

napwha national association of
people with HIV australia

A Guide to Health Literacy in the Context of HIV

Ronald Woods | NAPWHA © | 2020 (revised)

Table of Contents

Table of Contents	2
Introduction	3
Development of the 'health literacy' concept	4
Many definitions	4
A way of thinking and reasoning	5
We're all in it together	6
An attribute with personal and social benefits	7
Constantly changing	7
Multi-dimensional	8
Population health literacy approaches	9
Focus beyond individuals/patients	9
Determinant of health	9
Distributed resource	10
Systems approaches	11
Impacts of poor health literacy	12
Health literacy matters	13
Impacts in the context of HIV	13
Helping people to improve their health literacy	15
Addressing health literacy	15
Helping people to navigate the health care system	16
Improving health-related communications and interactions	17
Increasing the control people have over their health	18
Contributing to successful functioning in social contexts	19
Active community participation	20
Active engagement in health literacy programs	21
Active role in research and program evaluation	21
Making organisations more health literate too	22
From health literacy to health outcomes	24
Readings	29

Introduction

NAPWHA's HIV Health Literacy Framework project

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 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 in Australia. The project strives to promote and contribute to enhanced HIV health literacy at all levels: individual, community, organisational, sectoral, and policy.

Supporting an improved conversation with all PLHIV

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. Working in partnership with champions from diverse communities, NAPWHA will draft a *HIV Health Literacy Framework* to support an improved conversation with all PLHIV. The emerging health literacy framework should support the development of partnerships and networks, and health communication and campaign resources that better address the needs of PLHIV throughout Australia. These resources will be operationalised and assessed.

Participatory and action research approach

A strongly participatory and action research approach underlies the initiative. The objective is that project participants share their perspectives on living with HIV, receive the best possible information regarding HIV, and engage in health promoting actions with regards to HIV. 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. This process can then be extended to diverse cohorts within the body positive, and the developing Framework can be shared within the sector.

This Guide

This Guide provides all stakeholders with an overview of health literacy itself, so as to contribute to shared understandings, capacity-building, and partnership. Health literacy is a very active field of policy, research, practice and publication throughout the world, including Australia. The material in this Guide is solidly located in this literature.

In particular, the Guide is designed to serve as a resource for community leaders and NAPWHA's partners and co-investigators in the HLF project.

Development of the ‘health literacy’ concept

Summary of the material in this section

‘Health literacy’ has generated a great deal of research, policy and practice interest since it was first debated in the 1970s.

Commentators recognise that health literacy is **complex and multi-dimensional**. It can broadly be understood as a measure of the capacities that individuals have to find, process, understand, and communicate about health information and services to protect and promote their health.

Health literacy is **dynamic**. There are many opportunities for internal and external influences to maintain, strengthen or decrease the health literacy competencies that people have throughout their life span.

Health literacy is an **attribute with personal as well as social benefits**. It reflects the interactions between the demands and complexities of health organisations and systems on the one hand, and the skills of individuals on the other.

Many definitions

Health literacy was first used as a term in 1974 at a conference focusing on health education in schools as a social policy issue. 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.

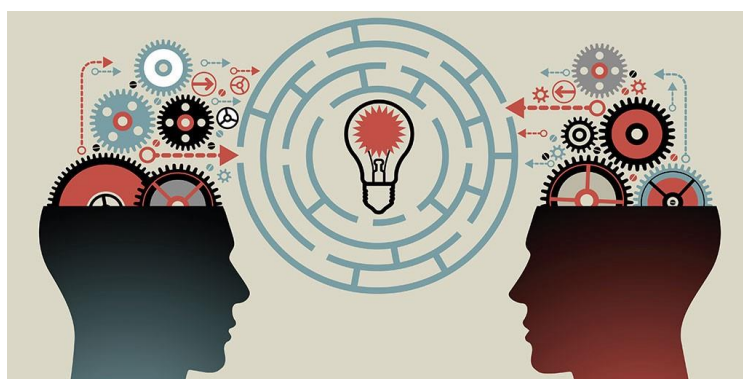
There are many other definitions. For example, on the basis of a systematic literature review, Sørensen et al (2012) derived 17 definitions of health literacy from the literature.

A way of thinking and reasoning

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)

Dawkins-Moultin et al (2016: 30), who examined a range of definitions of health literacy, found that **a common theme across all of the definitions is a focus on cognition**: while it manifests in the steps individuals take to manage their health, health literacy is 'more a way of thinking and reasoning than it is an observable action'.



Such reasoning affects the beliefs people may have of their capacity to understand often complex health and illness-related issues, 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. Health literacy in the context of patient-provider interactions contributes significantly to shared clinical decision-making and patient involvement (Palumbo 2015). Together, these may affect an individual's ability to stay healthy.

We're all in it together

As the debates on health literacy got going, people soon recognised that it's important to go beyond the health literacy skills and deficits of individuals or patients. More recent discussions highlighted the importance of considering it as an interaction between the demands and complexities of health systems and the skills of individuals (Sørensen et al 2012).

Rather than a one-dimensional focus on the abilities and deficits of individuals, then, health literacy can more accurately be described as **complex, multi-dimensional and dynamic sets of interactions**. 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 ... The 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.

