Digital Health Literacy
a starting point for digital health equity and systems reform

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We are leaving people behind because…

- There is a fundamental disconnect between how we **develop programs or interventions, and the way they are received by the members of community**.
- **As a result of this disconnect**, when we evaluate how effective interventions are, we find they are often weak, are not reproducible, and don't even seek to reach segments of the population.
- Many programs are designed for 'Mr and Ms Average' – consequently many people are left behind.
- The disconnect comes from no, or inadequate, inclusion of stakeholders in the development of the intervention and how it is operationalized.
- The Ophelia (OPtimise 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.

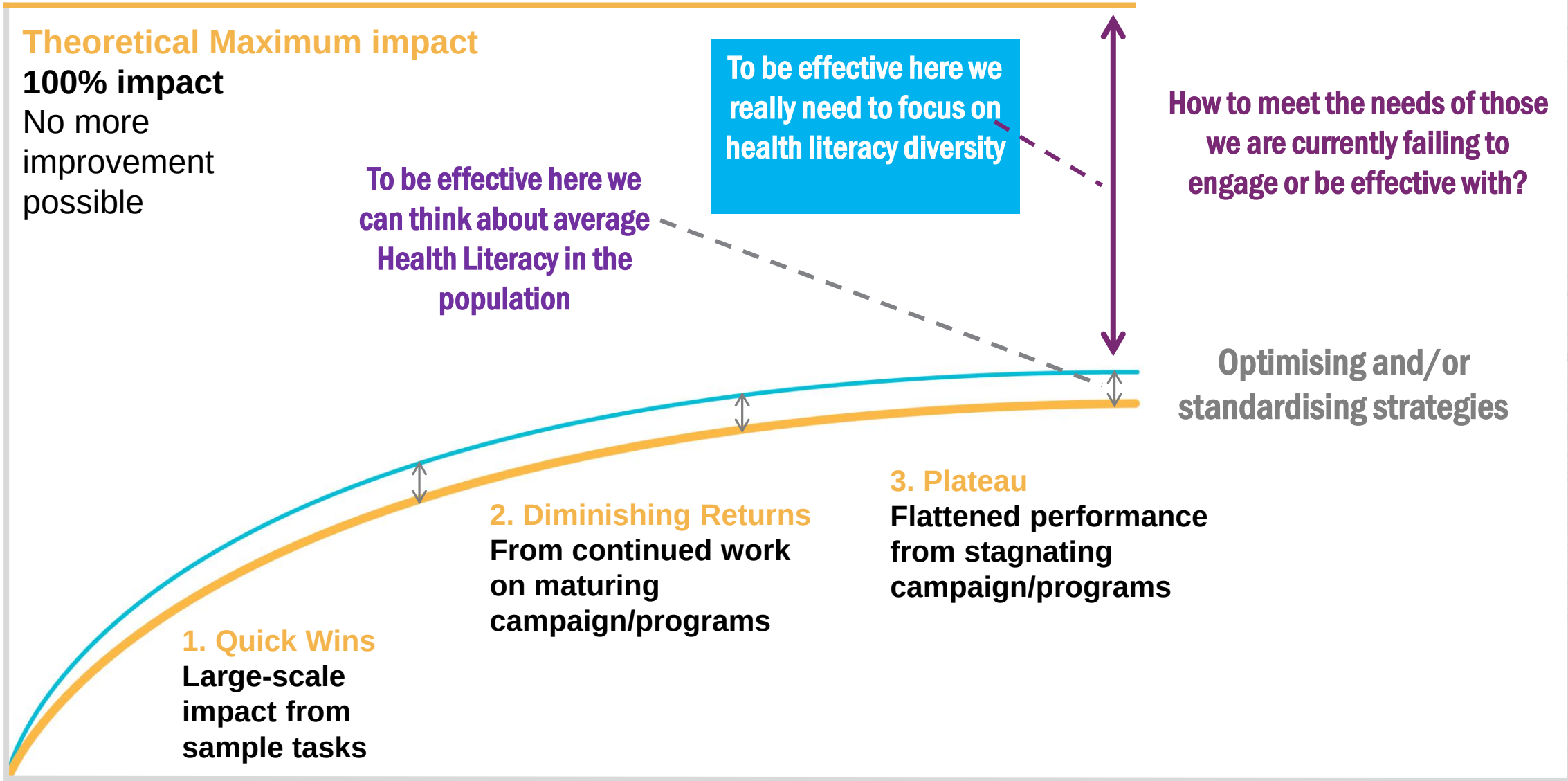
Can we ensure that the interventions we select or develop are not…

- Weak
- Only suitable for easy to find ‘average’ patients / highly empowered people
- Hard to implement in the real world
- Disappear when the ‘project’ stops

Projects can “look good”, have fashionable theory, be trendy, be pushed by a powerful person/impressive funding…

– **but are not really wanted, not scalable, and not sustainable**

Why are our interventions not reaching or effective with everyone?

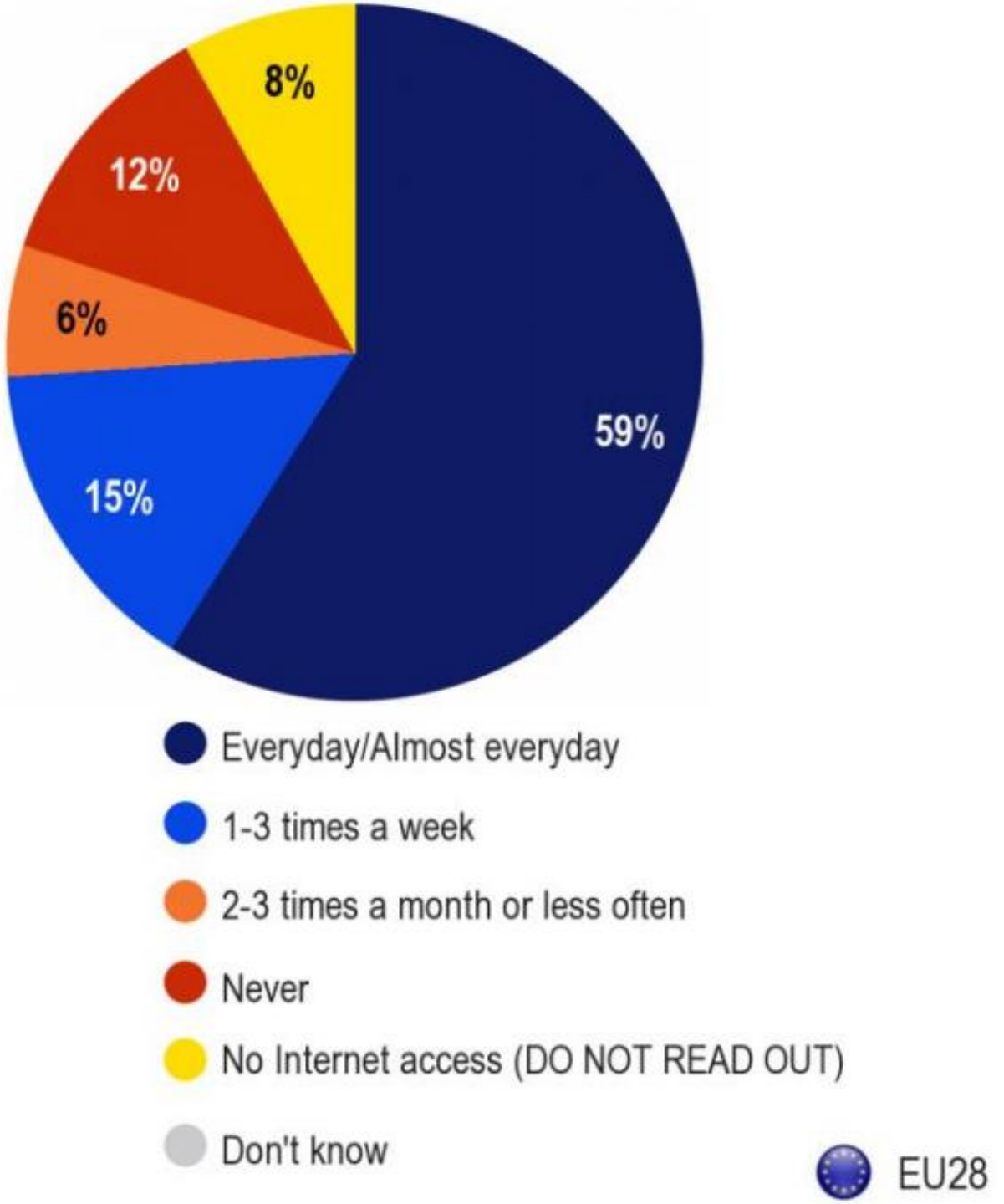


European Citizens Digital Health Literacy, Flash Eurobarometer 404, European Commission, 2014 (N=26,566)

Q1 On average, within the last 12 months,
How often have you used the Internet for
private purposes?

