Ophelia Toolkit
A step-by-step guide for identifying and responding to health literacy needs within local communities
This research was supported under Australian Research Council's Linkage Projects funding scheme (project LP120200111). The Victorian Department of Health contributed funds and in-kind support to the project. The views expressed herein are those of the authors and are not necessarily those of the Australian Research Council or the Victorian Department of Health.
Ophelia Toolkit

A step-by-step guide for identifying and responding to health literacy needs within local communities

Editors: Sarity Dodson, Alison Beauchamp, Roy Batterham and Richard Osborne
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Health literacy is the term used to describe the ability to engage with health information and services.

Health literacy brings together many concepts that relate to what people and communities need to make effective decisions about health for themselves, their families and their communities.\textsuperscript{1-6}

**Health literacy** refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health, or that have implications for health. Health literacy includes the capacity to communicate, assert and enact these decisions.

Health-related decisions may be about a person’s own health, the health of another person, or the health of the community. These decisions may be made either by a group of people (e.g., a family or community) or an individual. The health literacy of individuals and communities influences (and is influenced by) health behaviours and the characteristics of society and the healthcare system.\textsuperscript{2-5} Further, it is context- and content-specific, so health literacy in one setting or relating to one health decision may be different from another.\textsuperscript{4}
Individuals and communities have health literacy strengths and limitations that influence how effectively they engage with health information and services. Health and social service systems can also have strengths and limitations in how they respond to the health literacy of the people they serve.6,7

**Health-literacy responsiveness** describes the way in which services make health information, resources, supports and environments available and accessible to people with different health literacy strengths and limitations.
What is health literacy?

People interact with information, environments, resources and supports as they make health decisions.

Elements of decision making for health

Access
Appraise
Understand
Decide

Health decision-making process

Health Literacy Responsiveness

The interaction between health literacy and the health literacy responsiveness of services

Health Literacy

The health literacy responsiveness of services...

Availability
Accessibility

...interacts with...

...the health literacy of people making and supporting health decisions...

Ability and willingness to engage with available information, environments, resources and supports

Ability and willingness to communicate and assert decisions

Ability and willingness to enact decisions and to solve problems appropriately

...both influencing decisions made.
References


Suggested citation

Health literacy, inequity, and health outcomes

There is potential to improve health and reduce inequity by identifying and responding to the health literacy needs of communities and their members.

Health literacy and the promotion of health

“Health promotion is the process of enabling people to increase control over their health and its determinants, and thereby improve their health. It is a core function of public health and contributes to the work of tackling communicable and noncommunicable diseases and other threats to health.”

(Bangkok Charter for Health Promotion in a Globalized World, 2005)¹

Achieving the aims of health promotion requires coordinated effort at individual, community, national and international levels. The engagement of individuals and communities in sustained and widespread health-related change is critical to success, but continues to prove difficult to achieve. Health literacy is one factor underlying this challenge. Health literacy is not only a key determinant of individual and community health management and service access, it also influences broader engagement in community action.²
Sustained efforts at all levels of the health system and across sectors, with a focus on improving responses to health literacy needs, can help to decrease health and social inequities, promote empowerment, improve the targeting and impact of health and social development programs, and strengthen health systems overall.

**Links between health literacy, health behaviours and health outcomes**

The association between health literacy and a range of health-related outcomes has been demonstrated in numerous studies.* Low health literacy has been associated with:

- increased hospital admissions and readmissions
- poorer medication adherence and increased adverse medication events
- less participation in prevention activities
- higher prevalence of health risk factors
- poorer self-management of chronic diseases and poorer disease outcomes
- less effective communication with healthcare professionals
- increased healthcare costs
- lower functional status and
- poorer overall health status including increased mortality.

*Note: Measures of health literacy used in many of these studies focused on a limited range of health-related literacy and numeracy skills.

Health literacy influences health outcomes by influencing the decisions people make about their health and health care. Figure 1 shows the elements of health literacy, and the link between health literacy and health behaviours. These personal characteristics and social resources influence which decisions people make, and how effectively they access, understand and appraise information and support during the decision-making process.
Figure 1: Links between health literacy and health behaviours

LEGEND

Health decision making process
Health literacy
Health behaviour
Influences upon health decisions and behaviours

Salience of health issue and/or behaviour
Cultural beliefs and practices
Societal, political, economic, and environmental circumstances
Personal and situational factors
Treatment and service related factors
Other’s reactions to a health decision or behaviour
Other factors influencing health decisions and behaviours include social, political, economic and environmental circumstances, cultural beliefs and practices, the salience of particular health issues and actions, and the responses people receive from others about their actions or intentions. Health decisions will only influence health outcomes to the extent that the decisions are acted on. Health behaviours can only influence outcomes to the extent these outcomes are amenable to change.