A broad illustration of these interactions is provided in Figure 1:

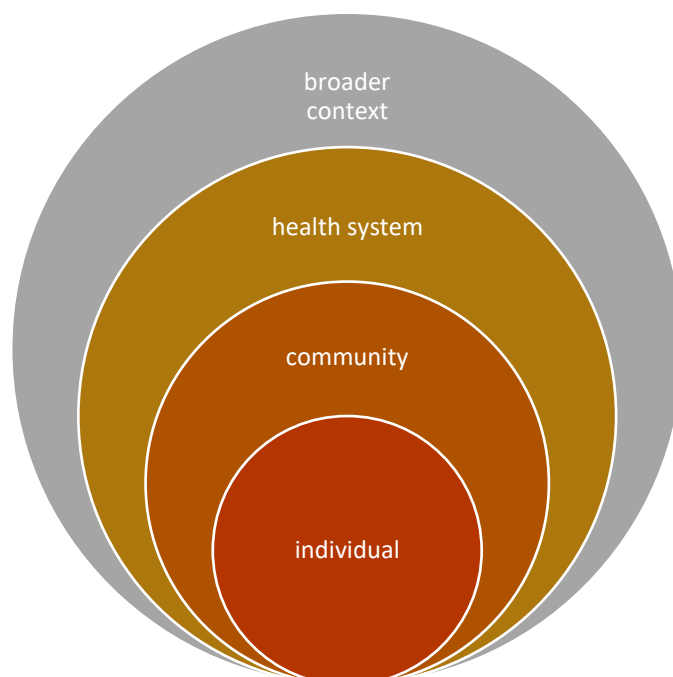
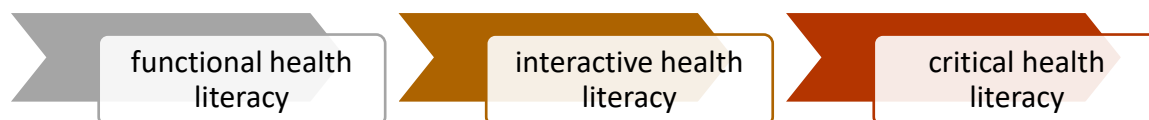


Figure 1: Interactions from individuals to the broader context

An attribute with personal and social benefits

Health literacy is a personal resource leading to personal benefits, but also – due to its impact on communication among all parties – an attribute with social benefits. On this basis, Nutbeam (2000) 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.
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.
3. At the **highest or 'critical' level**, people have significant level of knowledge, personal skills and confidence to manage their health. They also have confidence to act on the social and economic determinants that impact on their health.

Adopting this model suggests that steps can be taken to improve levels of health literacy i.e. to help people move beyond functional literacy; and that health literacy is not only about individuals, but also operates at broader social and political levels.

Constantly changing

As is evident from the discussion thus far, health literacy is not a static quality at either the individual or the population level.

Improvements to health literacy can occur in a systematic way through, for example, initiatives that focus on adult basic education. Health literacy also improves in keeping with any person's individual's own experiences and development, such as when they achieve mastery of a specific self-care skill. Similarly, literacy may decline. This may be in relation to, or independent of, conditions that increase with age, such as dementia (Paasche-Orlow and Wolf 2007: S24).

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 that provide a continuous challenge to their literacy skills
- Learning opportunities that may arise in the form of community-based literacy interventions.

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:

