ACCESS 3:

young people and the health system in the digital age

Final Research Report

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Catherine Hawke, Georgina Luscombe, Marlene Kong, Tim Usherwood

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Contents

Glossary

cf	(abbreviation) ‘compare’ or ‘compared with’
GP	General Practitioner
IEC	Intensive English Centre
IRSAD	Index of Relative Socioeconomic Advantage or Disadvantage
IQR	Interquartile Range
K10	Kessler 10
LGBTQiA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, plus
LHD	Local Health District
N, n	Number (in the sample)
NSW	New South Wales
SD	Standard Deviation
SEIFA	Socioeconomic Indexes for Areas
TAFE	Technical and Further Education

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Alice’s Speech

Before I begin I would also like to acknowledge the traditional custodians of this land, the Gadigal people of the Eora nation, and pay my respect to their elders, past, present and future.

My name is Alice and I’m one of the youth consultants for the Access 3 study. I am so grateful and excited to be here with all of you today to workshop and create a system that better serves us young people.

Here in Australia, and in NSW, we’re really lucky to have a great health network, but there’s always more that can be done. The health system should be here for everyone, and yet at times young people, especially marginalised young people, get left behind. And so it’s important to focus on young people as a distinct group when looking at access. Young people have cultural and linguistic differences to older generations. I’m only just exiting my teens now and there are already a myriad of slang words and lingo that I don’t understand. In general, it’s hard to keep up with but it’s so crucial to in order to communicate efficiently. We know that young people are more vulnerable than adults in many ways. Young people are still developing, and can be quite impulsive and exhibit risk taking behaviours. Young people often also don’t have a lot of authority in decisions that impact on them, both in a societal and family context. This is compounded when faced with intersecting issues presented by other aspects of a young person’s identity which might cause them to experience marginalisation, for example, homelessness.

As a young person who has experienced homelessness, I can speak with some authority on at least one of the priority groups in this study. Despite being high functioning and coming from an educated background, I struggled immensely with going to local GPs when having to move to various crisis refuges across Sydney every few months, or even sometimes finding bulk billing GPs that suited my availabilities that took into account work, school, and travel. Not to mention the general distrust of adults and authority figures held by homeless young people due to past traumas.

A lot of my fellow homeless friends were not as lucky as me, and often didn’t have a phone or internet to be able to search up or call GPs or dentists or specialists, who didn’t have parents to remind them to get check-ups, who often didn’t know anything about bulk billing. Many of them often relied on youth workers, but if you’re a young person who cycles through various refuges very fast, who gets into trouble a lot and goes through multiple caseworkers, you’re very likely to also have disrupted health care. And often, finding shelter or food will come above health.

Even while I was living at home, it was really hard for me to access services without first going through my parents, and despite all the confidentiality agreements in the world, I found it very hard to access services that I desperately needed. The only real exclusion to this was during hospitalisations, the only place where I really felt I was able to put my health at the forefront without barriers, and where the health system was facilitating this.

My psychiatric disability has also impacted on my access to health services greatly. The cultural focus on physical health as the main or only indicator of a person’s overall health and wellbeing has a toxic impact on a young person’s ability to access health services. Mental health services are *still very lacking and there's often an abrupt transition into a limited range of adult services. The level of support required to manage my disability has only been met due to the dedication of various health professionals that I've worked with, who have had to work to find loopholes in the system or at times, break the rules.*

Not only this, but it's also coloured my interactions with GPs and other professionals, who often display a lack of understanding of trauma and mental illness and pass value judgements, sometimes causing me to be re-traumatised. I know friends who have been outright refused treatment because they were labelled as 'too difficult to deal with' when in reality, they were the ones that needed help the most.

This was all on top of the general uncomfortable experiences of visiting a GP, which I'm sure you can all relate to: long waiting times, unfriendly reception staff and often GPs that rush through the appointment and minimise the symptoms you describe.

I'm one of the most privileged young people too as I mentioned earlier. And I do not doubt that most young people in the priority categories would have had even more colourful experiences than I've had, as even the Access 3 survey [Study 1] *itself required some discipline and moderately high literacy levels to complete. These are things that are not afforded to all young people.*

This study essentially gives young people a platform on which they can advocate for themselves. Young people aren't just a framework for which to view health, or a topic to discuss. We are real people with diverse issues and health concerns, and the health system needs to adapt in accordance with the constant changes in skills and literacies that each generation of young people brings.

This is also why it's so important that we have young people involved in every step of the process, in consultation, and here today. We might not be experts in health or know what all the really big science words mean, but we are an expert in our own experiences as young people and the context and culture that we are a part of.

Young people are not inherently lazy like the media likes to portray, however we are often faced with a complex and at times, clunky system that does not properly provide to our needs.

I'm incredibly heartened, and grateful to all of you, and I am eager to see what unfolds from today. Today is important because this is a coming together of various passionate gatekeepers in the health sector that centres a youth voice, and provides a channel for our needs to be heard. In capturing a snapshot of the youth voice, we can move towards bridging the divide and creating a more holistic health system that better services us as young people and meets our unique needs.

Alice Zhang, *Access 3* Youth Consultant

Opening Speech, Policy Translation Forum, 21 November 2016

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Executive Summary

Key recommendations

Health system navigation should be supported – this can happen informally (via a parent or carer) or can be explicit and formal (e.g. dedicated 'navigator' health staff). Individual health professionals and services can all play a role in providing navigation support, through education (teaching young people about the system), facilitation (assistance with making appointments, helping young people choose appropriate services, through to transport) and advocacy (around cost, flexibility, additional support). General practice remains a cornerstone of the health system for young people; to support navigation, general practice and other parts of the health system need to work in an integrated way.

Engagement with individual professionals and with services is fundamental to access and navigation. Engagement is facilitated by welcoming environments (including symbols such as rainbow flags, Aboriginal flags) and personal characteristics of staff (non-judgemental, respectful, caring, understanding). A service's online presence and information can facilitate engagement.

Affordability is a major issue for young people, and costs can be direct and indirect. Health professionals and services need to be aware and mindful of costs incurred by young people and their parents/ carers and include cost considerations when formulating management plans.

Layers of disadvantage can compound difficulties in navigating the health system. Efforts to enhance the understanding of intersectionality among health professionals and services are needed.

Technology should be fully utilised by health services to promote engagement (e.g. websites that include detailed information about access, cost, services offered, staff, making appointments, opportunities for feedback) as well as health care when appropriate (e.g. SMS reminders, communication, delivery of clinical interventions).

Health literacy should be enhanced through the inclusion of health system navigation in school curricula.

Youth participation underpins best practice and should always be incorporated in designing, delivering and reviewing health services for young people.

Key Findings

The *Access 3* research explored health care access and health system navigation for young people (12 – 24 years) with a focus on several marginalised groups. We targeted those who are: Aboriginal and/ or Torres Strait Islander, Homeless, of Refugee background, living in Rural/ Remote New South Wales, and /or those of Sexuality- and/ or Gender- Diverse background. The health and wellbeing status of the research participants was poorer when compared to a nationally representative sample of Australian young people. The great majority had had recent contact with the health system, especially general practice.

We found in our survey that cost was the most frequently cited barrier to accessing health care for all groups of young people and that sexuality and/ or gender diverse participants reported significantly more barriers compared to other groups. Most survey participants reported that they had a good understanding of the services available, and that they could access the health services they needed to.

We explored health system access and navigation in more depth with a smaller group of marginalised young people who participated in a series of interviews over 12 months. This further illustrated frequent contact with different parts of the health system, and elucidated important difficulties with access and navigation, which were reiterated and reinforced via our interviews with health professionals. Structural and systems factors could impede smooth movement through the health system, while accessing any individual service at a particular point in time (including follow up care) often only occurred after the young person weighed up a range of factors, such as direct and indirect costs, convenience, previous experience, and competing priorities. Interview participants were often multiply-disadvantaged, which compounded their access and navigation difficulties.

Health professionals similarly reported that services may not always have the capacity (through lack of experience or expertise, as well as bureaucratic factors) to meet the needs of young people who belong to more than one marginalised group.

Perceived or experienced forms of discrimination were prominent among interview participants, including age-related discrimination (being young), racism, and discrimination based on sexuality or gender. Having a person assist with navigation around the health system was highly valued. Some interview participants provided examples of a ‘navigator’ being a youth worker, general practitioner, carer or caseworker. Young people of refugee background often function as health system navigators for other members of their families, while trying to learn about the health system themselves.

Survey participants commonly used digital technology to look for health information, information about health services and to decide whether they need to visit a health service, and combined the use of digital technology with word of mouth or advice from parents, peers or health professionals when deciding which health services to visit. The majority of participants believed that visiting a doctor or health professional was better than the internet, a view that was reinforced by interview participants when describing the value of being able to engage with health professionals who were welcoming and non-judgemental.

Interview participants offered a range of solutions to facilitate engagement with health services, including technology solutions. Health professionals also expressed the view that services needed to be re-oriented and updated to meet the needs of marginalised young people, including being more flexible and out-reaching.

The preliminary data from the research with young people and health professionals informed a policy translation workshop with a range of stakeholders, which ensured that some of the key findings were incorporated into the NSW Youth Health Framework 2017 – 2024.

Background

In 2015, the Youth Health and Wellbeing Team in NSW Health sought to update the evidence on young people's access to health care, in order to inform the next NSW Youth Health policy.

The 2011 – 2016 NSW Youth Health Policy (Healthy Bodies, Healthy Minds, Vibrant Futures) had a strong focus on health services which had been informed by earlier research, *Access Phase 1* and *Access Phase 2*. These studies were qualitative, concentrated mainly on primary health care, and had taken place prior to 2005 and thus prior to the widespread use of digital technology.

The *Access 3* research was designed to extend previous work by including the influence of digital technology on access to health care and examining access to and navigation around all levels of the health system (primary, secondary, tertiary). In addition, there was a focus on marginalised young people and policy translation.

Method

The specific study objectives were to:

(1) describe experiences of young people accessing and navigating the health system in NSW

(2) identify barriers and facilitators to health care for young people and how these vary between groups

(3) describe health system inefficiencies, particularly for young people who are marginalised

(4) provide policy relevant knowledge translation of the research data

The *Access 3* project was made up of four separate but linked studies:

Study 1 – a cross-sectional survey of young people (12 – 24 years) in NSW with oversampling of young people who were: Aboriginal and/ or Torres Strait Islander, Homeless, of Refugee background, living in Rural/ Remote New South Wales, and /or those of Sexuality- and/ or Gender- Diverse background. This study aimed to quantify access barriers and explore associations between access and a range of sociodemographic and other variables.

Study 2 – a longitudinal, qualitative study of a subsample of young people who belonged to one or more of the five marginalised groups listed above. This study aimed to explore the ways in which young people accessed and navigated the health system over time, the barriers and enablers they encountered and the ways in which digital technology was used to facilitate these.

Study 3 – a cross-sectional, qualitative study among senior clinicians and managers within the NSW Health system (public, private and NGO sectors) to explore their opinions about services and system responses to the health care needs of young people, especially those who are marginalised. This study aimed to complement the findings from Studies 1 and 2, and provide additional information about overcoming barriers and improving navigation from provider perspectives.

Study 4 – a one-day policy translation forum with a range of key stakeholders. Preliminary findings from Studies 1, 2 and 3 were presented to key stakeholders, followed by discussion and workshops and facilitated by members of the research team, in order to translate findings into practical policy recommendations.

Main Findings

Study 1

1416 young people (12 – 24 years) completed the NSW Youth Health Survey between February 2016 and February 2017

Sociodemographic characteristics of the sample:

- The median age of survey participants was 18 years (interquartile range = 4)
- 703 (49.6%) were adolescents (12 – 17 years) and 713 (50.4%) were young adults (18 – 24 years)
- 68.4% reported their gender as female, 28.7% as male, and 3.0% as other
- 233 (16.6%) were born overseas and 208 (14.7%) spoke a language other than English at home
- The number of participants belonging to each of the five pre-defined marginalised groups was:
    - Aboriginal and/ or Torres Strait Islander n = 169
    - Homeless/ at risk of homelessness n = 118
    - Refugee background n = 75
    - Rural/ Remote n = 478
    - Sexuality and / or gender diverse and/ or intersex n = 426
- 84.3% were studying: 47.3% at high school and 37.0% at TAFE or university

Health status

- 80.8 % rated their health as 'excellent', 'very good' or 'good' and 19.2% rated their health as fair or poor
- 52.0% reported having at least one chronic health condition or disability
- 29.1% scored very high for psychological distress on the Kessler-10 questionnaire; 23.0% scored high, 22.6% moderate and 25.3% low
- 19.2% scored low on the WHO-5 Wellbeing index indicating likely depression, 23.9% in the low mood range, and 56.9% scored high, indicating normal mood
- Belonging to an increasing number of marginalised groups was associated with a greater number of chronic health conditions, a higher Kessler-10 score, time away from school or work due to illness and/ or in order to care for someone else

Technology

- 96.1% had access to the internet
- 87.0% owned a mobile phone with internet access, 8.4% owned a mobile phone without internet access
- 67.3% use the internet to help decide whether they need to visit a health service
- 50.7% use the internet to decide which health service to visit
- 63.3% did not believe that information on the internet is as good as visiting a doctor or health service

In the previous 6 months:

- 63.0% had used the internet to find information about keeping healthy. Of those, 74.6% found what they were looking for
- 58.1% used the internet to get information about health problems experienced
- 22.3% used the internet to get information about how to visit a health service
- 27.2% used internet based programs or apps to manage health issues themselves. Of those, 74.2% found them helpful

Health service utilisation in previous 6 months

- 81.4% had visited a general practitioner (GP)
- 29.3% had visited a counsellor or psychologist
- 14.2% had visited an Emergency Department
- 11.0% had had an admission to hospital
- 57.3% had a regular GP
- 64.3% had a good understanding of the services available
- 73.2% reported that they could access appropriate services when they needed to
- 27.6% were confused by the number of health services available

Barriers to health care

- Cost was the most frequently cited barrier to accessing health care across the whole sample (45.8%) and within each of the five marginalised groups, as well as those who did not belong to any of the five marginalised groups
- Structural barriers such as cost, opening hours and difficulty getting to a service tended to increase with age
- Concerns about confidentiality and feeling embarrassed were more prominent in the middle-adolescent years
- The frequency of all barriers reported, except language/ cultural issues were higher among those with a chronic condition compared to those without a chronic condition, regardless of whether they were marginalised or not
- Increasing psychological distress (as measured by the Kessler-10 questionnaire) was associated with an increased likelihood of citing most of the 11 barriers
- Participants with a regular general practitioner (GP) were less likely to cite several of the barriers
- The sexuality and/or gender diverse group stood out as being significantly more likely to experience several barriers compared to the whole sample – these included eight of the 11 barriers
- Refugee participants were more likely to cite language and cultural barriers compared to the whole sample
- Some barriers were negatively correlated with increasing marginalisation: cost, not having one's own Medicare card, opening hours and gender of health professional decreased in frequency with increasing marginalisation (belonging to more marginalised groups)

Study 2

- Forty-one young people participated in a baseline interview, and 35 young people completed all stages of the study (three to four interviews over six to 12 months) between March 2016 and May 2017
- The mean age of Study 2 participants was 19.3 years (range 12 – 24 years)
- Thirty of 41 identified as female, with two being gender diverse, 8 identified as male, with two being gender diverse, and 3 identified as Other gender, all of these were gender diverse
- Twenty-two of the 41 baseline participants belonged to one marginalised group, 15 belonged to two and four belonged to three groups
- At baseline all of the 41 participants had seen a GP, and 189 types of providers or services had been accessed in the previous 6 months
- At each interview wave, an average of 31 participants accessed an average of 90 types of providers or services
- Six major themes were identified through qualitative analysis: (1) multiple disadvantage makes navigation more challenging (2) health literacy embraces the connected, digitally disrupted world (3) deciding about health care involves weighing up convenient access, engagement, effectiveness and cost (4) marginalised young people perceive and experience multiple forms of discrimination (5) technology brings opportunities to connect and engage with services and (6) the complexity and fragmented health system can be mitigated by system knowledge and navigation support

Study 3

- 22 professionals participated in semi-structured interviews between May 2016 and May 2017; nine were female and seven worked in rural NSW
- Participants came from public sector (NSW Health) services including hospitals, emergency departments, state-wide services and Local Health District/Community/Youth Health services, general practice, Aboriginal Medical Services, peak bodies and primary health networks
- Three major themes were identified: Intersectionality and understanding the complexity of multiple disadvantage; Health system fragmentation leads to inefficiencies, inertia, and advocacy; and Services need to be turned on their head: rethinking service delivery and models of care

Study 4

- Sixty-four stakeholders participated in a one-day policy translation forum on 21 November 2016 which aimed to inform the next NSW Youth Health policy
- Participants were young people, policy makers and senior bureaucrats, academics, clinicians, and managers
- Six policy-relevant themes were identified:
    1. Technology solutions - including the development of health literacy solutions and the use of technology with health care
    2. Integrated care and investment to improve capacity
    3. More extensive use of the adolescent health check (including change in the Medicare model to better enable GPs to provide care)
    4. Building capacity of the workforce
    5. Youth participation - youth-centred approach to research, design, implementation and evaluation
    6. Best practice youth health indicators included in standard accreditation

- The NSW Youth Health Framework 2017 – 2024 was launched by the NSW Minister of Health on 6th July 2017. The Framework was informed by preliminary findings of the *Access 3* study, including focusing on youth participation, vulnerable young people, navigation support, health literacy and the role of technology.

Section 1: Access 3 background and design

Chapter1: Introduction

Purpose of the *Access 3* Final Research Report

This document provides technical information about the design, methods and governance of the *Access 3* project. It also presents summary analyses of all raw data from each of the four component studies of *Access 3*, and practice recommendations. This report is aimed at researchers, policy-makers, service and program managers (including Primary Health Networks, hospital networks and local health districts), educators, clinicians, youth health workers and young people. We hope that all stakeholders will find this report useful for informing future research, policy and practice. Some findings have been published in peer-reviewed journals and these are referenced in the relevant chapters. Some findings from the *Access 3* project have been disseminated via stakeholder forums and local, national and international conferences. Deeper analyses of data intended for publication, as well as summaries of the *Access 3* findings for young people, are currently underway or planned.

Background to the *Access 3* project

In NSW, 1.26 million or 16.5% of the population, are young people aged 12 – 24 years (Australian Bureau of Statistics, 2015). NSW Health has a strong track record of developing state-wide, evidence-based policy responses to youth health needs, the first NSW Youth Health Policy being launched in 1999. NSW youth health policies have had an emphasis on access to health care and orientation of existing services to become more accessible and acceptable to young people. NSW Health commissioned research between 2000 and 2002 to explore access barriers and models of youth friendly health services, the *Access Phase 1* and 2 studies (Booth et al., 2002; Kang et al., 2005). Findings from these directly informed the youth health better practice framework (NSW CAAH, 2011), youth health policy (NSW Department of Health, 2010) as well as other workforce capacity building strategies such as the GP Strategy (NSW CAAH, 2008).

The health system in NSW (and across Australia) has seen some areas of reform but has also become more complex since these early *Access* studies. In the primary care sector, there has been rapid growth in practice nursing in general practice, changes to after-hours primary care services, increased access to a range of allied health and psychological services through a general practice gatekeeper and the establishment and expansion of *headspace*, the national youth mental health initiative. Despite these positive developments, areas of concern remain. An independent evaluation of *headspace* found positive outcomes for young people with early onset and early intervention needs but that the initiative may not be reaching marginalised groups of young people (Muir et al., 2009). There is evidence that presentations to Emergency Departments are increasing among children and young people, with possible explanations including GP unavailability and cost (Freed, Gafforini, & Carson, 2015). In the hospital sector in Australia, there has been a trend towards children's hospitals admitting adolescents up until the end of secondary school age and more adolescent-specific wards in Australian hospitals, however there is still major scope to improve 'adolescent-friendliness', including in adult hospitals (Sawyer, Proimos, & Towns, 2010). Fragmentation of health care has been documented in important reviews such as the 2014 National Mental Health Commission Report (National Mental Health Commission, 2014) and the 2008 Garling Report on acute care in NSW (Garling, 2008), despite structural changes at federal and state levels that aim to improve coordinated and integrated care.

Possibly the most significant societal change in the past 15 years has been the emergence of digital technology as an integral part of everyday life. Research conducted by the Young and Well Cooperative Research Centre found that daily internet use for all young people in Australia increased from 95% to 99% between 2008 and 2012 (Burns et al., 2013). However, over this time levels of psychological distress did not change, implying low uptake of online mental health interventions (Burns et al., 2013). Thus, evidence about how young people use digital technology to access health information needs to be extended to understand how digital technology currently influences *access* to health care. A systematic review of the effectiveness of online mental health services in help-seeking for young people was inconclusive, but suggests that online services may play a small role in facilitating access (Kauer, Mangan, & Sanci, 2014). Online interventions may also help facilitate some access to sexual health care, particularly STI screening (Gold et al., 2012).

The barriers to accessing health care for young people have been studied in many countries with different health systems. A systematic review of the international literature exploring access, engagement and health system navigation for a range of marginalised populations of young people identified several themes (Robards et al, 2018). These included themes relating to young people's health literacy, their attitudes to help-seeking and awareness of services. Service-related themes included the importance of personal characteristics of providers as well as welcoming environments to facilitate engagement. Structural and systems barriers included fragmentation of health services and bureaucratic processes as a hindrance. Technology was recognised and valued as an adjunct to both access and clinical care as well as playing a role in health literacy, and youth participation was acknowledged as important (Robards et al, 2018).

The *Access 3* project aimed to take a fresh look at health access and navigation for young people in NSW who now live in a digital age. It will focus in more depth on marginalised young people who often have complex health and psychosocial needs, but whose access to health care has been less comprehensively studied.

Access 3 Design

The aim of the *Access 3* project was to explore ways in which young people in NSW access, navigate and experience all levels of the health system, how digital technology is integrated into these processes, and to translate findings into practice and policy-relevant recommendations.

The *Access 3* Study Protocol has been published and is available as Open Access (freely downloadable). Details of the design, methods and ethics approvals for all four studies in *Access 3* can be found in this publication. The Methods described in the remainder of this report for each of the four studies are summaries only. See: Kang M, Robards F, Sanci L, et al. *Access 3* project protocol: young people and health system navigation in the digital age: a multifaceted, mixed methods study. BMJ Open 2017;7:e017047. doi:10.1136/ bmjopen-2017-017047

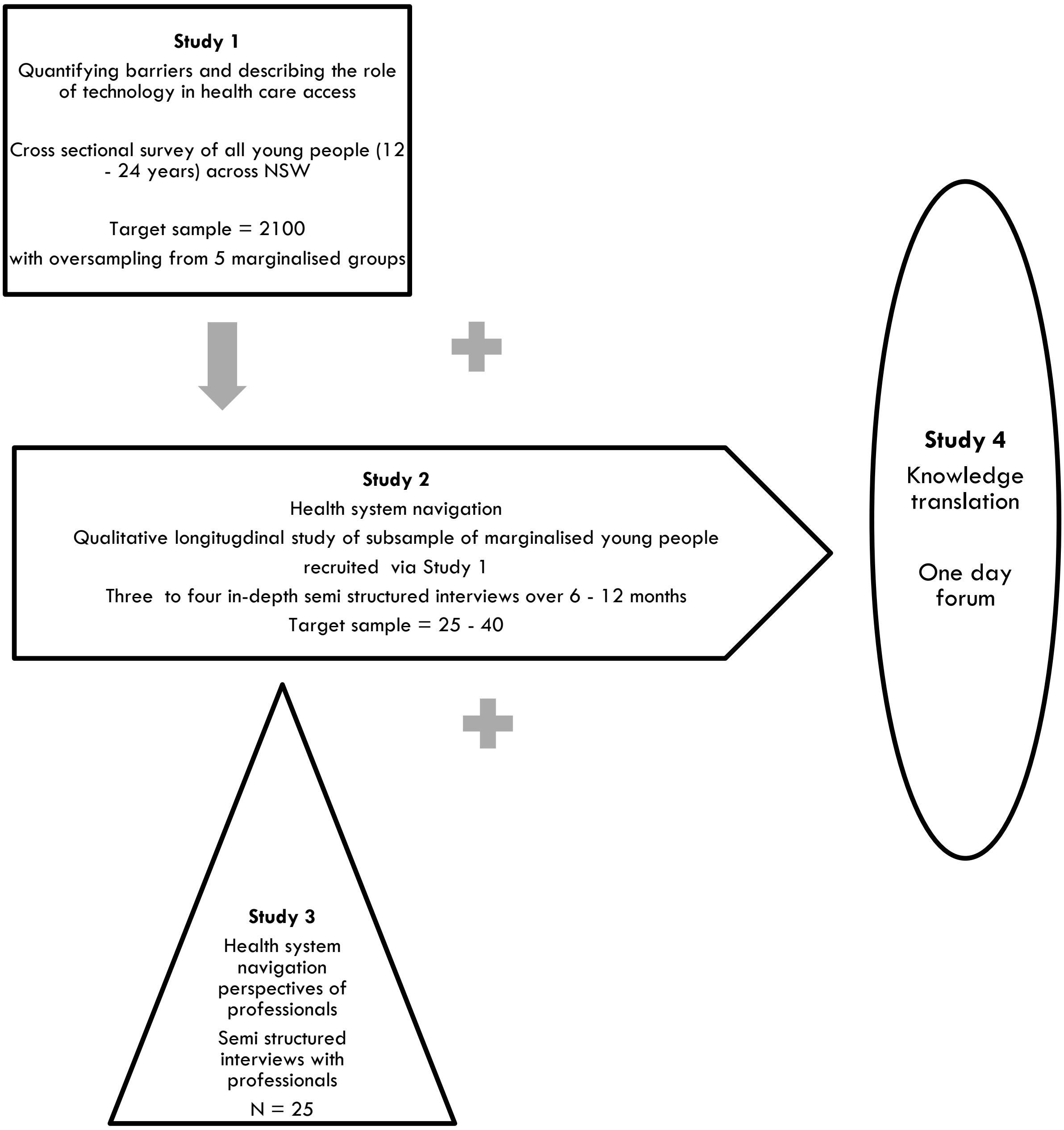

Figure 1: *Access* 3 project design, from Study Protocol publication (Kang et al, 2017)

Access 3 project governance and support

The *Access* 3 project was funded by NSW Health. The Chief Investigator group comprised researchers from five universities/ research institutes. This group was responsible for overall project governance, ensuring that ethical research principles were followed and scientific rigour was met.

