

Health literacy development for the prevention and control of noncommunicable diseases

Volume 1

Overview





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Health literacy development for the prevention and control of noncommunicable diseases: Volume 1. Overview

(Health literacy development for the prevention and control of noncommunicable diseases. Volume 1. Overview – Volume 2. A globally relevant perspective – Volume 3. Recommended actions – Volume 4. Case studies from WHO National Health Literacy Demonstration Projects)

ISBN 978-92-4-005533-9 (electronic version) ISBN 978-92-4-005534-6 (print version)

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Design and layout by Kasia Geernaert.

Case study illustrations by Mina Teh, Nicki Wragg, and Shivani Tyagi.

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Foreword by the WHO Director-General



The burden caused by the epidemic of noncommunicable diseases (NCDs) and mental health conditions and their modifiable risk factors on people, communities and economies is a major challenge to health, well-being and sustainable and equitable development. Governments need to address the urgency of investing in healthy populations and resilient health systems, with increased investments in prevention, screening, early diagnosis and appropriate treatment for NCDs. They must do so through inclusive, contextual and equity-driven strategies that are fit for local purposes and with a commitment to leaving no one behind.

A key enabler to accelerating progress towards the NCD targets in the Sustainable Development Goals is health literacy, to support people, communities and organizations to understand, recognize and take effective actions to protect and promote their own health.

This report provides practical recommendations for developing health literacy interventions to support countries to systematize the co-design of health literacy actions to enhance the impact of policies, programmes and services for the prevention and control of NCDs and mental health conditions, and their modifiable risk factors and determinants.

These recommendations draw from the findings of 16 case studies from low- to high-income countries, which have generated data supporting the development of locally owned and fit-for-purpose NCD strategies that are more likely to be embraced, implemented and sustained, especially among disadvantaged and poor communities.

The imperative is for rapid development and systematic implementation of country-relevant, context-specific solutions. The wide-scale implementation of the guidance contained in this report by World Health Organization (WHO) Member States will generate implementable and sustainable NCD health literacy development actions that respond to local contexts and demand. This will help to drive progress towards the WHO Triple Billion targets and improve health and well-being for current and future generations.

Tedros Adhanom Ghebreyesus

Acknowledgements

Acknowledgements are due to all those who contributed to this report.

This report is based on the findings of the WHO Global Coordination Mechanism on the Prevention and Control of Noncommunicable Diseases (GCM/NCD) Working Group on Health Education and Health Literacy for NCDs; recommendations emanating from the WHO Independent High-level Commission on Noncommunicable Diseases; global health literacy research and practice, including guidance and resources from across WHO and leading partners and stakeholders; consultations with people involved in health literacy practices; and insights from the WHO National Health Literacy Demonstration Projects (NHLDPs) undertaken in diverse contexts, cultures and countries using practical co-design approaches to accelerate responses for the effective prevention and control of NCDs and mental health conditions.

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The following experts provided content or reviewed the report: Rosmond Adams (Pan Caribbean Partnership Against HIV and AIDS, Saint Vincent and the Grenadines), Wagida A Anwar (Ain Shams University, Egypt), Mark M Bakker (Maastricht University, Netherlands), May Myat Cho (WHO, Switzerland), Xavier Debussche (Centre Hospitalier Universitaire de la Réunion, France), Sónia Dias (Nova University Lisbon, Portugal), Mohamed El Helaly (Population Sector and Primary Health Care, Egypt), Javier Gállego-Diéguez (Dirección General de Derechos y Garantías de los Usuarios,

