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Access 3 project protocol: young people and health system navigation in the digital age - a multi-faceted, mixed-methods study.

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Manuscripts

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3 **Title page**
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6 *Access 3 project protocol: young people and health system navigation in the digital age -*
7 *a multi-faceted, mixed-methods study.*
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ABSTRACT

Background:

The integration of digital technology into everyday lives of young people has become widespread. It is not known whether and how technology influences barriers and facilitators to health care, and whether and how young people navigate between face-to-face and virtual health care. To provide new knowledge essential to policy and practice we designed a study that would explore health system access and navigation in the digital age. The study objectives are to:

1. identify barriers and facilitators to health care for young people and how these vary between groups
2. describe experiences of young people accessing and navigating the health system in New South Wales (NSW), Australia
3. describe health system inefficiencies, particularly for young people who are marginalized
4. provide policy-relevant knowledge translation of the research data

Methods and Analysis:

This mixed methods study has four parts, including: (1) a cross-sectional survey of young people (12 – 24 years) residing in NSW, Australia (2) a longitudinal, qualitative study of a subsample of marginalized young people (defined as young people who: identify as Aboriginal and/ or Torres Strait Islander; are experiencing homelessness; identify as sexuality and/ or gender diverse; are of refugee or vulnerable migrant background; and/ or live in rural or remote NSW) (3) interviews with professionals (4) a knowledge translation forum

Ethics and Dissemination:

Ethics approvals were sought and granted. Data collection commenced in March 2016 and will continue until June 2017. This study will gather practice and policy-relevant intelligence

1
2
3 about contemporary experiences of young people and health services, with a unique focus on
4
5 five different groups of marginalised young people, documenting their experiences over time.
6
7 *Access 3* will explore navigation around all levels of the health system, determine whether
8
9 digital technology is integrated into this, and if so how, and will translate findings into
10
11 policy-relevant recommendations.
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STRENGTHS AND LIMITATIONS

Strengths

- Design allows for breadth and depth of enquiry about barriers, facilitators and health system navigation
- Stakeholder engagement assists with recruitment and interpretation of findings and policy relevance
- Policy translation as part of study design optimises incorporation into new youth health policy

Limitations

- Potential for recruitment bias due to sampling strategies
- Inclusion criteria for marginalised groups study will not capture the full range of young people who are potentially marginalised.

MANUSCRIPT

BACKGROUND

The health and wellbeing of young people (12 – 24 years) are shaped by developmental factors unique to this period of life, as well as by a range of social, cultural and environmental determinants. Despite variability between and within countries, at a global level the health of young people has not improved over recent decades relative to other age groups.[1] In high income countries including Australia, mental health problems (including self-harm and suicide) and chronic physical illness are the major health conditions experienced by young people.[1, 2] Over the lifetimes of the current generation of young people digital technology has become integrated into everyday life. In Australia today almost 100% of young people have internet access, the majority have smartphones with internet access and most use mobile devices to access the internet.[3, 4]

Timely access to appropriate health care is an important determinant of young people's health and overall wellbeing. Treatment of acute and chronic health conditions, including mental health disorders, and preventive health care are all within the remit of health services. Health services also have the capacity to identify health risk behaviours and intervene early. A recent Australian study found that over 90% of young people (14 – 24 years) presenting to general practice carry at least one psychosocial health risk, and further, that engagement with the service mitigated some negative health trajectories. This study found that screening for health risk behaviours led to less illicit drug use and STI risk at three-months, and less risk for unplanned pregnancy at 12 month follow up. [5]

Hospitalised young people have developmental needs that require specific service delivery and policy responses. A USA study of patient safety in hospital showed that adolescents (13-

1
2
3 20 years) were significantly more likely to experience an adverse event in hospital compared
4
5 to younger children (0-12 years). Most of these were attributed to ‘adolescent-specific
6
7 factors’ such as social, emotional and cognitive development, legal minor status and
8
9 ‘discomfort with adolescents’ on the part of hospital staff.[6]
10

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12
13
14 Young people with existing chronic health conditions transition into adolescence with needs
15
16 that can change abruptly and exacerbate health vulnerabilities. Health risk behaviours in this
17
18 population occur at similar or higher rates compared to their well peers. [7] Issues of
19
20 adherence and disengagement from health care are well reported and policy and
21
22 programmatic responses to transition care into adulthood have been established in many
23
24 countries including Australia.[8]
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28
29 Orienting health services to respond effectively to the multilayered needs of young people
30
31 across the health system requires an understanding of developmentally and culturally
32
33 appropriate care. Despite evidence-based guidelines for ‘youth friendly’ health services,[9]
34
35 young people continue to have suboptimal experiences. A study across eleven developed
36
37 countries (including Australia) found that young adults (18 – 25 years) had worse satisfaction
38
39 with health services and significantly higher cost barriers compared to older adults. The
40
41 authors concluded that negative experiences were partially explained by complex health
42
43 system factors which could be amenable to policy or practice interventions.[10]
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48
49 In Australia, access to and models of health care were described in the 1990s – early 2000s
50
51 [11-13] and have directly informed youth health policy.[14,15] Despite these initiatives,
52
53 health care for young people has become more fragmented [16,17] and presentations to
54
55 Emergency Departments are increasing among this age group, possibly due to general
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3 practitioner (GP) unavailability and cost.[18] In the hospital sector in Australia, there is also
4
5 major scope to improve 'adolescent-friendliness'.[19]
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9
10 Possibly the most significant societal change in the past decade has been the emergence of
11
12 digital technology as an integral part of life. Evidence is now needed to understand how
13
14 digital technology influences *access* to health care for young people generally, as well as
15
16 those with more complex or sensitive health needs or who might otherwise have difficulty
17
18 accessing health services. A recent systematic review suggested that online mental health
19
20 services in help-seeking for young people may play a small role in facilitating access.[20]
21
22 Online interventions may also help facilitate some access to sexual health care, particularly
23
24 STI screening.[21]
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29 This current study will focus on groups of marginalised young people who often have
30
31 complex psychosocial needs, but whose access to health care has been less comprehensively
32
33 studied. For example, in the Access Phase 1 study,[22] only five out of 86 focus groups were
34
35 conducted with out-of-school young people who were experiencing homelessness. A recent
36
37 systematic review of homeless youth and healthcare access identified only 13 studies that
38
39 focused on homeless youth specifically. Two of these were in Australia and were small
40
41 qualitative studies.[23] The Access Phase 1 study included a substantial proportion of young
42
43 people living in rural and remote areas, and found cost, availability of provider, qualities
44
45 (such as female GPs), and confidentiality were more prominent barriers compared to those
46
47 expressed by urban young people.[24] A recent Australian study of sexuality and gender
48
49 diverse young people found that fear of discrimination and concerns about coming out to
50
51 health professionals were major barriers to optimal health care.[25] However this latter study
52
53 explored a broad range of experiences of young people in schools and communities, rather
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3 than their access to health care. Aboriginal and/ or Torres Strait Islanders and young people
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5 of refugee background are two other groups whose access to health care has not been
6
7 comprehensively studied. There have been some recent Australian studies exploring access
8
9 among Indigenous young people [26] and young people of refugee background, [27] however
10
11 most have been cross-sectional qualitative studies and usually focusing on mental health care.
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16 Finally, there is consistent evidence of failure for research to be translated into policy and
17
18 practice which not only reduces cost-effectiveness and efficiencies in health care but can also
19
20 lead to poorer health outcomes.[28] Embedded in our study design is a knowledge translation
21
22 process allowing the research findings to be shared, interpreted and discussed with key
23
24 stakeholders to directly shape policy and advocacy agendas on health care for young people.
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29 This protocol describes a multi-faceted, mixed-methods study known as *Access 3*. It takes its
30
31 name from the previous research studies called Access Phase 1 [22] and Access Phase 2 [29]
32
33 and was funded by the state health department of New South Wales (NSW), Australia, in
34
35 2015 to gather policy-relevant intelligence about contemporary experiences of young people
36
37 and health services. *Access 3* aims to explore ways in which young people in NSW access,
38
39 navigate and experience all levels of the health system, how digital technology is integrated
40
41 into these processes, and to translate findings into practice and policy-relevant
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43 recommendations.
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49 **METHODS AND ANALYSIS**