**Links between health literacy and health inequity**

The field of health literacy has always been strongly linked to efforts to improve health equity: equity of access and equity of outcomes.\(^\text{19-21}\) Differences in health literacy are seen in gender, age, ethnicity, insurance status and educational attainment.\(^\text{22}\) These differences are likely, in part, to explain health inequities. For example, health literacy is shown to explain up to 22% of ethnic differences in health status.\(^\text{3}\)

It is important to note that many studies that explore the association between health literacy and outcomes use tools that measure numeracy and literacy skills only. Given that health literacy encompasses other personal characteristics and social resources (see Figure 1), it is likely that these studies underestimate the true effect of health literacy on health inequities.
References


**Suggested citation**

History and evolution of the term ‘health literacy’

The term ‘health literacy’ has expanded and developed over the past three decades. Modern definitions encompass a broad range of characteristics, assets and actions, and recognise the social dimension of health-related decision-making.

**Early uses of the term ‘health literacy’**

The earliest ideas about health literacy evolved from the more general concept of ‘functional literacy’ in the 1960s and 1970s. Functional literacy sought to capture the reading and writing abilities that people need to participate in society, including being able to complete forms, manage finances, and understand what they are entitled to. The term ‘health literacy’ was first used in 1974 to consider similar issues related to how people look after their health.

**Expansion of the term ‘health literacy’**

Through the 1970s, 1980s and 1990s the concept of health literacy was expanded to include other cognitive and social skills thought necessary for people to obtain and understand information so that they could use it to guide health-related decisions. These additional skills included concepts such as having the confidence to ask questions of doctors and health professionals; knowing what to do when they receive conflicting information; and being able to participate in public debates about health issues in their communities.
Health literacy and community health decisions

A more recent development in the study of health literacy is the focus on community participation in decision-making about health. The concept of ‘critical health literacy’ has emerged and it includes the extent to which people understand health concepts well enough to participate effectively in community debates and action.

Health literacy and decisions about the health of others

Another recent development is the introduction of the idea of ‘distributed health literacy’. This idea suggests that in some situations it may not be the health literacy of individuals that is most important in determining health outcomes but the health literacy of people around them such as their family, peer groups and community leaders.12-15

Thinking about health literacy strengths as well as needs

The third key development in health literacy is the introduction of the ‘asset model of health literacy’.6 This is similar to the concept of ‘asset-based community development’ in community and economic development work. It is a particularly appropriate concept in developing communities or where health literacy is low. Rather than focusing on how the health literacy of people in a community is limited, this approach tries to identify the resources that individuals, families and communities have in terms of health literacy, and to build on those strengths.
The definition of health literacy used within the Ophelia Approach

The following definition of health literacy has been developed by the Ophelia team, in consideration of the need for a comprehensive definition that provides conceptual clarity to organisations seeking to design and evaluate health literacy interventions.

Health literacy refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions that relate to health, or that have implications for health. Health literacy includes the capacity to communicate, assert and enact these decisions.

Defining health literacy responsiveness

It is important during discussions of the definition of health literacy to note the role of governments, systems and organisations. While health literacy relates to the attributes of people, the health and equity outcomes of interest result from the interplay between people and the world in which they live. Individuals and communities can have health literacy strengths and limitations that influence how effectively they engage with health information and services. Health and social service systems can also have strengths and limitations in their responsiveness to the health literacy of the people they serve.

The following definition of health literacy responsiveness has been developed by the Ophelia team, in consideration of the need for the health literacy of communities and community members to be considered alongside the attributes of their social world.

Health literacy responsiveness describes the ways in which services, supports, environments and products make health information and support available and accessible to people with different health literacy strengths and limitations.
References


Suggested citation

Health literacy brings together many concepts that relate to what people and communities need in order to make effective decisions about health for themselves, their families and their communities.