Gobierno de Aragón, Spain), Gaya Gamhewage (WHO Global Academy, Switzerland), Suvajee Good (WHO Regional Office for South-East Asia, India), Hanaa Hussein (Department of Health Education, Egypt), Norhayati Kassim (Ministry of Health, Brunei Darussalam), Manmeet Kaur (PIMGER, India), Graham Kramer (NHS Shetland, United Kingdom of Great Britain and Northern Ireland), Diane Levin-Zamir (International Union for Health Promotion Education, Israel), Isabel Loureiro (Nova University Lisbon, Portugal), Janis Morrissey (Irish Heart Foundation, Ireland), Christos Mylonas (WHO Global Academy, Switzerland), Amal Philip (Population Sector, Ministry of Health and Population, Egypt), Blythe Robertson (NHS Education for Scotland, United Kingdom), Nahla Roushdy (Population Sector, Ministry of Health and Population, Egypt), Kristine Sørensen (Global Health Literacy Academy, Denmark), Astrid Wahl (University of Oslo, Norway), Diane Webb (Department of Health, State Government of Tasmania, Australia) and Kenneth Anchang Yongabi (Imo State University, Nigeria).

The following experts contributed to the NHLDPs at country level: Australia – Mel Davis, Shandell Elmer, Rosie Nash and Richard Osborne; Brunei Darussalam – Khadizah Bakri, Hjh Norhayati Binti Hj Kassim; Canada – Rebecca Erker, Donna Goodridge; Denmark – Anna Aaby, Helle Maindal; Egypt – Wagida A Anwar; France – Xavier Debussche; Ireland – Laura Hickey, Janis Morrissey; Mali – Stéphane Besançon, Xavier Debussche; Netherlands – Mark M Bakker, Polina Putrik; Norway – Christine Råheim Borge, Astrid K Wahl; Portugal – Adalberto Campos Fernandes, Sónia Dias, Isabel Loureiro; Slovakia – Peter Kolarčik.

Acknowledgements

Abbreviations

eHLQ

eHealth Literacy Questionnaire

GCM/NCD

World Health Organization Global Coordination Mechanism on the Prevention and Control of Noncommunicable Diseases

HICs

high-income countries

HLQ

Health Literacy Questionnaire

LMICs

low- and middle-income countries

NCD

noncommunicable disease

NHLDP

National Health Literacy Demonstration Project

Ophelia process

Optimising Health Literacy and Access process

Org-HLR

Organisational Health Literacy Responsiveness

SDGs

Sustainable Development Goals

WHO

World Health Organization

Key terms and concepts

Being left behind

Being left behind relates to the motto of the Sustainable Development Goals – "Leave no one behind". This refers to groups or communities that are not included in services or do not have equitable access to health information and services for the prevention and control of NCDs. It indicates a gap in society where groups or communities are missing out on opportunities to prevent and control NCDs or to maintain, manage or improve their health, which leads to poorer health status compared with other groups in the society.

Co-design

This is the active and meaningful engagement and participation of relevant stakeholders (e.g. people with lived experiences, community members, health workers, clinicians and other professionals, managers, policy-makers) throughout the process of designing health-care services and health-promotion activities, drawing on their experience and in-practice wisdom.

Determinants of health

These are the range of personal, social, economic and environmental factors that determine the healthy life expectancy of individuals and populations. Health determinants vary for countries, regions, communities, villages, families and individuals.

Globally relevant perspective of health literacy

A globally relevant perspective of health literacy recognizes the diverse ways in which knowledge is produced, transferred, exchanged and used in different countries, cultures and settings around the world, especially how knowledge accumulates in families, communities and societies through daily, often communal, activities and social interactions within these diverse settings. This perspective recognizes that different strategies will almost certainly be required in different cultures and settings, and that deep engagement with local communities is needed to develop the most appropriate strategies.

Health literacy

This represents the personal knowledge and competencies that accumulate through daily activities and social interactions and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them.

Key terms and concepts

In this report, four different facets of health literacy are explored: community health literacy, health literacy development, health literacy of an individual, and health literacy responsiveness. Distinguishing these is important when taking a globally relevant perspective on health literacy for the purpose of improving health and equity in diverse settings.

