Position Statement: Adolescent & Young Adult Transition of Care

Purpose: The purpose of this position statement is to provide clarity about best practice, evidence-based approaches to the transition of care of Adolescents and Young Adults (AYA) 12-25 years. It is relevant for all services caring for young people and their families across all sectors in Queensland. It is applicable to all health transitions that young people face, including those between primary, community, and tertiary care and between Hospital and Health Services (HHS). This position statement clearly articulates a shared language on the need for, and objectives of, quality AYA care during transition. It clarifies the principles, practices, and responsibilities so that services and clinicians can work to meet these standards collaboratively to optimise the care and outcomes of young people and their families transitioning.

Audience: This document pertains to all professionals working across sectors with AYAs requiring health or mental health care and facing a transition in care, including: Health Service Executives, Health Workers, Medical Specialists, General Practitioners, Nurses, Psychologists, Social Workers and other Allied Health Professionals, Aboriginal and Torres Strait Islander Health Workers, Educators and others. It is relevant for public and private health professionals, primary care, community health and non-government organisations. It has been developed through partnerships between multidisciplinary healthcare professionals and consumer experts under the auspices of the Queensland Child and Youth Clinical Network and the AYA Subnetwork.

Since 2021, the Queensland Child and Youth Network have championed the health and wellbeing of all AYAs being provided healthcare in Queensland. This work has been guided by two documents that define the population and outline the quality care principles, approaches, and practices that are evidence-based and required to optimise AYA care, including recommendations and a roadmap to achieve these standards:

- The Quality Adolescent and Young Adult Care Position Statement
- The Optimising Adolescent and Young Adult Care in Queensland statewide strategy 2022-2027 (OPAYAC)

Background

Queensland's AYA Population and Their Health

Adolescents and Young Adults (AYA) 12-25 years of age are, developmentally, a unique population. They are navigating a complex life stage marked by rapid biological, cognitive, psychological, social, and spiritual development. These formative years play a crucial role in shaping identity and are strongly influenced by the social determinants of health. Young people and their families not only face the challenges of managing acute, chronic, mental health concerns and disabilities, but are expected to navigate these health complexities while contending with the developmental tasks of adolescence and the impact of income, education/vocation, food security and housing during these years.

In 2022, there were approximately 931,000 AYAs 12-25 years of age living in Queensland, meaning that almost 1 in 5 people in Queensland are AYAs (17.5%) [1]. This includes 44,204 Aboriginal or Torres Strait Islander young people (15-24 years of age), which equates to 18.6% of the total Aboriginal and Torres Strait Islander population of Queensland and approximately 6.5% of the 15-24 years AYA population [2]. In addition, the AYA cohort are significant users of the health system:

- There were 20,536 upcoming occasions of service within Children's Health Queensland for 12-18 year olds as of 1st of March 2023 [3].
- 5,997 12-25 year olds across the state are experiencing long waits (more than 12 months) in all referral categories to access tertiary specialist outpatient services in Queensland Health as of the 1st of January, 2023 [4].
- 71% of 12-24 years olds accessed primary healthcare via a general practitioner (GP) in Australia in 2020-2021 [5]. In addition, 15–24-year olds were the third most common age group accessing emergency departments (ED) across Australia after 0-4 year old's and adults aged 65 plus [6].
- The AYA cohort are the primary users of paediatric mental health services, accounting for 68% of all activity statewide and significant users of adult mental health services [7].

- The Royal Children's Hospital (RCH) Melbourne have estimated that healthcare services utilisation at the RCH for young people transitioning, who access two or more medical units, amounted to approximately $11 million in 2021-22 when the costs of specialist clinics, ED presentations, ICU encounters and ward stays were totalled, demonstrating high healthcare usage and need among this complex care cohort [8].

Technological advancements, improved survival rates, and chronic disease prevalence in paediatric populations have led to a growing number of individuals transitioning into adulthood with complex, multi-system and chronic health conditions. This includes young people with chronic conditions arising in childhood, such as congenital cardiac disease, spina bifida and muscular dystrophy, with over 90% now estimated to survive into adulthood [9]. The incidence of developmental disorders is on the rise, and the AYA years are known to be a critical period associated with increased risks of accidents, injuries, sexual health concerns, and the onset of mental health issues [10].