The project established four additional groups to guide and support the project: an Associate Investigator group, one metropolitan and one rural reference group, and a Youth Consultant Committee. Terms of Reference were developed for each of these groups. In addition, several research and administration assistants supported different aspects of the project.

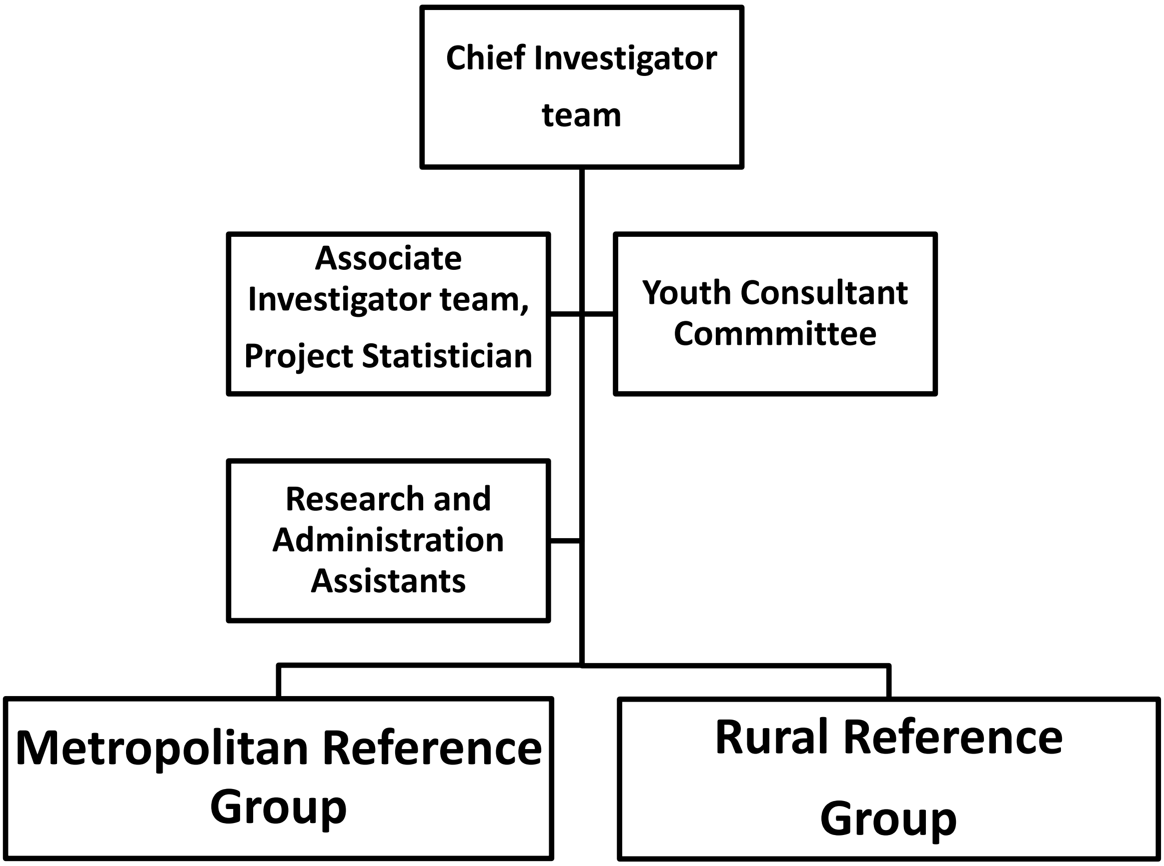

Figure 2: *Access 3* project governance and support structure

Membership of the Chief Investigator team, Associate Investigators, Reference Groups and Youth Consultant Committee, Project Statistician, as well as research and administration assistants, can be found on pages 80-81 (The *Access 3* mega-team).

Section 2

Study 1 NSW Youth Health Survey

Chapter 2: Study 1 Methods

Aim

The aim of Study 1 was to explore the role of digital technology in accessing health care, quantify barriers to health care and examine health service utilisation for young people 12 – 24 years living in New South Wales (NSW), and to explore the associations between these and a range of sociodemographic, sociocultural, and other factors.

Design

Study 1 was a cross-sectional survey.

Methods

Sample

The target group was all young people aged 12–24 years living in NSW with focus on five sub-populations of young people who were:

- Aboriginal and/or Torres Strait Islander
- homeless or at risk of homelessness
- of refugee background or a recently arrived migrant from a non-English speaking background
- living in rural/remote NSW
- sexuality and/ or gender diverse and/ or intersex

Sampling methods included convenience, snowball and purposive sampling.

Survey promotion and recruitment

The Study 1 survey was promoted online, such as through targeted emails to youth relevant networks, social media advertising (Facebook, Twitter, Instagram) as well as promotion by Youth Consultants, and opportunistic online promotion of the survey. Offline promotion included displays of flyers about the survey in a range of services and word of mouth.

Recruitment (young people actually commencing the survey) occurred on- and off- line. Links to the survey were included in paid social media advertisements, emails and other opportunistic social media posts. Offline recruitment occurred face-to-face in education-linked settings, youth accommodation services and forums where groups of young people meet (e.g. advocacy groups). To purposively sample marginalised young people, we worked with networks and advocates from a range of organisations to promote the survey among young people in rural areas, locations such as youth refuges, Intensive English Centres, sexuality diverse and gender diverse services such as Twenty10 Incorporating Gay and Lesbian Counselling Service of NSW, and various youth networks. An additional strategy included the employment of a youth ‘champion’ at Orange Aboriginal Medical Service who identified networks and disseminated paper surveys.

Data Collection – questionnaire

The survey instrument was a questionnaire developed by the Chief Investigator team in consultation with the Youth Consultant Committee, Associate Investigators and Reference Groups. The Youth Consultant Committee piloted the questionnaire and its online utility. It was delivered through the open source online survey system LimeSurvey (LimeSurvey GmbH, 2003). The questionnaire was guided by published evidence (Ambresin, Bennett, Patton, Sanci, & Sawyer, 2013; Booth et al., 2004; Kang et al., 2005) about known barriers to access and ‘youth-friendliness’ indicators applicable to primary and community based health services and hospitals. Demographic data included additional questions that allowed identification of young people who belonged to one of the five subpopulations we defined as being marginalised. Questions about the presence of chronic health conditions and/or disability were included, as well as the Kessler 10 (Kessler, 2002) and WHO-5 (Topp, 2015) wellbeing questionnaires. Knowledge about, attitudes to and experiences of health services and accessing care and questions about the impact of digital technology on whether, when and how to access health care were included, and free text responses allowed participants to describe factors that influenced their decisions to access health care and their experiences with health services.

Data Analysis

Quantitative analysis was conducted using the statistical software program SPSS version 24 (IBM, 2016). To report frequencies with a 95% CI for non-marginalised young people and any group of marginalised young people, and to be able to detect minimum clinically and policy-relevant differences in primary outcomes between groups, we aimed to survey approximately 350 participants from each of the five marginalised groups and 350 from young people who did not belong to any of these groups. Our target sample size therefore, was 2100.

Qualitative thematic analysis of free-text responses was undertaken to describe barriers and facilitators to access, use of digital technology in help seeking, young people’s understanding of the health system and the influences on their decisions to access health care.

Ethics

Study 1 was approved by the University of Sydney Human Research Ethics Committee (approval 2015/874) and the NSW Aboriginal Health and Medical Research Council Ethics Committee (approval 1142/15).

Chapter 3

NSW Youth Health Survey results: sociodemographic characteristics of the sample

Sample

Between February 2016 and February 2017, **1416 young people** (12 – 24 years) completed the survey. 1012 completed the survey online and 404 completed the survey via paper copies.

The median age of the sample was **18 years** (interquartile range = 4); 68.4% reported their gender as female, 28.7% as male, and 3.0% as other.

Completers and non-Completers

A 'completed' survey was one where all questions up to, but not necessarily including, the final section containing K10 and WHO-5 questionnaires, were answered. A 'non-completed' survey included demographic information and responses to questions about marginalisation, but no further information. Where demographic and marginalisation questions were not answered, surveys were discarded. 'Completers' and 'non-Completers' were compared.

2100 surveys were commenced; of these 1676 (79.8%) occurred online, and 424 (20.2%) were administered via paper copy. The surveys administered by paper copy were more likely to be completed than those commenced online, (95.3% cf 60.4%, p<0.001).

The 684 'non-completers' did not differ significantly by age (median 17 years, interquartile range 5) compared to completers (median 18 years, interquartile range 4; p= 0.12). The proportion of participants born in Australia also did not differ between completers (83.4%) and non-completers (84.5%) (p=0.58). There were no differences in terms of internet access - each 97% (p=0.85).

Completers were **more likely** to:
- identify as Aboriginal and/or Torres Strait Islander (12.0% cf 5.9% non-completers; p=0.001)
- be homeless (8.4% cf 4.8% non-completers; p<0.05)
- be of refugee background (5.3% cf 2.2% non-completers; p< 0.01)
- mainly speak a language other than English at home (14.8% cf 9.6% non-completers; p< 0.01)
- live outside a major city (33.9% cf 25.4% non-completers; p=0.001)

Completers were **less likely** to be sexuality and/or gender diverse (30.3% cf 39.9% non-completers, p=0.001).

Face-to-face compared with online recruitment (paper compared with online survey completion)

Face-to-face recruitment involved the distribution of paper surveys through a range of strategies, as described earlier. Because face-to-face recruitment was employed as a secondary measure to achieve a larger sample size among marginalised groups that were harder to recruit, it is not surprising that most completers of paper surveys belonged to a marginalised group. These included 55.0% of Aboriginal and/or Torres Strait Islander participants (93/169), 69.5% of homeless participants (82/118), 76.0% of all refugee participants (57/75), 45.0% of rural participants (215/478) and 23.2% (99/426) of sexuality and/or gender diverse participants.

85.6% (346/404) of the paper survey completers belonged to at least one of the five marginalised groups, compared with 54.4% (551/1012) of online survey completers.

Survey recruitment strategies

The most common ways in which participants heard about the survey were Facebook (21.0%), TAFE/University/work (13.8%) or via a youth worker (13.6%). Table 3.1 lists the frequencies for all survey recruitment strategies reported by participants.

Table 3.1: Survey Recruitment Strategies

How did you hear about the survey?	N*	% of sample* (n=1416)
Facebook	297	21.0
TAFE, Uni, work	195	13.8
Youth worker	192	13.6
A friend	154	10.9
Instagram	122	8.6
A health professional	70	4.9
Twitter	64	4.5
Parent/ carer	52	3.7
Email	48	3.4
Other (free text responses, n =292)		
Targeted face to face approaches (peer /other research assistant, Bilingual community educator, case worker, refuge staff)	69	4.9
Internet search engine	51	3.6
Website link (Sydney University, headspace, NSW Health)	49	3.5
School/ Teacher	30	2.1
Opportunistic targeting at events, lectures	22	1.6
Miscellaneous organisations	11	0.8
Miscellaneous individuals	8	0.6
Miscellaneous other media (newspaper, website, posters)	7	0.5
Health service	3	0.2
Other social media	3	0.2
No response/ don't know	39	2.8

*total exceeds 1416 / 100% because participants could select more than one response

400/404 of the paper survey completers heard about the survey through a personal contact such as a friend, youth worker, teacher, parent or carer. Four paper survey completers reported that they heard about the survey via Facebook.

Assistance completing the survey

One hundred and twenty-nine (9.4%) participants had a parent, carer or someone from school help them complete the survey. The median age of participants who had a parent, carer or someone from school help them complete the survey was 15 years (IQR 3). Participants who had help to complete the survey were significantly younger than those who did not have help (median age 15 cf 18 years; $p<0.001$) Fifty-five percent of those who had assistance completing the survey reported their gender as male, 44.2% as female and 0.8% as Other, and 80.6% belonged to at least one marginalised group. Participants who had a parent, carer or someone from school help them to complete the survey were more likely to be male (55.0% cf 25.5%, $p<0.0001$) and more likely to belong to at least one marginalised group (80.6% cf 60.5%, $p<0.0001$) compared to those who did not have assistance.

Sociodemographic characteristics of the survey sample (N = 1416)

Age and Gender

The median age of the sample was 18 years (IQR 4). About half the sample (49.6%) were adolescents (12 – 17 years) and half (50.4%) were young adults (18 – 24 years).

Of the 1416 participants, there were 968 females (68.4%), 406 males (28.7%) and 42 other gender (3.0%).

There was a statistically significant difference in age by gender: males had a median age of 17 years (IQR 5), females a median of 18 years (IQR 4) and other gender a median of 18 years (IQR 7) ($p<0.001$).

When females, males and other gender participants were grouped by age into adolescents and young adults, adolescents were more likely to select male gender and young adults were more likely to select female gender. In other words, there were more older female than younger female participants, and there were more younger male than older male participants. See Table 3.2

Table 3.2 Age by Gender

	Female* n (%)	Male* n (%)	Other* n (%)	Total N (%)
Adolescents (12 – 17 years)	434 (61.7)	249 (35.4)	20 (2.8)	703 (49.6)
Young adults (18 – 24 years)	534 (74.9)	157 (22.0)	22 (3.1)	713 (50.4)
Total	**968 (68.4)**	**406 (28.7)**	**42 42 (3.0)**	**1416 (100.0)**

*p < 0.001

Age, Gender and Marginalised Status

Adolescents (12-17 years) were more likely to belong to one or more marginalised groups than young adults (18-24 years), (68.0% cf 58.8%; $p<0.001$). See Table 3.3.

Males were significantly more likely to belong to one or more marginalised groups compared to females (73.6% compared with 57.4%; $p<0.001$).

Table 3.3 Age by Marginalised Status

	Belongs to at least one marginalised group n (%)	Does not belong to any of the marginalised groups n (%)	Total (%)
Adolescents (12 – 17 years)	478 (68.0)	225 (32.0)	703 (49.6)
Young adults (18 – 24 years)	419 (58.8)	294 (41.1)	713 (50.4)
Total	**897 (63.3)**	**519 (36.7)**	**1416 (100.0)**

Looking more closely at each of the five marginalised groups, there was a significantly higher proportion of adolescents (12 – 17 years) than young adults (18 – 24 years) among Aboriginal and/ or Torres Strait Islander (68.0% cf 32.0%, $p<0.001$) and the rural/remote (64.0% cf 36.0%, $p<0.001$) participants. There was a significantly higher proportion of young adults among sexuality and/ or gender diverse participants compared with adolescents (56.8% cf 43.2%, $p=0.002$). There were no differences in the proportion of adolescents compared with young adults among the homeless or refugee participants.

Participation of young people from the five pre-defined marginalised groups

The number of participants who belonged to one of the five marginalised groups is listed below. The total is greater than the sample size (1416) because participants could belong to more than one marginalised group. Details on the number and combinations of different marginalised groups are reported later.

- Aboriginal and/ or Torres Strait Islander n = 169
- Homeless/ at risk of homelessness n = 118
- Refugee background n = 75
- Rural/ Remote n = 478
- Sexuality and / or gender diverse and/ or intersex n = 426

Cultural diversity

Two hundred and thirty-three of 1416 participants (16.6%) were born overseas and 208/1416 (14.7%) mainly spoke a language other than English at home.

Religion

The most frequent response to the question 'What is your religion?' was 'No religion' (n=665/1416; 47.0%), followed by Christian (31.8%) and Not Sure (8.7%). Table 3.4 lists the responses to the question about religion.

Table 3.4 Religion

What is your religion?	**N**	% of sample
No religion	665	47.0
Christian	423	31.8
Muslim	65	4.6
Buddhist	32	2.3
Hindu	14	1.0
Jewish	10	0.7
Not Sure	123	8.7
Other (free text responses)		
Catholic	23	1.6
Agnostic	17	1.2
Anglican/ Church of England	6	0.4
Sikh	4	0.3
Spiritualism	3	0.2
Jedi	2	0.1
Pagan	2	0.1
All religions	2	0.1
Aboriginal religion	1	0.1
Atheist	1	0.1
Baha'i	1	0.1
Christian and non-believer	1	0.1
Christian and Hindu	1	0.1
Humanist	1	0.1
Jain	1	0.1
Mandean	1	0.1
Odinism	1	0.1
Orthodox	1	0.1
Roman Catholic and Buddhist	1	0.1
Tongan	1	0.1
No response	13	0.9
Total	1416	100.0

Current living situation

The majority of participants lived with one or both parents or carers, or moved between the homes of two parents/ carers. Table 3.5 shows the range of living situations and number and proportion of participants in each.

Table 3.5 Current living situation

Living situation	N	%
I live in my family home with both parents/carers	677	49.1
I live in my family home with one parent/carer	250	18.1
I move between two family homes because my parents/carers do not live together	59	4.3
I live with other relatives*	35	2.5
I live in foster care*	5	0.4
I live with my partner	72	5.2
I live in a share house/ flat with other people	117	8.5
I live in boarding school	3	0.2
I live on campus at uni	51	3.7
I live with a friend's family*	9	0.7
I live by myself	38	2.8
I live in a refuge/supported accommodation*	47	3.4
I stay with friends/couch surf in different homes*	5	0.4
I live in a boarding house*	7	0.5
I sleep on the street/outside*	3	0.2
Total	**1378**	**100.0**

NB: homelessness: participants who checked one of these* living situation options were classified as homeless or at-risk of homelessness. In addition, seven participants checked 'Other' and wrote responses in free text which were subsequently coded as homeless/at-risk of homelessness, including crisis accommodation, couch surfing, hotel, car, residential care, foster care, on the street. Thus the total number of participants counted as being homeless or at-risk of homelessness was 118.

Education, employment, income

The majority (84.3%) of participants were studying: 47.3% at high school and 37.0% at TAFE or university. 13.9% were not studying at all. Adolescents (12 – 17 years) were more likely to be in high school (including in an Intensive English Centre in high school), young adults were more likely to be in tertiary study either full time or part time. See Table 3.6.

Table 3.6 Current education status

Current study	Whole sample N (%)	Adolescents n (%)	Young adults n (%)
In high school	645 (45.8)	618 (88.5)	27 (3.8)
In an Intensive English Centre (IEC) in high school	21 (1.5)	16 (2.3)	5 (0.7)
In full time university or TAFE	441 (31.3)	17 (2.4)	424 (59.8)
In part time university or TAFE	80 (5.7)	9 (1.3)	71 (10.0)
Not studying at all	195 (13.9)	27 (3.9)	168 (23.7)
Other	25 (1.8)	11 (1.6)	14 (2.0)
Total	**1407 (100.0)**	**698 (100.0)**	**709 (100.0)**

Over one-third (506/1393; 36.3%) of participants were in part time or casual work and 106 (7.6%) were in full time work. Three hundred and fifty-eight (358/1393; 25.7%) were looking for work, 298

(21.4%) were unemployed and not looking for work, 37 (2.7%) unable to work due to sickness or disability and 22 (1.6%) not working because they were a carer or doing home duties. Table 3.7 shows current employment for the whole sample, and by age group.

Table 3.7 Current employment

Current employment	Whole sample N (%)	Adolescents n (%)	Young adults n (%)
In full time paid work	106 (7.6)	5 (0.7)	101 (14.2)
In part time or casual work	506 (36.3)	206 (30.1)	300 (42.3)
A carer or doing home duties full time (FT) or part time (PT)	22 (1.6)	7 (1.0)	15 (2.1)
Unemployed: looking for work	358 (25.7)	199 (29.1)	159 (22.4)
Unemployed, not looking for work, but studying FT or PT	283 (20.3)	196 (28.7)	75 (10.6)
Unemployed, not looking for work, not studying at all /other	15 (1.1)	9 (1.3)	18 (2.5)
Unable to work due to sickness or disability	37 (2.7)	15 (2.2)	22 (3.1)
Other	66 (4.7)	47 (6.9)	19 (2.7)
Total	**1393 (100.0)**	**684 (100.0)**	**709 (100.0)**

Of the 298 unemployed and not looking for work, 283 were studying. Sixty-nine per cent were in high school, including 5.1% in an Intensive English Centre; 25.5% were in full time university or TAFE and 1.3% in part time university or TAFE). Only 15 of the 298 participants (4.4%) were not studying at all and 0.7% checked 'other'.

When split by age, 95.6% of adolescents (12 – 17 years) who reported being unemployed but not looking for work were in high school and 2.0% were in university or TAFE. Only 2.0% of adolescents who were unemployed but not looking for work were not studying. By contrast, of the young adults (18 – 24 years) who reported being unemployed but not looking for work, 9.7% were not studying; 80.6% were in tertiary education and 8.6% were still in high school.

Of those who were earning income from work, young adults (18-24years) were more likely to earn more than adolescents (12-17years) (p<0.001). Table 3.8 shows how average weekly income from work before tax was lower among adolescents and higher among young adults.

Table 3.8 Average weekly income by age group

Average weekly income from work before tax	Whole sample N (%)	Adolescents n (%)	Young adults n (%)
\$1-\$49	46 (7.5)	32 (15.3)	14 (3.5)
\$50-\$99	100 (16.3)	66 (31.6)	34 (8.4)
\$100-\$199	150 (24.5)	85 (40.7)	65 (16.1)
\$200-\$399	136 (22.2)	20 (9.6)	116 (28.7)
\$400-\$599	69 (11.3)	3 (1.4)	66 (16.3)
More than \$600	112 (18.3)	3 (1.4)	109 (27.0)
Total	**613 (100.0)**	**209 (100.0)**	**404 (100.0)**

Across the whole sample, paid hours of work per week ranged between 0 and 80 hours. The median was 12 hours per week (IQR 19 hours). Across the whole sample, the typical income from work was between \$100 and \$199 per week.

Education, Employment and Income by Marginalised status

Because education, employment and income are different for adolescents compared with young adults, we analysed these by age group among participants who belonged to at least one marginalised group. Marginalised adolescents were more likely to be not studying at all compared to non-marginalised adolescents (5.3% cf 0.9%; p<0.01). The same was the case for young adults, with 28.0% of marginalised young adults not studying at all compared with 17.5% of non-marginalised young adults (p<0.001). See Table 3.9.

Table 3.9 Current study by age group and marginalised status

	Adolescents (12 – 17 years)		Young adults (18 – 24 years)	
Current study	**Not marginalised n (%)**	**Marginalised n (%)**	**Not marginalised n (%)**	**Marginalised n (%)**
In high school	207 (92.4)	427 (90.1)	6 (2.0)	26 (6.3)
University or TAFE	13 (5.8)	13 (2.7)	234 (79.6)	261 (62.9)
Not studying at all	2 (0.9)	25 (5.3)	52 (17.7)	116 (28.0)
Other	2 (0.9)	9 (1.9)	2 (0.7)	12 (2.9)
Total	**224 (100.0)**	**474 (100.0)**	**294 (100.0)**	**415 (100.0)**

Marginalised participants were significantly more likely to be unemployed and looking for work or unable to work due to illness or disability compared to non-marginalised participants (31.7% cf 22.7%; $p<0.001$). There was no significant difference in paid hours between those who did or did not belong to at least one marginalised group. However Aboriginal and/or Torres Strait Islander young people were earning significantly more than other young people ($p< 0.05$), they were also working more hours (median 20, IQR 26.3) than non-Aboriginal young people (median 12, IQR 18).

Youth allowance, Medicare card, Health Care Card, private health insurance

312/1389 (22.5%) participants received youth allowance, 634/1407 (45.1%) had their own Medicare card, 391/1413 (27.7%) had a Health Care Card and 634/1413 (44.9%) had private health insurance. Young adults were more likely to receive or have all these compared to adolescents, with the exception of private health insurance. See Table 3.10.

Table 3.10 Youth allowance, Medicare card, Health Care Card, private health insurance

	Whole sample N (%)*	**Adolescents n (%)***	**Young adults n (%)***
Youth allowance	312 (22.5)	75 (11.1)	237 (33.3)
Own Medicare card	634 (45.1)	154 (22.2)	480 (67.4)
Health Care Card	391 (27.7)	138 (19.7)	253 (35.5)
Private health insurance	634 (44.9)	297 (42.4)	337 (7.3)

*NB denominators vary slightly as not all participants answered all of the questions

All the demographic characteristics reported above were then examined for each of the five marginalised groups. These are presented as frequencies in Table 3.11, and further analysis will be reported in the next section that explores each marginalised group in more detail.

