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Title page

Access 3 project protocol: young people and health system navigation in the digital age - 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

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

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-

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

Young people with existing chronic health conditions transition into adolescence with needs that can change abruptly and exacerbate health vulnerabilities. Health risk behaviours in this population occur at similar or higher rates compared to their well peers. [7] Issues of adherence and disengagement from health care are well reported and policy and programmatic responses to transition care into adulthood have been established in many countries including Australia.[8]

Orienting health services to respond effectively to the multilayered needs of young people across the health system requires an understanding of developmentally and culturally appropriate care. Despite evidence-based guidelines for ‘youth friendly’ health services,[9] young people continue to have suboptimal experiences. A study across eleven developed countries (including Australia) found that young adults (18 – 25 years) had worse satisfaction with health services and significantly higher cost barriers compared to older adults. The authors concluded that negative experiences were partially explained by complex health system factors which could be amenable to policy or practice interventions.[10]

In Australia, access to and models of health care were described in the 1990s – early 2000s [11-13] and have directly informed youth health policy.[14,15] Despite these initiatives, health care for young people has become more fragmented [16,17] and presentations to Emergency Departments are increasing among this age group, possibly due to general practitioner (GP) unavailability and cost.[18] In the hospital sector in Australia, there is also major scope to improve ‘adolescent-friendliness’.[19]

Possibly the most significant societal change in the past decade has been the emergence of digital technology as an integral part of life. Evidence is now needed to understand how digital technology influences *access* to health care for young people generally, as well as those with more complex or sensitive health needs or who might otherwise have difficulty accessing health services. A recent systematic review suggested that online mental health services in help-seeking for young people may play a small role in facilitating access.[20] Online interventions may also help facilitate some access to sexual health care, particularly STI screening.[21]

This current study will focus on groups of marginalised young people who often have complex psychosocial needs, but whose access to health care has been less comprehensively studied. For example, in the Access Phase 1 study,[22] only five out of 86 focus groups were conducted with out-of-school young people who were experiencing homelessness. A recent systematic review of homeless youth and healthcare access identified only 13 studies that focused on homeless youth specifically. Two of these were in Australia and were small qualitative studies.[23] The Access Phase 1 study included a substantial proportion of young people living in rural and remote areas, and found cost, availability of provider, qualities (such as female GPs), and confidentiality were more prominent barriers compared to those expressed by urban young people.[24] A recent Australian study of sexuality and gender diverse young people found that fear of discrimination and concerns about coming out to health professionals were major barriers to optimal health care.[25] However this latter study explored a broad range of experiences of young people in schools and communities, rather than their access to health care. Aboriginal and/ or Torres Strait Islanders and young people of refugee background are two other groups whose access to health care has not been comprehensively studied. There have been some recent Australian studies exploring access among Indigenous young people [26] and young people of refugee background, [27] however most have been cross-sectional qualitative studies and usually focusing on mental health care.

Finally, there is consistent evidence of failure for research to be translated into policy and practice which not only reduces cost-effectiveness and efficiencies in health care but can also lead to poorer health outcomes.[28] Embedded in our study design is a knowledge translation process allowing the research findings to be shared, interpreted and discussed with key stakeholders to directly shape policy and advocacy agendas on health care for young people.

This protocol describes a multi-faceted, mixed-methods study known as *Access 3*. It takes its name from the previous research studies called Access Phase 1 [22] and Access Phase 2 [29] and was funded by the state health department of New South Wales (NSW), Australia, in 2015 to gather policy-relevant intelligence about contemporary experiences of young people and health services. *Access 3* aims 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.

METHODS AND ANALYSIS

The *Access 3* study objectives are to:

1. identify barriers and facilitators to accessing health care for young people in NSW and how these vary between groups

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

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

<u>Design:</u> cross-sectional survey

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

Recruitment: online and offline. Online recruitment has included targeted emails to youth relevant networks, social media (Facebook, Twitter, and Instagram) and opportunistic online promotion of the survey. Offline recruitment has 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 marginalized young people, we have worked with networks and advocates from a range of organizations in rural areas, supported accommodation services, community organisations and services who work with or for homeless young people, sexuality diverse and gender diverse young people, Aboriginal and / or Torres Strait Islander young people, young people living in rural areas and young people of refugee or refugee like background. We have also relied on convenience and snowball sampling methods to achieve our sample size.

