

Health literacy development for the prevention and control of noncommunicable diseases

Volume 4

Case studies from WHO National Health
Literacy Demonstration Projects



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Health literacy development for the prevention and control of noncommunicable diseases:
Volume 4. Case studies from WHO National Health Literacy Demonstration Projects

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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.

A handwritten signature in blue ink, which appears to read 'Tedros Adhanom Ghebreyesus'.

Tedros Adhanom Ghebreyesus

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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.

The report was developed under the leadership of Svetlana Akselrod (Director, Global Noncommunicable Diseases Platform), Ruediger Krech (Director, Health Promotion) and Bente Mikkelsen (Director, Noncommunicable Diseases).

The development of the report was coordinated by Guy Fones, Unit Head, Global Coordination Mechanism on the Prevention and Control of Noncommunicable Diseases, with the support, in order of contribution, of Richard H Osborne, Roy Batterham, Shandell Elmer, Melanie Hawkins, Christina Cheng and Ranjit Nadarajah from the Centre for Global Health and Equity, Swinburne University of Technology, Melbourne, Australia.

The GCM/NCD Working Group on Health Education and Health Literacy for Noncommunicable Diseases was co-chaired by Lixin Jiang (China) and Oxana Drapkina (Russian Federation). Members included Rosmond Adams (Saint Vincent and the Grenadines), Wagida A Anwar (Egypt), Kee-Seng Chia (Singapore), Lorie Donelle (Canada), Hla Mya Thway Einda (Myanmar), Norhayati Kassim (Brunei Darussalam), Abderrahmane Maaroufi (Morocco), Portia Mananfazira (Zimbabwe), Erika Placella (Switzerland), Ion Salaru (Republic of Moldova), Judith Segnon (Benin) and Pandup Tshering (Bhutan). Special advisors included Ishu Kataria (India), Ilona Kickbusch (Switzerland) and Don Nutbeam (Australia). The facilitator was Richard H Osborne (Australia). The WHO Secretariat included Faten Ben Abdelaziz (Unit Head, Enhanced Wellbeing, Health Promotion), Suvajee Good (WHO Regional Office for South-East Asia), Asmus Hammerich (WHO Regional Office for the Eastern Mediterranean), Anastasia Koylyu (WHO Regional Office for Europe), Maristela Monteiro (WHO Regional Office for the Americas/Pan American Health Organization), Adelheid Werimo Onyango (WHO Regional Office for Africa) and Angela Pratt (WHO Regional Office for the Western Pacific).

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,

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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

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.

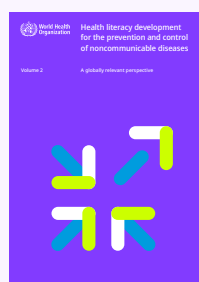
Health literacy development for the prevention and control of noncommunicable diseases

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



Volume 1

Overview



Volume 2

A globally
relevant
perspective



Volume 3

Recommended
actions



Volume 4

Case studies
from WHO
National Health
Literacy
Demonstration
Projects

National Health Literacy Demonstration Projects (NHLDPs) seek to systematize the development of informed health literacy actions in diverse contexts in Member States. The long-term purpose 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 prevention and control of noncommunicable diseases (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 project teams develop, refine, test and evaluate health literacy actions that develop and respond to health literacy. These range from low- or no-cost actions that are easy to implement through to complex health literacy actions. Each project collects evidence about how health literacy actions can be developed and what is effective and implementable in the particular context for the prevention and control of NCDs.



The WHO Global Coordination Mechanism on the Prevention and Control of Noncommunicable Diseases (GCM/NCD), through its Working Group 3.3 on Health Education and Health Literacy, initiated the concept of health literacy demonstration projects. The concept was based on systematic health literacy development methods outlined in the WHO *Health literacy toolkit for low- and middle-income countries* (2). Successful application of these projects in several countries led to the development of the WHO NHLDP concept. The initial NHLDPs were initiated and led by members of the GCM/NCD Working Group 3.3, arose from WHO health literacy capacity events, or were independent studies identified as useful case studies focusing on NCDs.

NHLDPs are guided by a set of eight principles for the development and implementation of health literacy actions (the Ophelia principles). The projects build local health literacy capacity of governments, health services, nongovernmental organizations, communities and academics for equitable prevention and control of NCDs.

The case studies describe the diverse project contexts and details of the study activities and outcomes, and provide key lessons to support other project teams. The case study approach highlights local narratives to reveal the what, why and how of elements of on-the-ground health literacy actions, and shares lessons learned from teams implementing projects across diverse regions of the world. Some projects offer insights into the gaps that exist in delivering health literacy-responsive services, including who is being left behind and why.

The case studies seek to assist readers to plan their own initiatives. In support of this, and linked to the GCM/NCD designation of a project as being part of NHLDP, the project teams accept they will participate in a global or regional community of practice coordinated by the Swinburne University of Technology's Centre for Global Health and Equity. The purpose is to encourage exchange and sharing of information and evidence, and to build capacity to expand good health literacy development practices to reduce the burden of NCDs and leave no one behind.

The Ophelia (Optimising Health Literacy and Access) process

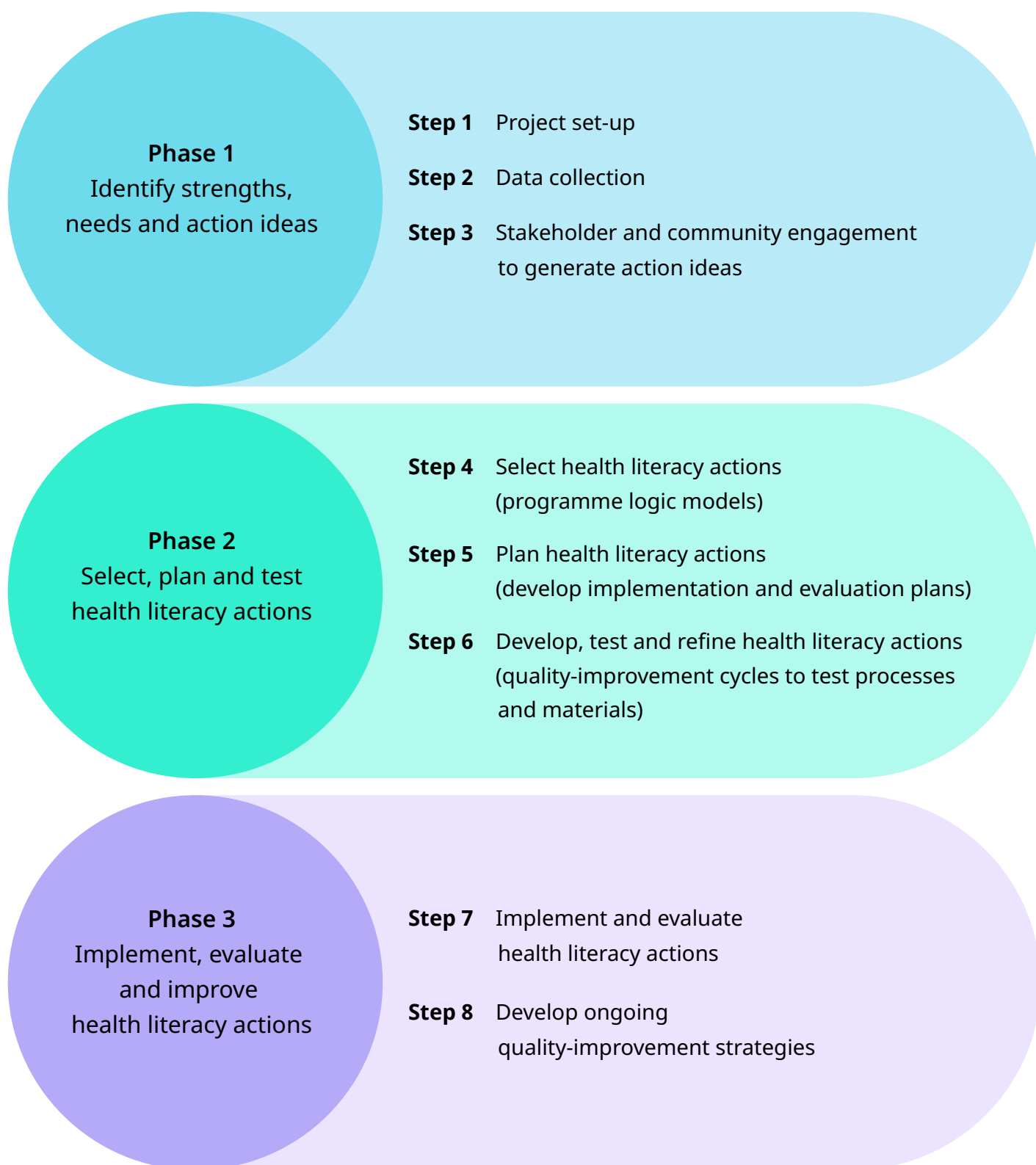
→ Key message

The outputs of the workshops are reviewed and potential actions are prioritized and tested using quality improvement cycles in a way that is responsive to contexts and health literacy or other relevant changes that might occur over time for individuals, groups, communities and organizations.

Like other collaborative co-design models, the Ophelia process undertakes meaningful engagement with community members, health workers, service managers and decision-makers to uncover local wisdom and ensure fit-for-purpose, needed and wanted health literacy-informed actions are developed (3). Using a strengths-based approach, the Ophelia process draws on methods such as intervention mapping (4–6), quality improvement collaboratives (7–9) and realist syntheses (10–12). It incorporates processes similar to assets-based community development (13, 14) and lean manufacturing (15, 16).

The Ophelia process was specifically designed to build health literacy actions that respond to local needs and effective and implementable. There are three phases of activities (Fig. 4.1). The process starts with a needs assessment using a multidimensional health literacy assessment that reveals key mechanisms determining people's ability to access, understand, appraise, remember and use health information and health services. These data are often collected in partnership with community organizations and service providers to generate deep local ownership of the processes and data and what the data mean. These data inform the development of vignettes (short narratives) of typical community members that clearly uncover their health literacy strengths, needs and preferences. The vignettes become the focus of deeply engaging workshops with a wide range of people with lived experiences of the target conditions or service engagement challenges and who live in diverse contexts in which the health literacy actions are to be implemented. Other stakeholders, such as health service providers, community workers and municipal staff with grounded insights into the daily lives of people from targets groups, are engaged in the same types of workshops.

Health literacy varies greatly across populations. Member State contexts, community health literacy assets, and potential barriers to health literacy vary, and the Ophelia process was designed to be flexible to meet the needs of local implementation teams. This is achieved through the application of eight clear principles. Implementation teams are strongly encouraged to adhere to the principles, but to adapt the Ophelia protocol where needed. The Ophelia principles are shown in Fig. 4.2. See details of the Ophelia process in the Ophelia Manual (1).



Ophelia, Optimising Health Literacy and Access process.

Fig. 4.2. The eight principles of the Ophelia process



1. Focus on outcomes

Focus on improving **health and well-being** outcomes



2. Driven by equity

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



3. Driven by local wisdom

Prioritize **local wisdom, culture and systems**



4. Diagnosis of local needs

Respond to **locally identified health literacy needs**



5. Co-design approach

Engage all relevant stakeholders in the **co-design** and implementation of actions



6. Responsiveness

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



7. Applied across systems

Focus on improvement at and across **all levels of health systems**



8. Sustainable

Focus on achieving **sustained improvements** through changes to environments, practices, cultures and policies

Ophelia, Optimising Health Literacy and Access process.

Case studies from WHO National Health Literacy Demonstration Projects around the world



WHO African Region

Mali

Health literacy and people with diabetes in low-resource settings
Contact: Xavier Debussche
(xavier.debussche@inserm.fr)

WHO Region of the Americas

Canada

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Contact: Donna Goodridge
(donna.goodridge@usask.ca)

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(aaby@phn.au.dk)

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(xavier.debussche@inserm.fr)

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(jmorrissey@irishheart.ie)

The Netherlands

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Contact: Mark Bakker
(mark.bakker@mumc.nl)

Norway

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Contact: Christine Råheim Borge
(c.r.borge@medisin.uio.no)

Portugal

Health literacy for prevention and control of type 2 diabetes
Contact: Isabel Loureiro
(isalou@ensp.unl.pt)

Portugal

Health literacy, health promotion and social cohesion for the prevention of NCDs among migrant populations
Contact: Sónia Dias
(sonia.dias@ensp.unl.pt)

Slovakia

Using health literacy profiles to improve chronic disease management
Contact: Peter Kolarčík
(peter.kolarcik@gmail.com)

WHO Eastern Mediterranean Region

Egypt

Health literacy of fishermen and their families living near Lake Borollos
Contact: Wagida Anwar
(wagidaanwar@gmail.com)

WHO Western Pacific Region

Australia

Improving breast screening awareness and participation among culturally diverse women
Contact: Mel Davis
(mdavis@breastscreen.org.au)

Australia

HealthLit4Kids – building health literacy from the schoolground up
Contact: Rosie Nash
(rose.mcshane@utas.edu.au)

Australia

Developing mental health literacy responsiveness education and training
Contact: Shandell Elmer
(slelmer@swin.edu.au)

Brunei Darussalam

Health literacy among people with type 2 diabetes
Contact: Khadizah Bakri
(khadizah.bakri@moh.gov.bn)



WHO African Region Mali

Setting

Rural, urban; hospital,
community health

Focus

Improved access to services
for people with diabetes

Target group

Adults with diabetes
attending health
services in Bamako,
Markala and Ségou



Background

Mali (population 20.3 million people) is a landlocked nation that is largely desert (65%). Bamako (population 2.6 million) is the main city located in the south along the Niger River. Mali is one of the poorest countries in the world, with nearly 45% of people living in extreme poverty. National illiteracy is high (65%) and higher among women (nearly 75%) than men (54%). Most people speak Bambara (80%), but the official language is French (spoken by about 30% of Malians). Conflict and political unrest counteract efforts to reduce poverty and improve health. It is estimated that NCDs account for 30% of all deaths.

