

napwha national association of
people with HIV australia

HIV Health Literacy Framework Project Women's Consultation in Melbourne VIC on 23 October 2019

Summary of findings compiled by:

Dr Lisa Fitzgerald and Dr Allyson Mutch | NAPWHA © | October 2019

Foreword and acknowledgements

Three Community Advocates (Sarah Feagan, Emma Sheldon-Collins, Precious Mapfumo) held and led a consultation (facilitated in a focus group-style) for NAPWHA to kick-start and investigate HIV health literacy strengths, gaps and needs for women living with HIV (WLHIV) in Melbourne.

The consultation was also observed by [Dr Lisa Fitzgerald](#) and [Dr Allyson Mutch](#) from The University of Queensland – who have compiled a summary of the community consultation in this report.

NAPWHA and Dr Fitzgerald and Dr Mutch would like to acknowledge and thank all the WLHIV 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; provided with taxi voucher(s); and where 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, the WLHIV 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](#) and [Positive Women Victoria](#), in this instance, for providing their offices in Southbank in Melbourne as a location for facilitating this meeting.

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:

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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. This phase of the project – ‘[Let Women Talk](#)’ – was 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/>

Supporting an improved conversation with women

Women living with HIV (WLHIV) is a primary focus of this project. Working in partnership with women Community Advocates who were recruited and trained by NAPWHA, a *HIV Health Literacy Framework* in 2019 to support an improved conversation with women. In 2020, the Community Advocates will facilitate in NAPWHA’s work in developing, implementing and evaluating a number of HIV Health literacy initiatives and interventions tailored for WLHIV. The objective is that women share their perspectives on living with HIV, receive the best possible information regarding HIV, and engage in health promoting actions with regards to HIV. This process would then, be extended to other community within the body positive, and the developing Framework can be shared within the sector.

‘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).

1. Study aims

The aim of this phase of the HLF project was to investigate HIV health literacy from the perspective of WLHIV. To support this aim, three key areas of focus were identified:

- a. Health literacy – what it means, and why health literacy matters in the context to living with HIV
- b. The HIV continuum of care and sources of HIV health information
- c. In which areas and how will we build health literacy in the context of WLHIV?

2. Methods

'[Let Women Talk](#)' is a community consultation aiming to support a conversation with women by women. As a participatory action research project, it was facilitated by, and designed by women who are community advocates for WLHIV. A focus group of six women and two peer facilitators was carried out in Melbourne on 23 October 2019. The focus group was conducted over a three-hour period.

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Let Women Talk!

**Come and be part of the first ever
national focus group run for and by
women living with HIV**

Wed 23 Oct 2019
6PM - 9PM
**Living Positive
Victoria
Southbank VIC**

Your voice will contribute towards women's health literacy initiatives that can inform future health practices.

We want to better understand how and where you currently access prevention and treatment health information and support.

A \$50 EFTPOS card and Cabcharge voucher (for travel from the event) will be provided to focus group participants

Register your interest
with Sarah & Emma, our
Community Advocates

Call
0490 132 604
Email
emma@positivewomen.org.au

NAPWHA Community Advocates

Three community advocates based in Melbourne Victoria, were recruited, contracted and remunerated by NAPWHA to co-lead HIV health literacy activities for WLHIV as part of this NAPWHA project in 2019. Each of these three Advocates are actively engaged community members who passionately advocate within and for their peers and communities:



Sarah Feagan is a queer woman who has been living with HIV since 2008. She is the previous chair of [Positive Women Victoria](#) and has been working with [Living Positive Victoria](#) as a [Peer Navigator](#). She also the [Vice President](#) of NAPWHA. Sarah is a co-facilitator of [Phoenix for Women](#) and the [Positive Leadership Development Institute](#) (PLDi).



