

# State of the Nation Report Summary

**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



# 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.

This Summary Report is an overview of the Kidney Health Australia Youth Program State of the Nation Report, which was undertaken to identify the major needs of the kidney youth community through a National Consultation Process conducted over the last 12 months.

We have identified best practice and gaps in care through direct conversations, focus groups and surveys with young people with kidney disease, their families and carers, and leading renal healthcare professionals involved in research and implementation of services for young patients.

The Kidney Health Australia Youth Program has identified 3 key priority areas with accompanying recommendations that aim to address these challenges and improve the wellbeing and outcomes of young people with kidney disease, and the wellbeing of their families and carers. The priorities and recommendations are now the focus of future activities and advocacy within the Youth Program.

## Key Priority Areas



### Community connections

Facilitate peer connections and mentoring opportunities for the kidney youth community



### Best practice care and education

Implement best practice equitable care regarding kidney youth support systems and services



### Recognition and support

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

# 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.

## Clinical Advisory Group members include:

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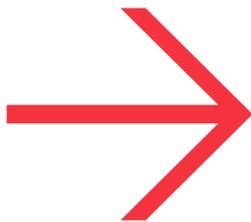
**Kidney Health Australia extends a special thank you to the kidney community, all the young people living with kidney disease, their families and carers, and others who contributed to the consultation process, sharing their experiences. In particular, and in reference to the young Indigenous Australians living with kidney disease section, we thank Rhanee Tsetsakos, Ramon Gadd and Nari Sinclair.**

We acknowledge and thank all the health professionals who participated and helped to facilitate consultation with the young people living with kidney disease and their carers.

We also acknowledge the Australia and New Zealand Dialysis and Transplant Registry for assistance with the delivery of the Renal Clinic Youth Services Survey and provision of specific data sets. In particular we thank Kylie Hurst, Dr Chris Davies and Dr Shahid Ullah.

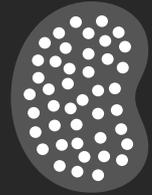
Finally we acknowledge and thank the generous grant awarded by the Government of Australia for the implementation of this Kidney Youth Program.

# Kidney disease in young people



**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)**.



In 2017, **524 Australians between the ages of 15 and 24 years were living with ESKD requiring dialysis or transplant.**<sup>4</sup>

Many more were living with earlier stages of CKD.



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.



Major health implications of kidney disease on young people include cardiovascular disease and other chronic health conditions, reduced life expectancy, decreased quality of life and increased risk of mental health issues.<sup>1, 2, 3</sup>

Adolescent and young adult kidney transplant recipients **have worse graft outcomes than any other age group up to 70 years of age** due to challenges with managing their healthcare needs, navigating health services, lifestyle restrictions and problems adhering to medication and other treatment regimens.<sup>5</sup>

Economic impact of current transplant 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**<sup>6</sup> as maintaining a graft is **significantly** cheaper than dialysis.

# Current situation

- Young patients with kidney disease at all stages face unique challenges due to their age and the impact of a chronic illness. This includes disruption to growth, education, social development and life participation.
- Transfer from paediatric to adult kidney services occurs around their 18th birthday, an age characterised by a high degree of social, psychological and brain development change. These changes result in challenges that complicate and prevent young people's effective self-management of a chronic medical condition, and navigation of health systems.<sup>7, 8</sup>
- Current efforts to improve young patients' outcomes 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**<sup>9, 10, 11</sup> but these services are somewhat isolated and require further promotion, coordination and targeted funding allocation.
- Several Australian hospitals have implemented adolescent **transition services, Transition Clinics** and **Young Adult Clinics** based on international guidelines and models which are considered best practice.<sup>12, 13</sup> These prepare paediatric patients to transfer to adult healthcare and provide extra support for young adults in adult healthcare respectively.<sup>14, 15</sup> However, in many cases dedicated Transition and/or Young Adult Clinics are aspirational due to a lack of personnel and resources and therefore not accessible to all patients, leaving significant gaps in care. It is proposed that investment in this area actually results in healthcare cost savings and significantly increases overall health outcomes.
- Current Transition and Young Adult Clinics already demonstrate very positive benefits for attending patients – for example, the Royal Adelaide Hospital Young Adult Clinic has seen **no incidents of graft loss since its establishment in 2013**, and attending patients have a high level of engagement and activation. This alone represents significant healthcare savings.
- Efforts to improve young patients' outcomes are **inconsistently available** across Australia leaving many adolescents and young adults with kidney disease and their families with insufficient support.
- There is no national consensus statement or guideline to inform the development of transition services for young people with kidney disease, or on broader support and care for adolescents and young adults with kidney disease.

