Providing Safe & Quality Care to Young People

A Practice Guide to Adolescent and Young Adult (AYA) Care

Written by young people in partnership with health - 2023

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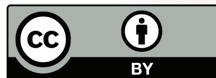

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Aboriginal and Torres Strait Islander people are advised that this document may contain images of deceased persons

We acknowledge the Traditional Owners of the land on which we walk, talk, work and live. We pay respects to Elders past, present and all generations of Aboriginal and Torres Strait Islander peoples now and into the future. (Artwork produced for Queensland Health by Gilimbaa)

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Preface

Providing Safe & Quality Care to Young People: A Practice Guide to Adolescent and Young Adult (AYA) Care speaks to the principles and outlines the practices that underpin and guide the delivery of quality adolescent and young adult (AYA) care within health.

This document has been co-authored and co-designed by eight young Queensland health consumers with lived expertise along with health professionals from the Clinical Excellence Queensland Child and Youth Clinical Network (QCYCN) AYA Subnetwork. During 2023, youth health consumers met with the QCYCN project officer to share their experiences of accessing healthcare in Queensland and talk about what quality and safe healthcare means for them. This group included young people from diverse locations in Queensland, 17 to 25 years of age who all represented unique population groups with diverse experiences of healthcare sectors including GPs, community healthcare, tertiary specialist care, medical, mental health, emergency, inpatient and outpatient care. Each month, practice that the group had identified as positively impacting their wellbeing were explored. Using their words and stories, this practice guide was crafted. This work echoes the sentiments of many AYAs and their families experiences of accessing healthcare in Queensland which QCYCN have gathered during the *Optimising Adolescent and Young Adult Care in Queensland* project (OPAYAC), as well as being reflected in literature (1-3). The authoring team would like to thank the Create Foundation for contributing to the design of this practice guide and to all the other incredible youth consumers and their families who have participated in the OPAYAC project and who provided feedback on this document.

The World Health Organisation defines terminology and age ranges when discussing the youth cohort in a health context. They define:

- "Adolescence"
  - those in the age range of 10–19 years
- "Youth"
  - those in the age range of 15–24 years
- "Young people"
  - the broader age range of 10–24 years
- "Young adult"
  - those in the age range of 18-25 years.

Considering these definitions, and the context of the Queensland Health system, QCYCN promotes the use of Adolescents and Young Adults (AYA) as an encompassing term to promote health structures for young people 12-25 years of age. The QCYCN believes that every AYA should have access to developmentally appropriate, quality care, regardless of where they live or receive physical and/or mental health care. This includes public and private health facilities, 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 (4).

This practice guide is relevant for all health staff providing care to all AYA patients aged 12-25 years across Queensland.

Jorja Campbell, she/her, 17yrs

Gold Coast, Yugembeh
High school champion & rights for women advocate

Hannah Payne, she/her, 24yrs

Sunshine Coast,
Kabi Kabi & Jinibara
Neurodiverse health advocate

Although all young people require developmentally tailored quality AYA care, there are priority populations to additionally consider. These include but are not limited to:

- Aboriginal and Torres Strait Islander AYAs
- AYAs who identify as LGBTIQ+
- AYAs living with disability
- AYA living with chronic health conditions
- AYA's with life-limiting conditions
- AYAs residing in out-of-home care
- AYAs from culturally and linguistically diverse backgrounds
- AYAs from refugee and asylum seeker families
- AYAs in youth detention
- AYAs who experience homelessness
- AYAs living in rural and remote areas of Queensland
- Young Women with Families
- Socioeconomically disadvantaged AYAs

A Message from Youth Health Consumers

The goal of the document is to give a deeper insight to all medical and health practitioners on what accessing care is currently like for young patients and some of the struggles we face whilst simultaneously providing tools to help with working with young patients to improve their health care experiences. Within Queensland, AYAs experience significant barriers to physical and mental healthcare, often deemed as too complex or incompatible with current care pathways. While the health system strives to better meet patients' needs in youth health, further change is required to make it a reality. This document elevates our voices, representing what we need from care providers to help us to grow into the strong youth of tomorrow. We hope it provides practical tips to help you feel more confident when caring for young people.

Thank you for considering this work in your practice and the care you provide to AYAs across our great state.

Zalie Roberts, she/her, 21 yrs.

Brisbane South, Yuggera.
Young mother and health consumer

Maddie Crothers, she/her, 20 yrs

Brisbane North, Yuggera. Youth Mental Health Advocate and First Nations Advocate

Kathan Winchester, he/him, 23 yrs

Ipswich, Tulmur
Youth advocate for mental wellbeing and LGBTIQA+

Elina Passant, she/her, 21yrs

Cairns, Gimuy
Multi complex illness, disability, hearing and vision loss youth advocate

Adolescent and Young Adult Development

Safe and quality adolescents and young adult (AYA) care must be developmentally tailored, holistic care, to meet the emerging needs of young people 12 to 25 years of age as they grow physically, psychologically and emotionally into adulthood. To understand why a developmentally tailored approach to care is needed, it is imperative to understand and recognise the complex, multifaceted, heterogeneous processes of AYA development, the influences on these processes that impact the lives of young people, as well as the inherent and socially driven biases young people experience during these formative years, specifically within Queensland Health. Understanding these processes and factors illuminates why the engagement and management needs of AYAs differ to those of younger children and older adults and why a unique approach to the care of young people is required to ensure safe and quality healthcare delivery.

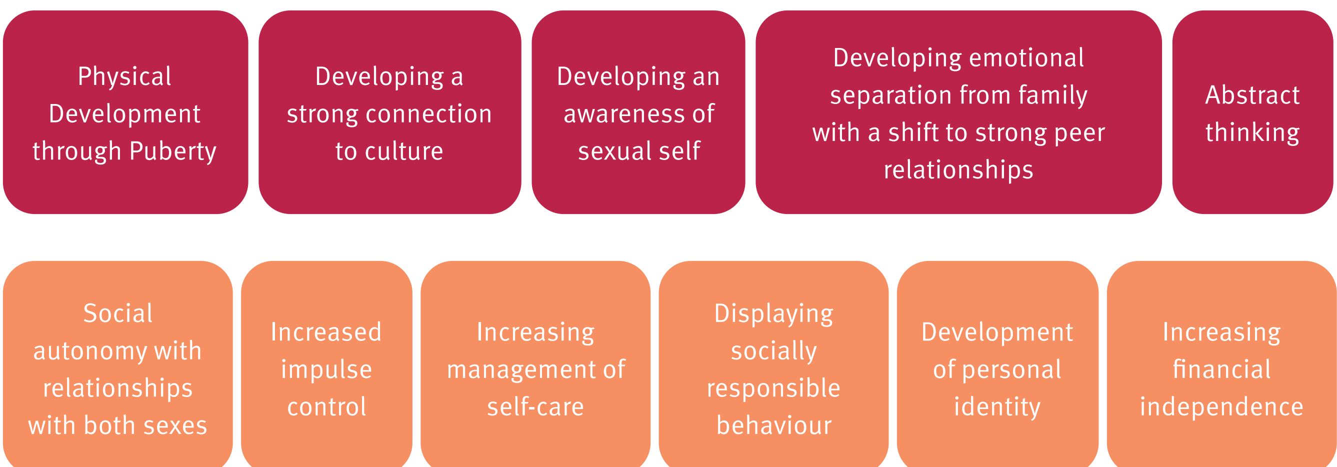
The life stage of 12-25 years is not merely a time of rapid physical change but has biopsychosocial implications on the young person's development into adulthood (5, 6). The AYA years are compounded by **physical (biological/pubertal), cognitive, social, psychological, identity and existential development** and therefore present a complex but significant opportunity for a growth in capabilities, behaviour, and development (7, 8). ***UNICEF recognise that this life stage presents a crucial "second window of opportunity" for cost-effective, scalable interventions to optimise wellbeing into adulthood*** (9). AYAs are developing the skills to make healthy life choices and build their emotional toolkit. If healthcare professionals can frame their work with young people to be empowering and strengths based, it will lead to positive outcomes and engagement, improving the health and wellbeing of our young Queenslanders.

Artwork: Blue
Artist: Jordan Frith
Description: Blue is the first in the strangers with Stories series (2015). It is a micro-series of digital illustrations of people who appeared in the background of photographs taken while travelling. The works describe the wonder of knowing that every person has unique and complex life stories, most of which the viewer will never know.