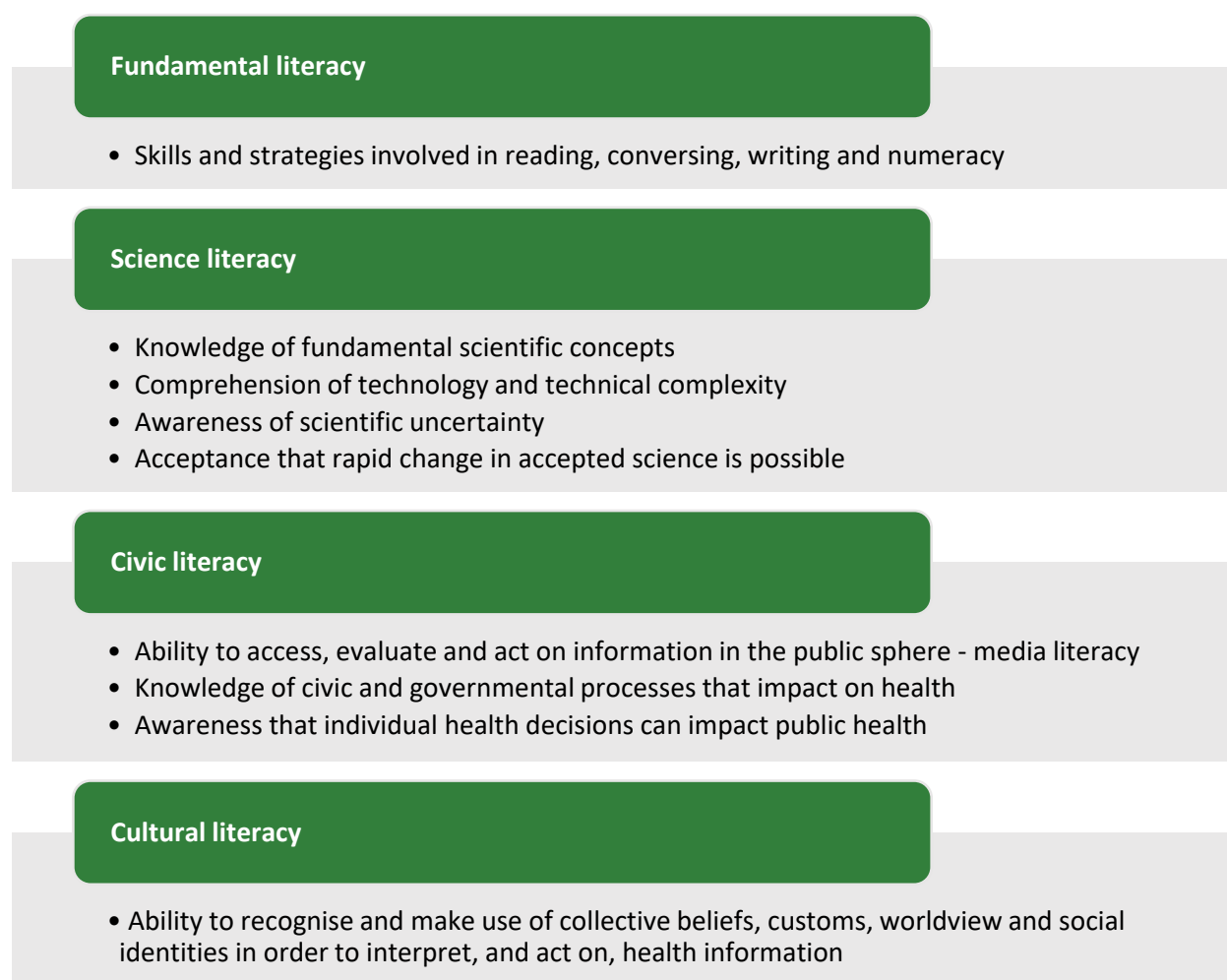


Figure 2: Domains of health literacy

Source: Zarcadoolas et al (2005: 197)

Population health literacy approaches

Summary of the material in this section

In keeping with broader definitions of health literacy, there has been an increased focus on going beyond individual competences and deficits and moving towards **population health literacy approaches**.

Health literacy is a **social determinant of health** that operates together with other determinants to promote or hinder the health of people.

The health literacy abilities, skills and practices of others in the social environment contribute substantially to an individual's health literacy. It is a **distributed resource**.

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.

We all function within a **health literacy ecosystem**.

Focus beyond individuals/patients

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).

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).

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 3:

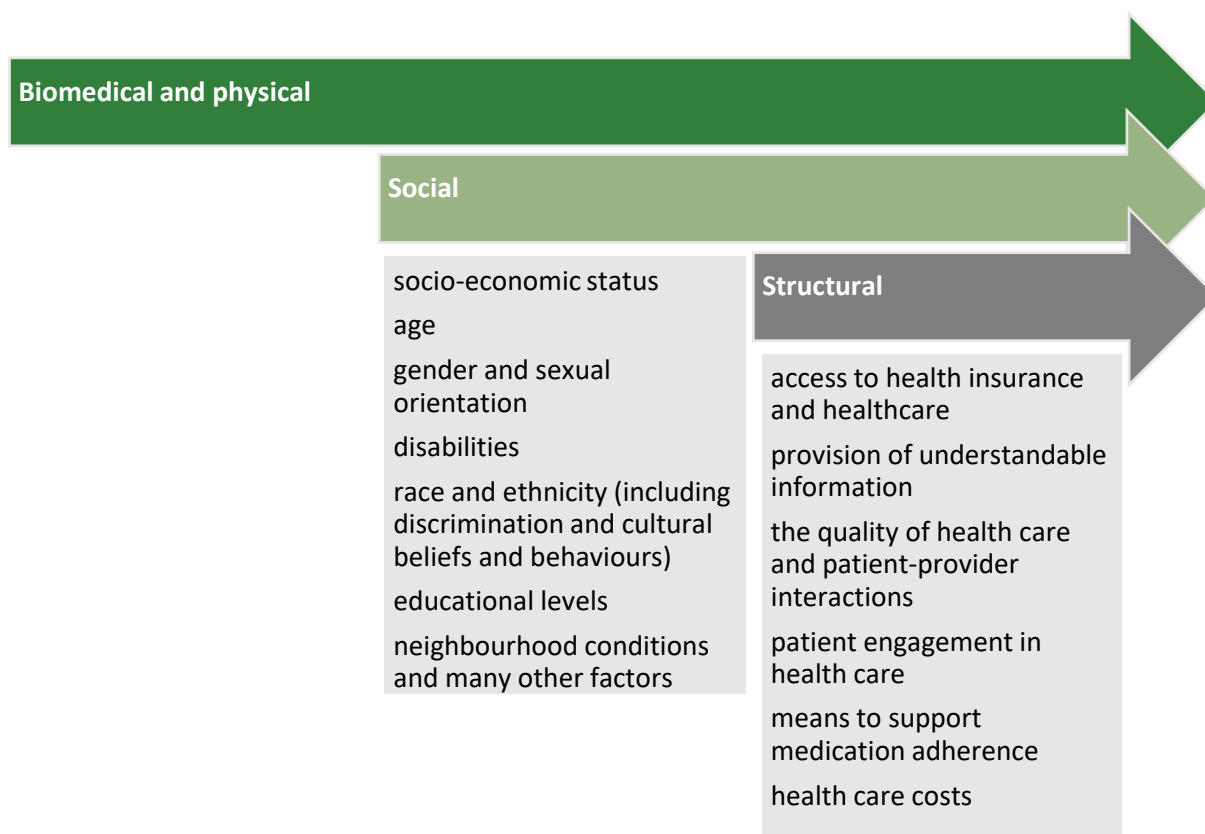


Figure 3: Determinants of health

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).

