

State of the Nation Report 2019

Kidney Health Australia Youth Program
Improving Outcomes for Adolescents and Young Adults with Kidney Disease



- Clinical consultation and mapping of kidney youth services
- Kidney youth and carer consultation responses and analysis
- Key priorities, recommendations and actions

Through the assistance of funding from the Australian Government Department of Health



When I was diagnosed with end-stage kidney disease at 23 years old, I couldn't imagine leading a normal life. I was the youngest on the kidney ward by decades, and all of my hopes and plans for the future changed. I desperately needed to meet another young person who had been through what I was about to go through, who not only succeeded in their health but also in their life. I didn't even imagine that someone like that existed.

Since working on the Kidney Health Australia Youth Program I've met inspiring people who have it worse and manage to be happier and more active than I am. They set an example that helps me think positively, work on accepting the hand I've been dealt, and focus on how I can use my experience to help others.

Every young person living with kidney disease deserves that experience. Everyone deserves hope.

Luke Macauley
Kidney Health Australia
Youth Program Patient Partner



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Kidney Health Australia Youth Program Report Overview

Kidney Health Australia is the national not-for-profit organisation with a vision of “healthy kidneys for all Australians” and a mission “to decrease the incidence of kidney disease and save and improve the lives of Australians affected by kidney disease”.



In July 2018 Kidney Health Australia received federal government funding to develop and pilot a Youth Program to engage and support young people (15-24 years) living with kidney disease. The project completion date is June 2020.

Young people with kidney disease face unique challenges due to their age and the impacts of chronic illness on their life and development. These include disruption to growth, education, social development, and life participation and are exacerbated when adolescent patients transfer to adult healthcare.

As a result, the kidney youth community has exceptionally high burden of disease with profound impacts on the mental health and wellbeing of young people with kidney disease, and further psychological and financial impacts on their families and carers.

These impacts compound young adults' poorer medical outcomes, and result in massive costs to their quality of life and to healthcare. However, these factors are either preventable or can be minimised to greatly improve young adults' wellbeing.

Low recognition of the kidney youth community's needs and insufficient funding in healthcare, particularly in adult clinical settings, limits much-needed access to professional support. Additionally, current services which are focused on providing extra support to young people with kidney disease are isolated and inconsistent or inequitable nationally.

The Kidney Health Australia Youth Program therefore aims to improve the wellbeing and health outcomes of young people living with kidney disease. The State of the Nation Report is the first step in identifying the major needs and key priorities of this cohort which will become the focus of future activities and advocacy within the program.

This report was informed through a National Consultation Process conducted over the past 12 months which involved conducting two separate surveys and speaking with healthcare professionals at major hospital renal units, and young people with kidney disease and their carers and families to identify current services, best practice methods, and gaps in care. A thorough literature review was also undertaken alongside discussions with current researchers in this area.

The key priorities and recommendations were established based on the major needs identified in the National Consultation Process and refined by key stakeholders at the Strategic Roundtable Meeting. The recommendations provide guidelines and direction for the combined efforts of Kidney Health Australia, healthcare professionals, government and kidney community members aimed at improving wellbeing and outcomes of young people with kidney disease and their carers.

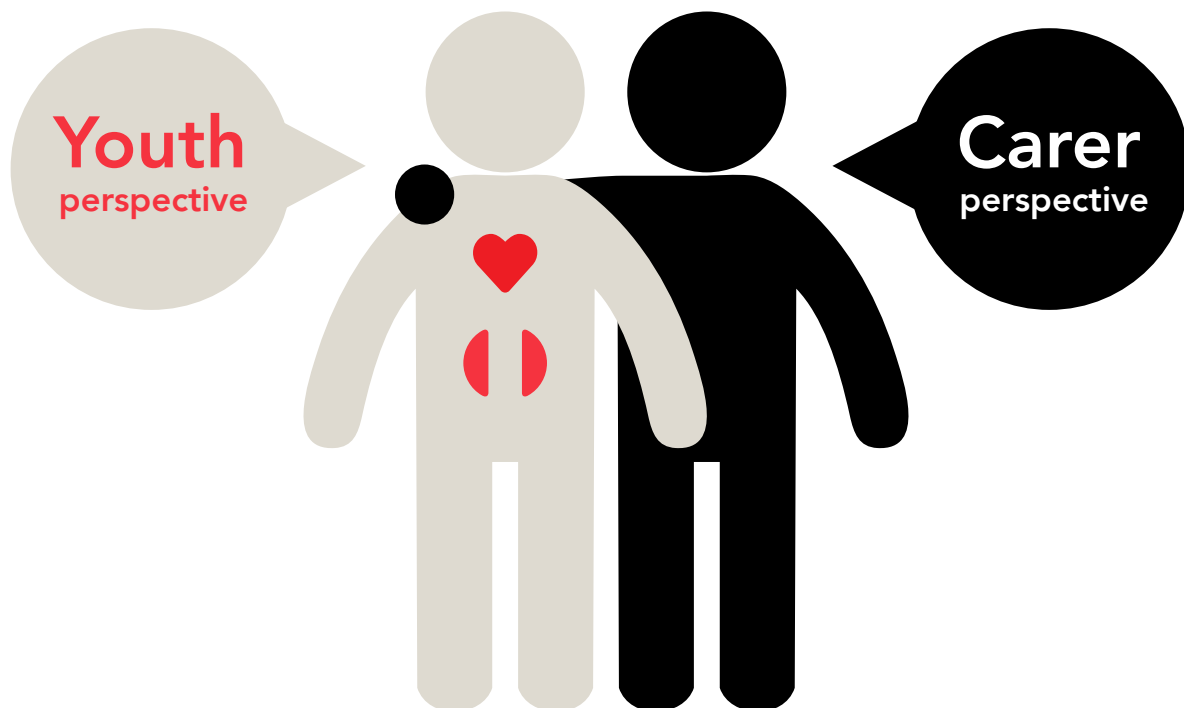
Major observations and findings

The Kidney Youth community highly desired opportunities to connect and socialise with their peers. Where peer connections and support existed, they were greatly valued by both kidney youth and their carers, and have been shown to improve health and social outcomes.

- Young people with kidney disease need increased youth-focused support and education, along with assistance navigating their own health, the healthcare system and other relevant support services.
- Several hospital clinics in Australia have best practice transition and transfer practices in place, which improve health outcomes and graft survival. However, in many cases dedicated transition and/or young adult clinics are aspirational due to a lack of personnel and resources. Promoting and achieving best clinical practice and investing in this area may actually result in healthcare cost savings and significantly increase overall health outcomes.
- Core clinical services were generally highly rated by kidney youth patients and carers. Adult healthcare however is generally not as well-resourced nor equipped to provide the similar wrap-around youth focused services and multidisciplinary support as paediatric healthcare. Increased funding and support for this area has been reported as a high priority.
- Increasing the general awareness and understanding of kidney disease in the community was also consistently raised as a priority as was recognising and responding to the financial impact and burden associated with chronic kidney disease on kidney youth, carers and families.



The challenges and priorities



Challenges and priorities for young people living with kidney disease

- **Impact on mental health:** Symptoms of kidney disease, side effects of treatment, and activity limitations can have significant psychosocial consequences.
- **Isolating:** Kidney disease limits participation in normal life activities.
- **Limited access to professional support:** Mental health support and acknowledgement was lacking inside and outside hospitals.
- **Unprepared:** They felt insufficiently prepared for transfer to adult healthcare and self-management, and wanted more education.
- **Navigating complex systems:** The kidney youth community requires more help to navigate highly complex government healthcare and support systems.
- **Specialised considerations and responses:** The high disease burden of kidney disease faced by young people is compounded for young Indigenous Australians, who experience exceptionally high impacts on their quality of life and health outcomes, and receive minimal support. Culture, Country and the Spirit represent important domains of Indigenous health and disease, and has a crucial role in healthcare, self-management and quality of life of Indigenous Australians, although healthcare often fails to acknowledge these considerations.

Challenges and priorities for carers of young people living with kidney disease

- **Impact on personal wellbeing and mental health:** Carers may not acknowledge their own wellbeing and care needs. Carers valued connecting with other carers to share experiences, coping strategies and support each other.
- **Recognition:** Carers are not financially supported or recognised by the government welfare system or healthcare services.
- **Financial impact:** Carers faced significant financial challenges from taking time off work to manage the young person's health and appointments.
- **Difficulty in transition:** Carers found transitioning out of the carer role to be full of uncertainty and emotionally challenging. Transition and other renal services did not acknowledge or integrate carers' needs.
- **Support:** Carers struggled to balance caring for their child with work, a healthy lifestyle and other children.

Summary of key priorities and accompanying recommendations



Priority 1. Community connections

Facilitate peer connections and mentoring opportunities for the kidney youth community

- 1.1** Encourage and facilitate kidney youth connection opportunities to reduce sense of isolation, share information, experiences and develop relationships.
- 1.2** Support Kidney Youth and Carer Champions in peer mentoring to assist with modelling positive healthcare management and providing peer support to address concerns about treatment and adjusting to life living with kidney disease.



Priority 2. Best practice care and education

Implement best practice equitable care regarding kidney youth support systems and services and assist kidney youth to understand, manage and optimise their health and navigate healthcare systems as they transition to self-management

- 2.1** Provide youth-focused education and resources.
- 2.2** Implement best practice care regarding kidney youth support systems and transition services.



Priority 3. Recognition and support

Increased advocacy, awareness and support for kidney youth and carers

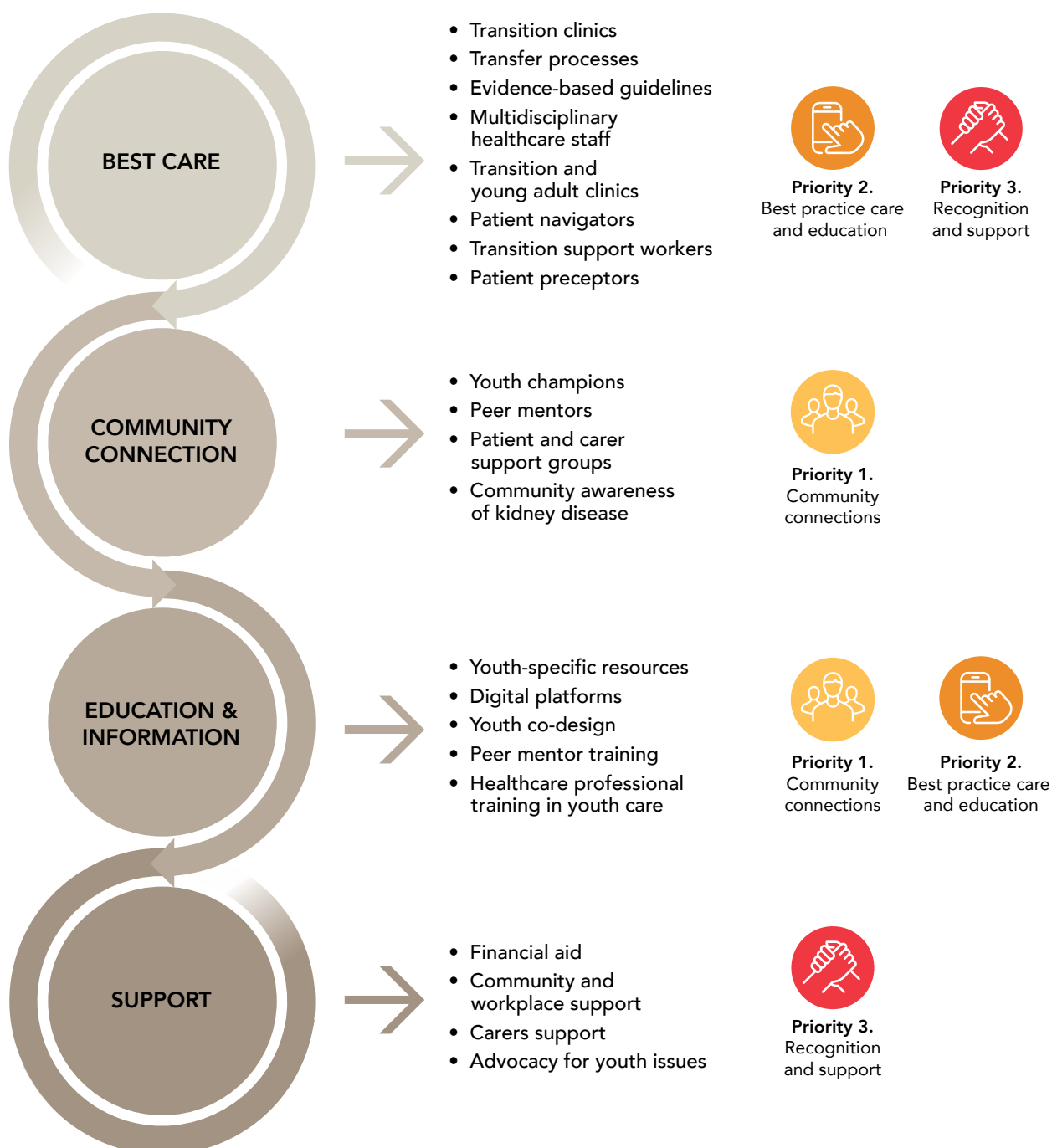
- 3.1** Increase local community awareness and support for kidney disease.
- 3.2** Advocate for increased support for kidney youth and their carers.
- 3.3** Advocate for the support to implement above recommendations.

Model of care: Incorporating key priorities and recommendations

The key priorities and accompanying recommendations form a comprehensive and holistic model of care for improving the wellbeing and outcomes of young people living with kidney disease, and the wellbeing of their families and carers (Figure 1).

The Young Patient Model of Care represents the implementation and integration of the key priorities and recommendations in both clinical healthcare and in the community, through the cooperation of community members and healthcare professionals with the support of government and other key stakeholders.

Figure 1: The Young Patient Model of Care



Key priorities, recommendations and actions

Table 1: Key Priority 1


 Key Priority 1. Community connections – peer support	
Recommendations	Actions
1.1 Encourage and facilitate kidney youth community connection opportunities to reduce their sense of isolation, share information, experiences and develop relationships	
1.1.1 Develop face-to-face and online young patient peer support groups and social outings to connect the kidney youth community.	<ul style="list-style-type: none"> • Locate children, adolescents and young adults living with kidney disease and their families and carers and establish a Kidney Youth Community. • Encourage communication within the community through various channels including social media, forums, groups and virtual or face-to-face meetings, etc. • Facilitate and design opportunities for this community to connect with each other to develop relationships and provide peer support, education and guidance. • Identify Kidney Youth and Carer Champions and involve them in the co-design of peer support and social activities. • Seek funding at state and national levels to support the Kidney Youth Community including associated activities and forums. • Seek partnerships and develop relationships with key organisations to obtain in-kind support for the Kidney Youth Community activities and forums.
1.1.2 Develop separate carer support groups to facilitate carer connections and sharing of management and coping strategies.	
1.2 Support Kidney Youth and Carer Champions in peer mentoring to assist with modelling positive healthcare management and providing peer support to address concerns about treatment and adjusting to life living with kidney disease	
1.2.1 Facilitate connections between newly diagnosed patients (and their families and carers) and more experienced patients as Youth Champions.	<ul style="list-style-type: none"> • Identify Kidney Youth and Carer Champions as candidates for peer mentoring. • Develop training opportunities, resources and supports to assist Kidney Youth and Carer Champions fulfill the role of a peer mentor. • Assist Youth and Carer Champions to connect with newly diagnosed/younger patients and their carers. • Focus support efforts and resources at key periods in healthcare journey, being point of diagnosis and beginning renal replacement therapy (dialysis or transplant). • Integrate Youth Champions into clinical care, including Transition Clinics and/or Young Adult Clinics as appropriate.
1.2.2 Provide training for and assist Youth Champions in providing peer mentoring.	
1.2.3 Implement educational components into peer support and social groups, including teaching life skills, positive self-management of healthcare, medical adherence etc.	

Table 1: Key Priority 2



Key Priority 2. Best practice care and education

Recommendations	Actions
2.1 Provide youth-focused education and resources to assist self-management	
<p>2.1.1 Adapt and tailor existing kidney care educational resources to be youth-focused.</p> <p>2.1.2 Identify and develop education that supports young patients maturing into adulthood by promoting independence, goal setting, life skills and holistic self-care practices.</p> <p>2.1.3 Identify and promote resources and services that help youth with self-management of their healthcare.</p> <p>2.1.4 Identify and promote resources and services that help carers' with their role.</p>	<ul style="list-style-type: none"> • Adapt or develop educational resources and services that are youth-focused, accessible and appropriate for patients, carers, siblings, partners and healthcare professionals. • Involve the kidney youth community to co-design educational and support resources and services. • Develop separate online youth and carer spaces to facilitate education and communication including website landing platforms, forums and dedicated children, family, and youth content. • Identify and promote a mobile app for patient and carer use to assist with self-management including tracking medications, prescriptions, appointments, test results, documentation etc. • Direct education through Youth and Carer Champions and social activities and networks. • Focus on education through peer connections and face-to-face and digital formats. • Develop resources that guide carers in talking to and educating young patients.
2.2 Implement best practice care regarding kidney youth support systems and transition services	
<p>2.2.1 Implement best practice in clinical care in relation to transition and transfer from paediatric to adult healthcare.</p> <p>2.2.2 Address peer support needs of young patients and carers by integrating peer workers into healthcare teams/clinical consultations.</p> <p>2.2.3 Facilitate access to a dedicated support person who will provide one-on-one education and assistance with managing and navigating diet, medications and pharmacies, hospitals, appointments, government systems, etc.</p> <p>2.2.4 Develop National Consensus Statement on Youth Care in Kidney Disease.</p> <p>2.2.5 Increase support, resources, education and training for healthcare professionals in managing transition and wellbeing for adolescents and young adults with kidney disease.</p>	<ul style="list-style-type: none"> • Advocate for best practice in clinical care, transition and transfer, including: <ul style="list-style-type: none"> - availability of Transition Clinics and Young Adult Clinics (including a youth space); - provision of Transition Coordinators and/or Champions, processes and procedures; - access to psychosocial support through allied health personnel within renal healthcare; - access to psychosocial support through peer connections and mentors; and - individualised care and transition plans. • Encourage the availability and use of Transition Support Workers and/or Patient Preceptors. • Encourage the availability and use of Patient Navigators. • Through research, improve the evidence base underpinning transition, young adult and peer support resources and services to inform best clinical practice (e.g. wellbeing, quality of life, graft loss, transition and transfer services, peer support, education and clinical training, etc.). • Development of a Kidney Health Australia – Caring for Australasians with Renal Impairment Guideline for adolescent transition and young adult support in kidney disease.

Table 1: Key Priority 3



Key Priority 3. Recognition and support for kidney youth and carers

Recommendations	Actions
3.1 Increase local community awareness and support for kidney disease	
<p>3.1.1</p> <p>Increase awareness within:</p> <ul style="list-style-type: none"> - young patients' social spaces (school, workplace, university staff and peers) about kidney disease burden and potential impacts of symptoms and medical appointments relating to attendance, performance, etc. - carers' social spaces (workplace managers and peers) about time demands of being a carer, impacts on availability and wellbeing, etc. 	<ul style="list-style-type: none"> • Continue current initiatives to improve awareness of and support for kidney disease in the wider community. • Specifically increase awareness of kidney disease burden and its impact on kidney youth and carers. • Identify and/or develop guidelines/proformas that facilitate communication between patients, healthcare team and patients' schools, universities and workplaces.
3.2 Advocate for increased support for kidney youth and their carers	
<p>3.2.1</p> <p>Increase support for paediatric to adult transition and transfer for kidney youth.</p> <p>3.2.2</p> <p>Reduce the financial impact of kidney disease on kidney youth, carers and families.</p>	<ul style="list-style-type: none"> • Advocate for increased support for kidney youth renal healthcare services (e.g. as identified by the Renal Medicine Clinical Committee – Medicare Task Force). • Advocate for official recognition of carers of kidney youth for government welfare purposes (i.e. increase access to the Commonwealth funded Carer Allowance).
3.3 Advocate for the support to implement above recommendations	
<p>3.3.1</p> <p>Establish Kidney Youth advocacy platform to encourage and assist with the implementation of these report recommendations.</p>	<ul style="list-style-type: none"> • Utilise the current Kidney Youth Clinical Advisory Committee to establish an appropriate advocacy platform to champion the implementation of the report recommendations (i.e. Committee or Advisory Group involving clinicians, healthcare professionals, Kidney Youth and Carer Champions).

Kidney Health Australia Youth Program Report

Kidney Health Australia is the national not-for-profit organisation with a vision of “healthy kidneys for all Australians” and a mission “to decrease the incidence of kidney disease and save and improve the lives of Australians affected by kidney disease”.

In July 2018, Kidney Health Australia received federal government funding to develop and pilot a Youth Program to engage and support young people (15-24 years) living with kidney disease. The project completion date is June 2020.

The Youth Program Report aims to identify the current state of the nation in relation to the young patient population, as well as their treatment and needs. This report includes observations, recommendations and strategies aimed at assisting to improve their health outcomes, quality of life in general and life expectancy. The report outcomes will assist in the design, development and implementation of the Kidney Health Australia Youth Program and also inform future clinical and service planning and advocacy.

Acknowledgements

Kidney Health Australia acknowledges the valuable contribution of the Kidney Health Australia Youth Program’s Clinical Advisory Group for their expert advice, guidance and support.

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Finally we acknowledge and thank the generous grant awarded by the Australian Government Department of Health for the implementation of this Kidney Youth Program.

Chapter 1: Kidney Youth

- Introduction and background

Chapter summary

- In 2017, 524 Australians between the ages of 15 and 24 years were impacted by end stage kidney disease. Many more were living with earlier stages of chronic kidney disease.
- Kidney disease has **significant health, social and welfare** implications for those young people and their carers impacted and burdened by this chronic illness.
- Major health implications include **reduced life expectancy and quality of life**, and cardiovascular disease.
- Young kidney patients face **unique challenges** due to their age, including **transferring to adult healthcare** (around 18 years) and **navigating adolescence** whilst being encouraged to **self-manage their health** and healthcare.
- Young kidney patients have the **highest risk of non-adherence to medication and lifestyle restrictions** imposed by chronic kidney disease and end stage kidney disease including renal replacement therapy (kidney transplant and dialysis).
- Adolescent and young adult kidney transplant recipients **have the worse graft outcomes of any other age group up to 70 years of age**.
- Up to **35% of young kidney transplant recipients will lose their transplant within 36 months after transferring to adult services**.
- Graft loss incurs significant costs to the healthcare system – on average each functioning kidney transplants result in a **saving to healthcare costs of \$50,000 per year, post-transplant year, per patient**.

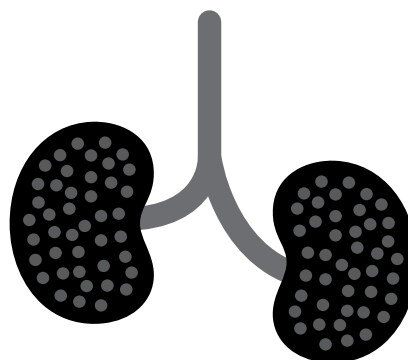
Definitions

Chronic kidney disease (CKD) refers to permanent reduction in kidney function, affecting the ability of the kidneys to filter blood, leading to increased fluid and waste within the body. There are 5 stages of chronic kidney disease with progressive severity.

Chronic kidney disease is in most cases a progressive disease towards Stage 5 chronic kidney disease, which is also called end stage kidney disease (ESKD).

People with ESKD are reliant on **renal replacement therapy** to remain alive. Renal replacement therapy may be provided in the form of **dialysis**, a treatment using external medical devices as a substitute for the normal function of the kidneys, or **transplant** of a graft kidney from a living or deceased donor.

In this report people between the ages of 18 and 24 are referred to as **“young adults”** and people between the ages of 15 and 18 as **“adolescents”**. People between the ages of 15 and 24 living with kidney disease are referred to as **“kidney youth”**.



Stage 5: End stage kidney disease (ESKD)

Kidney youth patient population and distribution

Data regarding non-end stage CKD is not routinely or robustly collected in population health datasets therefore the true prevalence of kidney disease in the youth cohort remains unknown.

According to the Australian Health Survey (2011-12), it was estimated that 17,100 Australians aged 18-24 had reduced eGFR and 143,600 Australians aged 18-24 had albuminuria.¹ These are both important indicators of early kidney disease however these statistics can only be referenced as a very broad approximation of the amount of young Australians with biomarkers of kidney disease.

As reliable statistics showing all young Australians diagnosed with kidney disease are not available, young people affected by ESKD are mainly discussed within this report as their statistics are accurate and available through the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA).

In 2017 there were 733 people aged 0-24 years affected by ESKD, with 186 receiving dialysis as treatment and 547 living with a kidney transplant.² Of these, 30 were aged between 0 – 4 years, 179 aged between 5 – 14 years and 524 (71%) aged between 15 – 24 years (refer Table 2; Figure 2).