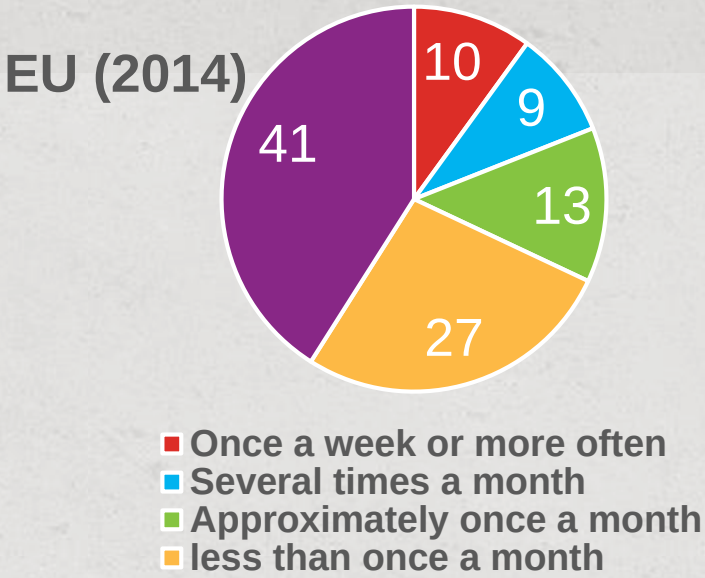
One person in five (20%) never used the Internet, including 8% who spontaneously say that they have no Internet access.

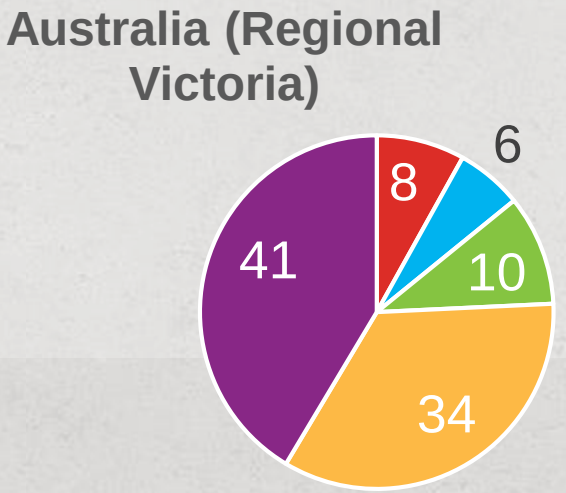
https://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_404_sum_en.pdf



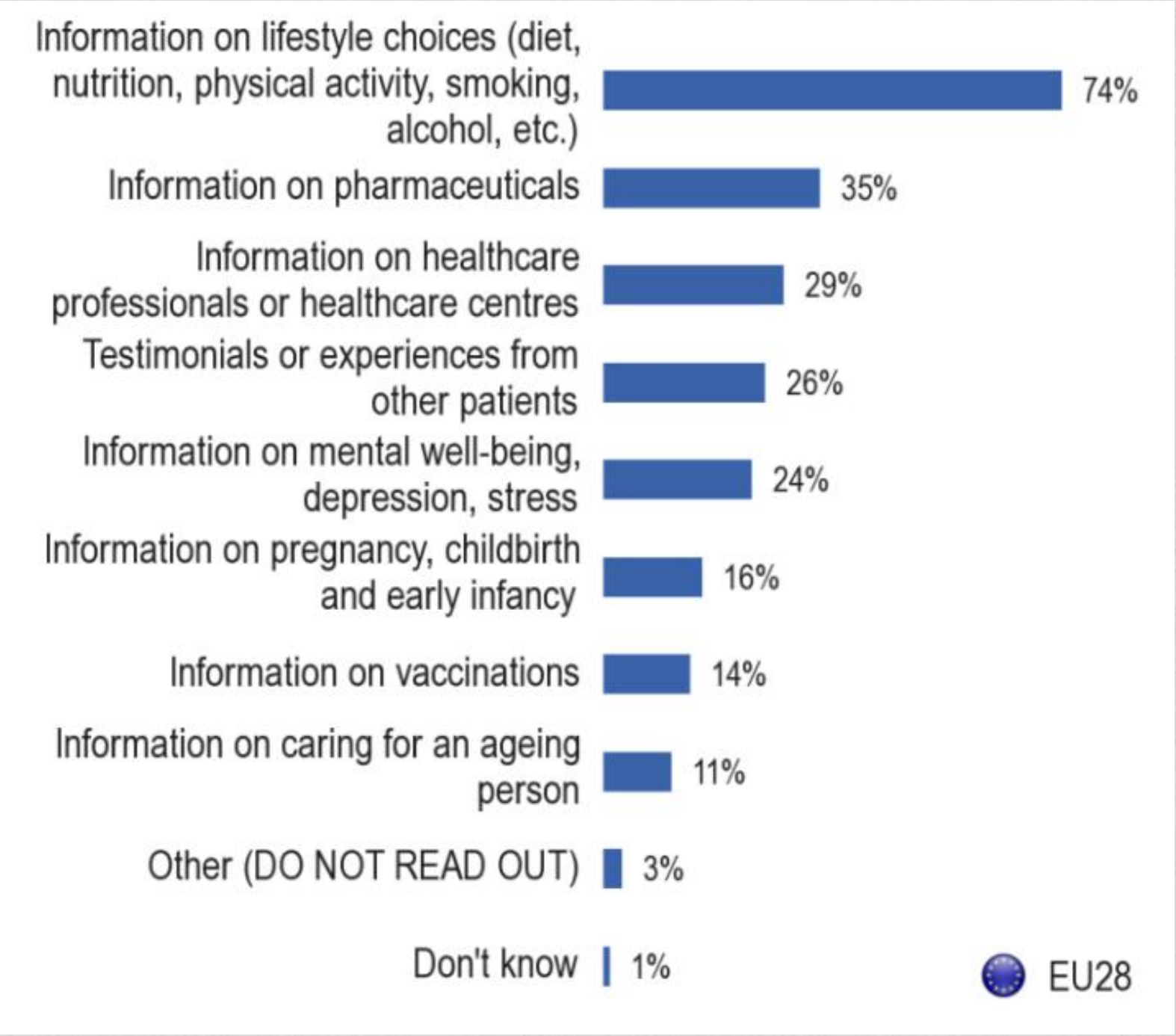
About 60% of people are accessing health information via the web

- This is the majority
  - Should we congratulate ourselves?
- Important questions
  - Who are they?
  - What do they access?
  - Does the information help or hinder?





Q4. More specifically, when trying to access general information on health-related topics or ways to improve your health, which of the following types of information did you look at? (multiple answers possible)



Some questions about digital data access:

- Among those people accessing information for health: do they understand it
  - 60% were broadly satisfied with the information they found
  - 25% agree that after looking online for health-related information they generally feel more confused than before.

- Unknown whether the health information accessed improved behaviour beyond their intentions/exiting knowledge

Research findings:
Low health literacy has been associated with...

- higher prevalence of health risk factors
- low participation in prevention activities
- poorer overall health status
- lower functional status
- poorer self-management of chronic diseases
- less effective communication with health care professionals
- poorer medication adherence and increased adverse medication events
- increased health care costs
- poorer disease outcomes
- increased hospital admissions and readmissions
- increased death/mortality

Health Literacy…
it is the concept, rather than the terminology, that's is the important thing..

Health literacy is how people come to…

- **think what they think,**
- **believe what they believe, and**
- **decide what they decide… about health.**

It is our job to understand what information and support people, their families, and communities as a whole need for health actions.

Health Literacy: several definitions

Largely health services

- An individual's overall capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (US Institute of Medicine)
- The capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health enhancing (UK National Consumers Council)

Broad range of public health settings

- **Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health (World Health Organization, 1988)**
- "Health literacy is the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena" (Kickbusch, 2001)
- People's competences to access, understand, appraise and apply information to make health decisions in everyday life throughout the life course (Sorensen et al 2011)

In practice, health literacy is:

The characteristics of the person + the things they need, such as

Skills	Knowledge	Motivation	Beliefs	Confidence	Resources	Supports

to…

1. Access	2. Understand	3. Appraise	4. Retrieve / remember	5. Use

…information and services to make decisions about their health and the health of their family and community

