

LIFE TRANSITIONS AND YOUTH PATHWAYS TO HEALTH SERVICES



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RECOMMENDATIONS

The Youth Health Forum's recommendations for the Federal Minister for Health and Aged Care / Minister for Education.

Navigation support: When young people move into the adult health system, it is vast, complex and very difficult to navigate. As it is unfamiliar to us, we can become lost and not receive the services we need, due to these challenges in navigating the system.

- Federal Government fund a national nurse navigator program that sits alongside hospitals to support and empower young people when they transition into the adult health system. An example of a successful federal program is the McGrath Foundation's Breast Cancer Nurse program.
- Government to review the Healthdirect website using a co-design approach to update it and make it more user-friendly and youth appropriate.

Youth age consistency across jurisdictions: Young people experience challenges in accessing health services due to their age as they can be classified differently between health services across States and Territories.

- Minister to work with States and Territories to determine a nationally consistent patient centred approach for young people accessing services in the health system that factors in mental maturity. Article 12 of the United Nations convention on the rights of the child is a reference point for these discussions.

Affordable access: Affordability of health service access is a challenge for many young people, particularly as they transition from adolescence and a reliance on parents into early adulthood.

- Provide young people aged 14 – 22 with a concession card to improve access to bulkbilled services and to make them eligible for the threshold and safety net limits to reduce the financial barriers to care.
- The Government has recently doubled the number of psychology sessions available with a Medicare rebate. We recommend allowing young people the autonomy to determine whether they are receiving 10 fully-funded sessions (no gap) compared to the nationally-allocated 20 partly-reimbursed sessions. This will have no change in cost to Government from currently allocated model, but will increase access and flexibility for young people who cannot afford co-payments.

Digital Healthcare Delivery: Young people living in remote and regional areas have significantly benefited from the changes to service delivery introduced during the Australian COVID-19 pandemic response. Providing more services through a digital channel has aligned services more closely to younger consumers' expectations, as well as being more cost effective. Access to a digitally delivered service requires good internet access to be equitable.

- Consumers should have access to health services, referrals, prescriptions and notifications via telehealth, phone, email or text and this should be supported with relevant MBS items.
- Ensure access to basic internet services for all Australians through updates of the Universal Service Guarantee. Currently, the Universal Service Guarantee is very 'household' based and this excludes people who may be experiencing homelessness and may not be able to access through public networks e.g. public libraries have been closed during parts of 2020.

Inclusive Delivery: Access to health services from Culturally And Linguistically Diverse young people is heavily dependent on their ability to access Translating and Interpreting Services and there are opportunities to improve these services for us and our communities.

- Government conduct a comprehensive review of interpreter and translation services in Australia to determine whether it meets current community needs.
- Government to provide funding for increased access to translation services. For example support for the Translating and Interpreting Services (TIS) to allow consumers to use the service for more than 1 hour to allow more flexibility
- Government mandate that all medical centres and GPs offer the service where a consumer requests or requires an interpreter
- Government to ensure TIS and health based translators have the required health or medical translation training to be able to interpret effectively and be respectful of privacy and patient confidentiality.

EXECUTIVE SUMMARY

Background & Rationale

In youth, there is a unique opportunity to establish health for life by equipping young people with the tools they need to get help when they need it, and by supporting young people to speak up about how they can live their healthiest possible lives. The 2020 Youth Health Forum (YHF) was created to make young people's ideas and experiences part of our national discussions about services for young Australians. It was co-hosted by the Consumers Health Forum of Australia (CHF) and the Wellbeing Health & Youth (WH&Y) NHMRC Centre of Research Excellence and supported by funding from the Australian Government Department of Health. The Youth Health Forum Report, produced by CHF and WH&Y, is based on the discussions, insights and ideas of YHF delegates.

Policy Context

In 2020, the federal Youth Taskforce was created to advise the Minister for Youth on the policy and programs available for young people across government agencies and finding ways to involve more young people in developing policies that affect them. CHF and WH&Y strongly support the Minister for Health's vision of ensuring that Australian young people have the best opportunities to fulfill their potential. In order to achieve this, we need to amplify the voices of Australia's young people, to ensure that they can readily access the right service at the right time.

Evidence Context

Healthcare professionals across Australia have long recognised the problem of young people falling through the gaps of a health system that wasn't designed for them. The Access studies were created to understand young people's experiences of accessing health services. The studies focused on several marginalised groups, with about one-third of young people recruited into the study from one or more of the following backgrounds: Aboriginal and/or Torres Strait Islander, homeless, of refugee background, living in rural/remote locations, sexuality and/or gender diverse. The young people in the studies identified multiple barriers to accessing health services: structural (e.g. cost and practical issues); attitudinal (e.g. worries or concerns about using health services) and barriers relating to emerging autonomy and adulthood (e.g. parental involvement and knowing where to go).

Methods

This report used three methods of data collection:

1. Review of the academic literature on access, usage and obstacles to healthcare services for young people in Australia.
2. Review of national and international examples of healthcare services designed for and/or with young people.
3. Consultation with sixty Youth Health Forum delegates recruited from around Australia.

Findings & Recommendations

Based on evidence developed by the WH&Y Centre of Research Excellence team, and in consultation with CHF youth leaders, six key challenges were identified, workshopped and ultimately used to form the basis of recommendations for improving youth pathways into health services in Australia.