### Health promotion concepts, their definitions, and links to health literacy

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
<th>Links to health literacy</th>
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<tbody>
<tr>
<td>Health education</td>
<td>Consciously constructed opportunities for learning which involve some form of communication designed to: improve health literacy, including improving knowledge and developing life skills which are conducive to individual and community health.¹</td>
<td>Health education is a strategy for improving the health literacy of community members.</td>
</tr>
<tr>
<td>Literacy</td>
<td>The ability to read and write.²</td>
<td>The ability to read, write, count and calculate influences access to information about health and assists with making decisions about health.</td>
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<tr>
<td>Concept</td>
<td>Definition</td>
<td>Links to health literacy</td>
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<td>Cultural competence</td>
<td>A set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals; enabling that system, agency or those professionals to work effectively in cross-cultural situations.³</td>
<td>A culturally competent health system responds more effectively to community members with varying health literacy strengths and limitations.</td>
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<tr>
<td>Patient empowerment</td>
<td>Empowerment-based interventions include both a process and an outcome component. The process component occurs when the true purpose of the intervention is to increase the patient’s capacity to think critically and make autonomous, informed decisions. The outcome component occurs when there is a measurable increase in the patient’s ability to make autonomous, informed decisions.⁴</td>
<td>An empowerment approach seeks to enhance consumer health literacy.</td>
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<td>Treatment adherence</td>
<td>Active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behaviour to produce a therapeutic result.⁵</td>
<td>People with higher health literacy often make informed decisions about their health and care. Their choices may or may not conform to the recommendations of health providers.</td>
</tr>
<tr>
<td>Concept</td>
<td>Definition</td>
<td>Links to health literacy</td>
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<tr>
<td>Patient activation</td>
<td>Activated patients believe they have important roles to play in self-managing care, collaborating with providers, and maintaining their health. They know how to manage their condition and maintain functioning and prevent health declines; they have the skills and behavioural repertoire to manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care.⁶</td>
<td>Activated patients often have health literacy strengths in areas relating to personal skills but may have varying access to social resources for health.</td>
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<tr>
<td>Cognitive capacity</td>
<td>The capacity to perform higher mental processes of reasoning, remembering, understanding, and problem solving.⁷</td>
<td>Cognitive capacity influences ability to access, understand, appraise and apply health information.</td>
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<td>Self-management</td>
<td>Engaging in activities that promote health, build physiologic reserve, and prevent adverse sequelae; interacting with health care providers and adhering to recommended treatment protocols; monitoring physical and emotional status and making appropriate management decisions based on the results of self-monitoring; and managing the effects of illness on the individual’s ability to function in important roles and on emotions, self-esteem, and relationships with others.⁶</td>
<td>Health-related behaviours and, consequently, self-management of health, are determined by an individual’s decisions about health. Decisions about health are influenced by an individual’s health literacy.</td>
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References


Suggested citation

Responding to community health literacy needs

Policies and practices must promote the identification of health literacy issues and the implementation of targeted responses.

Individuals and communities have health literacy strengths and limitations that influence how effectively they engage with health information and services. Health and social service systems can also have strengths and limitations in how they respond to the health literacy of their community.¹,²

Policies and practices need to promote the assessment of health literacy and focus efforts on responding to the issues identified. Responses to health literacy should be tailored to address the specific strengths and limitations of each individual and community.

Health-literacy responsiveness describes the way in which services make health information, resources, supports and environments available and accessible to people with different health literacy strengths and limitations.
There is potential to use health literacy responses to further improve and sustain health outcomes for community members. There are two approaches to responding to health literacy issues, both of which should be addressed in parallel.

1. **Make health information and services more available and accessible.**

People’s capacity to make informed health choices and take effective health actions is influenced by their level of access to services and information. If the required information or services are unavailable or offered in a way that makes them inaccessible to members of a community, inequities become systemic and people’s capacity to engage in healthy activities is reduced.

Not every member of a community has the capacity to attain the same level of health literacy, regardless of the information and care available. Some individuals, due to factors such as immobility, living conditions, cognitive impairment, work arrangements, family responsibilities/obligations, mental illness, and financial status are at a disadvantage compared with others in the same community. To facilitate access and engagement, programs must be tailored to the differing circumstances and needs of community members.

2. **Enhance the ability and willingness of community members to:**

   a. engage with health information and services that are already available;
   b. communicate and assert health decisions;
   c. take appropriate actions to implement the decisions they make about their health and that of their family.

Provision of high quality education is important but insufficient to facilitate members of the community to engage in positive health-related behaviors. For many communities, the barriers to action are complex. Capacity-building activities need to target locally identified barriers and be delivered in locally appropriate and accessible ways.
Embedding health literacy in public policies

Public policies act to shape social and physical environments. Policy makers must be mindful to create policies that act to enable access, and strengthen the quality and availability of information and services that support people to make and enact healthy choices.

The Health in All Policies (HiAP) approach recognises that some of the main drivers of health lie outside the healthcare system. Information and services required to make informed health promoting choices do not always reside within the healthcare system.

Consideration of the health literacy of communities within all policies will encourage the development of services, environments and products that:

1. enhance the ability of individuals and communities to engage with information and supports for health; and
2. improve the availability and accessibility of this information and support.

Actions to address health literacy issues will strengthen communities and reduce social and health inequities.
References


Suggested citation

Key considerations for health literacy interventions

The determinants of inadequate health literacy at a community and population level are highly context specific. Careful consideration of a population’s particular health, social, and cultural needs is required during the development and implementation of any health literacy intervention.

Focus on health and wellbeing outcomes

Health literacy influences health by influencing the decisions people make about their health and health care. Health literacy contributes to health outcomes in many areas although the link is not a direct one. Given the role that personal and social factors play in determining outcomes, we cannot know precisely how any given health literacy intervention will affect health and wellbeing. When addressing any social or personal determinant of health, it is important to maintain an overall aim to improve health and wellbeing outcomes. This applies equally to efforts to optimise health literacy and the health literacy responsiveness of the health system.

