

**napwha** national association of  
people with HIV australia

# **HIV Health Literacy Framework Project – Report on community consultations with Positive Heterosexual Men – Nov 2020**

Summary of findings compiled by:

**Ronald Woods Consultant** (with additions by Anth McCarthy and Saysana Sirimanotham)

## Foreword and acknowledgements

This report summarises community consultations which took place between Community Advocate, Anthony McCarthy, and 7 positive heterosexual men from June to August 2020. These were semi-structured interviews which were conducted via video calls during the CoVID-19 lockdown period in Victoria, and later transcribed and compiled into this summary by Ronald Woods – the research consultant for this NAPWHA HIV Health Literacy Framework project.

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

The project aims to build the knowledge and capacity to inform the process; and to allow participants to feel empowered to self-advocate in these important spaces. Participants were remunerated for their time; and if appropriate, given the opportunity to access to interpreter and/or subsidy for childcare or other travel expenses.

This report is made available to the Community Advocates of this NAPWHA project, the PLHIV 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 thank our community partners in various Australian state and territory for partnering on this project – particularly [Living Positive Victoria](#), in this instance, for their support.

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

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Saysana Sirimanotham NAPWHA	Project Co-ordinator	+61 424 898 698	<a href="mailto:saysana@napwha.org.au">saysana@napwha.org.au</a>

## Foreword from the Community Advocate

Anth McCarthy

It is safe to say that heterosexual men (HM) are not the most understood cohort of people living with HIV in Australia – even broadly speaking in the HIV sector. So being invited to join **NAPWHA’s HIV Health Literacy Framework (HLF) project** in 2020 as a community advocate – to be offered a role that facilitated a process of collaboration with them, was a welcome opportunity.



As a *Peer Navigator* employed at Living Positive Victoria (LPV), I provide HIV-focused peer support directly to HM. I am a link to individuals in my cohort, and I am well positioned to facilitate their involvement in HIV social research. For readers who are not already aware: **LPV’s Peer Navigator program\*** has HIV-positive peer workers providing one-on-one support to people living with HIV – whether newly diagnosed or not. Some people are self-referred to this service; some are referred by participating high-caseload clinics in Melbourne, Victoria – who LPV work collaboratively with.

For Australian-born HM living with HIV, identifying that HM peers are represented among the staff, holds significant symbolic value. It shows that they have been factored-in and catered for, and this can help create a sense of inclusion, and make that first connecting step easier. The presence of female peers can also play an important role in bridging barriers to engagement.

By ‘professionalising’ and investing in peers to support peers, LPV and NAPWHA champion the meaningful involvement of people living with HIV. The HLF project’s participatory action research model, placing community advocates at the centre, also reflects a fundamental commitment to meaningful involvement principles.

Coming on-board included education and training, and I was supported to deepen my theoretical understanding of health literacy across the HIV continuum of care\*\*. I discovered concepts like *health literacy ecosystems*, and *distributed resources*. I began to appreciate the opportunity to benefit vulnerable and under-served communities.

Successfully consulting HM would advance our understanding of health literacy dynamics among them. They in turn, might be able to reveal insights into the health literacy and messaging of the institutions and structures they encountered. The learnings might lead to purposeful interventions and contribute to the formation of a framework that would benefit all.

### Participants

I recruited 7 HM from among my peers, to explore HIV health literacy through personal experiences. CoVID-19 lockdowns prevented the preferred option of meeting face-to-face as a group, for shared conversations. So, I spent time designing, testing, and fine-tuning a semi-structured interview guide that I would use to have a dialogue with them individually.



I got lots of helpful feedback and direction from Ronald Woods (training and development consultant of this NAPWHA project), Saysana Sirimanotham (the project coordinator) and the other community advocates (pictured left).

\* Find out Living Positive Victoria’s Peer Navigator program – <https://livingpositivevictoria.org.au/programs-and-services/one-on-one-support/>

\*\* Download a Community Training Handbook [https://napwha.org.au/wp-content/uploads/2020/02/NAPWHA-HIVHealthLiteracyFramework-CommunityTrainingHandbook\\_v2.pdf](https://napwha.org.au/wp-content/uploads/2020/02/NAPWHA-HIVHealthLiteracyFramework-CommunityTrainingHandbook_v2.pdf)

### Recruitment based on digital literacy and access

Given the hard CoVID-19 lockdown in Victoria which restricted movement of households, lasting thereabouts from March right through to November 2020, there were limitations to this community engagement activity. I selectively recruited interviewees who were confident and articulate, able to elaborate upon their experiences and ideas, and who were comfortable and capable using technology.

Meeting with the men for video interviews (via Zoom platform) allowed more in-depth discussion of their personal journeys, but it lacked the synergistic effect that takes place when participants can bounce ideas around and contest ideas. However, the seven hours of qualitative data that was generated was valuable and revealing.

### HIV Health literacy findings synthesized in this report

Reading through Ronald Woods' analysis of the one-to-one interviews was like coming home after someone has cleaned and tidied your house in a very thoughtful way. His analysis fitted with what I knew (or thought I knew) but while mine was a chaotic collection of facts, anecdotes and hunches, some conscious, some not, Ron's synthesis was ordered and eloquent, with rational conclusions and cautious generalisations.

As I continue my work as a peer navigator, I have a new language at my disposal, and I will be looking through the health literacy lens often. I will not just be focusing on my peers, but on the systems with which they must engage. And whether that engagement is harmonious or not, I will be able to take a more analytical and critical stance.

The HLF project has actively sought out, respectfully engaged, and carefully listened to heterosexual men living with HIV. We have genuinely been consulted as experts and encouraged to guide and participate in a process of research and understanding. I am very grateful for this.

To the seven men who trusted the process, by allowing me to interview you – a big thank you. You have provided valuable insights and knowledge that will benefit the whole community of people living with HIV.

— Anth McCarthy  
November 2020



*Anth has lived openly with HIV since 2016. He works with a broad cross-section of PLHIV in his role as Peer Navigator at Living Positive Victoria. In particular, he provides targeted peer support to other heterosexual men living with HIV. He collaborates with them individually and in groups, to promote well-being, build resilience, build community and a sense of connection to the Body Positive.*

*Anth is a qualified social worker, and member of the Positive Speaker's Bureau in Victoria. He is a quiet and steadfast community advocate. He is married to Jennifer and has two teenagers.*