Diabetes is of growing concern in Mali. Prevalence in the adult population is estimated at 1.8%, with substantial avoidable morbidity and mortality in people aged under 60 years. Peer educator programmes have been implemented with success, but scaling up is difficult because of low resources. Although diabetes services have improved over the past 10 years, there remains inadequate health information and low awareness of diabetes-related health issues and limited access to health services.

This project is coordinated by Santé Diabète, a leading international nongovernmental organization in Mali in partnership with the Centre Hospitalier Universitaire de La Réunion Clinical Investigation Centre. Collaborative partners include Bamako University Hospital, Institut Coopératif Austral de Recherche en Education at the University of Réunion, and the Mali Ministry of Health. The project is funded by the French Development Agency.

Aim and objectives

To co-design and implement actions in local health-care settings at the national level to improve access to health education and services for people with diabetes.

- Assess the health literacy needs of people with diabetes living in rural and urban settings.
- Co-design and implement actions with Santé Diabète, local health workers, client associations, and government agencies.
- Improve diabetes, health and equity outcomes.

The nine-dimension HLQ was translated into the oral language of Bambara to facilitate meaningful local participation in needs assessment.

Study activities

The Health Literacy Questionnaire (HLQ) in French and in Bambara was used in six sites:

- three in the capital city Bamako (one hospital, two health centres);
- two in the regional town of Ségou (one hospital, one community health centre);
- one in the rural area of Markala, 35 km from Ségou (community health centre).

Meetings were held early in the project in March–May 2019 with physicians at each of the sites to raise awareness of the project, build local ownership, organize administration of the activities and documents, and train the interviewers and supervisors. Interviewers and supervisors attended three days of training, which included presentations about health literacy, the project and the associated documents (HLQ, information and consent forms). Questionnaire administration was demonstrated through role play. Regular Skype meetings were held between Santé Diabète, Centre Hospitalier Universitaire de La Réunion and each site.

The first rounds of data collection used the HLQ in Bambara and were held in Bamako and Ségou under the supervision of the Clinical Investigation Centre and local supervisors. Interviewers reported back every three weeks to discuss their experiences of data collection. Community participants and doctors in Ségou were committed to the study, but there was low involvement of some of the referring doctors in Bamako. Other barriers included lack of premises for questionnaire administration and having to ask participants to wait for administration of the HLQ. Nevertheless, full data collection (n=360) with the Bambara HLQ and French HLQ took place between May and September 2019 in all three locations. All participants received free glycated haemoglobin (HbA1c) testing.

Interviews were undertaken in Bamako and Ségou with 25 people with diabetes to inform the health literacy profiles for vignette development in October 2019. Ideas generation workshops with frontline health workers and community members were put on hold because of the COVID-19 pandemic.

Phase 2 of Ophelia will include local health providers, communities, associations, and decision-makers to select and plan health literacy actions for implementation in Phase 3.

Health literacy strengths identified include confidence in and commitment to health providers and good social and community support.

Outcomes

The involvement of different partners working with Santé Diabète made it possible to prepare and translate the HLQ into the oral language of Bambara.

Data collection was completed. Quantitative and qualitative data analyses and interpretation are in progress to develop vignettes for the ideas generation workshops.

Preliminary results show the difficulties people have in accessing health information and navigating the health system. Results indicate there is a health asset in people's confidence in and commitment to health providers, and in the social and community support they have.

Sustainability

Ophelia Phase 2 work will involve key stakeholders, including people who use the services, to co-design actions. Of particular interest is the development of actions to improve the health literacy responsiveness of services and decision-makers to embed service improvements.

Based on this NHLDP, plans are in place to set up two other projects with Santé Diabète in Burkina Faso and Comoros.

Key lessons



Setting up an NHLDP

Build and design together with stakeholders, under the governance of the lead organization, and in conjunction with political decision-makers, local health-care providers and community members.



Running an NHLDP

Commitment to the project and local ownership were very strong, which was due largely to the important preparatory work to adapt the Ophelia process to the African context.



What future NHLDP teams should know

Pay attention to local staff and participants during the assessment phase: facilitate cultural and contextual adaptation; consider available resources and premises and staff capacities; and be aware of activities that are time consuming for participants and providers.



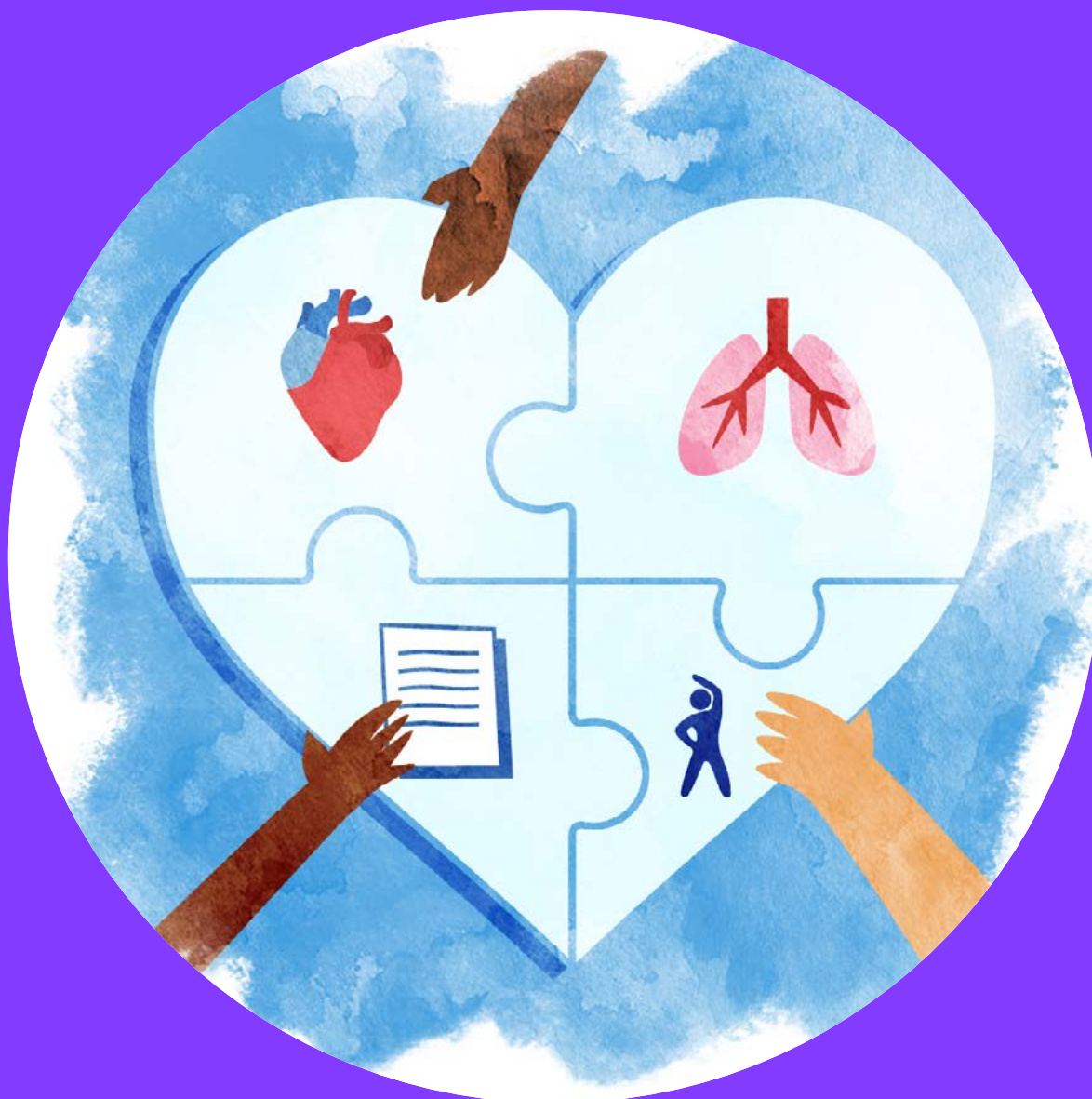
The most useful part of the project

- For community members and service providers – the affordability of health information and exchange of experience between community members and local health workers.
- For the project team – the involvement of local health workers and providers with the lead project team.

Selected further reading

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**WHO Pan American
Health Organization
WHO Region for
the Americas
Canada**

Setting
Urban; outpatient clinics

Focus
Improved access to services
and health outcomes
for people with COPD
or heart failure

Target group
People with COPD or
heart failure referred
to respiratory or heart
function clinics



Background

COPD is the fifth leading cause of death in Canada, with an age-standardized prevalence rate of 9% among adults aged 35 years and older. In 2016–2017, COPD exacerbations were responsible for nearly 90 000 admissions to Canadian hospitals and second in volume only to pneumonia in terms of emergency department visits. Nearly two-thirds of people admitted to hospital for COPD exacerbations have one or more comorbidities that affect their COPD. Heart failure is the most common reason for hospital admission, and hospital costs related to heart failure continue to escalate as the population ages. People with COPD or heart failure represent an older demographic who frequently have challenges with accessing and understanding health information. Through actions that address these health literacy needs, the well-being of people living with COPD or heart failure may be improved, with the potential to reduce hospital admissions.

This study is being conducted in the respiratory and heart function outpatient clinics of the Royal University Hospital in Saskatoon (population 325 000 people). These clinics serve people across the entire northern half of Saskatchewan (1.17 million people). People with COPD who attend the respiratory clinic are seen by a respirologist, may receive diagnostic testing, and may see a nurse clinician. Patients are referred to respiratory for advanced care beyond what their general practitioner can provide. The heart function clinic is a multidisciplinary outpatient clinic. Team members who could see a client during one comprehensive visit include a cardiologist, a nurse clinician, a dietitian, a social worker, a pharmacist and an exercise therapist. A client is referred to the heart function clinic by their regular cardiologist when it is felt they could benefit from more comprehensive support to stabilize their condition. It is expected that targeted strategies to address needs in age-appropriate and scalable ways will be developed by developing a more complete understanding of the health literacy assets and challenges among different client populations.

This work is supported by the Saskatchewan Center for Patient-Oriented Research and the Health Quality Council, which enables access to the Saskatchewan Health database to obtain data on use of health care.

Aim and objectives

To identify and compare the health literacy needs of people with COPD or heart failure, and investigate the associations between health literacy, quality of life and use of health care.

Study activities

This is a cross-sectional, mixed methods study of 50 people with COPD and 50 people with heart failure who will be consecutively recruited from outpatient clinics at the Royal University Hospital. Health literacy will be measured using the HLQ. Participants will be aged 40 years or older, able to communicate in English, and able to provide informed consent. A doctoral student will randomly select and interview 24 participants (12 with COPD; 12 with heart failure) who have agreed to be contacted following questionnaire completion. A client advisor working with the team will be actively engaged, particularly in data analysis, interpretation and translation to actions.

People with COPD will complete the eight-item COPD Assessment Test, which assesses the global impact of COPD on health status. People with heart failure will complete the Kansas City Cardiomyopathy Questionnaire.

Both groups of participants will complete the WHO-5 Well-being Index. Use of this index will allow comparison of quality of life between people with COPD and people with heart failure. Data will also be collected for sex, age, language spoken at home, highest level of education completed, self-rated health, assistance required with activities of daily living, employment, household status (living alone), location of residence and participation in available rehabilitation programmes. Data on the use of health care will be obtained using the Saskatchewan Health database available through the Health Quality Council and will include counts of COPD- or heart failure-related and all-cause hospitalizations, total in-patient days, re-admissions within 30 days, and emergency department visits in the 2 years preceding baseline data collection. Medical diagnoses and current medications will be obtained from health records.

Health literacy needs identified included people's difficulties actively managing their own health, but an observed strength was seen in people being able to actively engage with health care professionals.

Outcomes

Quantitative and qualitative data collection began in October 2019. The project was suspended due to COVID-19, but telephone interviews continued.