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

Analysis: Quantitative analysis, using the statistical software program, SPSS,[32] of the barriers and facilitators and use of digital technology, encountered by age, gender, rurality, country of birth, Indigenous status, and homelessness, refugee status, cultural background and same-sex attraction and/or identification as lesbian, gay, bisexual, transgender, queer, intersex and/ or asexual.

Qualitative thematic analysis of free text responses, with the aid of the software program NVivo,[33] will be 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 which services when.

Expected outcomes:

The primary outcomes will be self-report:

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

- of barriers and facilitators using Likert scale responses

To report frequencies with a 95% confidence interval 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 need approximately 350 respondents from each group. Our target sample size is 2100.

Consent and Ethics: Completion of the survey will be deemed to be consent to participate. University of Sydney Human Research Ethics Committee approval 2015/874; NSW Aboriginal Health and Medical Research Council Ethics Committee approval 1142/15.

Study Two

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

Design: longitudinal, qualitative study using one-on-one semi-structured interviews

Participants: Young people who:

1. belong to one or more of the marginalized groups and

2. have had contact with the health system in the previous six months which constitutes an *index event*. The index event will be defined as: presentation to an Emergency Department, discharge from hospital, contact with a hospital outpatient or community-based health service for one or more of the following health conditions: mental health, drug and alcohol, sexual health, physical harm or injury, chronic medical illness or disability. Having an index event as an inclusion criterion will narrow the target population to include those young people likely to need or want ongoing contact with the health system over the study period, which will be important for studying system navigation.

Recruitment: Participants will be recruited from the cross-sectional survey sample and selected on the basis of answers to identifier questions in the survey. We will recruit five to eight young people from each of the marginalized groups, noting that some young people belong to more than one of those groups.

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

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

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

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

Study Three:

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

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

Participants: Health service managers and experienced clinicians with in-depth knowledge about the health system and how it supports young people's access to health care, who can provide key informant perspectives on health system navigation for 12 – 24 year olds in NSW. The sampling frame is professionals from different sectors (health sector and non-government organisations) and different levels of the health system (primary, secondary, tertiary). A list of potential participants will be drawn from existing networks and contacts of the *Access 3* study investigator and reference groups. Data collection commenced in June 2016 and will be completed by May 2017.

Recruitment: direct approach by email

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

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

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

Consent and Ethics: Signed, written consent will be obtained from all participants prior to interviews. University of Sydney Human Research Ethics Committee approval 2016/232; 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

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

3. Direct engagement with policy makers

Regular meetings have been scheduled over the study between representatives of the chief investigator team and senior policy analysts and managers in NSW Health and the NSW Youth Health Policy Reference group.

ETHICS AND DISSEMINATION

Given the multi-faceted design of this study, ethics approvals have been reported above following the description of Methods and Analysis for each study component. In this study we are exploring the health service access and navigation experiences of young people in a generation where technology is integrated into daily life. This will provide new evidence, of national and international relevance, for policy makers and practitioners charged with improving the health of young people. To answer our research questions, we are employing quantitative and qualitative research methods and have broad stakeholder and youth engagement an integral component of the design.

The cross-sectional survey will provide for breadth of information-gathering across the youth population in NSW and quantitative analysis of data. Online surveys promoted through social media have the potential for wide reach, which is essential in a relatively short time frame. The survey has identified potential participants for the longitudinal study, and survey data for those participants will act as a springboard for the initial interviews. The longitudinal study is exploring the young person's journey through all parts of the health system, and allows an in-depth investigation into their navigation through the health system over time. There has been very little longitudinal research into health system navigation generally.

Our focus on subpopulations of marginalised young people is unique in its scope, since most research into marginalised groups of young people tends to focus on only one group. By targeting young people who are marginalised, we will also develop an understanding of how the health system supports those with complex needs and where there might be inefficiencies and gaps. This approach will enable comparison between groups and a better understanding of relative inequities in access to health care and variation in their use of technology for navigation of health services.

