

napwha national association of
people with HIV australia

HIV Health Literacy Framework: Literature Review

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Executive Summary

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 as an evidence-based means to maintain an undetectable viral load and have improved quality of life.

NAPWHA's HIV Health Literacy Framework project

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.

Supporting an improved conversation with women

The cohort within the body positive that will be focused upon is women living with HIV. Working in partnership with women champions, NAPWHA will draft a *HIV Health Literacy Framework* in 2019 to support an improved conversation with women. 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 can then be extended to other cohorts within the body positive, and the developing Framework can be shared within the sector.

'Health literacy' as a concept and contextualised with HIV treatment

Through identifying, describing, analysing and synthesising the literature on health literacy, this literature review forms an integral part of the HLF project. Findings from the literature review show that 'health literacy' as a concept has generated a great deal of research and practice interest since it was first introduced in the 1970s. Originally closely linked to literacy and numeracy skills, and understood as a measure of individual capacity (and deficit), health literacy can more accurately be described 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.

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.

In Australia and internationally, there has in recent decades been a strong policy, research and practice interest in health literacy. The literature review provides evidence that programs and initiatives have been developed to promote health literacy and to advance health literacy research.

Active involvement of communities is an integral part of health literacy interventions

Health literacy interventions focus on individuals, communities, organisations and the broader health context. Many interventions have a core communication component. This addresses language and communication skills, interactions between consumers and health professionals, and public discourse. It draws attention to health communications of educators and health care providers, and of the health system as-a-whole. It addresses the design of health print materials, medication labels and websites. Active involvement of communities is an integral part of health literacy interventions, as is the case in the HLF project.

The path from health literacy to health outcomes

Higher levels of health literacy are assumed to improve people's competence, awareness and motivation to access, understand, appraise, and apply health-related information. Health literate people are seen to be better equipped to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion in order to maintain or improve quality of life during their life course. The path from health literacy to health outcomes is, however, not smooth or linear. Intervening or 'mediating' factors influence whether people retain, retrieve, and decide to use the information they have access to when making health-related decisions. Several models have been put forward to better understand the pathways from health literacy to health behaviours and outcomes.

Evidence-based understandings that can be incorporated into health literacy interventions

There are considerable gaps in the evidence concerning which interventions are most effective in improving health literacy. There is a lack of research involving disadvantaged or hard-to-reach groups; and of research focusing on communicable diseases. Nevertheless, the literature provides evidence-based understandings that can be incorporated into health literacy interventions such as NAPWHA's *HIV Health Literacy Framework* project.

These include:

- **There is support for tailored HIV health literacy initiatives.** Programs address factors affecting the relationship between health literacy and living with HIV, often in the context of multimorbidity and polypharmacy. Both HIV- and literacy-related stigma are ideally addressed when assisting PLHIV who struggle with health literacy; and quality of life is an important consideration in HIV care.
- **The literature suggests that much work needs to be done when considering the online environment,** since there is evidence that eHealth literacy promotes as well as hinders HIV-related health outcomes.
- **Decades of research and practice highlight the multi-dimensional and dynamic nature of health literacy.** This complexity requires health literacy interventions to adopt participatory approaches to first identify, then address health literacy needs.

- **Successful health literacy initiatives are multi-faceted.** They address health communication, including design, issues. They address attitudes, knowledge, skills, abilities and interactions.
- **Organisational health literacy is a goal to strive for**, and health literacy is ideally embedded within systems.
- **HIV health literacy is not a static outcome.** It flourishes in an environment of mutual trust between health providers and individuals. Successful patient-provider interactions are built on acknowledging diverse and multiple social identities, and the hierarchy of needs impacting on people's health decisions and behaviours.
- **Health literacy may lead to health promoting actions**, including with respect to HIV, but consideration also needs to be given to the complex range of factors (opportunity, motivation, self-efficacy, context, etc.) that can hinder this.
- **Information-management and navigational skills**, together with attributes such as autonomy, competence and relatedness, help people translate their health literacy-informed thinking and reasoning into health actions. Depending on the situation, action may include attending to mental health, exercise and diet, or medication adherence.
- **Health literacy interventions that go beyond a focus on functional literacy can be empowerment strategies** that enable people to take greater control of their own health. Any conception of empowerment in the context of health literacy interventions needs to encompass understandings of the social and structural determinants of health.

To conclude, this document puts forward a draft HIV Health Literacy Framework as a theory and evidence-informed contribution to the community-based participatory work that will be undertaken over the life of the HLF project. This is considering the project's objective to develop, refine and test a health literacy framework suited to the context of HIV in Australia.

1. Introduction

1.1 Background to the project / study

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 HIV-related 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.

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1.2 NAPWHA's HIV health literacy framework (HLF) project

To address gaps in NAPWHA's outreach, communication and messaging to the total body positive in Australia, the *HIV health literacy framework* (HLF) project has been established to take place over the three years from 2019 to 2022. The HIV Health Framework Literature Review (this document) is an integral part of this initiative.

The project will develop, test and refine a HIV-focused 'health literacy framework' that is meaningful to, and resonates with, identified vulnerable populations.

The community that is to be focused upon is women living with HIV throughout Australia. Over three years, it is intended that the HLF project will:

1. Identify key dimensions of a national health literacy framework for HIV
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.

Improving both individual health literacy and health literacy environments

It is intended that the developing HIV Health Literacy Framework should aim to improve both individual health literacy and health literacy supporting systems and environments. This two-dimensional focus is in keeping with Australia's *National Statement on Health Literacy* and accompanying documentation (Australian Commission on Safety and Quality in Health Care 2014).

A strongly participatory and action research approach underlies the initiative. It is intended that women will be engaged to support the development of the 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.

The implication is that the emerging health literacy framework should support the development of specific health communication and campaign resources targeting women. 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 generalizable to cohorts and communities beyond those who are partners in the three-year project. For this reason, the HLF project is guided by a literature review, presented in this document.

1.3 Literature review

Through identifying, describing, analysing and synthesising the literature on health literacy, this review forms an integral part of the HLF project. The literature review contributes to the evidence base for the project for the benefit of all stakeholders, including community-based participants. It also puts forward a draft HIV Health Literacy Framework that integrates literature on the HIV Care Continuum or 'treatment cascade' with a selection of health literacy frameworks.

This Framework can contribute to the community-based participatory work that will be undertaken over the life of the HLF project, which has the objective to develop, refine and test a health literacy framework suited to the context of HIV in Australia. NAPWHA will partner with women to better address the HIV-related aspects of the health literacy ecosystems within which they live, with a direct focus on the organisation's own public communications and campaigns.

The Framework that is developed, trialled and tested in partnership with women should be generalisable so that it can also be applied to other vulnerable cohorts and/or priority communities. Consequently, insights, frameworks and techniques relating to health literacy best practice will be explicitly incorporated into the HLF program.

This document presents the process and outcomes of the study in the form of a narrative literature review. It provides program stakeholders with the foundational concepts, frameworks and evidence relating to health literacy in the context of HIV that can be applied, critiqued and revised over the life of the program.

Based on this exploration, the narrative review aims to provide answers to the following two questions:

What is Australian and international health literacy best practice, also in the context of HIV?

What conceptual frameworks can be developed that best link a HIV health literacy framework with current Australian HIV-related continuum of care and prevention and treatment-related strategies, approaches and campaigns?

2. Health literacy

'Health literacy' has generated a great deal of research, policy and practice interest since it was first debated in the 1970s. Understood as a measure of the capacities individuals have to find, process, understand, and communicate about health information and services to protect and promote their health, debates have emphasised its complex and multi-dimensional, as well as dynamic, nature. Health literacy is an attribute with personal as well as social benefits. It is a social determinant of health, reflecting an interaction between the demands and complexities of health organisations and systems, and the skills of individuals.

This section of the document considers developments in the understanding and application of this concept, population health literacy approaches, and the impacts of low health literacy.

2.1 Development of the 'health literacy' concept

Health literacy was first used as a term in 1974 at a conference focusing on health education in schools as a social policy issue (Frisch et al 2011: 117). It described the abilities people have to comprehend health information and to process the numerical data often included in health information (Wawrzyniak et al 2013: 2). In the early years, therefore, health literacy was used to refer mainly to people's 'ability to use written and oral material to function in healthcare settings' (Palumbo 2015: 417).

In keeping with this approach, a widely adopted definition put forward in 2004 by the National Academies of Science, Engineering and Medicine in the USA regards health literacy as '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).

There are many other definitions. For example, on the basis of a systematic literature review, Sørensen et al (2012) derived 17 definitions of health literacy from the literature. Frisch et al (2011: 119) summarised the definitional challenge as follows:

Current definitions of health literacy show that health literacy is more than functional literacy in the health domain. At the same time, no consensus exists about what to include in the concept of health literacy. This lack of consensus hinders the development of validated measures of health literacy reflecting its multidimensionality.

Dawkins-Moultin et al (2016: 30), who also examined a range of definitions of health literacy, found that a common theme across all the definitions was 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, and prompts consideration of health promoting actions, including whether and to what extent to engage with the health care system (Vernon et al 2007).

Once engaged in health care, health literacy continues to promote an exchange of information between the person and health care providers and in this way further contributes to shared clinical decision-making and patient involvement (Palumbo 2015). Together, these may affect an individual's ability to 'produce health', that is, to stay healthy (Vernon et al 2007: 4).

Recent discussions highlight the importance of considering health literacy as an interaction between the demands and complexities of health systems and the skills of individuals (Sørensen et al 2012). Health information is often 'complex and ambiguous', and it challenges the individual's ability to 'make informed choices and to effectively participate in the process of healthcare provision' (Palumbo 2015: 418). Rather than a one-dimensional focus on the abilities and deficits of individuals, therefore, 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.

When viewed in an interactional way, health literacy 'takes on a more reflective view of the health care system' (McCormack, McBride and Paasche-Orlow 2016), and is a 'shared function' of cultural, social, and individual factors (Nielsen-Bohlman et al 2004: 32). Squiers et al (2012: 47) discuss health literacy as a multi-dimensional and dynamic construct that functions at the level of the individual, while acknowledging that factors external to the individual – such as the family, neighbourhood, culture, and media – all have a powerful influence.

Literature-based insights into the complex, multi-dimensional and dynamic nature of health literacy are discussed next.

2.1.1 Complex

In an influential text, Nutbeam (2000) pointed out that health literacy is not only a personal resource leading to personal benefits, but also – due to its impact on communication among all parties in a community – an attribute with social benefits. This broader conception of health literacy has promoted understandings at the broader social and political, in addition to individual, levels.

On this basis, Nutbeam (2000: 65) proposed three levels of competence related to health literacy:

1. At the basic or 'functional' level, an individual has a fundamental understanding of a health problem and the ability to comply with prescribed actions to remedy the problem. Functional competence strongly reflects the intended outcome of traditional health education, which is based on communication of factual information on health risks and on how to use the health system.
2. At an 'interactive' level, a person has more advanced knowledge and skills to function in health promoting ways and the ability to seek out information in order to respond to changing needs.

This reflects an increased focus in recent decades on the development of personal skills in a supportive environment, including a focus on improving personal capacity to act independently on health-related knowledge and advice received.

3. At the highest or 'critical' level, people have significant level of knowledge, personal skills and confidence to manage their health. This is linked to a population in addition to an individual benefit, and supports effective social and political action. It includes a focus on people's confidence to act on social and economic determinants of health.

2.1.2 Multi-dimensional

According to Zarcadoolas Pleasant and Greer (2005: 196), a health literate person is able to apply health concepts and information to novel situations, and to participate in ongoing public and private discussion about health, medicine, scientific knowledge, and cultural beliefs.

On this basis, an expanded model of health literacy would include four domains:



Figure 1: Domains of health literacy

Source: Zarcadoolas et al (2005: 197)

Frisch et al (2011) expand on this multi-dimensionality by considering how several other 'literacy domains' can contribute to defining and measuring health literacy. These include media literacy, environmental literacy, and financial literacy.

2.1.3 Dynamic

As is evident from the discussion thus far, developing conceptions of health literacy have emphasised its complex and multi-dimensional, as well as dynamic, nature. It is not a static quality at either the individual or the population level. Paasche-Orlow and Wolf (2007: S24) note that improvements to health literacy can occur in a general sense through, for example, initiatives focused on adult basic education, as well as in an individual's own development, such as mastery of a specific self-care skill. Literacy may also decline over time, in relation to, or independent of, conditions that may increase in prevalence with age, such as dementia.

Von Wagner et al (2009: 864) write that there are many opportunities for external influences to maintain and strengthen health literacy skills throughout the life span. These include:

- Stimulation provided by parents; parent-child interactions
- Resources provided during formal education
- Life events that increase a person's exposure to written materials or provide a continuous challenge to his/her literacy skills
- Learning opportunities that may arise in the form of community-based literacy interventions.

Health literacy is also dynamic from a conceptual point of view. As Nguyen et al (2017: 200) write, its evolution is 'affected by language, culture, an increasingly global and mobile world, and sweeping health system changes taking place in many countries'. Since, as discussed earlier, health literacy is more 'a way of thinking and reasoning than it is an observable action' (Dawkins-Moultin et al 2016), it is subject to change depending on factors such as the individual's background knowledge, and experiences with the health care system. It is also strongly influenced by the demands that the health context places on individuals, families and communities.

In keeping with this broadening of the definition of health literacy, there has been an increased focus on including dimensions that go beyond individual competences within the medical context towards 'population health literacy' approaches (Sørensen et al 2012: 4), discussed next.

2.2 Population health literacy approaches

A population health approach to health literacy has been prevalent in the literature over at least the past two decades (see e.g. Nielsen-Bohlman et al 2004; Sørensen et al 2012; Dawkins-Moultin et al 2016; Crondahl and Karlsson 2016). This broader approach has been promoted in Australia, where health literacy is understood as the 'junction between literacy, health and healthcare' (Australian Commission on Safety and Quality in Health Care 2012: 2).

Bauer et al (2017: 6) define health literacy as referring both to ‘how people find, process, understand, and communicate about health information and services to protect and promote their health’, and to ‘how organizations and systems support or hinder people in these activities’.

A broader population health approach is especially important when considering that many communities are cut off from the large amount and variety of health information that exists beyond their personal and collective experiences (Bauer et al 2017).

2.2.1 Determinant of health

Strongly linked to the population health approach, there is a trend to view health literacy as a social determinant of health that operates together with other determinants to promote or hinder the health of people. Determinants of health are illustrated in Figure 2:

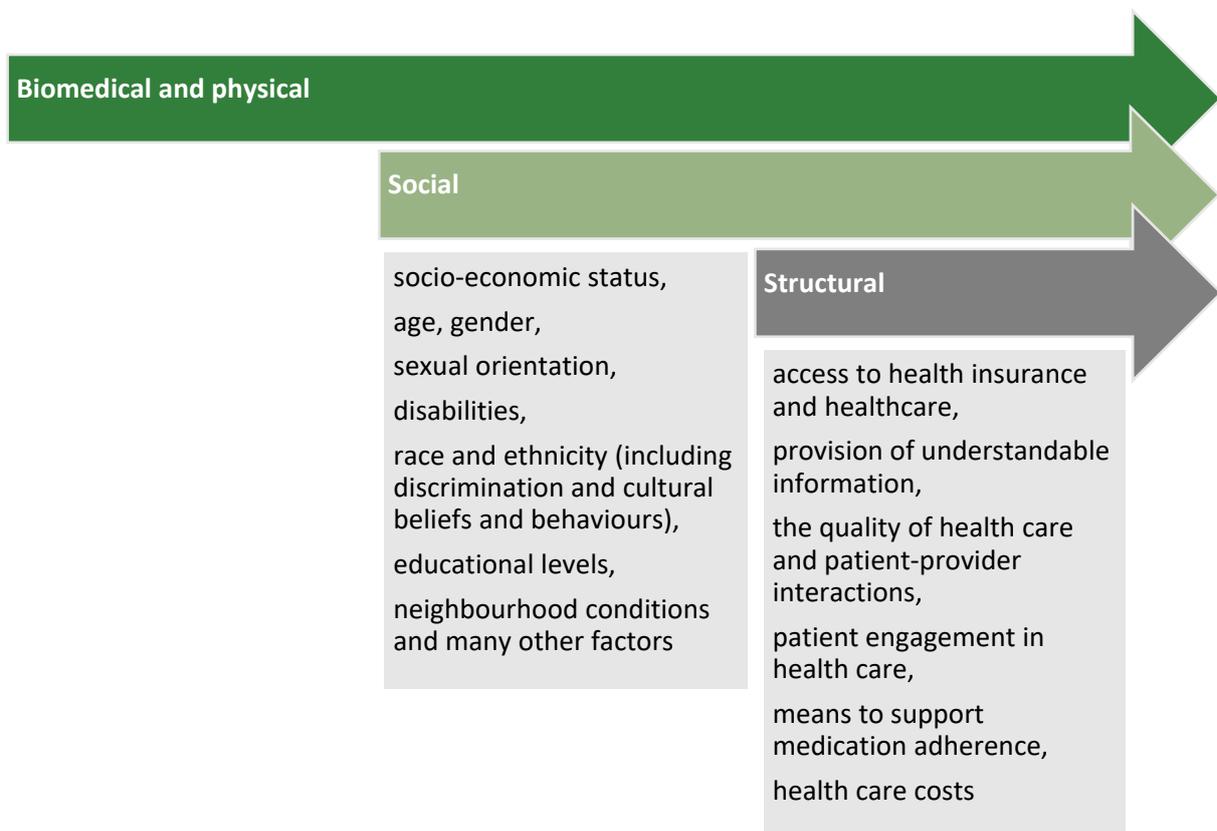


Figure 2: Determinants of health

Source: based on Neuhauser (2017)

Viewed in this way, health literacy becomes an essential determinant of good health due to its impact on the efficiency with which people seek care and receive treatment; and to the capability of the health system to ‘create and sustain supportive environments for health’ (De Leeuw 2012: 2).

If health literacy affects ‘the capacity of an individual to function in the healthcare environment’ (Brinkley-Rubenstein et al 2015: 251), the health literacy of individuals needs to be matched by the health literacy of the health and educational system as a whole, and thus also of health care and community-based organisations.

2.2.2 Health literacy as a distributed resource

The health literacy abilities, skills and practices of others in the social environment contribute substantially to an individual’s health literacy. In this sense, 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.

2.2.3 Systems approaches

The importance of broader social, ecological and systemic factors is increasingly being recognised as helping or hindering the process of enhancing health literacy attributes, knowledge and skills (Jordan et al 2010). As Farmanova et al (2018: 4) write:

From an ecological perspective, limited health literacy is viewed as a vulnerability that coexists and interacts with other social vulnerabilities...[I]nterventions addressing an array of influences on peoples’ lives are needed.

A social ecological health literacy perspective (McCormack et al 2017) draws on models widely adopted in the social sciences. These models recognise that individuals are influenced by factors in the physical and social environments, and that ‘interventions targeting multiples levels of influence reinforce each other and consequently should yield greater and more sustainable effects than interventions targeting only one level of influence’ (McCormack et al 2017: 9).

2.3 Impacts of poor health literacy

Based on a comprehensive review of the literature, Sørensen et al (2012) find strong evidence that health literate people live longer and have stronger incentives to invest in developing knowledge and skills. Evidence generated over the past two decades, in particular, provides firm ground for concluding that low health literacy, in combination with other factors, contributes to poorer health-related outcomes. These are summarised in Table 1.

Table 1: Outcomes for individuals with poorer health literacy

Health-related outcomes	References
Poorer self-reported health status and self-reported ability to deal well with health conditions	Palumbo (2015) Vernon et al (2007)
Less aware of the determinants of health and wellbeing and less likely to engage in illness prevention and health promotion measures	Vernon et al (2007) Palumbo (2015)
Greater prevalence of factors harmful to health such as smoking, lack of physical activity and obesity	Jayasinghe et al (2016)
Lacking the skills needed to navigate the health system, including a weaker ability to interpret labels and health messages	Vernon et al (2007) Berkman et al (2011)
Less likely to comply with prescribed treatment and self-care regimens	Vernon et al (2007)
More likely to use emergency services and to be hospitalised	Vernon et al (2007) NSW Health (2016) Palumbo (2015)
Higher morbidity and mortality rates, particularly among older people	Vernon et al (2007) Berkman et al (2011)

In the light of these insights, researchers and practitioners have presented inadequate health literacy as a ‘silent epidemic’ which affects a large proportion of the worldwide population (Palumbo 2015), and which also contributes to higher levels of public health spending (Vernon et al 2007: 5).