Table 2: Kidney Youth 15 – 24 years; 2017 ESKD prevalence and state/territory distribution²

State/Territory	NSW	VIC	QLD	WA	SA	TAS	NT	ACT	Total
Prevalence (N)	186	129	121	40	27	8	7	6	524
Percentage (%)	35.5	25	23	7.5	5	1.5	1.5	1	100

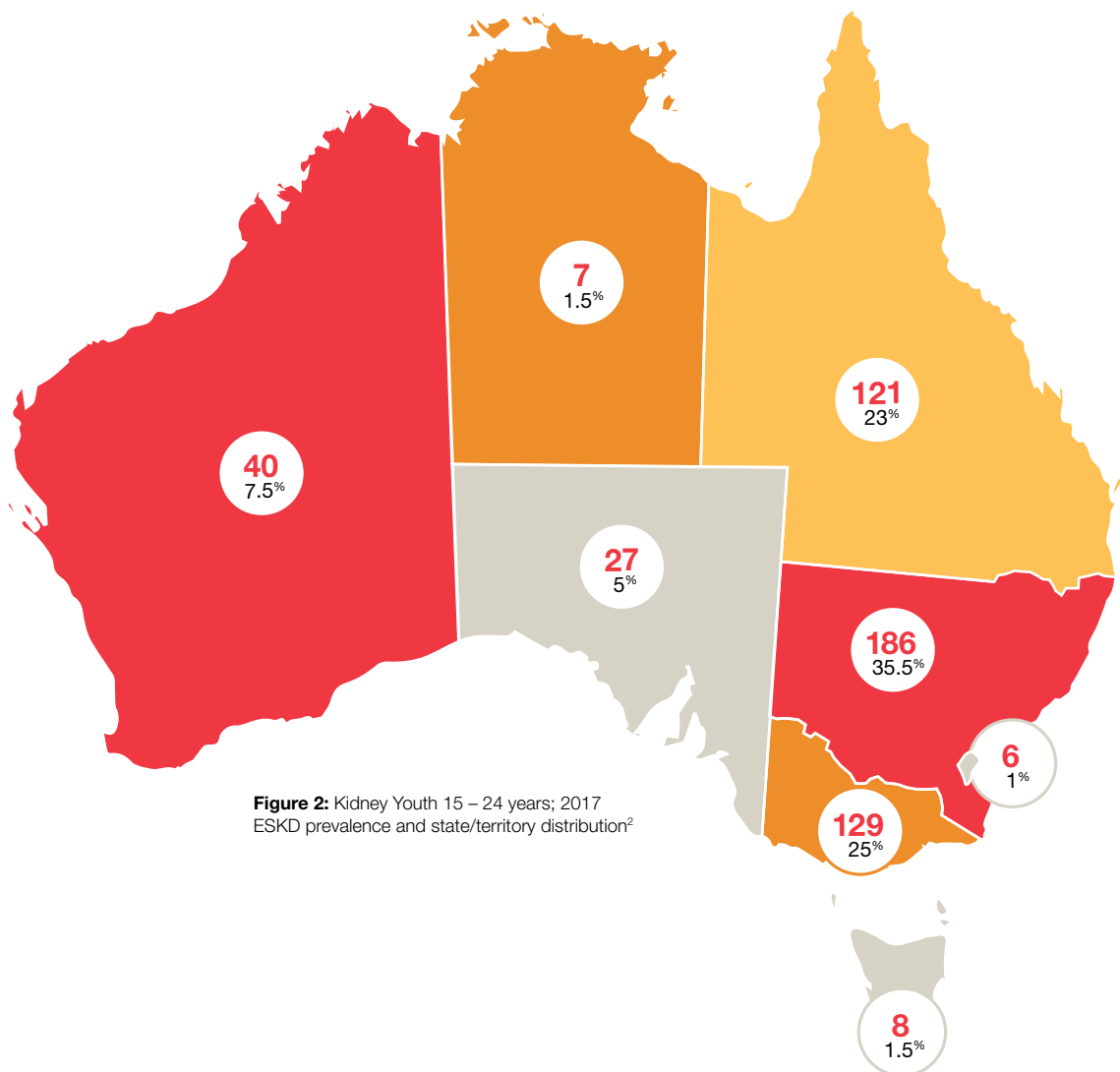


Figure 2: Kidney Youth 15 – 24 years; 2017 ESKD prevalence and state/territory distribution²

The proportion of young adult patients moving from paediatric to adult care has progressively increased over time due to improved treatment and management resulting in increased survival rates.⁴ For example, in 2017 there were 141 more young adult ESKD patients than in 1997, marking an increase of 43% (refer Table 3).

Table 3: Current (2017)² and historical (1997)³ ESKD prevalence and national distribution

State/Territory	NSW	VIC	QLD	WA	SA	TAS	NT	ACT	Total
1997 Prevalence (N)	146	94	53	28	29	14	4	15	383
2017 Prevalence (N)	186	129	121	40	27	8	7	6	524

However, the proportion of the Australian population with kidney disease, and their geographical distribution, have remained reasonably consistent within this age group over 1997 to 2017 at approximately 21 ESKD patients/million population within Australia (or approx. 163 per million age-related population; based on *ABS 2017 data 3,202,433 aged 15 – 24 years in 2017*).

Kidney youth with ESKD geographical distribution

Although figures fluctuate annually regarding geographical distribution, approximately:

- 70% of these young adults live in major cities;
- 15% live in inner regional urban areas;
- 10% in the outer regional areas and
- 5% live in remote or very remote areas.⁵

This young adult cohort therefore includes a relatively small but geographically dispersed group of young adult patients undertaking renal replacement therapy (dialysis or transplant) in Australia.

A more detailed patient population and geographical distribution is also represented in Chapter 4: Clinical Consultation – mapping kidney youth services.

Kidney disease in young people

Kidney disease poses significant health, social and welfare implications for those young people and their carers impacted and burdened by this chronic illness. Major health outcomes include reduced life expectancy and quality of life, and increased risk of cardiovascular disease.^{6, 7}

These impacts may include delayed growth and development, cognitive impairment, emotional and behavioural disorders, fatigue and restricted life participation. They are also burdened by the demands and costs associated with ongoing treatment involving complex medication regimes, ongoing monitoring, lifestyle modifications, strict fluid and diet restrictions and repeated operations.^{8, 9}

Living with kidney disease compounds the difficulty of navigating the usual milestones and challenges that healthy adolescents navigate as they mature into adulthood. The symptoms and impacts of kidney disease combine to drastically impact on young kidney patients' ability to participate in school and work, social and cognitive development, and particularly mental health.¹⁰

All youth in late childhood and adolescence are at high risk of developing mental illnesses, and youth with chronic physical conditions are 51% more likely to develop mental health conditions.¹¹ The impacts of kidney disease on young people are further spread across the families of young people with kidney disease, and have consequences on carers' mental health and financial resources.¹²

The burden of kidney disease can also be compounded by lack of social support from family and friends, lower socio-economic status, cultural considerations, regional or remote home location, lower health literacy, and managing other physical and mental health conditions.

The medical burden of kidney disease is greatest for young people with ESKD and especially those undergoing dialysis. The different forms of dialysis all involve high time demands which disrupt youth's ability to participate in life, including going to school and university, finding employment, and socialising. Dialysis also involves a high risk of infection and corresponding lifestyle restrictions based on hygiene, and long-term health consequences. Consequently kidney transplant is the best treatment for kidney patients, and is prioritised for paediatric patients.

Kidney youth living with ESKD

In 2017, 72% (378) of patients in the 15-24 age range were living with a donor transplant and 28% (146) were receiving dialysis treatment (refer Table 4).

Table 4: 2017 National ESKD patients between 15-24 by treatment modality²

ESKD 15 – 24 years	Number	%
Facility Haemodialysis	88	60
Home Haemodialysis	17	12
Automated Peritoneal Dialysis	32	22
Continuous Ambulatory Peritoneal Dialysis	9	6
Dialysis Total	146	28
Transplant Deceased Donor	167	44
Transplant Live Donor	211	56
Transplant total	378	72
Total	524	100

An even higher proportion of patients in the 5 – 14 years age range at 84% have received a kidney transplant as transplantation is a prioritised treatment during this time due to its restoration of growth and pubertal development in children.

As a result approximately 80% of young ESKD kidney patients transferring to adult healthcare (around the age of 18 years of age) have a functioning kidney transplant.

Risks associated with transition and transfer from paediatric to adult healthcare

Unfortunately up to 35% of these patients will have lost their transplant 36 months after transferring to adult services.¹³

These rates of graft loss persist despite progressive improvements in transplantation practice and immunosuppressive medication. Elevated rates of post-transfer graft loss have been linked to the drastically lower level of support for young adults in adult healthcare compared to paediatric healthcare, and the lack of appropriate transition services which aim to support young patients as they move to new adult healthcare services and learn to independently manage their health.

Young adults who present directly to adult healthcare also face unique challenges as they have not received the extensive and preemptive support provided in paediatric healthcare, nor peer support and networking opportunities more commonly available in paediatric hospitals than in adult hospitals.

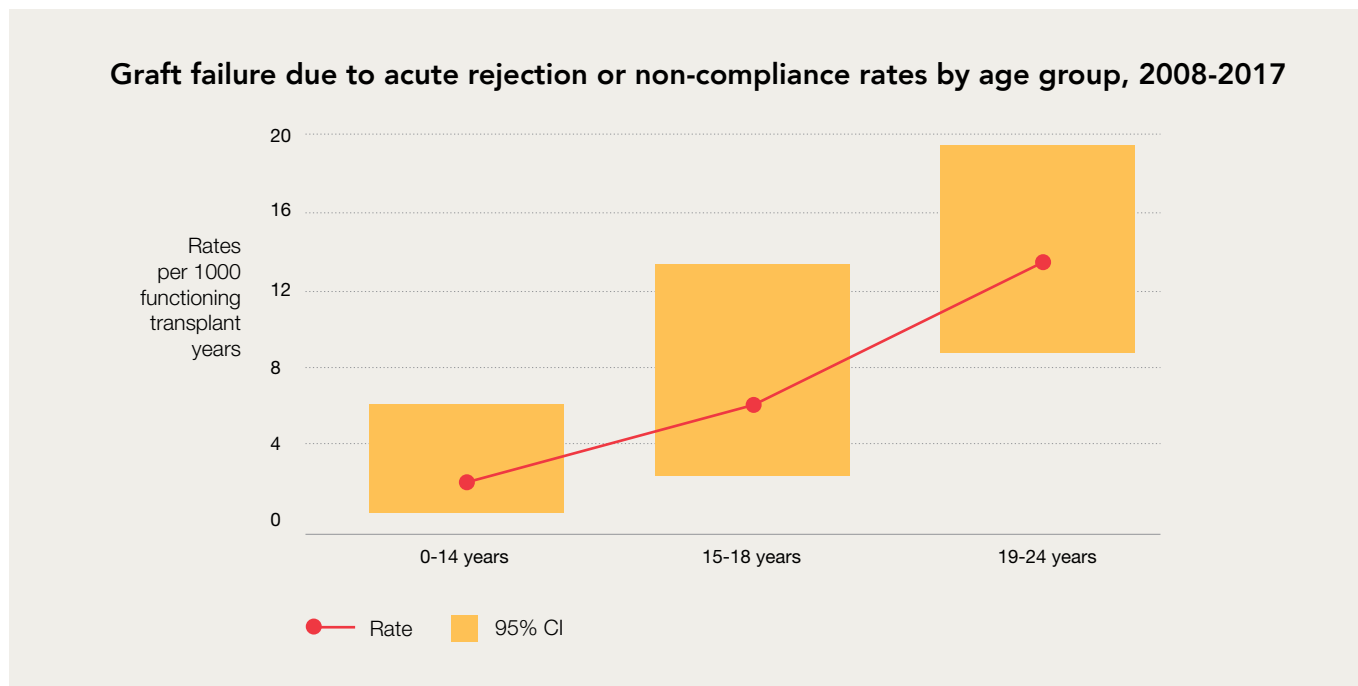
Disruptions to health and healthcare management are further challenged by the high degree of social, psychological, and brain development change that occurs during adolescence, including around 18 years of age, the age at which most young people transfer to adult healthcare. These developmental changes can serve to complicate young people's effective self-management of a chronic medical condition, and navigation of healthcare and other related government systems.

This adolescence life stage is an extremely challenging period for young patients and their carers and families. These challenges are further compounded by difficulties transitioning towards independently managing their chronic illness and healthcare, and the turbulent period of transition and transfer from paediatric to adult healthcare.^{13, 14} These challenges often result in major impacts on young patients' biomedical health outcomes, quality of life and overall wellbeing, and the wellbeing of their carers and families.

Consequently adolescent and young adult kidney transplant recipients have worse graft outcomes than any other age group up to 70 years of age.¹⁵⁻¹⁷

The young adult age group has been consistently shown to have the highest risk of non-adherence to medication and lifestyle guidelines and restrictions which contribute to graft survival.^{16,17} The associated risk of graft failure increased seven-fold in non-adherent transplant recipients.¹⁸ 44% of graft loss and 23% of late rejection episodes are associated with medication non-adherence.^{19,20}

Figure 3: Graft Failure due to Acute Rejection or Non-Compliance Rates by Age Group, 2008-2017 with 95% confidence intervals.



Source: Previously unpublished data, provided by ANZDATA specifically for this report.**

Over the last 10 years (2008 – 2017) Australian kidney graft recipients between 19-24 years old (i.e. immediately after the average age of transfer to adult healthcare) were twice more likely to lose their graft kidney than those between 15 and 18 years ($p = 0.002$). Kidney graft recipients between 19-24 years old were 6.5 times more likely than those between 0-14 years old to lose their graft kidney ($p = 0.082$) (refer Figure 3).

A 2016 study in the United States has also confirmed previously reported outcomes of an increased risk of graft loss after transfer of care for adolescent and young adult kidney recipients.²¹ This was also linked to post-transfer risk factors of medication non-adherence and acute rejection. In this study 30.8% of patients lost their graft 2 to 3 years after transfer. Two other trials referenced also showed graft loss rates post-transfer of 30% and 35%, whilst a third study showed graft loss rate as high as 67%.

Adolescent and young adult kidney graft loss have significant implications and impacts on healthcare costs. Considering the significantly reduced costs of maintaining a kidney transplant post-transplant year compared to the much higher costs of the various forms of dialysis, on average each functioning kidney transplants result in a saving to healthcare costs of \$50,000 per year, post-transplant year, per patient (refer Appendix 2 for more detail).²²

Graft kidney loss has further untold impacts on lost opportunity for future renal replacement therapy, return to dialysis, life expectancy, and the quality of life and life participation of kidney youth experiencing graft loss, as well as those of their families and carers (refer Table 5).

Adolescence and the transition and transfer from paediatric to adult healthcare is a period of high risk of non-adherence to medication and/or complex kidney transplant compliance regimes.^{19,20}

****Attribution statement**

The data reported here have been supplied by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). The interpretation and reporting of these data are the responsibility of the Editors and in no way should be seen as an official policy or interpretation of the Australia and New Zealand Dialysis and Transplant Registry.

Challenges related to poorer health outcomes for kidney youth

Table 5: Summary of health outcomes and challenges for young adults:

Life expectancy, quality of life and psychosocial impact	Quality of life, developmental and psychosocial impacts of kidney disease on young patients are significant and include negative self/body image, feelings of social isolation developing into depression and anxiety, behaviour and learning problems, delayed language and/or motor skills development (cognitive delay), lifestyle modifications, etc. Successful kidney transplantation dramatically improves quality of life and patient survival rates. ²⁴
Dialysis and return to dialysis for a young person	Quality of life and life expectancy are markedly reduced for children and adolescents on dialysis, and return to dialysis after kidney graft failure would have further consequences on young patients' wellbeing. ^{7, 25}
Transplant graft failure	Adolescent and young adult kidney transplant recipients have worse graft outcomes than any other age group up to 70 years of age, with late acute rejection and reduced 5-year graft survival. ^{9, 15-17, 21}
Poor transition, self-management and medication non-adherence	44% of graft loss and 23% of late rejection episodes are associated with medication non-adherence . ^{19, 20} This has been linked to poor transition, usually after transfer to adult healthcare, and poor self-management. Non-adherence can also affect a young adult's transplant prospects as being "well-dialysed" is often a pre-requisite to receiving a transplant.
Significant impact of graft loss	The implications and impact of graft loss are significant in terms of healthcare costs, lost opportunity and most importantly life expectancy and the associated health outcomes of the young adult. ^{7, 22} It cannot be understated the impact this can also have on families, friends and the broader healthcare team.
Lost opportunity	Although outcomes have improved for people receiving kidney transplants over the past 30 years, young people are likely to require multiple transplants in their lifetime. In general, for each additional transplant, accessing another donor kidney becomes more difficult due to the recipient's immune system reacting to subsequent grafts. This makes it important for each transplant graft to last as long as possible. The average lifespan of a kidney transplant is 15-20 years and to lose this graft within 5 years within this high risk period is a lost opportunity. ²³
Healthcare costs	Economic impact of current graft loss in the high risk age group (15 – 24 years) is approximately \$3M per year to the healthcare system. On average each functioning kidney transplant results in a saving to healthcare costs of \$50,000 per post-transplant year, per patient as maintaining a graft is significantly cheaper than dialysis (see Appendix 2). ²²

Chapter 2: Current response to improve kidney youth health outcomes

Chapter summary

- Current clinical efforts focus on improving medication adherence through **individualised holistic support for young patients when transferring to adult healthcare**, and for **young adult patients in adult healthcare**.
- Several Australian renal clinics have implemented **transition services** based on international models considered best practice, which prepare paediatric patients to transfer to adult healthcare.
- Young adult services within adult healthcare are similarly designed to support young adult kidney patients post transfer.
- Both transition services and young adult services tend to facilitate peer support between young kidney patients and address overall wellbeing issues with the support of a **multidisciplinary team which integrates allied health professionals into kidney healthcare**.

The aim of the response

Historically, efforts to address the problems associated with young kidney patients aimed to improve medication non-adherence, reduce the rate of late rejection of kidney transplant and improve kidney allograft survival, thus ultimately improving young patients' outcomes and quality of life.

Focus on transition and transfer and holistic healthcare

The clinical response to date has focused on the successful transition and transfer of a young person living with kidney disease from paediatric into adult healthcare. This often involves the holistic clinical and psychosocial care of the patient through the support of a multidisciplinary team of healthcare and social care professionals, and modifications to existing clinical models including joint transition clinics and dedicated young adult clinics.²⁶⁻²⁸

Consensus statement

Young kidney patients' health outcomes have been globally recognised by national healthcare bodies, culminating in an international consensus statement by the International Society of Nephrology and International Pediatric Nephrology

Association in 2011.²⁹ The statement provides a basis for the development of locally appropriate recommendations for clinical practice around the transfer of young patients from paediatric to adult renal care after a transition process which involves both sides.

Oxford-London transition model

Internationally, clinicians and healthcare professionals have trialed different models and practices. The UK Oxford-London transition model and experience has been widely accepted and reported as a successful model and has been adopted in a number of countries including Australia in 2013 (Transition Clinic and Young Adult Clinic, Adelaide SA).^{30, 31}

The integrated paediatric to adult clinical service for young adults with kidney failure trialed in the UK Oxford experience included transition and young adult clinics and a strategy for change. The successful experimental implementation of the revised clinical model resulted in **zero transplant losses in patients who participated in the revised clinical model**, compared to a **graft loss rate of 67% of patients treated in the traditional clinical model**.

Transition guidelines

Transition guidelines have since been co-designed and published in 2016 by the National Institute for Health and Care Excellence (NICE).³² Although the guidelines are detailed and comprehensive, they are also aspirational as implementing them completely in all healthcare contexts and locations is often unfeasible due to funding and structural limitations.

The Australian response

A range of transition practices have been implemented within Australia to cater for young adult patients in transition and transfer. Varying services and models exist nationally, which were identified and discussed as part of the Kidney Health Australia Youth Program National Consultation Process. This is discussed in detail in Chapter 4: Clinical Consultation – mapping kidney youth services, including a summary representation of kidney youth services in each state and territory.

The associated model of care and recommendations contained within this report advocate for **increased support** to achieve **best practice clinical care** in relation to transition and transfer from paediatric to adult healthcare.

Chapter 3: Kidney Health Australia Youth Program – National Consultation Process

Chapter summary

- The National Consultation Process consulted adolescents and young adults living with kidney disease, their carers and families, and healthcare professionals involved in kidney healthcare including nephrologists, nurses, and allied health professionals.
- The process involved meetings with **over 125 kidney youth and carers**, and **over 50 clinical staff**.
- The findings directly inform the outcomes of this report and the services proposed under the Kidney Health Australia Youth Program.

Figure 4: Youth Program National Consultation and Report Process



Kidney Health Australia Youth Program National Consultation (Sept 2018 – Aug 2019)

A national consultation process was undertaken with the major hospital renal units delivering youth services, young adults living with kidney disease and their carers around Australia to identify current service and best practice along with needs and gaps in care.

This consultation process including the use of surveys has been guided by the Clinical Advisory Committee along with the Kidney Youth Champions identified along the way (see Figure 4).



Consultation and research components

Clinical consultation

The clinical consultation involved:

- National **visitations and meetings** with over 50 clinical staff including all major paediatric and adult hospitals in all states and territories (apart from the ACT) linked via young adult transition and transfer along with other major kidney health stakeholder groups;
- The **Renal clinic youth services survey** which was designed (and ethics approved) to assist with mapping services nationally, distributed via ANZDATA to renal units and received 28 responses, capturing most major renal units. Results were collated alongside clinical consultations and the most recent ANZDATA report to present a national analysis.

Kidney youth and carer consultation

The kidney youth and carer consultation was comprised of:

- **Focus group sessions** and individual discussions with young adults living with kidney disease and their carers, including ten youth consultation sessions conducted nationally averaging approximately 10 attendees per session to capture patient/ carer experiences and feedback;
- An online **Kidney youth and carer survey**, distributed nationally to increase the scope of responses and reach those we could not engage with face-to-face. We received 138 responses including 114 youth living with kidney disease and 24 carers. Results have been collated for analysis alongside the Kidney Youth and Carer Consultation;
- Further information and data collected from attending four Young Adult Clinics (Adelaide, Brisbane, Hobart and Melbourne) and one Transition Clinic (Perth).

General research and information gathering included:

- A comprehensive literature review and discussions with a number of key researchers;
- Attendance at kidney health conferences, education and research workshops.

Advisory consultation throughout the National Consultation process involved:

- Meetings and discussions with the Kidney Youth Clinical Advisory Group;
- A Strategic Roundtable Meeting with key kidney youth stakeholders.

The consultation and research has been undertaken to assist in understanding young patients' challenges, identifying their needs, and recognising successful programs and supports that currently exist, with the aim of sharing these nationally whilst advocating for the implementation of best practice approaches based on the consultation findings.

The consultation has also helped identify and engage with key personnel to guide and support further activities within the program along with obtaining baseline data to assist post program evaluation.

Outcomes of the consultation process are discussed below. For further details of the consultation process and scope see Appendix 1.



Chapter 4: Clinical Consultation

– mapping of youth renal services

Chapter summary

- Clinical Consultation highlighted that services for young kidney patients, and access to these, is highly varied across Australia, with differing formats presenting benefits and challenges relating to funding, access to personnel, specific training and resources.
- The usual variations exist between states and territories and include access to funding, hospital personnel, policies and procedures, patient populations, cultural, socioeconomic and disability issues, regional and remote services, time and travel, etc.
- Generally paediatric hospitals are more appropriately funded to cater for the increased care required for adolescent patients than the adult hospitals are for young adults.
- The difference in services, resources and overall care available for young patients who transfer or present directly to adult healthcare was described as “not a gap, more like a cliff or a chasm”. Increased support for young adult patients in adult hospitals is required.
- Most renal clinics have the core multidisciplinary team in place to service young patients, especially the larger city based units. The main personnel desired included healthcare professionals to provide increased psychosocial support (i.e. Psychologist and/ or social or youth worker), assist with transition processes (i.e. Transition Coordinator and/ or Champion) and someone to provide peer support/youth mentoring.
- There is a variety of transition and transfer services and processes in place nationally. Best practice includes transition services and/ or transition and transfer clinics (cooperative between paediatric and adult hospitals) and young adult clinics following transfer.
- Whilst some clinics were able to achieve peer interaction and support (i.e. young adult clinics), this was lacking in most situations and strongly desired.
- Distance and travel is a major issue for a number of patients especially those in regional or remote locations. Access to clinics, services and peer support also diminish regionally.
- Patients in paediatric healthcare with multi morbidities often have a primary care specialist who can manage multiple disease conditions. When these patients move to adult healthcare they often need to see a different specialist for each disease condition (renal, endocrine, rheumatoid, etc.) which can be very challenging.
- Adult nephrology education, awareness and understanding of transition and related issues and services/supports should be improved to better work alongside young patients (i.e. broaden training for clinicians in managing and caring for young adults).

The following state and territory data and information has been extracted and summarised from consultations with renal clinics around Australia, the Renal Clinic Youth Services Survey and ANZDATA² statistics.