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).

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.

Systems approaches

Broader social, ecological and systemic factors help or hinder people as they go about improving their health literacy attributes, knowledge and skills (Jordan et al 2010). For health literacy to affect individuals' capacities to function in the healthcare environment, 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.

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).

In that respect, we all function within a **health literacy ecosystem**.



Impacts of poor health literacy

Summary of the material in this section

Low health literacy, in combination with other factors, **contributes to poorer health-related outcomes**. Many commentators have presented inadequate health literacy as a 'silent epidemic' which affects a large proportion of the population worldwide.

Health literacy is **not evenly distributed** within a population. For example, lower levels of HIV health literacy have been assessed among ethnic minority groups, older PLHIV with multiple co-morbidities, and people dealing with a range of other issues, such as poverty, substance abuse or unstable housing.

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.



Health literacy matters

There is plenty of evidence that low health literacy, in combination with other factors, contributes to poorer health-related outcomes. On the basis of evidence, outcomes for individuals with poorer health literacy 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 poorer 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).

Impacts in the context of HIV

According to Palumbo (2015: 426), HIV is ‘among the most prominent health topics addressed by the scholars dealing with health literacy’. Study after study shows that it is an important determinant of a healthy lifestyle and health status in the context of HIV, and can impact negatively on any of the outcomes described in Table 1 above. Drawing widely on the research-based evidence, Palumbo (2015: 417) is confident in identifying poor health literacy as a social barrier to access healthcare services and to appropriate health treatment among patients living with HIV.

Who is more likely to have lower levels of HIV health literacy?

Lower levels of health literacy are found especially among:

- PLHIV from ethnic minority groups, due to the powerful role that language and culture have in HIV-related health literacy
- People with refugee backgrounds
- Older PLHIV with multiple co-morbidities
- People who struggle with substance abuse
- People with mental illness
- People with a history of incarceration
- People experiencing unstable housing and homelessness

What are the impacts of low levels of HIV health literacy?

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

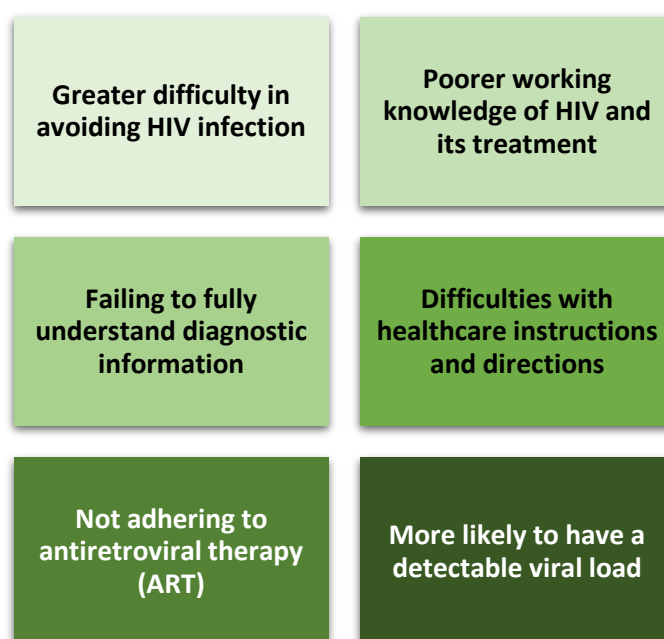


Figure 4: Impacts of poor health literacy in the context of HIV

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

Helping people to improve their health literacy

Summary of the material in this section

Health care systems have become more complex to navigate. Health literacy initiatives often target people's **abilities to navigate the health care system**. Navigation has an impact on the way people manage chronic conditions in particular.

Improvements to the ways in which **health information** is provided are a core aspect of health literacy programs. This places a focus on the language and communication skills of individuals, on the interactions between consumers and health professionals, and on the design of print materials, medication labels and websites.

From a health promotion perspective, health literacy interventions are concerned with issues of power and powerlessness, health equity, capacity building and social change. They can be an **empowerment strategy** to increase people's control over their health.

Health literacy is an attribute that contributes towards **successful functioning** of an individual within their social context. Programs can contribute to the development of more positive attitudes (including self-worth), higher motivation to act, and a sense of purpose.

Addressing health literacy

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, since the success of these measures relies on effective public communications about health issues.

Different levels of health literacy contribute to the health and health care inequities to be found in most countries, including Australia.

Health literacy initiatives and interventions have been undertaken throughout the world as a means of addressing these identified problems. There is concern (Dawkins-Moultin et al 2016) that interventions may on the whole 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. Such traditional behavioural approaches may be inappropriate for health literacy interventions.

In the discussion that follows, we briefly consider ways in which health literacy is addressed.

Helping people to navigate the health care system

To improve the capacity of individuals to function in the healthcare environment, attention is often given to the ways in which they navigate the health care system. 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'.

Higher levels of health literacy are assumed to enhance people's abilities to explore, access and negotiate the health care systems of the countries they live in. In recent years, these systems have on the whole become more complex to navigate.



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 with the HIV Care Continuum includes the need for individuals to 'navigate the spectrum of HIV care engagement' (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.

If a 'hierarchy of skills' approach is adopted, basic functional literacy processes are used as part of, and built into, more complex cognitive strategies. These include the ability to locate and select relevant information, follow instructions, and perform quantitative operations (Von Wagner et al 2009). These strategies are in turn necessary to eventually integrate, synthesize, and analyse health information, and to engage more fully in health care.

