

Position Statement: Adolescent and Young Adult Care

Purpose: The purpose of this position statement is to provide clarity about gold-standard, evidence based Adolescent and Young Adult (AYA) care for young people aged 12-25 years. It is relevant for all services caring for these young people and their families across sectors and across Queensland. This document is intended to clearly articulate a shared language about the need for, and objectives of, AYA care. It provides clarity about quality AYA approaches, principles and practices so services and clinicians can strive to meet these objectives and work collaboratively to optimise care and outcomes for young people and their families.

Audience: This document pertains to all professionals working across sectors with AYAs requiring health or mental health care. This includes: 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 professionals working in public and private health, primary care, community health and non-government organizations. It has been developed through partnership between multidisciplinary healthcare professional and consumer experts.

Background

Queensland's AYA Population and their Health

In 2016, 13% of Queensland's general population were young people aged 15-24 years and 54.6% of Queensland's Aboriginal and Torres Strait Islander population were aged under 24 years¹. These young people are developmentally unique, facing significant biopsychosocial change and transition. In addition, the AYA cohort are significant users of health services. In 2017-2018, the 15-18-year-old component of this cohort alone accounted for 90,960 emergency presentations in Queensland², 44,650 hospital admissions and 133,900 outpatient occasions of care². The AYA cohort are also the primary users of paediatric mental health services, accounting for 68% of all activity state-wide (i.e. 308,110 provisions of services for patients aged 13-17 years²). In addition, the burden of chronic and complex health conditions for the AYA population (aged 15-25 years) is increasing²⁻³.

Advances in technology, increasing survivorship and rising rates of chronic disease in paediatric years are resulting in an increasing proportion of this population entering adulthood with complex, co-morbid and/or 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 adulthood⁴. Rates of developmental disorders are also increasing and the AYA years are recognised to represent a peak risk for accident and injury, sexual health concerns as well as the onset of mental ill-health⁵. The recent COVID-19 pandemic has exacerbated the specific vulnerability of the AYA cohort in terms of mental health with increasing ED presentations and inpatient admissions, especially increases in eating disorders. This has also highlighted a current lack of capacity within community and tertiary based mental health services caring for young people. Within Queensland, the burden of disease in the AYA population is distributed across the state. However, access to specialist services is limited, especially with increasing distance from metropolitan centres. It is especially limited for lower socio-economic status communities with decreased access to services in communities with lower socio-economic status^{2,6}. There are also well recognised gaps in health and care for the state's significant Aboriginal and Torres Strait Islander population^{1,6}. The Aboriginal and Torres Strait Islander concept of health is holistic, incorporating the physical, social, emotional, and cultural wellbeing of

individuals and their whole communities⁷. For Aboriginal and Torres Strait Islander peoples, and in terms of best-practice AYA healthcare, health must be seen in terms of the whole life view.

AYA Care in Queensland: Systemic Challenges

Currently, AYA consumers aged 12-25 years and their families in Australia experience fragmented care and variable transition from paediatric to adult services⁸⁻⁹. This is particularly poor in Queensland where specific AYA services, especially in tertiary hospitals, are largely absent. AYA care is spread across paediatric and adult health and mental health services in the tertiary, community, primary care and education settings. Unlike children, care for AYAs is not centralised and young people are cared for across metropolitan, regional and remote locations⁸⁻⁹. At a health system level, published literature¹⁰⁻¹² suggests the net effect of poorly managed AYA care and transition results in:

- Poor clinical outcomes relating to physical health, mental health and social disengagement
- Poor patient reported outcomes associated with quality of life, wellbeing, mental health self-management and health literacy
- Healthcare disengagement and increased burden of disease and ill-health
- Higher hospitalisation rates and health system use in the AYA years and across the life-course
- Increasing Indigenous health inequality with poorer health outcomes for Aboriginal and Torres Strait Islander AYAs.
- Disempowerment for health care professionals, young people and families alike.

