

Health Literacy Toolkit

For Low- and Middle-Income Countries

A series of information sheets to empower communities and strengthen health systems



Contributors

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The Health Literacy Toolkit

For Low- and Middle-Income Countries

A series of information sheets to help empower communities and strengthen health systems

Editors: Sarity Dodson, Suvajee Good and Richard Osborne



Overview

This series of information sheets introduces health literacy, its relevance to public policy, and the ways it can be used to inform the promotion of good health, the prevention and management of communicable and noncommunicable diseases, and the reduction of health inequities. It provides information and links to further resources to assist organizations and governments to incorporate health literacy responses into practice, service delivery systems, and policy.

Audience

This publication seeks to inform:

- governments, politicians and policy makers at all levels
- academic institutions
- public, civil society, and non-governmental organizations, and practitioners
- relevant private sectors promoting health and well-being
- communities, community-based organizations and social networks
- WHO and other UN partners
- development organizations.

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Credit: istockphoto.com / Bartosz Hadyniak

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Foreword

Education improves lives. Reading and writing are precious skills for many people in the world, and can have long-lasting benefits for future generations. We have learned from our public health experiences that educating women reduces child mortality and improves maternal and child health. However, understanding health-related information requires knowledge, experience, and skills, and accessibility of health information. This means that information needs to be not only available, but also readable and comprehensible. Health practitioners' communication with patients and family members can be part of the therapeutic process, however, knowledge of health, health services, and resources will depend on levels of health literacy.

Health literacy plays an important role in how well individuals can access the health system and receive quality care. The World Health Organization recognized the importance of health literacy and included explicit calls for action in the Seventh Global Conference on Health Promotion in Nairobi in 2009. Since 1998, WHO had defined health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”.



Although initially the responsibility for health literacy was focused on individuals, there is increasing recognition that governments, health and community service providers, researchers, and consumer groups are also equally accountable. Equitable and achievable access to health care must be promoted at the individual, organizational and policy levels to achieve globally agreed agendas such as the Millennium Development Goals (MDG).

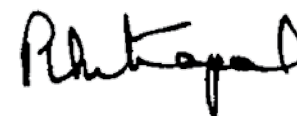
The Nairobi Call to Action for Closing the Implementation Gap in Health Promotion 2009 identified five key strategies and actions for reducing health inequities and poverty and improving health and quality of life through health promotion implementation. One of the five key strategies was to improve health literacy and health behaviours by designing health interventions based on health, social and cultural needs. Development of health literacy interventions is an important strategy for assisting organizations to make health care and services more accessible, and for empowering people to improve their own health literacy, as well as that of their families and their communities.

Health literacy interventions have been implemented in most high-income countries. There are several tools that have been used to measure health literacy and assess how well individuals understand health information. However, these tools inadequately capture the breadth of the WHO definition of health literacy, and do not provide the necessary data for lower- and middle-income countries to make decisions about effective health literacy interventions for individuals and communities. Deakin University, in collaboration with the

WHO Regional Office for South-East Asia, developed health literacy measurement tools which are suitable for use in low- and middle-income countries. The Information and Support for Health Actions Questionnaire (ISHA-Q) and Health Literacy Questionnaire (HLQ) are being used to better understand the health literacy strengths and difficulties of people from a range of socioeconomic and ethnic backgrounds, and of people living with disability or with long-term health conditions. The understanding generated through assessment of health literacy enables researchers and service providers to co-create health literacy responses that empower people to seek appropriate health and social services, as well as make health care and services more accessible.

The WHO Regional Office for South-East Asia has commissioned Deakin University to develop a toolkit for health literacy that can be used to guide health literacy initiatives in low- and middle-income countries. The “The Health Literacy Toolkit for Low- and Middle-Income Countries” explores health literacy and the approaches that may be used to assess responses to health literacy. Enhanced health literacy and improved responsiveness to health literacy needs can contribute to reducing health inequity and improving the health of populations.

Dr Poonam Khetrpal Singh
Regional Director
WHO South-East Asia



PART A:

An Introduction to Health Literacy

Effective responses to health literacy issues can improve health outcomes and reduce health inequities. Policies and practices must promote identification of health literacy issues and the implementation of targeted responses.

1

What is health literacy?

Health literacy is the term used to describe the ability to engage with health information and services.



Credit: WHO / SEARO / Nursila Dewi

Health literacy brings together many concepts that relate to what people and communities need to order to make effective decisions about health for themselves, their families and their communities.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. Health literacy includes the capacity to communicate, assert and enact these decisions.⁷

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.²⁻⁵ Further, it is context- and content-specific, so health literacy in one setting, or relating to one health decision, will be different from another.⁴

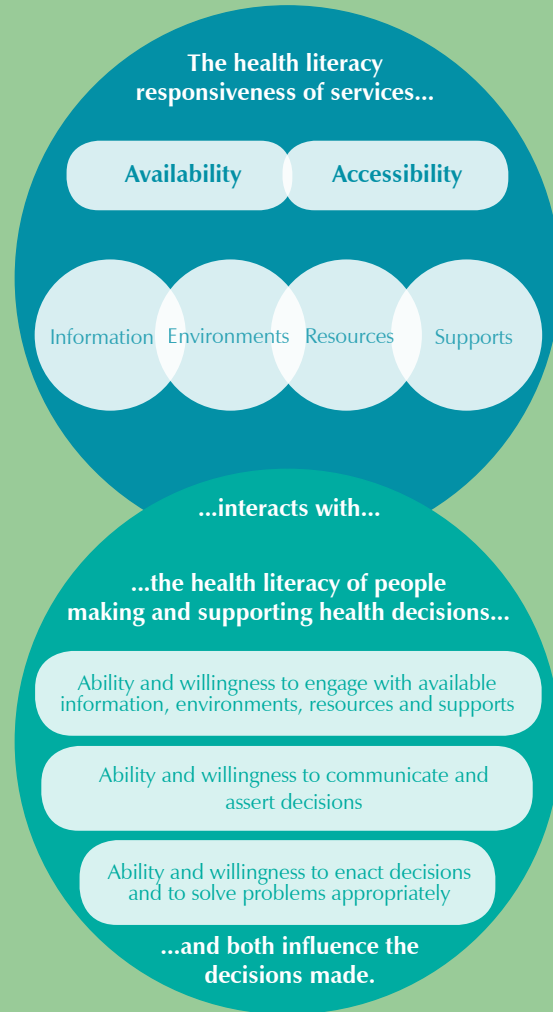
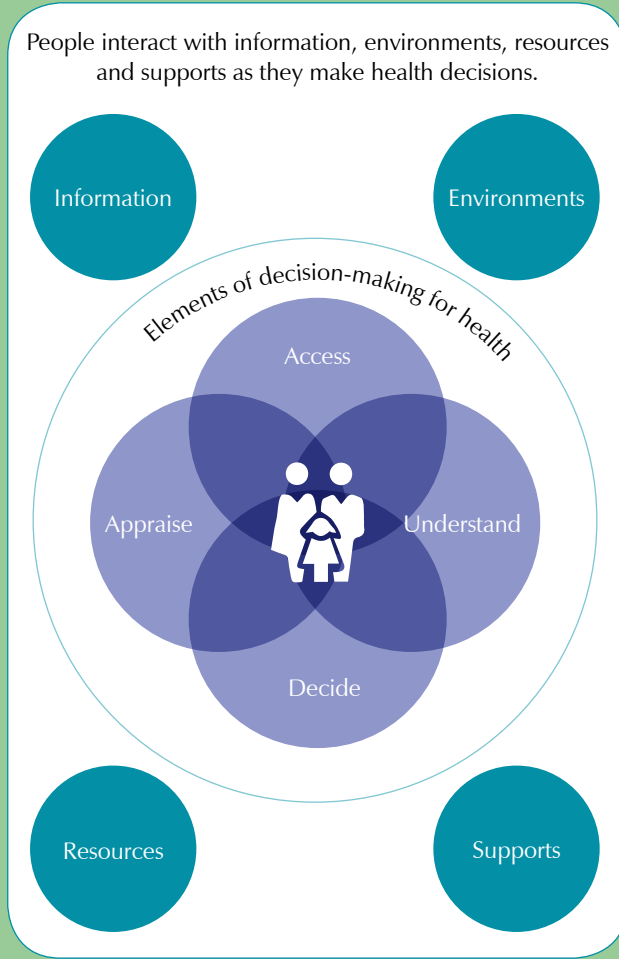
Individuals and communities have health literacy strengths and limitations that influence how effectively they engage with health information and services. Health and social service systems can also have strengths and limitations in their responsiveness to the health literacy of the people they serve.^{6,8}

Health literacy responsiveness describes the way in which services, environments and products make health information and support available and accessible to people with different health literacy strengths and limitations.⁷



The interaction between health literacy and the health literacy responsiveness of services⁷

Health decision-making process



Health Literacy Responsiveness

Health Literacy

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Source: Dodson S, Beauchamp A, Batterham RW and Osborne RH. Information sheet 1: What is health literacy? In Ophelia Toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities. Part A: Introduction to health literacy. 2014. Available from www.ophelia.net.au.

2

The relevance of health literacy for public policy

Effective responses to health literacy issues can improve health outcomes and reduce health inequities.



Credit: WHO / SEARO / Gary Hampton

“A healthy population is a key requirement for the achievement of society’s goals. Reducing inequalities and the social gradient improves health and well-being for everyone.

Good health enhances quality of life, improves workforce productivity, increases the capacity for learning, strengthens families and communities, supports sustainable habitats and environments, and contributes to security, poverty reduction and social inclusion. Yet escalating costs for treatment and care are placing unsustainable burdens on national and local resources such that broader developments may be held back.”¹

Adelaide Statement on Health in All Policies. WHO, Government of South Australia, Adelaide 2010

Health outcomes result from multi-directional relationships among attributes of communities and community members, and the educational, environmental, economic and social service systems, products and infrastructures available to communities. The Health in All Policies (HiAP) approach recognizes that some of the main drivers of health lie outside the healthcare system.¹ 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.