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51 The *Access 3* study objectives are to:

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54 1. identify barriers and facilitators to accessing health care for young people in NSW
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56 and how these vary between groups
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2. describe experiences of young people accessing and navigating the health system in NSW
3. describe health system inefficiencies for young people who are marginalized
4. provide practice and policy-relevant knowledge translation of the research data

Marginalised young people will be defined as meeting at least one of the following criteria:

- Living in rural/ remote NSW
- Being homeless or at risk of homelessness (using the cultural definition) [30]
- Being of refugee background or a recently arrived migrant from a non-English speaking background
- Being Aboriginal and/or Torres Strait Islander
- Being same-sex attracted or identifying as gay, lesbian, bisexual, transgender, queer, intersex or asexual (GLBTQIA)

These five groups have been selected to provide a purposive and varied sample, and our inclusion criteria are not intended to represent an exhaustive classification of all marginalised young people. However, by exploring the needs of young people belonging to one or more of these groups, we may also gain insight into the experiences of marginalised young people more broadly.

Access 3 comprises four separate but interconnected studies, illustrated in **Figure 1**.

Study One

Aim: to describe and quantify barriers, facilitators, and how technology is used, to access health care, and how these vary by age, gender and marginalization

Design: cross-sectional survey

Participants: non-probability sample of young people 12 – 24 years residing in NSW with oversampling of marginalized young people

1
2
3 Recruitment: online and offline. Online recruitment has included targeted emails to youth
4 relevant networks, social media (Facebook, Twitter, and Instagram) and opportunistic online
5 promotion of the survey. Offline recruitment has occurred face-to-face in education-linked
6 settings, youth accommodation services and forums where groups of young people meet (e.g.
7 advocacy groups). To purposively sample marginalized young people, we have worked with
8 networks and advocates from a range of organizations in rural areas, supported
9 accommodation services, community organisations and services who work with or for
10 homeless young people, sexuality diverse and gender diverse young people, Aboriginal and /
11 or Torres Strait Islander young people, young people living in rural areas and young people
12 of refugee or refugee like background. We have also relied on convenience and snowball
13 sampling methods to achieve our sample size.

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27 Data collection: anonymous questionnaire administered via an online survey platform or by
28 hardcopy. Data collection commenced in February 2016. The online survey was closed in
29 February 2017, and hardcopy data collection is about to close as of March 2017. The
30 questionnaire was guided by published evidence [22, 29, 31] about known barriers to access
31 and ‘youth-friendliness’ indicators applicable to primary and community based health
32 services and hospitals. Questions about the impact of digital technology on whether, when
33 and how to access health care were included. Demographic data were collected, as well as the
34 presence of chronic health conditions and/ or disability, and young people’s knowledge and
35 attitudes to health services and accessing care. The questionnaire was developed in
36 consultation with and piloted among a Youth Consultant group who also assisted with
37 promotion of the survey. The questionnaire topic headings are listed in **Figure 2**.

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52 Analysis: Quantitative analysis, using the statistical software program, SPSS,[32] of the
53 barriers and facilitators and use of digital technology, encountered by age, gender, rurality,
54 country of birth, Indigenous status, and homelessness, refugee status, cultural background
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3 and same-sex attraction and/or identification as lesbian, gay, bisexual, transgender, queer,
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5 intersex and/ or asexual.
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7
8 Qualitative thematic analysis of free text responses, with the aid of the software program
9
10 NVivo,[33] will be undertaken to describe barriers and facilitators to access, use of digital
11
12 technology in help seeking, young people's understanding of the health system and the
13
14 influences on their decisions to access which services when.
15

16 Expected outcomes:

17
18 The primary outcomes will be self-report:
19

20
21 - using yes/ no responses to a list of known barriers (awareness of services; confidentiality,
22
23 fear/ embarrassment; negative experiences; physical barriers including cost, transport,
24
25 availability of services, opening hours).
26

27
28 - of barriers and facilitators using Likert scale responses

29
30 To report frequencies with a 95% confidence interval for non-marginalised young people and
31
32 any group of marginalised young people, and to be able to detect minimum clinically and
33
34 policy relevant differences in primary outcomes between groups we need approximately 350
35
36 respondents from each group. Our target sample size is 2100.
37

38 Consent and Ethics: Completion of the survey will be deemed to be consent to participate.

39
40 University of Sydney Human Research Ethics Committee approval 2015/874; NSW

41
42 Aboriginal Health and Medical Research Council Ethics Committee approval 1142/15.
43
44

45 **Study Two**

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47 Aim: to explore in depth the health service-related experiences of marginalized young people
48
49 over time, to quantify contact with health services in real time, and to describe inefficiencies
50
51 or foregone care.
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54 Design: longitudinal, qualitative study using one-on-one semi-structured interviews
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57 Participants: Young people who:
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3 1. belong to one or more of the marginalized groups and
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5 2. have had contact with the health system in the previous six months which constitutes an
6
7 *index event*. The index event will be defined as: presentation to an Emergency Department,
8
9 discharge from hospital, contact with a hospital outpatient or community-based health service
10
11 for one or more of the following health conditions: mental health, drug and alcohol, sexual
12
13 health, physical harm or injury, chronic medical illness or disability. Having an index event
14
15 as an inclusion criterion will narrow the target population to include those young people
16
17 likely to need or want ongoing contact with the health system over the study period, which
18
19 will be important for studying system navigation.
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23 Recruitment: Participants will be recruited from the cross-sectional survey sample and
24
25 selected on the basis of answers to identifier questions in the survey. We will recruit five to
26
27 eight young people from each of the marginalized groups, noting that some young people
28
29 belong to more than one of those groups.
30
31

32 Data collection: we will conduct three to four interviews over six to 12 months with each
33
34 participant. These can be face-to-face, by telephone or Skype and will be audio-recorded and
35
36 transcribed. Interpreters will be used if needed and, if desired, a parent/ carer can be present
37
38 for participants under 14. Data collection commenced in March 2016 and will continue until
39
40 May/ June 2017. The interview schedule includes questions about experiences of each
41
42 contact with a health service as well as navigation through the health system over time
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44 (referral processes, communication between services, support for follow up, understanding of
45
46 the health system). The role of technology in making contact with services and moving
47
48 around the health system will be explored. The 'health system' is defined broadly as any
49
50 service delivering health care, including online services, general practice, emergency
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52 departments, allied health services, medical specialist services, pathology and imaging
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54 services, pharmacy services (e.g. seeking advice from a pharmacist about medication), school
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3 counselling services, hospital outpatient services, hospital admissions, and any other
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5 community or hospital based services (youth health, mental health, headspace, drug and
6
7 alcohol, sexual health, Family Planning etc.). The interviews will be piloted among three to
8
9 five youth consultants to ensure that questions are clear and the schedule flows logically. The
10
11 interview schedule headings are listed in **Figure 3**.

