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 PLHIV to engage actively with, the HIV Care Continuum and have improved quality of life.

NAPWHA has embarked on a three-year initiative – *HIV Health Literacy Framework* (HLF) project – that focuses on the role health literacy can play in contributing to these goals. The assumption is that the organisation can do more to improve its HIV-related health messaging to all PLHIV, and that improved HIV health literacy at all levels (individual, community, organisational, sectoral and policy) can be achieved. In addition to strengthening NAPWHA as a more health literate organisation, an outcome for the HLF project is increased HIV health literacy among individuals and communities.

Women living with HIV (WLHIV) is a primary focus of this project in its initial phase. Working in partnership with Community Advocates – who are HIV peers – our *HIV Health Literacy Framework* aims to support an improved conversation with women. Community Advocates are recruited and provided professional development by NAPWHA – with the objective that they will lead the design and facilitation of conversations with their women peers. These conversations form an essential process in developing, implementing and evaluating a number of HIV Health literacy initiatives and interventions tailored for WLHIV. The end goal 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 communities within the body positive, and the developing Framework can be shared within the sector. This report summarises the Framework and activities of year one (2019) of the project – supported by ViiV Healthcare Australia grant.
Towards a HIV health literacy framework

Three interconnected elements of the Health Literacy Framework are:

1. A systems perspective that places a health literacy initiative within its health context, and enables partners to map a project’s intended outcomes system-wide
2. Positioning the commitments, expectations, roles and interests of an initiative’s stakeholders by drawing on the systems perspective
3. Building on the first two elements through interweaving health literacy attributes, the HIV Care Continuum, and an outcomes focus

Each element is discussed and described in greater detail below with the aid of mappings and/or matrices.

Content relating to the NAPWHA Health Literacy Framework project is illustrated within the help of these three foundation elements, but the intention is that any other HIV-related health literacy initiative can be described within the same broad and generalisable Framework.

1. A systems perspective

Systems and social ecological approaches to health literacy (Jordan et al 2010; McCormack et al 2017; Farmanova et al 2018) suggest there is value in placing any health literacy initiative within its broader health context.

The health context includes social and structural determinants of health, health care systems and organisations, communities and communications. The intended outcomes of a health literacy initiative should ideally be mapped system-wide.

As can be seen in Figure 1 (right) which maps the HLF project outcomes from a systems perspective, the most direct outcomes relate to the organisation and the communities it represents. Through this project, NAPWHA aims to become a more health literate organisation and contribute to the growth of HIV health literacy among individuals, communities and organisations.
At the same time, the project has a ‘line of sight’ to health care organisations, including patient-provider interactions, and also to broader discourses on HIV and health systems and policies.

Based on strong partnership working, it is intended that there will be impacts on HIV health literacy also at these wider levels, although the reach of the initiative recedes the further away one moves from the program’s direct community-based participatory activities, outputs and outcomes.

2. Stakeholder positions

The second element of the draft Framework expresses the commitments, roles, interests and expectations of partners, participants and stakeholders in any health literacy initiative (their ‘stakeholder positions’) in values-based and theoretical terms.

For HIV health literacy programs in general, these stakeholder positions include:

a. PLHIV community and community-based organisations:

All have an interest and/or organisational mission to contribute to improved HIV-related health care and quality of life outcomes for PLHIV. All are committed to assisting all PLHIV to engage actively with the HIV Care Continuum as an evidence-based way of maintaining an undetectable viral load\(^1\) and having improved quality of life.

All are committed to improving HIV-related health messaging to all PLHIV on the basis of a developing understanding that improved health literacy at all levels (individual, community, organisational, sectoral and policy) contributes to improved HIV-related health outcomes.

b. Patient-provider interactions:

HIV health literacy is dynamic, complex and multi-dimensional, and is influenced by the relationship between PLHIV and their health care providers. Having an ongoing and trusting patient-provider relationship is one of the most important contributors to the health of PLHIV. Building this trust is an iterative and mutual process that occurs over time\(^2\).

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c. Health Care Organisations:
Enhancing organisational health literacy should be included under the umbrella of all organisational changes undertaken to enhance person-centred care. It should be tried as a strategy to improve health outcomes and quality of care, as well as to contain and reduce the cost of care\(^3\).