Data collected from people with heart failure (aged 53 – 93 years, >50% aged over 65 years) indicate they have difficulty actively managing their health (HLQ Scale 3 – Actively manage my health) but have good ability to actively engage with health-care professionals (HLQ Scale 6 – Ability to actively engage with health-care providers).

Preliminary analysis of data on people with heart failure indicated an association between employment status and HLQ Scale 1 (Feeling understood and supported by health-care professionals), Scale 2 (Having sufficient information to manage health) and Scale 3 (Actively managing my health). Participants who were working reported higher WHO-5 scores, but other associations (e.g. sex, age, income, education, New York Heart Association class) were not observed.

Sustainability

Partnerships are planned with community organizations such as the Heart and Stroke Foundation and the Lung Association.

Key lessons



Setting up an NHLDP

The study team is multidisciplinary and includes respirologists, cardiologists and two patient advisors. Working closely with nurse clinicians has been essential to understanding the flow of the clinics and recruiting participants.



Running an NHLDP

Respirology appointments at the hospital often take several hours and include pulmonary function tests. People with COPD tend to be less interested in staying after their appointments to complete the HLQ than people with shorter, less complicated appointments at the heart function clinic.



What future NHLDP teams should know

For clients, consider parking availability, fees and permitted time.



The most useful part of the project

- For community members – participants have been happy to take part in research and share their lived experiences.
- For service providers – the importance of health literacy to improving client outcomes has been reinforced. Most participants were not enticed by the \$20 gift card. This is interesting to consider for future projects, as a financial incentive may not be necessary to engage people in an applied research project such as this.
- For the project team – the opportunity to conduct a project that spans two populations with similar but distinct health trajectories and needs is a new approach that the team hopes to continue in the future.

Canada:
Health literacy – reducing inequities
and improving outcomes for people
using mental health services



**WHO Pan American
Health Organization
WHO Region for
the Americas
Canada**

Setting

Urban; community
and inpatient mental
health clinics

Focus

Improved access to services
and health outcomes for
people with mental illness
and their families

Target group

People aged 18 years and
over attending mental health
services, and their families



Background

Every year, one in five Canadians experiences a mental health problem. By age 40 years, about 50% of the population will have or has had a mental disorder. Navigation of the mental health system in the Saskatchewan region is difficult. Different groups of users may experience different challenges, including difficulty accessing or appraising information and lack of social support.

It is estimated that 20% of people accessing mental health services within the Saskatchewan Health Authority are Indigenous. A more complete understanding of the health literacy assets and challenges of all people attending these services will help to develop targeted strategies that address needs in culturally sensitive and scalable ways. Recognizing there is no health without mental health, this project addresses the imperative to engage people living with mental health disorders and their families in a collaborative effort to improve outcomes.

This project is a collaboration between the College of Medicine at the University of Saskatchewan and the Saskatchewan Health Authority's First Nations and Métis Health. The Royal University Hospital Foundation funded the project. Ethics approval was obtained from the University of Saskatchewan Research Ethics Board.

Aim and objectives

To improve client-reported health outcomes for people with mental disorders and their families.

- Measure experiences and preferences of people with mental disorders and their families.
- Determine existing, preferred and potential roles of information technology to improve access to information and services.
- Determine health literacy barriers and facilitators in health care environments.

This project used the HLQ and eHLQ to measure the experiences and preferences of people attending mental health services and their family members. The Org-HLR will be used to evaluate health-care environments.

Study activities

An advisory group for this project was set up comprising three client family advisors, managers from inpatient and community settings, and a lead consultant and a Knowledge Keeper from First Nations and Métis Health.

The HLQ and eHLQ were used to measure the experiences and preference of people attending mental health services and their family members. Interviews were conducted with 14 people attending mental health services and three family members. The Org-HLR will be used to evaluate health-care environments. Data collection was suspended because of the COVID-19 pandemic and will recommence when restrictions are lifted.

Health literacy actions will be developed using the Ophelia process. Evaluation of prioritized, tested and implemented action will occur at 3, 12 and 15 months.

Outcomes

A total of 87 people completed the questionnaire. Fourteen interviews were conducted with people attending the service, and three interviews were conducted with family members. The age range of participants was 19–72 years. A wide range of mental health diagnoses were reported, but the most common were anxiety and depression.

Sustainability

The involvement of key personnel from mental health services, including an Indigenous cultural liaison officer as a member of the project team, is critical to the sustainability of project outcomes. The outcomes of this project will be shared with the Patient and Family Advisory Council, and their feedback will help to refine actions.

Future opportunities include partnership with the Canadian Mental Health Association and collaboration with Alberta and Manitoba provinces to scale up actions. International partnerships will be sought.

Key lessons



Setting up an NHLDP

Early involvement of key stakeholders is essential, including setting up an advisory group.



Running an NHLDP

Consult with or engage people who are experienced with the Ophelia process and interpretation of HLQ and eHLQ data. High turnover of health staff and competing responsibilities can limit possibilities to engage staff in the process, so aim to allocate staff to the project.



What future NHLDP teams should know

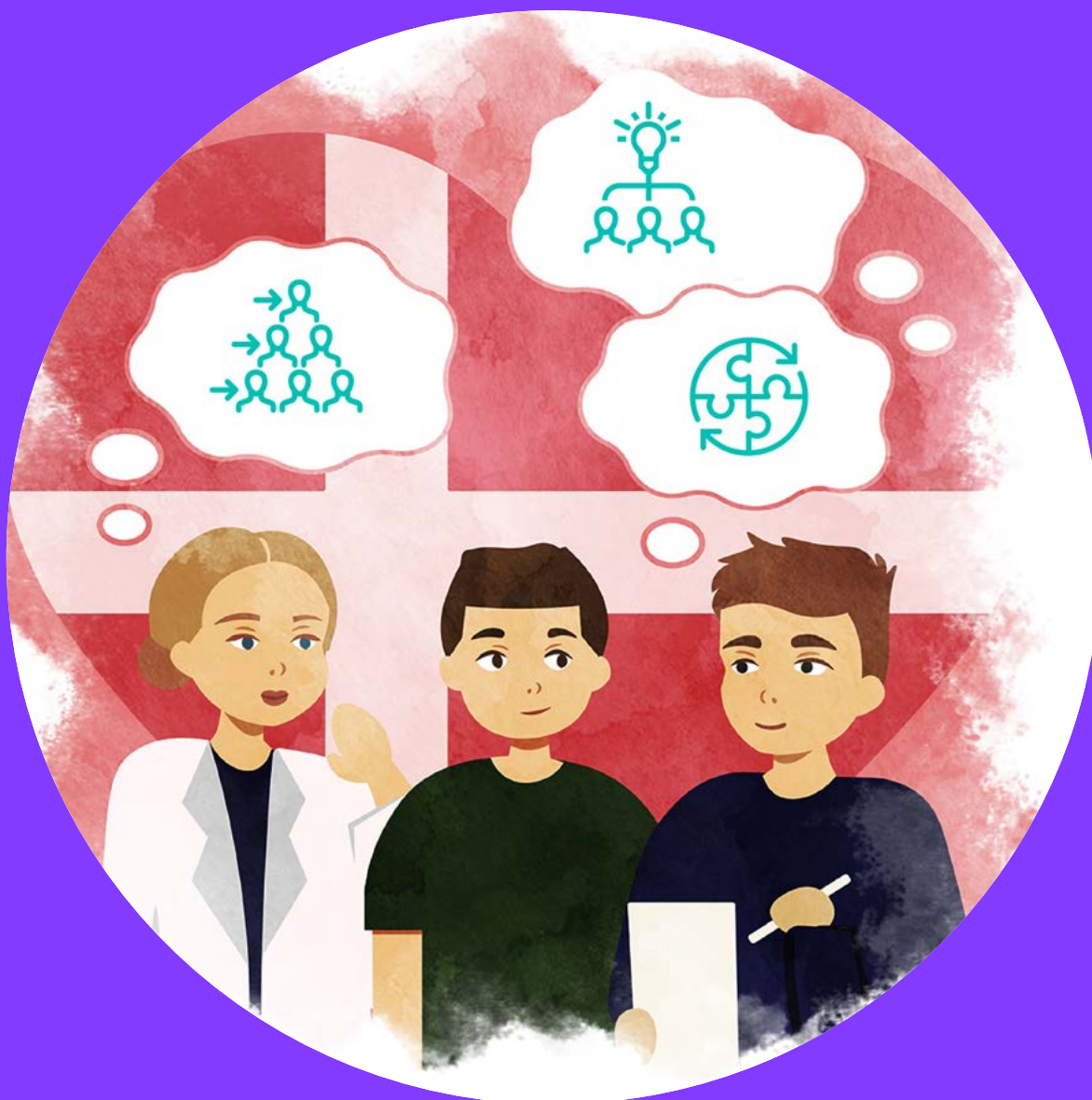
The ethics review board was very protective of people with mental health disorders in general, and Indigenous people in particular. Having representatives from these groups in the project was critical to secure ethics approval.



The most useful part of the project

- For community members – participants have been willing to share their stories and experiences and have expressed that they appreciate the opportunity to do this.
- For service providers – stakeholders were very engaged in the project, especially First Nations and Métis Health. The recruitment process has gone well with no refusals (the \$20 incentive may have helped).
- For the project team – the interviews have provided the project team with key insights into the strengths and challenges of health literacy for people living with mental illness and their family members.

Denmark:
The Heart Skills Study – health literacy
in people in cardiac disease rehabilitation



WHO European Region Denmark

Setting

Urban, rural, regional;
municipal rehabilitation unit

Focus

Improved access to services
and health outcomes for
people who need cardiac
rehabilitation

Target group

Health professional team
working with people with
cardiovascular disease, and
people attending cardiac
rehabilitation



Background

Denmark has a population of nearly 5.8 million people. Health spending is high, at 10% of the gross domestic product in 2017. All Danish citizens are covered by the public health insurance system. Although mortality from cardiovascular disease has decreased in recent years, it remains a leading cause of death in Denmark. International evidence has shown associations between low educational attainment and prevalence of cardiovascular risk factors and several cardiovascular diagnoses. Uptake of preventive behaviours, including cardiac rehabilitation, is higher in people who are higher on the socio-economic gradient.

The Heart Skills Study examines the potential for organizational health literacy to improve health outcomes among people with cardiovascular disease. The co-design process was used to improve organizational health literacy responsiveness in the Randers Municipal Rehabilitation Unit at Randers Health Centre. Randers Municipality (population 98 000 people) is situated in central Denmark. The unit provides free public rehabilitation programmes for people referred from general practitioners or hospitals across the municipality.

This project was a collaboration between the Department of Public Health, at Aarhus University and the Randers Municipal Rehabilitation Unit. Ethics approval was obtained from the Danish Data Protection Agency.

Aim and objectives

To develop health literacy actions to improve access and health outcomes for people attending a cardiac rehabilitation unit.

- Develop and test an organizational health literacy action.
- Evaluate the organizational impact of the application of the Ophelia process.

This highly participatory and innovative project sought to understand health literacy through organizational and community perspectives. The Org-HLR tool and the HLQ were used. The ideas generated from the Ophelia process based on findings of the HLQ were qualified by the organizational health literacy strengths and challenges identified through the Org-HLR.

Study activities

The Organisational Health Literacy Responsiveness (Org-HLR) tool and the HLQ, both in Danish, were used.

The Org-HLR process was conducted with health professional teams to identify organizational health literacy gaps and develop a multi-level organizational health literacy action plan. The Ophelia process was conducted to develop and test a specific organizational health literacy intervention in cardiac rehabilitation.

The Org-HLR self-assessment tool was used to guide group discussions in three workshops with two management staff and four therapeutic teams. From these workshops, ideas for organizational improvement were identified and prioritized. The rehabilitation unit's co-designed action plan consisted of 11 actions across strategic, managerial and practice levels to be carried out over periods of 3, 12 and more than 12 months.

All people referred to the rehabilitation unit in 2017 ($n=222$) were invited to complete the HLQ, and 162 of these were used for the cluster analysis. Collectively, 3 workshops generated 47 ideas for improving organizational health literacy responsiveness. Prioritizing and refining of the ideas resulted in two action packages:

- improve the social support of all people referred to cardiac rehabilitation (three activities);
- identify and respond to the needs of vulnerable people referred to the rehabilitation unit (two activities including using the Conversational Health Literacy Tool (CHAT) with new clients).

The project resulted in substantial organizational reform with 11 actions to deepen management and therapeutic teams' understanding of the needs and vulnerability of people in cardiac rehabilitation.

Outcomes

The HLQ and Org-HLR provide two ways to understand health literacy. They were combined in an innovative way that allowed the ideas generated in the Ophelia workshops to be qualified by organizational health literacy strengths and challenges identified through the Org-HLR. This added value to the Ophelia process.