In keeping with the effects of poor health literacy identified in studies over many decades, several authors (Osborn et al 2007; Kalichman et al 2013; Palumbo 2015) highlight its association with poorer outcomes in the context of HIV. Indeed, according to Palumbo (2015: 426), HIV is ‘among the most prominent health topics addressed by the scholars dealing with health literacy’.

On the basis of a review of the literature, Palumbo (2015: 417) identifies poor health literacy as ‘a social barrier to access healthcare services and to appropriate health treatment among patients living with HIV’. It is an important determinant of a healthy lifestyle and health status, especially among under-served ethnic minority groups, people with refugee backgrounds, and individuals at risk of receiving suboptimal and/or inappropriate health treatments due to histories of substance abuse, mental illness, incarceration, and unstable housing or homelessness. This is particularly the case for PLHIV from minority groups due to the powerful role that language and culture have in HIV-related health literacy (Mogobe et al 2016); and amongst older PLHIV with multimorbidity (Wawrzyniak et al 2013).

Drawing on the literature, impacts that low levels of health literacy may have in the context of HIV include:

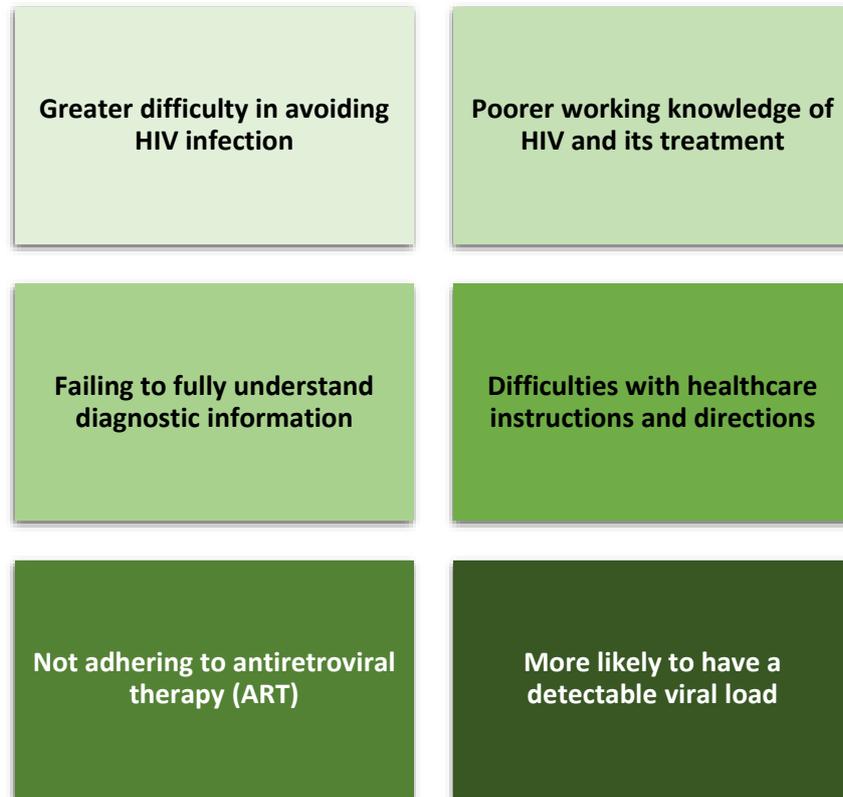


Figure 3: Impacts of poor health literacy in the context of HIV

Sources: Osborn et al (2007); Kalichman et al (2013); Wawrzyniak et al (2013); Palumbo (2015)

As can be seen in Figure 3, research suggests that poor health literacy has a negative impact on several aspects of HIV and HIV care. At the same time, findings from the literature on the relationship between health literacy and HIV treatment are not consistent. For example, people living with poor health literacy are more likely to report compliance with providers' prescriptions, and 'several scholars maintain that functional health literacy is not significantly related to medication adherence and appropriate treatment of HIV-related conditions' (Palumbo 2015: 425).

This highlights the need for ongoing rigorous research, including the development of tailored tools to measure health literacy skills that are relevant to manage HIV-related conditions. It also raises an issue frequently debated in the literature – acknowledgement that the links between health literacy and health outcomes are not straightforward, direct or linear, but are instead 'mediated' by factors that are themselves inseparable from each person's social environment. This key issue is discussed in greater detail in section 4 of this document.

In keeping with the strong policy, research and practice interest in health literacy discussed thus far, programs and initiatives have been developed in recent decades to advance health literacy research, and to address poor health literacy and health inequity. Drawing on the literature, health literacy interventions are discussed next.

3. Health literacy interventions

Governments and organisations are interested in health literacy because they acknowledge that many people have poor levels of health literacy, and that this has an impact on their health outcomes. Public health and illness-prevention measures are also negatively impacted, and variations in health literacy contribute to health inequities.

Health literacy initiatives and interventions have been undertaken throughout the world as a means of addressing these identified problems. By placing a greater focus on health literacy, countries may move closer towards patient-centred health care systems. This section considers developments in health literacy theory and practice over the past few decades, beginning with ways in which health literacy is measured.

3.1 Measuring health literacy

In an exploration of ways in which health literacy is measured, Nguyen, Paasche-Orlow and McCormack (2017) found that there was a large number of tools or instruments in use to measure it. Frisch et al (2011) and Hasnain-Wynia and Wolf (2010) describe two of the most commonly used assessments of literacy in health care settings: the *Rapid Estimate of Adult Literacy in Medicine* (REALM); and the *Test of Functional Health Literacy in Adults* (TOFHLA). While the REALM measures word recognition and pronunciation skills, the TOFHLA measures reading comprehension and numeracy skills.

There are also tools to measure HIV health literacy. Osborn et al (2010) report on the Brief Estimate of Health Knowledge and Action-HIV version (BEHKA-HIV). This is an eight-item assessment tool that assesses health knowledge and action with respect to HIV treatment. When applied in the field, the tool has been found to be a psychometrically sound instrument for assessing health knowledge and action regarding HIV treatment. It helps to predict non-adherence to HIV medications. Use of a tool such as this may be more acceptable as a health literacy screening option, compared with tools that directly measure a patient's literacy abilities (Osborn et al 2010).

Ownby et al (2013) report on the preliminary development and validation of a brief (20 questions) computer-administered health literacy test that includes content focused on medication adherence as well as questions based on a video simulation of an HIV-related clinical encounter. This HIV-Related Health Literacy Scale (HIV-HL) was administered as part of a larger project to evaluate a computer-based intervention to improve health literacy related to HIV infection. Results showed that the HIV-HL could predict whether someone had low health literacy.

Hartnett (2017) describes the Health Literacy Tool Shed. Launched in November 2015 as a collaboration between the National Library of Medicine and Boston University School of Medicine, the Tool Shed is a free, searchable database of validated health literacy measures – it currently contains 129 health literacy measures and instruments.

In their summary of the state of play with regard to the measurement of health literacy, Nguyen et al (2017) observe:

- Since there are many definitions of health literacy, it is not surprising that there are diverse instruments in use to measure it.
- Researchers and practitioners often make a choice between ‘subjective’ and ‘objective’ measures of health literacy.
- Most health literacy measures are not well validated for use in minority populations.
- It is important to think about novel mechanisms to measure domains – such as speaking and listening – that are rarely measured.

3.2 Individual/patient focused intervention

Lack of agreement on a defining and measuring health literacy has contributed to ‘a lack of conceptual unanimity and therefore difficulty in implementing HL [health literacy] interventions, given the variability in objectives and methodological limitations’ (Fernandez-Guiterrez et al 2018: 55). Interventions may be applying a ‘deficit model’ of health promotion that focuses on problems existing at the individual or population level and devises professional responses to these problems. However, such traditional behavioural approaches may be inappropriate for health literacy interventions (Dawkins-Moultin et al 2016). Lloyd et al (2018: 1) also point out that ‘most health literacy interventions described in the literature tend to be small and focused on either organisational or community aspects of health literacy rather than addressing both sides.’

Neuhauser (2017) notes that a challenge for those concerned with health literacy is to move beyond a focus on individual comprehension and address 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. This is supported by McCormack et al (2016: 5), who write that ‘health literacy as a research and clinical endeavor should not shame or blame patients for having low health literacy as if they are the problem’.

In the discussion on individual/patient focused intervention that follows, consideration is given to:

- Improved health care system navigation as a capacity-building objective
- Language and communication skills, and the interactions between consumers and providers of health care services
- Health literacy improvements as an empowerment strategy to increase people's control over their own health
- Personal beliefs

3.2.1 Health care system navigation

In order to enhance the capacity of individuals to ‘function in the healthcare environment’ (Brinkley-Rubenstein et al 2015: 251), attention needs to be given to health care system navigation. Commentators recognise that health care systems have become more complex to navigate.

Higher levels of health literacy are assumed to enhance people's abilities to explore, access and negotiate these systems (Von Wagner et al 2009).

Paasche-Orlow and Wolf (2007: S24-25) write that 'navigation' includes all the skills needed to 'go from one place to another in pursuit of medical care'. Navigation has an impact on the way people manage chronic conditions in particular (Elmer et al 2017: e101), which also applies to PLHIV. Pursuing HIV treatment and care in keeping, for example, with the HIV Care Continuum described in greater detail in section 7 of this document, incorporates 'navigation of the spectrum of HIV care engagement' at an individual level (Kay et al 2016: 1).

Information-management and navigational skills, in addition to fundamental literacy skills, are effective in helping people shift from the thinking and reasoning that lies at the heart of health literacy, to health action. To illustrate this, Von Wagner et al (2009) put forward a model that incorporates a hierarchy of skills. More simple processes are used as part of, and built into, more complex cognitive strategies such as ability to locate and select relevant information, follow instructions, and perform quantitative operations.

These in turn are necessary to eventually integrate, synthesize, and analyse health information, and engage more fully in health care.

3.2.2 Communication and interactions

Most health literacy interventions have a 'core communication component', based on the assumption that health communication converts biomedical findings into actionable and empowering information for the public (Neuhauser 2017: 154). 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). Babalola et al (2017: S5) define health communication as

...the art and science of promoting and protecting public health. Health communication is a process with multiple functions, including informing people about health-protective behaviors, persuading or motivating people to adopt health protective behaviors, building social connections, and fostering an enabling environment.

A focus on communication also draws attention to aspects of the wider health care system, such as the design of health print materials, medication labels, and websites. As Neuhauser (2017) writes, initiatives focused in healthcare systems aim to provide easier-to-use health information, and to improve patient-provider communication and the delivery of healthcare services. Programs include the redesigning of health information print materials, medication labels and websites, prompted by studies which have shown that the readability of texts often significantly exceeds the estimated reading skills of the audiences for whom they were developed.

Jordan et al (2010) agree with the broader factors that impact on patient health literacy abilities, such as socio-economic factors and attitudes and experiences, but also highlight the role of patient-health professional interactions. These are influenced by, for example, fear or anxiety on the part of the patient, and the use of complex medical terms by the health professional. An ideal would be to regard the interaction as an exchange of information that also acknowledges the influence of 'lay knowledge' (Jordan et al 2010: 40).

3.2.3 Empowerment strategy

From a health promotion perspective, health literacy interventions are concerned with issues of power and powerlessness, health equity, capacity building and social change.

Several authors discuss the relationship between health literacy and empowerment (Nutbeam 2000; Schulz and Nakamoto 2013). For Crondahl and Karlsson (2016), empowerment is the perception of oneself as having the motivation and power – based on self-esteem and self-control – to behave and act according to one's own decisions.

According to Sørensen et al (2012: 5), a health literacy intervention strategy that explicitly moves beyond basic functional literacy is a 'critical empowerment strategy to increase people's control over their health'. Schulz and Nakamoto (2013) write that high levels of health literacy without a corresponding high degree of patient empowerment can lead to patients having an unnecessary dependence on health professionals. At the same time, a high degree of empowerment without a corresponding degree of health literacy poses the risk of people making dangerous health choices.

3.2.4 Individual functioning within the social context

Health literacy is an attribute that contributes towards successful functioning of an individual within their social context. It contributes to more positive attitudes (including self-worth), higher motivation to act, and a sense of purpose and self-efficacy. These and other cognitive and psychosocial processes can contribute to improved health status, improved health behaviours, less frequent use of healthcare services and lower healthcare costs (Neuhauser 2017: 158).

Personal beliefs impact directly on people's self-care behaviours. Medication adherence is frequently a target of research and intervention in respect of self-care attitudes and behaviours: 'successful medication adherence is associated with an individual's confidence in their ability to take their medications as directed' (Kalichman et al 2005: 24).

Authors such as Neuhauser (2017), Paasche-Orlow and Wolf (2007), and Baker (2006) highlight the importance of confidence or 'self-efficacy' in discussions relating to health literacy. Self-efficacy can be described as the 'belief in one's capacity to organize and execute the courses of action required to manage a prospective situation' (Bandura, cited in Xu et al 2018: e68).

Considerations of self-efficacy in a health context draw attention to the determination and sense of confidence people have to accomplish self-care tasks that they know will do them good. It includes their own considerations of why they act, or why they do not act, and the sources of their beliefs. Stronger health literacy can help them to be clearer about their motivations to act (eg acceptance of the science; a sense of urgency), especially when needing to take on new behaviours. A program reported on by Kalichman et al (2005), for example, focused specifically on self-efficacy for HIV medication adherence, and found ways to measure self-efficacy through the use of pictographic scales.

Achieving outcomes related to navigation, communication, empowerment and psychosocial functioning all rely on the active participation of the people that are intended beneficiaries of health literacy interventions. This crucial aspect of health literacy intervention is discussed next.

3.3 Active 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 when people are actively engaged it leads to better health outcomes at the individual and population level. 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).

Neuhauser (2017) advocates for the integration of participatory design approaches with health literacy. This would help to generate ‘models of health literacy with better pathways related to the beliefs, habits, emotions, and motivations of intended users, and to apply these effectively to interventions’ (Neuhauser 2017: 165). 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).

Within a participatory approach to health literacy intervention, community members would, amongst others, be given the opportunity to think about and discuss what health literacy means to them; to critique current health communications; and to participate in skills- and confidence-building initiatives. 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 the research and evaluation connected to those initiatives (Neuhauser 2017). According to Morales (2017), participatory action research is explicitly community-based and requires that traditional roles of ‘participant’ and ‘researcher’ be mutually shared by the researcher, community organisations, and community members during different parts of the research process. When adopting this approach, ‘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). Adopting this approach allows participants a more active role in the research process by inviting them to reflect on and interpret their own roles in certain social practices. When applied in a health literacy context, a user-centred approach is used to design information resources, as well as incorporating user evaluations throughout the process (Morales 2017: 3).

Action research, especially community-based participatory action research, generally involves ‘long-term processes of community-researcher engagement, problem identification, reflection and intervention development, implementation and revision’ (Neuhauser 2017: 162). This long-term process does not always align well with the time constraints implicit in many health literacy efforts, and, despite the promise of participatory design approaches, intensive participation is still not the norm.

The challenge is to ‘build out conceptual models of health literacy with better pathways related to the beliefs, habits, emotions, and motivations of intended users, and to apply these effectively to intervention’ (Neuhauser 2017: 165).

Writing within the Australian context, Trezona et al (2017) conclude that a participatory research process is useful for generating models and frameworks for 'organisational health literacy', discussed next.

3.4 Health literate organisations

The earlier discussion of health literacy as a concept has highlighted its multi-dimensional and dynamic nature. Organisations within the broader health care sector are an integral part of this *health literacy ecosystem*, and there is a growing literature on promoting organisations themselves to be more health literate.

As noted by Hasnain-Wynia and Wolf (2010: 900), the problem of low health literacy should perhaps be viewed less as a patient problem and more as 'a challenge to health care providers and health systems to reach out and more effectively communicate with patients.

Organisational health literacy can be described as 'an organisation-wide effort to make it easier for people to navigate understand and use information and services to take care of their health' (Farmanova et al 2018: 1).

According to these authors, examples of interventions to promote health literate organisations include:

- Adopting proactive and system-level efforts to address limited health literacy
- The use of health literacy guides
- Change to organisational practices and processes, including 'culture' change
- Active offers of care to linguistic minorities
- A focus on health literate discharge practices.

In recent years, there has been a strong focus on redesigning health information, prompted by hundreds of studies focusing on health print materials (including medication labels) and websites. These have consistently showed that the quality and nature of the readability of texts significantly exceeds the estimated reading skills of the audiences for whom they were developed (Neuhauser 2017: 159).

Instruments such as the Vienna Health Literate Organisation (V-HLO) self-assessment tool are used to measure health literacy at the organisational level (Henrard et al 2019).

The Institute of Medicine within the National Academies in Washington DC campaigned to promote health literacy in health care organisations as a key health system reform in the United States.

On this basis, it investigated, identified and promulgated attributes that would help identify the health literacy of health care organisation:

Ten attributes of a health literate health care organisation

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors its progress towards this.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills, while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audio-visual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.

Source: Brach et al (2012)

These are worthy attributes to strive for, also in the Australian context.

In summary, and writing within the Australian context, Lloyd et al (2018: 2-4) write:

Developing community capacity and organisational practice requires interventions that address both the community and organisational aspects affecting health literacy...[O]rganisational and service-based initiatives are needed to ensure responsiveness to the various health literacies and cultural and language needs of patients.

As is evident from the discussion up to now, health literacy interventions need to acknowledge the interdependent impacts of a wide range of socio-economic, cultural and political factors if they are to achieve health outcomes. Also, these mediating factors or health determinants need to be managed in various ways in the context of health literacy interventions so as to improve health care, especially for people with limited health literacy. This is the topic of section 4.

4. From health literacy to health outcomes

An overriding objective for health literacy interventions is to improve health and health care. Higher levels of health literacy are assumed to enhance people's knowledge, motivation and competence to 'access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course' (Sørensen et al 2012: 3).

However, the path from health literacy to health outcomes is not smooth or linear. There are many confounding or 'mediating' factors that influence whether people retain, retrieve, and decide to use the information they have access to when making health-related decisions.

Drawing on the literature, this section considers some of the processes through which health literacy affects health and presents models that have been put forward to better understand these processes.

4.1 Complex pathways

Paasche-Orlow and Wolf (2007: S21) point to evidence that health literacy may not relate to health outcomes in a linear way because there are many factors that influence whether people 'retain, retrieve, and decide to use' the information they have access to when making health-related decisions.

In a systematic review, Wawrzyniak et al (2013) found that recent literature supports the view that health literacy can affect knowledge of HIV. Whether or not this knowledge then directly influences health behaviours among PLHIV is, however, less clear. As summarised by these authors, several studies did not find that health literacy sufficiently explained health behaviours, whereas other studies supported such a relationship (Wawrzyniak et al 2013).

The complexity of the pathways between health literacy and health outcomes is also highlighted when consideration is given to the role of knowledge in health literacy. Gellert and Tille (2014) examined the relationship between health literacy and health knowledge in the literature and found that some theorists view health knowledge as coming before and contributing to health literacy (knowledge as an 'antecedence'). Others regard it as an integral dimension of health literacy itself; yet others consider health knowledge to be a consequence or outcome of health literacy. The authors conclude:

This largely reflects the inconsistency between different theories and definitions of HL. Clarifying the role of health knowledge might be a step to structuring the diversity of HL theories and help us to better understand HL in order to improve HL and health outcomes.

(Gellert and Tille 2014: 273)

Von Wagner et al (2009: 862) agree that the translation of health literacy into health outcomes is 'likely to depend on a range of mediating processes, most obviously actions to promote health, prevent disease, or comply with diagnosis and treatment'. Several models that have been generated to describe this complexity are discussed next.