Table 3.11 **Summary of demographic characteristics for whole sample and each of five marginalised groups**

Characteristic	**Whole sample**	**None of the five marginalised groups***	**Aboriginal and/ or Torres Strait Islander***	**Homeless***	**Refugee***	**Rural***	**Sexuality and/ or gender diverse***
	N=1416	**n = 519**	**n=169**	**n=118**	**n=75**	**n=478**	**n=426**
Median age years (IQR)	18 (4)	18 (5)	16 (5)	17 (3)	17 (4)	17 (4)	18 (5)
Gender				**n (%)**			
Female	968 (68.4)	412 (79.4)	90 (53.3)	56 (47.5)	39 (52.0)	282 (59.0)	277 (65.0)
Male	406 (28.7)	107 (20.6)	75 (44.4)	54 (45.8)	36 (48.0)	182 (38.1)	109 (25.6)
Other	42 (3.0)	0 (0.0)	4 (2.4)	8 (6.8)	0 (0.0)	14 (2.9)	40 (9.4)
Cultural diversity				**n (%)**			
Born overseas	233 (16.6)	92 (17.7)	3 (1.8)	25 (21.6)	67 (89.3)	25 (5.3)	66 (15.6)
Born overseas, speak language other than English	126 (54.1)	47 (9.1)	0 (0.0)	14 (56.0)	51 (76.1)	12 (48.0)	29 (43.9)
Religion				**n (%)**			
No religion	665 (49.9)	225 (43.4)	92 (58.2)	47 (43.5)	2 (2.7)	234 (52.7)	243 (61.5)
Christian	423 (31.8)	173 (33.3)	47 (29.7)	36 (33.3)	38 (52.1)	148 (33.3)	76 (19.2)
Muslim	65 (4.9)	26 (5.0)	0 (0.0)	4 (3.7)	29 (39.7)	5 (1.1)	13 (3.3)
Buddhist	32 (2.4)	16 (3.1)	0 (0.0)	4 (3.7)	2 (2.7)	4 (0.9)	11 (2.8)
Hindu	14 (1.1)	7 (1.3)	1 (0.6)	1 (0.9)	1 (1.4)	3 (0.7)	3 (0.8)
Jewish	10 (0.8)	8 (1.5)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.5)
Not sure	123 (9.2)	39 (7.5)	18 (11.4)	16 (14.8)	1 (1.4)	50 (11.3)	47 (11.9)
Current study				**n (%)**			
High school	645 (45.8)	205 (39.5)	103 (62.0)	46 (39.3)	37 (50.0)	282 (59.7)	172 (40.6)
Intensive English Centre (IEC)	21 (1.5)	8 (1.5)	0 (0.0)	3 (2.6)	11 (14.9)	1 (0.2)	6 (1.4)
Full time university or TAFE	441 (31.3)	227 (43.7)	16 (9.6)	23 (19.7)	17 (23.0)	66 (14.0)	138 (32.5)
Part time university or TAFE	80 (5.7)	20 (3.9)	14 (8.4)	7 (6.0)	3 (4.1)	33 (7.0)	36 (8.5)
Not studying at all	195 (13.9)	54 (10.4)	30 (18.1)	34 (29.1)	4 (5.4)	73 (15.5)	66 (15.6)
Other	25 (1.8)	4 (0.8)	3 (1.8)	4 (3.4)	2 (2.7)	17 (3.6)	6 (1.4)
Current employment				**n (%)**			
In full time paid work	106 (7.6)	39 (7.5)	17 (11.0)	4 (3.4)	1 (1.4)	43 (9.3)	30 (7.1)
In part time or casual work	506 (36.3)	219 (42.2)	31 (20.0)	19 (16.1)	16 (21.9)	153 (33.3)	142 (33.8)
Carer/ home duties FT or PT	22 (1.6)	6 (1.2)	2 (1.3)	1 (0.8)	1 (1.4)	10 (2.2)	7 (1.7)
Unemployed: looking for work	358 (25.7)	109 (21.0)	54 (34.8)	46 (39.0)	24 (32.9)	120 (26.1)	124 (29.5)
Unemployed, not looking for work, studying	283 (20.3)	119 (22.9)	31 (20.0)	23 (19.5)	20 (27.4)	81 (17.6)	81 (19.3)
Unemployed, not looking for work and not studying	15 (1.1)	1 (0.2)	4 (2.6)	6 (5.1)	0 (0.0)	9 (2.0)	4 (1.0)
Unable to work: sickness/ disability	37 (2.7)	8 (1.5)	3 (1.9)	8 (6.8)	1 (1.4)	12 (2.6)	16 (3.8)
Other	66 (4.7)	15 (2.9)	13 (8.4)	11 (9.3)	10 (13.7)	32 (6.9)	16 (3.8)
Youth allowance, Medicare card, Health care card, private health insurance				**n (%)**			
Youth allowance	312 (22.5)	96 (18.5)	41 (26.5)	63 (54.8)	33 (46.5)	96 (20.9)	103 (24.5)
Own Medicare card	634 (45.1)	225 (43.4)	72 (43.9)	74 (62.7)	37 (49.3)	196 (41.6)	216 (50.9)
Health Care Card	391 (27.7)	113 (21.8)	54 (32.3)	61 (51.7)	43 (57.3)	136 (28.6)	127 (29.8)
Private health insurance	634 (44.9)	314 (60.5)	22 (13.1)	16 (13.6)	9 (12.2)	154 (32.4)	188 (44.1)

*Numbers in columns 3 – 8 total more than 1416 as participants could select more than one marginalised group

Socioeconomic status

Socioeconomic status is often measured using variables such as household income, highest educational attainment and employment status. Because our target population was young people, most of whom were living in families and engaged in secondary or tertiary studies, we chose not to ask questions about household income, or parental education and employment. The only measures we could use to approximate socioeconomic status and also socioeconomic disadvantage (as a form of marginalisation) were the Socioeconomic Indexes for Areas (SEIFA) and the ownership of a Health Care Card. We used postcode to determine the SEIFA Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) and grouped these into SEIFA deciles, where decile 1 represents the most disadvantaged Area and decile 10 the most advantaged. Table 3.12 shows the distribution of the sample across the SEIFA IRSAD deciles.

Table 3.12 Socioeconomic indexes for areas: index of relative advantage and disadvantage

SEIFA IRSAD decile	N (%)
1 most disadvantaged	89 (6.4)
2	113 (8.2)
3	96 (6.9)
4	153 (11.0)
5	216 (15.6)
6	194 (14.0)
7	78 (5.6)
8	63 (4.5)
9	169 (12.2)
10 most advantaged	217 (15.7)
Total	1388 (100.0)

The index of relative socioeconomic advantage and disadvantage was then compared to Health Care Card ownership, to see whether there was an association. Table 3.13 shows that the relationship between SEIFA IRSAD decile and Health Care Card ownership was not linear; however a greater proportion of participants from lower SEIFA IRSAD deciles owned Health Care Cards.

Table 3.13 Health Care Card ownership according to SEIFA IRSAD decile

SEIFA IRSAD decile	No n (%)	Yes n (%)	I'm not sure n (%)	Total N (%)
1 most disadvantaged	48 (5.8)	30 (7.9)	11 (6.3)	89 (6.4)
2	46 (5.5)	48 (12.7)	19 (10.9)	113 (8.2)
3	53 (6.4)	24 (6.3)	19 (10.9)	96 (6.9)
4	93 (11.2)	38 (10.0)	22 (12.6)	153 (11.0)
5	101 (12.2)	70 (18.5)	42 (24.0)	213 (15.4)
6	105 (12.6)	75 (19.8)	14 (8.0)	194 (14.0)
7	52 (6.3)	18 (4.7)	8 (4.6)	78 (5.6)
8	46 (5.5)	10 (2.6)	7 (4.0)	63 (4.5)
9	115 (13.8)	37 (9.8)	17 (9.7)	169 (12.2)
10 most advantaged	172 (20.7)	29 (7.7)	16 (9.1)	217 (15.7)
Total	**831(100.0)**	**379 (100.0)**	**175 (100.0)**	**1385 (100.0)**

When mean SEIFA IRSDA scores and deciles were analysed by Health Care Card ownership, there is a significant difference between those who do and do not own a Health Care Card, and between those who have a Health Care Card and those who are not sure, see Table 3.14.

Table 3.14: Mean SEIFA IRSAD score and mean SEIFA IRSAD decile by Health Care Card ownership

		No Health Care Card	Has Health Care Card	Unsure Health Care Card	Total
SEIFA IRSAD score^	Mean	1012.3*	982.1*†	983.9†	1000.5
	n	831	379	175	1385
	SD	76.3	64.2	66.8	73.4
SEIFA IRSAD decile	Mean	6.4*	5.2*#	5.2#	5.9
	n	831	379	175	1385
	SD	2.9	2.6	2.6	2.8

* p<0.001, † p<0.001, # p = 0.002 ^lower SEIFA IRSAD score = greater disadvantage

NB analyses were Health Care Card ownership cf no Health Care Card ownership, and Health Care Card ownership cf Unsure of Health Care Card ownership

The Index of Relative Socioeconomic Advantage and Disadvantage was next compared to private health insurance cover. As with Health Care Card ownership, the relationship is not linear, but there was a higher proportion of participants with private health insurance cover among the higher (more advantaged) SEIFA IRSAD deciles, see Table 3.15.

Table 3.15 SEIFA IRSAD decile by private health insurance cover

SEIFA IRSAD decile	No n (%)	Yes n (%)	I'm not sure n (%)	Total N (%)
1 most disadvantaged	44 (7.7)	30 (4.8)	14 (7.3)	88 (6.4)
2	65 (11.4)	33 (5.3)	15 (7.8)	113 (8.2)
3	51 (8.9)	29 (4.7)	16 (8.3)	96 (6.9)
4	73 (12.8)	56 (9.0)	24 (12.4)	153 (11.0)
5	101 (17.7)	68 (10.9)	45 (23.3)	214 (15.5)
6	81 (14.2)	85 (13.7)	28 (14.5)	194 (14.0)
7	28 (4.9)	39 (6.3)	11 (5.7)	78 (5.6)
8	24 (4.2)	32 (5.1)	7 (3.6)	63 (4.5)
9	55 (9.6)	95 (15.3)	19 (9.8)	169 (12.2)
10 most advantaged	48 (8.4)	155 (24.9)	14 (7.3)	217 (15.7)
Total	**570 (100.0)**	**622 (100.0)**	**193 (100.0)**	**1385 (100.0)**

Similarly, when SEIFA scores/deciles were analysed by private health insurance cover, there was a significant difference: the means were higher among participants with private health insurance cover compared to those without cover, and compared with those who weren't sure. Table 3.16 shows mean scores by insurance coverage.

Table 3.16 Mean SEIFA IRSAD score and mean SEIFA IRSAD decile by private health insurance cover

		No Private Health Insurance	Has Private Health Insurance	Unsure Private Health Insurance	Total
SEIFA IRSAD score^	Mean	982.0*	1021.9*†	986.3†	1000.5
	n	570	622	193	1385
	SD	66.2	76.6	63.5	73.4
SEIFA IRSAD decile	Mean	5.2*	6.7*†	5.3†	5.9
	n	570	622	193	1385
	SD	2.7	2.8	2.5	2.8

* p<0.001, † p<0.001^lower SEIFA IRSAD score = greater disadvantage

NB analyses were private health insurance cover cf no private health insurance cover, and private health insurance cover cf unsure of private health insurance cover

Of interest, 177 participants were not sure if they had a Health care Card, 196 were not sure if they had private health insurance, and 108 participants reported that they had both a Health care Card and private health insurance. It is feasible that individuals would have both private health insurance and be Health Care Card holders, particularly those with chronic health conditions. It is also possible that some participants may not have understood the questions (while others may not have known because these were managed by parents or carers). To explore this a little further, we looked at whether Health Care Card ownership or private health insurance cover were associated with having any type of chronic health condition. Having a Health Care Card was significantly associated with having a chronic health condition (Table 3.17) but having private health insurance cover was not (Table 3.18). NB Health status is further described in Chapter 5.

Table 3.17 Health Care Card ownership and chronic health condition

Do you have a Health Care Card?	**Any type of chronic health condition***		
	No (%)	**Yes** (%)	**Total** (%)
No	439 (64.7)	406 (55.2)	845 (59.8)
Yes	146 (21.5)	245 (33.3)	391 (27.7)
I'm not sure	93 (13.7)	84 (11.4)	177 (12.5)
Total	**678 (100.0)**	**735 (100.0)**	**1413 (100.0)**

* p<0.001

Table 3.18 Private health insurance cover and chronic health condition

Are you covered by private health insurance?	**Any type of chronic health condition***		
	No (%)	**Yes** (%)	**Total** (%)
No	260 (38.4)	322 (43.8)	582 (41.2)
Yes	311 (45.9)	323 (43.9)	634 (44.9)
I'm not sure	106 (15.7)	91 (12.4)	197 (13.9)
Total	**677 (100.0)**	**736 (100.0)**	**1413 (100.0)**

* p=0.06

Chapter 3 Summary

The NSW Youth Health Survey was completed by 1416 young people (12 – 24 years). The median age of the sample was 18 years. There were more female participants than male or other gender participants. Although there were roughly equal numbers of adolescents (12 – 17 years) and young adults (18 – 24 years), more adolescents were male and more young adults were female. Over 16% of the sample was born overseas, and 14.7% spoke a language other than English at home.

Those from marginalised groups were overrepresented, although we did not achieve our desired sample size of 350 for three of the five groups we targeted (Aboriginal and/or Torres Strait Islander young people, those experiencing homelessness or those of refugee background). To facilitate recruitment to reach these three groups, more face-to-face strategies were implemented. Reaching young people who lived in rural or remote locations and those who were sexuality and/or gender diverse, as well as young people who did not belong to any of the five marginalised groups, was relatively easier using online recruitment strategies.

Our final sample included:

- 169 Aboriginal and/ or Torres Strait Islander young people
- 118 Young people experiencing homelessness
- 75 Young people of refugee background
- 478 Rural/ Remote young people
- 426 Sexuality and/ or Gender diverse and/ or Intersex young people

Almost all adolescents (12 – 17 years) were studying as were most young adults (18 – 24 years). Over 43% were in casual, part-time or full-time work. Participants belonging to one or more marginalised groups were significantly more likely to be unemployed and looking for work, or unable to work due to illness or disability, compared to those who did not belong to any of the marginalised groups. There were participants from all ten deciles across the Index of Relative Socioeconomic Advantage and Disadvantage. There were more participants from areas of relative socioeconomic disadvantage who owned Health Care Cards and more from areas of relative socioeconomic advantage who had private health insurance.

Chapter 4

NSW Youth Health Survey results: marginalised groups

This chapter provides more detailed demographic information about each of the five marginalised groups.

Aboriginal and/or Torres Strait Islander participants

One hundred and sixty-one participants (11.4%) were Aboriginal, two (0.1%) were Torres Strait Islander, six (0.4%) were both Aboriginal and/or Torres Strait Islander and 23 (1.6%) said they were not sure.

Compared to non-Aboriginal participants, Aboriginal and/or Torres Strait Islander participants were:

- *more* likely to live in a rural or remote area (Aboriginal 142/167, 85.0% cf non-Aboriginal 335/1240, 27.0%, p<0.001)
- *more* likely to be homeless (Aboriginal 25/166, 15.1% cf non-Aboriginal 93/1240, 7.5%, p=0.001)
- *less* likely to be sexuality and/or gender diverse (Aboriginal 25/168, 14.9% cf non-Aboriginal 400/1244, 32.2%; p<0.001).

Participants who are homeless or at-risk of homelessness

There were 118 participants (8.3%) who were homeless, including 47 (3.3%) who were living in a refuge, 35 (2.5%) with other relatives, nine (0.6%) with a friend's family, seven (0.5%) in a boarding house, five (0.4%) staying with friends/couch surfing in different homes, five (0.4%) living in foster care and three (0.2%) sleeping on the street/outside.

Compared to those who were not homeless, homeless participants were:

- *more* likely to be Aboriginal and/or Torres Strait Islander (homeless 25/118, 21.2% cf not homeless 141/1288, 10.9%, p=0.001)
- *as* likely to be of refugee background (homeless 8/114, 7.0% cf not homeless 67/1287, 5.2%, p = 0.4)
- *as* likely to be living in rural areas (homeless 39/115, 33.9% cf not homeless 435/1286, 33.8%, p = 1.0)
- *as* likely to be sexuality and/or gender diverse (homeless 37/118, 31.4% cf not homeless 387/1288, 30.0%).

Participants of refugee background

Of those born overseas, 72 participants' families moved to Australia as refugees or asylum seekers, 165 (68.5%) moved to Australia as migrants and three (1.2%) were not sure, but were subsequently coded as refugee-background.

Compared to non-refugee participants, refugee participants were:

- *more* likely to live in a major city (refugee 67/74, 90.5% cf non-refugee 859/1330, 64.6%, p< 0.001)
- *as* likely to be homeless (refugee 8/75, 10.7% cf non-refugee106/1326, 8.0%, p = 0.4)
- *as* likely to be sexuality and/ or gender diverse (refugee 16/ 75, 21.3% cf non-refugee 406/1331, 30.5%; p = 0.09).

Participants living in rural and remote locations

Of the 1408 participants who provided postcode information, 930 (66.1%) lived in major cities, 416 (29.5%) in inner regional areas, 54 (3.8%) in outer regional areas and 8 (0.6%) in remote areas.

Compared with those living in major cities, participants living in rural and remote areas were:

- *more* likely to be Aboriginal and/or Torres Strait Islander (rural 142/477, 29.8%, cf major city 25/930, 2.7%, p<0.001)
- *less* likely to be refugee (rural 7/478, 1.5%, cf major city 67/ 926, 7.2%, p<0.001).
- *less* likely to be sexuality and/or gender diverse (rural 118/476, 24.8% cf major city 306/930, 32.9%, p=0.002)
- *as* likely to be homeless (rural 39/474, 8.2% cf major city 76/927, 8.2%, p = 1.0)

Sexuality and/ or gender diverse participants

Four hundred and twenty-six participants (30.1%) were sexuality and/or gender diverse. This included 386 (27.3%) who were sexuality diverse, 42 (3.0%) who were gender diverse and 14 (1.0%) who were intersex.

A participant was coded as being sexuality diverse if they answered yes to: being attracted to people of their own sex/ gender, more than one sex/ gender, 'not sure' who they were attracted to or did not feel attracted to people of any sex/ gender.

We became aware that for some participants of refugee background the responses 'not sure who I am attracted to' and 'don't feel attracted to people of any sex/ gender' did not necessarily mean the same thing as it did to participants who were not of refugee background. We understood this to be related to cultural understandings of sexuality which emerged during some of the subsequent interviews. We searched through all the responses where 'not sure who…' and 'don't feel attracted…' were checked and looked at all their other responses and comments, as well as their age and other demographic characteristics. This led to re-coding three participants as NOT sexuality diverse even though they had checked one of these two responses.

Compared to non-sexuality and/or gender diverse participants, those who were sexuality and/ or gender diverse participants were:

- *less* likely to be Aboriginal and/ or Torres Strait Islander (sexuality/gender diverse 25/425, 5.9% cf non-sexuality/gender diverse 143/987, 14.5%, p<0.001)
- *less* likely to live in rural areas (sexuality/gender diverse 118/424, 27.8% cf non-sexuality/gender diverse 358/982, 36.5%, p=0.002)
- *as* likely to be homeless (sexuality/gender diverse 37/424, 8.7% cf non-sexuality/gender diverse 81/982, 8.2%)
- *as* likely to be of refugee background (sexuality/gender diverse 16/422, 3.8% cf non-sexuality/gender diverse 59/984, 6.0%, p = 0.09)

Intersection between sexual identity and sexual attraction

Sexual identity and sexual attraction are different entities. A person could be sexually attracted to people of one or more genders that is the same, opposite or different to their own gender but have a sexual identity that is more consistent with a heterosexual, homosexual or bisexual identity. We explored the range of sexual identities and sexual attractions reported by participants.

Of the 383 sexuality and/ or gender diverse participants who answered questions about both sexual identity and sexual attraction, the great majority were congruent, i.e. an opposite-sex attraction and a heterosexual identity, a same-sex attraction and a gay or lesbian identity. Thirty-two participants reported being attracted to people of the same or more than one sex/gender but identified as heterosexual and 14 said that they were lesbian, gay, bisexual, queer or questioning their sexual identity but were attracted only to people of a different gender.

Sexuality diverse – sexual identity

383 of the 426 sexuality and/ or gender diverse participants responded to the question on sexual orientation. Of these, 112 (29.2%) reported being bisexual, 35 (9.1%) gay, 31 (8.1%) lesbian, 21 (5.5%) queer, 44 (11.5%) were questioning their sexual identity, 55 (14.4%) were unsure about their

sexual orientation and 19 (5.0%) were asexual/not sexual. The remainder reported being heterosexual (n = 55, 14.4%) or would rather not say (n = 11, 2.9%).

Sexuality diverse – sexual attraction

Of the 426 participants who were sexuality and/ or gender diverse, 43 (10.1%) were attracted only to people of a different sex/gender, 71 (16.7%) were attracted only to people of their own sex/gender, 218 (51.2%) were attracted to people of more than one sex/gender, 56 (13.1%) were not sure who they are attracted to, 29 (6.8%) reported that they don't feel attracted to people of any sex/gender and nine (2.1%) responded they would 'rather not say'.

Gender diverse young people

In response to the question are you female, male or other, 28 (1.9%) participants selected other. These participants used a range of terms to describe themselves including (copied *verbatim*): agender (1), androgyne (1), demi-girl (1), gender fluid (7), gender neutral (3), gender nonconforming (1), gender queer (1), intersex (1), neutrois-flux (1), non-binary (2), physically male, gender-fluid/agender (1), sexuality bisexual (1), Sis gender female (1), trans male (1), trans woman (1), transgender (2), transgender female (1) and transman (1). It is possible that some participants who selected male or female would also be transgender, selecting the gender that is affirming of their identity rather than their gender assigned at birth.

Intersex

Intersex is when someone is born with physical sex characteristics that are not typical. There are many different variations. Fourteen (1.0%) participants said they have an intersex variation and a further 55 (3.9%) said they did not know. A further 11 (0.8%) participants selected 'I'd rather not say'.

Intersections between marginalised groups

Participants could belong to up to four marginalised groups based on the indicators we used to define each group. Of the 897 who belonged to a marginalised group, most (n = 574; 64.0%) belonged to only one group, however almost one third of marginalised participants belonged to two groups. Table 4.1 shows the number of marginalised groups to which participants belonged.

Table 4.1 Number of marginalised groups to which participants belonged

Number of marginalised groups a participant belongs to:	N	%
None	519	36.7
One	574	40.5
Two	281	19.8
Three	38	2.7
Four	4	0.3
Total	**1416**	**100.0**

The combinations of marginalised groups to which participants belonged were enumerated and are listed below.

Two groups

Aboriginal + Rural = 104
Rural + Sexuality/Gender Diverse = 93
Homeless + Sexuality/Gender Diverse = 27
Homeless + Rural = 13
Refugee + Sexuality/Gender Diverse = 13
Aboriginal + Sexuality/Gender Diverse = 8

Homeless + Refugee = 7
Refugee + Rural = 4
Aboriginal + Homeless = 3
Aboriginal + Refugee =1 This appears to be an anomaly, however in examining all the information entered by the participant, it was not possible to know which group(s) to which they belonged.

Three groups
Aboriginal + Rural + Homeless = 18
Aboriginal + Rural + Sexuality/ Gender diverse = 13
Homeless + Rural + Sexuality/ Gender diverse = 5
Refugee + Rural + Sexuality/ Gender diverse = 2

Four groups (five possible combinations) N = 4
Aboriginal + Homeless + Rural + Sexuality/ Gender diverse = 3
Aboriginal + Refugee + Rural + Sexuality/Gender Diverse =1. This appears to be an anomaly, however in examining all the information entered by the participant, it was not possible to know to which group(s) they belonged.

Summary of Chapter 4

Of the 897 participants who belonged to at least one marginalised group, almost two thirds belonged to only one group and one third belonged to two or more groups. Aboriginal and/ or Torres Strait Islander participants were more likely to live in rural/ remote locations, which partly reflects our recruitment strategy for reaching Aboriginal and/ or Torres Strait Islander young people. Similarly, the predominance of metropolitan-dwelling participants of refugee background reflects recruitment methods employed to reach this group. Participants experiencing homelessness were equally likely to be from metropolitan and rural/remote areas, even though we used face to face recruitment methods such as outreach to youth refuges in metropolitan areas. However, because Aboriginal and Torres/ Strait Islander participants were overrepresented among those who were homeless as well as among rural/ remote participants, this could account for some of this.

Chapter 5

NSW Youth Health Survey results: health status of the survey sample

Self-rated health status

1410 participants answered the question about self-rated health status. 80.8% of participants rated their health as 'excellent', 'very good' or 'good' and 19.2% rated their health as fair or poor.
See Table 5.1.

Table 5.1 Self-rated health status for the whole sample

In general, would you say that your health is:	N	%
Poor	62	4.4
Fair	209	14.8
Good	521	37.0
Very good	461	32.7
Excellent	157	11.1
Total	**1410**	**100.0**

In our sample, the proportion of participants that rated their health as 'excellent', 'very good' or 'good' was similar for adolescents (12-17 years) and young adults (18-24 years). See Table 5.2.

Table 5.2 Self-rated health status by age group

In general would you say that your health is:	Adolescents 12-17 n (%)	Young adults 18-24 n (%)	Total N (%)
Poor	34 (4.9)	28 (3.9)	62 (4.4)
Fair	100 (14.3)	109 (15.3)	209 (14.8)
Good	254 (36.3)	267 (37.6)	521 (37.0)
Very good	221 (31.6)	240 (33.8)	461 (32.7)
Excellent	90 (12.9)	67 (9.4)	157 (11.1)
Total	**699 (100.0)**	**711 (100.0)**	**1410(100.0)**

Females and other gender participants were more likely to report poor or fair health, and less likely to report very good or excellent health compared to males (p=0.01). See Table 5.3.

Table 5.3 Self-rated health status by gender

In general would you say that your health is:	Female n (%)	Male n (%)	Other n (%)	Total n (%)
Poor	45 (4.7)	13 (3.2)	4 (9.5)	62 (4.4)
Fair	158 (16.4)	41 (10.1)	10 (23.8)	209 (14.8)
Good	375 (38.9)	129 (31.9)	17 (40.5)	521 (37.0)
Very good	311 (32.3)	140 (34.7)	10 (23.8)	461 (32.7)
Excellent	75 (7.8)	81 (20.0)	1 (2.4)	157 (11.1)
Total	**964(100.0)**	**404(100.0)**	**42(100.0)**	**1410(100.0)**

Other groups less likely to rate their health as 'excellent', 'very good' or 'good' included:

- Participants who belonged to at least one marginalised group (79.6% cf non-marginalised 82.8%, p=0.035) – Table 5.4
- Sexuality and/or gender diverse participants (71.8% cf not sexuality and/or gender diverse 84.6%, p<0.001) – Table 5.5
- Homeless participants (70.9% cf not homeless 81.9%, p=0.002) – Table 5.5

Table 5.4 Self-rated health status by marginalised status

In general would you say that your health is:	Does not belong to any marginalised groups n (%)	Belongs to at least one marginalised group n (%)	Total N (%)
Poor	18 (3.5)	44 (4.9)	62 (4.4)
Fair	71 (13.7)	138 (15.5)	209 (14.8)
Good	176 (34.0)	345 (38.7)	521 (37.0)
Very good	195 (37.6)	266 (29.8)	461 (32.7)
Excellent	58 (11.2)	99 (11.1)	157 (11.1)
Total	**518 (100.0)**	**892 (100.0)**	**1410 (100.0)**

Linear by linear chi-square test, p = 0.035

Table 5.5 Self-rated health status by marginalised group

In general would you say that your health is:	Aboriginal/ Torres Strait Islander (ns)	Homeless (p=0.002)	Refugee (ns)	Rural/ Remote (ns)	Sexuality/ gender diverse (p<0.001)
	n (%)	n (%)	n (%)	n (%)	n (%)
Poor	8 (4.8)	10 (8.5)	2 (2.7)	19 (4.0)	28 (6.6)
Fair	25 (14.9)	24 (20.5)	5 (6.8)	68 (14.3)	92 (21.6)
Good	67 (39.9)	36 (30.8)	22 (30.1)	190 (40.0)	163 (38.3)
Very good	44 (26.2)	27 (23.1)	26 (35.6)	140 (39.5)	114 (26.8)
Excellent	24 (14.3)	20 (17.1)	18 (24.7)	58 (12.2)	29 (6.8)
Total	**168(100.0)**	**168 (100)**	**73 (100.0)**	**475(100.0)**	**426(100)**

Chronic health conditions

Seven hundred and thirty-six participants (736/1416; 52.0%) reported having at least one chronic health condition or disability. Over two-thirds of these (508/736; 69.0%) reported having depression, anxiety or other mental illness, see Table 5.6.