Results from the study have shown substantial organizational reform that deepened the local management and therapeutic teams' understanding of the vulnerability and needs of clients, and increased their appreciation of user involvement in organizational improvement processes. The study integrated health literacy thinking and local ownership and engagement into strategic, managerial and therapeutic practices and innovations.

Related studies have found associations between health literacy and the likelihood of having a chronic disease or multimorbidity, several cardio-protective behaviours, and health-related quality of life in people with cardiovascular disease.

No long-term results about access or health outcomes of patients are available yet.

Sustainability

The study evaluation found positive indications of the integration of health literacy thinking into the organizational structures, with plans for further development and implementation of the actions planned. Managers and staff reported that they found the outcomes of the study to be sustainable. Several other health settings in Denmark have shown interest in the Heart Skills Study and are now planning or considering similar studies.

Key lessons



Setting up an NHLDP

- Map the power structures of the setting and consider their consequences. Consider how to include all stakeholders.
- Explain the process in detail to project partners to establish a common understanding of roles, responsibilities and results.
- Discuss the level of potential change given resources, time, external constraints and scope and ensure agreement from all partners.



Running an NHLDP

- Include all collaborators at an early stage allowing them to take part in the co-design process if they are to be part of the implementation. This supports their ownership and engagement and increases likelihood of effective implementation.
- Make sure facilitation is conducted by people representing different perspectives.
- Think carefully about the aim of the process – are “hard” outcomes needed or wanted, or is the focus on the process and changes in values and culture?



What future NHLDP teams should know

- Consult existing teams and examine their different structures and results.
- Consider whether the aim is to improve the health literacy of individuals or the health literacy responsiveness of an organization.
- Plan and consider each step carefully, but be prepared for local changes and adaptations along the way. Keep a detailed log of thoughts and decisions in order to be able to justify prioritizations later on.
- Prioritize active participation and engagement of all stakeholders, and make sure project facilitation is shared.



The most useful part of the project

- For community members, service providers and the project team – the most useful part of the study was the thinking it introduced and the organizational cultural changes it created. Working together towards an agreed goal proved more important than the individual actions taken.

Selected further reading

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WHO European Region France, Department of Réunion

Setting

Rural, urban; hospital,
community, pharmacies

Focus

Improved access to digital
health resources for people
with NCDs

Target group

People with diabetes,
cardiovascular disease
or kidney disease



Background

Réunion (population 900 000 people), is a French department and region in the Indian Ocean, east of Madagascar. There is a steep social gradient, with high unemployment rates, 40% of people living below the poverty line, and an adult illiteracy rate of 24%. Access to health information and services is a challenge for vulnerable communities and for people living in remote areas. Diabetes, cardiovascular disease and kidney disease are highly prevalent. Communities will have better disease control if they can more easily access, understand, use and evaluate health information and services electronically.

The Centre Hospitalier Universitaire de La Réunion Clinical Investigation Centre and the Icare Unit (University of Réunion) have invested in epidemiological and socioanthropological studies about NCDs. The Indian Ocean Health Innovation (OIIS) digital health platform was developed by GCS Tesis e-santé (Health Cooperative Group) to address the challenge of NCDs and to promote coordination among health-care professionals. OIIS was developed under the guidance of the Réunion Regional Health Agency (ARS Réunion) and includes electronic health records, coordination of resources for health-care providers, and web-based treatment and prevention solutions. Practical evidence is needed to guide the evolution and adaptation of the platform and its existing resources to equitably meet the needs of the people.

The first phase of the OIIS eHealth literacy project was led by the Clinical Investigation Centre in partnership with ARS Réunion and was funded by a research grant from the Groupement Interrégional de Recherche Clinique Sud-Ouest Outremer Hospitalier (French Ministry of Health).

The second phase will be under the governance of ARS Réunion and GCS Tesis e-santé, in partnership with the Clinical Investigation Centre. Funding will be sought from ARS Réunion based on the results from the first phase and grant opportunities.

Project partners are the Association for the Use of the Artificial Kidney on Réunion Island, the Laboratoire Icare, the Regional Union of Pharmacists, the RéuCARE Health Network, and the cardiology, nephrology and diabetology departments of the Centre Hospitalier Universitaire de La Réunion.

Health literacy challenges included difficulty in understanding health information and accessing medical specialists. People tended to rely on health-care advice instead of initiating self-management practices.

Aim and objectives

To design health literacy and digital health literacy actions to improve health equity and digital health literacy and decrease the burden of NCDs.

- Assess the health literacy and digital health literacy needs of people with NCDs living in urban and rural areas, in care for three years, and attending hospitals, dialysis centres, the RéuCARE health management network, and pharmacies.
- Engage community members, patient associations, health care providers and the Regional Health Agency in co-design processes to improve and add to digital resources on the OIIS platform.
- Co-design actions and practices to improve the responsiveness of health organizations to respond to the health literacy needs of people with NCDs.

Study activities

This study used the HLQ and eHealth Literacy Questionnaire (eHLQ) in French. Initial measurement of the health literacy needs of people with diabetes ($n=240$) using the HLQ in French was conducted before the larger study, which also included people with cardiovascular and kidney disease ($n=600$).

Data will be used to develop digital health literacy profiles to be used in workshops with health-care professionals, general practitioners, primary care nurses and specialists; people with NCDs; and members of the OIIS team and the Réunion Regional Health Agency.

Outcomes

Results from the study of people with diabetes found that people with diabetes in rural areas had difficulty understanding health information, and accessing specialists, and they relied on the advice of their health-care professionals rather than initiating self-management practices.

Sustainability

The Ophelia Phase 1 evaluation will include validity testing (cognitive interviews and psychometric analysis) of the eHLQ data to strengthen trust in the results and uptake of the findings. To further support interest and uptake of the developed health literacy actions, the phase will include statistical description of the diversity of people included in the survey and descriptions of the involvement of consumers, health-care professionals and policy-makers in the ideas generation workshops.

Phase 2 evaluation activities will include assessment of the attendance and participation of stakeholders during the co-design process. The evaluation for Phase 3 will be based on the planned actions.

The sustainability of the processes and outcomes of this study relies on the early, ongoing and committed involvement of the OIIS team, health and social workers, and funding and active and real involvement of health policy decision-makers for the second phase.

Key lessons



Setting up an NHLDP

It is challenging to convey the importance of incorporating health literacy when developing health resources and platforms. It has been difficult to maintain funding beyond the needs assessment phase.



Running an NHLDP

It is difficult to maintain staff resources, so make sure to regularly inform decision-makers and insert the NHLDP activities within other developing projects.



What future NHLDP teams should know

Plan the study in detail before starting, and bring together key partners to set up the project.

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Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Råheim Borge C et al. Acting together: WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. Copenhagen: WHO Regional Office for Europe; 2019 (<https://apps.who.int/iris/handle/10665/327059>, accessed 12 September 2021).

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WHO European Region Ireland

Setting

Urban, rural; schools

Focus

Prevention of obesity and cardiovascular disease in adolescents in partnership with schools and communities

Target group

Students aged 12–18 years (and their families) in secondary schools in the Delivering Equality of Opportunity in Schools programme



Background

Over the past 50 years, Ireland's high birth rate has made it one of the youngest populations in the European Union (21% aged under 15 years). In a population of almost 5 million people, 800 000 people in Ireland live in poverty, and 18% of adults and up to 30% of children from disadvantaged areas have literacy difficulties. Nearly 70% of adults and 1 in 4 children are overweight or obese, and cardiovascular disease is a leading cause of death and disability.

The Wellbeing Framework 2018–2023 and the Delivering Equality of Opportunity in Schools (DEIS) programme 2017 were developed by the Irish Department of Education and Skills. The Framework and the DEIS programme aim to improve well-being, educational opportunities and outcomes for young people who are at risk of disadvantage or social exclusion. Given the pervasive use of digital technology by young people, there is an opportunity to use technology-based platforms to access and engage young people in managing their health.

This project is led by the Irish Heart Foundation, a nongovernmental organization, in partnership with Dublin City University, Lifelab, University College Dublin, and a youth advisory panel formed specifically for this project during its inception. The Swinburne University of Technology Ophelia research team in Australia collaborated in the design and development of tools and processes.

The project explores adolescent health literacy and uses a grounded approach to co-design a conceptual model of health literacy strengths and needs in adolescents. Co-design of classroom and off-site technology-based actions support and encourage positive health behaviours in young people to help prevent obesity and cardiovascular disease in adulthood. The project aligns with the Irish Heart Foundation's strategic focus. Funding is provided through a legacy from Elizabeth O'Kelly's estate, which the Irish Heart Foundation Board allocated to childhood obesity initiatives. Ethical approval has been granted for the research components.

Young people have had the opportunity to have their voices heard and ideas incorporated into the project outputs.

Aim and objectives

To improve the health literacy of adolescents and support positive health behaviours into adulthood using a whole-of-school co-design approach that engages young people, parents, schools and local communities.

- Develop and test an adolescent health literacy needs assessment questionnaire.
- Collaboratively develop a health literacy action for the national Wellbeing Framework in the secondary school setting, incorporating digital technology.
- Apply an initial focus on schools in disadvantaged communities, followed by national dissemination and generation of international interest.

Study activities

Development of an adolescent health literacy questionnaire in parallel with the Ophelia process is used for action co-design, implementation and evaluation.

- Adolescent questionnaire development – the development of an adolescent health literacy questionnaire follows a grounded, validity-driven approach that draws on the lived experiences of adolescents in their daily lives, and involves cognitive testing and pilot testing with students from the five participating schools.
- Consultation – initial consultation took place in five schools with teachers and young people; co-design workshops involve a wide range of stakeholders.
- Scoping of curriculum – the Wellbeing Framework was published in 2018 and identifies where health literacy actions will align with the curriculum.
- Implementation plan – the action plan for implementation incorporates curriculum scoping, a literature review and data from co-design workshops.

The project has supported teachers by filling a gap in and supporting delivery of the Wellbeing Framework.

Outcomes

This project is in its early stages and there are no outcomes to date, other than establishing collaborative partners and building relationships with the pilot schools. The COVID-19 pandemic and closure of schools across Ireland prevented the planned engagement with schools. This has also delayed the national health literacy cross-sectional survey.

Sustainability

The Irish Heart Foundation will roll out the health literacy actions as part of a suite of school-based and off-site programmes to support delivery of the Wellbeing Framework.

The opportunity to engage in a comprehensive grounded approach gave service providers new perspective on action development and has informed other new projects.

Key lessons



Setting up an NHLDP

Planning was helpful to foresee resource requirements and partnership development.



Running an NHLDP

Reporting requirements are not onerous. It will be helpful to be part of and have the support of the NHLDP network.



What future NHLDP teams should know

This is a good opportunity to explore health literacy using the recognized Ophelia process, which is flexible in different settings and cohorts and for different project goals. Co-design is not easy, especially as the outcomes are intended to be practical for the community. It is important to make the goals clear to all partners because each stakeholder has their own objectives and ways of working.



The most useful part of the project

- For community members – young people have had the opportunity to have their voice heard and ideas incorporated into the project outputs.
- For service providers – the project has supported teachers by filling a gap in and supporting delivery of the Wellbeing Framework. The opportunity to engage in a comprehensive grounded approach gave service providers a new perspective on action development and has informed other new projects.
- For the project team – this has been a good opportunity to be innovative and to share this work through WHO.

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WHO European Region Netherlands

Setting Urban; hospital

Focus Improve access to services and health outcomes for people with rheumatic conditions

Target group People living with rheumatic conditions in outpatient settings



Background

Bordered by Belgium, Germany, and the North Sea, the Netherlands has a population of 17.1 million people of which 92% live in urban areas. In 2019, the unemployment rate was just over 4% and the poverty rate was 13.2% (the fifth lowest in Europe). The country has a 99% literacy rate and the world's highest non-native proficiency in the English language. There has been a rise in life expectancy and the number of people with NCDs, including those with rheumatic conditions, is expected to grow to 7 million (40% of the population) by 2030.

Three common rheumatic conditions, and the largest patient groups at the outpatient clinics participating in this project, are rheumatoid arthritis, spondyloarthritis and gout. Under-explored areas of research are the health literacy of people living with rheumatic conditions and how health care organizations are meeting the needs of this population. Assumptions underlying this project are that limited health literacy is prevalent among people with rheumatic conditions in the Netherlands and that rheumatology health care teams have limited awareness of health literacy. It is considered feasible that rheumatology teams can adapt care to meet the health literacy needs of people living with rheumatic conditions without an excessive increase in workload.

The project is a collaboration between Maastricht University Medical Centre (Maastricht) and the outpatient units at Maasstad Hospital in Rotterdam and Medisch Spectrum Twente hospital in Enschede. Ethics approval was obtained from the Medical Research Ethics Committee at Maastricht University Medical Centre, with local approval from the designated committees at the participating hospitals. Funding came from internal funds from the Rheumatology Division, Maastricht University Medical Centre and a Niels Stensen Fellowship granted to the postdoctoral fellow working on the project.