Stages and Tasks

Adolescents experience identifiable stages or tasks that are linked to their biopsychosocial development and the social determinants that impact their health and wellbeing as they grow into adulthood. These tasks have been researched since the mid-1940s and many frameworks now conceptualise tasks of development as non-linear, with social and cultural factors heavily influencing how young people traverse this life stage (10-12). This flexibility means best practice has moved away from defining unrealistic expectations on individuals who are yet to achieve tasks and now promotes the use of a youth-affirming strengths-based approaches to developing young people, leading to better wellbeing outcomes. Stages of adolescence can be subcategorised into early-mid adolescence (12+); mid-late adolescence; and young adulthood (19+) (11).

Some of these life tasks that are important to consider in how we provide healthcare to AYAs:



Influences on Development

An important part of AYA development involves young people being exposed to challenging opportunities within their communities and growing and learning from these experiences. The way in which a young person engages and grows from these experiences is influenced by risk and protective factors within a young person’s life. Health professionals should always consider risk and protective factors in young peoples lives and engage in conversations around risk in a compassionate way without judgement, encouraging the young person to ask questions and explore how they feel (13-15).

Positive Youth Approaches

At its core, applying positive youth approaches is about building capacity in young people. Capacity building is defined as the process of developing and strengthening the skills, instincts, abilities, processes and resources that people need to survive, adapt, and thrive in a fast-changing world (16, 17). Capacity building is facilitated by applying the practices outlined in this guide to develop strong therapeutic relationships, nurturing the assets that are our young patients. Building the capacity and resources of young people empowers them to lead healthier lives, ultimately facilitating opportunities for them to contribute more to their communities and society.

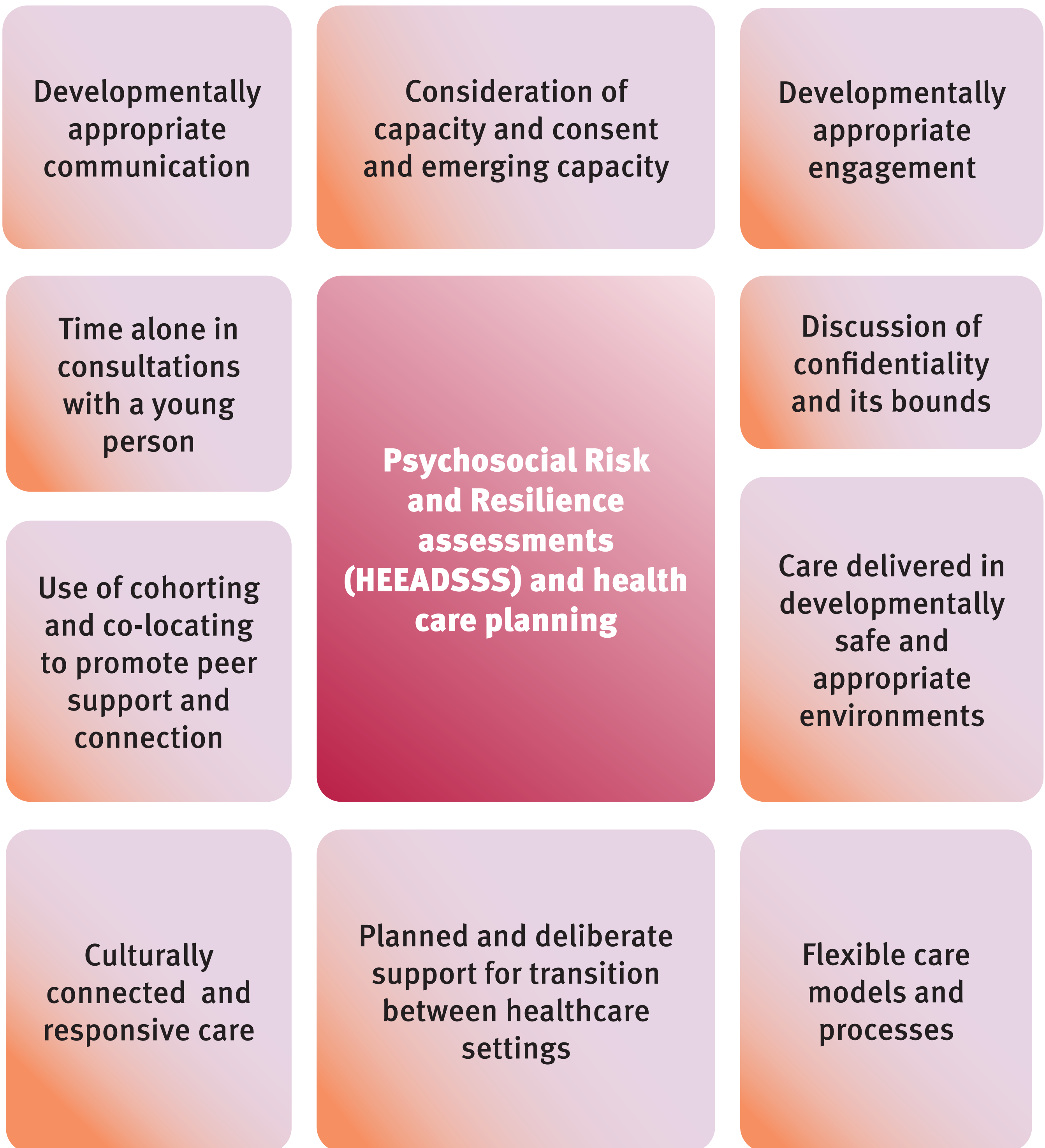
Young people are an enormous asset to our societies. We must cherish them, invest in them and empower them.

- António Guterres UN Secretary General

Adolescents and Young Adults are hard-wired to learn! It is a huge opportunity for health to play a positive role in a young person's life!

When AYAs interact with health services, it provides an opportunistic moment for health professionals to become a positive force and positive formative experience in that young person's life. Health professionals have the opportunity to provide young people with the healthcare they need whilst simultaneously contributing to their bio-psychosocial development.

How can health professionals provide safe and quality AYA care?



Queensland Child and Youth Clinical Network | Position Statement: Adolescent and Young Adult Care (2021)

Practices to Provide Safe and Quality AYA Care

Communication & Engagement

Communication

Why is AYA's communication needs different from children and adults?

Adolescents and young adults (AYA) have differing communication needs because of:

a) The complex developmental life stage they are experiencing

b) The new opportunities they are being exposed to interacting with adults within many unfamiliar environments, such as health

c) Young people want and need to develop trust in adults providing care to them. AYAs learn to trust when they see health professionals using core communication and engagement skills that align with those used by other trusted adults.

This is in contrast to older adult patients who have had many more opportunities to experience healthcare and engage with health professionals to manage acute and chronic illnesses (18). Conversely, young children are often more passive in their communication within health staff, with parents, care givers and families playing the dominant role in communication (19).

The impact of a negative health interaction is also amplified for AYAs who are less resourced than adults to manage and reason with these experiences. For Aboriginal and Torres Strait Islander young people, negative health interactions may involve a lack of culturally appropriate services, prompting feelings of mistrust of mainstream health care, racism, discrimination and fear of possible removal from their families (20). Adverse experiences can have long-term consequences for young people and their families and can both stem from, and contribute to, intergenerational trauma (21, 22).

Communicating effectively with AYA patients is the first step to developing the trust and rapport essential for quality care (23, 24).Ultimately, health professionals must adapt communication practices to meet their emerging developmental needs. This is achieved through listening and learning from the young person and their families to develop a contextual understanding of them as a person with health needs. To facilitate an environment where a young person is comfortable to share who they are and what is going on that's impacting their health and wellbeing, health professionals must communicate with:

1. Strengths-Based Communication
2. Empathy
3. Compassion and Care
4. Transparency and Honesty

and health professionals should:

5. Adapt to the communication and learning needs of the patient
6. Provide the time and space to allow this adaptation

Considered and adapted communication practices also help to develop a young person's sense of self and autonomy, whilst demonstrating to families that you are a trusted adult who can provide care to their emerging young person.