4.2 Models

4.2.1 From capacities to outcomes

Baker (2006) put forward a conceptual model illustrating the relationship between individual capacities, health-related print and oral literacy, knowledge and behaviour change, and health outcomes. This model is summarised in Figure 4:

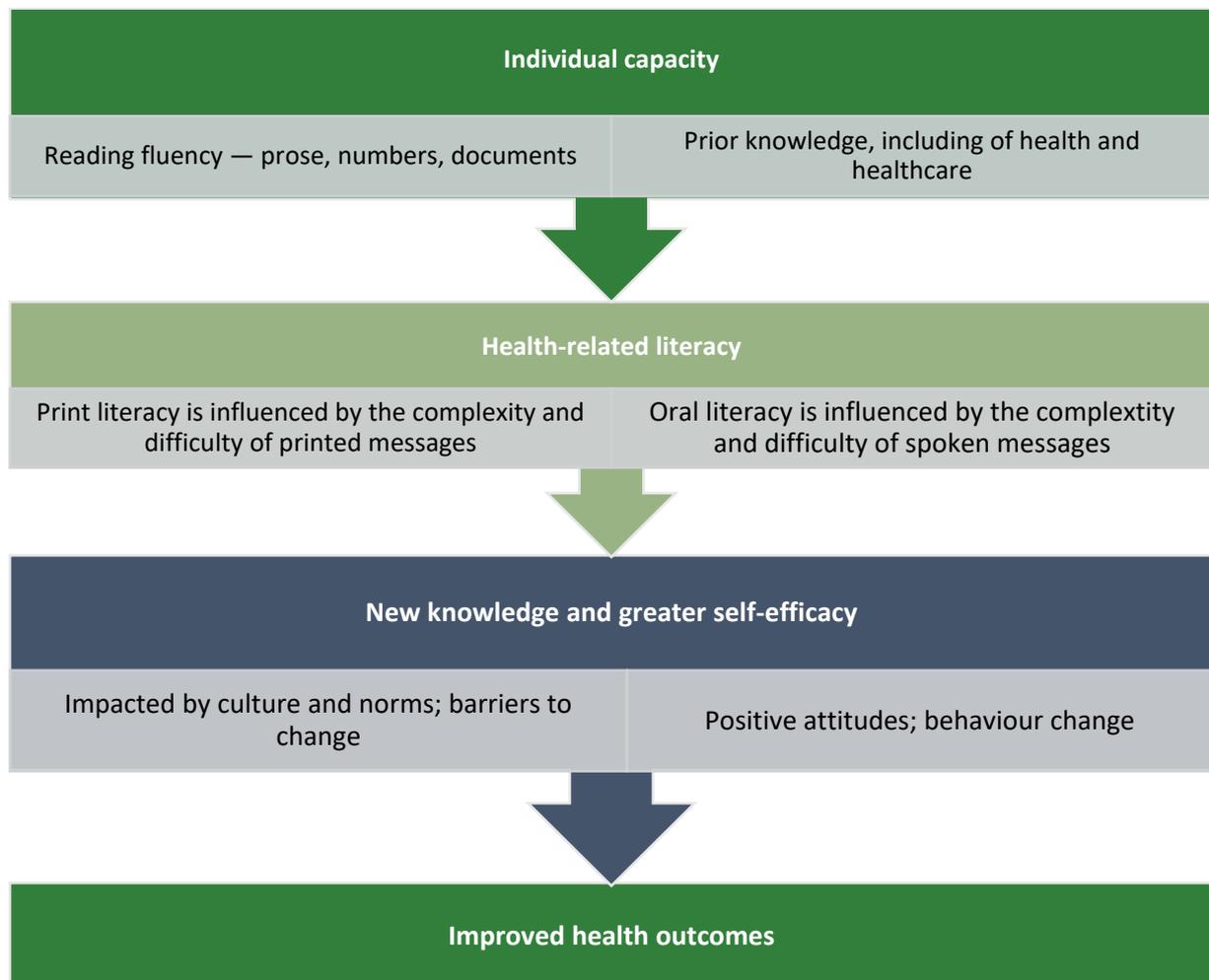


Figure 4: Relationship between individual capacity and health outcomes

The first domain within the model presented in Figure 4 is **individual capacity**. This is the set of resources that a person has in order to deal effectively with health information, health care personnel and the health care system. Two individuals with similar general reading fluency may have different abilities to read and understand health-related material as a result of differences in their prior or baseline knowledge of health vocabulary and of the conceptual knowledge they have of health and healthcare.

The second major domain in the model is **health literacy** itself, which is determined by characteristics of both the individual and the health care system. Print literacy is impacted upon by the individual's ability to understand written health information, but this in turn is impacted upon by the difficulty of the printed message (the 'stimulus'). Higher levels of health-related oral literacy influence the individual's ability to orally communicate about health, but this is strongly impacted upon by the complexity and difficulty of spoken messages.

At the third level, improved health-related print and oral literacy contribute to **new knowledge, positive attitudes, greater self-efficacy and behaviour change**.

All of these can contribute to **improved health outcomes**. In putting forward this conceptual framework, Baker (2006: 882) concludes:

It remains unclear whether it is possible to develop an accurate, practical 'screening' test to identify individuals with limited health literacy. Even if this goal is achieved, it remains unclear whether it is better to screen patients or to adopt 'universal precautions' to avoid miscommunication by using plain language in all oral and written communication and confirming understanding with all patients by having them repeat back their understanding of their diagnosis and treatment plan.

4.2.2 Mediating factors at the individual level

Paashe-Orlow and Wolf (2007) posit that health literacy has an impact upon three main factors at the individual level, and these in turn have an impact on health outcomes:

- Navigation skills, self-efficacy and perceived barriers influence an individual's access to, and use of, health care services
- Knowledge, beliefs and participation in decision-making influence patient/provider interactions
- Motivation, problem-solving, self-efficacy, and knowledge and skills influence self-care.

On this basis, these authors put forward a model for categorising the factors that influence whether people retain, retrieve, and decide to use the information they have access to when making health-related decisions:

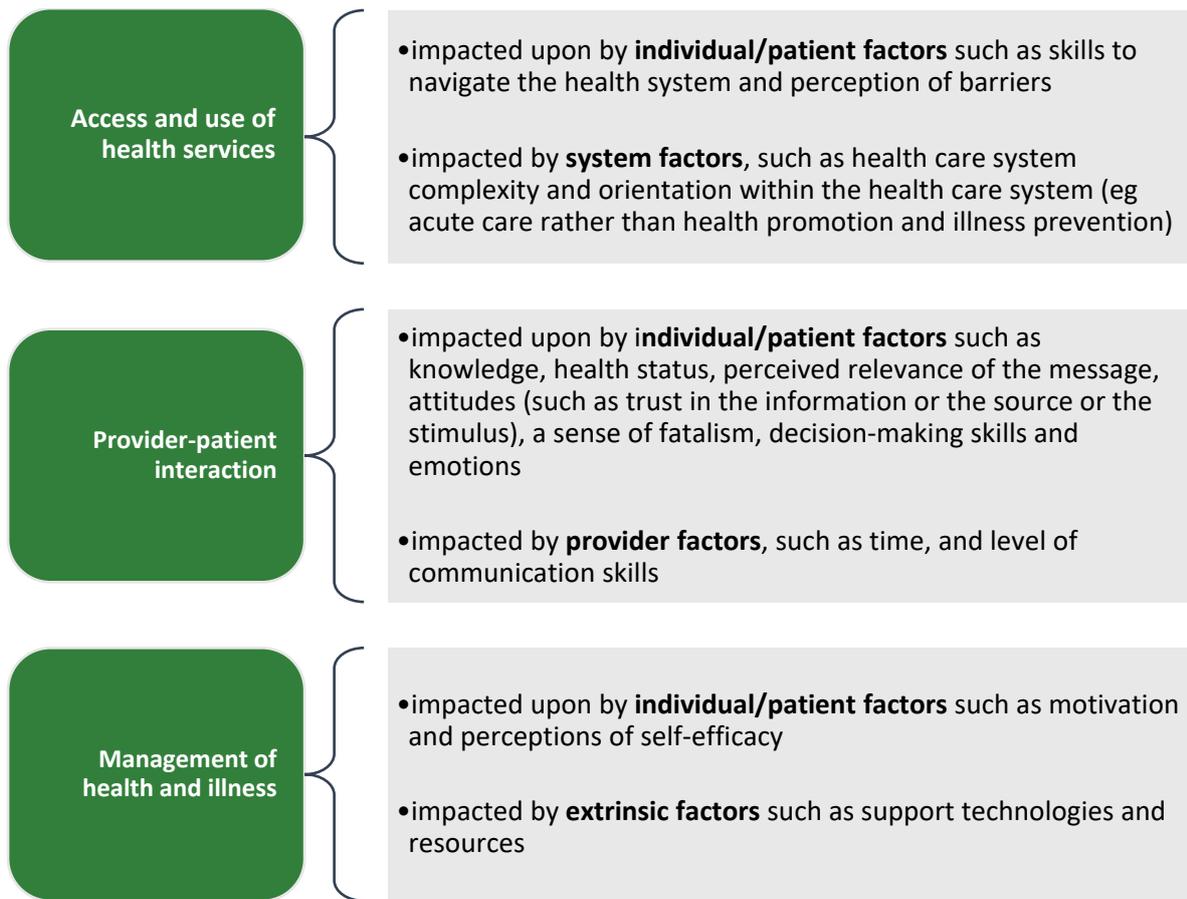


Figure 5: Mediating factors between health literacy and health outcomes

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

As can be seen in Figure 5, 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 ecosystems within which they function. Within this model, ‘individual/patient factors’ interact with ‘system factors’, ‘provider factors’ and ‘extrinsic factors’ in complex ways.

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).

4.2.3 Knowing what to do, and doing it

Von Wagner et al (2009) build on the conceptual framework developed by Paasche-Orlow et al (2007) above by outlining pathways through which health literacy affects either health actions themselves or the motivational and volitional (power of choosing) determinants of these health actions. These can be summarised as follows:

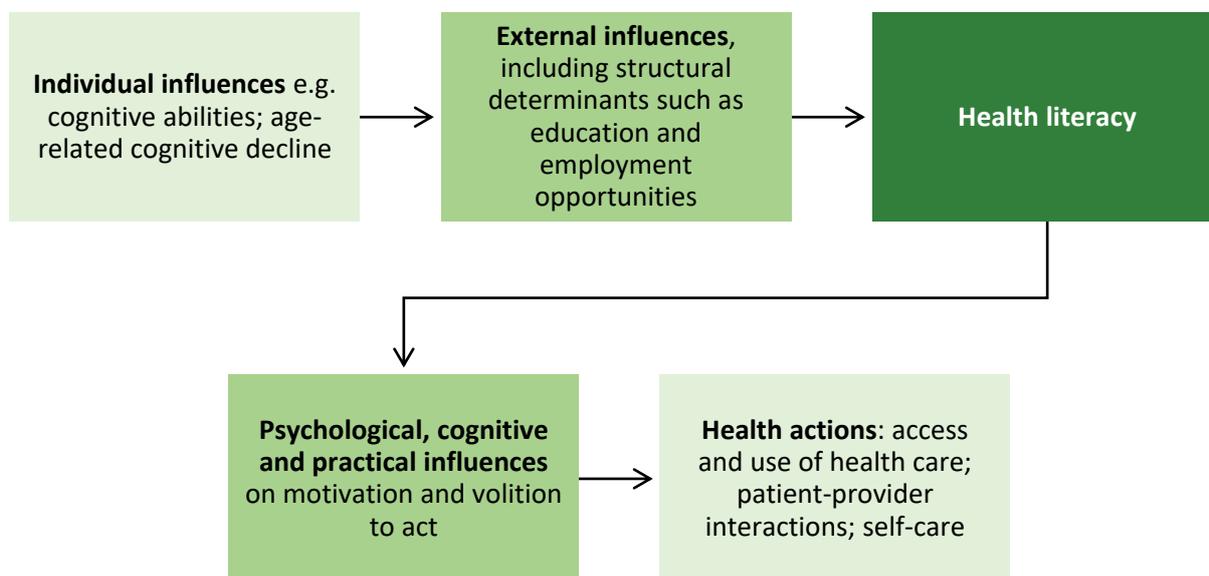


Figure 6: Psychological, cognitive and practical influences on health action

Source: based on Von Wagner et al (2009)

The framework places health literacy within the context of the external and individual variables that influence its development and maintenance. Beginning with the stimulation provided by parental figures, the social environment is critical in the early development of numeracy and literacy. Resources provided during formal education are also central. Together with health literacy influencers particular to the individual, such as age- or illness-related cognitive decline, a complex range of personal and social factors determine whether health-promoting behaviours will ensue, and what form they will take.

In particular, psychological and cognitive influences (such as feelings of urgency, self-worth, and self-efficacy), together with practical barriers (such as the financial costs associated with new behaviours and routines) influence the ‘translation of intentions into action, that is, the action phase’ (Von Wagner et al 2009: 865). Importantly, the model is based on the assumption that motivation alone does not sufficiently explain health actions.

4.2.4 Health care improvement

Hasnain-Wynia and Wolf (2010: 898) highlight a lack of evidence for ‘targeted, yet broadly applicable clinical interventions and tools to effectively aid health care providers and systems in identifying and responding to individuals marginalized by limited health literacy and health care inequities’. In order to address this gap, these researchers put forward a framework – incorporating a research agenda –

that intends to address the intersection of health literacy and health care improvement more effectively.

This framework is presented in Figure 7:

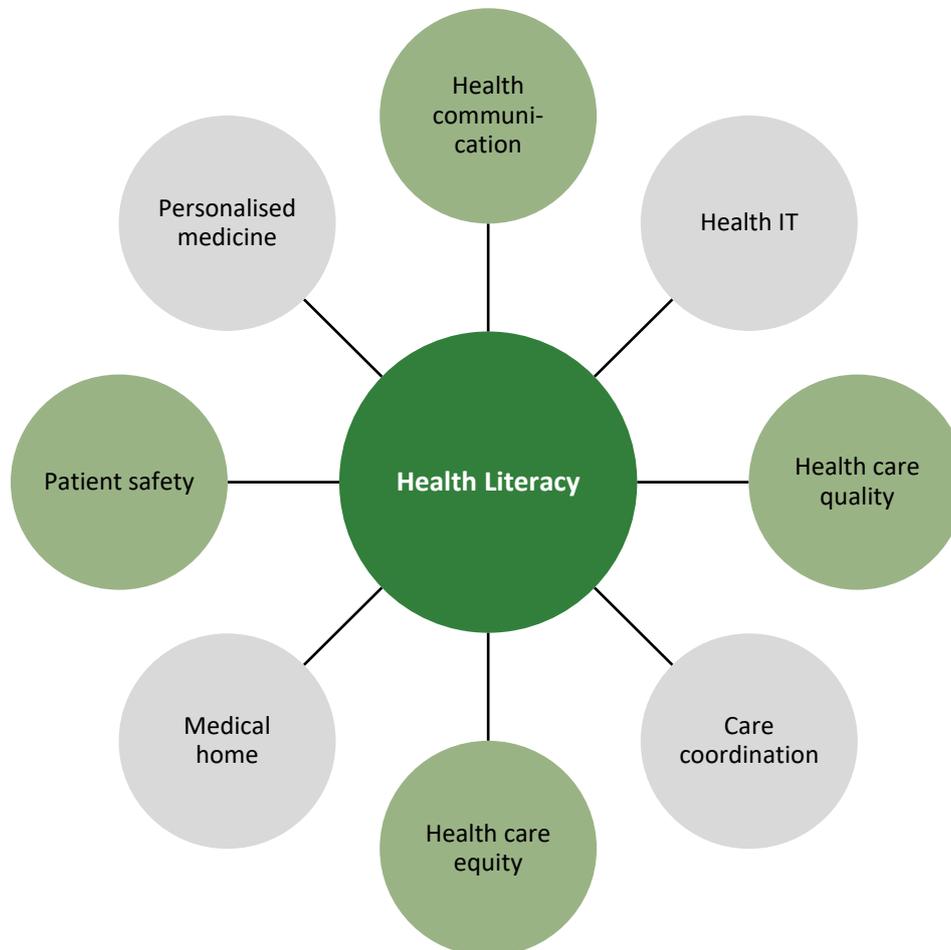


Figure 7: Intersection of health literacy with equitable health care improvement

Source: Hasnain Wynia and Wolf (2010: 901)

Within this model, health literacy is the 'missing link' that integrates all the health care factors that need to be addressed when considering and engaging in health care system reforms and improvements. It suggests that, at a jurisdictional level, evidence-based tools would be needed to support health systems' abilities to identify individuals at risk for low health literacy, to put in place robust intervention strategies, and to incorporate comprehensive evaluations in order to contribute to best practices.

In summary, 'by incorporating a greater focus on health literacy, we move closer toward a patient centered health care system' (Hasnain Wynia and Wolf 2010: 902).

5. Health literacy research

A review of the health literacy research literature was conducted in order to establish a firmer evidence base for the HLF project. Drawing on peer reviewed literature published in English from 2005 to 2019, studies that discuss the evaluations of discrete health literacy-related initiatives, as well as systematic reviews of such studies, are summarised in the table of evidence below. Insights from these studies are used to establish the state of play in what is an active field of research and publication.

The evidence is presented in Table 2 below. The table summarises 29 discrete research studies, around half of which are literature reviews (n=15). Each study is analysed on the basis of:

- Author(s), date of publication and location of the study
- Research design and methodology
- Findings
- Implications

The studies are presented alphabetically on the basis of the lead author.

Key insights from the research literature, as summarised in the table of evidence in section 5, are drawn upon in section 6 to highlight findings and best practices for the benefit of the HLF project.

