

**Navigating health care, navigating transitions:
experiences of the health system for young
people of refugee background**

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Participants
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Youth Consultant Committee

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Background

- Access 1 and 2 (2000 - 2004) identified barriers to access to primary health care, models of service delivery and principles of better practice in Youth Health
- Informs the *Youth Friendly Checklist of Health Services* in NSW Youth Health Policy (2011 - 2016)

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The Access 3 context and focus

Context

- The emergence of a 'digital age'
- Increasing complexity of the health system
- Fragmentation of health care

Focus

- The whole health system (primary, secondary and tertiary care)
- Marginalised young people
- Health system navigation

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Access 3 – young people and the health system in the digital age

The aim is to explore ways in which young people 12 to 24 in NSW access, navigate and experience the health system.

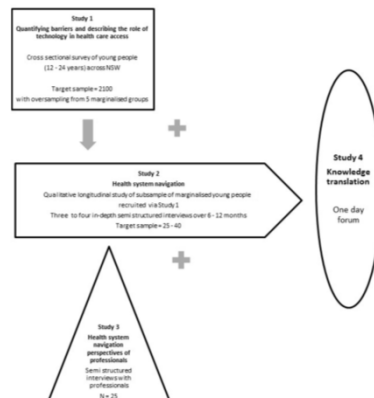
Particular focus on marginalised young people who are:

- refugee or vulnerable migrants
- homeless or at risk of homelessness
- Aboriginal and/or Torres Strait Islander
- living in rural and remote NSW
- gender and /or sexuality diverse and/or intersex

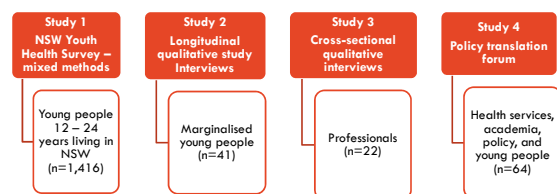
NSW Health funded the study to inform the new NSW Youth Health Policy.

Access 3 project design

Kang M, Roberts F, Sansi L, et al. Access 3 project protocol: young people and health system navigation in the digital age: a multifaceted, mixed methods study. *BMJ Open* 2017;e017047. doi:10.1136/bmjopen-2017-017047



Access 3: four studies



Study 1 - NSW Youth Health Access Survey – 2016 - 2017

- **Method** – A cross-sectional survey (online and offline)
- **Target population** - all young people 12 – 24 years living in NSW with oversampling of young people from marginalised groups.
- **Recruitment** – promotion via reference groups and youth consultants, outreach to services/ settings, paid social media advertising, employment of youth 'champion'
- **Survey** - developed in consultation with young people and reference groups. Interpreters and translation available.



NSW Youth Health Survey

Recruitment finished early February 2017

N = 2,100 in total with 1,416 completers

Rural Remote	Sexuality Gender Diverse Intersex	Aboriginal Torres Strait Islander	Homeless	Refugee	None of the above
478 (33.9%)	425 (30.1%)	169 (12.0%)	118 (8.4%)	75 (5.3%)	520 (36.7%)

Recruitment of refugee participants

- In the whole sample (1416 young people), 404 (28.5%) completed paper surveys
- By comparison, refugee participants mostly completed paper surveys: 57 out of 75 (76.0%)

Demographic characteristics of refugee participants

Characteristic	Whole sample N=1,416	Refugee n=75
Median age in years	18 years	17 years
Sex [n (%)]		
female	968 (68.4)	39 (52.0)
male	406 (28.7)	36 (48.0)
other	42 (3.0)	0 (0)
Religion [n (%)]		
No religion	665 (49.9)	2 (2.7)
Christian	423 (31.8)	38 (52.1)
Muslim	65 (4.9)	29 (39.7)
Buddhist	32 (2.4)	2 (2.7)
Hindu	14 (1.1)	1 (1.4)
Jewish	10 (0.8)	0 (0)
Not sure	123 (9.2)	1 (1.4)