Community health literacy

This refers to health literacy-related assets (knowledge, resources, abilities), including:

- knowledge held by people in the community;
- the extent to which knowledge is trusted, circulated and adapted freely in a community;
- health-promoting customs embedded in cultural beliefs and norms, and in traditional or emerging practices of daily life;
- relationships between the community and outside sources of information.

Family, peer and community conversations and interactions are central to determining community health literacy, behaviours and outcomes.

Health literacy development

This refers to the ways in which health workers, services, systems, organizations and policy-makers (across government sectors and through cross-sectoral public policies) build the knowledge, confidence and comfort of individuals, families, groups and communities through enabling environments. Enabling environments support people to access, understand, appraise, remember and use information about health and health care, through verbal, written, digital and other communication channels and social resources, for the health and well-being of themselves and those around them, within the circumstances and demands of their daily lives.

Health literacy of an individual

As viewed from a globally relevant perspective, this is people's knowledge, confidence and comfort – which accumulate through daily activities and social interactions and across generations – to access, understand, appraise, remember and use information about health and health care, for the health and well-being of themselves and those around them.

Health literacy responsiveness

This refers to the extent to which health workers, services, systems, organizations and policy-makers (across government sectors and through cross-sectoral public policies) recognize and accommodate diverse traditions and health literacy strengths, needs and preferences to create enabling environments that optimize equitable access to and engagement with health information and services, and support for the health and well-being of individuals, families, groups and communities.

National Health Literacy Demonstration Projects (NHLDPs)

NHLDPs were designed and supported by the WHO Global Coordination Mechanism on the Prevention and Control of Noncommunicable Diseases Global Expert Working Group on Health Education and Health Literacy for NCDs. NHLDPs implement the Optimising Health Literacy and Access (Ophelia) process in various forms, depending on the needs and resources of each project context.

NHLDP teams develop, refine, test and evaluate health literacy actions that develop and respond to health literacy strengths, needs and preferences. These actions can range from low- or no-cost actions that are easy to implement through to complex multilevel health literacy actions. Each project collects evidence about health literacy actions that prove effective for the prevention and control of NCDs and, importantly, the context in which the actions proved effective and why. The long-term purpose of a programme of NHLDPs is to promote and support sustainable and scalable health literacy development and responsiveness actions in communities, organizations, health systems, and local, regional and national policies to accelerate the prevention and control of NCDs.

Optimising Health Literacy and Access (Ophelia) process

This is a co-design approach used frequently in health literacy development. It generally uses multidimensional health literacy or digital health literacy questionnaires such as the Health Literacy Questionnaire (HLQ) and the eHealth Literacy Questionnaire (eHLQ), which specifically investigate the diverse health literacy strengths, needs and preferences of individuals and groups of people. In this way, the process uncovers who is being left behind and why services are not effective for them, and provides information about what to do next. The Ophelia process uses meaningful engagement to understand and build on local knowledge and wisdom and international evidence to co-design, develop and implement health literacy actions that are accessible, sustainable and useful for the people who need them. The Ophelia Manual (1) provides a detailed step-by-step method to undertake health literacy development projects, including the NHLDPs.

People

In this document, the term "people" refers not only to individuals but also to collectives such as families, communities and groups associated by kinship or land, and nations.

Settings

Health literacy development is undertaken across all settings where people's knowledge, understanding and behaviour about health can be influenced. This includes prenatal environments, people's homes, villages and cities, schools and workplaces – that is, all the places where people are exposed to health-related information and where their health behaviours may be influenced.

Guide to using this document

The report is a designated WHO Global Public Health Good and, as such, is in line with the primary function of WHO to ensure access to authoritative and strategic information about matters that affect human health. Effectively delivering on this function involves influencing the actions of others in ways that can be shown to improve health outcomes and equity. To accelerate efforts to prevent and control NCDs and mental health conditions, Member States are encouraged to explore and implement a wide range of health literacy development and responsive actions.

Health literacy development for the prevention and control of noncommunicable diseases

This report has 4 volumes. You are in Volume 1.