Systemically, there are challenges in the provision of AYA care that cut across diagnostic streams, specialty areas of care and geographic locations¹⁰⁻¹⁵. These challenges include:

- A lack of consensus about the objectives of gold standard, evidence-based AYA care
- A lack of funding for specialist AYA services
- A lack of state-wide governance and strategy to guide clinical practice in the delivery of AYA care and transition between paediatric and adult services for young people
- Inconsistent processes, standards and resources for when and how to optimally engage, assess and care for AYA patients as well as transition patients from paediatric to adult providers
- Gaps in health services especially in relation to mental health and care in the adult setting for those with medical complexity
- A lack of collaboration and coordinated knowledge sharing in AYA care and service improvement
- A lack of health professional education in AYA health and care
- A lack of advocacy to improve systemic barriers to best practice AYA care
- A lack of AYA health and care research across Queensland.

The Case for Change

While the AYA years represent a time of heightened risk, they also present a time of immense opportunity for secondary early intervention to promote developing capability and embedding health promoting behaviours, to foster optimal health and developmental outcomes^{9, 14-15}. This is crucial to ensure the health of current and future generations and reduce health system and social burden^{5,7-13}. The need to urgently optimise AYA care and align care provision with best-practice, evidence based approaches is being recognised within an increasing evidence base as well as:

- A 2020 Queensland Clinical Senate enquiry into AYA care
- Health Consumer's Queensland Youth Reference Group
- The Queensland Aboriginal and Indigenous Health Council's Youth Network Framework
- Queensland policy (e.g. "A Great Start for Our Children: Statewide plan for children and young people's health and services to 2026" and "My Health, Queensland's Future".)
- National policy and frameworks for practice (e.g. The Royal Australian College of Physicians, The Centre for Adolescent Health, The Royal Children's Hospital in Melbourne.)

- Resources, tools and online platforms to promote AYA care (e.g. 'Trapeze' the Sydney Children's Hospital, NSW Agency for Clinical Innovation, Raising children 'The parenting Website', The Royal College of Physicians).

Increasing evidence points to the benefits of Quality AYA care^{5,8-14} in:

- Improving health and mental health outcomes for young people and families
- Improving health engagement, reducing loss to follow up and reducing unnecessary hospital presentations
- Improving proactive health practices for young people
- Increasing social engagement for young people and the social capital of young people
- Improving quality of life and wellbeing
- Improving the confidence and satisfaction of professionals caring for young people and families.

The Statement of Intent¹⁶ outlines Queensland Health's commitment to addressing the health needs of vulnerable children and young people, including those who are transitioning to independence following a care experience (15–25 years of age). Queensland Health's commitment to these vulnerable young people is demonstrated by prioritising access to health services wherever possible.

Despite the long-established sub-specialities of adolescent medicine and health, there is currently no overarching, consensus-based statement for Queensland determining what Quality AYA Care entails. This position statement addresses this gap. It develops a shared language about best practice AYA Care. It aims to promote consistency in care and enable system wide reform in the delivery of best-practice AYA care for young people in Queensland.

Position Statement: Quality AYA Care

Quality AYA care is developmentally tailored, holistic care. It dually supports the best health and developmental outcomes through working in partnership with the young person and their family. It is strengths-based, capability-based, developmentally informed care.

Principles

Quality AYA Care adheres to the following philosophy and principles. It:

- Adheres to the Universal Declaration of Human Rights, the Convention on the Rights of the Child and the Charter on the Rights of Children and Young People in Healthcare Services in Australia
- Is developmentally founded and supports positive holistic youth development
- Promotes equity, ease of navigation and access to expert medical and psychosocial AYA care
- Recognises and fosters the inherent capabilities, values and strengths of young people
- Is respectful of diversity in culture, religion, gender, sexuality, goals, dreams and abilities
- Inclusive, accepting and nurturing of young people and diversity in all settings.
- Recognises that young people are partners in care and experts in their life.

Approaches

Quality AYA Care utilises the following approaches. It is:

- Relational at its core, with effective care founded in positive relationships and trust
- Undertaken in true partnership and is both patient and family centred
- Capability-based and strengths based, working to empower young people and foster control, skills, capability, health literacy and self-management
- Holistic, with dual focus on medical, psychosocial and spiritual care and multidisciplinary
- Integrated, working across systems and sectors to support the whole life of a young person with consideration of health, education and community settings
- Individually tailored and flexible to meet the needs of each young person and family
- Focusses on shared decision-making including setting shared goals and expectations of care.
- Trauma informed.