Table 5.6 Types of chronic health conditions

Chronic health conditions*	n	%
Depression, anxiety or other mental illness	508	35.9
Overweight/obesity	158	11.2
Chronic health condition since birth	84	5.9
Drug and alcohol problems	60	4.2
An eating disorder	58	4.1
Developmental or Intellectual disability	40	2.8
Physical disability	34	2.4
Diabetes	16	1.1
Other	140	9.9

*NB participants could check more than one box

Of the 140 participants who reported having an 'Other' chronic health condition, three reported that this was anxiety, depression or other mental health problem and a further five reported that they thought they 'might have' or did have 'undiagnosed' anxiety, depression or other mental health problem. (These eight participants did not check the box 'Depression, anxiety or other mental illness').

Fifty-eight participants who reported having an eating disorder described these as bulimia (n= 22), anorexia (n = 22) and 12 gave other descriptions, such as 'eating disorder not otherwise specified'.

Of the 16 participants who reported having diabetes, six had Type 1 diabetes, six had Type 2 diabetes, two were unsure and two did not provide a response to the question 'which type of diabetes do you have?'

The most frequently reported 'Other' chronic health condition or condition since birth was asthma (n = 36) with 24 of these participants reporting having asthma since birth. Nine of the participants with asthma reported also having eczema or allergies. Four participants reported having eczema (but not asthma).

Twelve participants reported a chronic health condition of the gastrointestinal tract (Coeliac disease/ gluten intolerance = 4; Crohn's disease = 1; colitis = 1, irritable bowel syndrome = 3; unspecified = 3).

The following were reported by between five and nine participants: epilepsy = 9; migraine = 7; chronic pain = 7, included chronic headache, chronic back pain, chronic nerve pain, complex regional pain syndrome; Attention Deficit Hyperactivity Disorder = 6; 'heart condition' = 5.

Other conditions reported more than once but less than five times included chronic fatigue syndrome, an autoimmune condition, an endocrine or metabolic disorder (thyroid, adrenal, polycystic ovarian syndrome), scoliosis, acne and anaphylaxis.

Multiple chronic health conditions

Among those who had a chronic health condition or disability (n = 736), 63.2% had one chronic health condition or disability, 27.7% had two, 6.9% had three and 2.2% had four or more (Table 5.7).

Table 5.7 Number of chronic health conditions reported by those who had at least one chronic health condition

No. of chronic health conditions reported	n (%)
1	465 (63.2)
2	204 (27.7)
3	51 (6.9)
4	11 (1.5)
5	4 (0.5)
8	1 (0.1)
Total	**736 (100.0)**

Chronic health conditions, age, gender and marginalised status

Having a chronic health condition varied with age. Among young adults (18 – 24 years), 389/713 (54.6%) had at least one chronic health condition compared with 347/703 (49.4%) of adolescents (12 to 17 years), $p = 0.05$.

Having a chronic health condition also varied by gender: 530/968 or 54.8% of females, 171/406 or 42.1% of males and 35/42 or 83.3% of other gender participants reported having a chronic health condition ($p < 0.001$).

Of the 519 who did NOT belong to one of the five marginalised groups, 239 (46.1%) had at least one chronic health condition or disability.

Marginalised young people and chronic health conditions

Marginalised young people (497/897; 55.4%) were more likely than non-marginalised young people (239/519; 46.1%) to have a chronic health condition, p = 0.001.

The number of health conditions differed for marginalised and non-marginalised young people. Those who belonged to at least one marginalised group had a median of 1 chronic condition (IQR 1), whereas the median number of chronic health conditions for those who were not marginalised was 0 (IQR 1), p<0.001.

Among each of the marginalised groups, some were *more likely* to report having at least one chronic health condition:

- sexuality and/ or gender diverse participants, 296/426 (69.5%) cf non-sexuality and/ or gender diverse participants, 440/988 (44.5%), p<0.001
- homeless participants 72/118 (61.0%) cf non-homeless participants 659/1290 (51.1%), p=0.039

Whereas some were *less likely* to report having at least one chronic health condition:

- Aboriginal and/or Torres Strait Islander, 73/169 (43.2%) cf non-Aboriginal and/ or Torres Strait Islander 663/1245 (53.3%), p=0.014
- refugee, 15/75 (20.0%) cf non-refugee 715/1333 (53.6%), p<0.001.

See Table 5.8.

Table 5.8 Self-reported chronic health condition by marginalised group

Marginalised group	Has a chronic health condition n (%)	P value
Aboriginal and/ or Torres Strait Islander	73 (43.2)	0.014
Not Aboriginal and/ or Torres Strait Islander	663 (53.3)	
Homeless	72 (61.0)	0.04
Not homeless	659 (51.1)	
Refugee	15 (20.0)	p<0.001
Not refugee background	715 (53.6)	
Rural/ Remote	235 (49.2)	0.14
Not rural/ remote	496 (53.3)	
Sexuality and/or gender diverse	296 (69.5)	<0.001
Not sexuality and/ or gender diverse	440 (44.5)	

The number of self-reported chronic health conditions increased by number of marginalised groups that a young person belonged to, p=0.001, see Table 5.9.

Table 5.9 Number of chronic health conditions by number of marginalised groups

Median and mean number of self-reported chronic health conditions	No marginalised group	Belongs to one marginalised group	Belongs to two marginalised groups	Belongs to 3 or 4 marginalised groups
Median (IQR)	0 (1)	1 (1)	1(1)	1 (2)
Mean (SD)	0.7 (0.8)	0.8 (0.9)	0.9 (1.0)	1.0 (1.1)

Time away from school or work

Among the sample of 1416 young people, 604 (42.7%) had stayed away from school or work in the past month due to illness or injury.

Adolescents (12 to 17 years) were more likely to spend time away from school or work due to illness or injury (339/701, 48.4%) than young adults (18 to 24 years) (265/713, 37.2%), p<0.001.

Females (450/967, 46.5%) and other gender participants (19/42, 45.2%) were more likely than males (135/405, 33.3%) to spend time away from school or work due to illness or injury, p<0.001.

Belonging to at least one marginalised group (398/895, 44.5%) was not significantly associated with spending time away from school or work due to illness or injury when compared to not belonging to at least one marginalised group (206/519, 39.7%); p = 0.08. However, spending time away from school or work due to illness or injury increased with belonging to more marginalised groups (no marginalised group, 206/519, 39.7% cf belonging to three or four marginalised groups, 22/42, 52.4%, p=0.032).

Young carers

Among the whole sample, 145 participants (10.2%) had stayed away from school or work to care for someone else. Being a young carer did not vary with age: among adolescents (12 to 17 years), 79/702 (11.3%) had stayed away from school or work to care for someone else and among young adults (18 to 24 years) 66/713 (9.3%) had done so, p=0.22.

However young carers were more likely to be female (110/967, 11.4%) than male (33/406, 8.1%) or other gender (2/42, 4.8%); p=0.030.

Marginalised participants were more likely to have stayed away from school or work to care for someone else (103/896, 11.5%) compared to non-marginalised participants (42/519, 8.1%), p=0.042. In addition the higher the number of marginalised groups that a participant belonged to, the more like likely they were to have done so (no marginalised groups 8.1%, one marginalised group 10.1%, two marginalised groups 28.6%, three or four marginalised groups 28.6%, p=0.001).

Psychological Distress

Among the entire sample of Completers (n = 1416), 1,399 young people filled out the Kessler-10 (K10) questionnaire (Kessler et al., 2002, Andrews and Slade, 2001). The K10 is a validated instrument that provides a measure of non-specific psychological distress in adolescents and adults, relating to symptoms of anxiety and depression experienced in the most recent 4-week period. The K10 is used widely in Australia in population surveys in community and mental health samples. The 10-item questionnaire is scored, with total score being classified into 'low', 'moderate', 'high' and 'very high' levels of psychological distress. Table 5.10 shows the K10 scores across the sample.

Table 5.10 Kessler-10 score for the whole sample

Level of psychological distress (K10 score)	N (%)
Low (10-15)	354 (25.3)
Moderate (16-21)	317 (22.6)
High (22-29)	322 (23.0)
Very high (30-50)	407 (29.1)
Total	**1400 (100.0)**

Psychological distress and age

Adolescents (12-17 years) were more likely to have high/very high K10 scores (386/690, 56.0%) compared to young adults 18-24 years (343/710, 48.3%), p= 0.020. See Table 5.11.

Table 5.11 Kessler-10 score by age group

K-10 score	Adolescents* (12-17years) n (%)	Young adults* (18-24 years) n (%)	Total n (%)
Low (10-15)	159 (23.0)	195 (27.5)	354 (25.3)
Moderate (16-21)	145 (21.0)	172 (24.2)	317 (22.6)
High (22-29)	162 (23.5)	160 (22.5)	322 (23.0)
Very high (30-50)	224 (32.5)	183 (25.8)	407 (29.1)
Total	**690 (100.0)**	**710 (100.0)**	**1400 (100.0)**

*p=0.020

Psychological distress and gender

Participants who identified as ‘other gender’ were significantly more likely to have high and very high levels of psychological distress compared with females and males. Females were significantly more likely to report very high levels of psychological distress compared with males. See Table 5.12.

Table 5.12: Kessler-10 score by gender

Kessler-10 score	Female* n (%)	Male* n (%)	Other* n (%)	Total n (%)
Low (10-15)	215 (22.4)	137 (34.5)	2 (4.8)	354 (25.3)
Moderate (16-21)	217 (22.6)	94 (23.7)	6 (14.3)	317 (22.6)
High (22-29)	208 (21.6)	100 (25.2)	14 (33.3)	322 (23.0)
Very high (30-50)	321 (33.4)	66 (16.6)	20 (47.6)	407 (29.1)
Total	**961 (100.0)**	**397 (100.0)**	**42 (100.0)**	**1400 (100.0)**

*p<0.001

Psychological distress and marginalisation

Participants were significantly more likely to have high or very high K10 scores if they:

- Belonged to at least one of the five marginalised groups (57.1% cf did not belong to one of the marginalised groups, 43.4%; p<0.001)
- Were sexuality and/or gender diverse (69.7% cf were not sexuality and/or gender diverse, 44.4%; p<0.001)
- Were homeless (61.5% cf were not homeless, 51.0%; p<0.05)
- Had a chronic condition and/ or disability but did not belong to one of the five marginalised groups) (66.4% cf did not have a chronic condition and/ or disability (regardless of marginalised status, 49.1%; p<0.001)

There was no significant association between K10 score and being Aboriginal and/or Torres Strait Islander, being of refugee background or living in rural/remote NSW.

Chronic health condition and K10 score

Participants with one or more chronic health conditions had significantly higher K10 scores compared to those without a chronic health condition (71.1% cf 31.2%, p<0.001), see Table 5.13.

Table 5.13 Kessler-10 score by presence of a chronic health condition

Kessler-10 score	No chronic condition* n (%)	Has at least one chronic* condition n (%)	Total n (%)
Low (10-15)	267 (40.0)	87 (11.9)	354 (25.3)
Moderate (16-21)	192 (28.8)	125 (17.1)	317 (22.6)
High (22-29)	136 (20.4)	186 (25.4)	322 (23.0)
Very high (30-50)	72 (10.8)	335 (45.7)	407 (29.1)
Total	**667 (100.0)**	**733 (100.0)**	**1400 (100.0)**

*p<0.001

Wellbeing (WHO-5)

The World Health Organisation Wellbeing Index (WHO-5) questionnaire was completed by1403 young people. The WHO-5 is a 5-item validated questionnaire that measures wellbeing and also has psychometric properties as a depression screening tool (Topp et al., 2015). 269/1403 (19.2%) of our sample had WHO-5 scores indicative of likely depression, 335/1403 (23.9%) of low mood, and 799/1403 (56.9%) were not likely to have depression.

Wellbeing and age

There was no association between age and WHO-5 wellbeing score, see Table 5.14.

Table 5.14 Wellbeing score by age group

WHO-5 Score	Adolescent* (12-17 years) n (%)	Young adult* (18-24 years) n (%)	Total n (%)
Normal mood (51-100)	400 (57.7)	399 (56.2)	799 (56.9)
Low mood (29-50)	165 (23.8)	170 (23.9)	335 (23.9)
Likely depression (0-28)	128 (18.5)	141 (19.9)	269 (19.2)
Total	**693 (100.0)**	**710 (100.0)**	**1403 (100.0)**

*p=0.78

Wellbeing and gender

There was a significant association between gender and wellbeing. Participants identifying as other gender (42.9%) were more likely to have likely depression based on WHO-5 score compared to females (22.1%) and males (9.5%), p<0.001. See Table 5.15.

Table 5.15 Wellbeing score by gender

WHO-5 Score	Female* n (%)	Male* n (%)	Other* n (%)	Total n (%)
Normal mood (51-100)	498 (51.8)	292 (73.2)	9 (21.4)	799 (56.9)
Low mood (29-50)	251 (26.1)	69 (17.3)	15 (35.7)	335 (23.9)
Likely depression (0-28)	213 (22.1)	38 (9.5)	18 (42.9)	269 (19.2)
Total	**962 (100.0)**	**399 (100.0)**	**42 (100.0)**	**1403 (100.0)**

p<0.001

WHO-5 Wellbeing and marginalisation

There was no association between WHO-5 score and belonging to a marginalised group compared to not belonging to a marginalised group (p=0.32).

There was significantly greater wellbeing as measured by WHO-5 among young people who:

- were Aboriginal and/or Torres Strait Islander (70.3% normal mood cf non-Aboriginal 55.2%; p<0.001)
- were of refugee background (72.2% normal mood cf non-refugee 56.2%; p<0.05)
- lived in rural/ remote NSW (66.0% normal mood cf major city dwellers 52.5%; p<0.001)

Wellbeing was significantly lower (based on WHO-5 score) among:

- sexuality and/or gender diverse participants (31.7% likely depression cf non-sexuality and/or gender diverse 13.8%; p<0.001)
- participants who did not belong to one of the five marginalised groups but who had a chronic illness and/ or disability (28.2% cf the rest of the sample 17.3%; p<0.001)

There was no association between WHO-5 scores and being homeless. There was no association between belonging to increasing numbers of marginalised groups and WHO-5 wellbeing score.

Wellbeing and chronic health conditions

There was a significant association between WHO-5 score and having a chronic health condition. Participants with one or more chronic health conditions were more likely to have a WHO-5 score indicative of depression compared to those without a chronic health condition, see Table 5.16.

Table 5.16 Wellbeing score by presence of a chronic health condition

WHO-5 score	No chronic health condition* n (%)	At least 1 chronic health condition* n (%)	Total N (%)
Normal mood (51-100)	513 (76.6)	286 (39.0)	799 (56.9)
Low mood (29-50)	107 (16.0)	228 (31.1)	335 (23.9)
Likely depression (0-28)	50 (7.5)	219 (29.9)	269 (19.2)
Total	**670 (100.0)**	**733 (100.0)**	**1403 (100.0)**

*p<0.001

Table 5.17 below summarises health status for the whole sample, and the five marginalised groups.

Table 5.17 Summary of health status for the whole sample and each marginalised group

Characteristic	Whole sample N = 1416	None of the five marginalised groups* n = 519	Aboriginal and/or Torres Strait Islander* n = 169	Homeless* n = 118	Refugee* n = 75	Rural* n = 478	Sexuality and/or gender diverse* n = 426
Proportion with at least one chronic health condition by marginalised group# [n (%)]		**p = 0.001**	**p=0.01**	**p=0.04**	**p<0.001**	**p<0.001**	p=0.14
Chronic conditions	736 (52.0)	239 (46.1)	73 (43.2)	72 (61.0)	15 (20.0)	235 (49.2)	296 (69.5)
No chronic condition	680 (48.0)	280 (53.9)	96 (56.8)	46 (39.0)	60 (80.0)	243 (50.8)	130 (30.5)
Time away from school or work due to ill health# [n (%)]		p = 0.08	p=0.48	p=0.55	**p=0.02**	**p<0.001**	p=0.44
	604 (42.7)	206 (39.7)	76 (45.2)	47 (40.2)	22 (29.3)	211 (44.3)	216 (50.7)
Time away from school or work to look after someone else# [n (%)]		**p = 0.04**	p=0.07	p=0.06	p=0.38	p=0.46	**p=0.02**
	145 (10.2)	42 (8.1)	24 (14.3)	18 (15.3)	10 (13.3)	62 (13.0)	47 (11.0)
Level of psychological distress (K10 score)# [n (%)]		**p <0.001**	p=0.20	**p=0.04**	p=0.14	**p<0.001**	p=0.34
Low (10-15)	354 (25.3)	158 (30.5)	52 (31.5)	22 (18.8)	19 (26.4)	132 (28.4)	57 (13.5)
Moderate (16-21)	317 (22.6)	135 (26.1)	35 (21.2)	23 (19.7)	18 (25.0)	100 (21.6)	71 (16.8)
High (22-29)	322 (23.0)	108 (20.8)	38 (23.0)	25 (21.4)	22 (30.6)	102 (22.0)	105 (24.9)
Very high (30-50)	407 (29.1)	117 (22.6)	40 (24.2)	47 (40.2)	13 (18.1)	130 (28.0)	189 (44.8)

p values represent comparison of each of six groups (i.e. each of the 5 marginalised groups and none of the five marginalised groups) with the remainder of the sample; *Numbers in columns 3 – 8 total more than 1416 as participants could select more than one marginalised group

Chapter 5 summary

Just over four-fifths (80.8%) of our sample reported their health as good, very good or excellent. This is a substantially lower proportion than the 91.1% of 15 – 24 year olds who rated their health as 'excellent', 'very good' or 'good' in the 2014-2015 Australian Bureau of Statistics National Health Survey among all Australian young people (AIHW, 2018).

Just over half our sample reported having a chronic health condition, and two-thirds of these were chronic mental health conditions. Further, of those who had a chronic health condition, over one-third had two or more chronic health conditions.

Our sample had substantially higher levels of psychological distress compared to the general youth population in Australia, as measured using the Kessler-10 questionnaire. Twenty-three percent of our sample of adolescents (12 – 17 years) had low levels of psychological distress, compared with 50.9% of adolescents aged 11 – 17 year in the Australian Child and Adolescent Survey of Mental Health and Wellbeing (Lawrence et al., 2015). Conversely, 56.0% of our adolescent sample had high or very high levels of psychological distress compared with 19.9% in the Australian Child and Adolescent Survey of Mental Health and Wellbeing (Lawrence et al., 2015). Among our young adult participants (18 – 24 years), 27.5% had low and 48.3% high or very high levels of distress. The proportion experiencing high/ very high levels of distress was substantially higher than young adults (18 – 24 years) in the 2015 – 2015 National Health Survey, where 20% of females and 11.1% of males had high or very high K10 scores (Australian Bureau of Statistics, 2015).

High levels of psychological distress as measured by the K10 score were associated with belonging to a marginalised group, being sexuality and / or gender diverse, being homeless and with having a chronic health condition without belonging to any of the five marginalised groups. Similarly, sexuality and/ or gender diverse participants and those with a chronic health condition who did not belong to any of the five marginalised groups were also more likely to have lower wellbeing scores on the WHO-5 scale.

Chapter 6

NSW Youth Health Survey results: technology's role in help-seeking

Access to the internet

Most participants had access to the internet (1356/1,411, 96.1%). Fifty-five (3.9%) participants did not have internet access or had access periodically (n=16) via school, the library or youth services. Young adults (18 to 24 years) were significantly more likely to have internet access than adolescents (12 - 17 years) (p<0.001).

Access to a mobile phone

Most participants also owned a mobile phone with internet access (1227/1411, 87.0%) or without internet access (119/1411, 8.4%). Only 4.6% did not own a mobile phone (65/1411). Participants with a mobile phone with internet access were older (median 18 years, IQR 5) than those with a phone but no internet access (16 years, IQR 3) and those without a mobile phone (15 years, IQR 3) (p< 0.001).

Table 6.1 summarises internet access for the whole sample by age, gender and marginalised group status.

Table 6.1 Internet access for the whole sample by age, gender and marginalised group status

	N	No mobile phone n (%)	Mobile + internet n (%)	Mobile without internet n (%)
Whole sample	1411	65 (4.6)	1227 (87.0)	119 (8.4)
Adolescents‡	700	60 (8.6)	558 (79.7)	82 (11.7)
Young Adults	711	5 (0.7)	669 (94.1)	37 (5.2)
Females	967	22 (2.3)	874 (90.4)	71 (7.3)
Males	404	40 (9.9)	322 (79.7)	42 (10.4)
Other	40	3 (7.5)	31 (77.5)	6 (15.0)
Marginalised groups				
Aboriginal/ Torres Strait Islander‡	168	21 (12.5)	119 (70.8)	28 (16.7)
Homeless‡	117	12 (10.3)	78 (66.7)	27 (23.1)
Refugee‡	74	8 (10.8)	51 (68.9)	15 (20.3)
Rural‡	478	45 (9.4)	385 (80.5)	48 (10.0)
Sexuality/gender diverse	424	16 (3.8)	367 (86.6)	41 (9.7)

‡ p<0.001(comparator group is those who do not belong in the category)

Online activity

The great majority (1326/1410; 94.0%) spent time online every day, with 728/1410 or 51.6% online for 2 – 6 hours/ day. Only 24 (1.7%) did not spend time online: within this group 20/24 (83.3%) were adolescents, 14/24 (58.3%) were male, 13/24 (54.2%) were Aboriginal and/ or Torres Strait Islander and 19/24 (79.2%) were rural. Participants were most active online in the afternoon and evening.

See Tables 6.2 and 6.3.

Table 6.2 Time spent online

Time spent online	n	%
I don't spend time online	24	1.7
Every couple of days, not every day	60	4.3
Less than 2 hours per day	215	15.2
2-6 hours per day	728	51.6
6-10 hours per day	280	19.9
More than 10 hours per day	103	7.3
Total	**1410**	**100.0**

Table 6.3 Time of day online activity

When most active online	n	%
Early morning (5am - 9am)	32	2.3
Mid-morning (9am - 12noon)	72	5.1
Early afternoon (12noon - 3pm)	74	5.3
Mid-afternoon (3pm - 6pm)	299	21.3
Evening (6pm - 11pm)	856	60.9
Late night (11pm - 5am)	72	5.1
Total	**1405**	**100.0**

Young adults (18-24 years) spent more time online than adolescents (12-17years). Eighty-eight young adults out of 241 (36.5%) spent 6-10 or more than 10 hours a day online compared to 45/183 (24.6%) of adolescents, p= 0.04. Young adults (18-24years) were significantly more active online at 6-11pm compared to adolescents (67.0% cf 54.7%, p<0.001).

Access to technology, online activity and marginalised status

Participants who belonged to one or more marginalised group were significantly less likely to have internet access (94.4%) compared to non-marginalised participants (99.0%, p<0.001).
Marginalised groups less likely to have internet access were:

- Aboriginal and/or Torres Strait Islander (87.5% cf non- Aboriginal and/ or Torres Strait Islander 97.3%, p<0.001)
- homeless (91.5% cf not homeless 96.5%, p=0.013)
- rural/ remote (92.9% cf urban 97.7%, p<0.001).

See Table 6.4.

Table 6.4 Internet access by marginalised group

Marginalised group	No internet access N (%)	Internet access N (%)	Total N (%)
Aboriginal and/or Torres Strait Islander*	21 (12.5)	147 (87.5)	168 (100.0)
Homeless#	10 (8.5)	107 (91.5)	117 (100.0)
Refugee	6 (8.1)	68 (91.9)	74 (100.0)
Rural*	34 (7.1)	444 (92.9)	478 (100.0)
Sexuality / gender diverse	15 (3.5)	409 (96.5)	424 (100.0)
Total	55 (3.9)	1354 (96.1)	1416 (100.0)

*p<0.001; #p=0.013

Marginalised participants were significantly less likely to own a mobile phone with or without internet access (93.1% cf 99.4%, p<0.001). Aboriginal and/or Torres Strait Islander participants, homeless participants and rural participants were significantly less likely to own a mobile phone, with or without internet access (p<0.001).

Marginalised participants spent significantly less time online ($p< 0.001$), with 25.2% spending less than 2 hours per day compared with 14.3% who do not belong to one of the five marginalised groups. Aboriginal and/or Torres Strait Islander ($p<0.001$), rural ($p<0.001$), homeless ($p=0.006$), and refugee participants ($p<0.001$) spent significantly less time online compared to the whole sample.

There was a subtle but statistically significant difference between the marginalised and non-marginalised groups in the time when they were most active online. For example, participants belonging to one or more marginalised groups were more likely to be online late at night (11pm – 5am) (56/887, 6.3% cf 16/518, 3.1% who do not belong to a marginalised group, $p=0.008$). Sexuality and/or gender diverse participants were most active online in the evening (6pm – 11pm) compared to non-sexuality and/ or gender diverse participants (269/422, 63.7% cf 586/981, 59.7%; $p<0.001$).