12
13
14 Data analysis: quantitative analysis will be descriptive and count frequencies such as number
15
16 of encounters and number of services visited per participant over the study period. Interview
17
18 transcripts will be entered into NVivo to assist with data coding; thematic analysis will be
19
20 conducted to derive major and minor themes.

21
22
23 Expected outcomes: Number of service encounters and services accessed, referral patterns
24
25 (including self-referral), foregone access due to a range of barriers, adherence to medications
26
27 and follow-up care, experiences of health encounters and the young person's perceptions
28
29 about their health after each encounter. We will also describe areas of inefficiency in the
30
31 system (such as duplication of services, multiple providers, long waiting times for specialist
32
33 appointments, post-hospital discharge care) as well as examples of integration, coordination
34
35 and system efficiency.

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37
38 Consent and Ethics: Signed, written consent will be obtained from all participants prior to
39
40 interviews. Parental consent was obtained for young people aged 12 and 13, in addition to
41
42 consent from the young person. University of Sydney Human Research Ethics Committee
43
44 approval 2015/971; NSW Aboriginal Health and Medical Research Council Ethics
45
46 Committee approval 1141/15.

47 48 49 **Study Three:**

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52 Aim: to obtain the perspectives of professionals about how young people (12 – 24 years) in
53
54 NSW access and navigate the health system

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57 Design: qualitative cross sectional study using one-on-one semi-structured interviews
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3 Participants: Health service managers and experienced clinicians with in-depth knowledge
4
5 about the health system and how it supports young people's access to health care, who can
6
7 provide key informant perspectives on health system navigation for 12 – 24 year olds in
8
9 NSW. The sampling frame is professionals from different sectors (health sector and non-
10
11 government organisations) and different levels of the health system (primary, secondary,
12
13 tertiary). A list of potential participants will be drawn from existing networks and contacts of
14
15 the *Access 3* study investigator and reference groups. Data collection commenced in June
16
17 2016 and will be completed by May 2017.

18
19
20 Recruitment: direct approach by email

21
22 Data collection: face to face or telephone interviews which will be audio-recorded and
23
24 transcribed. The interview schedule includes questions about barriers to care for young
25
26 people, health system integration and coordination, and client-centred care. Content and
27
28 themes derived from early young people interviews in Study 2 will be explored with the
29
30 professionals where relevant or appropriate. Interviews were piloted among two to three
31
32 Reference Group professional members to check for clarity and flow. Interview schedule
33
34 headings are listed in **Figure 4**.

35
36
37 Data analysis: Interview transcripts will be entered into NVivo to assist with data coding;
38
39 content and thematic analysis will be conducted to derive major and minor themes.

40
41
42 Expected outcomes: complementarity/ triangulation of data from Study 2; contrasting
43
44 perspectives between young people and professionals, practice or program examples and
45
46 recommendations that may inform policy.

47
48
49 Consent and Ethics: Signed, written consent will be obtained from all participants prior to
50
51 interviews. University of Sydney Human Research Ethics Committee approval 2016/232;
52
53 NSW Aboriginal Health and Medical Research Council Ethics Committee approval 1175/16.

Study Four:

Aim: to translate synthesized data from Studies 1, 2 and 3 into policy-ready recommendations

Design: one-day facilitated workshop with stakeholders

Participants: young people, policy analysts, senior NSW Health staff, health managers, senior/ expert clinicians, researchers, other key stakeholders (e.g. community advocates)

Recruitment: direct approach by email

Data collection: small group discussions/ focus groups, recorded in writing. We will use a workshop framework informed by Lavis [34] and Grimshaw.[28] Lavis et al 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 extend this framework to suggest that knowledge translation strategies need to consider likely barriers and facilitators to optimize their success. The workshop was held on 21 November 2016 and presented preliminary data analysis from Studies 1, 2 and 3. The NSW health department requested that the workshop be conducted before the end of the year, due to the need to inform the youth health policy framework.

Data analysis: content and thematic analysis of group discussions

Expected outcomes: To provide NSW Health with concise policy recommendations for access to health care and health system navigation for youth health policy and advocacy.

Ethics: Not required

Stakeholder engagement

Three strategies underpin the study's stakeholder engagement:

1. Involvement of young people

1
2
3 Youth participation [35] has been sought in several ways. A Youth Consultant committee was
4
5 convened for the life of the study to assist with design and piloting of instruments for Studies
6
7 1 and 2 and for promotion of the survey (Study 1). In addition youth representation was
8
9 sought on the study Reference Groups, and youth participants as key stakeholders at the
10
11 policy translation workshop.
12

13 14 2. Structure of study governance and advisory teams

15
16 Due to its complexity, five groups were convened to manage and guide the study. The *Chief*
17
18 *Investigator* team brings academic rigour and leadership to the research. An *Associate*
19
20 *Investigator* team brings a combination of academic, project management and network
21
22 expertise and will assist in some aspects of the research such as questionnaire and interview
23
24 design/ refinement, methods of recruitment, data analysis and dissemination. The *Youth*
25
26 *Consultant* committee provides ongoing advice to all aspects of the study. Two *Reference*
27
28 *Groups (Metropolitan and Rural)* have been convened to provide critical feedback on the
29
30 study at different stages. This group consists of stakeholders who will be invited to comment
31
32 on any aspects of the study but who may also be asked to assist with troubleshooting,
33
34 engagement with participants and policy translation. Policy makers are included on the
35
36 Reference Group.
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40 41 3. Direct engagement with policy makers

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43 Regular meetings have been scheduled over the study between representatives of the chief
44
45 investigator team and senior policy analysts and managers in NSW Health and the NSW
46
47 Youth Health Policy Reference group.
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51 52 **ETHICS AND DISSEMINATION**

53
54 Given the multi-faceted design of this study, ethics approvals have been reported above
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56 following the description of Methods and Analysis for each study component. In this study
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3 we are exploring the health service access and navigation experiences of young people in a
4
5 generation where technology is integrated into daily life. This will provide new evidence, of
6
7 national and international relevance, for policy makers and practitioners charged with
8
9 improving the health of young people. To answer our research questions, we are employing
10
11 quantitative and qualitative research methods and have broad stakeholder and youth
12
13 engagement an integral component of the design.
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18 The cross-sectional survey will provide for breadth of information-gathering across the youth
19
20 population in NSW and quantitative analysis of data. Online surveys promoted through social
21
22 media have the potential for wide reach, which is essential in a relatively short time frame.
23
24 The survey has identified potential participants for the longitudinal study, and survey data for
25
26 those participants will act as a springboard for the initial interviews. The longitudinal study is
27
28 exploring the young person's journey through all parts of the health system, and allows an
29
30 in-depth investigation into their navigation through the health system over time. There has
31
32 been very little longitudinal research into health system navigation generally.
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38 Our focus on subpopulations of marginalised young people is unique in its scope, since most
39
40 research into marginalised groups of young people tends to focus on only one group. By
41
42 targeting young people who are marginalised, we will also develop an understanding of how
43
44 the health system supports those with complex needs and where there might be inefficiencies
45
46 and gaps. This approach will enable comparison between groups and a better understanding
47
48 of relative inequities in access to health care and variation in their use of technology for
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50 navigation of health services.
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3 To understand structural issues and system inefficiencies more effectively, we are
4
5 interviewing professionals and service managers, whose perspectives are also important in
6
7 policy and practice translation. Key to our design therefore is the knowledge translation
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9 component of the study. To extend our academic interpretations of new knowledge, we will
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11 actively seek, document and translate our findings into policy- and practice- relevant
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13 recommendations. Whilst we have a knowledge translation study as part of the research
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15 design, we are incorporating knowledge translation theory [28, 34] into other aspects of the
16
17 study by involving stakeholders in formal reference groups and through academic
18
19 representation on the youth health policy advisory group. Feedback relating to new
20
21 knowledge will be sought from the research team. Simultaneously, members of the research
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23 team will be involved in broader policy consultation. Together these actions will provide
24
25 substantial iterative processes to guide knowledge translation.
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32 The main limitations of our study include the potential for recruitment bias due to our
33
34 sampling strategies. Although we aim to oversample young people from five marginalised
35
36 groups, we also want to include a broad cross-section of young people living in NSW in the
37
38 online survey. By recruiting participants through social media and stakeholder networks, we
39
40 will have a convenience rather than a representative sample of young people in NSW. Our
41
42 inclusion criteria for the longitudinal part of our study will not capture the full range of young
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44 people who are potentially marginalised.
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51 In conclusion, a collaborative and participatory ethos underpins our design and research
52
53 process. The study governance and support structure including young people and
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55 stakeholders, will be assembled at the outset of the study and will guide all stages of the
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57 study. By explicitly examining the use of digital technology as an integrated process in health
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3 seeking and health care, we will generate novel empirical evidence about access to health
4 care that will inform clinical practice, health service management and policy makers.
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6 Research outcomes can be used to focus policy and practice towards the alignment of
7
8 structures and processes which can target and reduce inequalities in health care access. The
9
10 ultimate objective is to improve health and well-being in vulnerable young people in NSW.
11
12