Table 2: Table of evidence

Author(s), date, place	Research design and methodology	Findings	Implications
<p>Bauer et al (2017)</p> <p>International</p>	<p>A scoping literature review was conducted to identify and describe the state-of-the-art of community-based health literacy interventions.</p> <p>Papers were included if they described interventions that intentionally brought together groups of people to participate in an intervention that addressed health literacy issues or tried to change health literacy skills, behaviours, status, or other outcomes.</p> <p>74 papers met the inclusion criteria</p>	<p>There is a wide variety of community-based health literacy interventions. In the interventions described in the literature, outcomes range from knowledge (the most frequently measured), to changes in social norms, healthcare service use, and physiological measures.</p> <p>Studies reflect a strong focus on knowledge outcomes. While knowledge is a step away from health or behavioural change, a focus on it is necessary because communities often are isolated from science-based health information and lack foundational knowledge.</p> <p>Relatively few papers reported quantifiable results expressed as pre- and post-test differences between intervention and comparison groups.</p> <p>Overall, health literacy intervention research shows positive, but uneven results.</p>	<p>High levels of community involvement at multiple stages in the intervention process are appropriate for health literacy improvement work.</p> <p>Health literacy considerations can be included at several points in an intervention:</p> <ul style="list-style-type: none"> • defining a community as ‘low health literate’ • measuring health literacy • designing programs or materials using health literacy principles or techniques • assessing changes in knowledge, self-efficacy, skills, behaviours or other outcomes. <p>Identified challenges in applying evaluation frameworks point to a lack of fit between public health interventions generally on the one hand and community-based health literacy interventions on the other.</p>
<p>Berkman et al (2011)</p> <p>International</p>	<p>Systematic literature review</p> <p>The aim of the study was to examine health care service use and health outcomes and their relation to</p>	<p>Differences in health literacy level were consistently associated with increased hospitalisations, greater emergency care use, poorer ability to demonstrate taking medications appropriately, poorer ability to</p>	<p>Design features to focus on include alternative document design, alternative numerical presentation, additive and alternative pictorial</p>

Author(s), date, place	Research design and methodology	Findings	Implications
	<p>differences in health literacy; and to examine interventions designed to improve these outcomes for individuals with low health literacy.</p> <p>81 studies examined the association between health literacy and numeracy and health outcomes; and 42 studies examined interventions that aimed to mitigate the effects of low health literacy.</p>	<p>interpret labels and health messages, and, among seniors, poorer overall health status and higher mortality.</p> <p>Evidence regarding the effect of specific design features of interventions for low-health-literacy populations is low or insufficient.</p> <p>Health literacy mediates the relationship between race and health for a variety of outcomes, including non-adherence to HIV medications.</p>	<p>representation, and improved readability and alternative document design.</p> <p>Specific design features can result in improvements in comprehension for low-health-literacy populations. These include:</p> <ul style="list-style-type: none"> • presenting essential information by itself, or first • adding icon arrays to numerical presentations of treatment benefit • adding video to verbal narratives.
<p>Brinkley-Rubenstein et al (2015)</p> <p>USA</p>	<p>This qualitative study aimed to explore how community-level factors affect health literacy.</p> <p>Data collection consisted of one-to-one semi-structured interviews with caseworkers (N=13) in an HIV/AIDS setting.</p>	<p>Interviewees emphasised the importance of the development of health literacy specific to the conditions and experiences unique to HIV.</p> <p>Caseworkers identified components necessary to the development of health literacy:</p> <ul style="list-style-type: none"> • Trust, which includes partaking in ‘commitment acts’ that help to create connections with clients • Acknowledging a client’s multiple social identities • Understanding the hierarchy of needs that a client might have – recognise the need to prioritise other issues that relate to health literacy, but which 	<p>HIV health literacy should be conceptualized and operationalized as a process rather than a static outcome in which knowledge is transmitted from practitioner to client.</p> <p>Recognise how health literacy might change dependent on a confluence of multiple factors.</p> <p>When viewed as a process, a focus on health literacy would include on an ongoing basis:</p> <ul style="list-style-type: none"> • assessing an individual’s capacity to gain access to age- and context-specific information from a variety of sources • person’s ability to discriminate between sources of information

Author(s), date, place	Research design and methodology	Findings	Implications
		<p>also may act as barriers to its advancement</p>	<ul style="list-style-type: none"> • ability to understand and personalise health information that has been obtained • the capacity to appropriately apply relevant health information for personal benefit.
<p>Brown et al (2018) Australia</p>	<p>The study aimed to develop, test and validate a brief 13-item PozQoL scale which assessed the health-related quality of life (HRQoL) among PLHIV.</p> <p>The scale was developed on the basis of existing models and was tested through an online survey of adult Australians living with HIV (N=465). This included a one-month follow-up survey (N=80; 53.7% of original survey participants).</p>	<p>The PozQoL scale assesses quality of life by focusing on:</p> <ul style="list-style-type: none"> • Health domain, including perception of owns health, health-related concerns, energy, and HIV management • Psychological domain, including mood, coping, hope and fear of the future, and self-worth • Social domain, including personal and social life, belonging, support, and social stigma • Functional domain, including the ability to live a ‘normal’ life, independence, meaningful occupation, and a satisfactory standard of living. <p>Respondents were asked to provide a rating (based on a 5-point scale) to 13 items linked to these four domains.</p>	<p>PozQoL displayed strong construct validity and very good reliability, including consistency and temporal stability.</p> <p>This study responds to an expressed need for an empirically validated instrument that measures the impact of programs on QoL among PLHIV.</p> <p>As a contribution to the evaluation and improvement of programs for PLHIV, the scale could be applied in diverse community, support and healthcare programs.</p>

Author(s), date, place	Research design and methodology	Findings	Implications
Cunha et al (2017) International	Literature review The aim was to analyse knowledge produced by research about health literacy for adults with HIV/AIDS. The focus was on literature published in Portuguese, English and Spanish until 2014. 14 articles met the inclusion criteria.	Low health literacy has negative impacts on a patient's understanding of health-related information. Several studies suggest that health education is a useful intervention. Analysis of the literature emphasises the role of health professionals in maintaining the quality of life of PLHIV. These professionals can carry out health education activities. Some studies point to low socio-economic status of many PLHIV. For many in this situation, even if they understand the importance of health measures, they may not have the resources to maintain quality of life.	Activities related to health education require scientific knowledge and personalised interventions. They should also involve the patient's family, because the guidelines apply to every situation or context. Investigating functional health literacy at a population level is a primary step for the implementation of any educational strategy, however there is a lack of studies in the area. Longitudinal research using scales to assess health literacy more specifically is needed.
Dawson-Rose et al (2016) USA Puerto Rico Botswana	An international network of nurse researchers conducted a multisite qualitative study. The aim was to gain a more in-depth understanding of the meaning of health literacy for PLHIV. Data were collected in 2013–2014 through a series of 28 focus group discussions at six sites in three countries. These groups included 135 PLHIV and 71 providers.	Participants consistently identified having an ongoing and trusting patient-provider relationship as one of the most important contributors to the health of PLHIV. Building this trust was described as an iterative, dynamic, and mutual process that occurred over time. Not only did patients need to trust providers, but providers also needed to trust their patients.	HIV health literacy and how it is defined is dynamic and multi-dimensional and is influenced by the relationship between PLHIV and their providers. An expanded definition of health literacy that includes gaining a patient's trust and engaging in a process of health education and information sharing over time could improve HIV care.

Author(s), date, place	Research design and methodology	Findings	Implications
		Contributors to developing trust were found to be mutual respect, partnership, and recognition that it takes time – it is an iterative process.	
D'Eath et al (2012) Europe	The researchers conducted a meta-review of systematic reviews. The aim was to identify and synthesise evidence on effective strategies for improving health literacy, highlight gaps in the evidence, and provide recommendations. Publications between 2000 and 2010 were focused upon. Five studies were included.	Most interventions identified in the reviews focus on the functional level of health literacy and work at the traditional health education level. There is little evidence of interventions targeted at the interactive or critical levels of health literacy. A typology of health literature interventions: <ul style="list-style-type: none"> • Written health information interventions, including those targeting plain language and increased readability • Alternative format interventions, including those which use technologies to support and enhance consumers' knowledge and skills • Low literacy initiatives which may target specific populations or cover geographical areas • Targeted mass media campaigns designed around specific health behaviours 	There are considerable gaps in the evidence reviewed concerning which interventions are most effective in improving health literacy. There is a paucity of research involving disadvantaged or hard-to-reach groups; and of research focusing on communicable diseases. The development of measures of health literacy at a level other than that of functional literacy is fundamental to any progression of health literacy.

Author(s), date, place	Research design and methodology	Findings	Implications
<p>Edwards et al (2013)</p> <p>South Wales UK</p>	<p>The study examined the development and practice of health literacy in people with long-term health conditions, living in South Wales.</p> <p>A longitudinal qualitative interview and observation approach was adopted.</p> <p>Participants were recruited from health education groups (N=14) and community education venues (N=4).</p> <p>The 44 interview transcripts generated over the course of the program were analysed using the 'Framework' approach.</p>	<p>'Distributed health literacy' is a term that can be used to explain that the health literacy abilities, skills and practices of others that contribute to an individual's level of health literacy. Thus, health literacy is a distributed resource within an individual's social network.</p> <p>Findings from the study pointed to health literacy being distributed through family and social networks. Participants often drew on the health literacy skills of others to seek, understand and use health information.</p> <p>Those who passed on their health literacy skills acted as health literacy 'mediators' who supported participants in becoming more health literate about their condition.</p> <p>Participants accessed their health literacy mediators through their personal and community networks.</p> <p>The distribution of health literacy supported participants to better manage their health, become more active in health-care decision-making processes, communicate with health professionals and come to terms with living with a long-term condition.</p>	<p>Becoming health literate in the context of managing a long-term condition is an ongoing process. It includes input from the formal health education system, communication with health professionals, and interactions within the person's social support network.</p> <p>Whatever their level of health literacy, individuals can benefit from the distribution of health literacy within their social network. Friends, family, colleagues and even acquaintances mediate the development and practice of health literacy by sharing knowledge, facilitating learning, contributing their own skills, and supporting decision making.</p> <p>The study has implications for future interventions. Bringing people together to develop health literacy within a community may be a useful way of distributing the responsibility and expectations that the current health system and policies impose on patients as individuals in managing their health.</p>

Author(s), date, place	Research design and methodology	Findings	Implications
<p>Elmer et al (2017) Tasmania</p>	<p>Evaluation of a program that aimed to improve the prevention and management of chronic conditions by responding to health literacy needs.</p> <p>Group programs (51 participants) were delivered by a multidisciplinary team of academic health professionals in consultation with three Neighbourhood Houses located in areas of socioeconomic disadvantage.</p> <p>Four focus groups (22; 43% of total participants) were conducted to elicit feedback about participants' experience of the program and their recommendations for future programs.</p>	<p>Themes of autonomy, competence, relatedness, and empowerment were evident across the participant data. Empowerment appeared as an outcome, and as part of the process.</p> <p>Three subthemes were identified by participants as significant to the program namely behaviour change, program content, and group composition.</p> <p>Participants identified several factors that make behaviour change difficult including lack of motivation, negative thinking, and the difficulty of change in general.</p> <p>Participants requested more sessions and content improvements to build on and support new knowledge and skills.</p> <p>Participants made recommendations about the composition of the group and suggested targeting subgroups in the community.</p> <p>Minimal negative feedback was received.</p>	<p>There is value in developing health promotion programs that include the use of a theoretically informed framework to measure change.</p> <p>In this study, incorporating self-determination theory principles to the content and delivery of a health literacy program showed that it requires:</p> <ul style="list-style-type: none"> • Acknowledging the difficulty of making changes • Clearly presenting the choice to make a healthy change • Providing specific advice about tackling the new behaviour • Boosting competence through feedback and social support. <p>Future programs would benefit from SDT together with empowerment, as a planning and evaluation framework. Programs would also benefit from incorporating longer-term follow-up.</p>

Author(s), date, place	Research design and methodology	Findings	Implications
<p>Farmanova et al (2012)</p> <p>International</p>	<p>Review of evidence on organisational health literacy (OHL)</p> <p>A systematic search of literature was combined with narrative syntheses and analyses.</p> <p>Studies published in English and French were included. There was no time limit, or country or study design restrictions.</p> <p>48 reports met the inclusion criteria.</p>	<p>Of the 48 texts included, 15 explicitly dealt with the theories and operational frameworks of OHL, 20 presented health literacy guides, and 13 addressed the implementation of OHL and the use of guides.</p> <p>Guides tend to focus broadly on communication actions such as targeted improvements in existing health information materials; and the organisation of health care, including preparation of the workforce to deliver health-literate care.</p> <p>Several studies point to the use of assessment tools provided with the guides as a useful and feasible exercise to provide direction for improvement.</p> <p>Barriers towards OHL include lack of commitment and low priority given to health literacy and related activities; no buy-in from leaders and no change champions in the organisation; lack of time; lack of resources; and the complexity of health literacy tools and guides.</p>	<p>Organisational health literacy has to make sense from both clinical and financial perspectives in order for organisations to embark on such a transformative journey. For many organisations, becoming health literate will require multiple, simultaneous, and radical changes.</p> <p>OHL has to acquire a new meaning and stretch beyond improving navigation, understanding, and use of information. Conceptualizations of OHL should continue to build on and include notions such as inter-sectoral collaboration and stakeholder empowerment.</p> <p>Ideally, OHL 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.</p>
<p>Fernandez-Guiterrez et al (2017)</p>	<p>Systematic review</p>	<p>Few health literacy interventions specific to immigrant populations were found.</p>	<p>Health literacy interventions should focus efforts at the individual, but also at the community and organisational, levels.</p>

Author(s), date, place	Research design and methodology	Findings	Implications
International	<p>The study aimed to identify and analyse health literacy interventions for immigrant populations.</p> <p>Studies published between 2000 and 2015 in English and Spanish were included.</p> <p>34 articles met the inclusion criteria; of these, nine used a validated instrument to measure health literacy.</p>	<p>There are several conceptual and assessment-related difficulties in studying immigrant populations. Studies have produced mixed results regarding their effectiveness. Changes related most positively to functional literacy, which addresses basic skills of reading, writing and arithmetic and consists of the level of knowledge and understanding of information about possible health risks and the use of health services.</p> <p>Interventions were less effective at improving interactive and critical literacy:</p> <ul style="list-style-type: none"> • Interactive literacy refers to more advanced social and cognitive skills that contribute to people’s active participation in health care. • Critical literacy includes health-relevant decision-making, the provision of information on social and economic health determinants, and opportunities to achieve change at political and organisational levels. 	<p>Doing so would help to broaden the scope of interventions beyond a focus on functional literacy to include also a focus on interactive and critical health literacy.</p> <p>Future studies could consider:</p> <ul style="list-style-type: none"> • The use of mixed methodology (qualitative and quantitative) to better understand users’ experiences • Use of a framework of health literacy that includes functional, interactive and critical dimensions • Use of causal models that explain the relationship between health literacy, the education system and the health system that are culturally relevant • Implementation of longitudinal studies

Author(s), date, place	Research design and methodology	Findings	Implications
<p>Han et al (2018)</p> <p>International</p>	<p>The study aimed to critically appraise studies addressing eHealth in PLHIV.</p> <p>A systematic review was carried out, targeting PLHIV published in English before May 2017 with eHealth literacy as a study variable.</p> <p>Seven papers met the eligibility criteria.</p>	<p>The majority of studies found high levels of eHealth literacy amongst the majority (65%-80%) of participants. Such a wide variance was due to 'high literacy' being defined differently in the studies.</p> <p>Findings were mixed, with instances of eHealth literacy both promoting as well as hindering health outcomes.</p> <p>In the areas of HIV transmission risk, retention in care, treatment adherence, and virological suppression, the role of eHealth literacy is still not fully understood.</p>	<p>The importance of eHealth literacy among PLHIV has only recently begun to be addressed.</p> <p>Understanding the role of eHealth literacy is an essential step to encourage PLHIV to be actively engaged in their health care.</p> <p>Avenues to pursue in the role of eHealth literacy and PLWH should consider the development and use of standardized eHealth literacy definitions and measures. In particular, there is a need for the use of validated instruments to measure eHealth literacy.</p>
<p>Hicks et al (2006)</p> <p>Atlanta GA</p>	<p>Prospective survey of patients offered a HIV test by their provider (N=372).</p> <p>Patients' health literacy level was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM) scale.</p> <p>Participants' HIV/AIDS-related knowledge was assessed using a 22-item questionnaire.</p>	<p>Respondents' mean HIV/AIDS knowledge scores differed significantly between those with inadequate health literacy and those with marginal or adequate health literacy.</p> <p>Misconceptions about HIV transmission were more common among patients with lower health literacy levels.</p>	<p>Knowledge of HIV/AIDS is associated with health literacy at the individual/patient level even after adjusting for income level, education level and risk perception.</p> <p>There is a need to tailor HIV prevention strategies toward a population with low levels of health literacy. Such a change could dispel misconceptions about HIV transmission and treatments that affect risk-taking behaviours and health care utilisation.</p>

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<p>Jayasinghe et al (2016)</p> <p>Australia</p>	<p>The <i>Preventive Evidence into Practice</i> study investigated the impact of health literacy on health-related quality of life (HRQoL) in a sample of Australian patients (N=739) engaged in primary health care.</p> <p>The mean age of participants was 55.5 years; and 69% were female.</p> <p>Patient-reported information was collected via a mailed questionnaire.</p>	<p>Low health literacy patients are more likely:</p> <ul style="list-style-type: none"> • to be smokers • to engage in insufficient physical activity • to be overweight • to have lower physical and mental health. 	<p>Addressing health literacy-related barriers to preventive care can play a role in reducing disparities relating to HRQoL.</p>
<p>Jordan et al (2010)</p> <p>Victoria, Australia</p>	<p>A qualitative study was conducted to better understand health literacy from the patient's perspective.</p> <p>Purposeful sampling was used to interview individuals across three cohorts (N=48):</p> <ul style="list-style-type: none"> • Those with a chronic condition • General community • People presenting at a hospital emergency department in a metropolitan area 	<p>Seven key abilities were identified at the individual level:</p> <ul style="list-style-type: none"> • Knowing when to seek health information • Knowing where to seek health information • Verbal communication skills • Assertiveness • Literacy skills • Capacity to process and retain information • Application skills <p>A range of factors at the health system (e.g. the approach of the health professional and</p>	<p>An individual's health literacy is dependent on the relationship between individual capacities, the healthcare system and the broader society.</p> <p>The importance of broader social, ecological and systemic factors is increasingly being recognised as helping or hindering the process of enhancing health literacy attributes, knowledge and skills.</p> <p>It is important for health professionals to be aware of the health literacy of their patients so that they can appropriately tailor the communication that they have with them.</p>

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		<p>use of medical terminology) and community level (socio-economic factors, patient attitudes and experiences, level of social support) also influenced respondents' abilities to seek and use health information. This was particularly so when they distinguished between reputable and non-reputable sources.</p>	
<p>Kalichman et al (2013) USA</p>	<p>The study focused on PLHIV with low literacy skills who requested assistance with medical information.</p> <p>PLHIV who were currently receiving ART and who scored below 90% correct on a health literacy test (N=474) were reached through community recruitment strategies.</p> <p>Information assistance groups were formed on the basis of responses to the three health-related information assistance questions. Those requesting informational assistance were compared to their counterparts who do not request assistance.</p>	<p>Health literacy is a robust predictor of HIV treatment adherence.</p> <p>Requesting help to interpret and understand medical information was associated with fewer years of education, poorer numerical literacy skills, and more likely to miss doctor appointments.</p> <p>Few participants had disclosed their reading difficulties to doctors or pharmacists, and this can be linked to literacy-related stigma, combined with HIV-related stigma.</p> <p>People who requested assistance remained the least adherent and had the poorest health outcomes.</p>	<p>Addressing both AIDS- and literacy-stigma plays a key role in developing strategies to assist HIV-positive patients with poor literacy skills.</p> <p>Individuals with moderate levels of reading literacy may benefit from adherence counselling and skills building interventions.</p> <p>More direct and intensive interventions may be needed for people who are the most challenged by poor reading skills. These approaches may include intensive counselling with long-term continuous adherence monitoring.</p>

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<p>Mackert et al (2014)</p> <p>International</p>	<p>Review of research published between 2000 and 2010 on eHealth and health literacy.</p> <p>95 articles were included for analysis.</p>	<p>There is a lack of theory-driven design and evaluation of eHealth applications. The overwhelming majority of studies included in this sample (93.7%) were not based on a theoretical framework.</p> <p>There is low use of established general health literacy measures.</p> <p>There are somewhat limited contributions by communication scholars.</p>	<p>Research in eHealth could be improved in a variety of ways:</p> <ul style="list-style-type: none"> • Not relying too heavily on surveys • Increasing the use of more exploratory data collection techniques • Grounding research more solidly in theory e.g. health communication theories, information systems research, and emerging conceptual models of health literacy
<p>Morales (2017)</p> <p>New York USA</p>	<p>The aim of this pilot study was to determine in what ways health literacy research may contribute to participant vulnerability and how the research design process can best address these vulnerabilities. The study was based on a user-centred approach, community-based participatory research, and research with vulnerable populations.</p> <p>Adopting an exploratory case study design, participants (N=3) were tasked with assessing health information resources rather than a study that assesses participants' comprehension of these materials.</p>	<p>The study identified specific features of health documents that affect the way an adult early reader evaluates consumer health information. These included linguistic and design features, participants' prior knowledge of the topic, the potential use of the documents, terminology, and the interpretation of statistical figures and bulleted lists.</p> <p>There is great variability in how people judge credibility, assess information quality and among the criteria they use to evaluate information.</p> <p>Examples of participant feedback included identifying information they felt were missing from the documents; and pointing out</p>	<p>The approach adopted in the study contributes to empowerment through allowing participants to take on the role of expert, editor, consultant, or judge of the quality of health information.</p> <p>Adopting a research design and methodology of this kind enables a deeper understanding of the unique experiences, challenges, and ways of knowing of marginalised and vulnerable groups. It also supports empowerment skills for members of these same communities, which can have transformative effects.</p> <p>By engaging members of marginalised communities as judges of health information quality, this kind of research supports</p>

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	<p>The methods used were:</p> <ul style="list-style-type: none"> • a short demographic survey questionnaire • an information evaluation task • a follow-up interview. 	<p>information that seemed confusing based on information they had either seen on television, learned from friends and family (second-hand knowledge), or otherwise previously known.</p> <p>An important challenge to address is the perceived difficulty of the task for some participants due to their level of interest, motivation, or reading experience.</p>	<p>community members' self-determination while promoting health literacy.</p>
<p>Osborn et al (2010) USA</p>	<p>The study used the Brief Estimate of Health Knowledge and Action—HIV version (BEHKA-HIV) and the Rapid Estimate of Adult Literacy in Medicine (REALM) as predictors of HIV medication adherence, which was measured through the Patient Medication Adherence Questionnaire (PMAQ).</p> <p>N=204</p>	<p>The study was one of the first to quantitatively report on a measure of health-related knowledge and action in the context of HIV treatment that may represent a proxy of patient health literacy in this context.</p>	<p>The BEHKA-HIV, a brief, 8-item assessment tool, is a psychometrically sound instrument for assessing health knowledge and action regarding HIV treatment and predicting non-adherence to HIV medications.</p>
<p>Ownby et al (2012) USA</p>	<p>Evaluation of an intervention that drew on research on health literacy in PLHIV and the relation of health literacy to medication adherence to develop an electronically delivered</p>	<p>Content for the intervention was initially developed through a survey of existing patient education materials with review by a multidisciplinary team. The content was organised into sections that focused on basic HIV-related information (viral life cycle and</p>	<p>An electronically delivered intervention designed to improve HIV patients' health literacy may have an effect on their medication adherence.</p>