**d. Health Care System:**
The *Australian National Statement on Health Literacy*\(^4\) agrees that strategies are needed to build the capacity of people to better understand the choices they have in making decisions about their health and health care; and to build the capacity of the health system to support, encourage and allow this to occur. The Statement supports action across three areas: embedding health literacy into systems; ensuring effective communication; and integrating health literacy into education for consumers and healthcare providers.

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**HIV Health Literacy Framework**

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3. **Integration**
The third element of the draft Framework integrates, and builds on, the first two elements outlined above. It does so by interweaving health literacy attributes, the HIV Care Continuum, and an outcome focus in a matrix.

The HLF project is used as an illustration of how this matrix might be applied in practice (Table 1: overleaf).

The HLF program has been described in some detail earlier in this report in terms of its rationale, focus, process and intended outcomes. While impacts in the wider context are envisaged, the most direct participants and intended beneficiaries (highlighted in colour in the table) are the PLHIV community and community-based organisations (beginning with NAPWHA itself), and people in their social contexts (starting with women). The majority of the women are living with HIV, but the project also addresses HIV testing and counselling, and thus pre-diagnosis situations.

When applied to the HLF initiative, the HIV health literacy matrix envisages a closer alignment between the steps of the HIV Care Continuum and the outcomes for individuals/patients, patient-provider interactions, and health care organisations than what it does for the PLHIV community/organisations and the broader health care system.

It is assumed that this alignment can be flexibly attenuated when the Framework is applied to other health literacy initiatives and contexts.
### HIV Health Literacy Framework – Matrix

<table>
<thead>
<tr>
<th>HIV Care Continuum</th>
<th>Health Care Organisations</th>
<th>Patient-provider Interactions</th>
<th>People in their Social Contexts</th>
<th>PLHIV community and organisations</th>
<th>Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV testing and counselling</td>
<td>Creating an environment that reduces health literacy demands – e.g. physical environment layout and signage; clear communication principles</td>
<td>Creating a safe environment for testing</td>
<td>HIV-related knowledge, attitudes, beliefs</td>
<td>Communities and organisations develop expertise in HIV and living with HIV, including adopting a holistic approach towards the HIV Care Continuum and health-related quality of life (HRQoL)</td>
<td>Health care system leadership sets the expectation that good health literacy policy and practice help individuals to live well, keep well and get well</td>
</tr>
</tbody>
</table>

**HIV testing and counselling**
- Better understandings of HIV
- Better understandings of health literacy and its impact on interactions
- Communication skills
- Social support
- HIV-related knowledge, attitudes, beliefs
- Perceptions of risk and benefit in light of the stigma associated with both poor health literacy and HIV
- Skills to access and navigate appropriate, quality and timely health services
- Attributes to make informed health-related decisions e.g. ability to understand medical information and derive meaning
- Communities and organisations together investigate ‘health literacy’ and become more health literate
- Health literacy-informed conversations are held with the total body positive in an atmosphere of partnership and co-learning

**Linkage to care and treatment – the period from a documented HIV diagnosis to initiation of medical treatment with an HIV care provider/prescriber**
- Patient-centred communication
- Patient and family support groups
- Making services and facilities more health literacy-friendly
- Reducing the demand (complexity and difficulty) of a HIV-related health information stimulus
- Promoting shared decision-making
- Personal attributes that contribute to an ability to access and navigate appropriate, quality and timely health services
- Attributes to make informed decisions on medical issues – e.g. ability to interpret and evaluate medical information
- Peer conversations and health communications with people from more vulnerable/underrepresented communities are strengthened through, for example, partnering with community champions and undertaking activities such as judging the quality and impact of current HIV-related health information