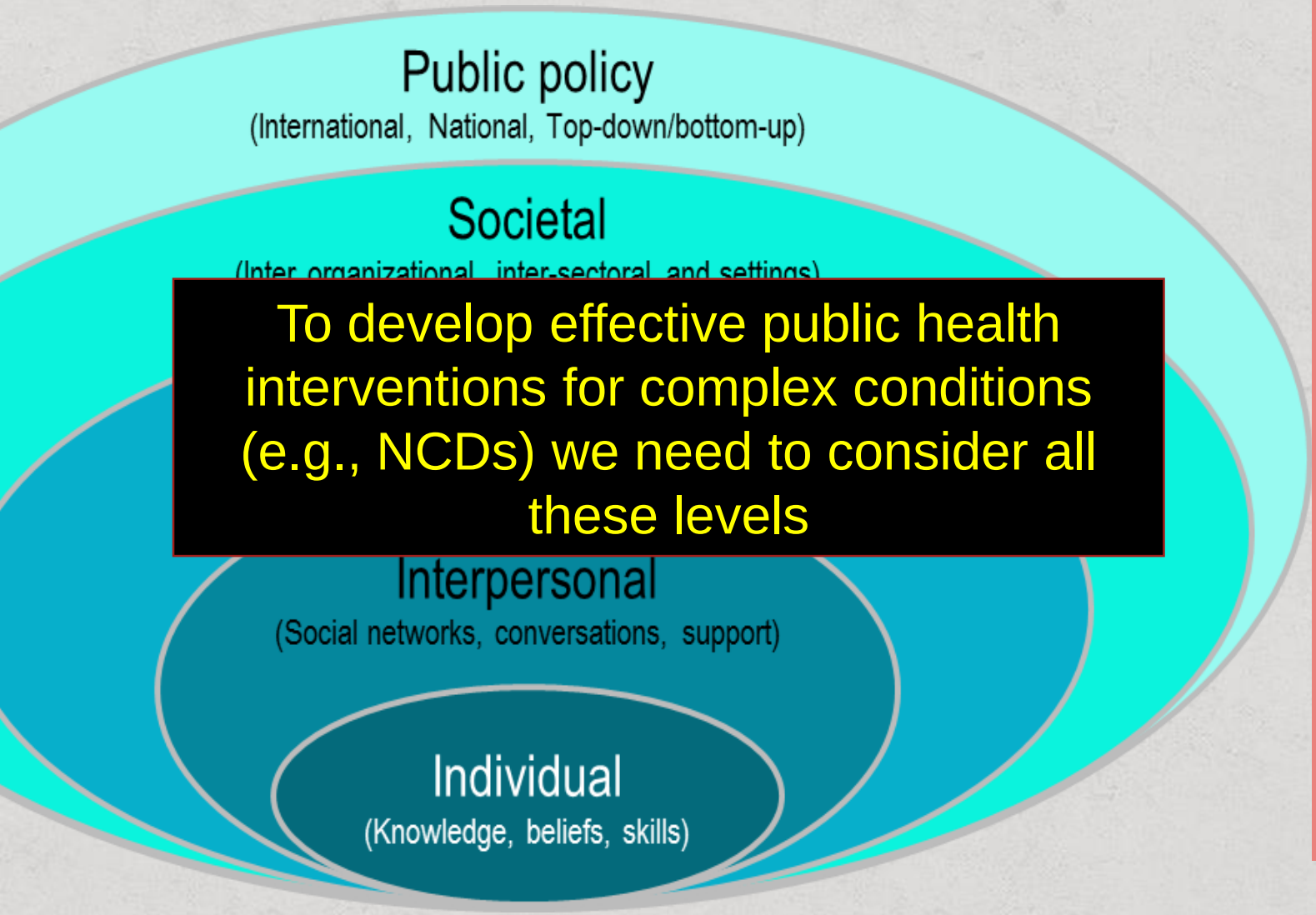
What is a health literacy approach?

1. Access	2. Understand	3. Appraise	4. Retrieve / remember	5. Use

A health literacy approach is where we ask questions like:

- **What patterns of health literacy strengths do people have**, especially those who we are not being effective with or are not reaching?
- What strategies are available to us to work with people with low health literacy? [including the critical role of community conversations]
- **How can we implement strategies** for the people with the lowest health literacy in the community or with people with special health literacy needs?
- **How can we assist health professionals** to use careful and sensitive assessments and to use different strategies based on people's needs?

Health Literacy - an ecological framework



To develop effective public health interventions for complex conditions (e.g., NCDs) we need to consider all these levels

The ecological framework gives us a basis for considering health literacy effects and interventions at many levels.

Specifically:

1. The **individual** level
2. The level of local **social networks** and communities
3. The **organizational level** with an emphasis on health services and health promotion organizations
4. **Inter-sectoral** roles
5. The **population and policy level**

Health service responsiveness and access to healthcare

A person from the community….

Approaches a health service

Receives a s

Service is responsive to needs

Fully engages with providers/ fully understands own health needs

Note: The worse a healthcare system performs, the higher a person's health literacy needs to be

Examples of health literacy barriers	Problem seen as….
• Little knowledge about entitlement to service	People not accessing the service
• v the service Difficulty explaining needs to intake workers	Large numbers of clients 'do not attend'
• Services don't tailor what they do to individual patients' learning needs or styles	Clients drop out; outcomes not achieved
• Providers unaware that patients are not able to put knowledge into practice – may lead to frustration and lack of trust	Fail to establish rapport or fully participate in own care

Health Literacy Questionnaire: Developed using a grounded approach

Thinking about your experiences in trying to look after your health (or that of your family), what does a person need to be able to get and use all of the information they need?

Best practice in concept development / questionnaire development

1. Brainstorming session
2. Sorting and rating of statements
3. Multivariate analysis
4. Interpretation of maps

Health Literacy Questionnaire

HLQ: Health Literacy Questionnaire (dimensions)

1. Feeling understood and supported by healthcare providers	6. Ability to actively engage with healthcare providers
2. Having sufficient information to manage my health	7. Navigating the healthcare system
3. Actively managing my health	8. Ability to find good health information
4. Social support for health	9. Understand health information well enough to know what to do
5. Appraisal of health information	

What is Health Literacy?
The Health Literacy Questionnaire (HLQ)

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Early feedback from primary care

Richard, these are the things doctors hate most about their patients…

(Prof Trish Greenhalgh, Oxford, UK)

1. Feeling understood and s… healthcare providers

- I can rely on at least one h…

2. Having sufficient inf… manage my health

- I am sure I have all the i… manage my health effect…

3. Actively managing m…

- I make plans for what I nee… healthy

4. Social support for health

- I have at least one person who can c… medical appointments with me

5. Appraisal of health information

- When I see new information about health, I check up on whether it is true or not

…o actively engage with …roviders

…with healthcare providers until …all you need to

…he healthcare system

…s the best care for you

…healthcare provider you need to

…y to find good health information

Get health information in words you understand

9. Understand health information well enough to know what to do

Psychometric properties of the English, French, Danish, German, Slovakian, (Dutch, Norwegian) HLQ… very strong

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Original Article

Characterisation of health literacy strengths and weakness… people at…

SAGE Open Medicine

PLOS ONE

RESEARCH ARTICLE

German translation, cultural adaptation, and validation of the Health Literacy Questionnaire (HLQ)

Sandra Nolte[1,2]*, Richard H. Osborne[2], Sarah Dwinger[3], Gerald R. Elsworth[2], Melanie L. Conrad[1], Matthias Rose[1,4], Martin Härter[3], Jörg Dirmaier[3], Jördis M. Zill[3]

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Abstract

The Health Literacy Questionnaire (HLQ), developed in Australia in 2012 using a 'validity-driven' approach, has been rapidly adopted and is being applied in many countries and languages. It is a multidimensional measure comprising nine distinct domains that may be used for surveys, needs assessment, evaluation and outcomes assessment as well as for informing service improvement and the development of interventions. The aim of this paper is to describe the German translation of the HLQ and to present the results of the validation of the culturally adapted version. The HLQ comprises 44 items, which were translated and culturally adapted to the German context. This study uses data collected from a sample of 1,058 persons with chronic conditions. Statistical analyses include descriptive and confirma-

OPEN ACCESS

Citation: Nolte S, Osborne RH, Dwinger S, Elsworth GR, Conrad ML, Rose M, et al. (2017) German translation, cultural adaptation, and validation of the Health Literacy Questionnaire (HLQ). PLoS ONE 12(2): e0172340. doi:10.1371/journal.pone.0172340

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Quality of Life Research (2018) 27:1695–1710
https://doi.org/10.1007/s11136-018-1815-6

SPECIAL SECTION: TEST CONSTRUCTION (BY INVITATION ONLY)

CrossMark

Application of validity theory and methodology to patient-reported outcome measures (PROMs): building an argument for validity

Melanie Hawkins[1] · Gerald R. Elsworth[1] · Richard H. Osborne[1,2]

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Abstract

Background Data from subjective patient-reported outcome measures (PROMs) are now being used in the health sector to make or support decisions about individuals, groups and populations. Contemporary validity theorists define validity not as a statistical property of the test but as the extent to which empirical evidence supports the interpretation of test scores for an intended use. However, validity testing theory and methodology are rarely evident in the PROM validation literature. Application of this theory and methodology would provide structure for comprehensive validation planning to support improved PROM development and sound arguments for the validity of PROM score interpretation and use in each new context.

Objective This paper proposes the application of contemporary validity theory and methodology to PROM validity testing.

Illustrative example The validity testing principles will be applied to a hypothetical case study with a focus on the interpretation and use of scores from a translated PROM that measures health literacy (the Health Literacy Questionnaire or HLQ).

Discussion Although robust psychometric properties of a PROM are a pre-condition to its use, a PROM's validity lies in the sound argument that a network of empirical evidence supports the intended interpretation and use of PROM scores for decision making in a particular context. The health sector is yet to apply contemporary theory and methodology to PROM development and validation. The theoretical and methodological processes in this paper are offered as an advancement of the theory and practice of PROM validity testing in the health sector.

Summary of requirements

People with diverse health literacy and learning styles

Matching mechanisms

1. Means for assessing health literacy:
   - Level
   - Strengths and limitations
2. Evidence relating strategies to HL strengths and limitations
3. Participatory process for planning for…
   - Individuals
   - Groups
4. Flexible service delivery and support systems

Range of evidence-based strategies to respond

What is Health Literacy?
The Health Literacy Questionnaire (HLQ)

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1. Feeling understood and supported by healthcare providers

- I can rely on at least one healthcare provider

2. Having sufficient information to manage my health

- I am sure I have all the information I need to manage my health effectively

3. Actively managing my health

- I make plans for what I need to do to be healthy

4. Social support for health

- I have at least one person who can come to medical appointments with me

5. Appraisal of health information

- When I see new information about health, I check up on whether it is true or not

6. Ability to actively engage with healthcare providers

- Discuss things with healthcare providers until you understand all you need to

7. Navigating the healthcare system

- Work out what is the best care for you
- Decide which healthcare provider you need to see

8. Ability to find good health information

- Get health information in words you understand

9. Understand health information well enough to know what to do

- Read and understand all the information on

What about the measurement of eHealth literacy?