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	<p>application targeting treatment adherence (N= 118).</p> <p>Medication adherence was assessed one month before and one month after completing the intervention.</p> <p>The content was presented in an interactive and tailored format.</p>	<p>mechanism of action of medications), factors and possible barriers related to motivation (misconceptions about medications and strategies for coping with stigma, depression, and substance abuse), and behavioural skills (strategies to remember to take medications).</p> <p>There is a relationship between baseline adherence and response to the intervention. Participants with lower baseline levels of adherence showed the largest changes after the intervention.</p>	<p>The smaller change observed in participants with higher levels of adherence can be attributed to a 'ceiling effect', since participants with high levels of adherence at baseline could not increase their adherence by a large amount.</p>
<p>Palumbo (2015) International</p>	<p>Narrative literature review on the effects of poor health literacy on PLHIV.</p> <p>41 papers were included for analysis.</p>	<p>HIV infection continues to be among the most prominent health topics addressed by health literacy scholars.</p> <p>Low health literacy is a social barrier for PLHIV in accessing healthcare services. It plays an important role in sharpening the role of social disparities with respect to access to care and enhancing the proper treatment of HIV-related conditions.</p> <p>Health literacy has been found to be an independent determinant of medication non-adherence. On the other hand, several authors have argued that health literacy is not</p>	<p>Greater attention should be paid to the confounding factors which affect the relationship between health literacy and the management of HIV infection. This includes patients voluntarily departing from clinical prescriptions; and their willingness to follow alternative and unconventional health treatments.</p> <p>In order to reduce the biases which affect the studies of the effects of health literacy on the management of HIV infection, a more reliable measure of the health literacy skills needed by PLHIV should be arranged and statistically tested.</p>

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		<p>strictly required for good medication adherence of PLHIV.</p> <p>In spite of a prevailing disagreement among scholars, health literacy is a determinant of a healthy lifestyle and of the health status of PLHIV, especially</p> <ul style="list-style-type: none"> • under-served ethnic minority groups • people with refugee backgrounds • individuals at risk of receiving suboptimal and/or inappropriate health treatments due to histories of substance abuse, mental illness, incarceration, and unstable housing or homelessness. 	
<p>Perazzo et al (2017)</p> <p>International</p>	<p>Systematic review of studies that described interventions aiming to promote the health literacy of PLHIV.</p> <p>Studies published in English between 1996 and 2015 were considered. To be included, they needed to contain at least once measurement of health literacy and to be intervention studies in which health literacy was a central focus of interest.</p>	<p>The six studies varied in overall quality, with limitations including small samples, lack of control conditions, and lack of control for confounding variables. Each study team provided a strong rationale for developing health literacy interventions tailored to PLHIV.</p> <p>Studies in which HIV-specific knowledge and behaviour skills were outcome measures provided the most significant results.</p> <p>An intervention designed to provide disease-specific education was found to have led to</p>	<p>There is insufficient evidence to arrive at a strong conclusion about the benefit or effect of any specific intervention.</p> <p>More research is needed to determine the influence of health literacy as a ‘process variable’ that influences the ability for PLHIV to manage their health.</p> <p>Due to increased longevity among PLHIV, future research efforts should examine the broad spectrum of literacy-related problems</p>

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	<p>From a potential 12,663 studies, only six studies were included in the systematic review, all of them conducted in the USA.</p>	<p>better knowledge about HIV and provided participants with skills for adhering to medication regimes.</p>	<p>that accompany the management of multimorbidity.</p>
<p>Sheridan et al (2011) International</p>	<p>Systematic review of studies that evaluate the effectiveness of interventions designed to mitigate the effects of low health literacy.</p> <p>The research questions centred on determining whether health literacy interventions:</p> <ul style="list-style-type: none"> • improve the use of health care services • improve health outcomes • affect the costs of care • reduce disparities in health care service use and/or health outcomes among different racial, ethnic, cultural, or age groups <p>Of the 38 studies included in the analysis, 26 studies provided the most direct evidence to respond to the research questions.</p>	<p>Several discrete design features improved participant comprehension:</p> <ul style="list-style-type: none"> • Presenting essential information by itself or first • Presenting information so that the higher number is ‘better’ • Presenting numerical information in tables rather than through text • Adding icon arrays to numerical information • Adding video to verbal narrative. <p>Studies have provided consistent and direct evidence that intensive mixed-strategy interventions focusing on self-management can reduce emergency department visits and hospitalisations.</p> <p>Intensive mixed-strategy interventions focusing on self-management and disease management also reduced disease severity.</p>	<p>There is scope for innovative interventions that, for example increase people’s motivation to process information; work around the problem of low health literacy, such as incorporating patient navigators; and help to change physician behaviours, practice structures, or existing health policy.</p> <p>Research should continue to address the methodological issues that will ensure high-quality inferences about what works in order to mitigate the effects of low health literacy.</p> <p>Research should continue to explore the features that make health literacy interventions successful. Although a combination of intervention features has been shown to ensure the success of interventions, reducing ineffective features could save on delivery time and be more cost-effective.</p> <p>Research should explore the best ways to disseminate and implement effective health literacy interventions.</p>

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<p>Sørensen et al (2012)</p> <p>International</p>	<p>A systematic literature review was performed to identify definitions of health literacy (How is health literacy defined?) and conceptual frameworks of health literacy (How can health literacy be conceptualised?).</p> <p>Content analysis of the definitions and conceptual frameworks was carried out to identify the central dimensions of health literacy and develop an integrated model.</p> <p>19 publications were retrieved which explicitly dealt with the definition of health literacy, and 12 with conceptual frameworks of health literacy.</p>	<p>17 definitions of health literacy were derived from the literature. A shared characteristic of these definitions is their focus on individual skills to obtain, process and understand health information and services necessary to make appropriate health decisions.</p> <p>Recent discussions on the role of health literacy highlight the importance of moving beyond an individual focus, and of considering health literacy as an interaction between the demands of health systems and the skills of individuals.</p> <p>12 conceptual models were identified in the literature. It is apparent from these models that health literacy is a multidimensional concept.</p> <p>Most conceptual models consider not only the key components of health literacy, but also identify the individual and system-level factors that influence a person’s level of health literacy. Many also identify the pathways that link health literacy to health outcomes.</p>	<p>Based on content analysis, an integrative conceptual model of health literacy was developed. The model contains 12 dimensions that refer to knowledge, motivation and competencies that enable people to better access, understand, appraise and apply health-related information within the healthcare, disease prevention and health promotion settings, respectively.</p>
<p>Trezona et al (2017)</p>	<p>The study aimed to develop a conceptual framework on health literacy responsive organisations in the Australian context, grounded in</p>	<p>Seven domains of health literacy responsiveness were identified:</p> <ol style="list-style-type: none"> 1. External policy and funding environment 	<p>A participatory research process has utility as a means to generate a conceptual framework for organisational health literacy. It can be used to guide the planning and monitoring of health</p>

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Australia (Victoria)	<p>the experiences and perspectives of health and social service professionals.</p> <p>A series of consultations was held with professionals working in the health and social services sectors, making use of face-to-face concept-mapping workshops, followed by a two-part online concept mapping process.</p> <p>Conducted in Victoria, a total of 42 professionals from 36 organisations participated in six workshops.</p>	<ol style="list-style-type: none"> 2. Leadership and culture 3. Systems, processes and policies 4. Access to services and programs 5. Community engagement and partnerships 6. Communication practices and standards 7. Workforce <p>Each domain included one to five sub-domains, with 24 sub-domains in total.</p>	<p>service and health system improvements, as well as effective health policy and health system reforms.</p> <p>Health and social service organisations may utilise the framework to inform quality improvement and organisational development activities. It has the potential to inform the development of training and education curricula for health and social service sector professionals. Researchers may utilise it to inform research programs on health literacy responsiveness and health system strengthening.</p>
Von Wagner et al (2009) International	<p>A review of the literature was undertaken to better understand the processes through which health literacy affects health.</p> <p>Drawing on ideas from health psychology, the researchers examined the links between low health literacy and health outcomes and the extant health literacy frameworks in order to put forward a comprehensive 'Framework of health literacy and health action'.</p>	<p>Health literacy has traditionally been associated with actions relating to the management of illness. Health literacy research has only recently been extended to examining health actions that have the aim of managing health in everyday life (such as healthy eating and exercise). The role of health literacy in contributing to everyday management of health, rather than managing ill-health, is comparatively less well understood.</p> <p>Many patients with reading problems are ashamed and hide their inability to read. Shame is a deep emotion that plays an</p>	<p>The relationship between health literacy and health action is mediated by at least two processes: motivation based and skill based.</p> <p>The authors put forward a framework incorporating a hierarchy of skills in which simple processes are used as part of more complex cognitive strategies, including the ability to locate and select relevant information, follow instructions, and perform quantitative operations, which in turn are necessary to eventually integrate, synthesize, and analyse information.</p>

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	<p>Implications for interventions are provided and discussed.</p>	<p>important role in understanding how low-literate patients interact with health care providers.</p> <p>The influences on an individual during a single-event decision such as screening for cancer screening are likely to be different from actions needed for the management of a complex, chronic disease.</p>	<p>Information-management skills, in addition to reading ability, should be promoted in adults with low health literacy. These should include health system navigational skills.</p>
<p>Wawrzyniak et al (2013) International</p>	<p>Review of the literature to provide a summary of research on the impact of health literacy on the health of PLHIV and to address future areas of need.</p> <p>15 articles met the inclusion criteria</p>	<p>Research has focused on:</p> <ul style="list-style-type: none"> • Exploring links between health literacy and retention in HIV care, knowledge, treatment-seeking intention and HIV suppression • The role of social support in compensating for low health literacy • Interventions targeting PLHIV with low health literacy • The use of technology to improve health literacy <p>Several studies have not found health literacy to sufficiently explain health behaviours, whereas other studies have supported such a relationship.</p>	<p>Recent literature supports the view that health literacy affects knowledge of HIV. Whether or not this knowledge then directly influences health behaviours among PLHIV is less clear.</p> <p>Health literacy cannot be completely separated from cognitive functioning. Since PLHIV have high rates of cognitive impairment, interventions and research on HIV-related health literacy would benefit from inclusion of measures of cognitive ability.</p> <p>Evidence suggests that older adults and those with multimorbidity are at a greater risk for low health literacy. They may also be more negatively impacted upon by low health literacy. A focus on health literacy should be a central component of work and studies with</p>

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		<p>Few studies have focused on specific populations at risk for low health literacy.</p> <p>The use of technology as an assessment and an intervention tool is well represented in the recent literature. Evidence suggests that health literacy evaluation and interventions delivered via technology are promising for future research endeavours.</p>	<p>PLHIV, a large proportion of whom are 50 years and older.</p>
<p>Yahia et al (2015) USA</p>	<p>Based on the HIV Care Continuum, this study examined changes over time in retention in care and viral suppression.</p> <p>The researchers followed 17,140 patients at 11 HIV clinics in the USA between 2010 and 2012.</p> <p>For each calendar year, patients were classified into one of five categories:</p> <ol style="list-style-type: none"> 1. Retained/suppressed 2. Retained/not-suppressed 3. Not retained/suppressed 4. Not retained/not suppressed 5. Lost to follow up 	<p>There were wide variations in individuals' future retention/suppression status based on their original classification in 2010. Patients retained/suppressed in 2010 were the most stable group.</p> <p>A high proportion (44.7–49.6%) of patients not-retained/suppressed in 2010 moved to the retained/suppressed category in subsequent years.</p> <p>Over the study period, 1.7% of persons retained/suppressed died, compared to 3.2% of retained/not suppressed, 1.5% of not-retained/suppressed, and 2.7% of those not-retained/not suppressed.</p> <p>Certain patient experiences are currently not captured by the HIV Care Continuum.</p>	<p>The HIV Care Continuum is a helpful framework for monitoring HIV care. Applying it in a longitudinal framework will enhance its utility.</p> <p>Strictly requiring 'retention in care' criteria to be met in order to consider individuals virally suppressed may underestimate the proportion of patients achieving viral suppression.</p>

Author(s), date, place	Research design and methodology	Findings	Implications
		<p>In particular, excluding patients who did not meet standard definitions of 'retention in care' underestimated the proportion that is virally suppressed by 13%.</p>	
<p>Zheng et al (2018) International</p>	<p>The study aimed to qualitatively and quantitatively evaluate the relationship between health literacy and QoL based on a systematic review and meta-analysis.</p> <p>33 studies were included in the qualitative synthesis; and 23 studies were included in the meta-analysis (quantitative analysis).</p>	<p>In the modern world, QoL is viewed as a significant outcome of health care. It has been increasingly used as a comprehensive health indicator in medical interventions and in population health surveys.</p> <p>Many studies have investigated the relationship between health literacy and QoL, but the results are inconsistent: some studies show that QoL has a positive association with health literacy, while other studies suggest that the association was negative.</p> <p>The results of the meta-analysis suggest that health literacy is moderately correlated with QoL.</p>	<p>More research is needed to better clarify the relationship between health literacy and QoL. In particular, studies with larger sample sizes and better data quality are desirable.</p>

6. Insights and best practices for HIV health literacy

6.1 Health literacy matters

Health literacy is an important resource for people. On the basis of a systematic literature review, Berkman et al (2011) found that differences in health literacy were consistently associated with:

- Increased hospitalisations
- Greater emergency care use
- Poorer ability to demonstrate appropriate use of medications
- Poorer ability to interpret labels and health messages
- Poorer overall health status and higher mortality among older patients.

In an Australian study, Jayasinghe et al (2016) found that primary care patients with low health literacy are more likely to be smokers, to engage in insufficient physical activity, to be overweight, and to have lower physical and mental health. These are indicators of poorer health-related quality of life (HRQoL). The researchers conclude that addressing health literacy-related barriers to preventive care can play a role in reducing disparities relating to HRQoL.

Evidence from several studies on the relationship between health literacy and HIV-related outcomes is presented in Table 3:

Table 3: Evidence for links between low health literacy and HIV-related outcomes

HIV-related outcome	Researchers
Levels of health literacy impact on knowledge of HIV/AIDS	Hicks et al (2006) Wawrzyniak et al (2013)
Levels of health literacy are predictors of HIV treatment adherence	Kalichman et al (2013) Osborn et al (2010)
Low levels of health literacy impact negatively on patients' understanding of health-related information	Cunha et al (2017)
Low health literacy is a social barrier for PLHIV in accessing healthcare services; and is in turn impacted upon by low socio-economic status	Palumbo (2015) Cunha et al (2017)

On the basis of a narrative literature review, Palumbo (2015) found that health literacy – conceived of as a social determinant of health – contributes to the life conditions and the health status of PLHIV. This is especially the case for people from under-served ethnic minority groups, those with refugee backgrounds, and those with histories of substance abuse, mental illness, incarceration, and unstable housing or homelessness.

Similarly, Cunha et al (2017) found that studies internationally often reported on the disadvantaged socio-economic status of many PLHIV. Socio-economic factors contribute to lower levels of health literacy. They also serve as limitations to the ways in which higher levels of health literacy could potentially lead to improved health outcomes. As Cunha et al (2017) note, many PLHIV in this situation – even if they do understand the importance of health measures – may not have the resources to put these measures into practice in order to maintain quality of life.

6.2 Tailored focus on HIV

In light of the evidence for a relationship between levels of health literacy on the one hand, and HIV-related outcomes on the other, there is value in tailoring health literacy interventions specifically to the HIV context. Perazzo et al (2017) conducted a systematic review of studies that described interventions aiming to promote the health literacy of PLHIV. Findings from the review strengthened the rationale for health literacy interventions specifically tailored to the HIV context and the needs of PLHIV. Studies in which HIV-specific knowledge and behaviour skills received explicit focus provided the most significant results. The researchers also pointed out that, due to increased longevity among PLHIV, future efforts should examine the broad spectrum of health literacy-related problems that accompany the management of multimorbidity (Perazzo et al 2017).

One of the conclusions from the Von Wagner et al (2009) study was that the influencers of health literacy on an individual during a single-event decision – such as screening for cancer – are likely to be different from the influencers of health literacy on an individual needing to manage a complex, chronic disease. HIV is an example of this.

In a study conducted in the USA, Hicks et al (2006) found that knowledge of HIV/AIDS is associated with health literacy at the individual/patient level even after adjusting for income level, education level and risk perception. On the basis of the study, the researchers conclude that there is a need to tailor HIV prevention strategies toward a population with low levels of health literacy. Such a change could dispel misconceptions about HIV transmission and treatments that could in turn lead to changes in risk-taking behaviours and health care utilisation (Hicks et al 2006).

6.3 Health literacy is many-faceted

Based on a study conducted in Victoria, Jordan et al (2010) contributed to the understandings of the skills associated with health literacy by focusing on the way people themselves view these skills. On the basis of this study, health literacy competences at the individual level are clustered as:

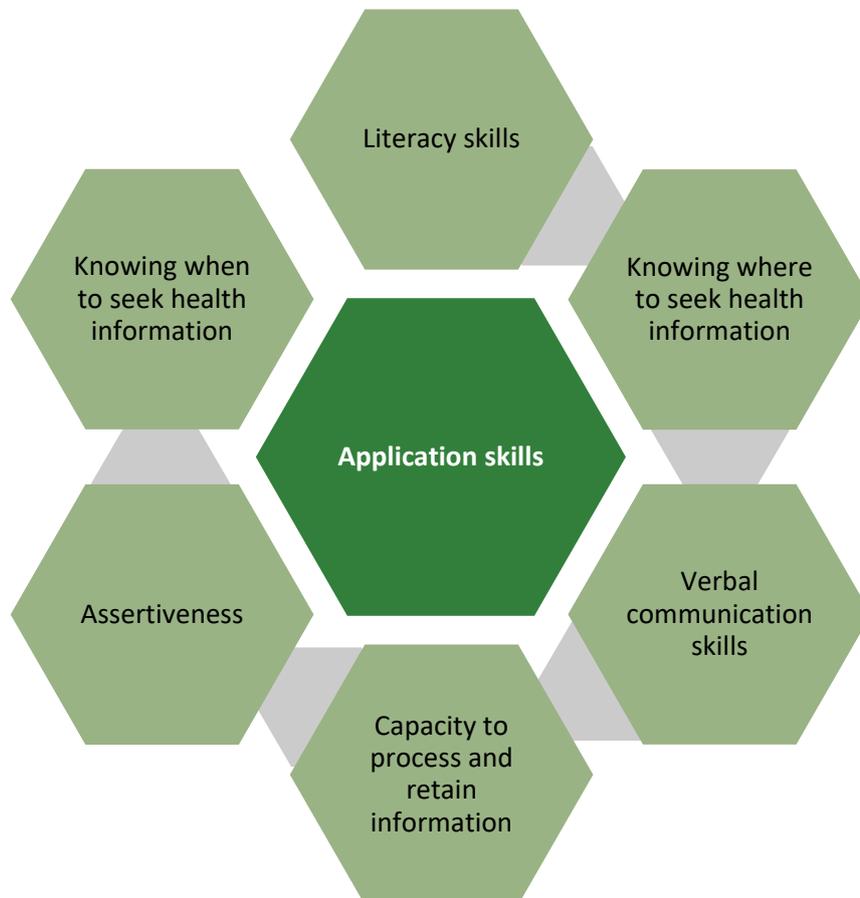


Figure 8: Health literacy competences at the individual level

Source: based on Jordan et al (2010)

The researchers also found that this wide range of skills is frequently not reflected in existing measures of health literacy. The implication is that future studies could consider incorporating a focus on these competences, knowing that community members themselves identified them as aspects of health literacy (Jordan et al 2010).