## Table of Contents

<i>Foreword and acknowledgements</i>	2
<i>Table of Contents</i>	5
<i>Background</i>	6
1.1. NAPWHA HIV Health Literacy Framework project	6
1.2. Community Advocates as Health Literacy ambassadors	6
1.3. Using participatory action research	7
1.4. Project activities – Investigative Phase	7
2.1. Why heterosexual men?	9
2.2. Process of engagement	9
2.3. Limitations	10
<i>Community Consultation Summary</i>	11
3.1. Key Insights	11
<i>Health literacy through the eyes of participants</i>	12
4.1. Meanings	12
4.2. Sources of HIV-related information	13
4.3. Content of HIV literacy	16
<i>Health Literacy via the HIV Care Continuum</i>	18
5.1. Pre-diagnosis	18
5.2. Testing and diagnosis	19
5.3. Engaging with the health care system and with HIV treatment	20
5.4. Adhering to treatment and staying undetectable	21
5.5. Quality of Life	22
<i>Views on HIV health literacy and services in Australia</i>	24
<i>Insights for NAPWHA campaign areas</i>	28
6.1. HIV treatment awareness campaign	28
6.2. Own Tomorrow campaign – aiming for good quality of life and patient self-advocacy	29
6.3. Pregnancy and parenting	30
<i>Strategic Plan for HLF Project x ACE Evaluation</i>	31
<i>Appendix</i>	34
8.1. Document Control	34
8.2. Related Documents	34
8.3. Organisational Contact Details	34

## 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.

### 1.1. NAPWHA HIV Health Literacy Framework project

NAPWHA's Health Literacy Framework Project is a three-year initiative (2019–2021) that addresses the role of HIV health literacy in improving HIV-related health care and quality of life outcomes for all PLHIV in Australia. The study is based on the recognition that:

- HIV health literacy in the broader population may not have kept up to date with the profound changes that have characterised HIV and AIDS since the mid-1990s, with consequences for stigma, perceptions of risk, and transmission.
- Changes in HIV notifications (especially over the past decade) have contributed to changes to the make-up of the body positive in Australia.
- Peer-based community organisations such as NAPWHA play an important part in the HIV health literacy ecosystem.

The overall objective is to generate, put into practice, evaluate, and revise, and disseminate a 'HIV health literacy framework' to support improved health literacy that would benefit diverse cohorts of PLHIV. Initially, the project has focused on positive women and heterosexual men, and there is a focus too on paying attention to HIV health literacy (or the lack of it) in the general community.

A key intended outcome is that community-based peer organisations, beginning with NAPWHA itself, will enhance their own health literacy so as to have improved conversations with people from groups – now increasing as a percentage of the total body positive – who may have been less visible in the HIV health literacy ecosystem up to the present.

See more: <https://napwha.org.au/health-literacy-framework/>

### 1.2 Community Advocates as Health Literacy ambassadors

The NAPWHA-based project team engages the countrywide peer networks to recruit individuals from the key priority populations as research partners. These partners support the development of the health literacy framework – which includes a focus on messages as well as channels of health-related information – and they contribute actively to the research and evaluation associated with the project.

These 'Community Advocates', coming from all over Australia, are provided with training on:

- HIV health literacy and its links with the HIV Care Continuum;
- communication and group facilitation skills; and
- a systems perspective on health literacy interventions.

Working as a team and individually, the community advocates reach out to other women and heterosexual men living with HIV in their regions.



Community Advocates (L-R) – Rita Broughton, Sarah Feagan, Emma Sheldon-Collins, Ron Woods (NAPWHA Training & Research consultant), Lara Kruizinga, (Above) Precious Mapfumo, Diane Lloyd, and Anth McCarthy.

### 1.3 Using participatory action research

Using participatory action research combined with community development approaches, Community Advocates seek to strengthen peer bonding. Drawing on these developing relationships, they work with the project team to build up a picture of how health literacy accompanies their peers on their journeys into living with the virus. This enables them to consider the strengths and shortcomings of current HIV-related messaging and platforms.

Based on the strengthened peer relationships and engagement with NAPWHA, community advocates – our research partners – suggest what changes could be made to improve health literacy and then put some of these changes into practice through helping NAPWHA improve its communications with women and heterosexual men. Supported by capacity-building approaches that include training and mentoring, they are also actively involved in evaluation of the project.

### 1.4 Project activities – Investigative Phase

In the first year of the project, three Community Advocates (Sarah Feagan, Emma Sheldon-Collins, Precious Mapfumo) were appointed by NAPWHA, provided training, and asked to design a process whereby to engage with their networks of women living with HIV. The aims of the community engagement were to investigate HIV health literacy strengths, gaps and needs for women living with HIV (WLHIV) and ask participants to engage in health promoting actions with regards to HIV health.

This initial investigative phase of the project was conducted as a series of facilitated community consultations:

- Two focus groups were run for and by women living with HIV was conducted in Melbourne in October 2019 and Darwin in November 2019. These events were called '[Let Women Talk](#)' –

and 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.

- In April and June 2020, in collaboration with [Positive Women Victoria](#) two additional community consultation with women were led by NAPWHA and Community Advocates to develop a health literacy initiative focused on supporting women living with HIV in Australia who are considering infant feeding options.
- In the second year of the project, four more Community Advocates (Lara Kruizinga, Diane Lloyd, Rita Broughton, and Anth McCarthy) were appointed by NAPWHA to continue a process of designing a way of broadening the engagement with PLHIV – including women in Victoria, Queensland, Western Australia and Canberra. Community consultations were conducted as one-to-one semi-structured interviews during the CoVID-19 lockdowns in Australia from June to September 2020.
- As this process would then be extended to other communities within the body positive, and the developing Framework shared within the sector, a smaller pilot for investigating the health literacy strengths, gaps and needs of positive heterosexual men was initiated by Anth McCarthy. This initiative, discussed in this document, provides therefore an early opportunity to apply and refine the Framework, as well as yielding rich qualitative insights.
- In the second phase of the project (2021) – the implementation and evaluation phase – Community Advocates will continue to contribute on NAPWHA-led health literacy initiatives and campaigns which have been informed by the beginning half of the project, or investigative phase. See: [Strategic Plan for HLF Project x ACE Evaluation on p 31-32](#)

## Heterosexual men as a HIV health literacy cohort

In the second year of the HIV Health Literacy Framework project, a pilot commenced to investigate HIV health literacy strengths, gaps and needs for heterosexual men living with HIV.

### 2.1 Why heterosexual men?

Heterosexual men who do not have sex with other men are not considered to be an at-risk demographic for acquiring HIV in Australia. Still, HIV notifications among heterosexual men have been increasing over the past decade, particularly among Australian-born males<sup>1</sup>. They are the second cohort – after women – focused upon in the HLF project. The aim, as with positive women, was to engage with peers in this ‘health literacy cohort’, to invite them to share insights about HIV health literacy from their perspectives, and to apply these insights in health literacy campaigns designed also as part of the project.

### 2.2 Process of engagement

One of our peer Community Advocates, Anth McCarthy, engaged with other heterosexual men and invited them to take part in the HLF project. Following the model adopted in earlier consultations with women, this was intended to take on the form of a focus group discussion moderated by the Community Advocate in Melbourne. A group size of four or five was considered achievable.