**Health Care System**
- The health care system builds an evidence base that identifies the changes needed to improve health literacy, reduce health care system demands, and support effective innovations
- The health care system is committed to good health literacy practice and invests in changing the way it is organised to improve outcomes
- Legislation
- Policies and strategies
<table>
<thead>
<tr>
<th>HIV Care Continuum</th>
<th>Health Care Organisations</th>
<th>Patient-provider Interactions</th>
<th>People in their Social Contexts</th>
<th>PLHIV community and organisations</th>
<th>Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retention in care and treatment</td>
<td>The health workforce is equipped with knowledge and skills that contribute to improved health literacy</td>
<td>Staff training – e.g. plain language best practices</td>
<td>Attributes to make informed health-related decisions based on better understanding medical information, deriving meaning, and understanding information on health determinants</td>
<td>Improved social marketing campaigns</td>
<td>Improved social marketing campaigns</td>
</tr>
<tr>
<td></td>
<td>Adoption of clinical guidelines</td>
<td>Team-based care and care co-ordination</td>
<td>PLHIV take opportunities to provide feedback on health services they use and contribute to quality improvement programs</td>
<td>Health literacy-informed eHealth communications</td>
<td>Health literacy-informed eHealth communications</td>
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<tr>
<td></td>
<td></td>
<td>Consumer assistance programs</td>
<td></td>
<td>Identifying and supporting social media influencers</td>
<td>Identifying and supporting social media influencers</td>
</tr>
<tr>
<td>ART adherence for viral suppression</td>
<td>Health education sessions</td>
<td>Adherence is promoted when patient-provider communications are of high quality</td>
<td>Ability to make informed decisions on medical issues, on risk factors for health, and on health determinants in the social and physical environment</td>
<td>Community-based participatory initiatives and research, including measuring and addressing health literacy skills, and program evaluation</td>
<td>Community-based participatory initiatives and research, including measuring and addressing health literacy skills, and program evaluation</td>
</tr>
<tr>
<td></td>
<td>Patient decision aids</td>
<td></td>
<td>Opportunity to focus on motivation, problem-solving, self-efficacy, knowledge and skills as influences on self-care</td>
<td>Promoting health literacy as a distributed resource, especially in a peer-based context</td>
<td>Promoting health literacy as a distributed resource, especially in a peer-based context</td>
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</tbody>
</table>
# HIV Health Literacy Framework Project

This document outlines year 1 of a NAPWHA three-year initiative (2019-2021) – HIV Health Literacy Framework (HLF) project – aimed at increasing HIV health literacy among key individuals and PLHIV communities.

## End of Year 1 — Report Summary: Project Activities from January–December 2019

<table>
<thead>
<tr>
<th>Establish internal project team</th>
<th>Internal project management and delivery team established</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• NAPWHA project management and coordination (Katy Roy; Saysana Sirimanotham)</td>
</tr>
<tr>
<td></td>
<td>• Research support and consultation (Dr Graham Brown; Dr John Rule; Ron Woods)</td>
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<tr>
<td></td>
<td>Detailed project plan developed – refer to <a href="#">HLF Evaluation Framework</a> p. 24</td>
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<table>
<thead>
<tr>
<th>Establish governance arrangements</th>
<th>Project governance established with Advisory Steering Group (ASG)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>• <a href="#">ASG Terms of Reference</a> agreed upon with ASG established to guide project scope and direction</td>
</tr>
<tr>
<td></td>
<td>• Representation includes ASG members from NAPWHA’s member PLHIV organisations from Australian State-based PLHIV organisations (Positive Women Victoria, Living Positive Victoria, Positive Life South Australia, Queensland Positive People, Pozhets NSW); as well as, AIDS councils (Northern Territory AIDS and Hepatitis Council); population-specific groups (Centre for Culture, Ethnicity &amp; Health, The Institute of Many); representation from the HIV clinical workforce (ASHM); and social research partner (Australian Research Centre in Sex, Health and Society, La Trobe University); and PLHIV representatives from linked priority groups (Femfatales, TIM Women)</td>
</tr>
<tr>
<td></td>
<td>• From the first ASG meeting on 24 July 2019, there was agreement on the HLF pilot would focus on women living with HIV</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NAPWHA website optimisation</th>
<th>NAPWHA website updated and optimised with current content</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Website optimised with W3C Web Content Accessibility Guideline (WCAG) compliance</td>
</tr>
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Q1. 2019

Q1+2 2019
### Phase 1: Establishment

#### Identify and engage stakeholders

- Developed a communication strategy to deliver timely and quality content to a broad range of stakeholders
  - This strategy includes utilising NAPWHA’s existing community-facing activities to consult and report back to our PLHIV organisational members and HIV sector stakeholders – e.g. annual NAPWHA AGM and SGM; bi-annually held HIV Treatment Officer Network education meetings; Femfatales and Positive Aboriginal Torres Strait Islander Network (PATSIN) meetings.

