

2019 – 2021

napwha national association of
people with HIV australia

HIV Health Literacy Framework: Evaluation Framework

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Introduction and overview

This document puts forward an evaluation framework for NAPWHA’s three-year *HIV Health Literacy framework* (HLF) project. The proposed framework’s approach to evaluation draws on literature (see e.g. Bossen et al 2016; Elmer et al 2017; Neuhauser 2017) that focuses specifically on the evaluation of health literacy programs. Insights for the structuring of the evaluation framework draw on a model put forward by Markiewicz and Patrick (2015).

The document contains several templates that may be useful over the life of the project as information comes to hand. If regarded as a ‘living document’, the evaluation framework can itself be included as one of the documents for analysis in the final evaluation phase.

Evaluation stakeholders

Key stakeholders for the evaluation of the *HIV Health Literacy framework* (HLF) project are summarised in Table 1 below.

Table 1: Stakeholder Mapping Matrix

Evaluation stakeholders	Roles in the evaluation process					
	Evaluation focus and scope	Development of key constructs	Development of the overall Framework	Endorsement of final Framework	Implementation of the Framework	Audience for outcomes of evaluation
NAPWHA and its research partner	X	X	X	X	X	X
Project Advisory Committee	X	X	X	X	X	X
PLHIV in identified groups		X	X	X		X
ViiV Healthcare	X		X	X		X
Broader healthcare sector		X				X

As with all templates and tables in this evaluation framework, Table 1 can be revised and updated as needed as the project progresses.

Background to the project

According to the project documentation, the National Association of People with HIV Australia (NAPWHA) has worked with community stakeholders over several years to develop, implement and evaluate a range of health promotion and treatment campaigns. These have aimed to encourage people living with HIV (PLHIV) to sustain optimal treatment as a foundation for improved health-related quality of life. Challenges that have been identified in the initiatives to date include:

- Reaching increasingly segmented audiences through a period of rapid demographic, HIV-related, communication and technological changes
- The need for more focused PLHIV health literacy in relation to emerging treatment options
- The changing profile of PLHIV in Australia.

In terms of the changing profile of PLHIV in Australia, concerns have been expressed that campaigns to date may have struggled to reach out to, and resonate with, diverse and vulnerable communities.

These include women; adolescents living with HIV and transitioning to adult services; Aboriginal and Torres Strait Islander communities; new and emerging culturally and linguistically diverse (CALD) communities; people living outside of metropolitan centres; people who are incarcerated; and people who inject drugs.

According to the project plan, it is intended over the course of three years (2019 – 2021) that the project will:

1. Identify the key dimensions of a national health literacy framework
2. Undertake baseline research and mapping, including identifying and working with the vulnerable communities/groups that will be focused upon
3. Develop, test and refine dimensions of the framework
4. Empower NAPWHA to provide support to a broader range of stakeholders through helping them better understand what – in terms of HIV-related health literacy – works for whom, when, and in what circumstances.

The longer-term outcomes are:

- improved quality of life for PLHIV, linked to enhanced health literacy
- reduction in HIV transmission rates
- increases in HIV testing
- engaging people in optimal treatment in line with best practice.

In consideration of vulnerable communities, in particular, the project aims to reduce identified health equity gaps for these communities in respect of testing rates, stigma and discrimination; and to increase their access to appropriate prevention, treatment and care services.

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Requirements and Expectations

NAPWHA will carry out this evaluation in collaboration with a research partner – [The Australian Research Centre in Sex, Health and Society \(ARCSHS\), La Trobe University](#).

As a means to address gaps in NAPWHA’s outreach, communication and messaging to the total body positive in Australia, the HLF project intends to develop, test and refine a HIV-focused health literacy framework that is meaningful to, and resonates with, identified vulnerable populations. It should support the development of specific health communication and campaign resources targeting those communities. These resources will be operationalised and assessed. At the same time, the processes, outputs and outcomes of the program should be in keeping with best practices for HIV-related health literacy initiatives in general, and thus generalisable to cohorts and communities beyond those who are partners in the three-year project.

A strongly participatory and action research approach underlies the HLF project. It is intended that members of key priority populations will be engaged to support the development of the health literacy framework – which includes a focus on messages as well as channels of health-related information – and to contribute to the research and evaluation associated with the project.

Through the conduct of this project, NAPWHA aims to expand its reach to 90 per cent of all PLHIV in Australia.

Project team capacity-building

Table 2 provides suggestions for capacity-building to support and enhance the project team’s engagement in the conduct and evaluation of the HLF project.

