Adolescent and Young Adult (AYA) Transition of Renal Care

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Service Improvement
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Sustained
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Summary

Managing your care is a guide targeting young persons (aged 12 years and over) and their families who under the care of the Queensland Children's Hospital (QCH) kidney team. It helps personal growth towards self-management of health care, alongside the rest of life, whilst preparing for the 'transition' from the QCH to adult kidney care services. This guide talks about the common

challenges young people face as they head towards transition. It will help you understand what transition is, how to support your health during transition, how adult services work and how to access adult services.
Key dates
Feb 2021
Jul 2021
mplementation sites
The project has been implemented with QCH Child and Adolescent Renal Service and is being distributed across all Queensland adult kidney health services and affiliated clinical networks.
Partnerships
The project was led by the QCH Child and Adolescent Renal Service in partnership with Advancing Care 2026 and the Statewide Renal Clinical Network.
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Aim

To create a guide to support young people and their families in the transition from the Queensland Children's Hospital (QCH) kidney service to adult kidney health care.

Benefits

- development of the first state guide to support transition of kidney care for adolescent and young adults (AYA) with kidney disease
- supports improved overall transition of care considerations, processes and practices for AYA under kidney health services and their primary care providers
- supports improved health outcomes for AYA with kidney health care needs
- supports improved relationships and communication between children, adult kidney speciality services and primary care providers across Queensland
- supports improved AYA experiences in their transition of kidney care.

Background

The creation of the 'Managing your care' booklet was in response to a high need as identified by leading clinicians and consumers for a Queensland-specific guide to support adolescent and young adult transitioning from specialist paediatric kidney care to adult kidney care services in Queensland. The project was enabled through Clinical Excellence Queensland partnering with the Queensland Child and Adolescent Renal Service, with funding and project support provided by Advancing Kidney Care 2026 and the Statewide Renal Clinical Network.

Solutions Implemented

A guide was developed o support young people and their families in the transition from the Queensland Children's Hospital Child and Adolescent Renal Service to Queensland adult kidney care service providers has been developed and published.

Evaluation and Results

The guide is now in use within the QCH Child and Adolescent Renal Service which includes informal feedback of its usage and design.

Lessons Learnt

- clearly defined and objective project scope, milestones and outcomes need to be endorsed both in writing and verbally to clearly identify and balance stakeholder expectations in timelimited projects
- establishing strong, meaningful stakeholder engagement with all parties (both clinical and consumer) is crucial to ensure a fit-for-purpose and meaningful product development. This engagement also offers a solid foundation for potential work moving forward such as a health care provider facing guide to support transition of AYA care, which was identified as a need by adult kidney care clinicians during consultation
- consideration and clear communication on decisions around consumer remuneration and reimbursement for their input into the co-design to improve resource language, content and relatability
- early identification of lead times for important consultation or technical matters (some external organisations had long waits to engage)
- establishment or identification of a formal project handover process to improve new staff understanding of project context, previous consultations, future tasks, inter-dependencies and considerations.

References

Transitioning to adult healthcare | Queensland Children's Hospital

Further Reading

Transition and Transfer: Your move from paediatric to adult health care services. Kidney Health Australia Consensus Statement: Improving outcomes for adolescents and young adults with kidney disease. Kidney Health Australia. State of the Nation Report 2019. Kidney Health Australia Youth Program – Improving outcomes for adolescents and young adults with kidney disease. Related programs:

- Children's Health Queensland Child and Adolescent Renal Service
- Children's Health Queensland Transitioning to adult healthcare
- Advancing Kidney Care 2026
- Statewide Renal Clinical Network
- Queensland Child and Youth Clinical Network

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