" I had a psychologist tell me my ADHD makes me talk in a way that is too distracting and confusing for her to follow. This has made me so anxious and self-conscious about how I communicate with everyone I talk to, especially my health providers. It made my mental health worse, and I stopped going to therapy." - Hannah, 24 yrs

"I then had a psychologist who was neurodiversity affirming who provided sensory items in her room to help me self-regulate and helped me to see the strengths I have from being neurodiverse, like hyper-empathy, creativity, problem-solving and working well under pressure. She advocated for me and empowered me to advocate for myself, and gave me tools to self-manage, but she never made me feel like I was the problem. When a young person is told the thing that makes them who they are (for me, my ADHD) is a problem, it leads to low self-esteem, anxiety, depression, suicidality, and comorbid chronic illness. The very system these young people seek out for help can, in fact, create more health problems if not done in a neurodiversity affirming (strengths-based) way" - Hannah, 24 yrs

Strengths-based Communication

A strengths-based approach views individuals as important and highlights their strengths and connections rather than only concentrating on their deficits. To apply strengths-based communication, health professionals should:

- Highlight what is going well whilst acknowledging gaps or concerns, but ultimately holding hope for their future
- Discuss what a young person's internal and environmental resources are
- Learn what the patients' health and life goals are
- Talk through alternative thinking for different situations to promote health and wellbeing (25)

Using a strengths-based approach with Aboriginal and Torres Strait Islander young people has also been shown to improve the delivery of health care specific to this population (20, 26).

Empathy

Demonstrating empathy within health is vital to unlocking communication and engagement with all patients, but especially adolescents and young adults developing their skills to form trusting relationships with health professionals. Displaying empathy in health can look like:

- Being able to 'put yourself in your patients shoes'
- Displaying emotions and nonverbals demonstrating that you share and acknowledge the feelings that the AYA and family are experiencing
- Wanting to learn about the holistic context of each individual AYA and how their health and wellbeing is uniquely impacted by their specific lived experiences
- Health professionals have different levels of training and experience around building rapport with patients and it can feel uncomfortable. Working on displaying empathy as a skill will improve your practice in providing patient-centred care
- Social communication is highly variable and some people may display and respond to empathy cues differently

Reflecting on these points and adapting your approach may prove useful if you are not developing rapport with your patient. Taking a moment to reflect on how this experience would have been for you and your family when you were this age may provide a lens to help you consider the emotional and nonverbals cues you demonstrate (27).

*"A phrase I found comforting was "whilst I **can not** begin to comprehend what it is/was like for you, I can empathise that it would be anything but easy." - Elina, 19 yrs*

Compassion and Care

It is evident from the literature and QCYCN's work that AYAs hold back from accessing the care they need due to discrimination and bias they experience when accessing health care. This is particularly relevant for young Aboriginal and Torres Strait Islander youth who disproportionately experience racism, discrimination and bias, impacting health pathways and care utilisation. Discrimination and bias for young people can feel like they are being dismissed, not believed and blamed by health providers for their health concerns. These attitudes do not lead to positive outcomes and must be overcome with compassion and care underpinning all interactions, regardless of the age, cultural or background of the patient (3, 28, 29).

Transparency and Honesty

Transparency and honesty about the system you work within, and the scope of your work are also important to building trust with young people. Being open, honest and transparent allows the disclosure of the boundaries in which you can provide care. Demonstrating appropriate levels of self-disclosure and vulnerability are also ways to help build rapport and connect with young people. This helps health professionals to 'meet patient's where they are', acknowledging the context around the young person presenting for care (30).

Adapt your communication - delivery, time and pace.

In communicating with AYAs, it is important to be mindful of the developmental age of the patient, their literacy levels and any neurodevelopmental or communication differences that a young person is living with. Young people with vision or hearing differences, ADHD, autism, dysarthria, intellectual or social communication differences, as well as those for whom English is a second language, benefit from crafted communication models to meet their needs. These different communication approaches will need to be adjusted to each patient. Taking time to explore what environmental factors can enhance communication may mean changing light levels, sitting beside/adjacent rather than across from, using visual supports, and including caregivers, interpreters or other trusted adults. Some young people use alternative and augmented communication systems which should always be made available. Providing extra time to allow for slower processing and the use of communication strategies may mean discussions feel slower. Empowering young people to have multiple ways of sharing information with clinicians can be helpful such as using written notes outside of sessions, email, and drawing (21).

Without good two-way communication and rapport, health professionals will struggle to gain a complete holistic understanding of the patient, leading to inhibited diagnosis and treatment and reducing opportunities to proactively support the young person's overall health and wellbeing.

"I am a young person who is profoundly deaf. When I went to ED, I saw many different specialists; none of the doctors or nurses would communicate with me despite trying to use a text-to-speech app. They stuck needles into me and ran tests without once explaining to me what they were doing, despite my Mum's attempts to help with communication. One test took away my vision, my only form of communication. Then they seemed frustrated when I couldn't answer questions because I couldn't read. After this experience, we called the ambulance for a medical episode, and the first thing the emergency service worker said when they found out I was deaf was, "What am I meant to do with you?". I no longer feel safe accessing medical care as these kinds of events have become the norm" - Elina, 19 yrs

Engagement

Developing authentic relationships with young people that feel genuine and honest is key to enhancing an AYAs engagement with their health. Together with developing rapport through communication, this encourages an environment where young people feel seen, validated, heard and safe to be honest about their health concerns.

Authentic engagement in healthcare should look like:

- Genuine curiosity, listening, yarning and learning about the young person and their life including their family
- Creating a space where the preferences of the young person and families are sought and integrated into all aspects of care. This promotes partnerships on an individual level but can also be championed by teams, services and organisations that partner with consumers for improvement (31)
- Honesty with acknowledgment of the constraints of our role
- Critical consideration of the natural power imbalances that are present in a patient-clinician relationship

When these steps are taken it can reduce constraints and power inequities through shared decision-making and goal setting. Health professionals will develop authentic therapeutic alliances with their patients more readily, leading to positive healthcare and life outcomes for young people. Positive outcomes for your patients will likely improve your capacity and confidence as a clinician, increasing job satisfaction in the care you provide (32).

"As a young person, if I feel like I'm not being listened to and believed, then straight away, this is a huge barrier for me accessing the healthcare I need to get better, both physically and mentally. I can recognise that I don't have the clinical knowledge that health professionals do, but I am the only expert in the room in my health and my life."
- Maddie, 20 yrs

"I had a really good experience recently in an emergency department where I felt really uncomfortable removing my shirt. I am a trans person and had not had surgery at the time. I expressed this to the health professional. Their response was great in that they genuinely asked me what I felt comfortable with, whether I would like another gendered staff member, needed more privacy, like keeping the curtains closed all the time and allowing my support person to stay and support me. They also checked about my preferred name and if this matched what they had in my chart. They were really proactive at helping me to feel comfortable in that space." – Kathan, 23 yrs

Consent and Capacity

It is vital to recognise the rights of minors (those under the age of 18 years) to participate in or make decisions about their healthcare. Providing opportunities for young people to be engaged in processes about their health facilitates empowerment and positive health engagement into adulthood (33). Despite this, within health, minors are often considered a homogeneous group who always require parental consent. Instead, it should be recognised that the capacity of consent and being involved in health discussions and the decision-making process is a spectrum and is the responsibility of each professional to embed (33).

In Australia, we use a common law standard of determining a 'minor's' capacity to consent to medical treatment known as *Gillick Competence*. *Gillick competence* applies if the health professional determines the person aged under 18 is able to fully comprehend the nature and consequences of the procedure (treatment or withholding treatment) proposed, irrespective of whether a parent consents (34). This can be difficult to apply in practice. There are a few key things to keep in mind when considering capacity and consent in healthcare:

- All medical professionals may not be aware of Gillick's competence, or they may not recognise it in an AYA
- Hospitals and health organisations may have policies and procedures which require parental consent for all adolescents under 18 years. These policies do not promote the recognition of Gillick's competence

- Upholding culturally safe practices for Aboriginal and Torres Strait Islander AYAs is essential, where strong therapeutic relationship are key to building the trust needed to assess capacity and inform consent. It may be appropriate to include Aboriginal and Torres Strait Islander Health Workers and Elders as supports during capacity and consent conversations
- If there is a conflict between the decision of the young person and the preferences of other people involved (parents, guardians, doctors, other health care staff etc), get legal advice. This is particularly important when the young person is close to 18 years of age
- There is a difference between consent to treatment and refusal of life-saving treatment, especially in emergencies. In Australia, courts tend to support treatment to preserve life for minors
- In rare situations, health care for people under 18 may also require consent from the Family Court, even when all the people involved agree. These include sensitive or ethically controversial issues. Consent to withdraw life-saving measures for a person under 18 is also a complicated circumstance (35). Family Court intervention can also be sought when medical practitioners recommend life-saving treatments and parents, or guardians refuse
- Capacity can fluctuate and change. Capacity needs to be assessed with each patient and at each time a decision is being made. This means exploring a young person's capacity in relation to specific healthcare decisions as they arise and over time

In Queensland Health, the [Guide to Informed Decision-making in Health Care] provides a reference for all health professionals working with adolescent patients (36):

- ✓ **16 and 18 is most likely able to consent**
- ✓ **14 and 16 is reasonably likely to be able to consent**
- ✓ **under the age of 14 may not have the capacity to consent, except for health care that does not carry significant risk**

For a person aged 18 and over, capacity to consent is assumed, and lack of capacity (such as if a person has severe intellectual disabilities or is otherwise unable to make legally recognised decisions) must be proven to treat without their consent (37). Remember that exceptions to these guidelines do exist, and consider each case carefully. Please consider researching your local policies regarding capacity and consent to ensure you follow best practices in upholding this legal right.