Due to the CoVID-19 pandemic, and the restrictions on movement and social contact that this entailed, the method of consultation was changed from a focus group discussion to one-on-one discussions conducted by the Community Advocate, all taking place in mid-2020. Use was made of the Zoom application (real time, virtual face-to-face, recordable). Through this method, seven men agreed to participate (n=7), following strict ethical research protocols such as de-identification, the safe gathering and storage of data, and the obtaining of informed consent.

In this document, the in-depth discussions are analysed qualitatively and in keeping with the objectives of the HLF project (see [project documentation](#)).

---

<sup>1</sup> In the 10 year period 2008–2017, the number of heterosexual notifications in Australian-born males increased by 45%, from 49 in 2008 to 89 in 2017 (Kirby Institute, 2018, *HIV in Australia: Annual Surveillance Short Report*, p. 18, [https://kirby.unsw.edu.au/sites/default/files/kirby/report/supplHIV2018\\_content\\_20180920r.pdf](https://kirby.unsw.edu.au/sites/default/files/kirby/report/supplHIV2018_content_20180920r.pdf))

## **2.3 Limitations**

While enabling more intense examination of personal experiences and perspectives, one-on-one interviews miss out on the rich interpersonal insights that emerge within a group context.

The participants were not a random sample of HIV positive men in Australia who would identify as 'straight', or 'heterosexual', or 'non-MSM (men who have sex with men)'. All participants were actively connected with HIV peer support networks, and, indeed, had a trusting peer connection with the Community Advocate conducting the interviews. Their perspectives may therefore be biased towards highlighting the importance of peer support. They may also have the enhanced HIV literacy that such peer contact enables and promotes. This may not reflect the reality for the majority of positive heterosexual men.

## Community Consultation Summary

### 3.1 Key Insights



From seven heterosexual men participants interviewed by Community Advocate, Anthony McCarthy, several insights regarding HIV health literacy can be highlighted.

#### The importance of peers –

Peer connection particularly with other positive heterosexual men and women, was identified by all participants as an important part of their health literacy ecosystem, together with health care providers and the internet. A trend was to identify establishing peer connections as early as possible after diagnosis as *the* factor that encouraged them to engage purposefully with the health care system.

#### Strong focus on the literacy required to understand and comply with HIV treatment –

From an often minimal understanding of HIV before diagnosis, the men sought as much information as they could around the time of testing and diagnosis. Their HIV literacy continued to grow as they engaged with, and adhered to, treatment, and focused on quality of life. Their discussions focused prominently on the functional literacy they needed to understand and comply with HIV treatment. This included knowledge of medication options, side effects, and drug interactions.

#### Confidence in the science promotes a focus also on broader aspects of health literacy –

Achieving an undetectable viral load soon after starting antiretroviral (ARV) treatment gave the male interviewees confidence in the science. For many, their regular contact with their treating physicians provided the best opportunity to focus on HIV, which did not occupy their minds a great deal otherwise. Some acknowledged that health literacy included a focus on lifestyle factors such as diet and exercise, and a broader striving for wellbeing. Some explicitly identified empowerment and improved self-confidence as part of health literacy.

#### Other common trends in the discussions –

- The narrow circle of people with whom they had shared their HIV status
- The intersection of substance use and HIV in their life journeys
- The impacts of stigma, fear of disclosure, isolation, and loneliness on quality of life
- The identification of heterosexually active men who travelled frequently to especially south-east Asian countries as being at higher risk for acquiring HIV
- Addressing low levels of HIV literacy within the wider community through improved messaging on testing, and on topics such as U=U (undetectable equals untransmissible)
- The value of PLHIV networks taking steps to become more health literate with respect to heterosexual PLHIV

## Health literacy through the eyes of participants

### 4.1. Meanings

'Health literacy' did not resonate as a concept for some participants. When thinking about what health literacy *could* mean, however, some easily identified the gaining of knowledge as central:

*I guess it is the availability of information regarding a particular topic, in this case, health. It is the access to information and the information itself – finding it, understanding it, and using it. And also, about how it is presented to you.*

— Bertie

*It's about looking for health information, for example whether HIV medications would react with other medications.*

— Charles

Others were more comfortable with the term – both knowledgeable about, and confident in, their own health literacy:

*Health literacy is finding information, understanding it, and making use of it. Like when I was looking at material on prostate health this morning! So, I feel comfortable about looking for health information.*

— Earl

*Having good health literacy is highly meaningful. Currently I have been dealing with HIV drug resistance, and my understanding of HIV has increased tremendously.*

— Arnold

When messaging around COVID-19 was briefly raised in the discussions as a topical and current example of health literacy in action, participants had no difficulty in identifying the health literacy aspects of the pandemic:

*Because of my job, I spend a lot of time on understanding COVID; it is very important for me to get all the information I can... I am responsible for a team, so I have to keep informed and up-to-date.*

— Bertie

*Under COVID, HIV has moved to the backburner. The questions around COVID have made me think. I feel worried that after so many years, they still have not found a cure for HIV – have to keep on dealing with it.*

— Felix

Participants were, as PLHIV, able to draw parallels between the two pandemics. Ginger mentioned that *‘the stigma around COVID brings up feelings for many poz people’*. Showing strong insight into the social determinants of health, Felix specifically mentioned economies opening up after the pandemic lockdowns, travel opening up, and people in many south-east Asian countries being desperate for work:

*Be careful FIFO [fly-in-fly-out] workers, especially after COVID! Sex will be on tap.*

— Felix



## 4.2 Sources of HIV-related information

### 4.2.1 Peers

Having contact with peers, and particularly with other positive heterosexual men (and women) was identified by all participants as an important part of their health literacy ecosystems, for example:

*The positive community plays a big part in my health literacy. It is all of our journey. I really value the lived experience in learning health literacy stuff with peers.*

— Arnold

Several reasons were given for the importance of peers:

**Trustworthiness of the information —**

*‘Peer organisations such as NAPWHA would be my first stop for health literacy information. If I find something online, I would always go to peer organisation websites to check if it’s OK.’*

— Dean

**Supportive of their mental health —**

*‘Engaging with a peer support organisation was a kick up the arse for me when I’d been feeling low and had stopped taking medications. It put me on track to gain control of my life. It is a welcoming PLHIV organisation where I didn’t feel excluded.’*

— Arnold

Providing an alternative to stereotypical images of PLHIV —

*'One of them made me feel that it's ok to be me. He was like a mother hen taking me under his wing. A human being who allowed me to have the feelings I was having. All in the first hour and a half.'*

— Ginger

Social connectivity —

A peer support organisation is *'not only a safe place – it provides opportunity for interaction, and resources for people with nowhere else to go.'*

— Ginger

Several of the participants spoke highly of a WhatsApp group for straight men as a useful source of accurate HIV information and support for them. A platform such as this provides an example of the distributed nature of HIV literacy, as noted by Anth, our Community Advocate:



*I am very glad to see that the peer navigation clients [heterosexual men] that I currently see suggested starting a shared WhatsApp group, and they moderate it, and share information – stuff that they have learnt – with each other.*

— Anthony



There were differences of opinion as to whether peer support in a face to face context was more effective if it was heterosexual-specific, for example:

*I have found that I am welcomed in what is predominantly a gay male environment. The gay guys are becoming more accepting of us being part of it. In recent online meetings with gays and straights, I've seen that this opens up avenues for working together, and it's good to have one community, rather than to separate out because of your sexuality. One community is experience shared; we are all human beings.*

— Dean

### Author's viewpoint

This is perhaps the issue that lies at the heart of the HIV Health Literacy Framework project: the Australian body positive, approximately 26,000 people, is at once a community in itself (PLHIV), and a mosaic of distinguishable cohorts – for example, women living with HIV.