Using the internet for health information and help-seeking

Participants were asked about the ways in which they used the internet to find health information and seek help.

To explore internet use in **finding health information**, we asked them how often they use the internet to:
- find health information
- decide whether they need to visit a health service
- decide which health service/s to go to and
- whether they thought the internet was as good as visiting a doctor or health service.

To explore internet use in **help-seeking behaviour** in the previous six months, including use of the internet to:
- stay healthy
- find information because of problems experienced
- find out how to visit a health services
- manage health conditions themselves using internet based programs or apps.

We also asked about whether they found the information they were looking for and whether they trusted it.

We examined the association between having and not having access to the internet. It should be noted however that when reporting 'no internet access' this refers to participants who accessed the internet intermittently and outside of home (e.g. via libraries, schools, youth services). This proportion (3.9%) with 'no internet access' was small.

Having *access to* the internet was associated with *using the internet*:
- to determine whether they needed to visit a health service ($p<0.001$)
- to decide which health service(s) they would go to ($p<0.01$)
- in the previous 6 months to find health information to keep healthy ($p<0.001$)
- in the previous 6 months to find information about health problems experienced ($p<0.001$)
- in the previous 6 months to find information about how to visit a health service ($p<0.05$)
- in the previous 6 months for Internet based programs or apps ($p<0.05$).

There was a trend towards believing that information on the internet is as good as visiting a doctor or health service for their health concerns and having access to the internet, ($p = 0.05$) although it should be noted that the number of participants without internet access was small.

See Table 6.5.

Table 6.5 Use of the internet for health information and help-seeking in past six months by internet access

FINDING HEALTH INFORMATION ONLINE	**Total** **n (%)**	**No internet access** **n (%)**	**Internet access** **n (%)**	**P value**
Use the internet to help work out if I need to visit a health service				**< 0.001**
Frequently	314 (22.3)	4 (7.5)	310 (22.9)	
Sometimes	632 (44.9)	17 (32.1)	615 (45.4)	
Not at all	461 (32.8)	32 (60.4)	429 (31.7)	
Use the internet to decide which health service(s) to go to				**0.01**
Frequently	217 (15.4)	3 (5.7)	214 (15.8)	
Sometimes	495 (35.2)	13 (24.5)	482 (35.6)	
Not at all	695 (49.4)	37 (69.8)	658 (48.6)	
Believe that the information on the internet is as good as visiting a doctor or health service for their concerns				**0.05**
Strongly agree	54 (3.8)	2 (3.7)	52 (3.8)	
Agree	156 (11.1)	10 (18.5)	146 (10.8)	
Not sure	305 (21.7)	19 (35.2)	286 (21.1)	
Disagree	608 (43.2)	12 (22.2)	596 (44.1)	
Strongly disagree	284 (20.2)	11 (20.4)	273 (20.2)	
HELP-SEEKING BEHAVIOUR PAST SIX MONTHS	**Total** **n (%)**	**No internet access** **n (%)**	**Internet access** **n (%)**	**P value**
Used the internet in the previous 6 months to find information about how to keep themselves healthy				**<0.001**
No	521 (37.0)	38 (70.4)	483 (35.6)	
Yes	889 (63.0)	16 (29.6)	873 (64.4)	
Used the internet in the previous 6 months to find information about health problems they have experienced				**<0.001**
No	590 (41.9)	40 (74.1)	550 (40.6)	
Yes	819 (58.1)	14 (25.9)	805 (59.4)	
Used the internet in the previous 6 months to find information about how to visit a health service				**0.02**
No	1093 (77.7)	49 (90.7)	1044 (77.2)	
Yes	314 (22.3)	5 (9.3)	309 (22.8)	
Used the internet in the previous 6 months so they could manage health issues themselves				**0.02**
No	1023 (72.8)	47 (87.0)	976 (72.2)	
Yes	382 (27.2)	7 (13.0)	375 (27.8)	

Finding health information online

We explored help-seeking behaviour and the internet by asking about whether participants:

1. use the internet to work out if they need to visit a health service
2. use the internet to decide which health service to go to
3. believe that information on the internet is as good as visiting a doctor or health service for health concerns

Two thirds of the sample (n=950/1412, 67.3%) used the internet to help decide whether they need to visit a health service, but were less likely to use the internet to decide which health service to visit. 50.7% of participants used the internet to decide which health service to visit. See Table 6.6.

Table 6.6 Use of the internet in help-seeking

	Frequently n (%)	Sometimes n (%)	Not at all n (%)	Total N (%)
I use the internet to help me work out if I need to visit a health service	316 (22.4)	634 (44.9)	462 (32.7)	1412 (100.0)
I use the internet to decide which health service(s) I will go to	217 (15.4)	499 (35.3)	696 (49.3)	1412 (100.0)

Use of the internet in finding health information by age and gender

Adolescents (12-17 years) and males were significantly less likely to use the internet to help them work out if they need to visit a health service compared to young adults ($p<0.001$) and females or other gender ($p<0.001$) respectively.

The majority did not believe that information on the internet is as good as visiting a doctor or health service for health concerns: 43.2% disagreed and 20.1% strongly disagreed. However adolescents (12-17 years) (16.4% cf 13.5% of young adults 18-24 years, $p<0.001$) and males (18.1% cf 16.7% other gender and 13.6% females, $p=0.001$) were significantly more likely to agree with the statement: 'information on the internet is as good as visiting a doctor or health service for my health concerns'.

Use of the internet in finding health information by marginalised status

Marginalised participants were significantly less likely than those who were not marginalised to use the internet to help them work out if they need to visit a health service ($p<0.001$) or to decide which health service(s) to go to ($p<0.05$).

Aboriginal and/or Torres Strait Islander participants (23.7% cf non-Aboriginal and/ or Torres Strait Islander, 13.8%, $p<0.001$), homeless participants (18.6% cf not homeless, 14.5%, $p=0.010$), and refugee participants (24.0% cf non-refugee, 14.3%, $p=0.003$) were significantly more likely to agree with the statement: 'information on the internet is as good as visiting a doctor or health service for my health concerns'.

Online help-seeking behaviour in past six months, age and gender

Seeking online information to keep healthy

Among survey participants, 891/1415 (63.0%) had used the internet in the previous 6 months to find information about keeping healthy. Of those, 74.6% found what they were looking for. Young adults (18 – 24 years) were more likely to look for online information about keeping healthy (490/713, 68.7%) compared to adolescents (12 – 17 years) (401/702, 57.1%), ($p<0.001$). However there was no difference between adolescents and young adults with respect to finding what they were looking for online (adolescents 73.1%, young adults 75.8%, $p = 0.63$). There was also no difference between adolescents and young adults with respect to trusting the information they found (adolescents 50.9%, young adults 50.4%, $p = 0.95$)

Males (49.8%) were significantly less likely than females (68.4%) or other gender participants (66.7%, $p<0.001$) to use the internet to find health information. However most males (78.2%) and females (74.3%) found what they were looking for, while participants of other gender were less likely to (53.6%, $p = 0.01$). There was no difference by gender in whether the information found could be trusted (male 54.2%, female 49.5%, other gender 50.0%, $p = 0.70$).

Seeking online information about health problems experienced

In the past six months, 821/1414 participants (58.1%) used the internet to get information about health problems experienced. Young adults (18-24years) were more likely than adolescents to use the internet for this purpose (65.7% cf 50.3%, $p<0.001$). Among those who did, there was no difference by age group with respect to finding the information they wanted (adolescents 69.5%, cf young adults 70.5%, $p = 0.55$) or in whether they trusted the information they found (adolescents 45.5% cf young adults 45.3%, $p= 0.64$).

Males were significantly less likely (39.4%), than females (65.1%) or other gender young people (76.2%, <0.001) to seek information online about health problems experienced. There was no difference by gender in terms of finding what they were looking for (males 77.6%, females 68.0%, other gender 71.9%, $p = 0.14$) or trusting the information found (males 53.4%, females 43.2%, other gender 46.9%, $p = 0.22$)

Seeking online information on how to visit a health service

In past six months 315/1412 (22.3%) participants used the internet to get information about how to visit a health service. Young adults (18-24 years) more likely to use the internet for this purpose than adolescents (30.3% cf 14.1%, $p<0.001$). Males were significantly less likely (16.8%), than females (24.5%) or other gender participants (26.2%) to use the internet to get information about how to visit a health service ($p=0.007$).

Using internet based programs and apps

In past six months 383/1410 (27.2%) participants used internet based programs or apps to manage health issues themselves. Of these, 74.2% found them helpful. There was no difference between adolescents and young adults with respect to using internet based programs and apps. Males were significantly less likely to use internet based programs or apps (20.1%), than females (29.3%) or other gender participants (45.2%, $p<0.001$).

Online health seeking behaviour in past six months and time-of-day internet use

Participants who used the internet mostly 'after hours' (6pm – 5am) were more likely to look for *health information* online compared to participants who mostly used the internet during regular ('business') hours, (after hours users 572/927; 61.7% cf regular hours users 247/477; 51.8%; $p<0.001$). However participants who were mostly online very late/ overnight (11pm-5am) were not more likely to look for health information online more frequently than others.

We examined whether time of day internet use was associated with looking for *health service information.* Neither after hours internet use (6pm – 5am) or very late/ overnight internet use (11pm -5am) were significantly associated with looking for health service information online compared to regular hours internet users.

After-hours internet users (6pm – 5am) were more likely to use *internet based programs or apps to manage health conditions* themselves compared to regular hours users (after-hours users 269/924, 29.1% cf regular hours users 113/475, 23.8%, $p = 0.03$). However when we looked only at very late/ overnight internet users (11pm - 5am), they were *not* more likely to use internet based programs or apps to manage health issues themselves.

Online health seeking behaviour in past six months and marginalised status

Participants belonging to at least one marginalised group were less likely to use the internet for health information compared to those who did not belong to one of the five marginalised groups (59.0% cf 69.8%, $p<0.001$). Marginalised groups that were *less* likely to use the internet for health information included those who were Aboriginal and/or Torres Strait Islander (42.6% cf 65.8% non-Aboriginal and/ or Torres Strait Islander, $p<0.001$), homeless (50.0% cf 64.4% not homeless, $p=0.002$), refugee (46.7% cf 64.1% not refugee, $p=0.002$), rural (52.4% cf 68.6% urban, $p<0.001$).

Sexuality and/or gender diverse participants were *more* likely to use the internet for health information (68.3% cf 60.7% non-sexuality and/ or gender diverse, p=0.006).

Marginalised participants were also *less* likely to use the internet to get information about health problems (54.6% cf 64.0% not marginalised, p<0.001). Among the groups of marginalised young people, those who were Aboriginal and/or Torres Strait Islander (36.1% cf 61.1% non-Aboriginal and/ or Torres Strait Islander, p<0.001), homeless (48.3 cf 59.2% not homeless, p=0.022, refugee (45.9% cf 58.9% not refugee, p=0.027) and rural (45.7% cf 64.4% urban, p<0.001) were *less* likely to use the internet to get information about health problems.

Sexuality and/ or gender diverse participants were *more* likely to use the internet to get information about health problems (67.8% cf 53.9%, p<0.001).

The groups significantly *less* likely to use the internet for service information included Aboriginal and/or Torres Strait Islander (15.0% cf 23.3% non-Aboriginal and/ or Torres Strait Islander, p=0.015) and rural (17.5% cf 24.8% urban, p=0.002) participants.

Sexuality and/or gender diverse participants were *more* likely to use internet based programs or apps to manage health issues themselves (32.7% cf 24.8% non-sexuality and/ or gender diverse, p=0.002), but also less likely to find them useful (66.9% cf 77.9% non-sexuality and/ or gender diverse, p=0.022).

Qualitative responses to questions about the internet and help-seeking

Participants could write free-text responses to the questions:

- How do you decide where to go? For example, do you use the internet to help you find information about health services you can go to, or do you ask other people?
- How does the internet help you decide about whether to go to a health service?

Nine hundred and nine participants wrote free-text responses to the first question, and 763 responded to the second question. These free-text responses were analysed by content and are summarised below.

Just over one-third of the 909 participants who entered free-text responses used the internet in some way to help them decide where to go. However the great majority used the internet in combination with another source of advice from a person they knew. For example, participants would look up symptoms then ask others for recommendations about services, or would look up the websites of services that others, including their GP, had recommended. A small number reported that they would NOT use the internet to decide on whether and how to seek help.

274 reported that they either rely completely on family or would ask a family member first before deciding where to go. Parents were the most frequently reported family member while some participants specified their mother, father, relative, sister or carer.

194 would ask their doctor, GP, or known health professional first or simply go there as they were known and trusted sources of help.

Just over 50 participants reported that they would ask friends, and a few stated they would ask a youth worker/ case worker or teacher.

In addition to these sources of advice, an additional 133 participants reported that they would ask "others" or use "word of mouth" to help decide where to go.

The ways in which participants used the internet, almost always as an adjunct, are illustrated below with quotes.

<u>Making the decision to seek help:</u>
The internet helps me determine if I am sick enough to go to a health service.

The internet can help me find out what certain symptoms mean and whether I need to visit a health service

Helping to decide whether a services is appropriate or likely to provide the right care
It [the internet] also helps as many people write reviews online of their good or bad experiences of certain medical and health care practices.

Practical information about access
The internet helps with knowing whether I'll need a referral and if the services I'm looking for can be bulk billed.

Using the internet in combination with personal advice
The internet is usually my starting point. I also tend to ask my existing health care professionals for recommendations. For example my psychiatrist recommended a good GP when I moved house.

I may use the internet to broadly investigate a particular symptom / issue I am experiencing. However, I will always take info on the net with caution and trust only specific doctors' advice.

Depending on the nature of the problem, I might ask others or find out online. If it's something I find embarrassing I rely more on online information as I don't want to talk about it with other people.

I do use the internet to access information but I am more likely to ask my parents.

Ask a health professional, or using the internet. Ask my GP doctor.

Mixture of both. I will ask other people and seek out further information on the internet.

Chapter 6 summary

Most participants had access to the internet and were online every day. This is unsurprising given the main recruitment strategies involved online promotion. Using the internet to find health information was common, while searching online for information about how to visit a health service was relatively uncommon. Most participants believed that the internet was not as good as visiting a doctor or health service for health concerns. To decide which health services to visit, participants used technology in combination with word-of-mouth and recommendations or direct referrals from a parent/ carer or health professional.

Although the use of online programs and apps to manage health problems was relatively uncommon, the majority found these useful if they did use them. Among the five marginalised groups, the sexuality and/ or gender diverse participants were more likely to use the internet to look for information as well as to seek help. Participants integrated technology into help-seeking, by combining information-seeking online with face-to-face conversations.

Chapter 7

NSW Youth Health Survey results: navigating the health system

To learn about the health services that young people in NSW access, and gain a snapshot of the way they move between services and around the health system, the Study 1 survey included several questions about health service utilisation in the previous six months, whether participants had a regular GP, and their attitudes towards and understanding of the health system. Asking about a regular GP was important because in the Australian health system, GPs remain the main providers of primary health care and are also gatekeepers to many other services including medical specialists, but also to a range of psychological and allied health services through a range of Medicare-funded management plans.

Health service utilisation

The great majority of the 1416 participants had visited at least one health professional in the previous six months, this was most likely to have been a general practitioner (GP, 81.4%). 29.3% had visited a counsellor or psychologist in the past six months. See Table 7.1.

Table 7.1 Health professionals visited in past six months

Health professional	**n***	**% (N=1411)**
GP/doctor	1149	81.4
Dentist	635	45.0
Pharmacist/chemist	594	42.1
Counsellor/psychologist	413	29.3
Medical specialist (e.g. a skin specialist, surgeon)	269	19.1
Nurse	204	14.5
Physiotherapist	171	12.1
Psychiatrist (Doctor specialising in mental health)	140	9.9
Nutrition/dietitian/food expert	89	6.3
Paediatrician	54	3.8
Traditional healer	25	1.8
Other	63	4.5
None	116	8.2

* total exceeds N=1411 as participants could select more than one health professional

Where reported, the types of traditional healer visited included an acupuncturist (n=9), Chinese medicine practitioner (n=4), naturopath (n=4), remedial massage therapist (n=4), crystal healing (n=1), kinesiologist (n=1) and spiritual healer (n=1).

Where reported, 'Other' health professionals in fact included a range of medical specialists (gynaecologist n = 2; heart specialist n = 2, allergy doctor, cancer doctor, diabetes specialist, foot and back doctor, gastroenterologist, obstetrician, pathologist, plastic surgeon, surgeon, urologist). Four participants had seen an optometrist, four a chiropractor, two an orthodontist, two an osteopath, two a podiatrist, two a radiographer/ XRay and two a remedial massage therapist. Others included one each of 'specialist', kinesiologist, occupational therapist.

Participants were also asked about whether they had visited non-general practice types of health services (mostly primary health care services). Fourteen percent of the sample had visited an Emergency Department in the previous six months, and 11% had had an admission to hospital.

See Table 7.2.

Table 7.2 Health services visited in past six months

Health service type	n*	% (N=1413)
None	741	52.4
Emergency Department	200	14.2
Online service where you interact with people (e.g. eheadspace)	175	12.4
headspace centre	172	12.2
Mental health service	171	12.1
School counsellor	169	12.0
Admitted to hospital	156	11.0
Youth health service	113	8.0
Sexual health clinic	79	5.6
Aboriginal Medical Service	72	5.1
Drug and alcohol service	33	2.3
Family planning service	30	2.1
Other	22	1.6

* total exceeds N=1413 as participants could select more than one health professional

Satisfaction

Of those who had visited one of the above services in the previous six months, 522/753 (69.3%) stated they felt like the service knew how to help them, and 70.0% (528/754) would recommend the service to other young people.

Multiple health service usage

Of the 1416 survey completers, 503 participants visited multiple services in the preceding six months. Among these, approximately half (50.9%) visited multiple health services for related or similar health problems and half (49.1%) for unrelated or different health problems.

The proportion visiting multiple health services for related/similar health problems did not vary by age (adolescents 134/254, 52.8%; young adults 122/249, 49.0%; p=0.40). The proportion of participants visiting multiple health services for related or similar health problems was similar for females (175/349, 50.1%) males (66/131, 50.4%) and other gender (15/23, 65.2%); p=0.37. There was no significant difference between marginalised and non-marginalised participants in visiting health series for multiple health problems, see Table 7.3.

Table 7.3 Reason for multiple health service usage by marginalised status and marginalised group

Marginalised group	Multiple health service usage in past six months for related/similar health problems n (%)	Multiple health service usage in past six months for unrelated/different health problems n (%)	p value
Marginalised	188 (53.7)	162 (46.3)	0.06
Non-marginalised	68 (44.4)	85 (55.6)	
Aboriginal and/or Torres Strait Islander	25 (46.3)	29 (53.7)	0.47
Homeless	32 (58.2)	23 (41.8)	0.24
Refugee	14 (60.9)	9 (39.1)	0.31
Rural	90 (54.5)	75 (45.5)	0.23
Sexuality and/or gender diverse	109 (55.3)	88 (44.7)	0.11

Health service utilisation by marginalised group

There was no difference in utilising a GP in the past six months by marginalised group.
Sexuality and/or gender diverse and homeless participants were more likely than other groups to have seen a counsellor/ psychologist and a psychiatrist in the past six months. Sexuality and / or gender

diverse participants were also more likely to have visited a pharmacist in the past six months, and rural/ remote participants were more likely to have visited a nurse. Some groups were significantly less likely to have utilised certain health professionals in the past six months. See Table 7.4.

Table 7.4 Health professionals visited in past 6 months by marginalised group

Health professional type:	Aboriginal/ Torres Strait Islander P value	Homeless P value	Refugee P value	Rural/ Remote P value	Sexuality/ gender diverse P value	All Marginalised P value
GP/doctor	Less likely 0.001	0.32	0.13	Less likely 0.045	0.06	0.24
Counsellor/psychologist	Less likely 0.047	More likely < 0.001	Less likely 0.005	Less likely 0.037	More likely < 0.001	More likely 0.003
Dentist	Less likely 0.004	0.07	0.18	Less likely < 0.001	0.25	Less likely < 0.001
Medical specialist	Less likely 0.038	0.27	0.11	Less likely 0.037	0.23	0.09
Nutritionist	0.62	0.17	0.39	0.25	0.14	0.13
Nurse	0.07	0.17	Less likely 0.048	More likely 0.016	0.50	0.27
Psychiatrist	0.21	More likely 0.019	Less likely 0.011	Less likely 0.033	More likely < 0.001	0.12
Paediatrician	0.55	0.79	0.60	0.72	0.60	0.59
Physiotherapist	0.11	0.12	Less likely 0.010	0.41	0.78	Less likely 0.041
Pharmacist/chemist	Less likely <0.001	0.97	Less likely 0.001	Less likely 0.002	More likely 0.024	0.07
Traditional healer	0.22	0.94	0.24	0.18	0.13	0.74
None	More likely <0.001	0.93	0.10	More likely <0.001	0.14	0.052

Having a regular GP

Eight hundred and nineteen participants of 1406 who answered the question (58.3%) reported having a regular GP. Table 7.5 shows the responses to the questions about having a regular GP, and includes only those who answered the question (n = 1406).

Table 7.5 GP utilisation

GP utilisation	N	%
I have a regular GP/doctor	819	58.3
I go to whatever GP/doctor is available when I need to	511	36.3
I usually go to a hospital emergency department instead of a GP/doctor	14	1.0
I usually call a telephone GP/doctor service	9	0.6
I don't go to a GP/doctor	53	3.8
No response	10	0.7
Total	**1416**	**100.0**

There was an association between having a regular GP and age group, but no association with gender or belonging to one or more marginalised groups. Having a chronic condition was associated with having a regular GP, whether or not the participant belonged to one or more of the five marginalised groups. See Table 7.6.

Table 7.6 Regular GP by age group, gender and marginalisation

	Has a regular GP n (%)	Does not have a regular GP n (%)	Total	P value
Adolescents (12 – 17yrs)	427 (61.5)	267 (38.5)	694	**0.014**
Young adults (18 – 24 years)	392 (55.1)	320 (44.9)	712	
Female	549 (57.1)	412 (42.9)	961	0.402
Male	243 (60.3)	160 (39.7)	403	
Other gender	27 (64.3)	15 (35.7)	42	
Belongs to at least one marginalised group	301 (58.4)	218 (41.6)	519	0.882
Does not belong to any of the marginalised groups	518 (58.0)	369 (42.0)	887	
Has at least one chronic condition	456 (62.1)	278 (37.9)	734	**0.002**
No chronic conditions	363 (54.0)	309 (46.0)	672	
Has at least one chronic condition but does not belong to any of the marginalised groups	153 (64.0)	86 (36.0)	219	**0.047**
Has at least one chronic condition but does belong to a marginalised group OR has no chronic conditions	666 (57.1)	501 (42.9)	1167	

Attitudes towards and understanding of the health system

To explore participants' perceptions of navigating the health system, a set of questions was developed to explore their understanding of and attitudes towards accessing the range of services within the health system. Overall, understanding and attitudes were positive, with most reporting that they had a good understanding of the services available and that they could access appropriate service when they needed to. See Table 7.7.

Table 7.7 Attitudes towards navigating the health system (N = 1416)

	Strongly Agree/ Agree n (%)	Not sure n (%)	Disagree/ Strongly Disagree n (%)
I get confused by the number of different health services available	391 (27.6)	381 (26.9)	628 (44.4)
I have a good understanding of the different health services that are available to me	911 (64.3)	306 (21.6)	184 (13.0)
I can find and access appropriate health services when I need them	1037 (73.2)	238 (16.8)	125 (8.8)
I have had to visit too many different services unnecessarily	238 (16.8)	301 (21.3)	859 (60.7)
I have been to lots of different services because I needed to	536 (37.9)	266 (18.8)	594 (41.9)
I would prefer to access online services than physically go to a health service for some health issues but not others	438 (31.0)	315 (22.2)	645 (45.6)

Chapter 7 summary

Contact with the health system in the past six months was common among our sample. Four-fifths of the participants had seen a GP in the past six months, while dentists and pharmacists had been seen by over 40%, counsellors and psychologists by almost 30% and a medical specialist by almost 20%. There had been contact across a broad range of non-GP primary health care services, as well as 11.0% reporting admission to hospital, in the past six months.

Among participants, 57.8% had a regular GP while 36.1% would visit whichever GP was available when needed. Only 1% reported that they would go to an Emergency Department instead of a GP. Adolescents were more likely to have a regular GP compared to young adults, and having a chronic health condition was also associated with having a regular GP, while marginalisation was not.

Attitudes towards the health system were positive, with almost three-quarters of the sample agreeing that they could find and access appropriate health services when they needed them, and 64.4% agreeing that they have a good understanding of the different health services available to them.

Chapter 8

NSW Youth Health Survey results: barriers to accessing health care

Participants were asked to choose from a list of potential barriers any which they thought would prevent them from visiting a health service. Cost was the most frequently cited barrier to accessing health care (45.8%) across the whole sample (n= 1416). Table 8.1 lists the barriers and their frequencies for the whole sample.

Table 8.1 Barriers to health care for the whole sample

Barrier	N=1,416# n (%)
Cost	649 (45.8)
Opening hours mean I need time off study or work	449 (31.7)
I would feel embarrassed	393 (27.8)
Difficulty getting there	336 (23.7)
I would have to ask my parents/ carers to take me	313 (22.1)
I would feel judged	287 (20.3)
The gender of the doctor/ health professional	267 (18.9)
I worry about confidentiality	217 (15.3)
I don't have my own Medicare card	173 (12.2)
I don't know which service/s to go to	165 (11.7)
Language or cultural reasons	83 (5.9)
Nothing*	302 (21.3)

participants could select more than one barrier, therefore total exceeds 1416;

*some participants who selected 'Nothing' also selected at least one of the other barriers

Barriers to health care and age

Citing any barrier to health care increased with age, but within each age-in-years group, over 50% cited at least one barrier. For those aged 15 years and over, more than 75% within each age-in-years group cited at least one barrier. Table 8.2 compares the proportion within each age-in-years group who cited no barriers with those who cited at least one barrier.

