad' and I was like 'Nothing, I hate dialysis, this is why I am sad, I hate dialysis' and she just kept like trying to talk about my childhood and I was just like I had an amazing childhood this is why I am upset, I am literally hooked up to a machine, all my friends are out and I am here! So, they prescribed me antidepressants ... I wasn't depressed I was just pissed off. Very pissed off. I didn't want to be there, I had had enough, I was frustrated and instead of doing anything to actually get that out of me and you know talk about that and talk through that they just threw antidepressants at me. Participant 6.

Two participants had spoken to counsellors, but expressed that this support was also not suitable for them at the time. Both participants expressed a desire for a more practical source of support than counselling or other talking therapies. For one participant, their sessions with the counsellor were cut short by staff absence.

I saw a counsellor ... that wasn't helpful because she just reinforced the thing about the difficulties with the doctors like the one in London did when I was living there and I tried to talk about having it, she didn't actually help me to like work around it or like have the

conversation though it, she'd be bound by the contract of confidentiality but she was basically anti their attitude and that didn't help me! I didn't need somebody to agree with me about that, I needed somebody to help me. Participant 4.

There is a renal counsellor at the Royal as well, which I did see a couple of times...um...did it help? No not particularly. It is almost very theoretical and I am not going to say indifferent ... almost too professional, like 'Ok I am following textbook, this is what I need to do. Now you go out and apply this tool' ... Counselling is good in very many situations, ok the only difference is I think you get to a point where you want solutions, and counselling is not going to give you a solution. Participant 5.

[The renal counsellor] wasn't available for 6 or 8 months ... She was off for a very long time ill, due to stress or...and there is only one counsellor. Participant 5.

Proactive and Personalised Support

The uniqueness of each participants individual transplant journey, and their own awareness of the variability of other transplant patients' recoveries, meant that no clear pathway or referral system for support was proposed. However, participants all expressed a view that they would have found more (or better) support during their transplant journeys to be useful. They expressed a desire for support to be flexible, so that it could meet the needs and requirements of individual patients, and to be available and signposted to throughout a patients' transplant journey.

Yeah you keep pushing forward because you just want ... you just want to be normal! You just want to carry on. But you do need somebody to talk to. Like for me, it's too late really, you just... I don't know.. I don't know when a good time would be to talk to someone. I think if they offered it, possibly before you get discharged, I think because you are still going through the process. Participant 2.

Probably in the lead-up to the transplant, probably. But it's difficult to know when that would be, because it's a bit of a, a bit open-ended when you go on the transplant ... Maybe when I'd gone on the list actually. When I'd officially been accepted on the transplant list and I knew I was going to get one at some point. Participant 3.

It is so specific, so specific that it is even difficult to pin-point exactly what would be the right point or the correct time, or. It just probably should exist and should appear to you at some point. Whether that be at various times and you only pick up at one point that you need it. Participant 5.

Participants also expressed different desires about the kind of support they would have benefitted from. Some expressed a preference with practical support, some talking therapies, and some for information and peer support. A number of participants, but not all, expressed an appreciation for informal peer support.

I found [the Facebook group] very useful and I didn't think I would. I'm not, I'm of a generation where social media does not come easily and I did literally make a profile just to join that group. That was my only interest but it has been very useful. And I think more so even than a local face to face group which I think I went to once and came out and went 'They're very nice', but there wasn't the breadth of experience' ... the Facebook group has something like 7 thousand members, so there's a fairly good chance that if you post something there's gonna be somebody who knows what you're talking about. Even if they live in Scotland. So that access to other people's experiences I did find very useful. Participant 1.

You need someone you don't know. Personally anyway... and you need someone you can break down on. Because just like, you just end up keeping everything bottled. Participant 2.

What would have been really useful and still would still be useful for me, would be to talk to people that I can say 'This muscle thing? Has anyone had that? What do you think?' Participant 3.

I feel like what would have been helpful is something around not over pressuring yourself. In terms of work, and like working out times where it is good to work, like you know that kind of coaching thing that is specifically focused ... you don't want to use the time that you could be productive to go and talk to somebody about what's wrong, unless there is a real way though, where they can help you. Participant 4.

I really do think that the hospital should have kind of a ...post-operative...I don't know ... almost like a kind of citizens advice that is open to impartial, kind information and some place where people don't show indifference. And they show a bit of empathy and I think that is essentially all anybody really needs. And follow up as well, not just kind of pushed from pillar to post. Participant 5.

