



Consensus Statement

Improving outcomes for
adolescents and young
adults with kidney disease

Improving outcomes for adolescents and young adults with kidney disease

This Consensus Statement includes core and other recommendations for the:

- Holistic care and support of a young person aged 14 – 24 years in Australia.
- Transition process towards self-management of healthcare.
- Transfer from paediatric to adult healthcare.

This Consensus Statement has been developed following national consultation in 2018–2020 involving healthcare professionals, young people with kidney disease and their carers coordinated through the Kidney Health Australia Youth Program, supported by a Federal Government grant.

This process also informed the State of the Nation Report 2019 – Improving Outcomes for Adolescents and Young Adults with Kidney Disease which is a parallel document and reference to this Consensus Statement.¹



Best care

Recommendations for best practice clinical care, successful transition and transfer from Paediatric through to Adult healthcare.

Individualised Plans for Transition from Paediatric to Adult Service

Core Recommendations

- Transition to adult services should be an active, planned process introduced early in adolescence (12 – 14 yrs) and continued into young adulthood with a view to transfer at an appropriate time considering major medical and psychosocial events.
- The transition process should involve a gradual, collaborative shift of responsibility from the parents/carers to the young person. This includes building knowledge, skills and lifestyle patterns enabling independent and autonomous self-management of their general wellbeing and medical care.
- The transition process and planning should include the patient, parents/carers and significant others (i.e. siblings, partners).
- The transition process and planning should be individualised based on developmental stage and/or intellectual ability.
- The transition and transfer process should be supported by appropriate youth-focussed resources, tools and services.

Continuity of Care During Transfer from Paediatric to Adult Service

Core Recommendations

- Transfer should include the compilation and sharing of comprehensive individual healthcare and transition plans between paediatric and adult care providers to facilitate continuity of high-quality medical care.
- Transition clinics should include introductory visitations by adult kidney staff (nephrologist, nurse, others) and/or the coordination of cross-over joint clinical appointments and management prior to transfer. This could be in person, by telephone or virtual meetings depending on preferences, locations and resources.

Other Recommendations

- Visits should be arranged to the adult service or Young Adult Clinic prior to transfer.
- Follow up should be coordinated in a timely manner post transfer by the paediatric unit to determine if the patient has engaged with the adult service and if there are any further requirements.

Service Requirements and Structures for Transition from Paediatric to Adult Service

Core Recommendations

- Transition Clinics should be coordinated where patient numbers and appropriate resources are available.
- A Multidisciplinary Team should be available to develop and implement the care and transition plans of young patients. The team ideally should include: Nephrologist, Nurse, Transplant Nurse, Pre-dialysis Nurse, Pharmacist, General Practitioner, Psychologist, Social Worker, Youth Worker, Occupational Therapist, Physiotherapist, Dietitian and Peer Support/Youth Mentor.
- The transition process should be a structured, documented process, managed by a lead clinician (Transition Champion) in both paediatric and adult units. A nominated key worker (Transition Co-ordinator) should also be responsible for coordination of the transition process in their unit (i.e. nurse, social or youth worker).

Requirements and Structures for Adult Kidney Services to Manage Youth with Kidney Disease

Core Recommendations

- A specialist support team for treating youth in adult services should be available such as a Young Adult Clinic. This team could be independent or co-exist with services from other chronic illness groups for efficiency.
- Training should be provided for adult health care professionals to understand the specific needs and management of young people with kidney disease.
- Psychosocial support should be made available through access to allied health professionals to improve mental health, wellbeing and life participation.

Other Recommendations

- Peer support within clinical settings as well as community connections should be encouraged by the clinic and actively facilitated by peer support workers or mentors.
- Access to a patient support person should be available to help the young person navigate the healthcare system, Medicare, Centrelink and other systems.

The group predominantly responsible for delivery of a recommendation is shown as follows:

- Clinical organisations and services
- Consumer organisations and services

At all times, close liaison between all stakeholders including consumers is strongly advised, to ensure there is co-design of programs that are feasible, suitable and acceptable.

