

# **Authentic community codesign for health programmes: How to co-create community ownership and co- implement what communities need and want**

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***Connecting planetary health, climate justice and community health***

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# Conflict of interest disclosure

I declare I have no conflicts of interest regarding the perspectives presented in this presentation. The funding bodies played no role in the content of the presentation.

I receive no financial benefit from any of the tools or processes or products that are presented today.

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# ACKNOWLEDGEMENT OF COUNTRY

La Trobe University acknowledges our campuses are located on the lands of many Traditional Custodians in Victoria and New South Wales. We recognise their ongoing connection to the land and value their unique contribution to the University and wider Australian society.

La Trobe University is committed to providing opportunities for Aboriginal and Torres Strait Islander people, both as individuals and communities, through teaching, learning, research and partnerships across all our campuses.



# Learning objective

*By the end of this session, you will be able to:*

Integrate good practices in codesigning a contextually appropriate plan that integrates local wisdom to improve implementation effectiveness and equity.

# What is authentic co-design?

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	Vested interest	Ownership	Advocate	Responsive	Cooperate	Aware	Passive resistance	Feel threatened
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2. End users and implementers experience partnership, know they were heard, were continuously engaged and informed				🎯	🎯	🎯		
3. A process of co-design that was active, but rushed or not inclusive						🎯	?	?
4. End users informed after decisions and protocol produced, told they were part of a consensus						?	?	?
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# Codesign methods to hear soft voices, hear local wisdom and authentically use for intervention codesign

# The Ophelia BreastScreen Victoria Project: Improving awareness and participation among Aboriginal, Arabic and Italian women



**Health Systems Improvement Unit**



*ophelia*

Global Health and Equity Development Hub  
Violet Vines Marshman Centre for Rural Health Research, La Trobe University, Australia



# The three phases and eight steps of the Ophelia process

**Phase 1**  
Identify strength,  
needs and action  
ideas

**Step 1** Project set-up

**Step 2** Data collection using Health Literacy Questionnaire (HLQ)

**Step 3** Stakeholder and community engagement to generate action ideas. Use vignettes (community stories) derived from local people's "hearts & minds" (real data)

**Phase 2**  
Select, plan and  
test  
health literacy  
actions

**Step 4** Select health literacy actions (program logic models)

**Step 5** Plan actions (develop implementation and evaluation plans)

**Step 6** 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 an ongoing quality improvement strategy



LA  
UN  
AUSTRALIA



# Overview

## Ophelia (Optimising Health Literacy and Access) in breast cancer screening Victoria

- Aim:
  - increase screening among under-screened groups
    - Arabic, Italian, Aboriginal, and Australian women
- The 9-dimension HLQ used to provide detailed information on the mechanisms by which people can and can't engage with health information and services
- These data were used for co-design with women and frontline health staff



Group	HLQ Survey	Interviews	Workshop participation
Aboriginal	52	9	17
Arabic	71	3	30
Italian	173	4	12
Australian	133	5	23
NW clinic staff		-	21
<b>TOTAL</b>	<b>429</b>	<b>21</b>	<b>103</b>

**Total number of people consulted: 553**

# Cluster analysis of HLQ – to generate evidence-based

(with qualitative interviews)

1. Do you recognise this person in your community?

2. What are their main issues?

3. What strategies could be used to help this individual?

4. If there were lots of people like this... What could services and community organisations do to improve outcomes for these people?

		1. Healthcare provider support	2. Has sufficient information	3. Actively managing health	4. Social support for health	5. Appraisal health information	6. Active engagement HCP	9. Understanding health information
A	0%	3.75			73	3.87	5.0	4.87
E	8%	3.71			82	3.72	3.9	3.15
C	8%	3.71			31	3.03	4.2	3.97
D	0%	2.88			65	2.73	3.9	3.69
E	7	2.82		2.46	2.89	2.46	2.8	2.46

Basira is aged 55 and lives with her husband and two children who are in their early 20s. She emigrated to Australia 25 years ago and became a citizen soon after that. Basira completed secondary education in her home country and works part-time in a local take shop. Basira firmly believes her family comes first, and feels she is lucky to be so healthy herself. Since the menopause she does sometimes feel quite anxious but thinks this is normal. She also has asthma and her GP has put her on an action plan but she often forgets to take her puffer with her when she leaves the house (Scale 3). Basira does have a GP who she will see when she gets sick (Scale 1, 6) but otherwise she doesn't use any other health services (Scale 7) and while she would like more information (Scale 2) and finds it OK (Scales 8), she finds it hard to work out if it is useful (Scale 5).