Focus on increasing equity in health outcomes and access to services for people with varying health literacy needs

Differences in health literacy are seen in gender, age, ethnicity, insurance status and educational attainment. These differences are likely, in part, to explain health inequities. Actions to address health literacy issues can strengthen communities and reduce social and health inequities. But interventions, if not responsive to those experiencing the greatest barriers to access and engagement, may act to further increase inequities. It is important when addressing any social or personal determinant of health, that the broader aim of reducing health and social inequities remains in focus. This applies equally to efforts to optimise health literacy and the health literacy responsiveness of the health system.
Prioritise local wisdom, culture and systems

Health literacy is complex and multi-dimensional. Limitations and strengths of individuals and communities will vary. Effective responses are those that capitalise on strengths and address needs. To determine the most appropriate mix of strategies and the best way to implement them within a particular community (or with a particular person), one must prioritise local insights and experiences and have a sound understanding of the local culture and health system.

Respond to locally identified health literacy needs

Health literacy issues vary from community to community, and within any given community there is likely to be a range of health literacy strengths and limitations. To facilitate access and engagement, programs must be tailored to the circumstances and needs of community members. Initiatives should therefore commence with a thorough needs assessment.

Respond to the varying and changing health literacy needs of individuals and communities

Health literacy strengths and limitations can change over time. Further, health literacy is context- and content-specific, so health literacy in one setting or about one health decision may be different from others. It is therefore recommended that health literacy initiatives embed mechanisms for responding to the varying and changing health literacy need of individuals and communities. It is also important that organisations and governments continue to monitor community health literacy and adjust services, products and environments in response to observed changes.
Engage all relevant stakeholders in the co-creation and implementation of solutions

Engaging community members, academics, policy makers, providers and managers in the co-creation and implementation of health literacy solutions has the potential to:\textsuperscript{4,5}

- generate novel responses to local needs
- decrease the gap between evidence and practice
- strengthen relationships between stakeholder groups
- facilitate the reciprocal transfer of expertise across stakeholder groups
- enhance insight into community culture and context and locally relevant social determinants of health
- increase the quality, utility and feasibility of interventions developed
- increase the cultural appropriateness of interventions developed
- improve intervention fidelity during implementation
- facilitate shared ownership of interventions and outcomes.

Focus on improvements at, and across, all levels of the health system

Health outcomes result from multi-directional relationships between characteristics of communities and community members, and the educational, environmental, economic and social service systems, products and infrastructures available to communities. Efforts to optimise health literacy and health literacy responsiveness as mechanisms for improving health outcomes must recognise the need to intervene at, and across, all levels of the health system.

Focus on achieving sustained improvements through changes to environments, practice, culture and policy

Sustained improvements to health and wellbeing are achieved most effectively through changes to environments, routine practice, organisational and community culture and policy. Small scale interventions, and capacity building activities can have significant impacts and are useful in demonstrating what changes can be achieved. Once success has been demonstrated, responses must be embedded and scaled up to avoid being superseded by staff turnover, and other organisational changes.
References


Suggested citation

The Ophelia Approach is a system that supports the identification of community health literacy needs, and the development and testing of potential solutions. It allows easy application of evidence-based health promotion approaches to the field of health literacy.

The Ophelia Approach involves the collaboration of a wide range of community members, community leaders, and workers to develop health literacy interventions that are based on needs identified within a community. Each Ophelia project seeks to improve health and equity by increasing the availability and accessibility of health information and services in locally-appropriate ways.

**Key resource:**
Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR and Osborne RH. The OPtimising HEalth LiIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. BMC Public Health 2014, 14:694

Link: [http://www.biomedcentral.com/1471-2458/14/694](http://www.biomedcentral.com/1471-2458/14/694)

**Ophelia means**

Optimizing
Health
Literacy and
Access to health information and services
### The Ophelia Principles

The Ophelia principles provide guidance to Ophelia projects and ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimised.

