

Title: Evaluation of a young adult renal and transplant transition clinic in a regional setting:  
supporting young adults and parents transition to self-management

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### **Acknowledgements**

This work was supported by a grant from the Royal Hobart Hospital Research Foundation (J0019788). The funding body had no input into the design, analysis, interpretation or writing of this manuscript. The authors wish to express their thanks for all the study participants who took part in interviews and in the workshop. We value the experiences and knowledge you have shared with us about the young adult clinic and services and supports

### **Disclosure and Conflict of Interest**

ALR and LJ declare no conflict of interest. Dr Kim Jose and Professor Matthew Jose declare that they are related. This relationship was known and reviewed by the Tasmanian Human Research Ethics Committee. All study participants were aware of this relationship prior to consenting to participate in the study. All interview data was collected by an independent researcher (ALR).

available.

### **Author Contributions**

KJ contributed to the study conceptualization, data curation, formal analysis, methodology, project administration, resources, supervision, visualization, writing-original draft, writing-review & editing (35%). MJ contributed to the study conceptualization, funding acquisition, methodology, project administration, resources, supervision, writing-review & editing (20%). ALJ contributed to data curation, formal analysis, investigation, visualization, writing-

original draft, writing-review & editing (30%). LJ contributed to the conceptualization, investigation, resources, validation, writing-review & editing (15%).

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**Title:** Evaluation of a young adult renal and transplant transition clinic in a regional setting: supporting young adults and parents transition to self-management

## **Abstract**

**Objective:** This study evaluated the impact of establishing a transition clinic in a regional Australian setting on the lives of young adults living with severe chronic kidney disease (CKD) and their families.

**Design:** A qualitative design using the Experienced Based Co-Design framework.

**Setting:** Interviews were held at the Royal Hobart Hospital (RHH) or the Menzies Institute for Medical Research. The co-design workshop was held at the RHH.

**Participants:** Twelve individuals participated in semi-structured interviews, including 6 young people aged 17 – 29 years with a kidney transplant or stage 4-5 CKD, 3 parents/carers and 3 health professionals. The co-design workshop was attended by 20 participants (young people, parents/carers and health professionals).

**Main outcome measure:** Impact of a transition clinic in a regional setting on the lives of young adults living with CKD and their families and suggestions for improvement.

**Results:** Four key themes were identified: The Model of Care; Peer support; Transition towards self-management; Building life skills; Suggestions for improvement and limitations of the service model. The non-institutional, informal clinic setting and social/educational activities facilitated engagement, self-management and peer support for young people and parents. Suggestions for improvement included involvement of older peers, additional life skills sessions and a youth worker.

**Conclusion:** This regional transition clinic is valued by the young people and their parents for generating peer support, building self-management and life skills. Sustainability of the clinic depends upon having the appropriate expertise available, access to a suitable venue and offering a program that meets the needs of young people.

## **Key words:**

Experience based co-design, qualitative, chronic illness, kidney, youth

**What is already known on this subject**

- Traditional service delivery models in which paediatric care is followed by direct transfer to adult clinics contribute to poor health and psychosocial outcomes for young adults living with chronic conditions.
- The establishment of transition clinics for young people living with CKD attached to transplantation centres has reduced transplant failure rates, but the impact of establishing a transition clinic in a regional setting is unknown.

**What this paper adds**

- Young adults and their parents valued the peer support and self-management skills gained through attendance at the young adult transition clinic. Including parents in the clinic supported parents facilitate the progression to self-management.
- Holding the clinic in a non-institutional setting with a flexible delivery model facilitated engagement with the clinic.
- In a regional setting establishing a transition clinic depends upon having the appropriate expertise available, access to a suitable venue and capacity to offer a program that meets the needs of young people.