Table 2: Proposals for project team capacity-building

Stage	Understanding, Knowledge, Skills
Initial Orientation	<ul style="list-style-type: none"> • Health literacy • HIV and HIV care • Health-related quality of life in the context of HIV • Vulnerable populations within the Australian context
Developing the Evaluation Plan	<ul style="list-style-type: none"> • Partnership working in the context of a formal program evaluation • Evaluation within a community-based participatory action research approach • The place of program theory and program logic in evaluation design and methodology
Implementing the Plan	<ul style="list-style-type: none"> • Community-based participatory design: values, processes and techniques • Looking at administrative and management reports with a research lens • Data gathering, analysis and synthesis
Managing the findings and reporting	<ul style="list-style-type: none"> • Report writing • Organisational context • Communication skills

Program theory and program logic

This section describes the conceptual foundation for the project itself (the ‘program theory’); and the strongly linked conceptual foundation for evaluation of the project (its ‘program logic’).

Program theory

The theory underpinning the HLF project draws on three broad areas (each is briefly discussed below) of research and practice that are addressed at greater depth in the forthcoming literature review:

- Health literacy
- Community participation
- Pathways linking health literacy and health outcomes.

Health literacy

‘Health literacy’ is a concept that has generated a great deal of research and practice interest since it was first introduced in the 1970s (Palumbo 2015). In a widely adopted definition, health literacy refers to ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions’ (Neuhauser 2017: 156).

While it was originally understood as a measure of individual capacity (and deficit), and closely linked to literacy and numeracy skills, health literacy can more accurately be described as a **complex, multi-dimensional and dynamic interaction**. As written by Nielsen-Bohlman et al (2004: 32):

The impact of health literacy arises from the interaction of the individual and the health context ... [T]he causes and the remedies for limited health literacy rest with our cultural and social framework, the health and education systems that serve it, and the interactions between these factors.

The Australian Commission on Safety and Quality in Health Care (2014: 2) adopts this broader approach by viewing health literacy as the ‘junction between literacy, health and healthcare’.

Within a ‘population health literacy’ approach (Sørensen et al 2012: 4), health literacy can also be described as a **social determinant of health**. It operates in tandem with other health determinants such as the institutions and structures in a given society, socio-economic status, level of education, and gender. Together, these may affect an individual’s ability to ‘produce health’, that is, to stay healthy (Vernon et al 2007: 4).

Dawkins-Moultin et al (2016: 30) write that a common theme across all the definitions of health literacy is a **focus on cognition**: while it manifests in the steps individuals take to manage their health, health literacy is ‘more a way of thinking and reasoning than it is an observable action’. Such reasoning affects the beliefs people may have of their capacity to understand often complex health and illness-related issues. Thoughts about their self-efficacy help people decide what health promoting actions to take, including whether and to what extent they want deeper engagement with the health care system (Vernon et al 2007). Once engaged in health care, health literacy further contributes to shared clinical decision-making and patient involvement (Palumbo 2015).

The health literacy abilities, skills and practices of others in the social environment contribute substantially to an individual’s health literacy. Thus, health literacy is a **‘distributed resource’ within an individual’s social network**, which is especially the case for people living with long term health conditions (Edwards et al 2013). An implication of adopting a distributed health literacy approach is to recognise that several individuals may each possess only some aspects of literacy; however, by combining their efforts, they may function as more fully literate individuals. The distributed nature of health literacy has implications for peer support in the context of long-term conditions, such as living with HIV

In combination with other factors, low health literacy **contributes to poorer health-related outcomes**. Impacts of poor health literacy in the context of HIV include greater difficulty in avoiding HIV infection; failing to fully understand diagnostic information; a poorer working knowledge of HIV and its treatment; not adhering to antiretroviral therapy (ART); difficulties with healthcare instructions and directions; and a greater likelihood of having a detectable viral load (Osborn et al 2007; Kalichman et al 2013; Palumbo 2015).

Most interventions aiming to improve health literacy have a core **communication** component (Neuhauser 2017). This places a focus on the language and communication skills of individuals, and on the interactions between consumers and health professionals (Jordan et al 2010). It also draws attention to aspects of the wider health care system, such as the design of health print materials, medication labels, and websites (Neuhauser 2017).

According to Nutbeam (2000), comprehensive health literacy interventions would address three levels of competence:

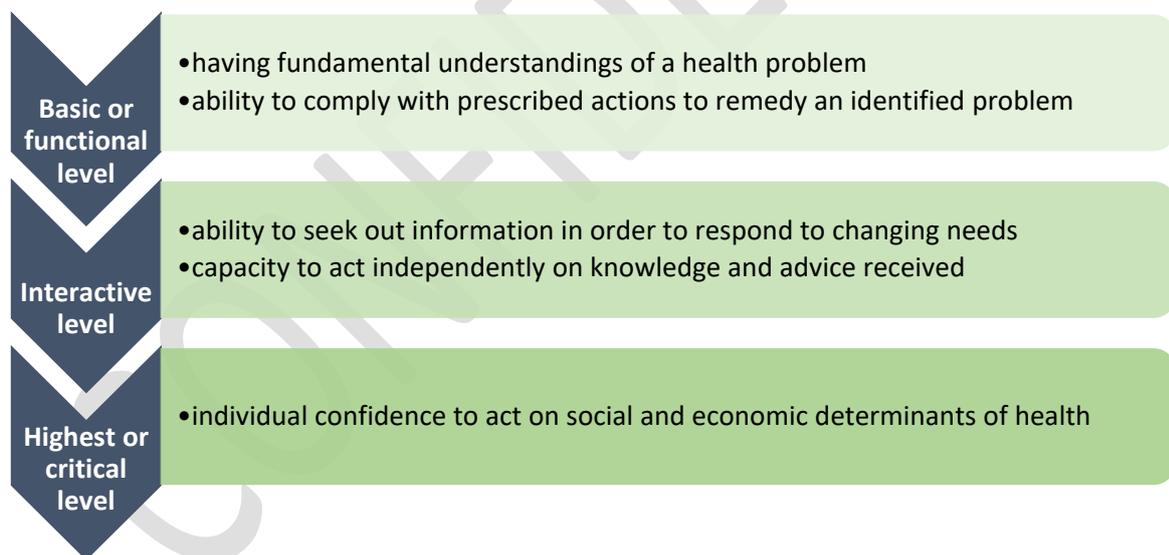


Figure 1: A framework for health literacy competences at the individual level

Source: based on Nutbeam (2000)

In addition to a focus on communication, health literacy interventions commonly address self-efficacy (Neuhauser 2017), empowerment (Cron Dahl and Karlsson 2016), and capacity-building (Dawkins-Moultin et al 2016). Achieving all of these outcomes relies on the active participation of the communities that are intended beneficiaries of health literacy interventions.

Community participation

Community participation has been a 'core element of local, national and global health mandates' since the Alma Ata Conference on Primary Health Care was held in 1978 (Neuhauser 2017: 161). Over the intervening decades, the evidence is overwhelming that engaging people in health care as individuals and as members of communities leads to better outcomes. Participation addresses 'deeper factors of motivation, self-efficacy and empowerment, as well as socio-environmental influences, and their impact to improve health outcomes and reduce health disparities' (Neuhauser 2017: 153).

Within a participatory approach to health literacy, community members would, amongst others, be given the opportunity to think about and discuss health literacy; to contribute to the design of health literacy interventions; and to participate in researching their impact. For example, active involvement of potential or current users in the design and testing of communication methods and resources is a widely used approach (Neuhauser 2017).

In addition to collaboratively designing health literacy initiatives, people should also ideally be included in research and evaluation connected to those initiatives (Neuhauser 2017). When adopting a participatory approach to research, 'the researcher is not the only expert and, in fact, is often not an expert at all in issues that affect the community and its members' (Morales 2017: 3). Participants are invited to reflect on and interpret their own roles in certain social practices. This generally involves long-term processes of 'community-researcher engagement, problem identification, reflection and intervention development, implementation and revision' (Neuhauser 2017: 162).

Community-based health literacy programs support the skill development of community members through social participation, but also through locating health promotion 'within its social, economic and political contexts' (Estacio, cited in Elmer et al 2017: e102). In order to enhance the capacity of individuals to 'function in the healthcare environment' (Brinkley-Rubenstein et al 2015: 251), attention could be paid to:

- **Autonomy** – occurs when the participant identifies with the importance of a health behaviour and takes action – especially new action – in areas of most relevance
- **Competence** – to adopt new behaviours requires that the person is, and feels, competent; this can be achieved through feedback from others, including health practitioners, until the person experiences behaviour mastery
- **Relatedness** – people are more likely to adopt changes if they are prompted by those they feel connected to and trust
- **Empowerment** – addresses ways in which participants gain control over, and feel that they have gained control over, factors and decisions that shape their lives

(Elmer et al 2017)

These are potentially useful indicators to focus upon when understanding and measuring the effects of the participatory aspects of the HLF initiative. Also important would be to better understand the pathways that lead from cognition (including perceptions of self-efficacy, and motivation) to action, since the project intends to have an impact on health-related outcomes.

Pathways linking health literacy to health outcomes

Paasche-Orlow and Wolf (2007: S24) point to evidence that health literacy may not relate to health outcomes in a linear way. Instead, the links between health literacy and health outcomes are mediated by influences derived from an individual's 'web of social relationships', including interactions within the health care context. According to these authors, intervention efforts need to acknowledge the interdependent impacts of a wide range of socio-economic, cultural and political factors on health outcomes. Also, these mediating factors need to be managed in various ways in the context of health literacy interventions so as to improve health care, especially 'for those with limited health literacy' (Paasche-Orlow and Wolf 2007: S24).