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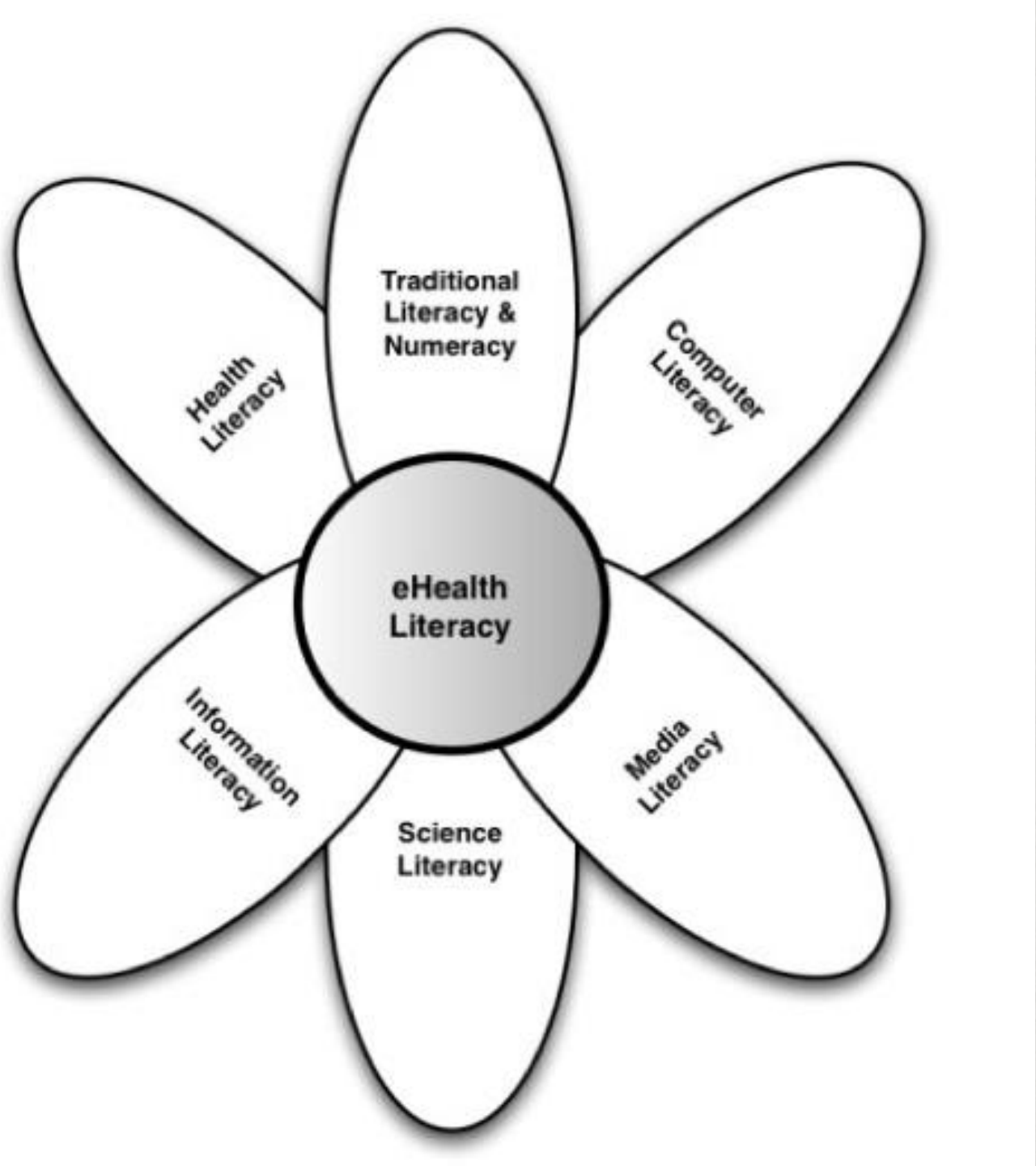
e-Health Literacy

An individual's ability to search for, successfully access, comprehend, and appraise desired health information from electronic sources and to then use such information to attempt to address a particular health problem

Norman & Skinner, 2006, JMIR

e-Health Literacy



Norman & Skinner, 2006, JMIR

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Tools to measure health literacy

eHealth Literacy specific	Health literacy + eHealth literacy
eHEALS	3 questions… Lin et al. 2014
eHLS (Hsu, Chiang, & Yang, 2014)	3 questions + other Mayberry, Kripalani, Rothman, and Osborn, 2011
PRE-HIT (Koopman et al., 2014).	Interactive Health Communication Application (IHCA) van der Vaart, Drossaert, Taal, and van de Laar , 2011
Digital health literacy tool (van der Vaart, 2017)	
eHLQ (Kayser et al, 2018)	

eHealth Literacy Model Development

Link to Pdf

Knowledge Management & E-Learning, Vol.7, No.4. Dec 2015

Knowledge Management & E-Learning

ISSN 2073-7904

The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems

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Global E-consultation for e-health literacy

- **Consultation: 22 Countries**
  - Australia, Austria, Belgium, Canada, Denmark, France, Germany, India, Japan, New Zealand, Norway, Saudi Arabia, Singapore, South Korea, Spain, Sweden, Switzerland, Taiwan, The Netherlands, Turkey, United Kingdom and USA
- **Respondents**
  - 136 people providing **1,144 statements**
  - reduced to **65 statements for field testing**

Understanding and measuring digital health literacy from the perspective of stakeholders

Thinking about citizens' experiences in trying to look after their health (or the health of their family), what does a person need to be able to do in order to use digital health services?

Best practice in concept development / questionnaire development

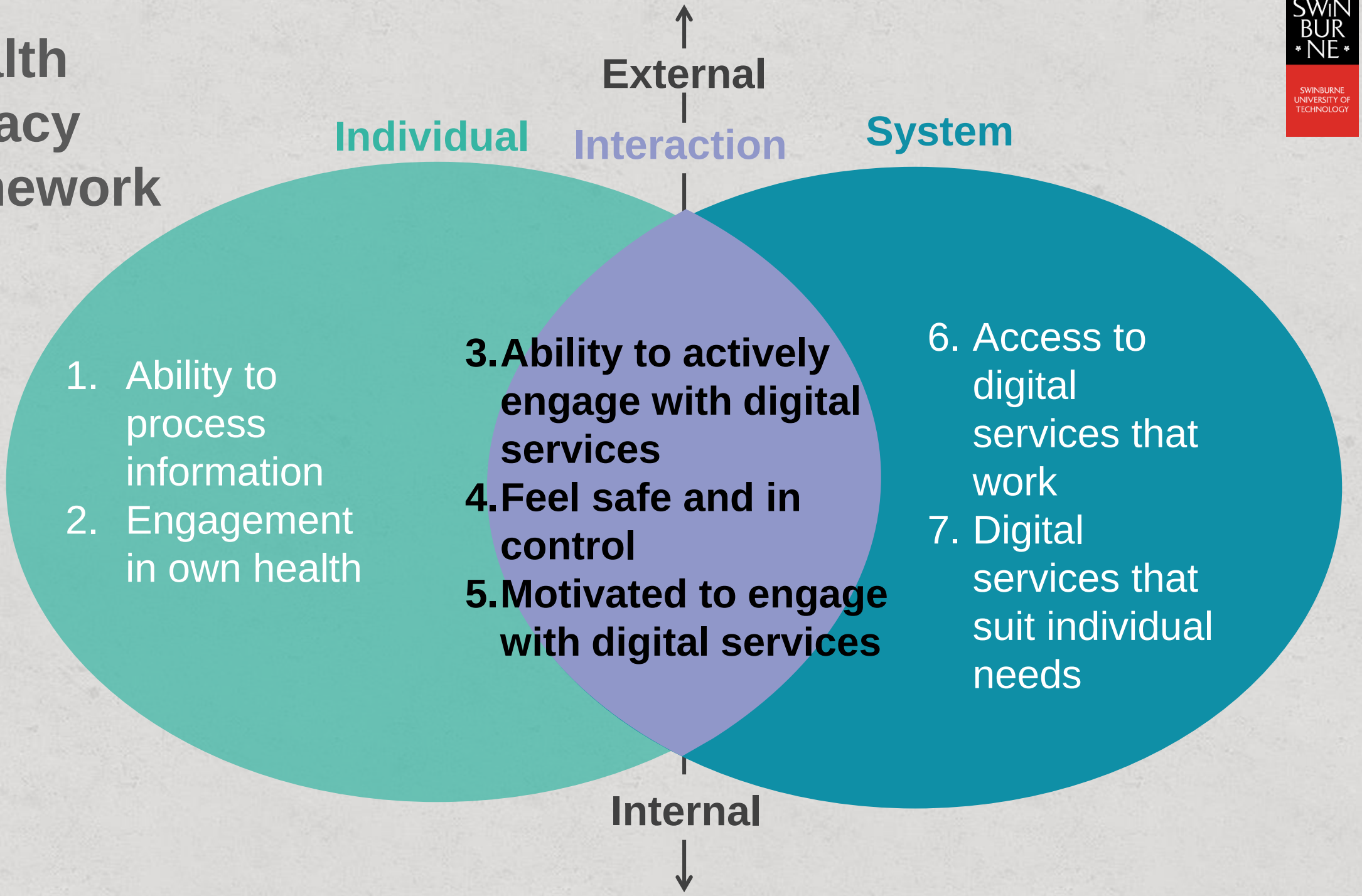
1. Brainstorming session
2. Sorting and rating of statements
3. Multivariate analysis
4. Interpretation of maps

Concept mapping
A structured process to capture the knowledge of patients, practitioners, and policy makers

eHLQ: e-Health Literacy Questionnaire (dimensions)

1. Ability to process information	**5.** Motivated to engage with digital services
2. Engagement in own health	**6.** Access to digital services that work
3. Ability to actively engage with digital services	**7.** Digital services that suit individual needs

eHealth Literacy Framework



Published on 12.02.18 in Vol 20, No 2 (2018): February

This paper is in the following e-collection/theme issue:

eHealth Literacy Research Instruments, Questionnaires, and Tools

Original Paper

A Multidimensional Tool Based on the eHealth Literacy Framework: Development and Initial Validity Testing of the eHealth Literacy Questionnaire (eHLQ)

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eHLQ

https://www.jmir.org/2018/2/e36/

Domain names and descriptors of the eHLQ

1. Ability to process information

Able 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. Know when, how and what information to use.