New South Wales

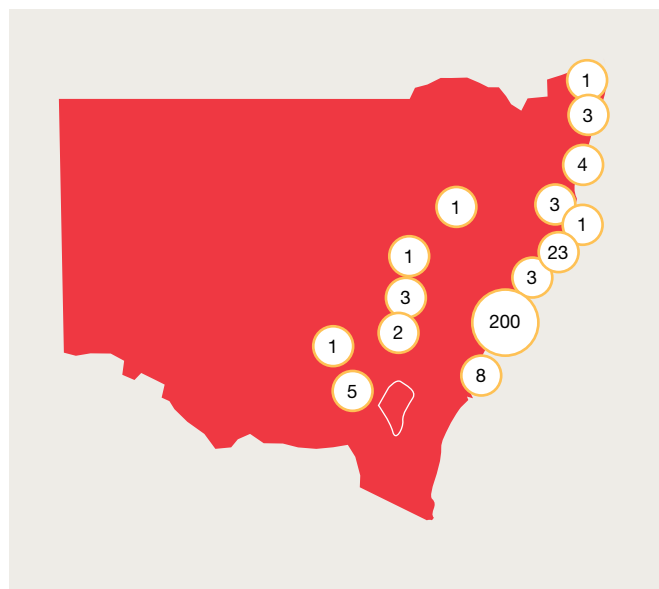
Table 6: Treatment of ESKD kidney patients between 15-24 in NSW

NSW Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	7	44	51	34.9
Transplant	44	91	135	35.7
Totals	51	135	186	35.5

Table 7: Treatment of ESKD kidney patients between 0-24 in NSW

NSW (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	12	7	44	63
Transplant	61	44	91	196
Totals	73	51	135	259

Figure 5: Numbers of young ESKD kidney patients treated at clinics in NSW



- 25 hospitals service the young adult ESKD patients.
- 2 main paediatric hospitals – Sydney Children’s and The Children’s Hospital at Westmead.
- 6 main adult hospitals (N > 7) including 2 regional (Woolongong and Newcastle).
- 11 hospitals located in and around metropolitan Sydney (200 young patients).
- 14 hospitals located regionally in Tweed Heads (1), Lismore (3), Coffs Harbour (4), Port Macquarie (3), Taree (1), Newcastle (23), Gosford (3), Wollongong (8), Wagga Wagga (5), Griffith (1), Bathurst (2), Orange (3), Dubbo (1) and Tamworth (1).

Clinical consultation notes

- Transition in NSW is supported through Trapeze Transition Services for 15 – 25yr olds.
- Transition discussion starts as early as 12 but mostly from 14 years. Transfer occurs at 18 years.
- An adolescent transition clinic is conducted by Sydney Children's in conjunction with the Prince of Wales for patients from 16 years.
- Transition and transfer occurs between Westmead Children's and Adult hospitals which are linked with a shared space under construction at the time of consultation, and an additional transitional "Young Adult Clinic" space being developed between the hospitals.
- Sydney Children's and The Children's Hospital at Westmead service many regional areas up to 600kms away including Port Macquarie to the north and Canberra to the south-west.
- Transfer also occurs to multiple adult hospitals within Sydney and regionally depending on home location.
- Distance and travel is a major issue in NSW for a number of patients.
- Paediatric services are reported to be fairly well resourced. There is however limited access to social workers and psychologists and more access is desired.
- Adult services are lacking the additional support and resources of paediatric services – the nephrologist is basically on their own.
- Patients in paediatric healthcare with multi morbidities often have a primary care specialist who can manage multiple disease conditions. When these patients move to adult healthcare they often need to see a different specialist for each disease condition (renal, endocrine, rheumatoid, etc.) which can be very challenging.
- High level of diversity in the Westmead area, including culturally, socio-economically, and in terms of capability and disability.
- Medication adherence post transfer is a major issue.

Main needs identified

- Adult nephrology education, awareness and understanding of transition and related issues and services/supports to better work alongside young patients.
- Social worker, youth worker, and/or occupational therapist – current emphasis is on regional support for families. It is a reactive service but staff would prefer a proactive service, e.g. one that provides case management of the patient (and their psychosocial needs).
- Further support to address many issues including disability, behaviour, education and navigating the health systems.
- Peer support/youth mentor program (some youth services available – see below).
- Parent mentoring system may also be useful.

Youth services

Other services for youth provided at the Sydney Children's and Westmead include ChIPS, Youth Arts and Groupwork Program and Starlight Children's Foundation - Livewire.

Resources

Sydney Children's – Growing Up booklet, Trapeze has multiple fact sheets, checklists, website, etc.

Case Study 1:

Trapeze Transition Service

Trapeze is an external transition service which works closely with the Agency for Clinical Innovation (ACI) Transition Care Network to provide comprehensive services to young people with chronic conditions in NSW. Trapeze is located within The Sydney Children's Hospitals Network (SCHN) and the ACI Transition Care Network provides a state-wide service, based in adult tertiary hospitals.

Trapeze accepts referrals for young people with a chronic condition aged 14-25 years who have received care from The Children's Hospital at Westmead or Sydney Children's Hospital, Randwick. Not all young people with chronic conditions require Trapeze support.

Those who benefit most are:

- Young people not adhering to treatment or engaging in health services (e.g. those who do not attend clinic appointments);
- Young people with frequent unplanned hospital admissions;
- Aboriginal and Torres Strait Islander young people;
- Young people from culturally and linguistically diverse backgrounds;
- Young people who will require complex transition coordination due to having multiple health conditions, and;
- Young people with complex psychosocial issues such as financial hardship, family problems, social isolation, unemployment or school absenteeism.

Victoria

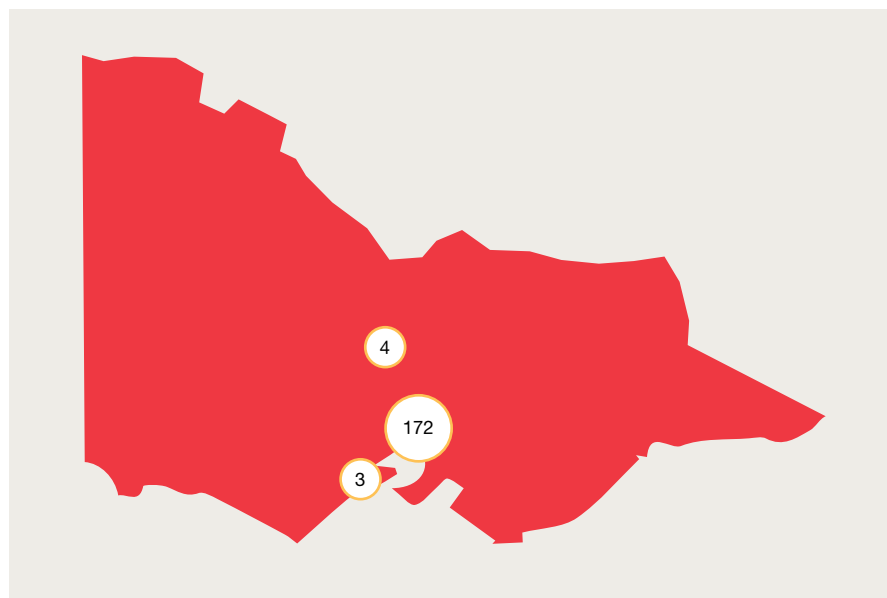
Table 8: Treatment of ESKD kidney patients between 15-24 in VIC

VIC Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	6	31	37	25.3
Transplant	25	67	92	24.3
Totals	31	98	129	24.6

Table 9: Treatment of ESKD kidney patients between 0-24 in VIC

VIC (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	14	6	31	51
Transplant	36	25	67	128
Totals	50	31	98	179

Figure 6: Numbers of young ESKD kidney patients treated at clinics in VIC



- 13 hospitals service the young adult ESKD patients.
- 2 main paediatric hospitals – Royal Children’s and Monash Medical Centre (Paediatric).
- 4 main adult hospitals (N > 7).
- 11 hospitals located in and around metropolitan Melbourne (172 young patients).
- 2 hospitals located regionally in Bendigo (4) and Geelong (3).

“Having this collaborative space, it’s good to get to know other people and see what their story’s like and help them out, so I think it’s a positive.”

Youth Champion Alic on the Young Adult Clinic space within the Victorian Comprehensive Cancer Centre.

Clinical consultation notes

- Transition discussion starts mostly from 15 years at Royal Children's and 12 years at Monash.
- Transition in VIC is supported mainly through Transition Services (refer below) at Royal Children's and transition meetings at Monash Paediatric.
- Transfer occurs at 18 years and to multiple adult hospitals depending on home location.
- Monash coordinates transfer between the Monash Paediatric and Monash Adult and involves two cross-over visits with both adult and paediatric nephrologists attending.
- Royal Children's conduct joint clinics with Royal Melbourne and Austin Hospital prior to Transfer (and has a "Graduation Ceremony" through Transition Services and Livewire).
- Royal Children's run joint transition clinics every 2 months in the evenings. 5 – 7 patients per clinic from 15 years of age. Discussions focus on self-management, goal setting, etc.
- A Young Adult Renal Clinic, established shortly before consultation in October 2018, at the Royal Melbourne located at the Victorian Comprehensive Cancer Centre.
- Head of Nephrology at Royal Children's is the nominated Transition Champion.
- Social worker is available at Royal Children's but is mainly focused on crisis care and family support (reactive), rather than a case management style of work with the patient (proactive).
- Distance and travel is an issue in VIC depending on regional location or if attending paediatric appointments from Tasmania.
- Patients can remain up to 19 years of age (reported at Monash Paediatric) to transfer if necessary and authorised by the doctor. Patients are usually transferred out at 18 years (e.g. completed after Year 12 schooling, not in crisis and a transition plan is utilised).
- Monash Paediatric use a shared doctor approach – patients get used to seeing other doctors which may assist when transferring to adult healthcare and doctors.

Main needs identified

- Social worker access at the adult hospital.
- Youth worker and peer support/youth mentor program.
- Group or service to support new patients >18 years who present with ESKD.
- Providing extra care and service by adult clinicians for patients 18 – 25 years following transfer.
- Broaden training for clinicians in managing and caring for young adults.
- 1-2 doctors in the adult hospital that have an interest in the young adult and transition, and possibly even youth trained and part of a young adult clinic.
- Extra support within the adult system as they don't have the funds/resources attached to the young adult. For example social support services (e.g. psychologist, social worker) are available in paediatric services but rarely in adult services.
- Resources / time to "chase up" the patient in the adult system like they do in the paediatric setting.

Resources

Transition Policies, Information handouts, Checklists, Tools, Transition Booklets have been specifically developed (e.g. Cystic Fibrosis, Heart Kids and Intellectual Disability), etc. (i.e. website reference for RCH Transition resources <https://www.rch.org.au/transition/>).

Services

Starlight Children's Foundation – Livewire

Livewire supports teenagers living with a serious illness, chronic health condition or disability by helping them connect with others, explore their creativity and develop new skills.

Each year, Livewire runs a range of creative workshops in hospital including music, art, photography, film making, creative writing, multi-media and celebrity visits.

Chronic Illness Peer Support (ChIPS)

Based at the Royal Children's Hospital (Department of Adolescent Medicine) in Melbourne, ChIPS works to engage young people from metropolitan and rural Victoria. Delivered for over twenty years, the program is currently 100% philanthropically funded via The Royal Children's Hospital Foundation.

ChIPS is a vibrant peer support program for young people, led by young people, which offers a wide range of opportunities for members who are:

- 12 (and started high school) to 25 years of age;
- living with a primary diagnosis of a chronic medical illness;
- able to attend an intake program, either eight week group or a two day intensive, and;
- ready and able to participate and function well in a group setting.



Case Study 2:

Transition Services Royal Children's Hospital Melbourne

- Transition Support Service works across all departments including the renal department.
- Transition Clinics are run and managed by the Transition Support Service.
- The Service works in partnership with all RCH medical and surgical departments and with relevant adult hospitals who receive these patients (renal includes the Royal Melbourne and Austin Hospitals).
- The Transition Support Service is led by a full-time Transition Manager. In addition to managing the Service and delivering direct clinical transition care particularly for patients with multiple medical and developmental concerns, the Transition Manager works in partnership with all paediatric and adult services to develop sustainable transition pathways and systems.
- The Transition Support Service is also staffed by a part time Transition Support Coordinator who is a senior adolescent nurse (0.6 FTE), 2 Transition Support Workers (2X 0.4 FTE), a Transition Study Coordinator (0.5 FTE) and an administrator (0.1 FTE).
- The two Transition Support Workers are paid roles (0.4 FTE) and assist patients from all departments. One of the two Transition Support Workers was recruited to be a good fit for the role based on having a chronic medical condition and being able to share the lived experience from the perspective of a peer. She is not officially trained in youth work but has an interest in supporting other young people with chronic health issues. The second Transition Support Worker is a qualified social worker.
- The Transition Support Service runs and participates in over 60 joint paediatric and adult service transition clinics annually and across multiple specialties. Renal transition joint clinics are coordinated with doctors, clinical nurse consultants and relevant allied health professionals (e.g. social workers) from the RCH, the Royal Melbourne and Austin Hospitals. The Transition Support Service team and clinicians from relevant RCH and adult sites come together to discuss clinics, with patients and carers present.
- Renal patients and families will attend a mid-year introductory transition joint clinic with the RCH and adult renal services and the Transition Support Service. Renal patients will also attend an end-of-year transfer clinic with these same teams.
- From 15 years, the Transition Support Service works with patients and their carers. At age 18 to 19 years patients will transfer to an adult service and this process is often dependent on timelines established in the patient's transition plan, transfer plans from other relevant medical and surgical teams, the patient's health status and completion of schooling.
- Transition/self-management topics include: goal setting, information sharing, personal confidence, risk factors, checklists, transition plan, comorbidities, personal needs and best hospital fit, regional consideration (for example, "shared care; local care is best care") and personal pathways for the young adult including university, further study, work, etc.
- Transition to self-management is seen as an individual process and can look different for each patient, and is therefore not treated as a one-model-fits-all approach. Patient is assessed on their ability to be an adult and make decisions.
- Resources such as checklists and information brochures developed by the Transition Support Service are available to assist with patient goal setting, transition readiness and other aspects of care such as school supports, work and other vocational supports, mental health care and other aspects of care relevant to young people. Focus on building protective elements and a well-resourced self-management approach.
- The RCH provides some support after transfer as needed, for example coordination of other non-renal care needs. Tracking of patient outcomes post transfer up to 3 years is currently being researched via an RCH-wide Transition study.
- In reference to Harden's work on transition clinics, transition clinic goals were seen as relatively unrealistic to achieve and fund (e.g. off-site care of young adults).^{20, 21, 22} Therefore the Transition Support Service and Clinical Team aim to develop a model that meets the needs and care of the young adult patients and can be funded within the hospital system.
"It is not so much about the [clinic] space but the people and the programs & services available".
- More resources for patients within the adult service and/or more support attached for the young person and their carers transferring into adult healthcare services are needed to achieve the above.
"There are great resources in the paediatric sector but then limited resources in the adult sector. It is not a gap, seems to be more like a cliff or a chasm"
- Adults and carers are valuable in their continued support and guidance of young adults where appropriate. For example, where patients have delayed cognitive development or when caring for a patient with a disability.
"Young Adult friendly care is the goal!"
- Regional care can be difficult in some cases including some areas that are not supported by the NDIS (e.g. Geelong and Bendigo were mentioned).
- Definite socio-economic issues disrupt ongoing care of patient, including access to support, services, resources, etc. Patients affected by such issues are less likely to have access and support, and suffering from reduced health outcomes as a result.
- Need for multiple support networks and peer gathering opportunities, including:
 - psychosocial support;
 - social connections;
 - Kidney Kids Camp/RCHM ChIPS program (see below);
 - education forums/workshops, and;
 - peer support/online forums/tele-connect.*"We need to normalise peer support; it is not opt in or opt out, it should or could be considered just another part of the care plan and support service."*

Philosophy: To empower young adult patients and their families/carers to manage their condition and care outside of hospital. To be well. To acknowledge they need help and support and how to access it, building protective elements and a well-resourced self-management approach.

Queensland

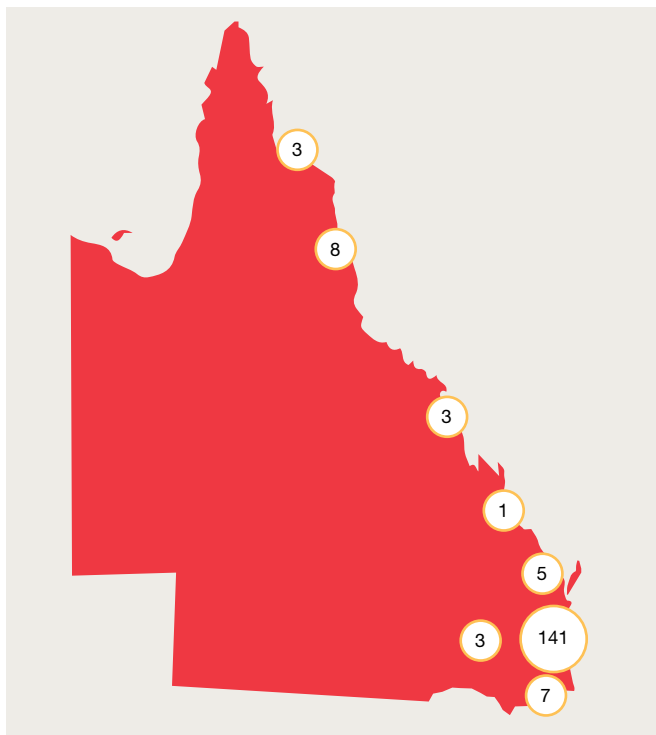
Table 10: Treatment of ESKD kidney patients between 15-24 in QLD

QLD Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	8	32	40	27.4
Transplant	27	54	81	21.4
Totals	35	86	121	23.1

Table 11: Treatment of ESKD kidney patients between 0-24 in QLD

QLD (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	9	8	32	49
Transplant	41	27	54	122
Totals	50	35	86	171

Figure 7: Numbers of young ESKD kidney patients treated at clinics in QLD



- 13 hospitals service the young adult ESKD patients.
- 1 main paediatric hospital – Queensland Children’s Hospital.
- 4 main adult hospitals (N > 7) including 1 regional (Townsville).
- 5 hospitals located in and around metropolitan Brisbane (141 young patients).
- 8 hospitals located regionally in Cairns (3), Townsville (8), Mackay (3), Rockhampton (1), Sunshine Coast (5), Toowoomba (3) and 2 on the Gold Coast (7).

Clinical consultation notes

- Transition discussion starts from 14 years at the Queensland Children’s, with some beginning from 12 years.
- Transition in QLD is supported mainly through the Young Adult Clinic which is an adolescent clinic from 16 years conducted in collaboration with the Queensland Children’s, Mater and Princess Alexandra at the Mater Hospital.
- Transfer occurs at 18 years. Patients are transferred to multiple adult hospitals depending their residence.
- Distance and travel is a major issue in QLD for a number of patients.

Main needs identified

- Regional and remote patient access and inclusion (some come into the clinic from the Sunshine Coast and Gold Coast but not from further regional and more remote areas).
- Peer networking outside of clinic, including access to online forums
- Youth worker to address high level of psychosocial needs.
- Peer support/youth mentor program.

Case Study 3:

Young Adult Clinic at the Mater inside “The Dome”

The Young Adult Clinic consists of doctors, renal nurses, administrator and a Young Adult Support Unit, comprised of psychologists, social workers, occupational therapists, and psychiatrists. A volunteer cook also assists prepare food for the young adult and carers.

- A youth space is provided at the Mater for Young Adult Transition Clinics to be held and is shared across the chronic illness group. The youth space was originally developed for young patients with Diabetes Type 1 and is now used by renal, respiratory (cystic fibrosis), cardiac, etc. departments.
- The occupational therapists and psychologist are also shared across these departments, and are funded by the hospital.
- This approach was encouraged by the clinical psychologists, who recognised many mental health conditions faced by young adults across the chronic illnesses and need for more mental health support.
- Clinics are held every 2 months for patients 14 – 24 years with doctors from across the three hospitals in attendance. All young adults gather from 8.15am up until 12 noon in a specialised youth friendly room called “The Dome”, which provides music, TV, games, cooking facility, coffee machine, lounges and catering for the patients and their carers.
- Patients are met by occupational therapists and mix as a group. Occupational therapists facilitate group discussions and individual conversations, encourage activities, cooking, etc. Carers are also welcome.
- Doctors collect patients for consultation from the clinic space which can be anytime, which encourages patients to stay throughout the clinic times and not just come for the consultation. This facilitates social interactions, opportunities to catch up with the psychologist and occupational therapists, and especially other young adults and carers.
- Consultation assesses bloods, medications, recent events, psychosocial, other needs, etc. All patient details are shared amongst the doctors at the end of session to prevent miscommunications and misunderstandings, and allow them to share analysis and information.
- A social activity is usually organised by the occupational therapists after the clinic and held external to the hospital (e.g. a movie, ten pin bowling, or a picnic).

The clinic is highly valued and has produced some encouraging early results.



“They want to start getting dialysis patients here, that would be the next best step. For us, we can see where we came from... for them, they can see how you can be after transplant. There’s four different stories in the room right now, all different, but all the same one course.”

Youth Champion Jesse on the Young Adult Clinic at the Mater, Brisbane.

Western Australia

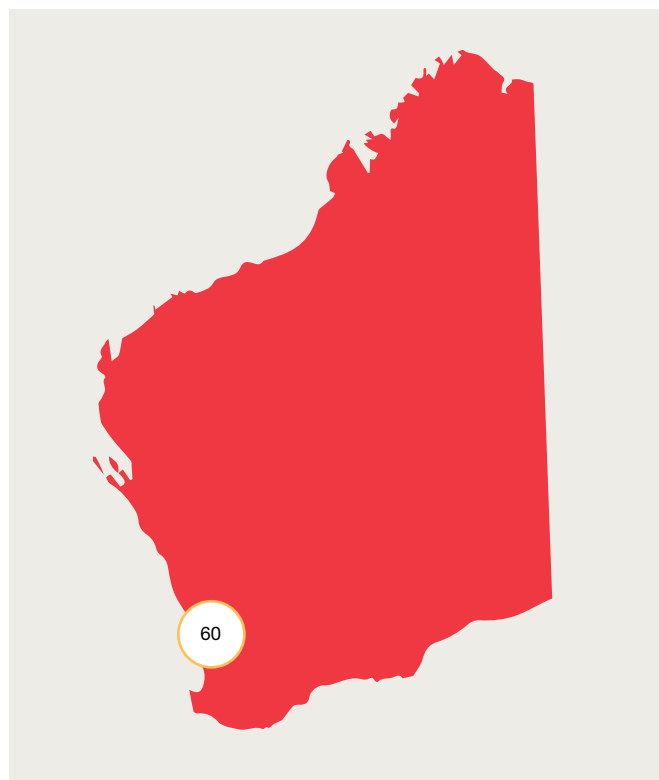
Table 12: Treatment of ESKD kidney patients between 15-24 in WA

WA Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	1	6	7	4.8
Transplant	9	24	33	8.7
Totals	10	30	40	7.6

Table 13: Treatment of ESKD kidney patients between 0-24 in WA

WA (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	3	1	6	10
Transplant	17	9	24	50
Totals	20	10	30	60

Figure 8: Numbers of young ESKD kidney patients treated at each clinic in WA



- 4 hospitals service the young adult ESKD patients.
- 1 main paediatric hospital – Perth Children’s Hospital.
- 3 main adult hospitals (N > 7).
- 4 hospitals located in and around metropolitan Perth (60 young patients).

Clinical consultation notes

- Transition discussion starts mostly from 14-15 years at Perth Children’s.
- Transition in WA is supported mainly through transition appointments with some cross-over visits with adult and paediatric nephrologists attending.
- Transfer occurs at 16 - 18 years to the Fiona Stanley, Sir Charlie Gairdner and Royal Perth. Due to government policy, when a young adult patient presents at over 16 years old they are immediately transferred to adult healthcare. Both paediatric and adult healthcare teams did not necessarily favour this model.
- Perth Children’s have recently introduced transition clinics which run every 2 to 3 months for patients from 14 years of age.
- No defined transition process post transfer but aiming to trial combined young adult clinics similar to Adelaide model.
- Distance and travel may be an issue in WA depending on regional residential location. Usually relocation to Perth is necessary.

Main needs identified

- Access to social workers and/or psychologist.
- Youth worker and peer support/youth mentor program.
- Increased access to the dietician, pharmacist and physiotherapist.
- A “youth space” in the adult hospitals associated with the clinic.

