HIV Health Literacy Framework Project
Health Care Provider’s Consultation in Cairns QLD on 23 August 2019
Foreword and acknowledgements

This NAPWHA consultation was facilitated with the in-kind support of Dr Lisa Fitzgerald and Dr Allyson Mutch from The University of Queensland – and later compiled as a report summary by NAPWHA research consultant, Ronald Woods, with supplementary information by NAPWHA Project Coordinator, Saysana Sirimanotham.

NAPWHA would like to acknowledge and thank people living with HIV (PLHIV) and health care providers who participated in the consultation for their time and insight; and conveying their experiences.

We recognise that much of the responses to HIV and AIDS relies upon people living with HIV continuing to put themselves forward and this social research is indebted to those past and present.

This report is made available to the healthcare providers and community health providers who participated in the consultation, and NAPWHA’s membership and associate membership comprised of incorporated people living with HIV (PLHIV) organisations in each Australian state and territory, and in Australasia.

NAPWHA also particularly thank the support of staff at Cairns Sexual Health Service – particularly Carla Gorton, Dr Darren Russell and Lucy Thallon in this instance, for assistance in mobilising participants at the Service in Cairns for this meeting.

With thanks to ViiV Healthcare for providing a research grant making this project possible.

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Background
The National Association of People with HIV Australia (NAPWHA) is committed to improving HIV-related health care and quality of life outcomes for all people living with HIV (PLHIV) in Australia. This includes promoting, and assisting all people living with HIV (PLHIV) to engage actively with, the HIV care continuum as an evidence-based means to maintain an undetectable viral load and have improved quality of life.

NAPWHA HIV Health Literacy Framework project
The NAPWHA HIV Health Literacy Framework (HLF) project examines the role of health literacy in enhancing the quality of life of PLHIV across the HIV care continuum. Women living with HIV (WLHIV) are a key focus of this project. The next phase of the project – ‘Let Women Talk’ – is designed to begin a conversation with women and enable them to share: their experiences of living with HIV and accessing high quality HIV related information, and to discuss and develop actions to support health literacy in relation to HIV. See more: https://napwha.org.au/health-literacy-framework/

‘Health literacy’ as a concept and contextualised with HIV treatment
HIV health literacy is a critical issue with personal and social benefits. As a social determinant of health, it reflects interactions between individuals, with varying skill levels, and the demands and complexities of navigating complex health organisations and systems (Woods, 2019). Within the context of this project, health literacy is understood as a measure of the capacities that individuals have to find, process, understand, and communicate health information and engage with services that can protect and promote their health.

Health literacy is complex, dynamic and multi-dimensional. In a literature review undertaken for this project, Woods defines health literacy as:

“a complex, multi-dimensional and dynamic interaction that is also a social determinant of health. It operates in tandem with other health determinants such as socio-economic status, level of education and gender to affect an individual’s ability to stay healthy.” (Woods: 2019).

A comprehensive HIV Health Literacy Framework Project Literature Review and Community Training Handbook (July 2019) authored by Ronald Woods is available via the NAPWHA website.
1. Introduction

Objectives
In keeping with the NAPWHA HIV Health Literacy Framework (HHLF) Project, consultations were held on 23 August 2019 with health care providers in Far North Queensland. The objectives of these consultations were:

- To identify corresponding strengths, gaps and limitations within the Australian health care system
- To identify opportunities and strategies for improving health literacy environments across the connected HIV-related quality of life domains

Process
A group consultation was held with 11 health care workers at the Cairns Sexual Health Service who provide HIV shared care to clients in Cairns and the surrounding region.

Another was held with five Aboriginal Health Care workers who work with Aboriginal and Torres Strait Islander clients in the same region.

Both consultations were digitally recorded and transcribed. In addition, brief interviews were held with a Doctor and Nurse. These were video recorded. Descriptive thematic analysis was conducted with key themes identified in relation to the key areas of focus. Quotes are used throughout the findings to illustrate key themes.

Ethical approval
This project remains the property and responsibility of NAPWHA and was conducted in accordance with the organisation’s processes.

This document
This document draws on the group and individual interviews to provide a qualitative analysis of key themes as they pertain to the consultation objectives and locates the findings within the context of the HHLF Project. The material is discussed in three broad themes:

- HIV and sexual health work in Far North Queensland, including features of working in and for Aboriginal and Torres Strait Islander communities.
- Understandings of health literacy – their own definitions, and their assessments of health literacy within the communities in which they work.
- Initiatives to enhance health literacy, beginning with an outline of priority populations.