## Introduction

Traditional service delivery models in which paediatric care is followed by direct transfer to adult clinics are increasingly recognised as inappropriate for young adults, contributing to poor health and psychosocial outcomes<sup>1</sup>. This is well demonstrated in recipients of solid organ transplants with graft survival rates lower in young adults when compared to young children (<11 years) and adult transplant recipients, and lower engagement in education and employment compared to same aged healthy peers<sup>2-4</sup>. The challenges of adherence with medical therapy combined with the timing of a transition from paediatric to adult health care – which typically occurs in the adolescent years – are considered to exacerbate the challenges faced by young adults at this transitional life stage<sup>3,5</sup>.

Young people living with chronic conditions in rural settings face additional challenges related to service access, appropriateness, convenience and engagement<sup>6</sup>. Research shows that adolescence (defined broadly here as 10 – 24 years of age) is a crucial transition life stage which is central to the development of an individual's health and wellbeing later in life. It is during this phase that young people develop the emotional and cognitive abilities for independence, complete education that leads to employment, and form lifelong relationships<sup>7</sup>.

In recognition of the challenges of managing a chronic illness during this transitional life stage, young adult transition clinics have been established nationally and internationally to facilitate the transition from paediatric to adult care for young people with chronic kidney disease (CKD). Research shows that the introduction of such clinics has reduced transplant failure rates<sup>8-11</sup>. In Australia, a young adult kidney transplant clinic was established in Adelaide in 2013<sup>12</sup>, followed by Hobart and Brisbane in 2016. The Hobart-based Young Adult Renal & Transplant Clinic (the Clinic) was initially established for young Tasmanians with kidney transplants and severe CKD when an audit of transplant outcomes in young people aged 13 – 17 years between 2006 and 2015 showed that five of the seven transplants had failed within 4 – 7 years. The clinic expanded in 2017 to include all young Tasmanians with heart or liver transplants. In addition to improved graft survival the clinic aimed to encourage self-management by adolescents in their medical care as well as support vocational and psychosocial outcomes. The new model of care was informed by other transition clinics established in Australia and internationally<sup>9,12</sup>, but adapted for the regional setting. This young adult clinic, described below, is the only Australian clinic situated in a regional, non-transplanting centre.

### The Model of Care

The Clinic originally operated from the Youth Arts Centre in Hobart ([www.youthartsandrec.org](http://www.youthartsandrec.org)) directly opposite the RHH in the city centre. The Clinic occurs bimonthly and is operated by specialist

clinicians including doctors (adult-qualified nephrologist), transplant nurses and allied health professionals based at the RHH. All young adults aged 14 to 25 years old living with CKD or transplant recipients are eligible to attend. There is no acute kidney, heart or liver transplant unit in Tasmania. Young adults under the care of a paediatric transplant unit in Melbourne were transitioned through a shared-care model from age 14 onwards until formal transfer, usually between 16-18 years of age. Young adults travel from all regional areas of Tasmania (up to 300km / 4 hours by road) to attend the clinic and parents are welcome to attend. Clinic sessions are scheduled for a 3-hour period with no set appointment times. During Clinic sessions educational and social activities are offered and the young adults consult one-on-one with the health care team. Afterwards the parents have an opportunity to speak to the health care team.

This qualitative study aimed to evaluate how the establishment of a transition clinic in a regional hospital had impacted the lives of young adults with severe chronic kidney disease and their families and inform ongoing development of the clinic. An Experience-Based Co-Design (EBCD) approach (Presentiahealth) was adopted in order to ensure the perspectives of young people and their families informed the ongoing development of the Clinic. Immediately prior to commencing data collection for this evaluation, a severe weather event resulted in the Youth Arts Centre being inaccessible and the Clinic moved to the standard outpatient clinic setting at the RHH. The key differences between the two settings is outlined in Table 1. Staffing, patient eligibility and frequency of clinics remained the same.

## Methods

This qualitative study was informed by the Experience-Based Co-Design (EBCD) framework<sup>13</sup> and the consolidated criteria for reporting qualitative research<sup>14</sup>. EBCD brings together a 'user centred orientation' (experience based) and a collaborative change process (co-design). EBCD involves two key phases; 1) gathering experiences from patients and staff (i.e. interviews in this study), and 2) bringing patients and staff together to explore the findings and work in small groups to identify elements that will improve the service (i.e. co-design workshop). The study was approved by the Tasmanian Health and Medical Human Research Ethics Committee (H0017238). All study participants provided written consent to participate in interviews and the workshop.