Health literacy is a potentially modifiable contributor to health inequities.

Studies have shown correlations between low health literacy* and:

- increased hospital admissions and readmissions²
- poorer medication adherence and increased adverse medication events³
- less participation in prevention activities^{4,5}
- higher prevalence of health risk factors^{6,7}
- poorer self-management of chronic diseases and poorer disease outcomes⁸
- less effective communication with healthcare professionals⁹
- increased healthcare costs¹⁰
- lower functional status¹¹ and
- poorer overall health status^{12,13} including increased mortality.¹⁴

Studies also suggest that differences in health literacy abilities may explain observed health inequities among people of different race and educational attainment.^{12,15}

To date, the evidence base for the link between health literacy and health outcomes includes studies from a wide range of countries from all regions of the world, including low- and middle-income countries.^{7,16}

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

Key resources:

Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, Holland A, Brasure M, Lohr KN, Harden E, Tant E, Wallace I, Viswanathan M. **Health Literacy Interventions and Outcomes: An Updated Systematic Review.** Evidence Report/Technology Assessment No. 199. Prepared by RTI International–University of North Carolina Evidence-based Practice Center under contract No. 290-2007-10056-I. AHRQ Publication Number 11- E006. Rockville, MD. Agency for Healthcare Research and Quality. March 2011

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Link: <http://www.iom.edu/~media/Files/Activity%20Files/PublicHealth/HealthLiteracy/2012-SEP-24/WorldHealthLit.pdf>

The Nairobi Call to Action for Closing the Implementation Gap in Health Promotion¹⁷ identifies five key strategies and actions for reducing health inequities and poverty, and improving health and quality of life:

1. Building capacity for health promotion
2. Strengthening health systems
3. Partnering and intersectorial action
4. Community empowerment
5. Health literacy and health behaviours

To advance the **health literacy and health behaviours** strategy, policy is needed to generate actions that:

- support empowerment, e.g., by ensuring communities can access and act on knowledge and overcome any barriers;
- embrace information and communication technologies; and
- build and apply the evidence base, e.g., by developing systems to monitor, evaluate, document and disseminate health literacy.¹⁷



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3

Responding to the health literacy needs of communities

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



Credit: WHO /Christopher Black

United Nations Economic and Social Council Ministers Declaration July 9, 2009:

“We stress that health literacy is an important factor in ensuring significant health outcomes and in this regard call for the development of appropriate action plans to promote health literacy.”¹

Key message 1:

“Scale up effective health literacy interventions in order to accelerate progress towards the achievement of the health-related MDGs and public health commitments, including the consideration of developing a regional action plan to promote health literacy.”¹

Key message 2:

“Develop a country-specific set of recommendations on the core content areas of health literacy and a set of guidelines for undertaking measurement.”¹

Key message 3:

“To increase the level of health literacy and reduce maternal and child mortality, HIV infections, under-nutrition as well as tobacco use, unhealthy diet and physical inactivity, actions must be taken by different professional groups in the health, education and other sectors. Key stakeholders within and outside the government sector at the national, regional and global levels must also be involved.”¹

The council set out five key messages conveying “how effective health literacy interventions can be scaled up so as to accelerate progress toward the achievement of the health-related Millennium Development Goals [MDGs] and public health goals and commitments”.¹

Key message 4:

“Actions should be taken to develop and deploy relevant and sustainable national information programmes based on the available technologies in the countries. There should also be collaboration among countries in the region to share best practices. Key indicators should be developed to measure and evaluate the benefits of information and computing technology [ICT] as a tool for enhancing health literacy in the region.”¹

Key message 5:

“To inform policy development and practice in building capacity so as to be able to develop and implement interventions to enhance health literacy, immediate actions are required to examine what capacity building areas are relevant and how the capacity of those areas can be built in countries at different levels of development, given the different social, economic, and political contexts of the countries in the Region, and the different health issues that the countries confront.”¹

Considerations for the development and implementation of health literacy interventions in low- and middle-income countries

Low- and middle-income countries face hurdles to achieving a range of development and public health goals. Addressing the health literacy of individuals and communities, and barriers to people's access to health information and services is critical to improving health and development outcomes.¹

Effective health literacy interventions respond to local needs and give consideration to local contexts. Local needs may range from the simplification of public health messages relating to diabetes prevention, or to the reduction of stigma associated with Ebola infection. Local contexts may vary in many ways, including the structure and function of healthcare systems, the use and availability of mass media (e.g., newspaper, radio, television, the internet), and cultural norms and learning preferences.

Co-creation of health literacy interventions with local stakeholders is an effective way to engage the community and discover novel solutions. For example, in Thailand, the Population and Community Development Association has used Thai humour to effectively raise public attention about taboo subjects such as contraception and HIV awareness.²

Using available health and social resources optimizes the sustainability and scalability of health literacy interventions. Novel approaches to increasing the availability, affordability and quality of healthcare services are often used in low- and middle-income countries to address gaps in public services.² Health care that is appropriate to and based within communities can decrease operating costs, increase staff availability and empower the local community.



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4

The Ophelia approach to optimizing health literacy

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.



Credit: WHO / SEARO /Shehzad Noorani

The Ophelia approach^{1,2} 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.

Ophelia means
Optimizing
Health
Literacy and
Access to health
information and services

Key resource:

Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR and Osborne RH. **The OPTimising HEalth LIterAcY (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>



Examples of Ophelia projects working to optimize health literacy

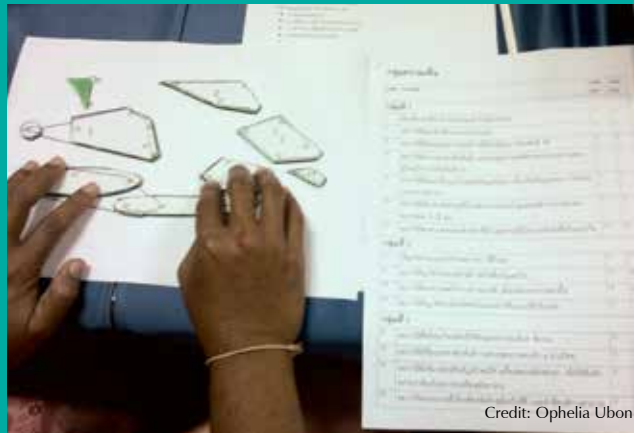
The participatory, systematic and grounded nature of the Ophelia approach ensure its suitability for health literacy projects conducted across a broad range of settings, including communities within low- and middle-income countries.



Credit: Mothers Unite

Identifying health literacy needs and developing local responses to health emergencies in Lavender Hill, an informal settlement, Cape Town: Ophelia South Africa

<http://www.mothersunite.org.za/efar/>



Credit: Ophelia Ubon

Optimizing health literacy needs of people in Thailand (Warin Chamrap, Ubon Ratchatani): An Ophelia project



Credit: National Hauora Coalition

Health literacy and Whanau Ora Outcomes:
Ophelia New Zealand

www.nhc.maori.nz



Credit: Ophelia Victoria

Optimizing health literacy to improve health and equity:
Ophelia Victoria

www.ophelia.net.au

The Ophelia principles

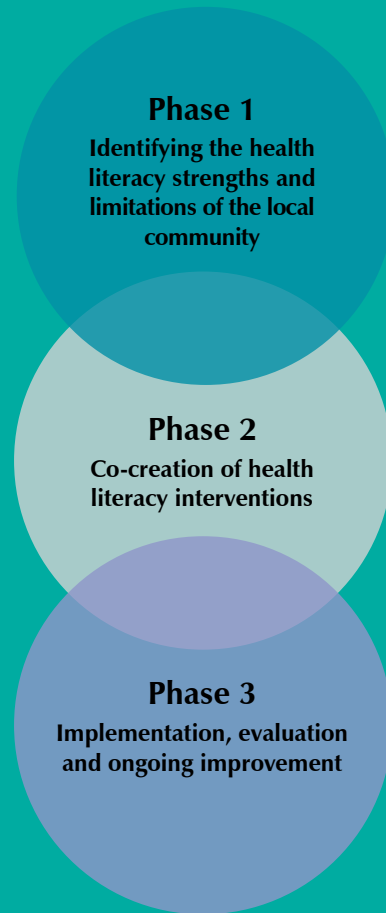
The Ophelia principles provide guidance to Ophelia projects and ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.²

Ophelia projects must:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

The Ophelia phases: 1 to 3

Each phase of the Ophelia process^{1,2} is drawn from three well-established methodological approaches: intervention mapping³, quality improvement collaboratives⁴⁻⁸, and realist synthesis.⁹⁻¹⁴ Tools and resources have been developed to support implementation of each phase.



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 analyzed and presented to stakeholders for discussion and interpretation. Effective local practices and innovative intervention ideas are then identified.

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.

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

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5

Health literacy recommendations for action

Governments, organizations, practitioners and community members must work in partnership to address health literacy issues contributing to poor health outcomes and inequities within local communities.



Credit: WHO / SEARO / Nursila Dewi

Key messages

1. 'Health literacy' is the term used to describe the ability to engage with health information and services.
2. Individuals and communities have health literacy strengths and limitations that influence how effectively they engage with health information and services.
3. Health and social service systems have strengths and limitations in their responsiveness to the health literacy of the people they serve.
4. Effective responses to health literacy issues can improve health outcomes and reduce health inequities.
5. Policies and practices must promote identification of health literacy issues and the implementation of targeted responses.