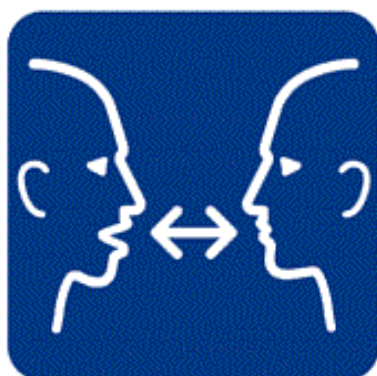
Improving health-related communications and interactions

Health communication is

... 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. (Babalola et al 2017: S5)

Most health literacy interventions have a 'core communication component', based on the assumption that health communication converts medical and scientific 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).

Patient-provider interactions are negatively impacted 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 each person's 'lay knowledge' (Jordan et al 2010: 40).



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.

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. A concerted focus on eHealth would be an essential step to supporting PLHIV to be more actively engaged in their health care in the coming decades (Han et al 2018).

Increasing the control people have over their health

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

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'.



Empowerment in the context of health 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

(Crondahl and Karlsson 2016)

Ideally, then, health literacy programs would also address deeper factors of motivation, self-efficacy, health equity and capacity building. They would acknowledge socio-environmental influences i.e. the social determinants of health and the impacts that these have in improving health outcomes and reducing health disparities.

Schulz and Nakamoto (2013) warn 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.

Contributing to successful functioning in social contexts

Health literacy is an attribute that contributes towards **successful functioning** of an individual within their social context. It does so by contributing to the development of more positive attitudes (including self-worth), higher motivation to act, and a sense of purpose.

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, such as confidence, impact directly on people's **self-care behaviours**. For example, 'successful medication adherence is associated with an individual's confidence in their ability to take their medications as directed' (Kalichman et al 2005: 24).

Considerations of **self-efficacy** draw attention to the sense of confidence people have to accomplish self-care tasks that they know will do them good. 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). It includes people's own considerations of why they act, or why they do not act.

The sources of their beliefs can also be better understood when one considers the five main influences on self-efficacy (Figure 5):



Figure 5: Influences on self-efficacy

Source: Based on the model generated by Albert Bandura (cited in Xu et al 2018)

Stronger health literacy can help people 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.

Active community participation

Summary of the material in this section

When people that are intended beneficiaries of health literacy programs are **actively engaged** in those programs, it leads to better health outcomes at the individual and population levels.

In the context of health literacy programs, people can participate in **skills- and confidence-building initiatives**. Active involvement of potential or current users in the critique, design and testing of communication methods and resources is a widely used approach.

In addition to **collaboratively designing** health literacy initiatives, people should also ideally be included in the **research and evaluation** connected to those initiatives.



Achieving outcomes related to health system navigation, communication, empowerment and psychosocial functioning (as discussed above) all rely on the active participation of the people that are the intended beneficiaries of health literacy interventions.

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 levels.

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).

Active engagement in health literacy programs

Community-based health literacy programs support the skills 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).

Active role in research and program evaluation

In addition to collaboratively designing health literacy initiatives, people should ideally be included in the research and evaluation connected to those initiatives (Neuhauser 2017). This can take several forms. For example, it is common practice to make use of user-centred approaches such as focus groups when designing health information resources. The intended beneficiaries of health literacy programs are often included in evaluations of those programs (Morales 2017: 3). 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)

Participants can be given a more active role in the research process by inviting them to reflect on and interpret their own roles in the social practices under discussion. 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).

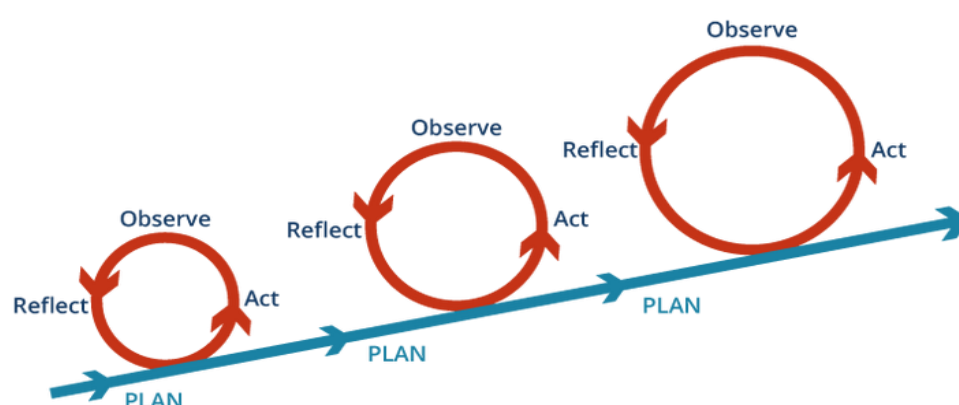


Figure 6: Participatory action research

This long-term process does not always align well with the time constraints that are built into many health literacy efforts. Despite the promise of participatory design approaches, intensive participation may still not be the norm (Neuhauser 2017).

Making organisations more health literate too

Summary of the material in this section

There are many ways in which organisations themselves can strive to be more health literate and thereby **make it easier for people to navigate, understand and make use of health information and services.**

Health literate health care organisations integrate health literacy into their everyday ways of working, also at the level of leadership. They **meet the needs of populations with a range of health literacy skills, while avoiding stigmatization.**

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.