To understand structural issues and system inefficiencies more effectively, we are interviewing professionals and service managers, whose perspectives are also important in policy and practice translation. Key to our design therefore is the knowledge translation component of the study. To extend our academic interpretations of new knowledge, we will actively seek, document and translate our findings into policy- and practice- relevant recommendations. Whilst we have a knowledge translation study as part of the research design, we are incorporating knowledge translation theory [28, 34] into other aspects of the study by involving stakeholders in formal reference groups and through academic representation on the youth health policy advisory group. Feedback relating to new knowledge will be sought from the research team. Simultaneously, members of the research team will be involved in broader policy consultation. Together these actions will provide substantial iterative processes to guide knowledge translation.

The main limitations of our study include the potential for recruitment bias due to our sampling strategies. Although we aim to oversample young people from five marginalised groups, we also want to include a broad cross-section of young people living in NSW in the online survey. By recruiting participants through social media and stakeholder networks, we will have a convenience rather than a representative sample of young people in NSW. Our inclusion criteria for the longitudinal part of our study will not capture the full range of young people who are potentially marginalised.

In conclusion, a collaborative and participatory ethos underpins our design and research process. The study governance and support structure including young people and stakeholders, will be assembled at the outset of the study and will guide all stages of the study. By explicitly examining the use of digital technology as an integrated process in health seeking and health care, we will generate novel empirical evidence about access to health care that will inform clinical practice, health service management and policy makers. Research outcomes can be used to focus policy and practice towards the alignment of structures and processes which can target and reduce inequalities in health care access. The ultimate objective is to improve health and well-being in vulnerable young people in NSW.

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Competing Interests

The authors declare that we have no competing interests.

Funding

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

Data sharing

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

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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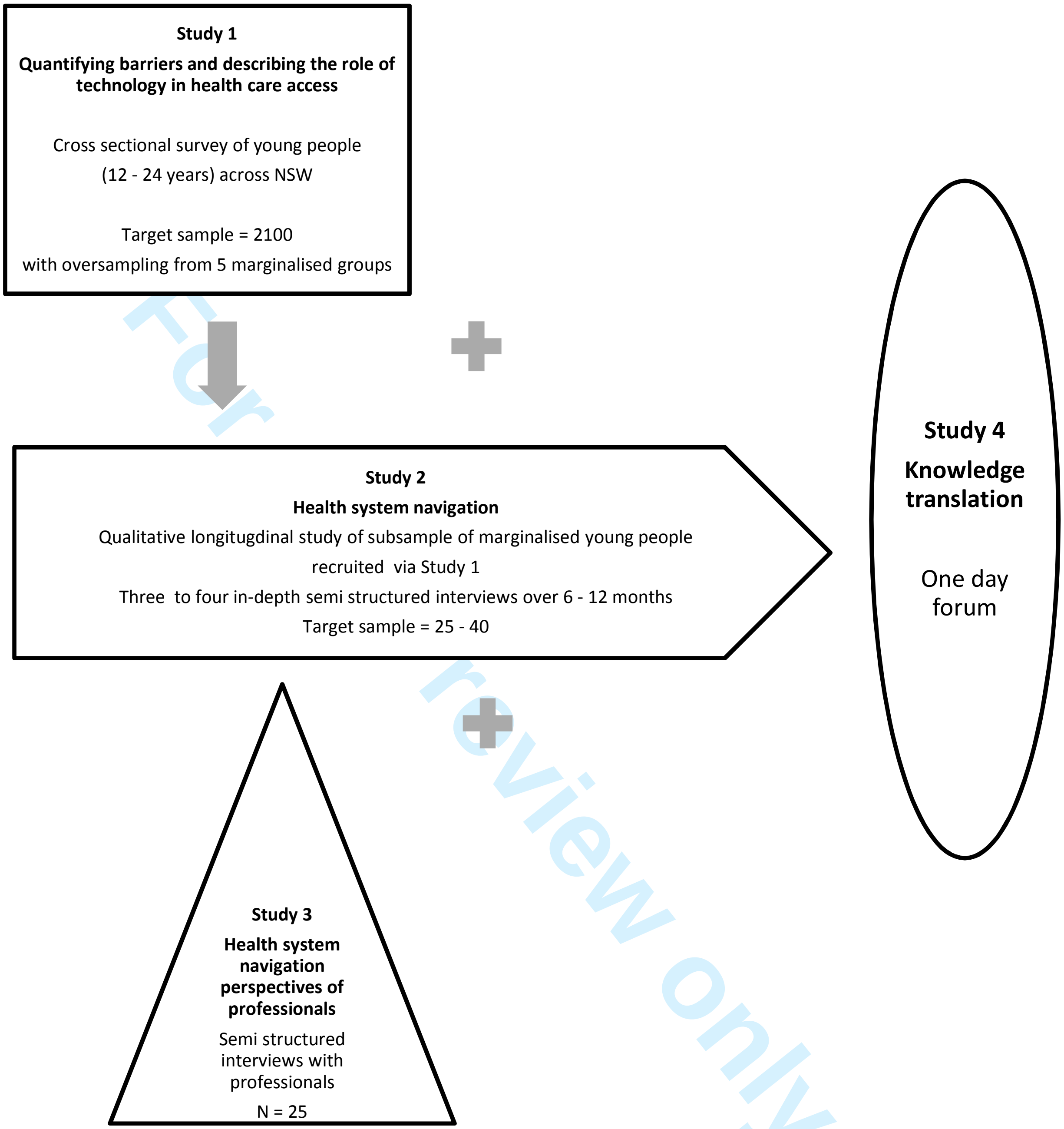