## Recruitment

### Interviews

Eleven young people aged 16 – 30 years living with CKD and/or transplant recipients in Tasmania along with a parent or carer (where applicable) were invited to participate in this study in person or



by letter. Four health professionals associated with the health service were also invited to participate. In total twelve participants (five clinic attendees, one non-attendee, three parents, three health professionals) completed semi-structured interviews between August 2018 and February 2019. One parent indicated interest in the study but was unable to schedule a suitable interview time.

#### Co-design workshop

Attendance at the workshop was not dependent on participating in an interview. Young people, parents and health professionals were invited to attend the workshop via email, letter or in person. A total of 20 people attended, including five young people, four parents, eight health professionals, two researchers and one community organisation representative. Nine workshop attendees had also participated in interviews.

#### Data Collection: Interviews and Co-design workshop

All semi-structured interviews were conducted by an experienced qualitative researcher (AL) either onsite at the RHH outpatient clinic during the young adult clinic or at the Menzies Institute for Medical Research. Young people and their parents were interviewed separately. The interview schedules were developed following a review of the literature and discussions with clinicians. Interviews with young people and parents focused on the experience of living with or supporting a child with CKD or a transplant, as well as their experience of the Clinic. The interviews with health professionals focused on the Clinic and more generally on the transition from paediatric to adult care. Interviews lasted on average 50 minutes.

For convenience, the co-design workshop was scheduled to coincide with a scheduled Clinic in late February 2019. The workshop was held in a training room at the RHH outpatient facilities and facilitated by an external facilitator experienced in working with young people and co-design processes. Findings from the interviews informed the workshop. The workshop included an overview of the establishment of the Clinic, feedback from the interview findings, and small group work focusing on the Clinic and suggestions for improvement. Each of four small groups at the workshop included one parent and one unrelated young person and one health professionals.

#### Data Analysis

All interviews were audio recorded, fully transcribed, deidentified and imported into qualitative data analysis software NVivo 12 (QSR International). Data were then analysed thematically using an iterative process that utilised coding and the constant comparison technique<sup>15</sup>. Transcripts underwent an initial preliminary analysis by researchers [author initials] and [author initials] soon

after the interview was conducted so the researchers could take insights from that interview into any subsequent interviews. Coding of interviews, focusing on the experience of living with CKD, self-management and their experiences of the young adult clinic was completed prior to the co-design workshop. Findings were summarised and presented at the workshop to inform discussions. The co-design workshop was audio recorded and researchers made notes following the workshop. All small group work notes were collected, collated and imported into NVivo 12 (QSR International) to facilitate analysis. AL then undertook thematic analysis across all data sources. [author initials] and [author initials] met regularly to engage in a process of reflective discussion, reviewing coding and refining the analysis, grouping the codes and initial themes into the larger thematic categories presented in this article. These were reviewed by the research team and finalised. Coding decisions, key concepts and reflections were identified and recorded in the project log and memos<sup>16</sup>.

## Results

At the time of data collection, four of the six young adults interviewed had received a kidney transplant, all of which remained successful. There were equal numbers of males and females with age ranging from 17 – 29 years. The young people were with either working full-time, part-time or still in school. At the time of data collection all except one of the young adults were living at home with one or both parents. Five out of the six young adults regularly attended the Clinic with four of the five regularly accompanied by one parent (Table 2). The one un-attending young adult was diagnosed with CKD in their mid-twenties and received a transplant within months of diagnosis, therefore they went directly into adult care. Due to skipping the transition from paediatric care they did not fit the targeted profile for Clinic attendees. Three parents (two mothers and one father) and three health professionals (two medical specialists and one allied health professional) were also interviewed. Further participant characteristics are not provided here to preserve anonymity. Results are presented according to the four key themes; 1) The model of care, 2) Peer support, 3) A transition towards self-management: Building life skills 4) Suggestions for improvement and limitations of the service model.