Basira has never had a breast screen, although her GP mentioned she should go when she turned 50. She was confused when her doctor said that breast screen can prevent you from dying as she knows that it is Allah's will when you die. Some of her friends (Scale 4) told her the staff are friendly, but that the procedure itself is quite uncomfortable and her friend didn't expect that her breasts would need to be handled quite so much. Basira thinks that she doesn't have the time anyway, there are always lots of other priorities (Scale 3).



# Integrated framework building

## Health literacy-informed interventions



# Outcome

- **244 ideas were generated by women and health professionals,** and referenced against the published evidence
  - Many novel ideas
- **Prioritised Action Areas for Testing**
  1. Outbound calls in their language
  2. Sending invitations in language
  3. Peer education program
  4. Information booths in pharmacies
  5. Staff training
  6. Media advertisements & animation
  7. Shawls designed by Aboriginal women



# Outcome

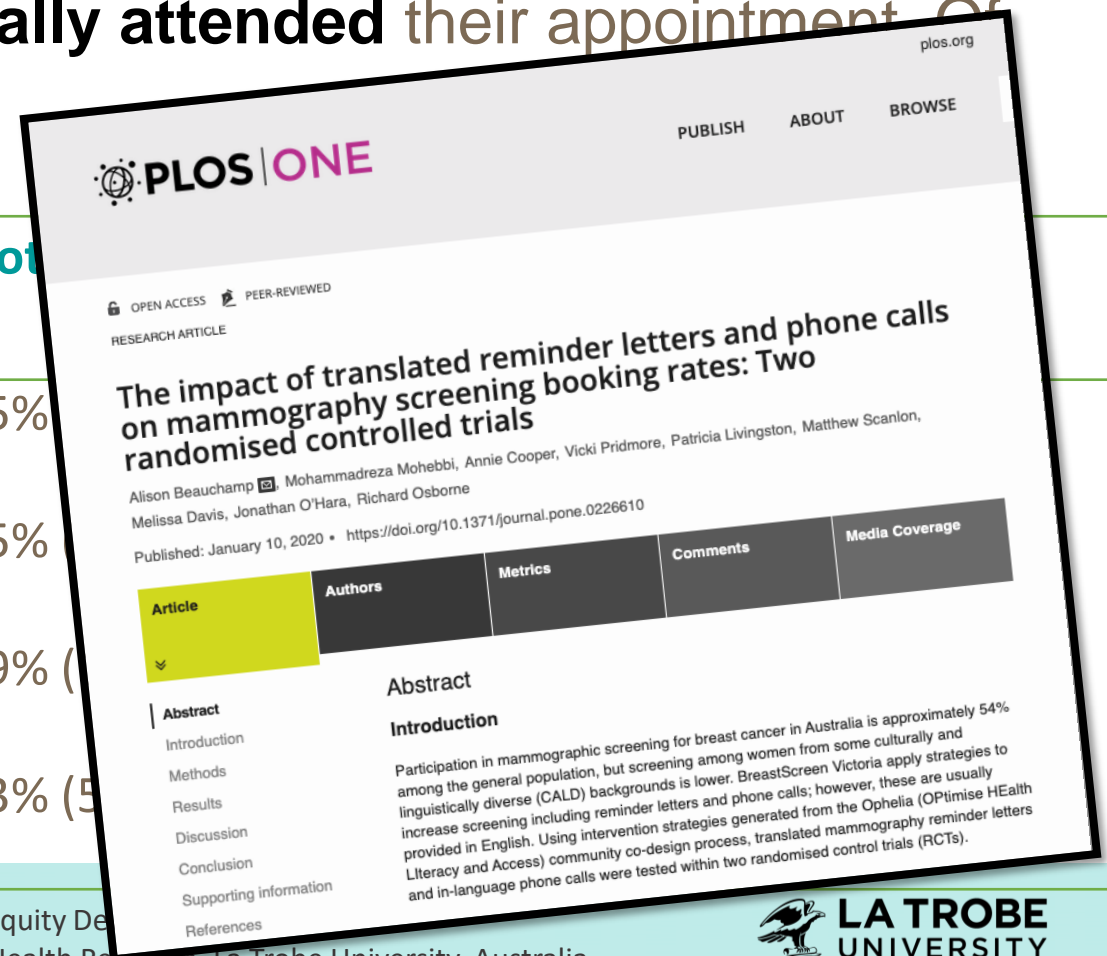
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  - Many novel ideas
- Prioritised Action Areas for Testing
  1. **Outbound calls in their language**
  2. *Sending invitations in language* (\*\*didn't work)
  3. Peer education program
  4. Information booths in pharmacies
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  6. Media advertisements & animation
  7. **Shawls designed by Aboriginal women**