Figure 1: *Access 3* design

Figure 2: Questionnaire topic headings for Study 1

PARTS 1 – 3 About you

Demographic information

Internet use

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

Education and employment

PART 4 - 6 Accessing health care

Attitudes to accessing health services

Experiences in past six months of accessing health services

Use of technology in accessing health information and health services

Barriers and facilitators to health care

PART 7 Your health

Self-rated health status

Chronic health conditions

Kessler-10 questionnaire

WHO-5 wellbeing questionnaire

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.

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Title page

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

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Keywords: Adolescents, youth, health services accessibility, knowledge translation, health policy

Word Count 3510

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

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

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 access to the internet [18] and most have smartphones,[19] evidence is now needed to understand how digital technology influences access to health care. A recent systematic review suggested that online mental health services may play a small role in facilitating access.[20] Online interventions may also help facilitate some access to STI testing.[21]

This study will update knowledge about access in the digital age, explore health care navigation, and will embed a knowledge translation process to address the evidence of failure for research to be translated into policy and practice.[22] There will be a focus on marginalised young people whose experiences have been less comprehensively studied. For example, a recent systematic review of homeless youth and healthcare access identified only 13 studies.[23] Recent Australian studies exploring access among Indigenous young people [24] and young people of refugee background, [25] have been small cross-sectional studies focusing on mental health care. Earlier research among young people living in rural and remote areas before the rise of digital technology identified that cost, confidentiality and provider availability were more prominent barriers compared to urban counterparts.[26] A recent cross-sectional study of sexuality and gender diverse young people found that fear of discrimination hindered optimal health care.[27] This study will target these groups of young people and explore barriers, navigation over time, and the role of technology in access to health care.

This protocol describes a multi-faceted, mixed-methods study known as *Access 3*. It takes its name from the previous studies called Access Phase 1 [28] and Access Phase 2 [29] and was funded by the state health department of New South Wales (NSW), Australia. *Access 3* aims 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.

METHODS AND ANALYSIS

The *Access 3* study objectives are to:

1. identify barriers and facilitators to accessing health care for young people in NSW and how these vary between groups
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

Recruitment: online and offline. Online recruitment has included targeted emails to youth relevant networks, social media (Facebook, Twitter, and Instagram) and opportunistic online promotion of the survey. Offline recruitment has 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 marginalized young people, we have worked with networks and advocates from a range of organizations in rural areas, supported accommodation services, community organisations and services who work with or for homeless young people, sexuality diverse and gender diverse young people, Aboriginal and / or Torres Strait Islander young people, young people living in rural areas and young people of refugee or refugee like background. We have also relied on convenience and snowball sampling methods to achieve our sample size.