While a focus on health literacy abilities at the individual level is important, many commentators highlight the need to focus on the skills and abilities of all parties involved in communication and decisions about health (Sørensen et al 2012). In addition to individuals/patients, these would include health care providers, health educators, informal carers, and policy makers.

Based on the literature included in the table of evidence, factors that influence an individual’s level of health literacy – the antecedents of health literacy – are summarised in Table 4.

Table 4: Factors that influence health literacy

Antecedents	Components	Sources
Demographic, social and cultural	<ul style="list-style-type: none"> • Parental and peer influences • Socioeconomic status, occupation, employment, income • Social support, culture and language 	Sørensen et al (2012) Jordan et al (2010)
Environmental and political forces	<ul style="list-style-type: none"> • General literacy within the society • Use of media within the society • Level of openness in the society • The society’s focus on health 	Sørensen et al (2012)
Individual characteristics	<ul style="list-style-type: none"> • The influences of age, race, gender and cultural background • Competences such as vision, hearing, verbal ability, memory and reasoning • Physical abilities • Social skills • Meta-cognitive skills associated with reading, comprehension, and numeracy • Prior experience with illness • Prior experience of the health care system 	Sørensen et al (2012)
Community level	<ul style="list-style-type: none"> • Good support network – affected by influences in the social environment and access to health care resources including health insurance • Priority afforded to health within the context of broader lifestyle commitments 	Sørensen et al (2012) Jordan et al (2010)

Consideration of these many influences highlights again the multifaceted nature of health literacy, as does the complexity of pathways from health literacy to health outcomes. This is discussed next.

6.4 Translating health literacy into health outcomes

The literature provides insights into ways in which interactions, thought processes, reasoning and feelings (including perceptions of self-efficacy, and motivation) lead, or do not lead, to action and outcomes.

On the basis of a narrative review on the effects of poor health literacy on PLHIV, Palumbo (2015) concluded that greater attention could be paid to the confounding factors which affect the relationship between health literacy and the management of HIV infection.

This includes patients voluntarily departing from clinical prescriptions on the basis of conflicting messages; and their willingness to follow alternative and unconventional health treatments.

Research carried out by Von Wagner et al (2009) found that the relationship between health literacy and health action is mediated by at least two processes: motivation based and skill based. On this basis, the researchers recommended that health and health system navigation skills, information management skills and reading skills be addressed when working with adults with low levels of health literacy.

More research is needed to better understand the ‘psychological, cognitive and practical influences on motivation and volition to act’ (Von Wagner et al 2009) and to improve individual and community health literacy interventions that will impact positively on all of these processes. In this regard, useful insights are provided by Elmer et al (2017), who identify the following as helpful attributes for translating health literacy into health behaviours and outcomes over the life course:

- **Autonomy** – occurs when a person 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 people gain control over, and feel that they have gained control over, factors and decisions that shape their lives

(Elmer et al 2017)

6.5 Impact of stigma

On the basis of research, several authors highlight the effect of literacy-related stigma when considering programs for low literacy populations. Von Wagner et al (2015: 868) point out that many patients with reading problems are ashamed and hide their inability to read: shame is ‘a deeply harboured emotion that plays an important role in understanding how low-literate patients interact with health care providers’.

Kalichman et al (2013) focused on low literate PLHIV and found that few participants had disclosed their reading difficulties to doctors or pharmacists. The researchers suggest that this could be linked to literacy-related stigma that is compounded with HIV-related stigma. Kalichman et al (2013) recommend that addressing both AIDS and literacy-related stigma would play a key role in developing strategies to assist PLHIV with poor literacy skills. In particular, more direct and intensive interventions may be needed for people who are the most challenged by poor reading skills. These approaches may include intensive counselling with long-term continuous adherence monitoring.

6.6 HIV Health literacy as a process

Focusing in particular on HIV health literacy, Brinkley-Rubenstein et al (2015) suggest that it should be conceptualised and operationalised as a process rather than as a static outcome in which knowledge is transmitted from practitioner to patient/client. According to these authors, the relational components necessary for the development of health literacy include:

- **Trust**, which includes ‘commitment acts’ that help to create connections with clients
- Acknowledging a client’s **multiple social identities**
- Understanding the **hierarchy of needs** that any person might have

(Brinkley-Rubenstein et al 2015)

Working with a better understanding of someone’s hierarchy of needs can go a long way to helping health care providers understand why people may need to prioritise other issues that relate to health literacy, when these issues at the same time act as barriers to greater health and wellbeing.

In a multi-site and multi-country study, Dawson-Rose et al (2016) found that HIV health literacy – and how it is defined – is dynamic and multi-dimensional, and is powerfully influenced by the relationships PLHIV develop with their health care providers. According to these researchers, a program based on an expanded definition of health literacy could improve HIV care. Such a program would include promoting mutual trust, and engaging in processes of health education and information sharing over time.

6.7 eHealth: the online environment

eHealth refers to ‘the delivery of health information and services via the Internet and related technologies’ (Eysenbach, cited in Mackert et al 2014: 516). The ability for an individual to judiciously evaluate information has become a major aspect of health literacy in recent years, due especially to advances in technology and the proliferation of Internet-based information.

The online environment has enabled a dramatic expansion in health communication and is also important as a locus for health literacy programs. As summarised by Wawrzyniak et al (2013: 6): ‘The mainstream use of portable devices such as laptops, tablet computers, and smartphones has expanded the tools for interventions aimed at improving health literacy’.

Based on a systematic review, Han et al (2018) examined the role of eHealth literacy in relation to diverse HIV-related health outcomes, including HIV transmission risk, retention in care, treatment adherence, and virological suppression. Findings were mixed. There were instances of eHealth literacy promoting as well as hindering health outcomes. In addition, studies suggested that there is much variability in the criteria people used to evaluate information, and thus how they assessed the quality of information and judged its credibility. Han et al (2018) concluded that the importance of eHealth literacy among PLHIV has only recently begun to be addressed, but it would be an essential step to supporting PLHIV to be more actively engaged in their health care in coming decades.

Mackert et al (2014) reviewed the literature published between 2000 and 2010 on eHealth and health literacy and concluded that, while the development of eHealth provides powerful tools to improve health, it is the users' health literacy that plays a more prominent role in influencing their ability to make the most of eHealth applications. The results of this study suggested that much work needs to be done. The researchers found that the overwhelming majority (93.7%) of studies included in the review were not based on theoretical frameworks and there were limited contributions by communication scholars.

A note of caution with regards to eHealth is also provided by Schulz and Nakamoto (2013). The authors found that the Internet can promote the unintentional misuse of information and can, for example, lead a patient to build a biased knowledge structure that is oriented to their wishes rather than to reality. 'It is important, therefore, to guide patients to approach the Internet with appropriate skepticism and to temper their perceptions of autonomy', conclude Schulz and Nakamoto (2013: 65).

6.8 Health literacy interventions

6.8.1 The value of community-based programs

Community-based health literacy interventions can be defined as 'any purposeful, organized activity to help a group of people find, understand, use, or communicate about health information, services, or issues for themselves or their communities' (Bauer et al 2017: 6). There is strong evidence in the research literature that health literacy programs that directly engage with the intended beneficiaries of those initiatives yield positive results.

In a scoping literature review to identify and describe the state-of the-art of community-based health literacy interventions, Bauer et al (2017) found that studies reflect a strong focus on knowledge outcomes. The authors recognise that, while knowledge is a step away from health or behavioural change, a focus on it is necessary because communities often are isolated from science-based health information and lack foundational knowledge. These researchers identified four ways in which the concept of 'health literacy' is used in community-based interventions:

1. **Community** – identifying or characterising the community of interest as 'low health literate'
2. **Measurement** – using a health literacy instrument or measure in the analysis
3. **Content** – using health literacy principles or techniques in the design of programs or materials
4. **Outcome** – assessing outcomes that are related to health literacy, such as changes in knowledge, self-efficacy or skills

(Bauer et al 2017: 29)

The researchers found that high levels of community involvement at multiple stages in the intervention process are appropriate for health literacy improvement work. They also caution that, when health literacy is included at several points in an intervention, it is important that the concept be applied consistently (Bauer et al 2017).

On basis of an analysis (see table of evidence), the researchers provide the following classification of community-based interventions:

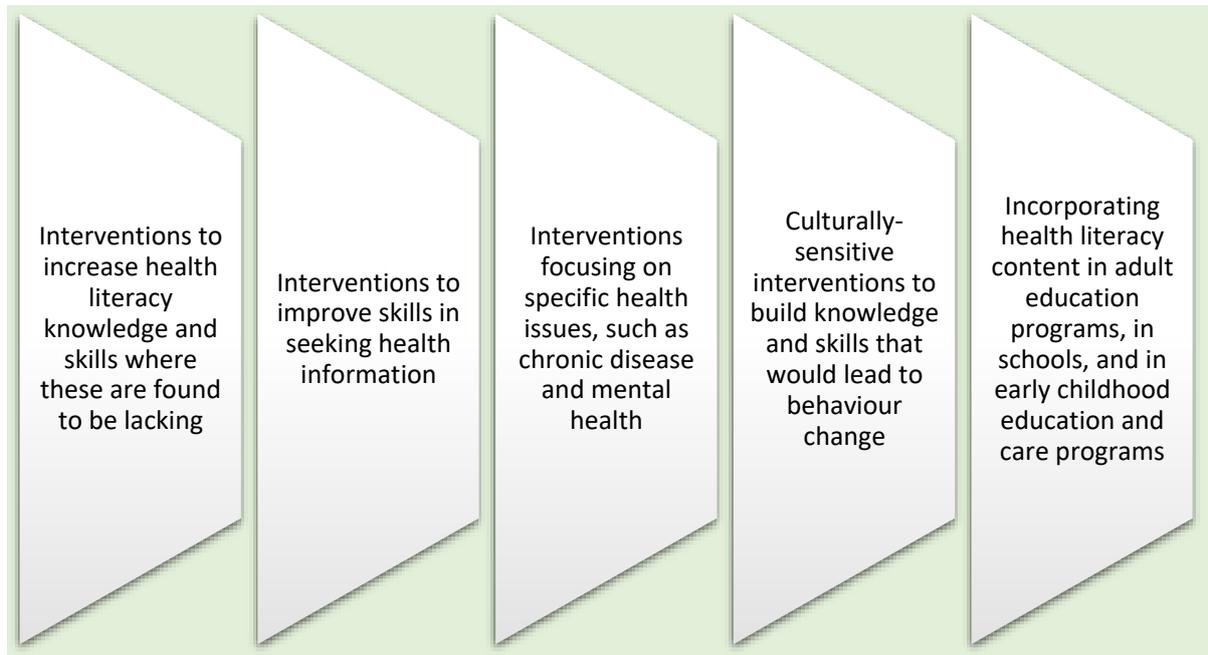


Figure 9: Classification of community-based health literacy interventions

Source: Bauer et al (2017: 11-28)

Evaluations suggest that interventions such as these have had positive effects on a range of outcomes for diverse groups of people. In addition to improved knowledge, outcomes have included changes to social norms, healthcare service use, and physiological measures (Bauer et al 2017: 28). While the authors conclude that high levels of community involvement at multiple stages in the intervention process are appropriate for health literacy improvement work, programs would benefit from applying insights from the expanding health literacy research base more explicitly into the design and evaluation of programs (Bauer et al 2017).

Elmer et al (2017) described a community-based health literacy program that focused on people living with chronic conditions in Tasmania, and reported on the evaluation of this program. The initiative aimed to develop participants' ability to communicate effectively with health care providers; to better understand their own behaviours; and to recognise the effect of those behaviours on illness prevention and self-management of their chronic conditions.

The content was delivered in two-hour sessions with six to ten participants by a multidisciplinary health professional team. The program is described in some depth in the table below as an example of a health literacy initiative that was planned, delivered and evaluated in the Australian context.

Table 5: A community-based health literacy program focused on people living with chronic conditions

Session	Theme	Content
1	Exercise is medicine	<ul style="list-style-type: none"> • Common myths about exercise • The physical and mental benefits of being physically active • Matching exercise to life stages and ages • How to fit extra (incidental) physical activity into everyday life • The opportunity to try different kinds of exercise and activity
2	Questions for the right answers	<ul style="list-style-type: none"> • Means to improve communication between consumers and health service providers • Techniques for exchanging information with health service providers • Practising communication skills through role play
3	Food myths	<ul style="list-style-type: none"> • Common myths about food • Information about healthy food choices • Practical activities, including reading and understanding food labels
4	Staying on track	<ul style="list-style-type: none"> • Setting health goals • Developing strategies to reach health goals • Maintaining motivation • Tracking progress
5	Understanding pain	<ul style="list-style-type: none"> • Causes of pain • Kinds of pain • Management of pain
6	Understanding the body	<ul style="list-style-type: none"> • Basic anatomy • Using anatomical models to better understand the location and function of various body parts
7	How far we have come	<ul style="list-style-type: none"> • Review of previous sessions • Using Type 2 diabetes as an exemplar • Evaluating participant experience of the program

Source: Elmer et al (2017)

In terms of evaluation of this program, the researchers acknowledged that contemporary understandings of health literacy focus on its many determining factors. This complexity requires a participatory approach to first identify, then address health literacy needs.

6.8.2 Functional literacy still the main focus

In a widely adopted conceptual framework, Nutbeam (2000) proposed that comprehensive health literacy interventions would address three levels of competence at the individual/patient level, with implications also at a health system-wide level:

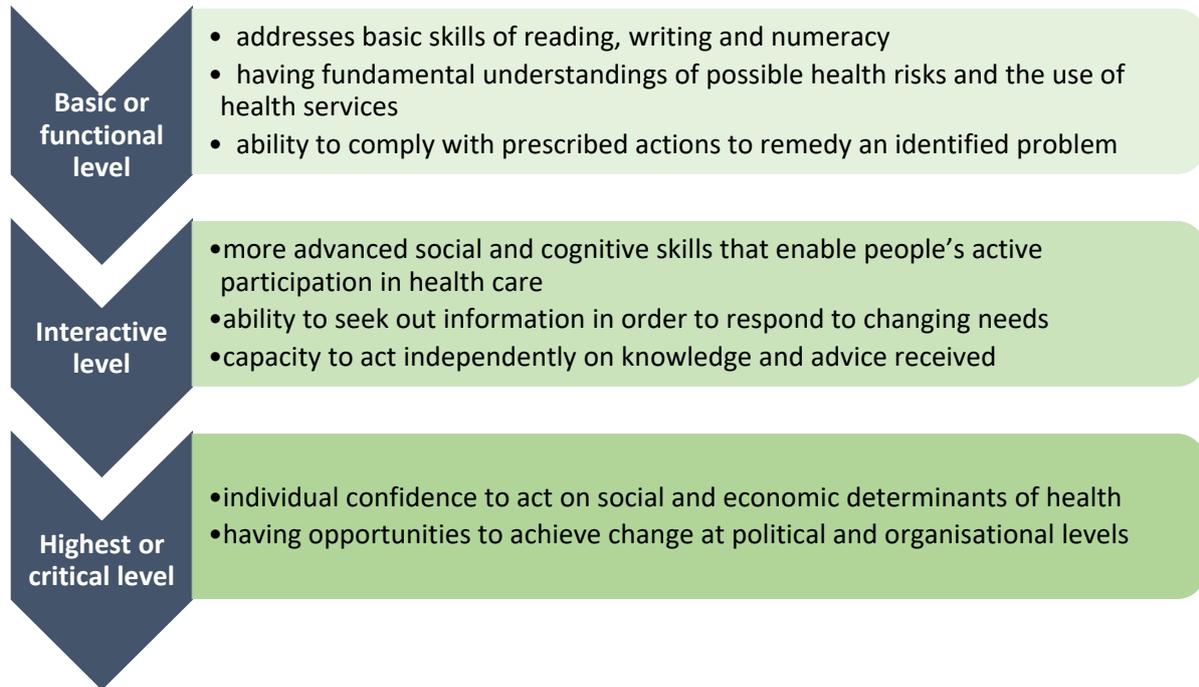


Figure 10: A framework for health literacy competences at the individual level

Sources: based on Nutbeam (2000); Fernandez-Guiterrez et al (2018: 57-61)

Commenting on the Nutbeam (2000) model, Frisch et al (2011: 118) note that the three-tiered concept of health literacy implies that 'more advanced skills lead to greater autonomy and personal empowerment', and these in turn would lead to decisions and behaviour that enhance health.

Drawing on this model, and on the basis of a meta-analysis of the literature, D'Eath et al (2012) identified that the focus in the health literacy intervention literature has remained on functional literacy.

D'Eath et al (2012) drew on their analysis to classify health literacy interventions as follows:

Written health information interventions

- targeting plain language
- increased readability

Alternative format interventions

- using technologies to support and enhance health care consumers' knowledge
- using technologies to support and enhance health care consumers' skills

Targeted mass media campaigns

- often designed around specific health behaviours

Low literacy initiatives

- targeting specific populations
- targeting geographical areas

Figure 11: Typology of health literacy interventions

Source: based on D'Eath et al (2012)

D'Eath et al (2012) also concluded that there are considerable gaps in the evidence concerning which interventions are most effective in improving health literacy. There is a paucity of research involving disadvantaged or hard-to-reach groups; and of research focusing on communicable diseases.

On the basis of a systematic review, Sheridan et al (2011) found evidence for the value of intensive, mixed-strategy health literacy interventions that focus on self-management as well as disease management. These researchers noted that there is scope for innovative interventions that, for example, increase people's motivation to process information; work around the problem of low health literacy, such as incorporating patient navigators; and that contribute to changing physician behaviours, practice structures, or existing health policy.

In a commentary on health communication, Schulz and Nakamoto (2013) wrote that a focus on empowerment contributes substantially to people engaging with health care and making informed and reasoned choices. On the basis of a scoping review, Crondahl and Karlsson (2016: 4) suggested that, in order for health literacy to also contribute to empowerment, any conception of it needs to encompass the social determinants of health.

In particular, there should be an emphasis on subjective perceptions of health and health needs, which encompass the broader aspects of social, cultural, and economic conditions present in the lives of individuals and communities.

Viewed in this way, and in keeping with the contributions made by Nutbeam (2000), empowerment is the ultimate goal of health literacy, but only when it

...evolves to higher levels of critical consciousness, including questioning and reflecting; a sense of power, self-esteem, and self-efficacy; and an understanding of how to make use of all available resources to engage in social and political actions.

(Cron Dahl and Karlsson 2016: 6)

A model of intervention that focuses explicitly on capacity building and empowerment is described in the box below.

A multi-level approach to health literacy

This model locates both health literacy and the interventions to address poor levels of health literacy at the interaction between individuals and their environments. It recognises that the same environment may have different effects on an individual's health, depending on factors such as financial resources, personality, perceptions, and individual behaviour.

It suggests having three levels of intervention:

- **Individual and interpersonal levels** – this recognises the influence of individual and interpersonal factors such as age, language, education, and family relationships. An aim would be to help participants pinpoint specific problems related to health literacy that they are experiencing.
- **The community level** – the approach recognises the communicative and interactive skills that people need to function within the context of their communities.
- **Societal level** – the approach recognises that critical-level skills are moderated by structures at the societal and policy level.

Key techniques include dialogue and reflection, problem-posing and problem-solving. Programs could include media campaigns and community-based activities. The impact of this multilevel approach would be reflected in changes in the problems identified by the community during dialogue and problem posing.

Outcomes may include greater engagement between doctors and patients or fewer emergency room visits, change in the practices of community health facilities, shift in beliefs about the cause of poor health, increase in knowledge about the social determinants of health, and provision of resources that support health. Overall, interventions should see, over time, an increase in individual and communal agency and a general improvement in the health and wellbeing of the community.

Source: Dawkins-Moultin et al (2016)

This approach moves beyond functional health literacy and closer to the development of critical-level skills, while remaining true to the goal of health promotion.

6.8.3 Co-designing health communications

Morales (2017) identified several features of health documents that could affect the way adult readers evaluate consumer health information. These included linguistic and design features, participants' prior knowledge of the topic, the potential use of the documents, terminology, and the interpretation of statistical figures and bulleted lists.

There is much variability in how people judge the quality and credibility of health information. There is also variability in the criteria they use to appraise the applicability of that information to their own lives and to people they love and care for. As highlighted by Morales (2017), people often pay attention to 'unintended' cues present in the text (such as style, tone and specificity) and many people would use these cues to evaluate the information, rather than the criteria endorsed by guidelines. Morales (2017) concluded that, by engaging members of marginalised communities as judges of health information quality, this kind of research supported community members' self-determination while promoting health literacy.