Volume 1

Overview

Volume 2

A globally relevant perspective

Volume 3

Recommended actions

Volume 4

Case studies from WHO National Health Literacy Demonstration Projects

Introduction

This report provides a pragmatic approach to health literacy development for the prevention and control of noncommunicable diseases (NCDs). It provides new insights into what people know about NCDs and their risk factors, and these new insights reveal the mechanisms behind how people, communities, and organizations learn and can be supported to take action against NCDs, including their risk factors and determinants. Importantly, health literacy is understood as a social practice whereby decisions about health, and the available support to change to, or maintain, healthy behaviours, are determined by powerful and unique community norms and cultures, and organizational and political factors impacting communities.

Practical processes are presented for developing health literacy, including case studies from lowto high-income countries.



Health literacy development for the prevention and control of noncommunicable diseases

NCDs are one of the greatest development challenges of our time. NCDs account for more than a third of the global burden of disease. This includes almost 800 000 deaths annually among people aged under 40 years, which is more than HIV, tuberculosis and maternal deaths combined (2). Most of these premature deaths can be avoided or delayed.

The World Health Organization (WHO) *World Health Statistics 2021* reveals that NCDs make up 7 of the world's top 10 causes of death *(2, 3)*. This is an increase from 4 of the top 10 leading causes in 2000. People living in lowand middle-income countries (LMICs) are the most affected and account for 86% of the 17 million premature deaths (deaths occurring between the ages of 30 and 70 years) due to NCDs in 2019. These and other factors are increasing inequality and reducing productivity across LMICs and highincome countries (HICs).

Air pollution is the second leading cause of NCDs globally (4). Dietary factors contributing to obesity and undernutrition are linked to an increased risk of NCDs. Mental health conditions are highly prevalent, are frequently overlooked and often coexist with other NCDs, and their risk factors overlap.

NCDs are also major causes of preventable disability worldwide. NCDs impact girls and women who are left exposed through persistent social, gender and economic inequalities, accounting for about 70% of all deaths in women in LMICs.

NCDs are causing unprecedented burden on communities, health-care systems and governments. Urgent action is needed. Member States must generate policies and programmes that reduce the prevalence of NCDs and their risk factors, and improve the availability, quality and equity of services for people with NCDs.

Progress towards relevant NCD targets and goals needs a major boost. To ensure WHO Member State action on NCDs is effective and reaches the whole community, including groups often left behind, a health literacy development and responsiveness approach is required. The WHO Global Coordination Mechanism on the Prevention and Control of NCDs (GCM/NCD) Working Group on Health Education and Health Literacy for NCDs and this report are responses to this call for urgent action to leave no one behind. The report provides a concept of health literacy that optimizes global NCD prevention and control and offers five practical action areas, including the introduction of the National Health Literacy Demonstration Projects (NHLDPs).

The NHLDPs use a frequently used co-design approach to health literacy development — the Ophelia (Optimising Health Literacy and Access) process — to develop, refine, test and evaluate health literacy actions tailored to people's health literacy strengths, needs and preferences. This report further presents 16 case studies and the Ophelia Manual (1) for the development and implementation of NHLDPs.

This report has four volumes:

- 1. **Volume 1. Overview** presents a summary of the report.
- Volume 2. A globally relevant perspective refines the concept of health literacy to maximize its global relevance and utility for improving health and equity outcomes across LMICs and HICs.
- 3. Volume 3. Recommended actions presents five integrated health literacy development areas that include specific practical activities with reference to case studies and key learnings. We recommend that Member States take immediate action to plan and implement key elements of these five health literacy action areas that suit their context.
- Volume 4. Case studies from WHO National Health Literacy
 Demonstration Projects provides an introduction to the WHO NHLDPs in the form of case studies.