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

Analysis: Quantitative analysis, using the statistical software program, SPSS,[32] of the barriers and facilitators and use of digital technology, encountered by age, gender, rurality, country of birth, Indigenous status, and homelessness, refugee status, cultural background and same-sex attraction and/or identification as lesbian, gay, bisexual, transgender, queer, intersex and/ or asexual.

Qualitative thematic analysis of free text responses, with the aid of the software program NVivo,[33] will be 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 which services when.

Expected outcomes:

The primary outcomes will be self-report:

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

- of barriers and facilitators using Likert scale responses

To report frequencies with a 95% confidence interval 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 need approximately 350 respondents from each group. Our target sample size is 2100.

Consent and Ethics: Completion of the survey will be deemed to be consent to participate. University of Sydney Human Research Ethics Committee approval 2015/874; NSW Aboriginal Health and Medical Research Council Ethics Committee approval 1142/15.

Study Two

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

Design: longitudinal, qualitative study using one-on-one semi-structured interviews

Participants: Young people who:

1. belong to one or more of the marginalized groups and
2. have had contact with the health system in the previous six months which constitutes an *index event*. The index event will be defined as: presentation to an Emergency Department, discharge from hospital, contact with a hospital outpatient or community-based health service for one or more of the following health conditions: mental health, drug and alcohol, sexual health, physical harm or injury, chronic medical illness or disability. Having an index event as an inclusion criterion will narrow the target population to include those young people likely to need or want ongoing contact with the health system over the study period, which will be important for studying system navigation.

Recruitment: Participants will be recruited from the cross-sectional survey sample and selected on the basis of answers to identifier questions in the survey. We will recruit five to eight young people from each of the marginalized groups, noting that some young people belong to more than one of those groups.

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

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

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

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

Study Three:

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

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

Participants: Health service managers and experienced clinicians with in-depth knowledge about the health system and how it supports young people's access to health care, who can provide key informant perspectives on health system navigation for 12 – 24 year olds in NSW. The sampling frame is professionals from different sectors (health sector and non-government organisations) and different levels of the health system (primary, secondary, tertiary). A list of potential participants will be drawn from existing networks and contacts of the *Access 3* study investigator and reference groups. Data collection commenced in June 2016 and will be completed by May 2017.

Recruitment: direct approach by email

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

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

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

Consent and Ethics: Signed, written consent will be obtained from all participants prior to interviews. University of Sydney Human Research Ethics Committee approval 2016/232; 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. Representatives from the 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.

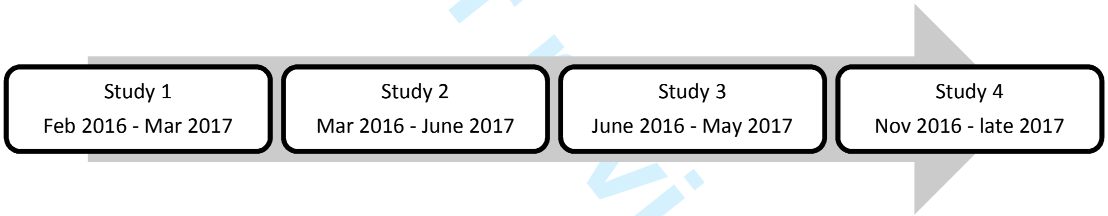
Data analysis: content and thematic analysis of group discussions

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*

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

3. Direct engagement with policy makers

Regular meetings have been scheduled over the study between representatives of the chief investigator team and senior policy analysts and managers in NSW Health and the NSW Youth Health Policy Reference group.

ETHICS AND DISSEMINATION

Given the multi-faceted design of this study, ethics approvals have been reported above following the description of Methods and Analysis for each study component. In this study we are exploring the health service access and navigation experiences of young people in a generation where technology is integrated into daily life. This will provide new evidence, of national and international relevance, for policy makers and practitioners charged with improving the health of young people. To answer our research questions, we are employing quantitative and qualitative research methods and have broad stakeholder and youth engagement an integral component of the design.

While we anticipate that this study will generate several important publications based on our findings, we also hope that this paper offers a protocol for a complex and large policy implementation initiative that will contribute to the translational research literature. Our design intends to address policy questions through robust research while embedding a way to maintain policy engagement.