Aim and objectives

To reduce the burden of rheumatic and musculoskeletal diseases by addressing health literacy needs, and the co-design of a health-literate rheumatology clinic.

- Focus on access to services, disease management and health outcomes.
- Increase awareness of health literacy among rheumatologists and nurses.

The project asked health-care providers to complete a questionnaire to obtain their perceptions of their clients' health literacy. The results showed relevant and problematic discordance existed between health professionals' perception of clients' health literacy and the clients' self-reported health literacy.

Study activities

The HLQ was administered to clients in three outpatient clinics ($n=895$). Health literacy profiles were developed and confirmed as being likely profiles by a client research partner. Analyses were performed to assess whether profiles were dependent on a condition or a participating centre. Ideas generation workshops were conducted with rheumatologists and nurses. Further project activities include workshops with people living with rheumatic conditions and further development and prioritization of action ideas.

Consulting health-care providers completed a questionnaire to obtain their perceptions of their clients' health literacy. The health-care providers ($n=40$) included rheumatologists ($n=24$), residents ($n=8$), physician assistants ($n=2$), nurse practitioners ($n=2$) and rheumatology nurses ($n=4$). Health-care providers gave two responses: their opinion of the client's health literacy for each domain, and their expectation of the client's self-reported score for each domain. Discordance between the perceptions of physicians and the clients' self-reported health literacy scores is being explored to uncover reasons for the differences.

In response to the COVID-19 pandemic, textual analysis and qualitative interviews were conducted during the first COVID-19 wave in the Netherlands (February to June 2020) to assess communication from health-care providers and client organizations to people with rheumatic conditions. Process and outcome evaluation will be done qualitatively.

Health-care staff engaged in open discussions and brought up learning points about how to address everyday challenges that are seldom discussed in regular practice. The project has led to increased awareness among medical professionals that addressing health literacy needs is a responsibility of health-care organizations and providers.

Outcomes

Analyses showed that health literacy profiles (with corresponding health literacy needs) can be distinguished in a Dutch population of people with rheumatic conditions. There were slight differences between hospitals and rheumatic conditions for the occurrence of some of the health literacy profiles, but these differences were not statistically significant. This indicates that the health literacy profiles were not specific to a hospital or a rheumatic condition.

Relevant and problematic discordance exists between health professionals' perception of clients' health literacy and the clients' self-reported health literacy. Factors appearing to be associated with this discordance include clients' education level and migration background, and the type of professional. Discordance seems more likely to occur in assessments by professionals in training, even after adjustment for the physician-reported perception of how well they know the client.

Increased awareness of health literacy needs was observed among staff in all three centres as the project rolled out.

Assessment of information provision to people with rheumatic conditions in the Netherlands during the first wave of the COVID-19 pandemic revealed that it generally adhered to principles of crisis communication and health literacy. Nevertheless, several lessons were identified for future crises, including simplification of information, increased collaboration between organizations, and use of diverse communication channels and techniques to reach diverse audiences, in consideration of their health literacy needs.

Sustainability

This project is receiving attention at national and European conferences in rheumatology, and engagement with professionals in these conferences has been rewarding. The project team has been invited to give several talks at patient organizations and the Dutch professional nurses' association. The European League Against Rheumatism has featured the project in two publications. Contact with participating centres is good, which promises good engagement and potential for sustainability at the implementation stage.

Key lessons



Setting up an NHLDP

Think carefully about and plan how best to include people with limited health literacy in the needs assessment.



Running an NHLDP

Reserve enough time for project implementation by clinical staff at partner centres.



What future NHLDP teams should know

The interpretation of cluster analysis is challenging, and consulting with experts is recommended. This includes people with statistical proficiency and people who know the community well, such as clients and providers.



The most useful part of the project

- For community members – service users are actively involved in improving delivery of care, and their contributions should result in the provision of more responsive and better care.
- For service providers – health-care staff engaged in open discussions and brought up learning points about how to address everyday challenges that are seldom discussed in regular practice. The project has led to increased awareness among medical professionals that addressing health literacy needs is a responsibility of the health-care organization and its providers.
- For the project team – the team has become more knowledgeable about how health literacy issues manifest in rheumatology practice and continues to learn about how to address clients' needs.

Selected further reading

Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Råheim Borge C et al. Acting together: WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. Copenhagen: WHO Regional Office for Europe; 2019 (<https://apps.who.int/iris/handle/10665/327059>, accessed 12 September 2021).

Bakker MM, Putrik P, Rademakers J, van de Laar M, Vonkeman H, Kok MR et al. Addressing health literacy needs in rheumatology: which patient health literacy profiles need the attention of health professionals? *Arthritis Care Res.* 2021;73(1):100—9. doi: 10.1002/acr.24480.



WHO European Region Norway

Setting

Urban; hospital and
community care

Focus

Improved health outcomes
for people with COPD

Target group

Adults with COPD



Background

In Norway's population of 5.4 million, about 300 000 people live with chronic obstructive pulmonary disease (COPD). This condition is associated with reduced quality of life and multiple symptoms, including breathlessness, cough, sputum, fatigue, pain, anxiety, depression and insomnia. People with COPD may have difficulty with physical activities and coping with activities of daily living, and they can experience exacerbations that can lead to hospitalization and re-admissions (26% re-admission within 30 days).

Norway is considered a wealthy country, but 7.5% of the population live below the poverty line. Health literacy challenges can prevent people from accessing the health care they need to manage their health. Economic issues, communication difficulties, and poor relationships with health-care providers can cause people living with COPD to experience barriers to adequate health care and prevent access to self-management programmes to help them understand and adhere to recommended treatments.

This project will develop and evaluate a health literacy action in the context of hospital re-admissions for people with COPD.

The project is a partnership health promotion action between Lovisenberg Diaconale Hospital, the University of Oslo, four community health-care services (Gamle Oslo, Grünerløkka, Sagene, St Hanshaugen), and users of COPD health services. Funding was received from the Dam Foundation through the Norwegian Association for Heart and Lung Diseases. Funds for collaboration in the Oslo municipality, the Kirsti Rønning's Fund, and financial or cooperation (in-kind) resources contributed from each project partner. Ethics approval was obtained from the Regional Ethics Committee in Norway.

Aim and objectives

To develop health literacy actions for people with COPD in collaboration with clients, hospitals and municipalities.

- Reduce hospital re-admissions.
- Increase health literacy, self-management and quality of life and decrease psychological symptoms for people with COPD.
- Reduce health-care costs.

Combining the results of a cross-sectional survey and seven focus groups with people living with COPD and multidisciplinary health-care professionals, four main health literacy needs were identified – security, knowledge, self-management and dignity.

Study activities

Phase 1 consisted of a cross-sectional needs assessment study using the HLQ ($n=158$), four focus groups with people living with COPD ($n=14$), and three focus groups with multidisciplinary health-care professionals ($n=21$).

Ideas generation workshops and Phase 2 action planning and testing were conducted with people living with COPD, health professionals and leaders from specialist and health-care services, and researchers.

A randomized controlled trial ($n=128$) in Phase 3 provided clients with usual care after hospital discharge or COPD support and training through motivational interviewing techniques during home visits by specialized COPD nurses: face-to-face once a week for eight weeks, with telephone calls once a month for an additional four months, and then no follow-up for six months. The purpose of the health literacy actions was to tailor information and follow-up (based on individual health literacy needs, COPD knowledge, understanding of medical and technical equipment, nutrition, quitting smoking, and psychosocial support), and to increase clients' access to community services and participation in community activities.

Outcomes

The needs assessment found that lower health literacy scores were associated with low self-efficacy, high hospitalization rates, smoking habits, living alone, low well-being and poor handling of medicines. The focus groups identified four main health literacy needs – security, knowledge, self-management and dignity. A collaborative health literacy approach between community health care services and medical specialists was developed to provide living people with COPD with supportive actions tailored to their individual needs.

Analysis of the effectiveness of motivational interviews with tailored follow-up on hospital re-admission to evaluate client health literacy, self-management, quality of life and psychological symptoms and cost to the health-care system is ongoing.

The Ophelia process makes sense to service providers. It has made it possible to communicate more and in a better way about clients who need complex follow-up, and to perform actions in a structured and planned way.

Sustainability

This project has increased knowledge about developing health literacy action for COPD, and the method will be suitable for other chronic health conditions. Working with health literacy has become a prioritized practice where time and resources are set aside, both in the hospital and in the municipality, so the system responsiveness to health literacy has increased.

To improve sustainability, the particular focus of this study is on cooperation across disciplines and sectors to resolve significant health challenges, the development of processes for identification of needs, and the increase in participation of users (people living with COPD) throughout a research process to ensure the relevance and impact of research.

The hospital and associated districts in Oslo municipality have decided that the action will continue as performed in the project. In addition, there is a focus on improving the collaboration between the specialist health service and the municipal health service due to the project and there is a need for more knowledge about COPD among health personnel. A procedure template on how to work together on the follow-up of clients is being prepared for this, and further teaching presentations on COPD follow-up will be developed and posted on websites in the municipalities.

This project also led to a new health literacy project that uses the Ophelia process – Optimizing Health Literacy in Cancer Follow-up (OpHealth Cancer) – which has a focus on people living with cancer and their carers.

Key lessons



Setting up an NHLDP

The Ophelia process requires good planning and support from the clinical environment and collaborators. Every step can be time consuming. Involvement of stakeholders in the planning, development and implementation of the project increases the feasibility of the project. Financial support is important, as is research support from the local, national and international research communities. The Ophelia process provides good opportunities to plan tasks that are economically manageable and implementable.



Running an NHLDP

This requires continuous contact and cooperation with collaborative partners to report on goal status, achievements and results.



What future NHLDP teams should know

Use the Ophelia Manual (1), get updates through published articles, and collaborate early with others who have undertaken Ophelia projects.



The most useful part of the project

- For community members – clients gained more ownership by being part of all processes, which has made it easier to implement the entire project.
- For service providers – the Ophelia process makes sense to service providers. It has made it possible to communicate more and in a better way about clients who need complex follow-up and to perform actions in a structured planned project.
- For the project team – the whole team is part of every step in the Ophelia process. Being an NHLDP project has provided contacts worldwide with other research teams.

Selected further reading

Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Råheim Borge C et al. Acting together: WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. Copenhagen: WHO Regional Office for Europe; 2019 (<https://apps.who.int/iris/handle/10665/327059>, accessed 12 September 2021).

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WHO European Region Portugal

Setting

Urban; health institution,
community health

Focus

Disease prevention and
improved health
outcomes for people
with type 2 diabetes

Target group

Adults with and without
type 2 diabetes



Background

Nearly 100% of Portugal's population (over 10 million people) is literate, but poverty is high, with almost 2.6 million people living below the poverty line. Behavioural factors such as poor diet, smoking and excessive alcohol consumption contribute to more than a third of all deaths in the country. The prevalence of type 2 diabetes is the second highest in Europe (14.2% of the adult population), and related mortality is high (38.7 per 100 000).

Type 2 diabetes and its complications can be prevented by a healthy diet, regular physical activity, maintaining a normal body weight and avoiding tobacco use. A series of cost-effective actions (e.g. blood glucose, blood pressure and lipids control) can help people manage their type 2 diabetes. Self-management of type 2 diabetes is a complex and demanding task that may be influenced by a range of factors, including health literacy.

Project management, implementation and reporting of this project were undertaken collaboratively between the NOVA University of Lisbon and the Portuguese Diabetes Association. Engagement of local stakeholders and recruitment of participants was managed by Oeiras Municipality. All collaborators and participating Oeiras local health institutions (elderly care, seniors' universities) were involved in co-design and implementation of actions.

Aims and objectives

To co-design actions that support behaviour change in adults living with or at risk of type 2 diabetes.

- Describe the health literacy needs and strengths of adults with and without type 2 diabetes.
- Reduce the proportion of people living with uncontrolled type 2 diabetes.

It is important for local service providers to be highly involved in mobilizing local stakeholders.

Study activities

Data collection has been put on hold because of the COVID-19 pandemic. The HLQ in Portuguese was administered to 470 people with type 2 diabetes from the Portuguese Diabetes Association and will be administered to 300 adults without diabetes. Staff will use the Org-HLR tool to inform priorities for organizational improvement. Idea-generation workshops will involve health professionals, people living with type 2 diabetes, community members without diabetes, and community stakeholders at Oeiras Municipality.

Outcomes

Outcomes are to be reported when the project recommences.

Sustainability

Sustainability is to be reported when the project recommences.

Key lessons



Setting up an NHLDP

The know-how and skills from the co-ordinating institutions are important for advocating for health literacy and sustaining the project. The previous experience of the researchers in participatory research and a long history of providing health care to people with type 2 diabetes means there is an existing wide network for mobilizing capacity.



Running an NHLDP

It is important to have human resources and sufficient funding dedicated exclusively to the project, to prevent overloading staff and reducing enthusiasm for the project. The Ophelia process respects local needs and strengths and promotes empowerment, but the process is challenging because the assessment tools demand strong involvement from participants and the data analysis is complex.