Some participants expressed a desire for support separate from the medical teams they were being treated under. They felt it would be easier for themselves and others to talk in a different setting, with people who did not work alongside those who they were being treated by. This demonstrates the importance of renal departments signposting to external organisations which may be able to offer this kind of support to patients.

I have never found renal counsellors that great ... I feel like it's kind of got to be a bit outside of the kidney domain for me because you know when you are looking at that and you are frustrated with people who are in their clinical team it doesn't always help to see somebody who is in that hospital in that clinical setting in that clinical team. Participant 4.

I think a different environment, because as soon as you get to the hospital you are nervous, you know you have already got experiences there and they are not necessarily great. So, I think a different thing away, where you have just got a safe space essentially. To talk, to chat, to ... Participant 6.

Participants also talked about the importance of having support continuously offered, with awareness that some people are less comfortable reaching out for support. Continual signposting could encourage patients to access support when they initially needed it, rather than waiting till a point of crisis.

I think what you got to bear in mind is, if you're at the point where you need to ask for help, you're already not thinking straight. Participant 1.

I just needed someone to break down on. It's... it's weird that. I think, if I had known about Kidney Care, would I have done it? Being stubborn, probably not. Participant 2.

One participant who'd had a good experience with counselling spoke about how it was beneficial in helping them work through their recovery and get back into work and socialising.

I had the counselling, so that must have overarched the dialysis through to being well enough to do something because I was still speaking to them then. And I think at that point she must have, she said something along the lines of, 'You're doing it now. You might not realise you're doing it, but you're doing it!' It's a bit like when you teach a kid to ride a bike with the stabilisers on and you're running along behind with your hand on the back and they're not watching what you're doing and you take your hand off and they go 'Don't let me! don't let go of me!' and you go 'I already did! You're doing that yourself!' because you feel supported but you're the one putting things into place. So I'd reached that stage and she'd said 'You're doing it! You're getting up every day. You're being part of a social group. You're going to work. You're doing things that are interesting to you. You're balancing that out with other things.' Participant 1.

One participant spoke about how valuable practical support with disposing of dialysis equipment would have been, and how the burden of needing to find a way to dispose a significant amount of medical equipment after surgery added an unnecessary stress to their life. This demonstrates that even small, practical measures could be beneficial for post-transplant patients.



The same day I came home was the same day they came to remove the equipment from the house. So, I kind of got home, they walked in, took the machine and I was left with everything else to dispose ... that to me was very very difficult. Because I knew I was physically throwing out thousands and thousands of pounds. And I spent days calling all kinds of associations and all kinds of hospitals and all kinds of anything, to see if they wouldn't accept the stuff, even if it were just for training. And they all refused. Participant 5.

In light of the multiple barriers' patients face in asking for help, it is imperative that this support is offered or signposted to by healthcare providers, and the responsibility is not placed on the patients to actively seek help on their own.

Impact on family not addressed or supported

As well as support for participants themselves, the impact of their transplant journey on their families was an issue that arose during the interviews. For some participants, familial support was particularly important as members of their family became living donors, but still faced little in the way of support. This was a difficult issue for participants and their families to deal with, and while some were able to cope with the situation, for others it caused familial rifts that continued even after the transplant.

Something really difficult happened in the family actually ... one of my sisters wanted to be a donor. The other one couldn't ... but the other sister went through the test ... but [her daughter] didn't want her mother to do it. Participant 3.

We had a few disagreements at the time because my brother was 100%, my dad was 75 ... the reason my dad did it was because basically he is going to die before my brother. That is the be all end all, my dad is older. He is going to pass away sooner so ... I never really had a choice. My brother argued for it, but once...once my dad's reasoning was explained more, we all kind of just backed off and said yeah that's alright. Participant 2.

Even when participants did not have live family donors, support for family members was something that they still expressed a wish for. Family members, even when not acting as carers or donors, still accompanied participants in their transplant journeys, and still had to also deal with the ups and downs of transplant and chronic illness.

My daughter needed support, definitely ... I mean she was probably 15 at the time... and, we basically were by ourselves. So, anything that would have been support would have been helpful. Because as much as I tried to help her, I was part of the problem. Participant 5.

[My fiancé] could have done with support. Especially during the transplant. Participant 2.

I think most of the information came from me about what was happening and what was going to happen. But at the same time, they might have been getting support but not told me because I probably would have been like stop interfering ha ha! Participant 6.