**Ophelia projects must:**

<table>
<thead>
<tr>
<th></th>
<th>Focus on improving <strong>health and wellbeing</strong> outcomes</th>
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<tr>
<td>2</td>
<td>Focus on increasing <strong>equity</strong> in health outcomes and access to services for people with varying health literacy needs</td>
</tr>
<tr>
<td>3</td>
<td>Prioritise <strong>local wisdom, culture and systems</strong></td>
</tr>
<tr>
<td>4</td>
<td>Respond to <strong>locally-identified health literacy needs</strong></td>
</tr>
<tr>
<td>5</td>
<td>Respond to the <strong>varying and changing health literacy needs</strong> of individuals and communities</td>
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<tr>
<td>6</td>
<td>Engage all relevant stakeholders in the <strong>co-creation</strong> and implementation of solutions</td>
</tr>
<tr>
<td>7</td>
<td>Focus on improvements at, and across, <strong>all levels of the health system</strong></td>
</tr>
<tr>
<td>8</td>
<td>Focus on achieving <strong>sustained improvements</strong> through changes to environments, practice, culture and policy</td>
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The Ophelia Phases: 1 to 3

Each phase of the Ophelia process is drawn from three well-established methodological approaches: intervention mapping\textsuperscript{2-5}, quality improvement collaboratives\textsuperscript{6-11}, and realist synthesis\textsuperscript{12-17}. Tools and resources have been developed to support implementation of each phase.

Phase 1
Identifying the health literacy strengths and limitations of the local community.

Health literacy data are systematically collected from a representative cross section of the community using a health literacy questionnaire and/or locally appropriate qualitative techniques. These data are analysed and presented to stakeholders for discussion and interpretation. Effective local practices and innovative intervention ideas are then identified.

Phase 2
Co-creation of health literacy interventions.

Local stakeholders make decisions about local priorities for action. Interventions with potential to respond to local health literacy limitations or improve information and service access and availability are designed and planned.

Phase 3
Implementation, evaluation and ongoing improvement.

Health literacy interventions are applied within quality improvement cycles, where organisations develop and implement trials, and actively improve the effectiveness, local uptake and sustainability of the interventions.
References


Suggested citation

Why it is important to assess health literacy

Assessment of the health literacy strengths and limitations allows interventions to be strategically designed and delivered to address health inequities and improve health outcomes.

Health literacy is a potentially modifiable contributor to health. Undertaking an assessment of health literacy strengths and limitations provides information about:

1. people’s ability to engage with health information and services; and
2. the ability of health and community services to respond to the needs of the local community.

An understanding of these factors allows organisations, researchers, policy makers and practitioners to strategically develop and implement interventions.

Actions to address health literacy and the responsiveness of services will improve health outcomes and reduce health inequities by reducing the gap between community needs and the support that is provided. These actions must be strategically targeted to the particular health literacy strengths and difficulties of local communities in order to efficiently achieve the desired outcomes.

Studies have shown correlations between low health literacy* and:

• increased hospital admissions and readmissions\(^1\)
• poorer medication adherence and increased adverse medication events\(^2\)
• less participation in prevention activities\(^3,4\)
• higher prevalence of health risk factors\(^5,6\)
• poorer self-management of chronic diseases and poorer disease outcomes\(^7\)
• less effective communication with healthcare professionals\(^8\)
• increased healthcare costs\(^9\)
• lower functional status\(^10\) and
• poorer overall health status\(^11,12\) including increased mortality\(^13\)

*Note: Measures of health literacy used in many of these studies focused on a limited range of health-related literacy and numeracy skills.
References


Suggested citation

Approaches to the assessment of health literacy

Assessment of health literacy must account for the multi-dimensional nature of health literacy, and be conducted in a way suited to the audience and aims of the activity.

The approach and tool employed to assess health literacy should be matched with the objectives of the activity and the context within which it will be undertaken (see Table 1).

**Table 1: Health literacy measurement objectives, and recommended tools and approaches**

<table>
<thead>
<tr>
<th>Objective: Assess health literacy strengths and limitations of an individual</th>
<th>Objective: Assess health literacy strengths and limitations of a group of people</th>
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<tbody>
<tr>
<td>Measuring the health literacy of individuals allows providers to identify the strengths and limitations of individuals and tailor their support accordingly. This can be particularly important when people have complex medical or psychosocial problems.</td>
<td>Measuring the health literacy of groups allows providers and organisations to identify common health literacy strengths and limitations, and design and deliver services, staff training, and staff decision supports accordingly.</td>
</tr>
<tr>
<td><strong>Tools</strong></td>
<td><strong>Tools</strong></td>
</tr>
<tr>
<td>A multi-dimensional questionnaire that provides scale scores.</td>
<td>A multi-dimensional questionnaire that provides scale scores.</td>
</tr>
<tr>
<td><strong>Approaches</strong></td>
<td><strong>Approaches</strong></td>
</tr>
<tr>
<td>Questionnaire and/or semi-structured interview.</td>
<td>Questionnaire, semi-structured interview and/or focus group.</td>
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</table>
### Objective: Assess health literacy strengths and limitations at a regional or national level

Measuring the health literacy of a population group allows organisations, researchers and governments to identify the strengths and limitations of the population, and any associations between health literacy, health behaviors, service engagement patterns, and health outcomes. This information can be used to inform funding allocation decisions, and to design and plan interventions, resources, staff training, and systems and service improvement.

| Tools | A multi-dimensional questionnaire that provides scale scores (where the objective is to identify associations and generate information for planning purposes).