South Australia

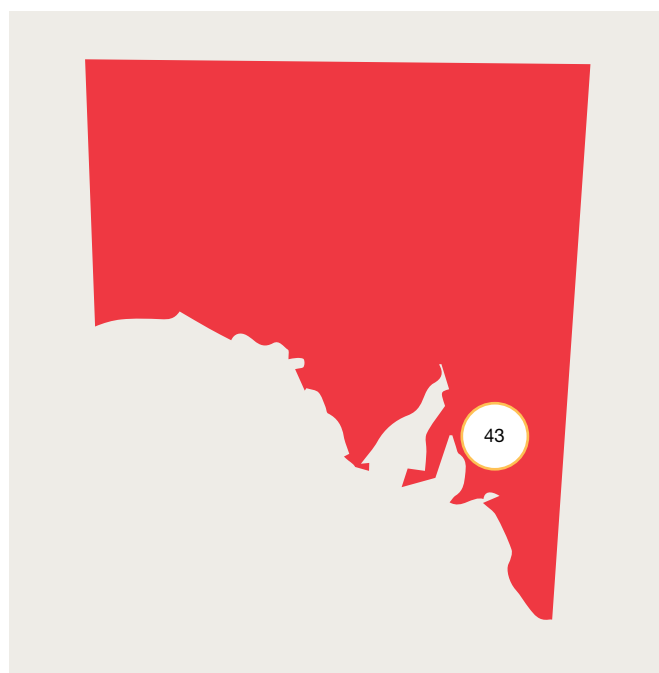
Table 14: Treatment of ESKD kidney patients between 15-24 in SA

SA Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	0	6	6	4.1
Transplant	7	14	21	5.6
Totals	7	20	27	5.2

Table 15: Treatment of ESKD kidney patients between 0-24 in SA

SA (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	2	0	6	8
Transplant	14	7	14	35
Totals	16	7	20	43

Figure 9: Numbers of young ESKD kidney patients treated at each clinic in SA



- 3 hospitals service the young adult ESKD patients.
- 1 main paediatric hospital – Women’s and Children’s Hospital.
- 1 main adult hospital (N > 7) Royal Adelaide Hospital and Central and Northern Adelaide Renal Transplantation Service (CNARTS).
- 3 hospitals located in and around metropolitan Adelaide (43 young patients).

Clinical consultation notes

- Transition discussion starts mostly from 14 years at Women’s and Children’s.
- Transition in SA is supported mainly through transition clinics which run every 2 to 3 months for patients with some cross-over visits with adult and paediatric nephrologists attending.
- Transfer occurs at 18 years, usually to the Royal Adelaide.
- A young adult clinic is conducted at the Royal Adelaide (refer Case Study 4).
- Distance and travel may be an issue in SA depending on regional location and if travelling from Alice Springs or Darwin. Usually relocation to Adelaide is necessary.

Main needs identified

- Access to social worker, occupational therapist and/or psychologist.
- Peer support/youth mentor program.
- Increased access to the dietician and pharmacist.
- Adult nephrology awareness and understanding of transition and related issues and services/supports.
- Specialised service including fast-tracked transition education for young adult patients (over 18) presenting directly to adult hospital.

Case Study 4:

Young Adult Clinic Royal Adelaide Hospital

The Young Adult Clinic consists of nephrologist and transplant nurse coordinators from the Royal Adelaide Hospital, as well as a social worker who is funded separately.

- The clinic is held twice-monthly (6 times/year) usually from 9.00 am – 12.00 noon with 15 – 25 patients attending depending on their availability. All patients are in adult care and (most) have transferred from paediatric care.
- The clinic is currently hosted in the Uni SA Medical Clinic, located close but external to the hospital. Different venues have been used in the past as non-hospital youth friendly spaces.
- There is a general meeting room area and consult room down the hall. All young people are met by the staff and gather in the meeting room.
- The social worker then engages them in discussion, activities, etc. whilst they wait for consultation. This allows patients to chance to catch up, connect, have a conversation (generally not about their illness), and participate in socially engaging activities which in the past have included art therapy, magician, board and card games, etc.
- The young adults have their usual clinical appointment as part of the clinic. All patients are encouraged to attend as much as the clinic time as possible to encourage peer interaction.
- This young adult clinic has been visited by a number of nephrologists and the model has been adopted in three locations (Brisbane, Hobart and more recently Melbourne) and is considered an example of best practice.
- There have been no recorded graft loss of patients attending since 2013 when the clinic first started operating under the design and practice of Dr Robert Carroll.



Tasmania

Table 16: Treatment of ESKD kidney patients between 15-24 in TAS

TAS Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	1	1	2	1.4
Transplant	2	4	6	1.6
Totals	3	5	8	1.5

Table 17: Treatment of ESKD kidney patients between 0-24 in TAS

TAS (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	0	1	1	2
Transplant	0	2	4	6
Totals	0	3	5	8

Figure 10: Numbers of young ESKD kidney patients treated at each clinic in TAS



- 2 hospitals service the young adult ESKD patients.
- 2 main adult hospitals in Launceston (6 young people) and Hobart (2).

Clinical consultation notes

- Tasmania is classified as a regional centre and Tasmanian hospitals do not perform transplants.
- Tasmanian hospitals work alongside the Royal Children's Hospital Melbourne, involving patients travelling for clinical visitations.
- Patients are admitted to Launceston and Hobart hospitals from 15 years old. Otherwise clinical visits are with the Royal Children's.
- Travel to and from Melbourne for patients and carers living in Tasmania is costly in time and money.
- Royal Hobart conducts a Young Adult Clinic and uses an interdisciplinary approach regarding personnel. This clinic is usually held external to the hospital in a "youth friendly" space.
- Young people attend clinic which is held 4 – 6 times per year. While some attend on their own, family and carers are welcome (especially with the younger patients).
- Refer also recent research, workshops and report on the "Evaluation of the Tasmanian Young Adult Renal and Transplant Clinic".

Main needs identified

- More routine access to a social worker for more regular case management work with the young person. The psychologist lacks time and resources needed to provide individualised care and ongoing case management.
- Peer support/youth mentor program.
- Increased access to the dietician and pharmacist.

Northern Territory

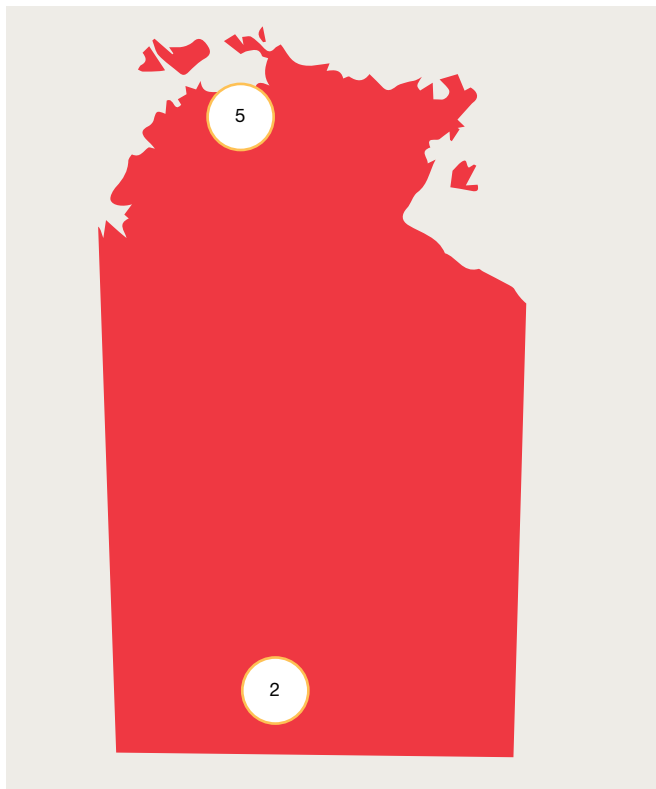
Table 18: Treatment of ESKD kidney patients between 15-24 in NT

NT Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	0	3	3	2.1
Transplant	1	3	4	1.1
Totals	1	6	7	1.3

Table 19: Treatment of ESKD kidney patients between 0-24 in NT

NT (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	0	0	3	3
Transplant	0	1	3	4
Totals	0	1	6	7

Figure 11: Numbers of young ESKD kidney patients treated at each clinic in the NT



Clinical consultation notes

- The introduction of a paediatric nephrologist to the Royal Darwin Hospital in 2017 has been a welcome initiative within Darwin and has met the needs of the younger kidney patients presenting in the Northern Territory.
- As there are no paediatric services, the adult renal teams are utilised with patients which include renal nurses and a renal dietician.
- Transplant is usually linked with Royal Adelaide Hospital (CNARTS) but can occur via other state hospitals (for example one young patient was transplanted in Brisbane).
- There is no formal transition process or policy, but transition discussions start around the ages of 14 – 15 years and transfer usually occurs at 18 years, depending on transition preparedness and vocational/educational needs of the individual.
- No specific major needs were identified, but broadly identifying access to trained paediatric (children and youth) staff including nurses, psychologist, social or youth workers, etc. was desired.
- All staff are stretched and need to be innovative and flexible to manage patients. Limitations on budgets and government funding support was mentioned based on the local economy.

- 2 hospitals service the young adult ESKD patients.
- 2 main adult hospitals in Darwin (5 young patients) and Alice Springs (2).

Australian Capital Territory

Table 20: Treatment of ESKD kidney patients between 15-24 in ACT

ACT Youth	15 – 18 yrs	19 – 24yrs	15 – 24 yrs	% of AUS Total
Dialysis	0	0	0	0
Transplant	0	6	6	1.6
Totals	0	6	6	1.1

Table 21: Treatment of ESKD kidney patients between 0-24 in ACT

ACT (0 – 24 yrs)	0 – 14 yrs	15 – 18 yrs	19 – 24yrs	Totals
Dialysis	0	0	0	0
Transplant	0	0	6	6
Totals	0	0	6	6

Figure 11: Numbers of young ESKD kidney patients treated at each clinic in the ACT



- 1 hospital services the young adult ESKD patients.
- 1 main adult hospital, Canberra (6 young patients).

Clinical consultation notes

- The ACT is classified as a regional centre and ACT hospitals do not perform transplants.
- ACT hospitals work with hospitals either in Sydney or Melbourne, which involves patients travelling for visitations.
- Travel for ACT patients and carers is costly in time and money.

Renal Clinic Youth Services Survey

Summary

- The Renal Clinic Youth Services Survey provided a national overview of current services for adolescent and young adult kidney patients, specifically around transition and transfer.
- The survey response was 28 from a possible 96 renal units (25%). This included the majority of major renal units associated with the provision of youth services.
- Although 66% of renal units reported having transition policies in place, only 17% documented these policies.
- At 71% of paediatric hospitals, kidney patients started transition services preparing for transfer around 14-15 years of age.
- 75% of renal units had no integrated peer support program, but desired one.
- 71% of renal units did not coordinate external peer networking and socialising opportunities for young adult patients.
- Main allied healthcare professionals not provided but desired by renal units included a youth worker (75%), peer support or youth mentor (75%), psychologist (58%), and transition coordinator or champion (54%).
- Respondents' free-form comments focused overwhelmingly on the lack of funding within adult healthcare to meet the identified need for supports for young adult patients.
- 33% of adult renal units coordinated or were involved in running Young Adult Clinics, reflecting lower funds available for support services within adult healthcare compared to paediatric healthcare.

“The renal team were and continue to be extraordinary, though when coming to deal with the psychological aspects of kidney disease tend to be lacking, especially in support for teens over 18.”

Survey analysis

Along with clinical visitations and meetings a Renal Clinic Youth Services Survey was also designed (ethics approved) and distributed to all renal units to assist with mapping services nationally.

- The survey response was 28 from a possible 96 renal units (25%). 24 of these were from the major renal units associated with provision of youth services which proved useful in analysis.
- Seven (7) of those 24 respondents were paediatric renal units (29%) representing all nationally and 17 adult renal units (71%), one of which identified as providing both paediatric and adult services.
- Patient numbers in the various age ranges (0-14 years, 15-18 years and 19-24 years) were reported (refer previous section).
- Based on the responses the number of young Australians living with non-end stage kidney disease has been estimated to be more likely between 2000 and 3000 based on the number of young patients reported as being treated per year.
- Transfers between hospital renal units varied greatly as expected with 5 units (21%) transferring or receiving between 11-20 patients annually, 7 (29%) transferred/received between 6-10 and 12 (50%) transferred/received 5 patients or less.
- The age of transfer reported from all paediatric hospitals was generally 18 years of age however one unit reported between 16-18 years. Commentary also indicated this was dependant on the **readiness of the individual** and in some cases was either earlier or later as hospital protocol allowed.
- Only 2 adult renal units (8%) from the 24 responses indicated there was no formal link or liaison with a transferring paediatric hospital renal unit when transferring or receiving a patient. 22 units indicated this was either formalised (17 or 71%) or was arranged through an external liaison (5 or 21%).
- New patients presenting to adult renal units indicated relatively small numbers annually with 1 unit reporting between 6-10 patients (6%), 4 units with 3-5 patients (24%) and 10 units under 2 patients (58%). 2 indicated they were unsure (12%). **A specialised response was identified as a need for young adults presenting directly to adult healthcare.**
- A majority of hospital renal units, 16 from 24 (66%) reported having transition policies in place whilst only 4 units (17%) indicated that these policies were actually documented and in place. 8 adult renal units (34%) indicated there was no formal policy regarding transition.
- 12 hospital renal units (50%) indicated they had a clinical lead responsible for the transition process. 1 was considering this approach and 1 mentioned that all clinicians took the "lead". 10 units (42%) indicated no clinical lead.
- Accepting the inter-individual variation in the readiness to commence the transition process, paediatric hospitals (only) reported 14-15 years as the most common age to start transition. This was reported by 4 of 7 units (57%), 16-17 years (2 or 29%) and 12-13 years (1 or 14%).
- 17 hospital renal units (71%) recognised and utilised an individualised response for transition which includes the development and use of a transition plan. 3 units (12%) were unsure whilst 4 units (17%) indicated they did not use a transition plan.
- 6 of the 7 paediatric renal units (86%) indicated they conducted transition clinics. The average age of patients that these are started is from 12-14 years of age and these are conducted between 4-6 times per year. One unit reported 7-9 times per year.
- Only 33% of the responding adult renal units had access to Young Adult Clinics for kidney disease care (this indicates 33% of the major adult renal units or 8% of all adult renal units). Overall 5 Young Adult Clinics were reported.
- 18 hospital renal units (75%) indicated they had no peer support program in place even though one was desired. 3 units indicated they did and 1 indicated they were developing a peer support program.
- Similarly the majority of hospital renal units (71%) found it difficult to coordinate external activities for young adult patients with only 5 units (19%) reporting they did so in some form. External activities were mainly facilitated through the young adult clinics or via other ancillary services (e.g. ChIPs program).

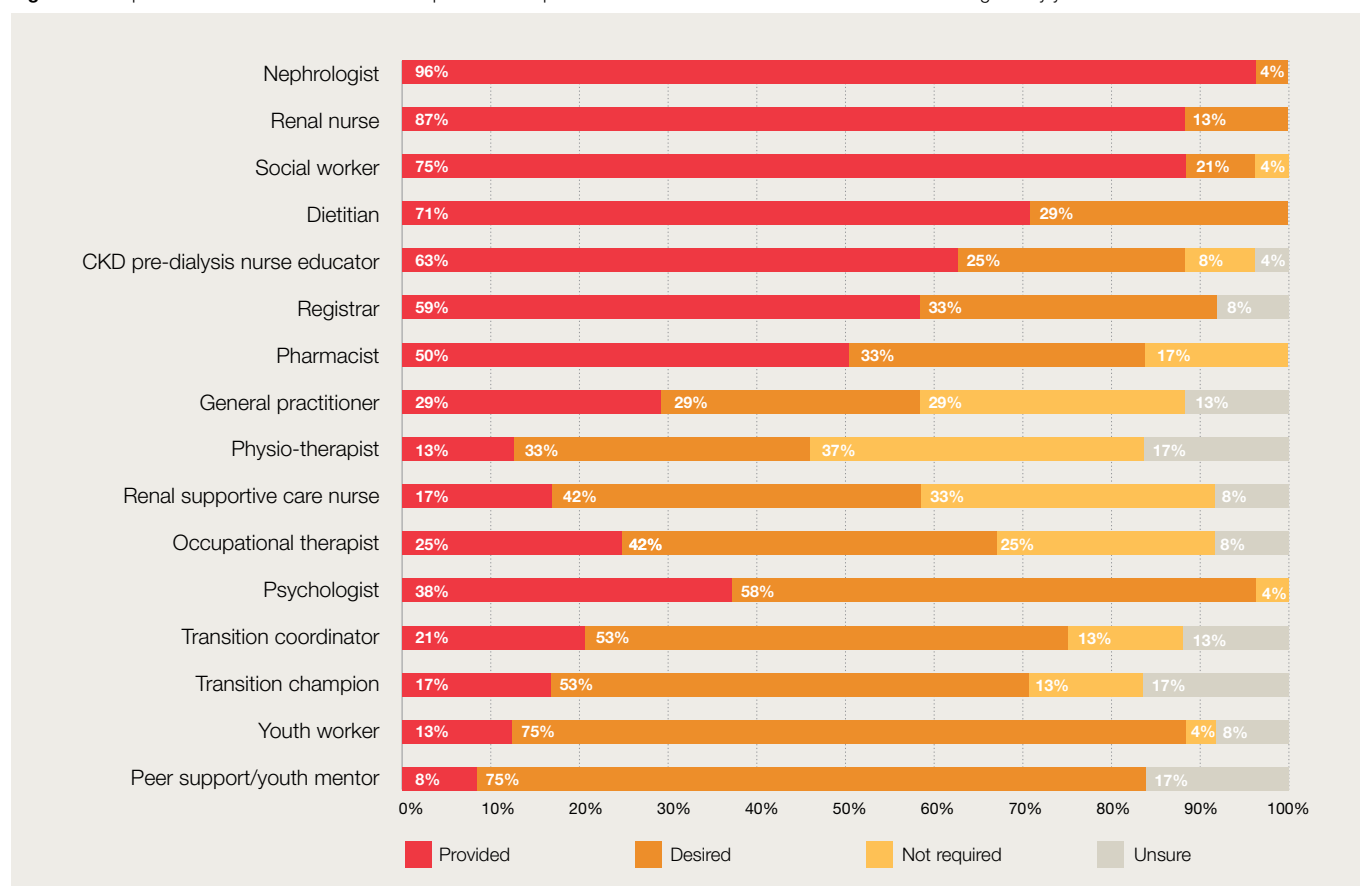
Multidisciplinary allied health team summary and analysis

The Renal Clinic Youth Services Survey presented clinic respondents with a list of healthcare professionals (refer tables below) and asked to respond as to whether each role was:

- Provided
- Not provided, but desired (Desired)
- Not provided and not required (Not Required) or
- Unsure

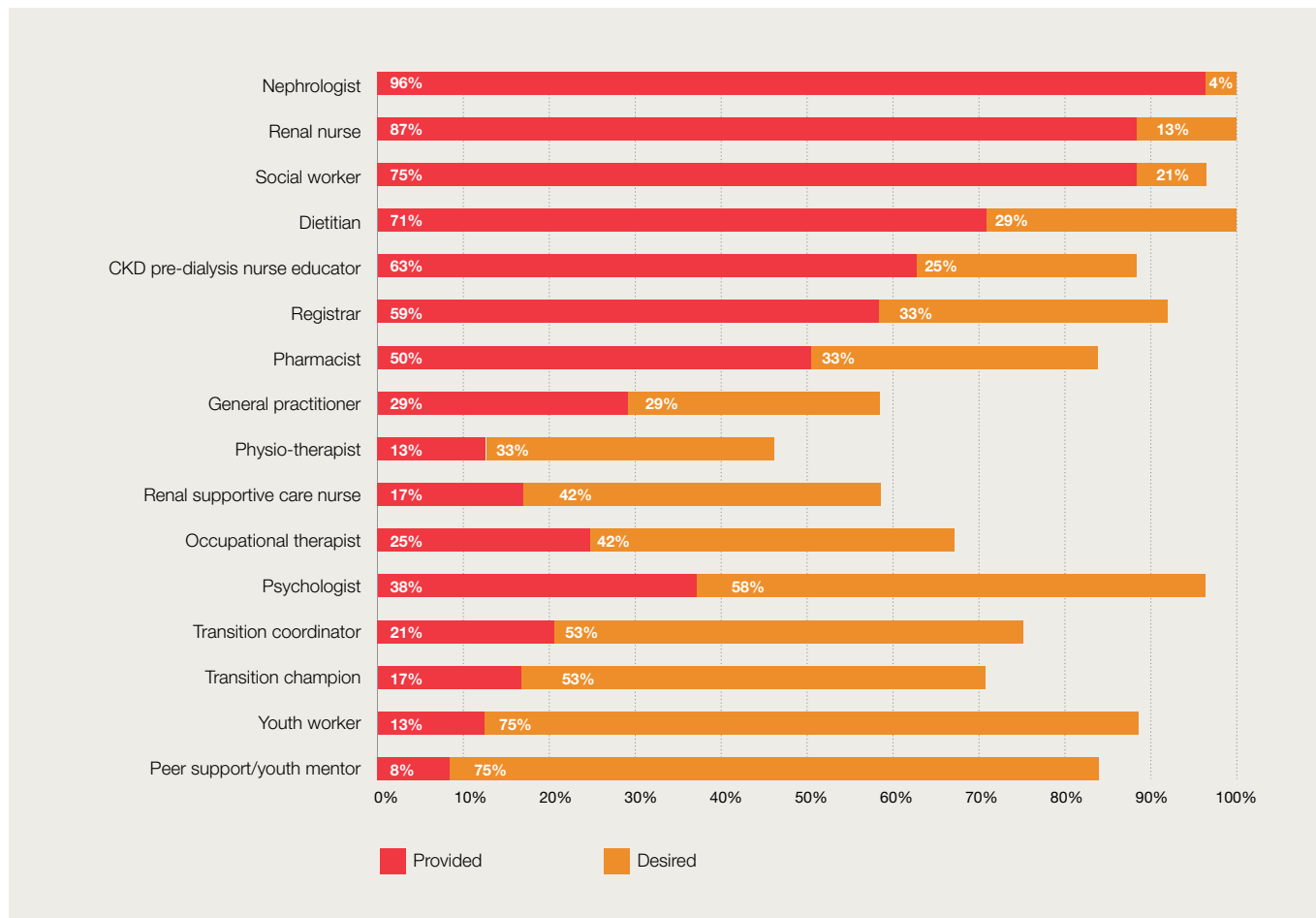
- A full analysis of the 24 main clinic responses obtained has been collated overall (example provided below), this has also been analysed by state and territory, by hospital and comparing paediatric and adult services.
- Best practice would ideally have most of these roles included or accessible as required within the multidisciplinary clinical team.
- Most renal clinics have the **core multidisciplinary team in place**, especially the larger units and this has been represented (in red) below. Most are either **Provided** or **Desired** (see Table 22 and Figures 13 and 14).
- The **main personnel identified as Desired** (in orange) includes a psychologist, youth worker (or occupational therapist), transition coordinator and/or champion (leader) and peer support/youth mentor (see Table 23 and Figures 15 and 16).
- This would reflect the reported need to provide increased psychosocial support, peer interaction and/or social activities.
- It has been reported that young adult clinics and transition clinics, where young adults (and carers) gather together in groups, assist in providing this environment and support.
- The remaining personnel were still either **Provided** or **Desired** by the majority.
- There may be limitations for some clinics including regional clinics achieving this with small patient numbers and may need to consider other strategies (e.g. combining/sharing personnel and services alongside other chronic illness young adult patients).

Figure 13: Proportions of core and allied healthcare professionals provided at the 24 main Australian renal clinics servicing kidney youth.



Source: Renal Clinic Youth Services Survey, Kidney Health Australia 2019

Figure 14: Proportions of provided and desired healthcare professionals at the 24 main Australian renal clinics servicing kidney youth.



Source: Renal Clinic Youth Services Survey, Kidney Health Australia 2019

Table 22: Percentage of Australian renal clinics providing core multidisciplinary team.

	Nephrologist	Renal nurse	Social worker	Dietician	Nurse educator	Registrar	Pharmacist
Provided	96%	87%	75%	71%	63%	59%	50%
Desired	4%	13%	21%	29%	25%	33%	33%
Not required	0%	0%	4%	0%	8%	0%	17%
Unsure	0%	0%	0%	0%	4%	8%	0%

Source: Renal Clinic Youth Services Survey, Kidney Health Australia 2019

Table 23: Percentage of Australian renal clinics desiring psychosocial and transition support.