The document is concluded with a summary of key points and putting forward a tentative response to the objectives outlined above drawing by on the qualitative analysis.
2. HIV and sexual health work in Far North Queensland

Diverse cohorts of PLHIV with high health literacy needs

In an individual interview, a Doctor identified a key feature of working in Far North Queensland as the wide variety of people living with HIV (PLHIV). The region contains the regional centre of Cairns, larger and smaller towns, rural areas, and remote areas. Cohorts of PLHIV include:

- Gay-identified men in the larger centres
- Fly-in fly-out (FIFO) workers, especially miners
- People who have acquired HIV overseas (countries such as Papua New Guinea and Thailand) and backpackers who are diagnosed in Australia
- Men who are non-gay identifying, but have acquired HIV through sex with other men
- Heterosexual women and men with often very limited knowledge of HIV
- Aboriginal and Torres Strait Islander people, who make up 16% of PLHIV in the region.

A consequence of this diversity is that health literacy needs tend to differ amongst the groups. On the whole, levels of HIV health literacy are low. As the Doctor noted:

"Some of the people who have been diagnosed have never heard of HIV before. Trying to explain those concepts, and the concepts of U=U [an undetectable HIV viral load means that it is untransmissible] and PrEP to a group who have never heard of HIV is, in fact, a big challenge. So, the health literacy needs are high."

Challenges

The participants in the group consultations had no difficulty in identifying key challenges of working in HIV and sexual health in Far North Queensland, summarised in Table 1.

Overleaf – Table 1: Challenges of working in rural/regional Queensland
### Challenges of working in rural/regional Queensland

<table>
<thead>
<tr>
<th>Factor</th>
<th>The factor as a challenge to health practice</th>
<th>Relevant comments made by health care workers in group discussions</th>
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<tr>
<td>Remoteness</td>
<td>Lack of both the quantity and the variety of services available due to it being a regional/rural/remote area.</td>
<td>“In terms of Brisbane or larger centres, you know, there are a variety of services and doctors, and all of that available, but the further north you go, you know, that reduces quite significantly.”</td>
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<tr>
<td>Social determinants of health</td>
<td>Of relevance to HIV health literacy, there were inadequate levels of HIV testing.</td>
<td>“One of the barriers at the moment is no testing, because no one knows what to do. If we get a positive, what do we do? I think that’s the issue. Us people that work in sexual health all the time, we talk about it all the time, and yeah, we’re doing it within our service, but then, outside, no one is doing it.”</td>
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<td>Discrimination and stigma</td>
<td>The powerful impact of social determinants such as socio-economic status and remoteness was acknowledged in all the discussions.</td>
<td>“...people you see that have more chaotic lifestyles, they live on a very day-to-day, hour-by-hour, minute-to-minute existence, and therefore the future stuff, about your health into the future, is just not something that they can even comprehend.”</td>
</tr>
<tr>
<td>Discourse and stigma</td>
<td>A wide range of fears and prejudices contributed to people being very hesitant to speak about issues such as sex, sexual health, HIV, and same-sex encounters.</td>
<td>“Clients...often have huge social and emotional issues and barriers, like issues around maybe homophobia or internalised homophobia, so that all plays in...”</td>
</tr>
<tr>
<td>Communication</td>
<td>Complexities around communication and shared information in a dispersed health provision setting involving several agencies, including issues such as security of emails and record keeping.</td>
<td>“…things like contact tracing and knowing who has been treated or who – the practicality side of the actual health system – really makes things difficult.”</td>
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<td>“I literally turn my computer screen around and show my clients how we make our information secure.”</td>
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### Costs

Participants described the complex pathways of care that required often very hands on, resource-intensive approaches to working with clients. They also spoke about funding arrangements, which could hamper continuity of care.

“I think that goes back to your point about resourcing. It’s incredibly labour-intensive, and there has to be very flexible models of care for it to work.”

“At the end of the day, it all comes down to funding...we work contract to contract. My specific job, I had eight months of funding and then wasn’t re-funded, so what’s that going to achieve?”