A tool that provides a single score (where the objective is to compare populations - e.g. countries - or examine changes at the population level over time).

| Approaches | Predominantly questionnaires. Recommend supplementing quantitative data with qualitative data from semi-structured interviews and/or focus groups. |

### Objective: Assess one element of health literacy

Measuring an element of health literacy is often used when there is a known issue in a particular area to do with health literacy, service engagement, or service responsiveness. In such a circumstance, measurement allows organizations, researchers and governments to quantify the problem, monitor its change over time, or identify associations with other outcomes of interest.

| Tools | A scale of a multi-dimensional questionnaire, or a single score tool that reliably and discretely measures the single element of interest.

| Approaches | Questionnaire, semi-structured interview and/or focus group. |

### Objective: Understanding the health literacy responsiveness of health and community services

Measuring the health literacy responsiveness of services allows organisations and governments to identify opportunities to enhance the availability and accessibility of information, environments, resources and supports for people with different health literacy strengths and limitations.

| Tools | Organisational and resource audit tools, checklists or questionnaires. |

| Approaches | A systematic practice, product, environment and document/resource audit. |
Measuring health literacy

Many health literacy tools measure only a small number of health literacy elements [e.g., capacity to comprehend medical terminology]. Broad conclusions about health literacy levels cannot be drawn from the scores they provide since they do not measure the full construct of health literacy. These tools can be useful where the objective is to measure one (or more) discrete elements of health literacy.

Tools that measure a comprehensive range of health literacy elements either provide a single number to indicate the level of health literacy, or provide a set of scores - one for each domain of health literacy assessed. Tools providing a single health literacy score can mask particular health literacy strengths or difficulties. Consequently, these tools are unsuitable for measuring the level of health literacy in individuals or groups, or for informing the development of health literacy interventions.

Multi-dimensional measurement tools that provide scale scores allow comprehensive and precise data to be collected about the health literacy of individuals and population groups. They produce profiles of relative health literacy strengths and limitations that can be used to identify and plan targeted health literacy responses.

Qualitative techniques allow for the collection of information that is often unobtainable through other means. Further, there are instances when surveys are neither culturally nor linguistically appropriate. In these cases, carefully structured qualitative strategies should be used.

A mixed-methods approach involves the use of both qualitative and quantitative data, and is often preferred to offset the weaknesses of each approach. A drawback of this method is the time and resources needed to collect both forms of data.

Measuring health literacy responsiveness

Examination of the responsiveness of organisations to the health literacy needs of their consumers should occur in parallel with the measurement of health literacy of individuals and groups. This can occur in two ways: 1) gain people’s perspectives about the responsiveness of local services by employing a health literacy measurement tool that assesses these constructs; and/or 2) assess the attributes of an organisation, the accessibility and availability of its information and services for consumers, and the patterns of consumer engagement with these services.
References


Suggested citation

The Health Literacy Questionnaire (HLQ) identifies the specific health literacy strengths and limitations of people and communities. It examines nine areas of health literacy.

**The Health Literacy Questionnaire (HLQ)** is a critical advancement in health literacy measurement. It is a multi-dimensional tool that has been designed to provide practitioners, organisations and governments with data that describes the health literacy strengths and limitations of individuals and populations.

These data allow development and selection of fit-for-purpose response strategies that optimise opportunities to improve equity in health outcomes and access.

**Key resource:**

Link: [http://www.biomedcentral.com/1471-2458/13/658](http://www.biomedcentral.com/1471-2458/13/658)
**Psychometric properties of the HLQ**

Modern and rigorous psychometric tests have shown the HLQ is a robust measure of nine identified health literacy dimensions. It has excellent psychometric properties, construct validity, reliability, and is shown to provide unbiased mean estimates of group differences.\(^1,2\)

**Structure and administration of the HLQ**

The HLQ consists of 44 questions and can be either self-administered or orally administered. It is available in paper and online formats (at Ophelia.net.au). Completion time varies depending on the skills and approach of the respondent. It usually takes between 7 and 30 minutes to complete. When orally administered by telephone or in person the HLQ takes between 20 and 45 minutes to complete.

**Scoring the HLQ**

The HLQ provides nine scale scores. Each score provides insight into the strengths and limitations of the respondent, but the scores are most powerful when viewed together to show the health literacy profile of the respondent.

The score for each scale is obtained by calculating the mean of the 4-6 questions from the scale. These scales, their corresponding question numbers in the HLQ and the interpretation of what each scale score tells you about a person’s health literacy are shown in Table 1. Scales 1-5 have a possible score range from 1-4. Scales 6-9 have a possible score range from 1-5.

**Average scale scores** for groups of respondents (along with standard deviations) provide useful insights into health literacy strengths and limitations. An Excel spreadsheet and SPSS syntax is available to assist with the calculation of scale scores. The simplest way to present the results of the HLQ is to report the means (and standard deviations) for each scale in a bar graph.