Interventions for the prevention and control of NCDs and mental health conditions, and their risk factors and determinants, often seek to change people's behaviours before they have experienced any symptoms of disease. This requires that people learn to think about risks, as well as symptoms, and about how risks can be encountered and managed in their daily lives. Common modifiable risk factors for NCDs include the use of tobacco products, harmful use of alcohol, physical inactivity, unhealthy diet, air pollution, and environmental and social stressors. Most commonly, individuals and societies are exposed to multiple risk factors, and people and communities are frequently under the burden of multiple NCDs.

As shown in Fig. 1.1, this is a major challenge. This report assists with understanding how the context of people's daily activities – local traditions, beliefs and social interactions – are interconnected with the risk factors for, and the social, economic and environmental determinants of, NCDs. Strong Member State policy leadership is required to create widespread enabling environments at all levels (from individuals to multisector government policy), where the healthy option is the easy option. For policies to be effective, they must meet the needs of people in the settings and experiences of their daily lives – policies must be health literacy-responsive. Health literacy actions must be based on a deep understanding of what individuals and communities actually experience, how they think, what they really need, and what is actually possible – policies must be based on a deep understanding of health literacy.

Fig. 1.1. The noncommunicable diseases (NCDs) a health literacy dilemma: disconnect between people's experiences of, and beliefs and attitudes about, disease risk factors and the determinants of disease

People may be unaware of, avoid or reject Daily habits and beliefs links between daily habits, lifestyle and their **NCDs** environments and NCDs (NCD risk factors) Cancer Fast food is a treat for my family Lung disease We have to cook with solid fuel People with one or many NCD risk factors may Heart disease I feed my family whatever food I can get end up getting no, one, or more NCDs and may Depression see link between the lifestyle and disease I smoke like my 90-year-old father Diahetes I do not have time to exercise My friends drink so I do too Some people are aware of links between daily habits and the development of NCDs, and they take preventive action



In daily life, the causal relationships between risk factors and disease development may go unnoticed or may be inconsistent with how people experience disease development in themselves or in people they know. Health literacy development approaches are needed to support individuals and the communities they live in to understand NCDs and take action to reduce risk factors for NCDs.

This report expands the concept of health literacy to maximize its global health and equity impact, especially among LMICs with the greatest burden of NCDs, and in the evolving context of social, economic and environmental determinants in the twenty-first century. Past health literacy research originates mainly from HICs, where discourses of individual autonomy over, and choice about, health and well-being tend to prevail. This perspective leads to activities that focus on encouraging behaviour change in individuals. For many people in most parts of the world, however, health decisions and actions occur within family, community and cultural practices and beliefs, which means health choices are often restricted by social and environmental factors beyond the control of individuals. People rarely make health decisions in isolation but rather through interaction and support from other people, institutions, organizations, services and systems. The health literacy concept is therefore positioned as a social practice where local contexts and mechanisms for behaviour change are carefully considered.

By viewing health literacy as a social practice, rather than primarily as a process of changing the behaviour of individuals, it is possible to generate a wide range of community-based activities that promote sustainable improvements in health and equity. This approach does not diminish the importance of health literacy actions taken at higher societal and policy levels, but it does require these activities to be undertaken with awareness of how they interact with people, workplaces and communities in the requirements of daily life. This requirement places effective and meaningful engagement with communities at the centre of all health literacy development activities.

This report promotes a globally relevant perspective of health literacy, health literacy development, and the processes to improve the health literacy responsiveness of governments and organizations.

Policies and activities for health literacy development must be built on an understanding of how people and communities develop their knowledge, understanding and practices about health. The core mechanisms for health literacy development in communities are the day-to-day experiences and conversations that people have about health with family, neighbours, peers, colleagues and health workers. Formal education and conventional and digital media also play important roles in shaping health literacy development.



Language for discussing health literacy diversity

Health literacy diversity in a community is often presented as "high and low" or "adequate and inadequate". These categories are based on averages and ignore the different strengths, needs and preferences in and among people and communities. For planning action, it is more helpful to use descriptive phrases about:

How people are able or prefer to acquire knowledge, such as based on traditional wisdom, acting by following instruction of those with authority in their family or community, prefering to use technology, having a high trust in health professionals, or being influenced mainly by their peer group.