Young people also have healthcare requirements that differ significantly from those of paediatric and adult populations. These relate to biopsychosocial development, legal processes, priorities and emerging capabilities [11]. To best provide healthcare to young people, approaches to quality AYA care with trained health providers in adolescent health are required to optimise developmental and health outcomes. Ideally, this would be executed through AYA specific teams and services in hospitals and community, supported by all health professionals who work with AYAs increasing their confidence working with this population [12, 13].

AYA Transition

AYA transition is the purposefully planned process of transfer of an adolescent between health services. AYA transition seeks to support and meet a young person's medical, psychosocial, and vocational needs as they move from childhood to adulthood [14]. Successful readiness for transition within health supports:

- Preparedness for engagement with ongoing care
- Reduced health burden and optimal health outcomes, utilisation, and cost over time
- Optimal satisfaction with care for young people, parents, and professionals alike.

Supporting transition in a planned, coordinated, culturally safe, holistic and biopsychosocial way, with appropriate health service policies, procedures, and AYA specific teams, is recognised as a core component of safe, quality healthcare provision for young people [15-17]. It is also well recognised that quality transition is phased and involves:

1. Early Introduction: To support a gradual increase in self-management and self-efficacy
2. Plan & Prepare: Resourced and structured care coordination with strong integration with GPs
3. Transition: Services working collaboratively to handover with both young people and families
4. Young Adult Care: Developmentally adapted models to meet the needs of emerging young adults
5. Evaluation: Partnering with patients through formal evaluation to optimise service delivery

Transition frameworks developmentally tailored for AYAs have been championed in Queensland [18-21] and are already embedded in New South Wales and Victorian health service delivery [22-24]. These frameworks have informed the structure of this position statement. Queensland Health business guidelines also exist for outpatient specialist transfers between Hospital and Health services [25] and while these guidelines do not provide governance that encompasses the complexity of executing a quality transition, it clearly advocates for AYAs engaged in tertiary care to receive continuity of specialist support with no break in care between service providers.

AYA Care in Queensland: Systemic Challenges

Queensland's current health system structure presents several challenges to the comprehensive, coordinated, consistent care of AYAs. Concerns about fragmentation and dispersed care, patient flow and access, quality and safety all justify the need for quality transition care. Young people in Queensland are provided healthcare across several sectors with no centralised service dedicated to AYA care, resulting in young people transitioning across multiple services, often with little application of approaches to care that are developmentally informed [26]. The transitions that young people face include those from primary healthcare to tertiary health services, from tertiary paediatric services to tertiary adult services and community care [14]. Often, the result is young people disconnecting and disengaging with healthcare, leading to loss to follow-up, ultimately increasing health burdens and health system costs over time.

The demand on emergency departments and acute inpatient services in Queensland hospitals is steadily increasing [27]. With limited resources available, providing coordinated outpatient care where feasible is crucial. By utilising the resources in outpatient clinics, general practice and community supports, we can improve healthcare delivery to patients and ensure that appropriate care is provided in the most suitable settings. This becomes especially important for patients with multiple comorbidities requiring healthcare input from more than one specialty service or provider. For instance, upon turning 18, AYAs diagnosed with attention deficit hyperactivity disorder (ADHD) require assessment and diagnosis from a psychiatrist for their GP to prescribe restricted medications every two years [28]. Another example is young adults with paedatric onset complex medical conditions, where there is a lack of like for like services to refer these young people, especially in rural and remote Queensland.

System challenges significantly impact AYAs with a disability as they transition between health service providers during these years. Some of these challenges include a lack of like for like services from paedatric to adult healthcare and a lack of understanding as to the scope and purpose of the National Disability Insurance Scheme (NDIS). In June 2023, 21,942 young Queenslanders 15-24 years of age had an NDIS funded disability plan [29]. NDIS Plans provide funding for young people with disabilities to support their activities of daily living, to gain greater independence at home and in the workplace, to engage with the community, and to access other services such as health care and education. There are many complex issues when disability funding and support intersects with health care. For young adults, this can include gaps in funding disability support while receiving health care (such as in hospital), problems with funding supports or equipment defined as 'health care' rather than 'disability', and issues with NDIS eligibility, access, and planning. As young people transition to adulthood, the supports funded through a NDIS Plan may increase significantly if they need services like high levels of day-to-day support, complex equipment, or access to specialised housing. For health care practitioners, this transition period can mean more requests for reports, letters of support, or other medical information about the young person's disability and its functional impacts in order for the NDIS to fund the supports and services a young person needs for greater independence and the goals of an adult life. As a sector, health has a continuing responsibility to provide access to quality healthcare that is adjusted to the needs of AYAs with disabilities, and a responsibility to understand and provide support for the complexities these young people and their families face when navigating multiple intersecting, often disconnected, systems.