2. Engagement in own health

Know 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 as well as navigating the health care system.

3. Ability to actively engage with digital services

Being comfortable using digital services for handling information.

4. Feel safe and in control

Feel that you have the ownership of personal data stored in the systems and that the data are safe and can be accessed only by people to whom they are

5. Motivated to engage with digital services

Feel that engaging in the use of digital services will be useful for them in managing their health.

6. Access to digital services that work

Have access to digital services that the users trust to be working when they need it and as they expect it to work.

7. Digital services that suit individual needs

Have access to digital services that suit the specific needs and preferences of the users. This includes responsive features of both IT and the health care system (including carers) as well as adaptation of devices and interfaces to be used by people with physical and mental

eHLQ

Please indicate how strongly you **disagree** or **agree** with each of the following statements.

Please check only one box per statement by crossing it like this: ☒

		Strongly Disagree	Disagree	Agree	Strongly Agree
1	I am sure that my health data are being used only by those who are supposed to use it	☐	☐	☐	☐
2	Technology makes me feel actively involved with my health	☐	☐	☐	☐
3	Information about my health is always available to those who need it	☐	☐	☐	☐
4	I know how to use technology to get the health information I need	☐	☐	☐	☐
5	The knowledge I have helps me to have good conversations about health	☐	☐	☐	☐
6	I know how to make technology work for me	☐	☐	☐	☐
7	I use technology to find information about health	☐	☐	☐	☐
8	I can enter data into health technology systems	☐	☐	☐	☐
9	My healthcare providers deliver services that I can access through	☐	☐	☐	☐

eHLQ: scales 3 and 5

Domain 3. Ability to actively engage with digital services

1. I know how to use technology to get the health information I need
2. I know how to make technology work for me
3. I can enter data into health technology systems
4. I quickly learn how to find my way around new technology
5. I easily learn to use new health technologies

Domain 5. Motivated to engage with digital services

1. Technology makes me feel actively involved with my health
2. I find technology helps me to take care of my health
3. I find I get better services from my health professionals when I use technology
4. Technology improves my communication with health professionals
5. I find technology useful for monitoring my health

eHLQ: levels of application

Places where eHLQ used (Yellow)

1. Provide insight into the maturity of a country's digital services
2. Evaluation of interventions
3. Implementation and adoption of digital health services
   - why digital health services implementations work or fail
4. Community and population surveys
5. Framework would support commissioning and purchasing of products / services
6. eOphelia
   - eHLQ + HLQ + heiQ + other

Intervention development that responds to individual, community, organisational and policy needs

Problem

- **I cannot** go to the literature to get Health Literacy interventions… there is nothing there that will fit my clinic/ community/ culture

Realisation

- There is nothing new in health literacy, it is what **great** frontline practitioners and community members do each day

Solution

- Work with frontline practitioners, managers and service users/patients to capture their experiential knowledge and wisdom
- Use data and experiences from ‘usual’ patients

ophelia VICTORIA
Optimising health literacy to improve health and equity

Australian Research Council Linkage Grant (2012-2015)

Investigators

- Richard Osborne
- Rachelle Buchbinder
- Roy Batterham
- Alison Beauchamp
- Sarity Dodson
- Brad Astbury
- Gerald Elsworth

Partners – Victorian Government

1. Home and Community Care (HACC)
2. Primary Care
3. Hospital Admissions Risk Program (HARP)

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DEAKIN UNIVERSITY AUSTRALIA Worldly

MONASH University
Medicine, Nursing and Health Sciences

Australian Government
Australian Research Council

State Government Victoria

hacc
home and community care

Ophelia

Ophelia aims to improve health outcomes and reduce health inequalities by:

Empowering health and community services to understand, prioritise and take action – to be responsive to clients with varying health literacy strengths and needs.

Developed in partnership with 9 organisations in Victoria

Ophelia means

Optimizing
Health
Literacy and
Access to health information and services

Ophelia protocol

The protocol draws on three discourses:

1. Intervention mapping
2. Quality improvement collaboratives
3. Realist evaluation thinking

http://www.biomedcentral.com/1471-2458/14/694

Batterham et al. BMC Public Health 2014, 14:694
http://www.biomedcentral.com/1471-2458/14/694

BMC Public Health

STUDY PROTOCOL Open Access

The OPtimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform

Roy W Batterham[1], Rachelle Buchbinder[2,3], Alison Beauchamp[1,3], Sarity Dodson[1], Gerald R Elsworth[1] and Richard H Osborne[1*]

Abstract

Background: Health literacy is a multi-dimensional concept comprising a range of cognitive, affective, social, and personal skills and attributes. This paper describes the research and development protocol for a large communities-based collaborative project in Victoria, Australia that aims to identify and respond to health literacy issues for people with chronic conditions. The project, called Ophelia (OPtimising HEalth LIterAcy) Victoria, is a partnership between two universities, eight service organisations and the Victorian Government. Based on the identified issues, it will develop and pilot health literacy interventions across eight disparate health services to inform the creation of a health literacy response framework to improve health outcomes and reduce health inequalities.

Methods/Design: The protocol draws on many inputs including the experience of the partners in previous co-creation and roll-out of large-scale health-promotion initiatives. Three key conceptual models/discourses inform the protocol: intervention mapping; quality improvement collaboratives, and realist synthesis. The protocol is outcomes-oriented and focuses on two key questions: 'What are the health literacy strengths and weaknesses of clients of participating sites?', and 'How do sites interpret and respond to these in order to achieve positive health and equity outcomes for their clients?'. The process has six steps in three main phases. The first phase is a needs assessment that uses the Health Literacy Questionnaire (HLQ), a multi-dimensional measure of health literacy, to identify common health literacy needs among clients. The second phase involves front-line staff and management within each service organisation in co-creating intervention plans to strategically respond to the identified local needs. The third phase will trial the interventions within each site to determine if the site can improve identified limitations to service access and/or health outcomes.

Discussion: There have been few attempts to assist agencies to identify, and respond, in a planned way, to the varied health literacy needs of their clients. This project will assess the potential for targeted, locally-developed health literacy interventions to improve access, equity and outcomes.

Keywords: Health literacy, Equity, Chronic illness, Access, Implementation, Intervention development, Intervention

Ophelia's Principles

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

3 phases of Ophelia

Phase 1:
Identify health literacy strengths & needs

- Collect health literacy and other data from community members/ clients
- Explore results (as vignettes/patient stories) in workshops to generate intervention ideas

Phase 2:
Co-design health literacy interventions

- Stakeholders identify which interventions have potential to address local health literacy needs or improve outcomes

Phase 3:
Apply interventions; evaluate on an ongoing basis

- Health literacy interventions are applied and evaluated (in quality improvement cycles)

How do we measure health literacy strengths and weaknesses to understand patients and the community?

1. Access	2. Understand	3. Appraise	4. Retrieve / remember	5. Use

Health literacy (and eHealth Literacy) is multi-dimensional, so:

- We use a questionnaire that is **sensitive to the different patterns of strengths and weaknesses** that people may have
- Understanding health literacy, especially people ***'missing out or we are not being effective with'*** informs intervention development
- **What exactly are the strengths and weaknesses?**

Understanding health literacy data – good and poor methods

The HLQ has nine individual scales								
1	2	3	4	5	6	7	8	9
Health provider support	Have enough info	Actively manages health	Social support for health	Appraisal health info	Active engage with HP	Navigate health services	Find good health info	Understand health info for action
3.4	3.1	2.8	3.8	2.4	4.3	3.4	3.2	4.5

Response Options:

Strongly disagree = 1

Strongly Agree = 4

Response Options:

Cannot do or always difficult = 1

Always easy = 5

Benchmarks? Cut offs?