In terms of the peer support network, and especially NAPWHA with its national reach, it's about achieving a balance in health literacy outreach, engagement and messaging between what is common to all, and what is specific to a definable cohort, all the while acknowledging the history of the epidemic in the country.

Within the distinguishable cohorts there are sub-cohorts with very different needs. For example, while some positive heterosexual men are held back from engaging with the body positive by homo-negative views, others are very comfortable to associate with gay, bi- and non-binary men.

#### 4.2.2 Patient/provider interactions

All participants obtained HIV-related information when interacting on a regular basis with their HIV health care providers. Although this generally referred to physicians, the primary provider for one participant was an HIV specialist nurse. Another noted:

*I am having a better relationship with GPs recently, am more confident in chatting with new GP about all kinds of issues, not only HIV.*

— Arnold

#### 4.2.3 Internet

Almost all participants obtained health-related information online and had a relationship with ‘Dr Google’, even if this relationship was not always satisfying. For example:

*I come across things online. Anything that I see that is in the news on the topic, I pay attention to, and try and check with independent sources.*

— Bertie

*You need to have your antenna out because sometimes a load of B.S. is sent out on the internet, like, around cures [for HIV].*

— Felix

*When first diagnosed, I was told by the doctor to avoid the internet, which I did. But then, when I went to [peer support service], they gave me a list of reliable sites and this is good for passing information on to partners, for example, around U=U.*

— Ginger

*Things change fairly rapidly in lots of areas, so I'm always on the lookout for new information. I'm able to work out quickly if a website is trying flog you something, and I'm wary of those bits of information.*

— Earl

While not as common as using a search engine, some of the men also obtained information through social media. The unreliability of this information was highlighted.

#### 4.2.4 Publications

Several participants mentioned *Positive Living*, NAPWHA’s publication of more than three decades – see: <https://napwha.org.au/positive-living/> – as a valued source of HIV-related information and of insights regarding lived experience. Since it is now a fully online resource, it is difficult to separate it – and other publications like it – from the internet/social media/digital space.

#### 4.2.5 Everyday contexts and social situations

None of the participants reported that HIV-related information or anything else to do with HIV literacy came up in everyday contexts and social situations with non-positive people.

#### Workplaces

The workplaces of some participants were sources of health-related information, and this included material on HIV within official documentation. A large employee such as the military, for example, was identified as having *'Standard Operating Procedures and Health Directives that contain guidelines that navigate you through to health issues such as degeneration of bones, infectious diseases.'* (DEAN).

Some participants suggested that discussions about the dangers of unprotected sex in foreign countries may be included in workplace banter, for example among men in the mining sector when discussing their upcoming leave.

### 4.3 Content of HIV literacy

At the time of the consultation, all participants were engaged in treatment and it was not surprising that their discussions of HIV literacy focused prominently on the functional literacy they needed as PLHIV to understand and comply with HIV treatment. This includes:

- knowledge of medication options
- side effects; and
- drug interactions.

There was some discussion of injectable medications in the not-too-distant future. One noted that it would help him with his sexual relationships, because the taking of medication would not be an interference – i.e. visibility through having pills around; and taking them.

A few mentioned news stories on a 'cure' for HIV, but also acknowledged that they were fairly sceptical of this kind of information.

Some participants expressed a broad understanding of 'health' through acknowledging, for example, that health literacy for them also included a focus on lifestyle factors such as diet and exercise, and the search for wellbeing through means other than taking medication.

Some explicitly identified empowerment and improved self-confidence as part of health literacy, for example:

*I feel much more empowered now. Health literacy is not only about what I know, but also what other people know, and this helps me to be empowered... It's not about pleasing the doctor, rather, it is the other way around.*

— Charles

None of the participants made links between their understanding of the 'HIV sector' and their health literacy. One did mention that *'the HIV sector seems to be very fragmented. They should streamline these websites – it is difficult to find a resource when they are all over the place. We need some clarification with all of the acronyms.'* (Earl).

## Case study: Understanding and application of U=U

The topic of U=U (undetectable equals untransmissible) emerged in all of the discussions with participants. It is a current and relevant example of HIV health literacy in practice.

Based on the levels of literacy they displayed and their active engagement with the health care system, participants easily identified that the goal of HIV treatment was to achieve and maintain an undetectable viral load.

Participants also understood that ‘being virally undetectable’ was good for their health, and good for reducing transmission to others – that treatment is prevention. Not all knew that this could be formulated with the concept ‘U=U’.

For example, it was only in this very conversation with the Community Advocate that it became clear to one of the participants that *‘being undetectable means I can’t transmit the virus’* can be labelled U=U. In other words, the slogan may not yet have wide reach, but the underlying message has.

Participants expressed positive feelings and attitudes towards U=U – however, there were some comments which suggest a cognitive struggle between old and new messaging.

*That changed the way I was looking at myself. I am no longer a contagion to society. U=U helped me to reverse to the person I really was.*

— Bertie

*I understand U=U but did not ‘believe’ it then when I heard it first.*

— Ginger



Participants recognised that U=U was not commonly known within the broader community.

At the same time, they felt that, if it were, it would go a long way towards improving the quality of life of PLHIV. This was identified as being due especially to the potential impacts this insight would have in helping the public recognise that HIV is a manageable condition and not a death sentence, and in addition that PLHIV were not a danger to society. Participants recognised the potentially enormous effect this change of attitude would have in reducing HIV stigma and shame.

Messaging around U=U was also identified as being especially important within a sexual context. For example, one of the participants related how he had phoned his peer navigator to clear up the U=U issue because he was contemplating sex with a woman.