	Psychologist	Transition coordinator	Transition champion	Youth worker	Peer support / youth mentor
Provided	38%	21%	17%	13%	8%
Desired	58%	53%	53%	75%	75%
Not required	4%	13%	13%	4%	0%
Unsure	0%	13%	17%	8%	17%

Source: Renal Clinic Youth Services Survey, Kidney Health Australia 2019

Table 24: Percentage of the 24 main Australian renal clinics servicing kidney youth **providing other healthcare professionals.**

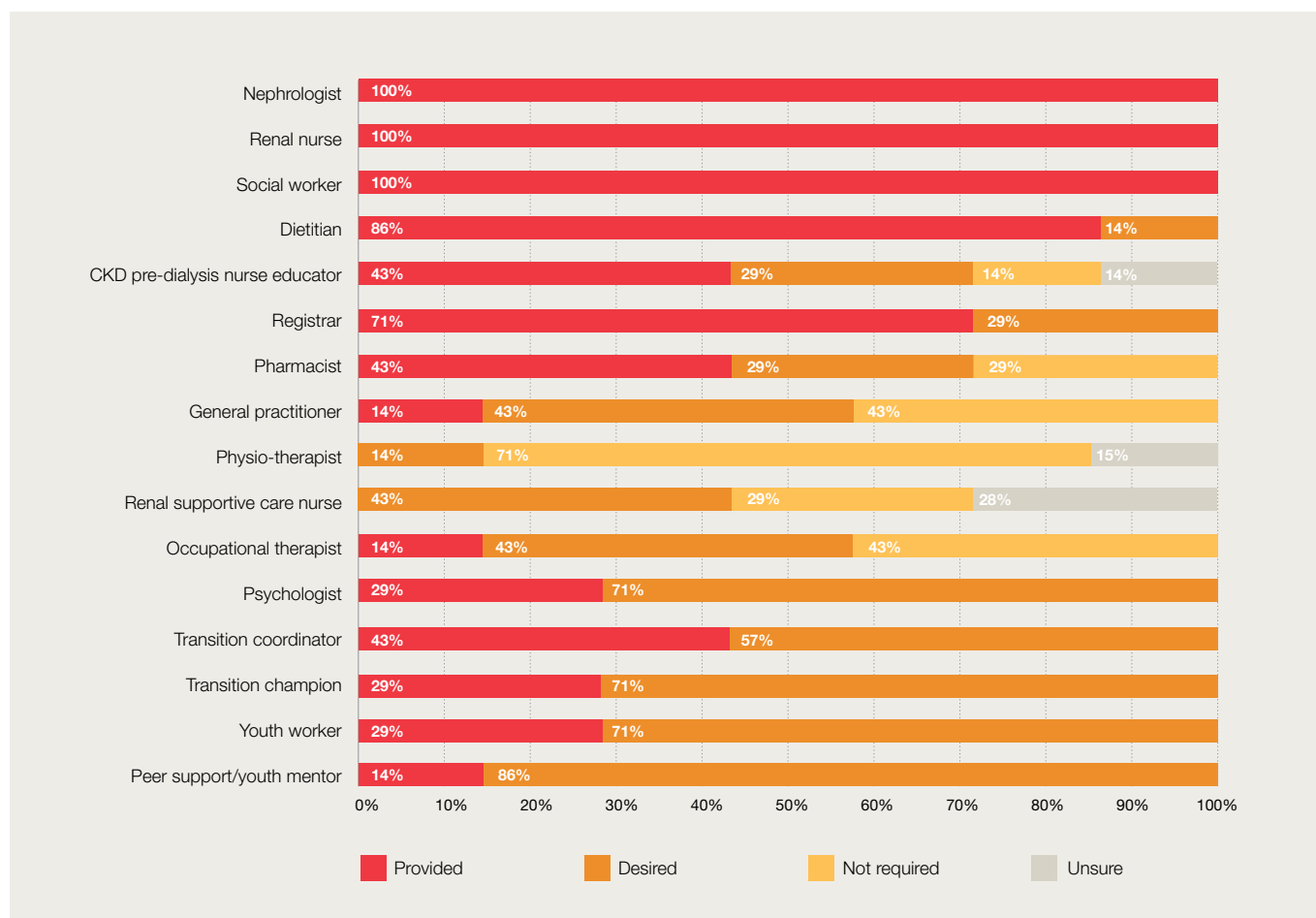
	General practitioner	Physiotherapist	Renal supportive care nurse	Occupational therapist
Provided	29%	13%	17%	25%
Desired	29%	33%	42%	42%
Not required	29%	37%	33%	25%
Unsure	13%	17%	8%	8%

Source: Renal Clinic Youth Services Survey, Kidney Health Australia 2019

Comparing the services and allied healthcare professionals available in paediatric care against those available in adult care (see Figures 15 and 16) highlights the difference in resources and overall care available for young patients who transfer to or present directly to adult healthcare.

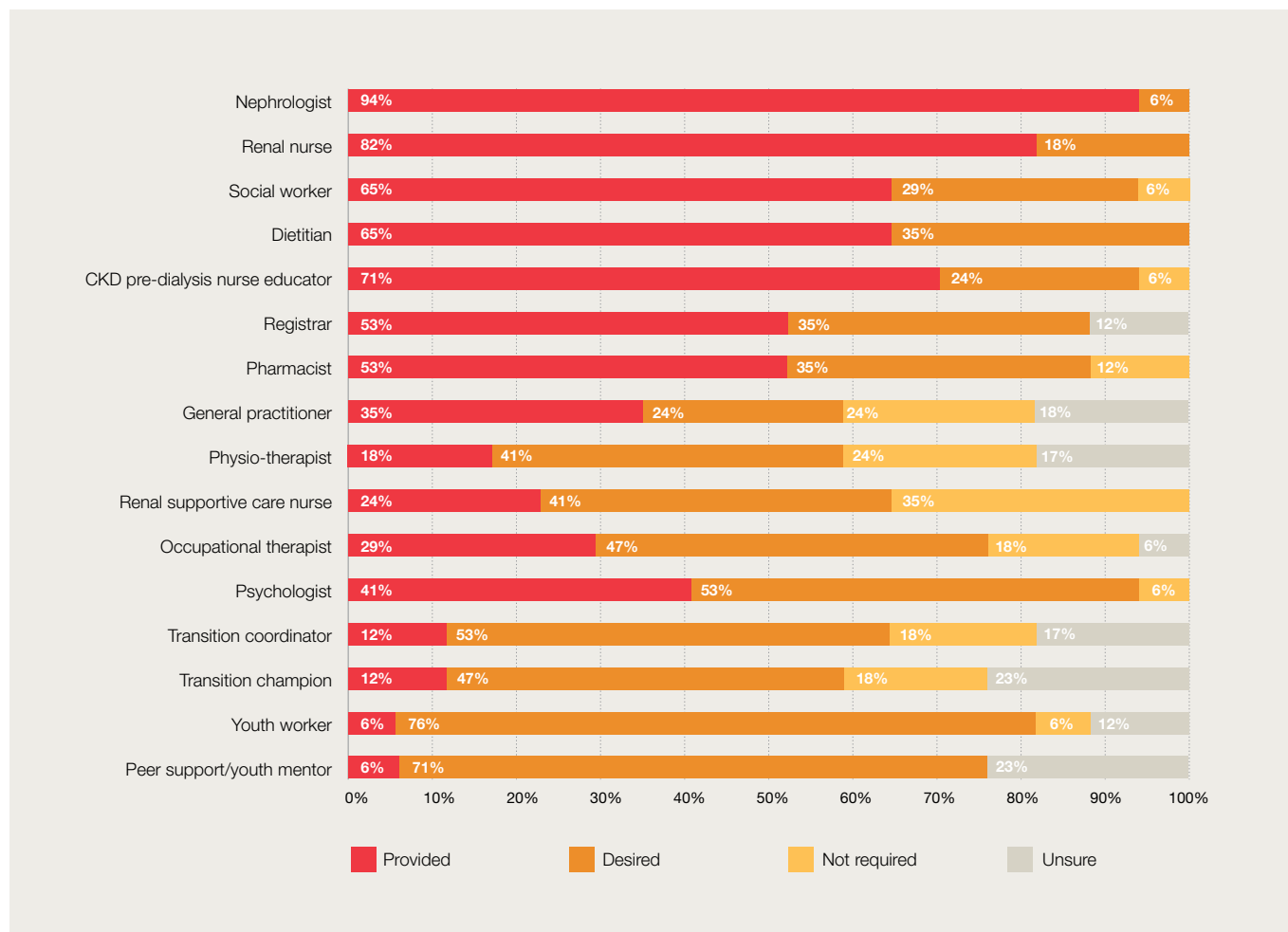
During the Clinical Consultation this difference was described as **"not a gap, seems to be more like a cliff or a chasm"**.

Figure 15: Healthcare professionals provided at paediatric renal units across Australia



Source: Renal Clinic Youth Services Survey, Kidney Health Australia 2019

Figure 16: Healthcare professionals provided at adult units across 16 of the main Australian renal clinics servicing kidney youth.



Source: Renal Clinic Youth Services Survey, Kidney Health Australia 2019

Summary examples: Clinician commentary regarding identified needs

- Paediatric hospitals are generally much better funded to cater for the increased care required for young adult patients than the adult hospitals.
- Increased care focused on young adult patients is recognised and desired by adult hospitals. Where funding and personnel are available this is being supported however funding within this area of response is generally not available in most adult renal units and is an identified need.
- There is a variety of transition and transfer processes in place nationally (some examples are provided below). Best practice reported includes transition services and/or transition and transfer clinics (cooperative between paediatric and adult hospitals) and young adult clinics following transfer.
- Need more support financially to access and/or train staff to provide the required care and support for this young adult group (should include allied health services particularly psychologists, social and/or youth work, dietician and pharmacist), and to be able to hold clinics more regularly.
- Youth care worker is seen as essential for a successful transition program or young adult clinic and provides the important link to consumer engagement. An appropriate youth friendly venue to hold young adult clinic at adult hospital or off-site is also desired.
- Need for social activities outside of the hospital setting and/or peer support program.

Examples of transition and transfer responses, services and resources in Australia

Transition and transfer services:
5 generalised examples are highlighted below:

- 1 Transition meetings/individual appointments** with doctors/nurses;
- 2 External transition service** (e.g. Trapeze NSW - external team and funding);
- 3 Internal transition service** (e.g. Royal Children's VIC - internal integrated multi-disciplinary team and funding) working across chronic illnesses and including the use of "Transition Support Workers");
- 4 Transition clinics:** Provide various services that aim to prepare adolescents with kidney disease to transfer to adult healthcare. Transition Clinics operate chiefly within paediatric settings, although often collaborate or cross over with one or more adult hospitals. Examples can be found in most states.
- 5 Young adult clinics:** Provide various services that aim to increase the care for young adults who have recently transferred from paediatric care, or present directly to adult healthcare at a young age. Introduced in Adelaide by the Royal Adelaide in 2013 using the Oxford-London model and implemented in Brisbane and Hobart in 2016 whilst working alongside transferring paediatric hospitals with transition clinics. In Adelaide and (until recently) in Hobart these clinics were external to the hospital whilst in Brisbane a suitable space is utilised within the Mater Hospital. Recently a young adult clinic was introduced in Melbourne by the Royal Melbourne.

Education, resources and training

A variety of resources currently exist including clinical information, transition and transfer policies and procedures, guides, tools and resources, appointment and medication management apps, and training for clinicians/healthcare staff.

Young adult support services

- **Individual case management and psychosocial support workers:** psychologists, social or youth workers, occupational therapists, etc.
- **Patient preceptors:** people living with kidney disease who are employed to provide advice, reassurance, mentoring, and education to peers with kidney disease.
- **Patient navigators:** employees who assist patients and carers to navigate hospital healthcare and government systems and services, and adjust to life with kidney disease.
- **Transition support workers:** employees in hospital transition support services who provide care for adolescents and their families/carers while undergoing transition to adult healthcare. They are ideally young people with lived experience of a chronic illness and either working or studying in a related field (social work, youth work, nursing, etc.). Transition support workers draw on their experience with chronic illness, transition and transfer to adult healthcare, where applicable, to support peers.

These services usually aim for a holistic and individualised based support and response which may involve topics or concepts such as: building wellbeing and resilience, identifying support mechanisms, navigating systems and services, strength based approaches, personal goal setting, self-management, education, work, home, psychosocial support, medication adherence, drugs and alcohol education and counselling, sexual activity education, physical activity, nutrition and sleep.

Peer support programs

Examples include ChIPS, Starlight Foundation (RCHM), Young Adult Clinics, Kidney Health Australia Programs (Camps, Activities, Networks and Forums).

Youth-focused services across chronic illnesses

Transition and transfer of adolescent patients does not just include kidney patients but also other chronic illnesses (e.g. Diabetes, Respiratory, Cardiac, etc). Consideration of this cohort together has provided value-added responses in some cases, especially where kidney patient numbers are not sufficient to warrant a certain response on its own (refer Medicare Benefits Scheme Review Taskforce Renal Medicine Clinical Committee Findings; Moving on Up Transition Framework TAS; the Mater Young Adult Clinic QLD).

Chapter 5: National Youth and Carer Consultation

Kidney Youth and Carer Consultation

- **Focus group sessions** and individual face-to-face discussions with over 125 adolescents and young adults living with kidney disease and their carers were conducted nationally to capture patient/carers experiences and feedback.
- Further information and data were collected from attending four **young adult clinics** (Adelaide, Brisbane, Hobart and Melbourne) and one **transition clinic** (Perth).
- A **Kidney Youth and Carers Survey** was also designed and promoted nationally to complete online increasing the scope of responses to those we could not engage with face-to-face.



Section 1: Youth and Carer Survey

Summary

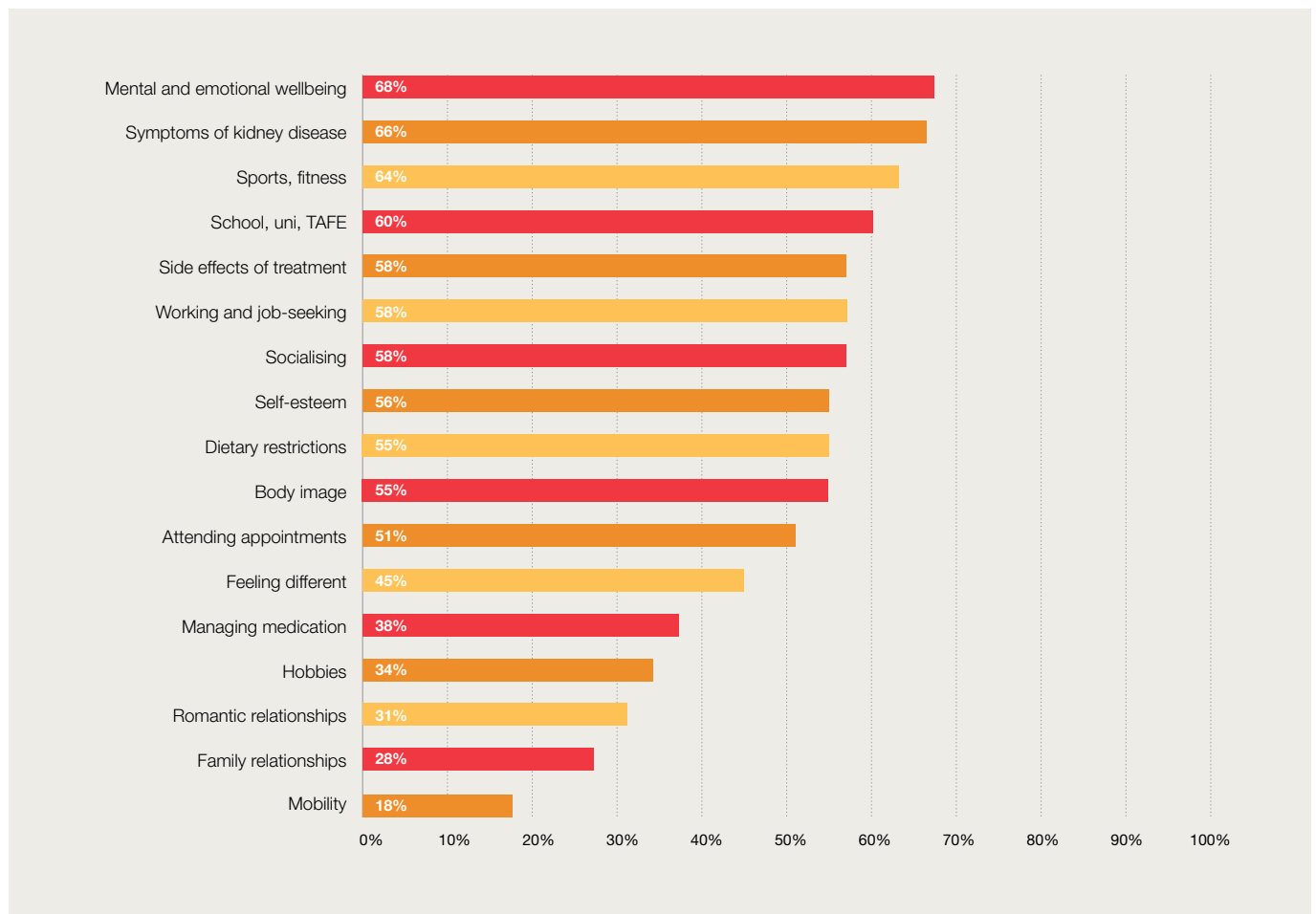
- Total of 138 responses to the Kidney Health Australia Youth and Carer Survey, comprised of 114 young patients and 24 carers.
- Both patients and carers reported kidney disease impacting on their mental and emotional wellbeing above all other areas of impact.
- Patients also reported kidney disease impacting on their life participation relating to socialising, participating in hobbies and sports, and education.
- Carers reported struggling to manage time demands of clinic appointments and life restrictions relating to managing kidney health and treatments at home.
- Both patients and carers reported desiring more access to peer support above all other forms of support and assistance.
- Patients rated their satisfaction with kidney healthcare overwhelmingly high, but desired more psychosocial support.

A summary analysis of the survey is below:

- For full survey content and analysis, including demographic information please contact Kidney Health Australia
- Total of 138 responses, 114 (83%) were living with kidney disease
- Remaining 24 (17%) were carers or a caregiving family member of a young person living with kidney disease
- Our survey effectively reached the target demographic; the majority of patient respondents (54.4%) were in the 15-18 and 19-24 age brackets
- Mean age of all patient respondents was 28.5 years
- Mean age of patient respondents within the 15 – 24 age bracket was 20.9 years

Youth responses

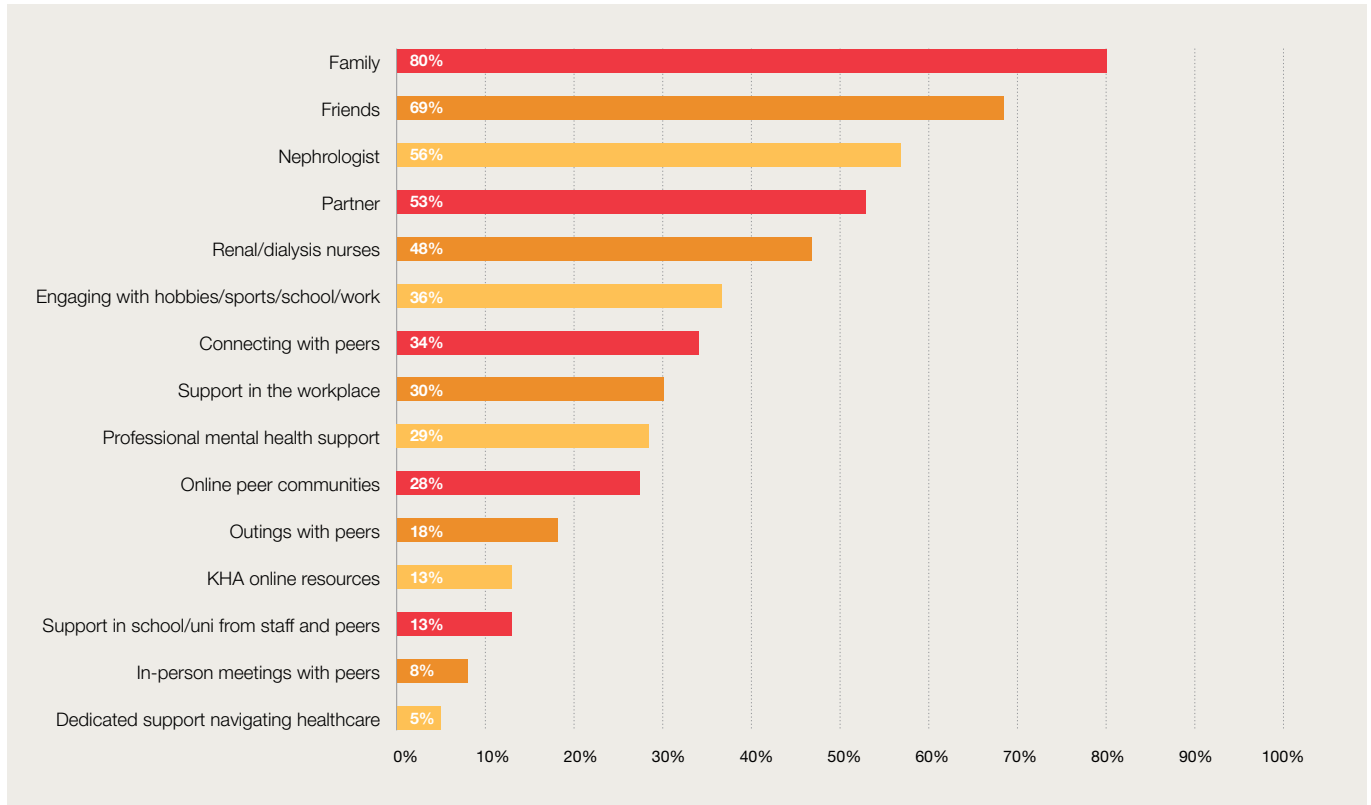
Figure 17: How CKD impacts on life and wellbeing of young patients (n=80)



Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

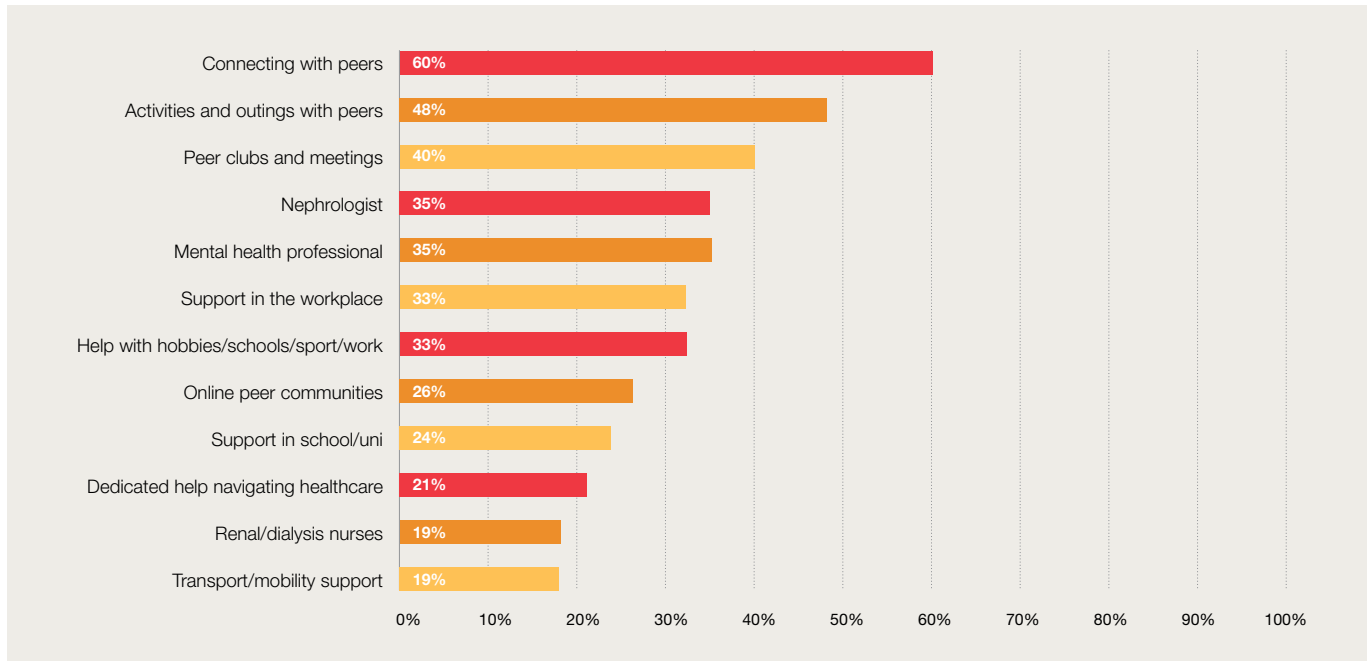
- Patient respondents overwhelmingly reported kidney disease impacting on their mental and emotional wellbeing (68%) [i.e. 78 from 114].
- The next two largest areas of impact were respondents' capacity to engage in sports and fitness (64%) and school, university, or TAFE studies (60%), both representing limited life participation.
- Major impacts of kidney disease came from symptoms of kidney disease (66%), followed by the side effects of treatment (58%) and dietary restrictions (55%).