1. The six key challenges were:
2. Trusting healthcare services
3. Transitioning to adult healthcare
4. Navigating the healthcare system
5. Delivering digital healthcare
6. Building a more equitable system
7. Developing health literacy

In recognition that many of the important issues underlying obstacles to healthcare services were common to several of the challenge topics, the youth leaders from the six YHF Working Groups consolidated their recommendations into cross-cutting themes. The Youth Health Forum's recommendations for the Federal Minister for Health are:

1. Age consistency across jurisdictions
2. Navigation support
3. Affordable access
4. Digital Healthcare Delivery
5. Inclusive Delivery

INTRODUCTION

Youth health is different from health at other ages. In childhood, health is mainly about growth milestones and infectious disease control. In middle-age and beyond, health is mainly about treating established chronic diseases like cancer and cardio-vascular conditions. But in youth, there is a unique opportunity to establish health for life by equipping young people with the tools they need to get help when they need it, and support them in living health lives.

To realise this opportunity, to turn it into reality, requires a shift in thinking away from negative stereotypes about young people and a commitment to move beyond 'business as usual'. We need to reinvent young people's healthcare, remove the stigma and inequity that prevents them from getting the support they need, and instead champion their strengths, their insights and their leadership.

The 2020 Youth Health Forum (YHF) was created to make young people's ideas and experiences part of our national discussions about health services for young Australians. It was co-hosted by the Consumers Health Forum of Australia (CHF) and the Wellbeing Health & Youth (WH&Y) NHMRC Centre of Research Excellence and supported by funding from the Australian Government Department of Health.

2020 has been a year like no other. COVID-19 has interrupted just about every aspect of our lives, not least re-shaping how we go about meeting to discuss important issues like young people's wellbeing and how-to shake-up pathways into health services. Face-to-face get togethers were on hold, but this topic was too important to be kept waiting which is why the 2020 Youth Health Forum workshops were turned into virtual events. YHF delegates met regularly, no matter which part of Australia they lived in.

The Youth Health Forum Report, produced by CHF and WH&Y, is based on the discussions, insights and ideas of YHF delegates. It addresses six key challenges in reinventing youth health services: Navigating the Healthcare System, Developing Health Literacy, Delivering Digital Healthcare, Trusting Healthcare Services, Transitioning to Adult Healthcare, and Building a More Equitable System. These form the basis of the recommendations presented for improving youth pathways into health services in Australia.



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BACKGROUND

Policy Context

In 2019, the Minister for Health released the National Action Plan for the Health of Children and Young People 2020 – 2030. The purpose of the National Action Plan is to provide a roadmap for a national approach to improve and ensure the health and wellbeing of all Australian children and young people. The Australian Government has committed to supporting three Youth Health Forum events to be convened by the Consumers Health Forum (CHF), commencing in 2020.

In 2020, the federal Youth Taskforce was created to advise the Minister for Youth on:

- the policy and programs available for young people across government agencies
- finding ways to involve more young people in developing policies that affect them.

The Youth Taskforce has produced an interim report,¹ which will support further consultation and guide the work on the National Youth Policy Framework.²

CHF and WH&Y strongly support the Minister for Health's vision of ensuring that Australian young people, from all backgrounds and all walks of life, have the best opportunities to fulfil their potential, and are healthy, safe and thriving. In order to achieve this, we need to amplify the voices of Australia's young people, drawing on their lived experiences and harnessing the benefits of their creativity and vision to ensure that they can readily access the right service at the right time. This is the remit of the three Youth Health Forum annual events.

Evidence Context

Youth Access to Health Services – where we are today

Healthcare professionals across Australia have long recognised the problem of young people falling through the gaps of a health system that wasn't designed for them.

In order to understand young people's experiences of accessing health services in more depth, researchers in NSW created the Access studies.^{3,4} These studies aimed to paint a picture of health service access and health system navigation for young people (12-24 years). In recognition that some young people face even greater barriers to accessing healthcare, the studies focussed on several marginalised groups, with about one-third of young people recruited into the study from one or more of the following backgrounds: Aboriginal and/or Torres Strait Islander, Homeless, of Refugee background, living in Rural/Remote locations, Sexuality and/or Gender Diverse.

A total of 1,416 young people completed surveys and 35 young people participated in in-depth interviews over 12-months.⁵ While most participants rated their health as being 'good' or 'excellent' (81%), almost half reported high or very high psychological distress.

The young people in the studies identified multiple barriers to accessing health services, with cost being at the top of the list. Participants with chronic conditions and psychological distress reported a greater number of barriers. These barriers can be grouped into three main categories: structural (e.g. cost and practical issues); attitudinal (e.g. worries or concerns about using health services) and barriers relating to emerging autonomy and adulthood (e.g. parental involvement and knowing where to go).

Table 1. Barriers to healthcare services for young people

Barrier	%
Structural	
Cost	46
Opening hours mean I need time off study or work	32
Difficulty getting there	24
Attitudinal	
I would feel embarrassed	28
I would feel judged	20
The gender of the doctor/health professional	19
I worry about confidentiality	15
Barriers relating to emerging autonomy/adulthood	
I would have to ask my parents/carers to take me	22
I don't have my own Medicare card	12
I don't know which service/s to go to	12

This research highlights the need to bring focus to two key concepts that together highlight what is unique about the experiences of young people seeking health services: 'transition' and 'pathways into health services'.