Precious is passionate about issues regarding people living with HIV. Originally from South Africa and Zimbabwe, she came to Australia in 2015, and after attending and graduating the [Positive Leadership Development Institute](#) (PLDi), she has been supporting and advocating for PLHIV in promoting resilience and fighting stigma. She joined Relationship Australia South Australia (RASA) and was part of planning a support group from women with HIV. She was also in the Community Advisory Board for PLHIV at [SAMESH](#) (a South Australian-based organisation that provides support, education and training about Sexual Health and HIV). She also facilitated in the first ever [Phoenix for Women](#) to be held in South Australia.



Emma Sheldon-Collins passionately cares about facilitating and assisting others to achieve optimal health. As a registered nurse since 2014, she has worked with a broad range of clients throughout a range of chronic illnesses – from cystic fibrosis to cerebral palsy. However, her area of nursing expertise excels particularly in paediatric care and care in oncology. Her journey from HIV diagnosis in 2017 to treatment management was a challenging experience, which motivates her to strongly advocate and empower others who may be going through that journey. She was a Peer Navigator at [Positive Women Victoria](#) in 2019, and as a NAPWHA Community Advocate looks forward to employing her insight, skills and experience in the intersection of community and clinical initiatives that benefit women.

Strengthening the HIV health literacy capacity of our NAPWHA community advocates is a core strategy and activity of the Health Literacy Project.

For the life of the project, NAPWHA provides our community advocates with training (including: support for group facilitation; updates on health literature and HIV treatment) – also providing professional and network development opportunities (including support to attend major HIV conferences) to allow for our community advocates to keep up to date with current information on HIV treatment and to build networks within the HIV sector.

Participants

The women living with HIV who participated in the focus group were diverse in age, length of time living with HIV, relationship and parenting status, health and co-morbid conditions, ethnicity and cultural backgrounds, and place of residence. Some common features across the group included:

- late diagnosis
- experiences of stigma in healthcare settings
- complexities in accessing health care services and information about HIV

Data collection and Analysis

The focus group discussion was digitally recorded, and detailed field notes were taken. Descriptive thematic analysis was conducted with key themes identified in relation to the three 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. At the time of this community consultation, separate ethics approval is in process via The Australian Research Centre for Sex, Health and Society (ARCSHS) at La Trobe University.

3. Community Consultation – Results

a) Health Literacy – what is it?

Participants discussed health literacy across a range of individual and community levels.

Health literacy was described as having understanding of broader health issues, in particular medication and having the resources to access information.

Understanding of medication including knowledge of side effects, changing medications and the impact on women's bodies was discussed as a key aspect of health literacy.

Biotechnological advancements such as U=U (Undetectable = Untransmittable) were considered important aspects of contemporary HIV health literacy.

Health literacy was a vital part of empowered self-management of HIV, good HIV literacy aided in making decisions regarding HIV care.

Some women discussed how HIV literacy enabled better personal responsibility and facilitated better collaboration/relationships with healthcare professionals.

At the individual level

At the individual level, participants' descriptions of health literacy included:

- *Understanding how mental, social, physiological, spiritual aspects of our lives fit together*
- *Our understanding of health*
- *Knowledge of what HIV does to the body and why ART works and how... where to go and what to do*
- *Comprehensive level of awareness – what to look out for*
- *Awareness of the resources available to us*
- *Knowing your rights*
- *Being heard, having a voice – in relation to the doctor you see*
- *Having a level of responsibility, acting responsibly*

Health literacy was strongly connected to knowledge about medication. Women recognised that HIV related medication was complex and ever-changing. Most had experienced (some major) side effects of medication. Those with co-morbid conditions discussed challenges managing polypharmacy and side effects of multiple medication – *“Knowing to check that prescriptions don’t impact HIV meds”*.

Women discussed the need to keep up to date with knowledge about medications yet had difficulties in knowing where to access this information.