The increased literacy raised other issues for him as well:

*I always have that disclosure issue, morally I should say something, but perhaps I don’t need to [in light of U=U]?*

— Charles

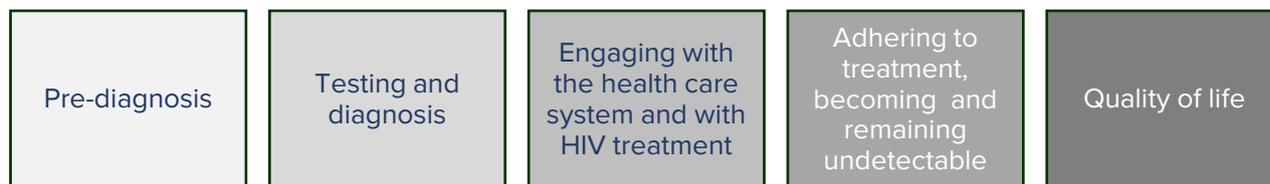
Linked to this was the sounding of a note of caution:

*‘There needs to be more information on what undetectable means, although this can also go the other way, you know, men becoming blasé about HIV.’*

— Felix

## Health Literacy via the HIV Care Continuum

Every person living with HIV has a unique journey with HIV. Through sharing key aspects of their individual experiences, participants were encouraged to focus on how health literacy emerges in and through these experiences, discussed below in five areas linked to the HIV Care Continuum:



### 5.1 Pre-diagnosis

Participants identified HIV as being a blood-borne virus that can be transmitted sexually. Before diagnosis, many had had the understanding that HIV was one of the sexually transmitted infections that would periodically need to be tested for. At the same time, HIV was not considered to be a threat to them as heterosexual men. As one noted:

*All my life I have been blasé about sex, thinking, ah, HIV could not possibly happen to me. I have been having condom-less sex all the time, unless the woman insists.*

*Lots of times, I'd get drunk, sleep with women, sometimes prostitutes, most of the time not use condoms, and worry about it afterwards, even jot it down that I need to have a HIV test. There were a few times I had chlamydia and gonorrhoea. So, it has always been in the back of my mind, HIV and other STIs, but when you are drunk, you forget about that.*

— Felix

This sense of HIV 'being in the background' was shared by others who paid regular visits to countries with a higher prevalence of HIV, especially when these visits included having casual sex with women (including sex workers) and/or pursuing relationships with women in those countries. Some participants remembered well the literacy around HIV in the 1980s, for example:

*I HAD some information on HIV. Got information when going to [south-east Asian country] in my 20s. It was the heady days of the Grim Reaper; it was all over the place. I knew what was needed to stay safe but did not do it, we got on the drink, and it all flew out the window.*

— Earl

One participant remembered as part of his pre-diagnosis understanding of HIV that he mistook a reduction in probability (as afforded by circumcision) as a sure 100% effective protection against sexual transmission of HIV. This is possibly a confounding issue for both circumcised and uncircumcised men, and indicative of a gap in HIV literacy for this individual and others.

**One of the participants has had a long journey with HIV:**

Both of his parents were HIV positive, the transmission in his case was paediatric, and he had grown up as a PLHIV in the era of antiretroviral therapy (ART). While in his own case, therefore, living with HIV was akin to having a chronic manageable condition, he had direct family experience (including the death of his mother) which enabled him to identify well with the more tragic times of the epidemic and the public messaging of the time.

## 5.2 Testing and diagnosis

As could be expected with any sampling of the experiences of PLHIV, the routes towards testing and diagnosis for these participants were unique and personal. Except for one paediatric transmission, the commonality was that participants were all heterosexual non-MSM men who were not regarded as being at risk for contracting HIV in the Australian context.

Lifestyle factors had nonetheless made some of them consciously aware that they may be at higher risk than perhaps the ‘average’ heterosexual male. All these factors impacted upon their testing and diagnosis experiences, and the thoughts about HIV and HIV literacy they were having at the time.

Linked to being at higher risk due to having casual sexual relationships in ‘high risk countries’, several of the men received their diagnosis overseas. For example:

*I went to [south-east Asian country] for dental work, went a bit silly on the women over there, and that is how I contracted it.*

*Got tested over there, came back negative, but I was in [another south-east Asian country] and I felt very sick. Got back to Queensland, had a test and it came back positive. Knowing that I had to come back and get tested in Australia shows a good level of health literacy.*

— Charles

As was true for Charles, it may not be uncommon for non-MSM Australian men to have their first set of often shattering personal experiences with HIV in another country, and then a more focused set of experiences in Australia.

The latter would have occurred once the initial shock and sense of dislocation had settled down somewhat, but a range of other emotions and fears may have taken their place. In many ways therefore, their first contact with the Australian health care system is their ‘second’ test and diagnosis, an insight that may be of use when considering health literacy improvements at the early contact phase.

**For a few of the men – a bout of illness had been the impetus for going for an HIV test.**

In their minds, each knew that they had engaged in casual sex in a high prevalence country, which could have led to the illness they were experiencing.

- For one of the participants, the route to a HIV test was a severe case of shingles, for which he had needed to take antibiotics and he was on a drip – in hindsight, he thinks that it was in his mind that the shingles was an indication of HIV infection.

- For another, the testing that was carried out in the case of another illness doctors were trying to understand delivered results that ‘*looked very much like HIV, but since it was in the acute phase, the results were not coming back 100 percent clear*’. It suggested to him that his diagnosis had come relatively early on after being infected.

Another common theme was that the men sought out as much information as they could around the time of testing and diagnosis, but also that this ‘crash course’ on HIV literacy was confounded by factors such as the state of mind they were in at the time. For example:

*[While overseas] I was locked in a room for three days after the positive diagnosis. I desperately needed to know about HIV and went online, trying to make sense of the billions of articles. It was very difficult at that time. I do not have much memory of what I was reading.*

— Bertie

### 5.3 Engaging with the health care system and with HIV treatment

Many of the participants had been recently diagnosed (in the previous five years). The currently accepted HIV treatment protocol is for individuals newly diagnosed to start with HIV medications as early as possible, to achieve ‘Undetectability’.

Thus, the HIV literacy for these men tended to include awareness that they should engage with the health care system as soon as possible after diagnosis, and that they should begin HIV treatment as soon as possible. This was indeed what most of them did.

**Participants nevertheless identified that the road from diagnosis to treatment was not always direct.**

- Some had to deal with their own denial.
- Some had to sort out their overseas affairs – often thrown into chaos exactly because of the HIV diagnosis – before starting treatment in Australia.
- Some needed to address other health issues before they felt strong enough to engage with HIV treatment.

**Key among the other health issues identified were addiction, and mental health.**

One participant related the following in connection with his engagement with the health care system:

*Based on my experience of HIV health care so far as a straight man living with HIV, I can say that the service is really good in Australia. On some of the days I do not even think about it. From a medical point of view, I’m dealing with the two sides – mental health and HIV, so it’s hard sometimes to put a clarity line down the middle, you know, which I am dealing with, where I’m feeling it. I struggle to separate the two.*

— Dean

### Peer connections as a motivator to engagement with healthcare:

A trend in the discussions was to identify peer connections as THE factor that pushed them over the line to engage purposefully with the health care system. As one participant noted:

*It is especially important for heterosexual men. Having that connection with other men definitely helps. As soon as they meet another straight man, they are more willing to engage with HIV. The role of positive women for them is just as important.*

— Arnold

Being referred as early as possible from a health care provider to a peer support organisation was seen by the men as highly desirable, and, in some cases, as the real start of their journeys with HIV.

