Health literacy development for the prevention and control of noncommunicable diseases

The Ophelia Manual

The Optimising Health Literacy and Access (Ophelia) process to plan and implement National Health Literacy Demonstration Projects

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Professor Richard H Osborne

Distinguished Professor of Health Sciences
NHMRC Principal Research Fellow
Swinburne University of Technology, Australia
Prof (Hon), University of Copenhagen, Denmark

Dr Shandell Elmer

Senior Research Fellow
Centre for Global Health and Equity
Swinburne University of Technology, Australia

Dr Melanie Hawkins

Research Fellow
Centre for Global Health and Equity
Swinburne University of Technology, Australia

Dr Christina Cheng

Research Fellow
Centre for Global Health and Equity
Swinburne University of Technology, Australia

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Foreword

The Ophelia Manual is the product of more than 20 years of research, evaluation, training and practice. The Manual provides guidance for using the Ophelia (Optimising Health Literacy and Access) process, which accelerates the development of fit-for-purpose, needed, wanted and useful programs to improve health and reduce inequities.

Early research and evaluation of chronic disease self-management programs revealed that many were not suitable for people with the greatest health needs, such as people with multiple chronic diseases, or those experiencing disadvantage and social exclusion. Some self-management programs were ‘parachuted in’ from other cultures and healthcare systems and local teams did not have the confidence or expertise to modify them for their local context. In other cases, the programs were proprietary, so could not be modified.

Although early evaluations of self-management programs frequently revealed poor uptake and small to very small effects, some educators noticed profound improvements in some individuals. As our approach to evaluation is underpinned by Realist Evaluation – determining what works, for whom, in what circumstances, and why – it seemed premature to declare a program a failure if some people were experiencing improvements.

We developed new measurement tools to help understand people’s health experiences. Use of a grounded approach helped us to develop measurement tools that generate appropriate, meaningful and useful data for making health decisions because the tools are derived from the hearts and minds, and daily practices, of people with lived experiences and front-line practitioners. These tools were tested and improved in challenging settings using the most rigorous statistical and qualitative techniques available.
We increased the standard of validity testing practices because we recognise and accept the responsibility bestowed on a worldwide collective of researchers, clinicians and, at times, governments to have the best possible data to make decisions about groups of people and national programs.

Our measurement priority is to deeply understand the core mechanisms underpinning people’s health experiences so the data inform actions for health that are needed, wanted and useful.

Guided by this priority, we recognised that different people have different needs, and may respond to different programs. Three questions arose:

1. How can programs (and organisations) be responsive to the needs of multiple subgroups instead of applying a one-size-fits-all approach?
2. How can programs be adapted – while maintaining the program intention – to accommodate people’s differences, and to support people’s needs, including social, emotional and cultural needs?
3. Given that our measurement tools reveal core mechanisms underpinning people’s health experiences, how can these tools be used to inform the development of programs to improve health outcomes and equity?

Foreword

From these questions, we established eight guiding principles for program developement and implementation. These became the foundation of the Ophelia (Optimising Health Literacy and Access) process.

While the Ophelia process was developed in collaboration with health service providers and government agencies in Victoria, Australia it is now used flexibly in different contexts around the world. All users of the Ophelia process need to study the eight Ophelia principles and use them to adapt the activities outlined in this Manual to their project context.

The needs assessment component of the Ophelia process uses our measurement tools, primarily the Health Literacy Questionnaire (HLQ) and the eHealth Literacy Questionnaire (eHLQ). Quantitative and qualitative testing of the nine scales of the HLQ and the seven scales of the eHLQ has shown these to be theoretically sound, which is critical for identifying different profiles of health literacy strengths, needs and preferences of population subgroups. Vignettes of these profiles are created and presented to community members, practitioners and managers, inspiring the sharing of expertise, insights and experience. This collective local wisdom combines to become wanted, needed and useful actions to improve health and equity in communities. Volume 4 of the WHO report *Health literacy development for the prevention and control of noncommunicable diseases* presents case studies of WHO National Health Literacy Demonstration Projects (NHLDPs) where this process is frequently applied.

We have supported partners to implement Ophelia projects in several countries to facilitate the development and implementation of meaningful health literacy actions, and we have provided training to inspiring clinical and research teams around the world. It has been our privilege to work with a range of governments, as well as with staff from WHO regional and country offices and the Geneva headquarters. All these projects and collaborations have informed this, our second iteration of the Ophelia Manual. As previously, the Manual is provided as open access to accelerate progress towards improving global health and equity.

I wish to thank the research and development team who helped produce this Manual: Melanie Hawkins, Christina Cheng, Shandell Elmer, Roy Batterham, Kerrie Paulger and Ranjit Nadarajah. I am also grateful for the collegiality, guidance, challenges and advice from Suvajee Good, Guy Fones and Bente Mikkelson from the World Health Organization.

We hope this Manual serves you well. As with Ophelia in general, the Manual is a work in progress. Please don't hesitate to get in touch with any feedback, including ways we can better meet your needs.

Distinguished Professor Richard Osborne
Centre for Global Health and Equity
Swinburne University of Technology, Australia
rosborne@swin.edu.au

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Contributors

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Design

Kasia Geernaert, Brand Creative Director kasia@kandcompanystudio.com

Further information

globalhealthandequity@swin.edu.au

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Abbreviations

HCP

Health care provider

HLQ

Health Literacy Questionnaire

eHLQ

eHealth Literacy Questionnaire

NCD

Noncommunicable disease

NHLDP

National Health Literacy Demonstration Project

Ophelia process

Optimising Health Literacy and Access process

SDGs

Sustainable Development Goals

WHO

World Health Organization

Key terms and concepts

Being left behind

Being left behind relates to the motto of the Sustainable Development Goals “leave no one behind”. This refers to groups or communities that are not included in services or do not have equitable access to health information and services for the prevention and control of noncommunicable diseases (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

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

Determinants of health

The range of personal, social, economic and environmental factors that determine the healthy life expectancy of individuals and populations. These 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 will be required to develop the most appropriate strategies.

Health literacy

Health literacy represents the personal knowledge and competencies that accumulate through daily activities, 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 wellbeing for themselves and those around them.

The Ophelia process explores four facets of health literacy: community health literacy, health literacy development, health literacy of an individual, and health literacy responsiveness. Distinguishing these different facets is important when taking a globally relevant perspective on health literacy for the purpose of improving health and equity in diverse settings.

Health literacy (continued)

Community health literacy

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

- the 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, as well as in traditional or emerging practices of daily life
- the relationships that the community has with outside sources of information.

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

Health literacy development

Health literacy development 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

The health literacy of an individual, as viewed from a globally relevant perspective, is people's knowledge, confidence and comfort – which accumulate through daily activities, social interactions, and across generations – to *access, understand, appraise, remember* and *use* information about health and health care, for the health and wellbeing of themselves and those around them.

Health literacy responsiveness

Health literacy responsiveness is 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 wellbeing of individuals, families, groups and communities.

Ophelia (Optimising Health Literacy and Access) process

The Ophelia process is a co-design approach that is frequently used in health literacy development. It generally uses the multi-dimensional health literacy or digital health literacy questionnaires – the Health Literacy Questionnaire (HLQ) and the eHealth Literacy Questionnaire (eHLQ) – that 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, as well as providing information about what to do next. The Ophelia process uses meaningful engagement to understand and build on local knowledge and wisdom, as well as international evidence, to co-design, develop and implement health literacy actions that are accessible, sustainable and useful for the people who need them.

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, from villages to cities, schools, workplaces – all the places where people are exposed to health-related information and where their health behaviours may be influenced.

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 Ophelia (Optimising Health Literacy and Access) 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-cost or no-cost actions that are easy to implement through to complex multi-level 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.

Introduction

The Ophelia Manual is the product of more than 20 years of research, evaluation, training and practice. The Manual provides guidance for using the Ophelia (Optimising Health Literacy and Access) process, which accelerates the development of fit-for-purpose, needed, wanted and useful programs to improve health and reduce inequities.

This Manual is a detailed resource designed to help you to put the Ophelia process into action. It describes how to implement the three phases and eight steps of the Ophelia process, and includes activities for each step. There are additional resources at the end of each activity section, including templates and examples of ways to complete activities. Some Ophelia project teams may need all the information in the Manual, whereas others may only need parts.

The **eight Ophelia principles** (Figure 1) are the foundation for any Ophelia project. Teams can adjust or adapt methods and activities in this Manual to suit local cultures, resources or other contextual circumstances, using the principles as a guide.

Please contact the WHO National Health Literacy Demonstration Project (NHLDP) Community of Practice, the Ophelia community, or other related communities of practice if you have questions about using Ophelia for your project.

Figure 1. The eight principles of the Ophelia (Optimising Health Literacy and Access) process

1. Focus on outcomes

Focus on improving **health and wellbeing** 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

Prioritise **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

The Ophelia (Optimising Health Literacy and Access) process

As with other co-design models, the Ophelia (Optimising Health Literacy and Access) process involves meaningful engagement with community members, health workers, service managers and decision-makers to uncover local wisdom and ensure that fit-for-purpose, needed and wanted health literacy informed actions are developed (1, 2). Using a strengths-based approach, the Ophelia process draws on methods such as intervention mapping (3–5), quality improvement collaboratives (6–8), and realist synthesis (9–11). It incorporates processes similar to Assets Based Community Development (ABCD) (12, 13) and Lean manufacturing (14, 15).

Ophelia was specifically designed to build health literacy actions that respond to local needs, are effective and can be implemented. The process starts with a needs assessment using a multidimensional health literacy assessment. This reveals key mechanisms that determine 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, 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 are then the focus of workshops that engage deeply with local people from diverse social backgrounds with lived experience of the target condition or service. Other stakeholders, such as health service providers, community workers and municipal staff who have grounded insights into the daily lives of target groups, are engaged in the same type of workshops.

The outputs of the workshops are reviewed and potential actions are prioritized and then tested using quality improvement cycles. This process is responsive to contexts and changes (health literacy or other relevant changes) that might occur over time for individuals, groups, communities and organisations.

Health literacy varies greatly across populations, and there is also great variation in local contexts, community health literacy assets and barriers to health literacy. As such, the Ophelia process was designed to be flexible and meet the needs of local implementation teams. The Ophelia principles are shown in Figure 1.

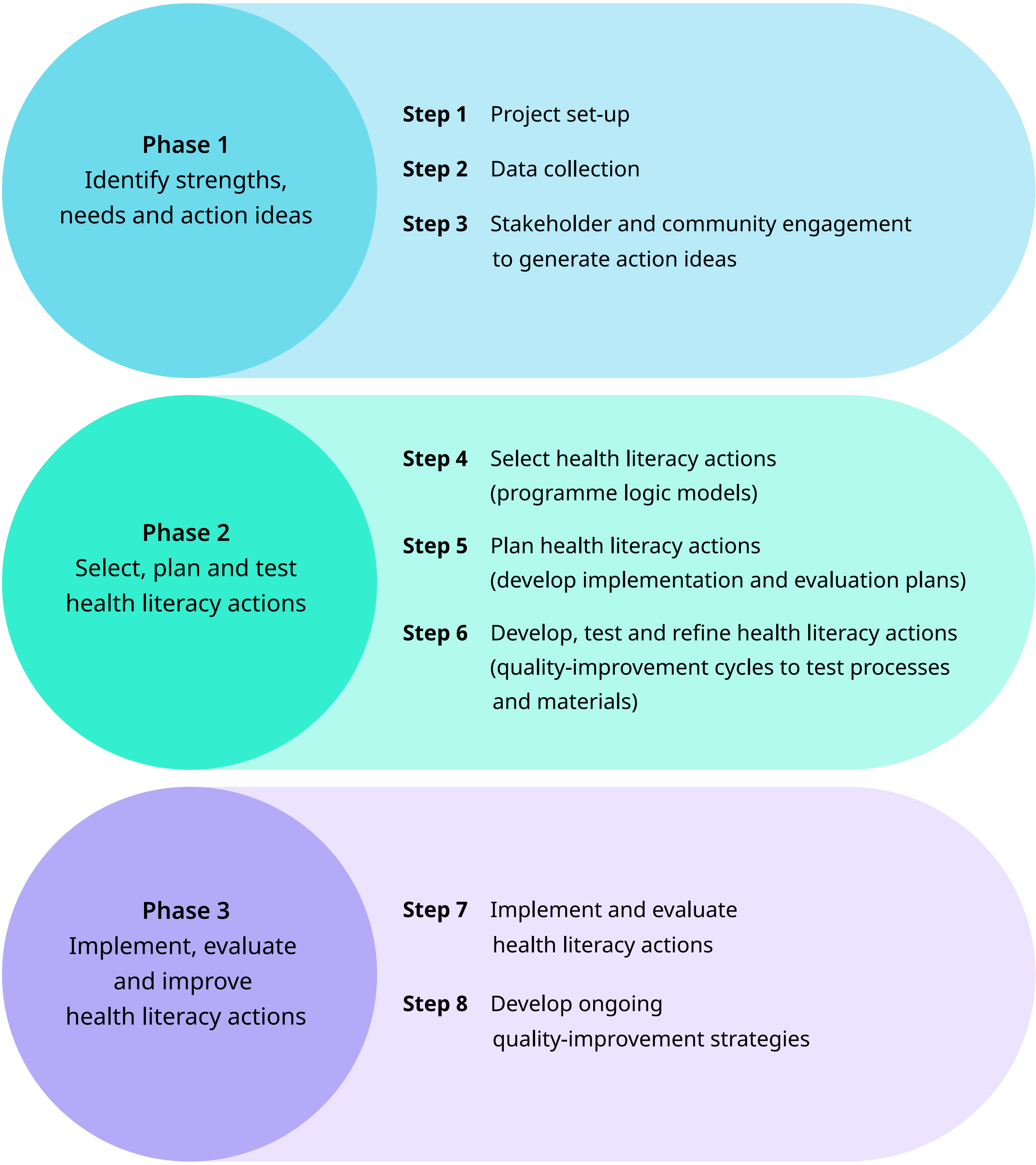
The Ophelia process has been refined through implementation in various community member and professional groups in many countries. This includes among people experiencing vulnerability, and in busy clinical settings (16–25). This Manual is a step-by-step guide to implementing an Ophelia project.

There are three phases of activities and each phase has several steps (see Figure 2):

Phase 1 – Identify strengths, needs and action ideas (three steps)
Phase 2 – Select, plan and test health literacy actions (three steps)
Phase 3 – Implement, evaluate and improve health literacy actions (two steps)

In this Manual, we talk about **actions** for health literacy development rather than interventions. This is because the range of activities necessary for health literacy development and responsiveness often requires small changes or integration into the daily practices of health workers at all levels, changes in education practices and health policy, as well as the formalised programs that we would normally refer to as ‘interventions’.

Figure 2. The three phases and eight steps of the Ophelia process



Phase 1
Identify strengths, needs and action ideas

Step 1 Project set-up

Step 2 Data collection

Step 3 Stakeholder and community engagement to generate action ideas

Phase 2
Select, plan and test health literacy actions

Step 4 Select health literacy actions (programme logic models)

Step 5 Plan health literacy actions (develop implementation and evaluation plans)

Step 6 Develop, test and refine health literacy actions (quality-improvement cycles to test processes and materials)

Phase 3
Implement, evaluate and improve health literacy actions

Step 7 Implement and evaluate health literacy actions

Step 8 Develop ongoing quality-improvement strategies

Viewed from a globally relevant perspective, health literacy is a multi-faceted mechanism that includes people's knowledge, confidence and comfort – which accumulate through daily activities, social interactions, and across generations – to *access, understand, appraise, remember* and *use* information about health and health care, for the health and wellbeing of themselves and those around them.

Questionnaires have been developed to better understand the health literacy strengths, needs and preferences of people and communities. Within the Ophelia process, the Health Literacy Questionnaire (HLQ) (20) and, increasingly, the eHealth Literacy Questionnaire (eHLQ) (21) can be used as part of the needs assessment process. Both questionnaires can be self-administered (paper-based or online) or completed by interview (face-to-face or telephone).

Health Literacy Questionnaire (HLQ)

The HLQ is a person-centred, multi-dimensional instrument that is used around the world and has been linguistically and culturally adapted to many languages and settings. The HLQ data are used to create profiles of the lived experiences of people attempting to engage with health information and services. It has nine domains (scales) that reveal people's diverse strengths and needs. The scales have high and low score descriptors to define the scope of each scale construct (see Box 1) (20).

Box 1. The Health Literacy Questionnaire (HLQ) scale, with descriptions of higher and lower scores

HLQ scale	Higher HLQ score	Lower HLQ score
1. **Feeling understood and supported by healthcare providers**	Has an established relationship with at least one healthcare provider who knows them well. The person trusts this provider to give useful advice and information and to assist them to understand information and make decisions about their health.	Is unable to engage with doctors and other healthcare providers. The person doesn't have a regular healthcare provider and/or has difficulty trusting healthcare providers as a source of information and/or advice.
2. **Having sufficient information to manage my health**	Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.	Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns.
3. **Actively managing my health**	Recognises the importance of and can take responsibility for their health. The person proactively engages in their care and makes their own decisions about their health.	Doesn't see their health as their responsibility. The person is not engaged in their health care and regards health care as something that is done *to* them.
4. **Social support for health**	The person's social system provides them with all the support they want or need.	Completely alone and unsupported.
5. **Appraisal of health information**	Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.	No matter how hard they try, the person cannot understand most health information and becomes confused when there is conflicting information.
6. **Ability to actively engage with healthcare providers**	Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional healthcare providers when necessary. Keeps going until they get what they want. Empowered.	Is passive in their approach to health care, inactive: does not seek or clarify information and advice and/or service options. Accepts information without question. Unable to ask questions to get information or to clarify what they don't understand. Accepts what is offered without seeking to ensure it meets their needs. Feels unable to share concerns.
7. **Navigating the healthcare system**	Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.	Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Does not look beyond obvious resources and has a limited understanding of what is available and what they are entitled to.
8. **Ability to find good health information**	Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.	Cannot access health information when required. Is dependent on others to offer information.
9. **Understand health information well enough to know what to do**	Can understand all written information (including numerical information) in relation to their health and write appropriately on forms where required.	Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.

HLQ data, collected in a wide range of settings for the purpose of health literacy needs assessment, have demonstrated strong construct validity, reliability and high acceptability to people and health workers. The HLQ is available in many languages and validity testing has shown that the items and scales in translated versions of the HLQ measure the constructs of the nine HLQ domains in ways that are comparable to the original English-language HLQ (22–30). Please email ghe-licences@swin.edu.au to access the HLQ and the user package, which includes information about translation, administration, scoring and data analysis.

eHealth Literacy Questionnaire (eHLQ)

In the same way as the HLQ, the eHLQ data are used to create profiles representing people's health literacy strengths and needs, but it has a specific focus on people's interactions with digital technologies in health and health care. It is increasingly used in combination with the HLQ. The eHLQ has seven domains (scales) (21) and descriptions that define high scores for each scale. See Box 2.

Box 2. The eHealth Literacy Questionnaire (eHLQ) and scale descriptions

eHLQ scale	Description
1. **Using technology to process health information**	Can use technologies to read, write and remember, apply basic numerical concepts and understand context-specific language (e.g. health, IT or English), as well as critically appraise information. Knows when, how and what information to use.
2. **Understanding of health concepts and language**	Knows about basic physiological functions and own current health status. Aware of risk factors and how to avoid them or reduce their influence on own health.
3. **Ability to actively engage with digital services**	Is comfortable using digital services for handling information.
4. **Feels safe and in control**	Feels they have the ownership of personal data stored and that the data are safe and can be accessed only by relevant people (own doctor/nurse etc.).
5. **Motivated to engage with digital services**	Feels that engaging in the use of digital services will be useful for them in managing their health.
6. **Access to digital services that work**	Has access to digital services and trusts that these will work when and how they need them to.
7. **Digital services that suit individual needs**	Has access to digital services that suit their specific needs and preferences. This includes responsive features of both IT and the healthcare system (including carers) as well as adaptation of devices and interfaces for people with physical and mental disabilities.

The eHLQ is used in various settings around the world (31–33). Data from the eHLQ have been shown to have robust psychometric properties (21). The eHLQ is available in several languages. Please email ghe-licences@swin.edu.au to access the eHLQ and the user package, which includes information about translation, administration, scoring and data analysis.

Other health literacy instruments and processes

The purpose of the Ophelia needs assessment is to provide information about the health literacy profiles of people in your target communities. As well as the HLQ and the eHLQ, other instruments and processes can be added to gather health literacy needs assessment data. In communities experiencing vulnerability or stigmatisation, or that have difficulty with questionnaires, qualitative research processes that identify needs within and across groups of target community members are often preferred. Interviews can be guided by a health literacy-informed interview guide such as the Conversational Health Literacy Assessment Tool (CHAT), which is based on the domains of the HLQ, or other guides or instruments that ensure collection of the breadth of potential health literacy mechanisms. Please email ghe-licences@swin.edu.au to access the CHAT and the accompanying user package.

Ophelia Phase 1

Ophelia Phase 1

Identify strengths, needs and action ideas

In Phase 1 of the Ophelia process, the project team collects local data (e.g. using the HLQ or eHLQ, and including demographic and other relevant data) to identify local health literacy strengths and needs. The team then collaborates with community members, frontline health workers and other stakeholders to identify local solutions and actions. Phase 1 has 3 steps (see Box 3).