Credit: WHO / SEARO / Tom Pietrasik

Key considerations

The Ophelia principles*¹ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

1. Dodson S, Beauchamp A, Batterham RW and Osborne RH. Information sheet 7: The Ophelia Approach to optimising health literacy. In Ophelia Toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities. Part A: Introduction to health literacy. 2014. Deakin University, Melbourne (<http://www.ophelia.net.au> [accessed 28 November 2014]).

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
 - the health of communities;
 - health behaviors within communities;
 - community engagement with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of communities.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of communities and community members.

- 2** use available health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
 - groups of people that have poorer health outcomes or less-than-optimal access to services;
 - health issues or behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
 - discussions about local needs and considerations;
 - discussions about universal precautions;
 - determining local priorities for action;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluating interventions and strategies; and
 - continuous quality improvement to ensure ongoing effectiveness and sustainability.

- 4** scale up effective interventions and strategies.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all community members.

6

Resources for the development of health literacy policies and responses

A growing number of tools and resources are available to assist policy makers, practitioners and organizations to develop and implement health literacy policies and responses.



Credit: WHO / SEARO / Nursila Dewi

Multi-dimensional tools for measuring health literacy

The Health Literacy Questionnaire (HLQ) is used to identify the specific health literacy strengths and limitations of people and communities. It examines nine areas of health literacy. The HLQ offers the potential for practitioners, organizations and governments to identify and understand the health literacy profiles of individuals and/or populations as a basis for intervention development. It is suitable for use in a range of different cultures and is available in several languages.^{1,2}

Link: www.ophelia.net.au

Key resource:

Osborne RH, Batterham R, Elsworth GR, Hawkins M, Buchbinder R. **The grounded theory, psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)**. BMC Public Health. 2013;13:658.

Link: <http://www.biomedcentral.com/1471-2458/13/658>



The nine scales of the Health Literacy Questionnaire (HLQ)²

The Information and Support for Actions Questionnaire (ISHA-Q) was developed to measure health literacy in low- and middle-income country settings, and cultures where decision-making about health often occurs as a collective activity of family or peer groups. The ISHA-Q has fourteen core scales and ten supplementary scales for people with chronic illnesses, people with a physical disability, people who are blind and people who are deaf.³

Link: www.ophelia.net.au

- Supports and abilities scales (37 questions)
- Barriers scale (4 questions)
- Health actions scales (19 questions)



The fourteen core scales of the Information and Support for Health Actions Questionnaire (ISHA-Q)³

Key reports and policies with a focus on health literacy

Health Literacy: A Prescription to End all Confusion

Institute of Medicine, National Academy of Sciences. Washington, DC, 2004 (<http://www.iom.edu/Reports/2004/Health-Literacy-A-Prescription-to-End-Confusion.aspx>).

Health literacy and the Millennium Development Goals: United Nations Economic and Social Council (ECOSOC) regional meeting background paper (abstracted)

J Health Commun 2010, 15 Suppl 2:211-23 (<http://www.tandfonline.com/doi/abs/10.1080/VA7yGVbGDZs>).

Health Literacy Around the World: Part 1 Health Literacy Efforts Outside of the United States

Pleasant A. Institute of Medicine Roundtable on Health Literacy, 2012 (<http://www.iom.edu/~media/Files/Activity%20Files/PublicHealth/HealthLiteracy/2012-SEP-24/WorldHealthLit.pdf>).

Health Literacy Interventions and Outcomes: An Updated Systematic Review

Berkman ND et al. Evidence Report/Technology Assessment No. 199. Rockville, MD. Agency for Healthcare Research and Quality, 2011 (www.ahrq.gov/downloads/pub/evidence/pdf/literacy/literacyup.pdf).

Health Literacy: The Solid Facts

Kickbusch I, Pelikan JM, Apfel F, Tsouros A. Copenhagen: World Health Organization, 2013 (<http://www.euro.who.int/en/health-topics/environment-and-health/urban-health/publications/2013/health-literacy.-the-solid-facts>).

Making it Easy: a Health Literacy Action Plan for Scotland

NHS Health Scotland, The Scottish Government, 2014 (<http://www.scotland.gov.uk/Publications/2014/06/9850/downloads>).

National Action Plan to Improve Health Literacy

Office of Disease Prevention and Health Promotion, United States Department of Health and Human Services. Washington, DC, 2010 (<http://www.health.gov/communication/hlactionplan/>).

Nairobi Call to Action for Closing the Implementation Gap in Health Promotion

World Health Organization. Nairobi: 7th Global Conference on Health Promotion, October 2009 (<http://www.who.int/healthpromotion/conferences/7gchp/en/>).

Improving Health Literacy for Older Adults: Expert Panel Report

United States Centers for Disease Control and Prevention. Atlanta, 2009 (<http://www.cdc.gov/healthliteracy/developmaterials/audiences/olderadults/index.html>).

Key websites with a focus on health literacy

Optimising health literacy and access to health information and services: Ophelia
ophelia.net.au

Harvard School of Public Health
hsph.harvard.edu/healthliteracy/

International Union for Health Promotion and Education (IUHPE)
iuhpe.org/

The Health Literacy Place
knowledge.scot.nhs.uk/healthliteracy.aspx

Worldwide Universities Network Global Health Literacy Network
<http://wun.ac.uk/wun/research/view/literacy-network>

Centre for Disease Control
cdc.gov/healthliteracy/

World Health Organization
who.int/healthpromotion/conferences/7gchp/track2/en/

Asian Health Literacy Association
ahls-asia.org/

WHO European Healthy Cities Network
euro.who.int/en/health-topics/environment-and-health/urban-health/activities/healthy-cities/who-european-healthy-cities-network

Key resource:

DeWalt DA, Callahan LF, Hawk VH, Brouckson KA, Hink A, Rudd R, Brach C. **Health Literacy Universal Precautions Toolkit.** (Prepared by North Carolina Network Consortium, The Cecil G. Sheps Center for Health Services Research, The University of North Carolina at Chapel Hill, under Contract No. HHS290200710014.) AHRQ Publication No. 10-0046-EF) Rockville, MD. Agency for Healthcare Research and Quality. April 2010.

Link: <http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthliteracytoolkit.pdf>

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PART B:

Understanding the Health Literacy of Communities

Measurement of the health literacy strengths and limitations of communities allows strategic design and delivery of interventions that address health inequities, improve health outcomes and strengthen health systems.

7

The importance of health literacy measurement

Measurement of the health literacy strengths and limitations of communities allows strategic design and delivery of interventions that address health inequities, improve health outcomes and strengthen health systems.



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Measurement of health outcomes and their determinants allow interventions that aim to improve health and equity to be designed, delivered and monitored strategically. **Health literacy is a potentially modifiable contributor to health**, and its measurement provides an indication of: 1) the capacity of community members to engage with health information and services; and 2) the responsiveness of health and community services to the variable health literacy strengths and limitations of the community.

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.

Each community and community member has resources, attributes, limitations and needs. They also each exist within a social and environmental context that influences their access to information and services. Careful consideration of these variables is required during the design and implementation of health promotion programs. **Informed by health literacy data, policymakers, researchers and health promotion practitioners can tailor responses to meet the needs of the populations they represent and serve.**

Studies have shown correlations between low health literacy* and:

- increased hospital admissions and readmissions¹
- poorer medication adherence and increased adverse medication events²
- less participation in prevention activities^{3,4}
- higher prevalence of health risk factors^{5,6}
- poorer self-management of chronic diseases and poorer disease outcomes⁷
- less effective communication with healthcare professionals⁸
- increased healthcare costs⁹
- lower functional status¹⁰ and
- poorer overall health status^{11,12} including increased mortality.¹³

Studies also suggest that differences in health literacy abilities may explain observed health inequities among people of different race and educational attainment.^{11,14}

To date, the evidence base for the link between health literacy and health outcomes includes studies from a wide range of countries from all regions of the world, including low- and middle-income countries.^{6,15}

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

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8

What health literacy measurement examines

Health literacy is a multidimensional concept. We must measure a representative set of health literacy indicators to identify opportunities for improvement.



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People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.¹ Health decisions often lead to health actions, which in turn contribute to health outcomes.

Health literacy and health literacy responsiveness are complex and multi-dimensional concepts, and it is the interplay between these that influences health decisions. It is not feasible to measure all aspects of the health literacy of a person or community. It is feasible, however, to measure a representative set of health literacy indicators to identify opportunities for improvement.