**Effect sizes** can be used to describe the difference in mean scale scores before and after an intervention, or of different groups. Effect sizes provide an indication of how large the difference is. An instructional guide is available to assist with the calculation of effect sizes. Effect sizes are usually presented in tables.

**Cluster analysis** is recommended to identify groups of individuals that have similar health literacy profiles. This approach to examining HLQ data reveals sub-groups of people who have particular strengths that can be built upon, or sub-groups with limitations, which services might need to provide support to improve. Statistical software and some statistics training is required to undertake this sort of analysis and interpret the results.

**Languages available**

The HLQ is available in several languages. Visit the Ophelia.net.au website for an up-to-date list of available translations. A strict protocol is followed for each translation to help ensure each version of the HLQ is linguistically, culturally and psychometrically robust. The translation protocol used to translate the HLQ is available from Ophelia.net.au.

**Accessing the HLQ**

Visit the Ophelia.net.au website to register and obtain a license to use the HLQ.
The nine scales of the Health Literacy Questionnaire (HLQ)

1. Feel understood and supported by healthcare providers
2. Have sufficient information to manage my health
3. Actively managing health
4. Have social support for health
5. Appraise health information
6. Ability to actively engage with healthcare providers
7. Ability to navigate the healthcare system
8. Ability to find good health information
9. Ability to understand health information well enough to know what to do
### Interpretation of the nine scales of the Health Literacy Questionnaire (HLQ)

<table>
<thead>
<tr>
<th>HLQ Scale</th>
<th>Item location in the HLQ</th>
<th>Interpretation - what do the scale scores mean?</th>
</tr>
</thead>
</table>
| 1. Feel understood and supported by healthcare providers | Part 1 - Q 2, Part 1 - Q 8, Part 1 - Q 17, Part 1 - Q 22 | **High**: Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.  
**Low**: People who are low on this domain are unable to engage with doctors and other healthcare providers. They don’t have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice. |
| 2. Have sufficient information to manage my health | Part 1 - Q 1, Part 1 - Q 10, Part 1 - Q 14, Part 1 - Q 23 | **High**: Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.  
**Low**: Feels that there are many gaps in their knowledge and that they don’t have the information they need to live with and manage their health concerns. |
| 3. Actively managing health | Part 1 - Q 6, Part 1 - Q 9, Part 1 - Q 13, Part 1 - Q 18, Part 1 - Q 21 | **High**: Recognise the importance of and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health.  
**Low**: People with low levels don’t see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them. |
| 4. Have social support for health | Part 1 - Q 3, Part 1 - Q 5, Part 1 - Q 11, Part 1 - Q 15, Part 1 - Q 19 | **High**: A person’s social system provides them with all the support they want or need.  
**Low**: Completely alone and unsupported. |
| 5. Appraise health information | Part 1 - Q 4, Part 1 - Q 7, Part 1 - Q 12, Part 1 - Q 16, Part 1 - Q 20 | **High**: Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.  
**Low**: No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information. |
<table>
<thead>
<tr>
<th>HLQ Scale</th>
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<th>Interpretation - what do the scale scores mean?</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Ability to actively engage with healthcare providers</td>
<td>Part 2 - Q 2</td>
<td><strong>High</strong>: Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional health care providers when necessary. They keep going until they get what they want. Empowered. <strong>Low</strong>: Is passive in their approach to health care, inactive, i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they don’t understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns.</td>
</tr>
<tr>
<td>7. Ability to navigate the healthcare system</td>
<td>Part 2 - Q 1</td>
<td><strong>High</strong>: Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level. <strong>Low</strong>: Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.</td>
</tr>
<tr>
<td>8. Ability to find good health information</td>
<td>Part 2 - Q 3</td>
<td><strong>High</strong>: Is an ‘information explorer’. Actively uses a diverse range of sources to find information and is up to date. <strong>Low</strong>: Cannot access health information when required. Is dependent on others to offer information.</td>
</tr>
<tr>
<td>9. Ability to understand health information well enough to know what to do</td>
<td>Part 2 - Q 5</td>
<td><strong>High</strong>: Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required. <strong>Low</strong>: Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.</td>
</tr>
</tbody>
</table>
Reference


Suggested citation

The Information and Support for Health Actions Questionnaire (ISHA-Q) was developed to measure health literacy in low- and middle-income settings, and cultures where decision-making about health often occurs as a collective activity of family or peer groups. The ISHA-Q includes supplementary scales for people with chronic illnesses, people with a physical disability, people who are blind and people who are deaf.