# Trial 1: Outbound calls in language

- Women who received a call in language were **x10 more likely to book** than women who didn't receive a call
- The **majority of women who booked actually attended** their appointment. Of those that didn't attend, most cancelled.

Group	Trial arm	Booked	Not
Arabic	In language call	<b>55% (21)</b>	45%
	No call	<b>5% (2)</b>	95%
Italian	In language call	<b>71% (41)</b>	29% (
	No call	<b>7% (4)</b>	93% (5



# Trial 7: Screening shawls for Aboriginal women (Beautiful Shawls project)

## Background

- Idea seen in New Zealand

## Trial

- Customised shawls with Aboriginal community designs
- Partnering with Aboriginal and Torres Strait Islander peak bodies
- Group booking model
- Clinic staff training
- Trial successful



# Beautiful Shawl Project sites



The Beautiful Shawl Project documentary

- Phase 1**  
Identify strength, needs and action ideas

  - Step 1** Project set-up
  - Step 2** Data collection using Health Literacy Questionnaire (HLQ)
  - Step 3** Develop vignettes (community stories) from real data (HLQ). Stakeholder and community engagement to generate action ideas. Develop overall health literacy strategy
- Phase 2**  
Select, plan and test health literacy actions

  - Step 4** Select health literacy actions (program logic models)
  - Step 5** Plan actions (develop implementation and evaluation plans)
  - Step 6** Test and refine health literacy actions (quality improvement cycles to test processes and materials)
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  - Step 7** Implement and evaluate health literacy actions
  - Step 8** Develop an ongoing quality improvement strategy



# Key messages from the Breast Screen Victoria study

- Community ownership
- Interventions can be simple, low cost, far reaching
- Create and ensure *psychological and cultural safety*
- Not all the identified interventions need to be implemented or will work



Australian Government  
Australian Research Council

MONASH University  
Medicine, Nursing and Health Sciences



# ophelia

The **Ophelia (OPTimising HEalth Literacy and Access)** process uses *health literacy thinking* to connect people at all levels in a community in co-design, prioritisation and the implementation of locally designed, fit-for-purpose solutions



Global Health and Equity Development Hub  
Violet Vines Marshman Centre for Rural Health Research, La Trobe University, Australia



# 8 Ophelia principles



## 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

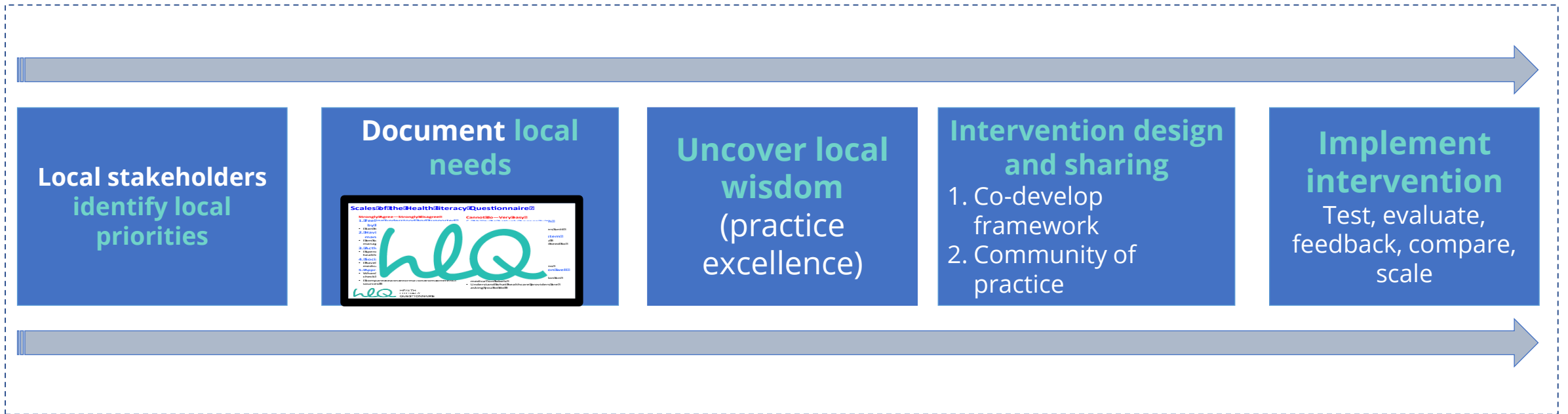
Focus on improvement at and across **all levels of health systems**