The HLQ has nine individual scales

1	2	3	4	5	6	7	8	9
Health provider support	Have enough info	Actively manages health	Social support for health	Appraisal health info	Active engage with HP	Navigate health services	Find good health info	Understand health info for action
High	Mod	Low	Very high	Very low	High	Low	Very low	Very high

Response Options:

Strongly disagree = 1

Strongly Agree = 4

Response Options:

Cannot do or always difficult = 1

Always easy = 5

Going beyond the average – health literacy diversity

In any given groups of patients, there will be different patterns of health literacy needs and strengths

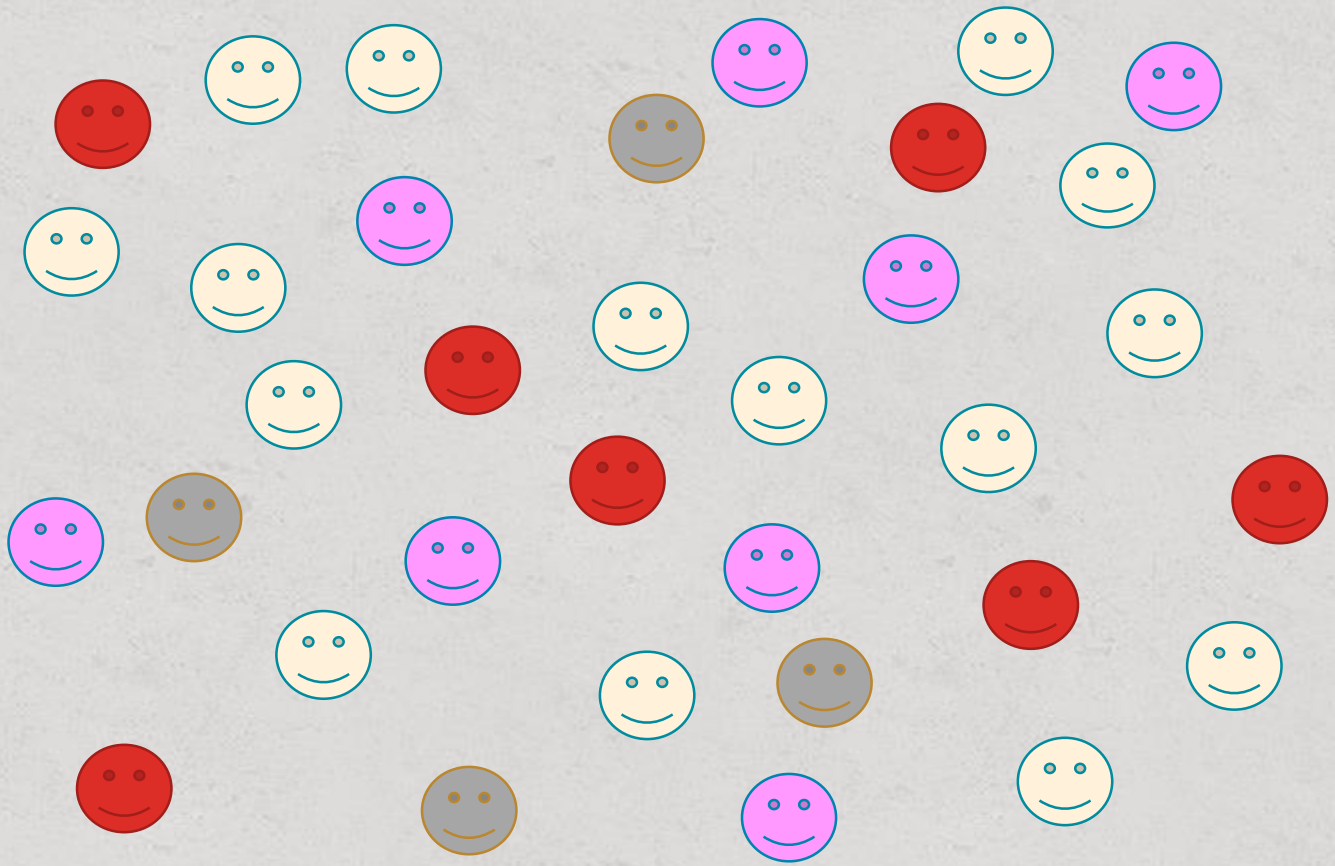
- For example, several people in your patient population may:
  - *Be confident in their health literacy skills but aren't that interested in their health*

    Others may:
    - *Deeply trust their doctor and see them as the font of wisdom, but find information hard to find, read and understand*

    Others may:
    - *Not trust the doctor at all and prefer to find their own information about health*

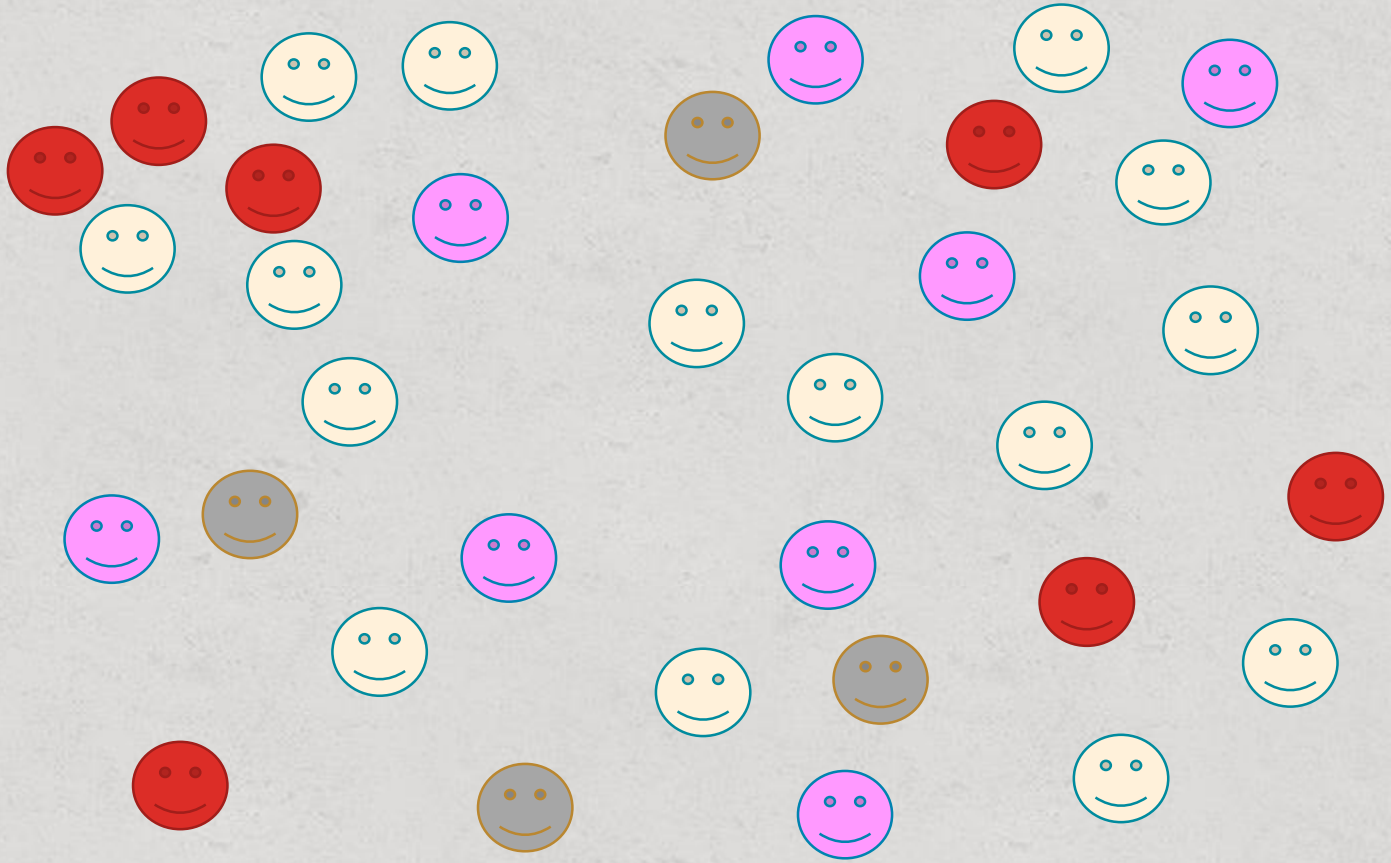
We can use Cluster Analysis for identify subgroups of individuals with similar patterns of HLQ scale scores

Each colour represents one person with **a particular eHLQ** set of scores across each of the 9 scales



Cluster analysis groups questionnaire respondents into groups with similar scores on each of the 9 scales

Each colour represents one person with **a particular eHLQ** set of scores across each of the 9 scales