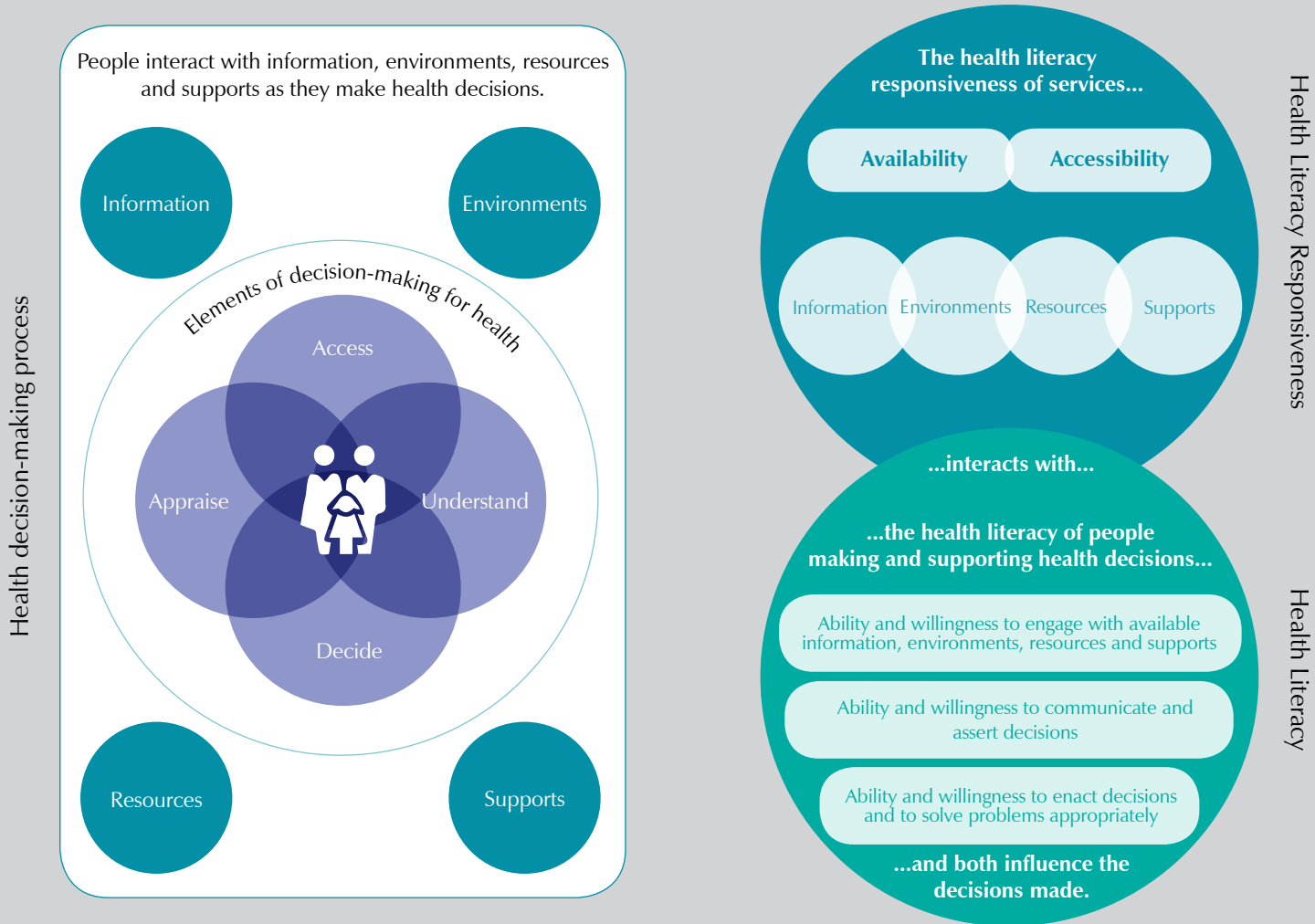
What is health literacy?

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 decisions that have implications for health. Health literacy includes the capacity to communicate, assert and enact these decisions.¹

What is health literacy responsiveness?

Health literacy responsiveness describes the way in which services, environments and products make health information and support available and accessible to people with different health literacy strengths and limitations.¹

Figure 1: The interaction between health literacy and the health literacy responsiveness of services¹



What we examine when we measure health literacy

A review by Sorensen and colleagues examined the dimensions captured by existing definitions of health literacy.² Haun and colleagues subsequently updated the resulting taxonomy.³ The 15 dimensions and associated definitions presented here include additional dimensions relevant to low- and middle-income settings. Collectively these dimensions cover people's ability and willingness to engage with available information, environments, resources and supports; communicate and assert their health decisions; and enact their health decisions and solve problems appropriately (see Figure 1).

1. *Literacy* - the ability to perform basic reading tasks
2. *Interaction* - the ability to communicate on health matters
3. *Comprehension* - the ability to derive meaning from sources of information
4. *Numeracy* - the ability to perform basic numerical tasks and arithmetic operations
5. *Information seeking* - the ability to find health-related information to manage one's health
6. *Application/function* - the ability to use, process or act on health-related information, and apply new information to changing circumstances
7. *Decision making /critical thinking* - the ability to make sound, health-related decisions and informed choices
8. *Evaluation* - the ability to filter, interpret, and evaluate information
9. *Responsibility* - the ability to take responsibility for one's health and healthcare decision-making
10. *Confidence* - the level of confidence to take action to improve personal and community health
11. *Navigation* - the ability to navigate in society and in health systems to manage one's health needs
12. *Social support for health* - the social resource one has to assist health decision-making and health management
13. *Rights and access* - the level of access one has to health information and services
14. *Trust* - the level of trust one has in the health system, health information, and in providers of healthcare
15. *Motivation* - the level of motivation to take action to improve personal and community health

This list of dimensions provides a guide to inform the measurement of health literacy of both individuals and population groups. The dimensions relate to the tasks of accessing, understanding, appraising and applying health information.² The interactions between these tasks are cyclical and evolving, and are specific to the context of the individual and health issue.⁴

What we examine when we measure health literacy responsiveness

A working group sponsored by the Institute of Medicine Health Literacy Roundtable identified ten attributes that organizations should strive for to ‘make it easier for people to navigate, understand and use information and services to take care of their health’.⁵

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 progress;
4. includes populations served in the design, implementation, and evaluation of health information and services;
5. meets 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; and
10. communicates clearly what health plans cover and what individuals will have to pay for services.

This list of attributes provides a guide to inform the measurement of the health literacy responsiveness of organizations.



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9

Approaches to health literacy measurement

The measurement of health literacy must account for the multi-dimensional nature of health literacy, and must be approached in a way suited to the context and objectives of the activity.



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There are several potential purposes for measuring health literacy. The measurement approach and tool employed should be matched to the objectives of the activity and the context within which it will be undertaken. Table 1 presents a set of recommendations regarding the type of tool and approach to employ. Considerations include: 1) whether to measure the health literacy of people or the health literacy responsiveness of organizations, or both; 2) whether to use a tool that measures a limited set, or a range, of health literacy elements; and 3) whether to employ a quantitative or qualitative approach, or a combination of the two. Information sheet 10 in this series provides a summary of available tools.

Measuring a limited set of health literacy elements

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 in order to quantify a known issue, monitor its change over time, or identify associations with outcomes of interest. Haun and colleagues provide a review of 51 health literacy measurement tools and a list of which elements of health literacy are assessed by each tool.³

Measuring a range of health literacy elements

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.



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

Objective: Assess health literacy strengths and limitations of an individual

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.

Tools A multidimensional questionnaire that provides scale scores.

Approaches Questionnaire and/or semi-structured interview.

Objective: Assess health literacy strengths and limitations of a group of people

Measuring the health literacy of groups allows providers and organizations to identify common health literacy strengths and limitations, and design and deliver services, staff training, and staff decision supports accordingly.

Tools A multidimensional questionnaire that provides scale scores.

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

Objective: Assess health literacy strengths and limitations at a regional or national level

Measuring the health literacy of a population group allows organizations, 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 multidimensional 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.

Table 1 (continued): Health literacy measurement objectives, and recommended tools and approaches

Objective: Assess one element of health literacy		Objective: Understanding the health literacy responsiveness of health and community services	
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.		Measuring the health literacy responsiveness of services allows organizations 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	A scale of a multidimensional questionnaire, or a single score tool that reliably and discretely measures the single element of interest.	Tools	Organizational and resource audit tools, checklists or questionnaires.
Approaches	Questionnaire, semi-structured interview and/or focus group.	Approaches	A systematic practice, product, environment and document/resource audit.

Tools providing a single health literacy score have been used to examine associations between health literacy and outcomes of interest.¹ They can be useful for measuring health literacy at a population level, where the objective is to compare levels of health literacy in population groups or measure changes in population health literacy levels over time. They do not however, account for the multidimensional nature of health literacy. Health literacy encompasses many personal characteristics and social resources.² Tools that provide a single health literacy score can mask particular health literacy strengths or difficulties, and offer little information about the nature of health literacy 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.

Multidimensional 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.⁴ These tools are often longer than tools that measure single elements of health literacy.



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Using qualitative approaches to measure health literacy

Qualitative techniques allow for the collection of information that is often unobtainable through other means. However, these must be undertaken using strong methods and careful analysis, given the risk of bias and the difficulty of generalizing findings from small samples of participants to other populations and contexts.⁵

Using a mixed-methods approach to the measurement of health literacy

A mixed-methods approach involves the use of both qualitative and quantitative data, and is often preferred to offset the weaknesses of each approach.⁶ 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 organizations to the health literacy needs of their consumers should occur in parallel with the measurement of health literacy of individuals and groups.⁷ 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 organization, the accessibility and availability of its information and services for consumers, and the patterns of consumer engagement with these services. See Information Sheet 10 in this series for further information about available tools.



Deciding which health literacy measurement approach to use

The most appropriate approach to measuring health literacy depends on the objectives of the activity. Tools that examine only one or two health literacy elements can be used when the objectives of the activity are to 1) identify the relative level of specific elements of health literacy; 2) evaluate the impact of an intervention on specific elements of health literacy; or 3) explore the association between specific health literacy elements and particular outcomes.

Tools that measure a broad range of health literacy elements and provide scores for each element can be used when the objectives are 1) to gain a broad understanding of the health literacy strengths and limitation of an individual or group; 2) to identify opportunities for intervention; or 3) to evaluate impacts of interventions on a broad range of health literacy elements.

It is important to measure the full range of health literacy dimensions when seeking to develop interventions. Interventions should be constructed with the aim of building upon strengths that exist within the community, and addressing limitations through the provision of supports and capacity-building programmes.

There are instances when surveys are neither culturally nor linguistically appropriate. In these cases, carefully structured qualitative strategies should be used. Where resources allow, a mixed-methods approach is often preferable.

Other considerations include the time and resources available for measurement activities. If these are limiting factors then it can jeopardize the quality of a study. It is better to reduce the scope of the measurement activity than risk drawing unreliable conclusions from data that is of poor quality or misaligned with the questions of interest.⁶



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10

Health literacy measurement tools

The most appropriate health literacy measurement tool for a given setting will depend on the purpose of the data collection and the aims of the project.