The cross-sectional survey will provide for breadth of information-gathering across the youth population in NSW and quantitative analysis of data. Online surveys promoted through social media have the potential for wide reach, which is essential in a relatively short time frame. The survey has identified potential participants for the longitudinal study, and survey data for those participants will act as a springboard for the initial interviews. The longitudinal study explores the young person's journey through all parts of the health system, and allows an in-depth investigation into their navigation through the health system over time. There has been very little longitudinal research into health system navigation generally.

Our focus on subpopulations of marginalised young people is unique in its scope, since most research into marginalised groups of young people tends to focus on only one group. By targeting young people who are marginalised, we will also develop an understanding of how the health system supports those with complex needs and where there might be inefficiencies and gaps. This approach will enable comparison between groups and a better understanding of relative inequities in access to health care and variation in their use of technology for navigation of health services.

To understand structural issues and system inefficiencies more effectively, we are interviewing professionals and service managers, whose perspectives are also important in policy and practice translation. Key to our design therefore is the knowledge translation component of the study. To extend our academic interpretations of new knowledge, we will actively seek, document and translate our findings into policy- and practice- relevant recommendations. Whilst we have a knowledge translation study as part of the research design, we are incorporating knowledge translation theory [22,, 34] into other aspects of the study by involving stakeholders in formal reference groups and through academic representation on the youth health policy advisory group. Feedback relating to new knowledge will be sought from the research team. Simultaneously, members of the research team will be involved in broader policy consultation. Together these actions will provide substantial iterative processes to guide knowledge translation.

The main limitations of our study include the potential for recruitment bias due to our sampling strategies. Although we aim to oversample young people from five marginalised groups, we also want to include a broad cross-section of young people living in NSW in the online survey. By recruiting participants through social media and stakeholder networks, we will have a convenience rather than a representative sample of young people in NSW. Our inclusion criteria for the longitudinal part of our study will not capture the full range of young people who are potentially marginalised.

In conclusion, a collaborative and participatory ethos underpins our design and research process. The study governance and support structure including young people and stakeholders, will be assembled at the outset of the study and will guide all stages of the study. By explicitly examining the use of digital technology as an integrated process in health seeking and health care, we will generate novel empirical evidence about access to health care that will inform clinical practice, health service management and policy makers.

Research outcomes can be used to focus policy and practice towards the alignment of structures and processes which can target and reduce inequalities in health care access. The ultimate objective is to improve health and well-being in vulnerable young people in NSW.

Acknowledgments

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Competing Interests

The authors declare that we have no competing interests.