Figure 18: Sources of support used by kidney youth (n=80)



Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

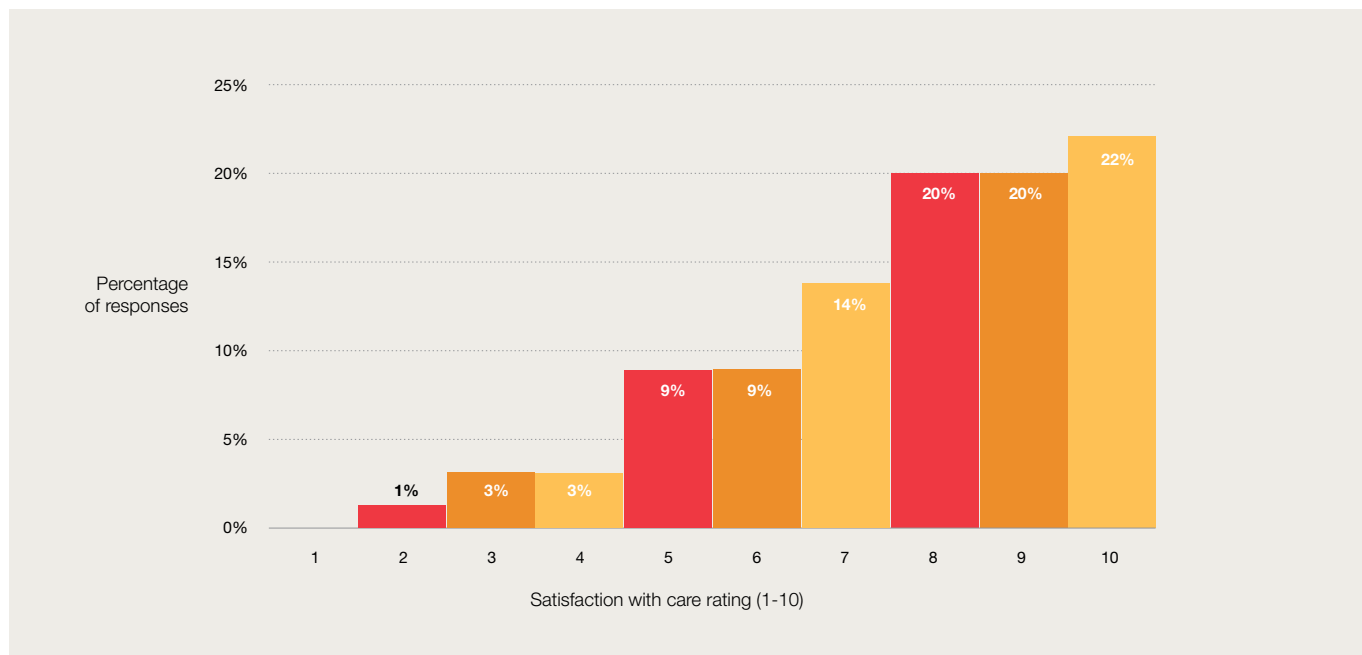
Figure 19: Supports kidney youth want to use (n=80)



Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

- Support used by most patient respondents was drawn from existing relationships with family, friends, and partners.
- 30% of patient respondents currently use or previously have used peer support, whereas 60% would like to use peer support but have no access.
- Patient respondents are most interested in activities and outings with peers (48%) as opposed to support group meetings (40%) and online communities (26%).
- A significant minority of respondents desired support integrated within the workplace (33%) or school/university (24%).

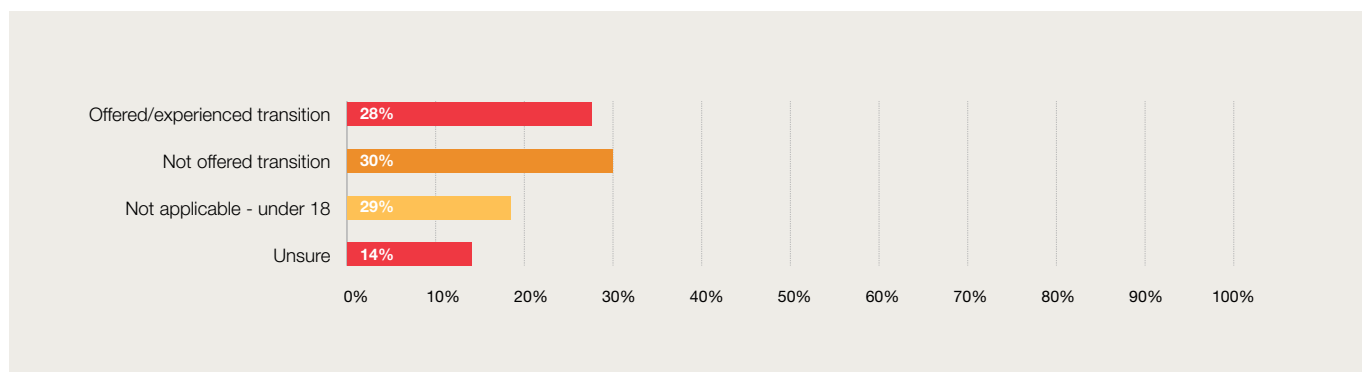
Figure 20: Patient satisfaction with care (n=79)



Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

- Kidney healthcare professionals also provided an important source of support.
- 56% of young patient respondents reported drawing on their nephrologist for support and 48% reported drawing on dialysis/renal nurses for support.
- Accordingly patient satisfaction with overall healthcare was extremely positive, with a mean rating of 7.7 out of 10.
- The minority of responses which gave neutral or negative ratings to healthcare focused on young patients' need for greater social support from healthcare professionals, and difficulty navigating healthcare systems and managing appointments.
- Free-form responses showed that some patient respondents desired more holistic psychosocial support from their kidney healthcare team.

Figure 21: Patient respondents' access to transition services (n=80)



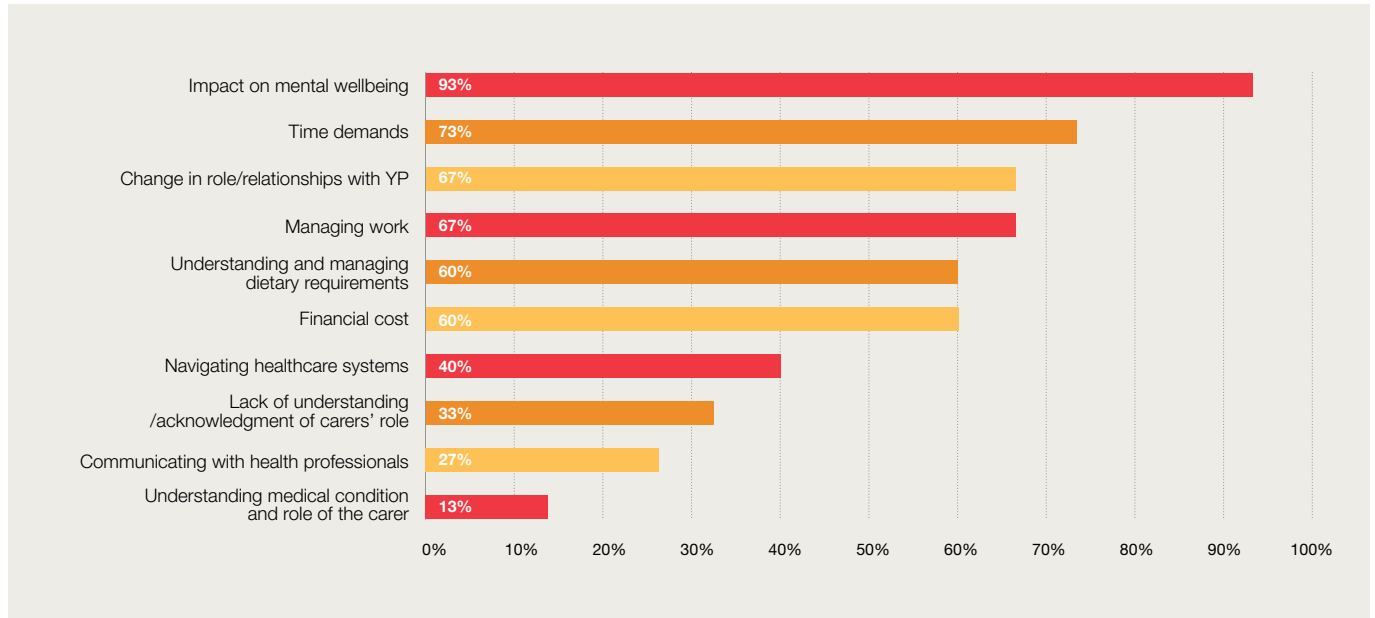
Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

- The survey did not find considerable information about transition services offered to adolescent patients as only 28% of patient respondents underwent or were offered participation in transition services.
- The 14% of respondents who were unsure whether they had been offered transition services might indicate a lack of awareness of transition services in medical settings where they are available but **insufficiently promoted or understood by the young person.**

Carer responses

- Kidney Health Australia recognises that carers of young patients may be neglected by medical and support services due to the focus being on the young patient.
- The Youth and Carer Survey directed carers to a separate set of questions enquiring about carers' experience during their child's healthcare journey.

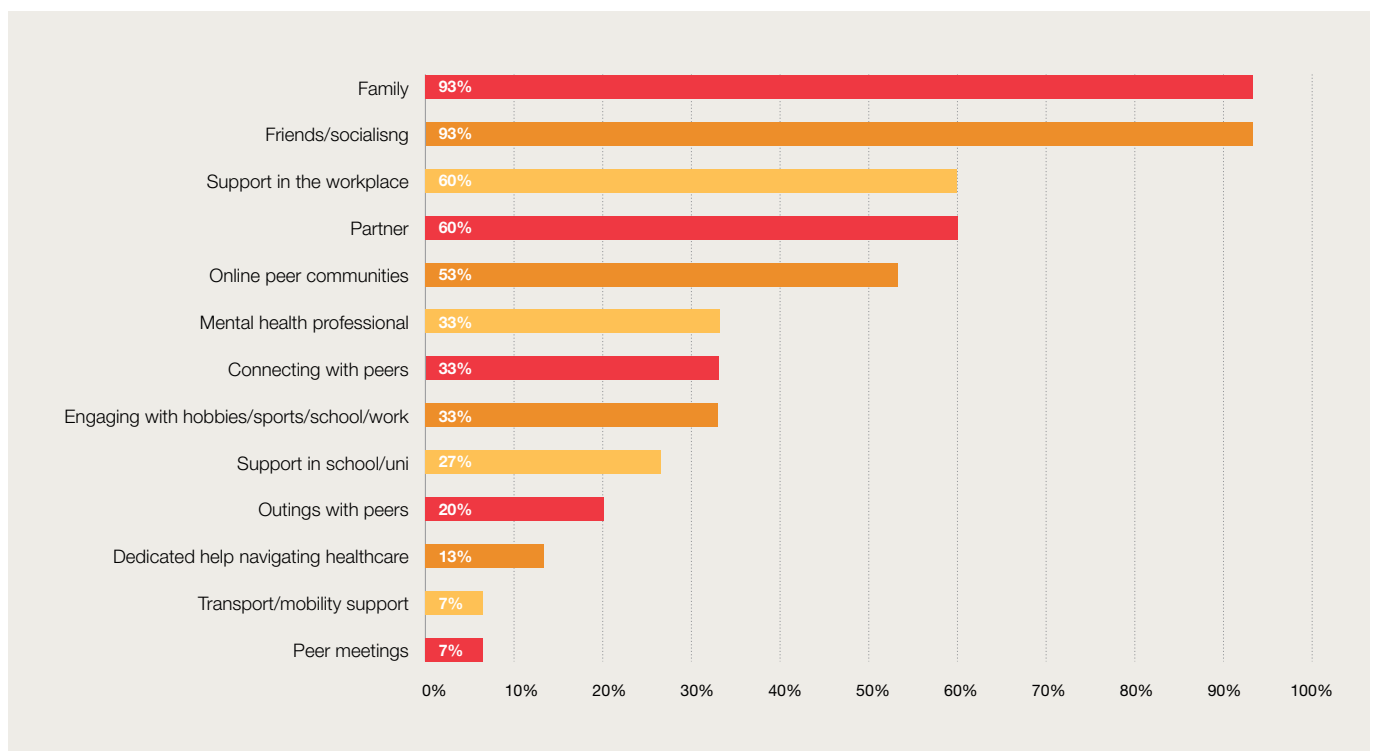
Figure 22: How caring for a young person with CKD impacts on carers (n=15)



Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

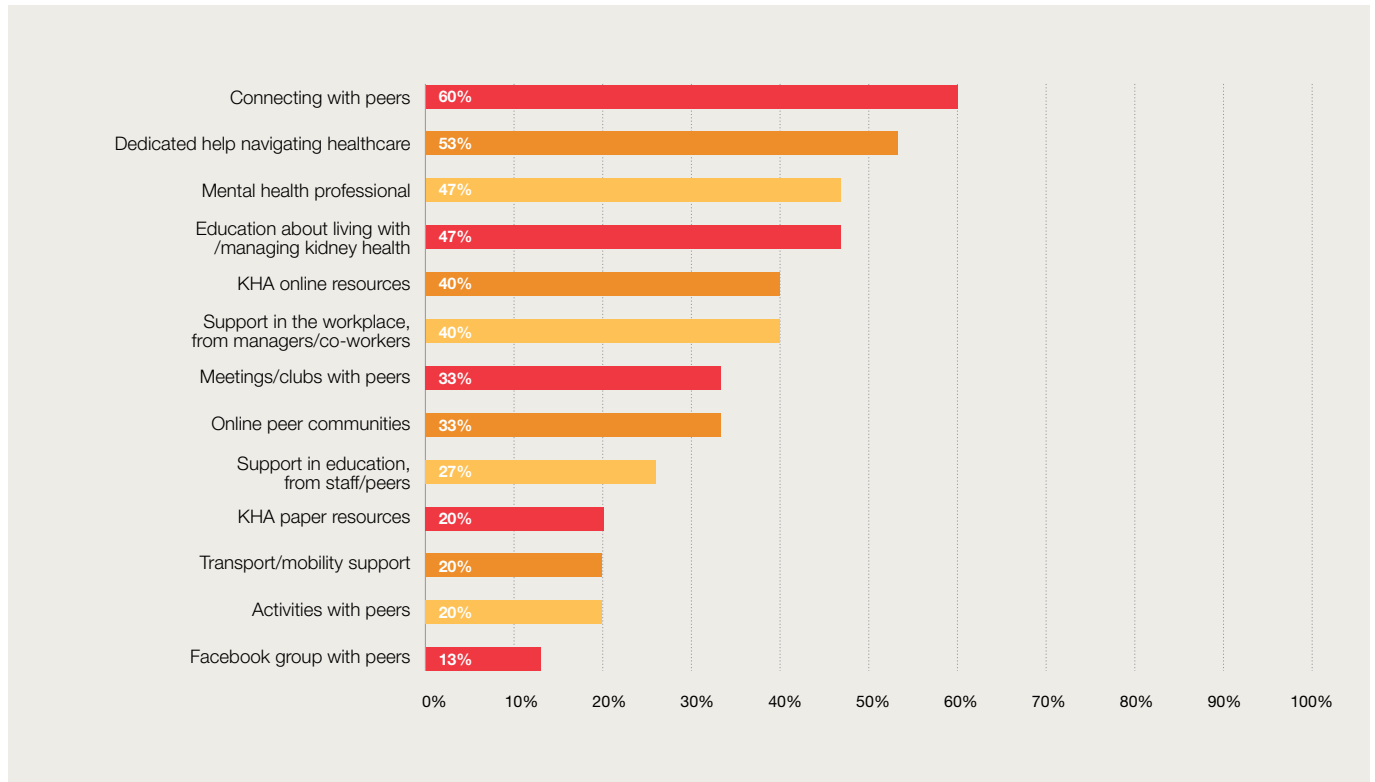
- An overwhelming majority of carer respondents reported impacts on their mental wellbeing as a result of caring for a young person with kidney disease (93%).
- Without contending with the disease and treatment burden of kidney disease like their children, carers' other main areas of impact focused on time and financial constraints.

Figure 23: Supports carers use (n=15)



Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

Figure 24: Supports carers want to use (n=15)



Source: Kidney Youth and Carers Survey, Kidney Health Australia 2019

- 33% of carers reported drawing on support from other carers of young people with kidney disease, while 60% of carers desired access to in-person peer support.
- 53% of carers also reported receiving support from online peer communities.
- Carers also received support from their families and within their workplaces.
- Carers desired more support targeting managing kidney disease in the home and navigating kidney healthcare in hospital and government welfare settings.

“You can talk to people so much about what’s going on, but I find unless you’re living it no one really understands the struggles you face.”

“The stress and shock at my son being at end stage kidney failure was incredible. Watching all the medical procedures my son was going through and not being able to help him was soul destroying and devastating.”

Section 2: Youth and Carer Consultation sessions

Section 2.1: The challenges and priorities

– Youth perspective

Summary

Challenges and priorities for young people living with kidney disease

Drawing on summary responses from approximately 150 young patients they stated that:

- CKD is isolating and limits participation in usual life activities.
- Symptoms of CKD, side effects of treatment, and activity limitations impacted on young patients' mental health.
- They felt insufficiently prepared for transition and wanted more education.
- Mental health support and acknowledgement was lacking inside and outside hospitals.
- The hospital and government healthcare systems are too complex to navigate.

Table 25 represents the major problems and challenges faced by youth in managing and living with kidney disease. The responses are drawn from the workshop sessions conducted during the National Youth and Carer Consultation Sessions and from the Kidney Youth and Carer Survey.

It is possible that the youth surveyed in our consultation were less likely to discuss certain topics such as experiences with bullying and illicit substances due to their sensitive nature, and the group format of the Consultation Sessions.

Other factors for consideration include;

- Influence of social media e.g. on body image and non-compliance.
- Bullying; youth with chronic disease experience higher rates of bullying.
- Peer pressure and influence on non-compliance and experimenting with illicit substances and alcohol.
- Relocating for healthcare resulting in displacement from support base.
- Relocating can be particularly difficult for young indigenous patients due to cultural disconnection.
- Missing school due to appointments and illness may result in social and developmental delay.
- Being limited by hygiene, mobility, and lacking energy despite wanting to engage in outings and activities external to hospitals.

"I got sick, and the first thing I thought of, was I can't play football again. I forgot about the whole I'm sick part."

"It's definitely hard to keep friends when you're sick. I've lost so many friends."

Table 25: Challenges faced by young people living with kidney disease

Impacts on life participation	
Missing out on socialising and making friends	<ul style="list-style-type: none"> • It's definitely hard to keep friends when you're sick. I've lost so many friends. • We were learning multiplications, and that wasn't what I was bummed about, I learnt about that in Grade 1. I was more bummed about that connection with friends, the friendship circle I had would disappear. • It's really hard going into classes and not have anyone that I would know... you were in classes with complete strangers... I missed half the grade so I didn't get the full- what all the other kids got, where they made groups.
Unable to participate in hobbies	<ul style="list-style-type: none"> • I got sick, and the first thing I thought of, was I can't play football again. I forgot about the whole I'm sick part. • When I had to disclose my CKD to my scout group I was excluded from more rigorous hiking and outdoor activities because they were scared I would not be able to complete the activity.
CKD is isolating	<ul style="list-style-type: none"> • Sometimes when I talk to my friends who are, you know, "normal", I just feel like I'm just begging for their attention. Like I don't want any pity party, you know what I mean? I just want them to hear me out but not... feel sorry for me. • I had a window where I could watch the school kids come out every afternoon. I could just sit in the hospital and watch school kids come out, that was like my day. Time disappears. • For us in the Northern Territory it's really isolating... but there are more, but it's just that they're not linked, there's no connection.
Romantic relationships and family planning	<ul style="list-style-type: none"> • After a divorce the infections reduced and I felt even though my ex-husband was extremely clean and conscientious about hygiene, when opportunity arises for non planned sexual relations I literally considered the risk of even a basic infection. • Struggling to start a family after being newly engaged I was diagnosed. • I haven't had any meaningful relationships as my condition holds me back. • Gut wrenching - so unsure of the future & what her quality of life will be. One of her dreams from since she was very young was to be a mother but we've told this will be highly unlikely.
CKD impacts on and is exacerbated by struggles with mental health	
Body image and self esteem	<ul style="list-style-type: none"> • All the medications I have to be on for the rest of my life – like the side effects of these medications include like moonface, so you can kind of see my face is a bit chubby. Like I was very stressed with that side effect, 'cause you know, I mean in teenagers they're like- they care about how they look and stuff, so I was very stressed. And then sort of like got really depressed.
Downward spiral relationship with anxiety and depression	<ul style="list-style-type: none"> • [losing employment] was a BIG push-down on my confidence. It made my anxiety skyhigh. • This time around I have developed a lot more anxiety and depression and have being seeing a social worker. • Diagnosed a few days after my birthday. Very stressed. Already had anxiety disorders and early signs of depression which didn't help.
Lacking mental health support	<ul style="list-style-type: none"> • The renal team were and continue to be extraordinary, though when coming to deal with the psychological aspects of kidney disease tend to be lacking, especially in support for teens over 18.
Fear and uncertainty about the future	<ul style="list-style-type: none"> • Biggest fear is not knowing what will happen as I get older (my disease is only "new" and unknown), and also negative side-effects of possible medication I would take if I relapse (eg. higher risk for various cancers or brain diseases). • I am nervous about the next stage of my life and the decisions I need to make for a career or study.

Barriers to self-management

Burden on patients to self-educate	<ul style="list-style-type: none"> I think explaining some things in detail pre-dialysis would have been good, I went into this blind and I learnt everything myself by joining Facebook groups and using Google.
Insufficient patient education	<ul style="list-style-type: none"> Before transplant I didn't overly know the reasoning behind all the medication I was on past things like this one's for blood pressure. It would have been nice to know exactly why each drug is taken.
Disability factors	<ul style="list-style-type: none"> It's certainly a worry, that _____ would not cope with transition... she's had speech therapy for years. I can't even understand a full conversation with _____ at times. So for her to be able to understand all that then verbally tell me, it's not going to happen.

Lack of support and awareness outside hospital

Lack of understanding in schools and workplaces	<ul style="list-style-type: none"> But what's really the worst is the teachers don't recognize that she's actually missing school because of an appointment. If she's really unwell and they need to monitor it closer and she's going to there more often, they will make an occasional comment. And I just think, well that was a bit nasty. I'm trying to get into uni courses... I need a lot of evidence proving that I've been sick.
No recognition of YP with kidney disease	<ul style="list-style-type: none"> You can be fine and full of energy one day and next you're at a function feeling pain, fever and sick. We do our best to present normal, as people cannot see you as ill and explain kidney infection in the work place isn't acceptable like the flu. I thought during the time I spent on dialysis I felt very secluded, everyone in the dialysis clinic was much older than me. The toughest thing is I look normal and healthy on the outside even compared to other CKD patients so I feel embarrassed about my current situation. I have a good support with my friends yet deep down I don't share the extent of my feelings.
Limits of support from non-peers	<ul style="list-style-type: none"> All my mates have been the same mates I've had since primary school and high school and they know just as much about kidney failure now than what I do because they've been through it all with me. So that's a sort of support, and then there's only so much those people can do.
Limited support inside hospitals	<ul style="list-style-type: none"> You don't really interact outside the hospital, and in the hospital, I don't think I've met anyone here for more than 5 minutes. So something like that, I would enjoy it, I think other people would do.

Challenges related to transition

<p>Reduced support in adult healthcare</p>	<ul style="list-style-type: none"> • Once you turn 18 and have to leave paediatric care, kidney disease can feel very isolating. It feels like you are the only 20 something going through this disease. Everyone you encounter seems to be above the age of 50... it can really feel like an old person's disease.
<p>Transition too brief</p>	<ul style="list-style-type: none"> • It was quite hard as it didn't feel like much a transition more like an introduction and then them going away and washing their hands with you. • It was too short, there was no time spent with going into adult care & prior relationships formed with care providers.
<p>Transition may exacerbate anxiety</p>	<ul style="list-style-type: none"> • When I transitioned from Professor Smith to you, I wasn't told either. 'Cause I struggle with anxiety, and so that was part of the reason I stayed in paediatric so long.
<p>Over reliance on carers</p>	<ul style="list-style-type: none"> • I've been aware numerous times since they kept hammering it into my head, 'oh you're going to transition, you might want to take care of your documents'. And I'm like 'nah, I'll let my mum handle it'.
<p>Youth presenting directly to adult healthcare miss peer support</p>	<ul style="list-style-type: none"> • I felt very isolated to be dialysing with elderly people. I was 22 and attending Uni and there was no support or anyone I could talk too. I felt the people whom I dialysed with were 40+ yrs older than me, how could they know what I am feeling as a young adolescent.

Challenges within hospitals

<p>Unable to navigate intricate hospital system</p>	<ul style="list-style-type: none"> • [health professionals] allow you to get lost in the system, no one to co-ordinate your healthcare. Between multiple doctor appointments. • Miscommunication or lack of communication between Drs. On the whole, we have been very lucky, but it is challenging across different specialties.
<p>Missing rapport with health professionals</p>	<ul style="list-style-type: none"> • I was uneasy around some of them. They acted like I was a baby. • They go by the textbook cases and assume all patients are the same. React the same, cope the same... • Talk down to you, be dismissive, ignore your concerns. • Lecture me and say that the medication side effects aren't that bad. Say that I should just put up with it.