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Health literacy measurement tools vary greatly in the elements of health literacy that they measure, the scoring approaches they use, and the results they generate. There is also variation in the amount of time and skills required for administration, and whether they are designed to assess the health literacy of people or the health literacy responsiveness of organizations.

This information sheet will discuss: 1) tools that measure a limited set of health literacy elements; 2) tools that measure a range of health literacy elements; and 3) tools that measure the health literacy responsiveness of organizations.

Tools that measure a limited set of health literacy elements

Haun and colleagues conducted a review of 51 health literacy tools and found that most tools measure a limited range of health literacy dimensions.¹

There are some instances in which assessment of a small number of health literacy dimensions is desired, such as to evaluate the impact of an intervention on a specific set of skills. Haun and colleagues outlined a list of measurement tools with descriptions of the health literacy dimensions that each tool measures.¹



Key resource:

Haun JN, Valerio MA, McCormack LA, Sorensen K and Paasche-Orlow MK. **Health literacy measurement: An inventory and descriptive summary of 51 instruments..** Health Communication: International Perspectives, 2014, 19:sup2, 302-333

Link: <http://dx.doi.org/10.1080/10810730.2014.936571>

Tools that measure a range of health literacy elements

Haun and colleagues¹ identified six health literacy tools that measure six or more dimensions of health literacy:

- Health Activities Literacy Scale of NALS²
- Health Literacy Skills Instrument; short form (HLSI)³
- Health Literacy Assessment Using Talking Touchscreen Technology (Health LiTT)⁴
- Health Literacy Management Scale (HeLMS)⁵
- Health Literacy Questionnaire (HLQ)⁶
- The European Health Literacy Survey (HLS-EU-Q)⁷

Two of these tools have psychometrically distinct scales that allow reliable identification of health literacy strengths and limitations for the individual or within the group being studied: the HeLMS and the HLQ. These tools also include questions and scales that focus on consumers' perspectives of the responsiveness of support and healthcare systems.

For low- and middle-income country settings, the Information and Support for Health Actions Questionnaire (ISHA-Q) has been developed to measure health literacy in cultures where decisions about health are often made by family or peer groups. The ISHA-Q includes a large range of psychometrically robust dimensions and supplementary scales for people with chronic illnesses, people with a physical disability, people who are blind and people who are deaf.



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Tools that measure the health literacy responsiveness of organizations

Kripalani and colleagues⁸ undertook a review of tools that measure an organization's health literacy responsiveness. They identified tools that addressed five or more of the Institute of Medicine's attributes of a health literate organization.⁹

- The Enliven Organizational Health Literacy Self-Assessment Resource¹⁰
- The Health Literacy Universal Precautions Toolkit¹¹
- Communication Climate Assessment Toolkit (C-CAT)^{12,13,14}
- Health Literacy Environment of Hospitals and Health Centers¹⁵
- Advancing Effective Communication, Cultural Competence, and Patient and Family-Centered Care: A Roadmap for Hospitals¹⁶
- Pharmacy Health Literacy Assessment Tool¹⁷
- Health Plan Organizational Assessment of Health Literacy Activities¹⁸
- Consumer Assessment of Healthcare Providers and Systems (CAHPS)¹⁹
- Literacy Audit for Health Literacy Settings (LAHS)²⁰

These tools range in content from checklists and surveys to organizational maps that can assist an organization to measure, monitor and report its level of responsiveness to the health literacy needs of its consumers.



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11

Considerations for measurement of health literacy in low- and middle-income countries

Measurement of health literacy in low- and middle-income countries must consider individual and community contexts.



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The social context of health-related decision-making

Decisions about health are often made by families and communities, and this is particularly so in communal cultures.¹ The available research provides little guidance about whose health literacy is most important in influencing health-related outcomes. **Tools that measure individuals' health literacy should be used with caution and need to be supplemented with data about family or community members' roles, influence and experiences in the decision-making process.** Sometimes it may be important to assess the health literacy of a whole village, or of subgroups or families.

Access to health information, services and resources

Variations in access to health information, services and resources place greater and lesser burdens on the health literacy of individuals. Where costs are high, availability is poor, or a system is complex to navigate, people require strong financial, personal and social resources to make and act on informed health choices. **In a community in which information, services and resources are more readily accessible, people's health literacy requirements can be lower.**

Education and literacy

People have varying levels of education and literacy and this often influences their health literacy.² People adapt and compensate for limitations, however, and therefore literacy will not always be a reliable indicator of health literacy. In cultures with oral communication traditions, people develop effective and sophisticated ways to access health information through their social network. **Measurement approaches must be able to detect the different capacities that people have for engaging with health information and services, allowing for the fact that individuals, families and communities may develop their own effective strategies for engagement.** A mixed-methods approach to measuring health literacy is often needed: a multidimensional health literacy tool that can be orally administered and combined with qualitative methods (such as interviews, focus groups, or community meetings) to supplement and enhance the quantitative data.

Beliefs about health and healthcare

Individual, family and cultural beliefs influence decisions made about health.¹ The variability of beliefs across people and cultures and how these influence decision-making about health, is often difficult to measure. **Qualitative investigation can help uncover beliefs, and supplement and inform quantitative health literacy measurement.**

Integration of traditional and modern health approaches

Traditional approaches to treatment and health management are important in many communities and cultures.³ Understanding these approaches, as well as the ways in which people go about integrating traditional and modern approaches, is important for the assessment of health literacy.

The extent to which health is a priority

Health is often in competition with other personal, family, community and national issues where trade-offs need to be made between caring for health and attending to other concerns. If health is viewed as separate from these other concerns then it can be neglected by individuals, by communities and by governments. However, if health is seen as being connected to community and development activities then opportunities to support and promote health will frequently emerge.

The speed and momentum of development

Many low- and middle-income countries are seeking to introduce universal access to health and to increase the range of services offered to the population.⁴ The speed and frequency of changes can make it difficult for people to understand the services that are available to them and how to access these. Health literacy measurement must take this into consideration.



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12

Health Literacy Questionnaire (HLQ)

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



Credit: Richard Osborne

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, organizations 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 optimize opportunities to improve equity in health outcomes and access.

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 20-45 minutes to complete.



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The nine scales of the Health Literacy Questionnaire (HLQ)



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 or community.

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

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. Cohen's d effect size³ is the difference between two means divided by the average of their standard deviations. A small effect size is between >0.2 and <0.5 ; a medium effect size is between >0.5 and <0.8 ; and an effect size >0.8 is large. 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 are 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 licence to use the HLQ.

Key resource:

Osborne RH, Batterham R, Elsworth GR, Hawkins M, Buchbinder R. **The grounded theory, psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)**. BMC Public Health. 2013;13:658.

Link: <http://www.biomedcentral.com/1471-2458/13/658>



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Source:

Dodson S, Beauchamp A, Batterham RW and Osborne RH. Information sheet 10: About the Health Literacy Questionnaire (HLQ). In Ophelia Toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities. Part A: Introduction to health literacy. 2014. Available from www.ophelia.net.au.

13

Information and Support for Health Actions Questionnaire (ISHA-Q)

The Information and Support for Health Actions Questionnaire (ISHA-Q) identifies specific health literacy strengths and limitations of people and communities. It was designed for cultures in which decision-making about health is often a communal activity.



Credit: [istockphoto.com/Kevin Landwer-Johan](https://www.istockphoto.com/Kevin-Landwer-Johan)

The Information and Support for Health Actions Questionnaire (ISHA-Q) was developed to measure health literacy in low- and middle-income settings, and in 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 multidimensional tool that offers providers, organizations 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 optimize 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, strong construct validity and reliability across a wide variety of groups, administered on paper, orally or by sign language. It is shown to provide unbiased mean estimates of group differences.

Languages available

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



Credit: istockphoto.com/ pressdigital

The fourteen core scales of the Information and Support for Health Actions Questionnaire (ISHA-Q)



The ten supplementary scales of the Information and Support for Health Actions Questionnaire (ISHA-Q)

Needs of people who are deaf

(13 questions)

- D1. Health service accessibility and helpfulness (for deaf people)
- D2. Equipment (to assist in communication for health care)
- D3. Use of interpreters

Needs of people who are blind

(13 questions)

- B1. Health service accessibility and helpfulness (for blind people)
- B2. Equipment (to assist in care of own health)
- B3. Accessing information in formats suitable for blind people

Needs of people with physical disability

(9 questions)

- PD1. Health service accessibility and helpfulness (for people with a physical disability)
- PD2. Equipment (to assist in care of own health)

Needs of people with chronic illness

(8 questions)

- CI1. Sharing information with others with the same condition
- CI2. Self-monitoring

Structure and administration of the ISHA-Q

The ISHA-Q has 14 core scales, and 10 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 being assessed, and the number of scales used. It usually takes 8-20 minutes for someone to complete the core scales on paper. When orally administered by telephone or in person, the core scales take 15-35 minutes to complete.



Credit: istockphoto.com/narvikk

Scoring the ISHA-Q and reporting the findings

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.

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

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. Cohen's d effect size¹ is the difference between two means divided by the average of their standard deviations. A small effect size is between >0.2 and <0.5 ; a medium effect size is between >0.5 and <0.8 ; and an effect size >0.8 is large. 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.

Accessing the ISHA-Q

Visit the Ophelia.net.au website to register for a license to use the ISHA-Q.

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1. Cohen J: Statistical power analysis for behavioral sciences (revised ed.) New York: Academic Press; 1977.