- Established linkages to clinical community including GPs and S100 HIV prescribers through project partnership support with ASHM and Cairns Sexual Health Service

- Developed stakeholder engagement and communications plan to identify and actively engage key partner organisations and networks to support project development
  - This includes: Cairns Sexual Health Service, Femfatales, Living Positive Victoria, Queensland Positive People (QPP), NTAHC (Northern Territory AIDS and Hepatitis Council), Positive Women Victoria

#### Develop evaluation framework

- Identified and engaged Australian Research Centre in Sex, Health and Society, La Trobe University as key research partner for life of project – with ethics approval to be submitted through La Trobe University
  - Principal Research Fellow, Dr Graham Brown, informs project of W3 Project principles – understanding what works and why in peer-based and peer-led programs in HIV (see more: [www.w3project.org.au](http://www.w3project.org.au))
  - Supplementary research support to be provided by Dr Lisa Fitzgerald and Dr Allyson Mutch, University of Queensland
  - NAPWHA also keeps informed with current HIV research through the research and studies of which NAPWHA represents in

- Developed participatory action research evaluation plan for overall Health Literacy Framework project
  - The [HLF Evaluation Framework](#) is available for download via the NAPWHA website
## End of Year 1 — Report Summary: Project Activities from January–December 2019

<table>
<thead>
<tr>
<th>Phase 2: Health literacy framework development</th>
<th>Literature and best-practice review</th>
<th>Detailed data review</th>
</tr>
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<tbody>
<tr>
<td>Q2. 2019</td>
<td>Q2. 2019</td>
<td>Q2. 2019</td>
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### Literature and best-practice review

Desktop review conducted of Australian and international health literacy best practice and models published

- In Australia and internationally, there has in recent decades been a strong policy, research and practice interest in health literacy. In July 2019, NAPWHA commissioned researcher consultant Ronald Woods to identify, describe, analyse and synthesize existing literature on health literacy — with a literature review forming an integral part of the HIV health literacy framework project.

- The HLF Literature Review of Health Literacy [PDF] is available for download via the NAPWHA website.
- The literature review was later adapted, condensed and modified as a Community Training Handbook: A Guide to Health Literacy in the Context of HIV [PDF]. The Guide is designed to serve as a resource for community leaders and NAPWHA’s partners and co-investigators in the HLF project.

### Detailed data review

Data review conducted to identify priority cohorts according to low health literacy, higher rates of HIV transmission, poor rates of testing, and sub-optimal treatment — including preliminary data review of health literacy gaps, enablers and barriers for these priority cohorts.

The data review summarised key literature (published data and grey literature) including:

- Changes in the lived experiences of women with HIV over two decades? A review of qualitative research in high income countries [PDF] — Authors: Lisa-Maree Herron, Allyson Mutch, Chi-Wai Lui, Lisa Fitzgerald. School of Public Health, Faculty of Medicine, The University of Queensland, Brisbane, Australia.
### Project champions

Agreement made on priority cohort for HLF pilot

With consultation from Advisory Steering Group, we agreed that the project pilot would focus on women living with HIV (WLHIV). Led by and through Community Advocates, NAPWHA will aim to support an improved conversation with women in a process to support the development, implementation and evaluation of specific health literacy initiatives targeting (and tailored for) women.

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### Recruitment and support

Recruitment conducted with appointment of PLHIV Community Advocates – i.e. project champions

- Four community advocates – three based in Melbourne, Victoria; one in Darwin, Northern Territory were recruited – contracted and remunerated under an enterprise agreement by NAPWHA to co-lead HIV health literacy activities for WLHIV as part of this NAPWA project.
- Each are actively engaged community members who passionately advocate within and for their peers and communities – and were nominated by Advisory Steering Group (and/or self-nominating).

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<th>Q3. 2019</th>
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### Delivery of baseline training and orientation to Community Advocate role (including health literacy, co-design, participation role) undertaken by NAPWHA in a one-day workshop on 8 August 2019, comprising:

- Orientation to NAPWA
- The power of peers: Understanding what works and why in peer-based and peer-led programs in HIV
- Mapping and design of a community consultation and evaluation

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<th>Q3. 2019</th>
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### Targeted focus groups – Healthcare Providers (HCP)

Delivered two targeted consultations in partnership with Cairns Sexual Health Service with healthcare providers (comprised of HIV S100 general practitioners, pharmacists, practice nurses, sexual health physicians, and allied-health workers including Aboriginal health workers and Aboriginal Community Controlled Health Organisation workers) on 23 August 2019.