Funding

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

Data sharing

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

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 Legends

Figure 1: *Access 3* design

Figure 2: Questionnaire topic headings for Study 1

Figure 3: Interview schedule headings for Study 2

Figure 4: Interview schedule headings for Study 3

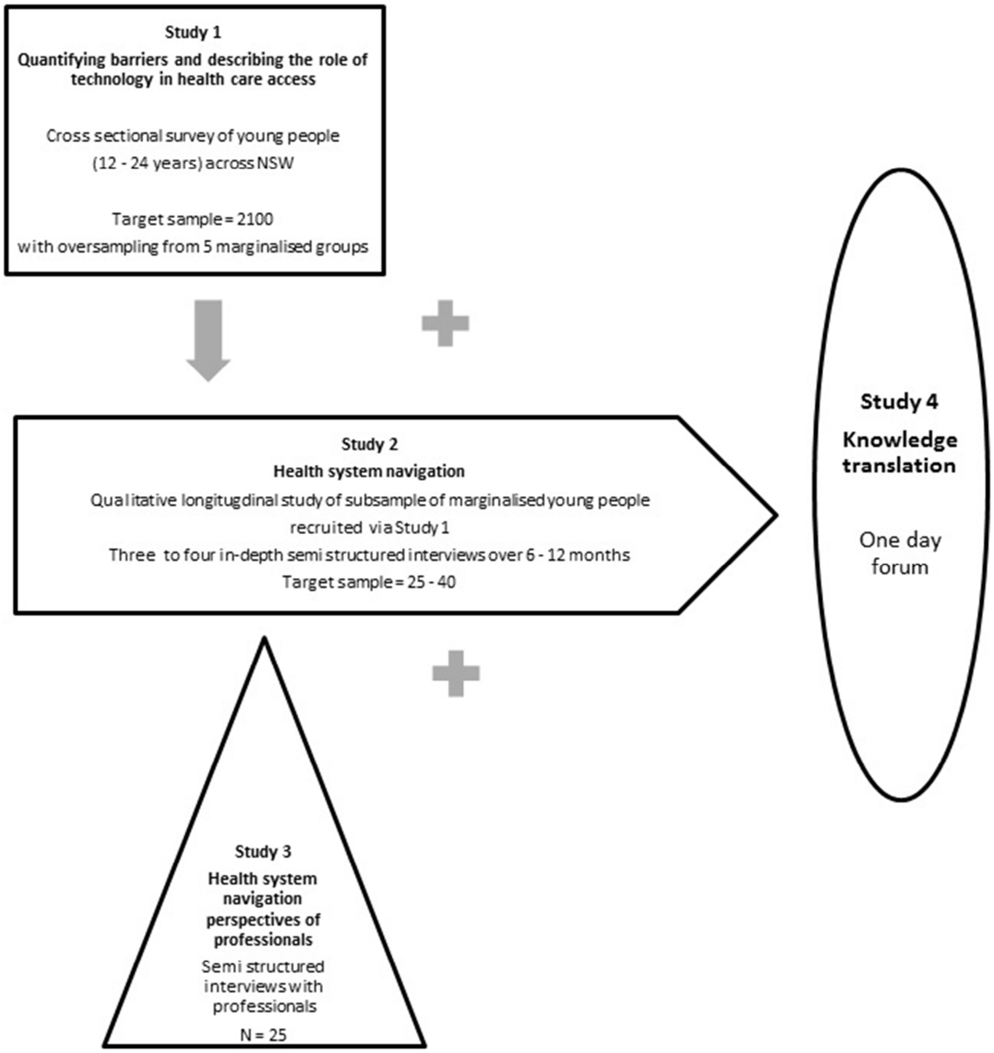

Figure 1: Access 3 design

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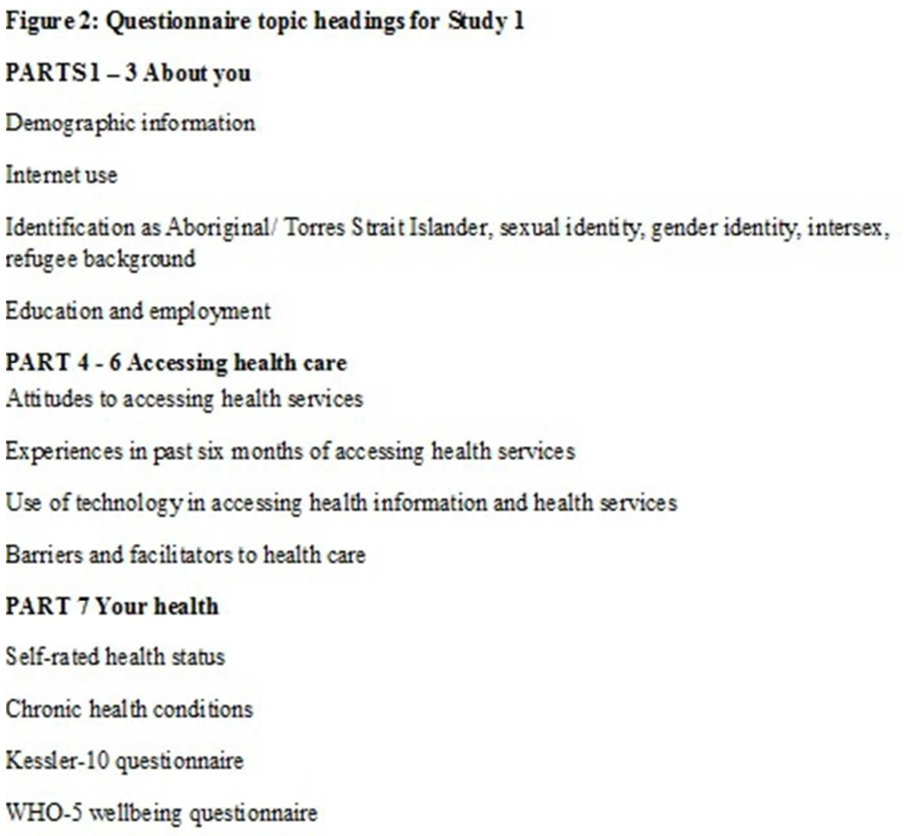