A model for categorising the mediating factors between health literacy and health outcomes – that is, the factors that influence whether people retain, retrieve, and decide to use the information they have access to when making health-related decisions – is summarised in Figure 2:

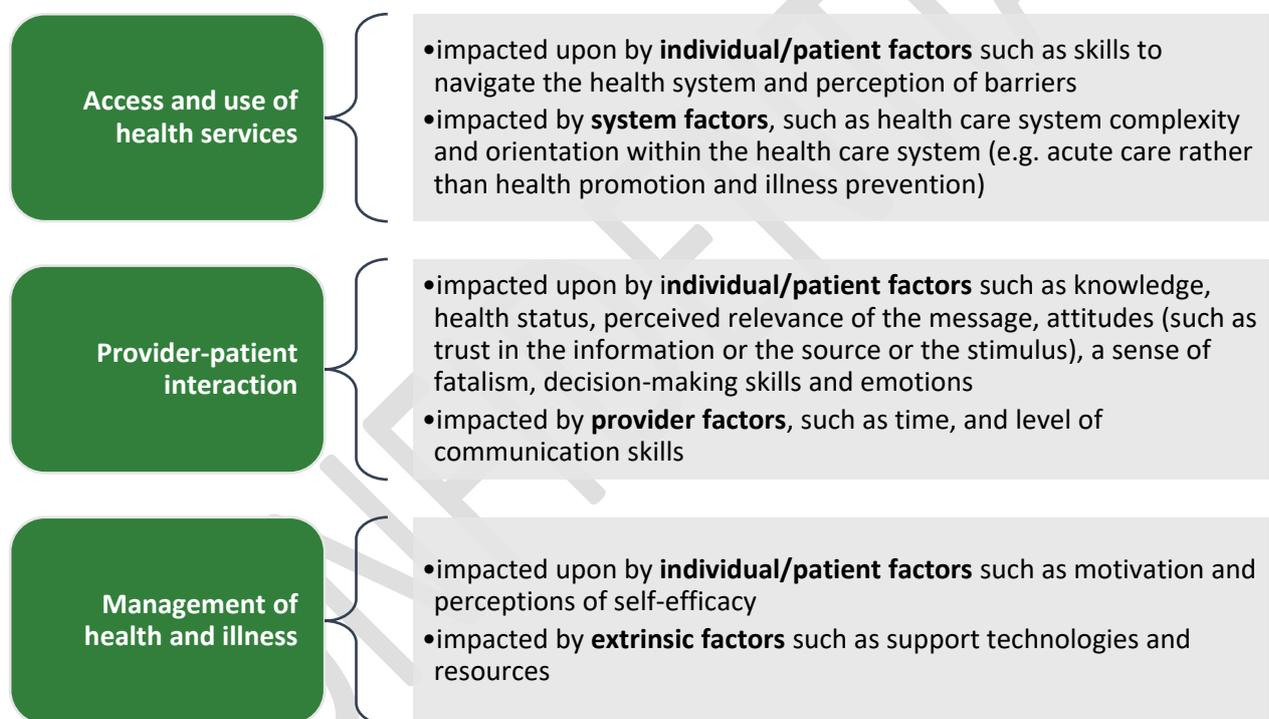


Figure 2: Mediating factors between health literacy and health outcomes

Source: based on Paasche-Orlow and Wolf (2007: S21)

As can be seen in Figure 2, factors that mediate between health literacy and health outcomes all reflect the dynamic interactions people have with other people and systems in their environments, that is, the health literacy ecosystem within which they function. Within this model, 'individual/patient factors' interact with 'system factors', 'provider factors' and 'extrinsic factors' in complex ways.

Zheng et al (2018: 6) write that developments in medical technology and increased life expectancy has contributed to greater attention being paid to quality of life (QoL). This means that professionals and researchers have become more concerned about whether improvements in health literacy also

contribute positively to QoL. For example, there is a research focus on the association between health literacy and health-related quality of life (HRQoL), which refers to how people subjectively assess their own wellbeing and their ability to perform physical, psychological and social functions (Jayasinghe et al 2016: 2).

Research to date suggests that the links between health literacy and QoL are not as clear-cut as might be hypothesised. For example, Couture et al (2017) found no relationship between health literacy and QoL among frequent users of health care services in Quebec. Zheng et al (2018) quantitatively evaluated the relationship between health literacy and quality of life based on a systematic review and meta-analysis. The study found that health literacy was only moderately correlated with quality of life – the authors called for more rigorous research to better clarify the potential correlation and the potential range of confounding factors, as summarised in Figure 2 above.

Brown et al (2018) draw on consistent findings in the literature to suggest that, beyond viral suppression through the use of ART, quality of life (QoL) is an important consideration in HIV prevention and care. Currently, there is no widely-accepted consensus as to what QoL is and what indicators are that constitute it; nor can QoL easily be measured by focusing on only one domain, such as ‘subjective life satisfaction’.

In light of this, the researchers developed a PozQoL scale using an approach embedded in the Greater Involvement of People with HIV/AIDS (GIPA) principles (Brown et al 2018). This brief 13-item PozQoL scale was tested and applied to a sample of PLHIV, and it was found to exhibit excellent construct validity and very good reliability, including consistency and temporal stability. The scale is presented in the table below.