## 8. Sustainable

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

# Ophelia processes and theoretical foundation



# Ophelia processes and theoretical foundation

Communities of practice,  
quality improvement  
collaboratives

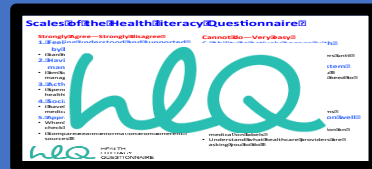
Realist program design  
and evaluation

Intervention  
Mapping,  
Complex interventions

Health service settings: participatory service development and quality improvement (also akin to Lean Manufacturing)

Local stakeholders  
identify local  
priorities

Document local  
needs



Uncover local  
wisdom  
(practice  
excellence)

Intervention design  
and sharing

1. Co-develop framework
2. Community of practice





Implement  
intervention  
Test, evaluate,  
feedback, compare,  
scale

Community settings: participatory and Assets Based Community Development (ABCD), participatory research

Whole of community perspective and  
focus on who is 'left behind'

Cycling between bottom-up and top-  
down planning



			
<b>Volume 1</b>	<b>Volume 2</b>	<b>Volume 3</b>	<b>Volume 4</b>
Overview	A globally relevant perspective	Recommended actions	Case studies from WHO National Health Literacy Demonstration Projects

<https://www.who.int/groups/gcm/health-literacy-development-for-ncd-prevention-and-control>

# Integrated conceptual framework for health literacy development

Health literacy development is influenced by settings and health determinants

Health literacy is developed over time through social practices, education and media

Health literacy is put into action

Accessing, understanding, appraising, remembering, using

Ways of learning

Conversation, arts, written word, health professionals, mass media, Apps

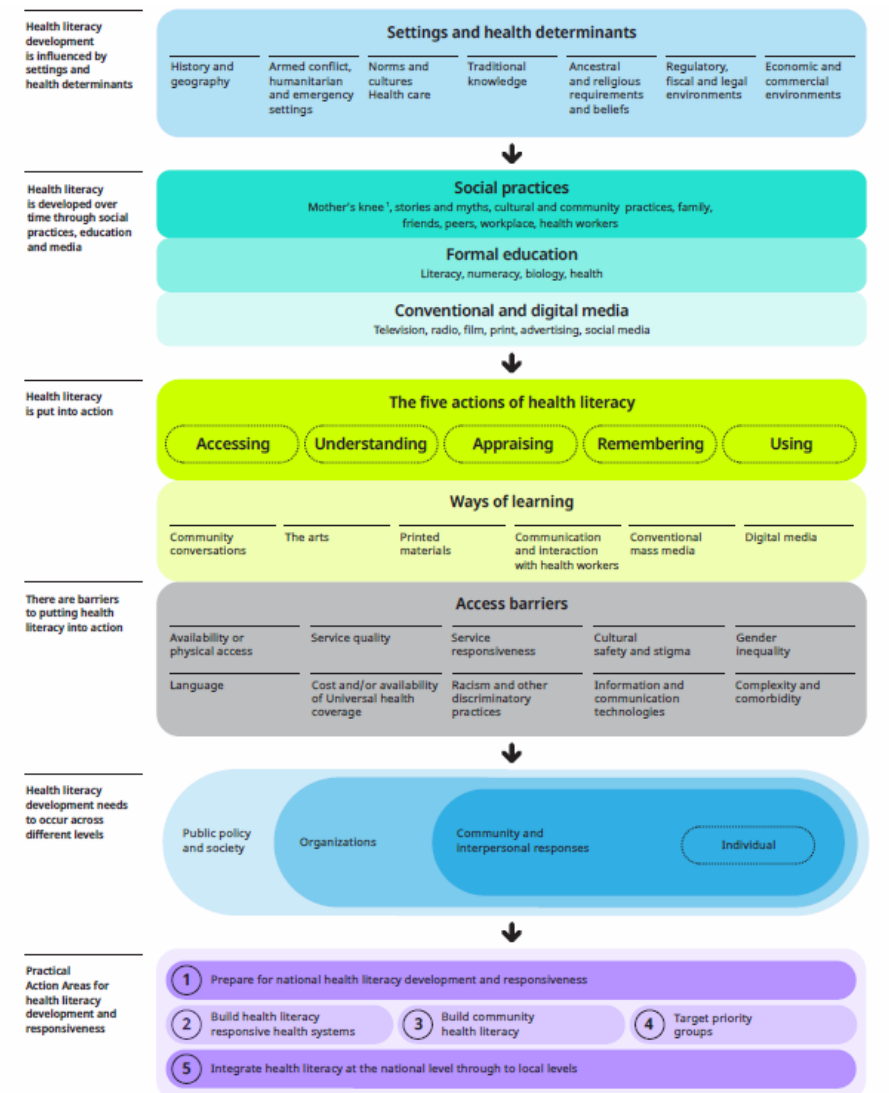
There are barriers to putting health literacy into action