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### Aboriginal and Torres Strait Islander communities

Aboriginal and Torres Strait Islander communities in rural and remote areas were seen to be particularly disadvantaged in respect of their HIV and sexual health literacy:

*I think that people get scared, in remote communities, that when they get a diagnosis, they’re going to be sent to town, so that’s a big thing, everyone knows. Why are you being sent to town? There’s a huge fear – that’s a barrier.*

*I don’t know if it’s a health literacy barrier, but it’s something we need to address, and it’s a cultural thing, and it’s from years and years of knowing that if you’re sick enough to have to go to Cairns, you’re going to come back dead.*

— Aboriginal Health Promotion worker

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— Aboriginal Health Promotion worker

*Urban? Yes, they know everything...[but]...for us mob to sit down and try and talk to our mob about HIV, syphilis and everything like that, it’s a different bailgame.*

*You’re coming out to a completely different level...HIV and stuff like that is not on their agenda, you know? I’ve seen young fellas being diagnosed with syphilis, that think they’ve got HIV and go kill themselves, go hang themselves, because they’ve got no understanding of it, you know?*

— Aboriginal Health Promotion worker
A theme in the discussions was how silence was maintained in rural and remote communities about ‘what was going on’ in terms of sexuality, and the impacts this had on all aspects of HIV and sexual health literacy. For example:

They were saying – it was interesting – about syphilis, that they were doing contact tracing over in this one community...The fact that there was a huge number of the elders and the men who are having sex with each other, and the wives were aware of that, the community was aware of it, but nobody talked about it.

They were saying, well, how can they be shoulder-tapped, in order to be highlighted that maybe they need to be tested more often, or be offered PrEP, but how does that happen in a community that it goes on, but nobody talks about it?

— Clinical Nurse Consultant

I think that’s where the issue is. People are still separating it from the health thing, it’s still the sexual health thing, like it’s a separate sort of illness. You know, when you talk about sex, it’s the most natural thing, but nobody wants to talk about it.

— Aboriginal Health Promotion worker

In the discussions, this silence was linked to the strong need people had for anonymity – some not even wanting their GPs to know about an HIV diagnosis – due to fears they had of being cast out from their social networks. A factor that was strongly linked to the silence and fear of talking about issues, was the still-pervasive impact of the discourse in the early years of HIV/AIDS. For example:

If you think back to, like, Grim Reaper days of the 80s, that was a huge public message, and I think since then, there’s no broad public message. So a lot of people are just in a gap where they don’t realise there’s any difference in living with HIV from those days.

— Clinical Nurse Consultant

I’ve been thinking a lot about health literacy lately, and I notice that the research says that it’s really hard to change people’s ideas, once they get an initial idea, and I think that’s why the Grim Reaper is stuck in people’s head.

— Aboriginal Health Promotion worker
Another barrier to more open discussion about HIV and sexual health was that sexual health could often be seen both as something that was distant, and something that needed to be kept at bay:

*Therein lies the problem...they’ve got that much else to worry about, HIV is just another little thing, you know? You look at the chronic disease and everything else, it’s just another thing – you know?*

— Aboriginal Health Promotion worker

*You’ve got health staff, you know, they’ll gladly go and talk about diabetes. Go in and talk about sexual health? Oh, no! Leave that for the sexual health team! There must be something wrong, the sexual health team is coming in now. We need to normalise it.*

— Aboriginal Health Promotion worker

The strong links in people’s minds between HIV and homosexuality played an important role too in diminishing avenues for enhancing HIV health literacy, for example:

*A lot of people look at HIV as a gay disease, and I suppose, my thing is getting the rest of the community to look at it, and I suppose that’s my big issue, is how we do it?*

— Aboriginal Health Promotion worker
3. Understanding HIV health literacy

Own understandings as health care workers

The knowledge that the health care workers had of health literacy in general, and HIV health literacy in particular, was filled with insights that are well in keeping with discussions of the concept in the literature (see literature review). Comments included:

**HIV literacy, to me, means a sort of practical, workable knowledge of HIV as an issue, but also the health systems that surround that.**

— Senior Public Health worker

**HIV health literacy can be what the entire society knows about HIV, attitudes towards HIV, attitudes towards people that are living with or affected by, or communities that are affected, and discrimination and prejudice and barriers. And then you can then go down to health literacy within different groups that are affected, then the individual – what they know.**

— Clinical Nurse Consultant

**For me, it’s the vernacular that we use as clinicians – does that translates to people? And I think, a lot of the time, it can get caught up in those terms. Literacy is not just about speech, it’s about what people see, how they communicate. So I think it’s a bit more holistic than just words, or Post-Its, and what are the messages that we want to get across.**