Figure 2: Questionnaire topic headings for Study 1

PARTS1 – 3 About you

Demographic information

Internet use

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

Education and employment

PART 4 - 6 Accessing health care

Attitudes to accessing health services

Experiences in past six months of accessing health services

Use of technology in accessing health information and health services

Barriers and facilitators to health care

PART 7 Your health

Self-rated health status

Chronic health conditions

Kessler-10 questionnaire

WHO-5 wellbeing questionnaire

Figure 2: Questionnaire topic headings for Study 1

38x40mm (300 x 300 DPI)

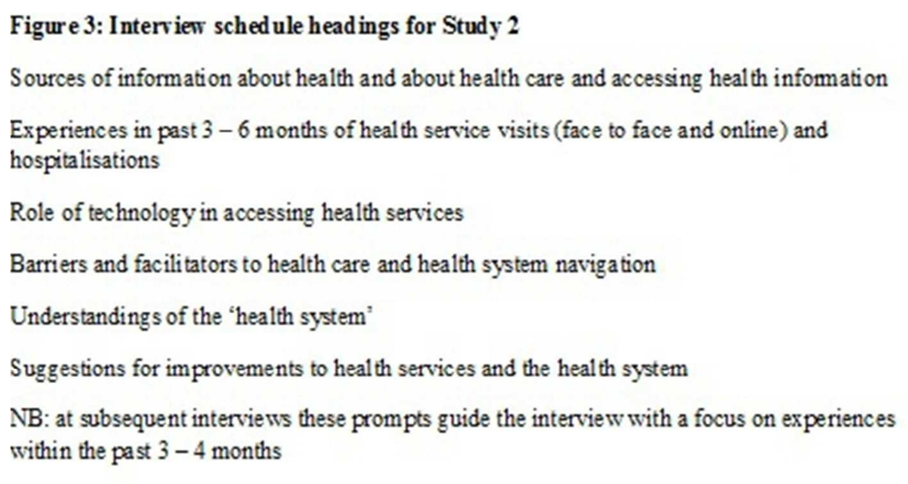

Figure 3: Interview schedule headings for Study 2

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 3: Interview schedule headings for Study 2

38x40mm (300 x 300 DPI)

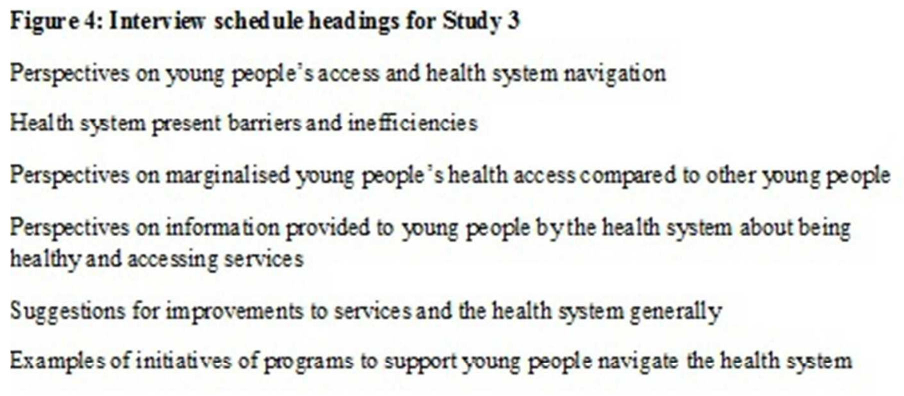

Figure 4: Interview schedule headings for Study 3

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

Figure 4: Interview schedule headings for Study 3

38x40mm (300 x 300 DPI)