Box 3. Phase 1: Steps 1 to 3, with activities and suggested time frames

Ophelia Phase 1	Purpose	Activities	Suggested time
Step 1 Project set-up	To define your project aims and scope, and identify who will be involved	1.1 Define the project focus, scope and aim 1.2 Establish the project team and define roles and responsibilities 1.3 Establish the project time frame and budget	1 to 2 months
Step 2 Data collection	To collect data from various sources and use these data to identify local strengths, needs and preferences	2.1 Identify existing sources of data 2.2 Establish a data collection plan 2.3 Obtain ethical and other required approvals 2.4 Collect data 2.5 Analyse data and prepare materials for stakeholder and community engagement activities	2 to 6 months (depending on complexity and breadth of data and sample)
Step 3 Stakeholder and community engagement	To identify any effective local initiatives and generate ideas for new health literacy actions	3.1 Establish a stakeholder and community engagement plan 3.2 Make arrangements for stakeholder and community engagement activities 3.3 Facilitate the engagement activities 3.4 Prepare a summary of the ideas from the engagement activities	1 to 2 months

Step 1: Project set-up

The purpose of Step 1 is to define the project aims and scope, and identify who will be involved.

Step 1 activities are:

1.1 Define the project focus, scope and aim
1.2 Establish the project team and define roles and responsibilities
1.3 Establish the project time frame and budget

Activities will help you define or refine your priority issue and identify how the project focus, scope and aim align with local, regional or national strategic health planning. You will also identify and recruit the members of your project team and build team 'ownership' and enthusiasm about the project and its potential.

Top tips

It can be difficult to identify a project focus, scope and aim from a blank page. While it is important to consider issues carefully, it is also important not to seek perfection at this stage. There will be opportunities to refine the details as the project is co-designed with stakeholders.

Activity 1.1.
Define the project focus, scope and aim

✓ **By the end of this activity, you will have a document that clearly states the focus, scope and aim of the project. See *Resource 1.1. Project focus, scope and aim* for a template for this activity.**

The project *focus* is the issue you want to address. The project *scope* identifies the service, group or population affected by the issue (that is, your target population). The project *aim* will guide you towards what you want to achieve and when you want to achieve it. See Box 4 for examples.

Box 4. Examples of project focus, scope and aim

Example	Project focus	Project scope	Project aim
1.	Limited awareness of a primary health centre's services in the local community	All eligible community members	To increase the proportion of eligible people accessing the service within 6 months
2.	People with diabetes attending a service are not engaged in active self-management	People over 70 years with Type 2 diabetes attending the service	To increase the proportion of people who actively engage in self-management of their condition
3.	Low rates of participation in cancer screening among new migrants in a region	Women from new migrant groups in the area who are eligible for free breast and cervical screening	To increase the proportion of women from new migrant groups who receive breast and cervical screening to meet the national average within 2 years
4.	High emergency department attendance by parents of children with self-limiting illnesses	Parents/carers of under-5s accessing one of several general practitioner/family doctor clinics	To give parents knowledge and skills to care for their children when they have common childhood illnesses, reducing unnecessary visits to family doctors and emergency departments

As you develop your project focus, scope and aim, consider:

- Are there suspected or known issues about the ways people access or engage with health services and health management activities?
- Are there issues with how services support people to access or engage with health services, health information or health management activities?
- Are there organisational strategic priorities or quality standards in relation to the above issues that need to be met?

Insight

Remember that health literacy affects how people engage with and benefit from health information and services. Consider:

- How easy is it for people to find out what your service does?
- Do people enrol in your service but then drop out?
- Are your services tailored to people's needs or abilities?
- How well do your service providers engage with the people they serve?

To help define your project focus, scope and aim, the Ophelia process includes considering all the ways people can access or engage with health information and services (see Figure 3). There may be many people who have not yet entered a health service (top of the left column) and few who eventually fully understand and engage with the service (bottom of the left column). The decreasing number of blue silhouettes of people at the background of Figure 3 illustrates how people can be progressively filtered out of or do not benefit from health services because of health literacy barriers.

Figure 3. Health literacy responsiveness matrix

A person from the community …	Problems perceived by health services	Problems perceived through a health literacy filter	Other filters
is unaware of services or approaches a service	Many people in communities do not access services	**People need …** • knowledge of services, including how to take the first step • confidence to approach services • trust in services • knowledge about healthcare entitlements	Openness of services e.g. cultural sensitivity, communication Physical environment e.g. location, transport, access to premises, parking Digital technology e.g. phone or internet access, computer Time e.g. opening hours, scheduling, waiting times
is accepted into the service	Many ‘drop outs’ or failures to attend Certain demographic or health status groups don’t participate	**People need to …** • understand health service processes • negotiate with health providers • have their needs understood	Prescriptive/pre-defined service types and times – e.g. rigid care protocols, scheduled group times, ‘one-size-fits-all’ Personal difficulties with providers or other service staff e.g. prejudice, embarrassment, past trauma
receives a service	Many ‘drop outs’ or failures to attend Certain demographic or health status groups don’t participate	**People need to …** • understand health service processes • negotiate with health providers • have their needs understood	Limited service variety and time options e.g. timetables, set programs Performance indicators and funding models e.g. target groups, program funding
participates in relevant programs and/or services	Difficult to recruit people to programs or services e.g. prevention Many ‘drops out’ and failures to attend	**People need to …** • be able to select what might be useful from a range of options • feel more comfortable making decisions about health, rather than “just doing what the doctor says” • address other concerns that are a higher priority before they can focus on their health	Limited service variety and time options e.g. timetables, set programs Performance indicators and funding models e.g. target groups, program funding
finds a service responsive	Many ‘drops out’ and failures to attend The care provided doesn’t achieve desired health outcomes	**People need to …** • engage with providers to explain needs, ask questions and negotiate • know what services can do and provide (and what they can’t do) • receive information in ways that suit different learning needs and styles	Resource constraints e.g. financial staffing Mainstream services that don’t cater to specific needs e.g. disability, culture, religion
fully understands and engages with a service	People find it hard to establish rapport with services or fully participate in their own care Disappointing experience (low user satisfaction) and outcomes	**People need to …** • make sense of health information in the context of their daily life • be supported to put what they’ve learned about health into practice • know what to do, and how and when to do it, i.e. they get practical information	Demographic of health providers e.g. bi-cultural, bi-lingual Follow-up e.g. after care, discharge planning

Resource 1.1. Project focus, scope and aim

What is the **focus** of your project?

What is your project about?/What issue do you want to address?

What is the **scope** of your project?

Who will be included?/Which service, group or population is affected by the issue?

What is the **aim** of your project?

What outcome do you want to achieve and by when?

Overall statement about the project focus, scope and aim

e.g. The focus of the project is participation in cervical screening by Indigenous women in the local government area. The aim is to increase screening rates for this cohort to meet or exceed the national average within 2 years.

Activity 1.2.

Establish the project team and define roles and responsibilities

✓ **By the end of this activity, you will have a list of your project team members and a brief description of their roles and responsibilities. See *Resource 1.2. Project team* for a template for this activity.**

As you do this activity, consider:

- Who will lead the project and be the main contact person for all project stakeholders?
- Who will be responsible for communicating and engaging with senior management?
- Who will do the daily project work?
- Who will provide expertise about the project focus?

Together, the project team should have all the skills needed to plan and implement the project activities. Team members may change over the course of the project. But it is strongly recommended that at least one team member is dedicated full-time to the project.

Resource 1.2. Project team

Role	e.g. Project manager
Name	
Responsibilities	e.g. Primary project lead and contact person for all stakeholders

Role	e.g. Project manager
Name	
Responsibilities	e.g. Lead person for project implementation/data collection

Role	e.g. Administration officer
Name	
Responsibilities	e.g. Administrative tasks/support for project officer

Role	e.g. Data officer
Name	
Responsibilities	e.g. Data management lead

Role	e.g. Clinical leads
Name	
Responsibilities	e.g. Clinical/practitioner support

Role	e.g. Consumer representative
Name	
Responsibilities	e.g. Consumer perspectives (may be optional)

Activity 1.3.

Establish the project time frame and budget

By the end of this activity, you will have a statement about the time frame and budget you have allocated to each step in the Ophelia process. See *Resource 1.3. Time frame and budget* for an example of a time frame and a template to draft a budget for your project.

You will need to establish a detailed time frame (e.g. Gantt chart) and budget for the project.

As you do this activity, consider:

- How much time do team members have to spend on the project?
- Is at least one full-time team member allocated to the project?
- What expenses (if any) will each step of the project incur, and what funding is available?
- Are there any reporting dates or other time limits imposed by funding bodies or management?
- Which project activities can be made part of the usual roles of team members, to make use of existing work tasks and communication channels?
- Given the overall time you have for the project, how long can you allow for each step of the Ophelia process?

Top tips

Consider how you can achieve multi-level objectives. The team leading the project is likely to have a strategic plan and may be required to meet quality or accreditation standards and program or policy guidelines set by funders. Person-centred care and issues relating to service access and equity often feature in these guidelines. Align the project with a related strategic plan, standards or policy guidelines (and with those of external agencies where relevant) and it will be easier to gain and maintain senior-level support for the project.

Anticipated time frame – example

Step	Time in months (example only) 1	2	3	4	5	6	7	8	9	10	11	12
1. Project set-up	▨											
2. Data collection		▨	▨									
3. Stakeholder and community engagement				▨								
4. Select health literacy actions					▨	▨						
5. Plan health literacy actions							▨					
6. Develop, test and refine health literacy actions								▨				
7. Implement and evaluate health literacy actions									▨	▨	▨	▨
8. Develop an ongoing quality improvement strategy												▨

Preliminary budget – example

Items	Considerations? How much do we have available? How much will it cost?
e.g. Staff	
e.g. Printing surveys for data collection	
e.g. Catering for workshops	
e.g. Venue hire for workshops	

Step 2:
Data collection

The purpose of Step 2 is to collect data from various sources, then analyse and use these data to identify local strengths, needs and preferences.

Step 2 activities are:

2.1 Identify existing sources of data
2.2 Establish a data collection plan
2.3 Obtain ethical and other required approvals
2.4 Collect data
2.5 Analyse data and prepare materials for stakeholder and community engagement activities

Step 2 is the needs assessment part of the Ophelia process.

The activities in Step 2 should help you better understand the factors that support and limit how people access, understand, appraise, remember and use information and services to manage their health.

You will collect and analyse data to develop vignettes (evidence-based but fictional case studies) about how people's health literacy and the health literacy responsiveness of services affect their ability to manage their health and the health of their families.

Through their daily work and lives, community members and health and community workers have a wealth of experience about activities that work (and don't work) to improve health and wellbeing in their local setting. These people will be shown the vignettes and asked for their ideas about relevant health literacy actions.

Activity 2.1.
Identify existing sources of data

✓ **By the end of this activity, you will have a list of the data you require to conduct your needs assessment. You will have also outlined how you will gather these data. Use *Resource 2.1. Sources of data* for a template for this activity.**

Think about your project focus, scope and aim and consider the types of data your project team needs to better understand your target group, including:

- health status or health outcomes
- engagement with health care and health services
- health literacy strengths and needs
- barriers and facilitators to engaging with and using health information and services
- socio-demographic characteristics.

See Box 5 for an example project with required data and data sources outlined.

You might already have easy access to some population data. If you see gaps in the data for your target group, you could consider collecting local data from community members (see *Activity 2.2. Establish a data collection plan*).

Insight

Access existing population health data. Many government agencies and professional and non-government organisations collect, source and/or manage population health data. This means there are likely to be existing data that could inform your project focus, scope and aim.

You can search the websites of these agencies and organisations to find data published in public reports, or email or call to ask about existing data and how you can access local data for your project. You can sometimes request access to data that has not been released in public reports.

Box 5. Examples of data needed for a project to reduce falls in elderly community members

Data required	Data type	Data source	How to obtain the data
Health status or outcomes	Prevalence data for falls in people over 75	Local government	Public reports from local government
Engagement with health care and health services	Number of people accessing falls prevention programs	Local health service	Reports from health services administrative data
Health literacy strengths and needs	Target group's capacity to find, understand and use services for falls prevention	No existing data available – collect from local community	Data collection using the HLQ and interviews
Barriers and facilitators to engaging with and using health information and services	Perspectives from people in the target group about engaging in falls prevention activities	No existing data available – collect from local community	Data collection using survey questions and focus groups or interviews
Sociodemographic characteristics	Age, sex, education, migration background and ethnicity, household members, employment, income etc.	Some general existing data available – may also collect from local community	Data collection using sociodemographic questions on survey

Resource 2.1. Sources of data

What data do we need to be well informed about our target group?

Data type: **Health status or outcomes data**

What data could we collect?	Data source	How could we access this data?
e.g. number of people in our service with diabetes and leg wounds; number of children under 5 with minor, self-limiting illness who present to emergency departments; rates of smoking in our region	e.g. self-report; administrative data; local government data	e.g. conduct community survey; generate report from administrative datasets; access local government websites

Data type: **Health/healthcare use**

What data could we collect?	Data source	How could we access this data?
e.g. rates of emergency department presentations; number of people who fail to attend appointments	e.g. administrative data; self-report; conduct community survey	e.g. generate report from administrative datasets

Data type: **Health literacy strengths and needs**

What data could we collect?	Data source	How could we access this data?
e.g. capacity to access, understand and use information and services in relation to the project focus	e.g. interviews; questionnaires	e.g. administer the HLQ; conduct interviews with community members

Data type: **Barriers and facilitators to engagement with health behaviours and services**

What data could we collect?	Data source	How could we access this data?
e.g. consumer attitudes; people's experiences with service providers; referral processes; number of services available; transport costs; social support	e.g. survey; service audits; administrative data; interviews	e.g. conduct community survey or interviews; generate report from administrative datasets; audit referral processes

Activity 2.2.

Establish a data collection plan

By the end of this activity, you will have a data collection plan for existing and new local data. The plan will describe the data you need to collect, and where and how to collect it. Use *Resource 2.2.1 Data collection plan* for a template for this activity.

In this activity, you will consider the resources and time you have available, and make a plan for sourcing and collecting the data.

If you decide to collect local health literacy data about the people in your community of interest, you can use the HLQ and/or eHLQ, as well as other relevant questionnaires in your survey. Demographic data can be collected at the same time by adding questions to the end of the survey. Health status and service use data can be collected in several ways: for example, through surveys, interviews, medical records or administrative datasets.

See Box 6 for examples of additional needs assessment data, and Box 7 for an example of a data collection plan.

When planning a local health literacy survey, consider:

- **How many people should you collect HLQ and/or eHLQ data from?** You will need to collect data from 50 to 100 people, depending on how varied the group is. If the community you are working with is highly variable, you may need more than 100. In general, a stable cluster analysis (see Activity 2.5) is achieved with 80 or so complete HLQ/eHLQ surveys. If you are collecting data from several groups and want to look at each group individually, you will need data from at least 80 people from each group.
- **How will you ensure you collect data from a representative sample of your community?** Your data collection strategy must consider methods for including people who can be harder to reach (see Box 8 for recruitment strategies). The people who are easy to recruit are often people who can also easily access health information and supports. It is important to ensure people with a wide range of potential health literacy challenges are included in your sample. This type of sampling is sometimes called 'maximum variation sampling'. See ***Resource 2.2.2 Sample size*** for more discussion about sample size consideration.
- **How will you collect more data for needs assessment?** It is strongly recommended that the health literacy survey data be supplemented by interviews with a small number of survey participants (e.g. 10% of the sample) to provide additional information for the needs assessment. This will allow for deeper understanding of the lived experiences of people in your sample, helping you develop the vignettes to present in the stakeholder and community engagement activities.

- **What demographic, social or lifestyle information will you need to help you understand the characteristics of the people who provide data?** There are standard demographic and social questions you can use (see Box 6), but you should also consider if any additional information is required, given your target group and project focus. Thinking about what other information is needed will help you understand the experiences of the people who provide data. For example, if your aim is to support people to better manage their diabetes, you might ask if they have ever seen a diabetes educator, and if so, what their experience was like (see Box 6 for examples).

Insight

The most critical type of data to collect at this stage are data that can tell you more about the nature of the problem and help you understand your community. This comprises:

- the health literacy strengths, needs and preferences of your community
- barriers and facilitators to their access or use of services
- facts about the community's health service use and health status.

These data can be collected through surveys using the HLQ or eHLQ, interviews with people from your community, and from administrative data from health services and government agencies.

Eligibility criteria needs to be as inclusive as possible. However, it may not be appropriate to collect data from some in your community, such as people who cannot make decisions for themselves, or people with health conditions that stop them from participating. Be specific with inclusion and exclusion criteria at the planning stage to minimise confusion.

Box 6. Examples of additional needs assessment data

Data type	Data example
Demographic, social and health questions	- Age (in years or in age brackets) - Sex and gender (including non-binary) - Country of birth, main language spoken at home - Living alone or with others - Literacy/highest level of education attained - Employment status - Health behaviours and beliefs related to project focus, such as smoking or physical activity - Self-rated health/number and type of health conditions
Clinical/service use data	- Number and type of services or programs available to people from the target group - Referral processes within or between services - Proportion of people in the target group with more than one chronic disease - Service attendance (e.g. rates of attendance at emergency departments among the target group over the past 12 months)

Box 7. Example of a data collection plan for a project to increase the uptake of cancer screening in migrant women

Example project	Scope
Time frame	August and September
Staff involved	Project officer
Source from community members	Survey 50 migrant women plus interview a sample of survey participants. Recruit women initially through the Migrant Community Support Service and use a 'snowball' recruitment (see Box 8) approach to access women not attending the service.
Survey data	• 9 scales from the HLQ and 2 scales from the eHLQ administered as an interview • 3 questions about screening experiences • Socio demographic data including social support, access to people who speak majority languages, questions about family cancer history
Interview data	Interview 6 to 10 women with different patterns of HLQ/eHLQ scores about how they engage with health professionals or find information about screening. Include a range of women from those who never screen to those who regularly screen.
Source from the health service's medical records, clinical data and service use data	• Proportion of women who attend screening services across cultural groups and age categories • Diagnosed health conditions

Box 8. Recruitment strategies to increase the representativeness of the sample

Group targeted	Possible recruitment strategies
General recruitment	• Invite every person from your community who attends your service on the same day of the week for 12 weeks. • Invite the next 50 people who attend the service and who are from your community. • For small communities or services, recruit as many as people as possible instead of aiming for a statistically representative sample.
Hard-to-reach groups	• Consider using a snowballing strategy, in which people who are already in a study refer others to it. Other useful strategies include using community leaders or peers within a particular community to recruit people directly. • Work with existing community organisations wherever possible. Use local media, such as community radio. • Other methods for collecting data from hard-to-reach communities include being aware of where and when groups may gather. For example, at religious venues, food markets or cultural festivals.

	Example 1	Example 2	Example 3
What data?	Health literacy and demographic data	Data related to people's experience of engaging with health services	People's patterns of service use
Source of data	Sample will be 80 to 100 people with chronic disease attending a community health service	Sample will be 15 people who have completed the HLQ and have consented to be interviewed	Routine administrative data collected by local health service
How will data be collected?	Paper-based HLQ with additional demographic questions	Telephone interviews using a semi-structured interview guide	Extracted from administrative database
Time frame	2 months	2 months	2 months
Staff involved	Project officer, staff at health service	Project officer	Medical records staff
Steps – specific data collection activities	Train staff in HLQ administration; invite all people at intake to complete the HLQ	Telephone people directly and conduct semi-structured interview (15 to 20 minutes)	Discuss data needs with appropriate staff and seek permission to access data

Sample size considerations for health literacy surveys

How many people should we collect data from? This will depend on the size and diversity of your target group, how much is already known, and your available resources. For example:

- A multicultural service wanted to explore health service use in migrants. It aimed to collect data from 150 people. Its sample included 75 new migrants (people who had arrived less than 5 years ago), and 75 people who had arrived more than 5 years ago
- A small service wanted to increase adolescents’ use of action plans to combat worsening asthma. Because it was a small service, it invited all eligible service users to participate in a survey. Data were collected from 73 of the 170 service users eligible to participate
- A university health service wanted to understand students’ health behaviours and how their health literacy might affect these behaviours, particularly for international students. The aim was to collect data from 600 students, who came from very diverse countries. Students from across three courses were surveyed. Half were international students, and half domestic. This allowed for comparisons between domestic students and several subgroups of international students across the courses.

Activity 2.3.

Obtain ethical and other required approvals

By the end of this activity, you will have obtained the approvals you require to conduct your data collection and consultation activities. See *Resource 2.3. Ethical concerns* for a template for this activity.

Considerations for the data collection process:

- Ethics approval may be required if you are undertaking the Ophelia process as a research study, or if you are planning to publish the findings.
- For a quality improvement activity, consider discussing ethical issues with your organisation's ethics adviser if you are working with people who might be experiencing vulnerability or disadvantage.
- Sometimes, implied consent can be used. For example, a short statement on the front of an anonymous survey about the purpose of the data collection, and what the results will be used for, may be sufficient. You should discuss this option with your organisation's ethics adviser (this may be an ethics committee chairperson, or the manager of your service).

Top tips

When recruiting participants, consider the nature of the relationship. Is it appropriate for you to recruit the person or would it be better for a colleague to do it? If the person raises potential problems about participating, be alert to the possibility that they may not want to participate.

If a consent form is required, consider the following:

- Signing forms can be distressing for some people. People with low literacy or from some cultural groups may be particularly affected by this. If this is likely to be a concern for your target group, seek ethics approval to use a verbal consent strategy.
- The consent form should clearly state that if a person decides not to take part, it will not affect any services they receive or their relationship with service providers. This should be strongly reinforced during the recruitment process and with each person recruited.

Resource 2.3. Ethical issues

Do we need approval from a human research ethics committee or institutional review board (IRB)?

e.g. The project aims to collect health literacy data and use it in a quality improvement activity. We will discuss with the ethics officer for our healthcare service if potential participants need to provide written informed consent.

What strategies will we use to ensure people do not feel pressured to participate?

e.g. Train staff in non-coercive methods of recruitment; ask staff who are not direct care providers to recruit participants; give people the option to discuss their participation with family or other staff first.

How will we help people feel safe if they decide to withdraw from the study?

e.g. If providing written consent, give people a ‘withdrawal from study’ form to keep in case they change their mind; ensure that those recruiting participants reinforce that withdrawal or refusal is permitted.