— Clinical Nurse

**How I see health literacy is more, not only for our clients, but as someone already said, it’s society – as a whole, including us, as clinicians, and those working with people with HIV. Not only about the condition itself, but how that affects somebody’s body, somebody’s life, accessing services, and about living with HIV, as a whole.**

— Doctor
Levels of health literacy in the communities

When considering what might contribute to a person’s level of health literacy, the health care providers gave responses that reflected a deep understanding of its social determinants:

A poor health literacy profile is a history of not much health engagement. So, he’s heterosexual, Indigenous, in his 20s. He hadn’t been to a doctor in 15 years, and he just randomly came, because he wanted a t-shirt, because we were doing them for our campaign, and then got a HIV diagnosis. So, for him, the idea of having to see a health practitioner every couple of months was completely foreign.

— Nurse (speaking of one clients)

People who have got most of those things [raised within a safe family environment, had access to education, don’t necessarily feel as much prejudice or discrimination, have employment], they probably have more of an idea of – they probably have more information, and especially if they’re connected to the gay community, and if it’s around same-sex transmission ... Whereas I think for clients that don’t, often have huge social and emotional issues and barriers.

— Clinical Nurse Consultant

Thinking of people with high and low literacy, it’s often that sort of social isolation or social connectedness. So, I think if people are socially connected, either to gay community or other people with HIV – they have some social understanding, as well as an individual understanding, or a way to discuss and understand. I’ve seen a lot of people struggle, you know, that are very isolated, or keep HIV very hidden, and don’t get an opportunity to then build that understanding, or connection, or a sort of common understanding.

— Senior Public Health worker

Another factor that was raised as contributing to poorer levels of health literacy was the confusion that could arise for people who were in contact with another health care system in addition to Australia’s. As a Clinical Nurse related:

We’ve got a lot of clients that, say, partners are in Bali or somewhere like that, and the information that they’re getting in Bali is very different to the information they’re getting here, so that’s interesting for me.

— Clinical Nurse
Links between health literacy and the HIV Continuum of Care

Participants considered the ‘touch points’ between health literacy and the HIV Continuum of Care, and acknowledged, as one of the Nurses pointed out, that health literacy comes into play ‘...before diagnosis, and obviously at the time of diagnosis’. Another highlighted that education about HIV was also ‘passed down from lover to lover, and I think that’s something that we forget about, that that sort of literacy or health literacy also comes from within the community.’

Participants acknowledged the challenges of retention in care and maintaining undetectable viral loads through medication adherence. For example:

“It’s really tricky for people to continually take medication if they’re worried about what they’re going to eat, where they’re going to live, those really basics...

— Social worker

There’s a couple of our clients – every time we see them, they got a new number. They lost the last phone, and we haven’t seen them for months, we’ve been trying to chase them, then they decide, oh shit, I better go see if I’m due back at the doctor’s again.

— Clinical Nurse Consultant

For people that having been living with HIV for many years, there may be additional issues of their HIV literacy being out of date. For example, two Clinical Nurses narrated:

“I had a client yesterday, and the CD4 count to him is so important, still, and sometimes we don’t even do that test anymore, but for him, he was explaining that, you know, 200 meant this, and you know, not letting go of the education from the past, because that’s really important.

— Clinical Nurse

Some people are resistant to actually going onto newer single dose regimens, because they think, well, this has worked, I don’t want to change it. I’m holding onto this, I feel fine.

— Nurse
There was additional discussion in connection with the HIV Continuum of Care of ways in which program design and funding have an impact on ensuring that appropriate and relevant information was available to people. A health care worker noted that

“It’s a lot of reinventing the wheel, over and over again. It’s a lot of competition, and not a lot of communication amongst all the providers.”

— Health care worker

The suggestion is that linking health literacy to the HIV Continuum of Care – including promotion of quality of life – requires continuity of care. This in turn is promoted when there is solid inter-agency collaboration as well as health promoting policy and funding settings.
### 4. Initiatives to enhance health literacy

**Key population groups**

Participants were encouraged to consider the key population groups that needed support around health literacy. An analysis of their responses is contained in Table 2.