- *How we get information, how we use it, who do we ask?*

“Being familiar with terminology” and having an understanding of biomedical indicators such as of CD4 counts, viral loads, undetectability, and U=U were important aspects of contemporary HIV health literacy:

- *Women should know about U=U*

HIV health literacy was described as important as it enabled women to feel empowered and manage their HIV in the context of their lives.

- *The more we know the more empowered to live and manage our illness*
- *Having an understanding and know what to ask and when.... You don’t know what you don’t know*

Gaining health literacy involved some responsibility to *“empower”* oneself, *“make good decisions”* and *“own up to your own health”*. It also involved collaboration with health care providers, and to partner in decision making. However, participants discussed and questioned the ability to have patient centred care in the context of living with HIV.

It should be a collaboration with Doctors – not just accepting it

Seeing mainly hospital doctors, not GPs, you need to know what’s going on to make the sensible decisions

At the community level

At the community level, health literacy involved gaining knowledge from peers, health care providers, and the non-positive community. Women recognised the long history within the positive community of sharing knowledge and empowering PLHIV. Participants discussed the importance and value of gaining health literacy through sharing knowledge between positive people.

- *Community is my peers*

Community living with HIV were described as *“a potent force, it is an empowering thing to meet a peer with HIV”*. Information shared across the community was an important aspect of HIV literacy *“the things learnt through the journey can be shared”*.

What impacts health (literacy)?

Participants discussed non-health related issues that facilitated stress in their lives, impacted their health and wellbeing, and ability to access HIV literacy. These social determinants of health, in particular, restricted finances and poor relationships caused much stress.

- *Non-health stress impacts health*

Good social support was important for health, having people who were understanding and supportive was health enhancing.

- *It's good to have people that put up with your shit!*

Good relationships with health care providers were also described as essential for good health (literacy). However, women engaged in much discussion about their experiences of poor relationships with healthcare providers. These experiences included healthcare professionals, providing misinformation about HIV – “*a lot of women think they can't have babies*”, not explaining or presenting information about key issues for women including medication/info about fertility and family planning. These poor relationships impeded health (literacy).

Women discussed with each other where to go to gain updated information about HIV, including new medications/discoveries, often finding it challenging to access this information. Women agreed it was difficult to keep track of changing bio-medicalisation of HIV.

Participants described how WLHIV with poor HIV literacy, mixed with limited societal understanding of HIV, could have major repercussions for WLHIV. An example provided was how religious beliefs could influence people to stop people taking ART.

What decreases health literacy?

Health issues including poor mental health, ageing and dementia; incorrect information gained from health professionals and/or the internet; “not asking the right questions” of healthcare providers; social determinants of health including issues associated with education, access to resources and locality; and social isolation - particularly when not linked to the HIV community - were all factors participants discussed as potentially decreasing health literacy. Participants also described the challenges they faced in relation to maintaining their health literacy when managing multi-morbidities and associated complex medication regimes.

Poor health literacy and miscommunication within the HIV community were discussed. One place that women experienced poor HIV literacy and miscommunication was TIM's Women's Group. One woman described how misinformation had led her to take medication breaks.

The first hour of the focus group concluded with slides about health literacy (see: figure 1).



Figure 1: Defining health literacy

b) The HIV Continuum of Care & sources of HIV health information

In the second hour of the focus group, the HIV continuum of care was introduced and described (see: figure 2).