*When I went to the [peer support organisation], they immediately sat me down and things went better from there. They treated me as a person, and it's not only the staff that are important, it's the other straight guys there as well.*

— Bertie

*When I was clean [following drug rehabilitation], I went to [peer support organisation] and met [peer support worker], and things went better from then on. I was happy to start on the meds straight away.*

— Felix

## 5.4 Adhering to treatment and staying undetectable

Viral load suppression is achieved if the patient adheres to combination antiretroviral (ARV) therapy. This generally implies three- or four-monthly visits to the HIV specialist, at which blood and other tests are undertaken, and HIV medication is prescribed. The medication obtained from hospital-based or community-based pharmacies is taken daily.

The participants reported a sense of achievement when an undetectable viral load was measured soon after starting ARV, and this gave them confidence in the science. Once this had occurred, some were able to start thinking about their health overall and the broader aspects of health literacy, including good diet and exercise.

One participant noted that this search for lifestyle improvements was *'buoyed up by the fact that there were many people like me who have been handling HIV well'*.

Participants acknowledged the importance of good relationships with their treating physicians, since this was key to keeping informed of HIV as it affected them, and to maintaining viral suppression. For many, their regular visits provided the best opportunity within their current lives to focus on HIV, which did not actually occupy their minds a great deal otherwise.

There was a sense for some of the participants that they spent less time actively searching for information on HIV when things were going well for them: the medications were working fine, and they could continue with their lives. At these times, improving their HIV literacy appeared not to be a strong concern for them, but this is an area that warrants further exploration.

In the case of the participant with paediatric experience of living with HIV, adhering to treatment became problematic when he was moved from paediatric into adult care. He attributed this to a lack of understanding of how the adult system worked, and specifically the need for proactive self-management.

## 5.5 Quality of Life

Several of the participants related that a diagnosis of HIV had had an immediate effect on their quality of life. Some noted that they were still struggling with a sense of wellbeing due to being HIV positive, despite being healthy and on treatment. For example:

*HIV has destroyed my life; it has been a huge burden on my life. My main concerns are around loneliness. It still feels unreal, I have not had sex since the diagnosis, and I don't feel OK about needing to share the information on HIV with sexual partners – there's the thing of not being accepted.*

— Felix

A trend among the participants was the narrow circle of people with whom they had shared their HIV status, and the consequences of this. For example:

*I've told one other person about living with HIV. It doesn't burden me, it's not a secret that's burning inside of me. But sometimes I think I should tell my Mum. I think it would change the relationship I have with a lot of people, so I rather say nothing.*

— Earl

*I have not told my family, only five people know about my status, two of them girls I was in a relationship with. If it did get out, so be it, it might be a relief.*

— Bertie

### Intersection of substance use and HIV

A strong common thread among the men is the intersection of substance use and HIV. For some, getting 'lost' in addiction contributed to them acquiring HIV. For some, treatment for substance abuse occurs parallel to HIV treatment, or needs to occur first.

For some, heavy drinking remains part of their total being. This intersection may be something to acknowledge in health literacy messaging that addresses quality of life issues for PLHIV.

### Stigma, fear of disclosure, isolation, loneliness

Participants shared insights into the role of stigma (including internalised stigma, fears of disclosure, isolation, loneliness) in affecting their quality of life, for example:

*Being on the bandwagon makes me want to know more. When off the bandwagon, then my mental health is low, the stigma issues get to me, and I stop caring. That's when I stop the medications.*

— Arnold

*It may be so that HIV is not a death sentence like it used to be, and U=U is great, but it's a burden, and there's the thing of not being accepted.*

— Felix

Part of maintaining wellbeing is addressing other health issues besides HIV. This means engaging with other health providers and needing to disclose their HIV status. Some participants spoke about this as a challenge, for example:

*I understand the fears for some guys, going to clinics, having to disclose, intertwined with stigma. But I don't see any difference to how I am treated [as a heterosexual man] and have a good GP at [name withheld] Clinic.*

— Ginger

## Views on HIV health literacy and services in Australia

A clear health literacy gap identified by participants was that messaging on HIV awareness and prevention was lacking in the Australian community at-large.

*There is an old guard and old school view of HIV. The epidemiology is changing, but organisations are not keeping up with the shift. They have been too rigid in their older approaches. Lack of general health promotion is the big thing.*

— Arnold

The focus on MSM in HIV-related messaging was also acknowledged – with the view also that there is not enough direct messaging that explains and encourages HIV testing among straight men.

*Most posters are aimed at the gay community, even posters on overpasses are for gays. Due to PrEP [HIV pre-exposure prophylaxis], there are declines in transmission among gays. HIV is definitely not a focus among straight men.*

— Arnold

The men did not want health care providers to make assumptions about their sexuality.

As Ginger said, ‘...I guess, from the healthcare provider, you know, they should not be making presumptions, no.’

Participants would also prefer that HIV-related information for PLHIV in printed form not so readily assume a LGBTQI connection on the part of the reader. The lack of materials for heterosexual PLHIV was also identified in other public services. As Bertie related:

*I had to apply at Centrelink, to get my Medicare card. It was the first time I had to discuss my status with anyone beyond health workers. They had no idea of how to help me. They gave me a LGBT pamphlet, not HIV. They had no resource to give me information. There is a gap at Centrelink.*

— Bertie

Despite these challenges, many of the men spoke positively about the health care system in Australia. The approval was often voiced in the context of the HIV treatment they had received and the psychosocial support available to them – e.g. ‘HIV care in Australia is very good. If you really want to talk to someone, there’s always help’ (Felix).

Many also had experience of health care in other countries, including services related to HIV testing and treatment, and thus could compare and contrast.

What some found particularly helpful was when service providers engaged with them as individuals and asked them ‘how did you get to where you are today?’ (Arnold).

In terms of the HIV peer support available and its health literacy impacts, participants recognised that much depended on where they lived – e.g. *‘Things seem to be working very well for heterosexual men in Victoria, less so in NSW.’* (Bertie).

They also recognised that heterosexual men and women were a ‘minority’ within the Australian body positive, and that face-to-face contact with peers was likely to be possible only in larger cities. Some were critical of this lack of focus – e.g. *‘Thinking now of the heterosexual HIV population, men and women, there are times when I don’t feel like our voice is heard, nor is there enough effort put into trying to do it.’* (Arnold).

Similar to the way they wished to be served in health care settings, participants expressed the preference for PLHIV organisations and staff to treat them *‘as a person’* (Bertie).