Health Literacy & Informed Consent

For any patient to provide informed consent, several principles must be followed (36), but of particular significance to the care of AYAs is the patient's ability to **clearly understand the information**. As literacy levels are strongly correlated with age, young people have not had the life experience to develop their health literacy to a level that supports easy engagement in healthcare decisions (38). It is well documented that health information is often written at a literacy level beyond the general population's capability. This is further compounded in adolescence when literacy levels may sit below the recommended Year 10 reading scale scores, the score that all public facing health information should be written at. To ensure informed consent, all healthcare professionals must adapt their communication methods to what is developmentally suited to the AYA patient. Practicing this approach will not only help fulfil the legal requirements around informed consent but will also deliver a patient-centred approach, aid the development of rapport and help build trust with the patient and their family.

"An example of informed consent I would like is for the health provider to communicate every step before and then at the time they are doing anything to my body, no matter how minor the procedure may seem. This means I feel safe and I know I can ask them to stop at any point if I become uncomfortable. Not knowing what is coming or when it is coming can be extremely anxiety provoking and traumatic. This applies even when I have had the procedure before." – Elina, 21 yrs

All patients have the right to research and proactively access information about their health, wellbeing and medical diagnosis. When patients, particularly young people are discouraged or dismissed for seeking information, it diminishes their autonomy. It is essential that all health professionals support and promote information seeking to ensure that patients continue to build their health literacy capacity and skills into adulthood.

"One of my health professionals is amazing and really is my biggest advocate. They have always really listened, particularly when I tell them what dealing with concerns is like for me. They always ask what my thoughts are on things and if I have done any research myself. They are really accepting and supportive, which gives me more confidence to take more control of my health. They often tell me that we can figure things out together and we explore options as a partnership." – Kathan, 23 yrs

Confidentiality

Understanding and respecting the confidentiality of all patients is a cornerstone of practising healthcare. All staff, contractors, students and volunteers are bound to patient confidentiality laws under Part 7 of the Hospital and Health Boards Act 2011. It is our duty to uphold patient confidentiality principles and create environments with our patients that allow for informed consent regarding the sharing and disclosure of personal information to aid health and care delivery (49).

"Disclosing confidential information with the consent of the person concerned has always been (and will continue to be) the most common and preferred mechanism for disclosure." – Confidential General Principles, Queensland Health

For adolescents, additional considerations around confidentiality are strongly linked with capacity and consent.

Section 144: Hospital and Health Boards Act 2011: A health professional may disclose confidential information if -

(b) If the disclosure of the confidential information is by a health professional who reasonably believes the adolescent is of sufficient age and mental and emotional maturity to understand the nature of consenting to the disclosure and the adolescent consents to the disclosure

"Today, I would like to better understand what is impacting your health and wellbeing. This will help me understand how I can help you with your medical needs and care. The information I gain from you is confidential unless I have concerns about your safety and health. By safety, I mean that I might have concerns that you might be at risk of harm or you might harm others. If I do have these concerns, it is important for us to talk through what we do with that information. If at any stage you feel uncomfortable, please let me know."

- Dr Penny Larcombe, Staff Specialist Adolescent Young Adult Medicine, Gold Coast University Hospital

Artwork: Artist: Elina Passant.
"Art gave me a sense of purpose outside of getting through medical, appointments and bad pain days. It unconsciously became a part of my physical therapy whilst simultaneously giving me a way to show people how I see the world and explain things in ways I don't always have words form."

(c) If the disclosure of the confidential information is by a health professional who reasonably believes the adolescent is of insufficient age or mental or emotional maturity to understand the nature of consenting to the disclosure; and the adolescent's parent or guardian consents to the disclosure

(d) If the disclosure of the confidential information is by a health professional who reasonably believes the disclosure of the information is in the adolescent's best interests

Best practice promotes that when health professionals are open and honest about confidentiality, it increases the capacity of young people to participate, strengthening rapport development. By working with young people and their families, health professionals can determine what level of involvement and disclosure is the most appropriate for all stakeholders and the individual circumstances of the young person and their healthcare needs.

Confidentiality standards are often implied in health but not always clearly stated. Here are some examples of how to start these conversations with young people:

"Anything you tell me is just between you and me. I can't tell anyone else, and I can't go and tell your family without your permission, but there are a couple of exceptions. One is that if I am worried that you're about to go out and seriously hurt yourself or somebody else, or if someone else is hurting you, then I have a duty to keep you safe, which might mean that I have to involve other people."

- Associate Professor Dr Melissa Kang, Adolescent and Young Adult General Medicine, NSW Health as demonstrated in the NSW Health HEEADSSS Assessment learning video resource as an initial 'form of words' when engaging with a young person.

When determining age and mental and emotional maturity pertaining to confidentiality it is important to remember:

Health professionals should start by assuming a person is capable of making their own decisions. The person might need simplified information, more time to make decisions, or support from people around them to understand all the options and possible outcomes

Complex disability does not negate the need for young people to be given information confidentiality and then shared with care givers in a collaborative way. Intellectual disabilities, severe mental health conditions, and other impairments may affecting a person's capacity

Embedding, promoting and supporting culturally safe decision-making processes for Aboriginal and Torres Strait Islander AYAs is essential when working with First Nations youth and their families

Under the Hospital and Health Services Board Act a parent of an Aboriginal and Torres Strait Islander adolescent includes a person who under tradition or custom is regarded as a parent of the child

If a person does not seem able to understand information about their own care, or to communicate that understanding, it is still important to include the young person as much as possible in conversations with parents, guardians, and other decision-makers, and not to speak about the person as if they were not present

In rare cases, a person might not be able to be supported to make decisions about their own care. These cases should be the exception to the 'rule' of independent decision-making, privacy and confidentiality of AYA patients

Medical Records

The impact of documented health information can have lasting impacts on the care that young people experience when accessing health services. When a patient is cared for, health professionals have a responsibility to gather information and document their clinical views. Young people have reported experiences of their clinical presentation and discussions with health professionals not matching the documented clinical notes. This misalignment has led to poor treatment recommendations, disengagement from care and experiences of bias and discrimination not only during acute treatment but often many years later.

"I have had experiences where I have felt discriminated against because of notes that had been documented in my clinical record. These experiences have made me question attending emergency departments for physical healthcare concerns when I know that notes about my previous mental health impact the way that care is provided to me. In an effort to take more ownership of my healthcare, I recently requested my medical records from Queensland Health, and after a three-month wait, when I received them, most of my appointment notes were redacted. This made me feel really sad and frustrated - what was written was deemed not in the public interest, but this was about my healthcare and about appointments that I was a part of."
– Kathan, 23 yrs

As a health professional, it is integral to remember that:

- Clinical notes documented in medical records were annotated with the professional view of the clinician at the time of noting
- All patients, and especially young people, need to understand what happens to the information they provide to Queensland Health that is documented in their medical records prior to them providing this (40)
- Providing care with a current contextual lens, free from bias, is essential to follow best practices and upholding the human rights of the patient seeking healthcare
- Previous notes should be considered an evidence base but should not solely inform the care you provide
- National and statewide patient-centred guidelines promote drafting clinical notes in partnership with all patients, aiding the patient to take ownership of their medical information and minimising the risk of a misalignment between the person's experiences and their medical records. This should include readily offering discharge summary notes to all patients, ensuring it is in language that they understand (41)

Some practical prompts for health professionals that have been suggested by the youth authors of this document include:

"Do you understand that information you provide to me will possibly be noted in your medical record? It really helps us to provide you with the best care if you share as much information as possible, but whatever information you provide may be noted in your medical record. Does that make sense? Do you have any questions about this?"

"I would like to summarise/upload this consultation to your medical record in this way. Do you agree with that summary?"

All patients have the right to access their medical records, and you can direct patients to do so by contacting the Qld Health Hospital and Health Services Rights to Information Office. The Health Consumers Queensland and Queensland Government Digital Health Charter defines the priories of what consumers need in relation to digital health.