# Terminology in models of care

Owing to the lack of national guidelines on care and support for young people with kidney disease, various models of care have been established across Australia. Below we have defined different terms used across these models of care to help distinguish between various roles and services.

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<b>Transition Clinics</b>	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.
<b>Young Adult Clinics</b>	Provide various services that aim to increase care for young adults who have recently transferred from paediatric care, or present directly to adult healthcare at a young age.
<b>Youth and Carer Champions</b>	Volunteer community leaders with lived experience of kidney disease, or caring for a young person with kidney disease. They contribute to all aspects of the Youth Program, particularly connecting with peers and providing peer mentoring to younger and/or newly diagnosed peers. Training and support for Youth and Carer Champions is provided by Kidney Health Australia.
<b>Patient Preceptors</b>	People living with kidney disease who are employed to provide advice, reassurance, mentoring, and education to peers with kidney disease.
<b>Transition Support Workers</b>	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 (e.g. social work, youth work, nursing, etc.). Transition Support Workers draw on their experience with chronic illness and transfer to adult healthcare, where applicable, to support peers.
<b>Patient Navigators</b>	Employees who assist patients and carers to navigate hospital healthcare and government systems and services, and to adjust to life with kidney disease.
<b>Transition Champions and/or Coordinators</b>	Clinicians or healthcare workers who are responsible for the oversight and management of all transition and transfer relevant issues within a specific clinical setting.

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# Kidney Health Australia Youth Program

## – National Consultation Process

The National Consultation Process aimed to draw on the perspectives and contributions of young people living with kidney disease, carers and families of young people living with kidney disease, and kidney healthcare professionals to **define young patients' and carers' concerns, and directly inform the report recommendations and subsequent design of the Youth Program.**

### Clinical consultation

- Visits and consultation with **over 50 clinical staff members** including all major paediatric and adult transition services across Australia;
- The **Kidney Youth Services Survey** which mapped youth services provided nationally by all paediatric and a majority of the major adult renal units/services (N = 28).

### Kidney Youth and Carer Consultation

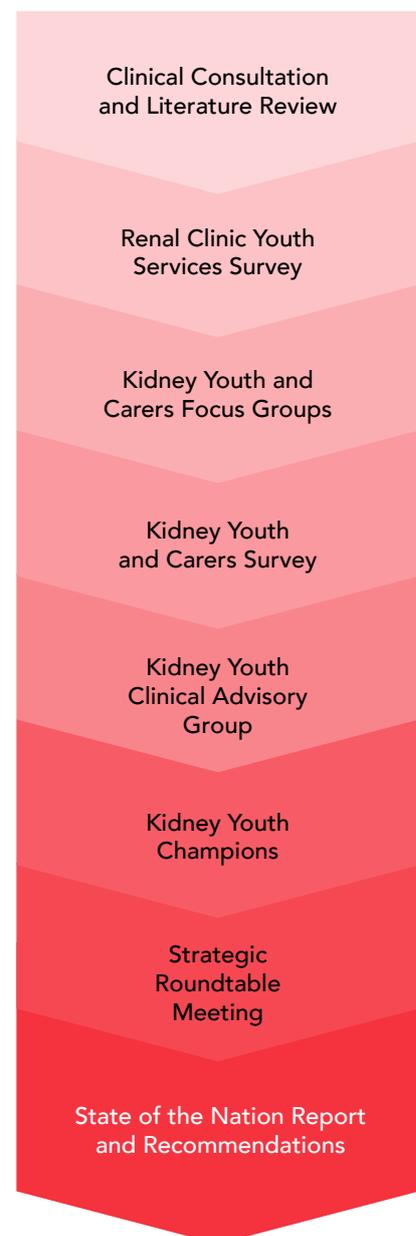
- **Group workshops** and individual discussions with young adults living with kidney disease and their carers, including 10 youth consultation sessions across Australia to capture patient/carer experiences, concerns and feedback;
- An online **Kidney Youth and Carer Survey** which was distributed nationally and received 138 responses including 114 youth living with kidney disease and 24 carers;
- Consultations with young Aboriginal Australians and community leaders;
- Consultation at 4 **Young Adult Clinics** (Adelaide, Brisbane, Hobart and Melbourne) and one **Transition Clinic** (Perth).
- Consultation at the Kidney Health Australia Kid's Camp in June 2019.

### 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 (patients, carers, and health professionals).



→ The National Consultation Process 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.