Negative experiences within PLHIV organisations could be linked for some to *‘the assumption that I was gay’* (Arnold). As confirmed by the Community Advocate:

*When these guys accessed PLHIV services, they appreciated that there were not any assumptions made about their sexuality – that they were just treated as a person. There was an initial fear that they would be perceived as gay, or a man having sexual contact with other men [i.e. MSM] but presenting as heterosexual. So, it is important for PLHIV services to be aware of that – to get that approach right.*

— Anth McCarthy

With respect to the online world, a key theme in the discussions was concerns they had about the trustworthiness of the information. As Bertie noted: *‘For me there is too much false information on social media platforms, it’s not even worth investigating’.*

HIV peer support – through contact with organisations or informally with peers – was described as important for them to help sort out the good websites and information from the not so good, as well as for delivering trustworthy HIV messaging. For example:

*I went to the Positive Living Centre in [city] and it was good. One of the ways they helped was to set up a list of trustworthy internet sites. These are also good to share with sexual partners when they are asking for more information, say, on U=U.*

— Ginger

Moreover, peer organisations were themselves seen as improving their literacy on issues ranging from advances in medical treatments to the insights gained from lived experience. Some men were building this online peer platform firmly into their HIV literacy ecosystem. As related by the Community Advocate:

*One of my recent interviewees spoke of how important NAPWHA and its email communications are to him. And I thought to myself; they make up an important part of his health literacy ecosystem. And he might be able to distribute some of the information because (smart man), he chooses to be in the WhatsApp group we [a group of heterosexual positive men] started. He is ensuring he has a community within which HIV health literacy can be shared.*

— Anth McCarthy

## Participants' suggestions for change

1. **Health literacy contexts and messaging** should include a focus on, and recognition of, PLHIV who would identify as non-MSM / heterosexual / straight men.

*'There could be better means of getting information out that speaks to straight men, and there should maybe be more groups with straight men. I have got no issues with gay men, but it is different.'*

— Earl

*'Straight men are difficult – often it's about them being a blokey-bloke – and it's more difficult for them to get to the point where they say that it's OK to not be OK. You have got to be persistent and hammer away at them, do not stop trying. Just don't be tokenistic about it.'*

— Arnold

2. **HIV health literacy for the general community** should be brought more up to date – on what HIV is; and what it means to live with the virus in the era of highly successful ARV therapies.

The low level of HIV literacy among the public in general was identified through statements such as:

*'There is a lack of education on HIV within the wider community, people still think you get AIDS straight out, that HIV and AIDS are the same thing.'*

— Dean

3. **HIV testing literacy** – There should be more public encouragement for non-MSM men to go for HIV testing, particularly if they are engaging in behaviours that could facilitate HIV transmission. This key issue is discussed in greater detail in the final section of this document.
4. **With mobile communities and the broader Australasian region** – In consideration of the risk of acquiring HIV internationally, participants identified a need for improved health literacy in destination countries that had poorer health infrastructure than Australia's.

*'There should be better HIV prevention messaging and public education in countries such as PNG and the African countries, perhaps Australia could support this, coming at it [improved HIV health literacy] from the other side.'*

— Earl

In reference to reaching men who were on R&R in south-east Asian countries:

*'I don't think it will make a big difference if you just have information – ideally you would walk around the bars with a box of good Australian condoms and advise the men to use. I picked up the idea of the importance of condoms from brothels in Australia...guys going to brothels have an advantage in understanding the importance of condoms.'*

— Charles

5. **Peer support organisations and networks becoming more health literate regarding the positive heterosexual community** – Congruent with the mission and aims of the HLF project, participants identified that it would be valuable if HIV peer support organisations and networks took steps to become more health literate with respect to heterosexual PLHIV – e.g. *‘What would be good is to diversify the peer networks so that everyone is included in the environment.’* (Dean)
6. **U=U literacy** – For a wide range of reasons (discussed earlier), there may be value in U=U being shared with people at or close to the time of diagnosis because *‘a light at the end of the tunnel might have been really useful at the start.’* (Bertie)

## Insights for NAPWHA campaign areas

### 6.1 HIV treatment awareness campaign

Participants discussed ways in which HIV-related messaging – encouragement for HIV testing in particular – could be improved for heterosexual men in Australia.

Their insights seem to suggest that for non-MSM men that having regular casual sex, particularly in an overseas-setting – **HIV was at once ‘there’, and ‘not there’**:

- **It was ‘there’** – in the sense that they had known prior to diagnosis that HIV was a sexually-transmissible infection and that the use of condoms during sex was a major means of preventing its transmission.
- **It was ‘not there’** – in the sense that health literacy messaging had not provided them with a strong enough conviction that heterosexual men could be at risk; and that concerns they might have had about transmission were forgotten in the presence of alcohol and other drugs, or mind-altering substances.

Several participants identified heterosexually active men who travelled frequently to especially south-east Asian countries as indeed being at risk for disease, including HIV infection, and also that this was known by at least some of the men themselves:

*in recent years, guys who do a lot of overseas travel, they talk about ‘suicide sex’.*

— Earl

There was a view that health messaging could be fruitfully targeted at this group, including by companies (especially mining companies) that employ a lot of FIFO workers. For example:

*If public health can tap into some of the organisations, before guys go on R&R and [work] leave, that would be good, and they could also get some guys who are happy to speak about it to share their experiences. That would be a strong preventative message.*

— Dean

*It should also be advertised that if you’re going to be doing the R&R thing overseas, and getting drunk, it’s more easy to get it. It is like playing Russian roulette.*

— Felix

Dean’s suggestion to ‘get some guys who are happy to speak about it to share their experiences’ in organisations with a large FIFO workforce is worthy of exploration. At the same time, the participants recognised the inherent difficulty of reaching men who were going on holiday for a fun time. They also

recognised the confounding influence of alcohol, and that knowledge of the risk of not using condoms was often not enough to counter the party feelings, the R&R. For example:

*When I think of other guys, they can be very blasé about using condoms, and I do not know what will work to reach them. Maybe spread the information that this is not the 1980s and that things have changed with HIV. There's not enough encouragement for testing.*

— Felix

*They've always said there's a river of AIDS running through [south-east Asian country]; it was common knowledge, you do a lot of drinking over there, it's like the 'Wild West', and you're caught up in the moment.*

— Charles

The instilling of fear/disgust was discussed by one participant as a possible approach to adopt in order to overcome this problem:

*There is a campaign in the military, when you go to [south-east Asian country], they give you a slide show with all of the information about diseases that can be picked up, including images of dripping dicks.*

— Dean

## 6.2 Own Tomorrow campaign – aiming for good quality of life and patient self-advocacy

### Social connection and relationships

Several of the men volunteered the importance of finding positive women with whom they could have intimate relationships. For reasons related to fear of disclosure, stigma, and rejection, they would prefer to have sexual relationships with positive women. For some, this meant searching for love internationally – for example:

*I am just learning how to do social media, and possibly make connections through that; perhaps meet with females with HIV. That would be great therapy.*

— Charles

Similarly, they would prefer to take part in positive events at which both straight men and women were active participants – for example: *'it would be good if more effort was put into the peer support for the heterosexual HIV population, both men and women.'* (Arnold).