Queensland Digital Health Consumer Charter Principles

- SECURITY
- CHOICE AND CONTROL
- PRIVACY AND TRANSPARENCY
- ACCURACY
- USER-FRIENDLINESS
- EQUITY OF ACCESS
- DESIGNING TOGETHER

It is essential that all health professionals support and promote information seeking to ensure that patients continue to build their health literacy capacity and skills into adulthood.

Time Alone

Key to upholding confidentiality standards for AYAs is having one-on-one conversations. International guidelines and the evidence base validate the importance of young people accessing time along with a health professional (42-44). Adolescents place a high value on this right. A young patient's compliance with health advice, attendance rates and their willingness to confide in health professionals is strongly influenced by the practice of confidentiality and time alone in health. Opportunities to access one on one time with young people will vary depending on many factors, including a young person's age, carer relationships, healthcare scenario, developmental maturity, communication needs, cultural considerations, previous trauma and patient preferences. Best practice recognises this complexity but still encourages young people to have an avenue to communicate confidentially, therefore, alone with health professionals from the age of 12 years (43).

- Time alone is essential to learn self-management skills and build confidence in attending healthcare appointments without carers
- Health professionals should increasingly engage children in conversations and include them in decisions about their care
- Discussing and normalising time alone with adolescents and their families is important to make determinations on the willingness and ability of a young person to have a discussion alone with their practitioner
- First, encourage patient to answer questions by themselves, then progress to encouraging short time alone
- Time alone with AYAs is also an opportunity to develop skills in carers and families who may not have previously experienced these scenarios with their young person, particularly in health. This may take time and flexible approaches to build relationships with families who may previously not had felt safe in allowing their young person to be autonomous within health
- If the patient and/or their family are not yet in a place to allow time alone, stay flexible and open, and loop back to this at a future time. A clinician should only encourage time alone if the young person is comfortable with it and the clinician believes it is appropriate for their age, communication needs and understanding level. Managing this process with sensitivity is essential

Artist: Wolf Woodroff, 10k nuts, Drawing
Description: to practice drawing concepts and busy ideas, I spend a lot of time drawing a variety of different things together, trying to create unique and interesting structures with random elements

- Always consider the additional cultural needs of First Nations youth in time alone with health professionals, including the importance of continuity of health professionals, gender matched staff, minimising shame, confidentiality and acknowledging cultural preferences around family. Aboriginal and Torres Strait Islander health workers or practitioners are a valuable resource to consider involving
- Flexible approaches may include a parents only session to hear their views, with evidence suggesting that when a family or carer feels heard and validated in their concerns, they more readily are able to develop trust with health professionals
- As a young person grows into adulthood, they will begin to experience adult healthcare services, sometimes by the time they are 15 or 16. It is vital to provide patients and their families with reassurance and information regarding the importance of developing autonomy in health

“When I was younger, I went with my Mum to see a health professional for my mental wellbeing. My mum came to the appointment with me. I felt really uncomfortable with her being there because I couldn’t share what I wanted to because I was worried it might upset her. Mum dominated the conversation. The health professional referred to me as a young adult and tried to encourage some time alone with me, and this made my Mum angry. I never saw that health professional again and this experience has always stuck with me. It would have been great if somehow the health professional encouraged me to reach out in another way if I needed help. I never got the help I needed until after I left home, and I really wish that I had gotten help and support earlier.”

“Part of being an adolescent is the chance to spend time alone with your health professional. Once you’re old enough to be in high school, we want to support you to gain the skill of talking about your health and to ensure you have the chance to be seen by yourself. Today, we’ll all start together, and then I’ll ask your parent/carer to step out for a bit – even if it’s just a few minutes. We’ll all come back together at the end, to ensure that the plan is clear. Would that be okay with you?”

- Dr Henry Goldstein, Staff Specialist Adolescent Young Adult Medicine, Gold Coast University Hospital

Holistic Patient-Centred AYA Care

To maximise the impact our services have on improving the health of AYAs, health professionals must understand the context in which young people are presenting for care, ultimately providing holistic patient-centred care. Patient-centred care approaches have improved safety, quality and cost-effective health service delivery (45) and is a National Safety and Quality Health Service (NSQHS) Standards (46).

HEEADSSS is the internationally validated psychosocial framework designed to support patient-centred care delivery for AYAs. Over the past 35 years, this framework has supported professionals to construct psychosocial consultations through a conversational approach to identify opportunities for intervention and prevention (47-49).

Conversations with AYAs: HEEADSSS Psychosocial Assessment and Engagement Framework

Home, **E**ducation & Employment, **E**ating & Exercise, **A**ctivities, **D**rugs, **S**exuality, **S**uicide/ **M**ental Health, **S**afety

The HEEADSSS psychosocial assessment consists of a series of open-ended questions to guide health professionals working with AYAs. The framework prompts professionals to begin conversations with less emotionally charged questions and moves to the more sensitive topics, allowing the professional to build rapport with the young person while systematically gathering information about their world, their family, peers, education, employment, lifestyle and health-risk behaviours.

Best practice guidelines provide some tips to support a HEEADSSS conversation (48).

- HEEADSSS framework should be used with “every young person who attends a health service or hospital, particularly if it is the first time they are being seen”
- The tool has been designed as a conversation framework, a yarn, not a formal interview. Communicating that young people are active partners in their healthcare through a conversational yarning approach will help build trust and rapport
- It is essential that communication conveys a sense of safety and a nonjudgmental environment for the AYA and family
- It should be used in conjunction with other formal diagnostic tools designed specific to concerns such as mental health, drug and alcohol use, or specific medical conditions
- Set up the conversation asking for consent, reiterating confidentiality bounds and seeking time alone
- It is good practice to understand how confident a young person is with communicating their needs prior to using the framework. This will help you navigate responses during the conversation
- The sequence and depth of questions in each domain need to be adjusted and considered alongside the young person’s developmental stage, your relationship with the patient and family and the context of the presentation
- Critical thinking, clinical reasoning, active listening, an understanding of culture and trauma-informed care is important to discern what questions are most suited and important to explore
- You can use the first categories of this framework with carers present but must consider how questions are framed and how answers may be influenced. Professional should return to the framework in future conversations when the young person and carer may feel more comfortable with the patient being alone
- Even if you only have time to ask a few of these questions, if completed with empathy and strong communication, this can help build rapport with the patient by demonstrating that you realise they are ‘more than a clinical presentation’
- Noticing any ques demonstrating anxious responses should be critically considered and followed up on

- Health professionals must consider how these conversations may impact the mental wellbeing of the patient. Young people who present with both physical and mental health concerns are sometimes labelled as 'too complex'. This can result in services considering the patient's needs to be out-of-scope, resulting in denied care or part of their concerns not addressed. All health professionals must strive to provide holistic, patient-centred care, utilising integrated and cross-sector pathways to best meet their needs in partnership with the patient.

Please head to NSW Health Website for more tips on setting up a HEEADSSS conversation.

"A young teenage girl presented to paediatric ED and was being assessed for rheumatic fever because she had a swollen knee. She completed a two-week admission where we completed a lot of medical investigations, with no diagnosis of her presenting concerns. This young person was discharged and a few days later readmitted with this ongoing swollen knee. During the first few days of her readmission, a medical intern had a HEEADSSS conversation with the patient and discovered she was sexually active. This information then contextualised the diagnosis as reactive arthritis from an STI. This case is just one example of the effort and time wasted and unnecessary harm caused to the patient, family and system just because we, as health professionals, didn't ask the appropriate questions for this young person through the admission and investigative process. If we don't use this tool and don't ask the right questions, we miss opportunities to provide good and cost-effective care to our patients and the health system."

- Associate Professor Dr Simon Denny, Adolescent Physician, Mater Young Adult Health Centre

Below are some scripted prompts reviewed and endorsed by the Youth Advisory Group of QCYCN who authored this document, to support you in conducting a HEEADSSS conversation.