How can we provide enough information to potential participants to allow them to give informed consent?

e.g. Provide a clear, plain-language statement if written consent is required; use teach-back to ensure that participants understand what they are being asked to do for the project; develop simplified wording and read information aloud for all participants.

What measures do we need to put in place for people who want to participate but do not want to sign a consent form?

e.g. If written consent is required, check with the ethics committee if verbal consent (with or without a witness) is an option.

Activity 2.4.

Collect data

By the end of this activity, you will have collected the raw data. See *Resource 2.4.1 Considerations for collecting data* for examples.

Consider the following as you undertake the health literacy survey:

- What training is needed for the staff or volunteers who are collecting survey or interview data? Staff must be skilled in engaging potential participants in a way that creates a sense of safety, including physical, psychological and cultural safety. See ***Resource 2.4.2 Example recruitment script***, which can be used when training staff or volunteers to recruit community members to the project.
- What quality control strategies do you need to put into place before you start collecting data? If there are several data collectors, how will you ensure that data are collected in the same way by everyone throughout the entire data collection period?
- What methods will you use to collect data? (See Box 9 for examples.) These will have been specified in your data collection plan but may need to be modified if data collection is not going as expected. For example, you may find that the people you are collecting data from are not representative of your community because some groups of people are not participating. You may decide to change from direct recruitment to snowball methods of recruitment, or you may decide to collect data from other settings.
- What strategies do you have in place to monitor how data collection is going and to address any issues raised? Is it taking staff or volunteers more time to collect data than anticipated? Do you need a strategy so that staff and volunteers can ‘debrief’ about their experiences and challenges collecting data?
- How are you going to record the data? Who will enter the data? What strategies will you use to check that data entry is correct? If interviewing, will these interviews be recorded and transcribed?
- Work with local health authorities to get local administrative data about your target groups.

Box 9. Data collection settings and methods for health literacy survey

Data collection	Settings	Methods
From individuals	• At the clinic or hospital • At home • In the community (e.g. community health centres, citizens’ groups, community organisations) • On the telephone	• Online surveys • Via mail-out (postal surveys) • Face-to-face • Over telephone or online video platform (e.g. Zoom) • In group settings (although it is important to note or record the answers from individual people)

Top tips

Should we use the HLQ and/or the eHLQ?

Which questionnaire you use depends on the focus and aims of your project. Think about how you intend to interpret and use the data. What sort of decisions do you need to make?

The HLQ is a self-report questionnaire that was developed using in-depth consultations with diverse community members. This work led to the nine HLQ domains that measure health literacy strengths and needs. It is, therefore, important to include all nine scales in your survey if possible – otherwise you may miss useful information.

The eHLQ consists of seven scales and measures *digital health literacy* specifically. You can use some or all the eHLQ domains along with the HLQ to get more in-depth information about the full range of strengths and needs of your target group. Measurement with the eHLQ is particularly important in a world where digital technology is increasingly used for health.

Tips for administering the HLQ or eHLQ

Participants can ‘self-administer’ – that is, they can take the HLQ or eHLQ by writing on paper or online. Or, they can be asked questions over the phone, via online video (e.g. Zoom) or in person. It usually takes 5 to 8 minutes for a person to complete the HLQ or eHLQ themselves, but it may take 7 to 20 minutes to complete verbally (known as verbal or oral administration).

The option of verbal administration should always be offered, but in a way that will not embarrass people who may have low literacy. Say something like, “You may have left your glasses at home today – I can read it to you if you like”, or “Many people prefer to have these sorts of things read aloud to them – I can do that if you’d like”.

Resource 2.4.1 Considerations for collecting data

Suggested considerations	Examples
Training of data collectors	
Who will deliver the training?	Two project team members
Who will we train?	4 volunteers, 3 clinicians and 2 reception staff
When and where will we deliver the training?	Date, venue/online and time
What additional resources are needed for delivery of training?	PowerPoint, handouts
Quality control strategies	Develop a step-by-step guide that all data collectors must use. Have a central contact person that collectors can call if there are any issues or queries. Review all data collected in the first few days and then weekly or so to ensure consistency.
Monitoring data collection	Set up a meeting with all data collectors after their first few interviews, then again after 2 weeks to discuss any issues. Have regular fortnightly meetings thereafter.
Data collection methods	
What strategies will we use?	All new community members attending the service will be invited by their clinicians and reception staff to answer paper-based surveys. Volunteers will be available to assist community members with the survey.
How will we know if these are working?	Meeting with data collectors every 2 weeks. Review demographic data every 2 weeks to ensure data are collected from a range of people.
Do we need to make changes to data collection methods?	Discuss at fortnightly meetings
Do we need to notify our ethics committee of any changes?	Yes
Recording the data	
How will paper-based surveys be returned for data collection?	Set up an appropriate method to return the surveys for data entry
Where will data be recorded and how?	Use statistical packages or professional spreadsheets Set up data entry procedures Check data quality frequently

Staff can use or adapt this recruitment script when asking community members if they would like to take part in data collection.

I'd like to ask you about being in a project that [name of organisation/ service] is involved in. They want to find out how well people understand the information they give them, and the ways people use health services.

Would you like to help briefly with this project? If so, you will be invited to complete a survey about health and health information. It takes about 20 minutes.

You can fill the survey in yourself or we can help you with it. It doesn't need to be done all at once.

Your answers are confidential. Only staff involved in the project will have access to your survey answers, and they won't know whose answers are whose. If you don't want to do the survey, that's fine. It won't affect or change anything about your care.

Please have a think about this or talk to your family about helping with this project and let me know.

[If signed consent to participate is required] If you do want to do the survey, you will need to sign a form from the ethics committee at [xxx] to say that you agree to be in the project.

Activity 2.5.

Analyse data and prepare materials for stakeholder and community engagement activities

✓ **By the end of this activity, you will have a report about the needs assessment, which will be used to support the stakeholder and community engagement activities in Step 3. See *Resource 2.5.1 Presenting vignettes and findings*.**

As you do this activity, consider:

- What type of data do you have and how can these data be integrated and presented in a meaningful way for your stakeholders?
- What information did you collect about the way in which people access, understand and use health information and services, in relation to the project focus? These data might include HLQ or eHLQ results, as well as interview findings. How can these data be presented?
- What demographic, service use and health status data did you collect? How can you present these in a way that describes your overall sample? Can you use these data with the health literacy data?
- Are there unexpected or unusual findings? Do these need further exploration to understand them better?

How to score the HLQ and present the results

The HLQ provides nine separate scores – one for each of the nine scales (scale scores). There are four response options for items in Scales 1 to 5 (‘strongly disagree’ to ‘strongly agree’) and five options for Scales 6 to 9 (‘cannot do’ or ‘always difficult’ to’ always easy’). Scale scores are obtained by summing the item scores in the scale and dividing by the number of items in that scale. Scale scores range from 1 to 4 for Scales 1 to 5 and from 1 to 5 for Scales 6 to 9.

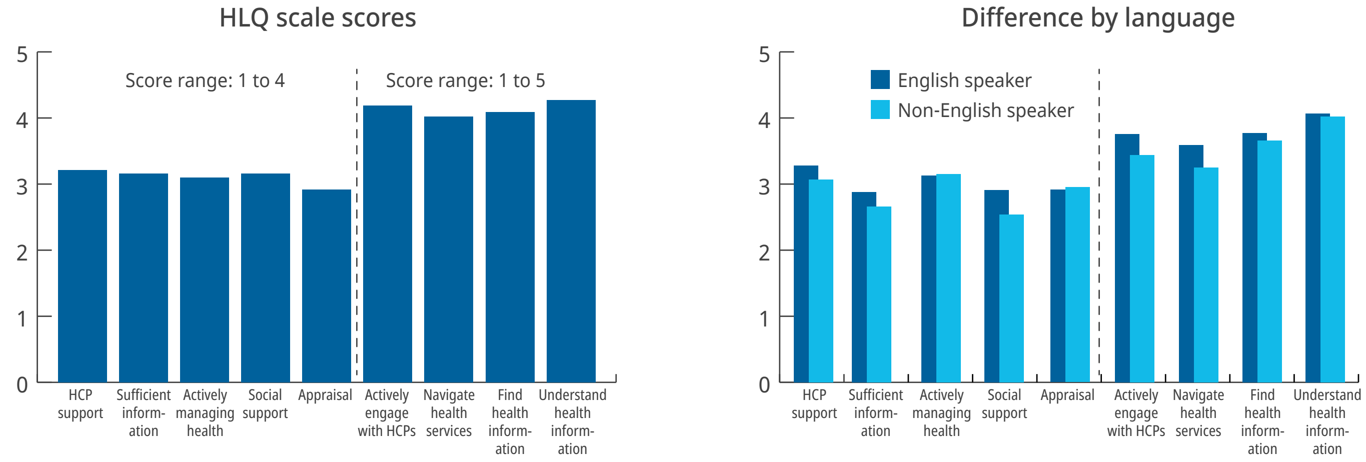
An Excel spreadsheet and SPSS syntax are supplied as part of the HLQ licence package to assist with the calculation of scale scores. A simple way to present the results of the HLQ is to report the means (and standard deviations) for each scale in a bar graph or table. Figure 4 provides an example of how to present mean scale scores for HLQ data for an entire study sample.

The nine scale scores highlight health literacy strengths and needs of study participants. When examined together, the nine scale scores show the health literacy profile of an individual or your community. You can also use demographic, health outcomes and service-use data to understand the health literacy profiles of different groups. For example, you can report the nine scale scores for men, or for people with diabetes, or for people who are frequent service users.

Within any group of people, there will be a variety of health literacy patterns (i.e. subgroups) showing different patterns of health literacy strengths and needs. However, this variation is hidden when only the overall mean scale scores for the whole study population are presented. To ensure that the needs of subgroups are addressed, and health literacy actions are in-line with the principle of ‘leaving no one behind’, identifying subgroups is an essential step in the Ophelia process.

The scoring of the eHLQ is similar to the HLQ, but all eHLQ items have four response options (‘strongly disagree’ to ‘strongly agree’). There are seven scale scores and each scale score range is from 1 to 4. The data for the eHLQ can be presented in a similar way to the data for the HLQ. Scoring instructions are also supplied as part of the licensing package.

Figure 4. Example of how to present HLQ scale scores for an overall sample



The mean scores for each of the nine scales can be presented for an overall group of people.

Or, the HLQ scores of two demographic groups can be compared to highlight differences in health literacy.

How to identify subgroups with different health literacy needs

Cluster analysis is the recommended statistical technique to group individuals with similar health literacy patterns. These groupings allow us to understand the health literacy strengths and needs of subgroups within the study population.

Cluster analysis can be done in several common statistical software packages, including SPSS. The results are then formatted by the pivot table function in Excel for presentation. See Box 10 for an example of the different health literacy profiles of a survey sample generated from a cluster analysis.

Steps of a cluster analysis for the nine scales of the HLQ, using 3 to 16 cluster solutions

These steps apply to the cluster analysis of the eHLQ scales, or a combination of the HLQ and eHLQ scales. The statistical software SPSS is used in the following instructions. Other software can also be used to conduct this analysis. Various algorithms can be used for cluster analysis. For the Ophelia process, the hierarchical clustering model, based on distance connectivity, is used.

Data preparation

Your data file should include all HLQ scores, including the nine scale scores and any demographic or other variables of interest (these variables are to be used to provide context for the development of your vignettes, e.g. age, sex, education). Ensure these demographic or other variables are either continuous (such as age, number of health conditions) or binary (i.e. yes/no, with coding yes = 1 and no = 0). Categorical data will need to be converted to binary. For example:

- for speaking the main language of a country at home, with yes = 1, no = 0
- for female, you can create a variable called 'female', with females = 1 and males = 0, or if you have a substantial number of other gender, you may consider setting up more gender variables
- for education, you can create one variable called 'secondary school or below' with yes = 1, no = 0 and a second variable 'university or above' with yes = 1, no = 0 or more education-related variables if you need more detail information about education.
- age can also be divided into age groups instead of a single continuous variable depending on your analysis needs.

Run cluster analysis in SPSS

1. Click 'Analyze' and choose 'Classify' option and then choose 'Hierarchical Cluster Analysis'.
2. Select the 9 scale scores into the 'Variables box'.
3. In the 'Label cases by' box, select 'caseid' (or participant IDs).
4. In the 'Cluster' box, click 'Cases'.
5. Click 'Statistics' button. Select 'Agglomeration schedule'. Then, select 'Range of solutions' option and enter 3 as Minimum number of clusters to 16 as Maximum number of clusters (you may decide on more or fewer for the maximum number of clusters, depending on your sample size). Click 'Continue'.
6. Click 'Plots' button. Select 'Dendogram'. Click 'Continue'.
7. Click 'Method' button. Click the drop-down menu of 'Cluster Method' and select 'Ward's method' option.
8. In the 'Transform Values' box, click the drop-down menu of 'Standardize' and select 'Z scores' option. Click 'Continue'.
9. Click 'Save' button. Click 'Range of solutions' and enter the same range of solutions as entered in step 5. Click 'Continue'.
10. You will be back to the 'Hierarchical Cluster Analysis' dialogue box. Click 'OK'. Save output to appropriate location.
11. You will now see new variables representing the cluster solutions in your SPSS file: CLU3_1 to CLU16_1.
12. Click 'Save as' option from 'File' menu. Save the SPSS file with cluster analysis results as an 'Excel 2007 through to 2010' file type with an appropriate file name and to an appropriate location.

Prepare Excel data file

1. Open the Excel worksheet with your cluster analysis results (exported from the SPSS file).
2. Use the ‘Find and replace’ function to find any designated missing values (i.e. values you assigned to any missing values in your original SPSS file, e.g. -1, 9999) and replace with nothing.
3. Create two ‘Standard Deviation’ (SD) columns after your scale score columns. One column labelled as P1SD for part 1 (Scales 1 to 5) scores of the questionnaire and one column labelled P2SD for part 2 (Scales 6 to 9) scores. Calculate SD using the STDEV.S function.
4. Create ‘Overall average score’ column. Calculate ‘Overall average score’ (AVESCORE) for all HLQ items using AVERAGE function.
5. Find and replace ‘#NULL!’ with nothing.

Create pivot table

1. In your Excel worksheet, select all data. Click the ‘Insert’ tab and select ‘PivotTable’. Under ‘Choose where you want the PivotTable report to be placed’ select ‘New Worksheet’.
2. Name new worksheet ‘Pivot Table’ and colour code it green.
3. To ‘Values’ field add:
   - Caseid or participant ID (change ‘Value Field Settings’ to ‘Count’)
   - Each scale score (change ‘Value Field Settings’ to ‘Average’)
   - Overall score (AVESCORE) (change ‘Value Field Settings’ to ‘Average’)
   - SD for parts 1 (P1SD) and 2 (P2SD) (change ‘Value Field Settings’ to ‘Average’)
   - Each scale score (change ‘Value Field Settings’ to ‘StdDev’) (may need to drag each scale score to the ‘Values’ field)
   - Add any demographic variables that will help you describe the people in each cluster. For continuous demographic/clinical variables such as age, change ‘Value Field Settings’ to ‘Average’. For binary variables, change ‘Value Field Settings’ to ‘Sum’. For example:
     - Age as a continuous variable (change ‘Value Field Settings’ to ‘Average’)
     - Female as a categorical variable (change ‘Value Field Settings’ to ‘Sum’)
     - Number of health conditions as a continuous variable (change ‘Value Field Settings’ to ‘Average’)

Examine cluster solutions

1. Add a worksheet and label it ‘Clusters’.
2. Set up column headings (as per your variables from the pivot table, the ‘Row Labels’ column in the pivot table will be named ‘Cluster Number’ and the rest will name after the corresponding variables) and ‘freeze’ top row.
3. Go back to the pivot table worksheet, add ‘CLU3_1’ (cluster 1, i.e. 3-cluster solution) to ‘Rows’ field.
4. Copy and paste results of ‘CLU3_1’ from pivot table into the newly created ‘Clusters’ worksheet (excluding the ‘Grand Total’ row). You should have 3 rows of data, each representing the HLQ scores and demographics of one cluster solution. Check data corresponds to heading labels.
5. In ‘Clusters’ worksheet, select the newly pasted data of CLU3_1 data. Change the scales scores and SDs to 2 decimal points. Click the Sort & Filter’ menu and select ‘custom sort’. Click ‘Sort’ by ‘Overall average scores’ from ‘Largest to Smallest’.
6. Select data from Scale 1. Click ‘Conditional Formatting’ menu, choose ‘Colour Scales’ and select the first option (i.e. the Green – Yellow – Red Scale). Then, use ‘Format Painter’ option to extend format to Scales 2 to 5. With this formatting, the scores will be displayed with a ‘traffic light’ system, with higher scores coloured green, medium scores coloured yellow and lower scores in red.
7. Select data from Scale 6. Click ‘Conditional Formatting’ menu, choose ‘Colour Scales’ and select the first option (i.e. the Green – Yellow – Red Scale). Then, use ‘Format Painter’ option to extend format to Scales 7 to 9.
8. Select ‘SD results’. Click ‘Conditional Formatting’ menu, choose ‘Highlight cell rules’ and select ‘Greater Than…’ option. Enter 0.6 into text field. Then, any cells with greater than 0.6 will be highlighted as ‘Light Red Fill with Dark Red Text’. With this formatting, you can easily identify any SDs that are greater than 0.6, which indicates there is considerable variation within that cluster (see Step 14a for more information).
9. Create a temporary worksheet named ‘Temporary’. Copy the column headings from the ‘Clusters’ worksheet to this ‘Temporary’ worksheet. Go back to the pivot table, remove ‘CLU3_1’ from ‘Rows’ field and add ‘CLU4_1’ to the ‘Row Labels’ (cluster 2, i.e. 4-cluster solution).
10. Copy and paste results of ‘CLU4_1’ to the ‘Temporary’ worksheet. Repeat Steps 5 to 7 to format this cluster solution. After formatting, copy the CLU_4 results to the ‘Clusters’ worksheet beneath the CLU_3 results, with two empty rows between the two sets of results.
11. Delete the CLU_4 results in the ‘Temporary’ worksheet. Go back to the ‘Pivot Table’ worksheet and repeat the above steps until you copy all the cluster solutions to the ‘Clusters’ worksheet. Delete the ‘Temporary’ worksheet.
12. For all the categorical variables (demographics or clinical data), create a percentage (%) column next to the corresponding variables so that numbers are presented as percentages. For example, if the total number in a cluster is 17 and 8 are female, then the percentage of females in that cluster is 8 divided by 17, i.e. 47.1%. For continuous variables, change the numbers to 1 decimal point. Also create a percentage for the sample size for each cluster. For example, if the total sample size is 100, and in the 3-cluster solution, the size of the first cluster is 33, then the percentage of the first cluster is 33%.
13. Examine each cluster solution to see which cluster splits and leads into the next cluster solution. You can highlight the parent cluster and the two newly split clusters for easy identification.

14. Examine available cluster solutions and select the most meaningful and usable solution, i.e. the optimal solution. Generally, the optimal solution will be somewhere between 6 and 12 clusters. The process requires both a quantitative and qualitative consideration. Here are some of the things to consider when choosing the optimal solution:
    a. Consider the SD. If SD > 0.6, this indicates there is still considerable variation within a cluster. However, if the number of people in that cluster is very small, SD is likely to be naturally high, so it is not a reliable indicator in this case.
    b. The agglomeration schedule can be used to help determine the optimal cluster solution (see SPSS handbook for more detail).
    c. Examine each split to see how different the splits are from their parent cluster (you can use line graphs to help you visualise the patterns). Examples of cluster split may include a cluster that leads to two clusters, with one similar to the parent cluster but the other displaying a different pattern. Another common situation is when one cluster has a generally higher score than the parent cluster and the other has a generally lower score than the parent cluster. Decide if the newly split clusters are different enough from the parent cluster to be considered a meaningful split, i.e. the split leads to a new cluster that gives insight into a group of people with health literacy needs that are different from those of the parent cluster. Also, examine demographic and clinical data associated with that cluster to determine if there are obvious differences between the new clusters. If two clusters have similar patterns but different demographics or clinical data, it may be worthwhile keeping both clusters, because clusters with different demographics may require different actions or strategies to address their health literacy needs.
    d. When seeing small clusters with different health literacy patterns, consider if they are disadvantaged or hard-to-reach groups. It is important for these groups to be included so that no one is left behind in any health literacy actions to be taken.

Preparing materials for presentation

1. Produce a cluster summary document with scores and relevant information for each solution. See Box 10 for an example of how to present the health literacy profiles generated by the cluster analysis.
2. Develop vignettes to present alongside each selected cluster. See the section ‘Develop vignettes to accompany HLQ profiles for stakeholder and community engagement activities’ for how to develop vignettes (see p.44). See Box 11 for information about developing a vignette from a cluster.
3. Select a range of clusters (usually from 6 to 12 clusters) that show the diversity of your findings for the presentation. You may not have time to present larger numbers of clusters and vignettes during the stakeholder and community engagement activities.

Box 10. Example of a cluster analysis result identifying five clusters with different patterns of health literacy strengths and needs

Cluster number	% of sample in each cluster	Scales 1 to 5 (score range: 1 to 4)					Scales 6 to 9 (score range: 1 to 5)			
		1. Feeling understood and supported by healthcare providers	2. Having sufficient information to manage health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with healthcare providers	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information well enough to know what to do
1	**22%**	3.68	3.45	3.40	3.50	3.16	4.55	4.40	4.26	4.46
2	**24%**	3.17	3.01	2.93	2.98	2.76	4.10	4.00	3.83	4.00
3	**20%**	3.35	2.91	3.08	3.12	2.84	3.74	3.47	2.96	2.83
4	**20%**	2.72	2.49	2.74	2.54	2.43	3.44	3.32	3.31	3.71
5	**14%**	2.83	2.39	2.70	2.68	2.23	2.38	2.19	1.94	2.24

Note: A 'traffic light' colour code is used. For each scale, cells in the green range represent higher scores: the yellow range represents medium scores and the red range represent lower scores.