The Community Advocate affirmed that the presence of positive women at social events for PLHIV *'provides a powerful incentive for straight men to come too – and therefore engage with peers.'*

### **Broader aspects of health**

Living with HIV and focusing on its treatment can help a person to be more health-conscious in a general way – for example: *‘Once I got on the medication, I started focusing on all aspects of my health, also nutrition, ramped up my healthy living up a few notches’*(Earl). There may be opportunities to highlight this kind of positive messaging.

From a mental health point of view, heterosexual men would *‘benefit from having the support of mentors, people you can talk to occasionally, just sharing your story, getting it off your chest.’*(Earl)

## **6.3 Pregnancy and parenting**

The participants did not discuss pregnancy and parenting to any great extent, although it is also the case that no prompts were given on this topic within the discussions. One participant noted that messaging around U=U would be very effective if it included an understanding that, in the modern era of strong and effective ART, positive- or sero-discordant couples could have children, and that these children would not be infected with the virus.

## Strategic Plan for HLF Project x ACE Evaluation

**Challenge** Campaigns are failing to reach and resonate with positive women (and heterosexual men) to improve health literacies in relation to emerging treatment options and achieving good quality of life.

**Intended outcomes** (1) Increases in HIV testing. (2) Engaging positive women in optimal treatment. (3) Reducing HIV transmission. (4) Improving quality of life. (5) Improving positive women’s connectedness with peers.

**ACE** ACE refers to Adaptive-Collaborative Evaluation—a revisioning of the W3 approach—that NAPWHA can use in partnership with Associate Professor Graham Brown to evaluate the HLF project.

HLF Level	Relevant definition of health literacy from the Health Literacy Framework	Practical example	Priority Activities selected during Scoping Phase			ACE
			Good Diagnosis	Living Well	Parenting	
Personal	Health literacy supports self-efficacy and empowerment for individual PLHIV. Action might be carefully considered or taken on the basis of trust and respectful relationships.	A doctor prescribes statins for high cholesterol. The patient asks friends for their experiences and decides to try a vegetarian diet first, which the doctor supports them to do.	<ul style="list-style-type: none"> <li>HIV 101 module for newly-diagnosed</li> </ul>	<p><i>Access to informed and supportive HIV Peer Support and Navigators offer positive women (and heterosexual men) support for HL around QoL.</i></p> <p><i>Treatment empowerment – Patient-led initiatives communicating about peer-led care in treatment optimisation</i></p>	<p><i>Positive women can easily find peer support for parenting and breastfeeding with HIV.</i></p>	<i>Engagement and Community Influence</i>
Organisational	A health literate organisation understands how to reach people and groups with diverse health literacies (CEH definition).	NAPWHA learns to anticipate how campaigns and resources may resonate	<ul style="list-style-type: none"> <li>Incorporating champions’ insights in HIV 101 Project</li> <li>Representing women’s needs in opt-out testing advocacy</li> </ul>	<ul style="list-style-type: none"> <li>‘Own Tomorrow’ campaign with ViiV Healthcare promoting self-advocacy and good quality of life</li> </ul>	<ul style="list-style-type: none"> <li>NAPWHA and partnership initiatives on breastfeeding and parenting for positive women including HIV 101, HPN and fact sheets.</li> </ul>	<i>Learning &amp; Adaptation</i>

		for different groups.		<ul style="list-style-type: none"> <li>• Women's edition of <i>Living Well with HIV</i> update</li> </ul>		
Community	HL is a 'distributed resource' within a social network. There is active participation of community in the co-production of health with HIV & general health services.	You and your close contacts might not understand something but you 'know someone who knows.'  There is a 'culture of care' among people with HIV.	<ul style="list-style-type: none"> <li>• Meaningful involvement of positive women in NAPWHA campaign development including HIV 101, HIV Peer Navigator and Living Well resources</li> </ul>	<i>Health literacy for improved quality of life (QoL)</i>	<i>Positive women are supported to build cultures of care around parenting with HIV.</i>	<i>Engagement and Community Influence</i>
Health Care	The health care ecosystem supports people with diverse health literacies to achieve good health.	Clinics and services encourage PLHIV to access multiple sources of health knowledge and support.	<i>Improving awareness of HIV testing and diagnosis in low-caseload clinics</i>	<ul style="list-style-type: none"> <li>• Advocate for services and research to use PozQoL and an HL measure in monitoring and surveillance</li> <li>• Patient-led care – expert patients; patient-mentors</li> </ul>	<ul style="list-style-type: none"> <li>• Community forum – what we know and how we know it about breastfeeding (with ASHM)</li> <li>• Breastfeeding module in the HPN training.</li> </ul>	<i>Alignment and Policy Influence</i>
Sectoral and Societal	HL is a social determinant that interacts with other 'causes of the causes' of poor health outcomes.	A lack of organisational health literacy means diverse PLHIV fall through the cracks in health care.	<i>Increased uptake of HPN and decrease in late diagnoses</i>	<i>Improved understanding of women's HIV-related QoL (e.g. in Futures 10 and Kirby reports)</i>	<ul style="list-style-type: none"> <li>• Clinical Guidelines on Breastfeeding</li> <li>• Advocate for a research project</li> </ul>	



## Appendix

### 8.1 Document Control

#### Revision History

The following changes have been made to this requirements specification:

Version	Prepared by	Date	Description of Change
0.1	Ron Woods	3-Nov-2020	Report provided
0.2	Anth McCarthy & Saysana Sirimanotham	3-Dec-2020	Report reformatted, supplementary content added – ready for Community Advocate’s evaluation and Advisory Steering Group for review

### 8.2 Related Documents

- [HIV Health Literacy Framework Project Literature Review](#) and [Community Training Handbook \(July 2019\)](#) [Author: Ronald Woods]
- [NAPWHA HIV Health Literacy Framework Project – Evaluation Framework \(June 2019\)](#) [Author: Ronald Woods]
- [HIV Health Literacy Framework Project Healthcare Providers Consultation](#) in Cairns QLD on 23 August 2019
- [HIV Health Literacy Framework Project Women’s Consultation in Melbourne VIC](#) on 23 October 2019
- [HIV Health Literacy Framework Project Women’s Consultation in Darwin NT](#) on 7 November 2019
- [HIV Health Literacy Framework Project – Report on community consultations with Positive Women \(WA and QLD\) – Dec 2020](#)

### 8.3 Organisational Contact Details

The community consultation is being carried out by the following people:		
Role	Name	Organisation
Community Advocates / Research co-designers	Sarah Feagan Lara Kruizinga Diane Lloyd Precious Mapfumo Anth McCarthy Emma Sheldon-Collins	NAPWHA In partnership with Positive Women Victoria. Living Positive Victoria Queensland Positive People NTAHC
Research	Ronald Woods Consultant	
Project Co-ordination	Saysana Sirimanotham	NAPWHA
<b>Research funder</b>	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.	