It is important that the effect the transplant journey can have on those close to the recipient is taken into consideration. If this is not addressed and they are not supported, this can have an impact on their ability to support the transplant recipient, or may discourage a transplant recipient from seeking informal support from them, for fear of being a burden. This is particularly important when family members act as live kidney donors.

There are also transition periods for the family and friends after a transplant which they could perhaps have help navigating.

I recently gave [my husband] a reminder that I'm more capable than he might give me credit for and if I need it I'll ask for it, because I'm better at asking for it now. There, there's a balance between seeing somebody very very unwell and very dependent and then being able to let that go a bit. And he needs to be able to have that confidence in my recovery as well.

Participant 1.

Summary of findings and recommendations

While the sample size for this study was small and therefore not generalisable, wider research has been conducted that discusses the psychological impact of kidney transplant on patients (Trzcinska & Włodarczyk, 2011; De Pasquale et al 2014; Lonargáin, Brannigan & Murray, 2017). Research conducted by Kidney Care UK, the British Renal Association and the University of Salford, which documented significant variation in the levels of psychosocial support provided to patients through their renal clinics, with few clinics providing the recommended number of psychologists for patients and no clinics providing the recommended number of social workers (Seekles et al, 2018).

The British Renal Association and Kidney Care UK's annual Patient Reported Experience Measure (PREM) also shows support, along with clear communication from renal departments, to be key issues affecting renal patients more generally in the UK (British Renal Association and Kidney Care UK, 2018, 2019). This indicates that the issues and experiences highlighted in this study are not exclusive to the six participants that were interviewed. Further in-depth research could be conducted, both locally and nationally, to see how similar the experiences of other kidney/SPK transplant patients were to the experiences of our participants, and how other kidney/SPK transplant patients view the support available to them throughout their transplant journey.

It was clear from all participants' stories that their transplant journeys had a strong psychological, emotional, physical, social, and sometimes financial impact, and continue to impact participants' lives in these ways.

As transplant is not a full cure for their kidney issues, participants will have to continually factor their general health, their kidney health, medication burden, and the complications of being immunosuppressed in their ongoing daily lives - on top of managing their work lives, family and intimate relationships, and other stressors people commonly face. For some participants, this was more of a burden than others, as their recovery from transplant had not been as smooth as they wished. However, all participants remained kidney patients, in some form or other. Some found this hard to accept and difficult to incorporate into their identity, and struggled with a perception they would be pitied, judged or labelled by others. In some cases, participants felt reluctant to disclose their situation to others, or felt the need to physically push their bodies hard to prove they were fit and capable.

Participants struggled with a lack of awareness about recovery from transplant and what it is like to live as a transplant patient, resulting in some inappropriate comments and assumptions from others, due to lack of empathy and understanding. This lack of awareness was widespread, affecting their interactions with the general public, friends, and family, as well as the wider medical system, particularly their interactions with GPs and the A&E service. This is particularly important, as GPs & A&E were often a first point of contact with the healthcare system for participants when they experienced other health issues and complications with their transplant. This lack of awareness also impacted on participants' interactions with the benefits system, with a number of participants sharing stories of having benefits withdrawn once they had received their transplants, even though they were unable to work.

Additional difficulties related to a constant need for patients to advocate for their own medical needs when dealing with the healthcare system. Participants shared their concerns and experiences of bearing the burden of responsibility to raise issues and problems they were experiencing with their recovery or with their medications, as these discussions were often not started by medical professionals.

Participants sometimes struggled to have their voices heard by medical professionals, and spoke passionately about the importance for medical professionals to engage in two-way dialogue, so they could have a say in their treatment and ensure their needs were taken into account.

Participants also felt a strong drive to be able to return to 'normal' life, which was hampered by the ongoing nature of their conditions, and the need for their transplanted organs to be frequently monitored by their renal teams. This could also be hindered by the psychological journey participants underwent as they moved through the transplant process, finding that coming to terms with their own mortality and getting a 'second chance' at life had altered their perception of the world. Again, this sometimes led to them over-exerting themselves to make the most of their new opportunities.

Transplant was a significant change for participants, and in many cases, it was a process they navigated without being signposted to formal and professional help and support. Where participants received organs from live family donors, and when they had young dependents, their families also went through that process with them lacking support. Everyone we spoke to expressed a desire or need for some additional help and support throughout their transplant journey. Support that participants felt could be useful to them ranged from online or face-to-face peer support, talking therapies with trained counsellors, and practical support with rebuilding their lives, returning to work, and paying for medication or transport to frequent outpatient appointments. Participants also expressed that support and physical rehabilitation in the period immediately following their transplant surgeries would have been useful.