Introduction *The first couple of questions I would like to ask are really about me getting to know you better, so we can make sure that we chat about anything I can help you with, from linking you in with services to support you to being able to better help your healthcare fit into your life. If at any time you don't want to answer a question I ask or discuss something, we can leave it for another time or come back to it at the end if you want.*

Category	Example script and questions to begin the discussion	Additional Resources
H	**HOME:** *First, I want to ask about your home.* • Who lives with you, and where do you live? Have you lived there for a long time or moved recently? Have you ever lived away from home? • What are relationships like at home: Do you get along with your siblings/family/housemates? At home, how confident are you to chat with your family/housemates and communicate your needs? • What is your/your family's cultural background? What language is spoken at home? • What does your room look like: Do you share a room or have your own space?	• Family and Child Connect (familychildconnect.org.au) • Aboriginal and Torres Strait Islander Family Wellbeing Services Queensland • Homelessness & Young People - The Facts | Brisbane Youth Service (brisyouth.org) • Young people experiencing domestic and family violence | Queensland Government • Refugee Health Network Queensland (refugeehealthnetworkqld.org.au)
E	**EDUCATION/EMPLOYMENT:** *Next, I want to ask you about education or if you work?* • Are you enrolled in a school, or are you working: where? How often do you go to school? How often do you have shifts at work? What are your favourite subjects/favourite parts of work? What are your future goals or ideas? Have you changed schools/workplaces recently? • Do you feel connected to your school or workplace? Do you have friends at school/work? Are there adults at school/work you feel you could talk to about something important? Is your school/work a safe place?	• Students (education.qld.gov.au) • Aboriginal and Torres Strait Islander Education • Young workers and students - Fair Work Ombudsman • Bullying and cyberbullying—preventing and responding (education.qld.gov.au)
E	**EATING & EXERCISE:** *Next, I want to chat briefly about your physical wellbeing with some questions about food and exercise. Are you comfortable talking about these?* • What are your favourite foods, and do you like eating out or prefer eating at home? What do you usually eat for breakfast/lunch/dinner? Has this or the foods you like changed at all recently? Have you ever talked to someone about your eating, like a friend or a professional? Have you dieted in the last year? • Do you exercise or like any sports: What sports? Have there been any recent changes in your body that you've noticed?	• Generation Queensland – Health and Wellbeing Queensland (hw.qld.gov.au) • Benefits of being active | Recreation, sport and arts | Queensland Government (www.qld.gov.au) • Home - Deadly choices • Queensland Eating Disorder Service (QuEDS) | Health and wellbeing | Queensland Government (www.qld.gov.au)
A	**ACTIVITIES:** • What do you like to do in your spare time? What do you like to do for fun? Do you have any hobbies? • How do you spend time with friends? Do you have friends from outside your own cultural group/from the same culture group? How do you get on with others your own age? • How do you spend your time online?	• Community activity & volunteering: teens | Raising Children Network • Supporting My Teenager To Find Their Spark | Spark their Future • Gaming | eSafety Commissioner • Help your teen build pride in their Aboriginal or Torres Strait Islander culture - ReachOut Parents

Category	Example script and questions to begin the discussion	Additional Resources
D	**DRUGS:** *The next few questions that I have are about drugs, sex and your safety. As I mentioned, you do not have to answer anything you feel uncomfortable talking about...but lots of young people have told us that they would like the opportunity to talk to a health professional about these topics. Are you ok for me to ask you a few more of these questions?* • Do you or any of your friends or family use tobacco/vapes? Alcohol? Other Drugs? Energy drinks? Do you/they use these with other people/friends or when you/they are alone? How often do you find yourself/do they use these? • Have you ever used tobacco/vapes, alcohol, other drugs or energy drinks in the past? • How confident are you to ask for help or advice with alcohol or drugs?	• Dovetail Resources: supporting the youth alcohol and other drugs sector in Qld • Alcohol and drug support | Aboriginal and Torres Strait Islander peoples | Qld Government • 24/7 Alcohol and Drug Support ADIS
S	**SEXUALITY:** • Are you sexually active? Have you ever been in a romantic relationship? • Tell me about the people you have dated? Have your relationships been enjoyable? • How confident are you to seek support and advice around sex and sexual health?	• Sexual health checks | Youth | Queensland Government (www.qld.gov.au) • FAQs - Failure to report sexual offending against a child to police - Queensland Health • Headspace: Sexuality & Gender, Relationships & Sex
S	**SUICIDE/MENTAL HEALTH:** • Have you felt sad or stressed recently? Is this more than usual? • Are you having any trouble getting to sleep? • Have you had any thoughts about hurting yourself? Someone else? How comfortable are you in communicating to others your mental wellbeing?	• Suicide and crisis care: warning signs and support | Queensland Government • Mental health and wellbeing | Queensland Government • 1300 MN Call: Mental health access line | Queensland Government • 13YARN - Call 13 92 76 | 24 /7 Crisis support for Aboriginal and Torres Strait Islanders
S	**SAFETY:** • Do you feel unsafe in any way, or have you felt unsafe in the past? • Have you ever been seriously injured? Are you taking any risks to calm down or feel better? Have you experienced violence at home or school/work? Have you ever met (or planned to meet) a person you've met online? How confident are you to seek help if you were ever feeling unsafe?	• Partnering for safety with First Nations families | Child Safety Practice Manual • Reporting child safety concerns - Queensland Health Guideline • Keeping kids safe online | Youth | Queensland Government

For more examples of HEEADSSS conversation prompts head to:

- NSW Health Youth Health Resource Kit section 3.2 Psychosocial Assessment
- RACGP - National Guide to a preventive health assessment for Aboriginal and Torres Strait Islander Young People: Chapter 4. The health of young people

Health care planning

After completing a HEEADSSS conversation with a young person, it is important to formulate this into a health care plan, ideally with the patient, to highlight protective factors, raise concerns and formulate further assessment and treatment that might be needed to support the young person's health and wellbeing. Health care planning can range from next steps over the next few hours, through to comprehensive documents with agreed plans, pathways and goals for the patient. Working with the patient and if appropriate, their family as active participants in their care, health professionals can promote the development of autonomy, advocacy and health literacy skills. It is essential to consider several lenses when generating ideas and recommendations after a HEEADSSS conversation, in order to effectively act on any concerns. Some may include:

- A holistic person and wellbeing lens
- The importance of culture and cultural diversity
- An understanding of trauma-informed care
- An awareness of additional inequities that Aboriginal and Torres Strait Islander young people may face
- An awareness of additional inequities that LGBTQIA+ young people may face
- Knowledge and consideration of neurodiversity
- Consideration of physical, cognitive and communication disabilities
- Social and economic considerations
- An understanding of community and locality

"I find it hard to advocate for my health when a health professional creates care plans without checking in with me. I have found that sometimes a health professional's methods of addressing what I'm saying do not align with what my actual health goals are, so their care plan doesn't achieve what I believe is in my best interest. For me, this has resulted in the 'care plan' kind of working in the opposite direction. This feels very disempowering." - Jorja, 17 years

To help strengthen these partnerships, our youth authors wanted to give all health professionals some tips.

- "First, ask us what we want to achieve, and then work with us to work out how we can achieve these"
- "Talk through and include us in discussions about our medical history – provide US with written communication using words that we understand so that we can be empowered to learn and own our health information"
- "Always remember to consider how we like to communicate and our cognitive/physical needs. There is no point in creating a plan with something on it that we might not be able to or willing to do"
- "Consider any neurodiversity we may have when developing plans. There might be scenarios or services we feel uncomfortable engaging in due to this diversity. Develop care plans in partnership with us to make sure that we are willing and invested in following through with plans"
- "Consider including our larger care team by asking us who else gives us healthcare and wellbeing support. Working with school, allied health professionals, NDIS supports, and community organisations could increase our access to support pathways that are right for us"
- "If you suggest a resource or a service, then help us navigate to and access these. Please take a moment to explain how to access things or send us a link to websites or referral forms"
- "Celebrate milestones with us. This shows us that you care"
- "Always note a review date for any plans, schedule follow-ups and encourage us to reach out if things in our life and health change"

Please escalate any significant concerns that may have been raised during a HEEADSSS conversation following your local procedures, policies and guidelines. Some additional links are provided in the HEEADSSS table as introductory resources for you to learn more about some of the significant concerns that may be raised during a HEEADSS conversation.

Youth Friendly Checklist for Health Services:

Adapted from the NSW Health Youth Friendly Checklist for Health Services

Domain 1: Accessibility	**Yes**	**Partially**	**No**
Does your service have a strategy to help AYAs feel welcome?			
Is the confidentiality policy widely practiced and publicised to young people, their parents and carers?			
Does your service use innovative strategies to improve young peoples engagement with your health service?			
Are services provided free, or at a low cost affordable to young people?			
Can young people access the service easily?			
Is the service open when young people can access it?			
Is the service sensitive to the cultural and language needs of AYAs?			
Is there capacity to offer longer sessions to discuss complex issues?			
Are waiting rooms and facilities welcoming, with health promotion materials that appeal to young people?			
Domain 2: Evidence-based approaches			
Does your service look at research and evidence to ensure healthcare provided to AYAs is quality and supported by the literature?			
Does your health service use HEEADSSS as a framework for engaging young people in healthcare?			
Does your service have a way to receive regular research updates in AYA healthcare?			
Domain 3. Youth Participation			
Does your service involve young people in service planning and review?			
Domain 4: Collaboration and Partnership			
Does your service work collaboratively with others to help young people navigate the health system?			
Domain 5. Professional Development			
Do staff receive training, supervision and support in working with AYAs aged 12-24 and youth health concerns?			
Domain 6: Sustainability			
Does your service develop sustainability strategies? For example starting with small initiatives or changes and gradually building on success			
Domain 7: Evaluation			
Does your organisation evaluate its services, including seeking feedback from AYAs and their families?			