Source:

Dodson S, Beauchamp A, Batterham RW and Osborne RH. Information sheet 11: About the Information and Support for Health Actions Questionnaire (ISHA-Q). In Ophelia Toolkit: A step-by-step guide for identifying and responding to health literacy needs within local communities. Part A: Introduction to health literacy. 2014. Available from www.ophelia.net.au.



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1

Understanding the health literacy needs of a South African community

Changes from within and by a community will outlast any project.



Credit: Mothers Unite

Mothers Unite

Mothers Unite was founded in 2008 by a group of mothers who realized that the children in their community were not getting enough food. Mothers Unite is now a registered non-profit organization supporting the children and families of Lavender Hill (near Cape Town) to improve their lives. The facilitators of Mothers Unite are also trained as Emergency First Aid Responders (EFARs) as part of a community-based health program linked into the local Emergency Medical System. Emergency First Aid Responders (EFARs) are community members who can respond quickly to emergencies and provide care until emergency services arrive. This and the many Mothers Unite projects offer a range of opportunities for improving the health literacy of the people in this community.

The Mothers Unite health literacy project

The aims of the Mothers Unite health literacy project were to determine how to empower people to better understand their health, to be more active participants in their health, and to be better engaged with the healthcare system. The first step was to undertake a needs assessment to understand the health literacy of the people within the Lavender Hill informal settlement.

Understanding the health literacy of the Lavender Hill community

Initially, an understanding of the community's health literacy needs was sought through focus groups. However, these proved difficult to arrange and the data difficult to interpret. Following this experience, it was decided to collect quantitative data using a multi-dimensional tool that enabled examination of a range of health literacy concepts. They chose the Health Literacy Questionnaire (HLQ) and to supplement the HLQ results with qualitative data from interviews.

The HLQ was translated into Afrikaans for the Mothers Unite project. However, after some initial testing of the translation, it was determined that community members preferred the HLQ to be in both Afrikaans and English so they could complete it in the language they preferred.

The Mothers Unite Emergency First Aid Responders (EFARs) approached and supported community members to complete the HLQ. Basic training to administer the HLQ was provided to 8 EFARs. They collected HLQs from 3 groups of people: 100 community members; 93 EFARs; and 100 patients presenting for care at a community health clinic.

The health literacy of the Lavender Hill community

The data from the HLQ presented findings that were unexpected. It was thought that health literacy would be highest among the EFARs, however, the data showed that all 3 groups had similar health literacy profiles. The EFARs only scored higher in being able to navigate the healthcare system, which may be a reflection of their training in emergency response care. Other than this, the similarity of health literacy profiles across groups may indicate that the EFAR training is specific to emergency situations and does not act as a basis for improving health literacy in the other areas measured by the HLQ.

Using the data to identify health literacy response ideas

Mothers Unite used the Ophelia Approach¹ to work with the local community to generate ideas about what to do in response to the findings of the HLQ and interview data. People from a variety of groups and services, with a range of skills and experience to offer, attended workshops to discuss the findings and plan what to do.

Prioritizing the response ideas

A key issue that emerged from the data was that community members found it difficult to navigate the healthcare system. This was confirmed by the participants of the Ophelia workshops. In response to this health literacy challenge, training and resources are being developed for EFARs to volunteer their time in community clinics to help people find what they need in the healthcare system. This might include finding the right healthcare service, making an appointment, or figuring out where to go for care.

Key learnings and reflections

It was found that the EFAR program and the Ophelia Approach¹ have important principles in common: respect local wisdom, encourage self-determination, and build local capacity. A strong alignment between the goals of Mothers Unite and the objectives of the health literacy project enabled the work to easily progress.

Mothers Unite offers this advice to others who wish to do similar health literacy research: *“Before doing anything, find out who is enthusiastic about the approach and wants to work in partnership. Handing out questionnaires is just the beginning; it is much longer than just data collection, and co-ownership is needed during the whole process.”*

Mothers Unite involved community members with the project right from the beginning. Information about the health literacy strengths and limitations of the community came directly from the people living in Lavender Hill. People from the community were participants in the workshops and heard the results of the assessment and helped with generating ideas to address the issues identified. As well as helping to develop solutions to health literacy challenges, being involved in the project appeared to build the capacity of those involved.

“A profound respect was gained for where people are going and what they already have in place. For change to happen quickly and effectively, in a way that flows with the community already, it has to come from within the community itself.”

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Link: <http://www.mothersunite.org.za/>

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Understanding the health literacy needs of a Thai community

Village health volunteers act as important sources of health information for the community, and can also be mobilized to collect data about community health literacy strengths and limitations.



Credit: istockphoto.com/ urf

The Warin Chamrap Ophelia Project

Warin Chamrap district is located in western Ubon Ratchathani Province, northeastern Thailand. The aim of the Warin Chamrap Ophelia Project was to understand the health literacy strengths and limitations of the local community, and the effects that health literacy has on access to healthcare. An important research question for this project is whether or not health literacy varies more *within* or *between* villages given that community resources are often the same for most people living in a village.

Understanding the health literacy of the Warin Chamrap community

The Information and Support for Health Actions Questionnaire (ISHA-Q) was developed in Thailand. It was designed to measure health literacy in cultures where decision-making about health often occurs as a collective activity of family or peer groups. The Warin Chamrap Ophelia Project used the ISHA-Q to conduct a health literacy needs assessment of people across the community. The local community hospital took leadership of the project, but highlighted the importance of collecting data from the whole community, not just people using hospital services.

To enable a whole-of-community approach, a single subdistrict was chosen for an initial pilot survey and people were randomly recruited from each of the 10 villages in this subdistrict. Village health volunteers were trained to administer the ISHA-Q.

The health literacy of older people in Warin Chamrap district

Data collection is ongoing, however early results from ISHA-Q data suggest that the strongest similarities in health literacy profiles appear between people *within* villages, rather than *between* villages. Another interesting finding is the apparent strong link between lower health literacy and lower levels of participation in physical activity. The link with physical activity appears even stronger than the link between health literacy and other behaviors, such as using medications as recommended.

Using the data to identify health literacy response ideas

Following the Ophelia Approach, the Warin Chamrap Ophelia Project will work with the local communities to generate ideas about what to do in response to the findings of the ISHA-Q community survey. People from a variety of groups and services, with a range of skills and experience to offer, will attend workshops to discuss the findings and plan what to do.

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PART C:

Responding to the Health Literacy of Communities

There is potential to use health literacy responses to further improve and sustain health outcomes for people in low- and middle-income countries.

14

Applying health literacy responses to improve outcomes in maternal and child health

There is potential to use health literacy responses to further improve and sustain maternal and child health outcomes in low- and middle-income countries.



Credit: istockphoto.com/ Bartosz Hadyniak

Maternal and child health outcomes in low- and middle-income countries

There have been steady improvements in maternal and child health outcomes since the introduction of Millennium Development Goals (MDGs) 4 and 5, which focus on the reduction of child mortality and improvement in maternal health. These improvements include a global under-5 mortality rate in 2012 that is almost half that of 1990, and a maternal mortality ratio that fell by 45% from 1990 to 2013.¹ However, the rate of maternal and child deaths in low- and middle-income countries remains higher than that of developed countries.¹ More work is needed to address chronic under-nutrition among young children, as well as the preventable diseases that are responsible for high rates of child mortality, and the largely preventable deaths during pregnancy and childbirth.¹

Women's engagement with and access to health information and services is affected by the social context within which they live. Women in low- and middle-income countries often have less personal autonomy, and less access to information about their health than do their male counterparts.² Other key barriers to women's access to healthcare include long distances to healthcare facilities, a lack of trust in the healthcare system and the quality of care provided, and the limited number of trained healthcare providers and properly-equipped facilities.³⁻⁷



Credit: iStockphoto.com/ Bartosz Hadyniak

The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.⁸ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain maternal and child health outcomes.

1. Make information and services for family planning, pre- and post-natal care, immunization, and child health more available and accessible.
2. Enhance the ability and willingness of women and their families to:
 - a. engage with family planning, pre- and post-natal care, immunization, and child health information and services that are already available;
 - b. communicate and assert decisions that relate to family planning, pre- and post-natal care, immunization, and the health of their young children;
 - c. take appropriate actions to implement the decisions they make about their health and that of their children.



Credit: istockphoto.com/ karelnoppe

Key considerations for the development and implementation of health literacy responses to improve maternal and child health outcomes in low- and middle-income countries

The Ophelia principles*⁸ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
- maternal and child health outcomes;
 - family planning, pre- and post-natal care, immunization, and child illness management behaviors;
 - family engagement with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of families.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of families.

- 2** use available maternal and child health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
- families that have poorer health outcomes or less-than-optimal access to services;
 - maternal and child health issues or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
- discussions about local maternal and child health needs and considerations;
 - discussions about universal precautions that relate to maternal and child health;
 - determining local maternal and child health priorities for action;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective maternal and child health interventions and strategies.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all families.

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15

Applying health literacy responses to improve outcomes for adolescents

There is potential to use health literacy responses to further improve and sustain outcomes for adolescents in low- and middle-income countries.



Credit: istockphoto.com/jcarillet

Adolescent health outcomes in low- and middle-income countries

Adolescence is a period of rapid growth when many social, emotional and physiological changes occur. During this time, many adolescents feel pressure to engage in risky behaviors, which can increase the likelihood of intentional and unintentional harms befalling them.¹

The leading causes of death among adolescents in low- and middle-income countries vary by age, sex and region. However, overall, road traffic injury is the most common cause of death, with HIV-related illness following closely behind it.^{1,2} In sub-Saharan Africa, the leading cause of death in females aged 15 to 24 years is communicable disease and pregnancy-related conditions.³

There is a high rate of alcohol use and violence among male youth, as well as the practice of unprotected sex.² Inequitable gender norms contribute to high rates of sexual coercion, gender-based violence, HIV and other STD infections as well as unwanted pregnancies.⁴ Culturally-appropriate youth-friendly health information and services to guide and support adolescents in low- and middle- income countries is lacking.³



Credit: istockphoto.com/ Peeter Viisimaa

The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.⁵ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain adolescent health outcomes.