In this example, 22% of the sample have overall 'higher' health literacy scores (cluster number 1 – first row), 34% of the sample have 'lower' health literacy scores (cluster numbers 4 and 5), and 44% have a mix of scores (cluster numbers 2 and 3). Importantly, the health literacy profiles of each cluster are distinctly different from each other.

According to the scores from each cluster, the health literacy patterns of the five clusters can be interpreted as below:

Cluster	Interpretation
Cluster number 1	People in this cluster have good healthcare (Scales 1, 6 and 7) and social support (Scale 4). They have good access to health information and can understand information well (Scales 2, 8 and 9). They are also taking control of their health (Scale 3).
Cluster number 2	People in this cluster generally have a good relationship with their healthcare providers (Scales 1 and 6) but do not always have good access to health information (Scales 2and 8) and they sometimes struggle with appraising health information (Scale 5).
Cluster number 3	People in this cluster usually see a regular healthcare provider whom they find helpful (Scale 1). However, they may have somewhat passive engagement with them (Scale 6) and they sometimes find it difficult to work out where to go or what to do for their care (Scale 7). They generally make plans to stay healthy (Scale 3) and they have good support from their social network (Scale 4).
Cluster number 4	People in this cluster tend not have a regular healthcare provider they can communicate well with (Scale 1) and frequently have limited social support (Scale 4). They do not know where to find good information (Scale 8) and what they find is only sometimes helpful (Scale 2). They sometimes struggle to manage their health in an active manner (Scale 3).
Cluster number 5	People in this cluster have limited healthcare and social support (Scales 1, 4 and 6) and have a limited understanding of the healthcare resources available (Scale 7). They really struggle to find and understand information (Scales 2, 5, 8 and 9).

Develop vignettes to accompany HLQ profiles for stakeholder and community engagement activities

Presenting evidence-based but hypothetical case studies (or vignettes) alongside the table helps to bring the profiles to life for participants in the consultation. Usually, four or more vignettes are useful to describe a target community, depending on what your data tell you.

A vignette is a brief description of a fictional person who might be typical of a group of people within your community. The vignettes need to read like stories about people's lives to help workshop participants to recognise or identify with them. To develop a vignette, HLQ scores and demographics from the needs assessment survey are used to build the background and stories about how people access and use health information and services. For example, if a certain cluster has very low scores in Scales '1. Feeling understood and supported by healthcare providers' and '7. Navigating the healthcare system', then a typical person in this cluster may not be seeing a regular healthcare provider. For them, finding the right health care is likely to be difficult.

The demographics will provide details about the characteristics of a typical person in this cluster. For example, if the average age is 75 years and 70% of the people in this cluster is female, then a typical person for this cluster will be a 75-year-old woman. The other demographics can help to provide more details about a typical person from this vignette. See Box 11 for an example of how to create a vignette.

It will be useful if your team can interview a sample of survey participants. Interviewing people from each cluster group will be particularly useful because these data help build realistic and engaging narratives about people's actual health literacy experiences.

Note that people's identity must be fully protected. People's personal stories must not be used in the vignettes unless details are sufficiently changed so they cannot be identified in any way.

See ***Resource 2.5.2 Interview template to support vignette writing*** for conducting interviews.

Top tips

What if you didn't use the HLQ or the eHLQ to collect health literacy data?

It may not always be possible or culturally appropriate for your organisation or community to use a questionnaire such as the HLQ. Instead, you may have decided to collect health literacy information using interviews or focus groups, and to develop vignettes from these. The Conversational Health Literacy Assessment Tool (CHAT) may help you to structure interviews or focus groups (email ghe-licences@swin.edu.au to access the CHAT).

It is important that you collect as much relevant and contextual data as possible, even if you do not use a structured questionnaire. For example, find information about the broad demographic characteristics of your local community or service user group, and service-level data about health behaviours or health service use.

Box 11. Developing a vignette from a cluster

Example of the health literacy profile of a group of people after the cluster analysis

		Scales 1 to 5 (score range: 1 to 4)					Scales 6 to 9 (score range: 1 to 5)			
Cluster number	% of sample in each cluster	1. Feeling understood and supported by healthcare providers	2. Having sufficient information to manage health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with healthcare providers	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information well enough to know what to do
4	20%	2.72	2.49	2.74	2.54	2.43	3.44	3.32	3.31	3.71

Average age of people in cluster	% in cluster who are female	% in cluster who live alone	% in cluster with low education	% in cluster with private health insurance	% in cluster born overseas	% in cluster who speak other primary language	Average number of chronic conditions in people in cluster	% in cluster who report feeling depressed
76.3 years	73%	84%	69%	30%	81%	69%	3	77%

Demographic data for the people in cluster number 4 show that a typical person is female (73% of people in this cluster are female), older (average age is 76.3 years) and lives alone (84% live alone). People in this cluster are also likely to have lower education (69% did not complete secondary school), and most do not have private health insurance (only 30% of people in this cluster have private health insurance), suggesting they may have lower socioeconomic status. They are likely to be born overseas (81% born overseas) and do not speak the local language (69% had a main language other than English). The average number of chronic health conditions for people in this cluster is 3, and 77% of this cluster reported feeling depressed.

Based on the health literacy scores, people in this cluster may not have a regular healthcare provider (Scale 1) and they have limited social support (Scale 4). They do not know where to find good information (Scale 8) and may not be actively managing their health (Scale 3).

We can now combine the health literacy profile from the cluster analysis with the demographic data to build a vignette (a story) about the challenges a person in this cluster might experience in looking after their health. A vignette that represents a typical person from this cluster might be:

Lucinda is a 76-year-old lady who lives alone. She was born in Poland and left there 35 years ago. She speaks limited English. Her husband died some years ago, and Lucinda has an adult daughter who lives on the other side of town. Lucinda doesn't like to ask her daughter for help to get to medical appointments because she knows she is busy with her own family (Scale 4). Lucinda has Type 2 diabetes, arthritis and back pain, and most of the time feels quite low in her mood. She sees lots of different health professionals but struggles to find one she can really talk to and trust (Scale 1).

Recently, her doctor told her that her blood pressure was too high and that she needed to start a low-salt diet. Lucinda was too afraid to ask her doctor questions about this (Scale 6) because he always seems in too much of a hurry, and now she is not sure where she can go for more help (Scales 2 and 7) or information (Scale 8). She thinks maybe she should ask her elderly neighbour for advice. She is not sure that she can be bothered anyway to change her diet – it all seems too hard, and she has plenty of other things to worry about (Scale 3).

Present a summary of the health literacy and demographic data that informed the vignette.

Overview

		Scales 1 to 5 (score range: 1 to 4)					Scales 6 to 9 (score range: 1 to 5)			
Cluster number	% of sample in each cluster	1. Feeling understood and supported by healthcare providers	2. Having sufficient information to manage health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with healthcare providers	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information well enough to know what to do
1	24%	3.10	3.01	2.98	2.91	2.76	4.10	4.00	3.83	4.00

Number of people in this cluster = 25; 24% of total survey participants
Average age = 48.8 years
% female = 80%
% attended tertiary education = 40%
Average number of health conditions = 0.9
% people with musculoskeletal conditions = 53%
Average BMI = overweight

Vignette 1: Fairly confident in own abilities but feels they have little support from others, including health professionals

Mrs Smith is a 50-year-old woman. When she and her husband divorced 10 years ago, she moved to an outer suburb of Melbourne, where she could afford to buy a house. She qualified as a primary school teacher, but since the birth of her first child 25 years ago, she has only done sessional work. All her children live and work away from the area.

She tries to keep healthy: she walks three times a week and would like to do more, but finds it difficult to fit exercise into her day. She sees a male general practitioner but sometimes feels that he is a bit impatient when she talks to him about her menopausal symptoms. She hears lots of things about how to manage hot flushes and mood swings, and sometimes goes on the internet to find out more, but isn't sure what is relevant for her, or if the information she finds is trustworthy.

Repeat this presentation structure for each of your vignettes.

Purpose: The main purpose of the interviews is to explore the experiences people have had that led to them their HLQ/eHLQ answers. The information collected is valuable context for the development of the stories in the vignettes.

Recruiting people to interview: At the end of your survey, you might like to invite the participant to take part in an interview. Ask (in writing or in person) whether they would be interested in taking part in a short interview to chat about their health information and what they need from services. Respondents who are interested can then be asked to provide their contact details.

Interview preparation: There are two ways to identify which people to interview. You can either examine the HLQ results and randomly identify people who appear to have overall patterns of lower, medium and higher scores, or you can undertake cluster analysis and then interview two or three people from three to five key clusters. To prepare appropriate questions, you will need to see where the person has lower and higher HLQ scores. Only ask questions about the most informative HLQ domains (scales) – there is no need to talk about all of them.

Example script for how to introduce the interview: "The information you give will contribute to the work we are doing to understand health information and health care. It will take 15 to 30 minutes to answer the questions. The questions are about the responses you gave on the questionnaire. There are no right or wrong answers, so please answer the questions according to your own experience. If you need to stop at any time, just let me know. With your permission, I will record the interview to make sure I capture your words accurately."

Examples of interview questions, as guided by higher and lower HLQ scores

HLQ scale	Higher HLQ scores	Lower HLQ scores
1. **Feeling understood and supported by healthcare providers**	Do you feel understood and supported by your healthcare providers? Why do you feel this way?	Do you feel understood and supported by healthcare providers? Has it always been this way? What would help to improve these relationships?
2. **Having sufficient information to manage my health**	What helps you to feel you have enough information to manage your health and make decisions?	What would help you to feel confident that you have enough information about your health?
3. **Actively managing my health**	How did you learn to manage your health? What do you do to manage your health?	What do you need to help you manage your health differently?
4. **Social support for health**	What kind of help do you get from your family, friends or community for your health?	What kind of help do you get from your family, friends or community for your health?
5. **Appraisal of health information**	What helps you to understand health information? How do you work out what is best for you?	What would help you to understand health information and work out what is best for you?
6. **Ability to actively engage with healthcare providers**	How comfortable do you feel about talking about your health with healthcare providers? What has helped you with this?	How comfortable do you feel about talking with healthcare providers? What would help you to feel more comfortable to talk with them about your health?
7. **Navigating the healthcare system**	How do you find out about the health and support services that you need?	What would help you to find out about health and support services that you need?
8. **Ability to find good health information**	What has helped you to find information about your health?	What would help you to find information about your health?
9. **Understand health information well enough to know what to do**	What has helped you to understand written health information?	What would help you to understand written information about your health?

Step 3: Stakeholder and community engagement

The purpose of Step 3 is to engage stakeholders and community members in consultations to identify any effective and innovative local initiatives and practices and generate ideas for new health literacy actions. In this step, you generate a pool of ideas to draw on in Phase 2, when you will select, plan and test health literacy actions.

Step 3 activities are:

3.1 Establish a stakeholder and community engagement plan
3.2 Make arrangements for stakeholder and community engagement activities
3.3 Facilitate the engagement activities
3.4 Prepare a summary of the ideas from the engagement activities

The activities in Step 3 will support you to engage key stakeholders to be innovative as they generate action ideas.

Step 3 is an important step for the co-design process.

It leads to generation of health literacy actions that are likely to be effective and equitable. This is because they are developed by people in the community, or by the health and community workers who work closely with groups in the community that are struggling to access services and that may be missing out on health care.

Step 3 provides experienced health workers, community workers and community members with the opportunity, environment and expectation to put forward their own innovative ideas for health literacy actions that fit with local needs and contexts. Engagement in the ideas generation process empowers the people who will later develop and implement the health literacy actions, and contributes to their desire for the initiatives to succeed.

The most common Ophelia engagement activity is the Ideas Generation Workshop (see *Activity 3.3. Facilitate the engagement activities*). Ideas Generation Workshops generate ideas that might be implemented in health literacy development activities, and also provide a platform for a wide range of groups to have their say and know their voice is being heard. This is a powerful process for meaningful engagement across the sector.

Activity 3.1.

Establish a stakeholder and community engagement plan

✓ **By the end of this activity, you will have a stakeholder and community engagement plan that specifies who is going to undertake the engagement, the people you are going to engage, and how and when the activities will take place. See *Resource 3.1. Stakeholder and community engagement plan* for a template.**

The engagement plan is important because the ideas generated from this activity will form the basis for your health literacy actions. **Engagement is best done in small-group Ideas Generation Workshops** to allow for rapid generation and sharing of ideas. The workshops can be conducted in person or online. Interviews with individuals or through online communication (e.g. email) may also be useful if it is not possible to conduct workshops. See Box 12 for an example of a stakeholder and engagement plan.

During the Ideas Generation Workshops, you will present the data reports you prepared in *Activity 2.5. Analyse data and prepare materials for stakeholder and community engagement activities*. The vignettes are used to engage workshop participants in a brainstorming exercise to identify potential ideas for action that respond to the issues shown in the data. This exercise inspires new ideas for health literacy actions and, importantly, also identifies existing strategies that may be working well for some individuals, groups or services in their unique context.

Consider the following as you plan your Ideas Generation Workshops:

- **Which people or groups do you need to engage?** You will want to engage the people who best understand the issues and who are likely to have useful ideas about potential solutions. Think about engaging:
  - community members experiencing the issue, including some who participated in data collection. You may also include carers and family members of people from the target group
  - health providers and other staff from a variety of backgrounds, and community workers who are experienced in the area of health care you are addressing
  - managers responsible for the area of health care you are addressing
- **Should certain groups of people be consulted together or separately?** You will want your workshop participants to speak freely. Some groups of people (e.g. community members) may not feel comfortable sharing all their ideas with certain other groups at the table (e.g. health professionals). Depending on the topics, it may be important to keep certain groups separate – such as community members and health professionals, women and men, junior and senior health professionals, or different kinds of health professionals – to enable free flow of ideas and to avoid actual or perceived power imbalances.
- **How many people do you need to engage?** This will depend on how many different perspectives you wish to include and how many people you think you can recruit. A workshop is most effective with 6 to 12 participants. Note that a participant's experience of this type of workshop can be inspiring and motivating because they see a range of potentially important health literacy actions emerge – many of which could be implemented. The workshops are not only to get good ideas, but to inform and inspire people who may well be important contributors to refining, testing and implementing the health literacy actions.
- **How will you record the ideas and insights generated during the workshops?** It is critical to capture the ideas and insights because they form the basis of the next phase of activities. Workshops can be audio-recorded if appropriate and with the permission of all participants. Each workshop needs at least one dedicated note-taker, who summarises the main ideas at the end of the workshop to check with the participants that the main ideas were captured. This summary of ideas may sometimes lead to more ideas.

Box 12. Example stakeholder and engagement plan for a healthcare organisation

Time frame	February
Staff	Assign staff (e.g. project manager, project officer and administrative assistant) to the roles of workshop facilitator, note-taker and workshop assistant.
Format	Four Ideas Generation Workshops – two with local healthcare staff and two with local community members. Professionals and community members will participate in separate workshops to enable each group to speak freely. The format (in person or online) of the workshop and venue will be decided after contacting potential participants.
Participants	Invite a mix of experienced clinicians, team leaders and managers to the staff workshops. Invite community members (including some who participated in the surveys) to the community member workshops.
Recruitment approach	Liaise with contacts within the organisation to select staff. Invite community members via service providers, local media and flyers, or through the health literacy survey.
Capturing the ideas and insights	Note-taking and audio-recording.

Time frame	Select time (e.g. February)
Staff responsible	Assign staff (e.g. project manager, project officer and administrative assistant) to the role of workshop facilitator, note-taker and workshop assistant. The workshop assistant can help with the logistics of an in-person workshop or monitor the chat for an online workshop.
Format	Four workshops: Two with local healthcare staff and two with local community members. Professionals and community members participate in separate workshops to enable each group to speak freely. Workshops can be conducted online or in person. If a workshop is not feasible then methods such as interviews or written communication can be considered.
Participants	Healthcare staff: Invite a mix of experienced clinicians, team leaders and managers to the staff workshop. The workshops work best when they include a range of disciplines from across care pathways, as well as the clinicians who really understand the service, community, their field and, importantly, the full range of people they serve. Community members: People who participated in surveys, and a broad cross-section of the target groups, including people with socioeconomic challenges. Where relevant, include people from a range of life stages, and with diverse education and diverse experiences of the target health problems and health services. Include a range of people with no illness, people recently diagnosed, and long-term self-managers of their health (successful and unsuccessful).
Recruitment approach	Liaise with key contacts within the organisation to select appropriate staff. Invite community members through direct contact, and through trusted service providers, local media and flyers.
How to capture ideas and insights	Note-taking and audio-recording.

Activity 3.2.
Make arrangements for stakeholder and community engagement activities

✓ **By the end of this activity, you will have organised the workshops with your key stakeholders and community members, including arrangements for materials, travel, venues and catering (depending on whether the workshops are in person or online). See *Resource 3.2.1 Organising stakeholder and community engagement activities* for a template.**

During this activity you will follow the plan you established in *Activity 3.1. Establish a stakeholder and community engagement plan* and invite participants to take part in the Ideas Generation Workshop or other engagement activities.

COVID-19 restrictions or other circumstances may make in-person consultation activities difficult or impossible. The Ideas Generation Workshops can be conducted in person in a community venue or online using digital platforms such as Zoom. For online workshops, it is a good idea to have an IT staff member managing the technology while other staff members lead the workshop.

Consider the following for both in-person and online workshops:

- Which types of participants will miss out if you can run only in-person or only online workshops? How can you make sure these people are included in consultation activities?
- Which days and times suit different groups of people (e.g. after work hours, during the day) and can you plan workshop times to accommodate these?
- What do you need to do to help participants to feel safe to express their ideas in the workshop?
- When recruiting community members, let them know that they do not need any special knowledge or expertise. The most important part of the workshop is to think about the people in the vignettes and, if they have been in a similar situation or know people in that situation, then to just talk about those experiences. Some people in workshops say very little, and that’s fine too.
- Is the workshop likely to bring up sensitive or distressing topics and concepts for participants? Should you therefore have a person (e.g. counsellor, psychologist) at the workshop who can talk privately with participants if needed?

Specific considerations for in-person and online workshops are provided in Box 13 and Box 14. See ***Resource 3.2.2 Example invitations to stakeholder and community engagement activities*** for examples of workshop invitations.

Box 13. Tips for in-person workshops

Consider:

- How many printed copies of the data collection findings will you need (***Resource 2.5.1 Presenting vignettes and findings***)?
- Do you need to send (post or email) background information to participants before the workshop?
- Do you have the equipment you need (e.g. audio-visual, white boards, paper and pens)?
- Is the venue appropriate, especially for community members (e.g. accessibility, transport options, parking, catering)?

Box 14. Tips for online workshops

Consider:

- Which online platform will you use, and can you get technical support from your organisation for this platform?
- Do your participants have the resources to attend an online workshop using this platform?
- Can you do a 'test run' the day before?
- Inviting participants to keep their web camera on during the whole workshop to encourage genuine engagement
- Some community members cannot travel (e.g. due to illness, distance, transport issues) or don't like face-to-face meetings. Online environments can increase participation (and therefore representation) of some diverse community members.

Top tips

Invite the right people to attend. You will want to engage people who best understand the issues and are most likely to have ideas about potential solutions. Examples of potential participants are:

- Community members, and their carers and family who are experiencing the issue you are addressing
- Health providers from a variety of backgrounds, and community workers who have many years of experience in the area of health care you are addressing
- Policy-makers who are responsible for the area of health you are addressing

Top tips

Duty of care

It is important to remember that, particularly for community members, some of the issues raised during the workshops may cause distress or embarrassment.

Be aware of your duty of care to all workshop participants. You can arrange to have an appropriate support person (e.g. counsellor, psychologist) or emotional support animal (e.g. a dog) at the workshop in case participants become distressed. Or you can provide advice and the contact details for appropriate support people.

Insight

Introduction of the workshop

Professionals often like to see some data. You may wish to present some quantitative data and explain how the vignettes were produced. At the same time, be aware that many community members may find it difficult to interpret the quantitative data.

Activity (example for in-person workshop)	**Who is responsible/Time frame**
Venue/online platform	
Catering	
Printing – Background reading for participants	
Audio-visual equipment (if required)	
Preparation and set-up on the day	

Example invitation to community members

(Ensure the font of your invitation letter has a minimum size of 12)

Re: Community workshop about access and use of health information and services

We invite you to attend a group workshop:

Date:
Time:
Venue:

What is the workshop about?

The workshop is to find out about how easy or difficult it is for you and people you know to:

- talk with healthcare workers such as your family doctor
- find good health information
- look after your health and the health of your family
- get the health services you need

People from the community – like you – already know what they need to do these things. This is what we will ask you about in the workshop.

What will happen in the workshop?

The workshop will be run by [name of person running the workshop]. We will first hear some short stories about different ways people look after their own health. The people in these stories are made up, even though they may sound like someone you know.

We will then ask you and other people in the group workshop some questions. These questions will be about:

- what you think that person might need, or
- what their local health or community services might do to help them look after their health more easily.

We will ask you these questions as a group. Please feel free to answer the questions honestly and put forward any ideas you have.

What will happen to the answers you give?

The answers the group provides will be recorded so that we can write them down and discuss them with local community organisations and health services.

You will not be identified in anything that we write about this workshop. Your name will be removed from any notes we take, and if you prefer, you can use a false name.

If you are interested in being part of this workshop, please contact [name] on [contact details].

Example invitation to health workers

(Ensure the font of your invitation letter has a minimum size of 12)

You are invited to attend a workshop to discuss the results from the [name of the project].

We have collected health literacy data from [number] users of our service. We now need to interpret and respond to these data, and we need your help to do this.

As an expert practitioner, team leader or manager, you have the knowledge and experience of what works and what doesn't work for the people we serve. In the workshop, we will be tapping into that collective wisdom to develop strategies to improve outcomes for the users of our service. We will present the results from the data collection as vignettes (evidence-based stories) about different health literacy profiles of clusters of people. We will then ask for your ideas about what you think might work to support the health literacy challenges of the fictional people represented in the vignettes.