*Table 2: Priority groups for health literacy initiatives*

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<tr>
<th>Priority Group</th>
<th>Specifics</th>
<th>Example comments by the practitioners</th>
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<tbody>
<tr>
<td>Newcomers to Australia</td>
<td>Young men who are Asian-born and/or Asian cultural background</td>
<td>“Due to attitudes in their home countries, they probably come here and they experiment more…this sort of sense of liberation from the condom, and HIV is not so much a concern.”</td>
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<td>Migrants from developing countries</td>
<td>“If you’re coming from a country where maybe the health professionals – you can’t tell them everything, and then you come to our service, which is very open, a lot of the time they don’t tell you everything on the first visit, like risk factors or what’s been going on, because they’re not used to that sort of service.”</td>
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<tr>
<td>Women</td>
<td>Heterosexual women generally</td>
<td>“A percentage of the community services are quite MSM heavy, you know, the focus is in that context, so to get a heterosexual woman engaging in services is pretty hard.”</td>
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<td>Aboriginal and Torres Strait Islander women</td>
<td>“For women, and particularly Indigenous women, it’s even harder to find anyone [a peer] at all. There is a whole, I guess, intensified stigma attached to being a woman with HIV, and part of that is through lack of understanding that, you know, it is seen as something that men who have sex with men have, rather than women. But as we kind of see HIV, some of those diagnoses coming out in community, it’s actually really, really difficult for women to come to terms with their diagnosis.”</td>
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<tr>
<td>Priority Group</td>
<td>Specifics</td>
<td>Example comments by the practitioners</td>
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<tr>
<td><strong>Women</strong></td>
<td>Women migrants</td>
<td>“We have worked a lot with some women recently, who – so, no idea that they could have children, or what it means to have a relationship, and being able to have the conversations within their relationship, with their male partner and things, particularly challenging, and particularly challenging to link them with other services, and other members of their community that can help.”</td>
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<td><strong>Non-gay identifying MSM (men who have sex with men)</strong></td>
<td>Aboriginal and Torres Strait Islander men</td>
<td>“My clients didn’t want to talk to me, because health workers are community members, and they don’t want the community knowing they’ve got HIV. They want to see a white face, that doesn’t live there, that helps them deal with their HIV.”</td>
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<td>MSM that are also injecting drugs</td>
<td>“That’s literacy, isn’t it? – providing them with a menu of prevention technologies, and also for positive people, around how they can protect themselves.”</td>
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<td></td>
<td>Older men, often well educated</td>
<td>“They missed the boat on that education, like way back.”</td>
</tr>
<tr>
<td><strong>The society at large</strong></td>
<td>In recognition of the lag in community understandings around HIV, which have barely changed since the 1980s</td>
<td>“The Grim Reaper is stuck in everybody’s head. Not everyone talks about how terrible it was, but everybody remembers it, you know, even the old people who, you know, don’t know anything else about it, but they know about AIDS and the Grim Reaper, that’s all they know.”</td>
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<td></td>
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<td>“There needs to be some sort of global campaign around HIV, that goes out to everybody, everybody in community, and then there needs to be targeted approaches within different communities.”</td>
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Incorporation into everyday practice

With a focus on their own practice, participants were encouraged to share ideas on how lower levels of health literacy could best be addressed. Some saw the steps they took to enhance health literacy as part of the holistic practice they provided as health care workers.

For example: *It has to be holistic to the needs of the client, or the person that you’re talking to, or what their concerns are* (Clinical Nurse Consultant).

A Senior Registrar noted that ‘as well as educating the individual, it’s often educating a partner. I do a lot of work with the female partner who didn’t have HIV, because she had a lot of control over the household, and taking medication, and the outcomes for the positive partner…’

Participants noted the value of adopting a more indirect approach to health literacy improvement, for example, by helping a client with psychosocial issues and allowing enhanced literacy emerge from these interventions:

> Sometimes you have to get people’s needs sorted before they can focus on anything, so it’s great we have psychology and social work here, that can assist that life-ing stuff...sometimes you do that, and then the other stuff just falls into place, all those other conversations come out, while you’re doing the other stuff...

— HIV, Viral Hepatitis and Sexual Health Coordinator

A comprehensive approach of addressing low levels of health literacy was provided by a Clinical Nurse Consultant, who’s key point was that it wasn’t essential for her to do the education herself, but rather ‘facilitating my patients’ contact with someone that can educate them.’ The reason she provided was that ‘we want to encourage them to come to the health centre for everything else as well, and we don’t want to just focus on their HIV’.

In keeping with this, there was positive mention of the role of pharmacists:

> We have a pharmacy here onsite, and it plays a really important role with our clients, and the pharmacists do spend a lot of time one-on-one with clients, helping them navigate all this stuff, so we’re very lucky...