Table 3: The PozQoL scale

FACTOR	RELATED STATEMENTS
HEALTH CONCERNS	I worry about my health I worry about the impact of HIV on my health I fear the health effects of HIV as I get older
PSYCHOLOGICAL	I am enjoying life I feel in control of my life I am optimistic about my future I feel good about myself as a person
SOCIAL	I feel that HIV limits my personal relationships I lack a sense of belonging with people around me I am afraid that people may reject me when they learn I have HIV
FUNCTIONAL	I feel that HIV prevents me from doing as much as I would like Having HIV limits my opportunities in life Managing HIV wears me out

Source: Brown et al (2018)

When the PozQoL scale is applied, participants record how the above statements apply to them on a 5-point scale where 1 = not at all; 2 = slightly; 3 = moderately; 4 = very; and 5 = extremely.

In the analysis carried out by Brown et al (2018: 7), all negatively-worded items were recoded so that higher scores for all items indicated better QoL. In further analysis, items were averaged to create the total score and scores for each subscale.

Program logic

Drawing explicitly on the program theory discussed above, this section puts forward a proposed program logic to underpin evaluation of the HLF initiative. A participatory approach to evaluation – as discussed earlier – is embedded within this program logic.

By making explicit a theory of change that derives from evidence, concepts and frameworks in the literature, the program logic seeks to describe a set of assumed relationships (associations, correlations, cause and effect relationships) among the inputs/activities, outputs and outcomes in relation to all that occurs in the context of the program. This can be expressed in general as follows:



Figure 3: A program logic model

Such an ‘outcomes hierarchy’ provides the basis for thinking about how a program needs to function to achieve desired outcomes (NSW Health 2017), and how it should best be evaluated.

Underlying assumption

As outlined earlier in the program theory, the HLF project draws on an established literature with a growing evidence base. Concepts, frameworks and evidence relating to health literacy in the context of HIV; community-based participatory and co-design approaches; and pathways linking health literacy and health outcomes, including health-related quality of life are integrated into and underpin the design of the program and its evaluation.

When these bodies of knowledge are located within a public health and social-ecological approach to health literacy that is prevalent in the literature (see Nielsen-Bohlman et al 2014; Dawkins-Moultin et al 2016; Crondahl and Karlsson 2016; Sørensen et al 2012), the underlying assumption for a theory of change for this project can be expressed as follows:

If

- NAPWHA partners with people from vulnerable communities to better address the HIV-related aspects of the health literacy ecosystems within which they live
- Insights, frameworks and techniques relating to health literacy are incorporated into the HLF program
- Stakeholders also address the potential mediating factors between health literacy and health and wellbeing outcomes

Then

This three-year initiative will have a positive impact on HIV-related health literacy, and on health and wellbeing outcomes for PLHIV from more vulnerable communities

Because

Health literacy is a social determinant of health. It emerges from, and is grounded in, the dynamic interactions people have with other people and systems in their environments. These multi-dimensional interactions constitute a health literacy ecosystem.

As a community-based HIV peer organisation, and an active participant in Australia's health literacy ecosystem, NAPWHA has a strong interest in contributing to improved HIV-related health literacy and health care outcomes for all PLHIV.

A suggested program logic for the HLF initiative is put forward in the pages that follow. In keeping with the participatory approach to evaluation, NAPWHA and its research partner would work together with participants and other stakeholders to refine the program logic and implement the evaluation. This may include striving for a shared understanding of outcomes at different levels, and agreement on what constitutes success.

The ethics application process is likely also to generate revisions to proposed data-gathering methods, which in turn will have implications for the proposed outcomes hierarchy outlined in Table 4 below as part of the program logic.

Program Logic for the HLF project

Table 4: Program logic

INPUTS:	<ul style="list-style-type: none"> • Contract between NAPWHA and ViiV Healthcare • Human resourcing – NAPWHA project team; research partner; Advisory Committee; engagement with stakeholders and intended beneficiaries; creative design • Financial resourcing – ViiV grant over three years
ACTIVITIES:	Activities relating to the following are undertaken for the life of the project:

Activities focused on HIV-related health literacy	Project-focused engagement and partnering	Research and evaluation	Engagement with the broader sector
<ul style="list-style-type: none"> • A three-year developmental approach is undertaken to test, refine and develop an emerging <i>HIV Health Literacy Framework</i> (HLF) for all PLHIV in Australia; this includes the conceptual, creative design and communication aspects of HIV-related health literacy 	<ul style="list-style-type: none"> • Project-specific engagement with members of three vulnerable communities, namely women, Aboriginal and Torres Strait Islander communities, and members of CALD communities • Relationships are established and strengthened with project and evaluation stakeholders; members of vulnerable communities participate in the co-design, delivery and evaluation of targeted pilot strategies and approaches tailored to their needs 	<ul style="list-style-type: none"> • Desktop literature and document reviews are undertaken • Baseline, process and an iterative participatory action research approach is adopted for the evaluation that seeks to understand what works for whom, when and in what circumstances, with a specific focus on diverse and vulnerable communities that are under-represented in testing and optimal treatment data • Reporting and dissemination 	<ul style="list-style-type: none"> • Engagement with the HIV body positive in connection with the project • Project learnings are shared with other PLHIV partners and the broader health and social services sectors to ensure the emerging HLF and related co-design learnings can be applied to other HIV prevention and treatment campaigns seeking to maximise impact across the diversity of the body positive.