The ineffective transition of AYAs to adult and community services can result in gaps in care, compromising the patient's ability to manage their health. Non-compliance with medical care, particularly during the AYA years, significantly impacts acute and long-term health outcomes, as demonstrated in young people with kidney disease [30]. Establishing effective transition processes promotes continued health compliance, helps create care pathways that can reduce ED presentations, avoid unnecessary inpatient admissions, positively impact hospital flow and improve healthcare safety and access for young people.

The Consumer Voice

Across Queensland, AYAs and their families report that the quality of services they receive, and their sense of safety in different medical environments, do not meet their minimum needs [26]. The lack of specific AYA services and adequately resourced multidisciplinary patient-centred approaches within adult health services creates a disparity in healthcare for young people. As they "age out" of paediatric services, these individuals are faced with the dual challenges of managing their health concerns and advocating for their physical and psychological wellbeing needs to be taken seriously.

Feedback from consumers and clinicians has highlighted that adolescents as young as 15 years old are being admitted to adult wards alongside significantly older patients of the opposite sex with significantly differing health concerns, often without parental support or additional supervision to ensure their physical and psychological safety. AYAs also report often feeling that they "are not supported to be a partner in their care", recounting circumstances in which they have been discouraged from exercising their decision-making rights as a patient.

These accounts are supported by evidence published by the Australian Commission on Safety and Quality in Healthcare. In 2017, they identified six key safety issues that need to be addressed as a priority to improve safe transfers and transitions of care [31]:

1. Poorly defined AYA transition models of person-centred care
2. Poorly defined responsibility and accountability for communication at transitions of care
3. Inadequate engagement of patients in care planning and communication
4. Limited access to complete and current health and social information
5. Limited opportunities for medication reconciliation
6. Inadequate discharge planning

Consumer Story - Ellie Buchan, complex disability AYA

Moving between health providers during my AYA years was traumatic and isolating. I did not receive any support or mention of transition prior to being discharged from tertiary paediatric just after my 18th birthday in Queensland. I have received hospital care since I was very young, as I have complex health needs which require lifelong management. After being discharged, I spent two years on a waiting list before being seen again in the hospital system. During this time, I felt invisible and insignificant; I lost my sense of personal identity and felt like another number; I didn't matter. These two years of disconnect in my care put my life on hold. I often felt suicidal and couldn't see a future for myself. I was left with very little guidance on managing my health, apart from the limited time and resources my GP could offer me. My health data was poorly managed during this time, leading to providers not having a complete picture of my health history or current needs. My GP and I felt there was no pathway to get a waiting list update or advocate to be seen in the adult services; our concerns were invalidated, and I was left to suffer the consequences.

As a 28-year-old, I now receive excellent care in adult services and realise how much the lack of system support impacted my experience during adolescence and young adulthood. I am now a true partner in my care; I finally feel seen and heard; I'm important, and I feel empowered to have choice and control of my healthcare. Working proactively and collaboratively with my care team has allowed me to choose the life I want to live. My complex health conditions and disabilities no longer define me. I'm proud of the capable young woman I have grown into despite my experiences.

Transition for young people needs to be a supported process. It must be holistic, patient-centred and coordinated, with good patient handover and clear and accessible contact points for young people and health providers when patients are transferred between services. Care provided during transition must meet the needs of young people because what is especially true for me and many young people is that 'no one cares how much you know unless they know how much you care'.

The Case for Change

Now is the time for Queensland Health and the broader health system to reflect on the evidence and the voice of young people to ensure our services play a positive role in the health and psychological development of the next generation of Queensland's adults. We must commit to implementing changes that guarantee all AYAs have access to transitional care that meets their biopsychosocial needs. We need to develop transition care models and embed the principles and practices of quality transition within community, primary, secondary and tertiary health services to improve the quality and safety of AYA care in Queensland.