The consultation aimed to:

- Identify corresponding strengths, gaps and limitations within the Australian health system; and
- Identify opportunities and strategies for improving HIV health literacy environments
- Consultation with HCP Report published and made available via the NAPWHA website

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<th>Q3. 2019</th>
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</table>
End of Year 1 — Report Summary: Project Activities from January–December 2019

### Targeted focus groups – Women living with HIV

**‘Let Women Talk’** – Community consultation with Women living with HIV – held in Melbourne, Victoria on 23 October 2019, conducted over a three-hour period.

- Held in partnership with Living Positive Victoria and Positive Women Victoria, three Community Advocates (Sarah Feagan, Emma Sheldon-Collins, Precious Mapfumo) identified and recruited participants for a peer-led community 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 (to be published via the [NAPWHA website](https://napwha.org.au) in early 2020).
- The consultation aimed to identify how and where participants currently access prevention and treatment health information and support; and opportunities and strategies for improving individual health literacy.

**‘Let Women Talk’** – Community consultation with Women living with HIV – held in Darwin, Northern Territory on 7 November 2019, conducted over a three-hour period.

- Held in partnership with Northern Territory AIDS and Hepatitis Council (NTAHC), Community Advocate (Emma Sheldon-Collins) and NTAHC Women’s Program Coordinator (Rebekah Lamb) identified and recruited participants for a peer-led community consultation (facilitated in a focus group-style) for NAPWHA to continue to investigate HIV health literacy strengths, gaps and needs for women living with HIV (WLHIV) in Darwin.
- A summary of the community consultation to be published via the [NAPWHA website](https://napwha.org.au) in early 2020.

### Project champions – Continuing professional development

For the life of the project, NAPWHA continues to build the capacity of community advocates through on-going 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 build networks within the HIV sector.

- Developing the HIV health literacy capacity of Community Advocates allows for strengthening their ability to advocate for and educate within/to their respective communities with up to date with current information on HIV treatment.
### Phase 2: Health literacy framework development

#### Mapping current strategies and best practice

- Existing and emerging Australian HIV prevention and treatment-related strategies, approaches and campaigns mapped into the draft framework – including NAPWHA content such as Positive Living editorial content and MyLife+ app

- Desktop review of international and Australian health literacy and models to respond to specific gaps, opportunities and needs of identified ‘key groups’
  - The [HLF Literature Review of Health Literacy](https://www.napwha.org.au/literature-review-of-health-literacy/) is available for download via the NAPWA website

#### Confirmation of HLF framework

- Based on desktop research, consultation process with NAPWHA members and stakeholder, and HIV community advocate-led consultations with WLHIV – NAPWHA has developed a health literacy framework with high-level emerging themes and opportunities focused on:
  - Improving individual health literacy and access to health information for Women Living with HIV across the HIV continuum of care;
  - Improving health literacy supporting systems and environments across communication functions (information, persuasion, social connection, and social structures); and the HIV continuum of care.

### Looking forward: Year 2 — Project Activities from January–April 2019

#### Refine framework

- Testing and refining the Health Literacy framework – with themes and opportunities with women living with HIV and partner agencies (Cairns Sexual Health Service, Femfatales, Living Positive Victoria, Queensland Positive People (QPP), NTAHC (Northern Territory AIDS and Hepatitis Council), Positive Women Victoria)

- Work has commenced to:
  - Refine and finalise first Framework for WLHIV
  - Prioritise recommendations for future action (including for example strategies, campaigns, messages and channels) to support improved individual health literacy and/or health literacy supporting systems, as determined through co-design process
  - Propose the broadening the process to a second PLHIV community in Australia
National Association of People With HIV Australia (NAPWHA)

For more information – contact NAPWHA:

<table>
<thead>
<tr>
<th>Name/Organisation</th>
<th>Position</th>
<th>Telephone</th>
<th>Email</th>
</tr>
</thead>
<tbody>
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<td>Katy Roy</td>
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<td>NAPWHA</td>
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Visit our website – napwha.org.au/health-literacy-framework/