OUTPUTS:	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM IMPACTS
Phase 1 – Establishment			
Internal team established Governance arrangements established	The resourcing, networks and partnerships for the project and its evaluation are negotiated and systematically put in place.	NAPWHA has successfully partnered with people from vulnerable communities to improve the HIV-related aspects of the health literacy ecosystems within which they live.	Through the conduct of this project, NAPWHA has expanded its reach to 90 per cent of all PLHIV in Australia.
NAPWHA website optimised	Changes to NAPWHA’s website make its format and messaging explicitly accessible to a broader segment of the body positive; and the website is geared up to receive material generated over the course of the project.	Participants express greater levels self-efficacy, motivation and competence to make and enact decisions in health promoting ways with regard to HIV.	There is a reduction in the identified HIV-related health equity gaps between people from vulnerable communities and those from the Australian community in general. In particular:
Key partner organisations identified and engaged Key research partners engaged Three vulnerable cohorts of PLHIV are identified and engaged Project champions within the three identified cohorts are identified and engaged	Building on strong partnerships developed over many years, NAPWHA engages leaders from Femfatales , PATSIN and CALD networks to actively participate in the project.	NAPWHA delivers health literacy strategies that specifically address the needs of people from vulnerable communities. The conceptual, creative design and communication aspects of HIV-related health literacy which emerge in the context of the program have become embedded within NAPWHA’s overall strategy, planning and operations.	<ul style="list-style-type: none"> • An increase in rates of HIV testing among people from vulnerable communities is evidenced through surveillance data • A reduction in HIV transmission rates among members of vulnerable communities is evidenced through surveillance data • A larger number and proportion of PLHIV in the identified cohorts is engaged in best practice prevention, treatment and care services, as evidenced through surveillance data
An evaluation framework, with a program logic based on an explicit program theory, is developed	Protocols for a community-based, participatory approach to evaluation are agreed upon.		

Phase 2 - Development			
A desktop literature and best practice review is conducted	NAPWHA has a better understanding of HIV-related health literacy concepts, frameworks, the current evidence base and best practice models from Australia and internationally	<p>NAPWHA receives feedback that its refined HHC health literacy framework can be generalised to other settings, that it has value as a shareable resource, and that it can be used as a professional development tool.</p> <p>Evaluation findings are widely disseminated and, in doing so, NAPWHA and its research partner contribute to the growing evidence base on HIV-related health literacy.</p>	<p>PLHIV from vulnerable communities enjoy increased health-related quality of life.</p>
Baseline research and data reviews are conducted	NAPWHA has a stronger and more evidence-based grasp of the health literacy gaps, enablers and barriers that pertain to each of the three priority cohorts		
Focus groups with members of the chosen priority cohorts are planned, held and recorded	Focus group participants conduct health literacy assessments of existing resources, are empowered to put forward their views on the strengths and weaknesses of current approaches, and can identify opportunities and strategies for improvement		
	Focus group participants have greater confidence, knowledge and skills to work with HIV-related health literacy concepts, approaches and materials		

Focus groups with health care workers are planned, held and recorded	Strengths, gaps and limitations within the Australian health system; and opportunities and strategies for improving health literacy environments are discussed		
Existing and emerging Australian HIV prevention and treatment-related strategies and campaigns are mapped and incorporated into the draft framework			
A draft HIV health literacy framework is developed			
Phase 3 - Delivery			
In keeping with the draft HHC framework, pilot health literacy strategies are co-produced with each priority cohort	The draft HHC health literacy framework is fit for purpose and translatable into concrete messages and communication formats		
The pilot health literacy strategies are delivered over a 12-month period (July 2020 to June 2021)	The conceptual, creative design and communication aspects of HIV-related health literacy are made explicit in the co-production, delivery, monitoring and refinement of health literacy strategies – and participants are on board with this		