Community Connections

Recommendations for facilitating community connection opportunities for kidney youth (and their carers) to provide peer support and information sharing.

Core Recommendations

- Young-adult peer connections via community-based communication and interaction forums including social media platforms, support groups and virtual or face-to-face activities should be supported and facilitated through local kidney clinical services and patient support organisations such as Kidney Health Australia.
- Peer mentors (Kidney Youth Champions) should be identified for each kidney clinic or service where they are trained, supported and encouraged to provide peer support and education. This activity could be shared between kidney clinics and services and patient support organisations such as Kidney Health Australia.
- Connections between newly diagnosed patients (and their families and carers) and more experienced patients should be facilitated by a peer support network.
- Carer support groups should be supported and facilitated to provide carer peer support including sharing management and coping strategies.

Education and Information

Recommendations for provision and dissemination of youth-focussed education, information and resources to assist transition to self-management.

Core Recommendations

- Kidney clinics and services should provide education about kidney disease management and self-care for young people and carers and ensure they are aware of associated educational resources and patient support services relevant to navigating transition and transfer.

Other Recommendations

- Appropriate educational resources associated with transition and transfer should be co-designed and developed specifically for young people through kidney clinics and services and patient support organisations such as Kidney Health Australia.
- Online youth and carer forums and spaces should be facilitated to provide education and the exchange of information.
- Local community awareness about kidney disease and the impact on young people should be increased through the education of workplaces, schools, educational institutions, etc.



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- Clinical organisations and services
- Consumer organisations and services

At all times, close liaison between all stakeholders including consumers is strongly advised, to ensure there is co-design of programs that are feasible, suitable and acceptable.

State of the Nation Report 2019: Key priorities and model of care

Key priorities and recommendations

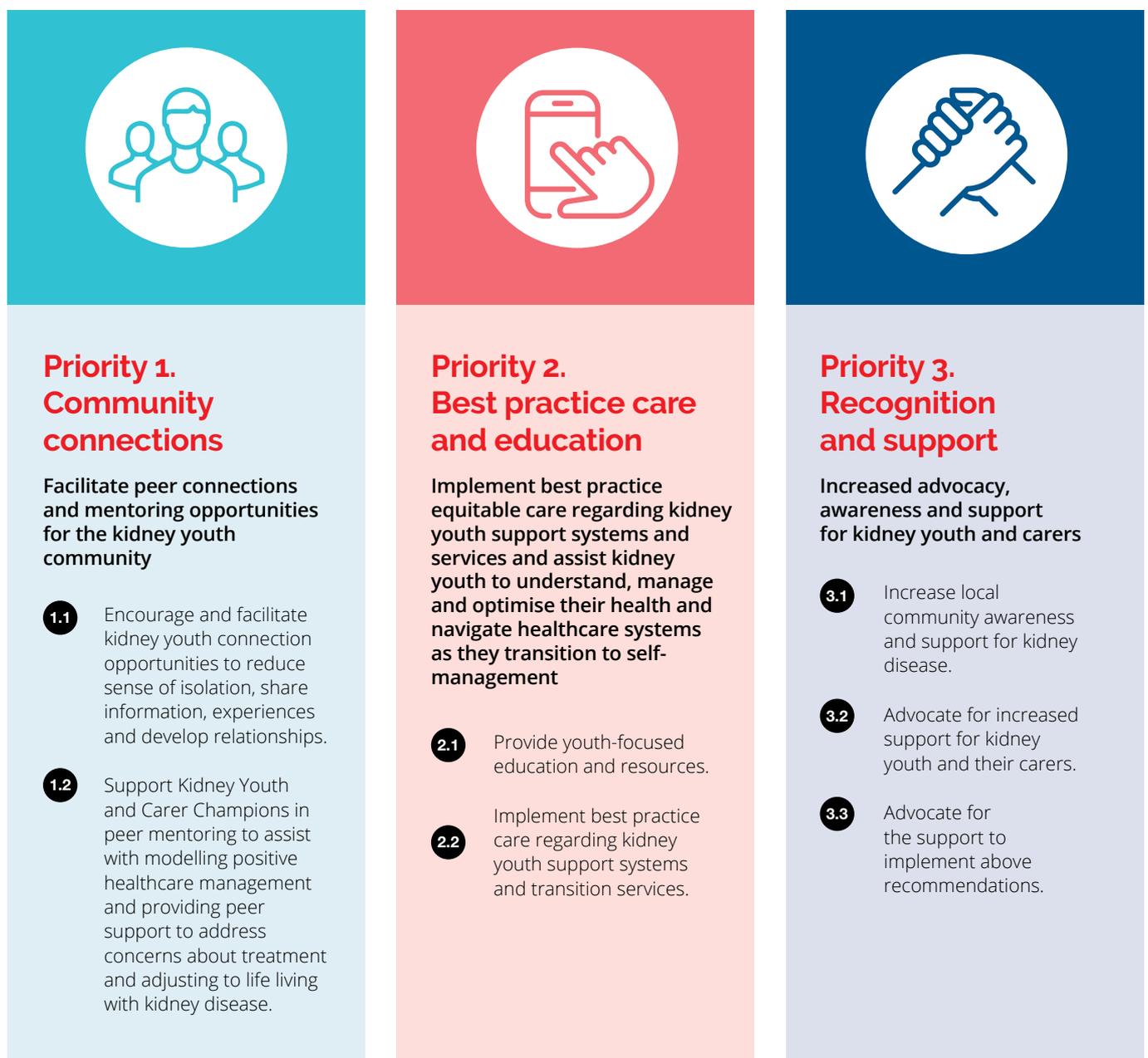
The State of the Nation Report 2019 sits alongside this Consensus Statement and also includes key priorities and recommendations established based on the major needs identified through the national consultation process.