— Clinical Nurse

> I’m one of the pharmacists, so obviously a lot of my counselling is always around their medication...[but]...even though we do focus on the medication, we try and touch base with other things that – like their lifestyle and everything obviously influences how they take their meds...We see a lot of things in pharmacy that the clinic doesn’t see.

— Pharmacist
Peer-based methods

The participants spoke favourably about peer-based means of enhancing health literacy through comments such as the following:

"I really valued when we had the Queensland Positive Speaker program that helped people to gather together in safe groups, and learn how to tell their stories to others, not necessarily in the public sphere, but almost as a training ground for perhaps linking peers. Also, I think we need to resource that.

— Social Worker"

"I guess they [health care workers] have their modules that they go through with individual clients, to help them understand the diagnosis... but the value in a peer doing it is the lived experience that they bring to that conversation, and what that can mean to the newly diagnosed person.

— Clinical Nurse"

"One particular woman, when she did have the opportunity – she was adamant that she was having this struggle with treatment, and no doctor that she went to agreed with the side effects that she was experiencing...She finally met another woman who was experiencing exactly the same thing, and for her, that was very powerful.

— Clinical Nurse Consultant"

In terms of peer work in Aboriginal and Torres Strait Islander communities, varied experiences and opinions were shared. A Nurse related that: "I had a newly diagnosed, young Aboriginal MSM guy, about February, and I saw him again just last month, and he’s like, I’ve been telling all my friends to come in, and heaps of them have come for check-ups. He coped particularly well on the day of his diagnosis, anyway, so he’d be a great peer navigator.

On the other hand, an Aboriginal Health worker said that ‘there are no Indigenous peers, and it’s just falling through the gaps, or they don’t feel comfortable asking the questions’.

An Aboriginal Health Worker related the following in connection with peers functioning as Indigenous Health Workers:

"In 2017, [name withheld] who was on the HIV response team in WA, and she was calling in, and she said, I don’t get it: these Indigenous people, they’re being diagnosed, they’re getting on treatment, they’re stopping treatment and they’re dying of AIDS. I spoke to her recently...and she said, well, it’s changed. These people are getting on treatment. They’re being diagnosed, they’re getting on treatment and they’re living a happy life. I said, well, what’s changed? She said, we started using the Indigenous Health Workers.

— Aboriginal Health worker"
Community education

There was some discussion about different ways in which HIV health literacy was, or could be, addressed through various forms of community education. A Nurse suggested that it was important that ‘it needs to be not clinic-based, it needs to be outreach, or community-based’; and this was supported by an Indigenous Health Worker, who noted critically that ‘there’s nothing out around primary healthcare anymore. Everybody’s sitting in the clinics, waiting for people to come to them’.

A Clinical Nurse Consultant spoke about undertaking a ‘rural roadshow’ to Atherton; speaking with GPs; and conducting sexual health forums.

In terms of sexual health forums, two participants pointed out the value of not focusing solely on sexual health. There was support instead for including HIV and sexual health literacy within programs that focus more broadly on wellness and healthy living, or to incorporate material in youth and men’s forums.

For example: ‘If we are having a men’s forum or whatever, we do go hey, you guys, do you want to come and do sexual health, do you guys want to? – you know, that sort of stuff.’

A Nurse pointed to the value of adopting a staged approach to improving HIV health literacy:

> Within the community working in sexual health setting, especially with young people – and not only Aboriginal and Torres Strait Islander young people – it’s essential to take a step back from HIV literacy. You have to get even more basic than that, to sexual health literacy, then we can move on to HIV literacy, and at a much later step – treatment.
> — Nurse

The role of community champions was discussed, particularly in respect of Aboriginal and Torres Strait Islander communities – someone who could establish community trust and understand how the community works.