### The Model of Care

The interviews and EBCD workshop identified key characteristics of the Clinic design that were most valued by participants (See Table 3). The non-institutional setting at the Arts Centre was discussed extensively by all participants with young adults and parents identifying this setting as a relaxed, informal, flexible space in which to interact with peers. While most young adults understood the main purpose of the Clinic was for medical review the elements they appreciated most were the social and educational activities incorporated into Clinic sessions. These included cooking classes,

games such as table tennis, indoor basketball, a music studio, and comfortable sofa lounges for seating. These activities facilitated engagement with peers. Participants reported the informal and flexible approach created by this setting resulted in a more enjoyable and less stressful experience, facilitating engagement between health professionals and young people. Similarly, parents appreciated the informal and relaxed nature of the Clinic at the Arts Centre. Most interviewees stated that operating the Clinic from a non-institutional setting would be ideal as the institutional environment restricted interaction with peers and limited social and educational activities. All parents and most young adults valued the importance and convenience of having a Clinic based in Tasmania. Prior to the establishment of the Hobart clinic young adults and parents routinely travelled to Melbourne for specialist appointments.

### **Peer support**

Peer support was identified by the young adults and their parents as a key short-term impact of the Clinic (Table 3). The young adults enjoyed engaging with others who were in a similar situation. Parents valued the opportunity the Clinic provided for their children to socialise with peers their own age. A few of the young adults noted their confidence levels had improved since they joined the clinic which supported socialisation with their peers. Peer support included practical strategies for managing their illness including sharing tips on remembering how to take medications, and what can be expected from a transplant from those who had already undergone the process. However, one young adult stated that although talking about transplant experiences was useful, it was also a topic that made them anxious and afraid. The support provided by the Clinic Psychologist and Youth Worker were noted and appreciated by the young adults.

Furthermore, parents valued the opportunity to engage and network with other parents, sharing their experiences and discussing concerns with other parents parenting in similar circumstances. A few parents described the clinic sessions as an opportunity to confirm that their child's medical outcomes and behaviour was in line with their peers', reassuring themselves their situation was not unique. One young adult noted that the Clinic was strengthening the relationships between young adults and their parents as parents gained insight into their children's lives.

### **Transition towards self-management: Building life skills**

Participants discussed how the Clinic was assisting in building the life skills of the young adults (Table 3). Through engaging the young adults directly they were improving their treatment knowledge and understanding. All the young adults interviewed understood the crucial elements for maintaining their health, namely: medication adherence, healthy diet, exercise and drinking plenty of water.

With the exception of cooking healthy meals, most of the young adults and their parents were confident they could manage these elements. A few of the young adults were responsible for booking their own doctors' appointments and managing their medications. In two cases they were responsible for managing their medication finances. Parents were also encouraging their children to be responsible for themselves, reinforcing health messages on diet and exercise as well as financial management. Most parents wanted their children to manage the long-term financial impact of their illness.

While it was evident from our interviews that young adults were gaining self-management skills and independence their parents continued to provide a safety net. This safety net was revealed when one young adult stated:

*Young adult: ...I've got used to refilling my medication boxes and filling scripts, going through all of that.*

*Interviewer: Right, and then when you do run out of medication, are you the one that generally remembers you've got to go... to the pharmacy?*

*Young adult: It depends. Sometimes I get a little slack and I forget to refill them. So, I don't really know sometimes where the meds are. Mum usually checks everything. Young Adult ID4*

Parents spoke about reminding their children to check whether they have enough medications, ensuring spare medications were kept in multiple key locations and reminding their children to keep a list of questions for when they saw their specialist. These discussions revealed the simultaneous transition parents need to go through during this phase of their child's care. Parents discussed how, when their children were younger, they were expected to know and do everything for them, ranging from medication management to diet and, in some cases, home dialysis. One parent explained their experience directly after their child's transplant:

*[my husband] and I weren't allowed to leave Melbourne until we knew every medication [child] was on, could spell it and know the doses. Parent ID5*

This management role had been reinforced by specialist medical staff over the years and highlights how parents need to learn to hand responsibility over to their young adult. The Clinic was considered to be supporting parents to enable this transition.