Table 8.2 Barriers to health care by age

Age in years	No barriers cited n (%)	At least one barrier cited n (%)
12	14 (43.8)	18 (56.3)
13	14 (29.8)	33 (70.2)
14	31 (37.8)	51 (62.2)
15	40 (24.1)	126 (75.9)
16	41 (21.2)	152 (78.8)
17	35 (19.1)	148 (80.9)
18	19 (14.8)	109 (85.2)
19	16 (12.0)	117 (88.0)
20	10 (9.1)	100 (90.9)
21	16 (16.8)	79 (83.2)
22	10 (13.3)	65 (86.7)
23	12 (14.6)	70 (85.4)
24	12 (13.3)	78 (86.7)
Total	**270 (19.1)**	**1146 (80.9)**

When the individual barriers were examined by age-in-years, there were different patterns. Structural barriers such as cost, opening hours and difficulty getting to a service tended to increase with age, while concerns about feeling embarrassed and confidentiality were more prominent in the middle-adolescent years. See Table 8.3.

Table 8.3 Individual barriers by age

Barrier	p value	Pattern
Cost	< 0.001	Increases as a barrier with age
Opening hours mean need time off study/ work	<0.001	Increases as a barrier with age
Difficulty getting there	<0.001	Increase with age up to 20 years
I would have to ask parents/carers to take me	<0.001	Decreases with age
I don't know which service to go to	0.036	Decrease with age
Nothing	<0.001	Decreases with age
I would feel embarrassed	0.012	Highest for 15 to 19 year olds
I don't have own Medicare card	< 0.001	Highest for 14 to 18 year olds
I would feel judged	0.09	Highest for 15, 18 and 24 year olds
The gender of the doctor/ health professional	0.51	Highest for 17 to 20 year olds
I worry about confidentiality	0.21	Highest for 14 to 19 year olds
Language or cultural reasons	0.11	No pattern

Barriers to health care and gender

Female and other gender participants were more likely to cite at least one barrier to health care compared to males (Table 8.4). However female participants were older on average than male participants, so this difference could also be an age-related association.

Table 8.4 Barriers to health care by gender

	Female* n (%)	Male* n (%)	Other gender* n (%)	Total N (%)
No barriers	132 (13.6)	134 (33.0)	4 (9.5)	270 (19.1)
At least one barrier	836 (86.4)	272 (67.0)	38 (90.5)	1146 (80.9)
Total	**968 (100.0)**	**406 (100.0)**	**42 (100.0)**	**1416 (100.0)**

*p < 0.001

Female and other gender participants were more likely to cite cost, opening hours, feeling embarrassed, feeling judged, gender of the doctor or health professional and concerns about confidentiality as barriers compared to male participants. See Table 8.5.

Table 8.5 Single barriers to health care by gender

	Female n (%)	Male n (%)	Other n (%)	p value
Cost	485 (50.1)	141 (34.7)	23 (54.8)	<0.001
Opening hours mean I need time off study or work	358 (37.0)	81 (20.0)	10 (23.8)	<0.001
I would feel embarrassed	297 (30.7)	79 (19.5)	17 (40.5)	<0.001
Difficulty getting there	240 (24.8)	82 (20.2)	14 (33.3)	0.06
I would have to ask my parents/ carers to take me	221 (22.8)	80 (19.7)	12 (28.6)	0.26
I would feel judged	210 (21.7)	64 (15.8)	13 (31.0)	0.01
The gender of the doctor/ health professional	240 (24.8)	18 (4.4)	9 (21.4)	<0.001
I worry about confidentiality	158 (16.3)	49 (12.1)	10 (23.8)	0.04
I don't have my own Medicare card	125 (12.9)	43 (10.6)	5 (11.9)	0.49
I don't know which service/s to go to	117 (12.1)	41 (10.1)	7 (16.7)	0.34
Language or cultural reasons	55 (5.7)	23 (5.7)	5 (11.9)	0.24
Nothing	150 (15.5)	146 (36.0)	6 (14.3)	<0.001

Relationship between income and cost as a barrier
Of the participants who were working, those who had a higher weekly income were more likely to cite cost as a barrier to visiting a health service ($p<0.05$).

Relationship between being in full time employment or study and opening hours as a barrier
There was a relationship between being in full-time employment or school and opening hours as a barrier. 68/106 (64.2%) of those in full-time employment responded that opening hours was a barrier, compared with 189/506 (37.4%) in part-time or casual employment and less than 30% for all other current employment categories ($p < 0.001$). Participants who were in tertiary studies (242/521, 46.4%) were more likely to find opening hours a barrier, compared with those at high school (138/666, 20.7%) or not studying at all (65/195, 33.3%; $p<0.001$).

Barriers by marginalisation and chronic condition
The frequency of all barriers reported, except language/ cultural issues, were higher among those with a chronic condition compared to those without a chronic condition, regardless of whether they were marginalised or not.

Barriers experienced by participants with increasing distress
Participants with increasing distress, as measured by K10 scores, experienced increasing barriers including: worrying about confidentiality ($p<0.001$), cost ($p=0.007$), not having their own Medicare card ($p=0.001$), feeling embarrassed ($p<0.001$), feeling judged ($p<0.001$), difficulty getting there ($p<0.001$), having to ask parent/carers to take them ($p<0.001$), not knowing which service to go to ($p=0.002$) and gender of the doctor/ health professional ($p<0.001$). Participants with increasing distress were also less likely to report nothing would prevent them visiting a health service ($p<0.001$).

Barriers experienced by participants with or without a regular GP
Participants who had a regular GP were less likely to cite the following barriers compared to those without a regular GP: cost (42.7% cf 50.8%, $p=0.003$), don't have own Medicare card (10.7% cf 14.5%, $p=0.035$), feeling judged (18.6% cf 23.0%, $p=0.042$), opening hours (28.2% cf 37.1%, $p<0.001$), don't know which service to go to (9.9% cf 14.3%, $p=0.011$). Further, those with a regular GP were more likely to report 'no barriers' compared to those without a regular GP (23.3% cf 18.4%, $p = 0.026$).

Barriers to health care and marginalised groups

Interestingly, there was a trend towards being *less likely* to cite at least one barrier for participants who belonged to at least one of the marginalised groups compared to those who did not belong to any of the marginalised groups, see Table 8.6. Therefore we analysed each barrier by each marginalised group to look at patterns. Table 8.7 displays the percentage cited for each barrier by each of the five marginalised groups, those who did not belong to any of the five groups and the whole sample. The p values (statistical significance) are based on comparing percentages within each group against the remainder of the sample.

Table 8.6 Barriers to health care by marginalised status

	Marginalised* **n (%)**	**Non-marginalised*** **n (%)**	**Total** **N (%)**
No barriers	185 (20.6)	85 (16.4)	270 (19.1)
At least one barrier	712 (79.4)	434 (83.6)	1146 (80.9)
Total	**897 (100.0)**	**519 (100.0)**	**1416 (100.0)**

*$p = 0.05$

Cost was the primary barrier for each of the marginalised groups, as well as those who did not belong to any of the marginalised groups.

The **sexuality and/or gender diverse** group stood out as being significantly *more likely* to experience several barriers compared to the rest of the sample – these included eight of the 11 barriers: worry about confidentiality, cost, not having their own Medicare card, feeling embarrassed, feeling judged, difficulty getting there, having to ask parent/carers to take them and gender of the doctor/ health professional. Thus structural and personal barriers were prominent for this group. No other marginalised group was significantly more like to cite a barrier compared to the whole sample except for **refugee** participants who were *more likely* to cite language or cultural reasons as a barrier.

By contrast **Aboriginal and/ or Torres Strait Islander** and **refugee** participants were *less likely* to cite cost, opening hours, difficulty getting there, feeling embarrassed, having to ask parents and gender of the professional.

Similarly, **rural and remote** participants were *less likely* to a range of structural and personal barriers, including cite cost, opening hours, difficulty getting there, feeling embarrassed, feeling judged, gender of the professional and having one's own Medicare card.

Homeless participants were *less likely* to cite opening hours, having to ask parents and gender of the health professional as barriers.

Participants who did not belong to any of the five marginalised groups were *more likely* to cite opening hours as a barrier, and *less likely* to cite language and cultural issues as a barrier.

Table 8.7 Individual barriers by marginalised group

Barrier	**Aboriginal/ Torres Strait Islander n=169**	**Homeless n=118**	**Refugee n=75**	**Rural/ Remote n=478**	**Sexuality and/or Gender Diverse n=426**	**None of the marginalised groups n=519**	**Whole sample n=1416**
	%	%	%	%	%	%	
Cost	27.8 p<0.001*	40.7 p=0.25	26.7 p=0.001*	40.0 p=0.002*	**56.8** p<0.001**	46.6 p=0.65	45.8
Opening hours	11.2 p<0.001*	21.2 p=0.010*	21.3 p=0.044*	19.7 p<0.001*	34.7 p=0.11	41.8 p<0.001**	31.7
Embarrassed	14.8 p<0.001*	22.9 p=0.22	12.0 p=0.002*	23.0 p=0.004*	**38.0** p<0.001**	27.4 p=0.80	27.8
Difficulty getting there	11.8 p<0.001*	23.7 p=0.99	9.3 p=0.003*	19.5 p=0.008*	**32.2** p<0.001**	23.9 p=0.91	23.7
Have to ask parents	13.0 p=0.002*	11.9 p=0.005*	12.0 p=0.029*	21.1 p=0.53	**27.0** p=0.004**	23.9 p=0.22	22.1
Feel judged	14.8 p=0.06	18.6 p=0.64	6.7 p=0.002*	16.5 p=0.011*	**29.3** p<0.001**	19.7 p=0.66	20.3
Gender of professional	8.9 p<0.001*	11.0 p=0.022*	9.3 p=0.029*	15.9 p=0.040*	**24.2** p=0.001**	18.7 p=0.87	18.9
Confidentiality	13.0 p=0.37	12.7 p=0.42	14.7 p=0.85	15.7 p=0.75	**20.0** p=0.001**	13.9 p=0.25	15.3
Own Medicare card	8.9 p=0.16	14.4 p=0.42	8.0 p=0.26	9.6 p=0.033*	**16.0** p=0.005**	10.4 p=0.11	12.2
Don't know where to go	8.9 p=0.24	11.9 p=0.94	6.7 p=0.17	9.6 p=0.09	13.6 p=0.13	13.1 p=0.20	11.7
Language/ cultural	3.6 p=0.17	6.8 p=0.67	**16.0** p<0.001**	6.3 p=0.60	7.3 p=0.14	3.9 p=0.014*	5.9
Nothing	40.8 p<0.001**	27.1 p=0.10	37.3 p<0.001**	27.8 p<0.001**	11.3 p<0.001*	18.9 p=0.09	

**more likely compared to remainder of sample *less likely compared to remainder of sample

Barriers and increasing marginalisation

We explored the relationship between barriers and belonging to an increasing number of marginalised groups. Interestingly, there was a negative correlation between several barriers and increasing marginalisation. The total number of barriers cited decreased with increasing marginalisation (p= 0.01). Table 8.8 shows the median and mean number of barriers by number of marginalised groups.

Table 8.8 Number of barriers by increasing marginalisation

No. of barriers identified	No marginalised group (n=519)	One group (n=574)	Two groups (n=281)	Three or four groups (n=42)
Median (IQR)	2 (3)	2 (3)	1 (3)	1 (3)
Mean (SD)	2.4 (1.9)	2.5 (2.1)	2.0 (2.0)	1.8 (2.0)

In addition, cost, not having one's own Medicare card, opening hours and the gender of the doctor all decreased as barriers cited with increasing marginalisation (Table 8.9).

Table 8.9 Barriers which significantly decreased with increasing marginalisation

	No marg. groups n (%)	One group n (%)	Two groups n (%)	Three or four groups n (%)	p value
Cost	242 (46.6)	280 (48.8)	115 (40.9)	12 (28.6)	0.019
I don't have my own Medicare card	54 (10.4)	89 (15.5)	27 (9.6)	3 (7.1)	0.017
Opening hours mean I need time off study or work	217 (41.8)	169 (29.4)	57 (20.3)	6 (14.3)	<0.001
The gender of the doctor/ health professional	99 (19.1)	128 (22.3)	34 (12.1)	6 (14.3)	0.004

Chapter 8 Summary

Cost was the most likely factor that would prevent participants from accessing a health service, and was the most frequently reported barrier for each marginalised group as well as for those who did not belong to any of the marginalised groups. Cost and other structural barriers such as opening hours increased with age, while confidentiality and feeling embarrassed were more prominent among the mid to late adolescent age group (14 or 15 to 19 years). Females and other gender participants were more likely than males to cite a range of barriers. Among the marginalised groups, sexuality and/ or gender diverse participants were more likely to cite several of the barriers compared to the rest of the sample.

Having a chronic health condition (regardless of marginalised status) was associated with a range of barriers, although having a regular GP (which was associated with having a chronic health condition, see Chapter 7) was associated with fewer or no barriers.

Increasing marginalisation (belonging to more than one marginalised group) was inversely associated with the number of barriers cited and specifically with cost, not having one's own Medicare card, opening hours and the gender of the doctor or health professional. This might suggest that programs, services and/or structural factors to support marginalised and disadvantaged young people are having some impact.

Chapter 9 Study 1 Discussion, Conclusions and Implications

The Study 1 sample consisted of self-selected participants in the NSW Youth Health Survey, where we purposefully oversampled young people (12 – 24 years) from five socio-culturally marginalised groups. Our sampling strategies varied over time as we continued to try to reach some of these groups.
Among the population of 12 – 24 year olds in NSW, 76.6% live in major cities, 4.8% are Aboriginal, and 1.3% are of refugee background. In our sample, 66.2% lived in major cities, 11.9% were Aboriginal and/ or Torres Strait Islander and 5.3% of refugee background. It is more difficult to estimate the proportion of young people in NSW who are homeless or sexuality and/ or gender diverse but we can be confident that we did oversample from these groups as well with 30.1% of our sample being sexuality and/ or gender diverse and 8.3% experiencing homelessness.

Among the 1416 young people who participated in the NSW Youth Health Survey, over half were living with a chronic health condition or disability, including 239 (16.9%) who did not belong to a marginalised group. The health of the sample as measured by self-reported health status, Kessler-10 scale of psychological distress, and the WHO-5 wellbeing score was poorer compared to surveys among the whole youth population in Australia. This is unsurprising given that the participants in our survey belonged to one or more marginalised groups, some of which are known to have higher levels of physical or mental health issues (Aboriginal and/ or Torres Strait Islander young people, homeless young people and young people who are sexuality and/ or gender diverse).

Access to the internet among the sample was almost universal, and technology was very frequently used to find out health information and seek help. However, word of mouth and personal recommendations or advice were more often sought when making decisions about which health services to visit. Technology and personal advice were integrated into help seeking and access.

Among our sample, there had been frequent contact with the health system over the previous six months, which again is not surprising given the degree of psychological distress and the prevalence of chronic mental and/ or physical health conditions. General practice was the most frequently utilised health service in the health system, and participants who had a regular GP reported fewer barriers. The generally positive attitudes towards understanding and navigating the health system could also reflect that fact that many participants had substantial familiarity with the health system, and knew where to access help when needed.

Sexuality and/ or gender diverse young people experienced higher levels of psychological distress and significantly more barriers to health care compared to the rest of the sample. Given the central place that sexuality has in adolescent development, and previous research that has identified the association between poorer mental and sexual health outcomes among sexuality and gender diverse young people, there is a pressing need for health services and the health system to respond in ways that help professionals identify and engage with sexuality and/ or gender diverse young people and proactively support their access to and navigation around the health system.

Cost was the most frequently cited barrier across the whole sample and for each of the marginalised groups. Participants who were sexuality and/ or gender diverse and/or intersex experienced the greatest number of barriers to access. Confidentiality was only cited as a barrier by 15% of survey participants, which contrasts with previous research in Australia and internationally, where confidentiality has been cited as the most prominent barrier. Our finding could reflect changes in young people's knowledge about confidentiality through experiences with health services and/ or through health education, but our youth consultants offered other possibilities, such as changing attitudes towards privacy in the age of social media and more openness in public discourse about mental health, sexual health and other previously stigmatised issues. The relationship between some types of barriers with age suggests that different strategies could be employed for adolescents and young adults. The inverse association between barriers and increasing marginalisation could be an artefact of the sample (see Limitations below), or could be because as health and psychosocial needs increase, there are more specialised and intensive supports available.

Limitations of the survey

The biggest limitation of Study 1 is the variation in sampling strategies employed. Although we oversampled from five marginalised groups, each group was recruited using different methods. As a result we had an over-representation of Aboriginal participants in rural areas and refugee young people in metropolitan areas, for example. We also had more adolescents (12 – 17 years) who were male. Although we controlled for a number of potential associations we need to acknowledge an inevitable degree of residual confounding. It seems likely also that our sampling strategies introduced some sampling artefact into our analyses of increasing marginalisation and barriers to health care.

The survey instrument appeared robust in the face of a diverse sample of young people, except for some of the questions exploring sexual attraction and identity which may not have been understood by some refugee participants. Although we piloted the survey among a range of young people from all marginalised groups, future research using questionnaire items and that explores sexual attraction and identity among young people of refugee or culturally and linguistically diverse backgrounds might require further testing and refinement of questions.

Study 1 Conclusions and Implications

- Services and health professionals need to be aware that they are just one of many services that a young person might access. Costs and structural barriers such as opening hours might therefore be additive.

- Individual services and professionals can play a role in supporting health system navigation by enquiring about and documenting information about other services accessed and how care can be better coordinated and navigated.

- Given that middle-adolescents are more likely to feel worried about confidentiality or feel embarrassed is a reminder that confidentiality and its limits should always be explained when a young person engages with a services. Interpersonal and communication skills can also assist with addressing a young person's embarrassment or potential discomfort when seeking health care.

- Service- and clinician-level strategies to reduce barriers and support navigation might vary for young people from different marginalised groups. Identifying what these are should be part of service provision. For example, understanding the different origins of discrimination associated with sexuality and gender diversity, Aboriginality and cultural and linguistic diversity will assist with culturally sensitive care.

- General practitioners and general practice remain a cornerstone of the health system in NSW. In order to support young people's navigation through the health system, it is critical to have general practice and other primary, secondary and tertiary health services working together.

- Services can make greater use of technology – at the service level, providing information on websites about cost, opening hours, being welcoming and inclusive of diverse groups of young people, confidentiality, how language barriers are addressed and how to access the service (appointments, need for Medicare card); at the clinical level finding more flexible ways to communicate with young people through technology through to greater use of online evidence based clinical interventions.

- e-health literacy can be addressed by improving ways in which young people can find what they are looking for and knowing how to find information that they trust. There is a need to increase use of internet for males and adolescents in help-seeking.

Section 3

Study 2 – marginalised young people's journeys: longitudinal qualitative study

Chapter 10 Study 2 Methods and Results

Aim

The aim of Study 2 was to explore, in depth, the experiences of marginalised young people's encounters with health services over time including barriers and facilitators to access, movement through the health system, system inefficiencies and foregone care. Study 2 also aimed to quantify encounters with health services in real time.

Design

Study 2 was a longitudinal, qualitative study using in-depth semi-structured interviews.

Methods

Sample

The sample was drawn from the participants of Study 1 who indicated a willingness to participate in Study 2. Young people belonging to one or more of the five pre-defined marginalised groups, and who had had contact with the health system in the preceding six months for a chronic or complex condition or disability, were eligible. Study 1 participants who met the eligibility criteria were contacted by email and invited to participate.

Data Collection

Interviews were piloted among youth consultant volunteers. The interview prompts for baseline and 2nd, 3rd and 4th interviews can be found in Appendix 2. All but one participant agreed to have their interviews audiorecorded and transcribed. Hand-written notes were taken during the interviews with the participant who declined audiorecording. Telephone interpreters were used for two participants.

Data Analysis

Transcribed recorded interviews were entered into NVivo software (QSR, 2017) for coding and to assist with thematic analysis. Several workshops were held among a core group of the research team to develop codes and discuss emerging themes.

Ethics

Study 2 was approved by the University of Sydney Human Research Ethics Committee (approval 2015/971) and the NSW Aboriginal Health and Medical Research Council Ethics Committee (approval 1141/15).

Results

Sample

In-depth, one-on-one interviews were conducted with young people between March 2016 and May 2017. Forty-one young people participated in a baseline interview, and 35 young people completed all stages of the study (three to four interviews over six to 12 months). Of the six young people who withdrew, five withdrew after the first (baseline) interview and one withdrew after two interviews. All six withdrew due to time constraints and other commitments. Interviews took place either in person or by phone or Skype.

The mean age of the Study 2 participants was 19.3 years (range 12 – 24 years). Thirty of 41 identified as female, with two being gender diverse, 8 identified as male, with two being gender diverse, and 3 identified as other gender. Twenty-two of the 41 baseline participants belonged to one marginalised group, 15 belonged to two and four belonged to three groups.

Thirty-five of the baseline participants had reported (in the survey) having a chronic physical and/ or mental health condition or disability, and the average Kessler-10 score for the whole sample was 29/50 (high risk).

Participants had a lot of contact with the health system over the study period. At baseline 100% of the sample had seen a GP in the previous six months. GPs remained the most frequently accessed health provider, with pharmacists and counsellors next. Over the study period, participants accessed services across all levels of the health system (primary, secondary, tertiary). At baseline interview, 41 participants had accessed 189 types of providers or services in the previous 6 months (41 had seen a GP; 14 attended outpatients or were admitted to hospital; 10 presented to Emergency Departments)

Interview waves 2, 3 and 4 were each about 3 months apart and captured movement through the health system over that time period. At each interview wave, an average of 31 participants accessed an average of 90 types of providers or services.

Findings: major themes

We found that marginalised young people experienced substantial barriers and discrimination when accessing health services and that they were ambivalent about engaging with health services. Although they knew their health was important, they experienced difficulty in deciding to seek help and subsequently access to care was delayed or forgone. Their ambivalence came from previous negative experiences, a lack of clarity about how services may help and the many factors they weighed up in deciding to seek care. Marginalised young people needed specific information and support to make health system navigation easier. We identified six major themes, described in more detail below.

Theme 1: Multiple disadvantage makes health system navigation more challenging

My life got a little bit insane and I forgot to make a lot of appointments… it can be a bit confusing trying to keep up with them all, because I have to see so many people.

- Female, 23 years, gender and sexuality diverse, rural

The impact of marginalisation due to homelessness, rurality, sexuality and gender diversity, Aboriginality and refugee background influenced health care access and navigation in multiple ways. Participants had complex life circumstances and substantial chronic health issues, yet fewer resources and supports to draw on. For example, having a mental health problem made accessing services more challenging due to needing to have the confidence to make contact with a service and organise to attend. It was difficult to navigate the health system and participants perceived that health professionals underestimated the difficulties they experienced.

Theme 2 Young people's health literacy embraces our connected, digitally disrupted world

If their websites had a bit more information, "We specialize in this, we're queer-friendly, we focus on the family," whatever else, so you get an indication from the get-go that you're picking the right service for you because I've found that's really hard.

- Female, 23 years, sexuality diverse, homeless

Participants' health literacy influenced how they interacted with the health system. In making decisions that shaped their health care journey, participants had varying levels of understanding of health, what services were available, how services could help and how to access them. Taking the first step to access a service required confidence and a sense of empowerment. Participants commonly reported that they liked to 'check out' a service online before attending, but had difficulty finding the information they wanted. Not knowing what to expect made participants reluctant to access care. Many reported that understanding how the health system works would make deciding about and accessing services easier. However participants said they currently have difficulty finding this information online and are not taught this information in school. Several participants suggested that health system navigation should be included in formal school curricula.

Theme 3: Deciding about health care involves weighing up convenient access, engagement, effectiveness and cost

There's not a whole lot of patient care involved. I've been reticent to go back to that medical centre, but I may end up having to because they're the only place I know in my area that's open past 6:00[pm].

- Female, 23 years, sexuality diverse, homeless

The barriers all young people experience can be exacerbated in marginalised young people. Participants found deciding to access care was complex because it involved weighing up a range of factors:

1. Convenient access - Participants appreciated flexible and relevant services that were easy to access in terms of location and opening hours. They wanted relevant services to be available and to provide timely access to care.

2. Engaging care - Professionals who were welcoming, non-judgemental and understanding were highly valued. Participants valued being able to develop an ongoing relationship and connection with health professionals and reported that it takes time to build trust. They preferred informal approaches and the use of clear language that they can understand. Most importantly, they wanted to be listened to and treated with respect.

3. Effective care - Participants wanted help to understand their health issues and treatments and to feel that their GP has expertise in their condition, including mental health issues. They were open to a holistic health check and were happy to answer questions about sensitive issues if asked carefully. They also valued professionals that considered their ability to follow up with a care plan, ie navigation.

4. Affordable care - Due to a lack of financial resources and family support, cost presented a significant barrier to health care access. Some services were hard to find for free or at low cost, including specialists, medications and pregnancy terminations. Some free services, such as psychological and allied health services provided via Mental Health Care plans, had limited availability. Further, there were often hidden costs such as needing to take time off work, transport or mobile phone data use (due to a lack of public Wi-Fi within health facilities). Participants were often unclear about cost and reported that professionals often did not adequately consider the impact of cost on their ability to navigate care.

Theme 4: Marginalised young people perceive and experience multiple discrimination

Imagine a 17-year-old pregnant, black female young person that had her hair looking really crazy, walk into a place and go like, "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 years, refugee

Perceived or real discrimination was based on age, cultural background, Aboriginality, sexuality, and gender. Many participants felt misunderstood, judged and not taken seriously. They also experienced discrimination by service systems. For example, transgender participants felt discriminated against by systems that did not acknowledge their preferred name and gender.

Participants wanted to be treated with respect, and this was felt when individual professionals as well as service environments and structures possessed qualities such as being welcoming, caring and understanding. Service promotion that recognised diversity and had welcoming signals, such as rainbow, Aboriginal and Torres Strait Islander and pro-refugee symbols and flags, were viewed positively.

Theme 5: Technology brings opportunities to connect and engage with services

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, and face-to-face is sort of longer-term multiple appointment.

- Male, 19 years, sexuality and gender diverse

I've got an app that logs my blood sugar and sort of graphs out the rises and falls throughout the day… I can easily walk into the doctor and… bring up the graph that I can see and show them.