Organisational health literacy is

...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).

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)

From health literacy to health outcomes

Summary of the material in this section

The path from health literacy to health outcomes is **not smooth or linear**. Motivation alone does not sufficiently explain health actions.

Factors that **mediate between health literacy and health outcomes** all reflect the dynamic interactions people have with other people and systems in their environments.

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.

Health literacy is like a 'missing link' that integrates the many health care factors that need to be addressed when reforming and improving health care systems. By incorporating a greater focus on health literacy, we move closer toward a **patient-centred health care system**.

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.

Where does knowledge fit in?

The complexity of the pathways between health literacy and health outcomes is highlighted when you consider 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:

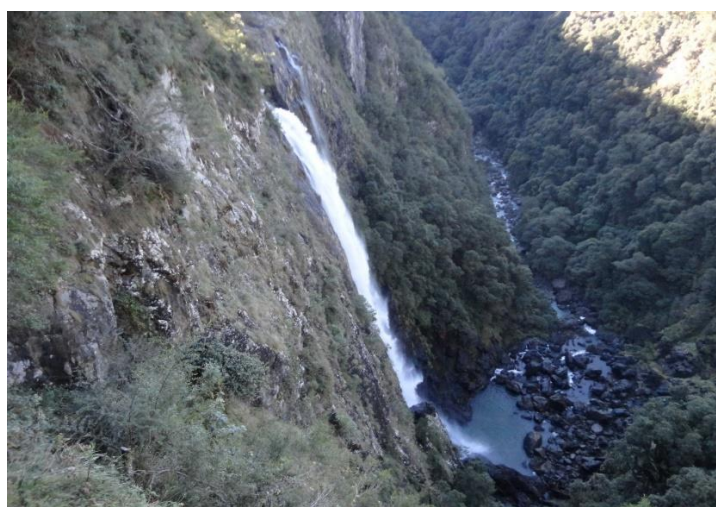
- Some theorists view health knowledge as coming before and contributing to health literacy (knowledge as an 'antecedence').
- Others regard it as an integral dimension of health literacy itself (knowledge as a part of health literacy).
- Yet others consider health knowledge to be an outcome of health literacy (knowledge as a consequence of health literacy).

Recent literature supports the view that health literacy can affect knowledge of HIV (Wawrzyniak et al 2013). Whether or not this knowledge then directly influences health behaviours among PLHIV is, however, less clear. While several studies have found that health literacy sufficiently explained health behaviours, other studies did not support such a relationship.

Many influencing factors

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.

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 put forward to describe this complexity are discussed next.



Mediating factors at the individual level

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

- Navigation skills, self-efficacy and perceived barriers all have an impact on 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:

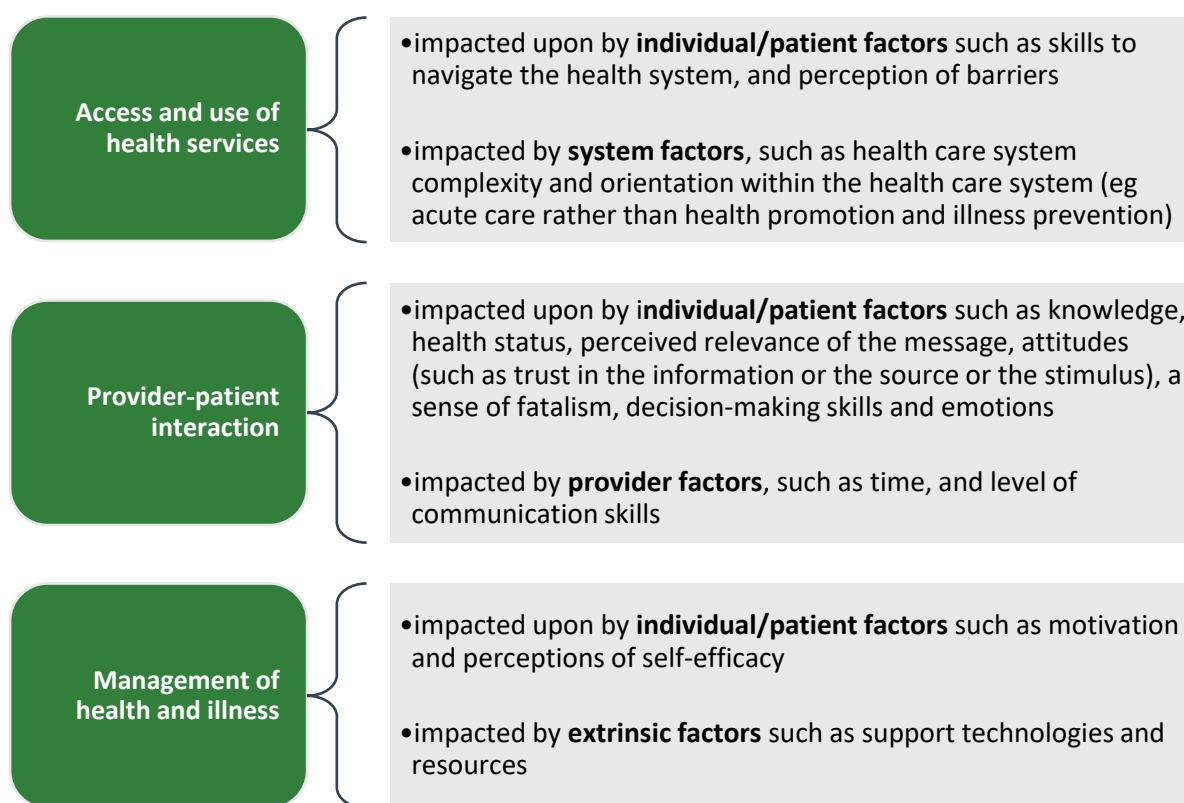


Figure 7: Mediating factors between health literacy and health outcomes

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

As can be seen in Figure 7, 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.