The workshop takes about 2 ½ hours.

Activity 3.3.

Facilitate the engagement activities

By the end of this activity, you will have the notes and recordings from the Ideas Generation Workshops. See *Resource 3.3. Example agenda of an Ideas Generation Workshop*.

This activity involves you and your team facilitating the Ideas Generation Workshops, and any other stakeholder and community engagement activities relevant to your project, as well as recording what the participants tell you.

A typical Ideas Generation Workshop takes 2 to 3 hours and the ideal number of participants for each workshop is 6 to 12 people. It starts with short introductions among participants. The facilitator then provides an overview of the workshop and presents a summary of the survey results. This is followed by a systematic discussion of each vignette, using four questions to guide the discussion and generate potential ideas for health literacy actions. See Box 15 for detailed information about the discussion process. The workshop process concludes with a summary of the ideas generated during the workshop.

Box 15. Discussion process for each vignette

Steps and rationale of the discussion process

Introduction and scene-setting

1.

Introduce the project and its purpose (the purpose of the workshop is to enable the wisdom and daily experiences of community members/professionals to be gathered)

Make sure participants are aware of their role. Tell them they will be invited to share their ideas and experiences, but that they do not have to say anything they don't want to. (This is particularly important for people experiencing vulnerability – but of course, take care not to single these people out.) People may wish to let you know their ideas afterwards, separate from the group, or write their ideas down.

2.

Provide a brief (1 to 2 minute) description of a 'typical person in this cluster' (professionals only).

Emphasise that the vignettes are fictitious (say a "typical person" rather than "this person").

3.

Talk about the demographic data and the key HLQ scales for that cluster (professionals only).

The demographic data provide background for each vignette.

Present the vignette

4.

Show the first vignette on the PowerPoint presentation and read it aloud slowly.

Reading out loud, and allowing people to read the vignette, permits people with different learning styles to engage with the content.

5.

Ask the first question. Depending on your group of participants, the question will be along the lines of either:

- **Have you had experiences similar to the person in this story? And/or do you know of anyone who has had similar experiences? [participant is a community member]**
- **Do you see people like this in your community or service? [participant is a health provider]**

Participants start to see the fictitious character in the vignette as someone real and they begin to identify with them.

Don't spend a lot of time on this, just allow people to briefly answer.

6.

Ask the second question: What issues is this person dealing with?

This question encourages participants to think about and talk about the breadth and depth of difficulties people can face in daily management of health.

Well-written vignettes that portray the health literacy challenges from the cluster analysis will often prompt participants (especially community members) to share detailed information about their similar experiences. It is important to allow participants to express themselves and to feel heard. This takes up time but is important to the process. These participant contributions help to identify issues that could be addressed through health literacy development. This leads to the third question.

7.

Ask the third question: What strategies could be used to help this person?

Answers to this question form the first set of critical health literacy development data drawn from local wisdom. This question encourages participants to consider action ideas at the individual person or clinician level that could improve the issues identified by the second question.

8.

Ask the fourth question: What could health services or community organisations do to help many people like this in a community?

Answers to this question form **the second set of critical health literacy development data** drawn from local wisdom. Encourage people to think about ideas for actions at the organisational/interagency/community level to help and support groups or communities of people.

Repeat steps 4 to 8 with the second and subsequent vignettes.

Top tips

Tips for facilitating a workshop

1. Use active listening skills to encourage participation and explore the ideas that participants propose.
2. Listen for full or partial action ideas – every idea can be a good idea. A partial idea may later become a full idea, or a set of ideas, through further discussion.
3. Prompt participants to think about actions and strategies that could be used by health or community care workers with community members, as well as actions and strategies that could be used to improve services, systems, products or health environments.

Knowing an idea when you hear one

Listen for suggestions that will improve people’s access to or engagement with health care, health information or health management activities.

The health literacy action ideas generated during your workshop can range from ambitious new programs through to subtle or small quality improvement and practice changes. Effective health literacy actions can take different forms and don’t need to be large in scope or complex in design. Often, small actions that build on existing practices can be very effective for improving access and engagement with information, services and other health resources.

Also, ensure you note the actions or strategies that participants say they are already using. Sometimes, an improvement project can involve wider roll-out of a strategy that has been demonstrated to be feasible and effective by a few early adopters.

Recording the workshop ideas

- The insights and ideas generated for each vignette are recorded by at least one note-taker. **The notes should be very detailed** because they will provide information and context for activities in Phase 2. Notes can be taken on paper, on a whiteboard or electronically. Take notes about the main issues identified for each vignette and the ideas put forward by participants for actions and strategies. A note-taking format is presented in Box 16.
- Audio-recording the workshop is a good idea in case ideas are missed by the note-taker (but remember to ask participants’ permission to record).
- For an in-person workshop, the main themes and ideas can be noted on a whiteboard or flip chart. This is useful for summing up at the end of the workshop.
- For an online workshop, the note-taker can read out the main themes and ideas to participants at the end of the workshop.

Box 16. Example format for taking notes in workshops

Workshop number: **Date:** **Time:**

Vignette 1

Key issues:

Action ideas:

Vignette 2

Key issues:

Action ideas:

Vignette 3 [etc.]

Key issues:

Action ideas:

Summing up the workshop ideas

An important part of the workshop is to sum up at the end. For participants, it can sometimes feel like they have just been chatting, so it is important to show them the wealth of ideas and responses to issues they have generated by providing a good summary.

Writing the key issues and ideas on a flip chart or a whiteboard as they arise can help you quickly summarise at the end.

This summing up may lead to more ideas. It can even help participants to see how some of the ideas from different vignettes could fit together to form a bigger idea with greater reach, or how a set of ideas could work together as a series of actions.

Top tips

How many ideas arise from vignette discussions?

The number and range of ideas that can arise from a workshop depends on the topics and complexity of the vignettes, the number of workshop participants, and the group dynamics. Each participant might just speak for a few minutes, or ideas might flow from one person to another and lead to further ideas. The first one or two vignettes can generate more discussion and ideas than later vignettes because participants often seek to have their say and describe their own situation in relation to the stories. It is possible for each vignette to generate 5 to 20 unique action ideas.

Generally, it is better to present the less complex vignettes at the start of the workshop. That is, first present the vignettes about people with higher health literacy, less complex social situations, and fewer diseases and risk factors. Then, as the participants become accustomed to the four questions and the discussion process, present the more complex vignettes.

Resource 3.3. Example agenda of an Ideas Generation Workshop

Time	Activity	Resources
10.00 – 10.15	Introduction	Audio-recording, if agreed to by participants
10.14 – 10.30	Background of the project, such as aims and focus, description of people who participated in the survey	PowerPoint
10.30 – 10.45	Discuss first vignette (see the four questions in Box 15)	Flip chart, whiteboard, note-taking
10.45 – 11.00	Discuss second vignette	Flip chart, whiteboard, note-taking
11.00 – 11.15	Break	
11.15 – 11.30	Discuss third vignette	Flip chart, whiteboard, note-taking
11.30 – 11.45	Discuss fourth vignette	Flip chart, whiteboard, note-taking
11.45 – 12.00	Summing up and discuss main themes or common ideas	Flip chart, whiteboard, note-taking

Activity 3.4.

Prepare a summary of the ideas from the engagement activities

✓ **By the end of this activity, you will have a summary of the action ideas generated during the stakeholder and community engagement activities. See *Resource 3.4. Example summary of ideas generated from stakeholder and community engagement activities.***

Following stakeholder and community engagement activities, such as the Ideas Generation Workshops, you will have a list of statements relating to action ideas that could help the people portrayed in the vignettes (i.e. the ideas generated by the third and fourth questions in the Ideas Generation Workshop).

Some of the ideas may be similar across vignettes, while some may be unique to a single vignette. The action ideas can vary from simple, self-contained actions to actions that can be organised as a package or series. There is no right or wrong way of organising the ideas. It is important that stakeholders work together to organise the ideas in a way that is meaningful for them and for the purpose of the project. The main aim of the process is to summarise the (often) vast range of ideas that arise from the workshops so key stakeholders can see the breadth of ideas without being overwhelmed by much detail.

Steps to organise the ideas:

1. Compile the action ideas based on the statements from workshop participants. Separate composite ideas. Remove duplicate ideas. (One way to collate and sort the ideas is to use an Excel spreadsheet.)
2. Consider if each idea is a standalone action or if it could be combined with other ideas that have the same or similar intent.
3. Organise the ideas in a way that is meaningful for the project. You could consider one or more of the following approaches:
    - Organise the ideas into the four levels at which health literacy actions can take place (some ideas might be relevant to more than one level):
        - with individuals
        - in families or communities
        - what practitioners need to do each day
        - for policies and procedures in organisations.
    - Organise the ideas according to healthcare and service pathways and for actions that improve and support people's knowledge of, access to, and use of information and services:
        - when people are well and living in the community (not yet needing information or services but need to know what to do if they do need these)
        - as people consider needing and wanting to use information and services, and as they enter services
        - as people engage with health services and information channels.
    - Undertake an inductive qualitative analysis of the ideas to identify the themes relevant to your project (e.g. thematic analysis according to your project context and purpose).
    - Invite key stakeholders to do an activity to rate the importance of the idea, the current implementation status (i.e. the extent to which it has already been implemented, if at all), and/or the feasibility of the idea for your organisation or project. See Box 17 for ratings scales.

Box 17. Rating scales to rate ideas for importance, current implementation status and feasibility

One way to organise ideas is to invite stakeholders to rate the action ideas in terms of 1) importance, 2) the extent to which the action is already implemented (or not) and 3) the feasibility of implementing the action.
A rating instrument that lists the ideas can be distributed to stakeholders with the following three questions:

- How important is this idea for your service?
  1 = Not important
  2 = Somewhat important
  3 = Important
  4 = Very important
  5 = Essential

- Based on your understanding, has this idea been implemented?
  1 = Never implemented
  2 = Implemented to a small extent
  3 = Implemented to some extent but inconsistently
  4 = Mostly implemented
  5 = Fully implemented

- How feasible is this idea for your service?
  1 = Not feasible
  2 = May be feasible but would be difficult to implement
  3 = Somewhat feasible in some areas
  4 = Feasible and can be implemented to a meaningful extent
  5 = Highly feasible and can be fully implemented

You don’t need a lot of people to do the rating, only key stakeholders who know your service well and those who have responsibilities for making decisions related to prioritisation and implementation. The results can be synthesised qualitatively if you only have a few people doing the rating, or you can do calculations (e.g. mean, median, range) if you have more people rating the ideas. The results would then be used to help discussions about prioritisation and selection of health literacy actions. See *Activity 4.2. Select a health literacy action (or set of actions)*.

Example summary of ideas generated from stakeholder and community engagement activities

Organise ideas into the four levels for health literacy action (some ideas may be relevant to more than one level).

Individuals

Make sure to match all education activities with how each person learns and what they want to know

People need help putting things into action – use teach-back in every interaction

Build on what people already know to be effective or what they already use

Find out each person's preferred learning style and use it to talk about their needs

Family/Community

Find out about local peer support groups

Talk to other providers and family members about ways of helping people to use their care plans

Use existing volunteers as health mentor buddies for socially isolated or less motivated people

Engage volunteers to drive older people to appointments

Practitioner

Train clinicians to use teach-back and other sensitive teaching methods

People need help putting things into action – use teach-back in every interaction

Find out each person's preferred learning style and use it to talk about their needs

Talk to other providers and family members about ways of helping people to use their care plans

Organisation

Source and provide education materials in a variety of learning formats

Advocate to improve access to related services

Develop a list of reliable online health resources

Train clinicians to use teach-back and other sensitive teaching methods

Ophelia Phase 2

Ophelia Phase 2

Select, plan and test health literacy actions

Phase 2 of the Ophelia process involves local stakeholders in selecting action ideas according to local priorities, and then working together to plan and test health literacy actions. This process may involve generating new initiatives or expanding the use of existing initiatives based on a synthesis of the data from the Ideas Generation Workshops. Phase 2 consists of Steps 4 to 6 with corresponding activities (Box 18).

Box 18. Phase 2: Steps 4 to 6 with activities and suggested time frames

Ophelia Phase 2	Purpose	Activities	Suggested time
Step 4 Select health literacy actions	To identify health literacy actions to achieve the intended outcomes.	4.1 Confirm the project focus, scope and aim, and specify project objectives 4.2 Select a health literacy action (or set of actions) 4.3 Link project objectives to the selected health literacy actions and evidence from the literature 4.4 Work through the logic of your health literacy action to specify how it will achieve the project objectives	1 to 3 months
Step 5 Plan health literacy actions	To identify who will implement the actions, when, how and using which materials.	5.1 Identify the implementation team, their roles and responsibilities, and confirm your time frame and budget 5.2 Develop the implementation and evaluation plan	1 to 3 months
Step 6 Develop, test and refine health literacy actions	To develop, test and refine the resources and processes needed to implement the health literacy actions.	6.1 Purchase or develop the materials, training and processes needed to implement your plan 6.2 Test the materials, training and processes using quality improvement cycles 6.3 Refine the materials, training and processes based on the findings of the quality improvement cycles	2 to 4 months

Step 4: Select health literacy actions

The purpose of Step 4 is to select a health literacy action (or a set of actions) that are feasible to implement and that will address the access and engagement issues that are the focus of your project (i.e. the intended outcomes of the project).

Step 4 activities are:

4.1 Confirm the project focus, scope and aim, and specify project objectives
4.2 Select a health literacy action (or set of actions)
4.3 Link project objectives to selected health literacy actions and evidence from the literature
4.4 Work through the logic of your health literacy action to specify how it will achieve the project objectives

The activities in Step 4 will help you to refine the purpose and objectives of the project to make sure they align closely with the needs assessment findings from Phase 1. They will then help you work with key stakeholders to prioritise and select a health literacy action or set of actions. The selected action(s) will be linked to your project objectives and evidence from a rapid review of the literature. Finally, a program logic will allow you to consider how your initiative will achieve your project objectives, which will help you with your evaluation activities. **This step is another important step in the co-design process.**

Insight

Co-design describes a process where stakeholders (e.g. practitioners, managers, consumers) work together to use information about local needs to develop health literacy actions and change practice.

Activity 4.1.

Confirm the project focus, scope and aim, and specify project objectives

✓ **By the end of this activity, you will have a (potentially revised) statement about the project focus, scope and aim, and your project objectives for the health literacy actions. See *Resource 4.1. Review of project focus, scope, aim and objectives* for a template.**

Before selecting your health literacy actions from the ideas generated during the workshops, you will need to specify the intended outcomes. There are two stages to this process:

1. Refer to Phase 1 Step 1 when you developed the project focus, scope and aim. Look at these again in light of the findings from the needs assessment (i.e. Phase 2 Step 2) and decide if you need to revise the project focus, scope and/or aim. If so, revise accordingly.
2. Next, you need to use your (revised) project focus, scope and aim to specify the outcomes you expect your health literacy actions to achieve. Consider the long-term outcomes (i.e. the long-term intended outcomes) as well as medium- and short-term outcomes, which are the outcomes needed to achieve the long-term outcomes. For example, short-term outcomes might be that people have increased knowledge about their health condition and how their medication helps them, which leads to medium-term outcomes of people taking medication more regularly, which leads to long-term outcomes of people having fewer medication-related admissions to hospital. These outcomes become the **objectives of the health literacy actions**. Defining the objectives is an important first step to selecting the relevant and appropriate health literacy actions.

As you do this activity, consider:

- Did the needs assessment data reveal important issues about how people engage with health services and information that are different from your priority issue set out in Phase 1 Step 1?
- If yes, do you want to pursue the newly identified priority issue or stay with your original issue?
- If you want to pursue the newly identified issue, are the project focus, scope and aim that you defined at the beginning of the project still relevant and appropriate?

What are the objectives of your health literacy project?

- Objectives are direct and measurable changes that you expect your health literacy actions to achieve. Most objectives aim for changes in or for your target group or community members.
- Objectives should be specific and measurable. They should be changes that can be reasonably achieved over the time frame of your project. These objectives usually fit into one or more of the following categories:
  - Behaviours (e.g. health management behaviour such as increase physical activity, how people engage with healthcare services)
  - Skills, knowledge and attitudes (e.g. recognise symptoms, increase motivation to exercise)
  - Supports and resources (e.g. education, teach-back, peer support groups)

Top tips

Ideas Generation Workshops can result in many action ideas across many different potential areas for health literacy development.

Some ideas can be small administrative changes that improve information and services for many people with little-to-no cost and modest effort.

Some ideas are obvious and feasible but have not been implemented. These ideas, with the right people implementing them, can be the catalyst for deeply embedded sustainable health literacy development.

Some ideas can be about large structural issues. Addressing these could see widespread improvements in health literacy, but change could take many years and require extensive resources.

When facilitating co-design and community development, it is essential to enable local ownership and innovation. Facilitation that creates a safe space for discussion to flow will support teams to feel empowered and to generate ideas that result in 'quick wins' (i.e. actions that are easily achieved). It will also support teams to feel they have permission to use their collective knowledge and wisdom to think creatively about ways to sustainably develop health literacy over time.

Resource 4.1. Review of project focus, scope, aim and objectives

Revisit your project focus, scope and aim in light of the findings of the needs assessment, and revise if needed. Then state your project objectives.

What is the **focus** of your project?

(What is your project about? What issue do you want to address?) e.g. To support people with heart failure to better manage their condition and avoid preventable exacerbations

What is the **scope** of your project?

(Who will be included? Which service, group or population is affected by the issue?) e.g. People with heart failure

What is the **aim** of your project?

(What outcome do you want to achieve and by when?) e.g. To reduce the proportion of patients who present to the emergency department with potentially preventable exacerbations of heart failure by 10% in 6 months

What are the **objectives** of the project?

(What are your expected short-, medium- and long-term outcomes?) e.g. Increase people's use of heart failure exacerbation plans from 30% to 50% in 6 months. e.g. People with heart failure can describe the steps required to manage exacerbation of their condition. e.g. Provide supports and resources to enable people to understand how to manage heart failure exacerbations.

Activity 4.2.

Select a health literacy action (or set of actions)

✓ **By the end of this activity, you will have selected a health literacy action or set of actions through working with key stakeholders. See *Resource 4.2. Prioritisation matrix for ideas* for a template to assist with prioritising the ideas.**

In this activity, you and your key stakeholders will be considering the how the action ideas fit the gaps you are trying to address in your project (i.e. your project focus, scope, aim and objectives). There are many ways to prioritise the action ideas. A common method is to host an action prioritisation workshop with key stakeholders to discuss and consider all the action ideas that came up in your consultation activities. Come to an agreement about the health literacy action or set of actions that you will plan and test in *Step 5: Plan health literacy actions*.

Your key stakeholders may include consumer representatives, frontline health workers, managers, the management team and other stakeholders who have an interest in generating outcomes for the target group(s) and who have an in-depth understanding of local and regional settings. It is especially useful to include stakeholders who will play a role in the local implementation of the project because the prioritisation (co-design) process assists with generating local ownership.

To help with the selection of practical, useful and implementable actions, it is important to ensure the participants of an action prioritisation workshop have a thorough understanding of the summary ideas (see ***Resource 3.4. Example summary of ideas generated from stakeholder and community engagement activities***) as well as the statements that came up in the Ideas Generation Workshops. In other words, selection and prioritisation will work best when the 'micro' (direct participant statements) and 'macro' (summary) and are considered together.

When selecting your health literacy action(s), consider:

- Is there a single health literacy action among the ideas that:
  - has the potential to address all (or many) of your objectives (*Activity 4.1.*), i.e. can it be reasonably expected to achieve the intended outcomes within the time frame?
  - is important and feasible to implement (this can be better understood through the rating of ideas described in *Activity 3.4*)?
  - has the support of key stakeholders (this can be indicated by the importance rating in *Activity 3.4.*)?
- If no single health literacy action meets the above criteria, which ideas – or elements of ideas – could be brought together to create a set of health literacy actions? Usually, a set of actions across the individual, family/community, practitioner and organisation levels (see *Activity 3.4.*) is more likely to achieve the objectives than a single action. See Box 19 for an example of a set of actions.

Box 19. Example of a set of actions

A carefully selected range of ideas for health literacy actions that work across different groups and different parts of the system is more likely to bring about sustainable and meaningful change than single narrow actions that impact on disconnected parts of the system. The following example shows a set of health literacy actions that supports individual behaviour change, trains clinical staff, improves clinical policy and procedures, and facilitates connections between services in a community.

Objective:
Help people understand how to put advice from their doctor into practice through a clinic-based initiative.

Set of health literacy actions:

- Encourage people to prepare for their appointment with the doctor including using a ‘Key questions to ask your doctor’ paper-based guide.
- Establish and support peer workers or health literacy navigators in the community to provide ongoing support to people at risk.
- Match patients to peer workers who live nearby. Ensure the peer workers are well supported with up-to-date information from the doctor’s practice and the pharmacist.
- Train clinical staff to use teach-back to help people understand information about their health.
- Set up clinic practice procedures so people can see a nurse immediately after seeing their doctor. This allows the nurse to help clarify the doctor’s instructions.
- Develop communication channels between medical centres and local pharmacies or other external providers (e.g. dieticians) to ensure all service providers understand what a patient needs to do.

Questions to consider in your prioritisation process:

- Which ideas build on, combine with, or add value to existing ideas and priorities (i.e. align with activities you are already doing)?
- Which ideas match up with known needs, gaps or problems in the community (especially for people who are missing out in some way on accessing and engaging with health information and care)?

One way to help you prioritise the ideas is to organise them into four priority categories (see ***Resource 4.2. Prioritisation matrix*** for ideas):

1. Quick wins – these ideas:

- are a current priority
- can be aligned with existing activities
- add value
- are relevant and meaningful to the community
- are strongly supported by the community and key stakeholders.

2. Priority for development – these ideas:

- are a current priority
- have been identified as a significant need or gap
- can build on existing activities
- use available resources
- are supported by the community and key stakeholders.