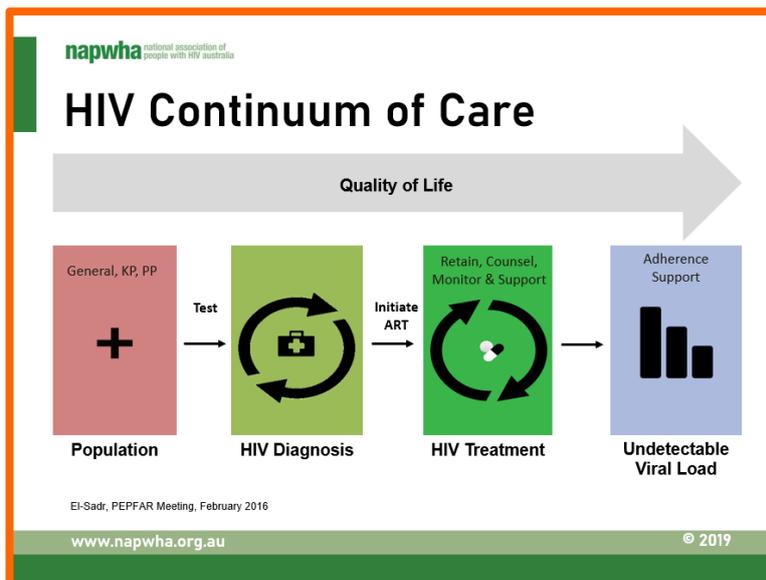


Figure 2: HIV Continuum of Care

Facilitators outlined the continuum of care as how one navigates the health system and sources of information. Women were asked where they gained health information along the HIV continuum – this included information about a number of existing sources of information (see: figure 3) and discussion of whether participants had used any of these sources.



Figure 3: Examples of sources of HIV related information

Participants accessed HIV related information from a variety of sources including:

- pharmacists, GPs, Infectious diseases (ID) specialists
- peers and support groups (e.g., Living Positive Victoria, Horn Harbour Health, NAPWHA)
- TIM and TIM women

Most had been to the [Phoenix for Women](#) group – the peer-led support group for WLHIV run by Living Positive Victoria.

Participants also accessed information online via a number of sources including:

- health/government websites
- WHO websites (e.g. to access breast-feeding guidelines – which was described as now outdated; and childbirth information).

Participants drew on the varied sources of information outlined above along the continuum of care.

However, many also described difficulties accessing information across the continuum due to:

- poor relationships between doctors (including across specialities and GPs)
- complex and diverse experiences related to health issues
- social determinants and locality.

Many described “*doctor-shopping*” and “*Internet-shopping*” to find appropriate sources of information across the continuum of care.

In terms of *internet shopping*, Google was used for checking things that doctors said (e.g., “*comparing numbers*”). Women used Wikipedia to lookup side-effects of medication.

They accessed health and government websites for information about HIV and women’s issues.

Women accessed few HIV-related websites and did not access any Apps:

- Few knew the '[Living Well – Women with HIV](#)' website, and those who did "*found it by accident*".
- None recognised or used '[Life in love](#)' website – the Canadian-based WLHIV editorial site.
- None were familiar with the '[HIV Drug interaction](#)' website (a clinically useful, reliable, comprehensive, up-to-date, evidence-based drug-drug interaction resource, freely available to healthcare workers, patients and researchers)
- None were familiar with the '[MyLife+ App](#)' – a smartphone app developed by ViiV Healthcare and curated by NAPWHA that has functionality to track medications, CD4 count and viral load, other health conditions, symptoms and even moods.

Interactions with health care providers was a key issue when accessing HIV information across the care continuum. Health care providers included pharmacists, GPs, ID specialists, and nurses. Participants described varied relationships with pharmacists and nurses.

GP and ID specialist interactions and relationships were key to gaining sources of HIV information.

Most participants relied on ID specialists for HIV related care and some struggled to find a GP they could trust to include in their 'healthcare team'.

- *Being health literate means can make own decisions*
- *Our own health changes the type of care we get*

Women described positive experiences arising from their relationships with healthcare providers and being empowered in making healthcare decisions. Many also described poor experiences, including enacted stigma arising from interactions with healthcare professionals (e.g., disclosure of their status, being asked how they *got* HIV).