Health literacy development needs to occur across different levels

5 Practical Action Areas for health literacy development and responsiveness

## 2.2

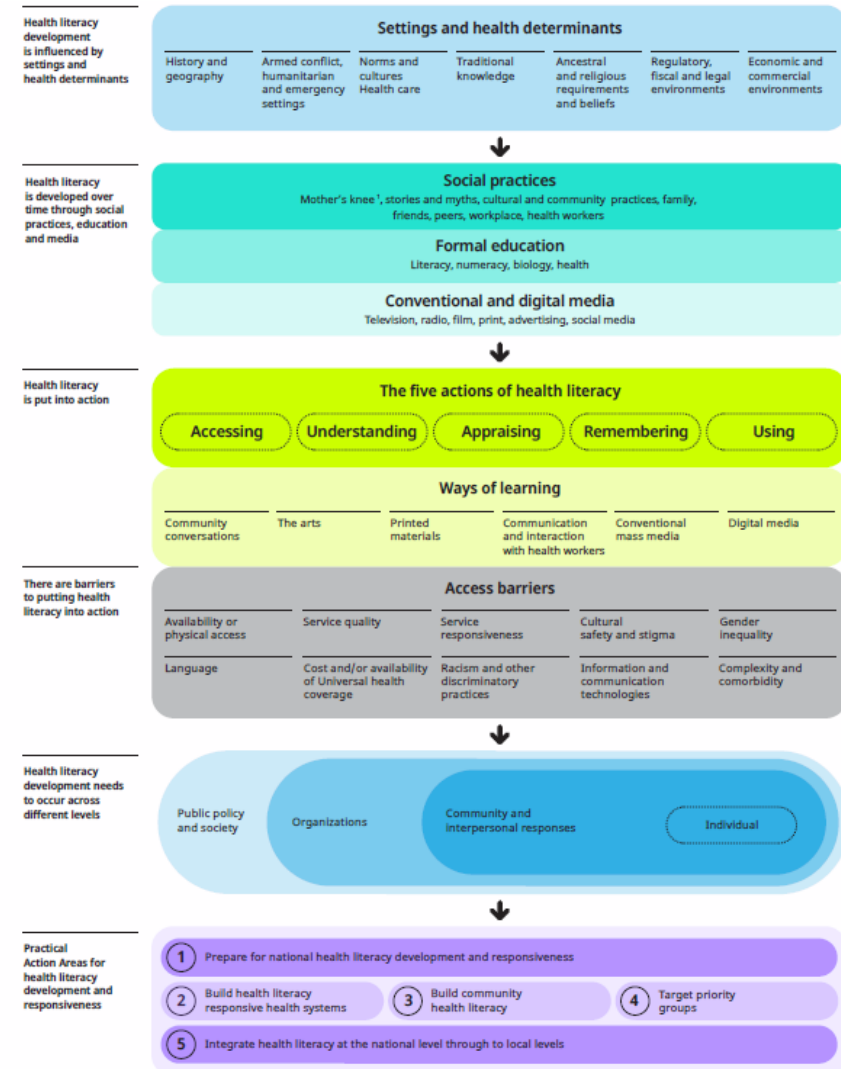
Figure 2.3. Integrated conceptual framework for health literacy development



<sup>1</sup> Mother's knee is a concept where an infant learns about social practices and health-related information from the people caring for them, often while sitting on their knee.