13 14 15 16 **Acknowledgments**

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18
19 members for your active engagement and support of this study. We also thank Jessica Harper
20
21 who provided assistance with Ethics applications for Studies 1 and 2, technical help in
22
23 developing the online survey and general research administration support.
24
25
26

27 28 29 **Competing Interests**

30 The authors declare that we have no competing interests.
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35

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38
39 members of the Project Reference Group. They have also been involved in planning the
40
41 knowledge translation one day workshop to ensure that policy relevant outcomes are
42
43 achieved.
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49 **Data sharing**

50 Data sharing is not applicable to this article; being a study protocol, as no datasets were
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52 generated or analysed.
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Authors' contributions

MKang led the study design, wrote the tender for the grant, is the lead investigator, and wrote the draft for the protocol manuscript. FR is the project manager responsible for day to day conduct of the study and contributed to the literature review and manuscript. LS, KS, SJ, CH, MKong and TU contributed to the study design, provide research leadership to the study, and provided feedback on the manuscript. All authors read and approved the final manuscript.

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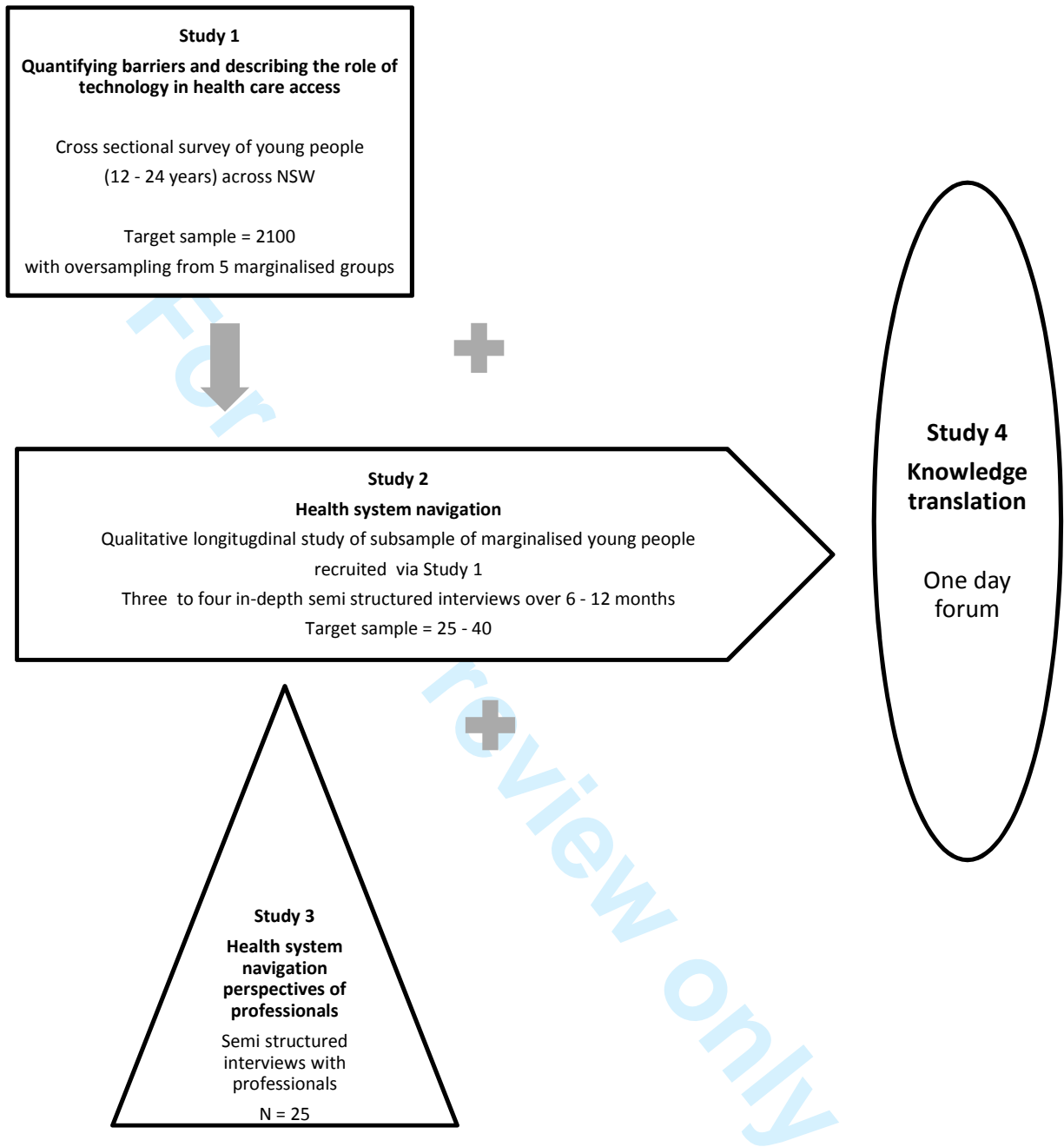


Figure 1: Access 3 design

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3 **Figure 2: Questionnaire topic headings for Study 1**
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5 **PARTS 1 – 3 About you**
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7 Demographic information
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9 Internet use
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11 Identification as Aboriginal/ Torres Strait Islander, sexual identity, gender identity, intersex,
12 refugee background
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14 Education and employment
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16 **PART 4 - 6 Accessing health care**
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18 Attitudes to accessing health services
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20 Experiences in past six months of accessing health services
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22 Use of technology in accessing health information and health services
23

24 Barriers and facilitators to health care
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26 **PART 7 Your health**
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28 Self-rated health status
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30 Chronic health conditions
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32 Kessler-10 questionnaire
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34 WHO-5 wellbeing questionnaire
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Figure 3: Interview schedule headings for Study 2

Sources of information about health and about health care and accessing health information

Experiences in past 3 – 6 months of health service visits (face to face and online) and hospitalisations