Section 2.2:

Young Indigenous Australians living with kidney disease

Summary

Challenges and priorities for young people living with kidney disease

- The high disease burden of kidney disease faced by young people is compounded for young Indigenous Australians, who experience exceptionally high impacts on their quality of life and health outcomes, and receive minimal support.
- Culture, Country and the Spirit represent important domains of health and disease to many Indigenous Australians, and has a crucial role in healthcare, self-management and quality of life of Indigenous Australians, although healthcare often fails to acknowledge these considerations.
- The needs of an Indigenous person's Spirit needs to be prioritised because there needs to be better practices in place to provide healthcare with a holistic approach. The needs of the Spirit are often forgotten in conventional healthcare.
- Some Indigenous Australians define youth ending and adulthood beginning at around 35-40. Organisation of Youth Program events, services and support which include young Indigenous Australians should consider this difference in conception of youth and adulthood.
- Many young Indigenous Australians take on roles and obligations as carers for their families, which are often prioritised over and clash with their own healthcare needs.
- Statistically, young Indigenous Australians face exceptionally high pressure relating to increased risk behaviours such as diets high in sodium and sugar, smoking and alcohol consumption, and therefore have a greater risk of developing diabetes, heart disease, CKD and other chronic diseases.³³
- Rural and remote young Indigenous Australians diagnosed with kidney disease are usually required to relocate to access treatment, which affects social and emotional wellbeing – making it difficult to comply with kinship systems and roles and responsibilities in their communities.

Kidney disease statistics among Aboriginal and Torres Strait Islander peoples³³

- In 2012–13, almost one in five (18 per cent) Aboriginal and Torres Strait Islander peoples aged over 18 had indicators of chronic kidney disease.
- After adjusting for age differences, Aboriginal and Torres Strait Islander peoples are more than twice as likely as non-Indigenous people to have indicators of chronic kidney disease.
- Aboriginal and Torres Strait Islander peoples are more likely to have end stage kidney disease and be hospitalised or die with chronic kidney disease than non-Indigenous people.
- Aboriginal and Torres Strait Islander peoples experience a higher burden of disease at two and a half times that of non-Indigenous people.
- Aboriginal and Torres Strait Islander peoples living in remote areas are more than twice as likely as those living in non-remote areas to have signs of chronic kidney disease. Amongst Aboriginal and Torres Strait Islander peoples, the heaviest disease burden impacts on people living in very remote (36.7%) and remote (27.6%) regions.³⁴

Young Indigenous Australians with kidney disease

The higher disease burden of kidney disease faced both young people and Indigenous Australians is compounded for young Indigenous Australians, who experience exceptionally high impacts on their quality of life and outcomes, and receive minimal support.

Young Indigenous Australians' exceptionally higher burden of disease warrants special attention within the Youth Program. After closing the Youth and Carer Survey, we found that only 8% (total of 11) of respondents identified as Aboriginal and/or Torres Strait Islander. We had also not seen significant Indigenous representation at the national workshops and focus groups, possibly due to cultural differences making the format of consultation methods more favoured by non-Indigenous Australians than by Indigenous Australians.

To address the lack of Indigenous representation in consumer contributions, we arranged consultations with three young Aboriginal and Torres Strait Islander community members who live with kidney disease. We invited them to discuss their unique challenges, experiences and perspectives relating to kidney disease as both Indigenous Australians and young people, to co-design a strategy for seeking further engagement from young Indigenous Australians in the Kidney Health Australia Youth Program, and to co-write this section of the report.

The content in this section is not representative of the attitudes and experiences of all young Indigenous Australians as we have not conducted a comprehensive survey needed to inform such a representation. Due to the diversity of Indigenous cultures and communities across Australia, the views in this chapter are not representative of all Indigenous Australian individuals or Indigenous Australian cultures. Instead, this section demonstrates Kidney Health Australia's ongoing commitment to helping young Indigenous Australians with kidney disease.

Table 26: Challenges and priorities for young Indigenous Australians living with kidney disease

Challenges and priorities	
<p>The role of the Spirit in health and healthcare</p>	<ul style="list-style-type: none"> • It plays a really big part in the preventative stage. If your spirit is right, you're less likely to get into bad habits that add to the high risk factors of kidney disease. • I've even found that within myself, keeping my spirit in check and going back to country is like a thing that recharges the spirit. So that when I come back to places like this here, you can feel your disconnect from country starts depleting the spirit. And then your attitude towards caring for yourself does change. • For Aboriginal people too, you gotta have the spiritual component in there because we're spiritual people. And when we're sick, our spirit is sick too. And if you don't have your spirit right, that even affects the ability to care and your attitude towards caring for yourself as well.
<p>Different conceptions of youth, adulthood and maturity</p>	<ul style="list-style-type: none"> • From a Western perspective, I'm not seen as young – I mean yes and no. You're more seen as an adult now. But in an Aboriginal context, I'm still a child. So your responsibilities, your obligations, your roles and responsibilities in the community are definitely that of the youth and younger. • From 35 to 40, in that is when you're sort of starting to be recognized as an adult then. I would say when you're in your 30s you're still recognized as a kid, even though you're maturing as an adult and whatnot, but then your obligations in the community are still [that of a young person's]. • When I'm around non-Aboriginal people who are my age, their roles and responsibilities within their family and community are totally different. They do seem more mature, I don't even know if mature is the right word. But just, the things they're thinking about in life in terms of the roles and responsibilities in their family are a lot different to mine. • I've been dealing with renal for over ten years, and I feel probably within the last three years that I've gotten confidence to know more about- it's taken that long to really know and be fully educated.
<p>Aboriginal Elders becoming younger due to lower life expectancy</p>	<ul style="list-style-type: none"> • When you look at the mortality rates in Aboriginal communities as well, our Elders are 60, now starting to almost be 50. So our Elders are getting younger as well, which means that you look at your lifespan and what you can fit in that time and how your roles and responsibilities are viewed. • An Indigenous person would be lucky to make 50. In the community an Indigenous person would be classed as an Elder when you're 50.

<p>Conflicting priorities to family and to self</p>	<ul style="list-style-type: none"> • You have your circle of your family obligation, your circle of your individual health, and they often won't sit within each other. Your health will be over here, your family obligations will be here, and you prioritise your family obligations. • The responsibility and the pressure put on you, because we come from that – it's not an individualistic society, it's a communal society, so you're more focused on the whole community rather than yourself... But I think now with the high risk factors of all the health issues, like it's having to move into that individual-style of priorities. • There's some kids who won't even go to school because they want to care for [relatives with kidney disease]. See I pulled out of school at year 10 and I cared for my grandparents because they both had cancer. And I cared for them until I died and I didn't worry about school. It didn't even worry me, to worry about school, I just had to look after my family. A lot of Indigenous families will do that. • Sometimes in the community they look after their family, no matter what age they are... my daughter, she's always with me and she cares for me. She's only 14. But I don't ask her to do too much, but she will help around the house. She likes coming with me to appointments. She used to come to dialysis with me.
<p>Adverse life events and socioeconomic factors disrupting capacity to attend treatment, follow food and medication guidelines etc.</p>	<ul style="list-style-type: none"> • Some of these unhealthy habits are just being so ingrained into the culture and the social context of your families, it's hard to escape from and it's hard to not be tempted to get involved in those sort of habits, because you learn it as a young kid, it just becomes embedded into your lifestyle which is just unhealthy anyway. • Dealing with issues like alcoholism in the family, family separation and breakdown, living in and out of other families' homes and not having that stability... What are Aboriginal people having to worry about and deal with? On top of prioritising their health and picking up things like blood pressure, getting diagnosed and treated. • In the community, I know in Yalata they've got a healthy store now. Other communities have just got Coke, they don't care about the health of the kids. • In the kids' school they've got hearing tests, they go and do the hearing tests on the kids. They go and do tackling smoking, they do all that in schools but never do renal stuff. Before I got on dialysis my kids wouldn't have known about dialysis and renal problems. Only 'cause I sit down and they ask about dialysis and all that.
<p>Difficulties of living across two cultures</p>	<ul style="list-style-type: none"> • Trying to adapt within the two cultures of life – you got the non-indigenous side where it's all numbers, we're treated as a number, where on the indigenous side it's unique because of the fact that we are in two different cultures, but we're trying to solve the same solution but split in the middle of the cultures is the barrier that we're trying to communicate and bridge within ourselves.
<p>Cultural concept of shame reduces support opportunities</p>	<ul style="list-style-type: none"> • Any health issues, there is that whole Shame factor. It's about people don't want to be vulnerable, they don't want to feel scared. But you know what, we got to embrace that if we want to survive really, at the end of the day. • Living in Aboriginal communities, there's this whole idea around Shame jobs. So talking about your health, talking about your symptoms or things that are wrong with you is Shame or it's bad. Even whether people are made to feel shame by other people or whether it's just that thing that they have within themselves. But definitely breaking down or changing the stigma around talking about health.

Services relevant and specific to young Indigenous Australians

Benefits of dedicated and Indigenous-specific support and services

- [Indigenous-specific groups are good because] you do get a range of young to older and carers as well. And because you can relate to the issues that they're facing as well, and especially when it comes to families and priorities and roles and responsibilities in the community, you can name those issues together and come up with the solutions together as well.
- for someone where English is their second language, they're not going to be able to look at a poster and retain all that information, they're not even going to be able to connect with the information on that poster compared to when they see an Aboriginal person on that poster and less words, more action.
- Sometimes online [peer support] can be hard too, I've even tried my own groups with peers to get information. But I guess if you're looking at doing it online, you need to have the right people – like-minded, motivated, passionate, and that are willing to go that bit extra as well.
- When I was living in Port Augusta, there is a kidney group there, but that's me sitting around all old white people. And it's just not a space where you feel like you're empowered, it's just the space ain't for me.
- Sometimes there is a really big difference and a big gap. And sometimes you do feel like the odd one out, or what you have to contribute doesn't really fit in this space.
- If an Indigenous person is going out to try and network and recruit advocacies, it's a lot more comfortable coming from an Indigenous person than a non-Indigenous person. Like for example for myself, I was very reluctant to go to the action group as it was a non-Indigenous person that approached me. For an Indigenous event, you would want Indigenous people to promote it. I think we need a promoter or some sort to actually get out to the rural communities and spread the word about the services and the support we do have, and find that advocate that might have the potential to be a representative for us. I prefer to speak to an Indigenous person about Indigenous issues.
- They feel more comfortable talking to an Indigenous person, because of the language barrier, the understanding of the culture, and the diversity around it all.
- There's one lady I was talking to yesterday, she didn't want to go [on dialysis], she wanted to go to the park lands and drink with her family. And I said, 'what are you doing that for?' She said, 'because my family want me to go.' I said, 'but how do YOU feel?' And she said 'I feel horrible'. I said 'well get in there and do dialysis, because that will make you feel better, then you can go and sit with your family in the park lands'.

Need for interpreters and cultural awareness in healthcare

- I just think if she had that person that she could communicate with and that could really understand where she's coming from and what her issues are, then her attitude towards caring for herself might be different.
- That's what traditional people probably wouldn't do, because they wouldn't know what to ask. At the conference I was saying, how come you haven't got a consent form in the language? Pitjantjatjara should be the first language they translate it to... they could be sick, but they don't understand. That's what we need, we need more interpreters. A lot of the younger kids are coming up to the thing and there's no language there for them to be able talk to the doctor and the interpreters.

<p>Health services lacking cultural awareness</p>	<ul style="list-style-type: none"> • I definitely notice the difference of nurses communicating with me compare to nurses communicating to someone who's English is their second language. And there's a big difference, like they're more happy and comfortable to come and talk to me, but when you see them trying to communicate with the other mob, you can see – it just can be done a lot better. • They [Queensland health services] ask you every visit, do you need to see the Aboriginal Liaison Officer? That was really good, being able to have that access. Because sometimes, with a lot going on, you forget to ask for certain services. So just to be prompted as well is good.
<p>Insufficient access to existing support services</p>	<ul style="list-style-type: none"> • They're supposed to have these Aboriginal Practitioners – I've never seen them! I've never seen any of the practitioners come up and say I'm the renal practitioner. I don't know what their roles are, I don't know if they should be working in the wards as well. But they should be there to communicate with Aboriginal people. Especially for people who have come from the lands, they come down with no money, hardly no clothes, and no family. So they'd want that all in one, but they can't provide it. I've seen a lot of traditional people in the Aboriginal room, and they ask for this, they ask for that. But the Aboriginal Practitioner go, 'we can't do it'. So what are their roles? I'd wanna be seeing them every week, especially if I'm a new patient to dialysis. Because you'd be frightened.
<p>Need for connected services, including Aboriginal support services integrated in healthcare</p>	<ul style="list-style-type: none"> • I was linked in with the X Hospital, and they have got a really excellent dialysis unit and renal team there. And I had access to everything, so in the one place, if I wanted to see the renal psychologist I'd just tell the dialysis nurses – they would arrange everything for me. It would all be done at the one location, at the hospital. They [South Australian services] just don't have it together like Queensland has it together, in terms of renal. • There's only one psychologist you can access through the Aboriginal Support Services, and that's a long waiting list.
<p>Need to acknowledge diversity of Indigenous cultures and localise services and resources</p>	<ul style="list-style-type: none"> • Whereas living in Queensland, even trying to connect with an Aboriginal community over there – because it's just so different. Wherever you go in Australia, people might think black fellas are all the same – nuh-uh, not the same at all. • If doctors go out to the land to visit, they should know all that, you know? They need to understand the community's culture... Each community have got different aspects. So I couldn't go up to Port Augusta and say I want this, I want that, because it wouldn't be culturally appropriate for me to do that. It's just different.

Section 2.3: The challenges and priorities – Carer perspective

Summary

Challenges and priorities for carers of young people living with kidney disease

Carers said that:

- Carers are not financially supported or recognised by the government welfare system or healthcare services.
- Carers faced significant financial challenges from taking time off work to manage their child's health and appointments.
- Transitioning out of carer role was full of uncertainty and emotionally challenging.
- Transition services did not always acknowledge or integrate carers' needs.
- Carers struggled to balance care for their child with work, healthy lifestyle, and care for other children.
- Carers may even fail to acknowledge their own wellbeing and care needs.

Table 27 represents the major problems and challenges faced by carers of young people with kidney disease. The responses are drawn from the workshop sessions conducted during the National Youth and Carer Consultation Sessions and from the Kidney Youth and Carer Survey.

The Consultation Sessions tended to focus on challenges faced by youth and what supports they used, with little input from carers about their unique and individual experiences in caring for a person living with kidney disease.

In recognition of this, the Kidney Youth and Carer Survey encouraged carers to reflect on their own experiences and challenges, rather than speaking for their child. Therefore most of the responses below are drawn from the survey.

This reflects the significant finding that **carers may even fail to acknowledge their own wellbeing and care needs.**

Table 27: Challenges and priorities for carers of young people living with kidney disease

Lack of acknowledgement and support	
No recognition as carer from government	<ul style="list-style-type: none"> • My biggest hurdle has been the financial burden that taking so much time off work has caused... Centrelink do not recognize renal impairment as a condition requiring a carer so no financial support is available from them.
Unrealistic demands when navigating welfare system	<ul style="list-style-type: none"> • The paediatrician was actually asking me to go back over the last 3 years of appointments, of every appointment she's had, and I'm going oh my goodness that's going to be wadloads of appointments. And I've got to put it into a document so the paediatrician can then use it to help support her with NDIS, and I'm going – for me I'm finding that really overwhelming because that's a huge amount of appointments.
Unsupported by healthcare and transition services	<ul style="list-style-type: none"> • Excluding the caregiver the day the patient turned 18 was hard. Nothing has changed with the care I give so it's difficult to be instantly excluded.
Carers prioritised child and failing to acknowledge their own wellbeing and needs	<ul style="list-style-type: none"> • I mean look, to be honest when this was all happening, I didn't really think about myself very much. I just kind of focused on P4, he was generally pretty unwell so most of that two years he was pretty sick. So I don't know, I didn't really think about what anything can be done to kind of help from my perspective. • You try to stay strong for your child but when results are no good those emotions are hard to control.
Devastating emotional impact with no understanding from others	<ul style="list-style-type: none"> • You can talk to people so much about what's going on, but I find unless you're living it no one really understands the struggles you face. • The stress and shock at my son being at end stage kidney failure was incredible. Watching all the medical procedures my son was going through and not being able to help him was soul destroying and devastating.
Adjusting to changes in role and relationship	
Uncertainty in role and care provision after transfer	<ul style="list-style-type: none"> • I guess I have concerns around that, in terms of how do we as parents still support our kids if we're not really sure about what's going on.
Transitioning out of carer role is emotionally challenging	<ul style="list-style-type: none"> • It's been such a long time being the boss, it's hard to let go. Even now he's 19, turning 20, it's still hard. • It's very hard as a carer to let go and let the kidney kid take over self-care. I think doctors etc need to be a little more empathetic.

Struggle to balance healthcare with work, life and care for other children

<p>High time and energy demands of appointments and at home</p>	<ul style="list-style-type: none"> • It was at times complicated and sometimes confusing. And I think the issue was that there was just so, so many appointments, one after the other. • I was home doing dialysis, 3 times a day preparing special meals pre dialysis, constantly at the hospital having check ups and blood tests. Also having 2 other children. It was a tough time but got through it. • As a single mother I have had to work full time and manage the hospital appointments with the support of my managers. • Life was hard. Life was a challenge. For seven years I chased my child around with food trying to tempt him with tasty morsels of food and was so excited if he ate a few rice crackers. He had an overnight pump to feed him for a long time and then it was 'peg' feeds. Lots of vomiting anywhere. • EPO injections which were nasty. Being poked and prodded and injected and tested. There was always something to watch or do - diet, fluids, toileting, preparing 'food' for the cannula feeds, liaising with teachers at school etc And then there were the dreaded hospital visits. • We only live about 1 1/2 hours from the city but driving, finding a carpark, walking, waiting for appointments and then finally driving home through all the traffic was so very tiring.
<p>Reduced time available to work resulting in financial pressure</p>	<ul style="list-style-type: none"> • I wasn't working, I was taking leave without pay [to be a carer] to do all the trips. Two weeks out of every month, for eleven straight months, we were in hospital, so I wasn't working. • Trying to hide the financial burden from the person with renal failure so they don't feel guilt. • For me to contemplate being a paid working mother with a job was incomprehensible. My priority was the health of my child.
<p>Impact on time available for self-care</p>	<ul style="list-style-type: none"> • There are limited times for treatment and factoring healthcare with work and healthy life balance is tricky. • Annual leave has to be saved up to be used for times when we are stuck in hospital treatment so I haven't enjoyed a medical free day off in years.
<p>Less time for other members of the family</p>	<ul style="list-style-type: none"> • It was difficult to balance the needs of other members of the family. • I've got a younger brother, and around that time I was 13, he would've been 10. So he's still young. I didn't want mum to stress over me 24/7, she's still got other people she needs to worry about.

Transition services do not integrate carer needs

<p>Transfer rushes to phase out parents' involvement</p>	<ul style="list-style-type: none"> • I can understand them trying to get the kids at this age trying to be more independent and own their own health. But I think there should be a little bit more than two visits and then that's it, you're out.
<p>Transfer dismisses carer contribution to specific care needs</p>	<ul style="list-style-type: none"> • As the carer, you go into the front entrance but then like we're in the waiting room and I'm trying to go through all her medical stuff with her, just to remind her before she went through to the next section where nobody else is allowed, to make sure she was going to disclose everything that they needed. Because I wasn't allowed to go in at all, just to check with the anaesthetist or anything. That was hard because you're relying on them to get all that information.

Section 2.4: The solution – Young patient and carer perspective

Summary

Kidney youth and carer needs and suggestions for increased support

Table 28 represents kidney youth and carer needs and suggestions for increased support. Following the Strategic Roundtable Meeting, these were arranged into the following key priorities:

Priority 1

Facilitate peer support and mentoring opportunities for kidney youth and carers

- 1.1 Encourage and facilitate kidney youth community connection opportunities
- 1.2 Support Kidney Youth and Carer Champions in peer mentoring

→ We drew on relevant research along with the clinical, youth and carer consultation process to develop the key priority areas and recommended actions, presented previously in Table 1.

Priority 2

Assist kidney youth and carers to navigate health and healthcare

- 2.1 Provide youth-focused education and resources
- 2.2 Implement best practice care regarding kidney youth support systems and services

Priority 3

Increased advocacy, awareness, support and research for kidney youth and carers

- 3.1 Increase local community awareness and support for kidney disease
- 3.2 Advocate for increased support for kidney youth and their carers
- 3.3 Advocate for the support to implement above recommendations

Table 28: What young people living with kidney disease and carers wanted or found useful

Facilitating peer support and mentoring	
Peer networking improves wellbeing and coping strategies	<ul style="list-style-type: none"> You don't necessarily have to talk about it at these camps, but you know they've got some sort of similar issue or similar situation, so it's good to kind of bond over that and like go through the same issues and see how they cope and share your coping strategies. So it's good to come from a similar background. [Connecting with older peers] shows you that there is hope. Like there is a brighter side to it.
Self-determination and providing peer mentoring to younger/newer patients	<ul style="list-style-type: none"> Having this collaborative space, it's good to get to know other people and see what their story's like and help them out, so I think it's a positive. They want to start getting dialysis patients here, that would be the next best step. For us, we can see where we came from... for them, they can see how you can come after transplant. There's four different stories in the room right now, all different, but all the same one course. So for them that's coming in going, "I'm sick, I'm sick, it's not going to get better". But actually, it might get better, you could end up like us.
Peer networking opportunities reduce sense of isolation and loneliness	<ul style="list-style-type: none"> Also when you're a teenager on dialysis you don't get to go out very much 'cause you feel like crap. So if you go to parties on the weekend you're like nuh, I'm tired, I don't want to. And you're on dialysis and you've had all your fluid drain out of you and you're like, ugh I want to go to bed. So you don't want to go out and go party, so you socialise at these camps as well.
NB: Peer support is not suited to everyone	<ul style="list-style-type: none"> My child was never keen to socialise with other kids with kidney disease as he just wanted to be a normal kid living a normal life and not have all this kidney sickness in his face.

Support to independently self-manage health and navigate healthcare and other systems

<p>Dedicated support person to help navigate healthcare system</p>	<ul style="list-style-type: none"> • Who do you get help from? It's the matter of fact of getting answers to difficult questions... the doctors are very helpful... but you need that go-to person who you're comfortable with just asking a question. • It would be useful to have someone on call that I can speak to about my medication, diet, lifestyle. Sometimes I don't know if what I'm doing is right, and when it comes time for the infrequent clinical check-up, I had forgotten to ask. • We were lucky enough to have an excellent transplant coordinator who acted as a 'go between' for us and was always available to answer our queries and address our concerns.
<p>Support to navigate government systems</p>	<ul style="list-style-type: none"> • I was trying to get on to Centrelink, but just trying felt like a fulltime job. I said to myself, it'll be easier if I applied for a job, got a job, and earned an income like that. Centrelink won.
<p>More consistent youth-focused patient education</p>	<ul style="list-style-type: none"> • I think explaining some things in detail pre-dialysis would have been good, I went into this blind and learnt everything by myself by joining Facebook groups and using google.

Support tailored to youths in school, university, work etc.

<p>Educating classmates and building support in school</p>	<ul style="list-style-type: none"> • When I got back to school I sat down my class, I said what was happening, this is how it's gonna work, this is what we can and can't do anymore... they were all on board. I still remember the day I got the transplant, the whole class was cheering. • Doing high school, everyone's so supportive, like do you need time off, do you need medical certificates... as well as counsellors and stuff.
<p>Use of an app to assist self-managing health and healthcare</p>	<ul style="list-style-type: none"> • I was talking to you about an app today about that aspect, you know, your Medicare card, your medications – for them to be able to track all their stuff in one place, instead of them going through their phones. • Also having access to our blood results through an app will help a lot – especially when our apps are weeks away and we don't feel well and just want to check the kidney side of things.
<p>Tailoring resources for youth and the individual</p>	<ul style="list-style-type: none"> • There's your problem straight away. Turn the front, two old people. No one, no kid's going to read that. You've lost me already on the front page. This looks too boring to read... That's actually not a bad shout, a young person version and an old person version. • They [health professionals] could recognise that I am an individual and therefore my treatment must be individual. Just because it works for others or is the way it's been done before, doesn't mean it works for me. As well as treating me as a whole, encompassing all of my conditions as well as my mental wellbeing.