Two key concepts: Transition and Pathways into Health Services

Transition

Transition is the process of changing from one state or condition to another. Young people go through many transitions as they grow from children to adults. Some of these transitions are about young people as individuals, like the physical and cognitive changes of puberty or changes in self-perception and thinking. Other transitions have a social context, such as moving from school into the workforce or from being a dependent child within a family to becoming independent adults in their own right. And against the context of these 'growing up and moving on' transitions comes the need for health and medical transitions, as young people take more and more responsibility for their own healthcare: for example, they are more likely to research health information for themselves, find their own doctors, and make their own appointments. Young people who have been involved with paediatric health services as a child will also begin to develop new relationships with adult healthcare teams.



Figure 1. Developmental & healthcare milestones

Pathways into Health Services

Pathways into Health Services are the journeys health consumers take to access the health services they need.

Some health pathways are straightforward with a clear destination in sight. Others are dead ends. Many are convoluted, confusing, and exhausting to navigate. Health pathways may be self-initiated, arise out of a referral, or be part of a complicated healthcare management plan.

Case Study - Youth Pathways into Health Services

Ayriane's story

When I was sexually active, around 17 years old, I was unsure about where to go and how to approach it. I used the internet to look up information on contraceptives, STI's, information on proper consent - it was overwhelming. I learned I had to go to the GP to get myself and my partner tested for STI's and get a prescription for contraceptives. I booked my appointment with my GP, and I asked about the privacy of health information - something I was very anxious about as I didn't want my parents to find out. I attended my appointment a week later. The experience was a little daunting. I learned you only needed a photo of your Medicare card, which was helpful as I didn't need to borrow the family Medicare card. I remember the GP asking if we were in a serious relationship or if it was just a fling. I found this question very disheartening because it gave me the impression that the GP was judging me on aspects of my life - regardless of the fact that I was there and taking initiative on my sexual health.

In many ways, Australia is a world-leader when it comes to youth health. We have many programs and services to support young people's health, but we can still do better. Our healthcare system is based on a 'binary model' – that is, we focus on two main things – very young children and ageing adults. This is where young Australians can fall through the gaps.

METHODS

This report used three methods of data collection:

1. Review of the academic literature on access, usage and obstacles to healthcare services for young people in Australia. Findings were grouped under six key 'challenge' headings and results shared with Youth Health Forum delegates to inform and guide the consultation process.
2. Review of national and international examples of healthcare services designed for and/or with young people (Appendices A and B).
3. Consultation with Youth Health Forum delegates.

Sixty youth delegates were recruited from around Australia to participate in the 2020 Youth Health Forum. Initial plans to bring youth delegates together with clinicians, researchers and policy-makers to a national roundtable were rapidly converted into online events and workshops as the COVID-19 pandemic unfolded.

The 2020 YFH timeline

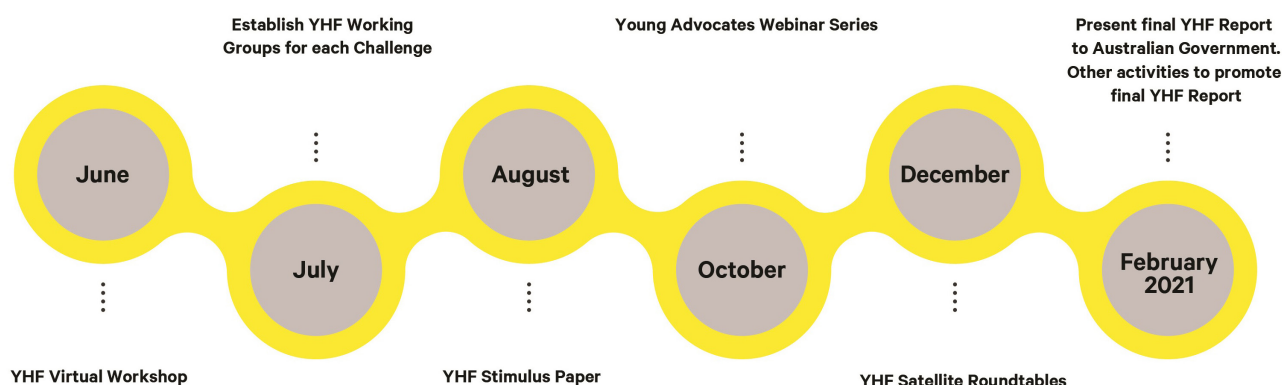


Figure 2. The 2020 YFH timeline on online events and workshops

The first YHF Virtual Workshop was held on 30 June 2020. Delegates were provided with an overview of the many overlapping life transitions young people go through as they become adults. Delegates were provided with some training on online tools such as Zoom and Miro, then formed into six YHF Working Groups, each of which was responsible for exploring one of the six key challenge topics. All YHF Working Groups were led by two youth leaders with interest and expertise in that particular area of health service access and navigation.

From July to December, the YHF Working Groups continued to discuss and explore their challenge topics.