What future NHLDP teams should know

The involvement of stakeholders in the needs assessment is useful for the development of trusting relationships and facilitates the project progress.



The most useful part of the project

- For service providers – it is important for local service providers such as Oeiras municipality to be highly involved in mobilizing local stakeholders.
- For the project team – it is important to have access to other teams with experience in setting up Ophelia for problem-solving.

Selected further reading

Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Råheim Borge C et al. Acting together: WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. Copenhagen: WHO Regional Office for Europe; 2019 (<https://apps.who.int/iris/handle/10665/327059>, accessed 12 September 2021).



WHO European Region Portugal

Setting Urban; community

Focus Prevention of NCDs and improved access and health outcomes for migrants

Target group Migrant populations in Lisbon



Background

Recent data have shown that some groups of migrants are particularly vulnerable to NCDs, with higher incidence, prevalence and mortality rate than host populations. Many migrants are also among the most socially vulnerable and disadvantaged populations in the world and frequently remain out of reach of health services. As a result, migrants are often missed by conventional disease prevention and health information strategies, and have delayed access to diagnosis and care, which increases their disadvantage. In addition, the COVID-19 pandemic has aggravated social and health inequities.

In Portugal, the foreign resident population increased by 22.9% to 590 348 between 2018 and 2019. In 2018, the foreign-born population represented 8.6% of the total population and 15.5% of the population of the capital, Lisbon. Most migrants in Portugal are from Asian countries, Brazil and Portuguese-speaking African countries. Portugal has a national health service with universal health care for Portuguese citizens and foreigners, regardless their migration status. Nevertheless, barriers still exist at individual, practitioner and service levels. It is important to consider health literacy when working with migrants who may face potential educational, cultural and structural barriers that limit access to health information, services and support. In Portugal, little is known about health literacy needs and NCDs in migrant populations.

The National School of Public Health, NOVA University of Lisbon has formed a consortium with Calouste Gulbenkian Foundation, the High Commission for Migration, Lisbon City Council and others to co-fund this project. Ethics approval was obtained from the Ethical Committee of NOVA Medical School.

Aim and objectives

To optimize health literacy, health promotion and social cohesion to support prevention of NCDs among migrant populations, thereby contributing to improving health outcomes and reducing health disparities.

The project procedures have been adapted to comply with restrictions under COVID-19 pandemic conditions. The recruitment approaches were designed to ensure the sample included participants with limited literacy, from culturally and linguistically diverse backgrounds and with diverse clinical or psychosocial needs.

Study activities

The first phase involves a local needs and strengths assessment. Progress to date includes contacting and engaging local stakeholders in the project and gaining approval for data collection at their sites. Translation and piloting of materials and instruments are complete, and the data collection team has been trained. Data collection using the HLQ in Portuguese started but was delayed by the COVID-19 pandemic. The project procedures have been adapted to comply with restrictions under pandemic conditions. Community workshops are planned to enable further collection of data, including health behaviours, health literacy abilities and needs, risk and protective factors for NCDs, barriers to accessing prevention, early diagnosis and care of NCDs, factors that promote social integration and cohesion, and health service engagement with and responsiveness to migrants' health needs. The second phase encompasses the selection and co-design of a set of multi-sectoral health literacy-based interventions to strategically address the identified needs.

The evaluation of the implemented health literacy-based interventions will be conducted during the third phase using a mixed-methods approach, actively collaborating with stakeholders during the quality improvement cycles.

Outcomes

Preliminary outcomes have shown that the benefits of existing long-standing service networks enable trust and engagement of community services and members. A cross-sectional survey was conducted with over 1100 migrants using the HLQ and other indicators (socioeconomic, migration context, perceived health status, chronic disease and incapacity, access to and use of health-care services perceived impact of COVID-19). The recruitment approaches ensured the sample included participants with limited literacy, from culturally and linguistically diverse backgrounds, and with diverse clinical or psychosocial needs.

Sustainability

Stakeholders and community leaders are project partners and will be involved in implementation activities, which will contribute to the integration of health literacy practice in their own workplaces. The project will also contribute to mobilizing the capacities of communities and stakeholders to continuously advocate for health literacy.

Key lessons



Setting up an NHLDP

Previous experience with a participatory approach, a network of a wide range of stakeholder, trusting relations with local associations are very useful for preparing and implementing the project to ensure it meets the real needs of communities and stakeholders.



Running an NHLDP

It is important to put effort in the initial stage to engage local organizations, other key stakeholders and community leaders. Establishing and maintaining partnerships requires negotiation skills to overcome the different agendas and priorities of partners, and the flexibility to share power while running the project. Human resources exclusively dedicated to the project, and PhD or master's students with motivation and commitment to the project, are valuable. The constraints caused by the COVID-19 pandemic required rapid adaptation and a search for new solutions.



What future NHLDP teams should know

The initial stages of engagement of local organizations and key stakeholders take time and require continuing effort and planning. This is crucial for the success of the project and is a worthwhile investment.



The most useful part of the project

- For community members – no detailed data are available yet, but there is a growing awareness of research skills and practice. Several informal leaders of migrants' communities were engaged as recruiters of potential participants within their social networks, and as interpreters.
- For service providers – growing awareness of and insight into health literacy.
- For the project team – the value of nurturing relationships with community partners, stakeholders and migrant groups, including the most vulnerable.

Selected further reading

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Slovakia:
Using health literacy profiles to improve
chronic disease management



WHO European Region Slovakia

Setting

Urban, rural; hospital

Focus

Improved access to services
and health outcomes
for people on dialysis

Target group

People on dialysis for
chronic and end-stage
kidney disease in
dialysis clinics



Background

Slovakia has a population of 5.4 million people, an affordable public health insurance system, and health-care facilities focused mainly on acute care rather than care for people with chronic conditions. Over 22% of the population has a chronic condition (e.g. cardiovascular disease, diabetes, respiratory disease) and there is an 8–16% prevalence of chronic kidney disease. Risk factors for chronic kidney disease (diabetes, hypertension, obesity) are rising in Slovakia. End-stage kidney disease requires costly haemodialysis therapy or kidney transplantation. The self-management tasks required by people who need dialysis are complex and demanding, and many factors, including health literacy, can lead to people having a poor diet and inadequate fluid intake, which can lead to hospitalization and increased risk of death.

Associations are expected but still poorly understood between health literacy and people's management of kidney disease. Health services in Slovakia are starting to implement coordinated client-centred care to improve the quality of care and to lessen the burden of chronic disease management on clients and their families. The NHLDP in Slovakia will address a range of NCDs; this case study describes the study of people receiving dialysis in 20 clinics in Slovakia.

The lead organizations on this project are the Faculty of Medicine, Pavol Jozef Šafárik University and Fresenius Medical Care dialysis services in Košice. The project is funded by the Slovak Research and Development Agency. Ethics approval was obtained from Pavol Jozef Šafárik University and the Fresenius Medical Care dialysis services.

Aim and objectives

To improve health care efficiency and responsiveness of the Slovak health-care system for people with NCDs. This part of the project has a focus on people receiving dialysis:

- Assess associations between health literacy and social connection, personality, functional health status and quality of life;
- Longitudinally monitor associations between health literacy and kidney disease progression and complications.

The project provided the team with networking opportunities within the NHLDP network, and allowed the team to establish personal contact with participants, develop interviewing skills and see the topic through the perspectives of different stakeholders (doctors, nurses, clients).

Study activities

The Slovak version of the HLQ was administered using a tablet computer during dialysis sessions for 542 people across 20 dialysis clinics (mean age 63.6 years, 60.7%). Other client-reported outcomes, including the Kidney Disease Quality of Life Instrument and the Satisfaction with Life Scale were used to assess quality of life and adherence to prescribed treatment. Other data collected included, anxiety, depression and subjective health change. Clinical data, including mortality, were obtained from the European Clinical Database with the consent of participants.

Outcomes

This study did not show that health literacy predicts mortality and the health status of people on dialysis over time (two years). Results have shown, however, that non-adherence to dietary and fluid intake recommendations is associated with lower scores on some HLQ domains (Scale 2 – Having sufficient information to manage my health; Scale 3 – Actively manage my health; Scale 6 – Ability to actively engage with health care providers). The project is in Ophelia Phase 2 (select, plan and test health literacy actions) but is delayed due to the COVID-19 pandemic.

Sustainability

The Fresenius Medical Care dialysis service is closely following this project. It plans to use the findings to inform recommendations to improve care standards of its Slovak practices and potentially other international Fresenius Medical Care dialysis services.

Key lessons



Setting up an NHLDP

Agreement with the Fresenius Medical Care international headquarters was required, and this took several months. After approval was granted, communication with dialysis clinics was effective and mutual collaboration was established at the local level in 20 clinics. It was crucial to establish strong relationships with the nurses and head nurses who provided support for data collection and ongoing issues related to the project.



Running an NHLDP

Managing such a project requires a stable and relatively large team of collaborators. The team for this project is small and relies on help and support from staff at the dialysis clinics. A larger team would make the project run more smoothly and efficiently.



What future NHLDP teams should know

Make sure resources are secured for ongoing project activities, including staff and one or two PhD students dedicated to the project.



The most useful part of the project

- For community members – clients had the opportunity to talk about their health conditions, experiences and problems with treatment with someone who listens.
- For service providers – to find new constructive ways of improving their jobs and to be more helpful to their clients.
- For the project team – networking possibilities within the NHLDP network, personal contact with participants, development of interviewing skills, and seeing the topic through the perspectives of different stakeholders (doctors, nurses, clients).

Selected further reading

Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Råheim Borge C et al. Acting together: WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. Copenhagen: WHO Regional Office for Europe; 2019 (<https://apps.who.int/iris/handle/10665/327059>, accessed 12 September 2021).

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WHO Eastern Mediterranean Region Egypt

Setting Rural; fishing villages

Focus Prevention of NCDs and improved access to services and health outcomes

Target group Fishermen and their families who live and work around Lake Borollos



Background

Lake Borollos, in the Kafr el-Sheikh Governorate of Egypt, is a northern coastal lagoon with agricultural land to its south and an opening to the Mediterranean Sea in the north. It is the second-largest lake in Egypt. Decades of inadequate environmental management have led to widespread pollution and unsustainable development of the lake. This has created long-term health hazards for the estimated 28 000 fishermen and their families making their living from the lake.

Fishing has played an important role in ensuring economic sustainability in Egypt. It is a difficult occupation. Fishermen are exposed to extreme weather conditions, hard physical labour and frequent injuries, and they often have inadequate diets. Consequently, the fisherman and their families are at high risk of NCDs but have limited access to health-care services. In recent years, attention has been directed towards many areas of lifestyle reforms in the area, including health. There is an urgent need to improve the community's understanding and management of NCDs.

With funding from the Egyptian Academy of Science and Technology, researchers from the Faculty of Medicine at Ain Shams University in Cairo embarked on a process to describe the health literacy profile of the Lake Borollos fishing community, and to document the health and environmental risk factors. Collaborative partners included representatives from the national government, the water resources union, local nongovernmental organizations, fishermen's syndicates and community health workers.

Aim and objectives

To develop a health literacy framework to improve the health status of fishermen and their families living around Lake Borollos, through enhancing access to health information and health services.

- Assess the health literacy challenges and strengths of Lake Borollos fishing families.
- Assess the health services.
- Assess health, environmental and social risk factors.
- Involve citizens and civil society organizations (nongovernmental organizations and fishermen's syndicates) in the needs assessment and co-design process.

To ensure the voices of the whole community were heard, four ideas generation workshops were undertaken involving fishermen and their families, members of the fishermen's syndicate, representatives from the Ministry of Health and Population, representatives from the Cooperative Union of Egyptian Water Resources, and primary care nurses (*raedat refeyat*).

Study activities

An existing Arabic version of the HLQ was assessed. Minor modifications were used to make it suitable for the linguistic, educational and social context of the area. The Arabic HLQ was administered by interview. Data collection took place in five villages: Almaksaba village, Ashakhloub, Borg El Borollos, Mastaroh, Metobas. Women engaged as *raedat refeyat* (female nurses of primary health centres serving fishing communities) were interviewed to increase the numbers of female respondents and to explore the health literacy of people who provide help and information to the fishing families. Potential survey participants aged 18 years and over were provided with a verbal explanation of the project, and those willing to take part provided written consent. A total of 436 people took part.

Four ideas generation workshops, with 59 participants, using vignettes based on the HLQ needs assessment data were held to identify potential actions to improve health and access to services. Two workshops involved fishermen, members of the fishermen's syndicate, representatives from the Ministry of Health and Population, and from the Cooperative Union of Egyptian Water Resources. The third workshop involved of *raedat refeyat*. The fourth workshop involved wives of fishermen.

The research team met with senior staff from the Ministry of Health and Population and nongovernmental organizations to discuss the health, environmental and social needs of the fishing families, and the availability and accessibility of health services.