Role of technology in accessing health services

Barriers and facilitators to health care and health system navigation

Understandings of the ‘health system’

Suggestions for improvements to health services and the health system

NB: at subsequent interviews these prompts guide the interview with a focus on experiences within the past 3 – 4 months

Figure 4: Interview schedule headings for Study 3

Perspectives on young people's access and health system navigation

Health system present barriers and inefficiencies

Perspectives on marginalised young people's health access compared to other young people

Perspectives on information provided to young people by the health system about being healthy and accessing services

Suggestions for improvements to services and the health system generally

Examples of initiatives of programs to support young people navigate the health system

BMJ Open

Access 3 project protocol: young people and health system navigation in the digital age - a multi-faceted, mixed-methods study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-017047.R1
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Manuscripts

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3 **Title page**
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6 *Access 3 project protocol: young people and health system navigation in the digital age -*
7 *a multi-faceted, mixed-methods study.*
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12 **Keywords:** Adolescents, youth, health services accessibility, knowledge translation, health
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ABSTRACT

Background:

The integration of digital technology into everyday lives of young people has become widespread. It is not known whether and how technology influences barriers and facilitators to health care, and whether and how young people navigate between face-to-face and virtual health care. To provide new knowledge essential to policy and practice we designed a study that would explore health system access and navigation in the digital age. The study objectives are to:

1. identify barriers and facilitators to health care for young people and how these vary between groups
2. describe experiences of young people accessing and navigating the health system in New South Wales (NSW), Australia
3. describe health system inefficiencies, particularly for young people who are marginalized
4. provide policy-relevant knowledge translation of the research data

Methods and Analysis:

This mixed methods study has four parts, including: (1) a cross-sectional survey of young people (12 – 24 years) residing in NSW, Australia (2) a longitudinal, qualitative study of a subsample of marginalized young people (defined as young people who: identify as Aboriginal and/ or Torres Strait Islander; are experiencing homelessness; identify as sexuality and/ or gender diverse; are of refugee or vulnerable migrant background; and/ or live in rural or remote NSW) (3) interviews with professionals (4) a knowledge translation forum

Ethics and Dissemination:

Ethics approvals were sought and granted. Data collection commenced in March 2016 and will continue until June 2017. This study will gather practice and policy-relevant intelligence

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2
3 about contemporary experiences of young people and health services, with a unique focus on
4
5 five different groups of marginalised young people, documenting their experiences over time.
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7 *Access 3* will explore navigation around all levels of the health system, determine whether
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9 digital technology is integrated into this, and if so how, and will translate findings into
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11 policy-relevant recommendations.
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For peer review only

STRENGTHS AND LIMITATIONS

Strengths

- Design allows for breadth and depth of enquiry about barriers, facilitators and health system navigation
- Stakeholder engagement assists with recruitment and interpretation of findings and policy relevance
- Policy translation as part of study design optimises incorporation into new youth health policy

Limitations

- Potential for recruitment bias due to sampling strategies
- Inclusion criteria for marginalised groups study will not capture the full range of young people who are potentially marginalised.

MANUSCRIPT

BACKGROUND

The health and wellbeing of young people (12 – 24 years) are shaped by unique developmental factors as well as a range of social, cultural and environmental determinants. In high income countries including Australia, mental health problems and chronic physical illness are the major health conditions experienced by young people.[1, 2] Timely access to appropriate health care is an important determinant of young people’s health. In primary care, identification of health risk behaviours and early intervention can mitigate some negative health trajectories.[3] For young people with chronic health conditions, health risk behaviours occur at similar or higher rates compared to well peers [4], thus transition policies and programs to prevent disengagement from health care have been established in many countries.[5] Hospitalised young people have needs that require specific service delivery and policy responses, since developmental factors, legal minor status and professional discomfort can contribute to adverse events for adolescents in hospital.[6] Despite evidence-based guidelines for ‘youth friendly’ health services,[7] young people continue to have suboptimal experiences. A study across eleven developed countries found that young adults (18 – 25 years) had worse satisfaction with health services and significantly higher cost barriers compared to older adults.[8]

In Australia, access to and models of health care were described in the 1990s – early 2000s [9-11] and have informed youth health policy.[12, 13] Despite these initiatives, health care has become more fragmented [14, 15] and presentations to Emergency Departments are increasing among young people, possibly due to general practitioner (GP) unavailability and cost.[16] In the hospital sector, there is also major scope to improve ‘adolescent-friendliness’.[17] Most importantly, since almost 100% of Australian young people have

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3 access to the internet [18] and most have smartphones,[19] evidence is now needed to
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5 understand how digital technology influences access to health care. A recent systematic
6
7 review suggested that online mental health services may play a small role in facilitating
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9 access.[20] Online interventions may also help facilitate some access to STI testing.[21]
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14 This study will update knowledge about access in the digital age, explore health care
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16 navigation, and will embed a knowledge translation process to address the evidence of failure
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18 for research to be translated into policy and practice.[22] There will be a focus on
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20 marginalised young people whose experiences have been less comprehensively studied. For
21
22 example, a recent systematic review of homeless youth and healthcare access identified only
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24 13 studies.[23] Recent Australian studies exploring access among Indigenous young people
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26 [24] and young people of refugee background, [25] have been small cross-sectional studies
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28 focusing on mental health care. Earlier research among young people living in rural and
29
30 remote areas before the rise of digital technology identified that cost, confidentiality and
31
32 provider availability were more prominent barriers compared to urban counterparts.[26] A
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34 recent cross-sectional study of sexuality and gender diverse young people found that fear of
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36 discrimination hindered optimal health care.[27] This study will target these groups of young
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38 people and explore barriers, navigation over time, and the role of technology in access to
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40 health care.
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47 This protocol describes a multi-faceted, mixed-methods study known as *Access 3*. It takes its
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49 name from the previous studies called Access Phase 1 [28] and Access Phase 2 [29] and was
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51 funded by the state health department of New South Wales (NSW), Australia. *Access 3* aims
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53 to explore ways in which young people in NSW access, navigate and experience all levels of
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3 the health system, how digital technology is integrated into these processes, and to translate
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5 findings into practice and policy-relevant recommendations.
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9 10 **METHODS AND ANALYSIS**

11 The *Access 3* study objectives are to:

- 14 1. identify barriers and facilitators to accessing health care for young people in NSW
15 and how these vary between groups
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17
- 18 2. describe experiences of young people accessing and navigating the health system in
19 NSW
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21
- 22 3. describe health system inefficiencies for young people who are marginalized
23
- 24 4. provide practice and policy-relevant knowledge translation of the research data
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27 Marginalised young people will be defined as meeting at least one of the following
28 criteria:
29

- 30 • Living in rural/ remote NSW
- 31
- 32 • Being homeless or at risk of homelessness (using the cultural definition) [30]
- 33
- 34 • Being of refugee background or a recently arrived migrant from a non-English
35 speaking background
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- 38 • Being Aboriginal and/or Torres Strait Islander
39
- 40 • Being same-sex attracted or identifying as gay, lesbian, bisexual, transgender,
41 queer, intersex or asexual (GLBTQIA)
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47 These five groups have been selected to provide a purposive and varied sample, and our
48 inclusion criteria are not intended to represent an exhaustive classification of all marginalised
49 young people. However, by exploring the needs of young people belonging to one or more of
50 these groups, we may also gain insight into the experiences of marginalised young people
51 more broadly.
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3 *Access 3* comprises four separate but interconnected studies, illustrated in **Figure 1**.