2.2

Figure 2.3. Integrated conceptual framework for health literacy development



<sup>1</sup> Mother's knee is a concept where an infant learns about social practices and health-related information from the people caring for them, often while sitting on their knee.

# Application of Ophelia



## Volume 4



### WHO Health Literacy Development projects (and other Ophelia projects)



Initial WHO



Additional WHO



New / other



JACARDI

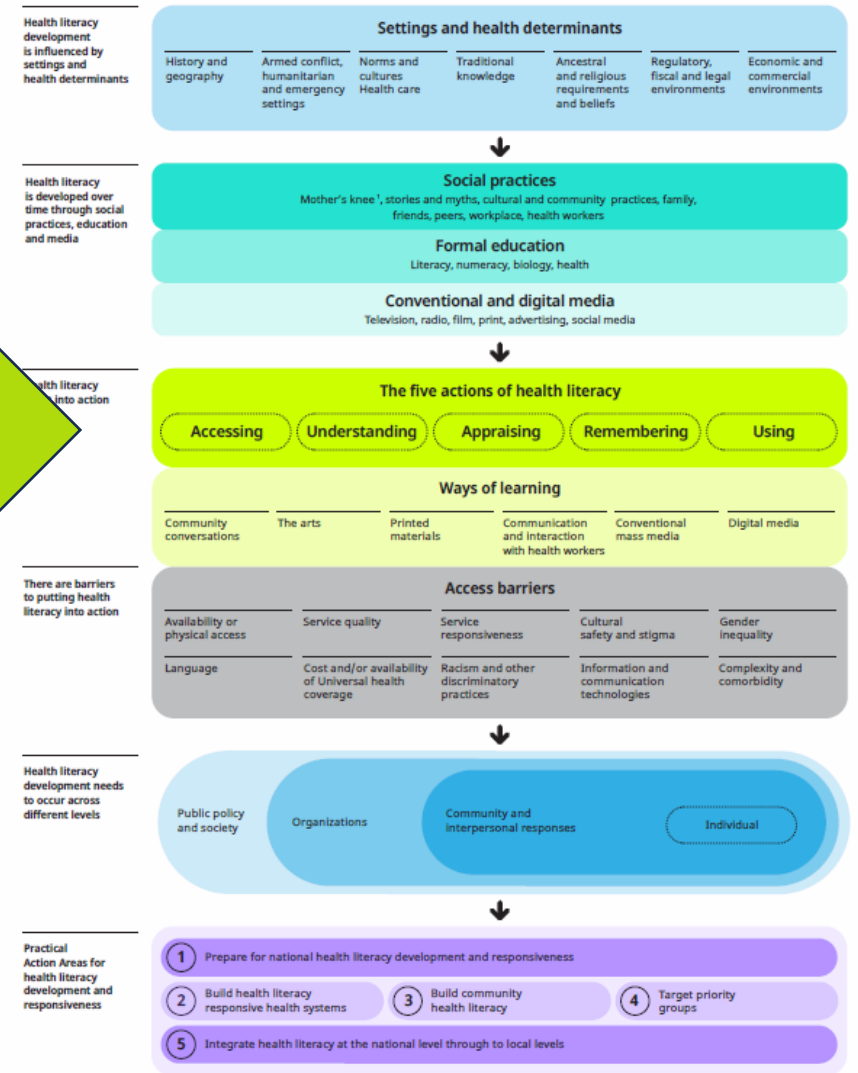
Joint action  
cardiovascular diseases  
and diabetes



# Health literacy Learning Matrix

2.2

Figure 2.3. Integrated conceptual framework for health literacy development



<sup>1</sup> Mother's knee is a concept where an infant learns about social practices and health-related information from the people caring for them, often while sitting on their knee.

# Five components of health literacy and the role each has in allowing people to effectively engage in healthy behavior

1. Accessing	2. Understanding	3. Appraising	4. Retrieving / remembering	5. Applying
<p>People have different preferred learning styles and need to access different sorts of information at different times:</p> <ul style="list-style-type: none"><li>• Foundational biological and disease concepts.</li><li>• For specific health issues need timely 'what to do', 'why to do' and 'how to do' information.</li></ul>				

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# A framework to understand the utility of current tools, and to plan development and implementation of health literacy and education programs.