The evidence tells us that robust transition models of care will lead to the following:

- Happier, healthier young people with equitable access to health
- Improved health and mental health outcomes for young people and families
- Improved health engagement, reducing loss to follow-up and reducing unnecessary hospital presentations
- Improved proactive health practices and health literacy for young people
- Increased social engagement for young people and the social capital of young people
- Improved confidence and satisfaction of professionals caring for young people and their families
- Improved delivery of cost-effective health services [10, 32-34]

Throughout 2022-2023, the Queensland Child and Youth Clinical Network AYA Subnetwork moved to concentrate efforts on transition as a specific component of Quality AYA Care, resulting in the creation of the Statewide AYA Transition Working Group and the inaugural *2023 QCYCN AYA Transition Workshop: Improving safe transfers of care into an adult health system*. Through these mechanisms, QCYCN has sought the expertise of 200 multi-disciplinary health professionals and consumers to draft and define the principles, practices, roles and responsibilities specific to quality AYA transition [35]. This position statement sets the standards for services that should be adapted and embedded to adequately meet the needs of young people interacting with health in Queensland.

Position Statement: Adolescent & Young Adult Transition of Care

Transition is the application of Quality AYA Care during a transfer in healthcare.

Transition is supported and scaffolded care.

Embedding robust transition models is the key to successfully improving the care and management of AYAs, especially young people from priority populations including those with long-term chronic health conditions. It is strengths-based, patient-centred, self-empowering and developmentally informed care.

Principles

Quality AYA transitions adhere to the following philosophy and principles and are:

- Adherent to the Universal Declaration of Human Rights, the Convention on the Rights of the Child and the Charter on the Right of Children and Young People in Healthcare Services in Australia
- Developmentally founded and support AYAs with a holistic and contextual lens. This is especially important to uphold through adapted practices for AYAs with a disability
- Equitable, affirming and safe access across priority populations, all streams, and in all locations AYA care is delivered
- Staged, with proactive early introduction and planning, informed by the reality of health services for 12-25 years olds, specific to the patients' healthcare needs and with consideration of their geographic location i.e., rural and remote Queensland
- Free from bias and discrimination, respectful and empowering of diversity in culture, religion, gender, sexuality, goals, dreams, and abilities
- Connection and integrated to ensure continuity of care, minimizing duplication and fragmentation across health

Approaches

Quality AYA transitions adhere to the following approaches:

- Flexible models of care coordination/navigation suited to the young person and their family's health needs
- Strengths-based, trauma-informed, culturally safe, and affirming to develop AYA's agency and capability managing their health into adulthood
- Dually patient and family-centred, individually tailored to the young person's development, health and wellbeing needs and undertaken in true partnership with the patient and family
- Consistent, integrated, and multidisciplinary, working across systems and sectors to support the whole life of a young person. This should champion the lifelong healthcare role of GPs, importance of education and vocation and opportunities within community to provide health and wellbeing support
- Underpinned by an integrated data system/medical record system to support comprehensive handover of care
- Support the holistic life development of the AYA, in particular continued engagement in education/vocation

Practices

Quality AYA Transition care utilises the following practice:

- Open and developmentally tailored communication and engagement with young people and their families
- Consistent practices specific to capacity, consent, confidentiality, and informed choice with all young people
- Adapted approaches considering health literacy, with practices promoting capability in young people and their families
- Meets and advocates for the physical and psychological safety of the young person within health environments
- Champions the quality of AYA care practices in service delivery through AYA specific services, youth-friendly environments, care structures and advocacy for patients
- Proactive, partnered, and staged care planning, defining the patient's goals of care with proactive access to information provided to the young person to support their pathways to adult services within their community such as transition and service resources, clear health summaries and healthcare information
- Timely care that supports the health and wellbeing of the patient meeting referral wait-times standards and providing services with no break in care when young people are transferred between HHS-HHS/within the same HHS
- Evaluated through patient follow-up opportunities such as PREMS and formal transition model review processes, throughout the transition process

Staged Pathway defining responsibilities of Health Services in AYA Transition

All principles, approaches & practices above and:

Early Intro 1

- Clinician-led introduction of the concept of Transition from 12 years old/high school
- Early planning for health in AYA years with documentation to support
- AYA offered the opportunity to be increasingly seen alone by the Health Professionals

Prepare & Plan 2

- Care coordination and system navigation support, particularly for AYAs in priority populations (see appendix)
- Developmentally adapted health education to all AYAs and families promoting increasing agency and health literacy, promoting the role of supportive decision makers when appropriate.
- Provide resources appropriate for the patient to assist them in managing their healthcare into adulthood. Children's Health Queensland has the Transition to Adulthood resource
- Partner with the patient and family in steps to prepare for the transition, including care planning. The Children's Health Queensland Readiness to Transfer Checklist or the Agency of Clinical Innovation Transition readiness checklist are valuable resources to support these conversations to prepare
- Evaluate the effectiveness of this stage through consumer assessment of progress via Transition PREMS
- Engagement and collaboration with GP in healthcare planning to support lifelong role of GP in AYAs health
- Prepare a shared transition plan, together with the AYA and family, which they can then take with them to their GP visit

Transition 3

- Action referrals to destination services, including follow up to ensure they have been received and actioned – that acceptance of care will be facilitated
- Facilitate a period of collaborative care where the current providers overlap with the ongoing providers, allowing a mechanism of communication for informed and documented patient handover. This includes all professional groups and services as outlined in this Position Statements *Audience*. Children's Health Queensland has the Integrated Transition Summary with may support written handover practices.
- Destination services actioning referrals within KPI timeframes for continuity of care as per the Specialist Outpatient Services Implementation Standard
- Application of developmentally adapted approaches by all health professionals to meet the needs of the AYA patient and their family
- Consistent communication with the AYA as the primary contact and their families
- Provide a welcoming introduction to the destination service, striving to build rapport with the patient
- Resourced navigation/care coordination enabling collaboration between all healthcare providers for the patient, including primary, community and NDIS providers. Care Coordination services are essential for AYAs belonging to priority populations and those who access multiple medical and mental health specialists.
- Medical correspondence/discharge summaries provided to primary care and to patients

Young Adult Care 4

- Provide quality AYA care principles, practices, and approaches, including adapted models of care and environments, including co-locating/cohorting AYAs in inpatient and outpatient services
- Proactive referral to support services internal and external to the organisation providing care, to meet holistic needs in partnership with the patient
- Continued engagement with the AYAs GP, ensuring the patient is connected with primary healthcare
- Ongoing navigation/care coordination to support equitable access and minimise FTA, particularly for AYAs belonging to priority populations (see appendix) and those who access multiple medical and mental health specialists.

Adult Care 5

- Evaluation of transition process in partnership with young adult patient (e.g. PREMS). Mapping health service utilisation and cost outcomes to be included in service evaluation measures.
- Adult Care delivered in partnership with primary healthcare providers into adulthood

National Safety and Quality Health Service Standards (NSQHS):

This position statement aligns with the Australian Commission on Quality and Safety in Healthcare NSQHS standards:

- Clinical Governance Standard Action 1.29
- Comprehensive Care Standard Actions 5
- Partnering with Consumer Standard Action 2.10
- Communication for Safety Standard Action 6.03

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- Queensland Child and Youth Clinical Network AYA Transition Working Group 19 July, 2023
- Queensland Child and Youth Clinical Network Subnetwork on 21 September, 2023
- Queensland Child and Youth Clinical Network Clinical Collaborative 12 October, 2023

Appendix:

Priority AYA Populations as defined in the Optimising Adolescent and Young Adult Care in Queensland - A statewide strategy 2022-2027 include:

- Aboriginal and Torres Strait Islander AYAs
- AYAs living with disability
- AYA living with chronic health conditions
- AYAs with a life limiting conditions
- AYAs living in rural and remote areas
- AYAs from culturally and linguistically diverse backgrounds, including those from refugee and asylum seeker families
- AYAs in out of home care
- AYAs who identify as LGBTIQA+
- AYAs who experience homelessness
- Young mothers/women with families
- AYAs in youth detention
- AYAs who experience violence and/or abuse
- AYAs who are socioeconomically disadvantaged

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