4
5 **Study One**

6
7 Aim: to describe and quantify barriers, facilitators, and how technology is used, to access
8 health care, and how these vary by age, gender and marginalization

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11 Design: cross-sectional survey

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14 Participants: non-probability sample of young people 12 – 24 years residing in NSW with
15 oversampling of marginalized young people

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18 Recruitment: online and offline. Online recruitment has included targeted emails to youth
19 relevant networks, social media (Facebook, Twitter, and Instagram) and opportunistic online
20 promotion of the survey. Offline recruitment has occurred face-to-face in education-linked
21 settings, youth accommodation services and forums where groups of young people meet (e.g.
22 advocacy groups). To purposively sample marginalized young people, we have worked with
23 networks and advocates from a range of organizations in rural areas, supported
24 accommodation services, community organisations and services who work with or for
25 homeless young people, sexuality diverse and gender diverse young people, Aboriginal and /
26 or Torres Strait Islander young people, young people living in rural areas and young people
27 of refugee or refugee like background. We have also relied on convenience and snowball
28 sampling methods to achieve our sample size.

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43 Data collection: anonymous questionnaire administered via an online survey platform or by
44 hardcopy. Data collection commenced in February 2016. The online survey was closed in
45 February 2017, and hardcopy data collection is about to close as of March 2017. The
46 questionnaire was guided by published evidence [28, 29, 31] about known barriers to access
47 and ‘youth-friendliness’ indicators applicable to primary and community based health
48 services and hospitals. Questions about the impact of digital technology on whether, when
49 and how to access health care were included. Demographic data were collected, as well as the
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3 presence of chronic health conditions and/ or disability, and young people's knowledge and
4 attitudes to health services and accessing care. The questionnaire was developed in
5 consultation with and piloted among a Youth Consultant group who also assisted with
6 promotion of the survey. The questionnaire topic headings are listed in **Figure 2**.
7
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10
11 Analysis: Quantitative analysis, using the statistical software program, SPSS,[32] of the
12 barriers and facilitators and use of digital technology, encountered by age, gender, rurality,
13 country of birth, Indigenous status, and homelessness, refugee status, cultural background
14 and same-sex attraction and/or identification as lesbian, gay, bisexual, transgender, queer,
15 intersex and/ or asexual.
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22 Qualitative thematic analysis of free text responses, with the aid of the software program
23 NVivo,[33] will be undertaken to describe barriers and facilitators to access, use of digital
24 technology in help seeking, young people's understanding of the health system and the
25 influences on their decisions to access which services when.
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32 Expected outcomes:
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34 The primary outcomes will be self-report:
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36 - using yes/ no responses to a list of known barriers (awareness of services; confidentiality,
37 fear/ embarrassment; negative experiences; physical barriers including cost, transport,
38 availability of services, opening hours).
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42 - of barriers and facilitators using Likert scale responses
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45 To report frequencies with a 95% confidence interval for non-marginalised young people and
46 any group of marginalised young people, and to be able to detect minimum clinically and
47 policy relevant differences in primary outcomes between groups we need approximately 350
48 respondents from each group. Our target sample size is 2100.
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3 Consent and Ethics: Completion of the survey will be deemed to be consent to participate.
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5 University of Sydney Human Research Ethics Committee approval 2015/874; NSW
6
7 Aboriginal Health and Medical Research Council Ethics Committee approval 1142/15.
8

9 **Study Two**

10 Aim: to explore in depth the health service-related experiences of marginalized young people
11
12 over time, to quantify contact with health services in real time, and to describe inefficiencies
13
14 or foregone care.
15
16

17 Design: longitudinal, qualitative study using one-on-one semi-structured interviews
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19 Participants: Young people who:
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- 21 1. belong to one or more of the marginalized groups and
- 22 2. have had contact with the health system in the previous six months which constitutes an
23 *index event*. The index event will be defined as: presentation to an Emergency Department,
24
25 discharge from hospital, contact with a hospital outpatient or community-based health service
26
27 for one or more of the following health conditions: mental health, drug and alcohol, sexual
28
29 health, physical harm or injury, chronic medical illness or disability. Having an index event
30
31 as an inclusion criterion will narrow the target population to include those young people
32
33 likely to need or want ongoing contact with the health system over the study period, which
34
35 will be important for studying system navigation.
36
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38 Recruitment: Participants will be recruited from the cross-sectional survey sample and
39
40 selected on the basis of answers to identifier questions in the survey. We will recruit five to
41
42 eight young people from each of the marginalized groups, noting that some young people
43
44 belong to more than one of those groups.
45
46

47 Data collection: we will conduct three to four interviews over six to 12 months with each
48
49 participant. These can be face-to-face, by telephone or Skype and will be audio-recorded and
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51 transcribed. Interpreters will be used if needed and, if desired, a parent/ carer can be present
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3 for participants under 14. Data collection commenced in March 2016 and will continue until
4
5 May/ June 2017. The interview schedule includes questions about experiences of each
6
7 contact with a health service as well as navigation through the health system over time
8
9 (referral processes, communication between services, support for follow up, understanding of
10
11 the health system). The role of technology in making contact with services and moving
12
13 around the health system will be explored. The 'health system' is defined broadly as any
14
15 service delivering health care, including online services, general practice, emergency
16
17 departments, allied health services, medical specialist services, pathology and imaging
18
19 services, pharmacy services (e.g. seeking advice from a pharmacist about medication), school
20
21 counselling services, hospital outpatient services, hospital admissions, and any other
22
23 community or hospital based services (youth health, mental health, headspace, drug and
24
25 alcohol, sexual health, Family Planning etc.). The interviews will be piloted among three to
26
27 five youth consultants to ensure that questions are clear and the schedule flows logically. The
28
29 interview schedule headings are listed in **Figure 3**.
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34 Data analysis: quantitative analysis will be descriptive and count frequencies such as number
35
36 of encounters and number of services visited per participant over the study period. Interview
37
38 transcripts will be entered into NVivo to assist with data coding; thematic analysis will be
39
40 conducted to derive major and minor themes.
41
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43 Expected outcomes: Number of service encounters and services accessed, referral patterns
44
45 (including self-referral), foregone access due to a range of barriers, adherence to medications
46
47 and follow-up care, experiences of health encounters and the young person's perceptions
48
49 about their health after each encounter. We will also describe areas of inefficiency in the
50
51 system (such as duplication of services, multiple providers, long waiting times for specialist
52
53 appointments, post-hospital discharge care) as well as examples of integration, coordination
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55 and system efficiency.
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3 Consent and Ethics: Signed, written consent will be obtained from all participants prior to
4 interviews. Parental consent was obtained for young people aged 12 and 13, in addition to
5 consent from the young person. University of Sydney Human Research Ethics Committee
6 approval 2015/971; NSW Aboriginal Health and Medical Research Council Ethics
7 Committee approval 1141/15.
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14 **Study Three:**

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16 Aim: to obtain the perspectives of professionals about how young people (12 – 24 years) in
17 NSW access and navigate the health system
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19