- Female, 23 years, gender and sexuality diverse, rural

Although technology featured in providing access to information about health and services which informed participants' decisions about accessing health care, technology themes also ran throughout the health care journey. Engagement with a service actually began via its website and online presence. Technology also enabled participants to make contact with services, particularly as young people said they felt uncomfortable phoning a service. Online modes of access made contacting a service easier.

Although online services were seen as convenient and were described as being particularly suitable for help after-hours in a crisis, they could lack engagement due to the short-term nature of the interaction. Many participants said they found face-to-face services ultimately more engaging than online services, due to human connection and the ongoing nature of the service.

Participants wanted face-to-face services to be technology-enabled to enhance convenience. Technology-based solutions to navigation support were positively regarded, including SMS appointment reminders, pharmacy apps (that manage documentation and send notification messages) and apps to help young people monitor chronic conditions (such as diabetes).

Theme 6: A complex and fragmented health system can be mitigated by system knowledge and navigation support

A lot of people are scared to ring up and make an appointment, and what if you don't have that family support as well, so just having that support person that they can talk to and say, "I'm feeling nervous. How do I ..." Yeah. The support person can give them that reassurance and just give them, not a push, but encourage them to pick up that phone and make the call.

- 24 years, female, sexuality diverse

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 like health funds, like all that jumbo… knowing if I'm allowed to and kinda like talking to them about it and stuff. That's all a bit confusing, like booking the appointment.

- 15 years, rural, sexuality diverse

A chart that says either the steps that you can go through or this can be a pathway. There's too many different ones and it's all so confusing and so complicated, they've made it so much more complicated than it needs to be.

- Female, 18 years, rural, sexuality diverse, homeless

What would make me get my own [Medicare] *card? I don't know. If it was sent to my door. <laughs>*

- Female, 18 years, sexuality diverse

Participants' ability to navigate the health system was challenged by system demands and complexity. However, they found that they could be buffered against the inefficiencies, duplications and fragmentation of a complex health system by understanding how to navigate the health system, including Medicare and health system structures. Many participants found benefit from professionals' active support to follow-up which helped them to persist in seeking health care.

General Practitioners (GP) were seen as critical components of the health care system to enable coordinated care and communication among health professionals. Many participants did not have a regular GP, but those who did valued having a trusted ongoing connection with a GP who could manage complexity and work holistically. Participants with a regular GP found that GPs helped them navigate their journey within the health care system and provided continuity of care.

Variation in themes between groups

Some variation in themes were observed between marginalised groups.

Aboriginal young people

[The Aboriginal Medical Service] is friendly and open but they also have... other services that come from that centre... you have the dentist, you have the doctors, you got a boot camp which is like the physical stuff.

- Female, 21 years, Aboriginal

Sometimes it comes down to I feel a bit too proud to ask for help.

- Female, 24 years, rural, Aboriginal

Drawing on family advice was a strong theme for Aboriginal and/ or Torres Strait Islander participants. However, shame about help-seeking arose from family and community expectations that participants should be self-sufficient and not need to ask for help. They appreciated Aboriginal and/ or Torres Strait Islander services' community engagement and holistic approach but stressed attendance should be their choice. They also appreciated the availability of low-cost services but felt there was stigma associated with identifying as Aboriginal.

Homeless young people

One GP that I went to, when I needed to get something followed up, he printed out the place I needed to go to, the contact number, he told me who to call, what to do, whereas some others... they just tell you, you need a referral and then they get their receptionist to give you that information, and from there you work it out yourself. And then if you need a follow-up they help you go through the steps of what you need to do, who to contact.

- Male, 18 years, homeless

Homeless participants frequently drew on support from services to understand and reach health care services they could afford.

Refugee young people

But whenever they hear that she is from this or that place, they judge if that one person did something bad from that country…they judge everyone…they think they are the same…

- Female, 18 years, refugee

It took a lot for me to actually go to a counsellor and a psychologist… if I talk to my parents and my friends about it, they go like, "Just pray to God, he will fix your problem," like you don't have to go there, why you're going there, what's wrong with you…

- Female, 21years, refugee

Refugee young people expressed discrimination based on their cultural background, language fluency and, for females, sexuality. Language issues were prevalent, including confidentiality concerns relating to the use of face-to-face interpreters. However, refugee participants were comfortable with the use of telephone interpreters. Cultural differences in health beliefs were noted in relation to mental health issues. Some participants described a lack of understanding or acceptance by parents or family members in relation to mental health problems. Some young women experienced judgemental attitudes from GPs when enquiring about contraception. While learning about the Australian health care system, many refugee participants described having additional responsibility for supporting family members' navigation. Many praised the quality of the health care system in comparison to their country of origin.

Living in rural and remote areas

There's no appointments. It's a medical centre. It's just a walk-in. There's one or two doctors – and then you go up there and they say it's a six-hour wait or something. We can't get into any of the other ones. Stuck with this one.

- Male, 12 years, rural

Participants living in rural and remote areas said they were aware they probably had a limited understanding of the possibilities of what services could be available in urban areas. Service availability was raised as an issue. Concern about privacy - being visible when attending services - was more pronounced for this group.

Sexuality and/or gender diverse young people

Just having gender and allowing for somebody to write on [the form], I think it's better... not everyone fits into a box.

- Transgender woman, 22 years, sexuality diverse, homeless

While there was significant diversity within this group, many described experiences of stigma and discrimination. This group often felt misunderstood by health professionals, who lacked understanding about their experiences and needs. Transgender young people experienced specific challenges due to some professionals' gatekeeping role to access specialist treatment, yet limited understanding of transgender issues. They valued online information to locate professionals who identified as allies.

Chapter 11 Study 2 Discussion, Conclusions and Implications

The Study 2 sample was a self-selected group of young people who had participated in the NSW Youth Health Survey (Study 1). The inclusion criteria for Study 2 participation meant that all participants belonged to at least one marginalised group, had either a chronic health condition or complex circumstances, and had had recent contact with the health system. Over one-third of the sample belonged concurrently to two marginalised groups, and over 10% belonged to three different groups. We achieved a high retention rate, with 35 out of 41 participants remaining in the study for the full study period (six – 12 months).

Participants had a lot of contact with different parts of the health system over the study period. There was an overarching sense that the health system was complex to navigate, often because of compounding disadvantage. While Study 1 found generally positive attitudes towards the health system in terms of knowing where to get help when needed and not feeling confused by the health system, the participants in Study 2 expressed different attitudes and experiences. These included not knowing what to expect when accessing some services through to experiences of feeling unwelcome or dis-respected. Engagement with individual professionals and with services was enabled in different ways, including having relevant information available on service websites, welcoming symbols, and intake forms and processes that accommodated preferred names and pronouns.

Navigation support was highly valued and could be provided by clinicians, particularly GPs. Integrating technology into service structures and systems could also increase efficiency and ease of access (e.g. SMS appointment reminders, making appointments online). Recognising the importance of cost as a barrier and the need to weigh up individual barriers and priorities at any given time when health care access is being sought implies that navigation is not straightforward.

The themes arising from our qualitative analysis contrast with the quantitative finding that barriers decreased with increasing marginalisation (See Chapter 9). This could in part reflect the small, self-selected sample who participated in interviews over six to 12 months. It might also be related to being able to follow health care journeys over time, gaining a more in-depth and nuanced understanding of the challenges of health system navigation, where the salience of individual barriers varies at different points in time.

Study 2 complemented Study 1 by providing a richer understanding of barriers and facilitators of health care access. Importantly, Study 2 demonstrated that movement through the health system over time was not always linear or smooth, but could depend on a range of factors at any given point in time.

Study 2 Conclusions and Implications

Navigation support

- Health care navigation support as a definitive component of health care is likely to enhance access for marginalised young people
- All professionals and services can play a role in navigation support
- In addition, health professionals need to recognise the distinct and diverse needs of marginalised young people, including the impact of multiple disadvantage (belonging to multiple marginalised groups)
- Practical aspects of navigation support include:
- exploring previous contacts with health care
- discussing and obtaining consent to share health information
- considering cost and accessibility when making referrals
- utilising entry points into the health system, such as emergency departments, as opportunities for engagement and linking young people with the services they need
- assertively supporting care from an entry point in the health system by following up referrals
- advocating for young people to negotiate reduced costs and access to free services
- providing support to obtain a Medicare or Health care card
- providing support or assistance with transport
- facilitating engagement with a trusted regular GP
- providing assistance to manage documentation
- Reducing system demands and complexity – via integrated services, clear referral pathways and transition tools - can create more efficient, straightforward and flexible services.

Health literacy

- Health services can utilise and enhance their online presence to provide young people with the information they want to facilitate help-seeking, decision-making and engagement. This includes information about the professionals, service approach, cost, opening hours, how to make appointments and how to reach the service via public transport
- Service promotion via social media would make finding information easier
- Health literacy can be enhanced formally by including health system navigation as a learning topic, with practical examples, into the formal school curriculum (eg Health and Physical Education), and informally by including more information online to explain how the health system works, including Medicare, after-hours health service options and how to navigate the health care system.

Integration of technology

- Young people want services to embrace technology as a communication tool to enhance face-to-face services
- Young people appreciate being able to email a service, or book-in online rather than by phone
- Young people appreciate SMS appointment reminders and active follow up
- Technology tools can be useful adjuncts to treatment
- Pharmacy apps help manage medication prescriptions
- Social media campaigns to alter family and community perceptions about help-seeking were suggested as ways to tackle shame and stigma.

Study 2 Conclusions and Implications continued

Engaging, welcoming and respectful health services

- Youth participation is a valuable way to make services relevant for young people. Youth participation enables professionals to understand young people's perspective, and the young people involved also benefit

- Services can be respectful and welcoming to all young people by recognising diversity, which can be demonstrated by:
    - using welcoming signals, such as rainbow and Aboriginal and Torres Strait Islander flags
    - use of inclusive imagery and positive messages about cultural diversity
    - asking young people their preferred name and pronoun, especially for gender diverse young people, and including a space to record this on forms and in databases
    - using professional interpreters whenever there are language barriers. Young people of refugee background might prefer telephone rather than face-to-face interpreters
- Timely access to services is helped by them being open at convenient times and located in places young people can get to easily
- Young people want more upfront information about cost, especially as they feel uncomfortable asking about or negotiating cost
- Young people value an ongoing relationship with health professionals who take time and build trust.
- Young people expect confidentiality and privacy
- Young people prefer informal approaches and the use of clear language that they can understand
- Young people value professionals who have a positive belief in them, focus on wellness and take a patient-centred and shared-care approach that involves them in decision-making and care planning.
- Use of holistic health checks reduces embarrasssment for young people because they don’t have to raise issues themselves (e.g the HEEADSS psychosocial risk assessment).
- Reminders to visit a service for a check-up were appealing because they make health care routine, and young people don’t need to go through the process of deciding if they need to visit a service.

Section 4

Study 3 – Health Professionals' Perspectives

Chapter 12 Study 3 Methods, Results, Discussion, Conclusions and Implications

The aim of Study 3 was to explore the perspectives of health professionals about how young people in NSW access and navigate the health system. This was seen as critical for informing policy and practice solutions to the issues identified by young people.

Methods

Design

The study was a cross-sectional, qualitative study using semi-structured interviews with individual health professionals.

Sample

The sample was purposively selected based on potential participants' experience and expertise within different parts of the health system as senior managers or expert clinicians. We deliberately sought individuals with in-depth knowledge about the health system and/ or about young people's health needs.

A sampling frame was devised to include professionals from different sectors (public health sector, general practice and non-government organisations) and different levels of the health system (primary, secondary, tertiary). A list of potential participants was drawn from existing networks and contacts of the *Access 3* study investigator and reference groups. The sample was recruited via direct approach by email.

Data collection

Interviews were piloted among two to three Reference Group professional members to check for clarity and flow. The interview prompts asked about barriers to care for young people, health system integration and coordination, and client-centred care. Interviews were conducted either face-to-face or by telephone and were audio-recorded and transcribed. Some of the preliminary themes as well as specific content that had been identified from early interviews with young people in Study 2 were explored with the professionals where relevant. Interview schedule headings are listed in Appendix 3.

Data analysis

Interview transcripts were entered into NVivo software (QSR, 2017) to assist with data coding; content and thematic analyses were conducted to derive major and minor themes.

Ethics

Study 3 was approved by the University of Sydney Human Research Ethics Committee (approval 2016/232) and the NSW Aboriginal Health and Medical Research Council Ethics Committee (approval 1175/16).

Results

The final sample included 22 professionals: 13 were managers and nine were senior clinicians. Forty-one percent were female. Participants came from public sector (NSW Health) services including hospitals, emergency departments, state-wide services and Local Health District/Community/Youth Health services, general practice, Aboriginal Medical Services, peak bodies and primary health networks. Seven of the 22 participants worked in rural NSW.

Three major themes were identified:

1. **Intersectionality: understanding the complexity of disadvantage leads to a better understanding of marginalised young people**

Participants recognised that marginalised young people experience disadvantage in various ways, but not all knew how to work with those experiencing multiple disadvantage. They recognised that health services and the health system broadly may not serve young people with multiple disadvantage well:

Unfortunately, the more complex and interwoven, and the more psycho-social factors that are driving the health issue, it can be more difficult…it's counterintuitive because the young person who needs that comprehensive service… they actually have less options than the people who are generally well and healthy.

- Youth Health Coordinator, rural

With those groups that you mentioned, there's such a richness of complexity within their life other than what we would define as a traditional health behaviour. There's socio-cultural factors. There are economic factors. There are language barriers. All of those can play a very varied role in why someone may or may not engage with health.

\- Urban GP

Further, many participants believed that transgender young people are particularly misunderstood, especially in rural areas:

My feelings are that the physical health types of services are probably not going to be nearly so open to transgender young people as they would be in the – the large city.

- Manager, community-based service, rural.

There was acknowledgement that systems could be discriminatory, by not having an 'other gender' option on clinical records:

...[hospital] electronic database - it doesn't actually have -(other). You know, our NSW Health form, EMR [electronic medical record] registration forms, doesn't have that. It has male, female. That's what you've got.

- Senior clinician, youth health service

2. **Health system fragmentation leads to inefficiencies, inertia and advocacy**

There was widespread acknowledgement that the health system is fragmented and outdated. Participants recognised that this could lead to inertia, believing that 'nothing can be done' and individual providers could perhaps unwittingly perpetuate fragmentation, leading to inefficiency. Participants also felt that at times, the frustrations they or others experienced could energise them to advocate for reform.

The process of accessing the health service hasn't practically changed for virtually a generation.

- Medical specialist, rural hospital

All these things are part of the system, and the problem is the service providers themselves put themselves in that cubbyhole and say, "I'm that service." Then by virtue of that, what do you think you've got? You've got the service providers defining the way in which the system actually works.

- CEO, urban PHN

3. Services need to be 'turned on their head'

Participants were unanimous in calling for reorientation and reform of individual services. They recommended better support for providers with the acknowledgement that GPs were crucial, and highlighted the need for use of technology by and within health services. They also reported a need for more flexible service delivery including outreach and after hours services, and called for a focus on prevention. To support young people in navigating through the health system, a 'navigator' needs to be identified and assertive follow up is required, and participants saw that health professionals and services need to play these roles.

The preventative approach has taken the backseat, and I think if we continue down that line then my advice to Government to is to forget about closing the gap. All we're going to do is maintain the gap.... We don't want to be reactionary. We want to say to young people that our focus is about preventative health care.

- CEO Aboriginal Medical Service, rural

And I think the social media stuff is really important. NSW Health should stop blocking (websites). It's such a big problem.

- Senior clinician, youth health service

As a GP I often talk to people about being the navigator of their ship and they remain the captain. Their ship is their health journey, right?

- GP, urban

Text messaging, and just continuing attempting to contact them. You don't give up on them, basically. You know that their life can be complicated for them at times.

- Senior clinician, youth health service

Discussion

Study 3 explored access and health system navigation for marginalised young people in NSW from the perspectives of health professionals within the same system. The need to understand compounding disadvantage and its impact on access, health system fragmentation, and the need for major system and service delivery reform were the major themes identified. These themes echoed and complemented the themes identified in Study 2, which followed marginalised young people over 12 months to examine their health care journeys over time.

Our findings suggest that the health system, which consists of many and diverse health services operating as individual units, is fragmented, and that there is suboptimal communication between services. There is also a sense that service provision and some models of care are outdated (e.g. centre-based, operating during standard business hours) and that more flexibility is needed within the system.

The health professionals we interviewed had a strong desire to support marginalised young people and wanted them to have a much more positive experience of health care. Many were powerful advocates for young people who nevertheless felt frustrated and sometimes defeated by the 'system'. There was a strong call for support to better understand the impact of compounding disadvantage on health care access and navigation, with participants admitting that services tend to focus on one subpopulation without always appreciating how individual young people can belong to multiple marginalised groups.

The *Access 1* study which took place in NSW in 2000 - 2001 also examined health professional perspectives on access to health care for young people (Booth et al., 2002). However, only GPs and youth health workers were included in the sample, and the focus was on what prevented them from providing optimal care to young people. The barriers for GPs identified in *Access 1* included lack of time, lack of skills and confidence, and poor linkages with other services. Youth health workers and coordinators described poor infrastructure and lack of financial support (e.g. for professional development), as well as poor communication between sectors (especially mainstream health services and youth health services which targeted marginalised young people; Kang et al., 2003). While these findings from *Access 1* and *Access 3* are not directly comparable, there is a sense that service provision remains fragmented.

The findings from Study 3 have been published in the Health Education Journal:

Robards F, Kang M, Tolley K, Hawke C, Sanci LA, Usherwood T. Marginalised young people's health care journeys: professionals' perspectives. *Health Education Journal,* February 2, 2018 https://doi.org/10.1177/0017896917752965

Study 3 Conclusions and Implications

- Professional development about the diverse needs of marginalised young people would be valuable for many health professionals
- Even for those who work with some groups of marginalised young people, professional development about multiple marginalisation and its impact on health, wellbeing and health care access, would be helpful
- Communication between, and better integration of, services would enhance health care for marginalised young people and support health care navigation.
- Health professionals could work with young people to look at how services can be reoriented or redesigned to improve access and health care navigation

Section 5

Study 4 – Policy Translation Forum

Chapter 13 Study 4 Methods, Results and Discussion

Aim

The aim of Study 4 was to translate synthesised findings from Studies 1, 2 and 3 into policy-ready recommendations.

Methods

Study 4 was designed as a facilitated workshop with stakeholders. It was a one-day event by invitation only for young people, policy analysts, senior NSW Health staff, health managers, senior/ expert clinicians, researchers, and other key stakeholders (e.g. community advocates).

Participants were purposively sampled based on role (youth consultant, policy-maker, clinician, manager, academic, other), health system level (primary, secondary, tertiary), health service type (public, private, NGO) with or without a service focus on specific marginalised group, and geographic location (metropolitan/ rural). They were recruited through direct email invitation.

The framework used for the Forum was informed by Lavis *et al* (2003) and Grimshaw *et al* (2012). Lavis *et al* (2003) developed a framework for knowledge transfer which asks five key questions: 1. What should be transferred? 2. To whom should research knowledge be transferred? 3. By whom should research knowledge be transferred? 4. How should research knowledge be transferred? 5. With what effect should research knowledge be transferred? Grimshaw *et al* (2012) extended this framework to suggest that knowledge translation strategies need to consider likely barriers and facilitators to optimize their success.

Pre-Forum planning

The Forum's agenda was planned by *Access 3* Chief Investigators, two NSW Health senior policy staff directly responsible for developing the new NSW Youth Health policy, some of the youth consultants, a knowledge translation academic/ expert and an experienced workshop facilitator. Planning took place over a series of face-to-face meetings, and email and telephone discussions, to revise and finalise the agenda and the workshop template/ data collection instrument (See Appendix 4). Some of the key principles included: credibility of the research to the stakeholders, end users being active contributors to translation of findings and structures being there to support the mobilisation of knowledge.

Forum agenda

The final agenda included presentations on policy context, research design, and synthesised preliminary research findings, followed by responses from youth consultants to provide their perspectives. A presentation on knowledge translation gave participants a practical approach to workshopping the policy recommendations. Small group workshops were then held, using data collection templates that provided specific prompts for discussion. Each group was asked to workshop individual themes derived from the research and to translate these into policy-ready recommendations. The Forum agenda can be found in Appendix 4.

Data collection

Small group discussions were recorded on the workshop templates.
Data synthesis from Studies 1, 2 and 3 had identified eight themes.

Theme 1: Young people's health literacy embraces our connected, digitally disrupted world
Theme 2: Traditional barriers remain but technology brings new opportunities for young people to connect and engage with services
Theme 3: Health system navigation must be assertively supported
Theme 4: Engagement in health care is about people and positive interactions
Theme 5: Young people perceive and experience multiple prejudices
Theme 6: Health care costs are high and ripple out
Theme 7: The ideal GP has many desirable qualities but is hard to find
Theme 8: Reducing system demands and complexity would create a more efficient and straightforward experience for young people

Each of the tables was allocated one of the eight themes and discussion was facilitated by an *Access 3* Chief or Associate Investigator.
Each group worked through a range of questions outlined on the templates.

Key questions included:
- How does the group understand and support this theme?
- Which groups or locations or health care settings is this theme particularly relevant for?
- How can this theme be implemented?
- What difference will this make?
- Who would need to be involved in its implementation?
- What would support implementation?

The workshop groups were asked to synthesise their ideas into three key implementation ideas. The Workshop template can be found in Appendix 4.

Knowledge Translation – practical approach

Dr Carmen Huckel-Schneider from the Menzies Centre for Health Policy at the University of Sydney gave a 15 minute presentation on knowledge translation to guide the participants in the most effective ways to workshop their discussions on policy recommendations. She encouraged participants to consider the following when finalising their recommendations:

- Think about possible conflicting priorities
- Accept bounded rationality
- Ask what might already be committed to. Be considerate of this commitment
- Will the knowledge be 'used' by a particular person or group?
- In what ways will the information "percolate through informed publics and shape the way in which people think about issues"?
- What other audiences might you want to have your information?

Data analysis: content and thematic analysis of group discussions

The content generated by each workshop group was analysed across all groups in real time, to identify broader themes. There were overlapping ideas between groups which were synthesized across workshop groups into six themes. This process involved individual small group presentations and the larger group (all participants) discussion to reach consensus. Within the six themes, there were several 'ideas for implementation' which were transcribed onto large sheets of paper and posted around the room. All participants were each given five red dots to vote for their preferred ideas for implementation across all of the workshop groups/themes. This allowed all participants individually to consider all implementation ideas across all themes. The implementation ideas with the highest number of votes in each of the themes became the final list for the Investigators to work with, translating these into policy recommendations which were subsequently presented to NSW Health.

Results

Participants

There were 64 Policy Translation Forum participants (including the Chief Investigators). These included eight young people, 14 policy makers, 15 academics, and 27 clinicians or managers from NSW Health services (n=22), general practice (n=4) and headspace (n=1).

Policy solutions

There were 25 individual policy recommendations that were grouped into six themes. Each individual recommendation received between three and 17 votes. The policy recommendations that received the highest number of individual votes were "Trained youth worker: advocacy, facilitator, navigating, training and education to practices and professionals" within the 'Workshop capacity building theme' (17 votes) and "Young people at the heart of decision-making – 'nothing for us without us'" within the "Youth Participation" theme (17 votes).

The key policy recommendations related to the following themes:

1. Technology solutions - including the development of health literacy solutions and the use of technology with health care (53 votes)
2. Integrated care and investment to improve capacity (39 votes)
3. More extensive use of the adolescent health check (including change in the Medicare model to better enable GPs to provide care) (38 votes)
4. Building capacity of the workforce (35 votes)
5. Youth participation - youth-centred approach to research, design, implementation and evaluation (21 votes)
6. Best practice youth health indicators included in standard accreditation systems (15 votes)

Table 9.1 shows the individual policy recommendations within each of the six themes.

Table 9.1 Policy translation forum policy recommendations

Theme	Votes
Technology solutions	
Streamlined portal: promotion through social media marketing, helping young people navigate efficiently and effectively, combining all websites and general health information	10
Apps to locate GPs and Allied Health Professionals via postcode that filter by cost, hours, rating, bulk-billing, LGBTQI friendly, map and travel info	9
Optimise trafficking to government websites through marketing e.g. paid media on Facebook and Google search	8
Health Online Pathways (Primary Care Networks): flowchart/platform specialised advice for this group, local/referral pathways, promotion with youth workers and practices, consumer flowchart for the young person	8
Broadening access to GPs: via technology e.g. YouTube education videos, common consultation, app chat	5
Online directory of services for young people including key information (e.g. bulk billing) and youth ratings	5
Infrastructures: access, quality, cost with cross-sector partnerships e.g. Telcos	4
Cultural change through a) empowerment of YP through access to information and education, b) youth-friendly services: campaigns (stickers), websites (cost, hours transport, bulk-billing, minimum standards, service mapping) and c) government valuing youth health, funding, equity to access to services across state.	4
Total	**53**
Integrated care and investment to improve capacity	
Establish Youth Medical Assessment Team (YMTA) in Local Health Districts that parallels geriatric services: Nurse practitioner tasked with navigation, salaried medical officer	14
Shared Care Model: Headspace accredited youth-friendly GPs, percolative health systems	10
ED: 24/7 targeted structures that link back to YMTA	5
Integrated care: Primary Health Care, GP and hospital sectors 'PHC team', pool-funding, time to do this	4
Capacity: service and systems level investment to deliver better and integrated services	3
Cross-sectoral work: training, planning, internal and external to health	3
Total	**39**
Medicare structures	
15+ youth check: incentive for GP and YP, digital pre-screen (red flags), long consultation item Navigation Universal Access Funnel, Low need, high need, very high need	15
Change in Medicare model: item number for youth health assessment, youth-accredited GPs	14
Medicare item numbers for youth health: making the case for appropriately funding youth-integrated services, YP learning how to navigate health	9
Total	**38**
Workforce capacity building	
Trained youth worker: advocacy, facilitator, navigating, training and education to practices and professionals	17
Build capacity of youth workforce (health, Aboriginal Medical Service, justice, education) to embed health literacy in core business	7
Ongoing professional development for all health providers: youth-friendly services training, especially for marginalised YP (multiple prejudices), current, up-to-date to our climate	4
Training, education and resources with CPD points for health professionals (including cultural and gender sensitivity) and key references like youth services and schools to promote engagement at first contact with health services.	4
Capabilities: knowledge and skills for young people, professionals, parents, educators and policy makers	3
Total	**35**
Youth participation	
Young people at the heart of decision-making - "Nothing for us without us"	17
User-centred approach to research, design, implementation and evaluation (youth participation and professionals)	4
Total	**21**
Quality systems	
Best practice youth health indicators included in standard accreditation systems e.g. GP/primary care accreditation, public health system accreditation	15
Total	**15**

Discussion

Translation: NSW Youth Health Framework 2017 – 2024

The Minister for Health, NSW Health, launched the NSW Youth Health Framework 2017 – 2024 (NSW Health, 2017) on 6 July 2017 at the national Youth Health Conference in Sydney.