Service Delivery to Provide Safe and Quality AYA Care

Youth Affirming Health Systems: Inclusive Youth Friendly Services

"Entering a healthcare setting, whether it be for an appointment or in an emergency, is typically already stressful enough for all people, however, when you combine these cold, sterile and anxiety-inducing environments with adolescents and young adults who may be uncertain about what is going to happen or have had negative healthcare experiences in the past, the situation is made drastically worse. I've found that oftentimes, something as simple as colour on the wall and artwork with descriptions can not only make me feel like I belong and am safe in that healthcare setting, but they also provide a temporary distraction from the stress of the appointment, allowing me to be calmer and for the patient-clinician interaction to be more effective." - Jorja, 17 yrs

Environment

Hospitals, health clinics and general practice offices are, by design, sterile clinical spaces that allow for disinfecting and are, rightfully, full of people who are unwell. This means they are generally not welcoming and warm environments. Engaging in these environments independently is often intimidating and overwhelming for young people. Young people report not finding a sense of comfort or belonging in neither paediatric or adult healthcare environments, with spaces and services not appropriately meeting the needs or minimum safety standards of AYAs 12-25 years of age (3).

Inclusive youth friendly services provide healthcare in fit-for-purpose physical spaces that are clean and have accessibility to the outdoors, with teen and young-adult-orientated information, resources and activities such as games and sensory devices available (50, 51). Young people value spaces that negate their clinical 'feel' using visuals and colour via art and displays. In these spaces, equity is maintained, ensuring that any physical barriers that could interfere with the movement of young people with mobility aids are taken into account, as well as ensuring cultural inclusivity through rich cultural displays within environments that may make First Nations patients feel more comfortable.

Research in AYA oncology patients, who, experience an intense increase in the amount of time they are required to spend in health environments, has found that youth-friendly and specific spaces can:

- increase a sense of control and provide comfort in a clinical environment
- facilitate personalisation, supporting young people's identity development and inclusion
- provides stimulation to support normative youth development
- enables connection to peers, normalising their experiences (52).

Safety

Adolescents under 18 years of age should be cared for in healthcare spaces that meet the minimum safety needs for paediatric patients. Adolescents admitted to inpatient settings must be physically separated from adult patients. Adolescents should ideally be admitted to an adolescent area (53) and where this is not possible, health services should identify designated areas where adolescents can be accommodated. Services must ensure compliance with local health service policies, guidelines and risk management strategies to ensure adolescents are physically and psychologically safe while in our care (54).

Please refer to the Queensland Health Safety and Security of Children and Young People in Queensland Health Facilities Guideline for more details on upholding the safety rights of young people in healthcare.

The Royal Australasian College of Physicians states the risks associated with placing adolescents into adults' services include (55):

- the rights of children and young people not being respected
- physical, psychological or sexual harm from other patients, staff or visitors
- compromised quality of care if it is provided by staff without education and training in the care and treatment of adolescents
- inadequate or inappropriate parent, carer or guardian support and involvement in care
- interruptions to normal development
- unnecessary trauma from witnessing distressing sights or sounds

Cohorting/Co-locating

Young people want to be with other young people. An important recommendation of the Optimising Adolescent and Young Adult Care in Queensland Strategy was co-locating or cohorting adolescents and young adults in safe, empowering ways (3). All participants in the strategy development supported service delivery models that group young people together. Cohorting is also essential to building a critical mass of expertise in care delivery to a specific patient cohort and to supporting the healthy and normative development of young people experiencing health concerns into adulthood (56).

Culturally Connected & Responsive

Elevating and embedding culturally safe and connected care is integral to improve health system safety and accessibility for Aboriginal and Torres Strait Islander youth and young people from culturally and linguistically diverse backgrounds. It is also essential to uphold commitments to Close the Gap for First Nations young people. By embedding practices that elevate and promote cultural connection, health professionals can harness the protective factor culture plays for indigenous young peoples physical health and social and emotional wellbeing (57). All young people's identity development is influenced by cultural connections as they grow into adulthood, and are especially important for these groups. Health professionals must think more openly, practice without judgment and utilise additional resources, such as Aboriginal and Torres Strait Islander healthcare workers when providing culturally connected and responsive AYA care (58). A person's cultural beliefs and values can affect how he or she engages in care and how they accept diagnosis (59, 60).

Family structures can be richer and more diverse within these populations than in nuclear families. There tends to be more parental and other family figures available for infants in collectivist cultures as opposed to one or two primary caregiver roles in individualist cultures (60). This places importance on health professionals applying flexible approaches around family structures and should consider the roles and responsibilities young people may have that are relevant for their culture and their family. When working with young Aboriginal and Torres Strait Islander and culturally

and linguistically diverse patients, using a narrative conversational approach or yarn to communication may aid rapport and engagement, as these patients and families may associate answering personal questions with increased fear and a sense of shame (61, 62).

Go to https://www.8ways.online/ to learn more about using a narrative approach and the Aboriginal pedagogies framework.

Aboriginal and Torres Strait Islander people have a deep connection with community, country and being and healing close to home. Discussing genealogy is a tool that can be used to demonstrate respect for First Nations culture and history. It is important to recognise and support these cultural practices and consider how health service delivery can be flexible to meet the young person's holistic needs. It is also important to hold in concert the amplified inequities that exist for priority populations such as for Aboriginal and Torres Strait Islander AYAs and AYAs from culturally and linguistically diverse backgrounds, but this background should never imply vulnerability or disadvantage (59, 60).

Flexibility

Young people have reported significant barriers to care due to inflexible service models that don't meet their needs. AYAs and their families highly value (50) care that has:

- Outpatient appointments that can be negotiated around home, education, and employment commitments, particularly with short timeframes from appointment notification to consultation
- Flexibility in the healthcare team in meeting patient needs, particularly considering gender and culturally adapted models
- Flexibility in the mode of consultation. If telehealth is an appropriate option for the outpatient consultation, then this should be offered. Not all young people prefer telehealth, so this should be optional, with other options offered
- Minimal cost. Young people, as a population cohort, do not have access to financial resources in the same capacity adults or children do. Health services should be mindful of out-of-pocket costs and aware of local, additionally funded, or low gap programs/services for those who are eligible
- Patient-centric and family-centric approaches. Some young people want their support networks included in care decisions, whilst other young people want total independence. Family dynamics and culture can influence this for young people. Some young people have also reported needing family present to advocate for their needs, as they have experienced discrimination when accessing healthcare previously

Health services must be considerate of these needs and be prepared to be flexible to truly provide inclusive youth friendly services.

Young people have also highlighted that long wait times between referrals and appointments impact their desire to attend, and leave them feeling disrespected by health professionals or services (50). These barriers, along with a lack of AYA quality care provision, impact a young person's ability to attend appointments, leading to young people 'falling between the cracks' and being discharged from specialist healthcare (63).

Within Queensland Health, there are different practices around incomplete appointments and discharge across services and the system, and whilst the authors of this document understand these practices from a business perspective, we would like to encourage all health service providers to consider the circumstances and vulnerability of young people who are needing care from health services. Ideally, young people who may display access concerns should be communicated with and offered supported follow-up, as referral letters and text messages often do not get to the patient, particularly when there has been lengthy referral wait times.