# Clinic Consultation and Kidney Youth Services Survey summary

The Kidney Youth Services Survey provides a national overview of current services provided by kidney healthcare for adolescent and young adult kidney patients.

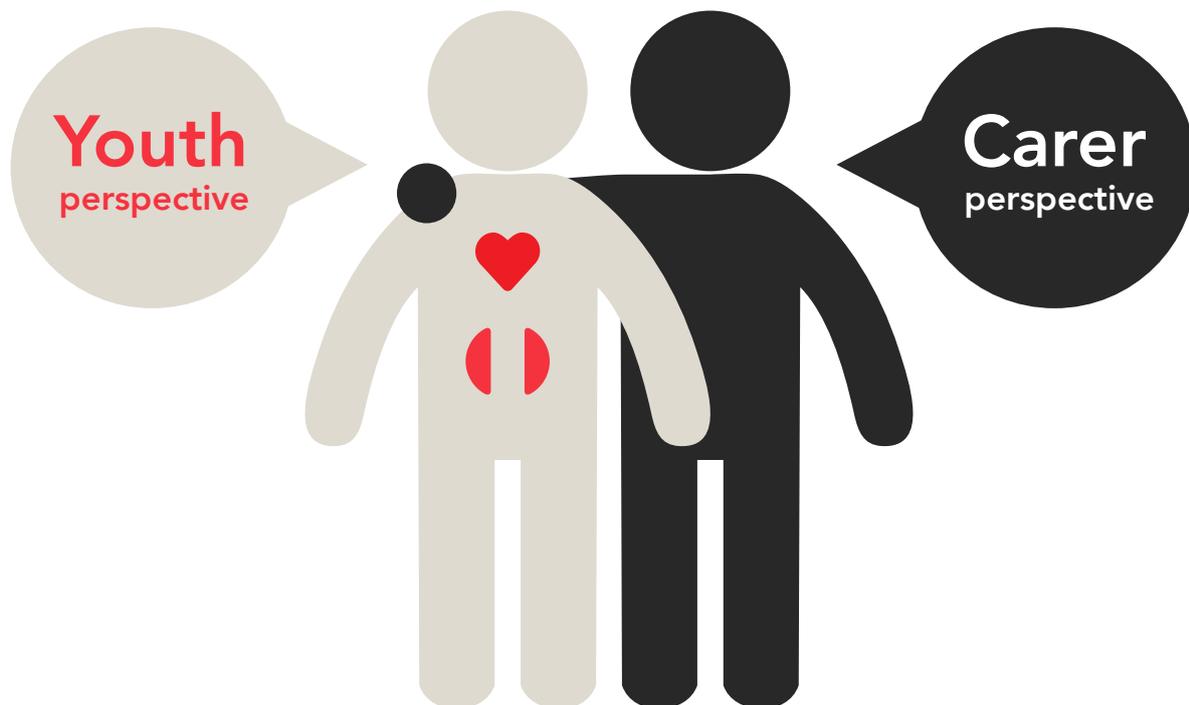
- The survey response was 28 from a possible 96 renal units (25%). 24 of these were from the major renal units associated with provision of youth services and proved useful in analysis including 7 of 7 paediatric (100%) and 21 of 89 adult renal units (23%).
- Although 66% of renal units reported having policies in place for transition of young people from paediatric to adult services, only 17% documented these policies.
- Kidney patients commenced preparing for transfer at 14-15 years of age (71% of renal units).
- 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.
- The main allied healthcare professionals desired by renal units included a youth worker (75%), peer support or youth mentor (75%), psychologist (58%), and transition coordinator or champion (54%).
- 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).
- Respondents' free-form comments overwhelmingly focused on the lack of funding within adult kidney units to meet the identified need for supports for young adult patients.

## Kidney Youth and Carer Survey

The Kidney Youth and Carer Survey was distributed across Australia to invite contributions of young people with kidney disease, their carers and their families, who could not attend in-person consultations.

- Total of 138 responses, 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 domains.
- 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.
- Core clinical services were generally highly rated by kidney youth patients and carers. However, adult healthcare is generally not as equipped to provide the same wrap-around youth-focused services and multidisciplinary support as paediatric healthcare.

# 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 care for child with work, healthy lifestyle, and care for other children.