In December, Delegates gathered together with subject experts for a series of Virtual Satellite Roundtables. These provided a unique opportunity for young people and subject experts to listen and learn from each other. Discussions were facilitated to ensure that ideas were fully explored and insights captured. The goals of the Satellite Roundtables were to:

- develop a shared understanding of the ways in which young people currently begin to take control of their own healthcare
- identify new ways to simplify youth pathways into health services; and
- develop youth-informed recommendations to be presented to the Australian Government in 2021.

The final event for the year was a national online consultation where youth leaders reported on their local consultations and recommendations were formed based on these insights. In recognition that many of the issues identified, and solutions suggested, were common to multiple challenge areas, the youth leaders from the six YHF Working Groups consolidated their recommendations into cross-cutting themes.

FINDINGS

The Six Key Challenges

There are many challenges to designing youth-friendly healthcare services that are accessible to all young people, but some of these stand out as areas that we can address here and now. Based on evidence developed by the WH&Y Centre of Research Excellence team, and in consultation with YHF youth leaders, six key challenges were identified, workshopped and ultimately used to form the basis of recommendations for improving youth pathways into health services in Australia.

The challenges were:

Challenge No. 1: Trusting healthcare services

Challenge No. 2: Transitioning to adult healthcare

Challenge No. 3: Navigating the healthcare system

Challenge No. 4: Delivering digital healthcare

Challenge No. 5: Building a more equitable system

Challenge No. 6: Developing health literacy

Challenge No. 1: Trusting healthcare services

Young people often need to put their trust in providers and services that are new to them. Sometimes, though, health care settings can make young people feel unsafe and unwelcome.

"If their websites had a bit more information - '...we specialize in this, we're queer-friendly, we focus on the family...' and whatever else, so you get an indication from the get-go that you're picking the right service for you." Female, 23

Young people face a number of barriers when they seek healthcare. Some of these are practical but others are about feeling anxious or uncomfortable, or even lacking in confidence when it comes to accessing a health service.

It is essential that young people trust the person or service that is helping them look after their health and yet many young people report feeling uncertain when they access healthcare, and worried that they will be made to feel unwelcome.

Trust addresses these concerns about being embarrassed or judged, about whether a consultation is truly confidential, and about whether a young person's knowledge will be questioned. Improving the trust between young people and their healthcare providers may reduce some of the barriers that young people face when they seek support for their health.

How can healthcare settings help young people feel more welcome and more confident?

We know that it is important for healthcare services to show that they are welcoming, for example by having the Aboriginal flag and rainbow flags in waiting rooms, displaying Aboriginal artworks, and by having information available in multiple languages.

Young people have also suggested that digital channels can be used to help them understand what they can expect when they attend a health care service, for example by providing:

- information about how to access a service and how much it will cost;
- information about referrals including what they are and how to get them;
- explanations of doctor-patient confidentiality;
- reviews from other young people about helpful or unhelpful experiences with certain medical and healthcare practices.

Challenge No. 2: Transitioning to adult healthcare

One in ten young people have a chronic physical condition that requires lifelong care. As they approach adulthood, these young people are expected to move from family-centred paediatric healthcare into an adult healthcare system that places a lot of responsibility on the individual.

“The adult hospital environment is dull and boring for young people. You have to deal with multiple departments, doctors who don’t know you, your condition or your history. Staff seem less caring, everyone is busy and no-one coordinates care – it’s impersonal and you feel like a number, not a name”. Male, 23

Some young people have health conditions that require lifelong management. In childhood, they will have received support from a paediatric health service. As adults, they will be supported by an adult healthcare team. The shift from the paediatric system to the adult system can be challenging, and we know that young people can fall through the gaps. There is evidence that the process of transition is often associated with a deterioration in the health of adolescents with chronic conditions.

Are there different ways to manage the transition?

There is a lot of interest in finding better ways to prepare young people and their families for the transition into adult care. Some of the approaches trialled so far have led to some improvements in transition-readiness, while others have been less successful. Those that seem to have made some difference include technology-based approaches that support young people to initiate contact with health professionals, telephone support calls from a designated transition coordinator, and shared clinics with paediatric and adult healthcare teams.

Two examples of programs developed in consultation with young people are Trapeze and Planning and Promoting Adolescent and Young Adult Services (PAPAYAS) (see Appendix A).

Challenge No. 3: Navigating the healthcare system

Australia has good quality health services, but the system is complicated and getting access to these services can be hard.

“I just went with my dad ‘cause I don’t know how to go by myself. I still hope to but, like, it’s kinda hard. First of all, there’s health funds, like all that jumbo... knowing if I’m allowed to, and talking to them about it and stuff. That’s all a bit confusing.” Gender diverse, 15

Health pathways are the steps taken to access health services. These pathways can be self-managed, for example, knowing that the local chemist can help with providing eye drops. Others are guided by a referral, for example when the doctor wants a specialist to take a closer look at a skin condition. When health needs are more complicated, those health pathways might be part of a larger healthcare management plan, put together by a healthcare team. Getting the support young people need from a healthcare service can be simple, especially if they know where to go and what to do to get help. Health pathways can also be convoluted and confusing — especially if young people are not sure what’s wrong, if they don’t know who to call or where to go, or if there are barriers that make it hard for them to access the support they need.

What are the benefits of improved health pathways?