Knowing what to do, and doing it

Von Wagner et al (2009) build on the conceptual framework developed by Paasche-Orlow et al (2007) (described 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 pathways can be summarised as follows:

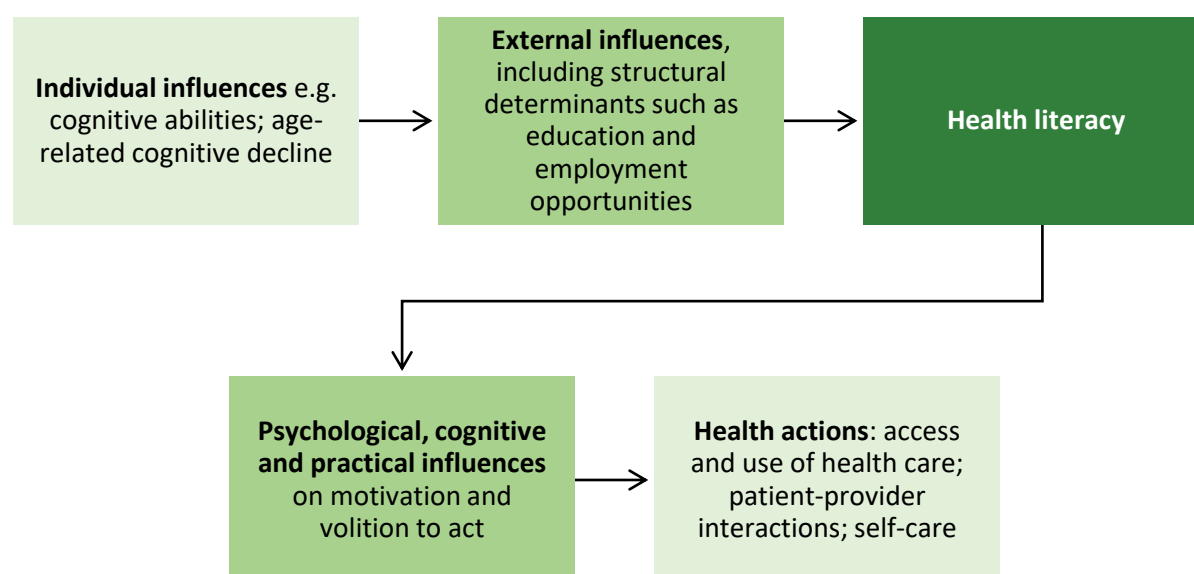


Figure 8: Psychological, cognitive and practical influences on health action

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 influences 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.

A systems perspective

NAPWHA adopts a systems perspective (Jordan et al 2010; McCormack et al 2017; Farmanova et al 2018) that places its HIV health literacy framework project within the broader Australian health context. It enables partners to map the project's intended outcomes system wide. 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 are mapped system-wide, as expressed in Figure 9:



Figure 9: The systems perspective underlying NAPWHA's HIV health literacy framework

The most direct outcomes relate to the organisation itself and the communities it represents. Through this project, NAPWHA aims to become a more health literate organisation and to 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 improved health literacy practices within health care organisations (including patient-provider interactions); to the ways HIV is discussed and understood in society in general; and to how it is addressed within the broader health system and at the level of policy.

Readings

Australian Commission on Safety and Quality in Health Care (ACSQHC), 2014, *Health Literacy: Taking action to improve safety and quality*, ACSQHC, Sydney.

Babalola, S., van Lith, L.M., Mallalieu, E.C., Packman, Z. R. et al., 2017, A framework for health communication across the HIV treatment continuum, *Journal Acquired Immune Deficiency Syndrome*, 74 (Suppl 1): S5-S14.

Bauer, C., Martinez, L.M., Tchangalova, N. and Rubin, D., 2017, *A review and report of community-based health literacy interventions*, National Academies of Sciences, Engineering, and Medicine, Washington DC.

Berkman, N.D., Sheridan, S.L., Donahue, K.E. et al, 2011, *Health literacy interventions and outcomes: An updated systematic review*, Agency for Healthcare Research and Quality, Rockville MD.

Brach, C., Keller, D., Hernandez, L.M., Baur, C. et al, 2012, *Ten attributes of health literate health care organisations*, Institute of Medicine of the National Academies, Washington DC.

Crondahl, K. and Karlsson, L.E., 2016, The nexus between health literacy and empowerment: A scoping review, *Sage Open*, April-June 2016: 1–7.

Dawkins-Moulton, L., McDonald, A. and McKyer, L., 2016, Integrating the principles of socioecology and critical pedagogy for health promotion health literacy interventions, *Journal of Health Communication*, 21 (sup 2): 30-35.

Dawson-Rose, C., Cuca, Y.P., Webel, A.R. et al., 2016, Building trust and relationships between patients and providers: An essential complement to health literacy in HIV care, *Journal of the Association on Nurses in AIDS Care*, 27(5): 574-584.

De Leeuw, E., 2012, The political ecosystem of health literacies, *Health Promotion International*, 27(1): 1-4.