<p>The draft HHC health literacy framework is refined on the basis of outcomes from delivery of the health literacy strategies</p>		<p style="text-align: center; opacity: 0.2; font-size: 48px; transform: rotate(-30deg);">CONFIDENTIAL</p>	
<p>The refined HHC health literacy framework is promoted and disseminated among specialist and mainstream providers as a shareable resource and professional development tool</p>	<p>At least three campaigns have been put into place</p>		
<p>Phase 4 – Final evaluation</p>			
<p>The final evaluation of the HLF initiative is carried out. While there is a specific focus on program impacts (an outcomes or impact evaluation), this would also be the opportunity to draw on a wide range of sources – including administrative documentation – to gauge the program’s appropriateness, effectiveness, efficiency, and processes.</p>	<p>The evaluation of the program is completed, and judgements are made on the program’s impact, appropriateness, effectiveness, efficiency, and processes as per the evaluation questions.</p> <p>The final evaluation report, containing implications and recommendations, is published and disseminated.</p>		
<p>Recommendations are put forward for the future development and sustainability of the HHC health literacy framework.</p>	<p>Particular attention is paid to strengthening the networks and partnerships that have developed with leaders and members of the vulnerable communities over the course of the program.</p>		

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Evaluation questions

Standard criteria adopted in evaluation studies – namely measures of the ‘appropriateness’, ‘effectiveness’, ‘efficiency’, ‘process’ and ‘impact’ of a program or initiative (see: Better Evaluation 2019) – are used as domains for the HLF initiative’s evaluation questions, as put forward in Table 5 below and in the remainder of this framework.

It is expected that the precise wording of the evaluation questions will be refined on the basis of research partner, stakeholder and participant input.

Table 5: HLF project Evaluation Questions (draft)

Domain	Evaluation Questions
Appropriateness	<p>Does the HLF project align with NAPWHA’s strategic plans and priorities? If so, in what ways?</p> <p>Does the project contribute applied understandings relating to health literacy in the context of HIV in Australia? In what ways does it do so?</p>
Effectiveness	<p>To what extent is the HCF project achieving its intended outcomes in the short, intermediate (medium) and long term?</p> <p>What were the particular features of the program that made a difference?</p>
Efficiency	<p>To what extent is the relationship between inputs/activities and outputs timely, cost-effective and to expected standards?</p>
Process	<p>How active and engaged are participants in the co-design of the program activities and outputs, and in the program evaluation?</p> <p>In what ways have community-based and partnership-working elements contributed to the program’s hoped-for outcomes?</p>
Impact	<p>Have the identified HIV-related health equity gaps between people from vulnerable communities and those from the Australian community in general been reduced? If so, to what extent?</p> <p>To what extent has NAPWHA expanded its reach in the total body positive in Australia?</p>

Evaluation design and methodology

Evaluation design

According to the project plan, it is intended that the evaluation be designed on community-based participatory action research principles. This approach to evaluation involves ‘long-term processes of community-researcher engagement, problem identification, reflection and intervention development, implementation and revision’ (Neuhauser 2017: 162). Adopting this research design gives participants a more active role in the evaluation by inviting them to self-reflect and interpret their own roles in the social practices being studied. In the context of health literacy research, this approach would, amongst others, focus ‘a critical and analytical lens on community participants’ own judgments about health information resources available to them’ (Morales 2017: 3).

Bossen et al (2016) argue that the purpose of evaluation within participatory action research should explicitly include empowerment, mutual learning and/or democratization objectives; and that project participants should work with project managers and internal or external researchers to define what should be evaluated, which criteria should be applied, and how the evaluation should be conducted. The suggestion is that, in participatory research, an evaluation framework is an iterative process that nevertheless adheres to its core assumptions.

Methodology

A mixed methods approach is adopted, carried out over three interlinked phases:

- I. Baseline data-gathering within the first year
- II. Continuous data-gathering, with a mid-project stocktake
- III. Final evaluation – synthesising findings generated over the life of the project together with new data gathered towards the end of the project

Data gathered by means of methods such as interviews and surveys could be supplemented with content analysis of management, organisational and process reports. The assumption is that, in a project of this nature, a wide range of reporting can be useful when viewed through an ‘evaluation-minded’, and particularly a ‘community-based participatory action research’ lens.

In light of these considerations, data collection methods could include, but would not be limited to:

- 1) **Focus group reporting** – including session plans and process reporting; process and outputs relating to the co-development of new communication resources, including design thinking exercises and usability tests; participatory qualitative analysis of focus group discussions to generate insights relating to participants’ own understandings of health literacy and of the mediating factors between health literacy and health and wellbeing outcomes
- 2) **In-depth interviews with leaders within the identified cohorts** – opportunity to explore their views on the initiative and their understandings of links to health literacy; use can be made of a conceptual framework such as the Autonomy, Competence, Relatedness, Empowerment model discussed earlier (Elmer et al 2017)
- 3) **Survey** – pre-intervention, mid-intervention and post-intervention survey, including making use of the PozQoL scale (Brown et al 2018)

- 4) **Organisation level (NAPWHA)** – the evaluation framework as a ‘living document’; performance indicators and targets; team discussions, meetings and reporting; feedback from partners and networks
- 5) **Sector level** – including surveillance data
- 6) **Monitoring of communication outputs** – the campaigns, platforms, messages and user data flowing from operationalisation of the framework
- 7) **Project officer’s diary**

Ethics

Since this project and the research and evaluation associated with it involves human subjects, and is to be conducted among vulnerable populations, ethics approval will be essential before any data-gathering is carried out in the field. Potential ethical issues can be outlined in respect of each data collection method, for example:

Table 6: Ethical considerations

Data Collection Method	Potential Ethical Issues
Focus group reporting	
In-depth interviews	
Survey	
Organisation level	
Sector level	
Monitoring of communication outputs	
Project officer’s diary	

Evaluation Plan

A range of templates is provided in the remainder of the document that can serve as management and recording tools; they may also prompt discussions and decisions as the framework is refined and operationalised in the context of an iterative and participatory approach to the evaluation.