Improving young people’s pathways into services will improve the health of individuals and lessen the load on the healthcare system. This is because many of the health services young people need are preventative – they prevent problems from arising or get in early to treat emerging health issues so that they don’t become worse and harder to treat. Not supporting young people with straightforward pathways to health services creates a missed opportunity. On the other hand, getting in early creates a ‘triple dividend’ of health for young people now, in their later lives as older adults, and as parents of the next generation.⁶

Challenge No. 4: Delivering digital healthcare

Talking to the doctor on the phone, having a Zoom consultation with a therapist or using an online physiotherapy program to recover from surgery... digitally delivered healthcare is becoming more common.

“I usually use online services if I’m having trouble in that moment. If I just need some advice to get me through what’s happening right now.” Male, 19

Prior to COVID19, young people mainly used digital healthcare to either to get general health information, to research decisions about whether or not they needed to see a health professional, or to access online support for mental health and wellbeing, with organisations such as eheadspace, ReachOut and KidsHelpline. The use of online programs and apps to manage health problems was relatively uncommon among young people.³

During the COVID-19 pandemic and the months of lockdown, many healthcare organisations moved to providing digital healthcare or ‘telehealth’ services. Typically, this meant providing consultations over the phone, in a Skype or Zoom call, or by some other digital means.

Because the shift to digital healthcare is so new, we don’t really know how young people feel about digital healthcare, or even how much they have been using it. Early reports are providing some insights, including these:

- young people at risk of homelessness who attend Youth Health Services in western Sydney much prefer to keep seeing the doctor or nurse in person;
- finding a way to speak privately to a doctor or other healthcare professional can be very difficult for young people who are in lockdown with their families;
- vulnerable young people may face the extra challenge of not being able to access digital healthcare outside of the home due to lack of mobile phone data;
- young people living in rural and remote areas have appreciated not having to travel large distances to city hospitals to see doctors;
- some young people are postponing their appointments with hospital specialists and teams until they can visit in person;
- some young people who were initially reluctant to try digital healthcare found that they quite liked it once they’d given it a go.

What online services are available for young people in Australia?

Even though digital healthcare is only just emerging for physical medical conditions, online services for mental health and wellbeing are well established in Australia. There is much to be learned from services like ReachOut, Headspace and KidsHelpline (see Appendix A).

Challenge No. 5: Building a more equitable system

Sometimes, the health needs of young people are overlooked or dismissed by health providers with entrenched negative views about teenagers and young adults. Young people from certain groups can experience even more difficulty in accessing the healthcare they need.

“Imagine a 17-year-old, pregnant, black, female young person that had her hair looking really crazy, walk into a place and go: ‘Oh, I need a place to stay’. You don’t get taken that seriously. Like everywhere you go, unless you present yourself like someone that can be listened to, you will be passed around like a ball, like over and over again... ‘Cause you have to say things in a certain way for you to actually get the outcome.” Female, 21

Young people are often the victims of community stereotypes, unfairly labelled as risk-takers, self-centred, irresponsible and rude, to name just a few. Health providers who hold those assumptions sometimes believe that young people bring their problems on themselves. Knowing that some people hold these attitudes can keep young people from accessing the health services they need.

Certain groups of young people are even more likely to be affected by negative stereotypes. These include Aboriginal and Torres Strait Islander young people, LGBTQI+ young people, young people who live in rural and remote areas; young people who are homeless or unstably housed, young people who are not in either school or work, and young people from refugee and other culturally and linguistically diverse backgrounds.

‘How does discrimination affect access to healthcare?’

All young people face barriers when they seek healthcare. These barriers are greater for those belonging to the groups above, and for young people with chronic conditions. Those from two or more of these groups experience even more difficulty in accessing the healthcare they need and deserve. Here’s what we know.³

- Young people who identify as sexuality and/or gender diverse are significantly more likely than their peers to report multiple barriers. They are particularly likely to feel challenged by feeling embarrassed or judged, and by issues including cost, difficulty getting to the health service, and having to ask parents or carers to take them.
- Young people with chronic conditions report more barriers of all types than young people without chronic conditions, with the exception of language and cultural issues.
- Young people who do not belong to marginalised groups are more likely to report opening hours as a barrier, and less likely to mention language and cultural issues as a barrier.

Challenge No. 6: Developing health literacy

Health literacy is about having the knowledge and skills you need to make informed decisions about your own health.

I feel my age group are endowed with the responsibility that comes with adolescence/young adulthood, but are not given the capacity to exercise this... If I could change one thing about my experience, it would be to have adequate education on aspects of this service seeking process, not just the health risks involved with sexual activity and promoting something like abstinence. I feel this would really help to normalise and encourage young people to seek health services and help, while tearing down stigmas surrounding this issue. Female, 22

Health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”.⁷

Young people develop their health literacy over many years and with the help of many trusted people like parents and carers, teachers and health professionals. For example, when deciding where to go to access healthcare,³ about 30% of young people rely completely on family, especially parents, 21% go straight to their doctor or other healthcare professional as a trusted source, 15% rely on “word of mouth” and 5% ask friends, a youth worker or a teacher.

In recent years, the internet has become an additional place for young people to get information about health, to work out whether they need to visit a health service, to research their decisions about which health service to go to, and to directly access online help and support.³

We know that young people who belong to marginalised groups are less likely to use the internet for general health information or for information about their own health problems than those who don't belong to marginalised groups.