Demographic characteristics of refugee participants

Characteristic	Whole sample N=1,416	Refugee n=75
Current study [n (%)]		
High school	645 (45.8)	37 (50.0)
Intensive English Centre (IEC)	21 (1.5)	11 (14.9)
Full time university or TAFE	441 (31.3)	17 (23.0)
Part time university or TAFE	80 (5.7)	3 (4.1)
Not studying at all	195 (13.9)	4 (5.4)
Other	25 (1.8)	2 (2.7)
Financial & health insurance support		
Youth allowance	312 (22.5)	33 (46.5)
Own Medicare card	634 (45.1)	37 (49.3)
Health Care Card	391 (27.7)	43 (57.3)
Private health insurance	634 (44.9)	9 (12.2)

Refugee young people (n = 75)

Refugee only	Refugee + sexuality/gender diverse	Refugee + homeless	Refugee + rural/remote	Total
51	13	7	4	75

ie, 24 out of 75 (32.0%) belonged to two or more marginalized groups

Health status of refugee participants

Compared to the whole sample*

- Less likely to have a chronic health condition
- More likely to score higher (better) on the wellbeing measure (WHO-5)
- No difference with respect to self-rated health and psychological distress

*(NB the whole sample is not in any way representative of all young people, there was a much higher prevalence of psychological distress and worse self-rated health in our sample)

Internet access and use (N = 1,416)

Have internet access: 96.1%

Less likely to have internet access:

- Marginalised 94.4% cf 99.0%, p<.001
- Aboriginal 87.5% vs 97.3%, p<.001
- Rural / remote 92.9% vs 97.7%, p<.001
- Homeless 91.5% vs 96.5%, p<.013

Barriers to health care

Would prevent me from visiting a health service:	Whole sample %	Refugee %
Cost	45.6	26.7
Opening hours mean I need time off study or work	31.7	21.3
I would feel embarrassed	27.6	12.0
Difficulty getting there	22.8	9.3
I would have to ask my parents/ carers to take me	22.0	12.0
I would feel judged	20.1	6.7
The gender of the doctor/ health professional	18.8	9.3
I worry about confidentiality	16.2	14.7
I don't have my own Medicare card	12.2	8.0
I don't know which service/s to go to	11.7	6.7
Language or cultural reasons	5.9	16.0

Health providers and services (N = 1,416)

Visited in past six months:	Whole sample (%)	Refugee (%)
GP/doctor	81.4	74.7
Dentist	45.0	37.3
Pharmacist/chemist	42.1	24.0
Counsellor/psychologist	29.3	14.7
Medical specialist (e.g. a skin specialist, surgeon)	19.1	12.0
Nurse	14.5	6.7
Physiotherapist	12.1	2.7
Psychiatrist	9.9	1.3
Nutritionist/dietitian	6.3	4.0
Paediatrician	3.8	2.7
Traditional healer	1.8	0.0
Other	4.6	0.0
None	8.2	13.3

Navigating the health system

Strongly Agree/ Agree	Whole sample %	Refugee %
I get confused by the number of different health services available	27.6	34.8
I have a good understanding of the different health services that are available to me	64.4	52.9
I can find and access appropriate health services when I need them	73.2	62.7
I have had to visit too many different services unnecessarily	16.8	22.9
I have been to lots of different services because I needed to	37.9	33.3
I would prefer to access online services than physically go to a health service for some health issues but not others.	31.0	20.3

Study 2 – Interviews with marginalised young people



Study 2 – Interviews with young people

- **Focus** - young people’s experiences of navigating the health system and identifying system inefficiencies
- **Method** - qualitative longitudinal study over 12 months using 3-4 in depth interviews
- **Target population** - 41 marginalised young people
- **Analysis** – grounded theory (Corbin and Strauss, 2015)

Study 2 Sample - Young people

Numbers in each marginalised group	n
Gender and sexuality diverse (sexuality diverse 22, gender diverse 7, intersex 1)	20
Rural	20
Refugee	9
Homeless	9
Aboriginal/Torres Strait Islander	5
Total (can belong to more than one group)	41

Study 2 themes

1. Multiple disadvantage makes health system navigation more challenging

– I put my dad as my next of kin and then they called him...[to] tell him to tell me to come like on Tuesday a certain time, but like my dad got all the message wrong, 'cause he can barely speak English, so I didn't go, but the next day I went and talked to them and they'll try to book another appointment for me...