This policy document explicitly states "The Framework is informed by learning from feedback from NSW Health, partner agencies and young people. It also takes account of relevant research and evidence including the Access research studies which explore young peoples' experiences of accessing and navigating health services in NSW." (NSW Health, p3) This includes the *Access* 3 Preliminary Report (Robards et al., 2017).

The Framework has three Goals:

GOAL 1 The health system responds to the health needs of young people, including targeted responses for vulnerable young people.
The Framework supports the provision of a holistic and integrated approach to health care for young people across NSW.

GOAL 2 Health services are accessible and young people are engaged and respected.
The Framework seeks to improve access to health services for young people. It recognises the important role that technology, online information and social media can play in engaging young people to manage their own health.

GOAL 3 Young people are supported to optimise their health and wellbeing.
NSW Health has an important role to support young people to make healthy choices and to be healthy now and into adulthood.

The emphasis on vulnerable young people in the Framework also reflects the focus of *Access* 3. The participation of young people from marginalised groups in Studies 1 and 2, and the high retention rate in Study 2, provided rich and meaningful data for understanding their needs. Having youth consultants who also represented each of the five marginalised groups involved in interpretation of the findings and presenting their perspectives at the Policy Translation Forum contributed to ensuring that vulnerable young people were central to the Framework.

Goal 1 of the Framework proposes that young people's health is assessed holistically and allows for identification of vulnerable young people. The emphasis on coordinated and integrated care reflects one of the six major themes from the Policy Translation Forum.

Goal 2 articulates clear, practical outcomes that relate to the Policy Translation theme of technology solutions. This Framework goal also addresses the cross-cutting subtheme of addressing barriers to access, engagement and navigation (e.g. cost, discrimination) which were presented at the Forum. Youth Participation, a major theme of the Forum, is also articulated as an Outcome for Goal 2.

Goal 3 focuses on health education, health promotion and early intervention, as well as transition care for young people with chronic illness and/ or disability. Health literacy particularly around health system navigation and access was identified in *Access* 3 and can be seen in the Policy Translation Forum recommendations within the Technology theme. While the Forum did not make recommendations explicitly about transition care and the National Disability Insurance Scheme, which are articulated in the Framework, the principles of transition, coordination and integration of care were highlighted.

Dissemination and Implementation
Implementation of the Youth Health Framework in NSW is being supported by the NSW Ministry of Health. Each Local Health District and Specialty Health Network is required to identify priorities for implementation at a local level that will be reported on annually. Many Local Health Districts have developed their own plans and governance mechanisms to assist this process. The Ministry also

implements activities to build workforce capacity in youth health and convenes regular teleconferences with Local Health District contacts to enable sharing of information and progress with implementation.

A Health Literacy project for the youth sector has been funded by NSW Health. Two Chief Investigators from the Access 3 study (MK and FR) have been involved formally and informally in some of these implementation activities. For example, both are supporting the NSW Ministry of Health's Health Literacy project, one as a Reference Group member and the other as a consultant. A series of presentations about the *Access 3* study to NSW Health staff, including those from the Ministry of Health and Local Health Districts, has been taking place throughout 2018. There have also been presentations to other stakeholders and in academic forums.

Access 3 findings have also contributed to the evidence base of several advocacy documents, including a submission to the MBS Taskforce Review of general practice Medicare Item numbers and a Position Paper published by the Australian Association for Adolescent Health in early 2018.

Summary

The Policy Translation Forum was an integral part of the *Access 3* project design, to ensure that new policy was informed by current evidence. Early engagement with stakeholders through formal governance structures (an Associate Investigator team, Youth Consultants, Metropolitan and Rural Reference Groups) included policy makers. Clarity and agreed purpose were discussed and ratified through formal terms of reference for each of these structures. *Access 3* researchers were included in the Ministry of Health's policy reference group so that both processes occurred concurrently and iteratively. The Policy Translation Forum was guided by knowledge translation theory. Some of the key findings in the Access 3 study at the time of the Forum were incorporated into the NSW Youth Health Framework 2017 – 2024.

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Appendices

Appendix 1	NSW Youth Health Survey
Appendix 2	Study 2 Interview prompts
Appendix 3	Study 3 Interview prompts
Appendix 4	Study 4 Policy Translation Forum materials

Appendix 1 – NSW Youth Health Survey

This survey may be copied and used with or without modification provided the source is acknowledged:

Kang M, Robards F, Sanci L, Steinbeck K, Jan S, Hawke C, Luscombe G, Kong M, Usherwood T. (2018). *Access 3*: young people and the health system in the digital age - final research report. Department of General Practice Westmead, The University of Sydney and the Australian Centre for Public and Population Health Research, The University of Technology Sydney, Australia.

Please note formatting and images used in the online and paper surveys for the *Access 3* study have been removed.

NSW YOUTH HEALTH ACCESS SURVEY

All * indicate mandatory questions

Before we start, please tell us how you found out about the survey?
(Please tick as many as apply)*

☐ A friend
☐ Facebook
☐ Twitter
☐ Instagram
☐ Email
☐ A teacher/ lecturer/ employer/ colleague from TAFE, Uni, work mentioned it
☐ Parent/ carer
☐ Youth worker
☐ A health professional
☐ Other (please specify):

PART 1: YOU AND YOUR INTERNET USE

1. How old are you? * (Please tick one)	☐ 12 years ☐ 13 years ☐ 14 years ☐ 15 years ☐ 16 years ☐ 17 years ☐ 18 years ☐ 19 years ☐ 20 years ☐ 21 years ☐ 22 years ☐ 23 years ☐ 24 years
2. What is the postcode where you live? *	
3. What is the name of your suburb or your nearest town? *	
4. What country were you born in? * (Please tick one)	☐ Australia ☐ Other (please specify):
5. What language do you mainly speak at home? * (Please tick one)	☐ English ☐ Other (please specify):
6. Do you have access to the internet? * (Please tick one)	☐ Yes ☐ No ☐ Other (please specify):
7. Do you have your own mobile phone? * (Please tick one)	☐ Yes, a mobile phone (without internet access) ☐ Yes, a smart phone (with internet access) ☐ No
8. How much time do you spend online? * (Please tick one)	☐ I don't spend time online ☐ Every couple of days, not every day ☐ Less than 2 hours per day ☐ 2-6 hours per day ☐ 6-10 hours per day ☐ More than 10 hours per day

9. When are you most active online? * (Please tick one)

☐ Early morning (5am - 9am)
☐ Mid-morning (9am - 12noon)
☐ Early afternoon (12noon - 3pm)
☐ Mid-afternoon (3pm - 6pm)
☐ Evening (6pm - 11pm)
☐ Late night (11pm - 5am)

PART 2: MORE ABOUT YOU
ALL YOUR ANSWERS ARE CONFIDENTIAL

10 Are you: * (Please tick one)

☐ Female
☐ Male
☐ Other (please describe):

Please feel free to tell us more about your gender/ gender identity if you want to:

11. Are you Aboriginal and/ or Torres Strait Islander? *(Please tick one)

☐ No, I am neither
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both Aboriginal and Torres Strait Islander
☐ I'm not sure

12. If born overseas, did you or your family move to Australia as a refugee or asylum seeker? *(Please tick one)

☐ Yes
☐ No
☐ I'm not sure(please comment):
☐ Not applicable – I was born in Australia

13. What is your religion? *(Please tick one)

☐ No religion
☐ I'm not sure
☐ Christian
☐ Muslim
☐ Jewish
☐ Buddhist
☐ Hindu
☐ Other religion (please describe):

14.Do you have an intersex variation? (Please tick one)

(*Intersex* is when someone is born with physical sex characteristics that are not typical. There are many different variations.)

☐ No
☐ Yes
☐ I don't know
☐ I'd rather not say

15. What is your current living situation? *(Please tick one)

☐ I live in my family home with both parents/carers
☐ I live in my family home with one parent/carer
☐ I move between two family homes because my parents/carers do not live together
☐ I live with other relatives
☐ I live in foster care
☐ I live with my partner
☐ I live in a share house/ flat with other people
☐ I live in boarding school
☐ I live on campus at uni
☐ I live with a friend's family
☐ I live by myself
☐ I live in a refuge/supported accommodation
☐ I stay with friends/couch surf in different homes
☐ I live in a boarding house
☐ I sleep on the street/outside
☐ Other (please describe):

PART 3: MORE ABOUT YOU

16. Are you: * (Please tick one)	☐ In high school ☐ In an Intensive English Centre (IEC) in high school ☐ In full time university or TAFE ☐ In part time university or TAFE ☐ Doing other studies (please describe) ☐ Not studying at all
17. Are you: * (Please tick one)	☐ In full time paid work ☐ In part time or casual work ☐ A carer or doing home duties full time or part time ☐ Unemployed: looking for work **(Go to Q20)** ☐ Unemployed: not looking for work **(Go to Q20)** ☐ Unable to work due to sickness or disability **(Go to Q20)** ☐ Other (please describe)
18. How many paid hours do you work each week? *	
19. What is your average weekly income from work (before tax)? * (Please tick one)	☐ $1-$49; ☐ $50-$99; ☐ $100-$199 ☐ $200-$399 ☐ $400-$599 ☐ More than $600
20. Do you receive any youth allowance from the government? *(Please tick one)	☐ Yes ☐ No ☐ I'm not sure
21. Do you have your own Medicare card that just belongs to you? * (Please tick one) (This is the green coloured card that the Government gives to families or individuals aged 15 and over to access health care)	☐ Yes ☐ No ☐ I'm not sure
22. Do you have a health care card? * (A health care card is a type of concession card for health care that you may have received from Centrelink – it allows you to access medicine at a cheaper rate as well as some health services.)	☐ Yes ☐ No ☐ I'm not sure
23. Are you covered by private health insurance? * (e.g. Medibank Private, HCF, BUPA) (Please tick one)	☐ Yes ☐ No ☐ I'm not sure

These questions ask about sexual identity and sexual attraction.
Many young people are still finding out about who they are, which is OK.

24. Which of these statements do you most agree with? *(Please tick one)	☐ I am attracted only to people of a different sex/ gender ☐ I am attracted only to people of my own sex/ gender ☐ I am attracted to people of more than one sex/ gender ☐ I am not sure who I'm attracted to ☐ I don't feel attracted to people of any sex/ gender ☐ I'd rather not say
25. Which of these statements do you most agree with? *(Please tick one)	☐ I am heterosexual (straight) ☐ I am gay ☐ I am lesbian ☐ I am bisexual ☐ I am queer ☐ I am questioning my sexual identity ☐ I'm not sure/ don't know ☐ I am asexual/ not sexual ☐ I'd rather not say ☐ Other (please describe):

PART 4: ACCESSING HEALTH CARE

In this section, **'visit a health service'** means a place you physically go to for health care (e.g. the doctor, dentist, hospital, counsellor at school or an office, chemist etc.).

By **'online services'** we mean websites, apps or social media sites where you can interact with a health professional or a website program

Please indicate how much you agree with each of the following statements:

26. I use the internet to help me work out if **I need to** visit a health service. * (Please tick one)	☐ Frequently ☐ Sometimes ☐ Not at all
27. I use the internet to decide **which** health service(s) I will go to. * (Please tick one)	☐ Frequently ☐ Sometimes ☐ Not at all
28. I believe information on the internet **is as good as** visiting a doctor or health service for my health concerns. * (Please tick one)	☐ Strongly agree ☐ Agree ☐ Not sure ☐ Disagree ☐ Strongly disagree

29. How do you decide where to go? For example, do you use the internet to help you find information about health services you can go to, or do you ask other people?
(Please describe):

30. How does the internet help you decide about whether to go to a health service?
(Please describe):

31. Please tick one box for each of the following six statements: *

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
I get confused by the number of different health services available					
I have a good understanding of the different health services that are available to me					
I can find and access appropriate health services when I need them					
I have had to visit too many different services unnecessarily					
I have been to lots of different services because I needed to					
I would prefer to access online services than physically go to a health service for some health issues but not others.					

32. For which health issues would you prefer to access online services?

33. For which health issues would you prefer to visit a health service?

PART 5: ACCESSING HEALTH CARE CONTINUED

34. Which best describes you? * (Please tick one) Comments:	☐ I have a regular GP/doctor ☐ I go to whatever GP/doctor is available when I need to ☐ I usually go to a hospital emergency department instead of a GP/doctor ☐ I usually call a telephone GP/doctor service ☐ I don't go to a GP/doctor
35. Would any of the following prevent/stop you from going to a health service? * (Tick as many as apply)	☐ I worry about confidentiality ☐ Cost ☐ I don't have my own Medicare card ☐ I would feel embarrassed ☐ I would feel judged ☐ Difficulty getting there ☐ Opening hours mean I need time off study or work ☐ I would have to ask my parents/ carers to take me ☐ I don't know which service/s to go to ☐ The gender of the doctor/ health professional ☐ Language or cultural reasons ☐ None
36. Are there any **other** reasons that you would find it hard to access health services?	
37. What would make it easier for you to access health services?	
38. Do you have any problems using online health services? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ I'm not sure
39. What would make it easy or easier for you to access online health services?	

PART 6: YOUR EXPERIENCE ACCESSING HEALTH SERVICES (INCLUDING ONLINE SERVICES) IN THE PAST 6 MONTHS

The next questions are about **your experiences** of accessing health care in the **past 6 months:**

40. **In the past 6 months** have you used the internet to find information about how to keep yourself healthy? * (Please tick one) Please comment:	☐ Yes ☐ No **(Go to Q43)**
41. Did you find what you were looking for? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure

42. Could you trust the information you found? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure
43. **In the past 6 months** have you used the internet to get information about health problems you have experienced? * (Please tick one) Please comment:	☐ Yes ☐ No **(Go to Q46)**
44. Did you find what you were looking for? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure
45. Could you trust the information you found? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure
46. **In the past 6 months** have you used the internet to get information about how to visit a health service? * (Please tick one) Please comment:	☐ Yes ☐ No **(Go to Q48)**
47. Did you find what you were looking for? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure
48. **In the past 6 months** have you used any internet based programs or apps so that you could manage health issues yourself? * (Please tick one) Please comment:	☐ Yes ☐ No **(Go to Q51)**
49. Were they helpful? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure
50. Would you recommend them to other young people? *(Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure

51. **In the past 6 months** have you been to any of the following * (Please tick all that apply)	☐ GP/doctor ☐ Counsellor/psychologist ☐ Dentist ☐ Medical specialist (e.g. a skin specialist, surgeon) ☐ Nutritionist/dietitian/food expert ☐ Nurse ☐ Psychiatrist (Doctor specialising in mental health) ☐ Paediatrician ☐ Physiotherapist ☐ Pharmacist/chemist ☐ Traditional healer (please specify): ☐ None ☐ Other health professional (please specify):
52. **In the past 6 months,** have you been to any of the following? * (Please tick all that apply)	☐ Online service where you interact with people (e.g. eheadspace) ☐ headspace centre ☐ Youth health service ☐ Aboriginal Medical Service ☐ Family planning service ☐ Sexual health clinic ☐ Mental health service ☐ Drug and alcohol service ☐ School counsellor ☐ Admitted to hospital ☐ Emergency Department ☐ None Other (please describe):

*If you answered "none" to **Q51** **<u>and</u>** **Q52** please skip to Q59.

53. Can you tell us in a few words why you went to this/ these health service/s?

54. How did you decide where to go?

55. How did you use technology (the internet, smartphone, social media etc.) to find health services?

56. Did you feel like the service knew how to help you? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure
57. Would you recommend the service you visited to other young people? * (Please tick one) Please comment:	☐ Yes ☐ No ☐ Not sure

58. If you went to multiple health services in the past 6 months, did you go for health problems that were: (Please tick one) *	☐ Related/similar health problems ☐ Unrelated/different health problems ☐ I did not go to multiple health services
59. How would you describe your experience in finding your way around health care services? (e.g. confusing, straightforward, took too long, frustrating, easy)	
60. Would you like to share any of these experiences? If so, please tell us a story about your experience.	
61. What would make it easier to find your way around health care services?	
62. Do you have any suggestions about how health services can be better for young people?	

PART 7: THIS SECTION ASKS ABOUT YOUR HEALTH

63. In general would you say that your health is: * (Please tick one)	☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor
64. Do you have any of the following: * (Please tick all that apply)	☐ Chronic health condition since birth/early childhood (please specify): ☐ Diabetes (please specify): ☐ Depression, anxiety or other mental illness ☐ Developmental or Intellectual disability ☐ Drug and alcohol problems ☐ An eating disorder (please specify): ☐ Physical disability ☐ Overweight/obesity ☐ None of the above ☐ Other (please specify):
65. **In the last month,** have you stayed away from school or work because you were sick or hurt yourself? *(Please tick one) Please comment:	☐ Yes ☐ No
66. **In the last month,** have you stayed away from school or work to look after someone else? * (Please tick one) Please comment:	☐ Yes ☐ No

67. **Anxiety and depression checklist (K10)**
This simple checklist aims to measure if you might have been affected by depression and anxiety in **the past four weeks.** Tick a box next to each question that best represents how you have been. *

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
About how often did you feel tired out for no good reason?					
About how often did you feel nervous?					
About how often did you feel so nervous that nothing could calm you down?					
About how often did you feel hopeless?					
About how often did you feel restless or fidgety?					
About how often did you feel so restless you could not sit still?					
About how often did you feel depressed?					
About how often did you feel that everything was an effort?					
About how often did you feel so sad that nothing could cheer you up?					
About how often did you feel worthless?					

68. **Please indicate for each of the five statements, which is closest to how you have been feeling over the last two weeks.** *

	All of the time	Most of the time	More than half of the time	Less than half of the time	At no time
I have felt cheerful and in good spirits					
I have felt calm and relaxed					
I have felt active and vigorous					
I woke up feeling fresh and rested					
My daily life has been filled with things that interest me					

69. **Anything else?**
Please tell us anything else you would like to about access to health services and/ or online health services:

70. **Did a parent or carer or someone from school/ IEC help you to complete this survey?** *
☐ **Yes** ☐ **No**

◊Kang M, Robards F, Sanci L, Steinbeck K, Jan S, Hawke C, Luscombe G, Kong M, Usherwood T. (2018). *Access 3*: young people and the health system in the digital age - final research report. Department of General Practice Westmead, The University of Sydney and the Australian Centre for Public and Population Health Research, The University of Technology Sydney, Australia.

Appendix 2 – Study 2 interview prompts

Interview 1

Preamble: In the online survey, you indicated that you had been to a health service in the past six months. In this interview we would like to find out about your experiences with health services and also your understanding of what we call 'the health system'.

What is your understanding of the words 'the health system'?
What do you consider makes up 'the health system'? [prompts: what services would you include?]
Now looking at the health service(s) you have been to in the past 6 months, how did you go about deciding what to do and finding out where to go before you went there?
[Prompts: did you look online?]
Could you explain how you came to have contact with that service? For example, did you already know the service? Did you refer yourself or did someone else suggest it or refer you?
Could you describe how you found your experience at that service?
[prompts: positives?/ negatives?/ understood the process? understood the 'management plan'?]
How did your contact with that service help with understanding your health concerns?
[prompts: ?clear explanation of diagnosis/es ?improved / reduced/ change in understanding of health issues]
Did you have a support person with you (like a parent or other person)?
[Prompt: Would having a support person be appealing/helpful?]/
If you are comfortable to tell us, what were the recommendations or 'management plans' that came from your contact with that service? Please feel free only to give general comments, you don't need to tell us specific diagnoses or treatment.
[prompts: ?follow up/ where ?referral to another service ?communication with others – parent/ carer/ partner/ other; other health professionals; other services]
Were you involved in planning or deciding about your management plan?
What did you think of the management plan? Did you feel able to act on them?
[Prompts: if you were referred to other service/s or asked to return for follow up, how easy or difficult did you find that? What support were you offered to follow up with the recommendations?]
Can you describe any practical issues with accessing that service, e.g. cost, transport, opening hours?
Can you describe any issues or concerns you had regarding confidentiality or privacy when you had contact with that service?
[If the index contact did not lead to further referrals or management plans]: **Apart from that service, have you had contact with any other health services in the past six months?**
How do you choose which health services you go to? Does digital media play any role in choosing health services? [how? E.g. directory of services /online reviews/ word of mouth on social media]?
Can you describe your experiences in these other services?
[map each one/ links/ referrals/ pathways]
Can you describe any practical issues with accessing these other services, e.g. cost, transport, opening hours?
Can you describe any issues or concerns you had regarding confidentiality or privacy when you had contact with these other services?
When you think about all the contacts with health services you have been to recently (over past 6 months), how do you find the experiences of going between different services?
[prompts: is it confusing? straightforward?]
What would you advise other young people in your situation?
What would make it easier for young people to access health services?
What is your impression of the health system in NSW based on your own experiences or understanding?
How would you like to improve the health system in NSW?

Interview 2

Have you experienced any health concerns since we last spoke 3 months ago?
Did you explore getting support? How did you go about deciding where to go and if you needed health care?
Did you attend or access a service in the last 3 months?
[Prompt: What kind of health service did you access? Can I ask what sort of health problem was it for? – you don't have to say if you'd prefer not to]
How did you choose that service, rather than another one?
What was your experience like?
[Prompt: cost, transport, confidentiality, positives/ negatives about the service]
Did you need to go to multiple services? What was it like finding your way around services?
Did anyone help you find where you needed to go?
Did you use technology to help you find your way?
Were there any health issue you thought you'd like to get help for but didn't for whatever reason?
[Prompt: What made it hard or got in the way?]
Did you have any appointments that you didn't end up attending?
[Prompt: What made it hard or got in the way?]
What would make it easier to access the services you need in future?
What would you advise other young people in your situation?
What would make it easier for young people to access health services when they need them?

Interview 3

[Begin with same three questions as in Interview 2]
What about not accessing services that you probably needed? Did you ever think "I really should find some help" or "I know I'm supposed to go to that service…" but didn't? What happened?
What would have made it easier to find your way around health services?

Interview 4

[Begin with same three questions as in Interview 2]
We've been talking for a while about your experience of accessing health care and navigating health system. What have you learnt through reflecting on your experience?
Do you have any recommendations about how to make the health system easier to navigate for young people?

Appendix 3 – Study 3 Interview prompts

Preamble:
The ACCESS 3 project was funded by NSW Health, the project to help shape the next NSW Youth Health Policy. The study aims to take a fresh look at health access and navigation for young people in NSW who live in a digital age. It will focus on marginalised young people who often have complex health and psychosocial needs, to explore ways in which they access, navigate and experience the health system.

What is it like for young people to access the services they need and navigate the health system in NSW? Why?
What parts of the health system present barriers to access and inefficiencies across the system for young people?

Do you have any particular comments about what it like for young people from these specific groups?
Young people:

- living in rural and remote NSW
- who are homeless or at risk of homelessness (using the cultural definition)
- of refugee background or vulnerable migrant background
- who are Aboriginal and/or Torres Strait Islander
- gender and sexuality diverse

Do you think that young people from these backgrounds have a different experience from young people generally? Why/Why not?
How well does the health system provide information to young people about keeping themselves healthy ?

How well does the health system provide information to young people about accessing services?

What can services do better to provide information for young people?

Can you give any examples of initiatives of programs to support young people navigate the health system? Are they effective?

What can health services do better to improve young people's experiences of navigating the health system?

What advice would you give young people who are navigating the health system?

What would make it easier for young people to access health services?

How would you like to improve the health system/health services for young people in NSW?

Appendix 4 *Access 3* Policy Translation Forum materials

Access 3: Policy Translation Forum

AGENDA

9:30 **Welcome and acknowledgement of country**
Ross Beaton
9:35 **Why today is really important for young people**
Alice Zhang
9:45 **About the *Access 3* project**
Associate Professor Melissa Kang
10:15 **Knowledge translation... thinking bigger and broader**
Dr Carmen Huckel-Schneider, Menzies Centre for Health Policy
10:30 **Language explained…** Young people
10.45 **NSW Youth Health Policy**
Dr Sally Gibson and Gemma Rafferty, NSW Health

11:00 Morning tea

11:30 **Presentation of research findings and responses from young people**
Fiona Robards and the *Access* 3 youth consultants
12:30 **Workshops – Question 1**

Workshop themes

1. Young people's health literacy embraces our connected, digitally disrupted world
2. Traditional barriers remain but technology brings new opportunities
3. Health system navigation must be assertively supported
4. Engagement in health care is about people and positive interactions
5. Young people perceive and experience multiple prejudices
6. Health care costs are high and ripple out
7. The ideal GP has many desirable qualities but is hard to find
8. Reducing system demands and complexity would create a more efficient and straightforward experience for young people

1:00 Lunch

1:30 **Workshops – Questions 2 – 5**
3:30 Afternoon tea
3.40 **Synthesis of the day and wrap up**
4:00 **Close**

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WORKSHOP THEME: ____________________

	Can you share your different perspectives on how you understand this theme? How much support in the group is there for this theme to be incorporated into policy?		
1. How does the group understand and support this theme?			
	Please describe	Can you give us 2 - 3 examples?	What difference will this make?
2. Which groups or locations or health care settings is this theme particularly relevant for?			
3. How can this theme be implemented? – consider the barriers and facilitators -Who would need to be involved in its implementation?			
4. What would support implementation? – practical suggestions – consider innovative, creative strategies