### **Suggestions for improvement and limitations of the service model**

The unanticipated change in Clinic location provided an opportunity for participants to reflect on the differences afforded by operating the Clinic from a non-institutional setting. Young adults, parents and health professionals preferred the informal and non-institutional elements of the Youth Arts Centre location (see Table 4). The vast majority of Clinic attendees said they would like to transition back to this location. Table 4 illustrates the characteristics of an 'ideal clinic' based on what participants enjoyed most about the Clinic, and shows the desired additional services identified by the EBCD workshop participants. A challenge raised by health professionals with respect to establishing a clinic in a regional setting where the healthcare team was inevitably smaller was the dependence on one or two key individuals. On completion of the workshop young people in attendance created two Facebook™ groups, one with young people and parents and one that excluded parents.

## Discussion

This study found that young adults, their parents/carers and health professionals valued the new model of care being offered by the young adult transition clinic. The Clinic was addressing many of the issues identified as impacting service use by young people from rural areas; namely access, appropriateness, convenience and engagement.<sup>6</sup> The unanticipated move to the institutional clinic setting immediately prior to commencement of this study provided a significant point of comparison, highlighting that the location and physical setting of the Clinic were important aspects of this model of care. The peer support facilitated by the Clinic was valued by young adults and their parents and the combination of health review, social and education development activities appeared to be meeting the needs of young adults and assisting the move to self-management. The reduction in interstate travel was appreciated by young adults and their parents. Suggestions for improvement included additional youth worker support, more peer support opportunities and additional life skills education sessions. The study also reveals the transition to self-management is a process that applies to parents as well as young people.

Combining a health review with social and education development activities in a non-institutionalised setting was identified by young people and parents in this study as assisting the move to self-management. Coordination of care for people with chronic conditions living in rural areas has been found to improve health outcomes in adults<sup>17</sup> and holistic approaches have been found to improve engagement with services by marginalised young people, including those living in rural areas<sup>6</sup>. The development of self-management skills is critical for all people living with chronic conditions and building understanding of their condition and the implications this has for their health and other aspects of their life are key transition goals<sup>18,19</sup>. Individual variation in the

development of self-management skills is recognised<sup>5</sup>. This Clinic model, adapted for a regional setting, combined aspects of the traditional paediatric transition models of care, where the transition clinic sits within the paediatric service and young adults then transfer to a young adult clinic at age 18<sup>18</sup>. The clinic provided an opportunity for development of self-management skills with no expectation of transfer of care at a particular age. Primary management by the transplanting paediatric centre in Melbourne was ceased when they felt it was appropriate on an individual basis. The return to the RHH had resulted in cessation of the education and life skills sessions offered during the Clinic. Workshop discussion clearly indicated support to reinstate these sessions and to broaden their scope. Health professionals were supportive of this if a suitable location and resources were available.

This study also found that the Clinic was providing support to parents alongside young people. Parents play a critical role in the transition process with parental support for the progression to self-management and autonomy of their children necessary for the transition to occur<sup>18,20</sup>. Parents are required to make significant adjustments to facilitate self-management and autonomy and transitional healthcare services are encouraged to support parents as well as young people through this process<sup>20</sup>. The additional support needs for parents of young people living in rural areas during this transition process is unknown. This study of the only transition clinic known to authors where parents attend along with young adults<sup>9,12,21</sup> highlights that parents have their own support needs during this transition. This study is unable to determine whether these needs differ from parents living in urban settings. In contrast to urban living young people, young people in this study relied on parents for transport to the Clinic hence, incorporating parents into the Clinic activities was expedient. Getting to know and trust the medical team assuming care for their child as well as the peer support provided by other parents were important for parents involved in this Clinic. Young people recognised the benefits of attendance for their parents but were also expressing a desire for more autonomy by indicating preference for separate social areas for parents and young people at the Clinic and separate social media groups. It was clear that continuing to include parents in the Clinic was important for supporting the transition process for young people.