"I had waited years for an important outpatient appointment with a particular specialist, and in the days before it was approaching, my health deteriorated significantly, and I was not medically well enough to attend. Three years down the track, and I still can't get back in to see this specialist, with any enquiries to the health service noting my FTA. Accessing these specialist appointments is so important for my health, and I feel devastated that the system is so rigid…and I'm still waiting" - Elina, 19yrs

"Receiving healthcare is a right, and it's important to remember that it's not just legal or policy issues that prevent access to health for young people. I have had instances of not attending follow-up appointments with specialists due to being left with trauma from past interactions with them and, by extension, being denied future care from anyone because I already had a referral to a specialist who I no longer felt comfortable seeing. I have also had instances where information regarding the date and time of a long-awaited appointment is communicated only a couple of days in advance, preventing attendance altogether. A holistic team of healthcare professionals, who monitor their patients' care at every step, would prevent people from falling through the cracks and feeling as though it is impossible to access any healthcare at all." - Jorja, 17yrs

Supported Transitions in Healthcare

Transition is the application of Quality AYA Care during a transfer in healthcare – ***Position Statement: Adolescent and Young Adult Transition of Care, QCYCN 2023***

AYA transition is the purposefully planned process of transfer of an AYA between health services, that is supported and scaffolded. AYA transition seeks to support and meet a young person's medical, psychosocial, and vocational needs as they move from childhood to adulthood, increasing their self-management and advocacy skills (64-67). Successful readiness for transition supports:

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

The importance of supporting transition in a planned, coordinated, holistic, biopsychosocial way, with appropriate health service policies and procedures, is recognised as a core component of safe, quality healthcare for young people (67, 68). Transition is generally optimised when there is a specific health care provider who takes responsibility for helping the adolescent or young person and their family through the process' (67, 69). It is also well recognised that good 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 integration to primary care
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

For more information about the principles, practices, approaches and pathways for transition for AYAs, please review the QCYCN position statement: Adolescent and young adult transition of care (health.qld.gov.au)

Want to gain more expertise in AYA healthcare?

Foundations of Adolescent and Young Adult (AYA) Health Care

QUT and Queensland Health are partnering to provide a detailed understanding of the foundations of evidence-based adolescent and young adult health and care for multidisciplinary professionals.

We're working to support professionals from various sectors in providing youth-affirming care and building confidence in working with young people.

Course duration: access 10 hours of flexible online learning over three months

This course has been developed in partnership between QUT and the Queensland Child and Youth Clinical Network.

For more information, visit qut.edu.au/study/aya

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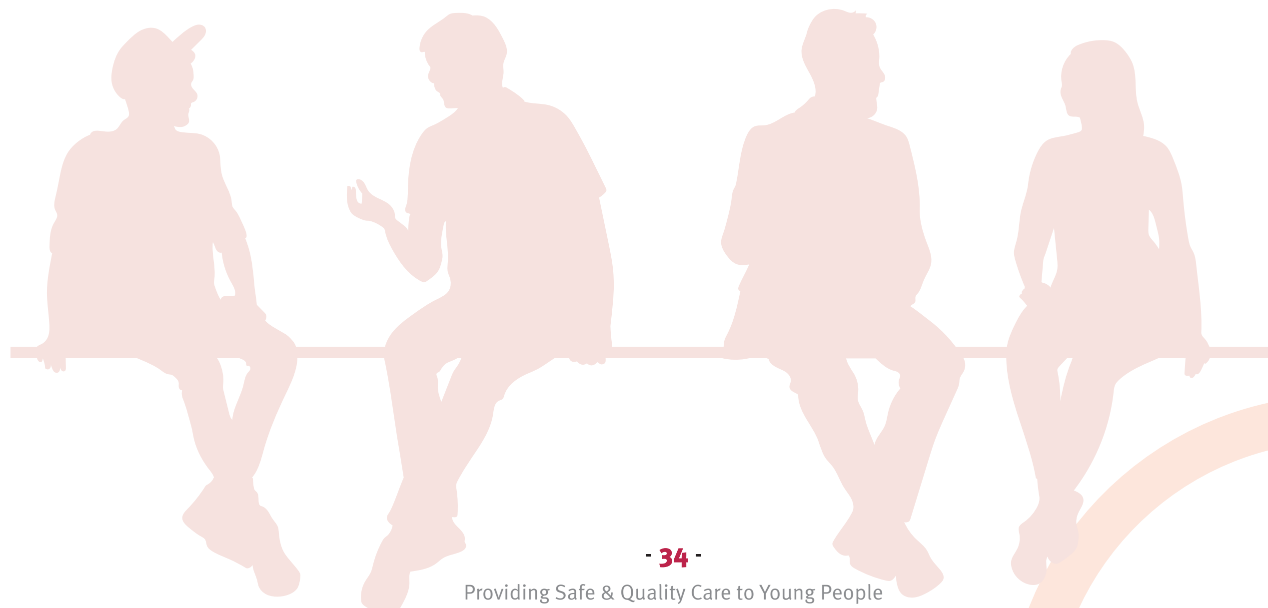
Optimising Adolescent and Young Adult Care in Queensland Strategy: What young people told us

From February 2022 to June 2023, QCYCN spoke with many young health consumers via focus groups to understand their experiences of healthcare in Queensland (3). Below is a summary of what they told us:

- AYAs want to be listened to, have their health concerns validated and investigated
- AYAs want to be believed and receive healthcare that is free from assumptions, discrimination, bias and racism
- AYAs want to feel empowered, engaged and be partners in investigating and improving their physical and mental health concerns
- AYAs need healthcare that promotes partnership, flexibility in choice and is wellbeing affirming
- AYAs need healthcare that has continuity and consistency, is humanistic and promotes disclosure and sharing through communication, engagement, and rapport development
- AYAs need healthcare that is proactive and promotes long-term wellbeing, with increased capacity for health professionals to address acute and chronic concerns. This requires appointment and consultation times to be considered. AYAs believe this approach will strengthen relationships between health professionals and young people
- AYAs need healthcare that encourages them to learn about themselves and their condition
- AYAs need healthcare that is easier to navigate, youth-affirming and physically and psychologically safe
- AYAs need healthcare that is trauma-informed and holistic in approach
- AYAs need healthcare that promotes the importance of education, vocation, and support to engage in living a healthy and safe life
- AYAs need healthcare that provides follow-up and care coordination
- AYAs need healthcare that provides privacy and practices confidentiality and informed consent
- AYAs need healthcare that provides developmentally and culturally responsive choices, e.g., gender of the doctor
- AYAs need healthcare spaces to be physically and psychologically safe, and youth-affirming, with access to patient rights information and functions to support AYAs and their families to exercise those rights. This is particularly relevant for 12–18-year-olds
- AYAs need healthcare that continues to support them in addressing complex health needs, with integration across services and sectors that supports referral pathways to escalate complex health concerns. This is particularly important when young people are prescribed medication but not provided referral pathways to support and address their complex concerns



- AYAs want equal access to healthcare that is considerate of the additional barriers young people face. This includes a lack of services in rural and remote areas, a lack of youth-specific services in Queensland, financial barriers and employment and education barriers that impact the ability to attend health services within business hours
- AYAs want to be provided care in a timely way, with their age not a defining factor influencing waitlist triaging
- AYAs want to be supported if they are moving from one health provider to another, with access to a point of contact that can help navigate the health system and ensure they can successfully engage with health
- AYAs need health information, resources, and discharge information in accessible formats at literacy levels that meets their capabilities and information needs
- AYAs want their health concerns to be triaged and treated in an equal way to all other age groups, without bias discrimination
- AYA care is bio-psychosocially complex, and Health Professionals should feel confident in providing care to AYAs to ensure communication, engagement and rapport development do not impact care
- Occasions of care and complexity of AYA care are increasing with more ED presentations, youth justice, mental health and eating disorders
- AYAs need healthcare that understands how an illness and medical treatment may impact other aspects of their lives such as school, work and adolescent milestones including special social events. Healthcare should be curious about our lives and work with us to ensure treatment is successful and our illness and treatment impact our lives as little as possible

Systemic Barriers

All focus group participants told us there is a need for increased

- awareness of AYA development and the unique needs of young people
- awareness about adolescent health and quality AYA care
- AYA services, resources and supports for young people and families
- medical record sharing across sectors and HHS. Different systems across sectors
- appropriately trained and skilled health professionals across disciplines

Some focus group participants told us there is a need for increased:

- awareness about the needs of families and carers
- Medical systems and forms that support quality AYA care, e.g. not identifying complex patients, include the phone number of a young person etc.
- patient-held records; paediatric records are often destroyed
- medical training pathways in Australia and specifically Queensland
- clinical AYA champions and workforce stability, especially in remote and rural areas

Education Information Resources

All focus group participants told us there is a need for increased:

- professional education and training in AYA development, health and care for health professionals
- education and information resources for young people impacting health literacy through reliable sources in health and educations settings

Some focus group participants told us there is a need for increased:

- education and information resources for carers and parents

Consumer Engagement

All focus group participants told us there is a need for increased:

- meaningful, consistent partnership
- forums for consumer connection to facilitate advocacy and awareness

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