Pre/post test evaluation of the health education sessions used health knowledge questions. Focus group discussions and in-depth interviews with stakeholders were used to discuss the impact of the work.

New education resources and sessions were developed and provided to the community. The project team developed new scientific skills over the project, and the results were used by the government to improve the quality of health services.

Outcomes

The mean age of survey participants was 42 years, 50% were male, 42% were working in the fishing sector, 18% had internet access, and 37% were illiterate. Data from the HLQ indicated that most people did not have enough information to manage their health. Women had less ability to actively manage their health and less social support for health compared with men. Participants actively involved in fishing had low skills to navigate the health-care system. Based on the data, seven health literacy profiles were identified, which were used to develop vignettes for discussion in the ideas generation workshops.

Workshops elicited 80 action ideas summarized into 5 themes to be operationalized at 2 levels:

1. The Egyptian Government, nongovernmental organizations and fishermen's syndicates need to enhance education in the fishing communities, improve the quality of health-care services, and provide financial support for health (e.g. pensions, social support, health insurance).
2. Nongovernmental organizations and fishermen's syndicates need to promote social support for health and better health-related quality-of-life practices among fishing communities.

The following actions were selected and implemented:

- raising awareness of the fishermen and their families through health sessions and dissemination of leaflets and brochures;
- training for *raedat refeyat* and providing them with educational materials to support sustainable distribution of information.

Sustainability outcomes include:

- capacity-building of *raedat refeyat* to distribute information as part of routine practice;
- ongoing health education session in the community to raise awareness of health with provision of accessible educational materials (e.g. brochures, booklets) as take-home messages for the families.

Key lessons



Setting up an NHLDP

- Ensure funding is secured to support financial implementation of the project.
- It was difficult for the research team to obtain administrative approvals at the local government level.
- This project engaged an national government, the water resources union, nongovernmental organizations, and *raedat refeyat*. This engagement was important for aligning project goals and activities with key strategic goals and for establishing ownership of the project.



Running an NHLDP

Seek the help of a person experienced in the Ophelia process when applying the model for the first time.



What future NHLDP teams should know

Understand all the Ophelia phases well before starting. Project administration, including ethics and approvals, can take a long time.



The most useful part of the project

- For community members – receiving health education sessions that arose from the project.
- For service providers – new education resources to provide to the community.
- For the project team – developing new expertise from undertaking the project; publishing scientific work about the process, activities and outcomes; and seeing the government use the project results to improve the quality of health services.

Selected further reading

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**WHO Western
Pacific Region**
Victoria, Australia

Setting
Urban, rural, regional;
community screening service

Focus
Improved access to breast
screening for culturally
diverse women

Target group
Aboriginal and Torres Strait
Islander, Arabic and Italian
women aged 50–74 years



Background

Under the Australian Federal cancer screening programme, each state and territory has a breast cancer screening service. In the state of Victoria (population 6.7 million people), BreastScreen Victoria has 42 fixed screening sites and 2 mobile vans that travel to remote and rural areas of the state. The service screens about 270 000 women a year. Based on electoral roll registrations, women are invited to screen when they turn 50 years old. Although screening is free to women aged 50–74 years old, only 54% of eligible women take part in the programme.

BreastScreen Victoria measures participation in screening by language group. It found that participation from some language groups, including women who speak Arabic or Italian at home, is less than 50%. Only 36% of Aboriginal and Torres Strait Islander women took part in the programme according to the 2017–2019 BreastScreen Victoria data. This project was aimed to achieve equitable participation across all groups.

BreastScreen Victoria partnered with the Victorian Department of Health and Human Services (project funders) and the developers of the Ophelia process for this project.

Aims and objectives

To improve breast screening awareness and participation among culturally diverse women.

- Conduct a needs analysis to identify barriers to screening participation.
- Identify the association between health literacy and participation in breast screening.
- Develop, test and implement activities to improve screening rates.

Aboriginal women reported feelings of shame around being uncovered during screening and that they did not feel culturally safe. As such, a screening shawl designed by a local Aboriginal artist was designed and used during screening. In 2019, BreastScreen Victoria observed greatly increased screening among Aboriginal women in only two months across eight communities. The shawls remain in the communities and can be used for other women's business.

Study activities

The needs analysis included a total of 553 people: 429 completed the HLQ ($n=52$ Aboriginal and Torres Strait Islander, $n=71$ Arabic, $n=173$ Italian, $n=133$ community members as a control group).

Interviews were conducted with 21 women, and 103 women took part in workshops or yarning circles. Yarning circles were for Aboriginal and Torres Strait Islander community members to talk about the concepts of the HLQ in a culturally appropriate and safe space.

Outcomes

The study identified five barriers to breast screening for the target groups:

- lack of knowledge about breast screening (e.g. importance of screening, eligibility, what to expect at an appointment);
- fear of being unable to communicate with clinic staff, anticipation of pain, fear of being touched by a stranger and fear of being diagnosed;
- having other priorities that conflict with screening (e.g. caring for family, having chronic conditions that require ongoing care);
- having health beliefs that negate the benefit of screening (e.g. believing cancer cannot be cured);
- access issues (e.g. cannot read invitation letters, lack of transport to appointments, unfamiliar with public transport).

When comparing health literacy with the health literacy outcomes of the community control group:

- Aboriginal and Torres Strait Islander women were less likely to have a trusted health-care provider they could rely on, less likely to actively manage their health, and had greater difficulty understanding health information;
- Arabic women had greater difficulty navigating the health-care system, finding health information and understanding health information;
- Italian women had greater difficulty understanding health information.

More than 300 ideas to improve screening participation were generated by the women and health service providers. From these, seven were selected for implementation and evaluation:

- reminder letters in the appropriate language;
- reminder calls in the appropriate language;
- media advertisements and educational animations in the appropriate language;
- peer education programme;
- pharmacy engagement;
- staff training;
- use of cultural shawls designed by local Aboriginal artists to be used during screening procedures.

Reminder calls in the appropriate language were implemented.

Underscreened Arabic and Italian women who received calls in the appropriate language were 10 times more likely to book screening appointments. Calls in the appropriate language are now usual practice in Arabic, Cantonese, Greek, Italian, Mandarin, Polish, Russian, Spanish and Vietnamese.

The most effective of these interventions were reminder calls in appropriate language and the cultural screening shawls for Aboriginal women.

Reminder calls in appropriate language

- Arabic- or Italian-speaking women ($n=115$ and $n=80$ women, respectively) who had previously attended screening but not returned for 27 months were called in their own language and invited to book screening appointment. This was tested in a randomized controlled trial format (telephone call versus no telephone call).
- This was tested in a randomized controlled trial format (telephone call versus no telephone call).
- Calls in the appropriate language are now usual practice in Arabic, Cantonese, Greek, Italian, Mandarin, Polish, Russian, Spanish and Vietnamese.

Aboriginal cultural screening shawls

- In the needs assessment, Aboriginal women reported feelings of shame around being uncovered during screening and that they did not feel culturally safe. A screening shawl was designed by a local Aboriginal artist for use during screening.
- Using a group booking model, 14 women were screened. The women stated they would not otherwise have attended and that they felt culturally safe.
- The shawls remain in the communities and can be used for other women's business.
- In 2019, BreastScreen Victoria observed greatly increased screening among Aboriginal women ($n=162$) in only two months across eight communities.

Sustainability

Of the seven tested interventions, six have been implemented widely. Further health literacy responsiveness improvements, derived from the Ophelia process, have been implemented through incorporation in BreastScreen Victoria's operational plans. The practice of including clients and community members is now embedded in the policy and governance structure of BreastScreen Victoria. Community members are consulted early, are on project advisory groups and are integral to co-design and evaluation. The process of calling women in their own languages has been applied to many other migrant groups and is now routine practice.

Key lessons



Setting up an NHLDP

It is important to take the time for genuine engagement with community groups and put them in control of the project to develop ownership of the process and the outcomes.



Running an NHLDP

When working with migrant groups, it is important to carefully select bilingual health workers who can quickly support migrant groups to understand the co-design process and be part of the solution. The process of engaging community members in the Ophelia process is informative and educational for the people involved and can build trust and engagement beyond the life of the project.



What future NHLDP teams should know

Many ideas can come out of the ideas generation process. Many may appear to be small and trivial but have profound meaning and effects for communities. It is important to respect and include all ideas and implement groups of ideas that work together.



The most useful part of the project

- For community members – there was a 10-fold increase in booking rates when culturally diverse women received reminder calls in their own languages. Aboriginal women reported having a positive screening experience when wearing the cultural screening shawl.
- For service providers – many procedural and structural improvements have led to improvements in health literacy responsiveness and health equity.
- For the project team – the experience of working closely with the organization to undertake rigorous evaluation and the evidence generated led to strong communication across states and wide-scale national improvements in services.

Selected further reading

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**WHO Western
Pacific Region:**
Tasmania, Australia

Setting
Urban, rural, regional;
primary schools

Focus
Prevention of NCDs
through health education
of school children

Target group
Children aged 4–12 years
in primary schools



Background

This project is undertaken in Tasmania, Australia. Tasmania's population has demonstrated lower health literacy levels and chronic disease risk factors above the national average, including smoking, obesity, physical inactivity and elevated cholesterol levels.

HealthLit4Kids is an education programme to increase health literacy awareness, build community capacity, and support educational outcomes for young people to reduce health inequities for families. It is designed for use in schools to support school responsiveness and preparedness to cultivate health literacy within the school environment and across the curriculum, and to prompt discussions about health among teachers, children, families and communities. In recognizing that a one-size-fits-all approach does not always work, HealthLit4Kids provides teachers with an opportunity to consider the health literacy needs of their students and the health issues of concern in their local school communities. The focus of HealthLit4Kids is on prevention of chronic diseases (cardiovascular disease, diabetes, cancer) and a reduction in associated modifiable risk factors through health education of primary school children.

The programme is housed within the University of Tasmania (<https://www.utas.edu.au/hl4k>) and is a collaboration between researchers at Flinders University, Swinburne University of Technology, the University of Canberra and the University of Tasmania. Ethics approval was received from the Tasmanian Social Sciences Human Research Ethics Committee. Funding for the project was provided by the Tasmanian Community Fund and the University of Tasmania.

Aim and objectives

To improve health literacy to support positive health outcomes and educational achievements for children and to narrow the health inequality gap for families by working at a local level with children, schools, families and communities.

- Conduct professional development workshops to support teachers and students to explore, discuss, design and share resources.
- Support children to create health messages in ways that make sense to them to provide them with a voice and means of expressing health concepts and actions.
- Develop school health literacy action plans to guide initiatives across school communities and support changes in school practices and policies.

Children become HealthLit4Kids Heroes to champion health messages and participate in activities. Classroom-based activities result in artefacts or creative pieces that illustrate the children's learning and messages about health and well-being, which are showcased in an exhibition attended by family members and local organizations.

Study activities

A programme logic model and nine discrete research questions were used to determine if health literacy could be taught and developed in the primary school context.

Three facilitated workshops are held at primary schools during the school year:

- development of a shared understanding of health literacy and self-assessment of the health literacy responsiveness of the school and Health Literacy Action Plan;
- development of lesson plans and individual classroom learning activities and review exemplars;
- evaluation of programme success and repeat baseline measures.

Children within the schools become HealthLit4Kids Heroes to champion health messages and participate in activities. Schools are encouraged to focus on HealthLit4Kids in the classroom for a whole term. Health literacy is included as a thread in multiple areas of the curriculum, rather than being an add-on to the curriculum. The classroom-based activities result in artefacts or creative pieces that illustrate the children's learning and messages about health and well-being.

An exhibition to showcase the children's learning happens at the end of the first year. Family members and local community health and well-being organizations are invited to attend. The artefacts and their accompanying lesson plans are submitted to an open education resource to provide exemplars and resource materials for future HealthLit4Kids schools.

The health literacy knowledge, skills and experience of the teaching staff are assessed at the start and end of the programme. Teachers write reflections on their participation and the effect on their teaching practice. An evaluation protocol informs the development of the school's health literacy action plan and contributes to continuous improvement of the programme.

A total of 132 teachers, 1725 students and 3450 family members and people from the wider community are now aware of the concept of health literacy. Teachers' confidence to teach health literacy in the classroom increased. Wider community benefit was evidenced through artefact mobility (between home and school), exhibition attendance, community partner support and invitations to run additional pop-up community events. HealthLit4Kids is now running in five schools, independently of the research team.

Outcomes

Pre/post intervention data from schools showed improvements in the following areas:

- Individual health literacy knowledge, skills and experience of the 79 teachers increased on all 14 questions about knowledge, skills and experience over the 7-month timeframe.
- Whole-school health literacy responsiveness was determined against all six domains of the HeLLOtas survey tool. All five schools demonstrated an overall improved view of their health literacy responsiveness after participating in the first year of the health literacy action.
- A total of 132 teachers, 1725 students and 3450 family members and people from the wider community are now aware of the concept of health literacy.
- Teachers' confidence to teach health literacy in the classroom increased.
- Students' health literacy development was evidenced in the artefacts, teachers' written reflections, and teacher and parent focus group data. Student behaviour change was noted in the parent and teacher data.
- Wider community benefit was evidenced through artefact mobility (between home and school), exhibition attendance, community partner support, and invitations to run additional pop-up community events.
- Schools with unique needs successfully set individual action plans relevant to their students, parents and local school communities.