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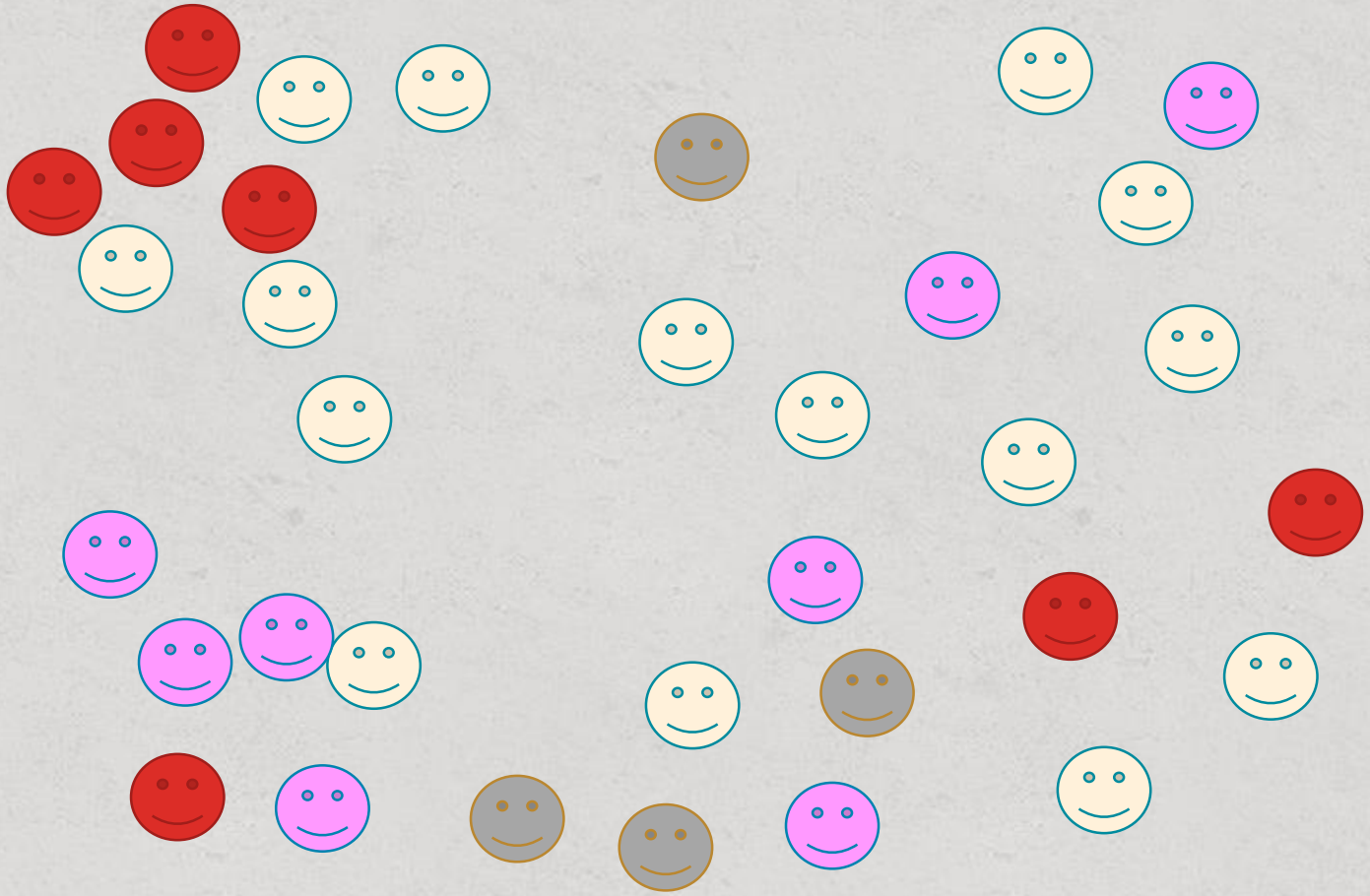

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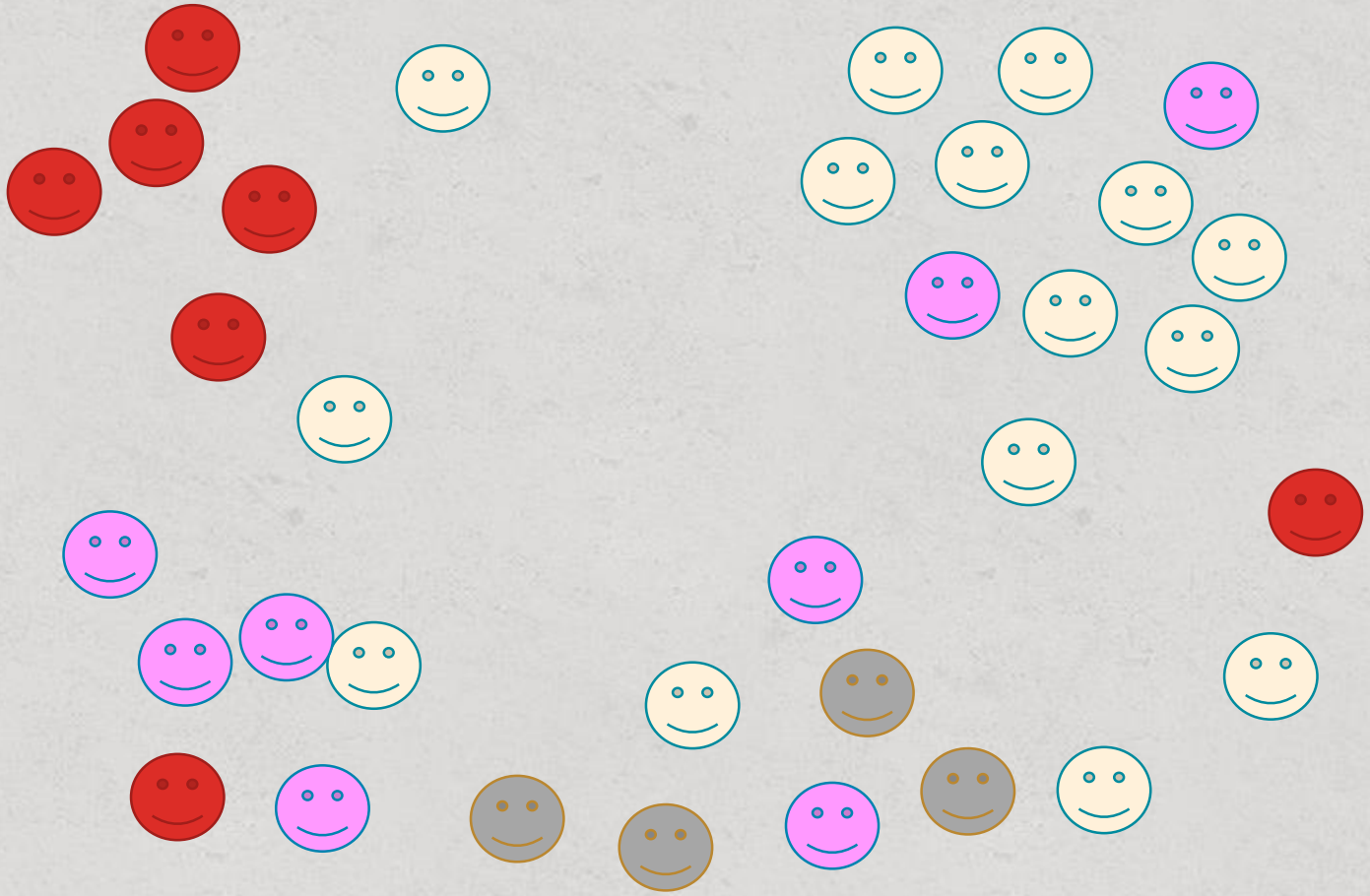

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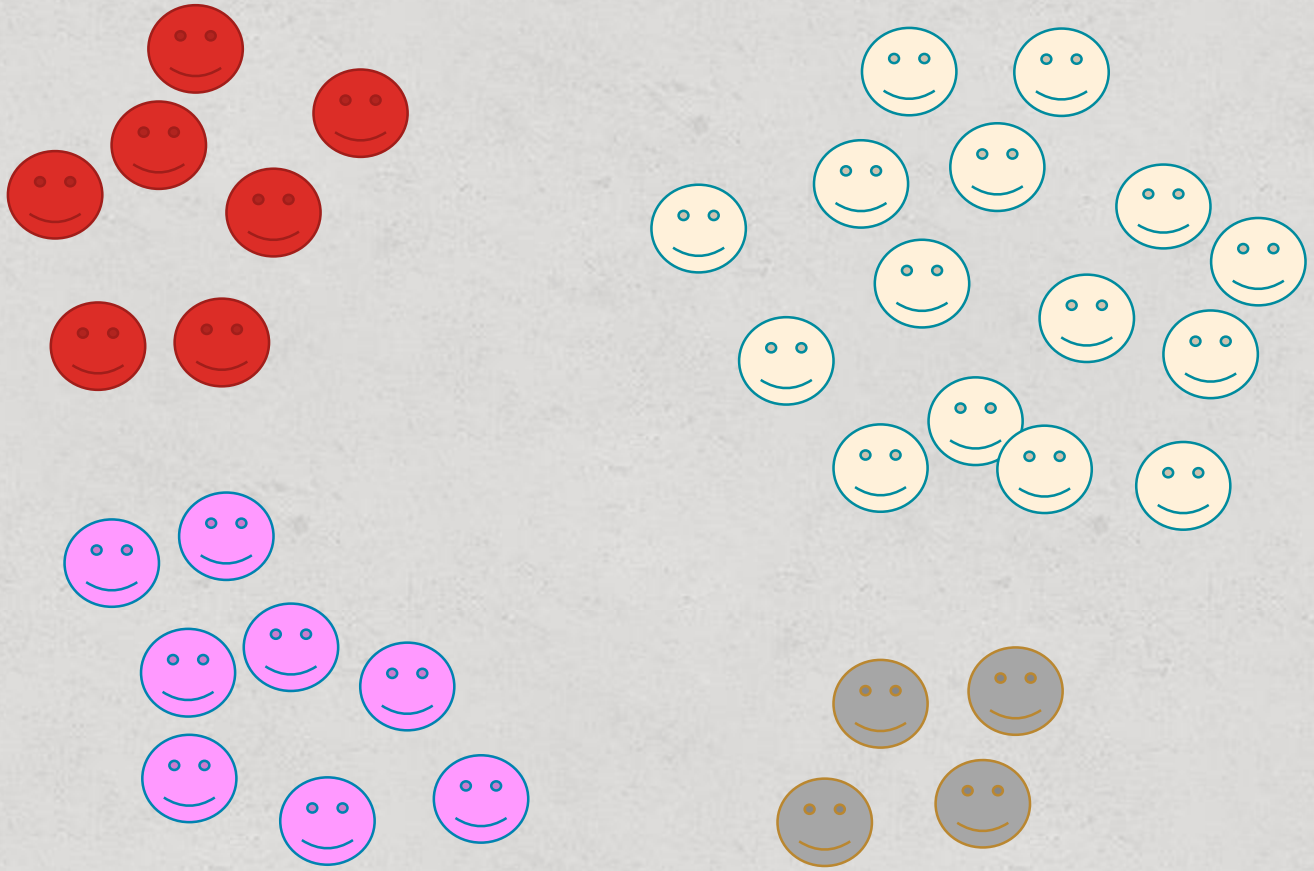