Some of these experiences are outlined below:

- A participant went to specialist to discuss side effects of medication, which was not recognised, and she was '*pushed back*'. Her experiences were later confirmed by a peer who experienced similar side effects. The side effects listing on the medication have since been changed.
- Some participants had limited choice of specialists in their locality (e.g. regional areas) and had to navigate poor relationships with ID specialists.
- Many experiences of treatment side effects and trying to access information
- One ID specialist did not believe the participant's description of symptoms and ordered many unnecessary tests.
- One nurse asked a participant, in front of other patients, what her medication was for.
- Experiencing diverse and policies and systems across different healthcare settings
 - *We need careful review of policies*

c) In what areas and how do we build health literacy in the context of WLHIV?

In the third hour, the community advocates facilitated a discussion: The women participants were asked how they could build health literacy for WLHIV. The broad themes are summarised below.

Improving the health literacy of health care workers

Participants suggested the healthcare industry and healthcare workers needed better HIV health literacy and this was a priority for action. Women discussed their many experiences of stigmatising attitudes – “*Stigma can kill you*” - and limited understanding by some healthcare providers.

- *Everyone in healthcare needs knowledge*
- *GPs make a lot of assumptions*
- *Health care workers need to be trained*

Improving health care providers HIV literacy was described as essential for building health literacy in women. Women called for better and more consistent education of healthcare providers and suggested positive speakers had an important role to play in educating healthcare professionals. Participants also discussed the importance of educating doctors in relation to the role and value of peer support and the need to provide healthcare professionals with a directory of positive services. Participants highlighted the need to increase referrals from healthcare professionals to peer support services to enhance mental health and dissipate social isolation.

- *GPs need to be given information of resources and supports for positive people*

Women discussed their complex healthcare needs, which require more integrated, streamlined approaches in the healthcare system. The fragmentation of services was impacting their (mental) health and creating significant financial strain. They also discussed the need for more systematic, time specific, mandatory review dates across their care.

- *We need time specific mandatory review dates*
- *Timewasting = poor mental health!*

For one participant, gaps in care could be managed by the establishment of a “dream” “*Super clinic*”, made up of different specialists who would bulk bill, have *amazing technology*, synched up appointments and joined up services.

Initiatives to improve the newly diagnosis experience

Participants discussed diagnosis as a critical moment in the care continuum that required urgent attention, because currently “*We have to do it all ourselves*”.

They called for better guidelines around diagnosis, and stressed the diagnosis experience must be improved to include:

- Guidelines of what a diagnosis should look like, particularly in relation to timing, language and without stigma

- Pre and post testing counselling
- Recognition of the valuable role allied health workers such as ID clinic nurses played, particularly at diagnosis where they operated as counsellors delaying fear and providing support
- Peer support for women post-diagnosis
- Education/information to be continued across the continuum of care
Can't be a hit-and-miss... we need consistency and full portfolio of services!

Initiatives to improve HIV literacy in the general community

Women discussed the urgent need to improve the HIV literacy of the general public. They spoke of the continued power of the Grim Reaper campaign in driving stigma, and the outdated understandings of HIV many people had. They spoke of the need for a community based/national advertising campaign to reduce stigma.

They also discussed media such as The Project and 'You can't ask that' as examples of TV programmes that could be used to drive stigma reduction. For some, living by example was discussed as a powerful and important stigma reduction measure.

- *I am a functioning human being- living as a normal person with HIV - I can challenge stigma*
- *Living by example is a great way to reduce stigma*

Proposal of New Guidelines and policies

Women discussed the urgent need for the development of new HIV related guidelines and policies in line with current treatment and HIV science.

One area that women were keen to see changes was in policies around STI and HIV testing, including protocols or how often women should test for STI-HIV.

Women wanted mandatory HIV testing, with opt-out policies, and a change of law regarding signing a waiver to test for HIV. Making HIV testing mandatory in STI testing needs urgent attention.

A review of policies and updates, such as those around breastfeeding and childbirth were also seen as essential.