Qualitative data from teacher focus groups and reflections demonstrated improvements in personal and professional development as a result of being involved in HealthLit4Kids.

Sustainability

At the individual child level, the learning culminated with an artefact that provided each child with an age-appropriate voice or vehicle for communication about a health issue. The artefact was transported between home and school and proudly displayed and explained at the school wide exposition. The artefacts supported children to start conversations with their parents about health issues.

To support sustainability, schools were encouraged and supported to develop their own health literacy policy (a four-year cycle that seeks continuation of the health literacy action plan). The HealthLit4Kids facilitators from within the school and the HealthLit4Kids Heroes (nominated children) review the action plan annually and work to deliver on the objectives.

HealthLit4Kids is now running in five schools, independently of the research team.

Key lessons



Setting up an NHLDP

When preparing grants or requesting funding, sponsors, philanthropy and donors, it is important to distinguish the programme and its evaluation in the school from the associated research. The data collected in the initial stages informs the school action plan and become baseline data for future evaluation.



Running an NHLDP

Given that the informed consent process can be burdensome on researchers, teachers and parents, and may inadvertently exclude some schools and potential participants, consider using opt-out models or request that school principals add it to annual forms.



What future NHLDP teams should know

Evidence showing that the Ophelia principles and elements of the programme co-design such as the whole-school approach, action plans, policy development, alignment to curriculum, lesson planning, and HealthLit4Kids Heroes were put in place is important for understanding scalability and sustainability.



The most useful part of the project

- For community members – children and their families and carers were exposed to many healthy options.
- For service providers – teachers developed confidence and skills in teaching health.
- For the project team – the HealthLit4Kids team learned much about social entrepreneurship and how to create sustainability of a health literacy action.

Selected further reading

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Australia:
Developing mental health
literacy responsiveness education
and training



**WHO Western
Pacific Region:
New South Wales, Australia**

Setting

Urban, rural; mental
health services

Focus

Improved access to and
responsiveness of mental
health services

Target group

Health-care and other
frontline workers, and
organizations providing
services and training



Background

Access to mental health services and mental health outcomes vary widely across most countries, including Australia. This is due to a wide range of factors, including rurality, income, indigenous ethnicity, comfort with using technology, and LGBTQI+ (lesbian, gay, bisexual, transgender, queer or questioning or intersex) identification. Stigma and differing understandings of mental health remain a barrier to access to care for many community members. What people in a community understand about mental health – including in families, workplaces and health services – can profoundly influence whether they obtain support and services, including for prevention. People with mental health issues also have many challenges with managing their conditions and have further complexity when managing their physical health (e.g. hypertension for cardiovascular disease, diabetes, obesity) in terms of knowing what to do and obtaining coordinated services.

How well people can get the help they need is largely dependent on how services provide access and respond to people with different health literacy needs, strengths and preferences. The ability of services to effectively engage this diversity of people is referred to as health literacy responsiveness.

This project, initiated by the Australian and New South Wales (NSW) governments and led by the Mental Health Commission of NSW, is a capacity-building project that seeks to build the health literacy responsiveness of all agencies and organizations that provide services to people with lived experiences of mental health disorders and their families and kinship groups. This includes services contracted through primary health networks, regional hospital services and a wide range of community organizations.

Ethics approval was obtained through Swinburne University of Technology and other governing authorities. A total of AU\$ 5 million is provided by the Australian Government over 3 years.

The project used results from the 2018 Australian Bureau of Statistics National Health Survey, which used the HLQ. Additional HLQ data were collected from 403 people who were likely to be underrepresented in the National Health Survey, including people from the Pacific region, LGBTQI+ people, people from culturally and linguistically diverse backgrounds, people living with disability, young people and elderly people.

Aims and objectives

To enable health services and providers to responsively meet the needs of people with lived experiences of mental health disorders and their families and kinship groups in all their diversity.

- Apply the Ophelia process to co-design a wide range of actions to improve health literacy responsiveness of organizations that provide services to people with lived experiences, not only as individual organizations but as an integrated system.
- Implement a local planning process and a package of capacity-building interventions, first in two primary health networks and then in other primary health networks across NSW.
- Evaluate the package of capacity-building interventions for its:
 - capacity to be developed within organizations and across the health-care system;
 - capacity to improve access, satisfaction and perceived well-being of people with lived experiences of mental health disorders and their families and kinship groups in all their diversity;
 - feasibility for transfer to other jurisdictions.

Study activities

The project uses the HLQ and other data from the 2018 Australian Bureau of Statistics National Health Survey ($n=1018$). Additional HLQ data were collected from 403 people who are likely to be underrepresented in the National Health Survey. Priority groups include people from the Pacific region, LGBTQI+ people, people from culturally and linguistically diverse backgrounds, people living with disability, young people and elderly people.

There has been extensive engagement across stakeholder groups, including senior management and leadership of primary health networks and priority groups, people with lived experiences and their carers and families, and service providers. The HLQ data formed the basis of 13 vignettes or stories that were shared during 15 idea-generation workshops held with people with lived experiences ($n=11$) and service providers ($n=4$). Other information collected as part of the needs assessment included a situational analysis of mental health literacy (and general health literacy) and activities currently under way within primary health networks. Evidence was gathered from research and grey literature about activities that improve mental health literacy responsiveness.

The 11 action areas resonate strongly with what practitioners need and what the community wants.

Outcomes

The data contributed to the development of 11 action areas to enhance responsiveness of services to people with lived experiences of mental health disorders. These 11 action areas were grouped into three theme areas:

- training and capacity-building in health and community services;
- accessing help at the right time in easy and friendly ways;
- connection between health services and the community.

Three state-wide forums have been undertaken and a community of practice network has been launched. Nine of the 10 primary health networks in NSW are participating and are developing their implementation plans.

Sustainability

A programme logic model and process evaluation of this project is planned to continuously monitor and improve the project so it meets the needs of the community. The project team is constantly engaging with stakeholders in a way that develops local ownership so that fit-for-purpose, wanted and needed health literacy-responsive activities are put in place that not only support practitioners and their organizations, but also improve outcomes for community members.

A critical element for sustainability is the deep and broad engagement of community members, practitioners, managers and policy-makers at all levels. The 11 action areas resonate strongly with what practitioners need and what the community wants, so that implementation will be supported. The development and facilitation of numerous communities of practice, based on the demand of frontline practitioners, will facilitate local ownership and a good fit with organizations.

Key lessons



Setting up an NHLDP

The design of this study was modified to comply with social distancing requirements during the COVID-19 pandemic. These modifications enabled the Ophelia process to be undertaken entirely online. This may have increased the depth and breadth of engagement of community members (including those living with disabilities) and professionals in diverse settings (including remote rural areas) to deeply engage.



Running an NHLDP

The project is overseen by a large collaborative working group with diverse membership. This group has allowed for prompt problem-solving, support for recruitment and advocacy. The Ophelia process is a fully end-to-end development and implementation system. It is important to regularly provide information to all stakeholders at each stage for the Ophelia process to maximize understanding.



What future NHLDP teams should know

Online Ophelia projects need an administrative coordinator familiar with technology platforms used to collect data and run workshops, and whose job is dedicated to administration of the questionnaire and scheduling, promoting and running workshops.



The most useful part of the project

- For community members – some people who would have struggled to attend face-to-face workshops for a range of reasons were able to attend online meetings. A lot of work was put into making the workshop space a safe and comfortable place for all participants. A psychologist was always in attendance for people to talk with, and a breakout room was created for privacy.
- For service providers – many service providers and managers have had in-depth opportunities to provide their wisdom and have input into decision-making in their own organizations. Many providers have welcomed the highly practice-based processes and the generation of a useful roadmap for implementation.
- For the project team – the use of online workshops meant that many more people could attend than would have been possible with face-to-face workshops. This reduced the burden of travel. Weekly 90-minute project team meetings and 60-minute collaborative working group meetings every 2 weeks have developed a close-knit team that is highly skilled and focused on the project's intended outcomes.

Selected further reading

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**WHO Western
Pacific Region:
Brunei Darussalam**

Setting

Urban, rural, regional;
hospitals, health centres

Focus

Improved prevention,
access to care, and health
outcomes for people with
type 2 diabetes

Target group

Adults with
type 2 diabetes



Background

Brunei Darussalam is a small country (population 459 500 people) on the northern coast of the island of Borneo. It is a high-income country with major exports of petroleum and natural gas. Illiteracy is low (<5%) and health care is fully subsidized by the government. Nearly 80% of the population live in urban areas. NCDs are estimated to account for 85% of all deaths in Brunei Darussalam, with about 10% due to type 2 diabetes.

Management of type 2 diabetes can be a challenge for many people. Having type 2 diabetes usually means lifestyle changes are needed, can influence people's ability to work, and often means an increase in health-care costs. There can be difficulty understanding instructions about taking medicines and remembering to attend medical appointments and do other self-care tasks. People who find it difficult to manage their condition over many years may be hospitalized with serious conditions, including blindness and serious blood circulation problems that may lead to amputation.

The Brunei Darussalam Ministry of Health led and funded this project in partnership with the University Brunei Darussalam. Eight hospitals and health centres are taking part in the project to better understand the health service needs of people with type 2 diabetes. Ethics approval was obtained from the Medical and Health Research Ethics Committee, Ministry of Health, Brunei Darussalam.

Aims and objectives

To explore the health literacy needs among adults with type 2 diabetes, and the development of a range of health literacy actions.

- Investigate people's views about existing information and services for people with type 2 diabetes.
- Assess people's needs and preferences for health information about managing type 2 diabetes.
- Determine how people use information and services to make decisions about managing their type 2 diabetes.

Exposure to the concept of health literacy among staff from different health centres and hospitals has been useful. The project has given the team the opportunity to work with different departments and apply health literacy within their workplaces.

Study activities

The study involved interviewing 25 people with type 2 diabetes using a semistructured interview. Interview sessions lasted 17–46 minutes. The study took place at four district hospitals and four health centres in Brunei-Muara district. A pilot study was conducted before the main study involving seven participants from one hospital. Inclusion criteria were age 18 years or over, diagnosed with type 2 diabetes by a physician, taking medicine for type 2 diabetes for at least a year, and with or without comorbidities. Results from this pilot study will inform project implementation in the other health centres and hospitals. Health literacy actions will be selected for people with type 2 diabetes, which will be the demonstration project, including creating appropriate health education materials.

Outcomes

Most participants exhibited an inadequate understanding of their condition, especially the underlying causes, and awareness and symptoms of hypo- and hyperglycaemia. Some participants had knowledge about type 2 diabetes self-management, but their skills for self-management were lacking. Participants preferred to receive their health education and consultations in a group. The study highlighted the importance of good communication skills among health-care professionals. In terms of alternative treatment of diabetes (treatments not prescribed by health-care providers), participants preferred natural and herbal remedies because they perceived that such remedies do not cause side-effects.

Sustainability

In 2022, depending on the progress of the project given the COVID-19 pandemic, it is expected that work will begin on a national health literacy action plan to inform the integration of health literacy actions across the health sector.

Key lessons



Setting up an NHLDP

Support the start-up team to thoroughly understand health literacy, especially among health professionals, so the team understands the importance of responding to clients' health literacy needs.



Running an NHLDP

Make sure enough time is allocated to data analysis and write-up tasks.



What future NHLDP teams should know

The qualitative data enable an in-depth exploration of what health information people with type 2 diabetes do and do not understand.



The most useful part of the project

- For service providers – exposure to the concept of health literacy among staff from different health centres and hospitals has been useful.
- For the project team – there has been an opportunity to work with different departments and apply health literacy within their workplaces.

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Health literacy development for the prevention and control of noncommunicable diseases



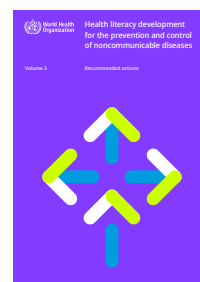
Volume 1

Overview



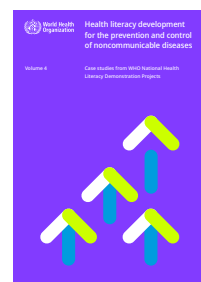
Volume 2

A globally relevant perspective



Volume 3

Recommended actions



Volume 4

Case studies from WHO National Health Literacy Demonstration Projects

For further information,
please contact:
Global Coordination Mechanism
on the Prevention and Control
of Noncommunicable Diseases,
World Health Organization
Avenue Appia 20
1121 Geneva 27, Switzerland
gcmncd@who.int