3. Investigate feasibility – these ideas:

- have been identified as a significant need or gap
- are not aligned with current activities
- are a new area of activity
- require additional resources and capacity building
- require or have only minimal support from the community and key stakeholders.

4. For future consideration – these ideas:

- are not a priority
- are not a significant need or gap
- are not aligned with current activities
- require additional resources
- are not supported by the community and key stakeholders.

Insight

Making good practice the usual practice is a health literacy action

Health literacy actions don't need to be new initiatives or big ground-breaking projects. Every day, health and community workers use strategies that are effective for people with all sorts of needs.

Sometimes, usual practice in one setting can be a breakthrough improvement in another setting. Sometimes, making slight changes to an existing procedure, and actively integrating the procedure into usual practice, can be a health literacy action that reaches many people.

Top tips

Building complete health literacy actions from partial ideas

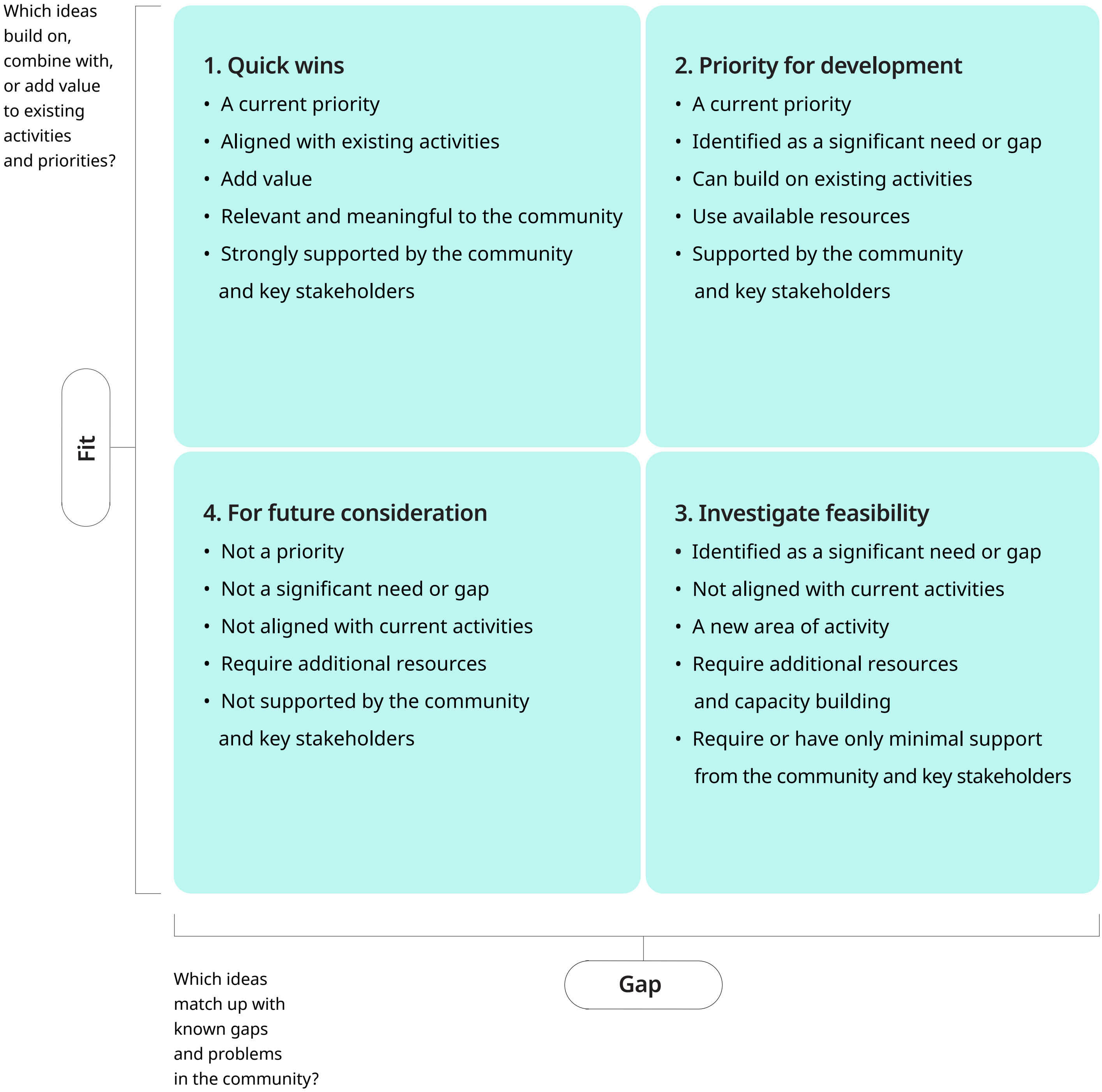
As you explore the ideas generated during the Phase 1 workshops, you are likely to find that some ideas are partial or incomplete: they don't yet translate to an action. A partial idea can often be combined with other ideas, or you can build it into the action, or set of actions, you have selected.

Designing equitable health literacy actions

All too often, healthcare initiatives are not designed to meet the needs of people who are underserved or who are experiencing vulnerability (especially people experiencing many health literacy challenges). Some actions or initiatives can even widen inequities because they are mostly accessed by and mostly benefit people who are more literate and better resourced.

The health literacy actions developed using Ophelia are potentially more equitable because they are based on the needs of the full range of people in a group or community. When co-designing your health literacy action, consider how it can be tailored to reach all community members, especially the people who need it most. For example, if you design a falls prevention program that is delivered through a senior citizens community group, consider how the program could also be delivered to people who are unable or unwilling to attend such a group.

Resource 4.2. Prioritisation matrix for ideas



Which ideas build on, combine with, or add value to existing activities and priorities?

Fit

1. Quick wins

- A current priority
- Aligned with existing activities
- Add value
- Relevant and meaningful to the community
- Strongly supported by the community and key stakeholders

2. Priority for development

- A current priority
- Identified as a significant need or gap
- Can build on existing activities
- Use available resources
- Supported by the community and key stakeholders

4. For future consideration

- Not a priority
- Not a significant need or gap
- Not aligned with current activities
- Require additional resources
- Not supported by the community and key stakeholders

3. Investigate feasibility

- Identified as a significant need or gap
- Not aligned with current activities
- A new area of activity
- Require additional resources and capacity building
- Require or have only minimal support from the community and key stakeholders

Gap

Which ideas match up with known gaps and problems in the community?

Activity 4.3.

Link objectives to selected health literacy actions and evidence from the literature

By the end of this activity, you will have linked your selected health literacy actions with your objectives and relevant evidence from the literature. See *Resource 4.3. Linking project objectives to action and evidence* for a template.

You will need to ensure that the selected health literacy actions are aligned with your objectives (see *Activity 4.1. Confirm the project focus, scope and aim, and specify project objectives*). This will also guide your implementation plan in *Step 5: Plan health literacy actions.*

The Ophelia process seeks to build on what is already good and working well. In particular, Ophelia seeks to build on local wisdom to develop and implement locally relevant, meaningful and useful innovations. A rapid review of existing evidence about actions that are the same or similar to the actions you have selected might help you to develop your implementation plan.

Review the research published in peer-reviewed journals, as well as what has been done in practice, which is likely to be found in reports and on web pages (i.e. 'grey literature'). You may find information about existing actions that have good evidence of effectiveness in a related setting. You may also find evidence that certain actions are not effective and should not be attempted. Ensure you consider the setting in which other actions have been developed and implemented. Something developed and implemented in one setting could be far more effective in another – or, it may not be effective at all.

Top tips

Rapid review notes:

A rapid review means briefly collecting and evaluating available research evidence. When doing a rapid review, note that:

- There may not be relevant research literature for many health literacy action ideas, especially for those beyond Western research settings
- A rapid review does not need to be a comprehensive review of all the research literature about your topic of interest
- A librarian may be able to assist you to develop a suitable search strategy to find relevant research

Insight

Changing people's experiences of a service

An underlying premise of Ophelia projects is that the activities or actions should improve people's experiences when they interact with health information and services.

Examples of improvement in people's experiences include feeling that a practitioner has listened better than before, that information is easier to understand and use, and that navigating a health service is simpler.

Resource 4.3. Linking project objectives to actions and evidence

Objectives	Health literacy actions	Evidence
Example 1 – Project aim: To improve management of acute exacerbation of heart failure		
• Increase use of exacerbation plans from 30% to 50% in 6 months • People with heart failure can describe the steps required to manage exacerbation of their condition • Provide support and resources to enable people to understand how to manage heart failure exacerbations	• Find out each person’s preferred learning style and use it to talk about their individual information needs • Provide health information materials in multiple formats to suit different needs • Train clinicians to use teach-back in every interaction • Build on what people already know to be effective, or what they already use	Use of teach-back shown to improve medication adherence in people with heart failure (references from literature and grey literature)
Example 2 – Project aim: To improve physical activity levels of cancer survivors		
• Increase average physical activity levels among cancer survivors from 30 to 120 minutes per week over the next 5 years • Cancer survivors have increased confidence and motivation to exercise • Provide supports and resources to enable cancer survivors to feel more confident and motivated to exercise	• Use existing volunteers as health mentor ‘buddies’ for socially isolated or less motivated people • Link cancer survivors to groups that already exist in the community • Share success stories about how people have managed to increase their physical activity	Use of peer buddies to increase physical activity (references from literature and grey literature)

Activity 4.4.

Work through the logic of your health literacy action to specify how it will achieve the project objectives

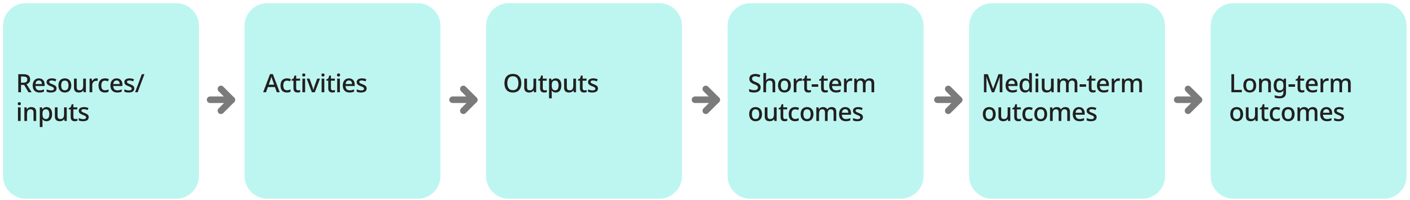
✓ **By the end of this activity, you will have a program logic model that describes how your health literacy action is intended to work. This will link the activities with outputs, intermediate impacts and longer-term outcomes. See Figure 5 for an outline, and *Resource 4.4.1 Steps to create a program logic model starting with outcomes*.**

Using the information you have from the previous activities, you now need to work through the logic of how the action can achieve your project objectives. This can be done using a program logic model (see Figure 5). Other terms to describe program logic include 'program theory', 'logic model', theory of change, 'results chain', and 'intervention logic'. Consider hosting a meeting with the key decision makers and project drivers to discuss the initial draft of this model. **This is another important co-design activity.** (Refer to ***Resource 4.4.2 Developing a program logic*** for a discussion about program logic model development and theory. See also ***Resource 4.4.3 Example program logic model*** for an example of a program logic model.)

Before developing the program logic model, it is helpful to carefully consider any assumptions that you and other stakeholders may have about the health literacy action, why it is needed and how it will work. This will help to identify and anticipate any unintended or unforeseen consequences. Then, as you develop the program logic model, systematically question the assumptions between each of the links in the causal chain. For example, what are the assumptions about the link made between the activities and the outputs, and what is the evidence for this.

To develop your own program logic model, use ***Resource 4.4.1 Steps to create a program logic model starting with outcomes***. Program logic aims to show how the activities link with the outputs through to the outcomes. It it can be useful to start by identifying the longer-term outcomes, then working backwards. This is known as 'backcasting' and involves working backwards to identify the steps needed to achieve these outcomes. Backcasting is useful because it focuses on what is needed to create the outcome.

Figure 5. Outline of a program logic model



Step 1: Develop an outcomes hierarchy

Outcomes are changes due to effective implementation of the health literacy action. An outcomes hierarchy arranges the outcomes from short- (or immediate-), to medium- and long-term to follow the causal pathway of changes. This hierarchy shows what is required to achieve the goal of the health literacy action.

Step 2: Identify the deliverables (outputs)

The deliverables are also known as the outputs. These outputs are produced or created from the specific activities; for example, clinicians will use teach-back with patients.

Clearly state the activities or the specific tasks that are needed to implement the health literacy action; for example, training clinicians in teach-back.

Identify what resources (or inputs) are required for the activities. These may include combinations of human, organisational and community resources, planning, and activities; for example, develop a teach-back training program.

Step 3: Identify assumptions

Systematically question the assumptions between each of the links in the causal chain.

Resource 4.4.1 Components of a program logic model

Component	Examples	Guiding questions
Long-term outcomes	e.g. Reduce unplanned admissions to hospital for heart failure	What assumptions are made about the link between medium-term and long-term outcomes? Are these assumptions supported by evidence?
Medium-term outcomes	e.g. People use their heart failure action plans more effectively	What assumptions are made about the link between short-term and medium-term outcomes? Are these assumptions supported by evidence?
Short-term outcomes	e.g. People have increased knowledge and confidence to put their heart failure plans into action	What assumptions are made about the link between short-term and medium-term outcomes? Are these assumptions supported by evidence?
Outputs (deliverables)	e.g. Clinicians use teach-back to help people understand how to use their heart failure action plan	What assumptions are made about the link between outputs and short-term outcomes? Are these assumptions supported by evidence?
Activities	e.g. Train clinicians in use of teach-back and provide supporting resources	What assumptions are made about the link between activities and outputs? Are these assumptions supported by evidence?
Resources/inputs	e.g. Assess people's learning styles and preferences; develop and provide understandable information; provide a heart failure action plan; develop a teach-back training program and resources for clinicians	What assumptions are made about the link between inputs and activities? Are these assumptions supported by evidence?

A **program logic model** is, as the name suggests, a model of the logic of a program. A program logic model proposes the theory for how a program (e.g. a health literacy action or set of actions) is expected or intended to work. That is, it describes the **mechanisms** that are expected to achieve the intended outcomes of the program by showing the intended causal links[43]. Mechanisms are described in this Manual as resources, inputs, activities, and outputs. However, depending on the context, they can also be social and psychological drivers of actions (e.g. social norms, beliefs about health).

It is important to distinguish between a program logic model that describes all components of a large or complex program, and a program logic model that describes a smaller or simple program. The actions you select to develop, test and implement may be single, separate actions or sets of interrelated actions (or something in between or different). For a single action, your program logic model may be quite simple. However, for a set of actions or a complex program, your program logic model might involve several components or levels that describe interconnecting mechanisms that are expected to lead to the intended outcomes.

The Ophelia process is based, in part, on realist thinking[1]. In Steps 1 to 4 of the process, you collected health literacy and other information and the local wisdom of community members, health providers and other key stakeholders to develop action ideas. You also reviewed relevant existing research. Now you will use this information to develop the theory for how you expect your chosen health literacy action to achieve the intended project outcomes.

One of the purposes of developing a program logic model is to think about which mechanisms might be important and how they could be activated successfully for different people in different circumstances. This is based on Pawson and Tilley’s theory-driven realist evaluation approach, which seeks to determine what works, for whom, in which circumstances (or contexts) and why[44]. This approach is different from evaluation approaches that only ask “Does the program work?”. The realist evaluation approach starts with the theory for how a program is expected to work, then tests and refines the theory to understand what mechanisms work, for whom, why, and in what circumstances.

Applying realist thinking to your program logic model requires you to focus on what exactly in the program (health literacy action) creates the outcomes, and in what conditions. By thinking this way, the outcomes are understood as the result of the interaction between the inputs/resources, activities and outputs (the mechanisms), and the way that participants respond to these. This interaction is influenced by the setting (context), and the response will be different under different circumstances. Try to identify the mechanisms that you expect will generate the outcomes and describe how the setting (context) could affect the way these mechanisms might work.

Mechanisms always involve some change in people's experiences. A change could be a specific activity (e.g. an educational initiative), a change in the way services are delivered (e.g. improved clinician communication with patients), or exposure to new influences (e.g. a peer support program, access to online information). The intended outcome is nearly always expected to be improvement in a person's health knowledge and beliefs, with the aim that this might result in behaviour change. For example, a person learns to balance their health with their other priorities, or a person's ability to link advice to action is improved. If the mechanisms of the health literacy action do not cause a person to experience something new or different (i.e. to experience change), then their behaviour will not change.

Three examples of **mechanisms** of health literacy actions that could lead to change are:

- People who contact the service for the first time **feel that they are being listened to and that their concerns are the primary interest of the staff**, rather than just a set of bureaucratic activities. This improvement in staff communication (the mechanism) is hypothesised (expected) to lead to people having greater trust in the organisation, a stronger belief in its relevance to them, and the sense that it will help them. As a result, it is more likely that the person will attend future appointments.
- Following a consultation with the doctor, people are given **support to plan exactly how they will put the doctor's advice into action**. This improved support (the mechanism) is hypothesised to lead to people's increased ability to understand medical advice and apply it to their daily activities.
- People can **discuss practical issues related to caring for their health with those they consider to be "like them"**. This opportunity to have access to peer support (the mechanism) is hypothesised to lead to people having a stronger belief that looking after their health is possible, and a feeling that they have access to a pool of practical ideas and problem-solving support.

Health literacy actions can be used in different ways to activate the same mechanism, depending on people's needs, the local context and the way a service is organised. For example, in the second point above, the mechanism of providing support for action planning could be implemented by a doctor, a follow-up nurse consultation, community health volunteers, or by a follow-up phone call. The most appropriate strategy might depend on workforce and scheduling issues, proximity to the community, availability of phones, community health infrastructure, and so forth.

A benefit of making the connection between mechanisms and people's experiences is that you can then search for evidence, including research literature and other sources (e.g. reports, web sites), for how and where these mechanisms have been used before. For example, you may search for information about questions such as:

- What experiences build trust between people and their doctors?
- What experiences help people translate advice into an action plan?
- What experiences make people feel confident that they know which advice to trust?

Understanding the evidence base and how particular mechanisms work within your organisation or service will help to develop a set of organisational principles for your context, culture and health system. These principles will help you put in place the mechanisms needed to provide people with better health outcomes and experiences.

Resource 4.4.3 Example program logic model

Example of a program logic model for an initiative to train Country Women’s Association (CWA) members to mentor frail elderly community members by supporting them with gentle exercise and delivering health messages.

Resources/ inputs	Activities	Outputs	Short-term outcomes	Medium-term outcomes	Long-term outcomes
Resources and training content for educating CWA members are developed.	Training for CWA members in delivery of health messages and gentle exercise programs. CWA members then mentor elderly people, guiding exercise and delivering health messages.	CWA mentors are able to support elderly people with gentle exercise and deliver simple health messages.	CWA mentors engage with elderly community members during group exercise programs.	Elderly people feel cared about and gain practical support and information. CWA mentors improve their communication skills. Both groups have increased social connectedness.	Improved knowledge about falls prevention and simple health activities among elderly community members at risk of falls.

Step 5: Plan health literacy actions

The purpose of Step 5 is to identify who will implement the health literacy actions, when and how they will be implemented, and the resources and materials that will be needed.

The activities in Step 5 will help you to establish the next stages of your project and specific milestones so you can plan the resources and materials you will need.

Step 5 activities are:

5.1 Identify implementation team members and their roles and responsibilities, and confirm your time frame and budget
5.2 Develop the implementation and evaluation plan

Careful design of the implementation and evaluation plan will help you to think about the ways your health literacy actions could improve knowledge, access and engagement opportunities for people in your community.

Activity 5.1.

Identify the implementation team, their roles and responsibilities, and confirm your time frame and budget

✓ **By the end of this activity, you will have a list of the people on the project team, a brief description of their roles and responsibilities, a project time frame, and a project budget. See *Resource 5.1. Project team, time frame and budget* for examples to help you plan.**

At the start of this project, you set up your project team and identified the time frame and budget available for the project. Now that you have more clearly identified the health literacy action(s), it is time to revisit these to make sure you have the resources you need.

As you do this activity, consider:

- Are there members of your original project team who no longer need to be involved? Do you need to engage new people to undertake implementation and evaluation activities?
- Do you have a large team? Would it be more effective to create a central project management team, with working groups to undertake specific activities?
- Is the time frame realistic?
- What funds do you have to cover costs for resources such as staff, technology requirements and other equipment, travel, venue hire, catering and printing?

Project teams – example

Role	Name	Responsibilities (examples)
Project manager		Manage the day-to-day aspects of the project and liaise with stakeholders
Project officer		Lead person for implementation and evaluation of action(s)
Administration officer		Administrative tasks and support for project officer
Training lead		Trains staff in delivery of the action(s)
Community, clinical, policy leads (if relevant)		Engagement support

Working groups – example

Working group activities	Name
Develop implementation and evaluation plan	
Develop training program and materials for staff	
Develop resources for delivery of the action(s)	
Pilot testing	
Evaluation of action(s) and final report	

Time frame – example

Task	Time frame
Finalise implementation and evaluation plans	2 weeks
Prepare resources for training and for delivery of the action(s)	4 weeks
Pilot the resources and processes	1 month
Deliver training to relevant staff	2 weeks
Deliver health literacy action(s)	3 months
Evaluate the action(s)	1 month (or longer if longer-term follow-up is possible)

Budget – example

Items	Cost
Staff training in delivery of the action(s)	
Staff time for delivering the action(s)	
Venue for staff training	
Printing of resources used in training	
Printing of resources used in delivery of the action(s)	

Activity 5.2.
Develop the implementation and evaluation plan

By the end of this activity, you will have a detailed plan for the implementation and evaluation of your health literacy action.
See *Resource 5.2. Example implementation and evaluation plan*.