As has been found in previous evaluation of young adult clinics this study found that peer support and social connections were important aspects of the model of care that fostered confidence and contributed to developing self-management skills<sup>12,21,22</sup>. Peer support programs with adults in rural areas have been found to improve social support and build skills<sup>23</sup>. Their impact on young people with chronic conditions living in rural areas is unknown. In this clinic young people shared ideas and tips for managing their condition with their peers during the Clinic. Being able to interact with other young people going through similar experiences was valued by young people and recognised as

important by their parents. This may be particularly important for young people living in rural and regional areas with strengthening of peer relationships a key feature of adolescence<sup>7,24</sup>. In this study young adult participants and their parents wanted young people to interact with peers who were slightly older than they were. The reasons for this included the capacity for them to act as role models, demonstrating that living with CKD had not prevented them living meaningful lives through involvement in sport, employment and relationships.

This study has some limitations. The sample size was small, but the potential sample for this study was limited by the small number of young people living with CKD or transplants in the state.

Allograft function and survival data were not included in this study. Given the focus on evaluating the Model of Care and limited capacity to provide meaningful comparative analysis between attendees and non-attendees due to the small numbers this was considered appropriate at this time. With one exception young people who were eligible to attend the Clinic, but who did not, chose not to participate in the study. Study strengths were the inclusion of parents and health professionals as well as young adults. The use of the EBCD guidelines, with its focus on informing service design and ensuring client perspectives are incorporated into this process was a strength as was the range of attendees at the workshop.

## Conclusion

Establishing the young adult transition clinic for adolescents with a kidney transplant or severe CKD in a regional setting was supporting young people and their parents through the paediatric – adult health care transition and assisting the development of self-management skills. Critical factors facilitating this were the non-institutionalised setting, informal and flexible delivery, inclusion of life skills and education settings and opportunities for peer support. These characteristics would be possible to incorporate into services designed to support rural living young people during the transition from paediatric to adult care with other chronic conditions, such as diabetes. However, the holistic approach outlined in this study is dependent upon having the appropriate expertise available, access to a suitable venue and offering a program that meets the needs of young people.

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**Table 1: Characteristics of the two Clinic locations**

Youth Arts Centre location	Outpatient Clinic RHH location
Separate from RHH (but nearby to pathology and pharmacy services)	Within RHH
A social environment that encourages interaction between the young adults through various engaging facilities	A clinical environment where young adult interactions are limited to conversation in the waiting area.
Facilities: <ul style="list-style-type: none"> <li>- kitchen for cooking classes</li> <li>- games</li> <li>- conversation space (lounges)</li> </ul>	Facilities <ul style="list-style-type: none"> <li>- Seating available in waiting area</li> </ul>
1 private room available for consultations;	Numerous clinic rooms
Non-institutional space	Formal health service

**Table 2: Characteristics of young people**

Young people (total N=6)	
Age, years (range)	20.2 (17 – 29)
CKD as child	N = 5, 83%
Transplant	N = 4, 67%
Studying	N = 3, 50%
Working (Casual, part-time)	N = 3, 50%

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**Table 3: Illustrative quotes for the key themes**