Practices

Quality AYA Care utilises the following practices:

- Developmentally appropriate engagement
- Developmentally appropriate communication
- Discussion of confidentiality and its bounds
- Consideration of capacity and consent and emerging capacity
- Time alone in consultations with a young person
- Developmentally appropriate psychosocial risk and resilience assessment (e.g. the HEADSS assessment¹⁴) and care planning
- Supporting self-management, developing capabilities, health literacy and fostering independence
- Providing support for family, partners and peers
- Promoting healthy peer connection and peer support
- Planned and deliberate support for transition between paediatric and adult care including care coordination and navigation especially in the 12 months pre and post-transfer of care
- Care delivered in developmentally appropriate environments, alongside other young people.

Every young person aged 12-25 years should have access to developmentally appropriate, quality AYA care, regardless of where they live or receive physical health and/or mental health care. This includes public and private health facilities, in primary care, community care and educational settings. Quality AYA Care should be delivered by appropriately trained, multidisciplinary healthcare professionals. It should be designed, delivered and evaluated in partnership with youth and family consumer experts.

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- Champion Health Agency on 28/06/2021
- Queensland Child and Youth Clinical Network AYA Sub-Network on 29/06/2021
- Queensland Child and Youth Clinical Network Clinician Collaborative on 14/07/2021.

References:

1. Australian Government (2016). *Australian Census Data: Queensland's Population*. Australian Government: Canberra.
2. Queensland Children's Hospital. (20178). *Emergency Department Information Systems (EDIS) Data*. Queensland Health: Brisbane.
3. Queensland Health. (2018). *Queensland Hospital Admitted Patient Data Collection (QHAPDC)*, Department of Health: Brisbane.
4. Queensland Health. (2018). *Consumer Integrated Mental Health Application (CIMHA) Data: Mental Health Alcohol and Other Drugs Branch*. Department of Health: Brisbane.
5. Patton, G. C., Sawyer, S. M., Santinelli, J. S., Ross, D. A., Afifi, R. & Allen, N. B. et al. (2016). Our Future: A Lancet commission on adolescent health and wellbeing. *Lancet*,
6. AIHW (2018). *Aboriginal and Torres Strait Island Adolescent and Youth Health and Wellbeing 2018* (Online).
7. Dudgeon, G., Schultz, P., Hart, C., Kelly, A. (2014). *Aboriginal and Torres Strait Islander social and emotional wellbeing*
8. Sawyer, S. Drew, S. Yeo, M. & Britto, M. (2007) Adolescents with a chronic condition: challenges living, challenges treating. *The Lancet*, 369 (9571), 1481-1489.
9. English, A., Park, M. J., Shafer, M. A., Kriepe, R. E., & D'Angelo, L. J. (2009). Health care reform for adolescents - an agenda for the lifespan: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 6, 1-6.
10. Blum RW, Hirsch D, Kastner TA, Quint RD, Sandler AD. A Consensus Statement on health care transitions for young people with special health care needs. *Pediatrics* 2002;**110**: (6)1304-1306.
11. Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: a systematic review. *J Pediatrics*. 2017; 188:263–269.e15
12. Institute of Medicine. (2014). *Investing in the Health and Wellbeing of Young Adults*. Washington: Institute of Medicine and National Research Council.
13. Sawyer, S.M., Afifi, R. A., Bearinger, L. H., Blakemore, S. J., Dick, B., Ezech, A., & Patton, G. C. (2012). Adolescence: a foundation for future health. *Lancet*, 6736(12), 1630-1640.
14. World Health Organisation (WHO; 2002). *Adolescent Friendly Health Services: An Agenda for Change*. Geneva: World Health Organization, 2002: p. 1-44.
15. Goldenring, J. & Rosen, D. (2004). Getting into Adolescents Heads: An essential update. *Contemporary Pediatrics*. 21 (1), 64-90.
16. Queensland Health. (2021). *Statement of Intent regarding the prioritisation of health services for children and young people in the child protection system – Queensland Health Guideline*. Office of the Director-General and System Strategy Division, Department of Health: Brisbane.

Version	Author	Date Endorsed	Changes	Proposed review date
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