On the basis of a systematic review, Berkman et al (2011) found that health communication design features to focus on include alternative document design, alternative numerical presentation, additive and alternative pictorial representation, and improved readability and alternative document design. When these findings are placed together with research carried out by Sheridan et al (2011), best practice trends for low-health-literacy populations begin to emerge.

These are summarised in Figure 12:

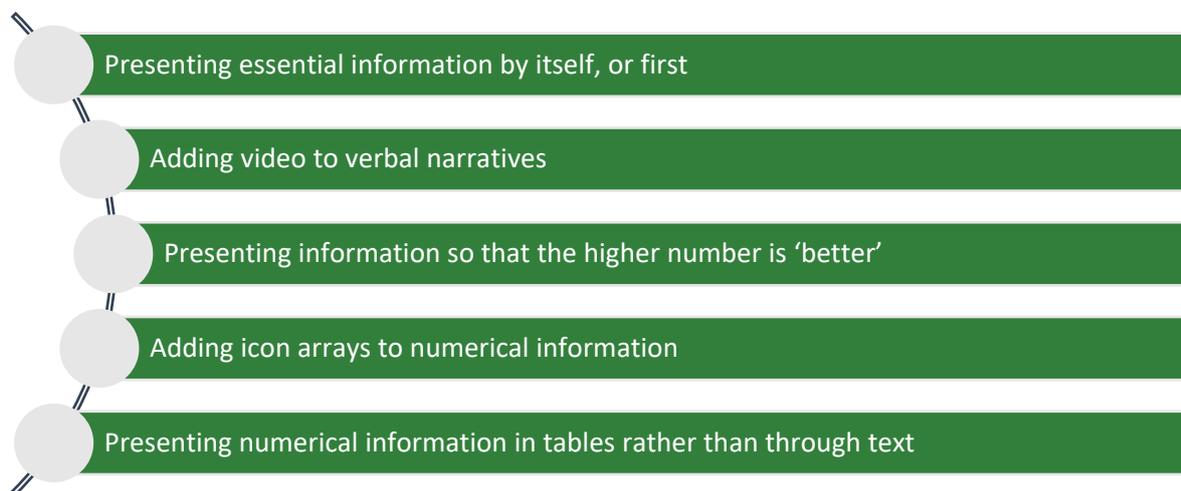


Figure 12: Evidence-based design features

Sources: Berkman et al (2011); Sheridan et al (2011)

Organisations can draw on findings such as these to improve their written health communications.

6.8.4 Adherence to ART

Kalichman et al (2008) found that successful interventions to improve medication adherence for lower-literacy populations of PLHIV are characterised by:

- Breaking down complex skills into simple achievable steps.
- Providing instructions with limited verbal content (not using too many words).
- Building specific behavioural skills central to the task of taking medications as directed.

Ownby et al (2012) showed that an electronically delivered intervention designed to improve HIV patients' health literacy may have an effect on their medication adherence. The content, presented in an interactive and tailored format, should: address basic HIV-related information; the factors and possible barriers related to motivation; and behavioural skills. Concept-checking occurs through participants being asked to respond to multiple choice questions about the information presented. If they responded correctly, the intervention moved on to the next element; if not, the material was presented again.

6.8.5 Management of health and quality of life outcomes

Von Wagner (2009) reviewed the literature and found that health literacy has traditionally been associated with health actions relating to the management of illness. Research had only more recently been extended to understanding and promoting health actions (such as healthy eating and exercise) that are directed at managing health in everyday life. Put differently, the role of health literacy in contributing to people's everyday management of their health and wellbeing is less well understood than its role in contributing to the management of ill-health.

Zheng et al (2018: 6) write that developments in medical technology and increased life expectancy have contributed to greater attention being paid to wellbeing and quality of life (QoL). Providers and researchers have become increasingly interested in whether health literacy improvements also contribute positively to QoL. Jayasinghe et al (2016: 2) identified 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

Findings to date suggests that the links between health literacy and QoL outcomes are not strong, but research is continuing. 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, and the authors called for more rigorous research to better clarify the potential correlation and the potential range of confounding factors between health literacy and QoL (Zheng et al 2018).

Brown et al (2018) drew on consistent findings in the literature to suggest that, beyond viral suppression through adherence to ART, quality of life (QoL) was an important consideration in HIV prevention and care. Currently, there is no widely accepted consensus as to what QoL is and what they 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 Table 6:

Table 6: 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
- 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.

6.8.6 Promoting health literate organisations

Farmanova et al (2012) conducted a review of the evidence on organisational health literacy (OHL). The study found that many organisations make use of health literacy guides but tend to focus broadly on communication actions such as targeted improvements in existing health information materials; and the organisation of health care, including preparation of the workforce to deliver health-literate care.

Several studies pointed to the assessment tools often provided with the guides as useful. The researchers concluded on the basis of the review that barriers towards organisational health literacy can be clustered as:

- Lack of commitment and low priority given to health literacy and related activities
- No buy-in from leaders
- Lack of change champions in the organisation
- Lack of time and other resources
- The complexity of existing health literacy tools and guides.

(Farmanova et al 2012)

Trezona et al (2017) found that a participatory research process has utility as a means to generate a conceptual framework for organisational health literacy. On the basis of research conducted in Victoria, Trezona et al (2017) identified seven domains of organisational health literacy responsiveness.

These researchers integrated these domains within a framework that can be applied in the context of strategic planning and management:



Figure 13: Framework for organisational health literacy

Source: based on Trezona et al (2017)

Within the context of organisational health literacy interventions, this framework can be used to guide the planning and monitoring of improvements, as well as to appraise health policy and health system reforms.

6.8.7 Health literacy at the level of public policy

It is estimated that 60 per cent of adult Australians have low health literacy (ABS, cited in NSW Health 2016: 4). In keeping with the *Australian National Statement on Health Literacy* (Australian Commission on Safety and Quality in Health Care [ACSQHC] 2014), there is agreement 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.

To address health literacy in a coordinated way in Australia in keeping with this National Statement, it was recognised that action needs to be taken across three areas:

1. **Embedding health literacy into systems** – This involves developing and implementing systems and policies at an organisational and societal level that support action to address health literacy. These systems could include altering funding mechanisms to encourage awareness and action on health literacy, implementing policies that prioritise health literacy in program planning, and designing healthcare organisations in a way that makes it easier for people to find their way.
2. **Ensuring effective communication** – This involves providing print, electronic or other communication that is appropriate for the needs of consumers. It also involves supporting effective partnerships, communication and interpersonal relationships between consumers, healthcare providers, managers, administrative staff and others.
3. **Integrating health literacy into education** – This involves educating consumers and healthcare providers and could include population health programs, health promotion and education strategies, school health education, and social marketing campaigns as well as formal education and training of healthcare providers.

(ACSQHC 2014)

An example of the operationalisation of health literacy principles and practices at the local level is provided in the box below.

Sydney Local Health District Health Literacy Framework 2016-2020

Health services have a responsibility to become health literate organisations and to develop workforces that can build partnerships and enhance health literacy for all the people who use their services. In the quest to be a health literate organisation, strategic and managerial commitment provides the foundation for becoming a health literate organisation. This is followed by an accessible educational technology infrastructure, a well-trained workforce, and policies and procedures that the workforce and the infrastructure can support so that effective two-way communication can take place.

The following can be listed as attributes of a health literate organisation:

1. Has leadership that makes health literacy integral to its mission, structure and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety and quality improvement.
3. Prepares the workforce to be health literate and monitors its progress towards this.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills, while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audio-visual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.

Source: Sydney Local Health District (2016)

As can be seen from this description, the Framework draws on the work of Brach et al (2012) on organisational health literacy, described in section 3.4 of this document.

6.9 Recommendations for future research

Table 2 (the table of evidence) identifies recommendations for future research put forward by researchers themselves. Several authors provide recommendations specific to HIV health literacy research. Palumbo (2015) suggests that, in order to reduce the biases which affect the studies of the effects of health literacy on the management of HIV infection, more reliable measures of the health literacy skills needed by PLHIV should be developed and statistically tested. In similar vein, and in connection with eHealth, Han et al (2018) suggest that avenues to pursue in the role of eHealth literacy among PLHIV should consider the development and use of standardised eHealth literacy definitions and measures. In particular, there is a need for the use of validated instruments to measure eHealth literacy.

Perazzo et al (2017) call for more research to determine the influence of health literacy as a 'process variable' that influences the ability for PLHIV to manage their health. Due to increased longevity among PLHIV, future research efforts should examine the broad spectrum of literacy-related problems that accompany the management of multimorbidity.

Researching the impact of health literacy on the health of HIV-infected individuals, Wawrzyniak et al (2013) found that health literacy cannot be completely separated from cognitive functioning. According to these authors, and as a result of PLHIV having high rates of cognitive impairment, interventions and research on HIV-related health literacy would benefit from inclusion of measures of cognitive ability. In addition, since evidence suggests that older adults and those with multimorbidity are at greater risk for low health literacy, and may be more negatively affected by low health literacy, a focus on health literacy should be a central component of studies with PLHIV, a large proportion of whom are 50 years and older (Wawrzyniak et al 2013).

There is strong support for research to be based on reliable, valid and generalizable measures of health literacy. For example:

- D'Eath et al (2012) suggest that the development of measures of health literacy at a level other than that of functional literacy is fundamental to any progression of health literacy.
- Cunha et al (2017) call for longitudinal research that makes use of validated scales to assess health literacy.
- To improve the quality of future studies, Fernandez-Guiterrez et al (2017) recommend use of a framework of health literacy that includes its functional, interactive and critical dimensions.

In addition to stronger definitions and measures of health literacy, several authors call for future research to be more explicitly based on theory. For example, with regard to eHealth literacy, Mackert et al (2014) recommend that research be grounded more solidly in theory, for example, health communication theories, information systems research, and emerging conceptual models of health literacy. Fernandez-Guiterrez et al (2017) call for the use of causal models that explain the relationship between health literacy, the education system and the health system that are culturally relevant. In light of inconclusive findings in the current literature, Zheng et al (2018) call for more research to better clarify the relationship between health literacy and QoL. In particular, studies with larger sample sizes and better data quality are desirable.

Several studies make recommendations for improved research methods. Mackert et al (2014) recommend that research in eHealth and health literacy could be improved by not relying too heavily on surveys; and increasing the use of more exploratory data collection techniques.

Fernandez-Guiterrez et al (2017) suggest that future studies could consider the use of mixed methodology (qualitative and quantitative approaches) to better understand users' experiences; and for the implementation of longitudinal studies.

In a more general statement, Sheridan et al (2011) suggest that research should continue to address the methodological issues that will ensure high-quality inferences about what works in order to mitigate the effects of low health literacy.

Bauer et al (2017) call for stronger evaluations of health literacy interventions. These researchers suggest that the identified challenges in applying evaluation frameworks in the studies to date point to a lack of fit between public health interventions generally and community-based health literacy interventions in particular.

Sheridan et al (2011) recommend research that continues to explore the features that make health literacy interventions successful. Although a combination of intervention features has been shown to ensure the success of interventions, reducing ineffective features could save on delivery time and be more cost-effective. Research should also explore better ways to disseminate and implement effective health literacy interventions.

6.10 Summary

HIV health literacy best practice includes:

- ✓ Recognising that health literacy matters and promoting higher levels of population health literacy through policy, program and practice innovations
- ✓ Tailoring a health literacy focus specific to HIV in light of evidence that different levels of health literacy are associated with different HIV-related outcomes
- ✓ Associating HIV health literacy not only with actions relating to the management of illness, but also with actions directed at managing health in everyday life and maintaining quality of life
- ✓ Working with the many dimensions of health literacy in theory- and evidence-informed, as well as participatory, ways
- ✓ Addressing less tangible attributes such as motivation, relatedness and self-efficacy to support people in their diverse pathways from health literacy to health outcomes
- ✓ Recognising and addressing the impacts of stigma related to both HIV and low literacy
- ✓ Viewing HIV health literacy as a process that is strongly influenced by the relationships PLHIV build up with their health care providers, and by changes over the lifespan
- ✓ Developing expertise in eHealth and the online environment

Although there are still considerable gaps in the evidence base concerning which interventions are most effective in improving health literacy, studies do provide support for the following:

- ❖ Programs work best with high levels of community involvement at multiple stages, including active participation in evaluation processes.
- ❖ Comprehensive and intensive mixed-strategy health literacy interventions are particularly effective if they focus on self-management as well as disease-management.
- ❖ An intervention focus on functional literacy remains important, but programs are more effective if they also focus on issues such as empowerment and competence-building.
- ❖ Findings from several studies involving people in the design of health communications (written health information and alternative formats) have generated insights into what works better in terms of reducing the health literacy demands placed on consumers.
- ❖ A concerted approach to promoting health literate organisations has benefits for communication practices and standards, and impacts positively on other issues, such as organisational culture, workforce, community engagement and partnerships.

There is also value in addressing health literacy at the level of public policy, as is the case in both Australia and New Zealand.

To improve health literacy research, experts call for more rigorous and comprehensive measures of health literacy; research that is more strongly informed by theory; and improved research and evaluation methods. HIV health literacy research can be improved through more reliable measures of the health literacy skills needed by PLHIV, examining the broad spectrum of literacy-related problems that accompany the management of multimorbidity, and including measures of cognitive ability.

7. HIV health literacy framework

According to the HLF project plan, a draft HIV Health Literacy Framework will be developed that can guide interventions to improve both individual health literacy and the health literacy-supporting systems and environments. It is intended that it be applicable across communication functions (information, persuasion, social connection and social structures), and to the HIV Care Continuum.

As a contribution towards the drafting of this Framework, this section considers:

- The HIV Care Continuum
- A selection of health literacy frameworks identified in the literature
- Recommendations for a draft HIV Health Literacy Framework.

7.1 The HIV Care Continuum

The ‘HIV Care Continuum’ has been developed and adopted in several contexts, including Australia, as a means of identifying ‘gaps and opportunities for improving the delivery of HIV care’ (Yehia et al 2015: 2). Its underlying principle is that, in the context of HIV, adherence to ART is critical for achieving viral suppression, improved immune function, reduced risks of HIV-related morbidity and mortality, and reduced HIV transmission. Consequently

...for ART to achieve its maximum benefits at the population level, people living with HIV must be diagnosed early, must initiate treatment, must adhere to their medications, and ultimately must achieve and sustain an undetectable viral load.

(Babalola et al 2017: S4)

Kay et al (2016: 1) recognise that the terms ‘HIV care continuum’ and ‘HIV care cascade’ are often used interchangeably. They suggest that one way to differentiate between the two would be to make use of the ‘continuum’ to refer to navigation of the spectrum of HIV care engagement at an individual level. Use can then be made of the ‘treatment cascade’ to examine a static, cross-sectional representation of these steps at a population level.

The HIV Care Continuum is generally described with five or three levels. According to Kay et al (2016), the HIV care continuum, when conceived as five steps, can be described as follows:

1	2	3	4	5
Diagnosis	Linkage to care	Retention	ART adherence	Viral suppression

Diagnosis	Linkage to care	Retention	ART adherence	Viral suppression
Entry into the HIV treatment cascade begins with a diagnosis of HIV infection; from a policy level, decisions need to be made on offering HIV tests as a screening for all people or as a risk-based practice.	The period from documentation of diagnosis to initiation of medical treatment with an HIV care provider/prescriber; ideally, this should occur over a period of three months or less.	Retention or continuity in HIV care; there is a lack of consensus about how best to measure retention, but it generally includes indicators for kept and missed appointments.	Challenging to measure, as it relies largely on patient self-report.	This is the primary goal of HIV treatment and public health interventions.

Drawing on Babalola et al (2017), and when understood as three broad levels, the continuum can be expressed as follows:

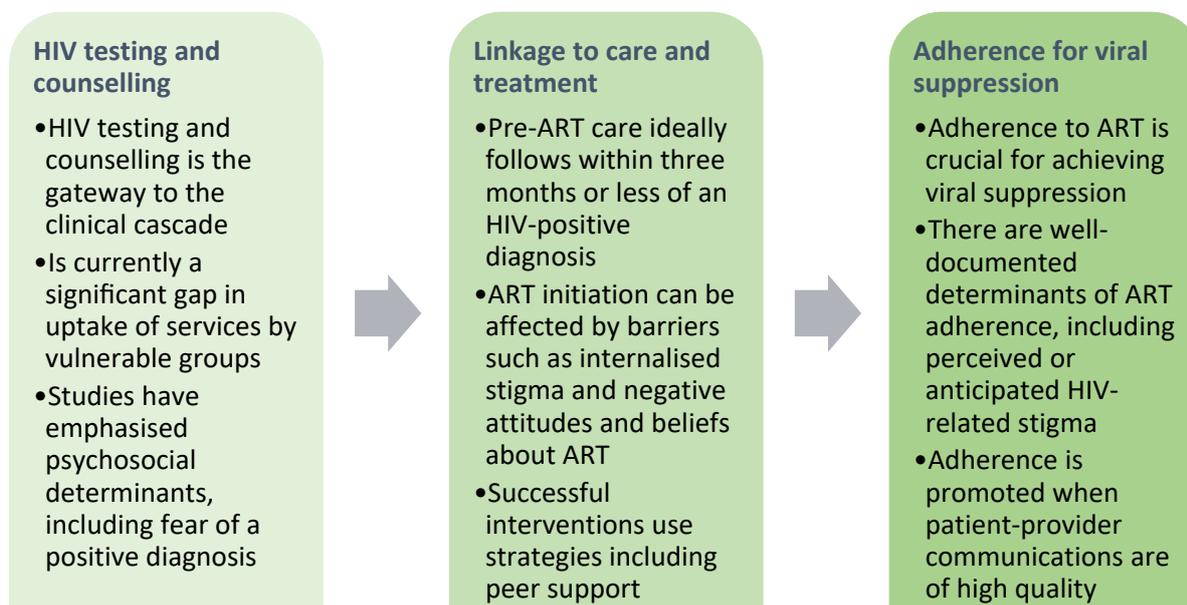


Figure 14: A three-step model for conceptualising the HIV treatment continuum

Source: based on Babalola et al (2017: S6)

These authors note that ‘interventions that include health communication components have been successful in addressing the determinants of the behaviours along the HIV treatment continuum’ (Babalola et al 2017: S9), and this has implications for the health literacy focus of the HLF study. For example, ART literacy can be achieved by helping patients better understand the negative association between CD4 (where high is ‘good’) and viral load (where high is ‘bad’), which could help them to appreciate the need for repeated viral load testing (Babalola et al 2017).

The UNAIDS 90-90-90 target (see <https://www.aidsmap.com/90-90-90>) calls on countries to reach the following goals, which are in keeping with the three-step approach to the HIV care continuum:

- 90% of people living with HIV diagnosed by 2020
- 90% of diagnosed people on antiretroviral treatment by 2020
- 90% of people in treatment with fully suppressed viral load by 2020

There is strong evidence in the literature (Babalola et al 2017; Kay et al 2016; Keen et al 2018) that Australia is amongst the countries in the world that is performing well on achieving these targets.

Based on an estimation of the HIV diagnosis and care cascade for NSW, for example, Keen et al (2018) found:

- 10,110 PLHIV (in a range from 8,400 to 11,720) resided in NSW in 2016.
- Of these, 9,230 (91.3%) were diagnosed.
- 8,490 (92.0% of those diagnosed) were receiving ART in 2016.
- Among the PLHIV receiving ART in 2016, 8,020 (94.5%) had suppressed viral load (<200 HIV-1 RNA copies/mL).

On this basis, the researchers concluded that 79.3% of all PLHIV in NSW had HIV virological suppression, 'the highest rate reported in the peer-reviewed literature' (Keen et al 2018: 4). At the same time, a study carried out by Levi et al (2016), which analysed 69 country cascades, including Australia, found that no country met the 90-90-90 targets, and that large disparities were identified between countries. One of the challenges these researchers identified in making such international comparisons was that countries used vastly different approaches when reporting the stages of a cascade. According to Yehia et al (2015: 2), additional challenges in adopting the HIV Care Continuum approach include:

- The Continuum focuses on populations, not individuals. As such, data are presented in the aggregate and may not accurately capture changes across time for individual patients.
- The Continuum is largely static, providing a snapshot of HIV testing, engagement in care, and viral suppression at a specific time point or during a set time period.
- There is a group that is not adequately covered in the Continuum – patients who are virally suppressed, but who do not meet standard definitions of retention in care; few studies have estimated the size of this group.