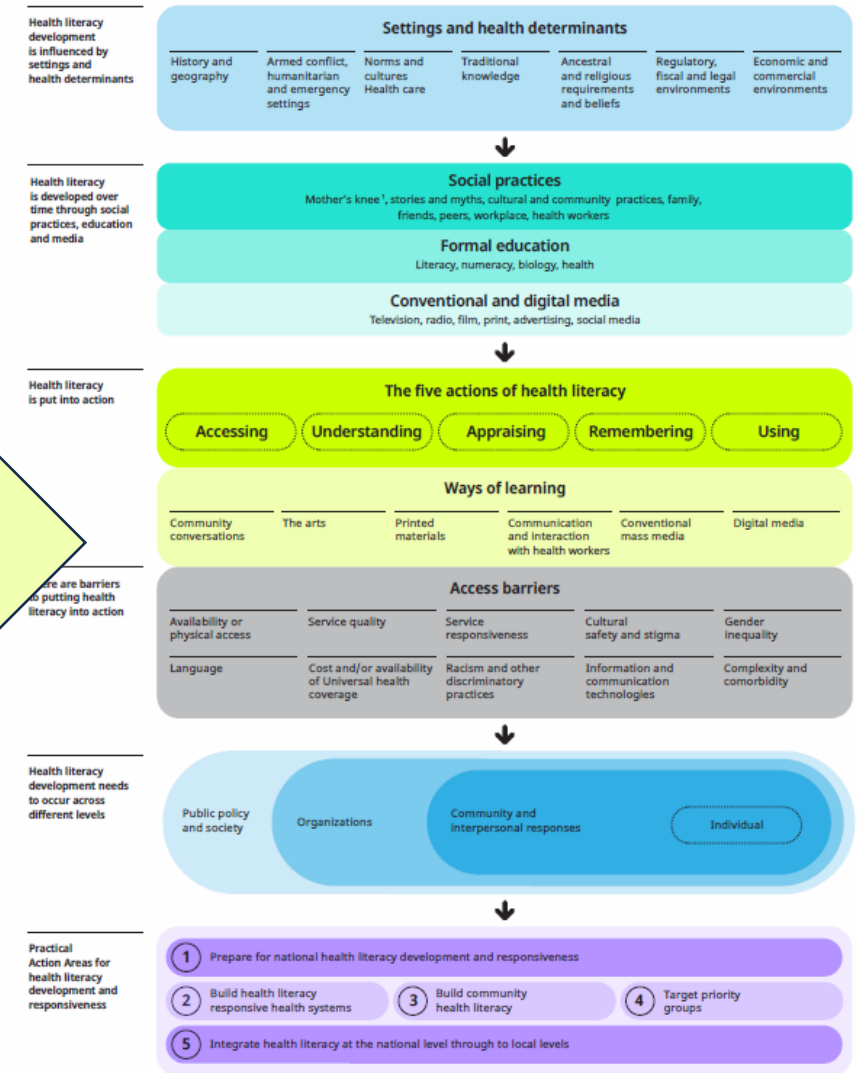
1. Printed materials (pamphlets, posters, written resources)
2. Talk with health staff
3. Media, TV, radio
4. Community conversations (friends, family neighbours, religious / community)
5. Internet, social media, apps, AI
6. Arts (songs, plays, paintings, drawings)

A well-considered mix of in for effective and scalable i

But how do people lo our complex messag

## 2.2

Figure 2.3. Integrated conceptual framework for health literacy development



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# Health Literacy Learning Matrix - Observations on the roles of modalities for the tasks in health knowledge work to impact on disease prevention and control