- Female, 21 yrs, refugee

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

Sometimes Google is better than like GPs, no offence.

– Female, 21 years, refugee

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

[In relation to the young person's family GP, who speaks the same language as she does]

...if it's something...like mental health issues, I won't actually consider going... but if it's something physical, I can.

...I never talk about anything got to do with my mental health at all...if I go wouldn't he tell me mum accidentally? I'll be sitting down with my mum and he'll be like "Oh, so how did this and that?" I'm like, "Oh my God, didn't I just tell you it was my consultation, not with my mum?"

...I wait too long for nothing, and then give me not enough time to speak and he'll just talk to my mum... You go to a pathetic one that just drinks coffee and says nothing to you. Honestly. I just feel, well, I don't know English. Where else am I gonna go?

Every couple of months, I'll go to specialists for different stuff. And they're not really costly because my parents pay for it. But if it was to me I had to pay it for my own, I think it would be a problem

I'm always paying for medication. Well, because now my [healthcare card] claim is still in process so around three months, I have to pay the full amount without the health whatever. So, like for a drop this small I pay 40 dollars or I can get that for six. Like six dollars.

– Female, 17 years, refugee

4. Marginalised young people perceive and experience multiple discrimination

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

Female, 18 years, refugee

5. Technology brings opportunities to connect and engage with services

We are young and we use technology...like if you want to go to special doctor you can type in network and you can see who is good and which one recommended by people...maybe we can help our parents like this...telling them who is good and who to go based on people comments on it....

Male, 16 years, refugee

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

Trial and error

You just have to try a lot of them until one of them fit. I love this country for that reason. There're a lot of options out there. You just have to figure them out yourself and keep trying. I think that one of the biggest problems that faced refugee youth is because we don't know of the services that are available to us.

Disseminating system knowledge

Schools are a big thing. This PCYC, Community Centre...you know like places that you go after school and like play sports and stuff, that'd be pretty good. I know...the Youth Centre Community is there after school hours and that's such a great place to share information to young people and most of those young people are actually from like CALD communities.

Navigation support

Because at the end of the day, like the system is the main system for everyone, that everyone can access it, and as a young person or like immigrant or anything... It's kinda our job to adapt to it and find our way through it and it's just something, for me, I feel like it won't be fair to ask for any kind of – there's a positive discrimination in that regard But at the same time, what if in the medical centres, if they have like a caseworker or someone there that you can go and see first...someone that will actually understand these things.

The health worker for refugee youth, that's from like a multicultural background that kinda understand, you know so then you feel more connected, they relate to you, they're not really judging you to some degree.

-Female, 21 years, refugee

Refugee-specific themes

- Act as navigators for whole family
- Language
- Health beliefs
- Stigma (eg mental health, female sexuality)
- Gratitude (despite many barriers)
- Confidentiality
- Racism

Summary

- Limitations include sample size and sampling method
- Survey data don't tell the whole story
- Barriers are reported with less frequency but are still substantial, especially COST
- Understanding the health system is hard, though there is a perception that it is a good health system
- Navigation over time is complex and met with many challenges and obstacles

Further reading:

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

Robards F, Kang M, Luscombe G, Sancil L, Steinbeck K, Jan S, Hawke C, Kong M, Usherwood T. [Predictors of young people's healthcare access in the digital age](#). Australian & New Zealand Journal of Public Health, Online; doi: 10.1111/1753-6405.12936

Robards F, Kang M, Steinbeck K, Hawke C, Jan S, Sancil L, Liew YY, Kong M, Usherwood T. [Health care equity and access for marginalised young people: a longitudinal qualitative study exploring health system navigation in Australia](#). *International Journal for Equity in Health* 2019; 18:41.

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