7.2 Health literacy frameworks in the literature

Health literacy research has 'created multiple conceptual frameworks with an increasing number of dimensions, causal pathways and measurable constructs' (Neuhauser 2017: 159). Several of these are illustrated next on the assumption that the elements (dimensions, pathways, constructs) they describe will also have a place within the draft HIV Health Literacy Framework.

7.2.1 Framework for health literacy competencies

Sørensen et al (2012) identified 12 conceptual models of health literacy in the literature, all of which highlight the multidimensional nature of health literacy. Most conceptual models consider not only the key components of health literacy, but also identify the individual and system-level factors that influence a person's level of health literacy. Many also identify the pathways that link health literacy to health outcomes.

On the basis of this analysis, the researchers generated a comprehensive conceptual framework that is provided in the table below.

Table 7: Framework for health literacy competencies

Health domain	Dimension of health literacy			
	<i>Access/obtain information relevant to health</i>	<i>Understand information relevant to health</i>	<i>Process/appraise information relevant to health</i>	<i>Apply/use information relevant to health</i>
Health care	Ability to access information on medical or clinical issues	Ability to understand medical information and derive meaning	Ability to interpret and evaluate medical information	Ability to make informed decisions on medical issues
Disease prevention	Ability to access information on risk factors for health	Ability to understand information on risk factors and derive meaning	Ability to interpret and evaluate information on risk factors for health	Ability to make informed decisions on risk factors for health
Health promotion	Ability to update oneself on determinants of health in the social and physical environment	Ability to understand information on determinants of health in the social and physical environment, and to derive meaning	Ability to interpret and evaluate information on health determinants in the social and physical environment	Ability to make informed decisions on health determinants in the social and physical environment

Source: Sørensen et al (2012: 10)

As can be seen in this framework, Sørensen et al (2012) draw attention to 12 individual capabilities spread across three health domains and four health literacy domains. These capabilities should be transferable, applicable, and measurable if they are to be valid constructs that are of use within health literacy programs.

7.2.2 Health literacy skills framework

Squiers et al (2012) put forward a framework that illustrates the ‘full pathway from development and moderators of health literacy skills, their application, and the outcomes that result’.

The Health Literacy Skills Framework of Squiers et al (2012) is illustrated in Figure 16:

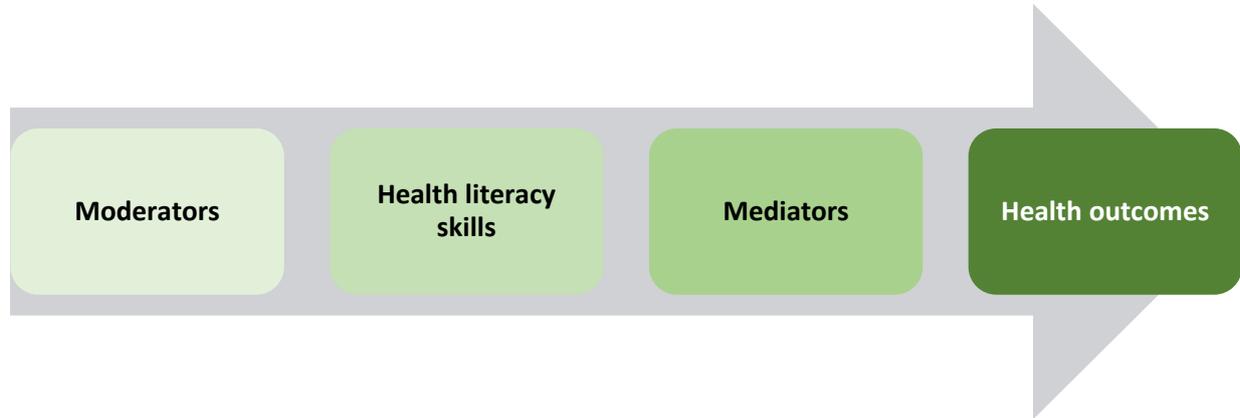


Figure 15: Health Literacy Skills Framework

Source: Squiers et al (2012: 32)

Within this model, the health literacy skills at the level of the individual can be clustered as follows:

- Factors that influence the development and use of health literacy skills (moderators) are also impacted upon by the demand (complexity and difficulty) of a health-related stimulus
- Individuals make use of a variety of skills (e.g. obtain, process, understand, communicate) to comprehend the stimulus and perform the task
- A similarly complex range of factors (mediators) influences or mediates the relationship between health literacy skills and health outcomes (Squiers et al 2012: 47-50)

7.2.3 Distributed health literacy within a pathway model

Edwards et al (2013) focused on health literacy in people with a long-term health condition and introduced the health literacy pathway model to describe how participants develop their health literacy through five stages and identified facilitators and barriers in addition to personal outcomes (e.g. building their knowledge and skills, communicating with health-care professionals, participating in shared decision making).

The research and the model draw on the assumption that health literacy is a ‘distributed’ resource (Edwards et al 2013; discussed in section 2.2.2 of this report). Whatever their level of health literacy, individuals can benefit from the distribution of health literacy within their social network. Friends, family, colleagues and acquaintances mediate the development and practice of health literacy by sharing knowledge, facilitating learning, contributing their own skills, and supporting decision making.

The 'pathway model' that is central to the approach put forward by these researchers can be illustrated as follows:

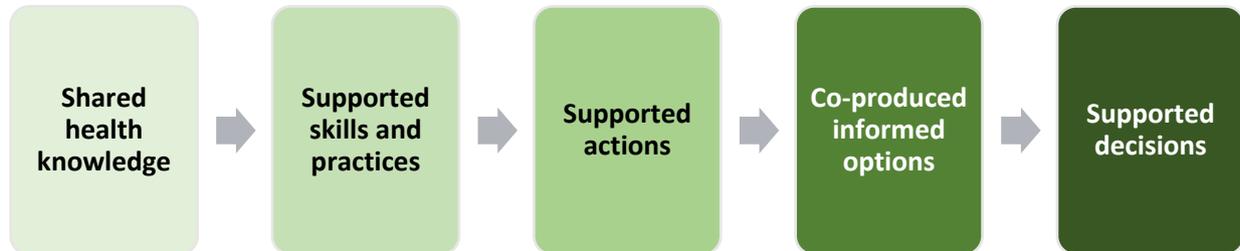


Figure 16: Distributed health literacy within a pathway model

Source: Edwards et al (2013)

Within this model, potential intervention points for health care providers are those in which people in a participant's social network influence the individual's progression through the stages:

1. Knowledge and skills are merged in order to inform the person with a long-term health condition
2. Knowledge and skills are used to support and motivate the person to search for, appraise and apply the information, and become more active in consultations
3. The person is supported to think about different options or new options
4. The person with a long-term condition is supported in their decision-making, including family and friends having an input into the decision

(Edwards et al 2013: 1189-1190)

7.2.4 A social ecological health literacy framework

McCormack et al (2017) put forward a framework to conceptualise health literacy interventions within a social ecological perspective. A social ecological health literacy perspective draws on models widely adopted in the social sciences. These models recognise that individuals are influenced by factors in the physical and social environments and that 'interventions targeting multiples levels of influence reinforce each other and consequently should yield greater and more sustainable effects than interventions targeting only one level of influence' (McCormack et al 2017: 9).

The framework is summarised in Table 8.

Table 8: Framework for health literacy interventions within a social ecological approach

LEVEL OF INFLUENCE	INFLUENTIAL FACTORS	INTERVENTIONS TO ADDRESS LIMITATIONS
INDIVIDUAL	Health-related knowledge, attitudes, beliefs; perceptions of risk and benefit; health literacy skills	Use of plain language best practices; clear communication principles; health education sessions; patient decision aids
INTERPERSONAL	Communication skills; social support	Patient-centred communication; patient and family support groups; shared decision-making
ORGANISATIONAL	Infrastructure planning and implementation; system integration and coordination	Staff training; team-based care and care coordination; physical environment layout and signage; consumer assistance programs
COMMUNITY	Community-based programs; integration of public health and health care systems	Social marketing campaigns; eHealth communication; social media influencers; community-based participatory research
MACRO-POLICY	Public policy, regulation, incentives, evidence-based policies	Legislation; policies and strategies; adoption of clinical guidelines

Source: McCormack et al (2017: 10)

Within this comprehensive approach, the impact of interventions at different levels accumulate to have an impact on improved health literacy and patient engagement. Interventions at different levels ‘influence an outcome by mutually reinforcing each other and changing interaction patterns’ (McCormack et al 2017: 11).

7.2.5 A system-wide approach to health literacy (New Zealand)

A health literacy framework in New Zealand comprehensively addresses the interactional nature of health literacy. It does so by reflecting on how each part of the health system can contribute to building health literacy. This includes outlining expectations for the health system, health organisations and the health workforce to take action that supports a ‘culture shift’. The aim is to make health literacy core business at all levels of the health system; to reduce health literacy demands; and to recognise that good health literacy practice contributes to improved health outcomes and reduced health costs (Ministry of Health 2015).

The New Zealand health literacy framework is summarised in Table 9.

Table 9: Health literacy framework (New Zealand)

LEVEL	LEADERSHIP AND MANAGEMENT	KNOWLEDGE AND SKILLS	HEALTH SYSTEM CHANGE
HEALTH SYSTEM	Health system leadership sets the expectation that good health literacy policy and practice help individuals to live well, keep well and get well.	The health system builds an evidence base that identifies the changes needed to improve health literacy, reduce demands and support effective innovations	The health system is committed to good health literacy practice and invests in changing the way it is organised to improve outcomes
HEALTH ORGANISATION	Leadership and management ensures that health literacy is a core organisational value that helps drive quality improvement and achieves health equity	Health organisations build knowledge about how they can improve health outcomes by making their services and facilities health literacy-friendly	Health organisations express their commitment to health literacy by creating an environment that reduces health literacy demands
HEALTH WORKFORCE	Leaders and managers are seen by peers, individuals and patients as effective communicators, who champion good health literacy practice	The health workforce can contribute to improved understanding of good health literacy practice	The health workforce is committed to good health literacy practice as a routine part of how they do things
INDIVIDUALS AND PATIENTS	People are partners in actively managing their own health and wellbeing; they take opportunities to provide feedback on health services they use and contribute to quality improvement programs	People can obtain, process and understand health materials	People are able to make informed decisions; they have the ability to access and navigate appropriate, quality and timely health services

Source: Ministry of Health (2015)

This framework provides a model for a comprehensive health literacy strategy at a national level. Together with the other frameworks described above, it is drawn upon and extended in the drafting of a HIV health literacy framework in the context of the HLF initiative, presented as a conclusion to this literature review next.

7.3 Towards a HIV health literacy framework

Three interconnected elements of the draft Framework are:

- I. 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
- II. Positioning the commitments, expectations, roles and interests of an initiative's stakeholders by drawing on the systems perspective
- III. 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 HLF 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.

7.3.1 A systems perspective

Systems and social ecological approaches to health literacy discussed earlier in this document (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.

Figure 18 below maps the HLF project outcomes from a systems perspective.

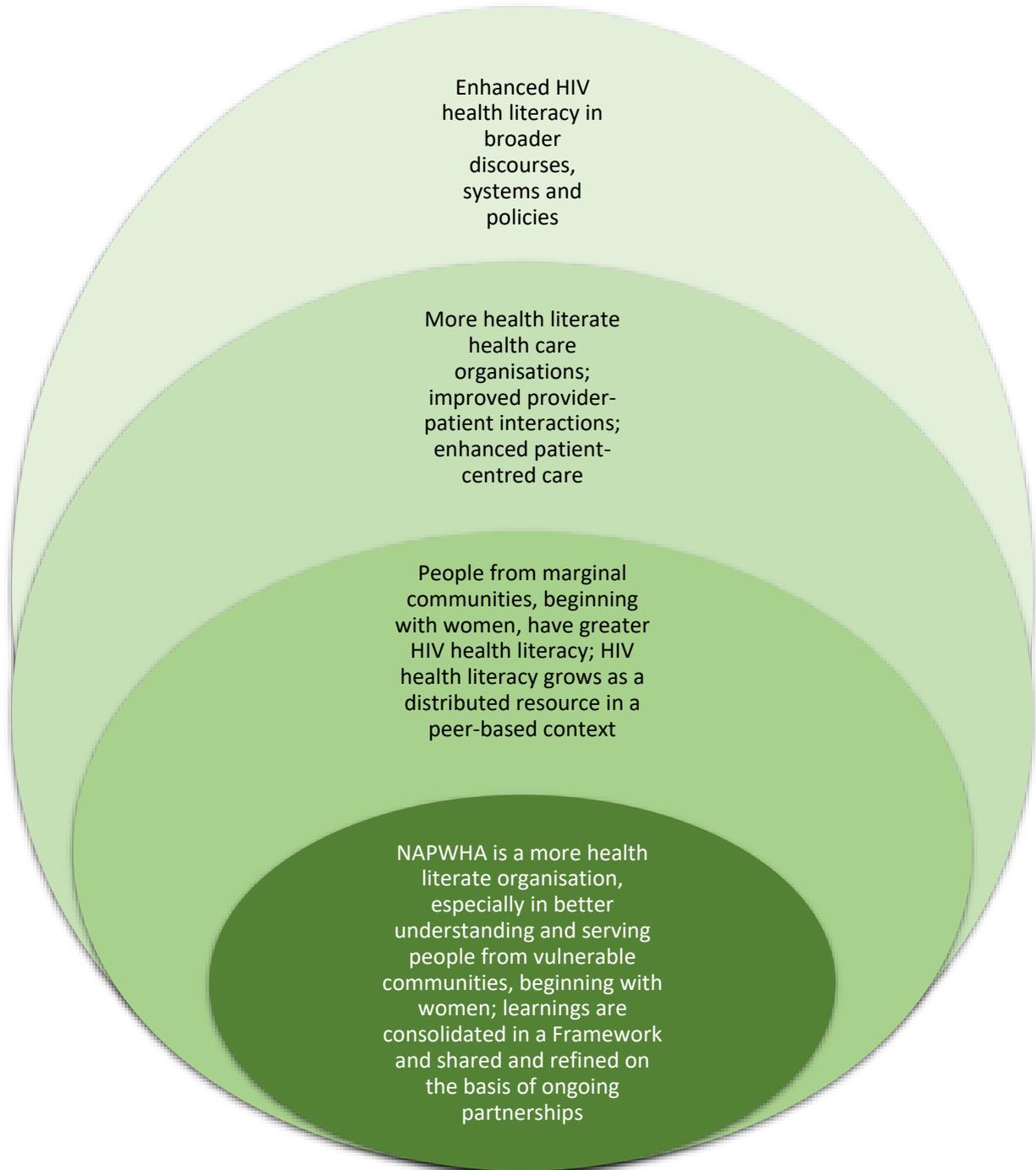


Figure 17: The HLF project outcomes from a systems perspective

As can be seen in Figure 18, 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.

7.3.2 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 may include:

- **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 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.
- **People in their social contexts:**
For ART to achieve its maximum benefits at the population level, PLHIV must be diagnosed early, must initiate treatment, must adhere to their medications, and ultimately must achieve and sustain an undetectable viral load¹. Health literacy contributes to outcomes at all points on this continuum of care.
- **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 time².
- **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 care³.

¹ Drawing on an interpretation of the HIV Care Continuum provided by Babalola et al (2017)

² Drawing on Dawson-Rose et al (2016)

³ Drawing on Farmanova et al (2012)

- **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.

7.3.3 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 outcomes focus in a matrix. The HLF project is used as an illustration of how this matrix might be applied in practice (Table 10 below).

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 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 draft Framework is applied to other health literacy initiatives and contexts.

⁴ ACSQHC (2014)

Table 10: HIV health literacy matrix

HIV Care Continuum	Health literacy interventions				
	Health Care Organisations	Patient-provider Interactions	People in their Social Contexts	PLHIV community and organisations	Health Care System
HIV testing and counselling	<p>Creating an environment that reduces health literacy demands – e.g. physical environment layout and signage; clear communication principles</p> <p>Creating a safe environment for testing</p>	<p>Better understandings of HIV</p> <p>Better understandings of health literacy and its impact on interactions</p> <p>Communication skills</p> <p>Social support</p>	<p>HIV-related knowledge, attitudes, beliefs</p> <p>Perceptions of risk and benefit in light of the stigma associated with both poor health literacy and HIV</p> <p>Skills to access and navigate appropriate, quality and timely health services</p> <p>Attributes to make informed health-related decisions e.g. ability to understand medical information and derive meaning</p>	<p>Communities and organisations develop expertise in HIV and living with HIV, including adopting a holistic approach towards the HIV Care Continuum and HRQoL</p> <p>Communities and organisations together investigate ‘health literacy’ and become more health literate</p> <p>Health literacy-informed conversations are held with the total body positive in an atmosphere of partnership and co-learning</p> <p>Peer conversations and health communications with people from more vulnerable communities are strengthened through, for example, partnering with community champions and undertaking activities such as judging the</p>	<p>Health care system leadership sets the expectation that good health literacy policy and practice help individuals to live well, keep well and get well</p> <p>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</p> <p>The health care system is committed to good health literacy practice and invests in changing</p>
Linkage to care and treatment – the period from a documented HIV diagnosis to initiation of medical treatment with an HIV care provider/prescriber	<p>Patient-centred communication</p> <p>Patient and family support groups</p> <p>Making services and facilities more health literacy-friendly</p>	<p>Reducing the demand (complexity and difficulty) of a HIV-related health information stimulus</p> <p>Promoting shared decision-making</p>	<p>Personal attributes that contribute to an ability to access and navigate appropriate, quality and timely health services</p> <p>Attributes to make informed decisions on medical issues – e.g. ability to interpret and evaluate medical information</p>	<p>Peer conversations and health communications with people from more vulnerable communities are strengthened through, for example, partnering with community champions and undertaking activities such as judging the</p>	<p>The health care system is committed to good health literacy practice and invests in changing</p>

HIV Care Continuum	Health literacy interventions				
	Health Care Organisations	Patient-provider Interactions	People in their Social Contexts	PLHIV community and organisations	Health Care System
Retention in care and treatment	<p>The health workforce is equipped with knowledge and skills that contribute to improved health literacy</p> <p>Adoption of clinical guidelines</p>	<p>Staff training – e.g. plain language best practices</p> <p>Team-based care and care co-ordination</p> <p>Consumer assistance programs</p>	<p>Attributes to make informed health-related decisions based on better understanding medical information, deriving meaning, and understanding information on health determinants</p> <p>PLHIV take opportunities to provide feedback on health services they use and contribute to quality improvement programs</p>	<p>quality and impact of current HIV-related health information</p> <p>Improved social marketing campaigns</p> <p>Health literacy-informed eHealth communications</p> <p>Identifying and supporting social media influencers</p>	<p>the way it is organised to improve outcomes</p> <p>Legislation</p> <p>Policies and strategies</p>
ART adherence for viral suppression	<p>Health education sessions</p> <p>Patient decision aids</p>	<p>Adherence is promoted when patient-provider communications are of high quality</p>	<p>Ability to make informed decisions on medical issues, on risk factors for health, and on health determinants in the social and physical environment</p> <p>Opportunity to focus on motivation, problem-solving, self-efficacy, knowledge and skills as influences on self-care</p> <p>Empowerment of PLHIV as partners in actively managing their own health and wellbeing</p>	<p>Community-based participatory initiatives and research, including measuring and addressing health literacy skills, and program evaluation</p> <p>Promoting health literacy as a distributed resource, especially in a peer-based context</p>	

Sources: drawn upon McCormack et al (2017); Babalola et al (2017); Sørensen et al (2012); Squiers et al (2012); Edwards et al (2013); Ministry of Health (2015)

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9. Appendix

9.1 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	23-Jul-2019	Draft provided
0.2	Saysana Sirimanotham	30-Jun-2019	Draft formatted and sent to Advisory Steering Group for review, and project co-investigators

Related Documents

- [NAPWHA HIV Health Literacy Framework Project – Evaluation Framework \(June 2019\)](#)
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