	1. Accessing	2. Understanding	3. Appraising	4. Retrieving / remembering	5. Applying
<b>1. Printed materials (pamphlets, posters, written resources)</b>	Limited value as the primary source for many people. More important for remembering.	Often applied but not helpful for low literate people.	Often applied but not helpful for low literate people.	High impact if materials kept in place that is accessible in the future when the need for the information arises.	High value for practical knowledge on how-to-do self-care tasks (e.g. recipes, exercise sheets).
<b>2. Talk with health staff</b>	Useful if person is able to get to see knowledgeable and communicative professional.	Often best way, especially if combined with other modes and with Teach-back.	Helpful if staff take time to explain.	Can assist with reminders. Health service recall/reminder systems.	Important to assist with problem-solving and to build confidence.
<b>3. Media, TV, radio</b>	Can be the only source of information. Main source in some rural/remote settings. Relevant to illiterate people and sometimes to minority language groups.	Strong method for many people. Effective if affected people discuss in narrative/interview formats. Declining youth engagement in these media.	Can be very valuable if it allows real people to share and discuss experiences (life stories, talk-back radio).	Most programs/media is one-off, but can provide repeated exposure to key messages to aid memory and to prompt action.	Can assist people to know how to use health services. Practical advice and examples.
<b>4. Community conversations (friends, family, neighbours, religious and community leaders)</b>	Word of mouth among peers and intergenerational transfer of information. Only method for some groups.	Particularly important in working out what it would mean to translate advice into action. Can also leading to misunderstanding (e.g., myths about vaccines causing MS).	Highly and consistently important. The work of deciding what to believe and what is relevant and feasible occurs through discussion with family and friends.	Family and group processes can assist in making actions routine. Family, friends, colleagues often remind and prompt each other.	Friends influence how health actions are applied and sustained. A sources of practical ideas and problem solving from within local contexts
<b>5. Internet, social media, apps, AI</b>	Useful if person or family have devices. People who are socially isolated or remote can be informed about access options.	Useful if devices accessible. Can be primary source of understanding. Can introduce erroneous information.	Social media can be a substitute community but this can also be a source of misinformation and confusion. Some apps are good personal planning tools.	Highly useful. Wide use of recall and reminders for NCD management. Can support regular monitoring.	Useful if have access to devices. Can facilitate remote healthcare, accurate use of strategies, monitoring and motivation.
<b>6. Arts (songs, plays, paintings, drawings)</b>	Can overcome language, literacy and other learning barriers.	Some people are visual or narrative etc learners, thus helps catch attention and easier to remember.	Can help make ideas and strategies relevant and feasible.	Embedded community art and music can provide reminders and prompts with positive associations.	Can provide examples of simple practical action undertaken in familiar local contexts.

# Health Literacy Learning Matrix - Observations on the roles of modalities for the tasks in health knowledge work to impact on disease prevention and control

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## Health Literacy learning Matrix:

Hypothetical observations on the roles of different health literacy tasks in generating impact on individuals and groups

Consider people with low health literacy	1. Accessing	2. Understanding	3. Appraising	4. Retrieving / remembering	5. Applying
1. Printed materials (pamphlets, posters, written health resources)					
2. Talk with health staff					
3. Media, TV, radio					
4. Community conversations (friends, neighbours, family, colleagues)					
5. Internet, social media, apps, AI					
6. Arts (songs, plays, paintings, drawings)					

# Health literacy tasks

	1. Accessing	2. Understanding	3. Appraising	4. Retrieving / remembering	5. Applying
1. Printed materials (pamphlets, brochures, written materials)	Limited value as the primary source for many people. More important for remembering.	Often applied but not helpful for low literate people.	Often applied but not helpful for low literate people.	High impact if materials kept in place that is accessible in the future when the need for the information arises.	High value for practical knowledge on how-to-do self-care tasks (e.g. recipes, exercise sheets).
2. Talk with health staff	Useful if person is able to get to see knowledgeable and communicative professional staff.			Can assist with reminders. Health reminder systems.	Important to assist with problem-solving and to build confidence.
3. Media (radio, TV, newspapers, magazines)	Can be the only source of information. Mainly for rural/remote settings. Useful for illiterate people and minority language groups.			Media is one-off, repeated exposure needed for memory and recall.	Can assist people to know how to use health services. Practical advice and examples.
4. Community conversations (family, friends, religious leaders, community groups)	Word of mouth and intergenerational information. Common in some groups.			Community conversations can be routine. People often learn from each other.	Friends influence how health actions are applied and sustained. A source of practical ideas and problem solving from within local contexts
5. Internet (websites, apps, social media)	Useful if person or family has access to devices. People who are isolated or remote can be informed about access options.			Can facilitate use of recall and management. Support regular monitoring.	Useful if have access to devices. Can facilitate remote healthcare, accurate use of strategies, monitoring and motivation.
6. Arts (songs, plays, paintings, posters)	Can overcome language, literacy and other learning barriers.	Some people, such as low literacy learners, thus attract attention and easier to remember.	Some people, such as low literacy learners, thus attract attention and easier to remember.	Embedded community art and music can provide reminders and prompts with positive associations.	Can provide examples of simple practical action undertaken in familiar local contexts.

How people learn

Daily health literacy skills and ability  
By individuals and/or by, with and for, the people around them

# Thank you



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