Before you develop your implementation and evaluation plan, you should establish a list of milestones for your project with related activities. Typically, project milestones include:

1. Final plan for materials development, and implementation and evaluation
2. Ethics approval (if required)
3. Completion of implementation and evaluation activities
4. Final report

Once you have identified the project milestones, you can outline the activities associated with completing those milestones. See Box 20 for examples of activities associated with each milestone.

Box 20. Typical project milestones and activities

Milestone	Activities
1. **Final plan for materials development, and implementation and evaluation**	• Test and refine the materials, training process, manuals, tools and equipment. • Produce a project implementation and evaluation plan (see ***Resource 5.2 Example implementation and evaluation plan***). • Produce a spreadsheet detailing the project milestones and activities, responsible staff and time frame.
2. **Ethics approval (if required)**	• Submit ethics application(s) and refine processes as required to obtain ethical approval from relevant institutions.
3. **Completion of implementation and evaluation activities**	• Implementation tasks and activities completed. • Evaluation tasks and activities completed.
4. **Final report**	• Describe the project background, method and results, and discuss the findings, including what worked and didn’t work for which groups and why. • Final report completed.

A project implementation and evaluation plan should include (see ***Resource 5.2 Example implementation and evaluation plan***):

- an overview of the background and focus of the project, including the overall aims and specific objectives for the health literacy action
- the program logic model
- a table specifying the evaluation plan (what will be measured, when and how)
- an outline of project staff, time frame and budget
- a table specifying the materials, staff training and other resources required and their availability and cost. Plan for which items will need to be purchased or developed by the project team.

Top tips

Co-design implementation and evaluation procedures

Wherever possible, co-design the implementation and evaluation procedures with stakeholders who have interest in and responsibilities for elements of your project, including publicising your achievements. The more you work with people who support and understand what you are doing, the better their sense of ownership of the process and outcomes, and the more informed and detailed your implementation and evaluation plan will be.

A detailed evaluation plan could include steps for process, outcome and impact evaluations (see Box 21). A detailed evaluation plan will help you to work out how you will test if:

- you did what you planned to do, and if your health literacy action was implemented as you intended (process evaluation)
- your health literacy action achieved the project objectives (outcome evaluation)
- you identified a clear link between causes (mechanisms) and effects (intended outcomes), and can explain, for your project circumstances, how the action worked, for whom, and why (impact evaluation – usually observed over time).

For each type of evaluation, identify one or more ways to measure processes and changes during the implementation phase. Ways to identify change can range from direct observation of change in procedures (new policies and procedures are in place), to interviews with staff and community members, to assessment of change over time using administrative data or specific questionnaires.

An evaluation plan can be as simple as a one-page table, such as the one in Box 21. You might choose to only include process and outcome evaluation activities in your plan if you have limited capacity to conduct follow-up impact evaluation activities over a longer period.

Box 21. Example of an evaluation plan
Health literacy actions to improve the way renal transplant patients prepare for the transplant, and to improve the success of the transplant

	Health literacy actions	How each activity could be measured
Process evaluation	Run group education sessions for patients and their families; provide written, visual and other educational material based on patients' preferred learning styles.	Number of sessions run, number of attendees at each session, attendee satisfaction with the sessions.
	Establish a call line for patient transplant queries.	Number of calls received, number of patients making calls, patient satisfaction with the call line service.
	Project objectives	**Measure of achievement**
Outcome evaluation	Reduce the time patients require for pre-transplant preparation and assessment from 9 to 3 months.	Measure time from commencement of assessment for transplant until completion for each enrolled patient.
	Provide sufficient education to enable all patients to: 1. have an appropriate level of understanding to make an informed decision about proceeding to transplant 2. be well prepared to receive the transplant and be able to independently self-manage at home	Interview patients following exposure to the health literacy action to: ● assess their understanding of the transplant ● address their remaining questions and concerns ● ask if their information needs have been met ● determine their knowledge about and plans for self-management of their graft ● ask about their overall health post-transplant surgery.
Impact evaluation	Improved graft success	Patients who had the largest improvements in HLQ Scale, '2. Having sufficient information to manage my health', and '3. Actively managing my health' were more likely to have attended all the educations sessions and had the most successful transplants.

Insight

Examples of evaluation measures:

- The HLQ (or relevant scales) could be used before and after implementation of the action
- Interviews with people about how useful the health literacy action is for their everyday lives
- Disease-specific questionnaires related to knowledge or self-management skills
- Number, duration and type of hospital presentations
- Audits of patient files (e.g. Did clinicians record delivery of the health literacy action?)

Use routinely collected data (e.g. administrative datasets) as much as possible to evaluate your health literacy action, but remember that it is changes in people's experiences and behaviours that are the most important (and often the most difficult) outcomes to capture.

Top tips

Consider evaluating your health literacy actions across multiple levels

What changes might occur for individual participants? What changes might occur for each clinician or among clinicians? What changes might occur for groups or communities? Or what changes within an organisation, such as changes to procedures and policies, could be measured?

Resources 5.2. Example implementation and evaluation plan

Project focus: The overall project focus is for people with chronic conditions to better self-manage their health

To make the action work we need:	**The action is:**	**The outputs are:**	**What we want to achieve**		
Resources/inputs (what is needed for activities to occur)	**Activities** (specific activities that make up the action)	**Outputs** (what the specific activities will produce)	**Short-term outcomes**	**Medium-term outcomes**	**Long-term outcomes**
• Develop clinician training materials and content • Develop materials for ongoing support • Develop strategy for engaging staff in the health literacy action	• Deliver 1-hour training session to staff on teach-back and assessing learning styles • Implement the action using a staged approach • Provide resources to support staff in ongoing delivery of the action	• Clinicians are skilled and confident to engage with people with chronic conditions in appropriate education activities • Mode of delivery of the action is matched to individual health literacy needs of people with chronic conditions	• People with chronic conditions and clinicians have increased rapport	• People with chronic conditions have improved health literacy in relation to self-management	• People with chronic conditions have established and effective health management routines that they can maintain independently • Increased appropriate demand for early action and self-management services
How these activities and outcomes could be evaluated					
• Staffing time and costs for training • Staffing time and costs for ongoing delivery of the action • Costs related to printing of resources	• Response and continued participation rates (people with chronic conditions and clinicians)	• Clinicians' confidence and skill evaluated via focus groups after 2 months • Satisfaction with delivery evaluated using semi-structured interviews with a sample of people with chronic conditions	• Shorter-term outcomes measured by interviews with people with chronic conditions and clinicians	• Medium-term outcomes measured using pre- and post-test of relevant domains of the HLQ and/or eHLQ	• Longer-term outcomes measured by interviews or self-management questionnaires with people with chronic conditions and clinicians • Increased use of services measured by changes in the number and types of services engaged

What materials, staff training, manuals, tools and equipment are required for implementation and evaluation of the health literacy action?	**Materials**	**Available**	**Need to purchase?**	**Time to develop**
	Training content for clinician training	No	No	4 weeks
	Resources to support staff in assessing learning styles			
	Staff training			
	Tools and equipment			

Step 6:
Develop, test and refine health literacy actions

The purpose of Step 6 is to develop, pilot test and refine the resources and processes needed to implement the health literacy action(s). This will help you to work out issues and problems before implementation.

Step 6 activities are:

6.1 Purchase or develop the materials, training and processes needed to implement your plan
6.2 Test the materials, training and processes using quality improvement cycles
6.3 Refine the materials, training and processes based on the findings of the quality improvement cycles

The activities will help make sure the health literacy action is appropriate, meaningful and useful for the people and the context.

Early engagement with the people who will implement the health literacy action (e.g. health workers, community workers) in pilot testing means that they will be able to contribute to making the action as fit-for-purpose as possible.

You can set up small-scale quality improvement cycles that minimise effects on normal clinical or community activities (see Figure 6 in *Activity 6.2. Test the materials, training and processes using quality improvement cycles*).

Activity 6.1.

Purchase or develop the materials, training and processes needed to implement your plan

✓ **By the end of this activity, you will have a full set of draft materials, training and processes required for the health literacy action to be delivered. A template is provided in *Resource 6.1. Materials, training and processes plan.***

In *Activity 5.2. Develop the implementation and evaluation plan*, you considered all the project materials and resources you would need. In this activity, you will work with your project team and stakeholders to source and develop these resources.

This activity may also involve developing protocols or manuals to support the application of the health literacy action. For example, your action may need new processes to be set up between health services (e.g. a new referral pathway). Processes for such activities will need to be developed and pilot tested.

Sometimes, new resources and materials may not need to be developed. Many resources may already exist and be available for use – you may have found these in your literature review. However, the processes to implement them in your project context will probably need to be tested in *Activity 6.2. Test the materials, training and processes using quality improvement cycles*.

Resource 6.1. Materials, training and processes plan

Materials/training/processes	Staff responsible	Planned completion date

Activity 6.2.
Test the materials, training and processes using quality improvement cycles

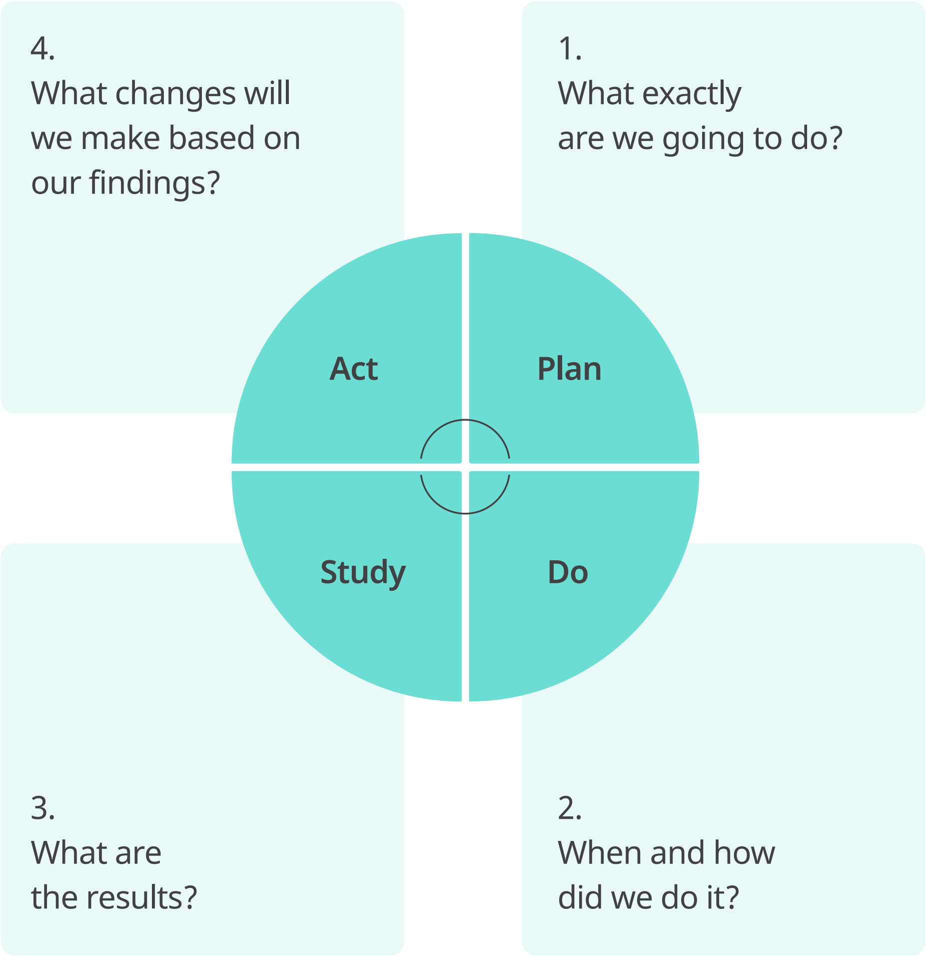
By the end of this activity, you will have information about improvements that need to be made to the materials and processes developed in Activity 6.1. You will then purchase or develop the materials, training and processes needed to implement your plan. See *Resource 6.2. Example of a quality improvement cycle* for a template.

In this activity, quality improvement cycles are used to test materials, training and processes (and associated protocols or manuals). A quality improvement cycle is a planned sequence of activities that seeks to test and improve a resource or process (see Box 22 for examples).

Quality improvement cycles can be repeated as often as needed and can be conducted over a short period. See Figure 6 for an example quality improvement cycle – the Plan, Do, Study, Act (PDSA) cycle.

For example, a PDSA cycle can be applied to a health worker training program. The first full cycle might identify that health workers did not understand a section of the training. A different method of teaching could then be used in a second training session a week later and evaluated with a second PDSA cycle.

Figure 6. Plan, Do, Study, Act (PDSA) cycle



Box 22. Examples of pilot test activities

- Undertake a mock audit of three medical histories to test the feasibility of conducting this type of audit as part of an evaluation.
- Administer three scales of the HLQ to 10 different people to test the feasibility of using these scales as a pre-post measure.
- Deliver orientation and training to three health workers to implement a health literacy action, then administer a post-training survey about the value of the orientation and training.
- During a pilot training session with health workers, ask them to undertake relevant role-play activities.
- Conduct a focus group with health workers to ask them about the feasibility and usefulness of proposed evaluation activities.
- Conduct three mock telephone interviews with staff or volunteers about potential barriers to implementing the health literacy action.
- If testing new processes, pilot test from beginning to end with three people.

Project aim: To improve referral processes between co-located dental and primary health services

Cycle	Activities	Planned completion date
Plan	Preparatory activities include: ● Establish electronic referral processes between dental services and primary health services ● Develop marketing material for dental team and for primary healthcare team ● Orientate dentist(s) and primary health central intake staff to the pilot project to test the health literacy action	
Do	Implement health literacy action as a pilot test. ● One dentist was engaged to refer 1 to 2 dental patients to the primary health service following an agreed process. The referral was actioned by central intake staff. Modify process and repeat if necessary. ● Provide marketing material to a maximum of 5 staff from each service. Modify and repeat if necessary.	
Study	Undertake the following evaluation activities, review results and make decisions about needed modifications to the health literacy action or the evaluation plan. ● Evaluation activities 1: Involve participants who were referred between the dental service and the primary health services, and participants viewing marketing material. Data collection by semi-structured telephone interviews to assess satisfaction with the referral, the marketing material and the usefulness of service for their daily lives. Review results and modify questions – repeat if necessary. ● Evaluation activities 2: Involve all referring clinicians, participants who were referred and the intake staff. Data collection by semi-structured telephone interviews to assess satisfaction with the referral process. Review results and modify questions – repeat if necessary. ● Evaluation activities 3: Examine documentation of referrals and the rates of attendance of participants referred to primary health services.	
Act	● Modify evaluation activities and repeat if necessary. ● Modify health literacy actions and repeat if necessary.	

Activity 6.3.

Refine the materials, training and processes based on the findings of the quality improvement cycles

✓ **By the end of this activity, you will have a full set of refined materials and manuals, and the equipment and tools required for delivery of the health literacy action. See *Resource 6.3. Refine materials, training and processes plan* for a template.**

In *Activity 6.2. Test the materials, training and processes using quality improvement cycles*, you pilot tested your health literacy action. Now examine the results of the quality improvement cycles and consider refinements that need to be made to the materials, training and processes before the health literacy action can be implemented more widely in the target population.

As you do this activity, consider:

- What changes do you need to make to materials, training and processes based on the findings from the pilot testing quality improvement cycles? See Box 23 for examples.
- Do any of these changes affect your time frame, staffing or budgets?

Box 23. Examples of changes made to materials, training and processes after pilot testing

Example of changes made to a new care coordination process

- Changed the checklist to one page rather than two
- Checklist to stay at the front of the medical file
- Educated staff on the usefulness and benefits of the program
- Introduced care coordination with new people only

Example of changes made to an action supporting people to ask their doctor questions

- The videos used were developed in another country and were not well accepted by the target population, so the service filmed their own videos using iPads.
- Modified the ‘Good Questions for Good Health’ form to be more user-friendly

Top tips

The importance of pilot testing

It is important to test any materials, training and processes that will be used as part of a health literacy action. This will help to make sure they are acceptable to key stakeholders (e.g. the target group or population, health workers, community workers) and that the action can achieve its purpose.

Pilot testing can be done on a very small scale

For example, you might wish to train two health workers to use the teach-back method of education, then ask them to each test this process with two more people. Feedback from the health workers about the training and their delivery of teach-back, and the reactions of the people they used teach-back with, will provide important information that can be used to refine the training and delivery before implementing this method more widely. Further testing could then be undertaken with other health workers.

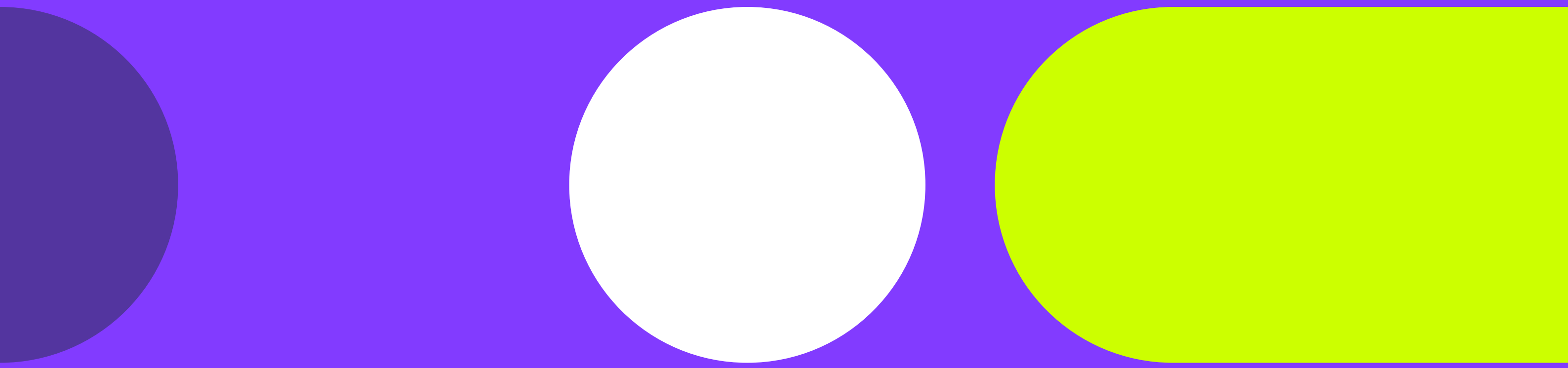
Plan, Do, Study, Act (PDSA) cycles can be rapid

For some activities, PDSA cycles can be conducted very quickly. For example, if you are testing the use of teach-back, apply the method with two people in the morning, make changes based on their feedback, then test the modified method with two new people in the afternoon.

Resource 6.3. Refine materials, training and processes plan

Materials/training/processes	Changes required	Staff responsible	Planned completion data

Ophelia Phase 3



Ophelia Phase 3

Implement, evaluate and improve health literacy actions

In Phase 3 of the Ophelia process, you will develop and implement your health literacy action (or set of actions), and improve the effectiveness, local uptake and sustainability of the action using quality improvement cycles. Phase 3 consists of Steps 7 and 8 with corresponding activities (see Box 24).

Box 24. Phase 3: Steps 7 to 8, with activities and suggested time frames

Ophelia Phase 3	Purpose	Activities	Suggested time
Step 7 Implement and evaluate health literacy actions	To implement the health literacy action (or set of actions) and evaluate the processes and outcomes	7.1 Refine the implementation and evaluation plan 7.2 Implement the health literacy action 7.3 Conduct the outcome evaluation activities	Can vary depending on the health literacy action. You may need 1 to 6 months to observe change in short- to medium-term outcomes.
Step 8 Develop an ongoing quality improvement strategy	To develop and embed mechanisms for continuously improving the effectiveness, uptake and sustainability of the health literacy action	8.1 Identify the components of the health literacy action that can be embedded into usual practices 8.2 Develop a plan for ongoing quality improvement	Ongoing

Step 7:
Implement and evaluate health literacy actions

The purpose of Step 7 is to implement the health literacy action (or set of actions) and evaluate the processes and outcomes.

Step 7 activities are:

7.1 Refine the implementation and evaluation plan
7.2 Implement the health literacy action
7.3 Conduct the outcome evaluation activities

The activities in Step 7 will enable you to carefully consider the findings from *Step 6: Develop, test and refine health literacy actions to refine your implementation and evaluation plan*.

Engagement with all stakeholders in the final refinement of the implementation and evaluation plan will help them to better understand the processes involved in applying and evaluating the health literacy action.

Evaluation activities during and after the implementation of the health literacy action help to provide feedback to all stakeholders involved in the implementation and evaluation. This involvement can increase everyone's engagement in the final step of the Ophelia process – *Step 8: Develop an ongoing quality improvement strategy*.

Activity 7.1.

Refine the implementation and evaluation plan

By the end of this activity you will have a final implementation and evaluation plan for your health literacy action. See a template in *Resource 7.1. Changes to implementation and evaluation plan* to help you refine your implementation and evaluation plan.

The quality improvement cycles you conducted in *Step 6: Develop, test and refine health literacy actions* might have indicated that your implementation and evaluation plan needs adjustments.

As you do this activity, consider:

- Given your findings from *Step 6: Develop, test and refine health literacy actions*, what changes are needed to the implementation and evaluation plan? See Box 25 for some examples.
- Who can you involve in discussions to make sure your implementation and evaluation plan matches as closely as possible your project focus, scope and aim?
- Do any of the refinements you made to your implementation and evaluation plan affect your project focus, scope and aim, or your health literacy action objectives?

Box 25. Examples of changes to implementation and evaluation plan

- If it is difficult for health workers to recruit participants to an initiative because of confidentiality concerns, a different recruitment method will be needed (e.g. external recruitment agency or word-of-mouth among peers).
- If it is difficult to engage people in an evaluation activity (e.g. completing a questionnaire that is posted to them), then change the way this evaluation activity is approached (e.g. provide the questionnaire at the end of a face-to-face activity, administer it online, or provide a small reward or gift to participants once completed).