The types of knowledge where people are strong or have limitations, such as traditional survival knowledge, understanding of chronic disease that exists even without symptoms, understanding health related to religious concepts such as "sin" or "fate", know and understanding modern health services, or understanding lifestyle risk factors.

In thinking about how to describe the health literacy differences that exist in a country, officials will develop a specific understanding of health literacy that fits the country's uniqueness and context.

- 1. Access
- 2. Understand
- 3. Appraise
- 4. Remember
- 5. Use











Health literacy involves five actions.

These five actions are rarely the efforts of single individuals and usually happen collectively among people. These five actions can be influenced and assisted in many ways, including through community conversations, the arts, printed materials, conventional mass media, digital media, and communicating and interacting with health workers. Many overt or hidden barriers, including but not restricted to language, racism and other forms of discrimination, physical access, poverty and peer pressure, can inhibit the effectiveness of health literacy development efforts. Table 1.1 provides an overview of the defining characteristics of health literacy development, individual health literacy, community health literacy and health literacy responsiveness.

Table 1.1. Defining characteristics of health literacy development, community health literacy, health literacy of an individual, and health literacy responsiveness

Facet of health literacy

Health literacy development

Defining characteristics

The ways in which health workers, services, systems, organizations, and policy-makers (across government sectors and through cross-sectoral public policies) build the knowledge, confidence and comfort of individuals, families, groups and communities through enabling environments. Enabling environments support people to *access, understand, appraise, remember* and *use* information about health and health care, through verbal, written, digital, and other communication channels and social resources, for the health and well-being of themselves and those around them, within the circumstances and demands of their daily lives.

Community health literacy

Health literacy-related assets (knowledge, resources and abilities), including:

- knowledge held by people in the community;
- the extent to which knowledge is trusted, circulated and adapted freely in a community;
- health-promoting customs embedded in cultural beliefs and norms, and in traditional or emerging practices of daily life;
- the relationships between the community and outside sources of information.

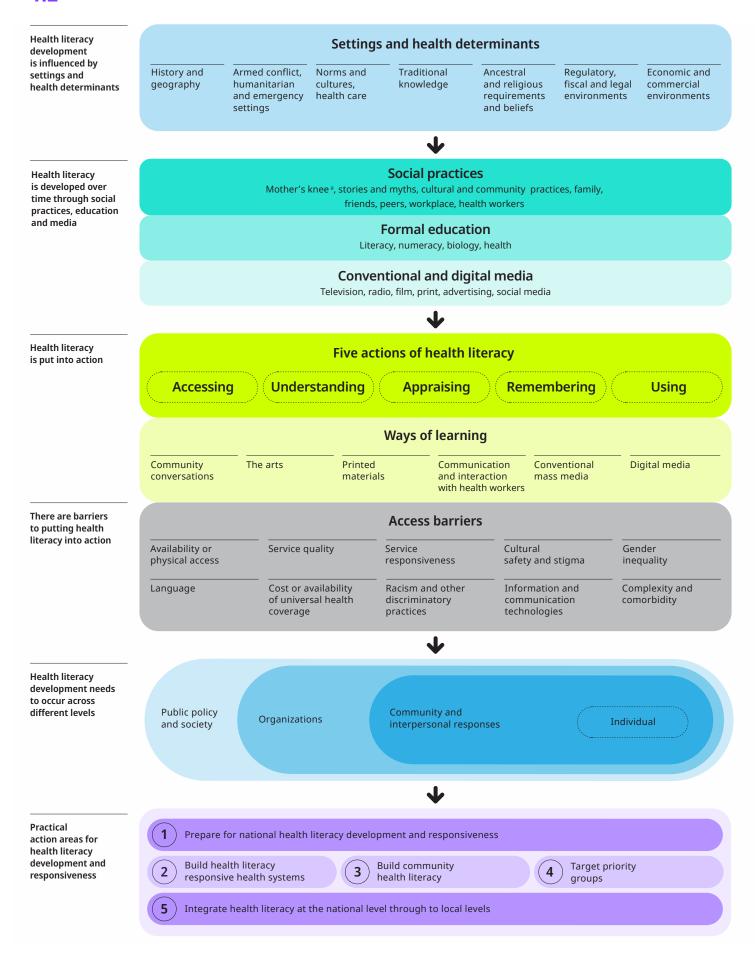
Family, peer and community conversations and interactions are central to determining community health literacy, behaviours and outcomes.