> You actually need champions on the ground, in the community, that live there and are part of that community, not fly-in-fly-out...not somebody who is on a two-year rotation, you know, because so much of it is about trust, and building those connections with people.
> — Social Worker

> We’ve got to be very careful of how we work with the community, because that’s where we live. If there’s an Indigenous thing that’s happening in the community, most of the indigenous people would be there. You’ve got NAIDOC, you know, All Blacks carnivals, things like that...that’s where we’ve got to be careful of where we work, what we do, what we say in our community, because they’re watching us all the time.
> — Aboriginal Health Worker
Another Aboriginal Health Worker pointed out the issue of potential community ‘labelling’ that would be important to consider with respect to community education in more remote areas:

*"I think if you focus on one group of people, they think, well, that’s just THEIR mob, that’s the mob who are going to get it. If anybody going to get it, it’ll be THAT mob, because that’s who they come and educate. Like, we’ve got to be very careful, if we go into Yarrabah [an Aboriginal community about 53 kilometres by road from Cairns on Cape Grafton] and do something, because we don’t want the community thinking, oh, it must be here, because they’re all coming here and doing the education. So, you know, we’ve got to sort of do it without attaching it to the community.*  
— Aboriginal Health Worker Nurse

**Proving education for other health professionals**

It became evident in the discussions that the participants played a part in educating GPs and other health workers in their communities around sexual and HIV health.

A Social Worker suggested that ‘the education side is needed for health professionals, as well. I went and did a talk the other day, in the hospital, to the social work department, and it was actually really scary, the lack of knowledge that they had, not only around medications and things like that, but around the stigma and the shame’.  

Other participants related, for example, that ‘we sometimes run the S100 prescriber doctor courses…’; and spoke about some of the challenges, for example: ‘Some of the doctors were concerned that there was too much…too many gays on the telly’.

Participants also spoke approvingly of more subtle means of sharing information, such as the wearing of t-shirts and the creation of a welcoming atmosphere in health care settings. For example:

*"…people are wearing the shirt, with HIV written on it, and they’re happy to wear it because it’s really attractive, I think it’s that very subtle acceptance.*  
— Clinical Nurse Consultant

**Maintaining one’s own health literacy**

Participants spoke favourably about their work situations enabling them to maintain and improve their own health literacies. This included online education, sharing with colleagues, specific events (such as planned dinner functions with guest speakers), and attending conferences. At the very basic level, it often just came down to: ‘Ask questions a lot’.
5. Summary and Conclusion

Summary of key points

Diverse communities mean diverse health literacy needs

HIV has an impact on diverse communities in Far North Queensland. The health literacy needs of these communities are thus also diverse. A commonality is that levels of HIV health literacy tend to be low, with consequences for health outcomes. Other challenges for health care workers include a lack of services – including inadequate levels of HIV testing – often linked to remoteness; the impact of social determinants of health; the pervasive effects of discrimination and stigma; and the communication difficulties and costs involved in working in a dispersed service provision context.

Indigenous communities in rural and remote areas

Aboriginal and Torres Strait Islander communities in rural and remote areas were seen to be particularly disadvantaged in respect of their HIV and sexual health literacy, and their health and wellbeing outcomes. Contributing factors were reported as the strong need people have for anonymity within their communities; that sexual health could often be seen both as something that was distant, and something that needed to be kept at bay; and the still-pervasive impact of discourses from the early years of the epidemic, including linking HIV with homosexuality, and viewing HIV/AIDS with trepidation as a terminal illness.

A congruence between health literacy knowledge of health workers and a systems perspective

The knowledge that the health care workers had of health literacy in general, and of HIV health literacy in particular, was in keeping with discussions of the concept in the literature. This includes its communicative and cognitive aspects, as well as its multi-dimensionality. There would appear to be strong congruence between their views, and the holistic, systems perspective that is integral to the emerging HIV Health Literacy Framework for this project. Participants also identified several ‘touch points’ between health literacy and the HIV Continuum of Care. They noted program design and funding impacts on their abilities as health care workers to provide continuity of care, including appropriate health literacy input at the various stages of care and to maintain quality of life.

When considering what might contribute to a person’s level of health literacy, the health care providers gave responses that reflected their deep understanding of its social determinants. These factors include: the impact of many people’s – especially men’s – lack of engagement with their own health or the health care system; and few opportunities to develop common understandings due to silence around sexual issues in general, and fear, stigma and discrimination in respect of HIV. These are all highly pertinent considerations for HIV health literacy initiatives within communities, not only in Far North Queensland, but in many other regions of Australia as well.
Key population groups identified

According to the health care workers, key population groups that needed support around health literacy include newcomers to Australia (specifically young Asian men and migrants from developing countries), women from all communities, and non-gay identifying MSM. There was also the suggestion that society at large needed to be addressed, due especially to the lingering impact of the 1980s messaging around HIV/AIDS. The consultations highlight the immense power of public health messages such as the ‘Grim Reaper’ campaign, and provide impetus for a new nationwide campaign that would bring a very basic level of modern-day HIV health literacy into the public domain.