Resource 7.1. Changes to implementation and evaluation plan

Changes required	Staff responsible	Additional resources required	Planned completion data

Activity 7.2.

Implement the health literacy action

✓ **By the end of this activity, you will have implemented the health literacy action, conducted a process evaluation and written a brief report about the implementation activities. The report can be used as the foundation for continuous quality improvement activities. See *Resource 7.2. Template for recording process evaluation activities.***

This activity involves implementing the health literacy action, recording the implementation process and writing a brief process evaluation report.

As you do this activity, consider:

- How will you record your implementation activities?
- What strategies do you need to use to monitor implementation activities for quality of delivery, adverse events or other issues?

Example aim: Health literacy action to increase people’s use of heart failure action plans.

Example objectives: Provide information in a variety of presentation formats and use teach-back.

Report monthly about	Results and comments
Number of eligible people	
Number of people seen	
% that chose each of the information presentation preferences	
% who had their preferences met	
% clinicians who reported applying teach-back	
Reason for using teach-back	
Average number of times teach-back was used for each person	
Challenges noted by clinicians or people living with a heart condition	
Adverse events or other issues	
Changes made to the action because of the adverse event	

Activity 7.3.
Conduct the outcome evaluation activities

✓ **By the end of this activity, you will have a report that details the outcome evaluation. See *Resource 7.3. Example evaluation report*.**

This activity involves assessing the short- to medium-term outcomes of the health literacy action (outcomes evaluation). These evaluation activities will have been clearly specified in your implementation and evaluation plan. Findings from the evaluation will then need to be prepared in the form of a report.

As you do this activity, consider:

- Who are the target audiences for the evaluation report?
- What format should the report take?
- Who will prepare the evaluation report?
- How will you disseminate the report?

Top tips

Note the differences between your original plan and what happened

External or other factors might have meant that your health literacy action needed to change. If so, a useful exercise is to compare the expected plan with what actually happened. This can help you to identify where the external or other factors and influences need to be taken into account during *Step 8: Develop an ongoing quality improvement strategy*.

Unintended outcomes

Health literacy actions can have unintended outcomes. If an unintended outcome is observed (beneficial or not), make sure it is recorded so it can be considered during discussions about the findings from *Step 7: Implement and evaluate health literacy actions*.

Should the health literacy action be allowed to change during the implementation?

Implementation and ongoing evaluation of your health literacy action in a real-world setting allows you to identify if the action achieved the objectives you established in *Step 4: Select health literacy actions.* Sometimes, your implementation and evaluation plan will need to change while the action is being implemented. If this happens, record what has occurred up to the point where the change takes place, then make the changes as needed, and continue with the modified plan. You will need to ensure that the final evaluation report includes these changes and the reasons why they occurred.

Actions implemented and evaluated over a 9-month period

- A total of 13 volunteers were trained in the delivery of health messages.
- Volunteers then delivered health messages in five different groups: a tai chi group, a community exercise group, during home visits, among family and among friends.

Evaluation activities

- HLQ Scales 2, 5 and 6 administered before and after the health literacy action with community members and volunteers
- Interviews with volunteers and community members
- Participation rates
- Unintended outcome – capturing of ripple effects via interviews, i.e. if groups outside the immediate intended target groups also received the health information messages

Results: HLQ scores for participants who completed pre- and post-tests (n=19 for Scales 2 and 5; n=18 for Scale 6)

HLQ data (volunteers and community members)	**HLQ 2. Having sufficient information to manage my health**	**HLQ 5. Appraisal of health information**	**HLQ 6. Ability to actively engage with healthcare providers**
	Mean (SD) Range: 1 to 4	Mean (SD) Range: 1 to 4	Mean (SD) Range: 1 to 5
Pre-test	2.95 (0.49)	2.89 (0.49)	4.03 (0.50)
Post-test	3.22 (0.50)	3.07 (0.29)	4.34 (0.61)
Effect size for difference (95% confidence interval)	0.56 (-0.09, 1.20)	0.52 (-0.13, 1.16)	0.56 (-0.11, 1.22)

Summary of interview findings

Volunteers (seven in one focus group and three phone or face-to-face interviews)

Community members (four in one focus group and two phone interviews)

- Volunteers who were already active community members delivered rural health promotion messages through talking with members of their community. Health and community groups reported the initiative was useful for delivering health messages to rural community members. Volunteers reported feeling useful, as well as pride and achievement from participating in a health-promoting project. The usual pathways for the participating volunteers to discuss health was with close family and friends and in social, health and community groups. Unintentionally, the study's health messages were spread by a 'ripple effect' through participating clinicians, volunteers and community members to social circles outside the project.

Lessons learned

- Training was well accepted by volunteers, and suggestions were made to provide additional support to participating volunteers, as required, in future sessions.
- Success stories of volunteers' experiences in the field were used as training material – this tended to increase the quality of the training and the authenticity of the messages delivered to the target groups.
- Delivery of training more broadly (e.g. to community groups, local staff) would assist roll-out.
- Promoting the project more widely (e.g. through advertising, posters around town and in GP clinics) would have increased reach.

Unintended outcome

- Volunteers discussed health messages with people in wider community networks.

Participation rates

Participants and activities	Number of participants
Volunteers participating in training and delivery of the message	14
Volunteers and community members participating in evaluation (pre- and post-test using HLQ Scales 2, 5 and 6)	19
Volunteers participating in focus group or interviews	10
Community members participating in focus group or interviews	6

Step 8:
Develop an ongoing quality improvement strategy

The purpose of Step 8 is to plan a strategy (i.e. a set of mechanisms) to continuously evaluate the health literacy action to improve its effectiveness, uptake and sustainability.

Step 8 activities are:

8.1 Identify the components of the health literacy action that can be embedded into usual practices
8.2 Develop a plan for ongoing quality improvement

The activities of Step 8 will help you to make a formal decision about whether or not to continue the health literacy action (and in what form), and how to ensure that it will be seen as a health literacy priority.

The use of continuous quality improvement cycles means the evaluation findings will help to guide the evolution and adaptation of the health literacy action in changing circumstances.

Your health literacy action can be made more sustainable by embedding it within usual practices.

Activity 8.1.
Identify the components of the health literacy action that can be embedded into usual practices

By the end of this activity, you will be able to make a decision about whether or not the health literacy action, or components of it, can be sustainably embedded into usual practices, or if the action needs to be modified. See *Resource 8.1. Decision to embed health literacy action into usual practice* for a list of questions to help you make this decision.

Following evaluation of the health literacy action, you will now decide if the action, or some components of the action, will continue. Formalising a decision will ensure that it is much more likely to be seen as a priority within your organisation. This activity will also help you to see what modifications are needed to support the sustainability of your health literacy action.

Resource 8.1. Decision to embed health literacy action into usual practice

Do you see benefits associated with continuing to offer all or some components of the health literacy action?

Does your organisation plan to continue to provide all or only some components of the health literacy action? If not the entire action, which components are to be embedded in usual practices?

How can the action or components of the action be embedded within usual practices to ensure sustainability?

Do you see any problems or barriers to continuing to offer all or some components of the health literacy action?

Do you plan to make changes to the materials, training or processes associated with the health literacy action?

Activity 8.2.

Develop a plan for ongoing quality improvement

✓ **By the end of this activity, you will have a continuous quality improvement plan. See *Resource 8.2. Strategy to develop a quality improvement plan* for a template to outline your strategy.**

As with the small quality improvement cycles in *Activity 6.2. Test the materials, training and processes using quality improvement cycles*, continuous quality improvement refers to improvements on an ongoing basis, usually in incremental steps. It is a continual process of evaluation and improvement.

As you do this activity, consider:

- What is the strategy for wider implementation of the health literacy action (e.g. with health workers, in an organisation, throughout a community)?
- What strategies or other mechanisms exist or can be developed to continuously monitor and evaluate the health literacy action and detect changing circumstances?

Some organisations use established procedures for continuous quality improvement activities. These include registration of the quality improvement activity, reporting requirements, risk management strategies and alignment with strategic goals of the organisation.

Top tips

The benefits of a continuous quality improvement plan

By developing and using a continuous quality improvement plan, you can continue to refine, adapt and build on actions. This will ensure that actions are responsive to changing needs and contexts within your organisation.

What are the next steps?

Who will be responsible for developing the quality improvement plan?

What will you do to overcome potential risks or problems?

What approach will you take to monitor and review progress and success?

What resources and supports do you or would you need to continue to offer the health literacy action and ensure it develops and is successful?

How, when and to whom will the quality improvement activities be reported?

How will you ensure that the health literacy action continues to be implemented and evaluated?

Where to from here?

Consider what your organisation or community has learned from implementing the Ophelia process. Have there been wider beneficial effects within your organisation or community that can be harnessed and built on? For example, are more health workers now aware of the importance of health literacy? Does this in turn provide an opportunity to train other health workers in effective health literacy strategies?

What about external effects? Findings from your Ophelia project will be of great interest to your external stakeholders and to other similar organisations and communities. Consider how you might be able to disseminate your findings. Are there professional networks, local seminars or newsletters, or even national conferences in which you can present your work?

References

1. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPtimising HEalth LIterAcy (Ophelia) process: Study protocol for using health literacy profiling and community engagement to create and implement health reform. BMC Public Health. 2014;14(1):694. doi:http://doi.org/10.1186/1471-2458-14-694.

2. Batterham RW, Hawkins M, Collins PA, Buchbinder R, Osborne RH. Health literacy: Applying current concepts to improve health services and reduce health inequalities. Public Health. 2016;132:3-12. doi:http://doi.org/10.1016/j.puhe.2016.01.001.

3. Bartholomew LK, Parcel GS, Kok G. Intervention mapping: a process for developing theory- and evidence-based health education programs. Health Educ Behav. 1998;25(5): 545-63. doi:http://doi.org/10.1177/109019819802500502.

4. Schmid AA, Andersen J, Kent T, Williams LS, Damush TM. Using intervention mapping to develop and adapt a secondary stroke prevention program in Veterans Health Administration medical centers. Implement Sci. 2010;5:97. doi:http://doi.org/10.1186/1748-5908-5-97.

5. Wolfers ME, van den Hoek C, Brug J, de Zwart O. Using intervention mapping to develop a programme to prevent sexually transmittable infections, including HIV, among heterosexual migrant men. BMC Public Health. 2007;7:141. doi:http://doi.org/10.1186/1471-2458-7-141.

6. Nadeem E, Olin SS, Hill LC, Hoagwood KE, Horwitz SM. Understanding the components of quality improvement collaboratives: A systematic literature review. Milbank Q. 2013;91(2):354-94. doi:http://doi.org/10.1111/milq.12016.

7. Hulscher ME, Schouten LM, Grol RP, Buchan H. Determinants of success of quality improvement collaboratives: What does the literature show? BMJ Qual Saf. 2013;22(1):19-31. doi:http://doi.org/10.1136/bmjqs-2011-000651.

8. Schouten LM, Hulscher ME, van Everdingen JJ, Huijsman R, Grol RP. Evidence for the impact of quality improvement collaboratives: Systematic review. BMJ. 2008;336(7659):1491-4. doi:http://doi.org/10.1136/bmj.39570.749884.BE.

9. Greenhalgh T, Wong G, Westhorp G, Pawson R. Protocol--realist and meta-narrative evidence synthesis: evolving standards (RAMESES). BMC Med Res Methodol. 2011;11:115. doi:http://doi.org/10.1186/1471-2288-11-115.

10. Rycroft-Malone J, McCormack B, Hutchinson AM, DeCorby K, Bucknall TK, Kent B, Schultz A, Snelgrove-Clarke E, Stetler CB, Titler M, Wallin L, Wilson V. Realist synthesis: Illustrating the method for implementation research. Implement Sci. 2012;7:33. doi:http://doi.org/10.1186/1748-5908-7-33.

11. Pawson R. Evidence-based policy : A realist perspective. First ed.: London: SAGE Publications; 2008. (ProQuest issuing b, editor.). ISBN: 9881412910606.

12. Mathie A, Cunningham G. From clients to citizens: Asset-based community development as a strategy for community-driven development. Development in Practice. 2003;13(5):474-486. doi:http://doi.org/10.1080/0961452032000125857.

13. Boyd CP, Hayes L, Wilson RL, Bearsley-Smith C. Harnessing the social capital of rural communities for youth mental health: An asset-based community development framework. Aust J Rural Health. 2008;16(4):189-193. doi:http://doi.org/10.1111/j.1440-1584.2008.00996.x.

14. Lawal AK, Rotter T, Kinsman L, Sari N, Harrison L, Jeffery C, Kutz M, Khan MF, Flynn R. Lean management in health care: definition, concepts, methodology and effects reported (systematic review protocol). 2014;3:103-103. doi:http://doi.org/10.1186/2046-4053-3-103.

15. Dias A, Reis A, Oliveira R, Maruyama U, Martinez-Sánchez PMT. Lean manufacturing in healthcare: A systematic review of literature Revista Produção e Desenvolvimento. 2018;4:111-122. doi:http://doi.org/10.32358/rpd.2018.v4.285.

16. Bakker MM, Putrik P, Aaby A, Debussche X, Morrissey J, Råheim Borge C, Nascimento do Ó D, Kolarčik P, Batterham R, Osborne R, Maindal HT. Acting together – WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region. Copenhagen: World Health Organization. Regional Office for Europe; 2019 2-3. Public health panorama. Available from: https://apps.who.int/iris/handle/10665/327059.

17. Kolarčik P, Belak A, Osborne RH. The Ophelia (OPtimise HEalth LIteracy and Access) process : Using health literacy alongside grounded and participatory approaches to develop interventions in partnership with marginalised populations [Journal Article]. European Health Psychology Society; 2015. https://ehps.net/ehp/index.php/contents/article/view/828.

18. Beauchamp A, Mohebbi M, Cooper A, Pridmore V, Livingston P, Scanlon M, Davis M, O'Hara J, Osborne R. The impact of translated reminder letters and phone calls on mammography screening booking rates: Two randomised controlled trials. PLOS ONE. 2020;15(1):e0226610. doi:http://doi.org/10.1371/journal.pone.0226610.

19. Jessup RL, Osborne RH, Buchbinder R, Beauchamp A. Using co-design to develop interventions to address health literacy needs in a hospitalised population. BMC Health Services Research. 2018;18(1). doi:http://doi.org/10.1186/s12913-018-3801-7.

20. Anwar WA, Mostafa NS, Hakim SA, Sos DG, Cheng C, Osborne RH. Health literacy co-design in a low resource setting: Harnessing local wisdom to inform interventions across fishing villages in Egypt to improve health and equity. Int J Environ Res Public Health. 2021;18(9). doi:http://doi.org/10.3390/ijerph18094518.

21. Beauchamp A, Batterham RW, Dodson S, Astbury B, Elsworth GR, McPhee C, Jacobson J, Buchbinder R, Osborne RH. Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). BMC Public Health. 2017;17:1-18. doi:http://doi.org/10.1186/s12889-017-4147-5.

22. Dias S, Gama A, Maia AC, Marques MJ, Campos Fernandes A, Goes AR, Loureiro I, Osborne RH. Migrant communities at the center in co-design of health literacy-based innovative solutions for non-communicable diseases prevention and risk reduction: Application of the OPtimising HEalth LIteracy and Access (Ophelia) process. Frontiers in Public Health. 2021;9(616). doi:http://doi.org/10.3389/fpubh.2021.639405.

23. Hawkins M, Massuger W, Cheng C, Batterham R, Moore GT, Knowles S, Nadarajah RG, Raven L, Osborne RH. Co-design and implementation of an equity-promoting national health literacy program for people living with inflammatory bowel disease (IBD): A protocol for the application of the Ophelia (Optimising Health Literacy and Access) process. BMJ Opne (forthcoming). 2021.

24. Kinsman L, Radford J, Elmer S, Ogden K, Randles S, Jacob A, Delphin D, Burr N, Goss M. Engaging "hard-to-reach" men in health promotion using the OPHELIA principles: Participants' perspectives. Health Promot J Austr. 2021;32 Suppl 1:33-40. doi:http://doi.org/10.1002/hpja.403.

25. Bird ML, Elmer S, Osborne RH, Flittner A, O'Brien J. Training physiotherapists to be responsive to their clients' health literacy needs. Physiother Theory Pract. 2020:1-9. doi:http://doi.org/10.1080/09593985.2020.1850956.

26. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health. 2013;13:658. doi:http://doi.org/10.1186/1471-2458-13-658.

27. Kayser L, Karnoe A, Furstrand D, Batterham R, Christensen KB, Elsworth G, Osborne RH. A multidimensional tool based on the eHealth Literacy Framework: Development and initial validity testing of the eHealth Literacy Questionnaire (eHLQ). J Med Internet Res. 2018;20(2):e36-e36. doi:http://doi.org/10.2196/jmir.8371.

28. Elsworth GR, Beauchamp A, Osborne RH. Measuring health literacy in community agencies: a Bayesian study of the factor structure and measurement invariance of the health literacy questionnaire (HLQ). BMC Health Services Research. 2016;16:1-14. doi:http://doi.org/10.1186/s12913-016-1754-2.

29. Hawkins M, Elsworth GR, Nolte S, Osborne RH. Validity arguments for patient-reported outcomes: justifying the intended interpretation and use of data. Journal of Patient-Reported Outcomes. 2021;5(1):64. doi:http://doi.org/10.1186/s41687-021-00332-y.

30. Boateng MA, Agyei-Baffour P, Angel S, Enemark U. Translation, cultural adaptation and psychometric properties of the Ghanaian language (Akan Asante Twi) version of the Health Literacy Questionnaire. BMC Health Serv Res. 2020;20(1). doi:http://doi.org/10.1186/s12913-020-05932-w.

31. Debussche X, Caroupin-Soupoutevin J, Balcou-Debussche M, Fassier M, Boegner C, Hawkins M, Ballet D, Osborne RH, Corbeau C. Health literacy needs among migrant populations in France: validity testing and potential contribution of the Health Literacy Questionnaire (HLQ). Journal of Public Health. 2021. doi:http://doi.org/10.1007/s10389-020-01423-8.

32. Hawkins M, Cheng C, Elsworth GR, Osborne RH. Translation method is validity evidence for construct equivalence: Analysis of secondary data routinely collected during translations of the Health Literacy Questionnaire (HLQ). BMC Med Res Methodol. 2020;20(1):130-130. doi:http://doi.org/10.1186/s12874-020-00962-8.

33. Kolarčik P, Cepova E, Madarasova Geckova A, Elsworth GR, Batterham RW, Osborne RH. Structural properties and psychometric improvements of the Health Literacy Questionnaire in a Slovak population. International Journal of Public Health. 2017;62(5):591-604. doi:http://doi.org/10.1007/s00038-017-0945-x.

34. Kolarčik P, Cepova E, Madarasova Geckova A, Tavel P, Osborne R. Validation of Slovak version of Health Literacy Questionnaire. European Journal of Public Health. 2015;25(suppl_3). ckv176.151. doi:http://doi.org/10.1093/eurpub/ckv176.151.

35. Nolte S, Osborne RH, Dwinger S, Elsworth GR, Conrad ML, Rose M, Härter M, Dirmaier J, Zill JM. German translation, cultural adaptation, and validation of the Health Literacy Questionnaire (HLQ). PLoS One. 2017;12(2):e0172340-e0172340. doi:http://doi.org/10.1371/journal.pone.0172340.

36. Rademakers J, Waverijn G, Rijken M, Osborne R, Heijmans M. Towards a comprehensive, person-centred assessment of health literacy: translation, cultural adaptation and psychometric test of the Dutch Health Literacy Questionnaire. BMC Public Health. 2020;20(1):1850. doi:http://doi.org/10.1186/s12889-020-09963-0.

37. Saleem A, Steadman KJ, Osborne RH, La Caze A. Translating and validating the Health Literacy Questionnaire into Urdu: a robust nine-dimension confirmatory factor model. Health Promotion International. 2020. daaa149. doi:http://doi.org/10.1093/heapro/daaa149.

38. Wahl AK, Hermansen Å, Osborne RH, Larsen MH. A validation study of the Norwegian version of the Health Literacy Questionnaire: A robust nine-dimension factor model. Scand J Public Health. 2021;49(4):471-478. doi:http://doi.org/10.1177/1403494820926428.

39. Cheng C, Elsworth GR, Osborne RH. Co-designing eHealth and equity solutions: Application of the Ophelia (Optimizing Health Literacy and Access) process. Frontiers in Public Health. 2020;8(792). doi:http://doi.org/10.3389/fpubh.2020.604401.

40. Holt KA, Karnoe A, Overgaard D, Nielsen SE, Kayser L, Røder ME, From G. Differences in the level of electronic health literacy between users and nonusers of digital health services: An exploratory survey of a group of medical outpatients. Interactive Journal Of Medical Research. 2019;8(2):e8423-e8423. doi:http://doi.org/10.2196/ijmr.8423.

41. Villadsen SF, Hadi H, Ismail I, Osborne RH, Ekstrøm CT, Kayser L. ehealth literacy and health literacy among immigrants and their descendants compared with women of Danish origin: A cross-sectional study using a multidimensional approach among pregnant women. BMJ Open. 2020;10(5):e037076. doi:http://doi.org/10.1136/bmjopen-2020-037076.

42. Cheng C, Elsworth G, Osborne RH. Validity evidence based on relations to other variables for the eHealth Literacy Questionnaire (eHLQ): A Bayesian approach to test for known-groups validity. J Med Internet Res (in press). 2021. doi:http://doi.org/10.2196/30243.

43. Funnell SC, Rogers PJ. Purposeful Program Theory: Effective Use of Theories of Change and Logic Models. Hoboken: Wiley; 2011. Centre for Epidemiology and Evidence. Developing and Using Program Logic: A Guide. Evidence and Evaluation Guidance Series, Population and Public Health Division. Sydney: NSW Ministry of Health, 2017.

44. Pawson R, Tilley N. Realistic evaluation. Thousand Oaks, CA, US: Sage Publications, Inc.; 1997

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