Professional psychosocial and mental health support integrated into care teams

<p>Multidisciplinary teams to address psychosocial and mental health needs</p>	<ul style="list-style-type: none"> • OTs are great because they drive you, they really drive you to be more than what you can be. And that's why I wanna be an OT... They do so much, I want to build on that variety, there could be more here [in CKD]. This is why an OT's a necessity, they could be anywhere and everywhere. • The part that is really lacking is mental health. Declined kidney function whilst physical due to the symptoms can be incredibly mentally draining or overwhelming. It shouldn't be in my hands to search and find a psychologist that understands what I'm going through and gels well with me. • The only things I can think of that really would have helped would have been maybe a one a month or every 2nd month meetup with a psychologist familiar with symptoms of decreasing kidney function. Just to check in on the mental side of things and give advice.
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Key priorities and accompanying recommendations

The key priorities and recommendations were established based on the major needs identified in the National Consultation Process and refined by key stakeholders at the Strategic Roundtable Meeting.

The recommendations provide guidelines and direction for the combined efforts of Kidney Health Australia, healthcare professionals, government and kidney community members aimed at improving wellbeing and outcomes of young people with kidney disease and their carers.



Priority 1. Community connections

Facilitate peer connections and mentoring opportunities for the kidney youth community

- 1.1 Encourage and facilitate kidney youth connection opportunities to reduce sense of isolation, share information, experiences and develop relationships.
- 1.2 Support Kidney Youth and Carer Champions in peer mentoring to assist with modelling positive healthcare management and providing peer support to address concerns about treatment and adjusting to life living with kidney disease.



Priority 2. Best practice care and education

Implement best practice equitable care regarding kidney youth support systems and services and assist kidney youth to understand, manage and optimise their health and navigate healthcare systems as they transition to self-management

- 2.1 Provide youth-focused education and resources.
- 2.2 Implement best practice care regarding kidney youth support systems and transition services.



Priority 3. Recognition and support

Increased advocacy, awareness and support for kidney youth and carers

- 3.1 Increase local community awareness and support for kidney disease.
- 3.2 Advocate for increased support for kidney youth and their carers.
- 3.3 Advocate for the support to implement above recommendations.

Please refer to Table 1 for the full list of key priorities, recommendations and actions.

References

1. Australian Bureau of Statistics, National Health Measures Survey: 2011-12.
2. ANZDATA Registry (2018) 41st Annual Report, Chapter 2; prevalence of end stage kidney disease. Australia and New Zealand Dialysis and Transplant Registry, Adelaide
3. ANZDATA Registry (1997) 20th Annual Report, Chapter 2; prevalence of end stage kidney disease. Australia and New Zealand Dialysis and Transplant Registry, Adelaide
4. Ferris ME, Gipson DS, Kimmel PL, Eggers PW (2006) Trends in treatment and outcomes of survival of adolescents initiating end-stage renal disease care in the United States of America. *Pediatr Nephrol* 21:1020-1026
5. Ritchie AG, Clayton PA, Mackie FE, Kennedy SE. Nationwide survey of adolescents and young adults with end-stage kidney disease. *Nephrol*, 2012; 17: 539-544
6. Cruz MC, Andrade C, Urrutia M, Draibe S, Nogueira-Martins LA, & Sesso Rde C. (2011). Quality of life in patients with chronic kidney disease. *Clinics (Sao Paulo)*. 2011;66(6):991-995. doi:10.1590/s1807-59322011000600012
7. McDonald, SP & Craig, JC. (2004). Long-Term Survival of Children with End-Stage Renal Disease. *The New England Journal of Medicine*, vol. 350, no. 26, pp. 2654-2662.
8. Tjaden L, Tong A, Henning P, Groothoff J, Craig JC. Children's experiences of dialysis: a systematic review of qualitative studies. *Arch Dis Child*. 2012;97(5):395-402
9. Roumelioti ME, Wents A, Schneider MF, et al. Sleep and fatigue symptoms in children and adolescents with CKD: a cross-sectional analysis from the Chronic Kidney Disease in Children (CKiD) Study *Am J Kidney Dis*. 2010;55(2):269-280
10. Allison Tong, Paul Henning, Germaine Wong, Steve McTaggart, Fiona Mackie, Robert P. Carroll, Jonathan C. Craig, Experiences and Perspectives of Adolescents and Young Adults With Advanced CKD. *American Journal of Kidney Diseases*, Vol. 61, Issue 3, p375-384, Jan 14, 2013
11. World Health Organisation website <https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health>
12. John S. Adams, Alyna T. Chien, Lauren E. Wisk. Mental illness among youth with chronic physical conditions, *Pediatrics* July 2019, VOLUME 144/ISSUE 1
13. Wong LH, Chan FW, Wong FY, Wong EL, Huen KF, Yeoh EK, et al. Transition care for adolescents and families with chronic illness. *J Adolesc Health*. 2010;47:540-6.
14. Rory F. McQuillan, Alene Toulany, Miriam Kaufman, Jeffrey R. Schiff. Benefits of a transfer clinic in adolescent and young adult kidney transplant patients *Canadian Journal of Kidney Health and Disease* (2015) 2:45.
15. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr. Nephrol.* 2000; 14: 469-72
16. Van Arendonk KJ, James NT, Boyarsky BJ et al. Age at graft loss after pediatric kidney transplantation: Exploring the high-risk age window. *Clin. J. Am. Soc. Nephrol.* 2013; 8:1019-26.
17. Ritchie, A. G., Clayton, P. A., McDonald, S. P., & Kennedy, S. E. (2018). Age-specific risk of renal graft loss from late acute rejection or non-compliance in the adolescent and young adult period. *Nephrology*, 23(6), 585-591. <https://doi.org/10.1111/nep.13067>
18. Butler JA, Roderick P, Mullee M, Mason JC, Peveler RC. Frequency and impact of nonadherence to immunosuppressants after renal transplantation: A systematic review. *Transplantation* 2004; 77:769-76.
19. Dobbels F, Ruppert T, De Geest S, Decorte A, Van Damme-Lombaerts R, Fine RN. Adherence to the immunosuppressive regimen in pediatric kidney transplant recipients: a systematic review. *Pediatr Transplant*. 2010;14:603-13.
20. Dobbels F, Van Damme-Lombaerts R, Vanhaecke J, De Geest S. Growing pains: non-adherence with the immunosuppressive regimen in adolescent transplant recipients. *Pediatr Transplant*. 2005;9:381-90.
21. Bethany Coyne, Patricia J. Hollen, Guofen Yan and Kenneth Brayman. Risk Factors for Graft Loss in Pediatric Renal Transplant Recipients after Transfer of Care. *Progress in Transplantation* 2016, Vol. 26(4) 356-364
22. Cass A, Chadban S, Craig J, Howard J, McDonald S, Salkeld G, White S. (2006) The Economic Impact of End-Stage Kidney Disease in Australia, *Kidney Health Australia*, Melbourne
23. Maarten Coemans et al, Analyses of the short- and long-term graft survival after kidney transplantation in Europe between 1986 and 2015, *Kidney International* (2018). DOI: 10.1016/j.kint.2018.05.018
24. Allison Tong, Lidwien Tjaden, Kirsten Howard, Germaine Wong, Rachael Morton, Jonathan C. Craig. Quality of Life of Adolescent Kidney Transplant Recipients. October 2011 Volume 159, Issue 4, Pages 670-675.e2 *Journal of Paediatrics*
25. Francis A, Didsbury MS, van Zwietaen A, Chen K, James LJ, Kim S, Howard K, Williams G, Bahat Treidel O, McTaggart S, Walker A, Mackie F, Kara T, Nassar N, Teixeira-Pinto A, Tong A, Johnson D, Craig JC, Wong G. Quality of life of children and adolescents with chronic kidney disease: a cross-sectional study. *Arch Dis Child*. 2018 Jul 17. pii: archdischild-2018-314934. doi: 10.1136/archdischild-2018-314934.
26. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, Slap GB. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993;14(7):570-6.
27. Watson, A.R., Phillips, D., and Argles, J. Transferring adolescents from paediatric to adult renal units. *Br J Ren Med*. 1996; 1: 24-66
28. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr. Nephrol.* 2000; 14: 469-72
29. Watson AR, Harden PN, Ferris ME, Kerr PG, Mahan JD, Ramzy MF; Transition from paediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Paediatric Nephrology Association (IPNA). *International Society of Nephrology; International Paediatric Nephrology Association. Pediatr Nephrol* 26:1753-1757
30. Harden PN, et al. Bridging the gap: An integrated pediatric to adult service for young adults with kidney failure. *BMJ* 2012; 344: 3718.
31. Harden PN, Nicholas S. Optimal management of young adult transplant recipients: the role of integrated multidisciplinary care and peer support. *Ann Saudi Med* 2013; 33(5): 489-491
32. Transition from children's to adults' services for young people using health or social care services. NICE guideline [NG43] Published date: February 2016. NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE) <https://www.nice.org.uk/guidance/ng43>
33. Kidney Health Australia. (2019) Kidney disease among Aboriginal and Torres Strait Islander people. Retrieved from <https://kidney.org.au/advocacy/guidance-and-tools/indigenous-health/health-statistics>
34. ANZDATA Registry. 38th Report, Chapter 12: Indigenous People and End Stage Kidney Disease. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2016. Available at: <http://www.anzdata.org.au>

**Attribution statement

The data reported here have been supplied by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). The interpretation and reporting of these data are the responsibility of the Editors and in no way should be seen as an official policy or interpretation of the Australia and New Zealand Dialysis and Transplant Registry.

Appendices

Appendix 1: Kidney Health Australia Youth Program – National Consultation Process

Kidney Health Australia Youth Program National Consultation (Oct 2018 – Aug 2019)

A national consultation process was undertaken with the major clinical services, young adults living with kidney disease and their carers around Australia to identify needs and gaps in care.

Clinic and Key Stakeholder Consultation and Young Adult Clinic visits (Oct 2018 – July 2019)		
VIC	Royal Children's and Royal Melbourne Hospitals	15 Oct 2018
	RCHM Transition Services	15 Jan 2019
	Monash Children's Hospital	16 Jan 2019
WA	Perth Children's, Sir Charlie Gairdner & Fiona Stanley Hospitals	26 Nov 2018
	Attended Perth Children's Transition Clinic	4 July 2019
QLD	Mater, Princess Alexandra and Queensland Children's Hospitals	16 Nov 2018
	Attended Mater Hospital young adult clinic	16 Nov 2018
NSW	Sydney Children's and Prince of Wales Hospitals	4 Dec 2018
	Westmead and Westmead Children's Hospitals	4 Dec 2018
	Centre for Kidney Research, PKD Australia, Transplant Australia	4 Dec 2018
SA	Woman's and Children's Hospital	3 Dec 2018
	Attended Royal Adelaide Hospital young adult clinic	13 Feb 2019
TAS	Royal Hobart and Launceston Hospitals	12-13 Dec 2018
	Attended Hobart young adult clinic	12 Dec 2018
NT	Royal Darwin Hospital, Purple House	5 July 2019

Renal Clinic Youth Services Survey (Feb – June 2019)

ANZDATA distributed the survey link from Kidney Health Australia via e-mail to 96 heads of renal units. As at the end of June we received 28 responses from most of the major renal units. Results have been collated for analysis alongside clinical consultations.

National Youth Consultation Sessions (Jan – July 2019)

We have conducted the following youth consultation sessions nationally averaging approximately 10 attendees per session to capture patient/carer experiences and feedback.

Adelaide General	1 – 3.30pm	Sun January 13	Kidney Health Australia (SA)
Hobart RHH	9 - 11am	Wed 27 Feb	Workshop at RHH (TAS)*
Brisbane Mater	9 – 11.30am	Fri March 15	Young Adult Clinic at Mater (QLD)
Melbourne General	6 – 8pm	Wed March 20	Kidney Health Australia (VIC)
Melbourne RMH	5.30 – 7.30pm	Thurs March 21	Young Adult Renal Clinic, VCCC (VIC)
Sydney General	6 – 8pm	Tues 26 March	Kidney Health Australia (NSW)
Adelaide General	6 – 8pm	Wed April 3	Kidney Health Australia (SA)
Perth Children’s	6 – 8pm	Wed 3 July	Perth Children’s Hospital (WA)
Darwin RDH	1.30 – 3.30pm	Fri 5 July	Menzies Centre Darwin (NT)

* Youth workshop attended as observer with Tasmanian Young Adult Clinic Co-Design Workshop

National Kidney Kids Camp – Youth Hub Consultation

Melbourne - Lord Somers Camp, Mornington Peninsula, 29 May – 2 June

National Kidney Youth and Carer Survey (April – June 2019)

Kidney Health Australia distributed the survey link by e-mail to known contacts, via social media and through key stakeholder groups to the kidney community. We received 138 responses including 114 youth living with kidney disease and 24 carers. Results have been collated for analysis alongside kidney youth and carer consultations.



Kidney Youth and Children's Program Strategic Roundtable Attendees – Thursday 8th August 2019

Kidney Youth Champions (Young adults and carers)

Jesse Steel (QLD)	Mitra Burns (consumer rep - VIC)	Mark Wolfenden (dad/carer) VIC
Joanne Tang (QLD)	Chelsea Bury (NSW)*	Julie Cameron (mum/carer - country VIC)
Alic Bope Jayawardana (VIC)	Michael Cornell (NSW)	Robert Cameron (dad/carer - country VIC)
Sebastian Wolfenden (VIC)	Ramon Gadd (SA)	Scott Webb (dad/carer – TAS)
Amy Cameron (country VIC)	Sarah Webb (TAS)	

National Consumer Council (Kidney Health Australia)

Paolo Cardelli NCC Chairperson*

Kidney Youth Advisory Committee Members (Kidney Health Australia)

Matthew Jose	Nephrologist, Royal Hobart Hospital (TAS)
Sean Kennedy	Paediatric Nephrologist, Sydney Children's Hospital (NSW)
Anna Francis	Paediatric Nephrologist, Queensland Children's Hospital (QLD)
Nick Larkins	Paediatric Nephrologist, Perth Children's Hospital (WA)
Thomas Forbes	Paediatric Nephrologist, Royal Children's Hospital Melbourne (VIC)

Kidney Youth Clinicians/healthcare workers/researchers

Amelia LePage	Paediatric Nephrologist, Monash Children's Hospital (VIC)
Germaine Wong	Nephrologist, Westmead Hospital (NSW)
Rosemary Masterson	Nephrologist, Royal Melbourne Hospital (VIC)
Ross Francis	Nephrologist, Princess Alexandra Hospital (QLD)
Robert Carroll	Nephrologist, Royal Adelaide Hospital (SA)
Alan Headey	Psychologist, Mater Health, Mater Health (QLD)
Jacinta Winderlich	Renal Dietician, Monash Health, (VIC)
Noella Sheerin	Antecedents of Renal Disease in Aboriginal Children and Young People Study (NSW)

Kidney Kids Camp health professionals advisory group representatives

Matthew Sypek	Paediatric Nephrologist, Royal Children's Hospital Melbourne (VIC)
Aimee Crawford	Renal Nurse, Queensland Children's Hospital (QLD)
Loren Shaw	Renal Nurse, Royal Children's Hospital (VIC)
Yogarani Jeyakumar	Renal Nurse, Monash Children's Hospital (VIC)
Kathryn Boundy	Renal Nurse, Women's and Children's Hospital (SA)

Kidney Health Australia staff

Chris Forbes	Chief Executive Officer
Shilpa Jesudason	Kidney Health Australia Clinical Director
Lisa Murphy	General Manager Prevention and Advocacy
Maria O'Sullivan	Head of Marketing and Communications
Ben Hoban	Information Technology Consultant
Stephen Cornish	Youth Program Manager
Luke Macauley	Youth Program Consumer Partner and Research Assistant
Grant Monks	Youth Ambassador
Sarah Baldacchino	Children's Program Manager
Shannyn Floyd	Community Service Manager

*could not attend – contributed via phone prior to and following the session

Appendix 2: Healthcare cost discussion - Kidney transplant v dialysis

Kidney Health Australia research reported the following estimated annual costs for kidney transplantation and dialysis (based on 2010 costs).

Reference: Cass A, Chadban S, Craig J, Howard J, McDonald S, Salkeld G, White S. (2006) The Economic Impact of End-Stage Kidney Disease in Australia, Kidney Health Australia, Melbourne

Table 29:

Estimated annual costs for kidney transplantation	
Kidney transplant costs per annum	Dialysis costs per annum
Year of transplant: \$81,549	Hospital haemodialysis: \$79,072
Subsequent years: \$11,770	Satellite haemodialysis: \$65,315
	Home haemodialysis: \$49,137
	Peritoneal dialysis: \$53,112

Figure 25 shows a cost-benefit analysis between **maintaining a kidney transplant** and **dialysis** (various modalities) after 2 years post-transplant year, returning a **cost differential between \$40k and \$130k**.

Figure 25: Recorded cost differential between transplant and dialysis over 2 years

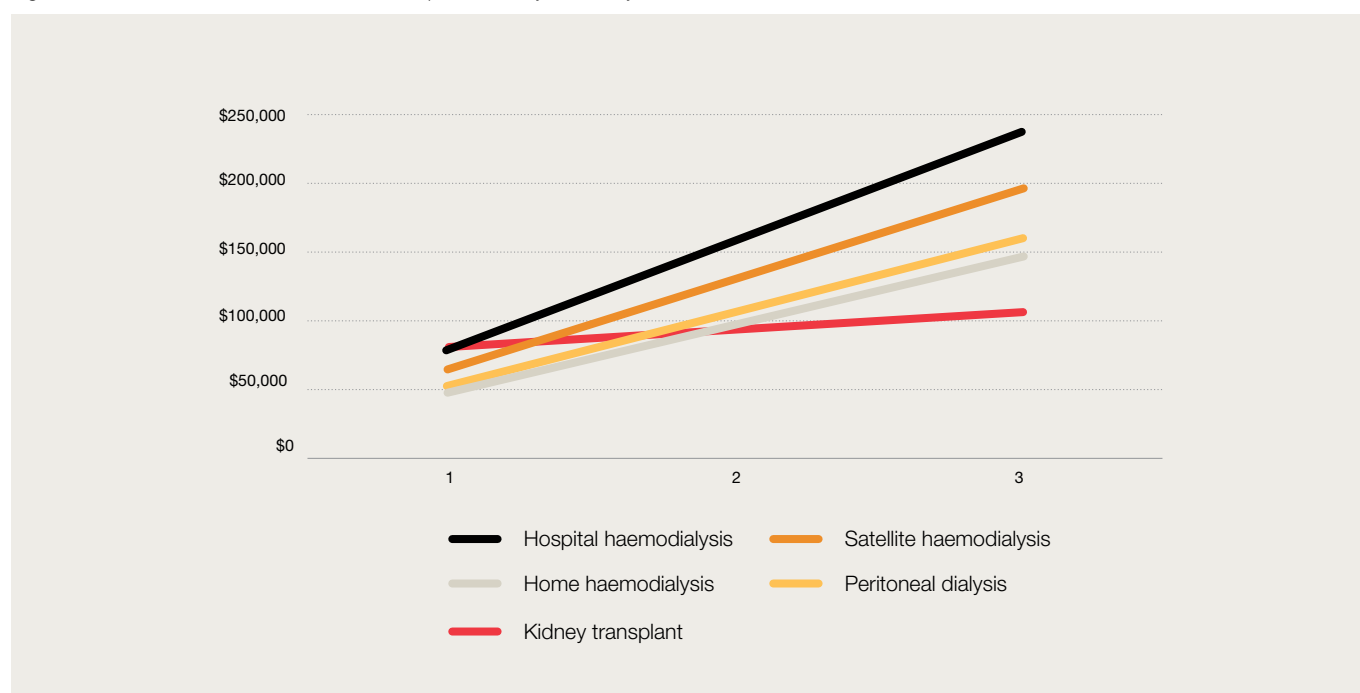
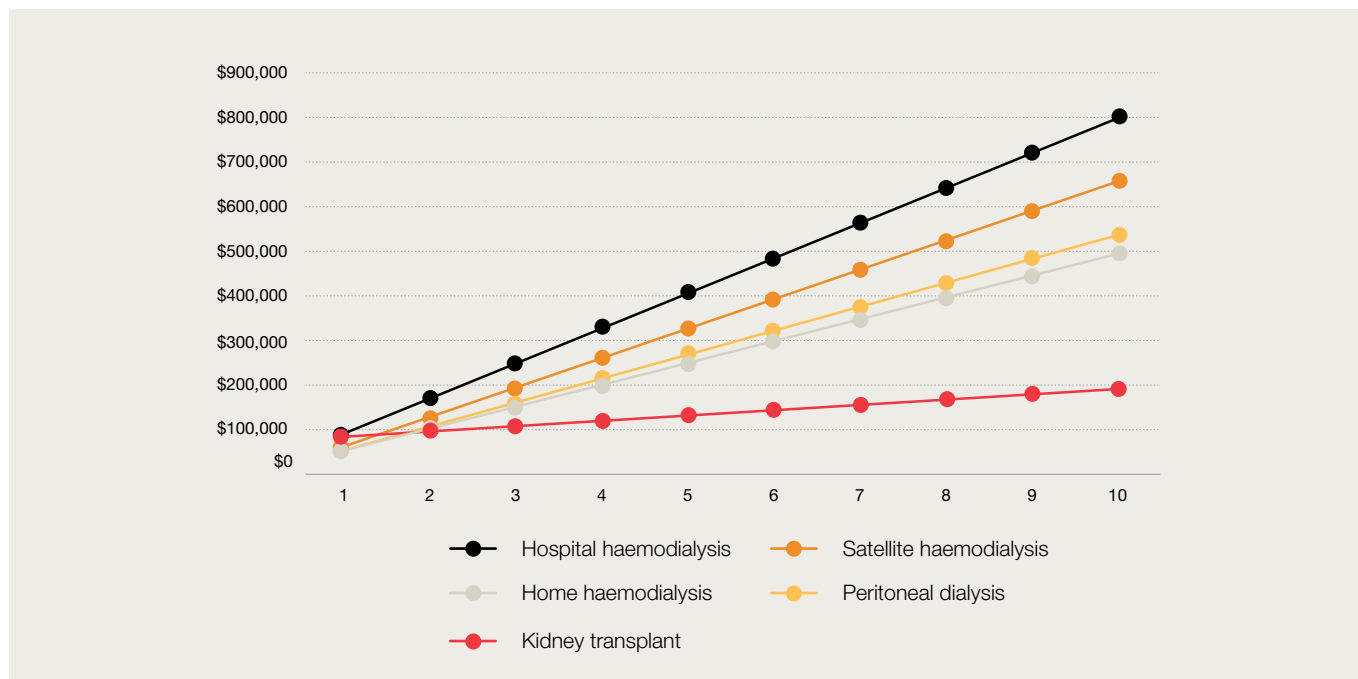


Figure 26 shows the same figures from Figure 25 projected over ten years post-transplant year, demonstrating a cost differential between \$340K and \$600K for one patient.

Figure 26: Projected cost differential between transplant and dialysis over 10 years



Therefore, on average each functioning graft kidney represents a differential of \$50,000 per year, post-transplant year, per patient.

It has been estimated that the economic impact of current graft loss in this high risk (15 – 24 years) young adult age group is approximately \$3M per year. Healthcare cost savings of ~\$50,000 per year post transplant year per patient on average are significant if a young adult can maintain their graft.

ESKD dialysis vs. transplant trend data

In 1997, 67% of young adults with ESKD were living with a kidney transplant, with the remaining 33% receiving dialysis. In 2017, 75% of young adults with ESKD were living with a kidney transplant, and 25% were on dialysis, representing an increase of 8% young adults with ESKD from dialysis to transplant in the past 20 years.

Functioning transplants not only result in better health outcomes, quality of life (QoL) and patient survival rates, but also represent an annual saving of \$50,000 per year post transplant per patient each year their graft survives. Therefore, in 2017, functioning transplants in the young adult renal patient population represented an approximate saving of around \$2.1 million to healthcare costs when considering healthcare costs saved by more costly dialysis treatments.

Increasing rates of kidney transplant for young patients are likely to continue, resulting in further savings to the healthcare system. A modest amount taken from these savings and re-invested into services aimed at increasing graft survival and longevity in the youth population would seem a prudent measure. Doing so would reduce the estimated annual \$3M economic impact through graft loss, save on immeasurable impacts to patients and carers including losses in productivity, and improve the overall health outcomes for young adult patients.

The Renal Medicine Clinical Committee also recognised the potential savings to the healthcare system by increasing kidney graft longevity in December 2016 in their recommendations to the Medicare Benefits Schedule Review Taskforce.

Increasing donors, increasing transplants, and increasing graft survival and longevity represent significant ongoing healthcare savings, along with improved quality of life and better outcomes for patients and carers.

Investment in services and practices that assist maintain graft survival in the high risk (15 – 24 years) young adult age group is recommended and represents a positive value spend proposition.

Effectively implementing the intervention services and practices suggested in this report will result in health, social and economic benefits to patients, carers, hospitals and healthcare personnel, and government. Increasing health, quality of life and social outcomes whilst decreasing disease burden including impacts on mental health ultimately saves finances and costs within the healthcare system.

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Disclaimer

The recommendations contained in this report were formed from feedback obtained through consultation with clinicians, healthcare professionals, young renal patients, carers, family and community members. It is designed to provide information and assist decision-making. The authors assume no responsibility for personal or other injury, loss or damage that may result from the information in this publication.

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