Health literacy of an individual

Viewed from a globally relevant perspective, this is people's knowledge, confidence and comfort — which accumulate through daily activities and social interactions and across generations — to access, understand, appraise, remember and use information about health and health care, for the health and well-being of themselves and those around them.

Health literacy responsiveness

The extent to which health workers, services, systems, organizations and policy-makers (across government sectors and through cross-sectoral public policies) recognize and accommodate diverse traditions and health literacy strengths, needs and preferences to create enabling environments that optimize equitable access to and engagement with health information and services, and support for the health and well-being of individuals, families, groups and communities.



a Mother's knee is a concept whereby infants learn about social practices and health-related information from the people caring for them, often while sitting on their knee.

Fig. 1.2 is an **integrated conceptual framework for health literacy development** based on the understanding that policy development and actions that reduce the prevalence and impact of NCDs must integrate bottom-up and top-down approaches. Specifically, it is critical to understand the lived experiences of people and communities as they develop health knowledge, make health-related decisions, and attempt to protect their health and manage illness and disease in the settings and requirements of daily life.

Fig. 1.2 describes an integrated conceptual framework to understand and act on health literacy development for the prevention and control of NCDs.

- Health literacy development is influenced by settings and health determinants that affect how people learn about and understand health, and make decisions about health. Determinants and settings include history and geography; armed conflict and humanitarian and emergency settings; norms and cultures; traditional knowledge; ancestral and religious requirements and beliefs; regulatory, fiscal and legal environments; and economic and commercial environments.
- Health literacy is developed over time through social practices, education and media. Some of the strongest influences on people's health literacy development are social practices that start from early infant experiences. They include stories and myths; cultural and community practices; family, friends and peers; the workplace; and health workers. Formal education develops health literacy through literacy and numeracy, and education about biology and health. Health literacy development is also influenced by conventional and digital media, including television, radio, film, print, advertising, and, more recently, social media.
- Health literacy is put into action, but there are barriers. Accessing, understanding, appraising, remembering and using information about health and health care are the ways that health literacy is put into action to learn, understand and make decisions about health. Different people have different ways of learning about health: through community conversations, the arts, printed materials, communication and interaction with health workers, conventional mass media; and digital media. There are, however, barriers to people accessing information about health and health care, including the availability of information or services and physical access to these, service quality, service responsiveness, cultural safety, stigma and gender inequality.
- To counteract these barriers, **health literacy development needs to occur across different levels**, including public policy and society, organizations, communities, interpersonal responses and individuals.

Practical action areas for health literacy development and responsiveness

Volume 2. A globally relevant perspective provides an elaboration of the background determinants – that health literacy is developed over time, and how health literacy is put into actions across contexts – and provides the foundations for practical action areas for health literacy development and responsiveness. Five priority action areas are described in Volume 3. Recommended actions. Actions are demonstrated through the case studies of the NHLDPs in Volume 4. Case studies from WHO National Health Literacy Demonstration Projects.

Action area 1

Prepare for national NCD health literacy development and responsiveness, including building new health literacy-informed programmes and policies, or strengthening existing initiatives:

- Establish a health literacy coordination unit (multidisciplinary, multisectoral).
- Develop an understanding of health literacy that is appropriate to the country context.
- Measure health literacy to understand the differences and determine who or which groups may be missing out because of their unmet health literacy needs.
- Make new health literacy development policies and programmes to impact on health and equity.
- Integrate health literacy into existing NCD policies, guidelines and programmes.
- Enhance the reach and acceptability of WHO Best Buys and other recommended interventions.
- Overcome barriers to health literacy development and responsiveness.