What are young people doing online for their health?

Despite being skilled users of technology, most young people are overwhelmed by the volume and inconsistency of health information available online, and struggle to identify trustworthy sources. Also, many have difficulty using online health information to make a decision about whether or not to see a health professional.³

Table 2. What are young people doing online for their health?

Young people are using the internet for information on how to stay healthy. ³	Young people are using the internet for information about health conditions. ³	Young people are using online information to plan their visits to health services. ³
<ul style="list-style-type: none">• Almost two-thirds (63%) of young people use the internet to find information about keeping healthy, and most of these (75%) find what they are looking for.• About half of young people trust online information about keeping healthy.• Young adults aged 18 and over are more likely to look for online information about keeping healthy than teenagers (69% vs. 57%).	<ul style="list-style-type: none">• More than half of young people (58%) use the internet to get information about their health problems. Of these, 70% find the information they are looking for, but less than half (45%) trust the information they find.• A bit over a quarter of young people (27%) use internet-based programs or apps to manage health issues themselves, and about three-quarters (74%) find these helpful.• 63% of young people ‘disagree’ or ‘strongly disagree’ that information on the internet is as good as visiting a doctor.	<ul style="list-style-type: none">• 67% of young people use the internet to help decide whether they need to visit a health service.• 50% use the internet to decide which health service to visit.• Just 22% use the internet to get information about how to access a health service

Recommendations

The members of the Youth Health Forum are offering these recommendations based on their experiences as users of the Australian healthcare system. Below, they outline the key issues they believe Government can tackle, and suggest actionable recommended solutions.

Ultimately, the Youth Health Forum delegates want services to work well together and for the focus to be on clear information and evidence-based implementation. They would like digital tools to improve their experience of healthcare by streamlining processes and freeing time to focus on those important face to face interactions and services for those who need additional support, for example by the introduction of translators and navigators who understand both young people and the Australian healthcare system.

The Youth Health Forum's recommendations for the Federal Minister for Health and Aged Care / Minister for Education.

Navigation support: When young people move into the adult health system, it is vast, complex and very difficult to navigate. As it is unfamiliar to us, we can become lost and not receive the services we need, due to these challenges in navigating the system.

- Federal Government fund a national nurse navigator program that sits alongside hospitals to support and empower young people when they transition into the adult health system. An example of a successful federal program is the McGrath Foundation's Breast Cancer Nurse program.
- Government to review the Healthdirect website using a co-design approach to update it and make it more user-friendly and youth appropriate.

Youth age consistency across jurisdictions: Young people experience challenges in accessing health services due to their age as they can be classified differently between health services across States and Territories.

- Minister to work with States and Territories to determine a nationally consistent patient centred approach for young people accessing services in the health system that factors in mental maturity. Article 12 of the United Nations convention on the rights of the child is a reference point for these discussions.

Affordable access: Affordability of health service access is a challenge for many young people, particularly as they transition from adolescence and a reliance on parents into early adulthood.

- Provide young people aged 14 – 22 with a concession card to improve access to bulkbilled services and to make them eligible for the threshold and safety net limits to reduce the financial barriers to care.
- The Government has recently doubled the number of psychology sessions available with a Medicare rebate. We recommend allowing young people the autonomy to determine whether they are receiving 10 fully-funded sessions (no gap) compared to the nationally-allocated 20 partly-reimbursed sessions. This will have no change in cost to Government from currently allocated model, but will increase access and flexibility for young people who cannot afford co-payments.

Digital Healthcare Delivery: Young people living in remote and regional areas have significantly benefited from the changes to service delivery introduced during the Australian COVID-19 pandemic response. Providing more services through a digital channel has aligned services more closely to younger consumers' expectations, as well as being more cost effective. Access to a digitally delivered service requires good internet access to be equitable.

- Consumers should have access to health services, referrals, prescriptions and notifications via telehealth, phone, email or text and this should be supported with relevant MBS items.
- Ensure access to basic internet services for all Australians through updates of the Universal Service Guarantee. Currently, the Universal Service Guarantee is very 'household' based and this excludes people who may be experiencing homelessness and may not be able to access through public networks e.g. public libraries have been closed during parts of 2020.

Inclusive Delivery: Access to health services from Culturally And Linguistically Diverse young people is heavily dependent on their ability to access Translating and Interpreting Services and there are opportunities to improve these services for us and our communities.

- Government conduct a comprehensive review of interpreter and translation services in Australia to determine whether it meets current community needs.
- Government to provide funding for increased access to translation services. For example support for the Translating and Interpreting Services (TIS) to allow consumers to use the service for more than 1 hour to allow more flexibility.
- Government mandate that all medical centres and GPs offer the service where a consumer requests or requires an interpreter.
- Government to ensure TIS and health based translators have the required health or medical translation training to be able to interpret effectively and be respectful of privacy and patient confidentiality.