Table 7: Evaluation planning template

Evaluation Questions	Methods	Indicators	Data synthesis
<p>Appropriateness</p> <p>Does the HLF project align with NAPWHA’s strategic plans and priorities? If so, in what ways?</p> <p>Does the project contribute applied understandings relating to health literacy in</p>	<p>Organisation level</p> <p>Sector level</p> <p>Monitoring of communication outputs</p> <p>In-depth interviews</p>	<p>Linked to the evaluation questions</p> <p>Operationalisation of the indicators within each of the data-gathering methods</p>	<p>Recording the decisions made on how data from the various methods would be brought together (triangulated) in order to respond to each evaluation question – making an</p>

<p>the context of HIV in Australia? In what ways does it do so?</p>	<p>Focus group reporting</p>		<p>argument for why the synthesis makes sense</p>
<p>Effectiveness To what extent is the HHC-HCF project achieving its intended outcomes in the short, intermediate (medium) and long term? What were the particular features of the program that made a difference?</p>	<p>Project officer's diary Focus group reporting Organisation level Survey Monitoring of communication outputs</p>		
<p>Efficiency To what extent is the relationship between inputs/activities and outputs timely, cost-effective and to expected standards?</p>	<p>Organisation level Project officer's diary Focus group reporting</p>		
<p>Process How active and engaged are participants in the co-design of the program activities and outputs? In what ways have community-based and partnership-working elements contributed to the program's hoped-for outcomes?</p>	<p>Project officer's diary Focus group reporting In-depth interviewing</p>		
<p>Impact Have the identified HIV-related health equity gaps between people from vulnerable communities and those from the Australian community in general been reduced? If so, to what extent? To what extent has NAPWHA expanded its reach in the total body positive in Australia?</p>	<p>Organisation level Sector level Survey</p>		

Making evaluative judgments

A table such as the following can be used in connection with each question

Table 8: Template for making evaluative judgments

Criterion/ standard for assessing level of performance	Evaluation Question:					
	Data Synthesis	Standards				Evaluative Judgements
		Excellent	Good	Adequate	Poor	

Reaching Conclusions

Table 9: Template for reaching evaluative conclusions

Evaluation Questions	Data Synthesis	Evaluative Judgements	Evaluative Conclusions
Appropriateness			
Effectiveness			
Efficiency			
Process			
Impact			

Implementation, Reporting and Dissemination

Implementation work plan

Program Management Arrangements

Work Planning

Table 10: Template for work planning over three years

2019 Activities	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Report to F2F ViiV Healthcare												
Development of project plan												
Establish representation from partner orgs and PLHIV reps												
NAPWHA website optimisation												
Develop evaluation framework												
Identify/engage key research partner												
Apply for research ethics approval												
Establish governance/Steering Group												
Hold Steering Advisory Group meeting												
Conduct desktop review of health literacy best practice and models												
Conduct detailed HIV data review (State of Play of AUS States; cohorts)												
Identify/recruit project champions												
Provide project champion training												
Run focus group: health care providers												
Run focus group: Women (1 st location)												
Run focus group: Women (2 nd location)												
Map current strategies & best practice												
Develop draft framework												

Reporting and Dissemination Plan

Table 11: Template for reporting and dissemination planning

Report Type	Due Date	Audience & their Interests	Overall Focus	Contents	Dissemination
Formal Reports					
Evaluation Framework	June 2019				
Literature Review on Health Literacy Models	July 2019				
Ad Hoc and Event Reports					
Steering Advisory Group – Terms of Reference	June 2019				
Steering Advisory Group – Meeting Record	July 2019				

Monitoring and Review of Framework

Table 12: Template for monitoring and review off the framework

Overall Focus	
Specific Areas	
Structure of the Framework	Implementation of Framework

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Appendix

Document Control

Revision History

The following changes have been made to this requirements specification:

Version	Prepared by	Date	Description of Change
0.1	Ronald Woods	21-Jun-2019	Draft provided
0.2	Saysana Sirimanotham	21-Jun-2019	Draft formatted and sent to Advisory Steering Group for review
0.3	Saysana Sirimanotham	2-Jul-2019	Feedback incorporated

Related Documents

- [NAPWHA HIV Health Literacy Framework Project – Literature Review \(July 2019\)](#)

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