Themes	Illustrative quotes
The Model of Care	<p><i>It helps that it's a little bit more social now even though I have anxiety. I don't like social situations, but it helps that it's a more relaxed social thing. Young Adult ID6</i></p> <p><i>It was much harder for me to engage with them [at RHH clinic setting] Health Professional ID9</i></p> <p><i>Now, everything is good, because my doctor is local. I had to go to Melbourne after the transplant because there weren't any doctors in Tasmania. So, I had to go over there monthly. Young Adult ID4</i></p> <p><i>The art centre is probably a better spot. As I said, it is away from the hospital. ... if we're out here, sitting here [RHH clinic], they'll sit next to me. They won't go and talk to anyone but down there [Art Centre], they went with the other kids and played the games ... they were there cooking, [doing] different things. Parent ID11</i></p> <p><i>I think it is, probably more so when it's at the actual youth [Arts] centre, rather than here at the clinic [RHH Outpatient Clinic] because it's a bit more clinical. Whereas, at the youth centre, the kids are a bit more relaxed. The adults are a bit more relaxed. You're all there in the one room together and you can talk and the kids can go off and play a game of pool or air hockey or whatever's there and the parents are off talking.... Parent ID7</i></p> <p><i>It's just that the clinic runs from 9 to 12, and if you just show up whenever, you can talk to the doctor, go get some food or something, and then play some games, and there's not a set ... it's not like a set timetable. It's not like a schedule. It's just whatever you want to do. Young Adult ID4</i></p>

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*Yeah, that's one thing that's changed, becoming more comfortable with that [meeting new people]. I wouldn't say in general confidence, I would just say being more comfortable with that.*

*Young Adult ID3*

*... to meet other young adults that are going through the same stuff, or going through worse stuff, easier stuff, and just talking about it, and having friends that you can understand. Young Adult ID4*

#### Peer Support

*The main purpose is to obviously talk to [specialist] about my health and what's going on but as well as to see the others. ... The thing I like most about the clinic is being able to do stuff with the others. Young Adult ID6*

*What this is adding on is two things; one is taking it away from the hospital and the second thing is that peer support. And some of the peer support I've seen is simply having a discussion in the couches about "How do you remember to take your medicines?"*

*Health Professional ID1*

*...this young adults' clinic is invaluable to me because I can discuss that with other [parents] – I know I'm not the only one going through it. ... you know every family struggles with everything you're going through, medications etc, and the finances and what it all entails. Parent ID5*

*I think so. I think mostly, it's the parents are getting closer with their children. I think that's the most. ... I think that hearing what others have gone through, comparing it to their own child, there's kind of like, "Oh, I didn't even know she went through that Young Adult ID4*

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*They don't teach those life skills even at school ... it's like, 'Well, yes, this is what you do when you ring up the pharmacy. This is what you've got to ask for. This is what you do when you need to ring the doctor' ... I think [the Clinic is] trying to help them with the day-to-day of how to go into that phase of looking after themselves. Parent ID7*

Transition towards self-management: Building life skills

*I think my social interactions. I'm more confident to talk to people about what happened and what I'm going through. Young Adult ID4*

*We've taught [child] now, if [they are] not going to tell us, put notes in [their] phone so that [they] can say to [specialist] I've got this and this and this issue. And [they] can ask. Parent ID5*

*I think it's a good way of introducing the rest of the team to them in a different way. And also, for the parents too because they're the ones that have got to feel confident to be able to let go and for the kids to learn how to self-care and self-manage. Health Professional ID9*

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**Table 4: Suggestions for change**

Location, facilities and approach
Informal, non-institutional setting
Facilities: Social spaces allowing for young adults and parents to socialise separately
Activity space for cooking, games, other activities
Relaxed environment
Conversation space (couches/lounge area)
Free/cheaper parking facilities
Access to a private space for each allied health professional to carry out their necessary functions
Regular clinic dates and timeslots (clinic attendees should make this decision collectively to suit education and employment commitments)
Additional services
Engage a youth worker to facilitate Clinic sessions
Invite older peers (mid-20 to early 30 years of age) living with CKD/successful transplants as guest speakers or to provide other support
Life skills educational sessions: vocational training options and institutions, navigating Centrelink, managing employment with a CC, resume writing, mental health information sessions (eg. Beyond Blue, Headspace)
Social activities outside of the Clinic sessions.

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Central Clinic contact number for general inquiries (available during office hours). Currently all enquiries managed by medical specialist.

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Pre Proof