1. Make information and services for adolescent health, and about safe sexual practices and alcohol use more available and accessible.
2. Enhance the ability and willingness of adolescents to:
 - a. engage with adolescent and sexual health, and alcohol-related information and services that are already available;
 - b. communicate and assert their health decisions;
 - c. take appropriate actions to implement the decisions they make about their health.



Credit: istockphoto.com/ Bartosz Hadyniak

Key considerations for the development and implementation of health literacy responses to improve adolescent health outcomes in low- and middle-income countries

The Ophelia principles*⁵ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
 - adolescent health outcomes;
 - safe sexual practices and alcohol use;
 - adolescent engagement with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of adolescents.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of adolescents.

- 2** use available adolescent health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
 - adolescents that have poorer health outcomes or less-than-optimal access to services;
 - adolescent health issues or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
 - discussions about local adolescent health needs and considerations;
 - discussions about universal precautions that relate to adolescent health;
 - determining local adolescent health priorities for action;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective adolescent health interventions and strategies.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all adolescents.

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16

Applying health literacy responses to improve outcomes for women

There is potential to use health literacy responses to further improve and sustain outcomes for women in low- and middle-income countries.



Credit: istockphoto.com/ Africanway

Women's health outcomes in low- and middle-income countries

Over the past three decades, the global female life expectancy at birth increased from 61 to 73 years.¹ Other regional trends include a striking decline in female mortality in South-East Asia. However, these gains have been alongside substantial increases in HIV-related adult female mortality occurring in sub-Saharan Africa and in countries in or related to the former Soviet Union.²

Many women in low- and middle-income countries face health challenges that are gender-related and influenced by social, cultural and demographic factors. The public health focus for women has been on sexual and reproductive health although, increasingly, chronic diseases are gaining attention.^{2,3} While there have been small gains in MDG3 (to promote gender equality and empower women) such as improvements in early education, issues such as violence against women and discrimination in education and employment continue to contribute to the disempowerment of women.⁴

There is a strong association between the empowerment of women and the health of communities.⁵ Women are key seekers and disseminators of health information.^{6,7} It is estimated that women make 80% of family health decisions and are usually the primary care givers.⁸



The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.⁹ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain women's health outcomes.

1. Make information and services for women's health, chronic disease and about sexual and reproductive health more available and accessible.
2. Enhance the ability and willingness of women to:
 - a. engage with women's, chronic disease, and sexual and reproductive health information and services that are already available;
 - b. communicate and assert their health decisions;
 - c. take appropriate actions to implement the decisions they make about their health.



Key considerations for the development and implementation of health literacy responses to improve health outcomes for women in low- and middle-income countries

The Ophelia principles*⁹ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
 - women's health outcomes;
 - diet, physical activity levels, safe sexual practices, and family planning behaviors;
 - women's engagement with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of women.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of women.

- 2** use available women's health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
 - women that have poorer health outcomes or less-than-optimal access to services;
 - women's health issues or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
 - discussions about local women's health needs and considerations;
 - discussions about universal precautions that relate to women's health;
 - determining local women's health priorities for action;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective women's health interventions and strategies.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all women.

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17

Applying health literacy responses to improve outcomes for the elderly

There is potential to use health literacy responses to further improve and sustain outcomes for older people in low- and middle-income countries.



Credit: istockphoto.com/ Bartosz Hadyniak

Health outcomes for older people in low- and middle-income countries

It is estimated that people aged 60 and over will comprise over 20% of the world's population by mid century¹, increasing in number from 841 million in 2013 to over 2 billion in 2050. Two thirds of the world's elderly live in low- and middle-income countries, and this is expected to rise to 80% by 2050.¹

Older people from developing countries carry a greater disease burden than their counterparts in developed countries, with noncommunicable diseases such as heart disease, stroke and chronic lung disease being the major causes of death.² Since poverty is a strong predictor of ill health, and the prevalence of malnutrition is higher among poor older people³, ignoring the wellbeing of the elderly is detrimental to achieving Millennium Development Goal (MDG) 1 to eradicate extreme poverty and hunger.⁴



Credit: istockphoto.com/ pressdigital

The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.⁵ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain health outcomes for older people.

1. Make information and services for chronic disease management and functional decline more available and accessible.
2. Enhance the ability and willingness of older people to:
 - a. engage with chronic disease, and functional decline related information and services that are already available;
 - b. communicate and assert their health decisions;
 - c. take appropriate actions to implement the decisions they make about their health.



Credit: istockphoto.com/ leungchopan

Key considerations for the development and implementation of health literacy responses to improve health outcomes for elderly people in low- and middle-income countries

The Ophelia principles*⁵ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HHealth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
- health outcomes of older people;
 - diet, physical activity levels, and chronic disease and physical function management behaviors;
 - engagement of older people with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of older people.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of older people.

- 2** use available health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
- older people that have poorer health outcomes or less-than-optimal access to services;
 - health issues relating to older people or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
- discussions about local health needs and considerations relating to older people;
 - discussions about universal precautions that relate to the health of older people;
 - determining local health priorities for action relating to older people;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective health interventions and strategies for older people.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all older people.

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18

Applying health literacy responses to improve outcomes for people with chronic disease

There is potential to use health literacy responses to further improve and sustain outcomes for people with chronic disease in low- and middle-income countries.



Credit: istockphoto.com/ Bartosz Hadyniak

Health outcomes for people with chronic diseases in low- and middle-income countries

Chronic diseases are a leading causes of death and disability globally.¹ It is estimated that 38 million people die from chronic diseases annually, of which 85% are in low- and middle-income countries.²

Chronic diseases present a major challenge to developing countries where 33 million people are living with HIV/AIDS, 246 million have diabetes and 1 billion have hypertension.¹ The majority of overweight or obese children live in developing countries. In the African region alone, the number of overweight or obese children increased from 4 to 10 million between 1990 and 2012.³ Chronic diseases are also driving many people into poverty due to the cost of treatments.⁴

In the action plan for prevention of noncommunicable diseases, the WHO has advocated for plans to promote health literacy as part of the effort to prevent chronic diseases.⁵ Health literacy responses also support people with chronic conditions to understand health information, follow treatment regimens, access healthcare services, and make healthcare decisions.^{6,7}



Credit: istockphoto.com/ fotofritz16

The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.⁸ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain health outcomes for people with chronic diseases.

1. Make information and services for chronic disease management more available and accessible.
2. Enhance the ability and willingness of people with chronic disease to:
 - a. engage with chronic disease related information and services that are already available;
 - b. communicate and assert their health decisions;
 - c. take appropriate actions to implement the decisions they make about their health.



Credit: istockphoto.com/ michelangeloop

Key considerations for the development and implementation of health literacy responses to improve health outcomes for people with chronic disease in low- and middle-income countries

The Ophelia principles*⁸ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
 - health outcomes of people with chronic disease;
 - diet, physical activity levels, and chronic disease management behaviors;
 - engagement of people with chronic disease with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of people with chronic disease.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of people with chronic disease.

- 2** use available health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
 - people with chronic disease that have poorer health outcomes or less-than-optimal access to services;
 - chronic diseases or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
 - discussions about local chronic disease issues and considerations;
 - discussions about universal precautions that relate to people with chronic disease;
 - determining local chronic disease priorities for action;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective chronic disease interventions and strategies.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all people with chronic disease.

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Applying health literacy responses to improve outcomes for ethnic minority groups

There is potential to use health literacy responses to further improve and sustain outcomes for ethnic minority groups in low- and middle-income countries.



Credit: istockphoto.com/ Mr_Khan

Health outcomes for ethnic minority groups in low- and middle-income countries

In almost all countries, minorities and indigenous peoples are among the poorest and most vulnerable groups, experiencing worse health and receiving poorer quality of care than the rest of the population.^{1,2} Ethnic minorities have higher burdens of chronic disease, nutritional deficiencies, maternal and infant mortality, sexually transmitted diseases, mental health conditions and access to health services.¹⁻⁸

Whilst some progress has been made towards MDGs 1,2 and 3 to address the social determinants of health for minority groups, much work remains. There is widespread agreement that tackling inequality using a human rights approach should be central to the post-2015 Development Framework that will replace the MDGs.¹

There are many barriers to health care for ethnic minority groups, including low health literacy, different beliefs about health and illness and professional support, lack of culturally-appropriate services and information, uneven distribution of healthcare resources and geographical barriers.^{9,10}



Credit: istockphoto.com/BDphoto

The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.¹¹ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain health outcomes for people from ethnic minority groups.

1. Make health information and services more available and accessible to people who speak different languages and share different cultural beliefs.
2. Enhance the ability and willingness of people from ethnic minority groups to:
 - a. engage with health information and services that are already available;
 - b. communicate and assert their health decisions;
 - c. take appropriate actions to implement the decisions they make about their health.



Credit: istockphoto.com/ pressdigital

Key considerations for the development and implementation of health literacy responses to improve health outcomes for people from ethnic minority groups in low- and middle-income countries

The Ophelia principles*¹¹ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
 - health outcomes for people from ethnic minority groups;
 - health and illness management behaviors of people from ethnic minority groups;
 - engagement of people from ethnic minority groups with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of people from ethnic minority groups.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of people from ethnic minority groups.