20 Design: qualitative cross sectional study using one-on-one semi-structured interviews
21
22

23 Participants: Health service managers and experienced clinicians with in-depth knowledge
24 about the health system and how it supports young people's access to health care, who can
25 provide key informant perspectives on health system navigation for 12 – 24 year olds in
26 NSW. The sampling frame is professionals from different sectors (health sector and non-
27 government organisations) and different levels of the health system (primary, secondary,
28 tertiary). A list of potential participants will be drawn from existing networks and contacts of
29 the *Access 3* study investigator and reference groups. Data collection commenced in June
30 2016 and will be completed by May 2017.
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34 Recruitment: direct approach by email
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40 Data collection: face to face or telephone interviews which will be audio-recorded and
41 transcribed. The interview schedule includes questions about barriers to care for young
42 people, health system integration and coordination, and client-centred care. Content and
43 themes derived from early young people interviews in Study 2 will be explored with the
44 professionals where relevant or appropriate. Interviews were piloted among two to three
45 Reference Group professional members to check for clarity and flow. Interview schedule
46 headings are listed in **Figure 4**.
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3 Data analysis: Interview transcripts will be entered into NVivo to assist with data coding;
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5 content and thematic analysis will be conducted to derive major and minor themes.
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7 Expected outcomes: complementarity/ triangulation of data from Study 2; contrasting
8
9 perspectives between young people and professionals, practice or program examples and
10
11 recommendations that may inform policy.
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14 Consent and Ethics: Signed, written consent will be obtained from all participants prior to
15
16 interviews. University of Sydney Human Research Ethics Committee approval 2016/232;
17
18 NSW Aboriginal Health and Medical Research Council Ethics Committee approval 1175/16.
19

20 **Study Four:**

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22 Aim: to translate synthesized data from Studies 1, 2 and 3 into policy-ready recommendations
23

24
25 Design: one-day facilitated workshop with stakeholders
26

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28 Participants: young people, policy analysts, senior NSW Health staff, health managers,
29
30 senior/ expert clinicians, researchers, other key stakeholders (e.g. community advocates)
31

32
33 Recruitment: direct approach by email

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35 Data collection: small group discussions/ focus groups, recorded in writing. We will use a
36
37 workshop framework informed by Lavis [34] and Grimshaw.[28] Lavis et al developed a
38
39 framework for knowledge transfer which asks five key questions: 1. What should be
40
41 transferred? 2. To whom should research knowledge be transferred? 3. By whom should
42
43 research knowledge be transferred? 4. How should research knowledge be transferred? 5.
44
45 With what effect should research knowledge be transferred?
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48 Grimshaw et al extend this framework to suggest that knowledge translation strategies need
49
50 to consider likely barriers and facilitators to optimize their success. The workshop was held
51
52 on 21 November 2016 and presented preliminary data analysis from Studies 1, 2 and 3. The
53
54 NSW health department requested that the workshop be conducted before the end of the year,
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56 due to the need to inform the youth health policy framework. Representatives from the
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research team will continue to work with policy analysts on drafts and consultations of the youth health policy framework until it is finalized and approved by the NSW health department in the second half of 2017.

Data analysis: content and thematic analysis of group discussions

Expected outcomes: To provide NSW Health with concise policy recommendations for access to health care and health system navigation for youth health policy and advocacy.

Ethics: Not required

Study Timeline

The Access 3 study as a whole commenced in February 2016. Data collection for Study 1 was completed in March 2017, but is ongoing for the other components. The timeline for the Access 3 study is depicted below:



Stakeholder engagement

Three strategies underpin the study's stakeholder engagement:

1. Involvement of young people

Youth participation [35] has been sought in several ways. A Youth Consultant committee was convened for the life of the study to assist with design and piloting of instruments for Studies 1 and 2 and for promotion of the survey (Study 1). In addition youth representation was sought on the study Reference Groups, and youth participants as key stakeholders at the policy translation workshop.

2. Structure of study governance and advisory teams

Due to its complexity, five groups were convened to manage and guide the study. The *Chief Investigator* team brings academic rigour and leadership to the research. An *Associate*

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3 *Investigator* team brings a combination of academic, project management and network
4 expertise and will assist in some aspects of the research such as questionnaire and interview
5 design/ refinement, methods of recruitment, data analysis and dissemination. The *Youth*
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7 *Consultant* committee provides ongoing advice to all aspects of the study. Two *Reference*
8
9 *Groups (Metropolitan and Rural)* have been convened to provide critical feedback on the
10 study at different stages. This group consists of stakeholders who will be invited to comment
11 on any aspects of the study but who may also be asked to assist with troubleshooting,
12 engagement with participants and policy translation. Policy makers are included on the
13 Reference Group.
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22 23 3. Direct engagement with policy makers

24 Regular meetings have been scheduled over the study between representatives of the chief
25 investigator team and senior policy analysts and managers in NSW Health and the NSW
26 Youth Health Policy Reference group.
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34 **ETHICS AND DISSEMINATION**

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36 Given the multi-faceted design of this study, ethics approvals have been reported above
37 following the description of Methods and Analysis for each study component. In this study
38 we are exploring the health service access and navigation experiences of young people in a
39 generation where technology is integrated into daily life. This will provide new evidence, of
40 national and international relevance, for policy makers and practitioners charged with
41 improving the health of young people. To answer our research questions, we are employing
42 quantitative and qualitative research methods and have broad stakeholder and youth
43 engagement an integral component of the design.
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3 While we anticipate that this study will generate several important publications based on our
4 findings, we also hope that this paper offers a protocol for a complex and large policy
5 implementation initiative that will contribute to the translational research literature. Our
6 design intends to address policy questions through robust research while embedding a way to
7 maintain policy engagement.
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16 The cross-sectional survey will provide for breadth of information-gathering across the youth
17 population in NSW and quantitative analysis of data. Online surveys promoted through social
18 media have the potential for wide reach, which is essential in a relatively short time frame.
19
20 The survey has identified potential participants for the longitudinal study, and survey data for
21 those participants will act as a springboard for the initial interviews. The longitudinal study
22 explores the young person's journey through all parts of the health system, and allows an in-
23 depth investigation into their navigation through the health system over time. There has been
24 very little longitudinal research into health system navigation generally.
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36 Our focus on subpopulations of marginalised young people is unique in its scope, since most
37 research into marginalised groups of young people tends to focus on only one group. By
38 targeting young people who are marginalised, we will also develop an understanding of how
39 the health system supports those with complex needs and where there might be inefficiencies
40 and gaps. This approach will enable comparison between groups and a better understanding
41 of relative inequities in access to health care and variation in their use of technology for
42 navigation of health services.
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54 To understand structural issues and system inefficiencies more effectively, we are
55 interviewing professionals and service managers, whose perspectives are also important in
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3 policy and practice translation. Key to our design therefore is the knowledge translation
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5 component of the study. To extend our academic interpretations of new knowledge, we will
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7 actively seek, document and translate our findings into policy- and practice- relevant
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9 recommendations. Whilst we have a knowledge translation study as part of the research
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11 design, we are incorporating knowledge translation theory [22,, 34] into other aspects of the
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13 study by involving stakeholders in formal reference groups and through academic
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15 representation on the youth health policy advisory group. Feedback relating to new
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17 knowledge will be sought from the research team. Simultaneously, members of the research
18
19 team will be involved in broader policy consultation. Together these actions will provide
20
21 substantial iterative processes to guide knowledge translation.
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27 The main limitations of our study include the potential for recruitment bias due to our
28
29 sampling strategies. Although we aim to oversample young people from five marginalised
30
31 groups, we also want to include a broad cross-section of young people living in NSW in the
32
33 online survey. By recruiting participants through social media and stakeholder networks, we
34
35 will have a convenience rather than a representative sample of young people in NSW. Our
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37 inclusion criteria for the longitudinal part of our study will not capture the full range of young
38
39 people who are potentially marginalised.
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45 In conclusion, a collaborative and participatory ethos underpins our design and research
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47 process. The study governance and support structure including young people and
48
49 stakeholders, will be assembled at the outset of the study and will guide all stages of the
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51 study. By explicitly examining the use of digital technology as an integrated process in health
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53 seeking and health care, we will generate novel empirical evidence about access to health
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55 care that will inform clinical practice, health service management and policy makers.
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3 Research outcomes can be used to focus policy and practice towards the alignment of
4 structures and processes which can target and reduce inequalities in health care access. The
5 ultimate objective is to improve health and well-being in vulnerable young people in NSW.
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9 **Acknowledgments**