Action area



Build health literacy-responsive health systems that recognize and accommodate diverse cultures and diverse health literacy strengths, needs and preferences to optimize access and engagement:

- Ensure services are user-friendly and as accessible as possible for all people living with or affected by NCDs.
- Address health literacy barriers.
- Use co-design for health literacy-responsive actions.
- Choose an appropriate tool to assess organizational health literacy responsiveness.
- Improve health literacy responsiveness of health workers through education and training.
- Incorporate health literacy-responsive practices into health education curricula and continuing professional development.

1.3

Action area



Build community health literacy, which includes the total health literacy-related assets in a community where strong social networks are a powerful means for disseminating, reflecting on and, where necessary, adapting health information. Local and regional authorities need to participate in active dialogue with communities to understand their health literacy strengths, needs and preferences. Practical actions include the following:

- Strengthen or establish community health worker programmes or local civil society organizations to assist communities to access and use appropriate health information and services for the prevention and control of NCDs.
- Implement the Action for Healthier Families Toolkit to assist families to discuss health.
- Strengthen the competencies of trusted community influencers, leaders and connectors to facilitate discussion, dialogue, co-design and adaption of health information and services to local contexts.

Action area



Target priority groups that are not receiving or easily accessing health information or health care relevant to the prevention and control of NCDs or whose needs are not met by current approaches to health service delivery. These groups are likely to be cultural minority groups, migrants, people with disabilities, people with mental health problems, people with low education and socioeconomic status, young people, people with limited digital skills and access, and other marginal groups. Practical actions to be taken include the following:

- Identify and prioritize groups that are not engaging effectively with health care services or do not return to services.
- Undertake NHLDPs, including meaningful engagement across priority groups to determine, from their perspective, their strengths, needs and preferences, including how they prefer to be engaged.
- Apply health literacy and co-design principles when implementing digital services to maximize participation.

Action area 5



Integrate health literacy at the national level through to local levels.

This can be accomplished by the health literacy coordination unit with support from policy-makers and local authorities (action area 1). NCD prevention and control requires a whole-of-society approach to optimize reach and effectiveness. Practical actions include the following:

- Develop a NCD national action plan that integrates action areas 1 4, or integrate action areas 1 4 into existing NCD plans.
- Establish a series of NHLDPs involving stakeholders from diverse sectors within and outside health.
- Establish a health literacy knowledge repository and communities
 of practice to share and build on effective NCD actions. Scale up actions
 that work.

1.3

Health literacy development requires bottom-up, co-design, and top-down approaches to ensure policies and programmes are informed by, and specifically address, the strengths, needs and preferences of people at risk of, living with, and affected by NCDs. A focus on improving the health knowledge of individuals is rarely enough to develop health literacy actions that facilitate behaviour change and sustain optimal health outcomes. Taking a globally relevant perspective of health literacy, combined with a whole-of-society approach, is central to the prevention and control of NCDs.

The WHO NHLDPs describe projects that apply, develop, test, refine and evaluate actions for health literacy development and responsiveness to support villages, urban settings, communities, organizations, health services and governments to collaboratively address local health disparities and NCD health and equity outcomes. This report presents 16 NHLDP case studies in diverse settings such as an initiative in Mali for improved access to services for people with diabetes; an extensive undertaking in Denmark to develop health literacy actions to improve access and health outcomes for people with heart disease; and an initiative that improves access to digital health resources for people with NCDs on Réunion Island.

This report is forward-looking, is grounded in current and emerging practices across WHO Member States, and is intended for a broad audience, including governments, nongovernmental organizations, policy-makers, educational and research institutions, practitioners and community-based organizations.

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