APPENDIX A: EXAMPLES OF HEALTH SERVICES DESIGNED FOR YOUNG PEOPLE IN AUSTRALIA

Youth Health Services

NSW

In response to a national inquiry into youth homelessness in the 1980s, commonwealth funding was allocated for developing innovative health services for homeless young people. A 'Youth Health Service' (YHS) model was developed that was a one-stop shop, and practised a multidisciplinary and multifaceted approach to health care. These services offer counselling, medical, nursing and dental services, assertive case management, group programmes and referrals to other agencies such as housing support. The YHSs are accessed via drop-in or outreach and have cultivated strong connections with mainstream community health-care partners.⁸

The Western Sydney Local Health District in NSW, Australia, has two YHSs that provide the one-stop shop model of care. One doctor provides a weekly service (alternating between the two YHSs) and is supported by three full-time nurses across both services.

Headspace

75% of mental health issues develop before a young person turns 25, but many traditional services don't address the unique barriers that young people face in accessing mental health support. To try to overcome this, Headspace was launched in 2006 to focus on early intervention and provide support to help young people 'get back on track' and strengthen their ability to manage their mental health in the future.⁹

Headspace now has over 100 'one-stop-shop' centres around Australia for young people who need help with mental health, physical health (including sexual health), alcohol and other drugs or work and study support.

ehheadspace is their national online and phone support service. It provides young people and carers with a safe, secure and anonymous place to talk to a professional – wherever they are in Australia.

KidsHelpline

KidsHelpline (KHL) has provided telephone support services to young Australians for 29 years. They focus on three age groups: Kids (5-12), Teens (13-17), Young Adults (18-25). In more recent years, KidsHelpline has developed online resources to answer young people's questions. Most recently, KHL launched 'Kids Helpline Circles', which is a free, safe and anonymous peer support group for improving overall wellbeing and mental health for young people in Australia aged 13-25.¹⁰

Doctors in Secondary Schools

Victoria

In order to make it easier for school students to visit a doctor, the Victorian government has created the 'Doctors in Secondary Schools' program. Each participating school has a doctor (general practitioner – GP) and a practice nurse in a purpose-built clinic for one day a week. This means that students can make an appointment to see the doctor or nurse without having to take time off school or travel anywhere, all at no cost to the students.¹¹

The objectives of the Doctors in Secondary Schools program are to:

- make primary health care more accessible to students
- provide assistance to young people to identify and address any health problems early
- reduce the pressure on working parents.

Importantly, the program recognises that:

- any student who wants to see the doctor will be permitted to book an appointment

- the doctor (GP) will decide whether the young person is mature enough to consent to medical treatment or whether parent/carer consent is needed - as is the case with all GPs in the community
- the right for a young person's health information to be kept confidential will be respected unless the disclosure is with the consent of the young person or it is otherwise permitted by law – as is the case with all doctor (GP) practice in the community

The Link Youth Health Service

Tasmania

The Link provides high quality primary and clinical health services as well as information, advice and referral services for young Tasmanians aged 12-25 years.¹² The service is free and confidential. The Link works with others in the health sector to developing innovative and responsive models of service. They also assist in delivering training and support to other professionals and the wider community.

One of the best things about The Link is their 'Open Access Area' that offers practical support for young people with: a washing machine/dryer, shower, personal hygiene items, telephone for health-related calls, mail service and food. Other services include;

- Phone charge bar and internet kiosk
- Free Lunch - every Wednesday from 1pm-2.30pm
- Lockers - for people to store personal effects
- Centrelink worker – onsite every Wednesday from 1.00pm.

Teen Clinic

NSW

Teen Clinic is a free and confidential service that provides local teenagers with the opportunity to talk to a nurse about a range of issues in a non-judgmental environment. The nurses are there to help advise young people on both medical and non-medical issues allowing them to make educated, healthy choices.¹³

Teens may attend for relationship advice, mental health issues, STI screening, contraception, homelessness, family issues or general health advice and education. No appointment necessary!

Trapeze Transition Service

NSW

Trapeze is a free service to help young people with chronic conditions to make the leap from their children's hospital to adult health care services in NSW. Their goal is to make dealing with the health system less frustrating and confusing so that young people can more easily access the services they need. Here's is what they do:

- Find a GP who can help
- Get you a Medicare card
- Respect your privacy
- Listen to you
- Connect you to the right professionals
- Social and emotional support
- Help coordinate your care
- Be your advocate
- Respect your confidentiality
- Tell you about your rights and responsibilities
- Link you to support groups
- Send SMS appointment reminders

PAPAYAS – Planning and Promoting Adolescent and Young Adult Services

WA

In Western Australia, action is underway to develop a transition service modelled on the Trapeze principles. PAPAYAS – Planning and Promoting Adolescent and Young Adult Services – is a collaboration that began in 2018 in recognition of the complexities in the treatment of young people with chronic conditions as they transition from paediatric to adult health services. The goal of PAPAYAS is to “ensure that no adolescent drops out of our health system during this critical time in their life particularly when the young person is dealing with a rare or undiagnosed condition.”¹⁴

Next steps for PAPAYAS are:

- co-design with young people and parents/carers
- deliver education and resources to patients and families
- develop a comprehensive transition website
- utilise technology for youth health screening, coordination of care and communication.

Mater Young Adult Health Centre

QLD

The complex healthcare needs of young people are being recognised in Queensland at The Mater Young Adult Health Centre, Brisbane.¹⁵ The Young Adult Health Centre is a specialised service to provide adolescents and young adults with unique programs to address their emotional, social and developmental needs. The centre has a holistic, inclusive approach to allow young patients access to a range of health professionals who work together to care for the patient as a team.