The ISHA-Q is a multi-dimensional tool that offers providers, organisations and governments the capacity to identify and understand the health literacy strengths and limitations of individuals and populations. These data allow development and selection of fit-for-purpose response strategies that optimise opportunities to improve equity in health outcomes and access.
**Psychometric properties of the ISHA-Q**

Modern and rigorous psychometric tests have shown the ISHA-Q to be a robust measure of the identified core and supplementary scales. It has excellent psychometric properties, construct validity and reliability across a wide variety of groups, and when administered on paper, orally or by sign language. It is shown to provide unbiased mean estimates of group differences.

**Structure and administration of the ISHA-Q**

The ISHA-Q has fourteen core scales, and ten supplementary scales that can be used depending on the relevance to the respondent and the purpose of administration. The ISHA-Q can be either self-administered or orally administered.

Completion time depends on the format, the skills and approach of the respondent, and the number of scales used. It usually takes between 8 and 20 minutes for someone to complete the core scales on paper. When orally administered by telephone or in person, the core scales take between 15 and 35 minutes to complete.

**Scoring the ISHA-Q**

The ISHA-Q provides separate scores for each scale. Each score provides insight into the strengths and limitations of the respondent, but the scores are most powerful when viewed together to show the health literacy profile of the respondent.

The score for each scale is obtained by calculating the mean from the questions that make up that scale.

**Average scale scores** for groups of respondents (along with standard deviations) provide useful insights into the health literacy strengths and limitations of populations. And Excel spreadsheet and SPSS syntax is available to assist calculation of scale scores. The simplest way to present the results of the ISHA-Q is to report the means [and standard deviations] for each scale in a bar graph.

**Effect sizes** can be used to describe the difference in mean scale scores before and after an intervention, or of different groups. Effect sizes provide an indication of how large the difference is. An instructional guide is available to assist with the calculation of effect sizes. Effect sizes are usually presented in tables.

**Cluster analysis** is recommended to identify groups of individuals that have similar health literacy profiles. This approach to examining ISHA-Q data reveals sub-groups of people who have particular strengths that can be built upon, or sub-groups with limitations, which services might need to provide support to improve. Statistical software and some statistics training is required to undertake this sort of analysis and interpret the results.

**Languages available**

The ISHA-Q is available in several languages. Visit the Ophelia.net.au website for an up-to-date list of available translations. A strict protocol is followed for each translation to help ensure each version of the ISHA-Q is linguistically, culturally and psychometrically robust. The translation protocol used to translate the ISHA-Q is available from Ophelia.net.au.

**Accessing the ISHA-Q**

Visit the Ophelia.net.au website to register for a license to use the ISHA-Q.
The fourteen core scales of the Information and Support for Health Actions Questionnaire (ISHA-Q)

1. Support for health in the community
2. Ability to access health services
3. Communication skills to get what you want from health professionals
4. Family support for health
5. Ability to access health information
6. Recognising rights
7. Evaluating trustworthiness of health information
8. Taking responsibility for own health
9. Physical/travel barriers to taking care of health
10. Eating for good health
11. Exercising for good health
12. Managing stress
13. Using medicines
14. Using herbs and supplements

Supports and abilities scales (37 questions)
Barriers scale (4 questions)
Health actions scales (19 questions)
The ten supplementary scales of the Information and Support for Health Actions Questionnaire (ISHA-Q)

<table>
<thead>
<tr>
<th>Needs of people who are deaf</th>
<th>Needs of people who are blind</th>
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<tbody>
<tr>
<td>Needs of people who are deaf</td>
<td>(13 questions)</td>
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<tr>
<td>Needs of people who are blind</td>
<td>(13 questions)</td>
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<tr>
<td>D1.</td>
<td>Health service accessibility and helpfulness</td>
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<td>(for deaf people)</td>
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<td>B1.</td>
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<td>D2.</td>
<td>Equipment (to assist in communication</td>
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<td>Equipment (to assist in care of own health)</td>
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<tr>
<td>D3.</td>
<td>Use of interpreters</td>
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<tr>
<td></td>
<td>B3.</td>
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<td>Accessing information in formats suitable for</td>
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<td>blind people</td>
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<tr>
<th>Needs of people with physical disability</th>
<th>Needs of people with chronic illness</th>
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<tr>
<td>Needs of people with physical disability</td>
<td>(9 questions)</td>
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<tr>
<td>Needs of people with chronic illness</td>
<td>(8 questions)</td>
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<td>PD1.</td>
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<td>CI1.</td>
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<td>Sharing information with others</td>
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<td>with the same condition</td>
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<td>CI2.</td>
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<td>Self-monitoring</td>
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<tr>
<td>PD2.</td>
<td>Equipment (to assist in care of own</td>
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<td>health)</td>
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Suggested citation

Additional Ophelia Resources

Ophelia Manual
How to apply the Ophelia health literacy process for improving health outcomes

Ophelia Templates and Additional Resources
Templates and resources to support application of the Ophelia Manual