10 We would like to thank all our youth consultants, associate investigators, reference group
11 members for your active engagement and support of this study. We also thank Jessica Harper
12 who provided assistance with Ethics applications for Studies 1 and 2, technical help in
13 developing the online survey and general research administration support.
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20 **Competing Interests**

21 The authors declare that we have no competing interests.
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23
24

25 **Funding**

26 The *Access 3* study is funded by NSW Health. Representatives from the funding body are
27 members of the Project Reference Group. They have also been involved in planning the
28 knowledge translation one day workshop to ensure that policy relevant outcomes are
29 achieved.
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36 **Data sharing**

37 Data sharing is not applicable to this article; being a study protocol, as no datasets were
38 generated or analysed.
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43 **Authors' contributions**

44 MKang led the study design, wrote the tender for the grant, is the lead investigator, and wrote
45 the draft for the protocol manuscript. FR is the project manager responsible for day to day
46 conduct of the study and contributed to the literature review and manuscript. LS, KS, SJ, CH,
47 MKong and TU contributed to the study design, provide research leadership to the study, and
48 provided feedback on the manuscript. All authors read and approved the final manuscript.
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15 1343/www.youngandwellcrc.org.au/wp-content/uploads/2014/04/0_Young-and-Well-CRC-
16 [Youth-Involvement-Guidelines_150414_RM_v4.1.pdf](http://1343/www.youngandwellcrc.org.au/wp-content/uploads/2014/04/0_Young-and-Well-CRC-). [Accessed 2 February 2017]
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20 21 **Figure Legends**

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23 Figure 1: *Access 3* design

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25 Figure 2: Questionnaire topic headings for Study 1

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27 Figure 3: Interview schedule headings for Study 2

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29 Figure 4: Interview schedule headings for Study 3
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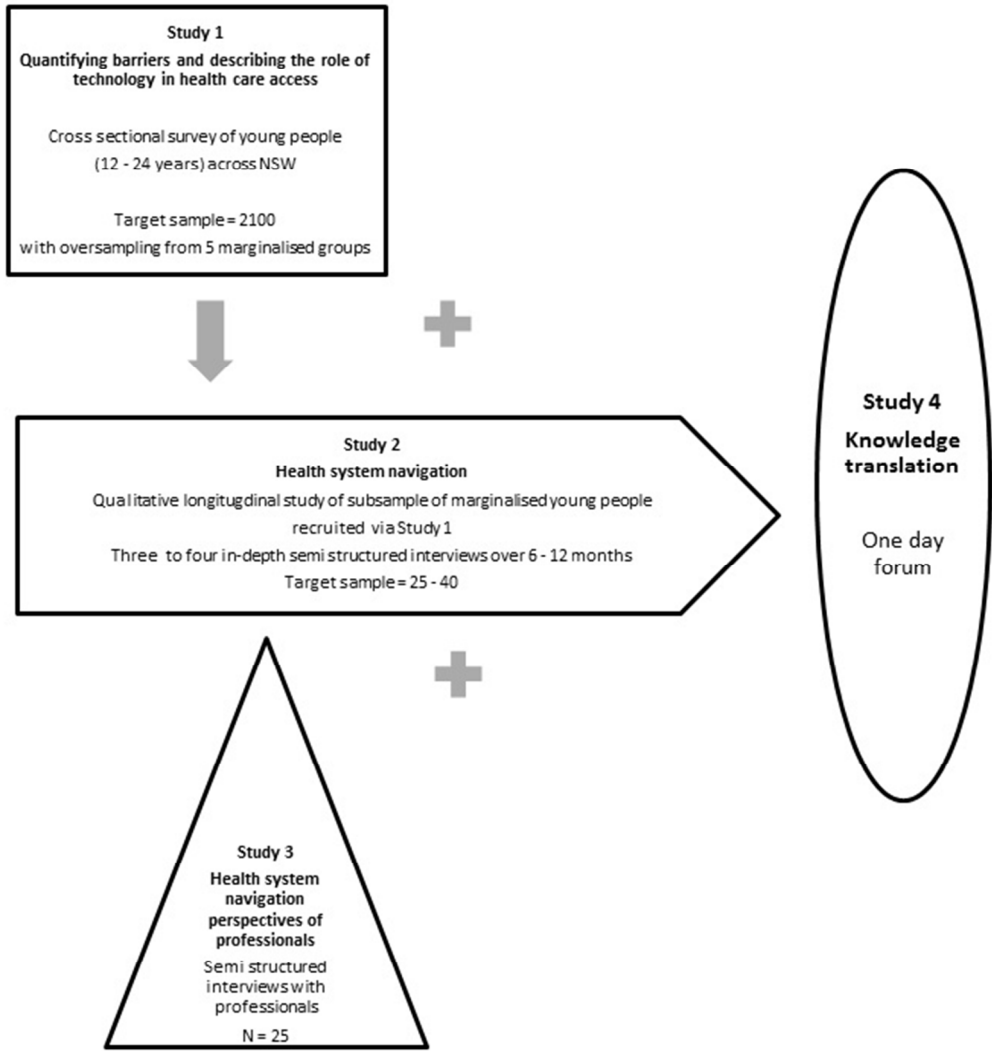


Figure 1: Access 3 design
55x60mm (300 x 300 DPI)

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7 **Figure 2: Questionnaire topic headings for Study 1**

8 **PARTS 1 – 3 About you**

9 Demographic information

10 Internet use

11 Identification as Aboriginal/ Torres Strait Islander, sexual identity, gender identity, intersex,
12 refugee background

13 Education and employment

14 **PART 4 - 6 Accessing health care**

15 Attitudes to accessing health services

16 Experiences in past six months of accessing health services

17 Use of technology in accessing health information and health services

18 Barriers and facilitators to health care

19 **PART 7 Your health**

20 Self-rated health status

21 Chronic health conditions

22 Kessler-10 questionnaire

23 WHO-5 wellbeing questionnaire
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Figure 2: Questionnaire topic headings for Study 1

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7 **Figure 3: Interview schedule headings for Study 2**

8 Sources of information about health and about health care and accessing health information

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10 Experiences in past 3 – 6 months of health service visits (face to face and online) and
11 hospitalisations

12 Role of technology in accessing health services

13
14 Barriers and facilitators to health care and health system navigation

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16 Understandings of the 'health system'

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18 Suggestions for improvements to health services and the health system

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20 NB: at subsequent interviews these prompts guide the interview with a focus on experiences
21 within the past 3 – 4 months

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38 Figure 3: Interview schedule headings for Study 2

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7 **Figure 4: Interview schedule headings for Study 3**

8 Perspectives on young people's access and health system navigation

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10 Health system present barriers and inefficiencies

11 Perspectives on marginalised young people's health access compared to other young people

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13 Perspectives on information provided to young people by the health system about being
14 healthy and accessing services

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16 Suggestions for improvements to services and the health system generally

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18 Examples of initiatives of programs to support young people navigate the health system

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39 Figure 4: Interview schedule headings for Study 3

40 38x40mm (300 x 300 DPI)