These provide guidelines and direction for the combined efforts of all relevant stakeholder groups and form a comprehensive and holistic model of care aimed at improving the wellbeing and health outcomes of young people with kidney disease and their families and carers.

The State of the Nation Report 2019 – Improving Outcomes for Adolescents and Young Adults with Kidney Disease is available to download from the Kidney Health Australia website.

[kidney.org.au/ways-we-help/kids-and-youth-programs](https://www.kidney.org.au/ways-we-help/kids-and-youth-programs)

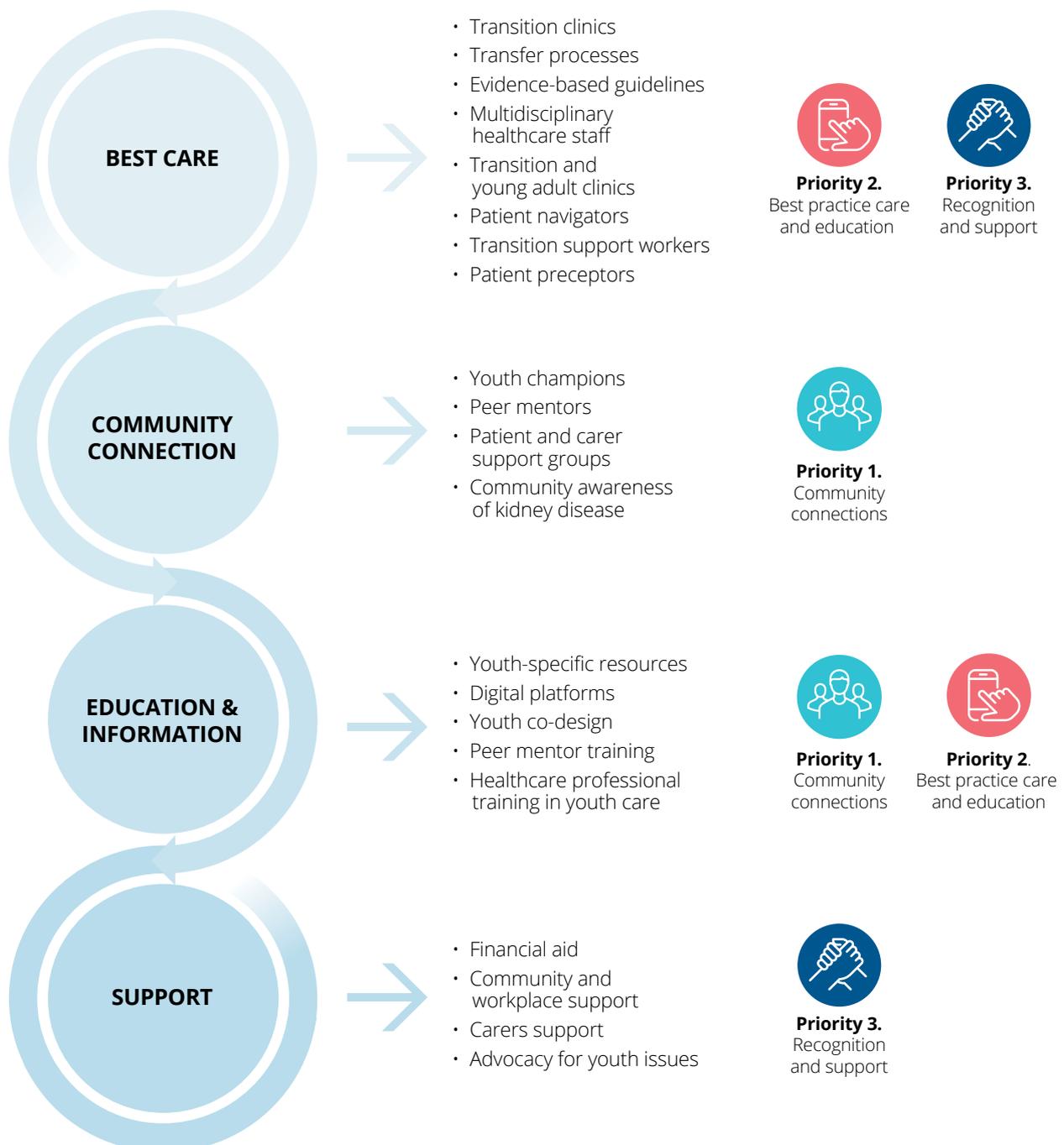
Figure 1: Summary of key priorities and accompanying recommendations



The young patient model of care

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 2: Young patient model of care



Acknowledgements

Kidney Health Australia acknowledges the valuable contribution of the Kidney Health Australia Youth Program's Clinical Advisory Group in developing this Consensus Statement.

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Glossary of terms

Transition	The purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems including initial planning, the actual transfer between services, and support throughout.
Transfer	The actual point at which the responsibility for providing care and support to a person moves from a paediatric to an adult provider.
Transition Champion	The designated lead health professional in both the paediatric and adult units who are identified to manage the transition process and ensure it is documented, resourced, implemented and evaluated.
Transition Coordinator	The key worker providing care and support of the young person, who has been designated to take a coordinating role. It could be, for example, a nurse, youth worker, an allied health professional or another health and social care practitioner.
Transition Clinic	Paediatric clinical group sessions for adolescent patients (from 14 yrs) who are entering the transition phase aimed at providing educational and peer support opportunities alongside their clinical appointments prior to transfer.
Young Adult Clinic	Clinical group sessions offered to young adult patients aimed at providing educational and peer support opportunities alongside their clinical appointments post transfer or on presentation to the adult service.
Kidney Youth Champions	Young adults living with kidney disease who are engaged in peer mentoring and/or peer support activities with other young kidney patients.

Reference

1. Cornish, S., Macauley, L., Jesudason, S. and Murphy, L. Kidney Health Australia Youth Program – State of the Nation Report. Kidney Health Australia, Melbourne, 2019.
Further relevant source documents are recognised within the reference section contained within this report.

This consensus statement has been reviewed and endorsed by:



Australian and New Zealand
Paediatric Nephrology
Association



TSANZ

The Transplantation Society of Australia and New Zealand



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