Edwards, M., Wood, F., Davies, M. and Edwards, A., 2013, Distributed health literacy: Longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition, *Health Expectations*, 18: 1180-1193.

Elmer, S., Bridgman, H., Williams, A., Bird, M., Murray, S., Jones, R. and Cheney, M., 2017, Evaluation of a health literacy program for chronic conditions, *Health Literacy Research and Practice*, 1(3): e100-e108.

Farmanova, E., Bonneville, L. and Bouchard, L., 2018, Organizational health literacy: Review of theories, frameworks, guides and implementation issues, *Inquiry: The Journal of Health Care Organization, Provision, and Financing*, 55: 1 –17.

Gellert, P. and Tille, F., 2014, What do we know so far? The role of health knowledge within theories of health literacy, *The European Health Psychologist*, 17(6): 266-274.

Han, H-R., Hong, J., Starbird, L.E. et al., 2018, eHealth literacy in people living with HIV: Systematic review, *JMIR Public Health Surveillance*, 4(3): e64.

Hasnain-Wynia, R. and Wolf, M.S., 2010, Promoting health care equity: Is health literacy a missing link?, *Health Services Research*, 45(4): 897-903.

Jayasinghe, U.W., Harris, M.F., Parker, S.M., Litt, J. et al, 2016, The impact of health literacy and life style risk factors on health-related quality of life of Australian patients, *Health and Quality of Life Outcomes*, 14(68): 1-13.

Jordan, J.E., Buchbinder, R. and Osborne, R.H., 2010, Conceptualising health literacy from the patient perspective, *Patient Education and Counselling*, 79: 36-42.

Kalichman, S., Pellowski, J. and Chen, Y., 2013, Requesting help to understand medical information among people living with HIV and poor health literacy, *AIDS Patient Care and STDs*, 27(6): 326- 332.

- Kalichman, S., Cain, D., Fuhrel, A., Eaton, L. Di Fonzo, K. and Ertl, T., 2005, Assessing medication adherence self-efficacy among low-literacy patients: Development of a pictographic visual analogue scale, *Health Education Research*, 20(1): 24-35.
- Kay, E.S., Batey, D.S. and Mugavero, M.J., 2016, The HIV treatment cascade and care continuum: Updates, goals, and recommendations for the future, *AIDS Research and Therapy*, 13: 35.
- Lloyd, J., Thomas, L., Powell-Davies, G., Osten, R. and Harris, M., 2018, How can communities and organisations improve their health literacy?, *Public Health Research and Practice*, 28(2): e2821809.
- Mackert, M., Champlin, S.E., Holton, A., Munoz, I.I. and Damasio, M.J., 2014, eHealth and health literacy: A research methodology review, *Journal of Computer-mediated Communication*, 19: 516-528.
- McCormack, L., Thomas, V., Lewis, M.A. and Rudd, R., 2017, Improving low health literacy and patient engagement: A social ecological approach, *Patient Education and Counseling*, 100: 8-13.
- Morales, M., 2017, Health literacy research methods: A pilot study investigation with adult beginning readers, *International Journal of Qualitative Methods*, 16: 1-9.
- Neuhauser, L., 2017, Integrating participatory design and health literacy to improve research and interventions, *Information Services and Use*, 37: 153-176.
- Nielsen-Bohlman, L., Panzer, A.M. and Kindig, D.A. (Eds.), 2004, *Health Literacy: A prescription to end confusion*. The National Academies Press, Washington DC.
- Nutbeam, D., 2000, Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st Century, *Health Promotion International*, 15(3): 259-267.
- Osborn, C.Y., Paasche-Orlow, M.K., Davis, T.C. and Wolf, M.S., 2007, Health literacy: An overlooked factor in understanding HIV health disparities, *American Journal of Preventive Medicine*, 33(5): 374-378.
- Paasche-Orlow, M.K. and Wolf, M.S., 2007, The causal pathways linking health literacy to health outcomes, *American Journal of Health Behaviour*, 31(Suppl): S19-S265.
- Palumbo, R., 2015, Discussing the effects of poor health literacy on patients facing HIV: A narrative literature review, *International Journal of Health Policy Management*, 4(7): 417-430.
- Schulz, P.J. and Nakamoto, K., 2013, Health literacy and patient empowerment in health communication: The importance of separating conjoined twins, *Patient Education and Counselling*, 90(1): 4-11.
- Sørensen, K., van den Broucke, S., Fullam, J. et al., 2012, Health literacy and public health: A systematic review and integration of definitions and models, *BMC Public Health*, 12: 80.
- Vernon, J.A., Trujillo, A., Rosenbaum S. and de Buono, B., 2007, *Low health literacy: Implications for national health policy*, https://publichealth.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf – accessed June 2019.
- Von Wagner, C., Steptoe, A., Wolf, M.S. and Wardle, J., 2009, Health literacy and health actions: a review and a framework from health psychology, *Health Education and Behaviour*, 36(5): 860-877.
- Wawrzyniak, A.J., Ownby, R.L., McCoy, K. and Waldrop-Valverde, D., 2013, Health literacy: Impact on the health of HIV-infected individuals, *Current HIV/AIDS Rep.*, 10(4): 295-304.
- Xu, X.Y., Leung, A.Y.M. and Chau, P.H., 2018, Health literacy, self-efficacy and associated factors among patients with diabetes, *Health Literacy Research and Practice*, 2(2): e67-e77.