Recommendations and learning points

Through our interviews with participants, we have identified a number of areas where their experiences and access to support could have been improved.

While this is a one-off report, we would encourage commissioners and clinics to use other ongoing research projects, such as the Patient Reported Experience Measure (PREM), an annual survey of renal patients conducted by the British Renal Association and Kidney Care UK, to monitor patient experience at a local and national level over time.

We have split our conclusions into general learning points and specific recommendations. General learning points highlight areas where improvements can be made, whereas specific recommendations are things that we, as a Healthwatch, have the power to follow up on.

Learning point: Periods of rehabilitation for other serious and life-changing surgical interventions or illnesses are followed by more structured periods of rehabilitation for patients. For example, clinical guidance published by the National Institute for Health and Care Excellence (NICE) recommends patients who have experienced a heart attack undertake a cardiac rehabilitation course, something that is also often offered to patients who have undergone heart surgery (BHF, 2019). From our conversations with participants, and through desktop research, it does not seem that equivalent programmes exist for kidney/SPK transplant patients, even though patients have expressed such programmes may be beneficial. Specialist commissioners and NICE should consider developing clinical guidance on rehabilitation for kidney/SPK transplant patients, to ensure a consistent and evidence-based rehabilitation programme is offered to kidney/SPK transplant patients across the country.

Learning point: While support, such as renal counselling, is available to kidney/SPK patients, some participants we interviewed spoke about how their ability to access this support was affected by low staffing levels, staff absence and shortages.

Recommendation Sources of support, such as renal counselling, need to be consistent and reliable in order to best meet patient need. Renal clinics, including the renal clinic at The Royal Liverpool Hospital, should take steps to ensure staffing levels are adequate to meet patient need.

Learning point: Participants discussed having high levels of anxiety in presenting to A&E with health issues that presented a risk to them because of their transplant and immunocompromised status. As A&E is often signposted to transplant patients as their best first point of contact with the healthcare system in case of any risks affecting the transplant, this anxiety may deter patients from seeking medical help and attention when they need it.

Recommendation

A&E departments, including at The Royal Liverpool Hospital, should consider establishing specific care pathways for transplanted patients presenting at A&E. They should also take into consideration the potential benefit for other immunocompromised patient groups when doing this. If any care pathways are developed, information about this should be provided to potentially affected patients.

Learning point: Information-sharing between specialist clinics and a patient's GP clinic is important in their post-transplant care. Delays in delivering discharge letters, or a general lack of knowledge about post-transplant care from GPs can have a negative effect on patients' relationship with the healthcare system and can cause them further stress.

Recommendation

Clinics, including at The Royal Liverpool Hospital, should take steps to ensure that discharge letters arrive promptly with a patient's GP following their transplant, including better use of electronic discharge records.

Recommendation

Transplant services should, in liaison with local GPs and Clinical Commissioning Groups (CCGs), consider what information, if any, GPs would find it useful to receive alongside a discharge letter for transplant patients, to improve their understanding of those patients needs and improve the care they are able to provide for them.

Learning point: Despite the life-changing nature of transplant surgery, participants fed back that they were not always offered emotional or psychological support to help them cope with life changes, and nor were they signposted to other sources of support.

Recommendation

Clinics, including at The Royal Liverpool Hospital, should signpost transplant patients to external organisation where they can receive support as a routine part of their interactions with those patients. Information about external organisations who can provide information, advice, and support should be included as standard in patient information booklets. This should cover local kidney patient organisations or associations, such as CaMKIN; specialist kidney charities such as Kidney Care UK; and general support and advice services, such as Citizen's Advice.

Learning point: Even within our small sample size, participants all expressed preferences for multiple different kinds of support, ranging from peer support, talking therapies, life coaching, practical support and advice, and financial support. Thus, a one-size-fits-all approach to support for transplant patients should not be taken, and the existence of peer-led support groups should not be a reason for formal support to be withheld or withdrawn. The uniqueness of each patient's transplant journey means they may need different forms of support at different times, and the availability of support should reflect this.

Recommendation

Improving Access to Psychological Therapies (IAPT) services and CCG Mental Health Commissioners should consider the suitability of services they offer locally to transplant patients and/or other people with life-changing health conditions, as standard talking therapies programmes may not be suitable for this demographic of people.