# Summary of 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.

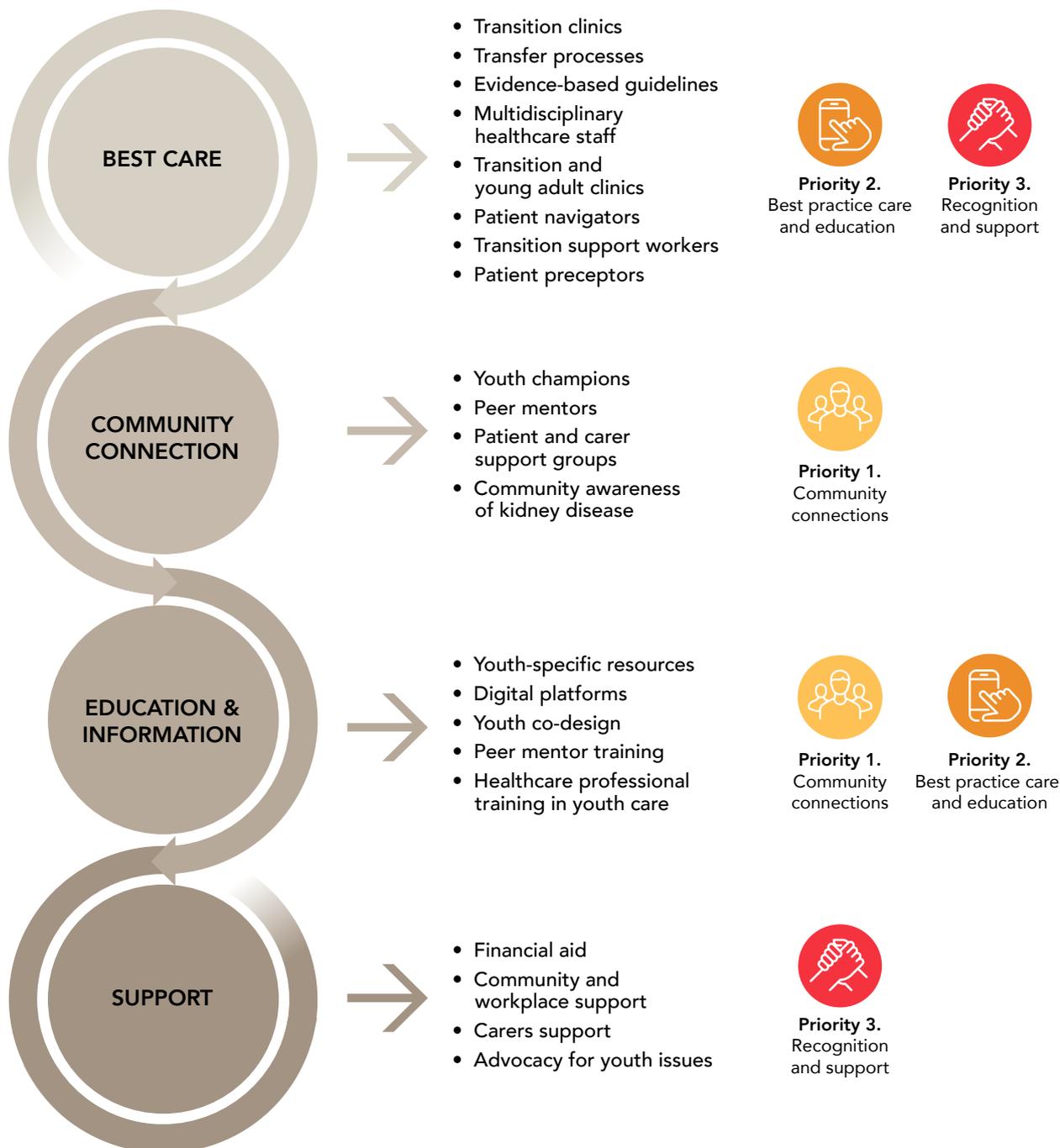


## Priority 3. Recognition and support

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.

# Model of care: incorporating key priorities and recommendations



# Key priorities, specific recommendations and actions



## Key Priority 1. Community connections – peer support

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



## Key Priority 2. Best practice care and education

### Recommendations

### Actions

#### 2.1 Provide youth-focused education and resources to assist self-management

2.1.1

**Adapt and tailor existing kidney care educational resources to be youth-focused.**

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.**

2.1.3

**Identify and promote resources and services that help youth with self-management of their healthcare.**

2.1.4

**Identify and promote resources and services that help carers' with their role.**

- 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

2.2.1

**Implement best practice in clinical care in relation to transition and transfer from paediatric to adult healthcare.**

2.2.2

**Address peer support needs of young patients and carers by integrating peer workers into healthcare teams/clinical consultations.**

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.**

2.2.4

**Develop National Consensus Statement on Youth Care in Kidney Disease.**

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.**

- Advocate for best practice in clinical care, transition and transfer, including:
  - 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.



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

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

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