The centre also recognises that it is important for young adults to be cared for with people their own age so they can share their experiences with a peer, and that being able to interact with someone else their age normalises their experience and helps them process what they're going through.

ReachOut

ReachOut is Australia's leading online mental health organisation for young people and their parents.¹⁶ They offer practical support, tools and tips to help young people get through anything from everyday issues to tough times – and the information they offer parents makes it easier for them to help their teenagers, too.

ReachOut has been changing the way people access help since launching as the world's first online mental health service more than 20 years ago. Everything they create is based on the latest evidence and designed with experts, and young people or their parents.

Twenty10

NSW

Twenty10 is a Sydney based service that provides a broad range of services for young people 12-25 who are lesbian, gay, bisexual, transgender and gender diverse, non-binary, intersex, questioning, queer, asexual and more (LGBTIQA+). Services include housing, mental health, counselling and social support.¹⁷

They also offer inclusivity training and consulting for organisations and service providers across most sectors.

APPENDIX B: INTERNATIONAL EXAMPLES OF YOUTH PATHWAYS TO HEALTH SERVICES

Internationally, there are some excellent examples of initiatives to support youth pathways to services. Here we consider examples from countries that have similar health systems to those in Australia – namely a universal health care system with strong public health and primary care arms.

1. UNITED KINGDOM: The YOU'RE WELCOME Initiative

The YOU'RE WELCOME initiative offers a way for health services to review and develop their service to ensure it is youth friendly.¹⁸

YOU'RE WELCOME includes a list of seven 'standards of care'. These standards were developed with young people who gave advice on how to 'get it right'. The seven standards are:

1. Involving young people in their care and in the design, delivery and review of services
2. Explaining confidentiality and consent
3. Making young people welcome
4. Providing high-quality health services
5. Improving staff skills and training
6. Linking with other services
7. Supporting young people's changing needs

The YOU'RE WELCOME quality standards ring true in Australia. However, the UK experience tells us that it is difficult to embed these standards into healthcare systems and that each country needs to work out how to make this work in their own healthcare systems.

2. NORWAY: CO-CREATE The Youth Obesity Challenge

Norway has a number of similarities to Australia for health consumers and some interesting initiatives to improve youth health.¹⁹ One of these is CO-CREATE,²⁰ which aims to prevent overweight and obesity in adolescents by making the healthiest eating choices the preferred ones. As their name suggests, CO-CREATE works with young people to map out the societal obstacles to leading a healthier life. This appears to be a promising project on health pathways but we will have to wait to see the results.

3. CANADA: Youth Transitions to Adult Service

Like Australia, Canada takes an active role in researching and developing services for young people with chronic illness who 'age-out' of paediatrics and need to transition to adult healthcare services. In British Columbia, Canada, the 'Youth Transitions to Adult Service'²¹ is an initiative that includes:

"planning and preparation to help youth develop independent self-management skills - learning to navigate a new system of care, developing relationships with new providers, and applying for new benefit programs"

The Youth Transitions to Adult Service acknowledges that medical transition overlaps with other milestones in young people's lives, such as changes in education, employment, housing, and social and family relationships.

This website has sound information but with a paediatric focus that does not fully address the needs of the adult services to which these young people transition.

'A Guideline for Transition From Paediatric to Adult Health Care for Youth with Special Health Care Needs' is a resource available on the Youth Transitions to Adult Service website. The guideline was developed with young people and took a community of practice. What is needed is a clear 'implementation strategy', or way of embedding transition principles into services, and a way of tracking young people's outcomes as they make the transition and beyond.

4. The Lancet Publications and the Lancet Commission on Adolescent Health and Wellbeing

In 2007,²² The Lancet (one of the oldest and most influential medical journals in the world) published a series of articles on adolescent health. This shone a light on the importance of young people's sexual and reproductive health, mental health, substance use, chronic conditions and the prospects for youth-friendly health services.

In 2012, The Lancet published a second series, but this time the goal was "to put the young person, not the specific issue, centre stage".²³

By 2016, the need to prioritise adolescent health was becoming much better understood and 'Our future: a Lancet Commission on adolescent health and wellbeing' was announced.²⁴ Since then, six 'Youth Network Members' have joined the Commission to develop a plan for broad youth engagement.²⁵

Where are we now? In 2020, there was a call to 'Join the Lancet 2020 Campaign on Child and Adolescent Health', featuring a special communications strategy to support the campaign and facilitate partnerships with as many communities as possible. The aim of the campaign is "to engage and galvanise political leaders, policy makers, civil society and non-governmental organisations, researchers and clinicians, funders and responsible commercial organisations, and children and young people themselves."²⁶

APPENDIX C: FURTHER READING

- chf.org.au Consumers Health Forum of Australia
- why.org.au Wellbeing Health & Youth, NHMRC Centre of Research Excellence in Adolescent Health
- World Health Organisation 'Second Chance in the Second Decade' online portal: <https://apps.who.int/adolescent/second-decade/>
- trapeze.org.au Trapeze Transition Service
- headspace.org.au Headspace
- reachout.com ReachOut
- twenty10.org.au Twenty10

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