Learning point: The high levels of uncertainty involved in undergoing a kidney/SPK transplant, mean that recipients of transplants may require help in managing their expectations of what life after transplant will involve. This may help prevent them from developing coping mechanisms that are both physically and psychologically detrimental to their health.

Learning point: Transplant patients' lives are also affected by how well non-medical institutions, such as the Department for Work and Pensions (DWP) and their assessors understand the impact of transplant and potential difficulties in recovery. In addition to more change and support being offered and signposted to through the healthcare system, a more supportive and person-centred approach through the benefits system would help transplant patients.

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Appendix 1

Initial questionnaire

Post-kidney transplant patient questionnaire

healthwatch
Liverpool

We are asking these questions so that we can have some context as to your experience and your current situation. The information you give us will also help us prepare more tailored questions to your experience during our interview.

Which of the following describes how you think of yourself?

Woman Man In another way (please state) Prefer not to say

Age Prefer not to say

1. What was your initial diagnosis?

2. How long was it between your diagnosis of renal failure to your transplant?

3. What form of dialysis treatment were you under? Hemo Peritoneal

4. For how long did you undergo dialysis treatment?

5. What support did you receive during this period? From whom?

6. When was the transplant performed?

7a. Was the organ donated by a living or deceased donor?

7b. If it was a living donor, was this a family member, friend or someone known to you?

Family member Friend Someone known to you Other

Please turn over

After your transplant

8. How long did it take for you to recover physically or do you feel you are still recovering?

9. How long did it take for you to recover emotionally / psychologically or do you feel this is an ongoing process?

10. Were you told at any point about any patient support groups or services you could access after your transplant? If yes which groups or services were you told about?

11. Do you have any additional communication needs or access needs to be able to participate in the interview (e.g. you may have limited understanding of English or are deaf/Deaf and need a translator)? If so please let us know in the box below and we will do our best to meet your needs.

*Thank you for providing us with this information.
We will be in contact with you shortly.*

Appendix 2

Consent Form

Post-kidney transplant research project

healthwatch
Liverpool

1. I confirm that I have read and understand the information provided for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview or withdraw my data within a month after the interview, without giving a reason.
3. I understand that any personal information collected during the study will be anonymised and remain confidential.
4. I agree to take part in the above project by being interviewed.
5. I understand that the interview will be audio recorded and I am happy to proceed.
6. I understand that parts of our conversation may be used word for word in future publications or presentations but that such quotes will be anonymised.
7. I am happy to give feedback via email concerning the findings if I am asked to do so. Yes No

Name of
participant:

Date:

Signature:

Name of
interviewer:

Date:

Signature:

If you have any further questions concerning your involvement in this project please do not hesitate to contact us:

Email: enquiries@healthwatchliverpool.co.uk

Call: 0300 77 77 007

Appendix 3

Interview Schedule

1. How are you feeling at the moment? Physically as well as mentally.
2. Can you tell me about your experience of (whichever dialysis they said they received)? (Refer to type of dialysis from questionnaire. If they say they had Peritoneal then mention that we have heard that this can be a lonely experience, is that how it felt to them? Ask them about how this affected their daily activities/lifestyle, their emotions and whether they had support during this time)
3. Have you been able to connect with others that have gone through similar experience to you? If yes, how and has that been beneficial. If no, what have been the barriers and is that something you feel you would have benefited from or could still benefit from? If you have developed relationships with people with similar experiences when did you develop those relationships and have you kept them going? How?
4. How do you feel you have emotionally handled all the different aspects of the illness and recovery?
5. Have you experienced any complications (medical as well as psychological or social) post-transplant? How well do you think these have been managed by services and by yourself?
6. Did you at any point after the transplant feel a lack of support or aftercare from the health professionals, services or people in your personal life?
7. Are you feeling any kind of lack of support or care at the moment?
8. Who would you want to receive this support from? At what point in your journey would you want to receive this support?
9. Do you feel you have physically recovered well / totally?
10. How responsive have services been to your minor injuries and infections (if you have had any)?
11. What impact has this transplant had on you? What has it meant to you (psychologically, physically, financially, socially)?
12. What do you think are the most important things someone who has had a transplant should get support around? This can also include things like signposting to services or help with benefits and employment/re-employment?
13. What would you say have been the main challenges you have faced after your transplant?
14. Have the people close to you had support before or after your transplant? What kind of support was this and from where did they get it? Do you feel it was adequate support? What support do you feel they would need?