- 2** use available health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
 - people from ethnic minority groups that have poorer health outcomes or less-than-optimal access to services;
 - health issues of people from ethnic minority groups or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
 - discussions about local health needs and considerations for ethnic minority groups;
 - discussions about universal precautions that relate to the health of people from ethnic minority groups;
 - determining local health priorities for action that relate to the needs of people from ethnic minority groups;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective health interventions and strategies for people from ethnic minority groups.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all people from ethnic minority groups.

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20 Applying health literacy responses to improve outcomes for refugee and asylum seekers

There is potential to use health literacy responses to further improve and sustain outcomes for refugee and asylum seekers in low- and middle-income countries.



Credit: istockphoto.com/ Bartosz Hadyniak

Health outcomes for refugee and asylum seekers in low- and middle-income countries

During the past four decades, millions of people have fled their homes and sought asylum in other countries. Half of the world's asylum seekers and refugees live in non-camp settings¹, mainly in urban areas², and nearly 80% are located in low- and middle-income countries (mostly sub-Saharan Africa and Asia).³

Common health concerns for refugees and asylum seekers include psychological disorders, injuries, infectious diseases, and chronic disease.⁴⁻⁷ The management of refugee health needs in camp settings can be particularly challenging given the limited resources available.⁶ Refugees in urban areas in low- and middle-income countries also face access issues due to limited resources, the hidden and scattered nature of the population, lack of security, and cultural and language barriers. Issues of legal recognition can be additional obstacles to care, even in countries with good healthcare systems.



Credit: istockphoto.com/ sadikgulec

The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.⁸ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain health outcomes for refugee and asylum seekers.

1. Make health information and services more available and accessible to refugees and asylum seekers and to people who speak different languages and share different cultural beliefs.
2. Enhance the ability and willingness of refugees and asylum seekers to:
 - a. engage with health information and services that are already available;
 - b. communicate and assert their health decisions;
 - c. take appropriate actions to implement the decisions they make about their health.



Credit: istockphoto.com/ journalturk

Key considerations for the development and implementation of health literacy responses to improve health outcomes for refugee and asylum seekers in low- and middle-income countries

The Ophelia principles*⁸ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
 - health outcomes for refugees and asylum seekers;
 - health and illness management behaviors of refugee and asylum seekers;
 - engagement of refugee and asylum seekers with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of refugee and asylum seekers.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of refugee and asylum seekers.

- 2** use available health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
 - refugees and asylum seekers that have poorer health outcomes or less-than-optimal access to services;
 - health issues of refugee and asylum seekers or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
 - discussions about local health needs and considerations for refugee and asylum seekers;
 - discussions about universal precautions that relate to the health of refugee and asylum seekers;
 - determining local health priorities for action that relate to the needs of refugee and asylum seekers;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective health interventions and strategies for refugee and asylum seekers.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all refugee and asylum seekers.

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21

Applying health literacy responses to improve outcomes for people with disabilities

There is potential to use health literacy responses to further improve and sustain outcomes for people with disabilities in low- and middle-income countries.



Credit: istockphoto.com/ Shutterstitch

Health outcomes for people with disabilities in low- and middle-income countries

Disability affects approximately 15% of the world's population.¹ Disability rates globally are on the rise due to aging populations and increasing rates of chronic disease.¹ Low- and middle-income countries are particularly affected because of a higher proportion of disabled people than in the high-income countries.² The mortality rates and health concerns of disabled people vary between settings and conditions.

Individuals with intellectual disabilities are particularly vulnerable to chronic disease, and have poorer access to appropriate health care.³ The negative financial effects of living with a disability are also significant, and access to personalized education is often unavailable or insufficient.⁴ With limited access to education, people with disabilities tend to have lower literacy skills.⁵



Credit: istockphoto.com/ zhaojiankang

The role of health literacy responses

People interact with information, environments, resources and supports as they make health decisions. The health literacy responsiveness of services interacts with the health literacy of people making and supporting health decisions, and both influence the decisions made.⁶ Health decisions often lead to health actions, which in turn contribute to health outcomes.

There is potential to use health literacy responses to further improve and sustain health outcomes for people with disabilities.

1. Make health information and services more available and accessible to people with disabilities.
2. Enhance the ability and willingness of people with disabilities to:
 - a. engage with health information and services that are already available;
 - b. communicate and assert their health decisions;
 - c. take appropriate actions to implement the decisions they make about their health.



Key considerations for the development and implementation of health literacy responses to improve health outcomes for people with disabilities in low- and middle-income countries

The Ophelia principles*⁶ provide guidance to projects and help ensure that, at each phase, the potential to improve health and equity through health literacy responses is optimized.

* *Ophelia means OPTimizing HEalth Literacy and Access to health information and services.*

The Ophelia principles:

- 1 Focus on improving health and wellbeing **outcomes**
- 2 Focus on increasing **equity** in health outcomes and access to services for people with varying health literacy needs
- 3 Prioritize **local wisdom, culture and systems**
- 4 Respond to **locally-identified health literacy needs**
- 5 Respond to the **varying and changing health literacy needs** of individuals and communities
- 6 Engage all relevant stakeholders in the **co-creation** and implementation of solutions
- 7 Focus on improvements at, and across, **all levels of the health system**
- 8 Focus on achieving **sustained improvements** through changes to environments, practice, culture and policy

Key recommendations for action

- 1** develop systems for measuring, monitoring and reporting:
 - health outcomes for people with disabilities;
 - health and illness management behaviors of people with disabilities;
 - engagement of people with disabilities with health and community services;
 - the health literacy responsiveness of organizations; and
 - the health literacy strengths and limitations of refugee and asylum seekers.

Note: Use a multi-dimensional measure of health literacy and/or qualitative methods to identify the health literacy strengths and limitations of people with disabilities.

- 2** use available health, health behavior, service engagement, organizational responsiveness, and health literacy data to identify local needs. Identify:
 - people with disabilities that have poorer health outcomes or less-than-optimal access to services;
 - health issues of people with disabilities or related behaviors of concern for the community; and/or
 - barriers to service access, equity or availability. These barriers may exist within the health system or they may be broader social or environmental factors.

- 3** engage local, regional and/or national stakeholders in:
 - discussions about local health needs and considerations for people with disabilities;
 - discussions about universal precautions that relate to the health of people with disabilities;
 - determining local health priorities for action that relate to the needs of people with disabilities;
 - identifying interventions and strategies to address priority issues;
 - designing and developing interventions and strategies;
 - implementing and evaluation interventions and strategies; and
 - continuous quality improvements to ensure ongoing effectiveness and sustainability.

- 4** scale up effective health interventions and strategies for people with disabilities.

- 5** develop and implement policies that promote identification of health literacy issues and the implementation of targeted responses.

- 6** develop and implement policies that promote equitable access to information and services for all people with disabilities.

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3

Responding to health literacy needs of the Roma in Slovakia

Key strengths of the Healthy Communities Project include the value it places on community participation, its flat management structure, and the explicit prioritization of programme sustainability and ongoing development.



Credit: Platform for Support of the Health of Disadvantaged Groups

The Roma of Slovakia

Roma people in Central and Eastern Europe have shorter life expectancies and higher morbidity than non-Roma people.¹ There are 400,000 Roma who reside in Slovakia, with about half living across 500 disadvantaged and segregated settlements.² Health disparities are particularly stark for segregated Roma communities³⁻⁵ with ongoing structural disadvantage and poor health literacy believed to account for these disparities.³⁻⁵

The Healthy Communities Project

The Healthy Communities Project started as a small pilot programme in 2002. It sought to actively engage Roma to address the health issues of segregated communities.

Responding to the health needs of Roma communities in Slovakia

The Healthy Communities Project involves targeted recruitment of health assistants from within selected segregated Roma communities. The only formal requirement for employment is to have completed elementary education. The health assistant role involves providing opportunistic face-to-face health information and encouragement to increase the knowledge and motivation of community members in the management of their health. Their role also involves facilitating access to healthcare services where necessary. Health assistant coordinators in each locality support and supervise health assistants and establish networks of cooperation among local authorities to address structural disadvantages in the communities.



Credit: Platform for Support of the Health of Disadvantaged Groups

Outcomes of the Healthy Communities Project

Since its inception, the Healthy Communities Project has expanded substantially and is now managed by The Platform for Support of the Health of Disadvantaged Groups.⁶ The Platform now offers services across two thirds of Slovakia and is staffed predominantly by Roma. It employs over 200 health assistants recruited directly from within the segregated settlements, over 20 health-assistant coordinators, and a small team of managers and executives.

Over a three month period in 2014, across more than 100 localities, staff reported providing services to over 18,000 Roma. They report referring over 10,000 individuals to preventative general practitioner visits, and over 11,000 individuals for vaccination. Staff members regularly report anecdotes of rewarding changes they have observed in the families they support. These include reports of Roma people who have registered for long-term therapeutic programmes, or who are carrying out care recommendations for newborns and infants, engaged with vaccination programmes, or who have had insurance access issues resolved.⁷ The initiative is increasing Roma understanding, access and use of health information and services; that is, increasing health literacy.

Key learnings and reflections

Key strengths of the Healthy Communities Project include the value it places on community participation, its flat management structure, and the explicit prioritization of programme sustainability and ongoing development. The programme's management structure has enabled substantial growth during its 12 years of operation.

A qualitative evaluation of the programme's day-to-day operations was conducted by an independent anthropologist in 2014. The report confirmed the successful aspects of the programme and identified areas for improvement. These recommendations included putting greater emphasis on network building; studying the effectiveness of the interventions provided by the health assistants; and strengthening mechanisms for collecting feedback from the community.⁸ Collaboration with researchers from the P.J. Sagarik University in Kosice has led to a mixed-methods intervention study being undertaken to advance the understanding of the real impact of the programme on the health and health literacy of the Roma people in Slovakia.

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For Low- and Middle-Income Countries

A series of information sheets to help empower communities and strengthen health systems

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