Holistic practice approaches to patient health literacy

The health care workers took steps to enhance their patients’ health literacy as part of the holistic practice they provided, and engaged in community education wherever possible. They spoke highly about peer-based means of enhancing health literacy in target communities, including support for peers to be trained and resourced as Indigenous Health Workers. Participants also identified an important health literacy enhancing role for pharmacists, and spoke approvingly of more subtle means of sharing information, such as the wearing of t-shirts and the creation of an open and welcoming atmosphere in health care settings.

Conclusion

In recognition of the difficulty in generalising with confidence based on one set of consultations held in one region of the country, tentative conclusions are provided below. These are structured through addressing the objectives put forward for consulting health care workers within the HIV Health Literacy Framework project, described in the Introduction.

Strengths, gaps and limitations within the Australian health care system

Strengths identified through these consultations include:

- Insightful understandings about health literacy amongst health care providers working in HIV and sexual health provide a strong foundation upon which to plan HIV health literacy initiatives.
- The social determinants of health and health literacy are well appreciated by health care workers. Addressing these determinants is facilitated through the operation of multi-disciplinary teams. The role of pharmacists in these teams should not be overlooked.
- There is a well-recognised role for PLHIV as peer supporters, peer navigators and positive speakers. This is particularly important when considering the enhanced potential they would have Indigenous Health Workers.

Limitations and gaps include:

- There is an outdated conception of HIV not only in communities, but also among many health care workers, outside of those working in HIV and sexual health. This has profound impacts, beginning with inadequate levels of HIV testing.
• Program design and issues such as the often short-term nature of funding impacts on the ability of health care workers to provide continuity of care.
• While recognising decades of effort, greater attention could be paid to bringing about a better match between HIV and sexual health initiatives and the needs and realities of Aboriginal and Torres Strait Islander communities, especially those in more remote areas.

Opportunities and strategies for improving health literacy environments

Support health care workers to incorporate HIV health literacy into their everyday health care practices. Encourage work situations that enable them to maintain and improve their own health literacies. Provide opportunities for them to strengthen the roles they already have in educating GPs and other health workers in their communities around sexual and HIV health.

Promote and resource peer-based methods of enhancing health literacy, including an enhanced role for community champions, especially in Aboriginal and Torres Strait Islander communities. There is a particular need to encourage women living with HIV (WLHIV) to adopt peer support roles in regional, rural and remote parts of Australia.

Adopt outreach, or community-based approaches to health literacy development to complement the clinic-based approaches. Consideration could be given to programs that focus more broadly on wellness and healthy living, and that incorporate sexual health material in events such as youth and men’s forums. The issue of potential community ‘labelling’ is important to consider and sensitively address with respect to community education in more remote areas.

A nationwide HIV awareness campaign that explicitly counters the Grim Reaper campaign of the 1980s would go a long way to enhancing all of these potential strategies.
6. Appendix

Map of Queensland Primary Health Networks
Map of Hospital and Health Services, Queensland Health
by Recognised Public Hospitals and Primary Health Centres
(detail of Cairns and Hinterland and Torres and Cape)
**Document Control**

**Revision History**

The following changes have been made to this requirements specification:

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<th>Version</th>
<th>Prepared by</th>
<th>Date</th>
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<tr>
<td>0.1</td>
<td>Ronald Woods</td>
<td>23-Oct-19</td>
<td>Transcripts transposed into report provided</td>
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<tr>
<td>0.2</td>
<td>Saysana Sirimanotham</td>
<td>15-Mar-20</td>
<td>Report reformatted; supplementary content added – ready for circulation</td>
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**Related Documents**

- [NAPWHA HIV Health Literacy Framework Project – Evaluation Framework (June 2019)](Author: Ronald Woods)
- [HIV Health Literacy Framework Project Women’s Consultation in Melbourne VIC on 7 November 2019](
- [HIV Health Literacy Framework Project Women’s Consultation in Darwin NT on 7 November 2019](
- [HIV Health Literacy Framework Project Literature Review and Community Training Handbook (July 2019)](Author: Ronald Woods)

**Organisational Contact Details**

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<td><strong>Research funder</strong></td>
<td></td>
<td>The study is being run by the National Association for People with HIV Australia (NAPWHA) in partnership with Living Positive Victoria and Positive Women Victoria. ViiV Healthcare are providing financial support.</td>
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