4. Evaluation of Community Consultation

Emma Sheldon-Collins

Community Advocate / Session Facilitator



“I believe that this Melbourne community consultation did achieve its intended outcome – that is, to provide a safe space for women within the HIV community in Melbourne to openly express and communicate their opinions and knowledge with each other and to us on matters that they feel are important to them in regards to their health literacy.

It was a great group of women participants who were all passionate about their health and the care they receive. Offering up lots of information about gaps that need to be addressed.

What were areas for improvement? More time between sending out the invitations [to participants] and the event (which was 2 to 3-week lead-up). Given that women within the community can be very busy working and/or taking care of families, the more notice we give them to be able to organise time off, or for child-sitters, etc.

How would I describe the health literacy gaps of peer-based HIV organisations with respect to the conversation they have or have had with women over the past years?

It would be great to have clearer information about U=U. A thing that’s really unclear is – is breastfeeding ok? Seems to be some confusion about how to put out the information about this, and what will make sense for women with children or thinking about having children.

Another gap is that many women aren’t getting involved because activities are often not accessible to them, due to the time they happen. There are issues of childcare, and the need to have a babysitter, they have to take into account.

What are my hopes and expectations for the remainder of the project?

For myself: I want to be more health literate and better able to act on the knowledge I have.

For your peers: Similarly, I want for them to have the knowledge and to be able to act on it.

For peer-based organisations: To better know what the gaps in understanding are that they have, and especially for what we need as women.”

Sarah Feagan

Community Advocate / Session Facilitator



“Just the convening of the women [the *Let Women Talk* community consultation, led by Community Advocates] was a success. It has given them [women participants] a VOICE.

There are many gaps for HIV health literacy gaps for Australian women. [I observe through my Peer Navigation work; and other roles] a lot of women are not sure about how to interact with the health care system. Many are not sure or confident about how to be in community spaces. There are gaps related to testing and reproductive health; to relationships with men; to contraception toxicity and drug interactions, and that there are choices available to them. There are gaps relating to breastfeeding, and whether it is safe. Many women would benefit from knowing more about the psychological stuff, and the influence of culture.

Most women are good with treatment, but can improve regarding the questions to ask, and understanding the answers they receive. They can also improve regarding consent, and regarding self-worth issues. Many lack confidence and are afraid of asking things for fear of being stigmatised.

Yes, there is a persistent HIV stigma, and this has strong links to things such as consent and self-worth. It's a particular problem for women from overseas.

What are my hopes and expectations for the remainder of the project?

For myself: The project's systems perspective framework can be a good tool to be used, it is good for self-reflection on what I am doing in the project.

For my peers: I'd love to see women being more confident. Give them knowledge – it lets them feel that it doesn't make them a bad person to have HIV; it reduces stigma.

For peer-based organisations: My hope is that women feel more confident with organisations and will want to come and talk about issues like breastfeeding. There should be a focus on capacity-building, and the organisations should have the potential to form new peer groups. There should be a policy change in mainstream settings – where talking about HIV becomes part of the normal language, where there is better dialogue with patients.”

5. Appendix

5.1 Document Control

Revision History

The following changes have been made to this requirements specification:

Version	Prepared by	Date	Description of Change
0.1	Dr Fitzgerald and Dr Mutch	23-Nov-2019	Report provided
0.2	Saysana Sirimanotham	15-Jan-2020	Report reformatted, supplementary content added – ready for Community Advocate’s evaluation and Advisory Steering Group for review

5.2 Related Documents

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

5.3 Organisational Contact Details

The community consultation is being carried out by the following people:		
Role	Name	Organisation
Community Advocates / Research co-designers	Sarah Feagan Precious Mapfumo Emma Sheldon-Collins	NAPWHA In partnership with Positive Women Victoria and Living Positive Victoria
Consultation Co-observers	Dr Lisa Fitzgerald Dr Allyson Mutch	University of Queensland
Project Co-ordination and Management	Katy Roy Saysana Sirimanotham	NAPWHA
Research funder	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.	