Cluster analysis groups questionnaire respondents into groups with similar scores on each of the 9 scales

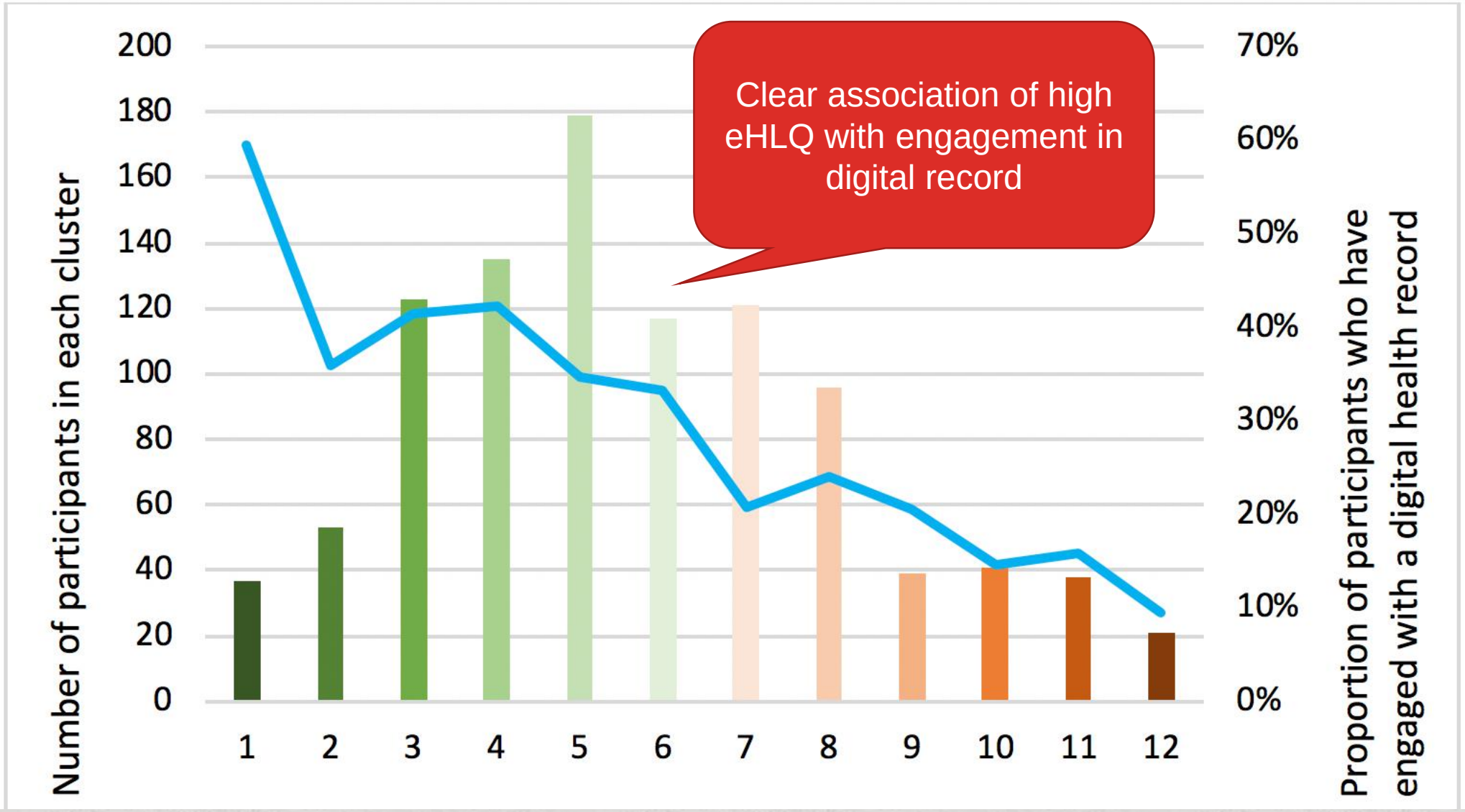
Cluster analysis with eHealth Literacy Questionnaire (eHLQ) data

12 Cl #	Cl Ord *	Num people	eHLQ1 Using technology to process health information	eHLQ2 Understand health concepts & language	eHLQ3 Ability to actively engage with digital services	eHLQ4 Feel safe and in control	eHLQ5 Motivated to engage with digital services	eHLQ6 Access to digital services that work	eHLQ7 Digital services that suit individual needs
3	1	37	3.17	3.60	3.26	3.65	3.37	3.57	3.43
12	2	53	3.25	3.66	3.45	2.66	3.20	2.80	2.83
2	3	123	2.90	3.04	2.87	3.00	2.95	2.96	2.95
8	**4**	**135**	**2.63**	**2.90**	**2.81**	**2.46**	**2.67**	**2.60**	**2.56**
10	5	179	2.30	2.88	2.35	2.96	2.47	2.71	2.64
7	**6**	**117**	**2.45**	**2.92**	**2.75**	**1.92**	**2.46**	**2.31**	**2.13**
5	7	121	2.00	2.72	2.10	2.78	2.01	2.36	2.04
6	8	96	2.15	2.69	2.30	2.16	2.13	2.22	2.10
9	9	39	1.56	2.90	1.41	2.86	1.75	2.29	1.92
4	10	41	1.75	2.87	1.89	1.74	1.75	1.92	1.60
1	11	38	1.07	2.99	1.13	2.79	1.09	1.79	1.18
11	12	21	1.16	2.48	1.29	1.50	1.23	1.44	1.25

Cluster number (as derived from cluster analysis)

* Cluster number when ordered from highest eHealth literacy to Lowest eHealth literacy.

Number of participants in each cluster by engagement with a digital health record



Highest eHLQ

Lowest eHLQ

Cluster analysis with eHealth Literacy Questionnaire (eHLQ) data

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Jeannie is a 74 year old woman who lives alone and uses the internet to email family who live interstate. While she has good friends nearby, she often feels lonely after the death of her husband. She mostly visits the doctor for occasional flare-ups of back pain and to renew prescriptions for blood pressure. While she doesn't like the fact that the doctors surgery seems to always have a new doctor, she knows the nurse there well. She hasn't really heard or thought much about new ways of using the internet for dealing with health services) and if asked doesn't see the point since everything is 'just a phone-call away'. Jeannie went to the doctor recently to get a new prescription. It was a new younger doctor and they tried to talk to her about the online health records. Jeannie had no idea what the doctor was talking about or what she was meant to do. She told the doctor she wanted him to manage her health for him. She didn't want to have anything to do with any of the technology.

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Jeannie is a 74 year old woman who lives alone and uses the internet to email family who live interstate. While she has good friends nearby, she often feels lonely after the death of her husband. She mostly visits the doctor for occasional flare-ups of back pain and to renew prescriptions for blood pressure. While she doesn't like the fact that the doctors surgery seems to always have a new doctor, she knows the nurse there well. **She hasn't really heard or thought much about new ways of using the internet for dealing with health services (eHLQ 1)** and if asked doesn't see the **point since everything is 'just a phone-call away' (eHLQ 7).** Jeannie went to the doctor recently to get a new prescription. It was a new younger doctor and they tried to talk to her about the online health records. **Jeannie had no idea what the doctor was talking about (eHLQ 3)** or what she was meant to do **(eHLQ 1)**. She told the doctor she **wanted him to manage her health for him (eHLQ 5, 7)**. She **didn't want to have anything to do with**

1. Do you recognise this person in your community?

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

3. "If there were lots of people like this…
What could services/ community organisations etc do to improve outcomes for these people?

Jeannie is a 74 yea old woman wh es alone and uses the
interstate. While she has good friend earby, she often feels lonely ter the death of her husband. She mostly visits the doctor or occasional flare-ups of back pain and to renew prescriptions for blood pressure. While she doesn e fact that the doctors surgery seems to always have a new doctor, she knows th **asn't really heard or thought much about new ways of using the int ealth services (eHLQ 1)** and if asked doesn't see the **point since ever all away' (eHLQ 7)**. Jeannie went to the doctor recently to get a n unger doctor and they tried to talk to her about the online health record **idea what the doctor was talking about (eHLQ 3**) or what she was me d the doctor she **wanted him to manage her health for him (eHLQ 5, 7)**. She **didn't want to have anything to do with any of**

100s & 100s of ideas from the community + professionals

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4	10	41	1.75	2.87	1.89	1.74	1.75	1.92	1.60
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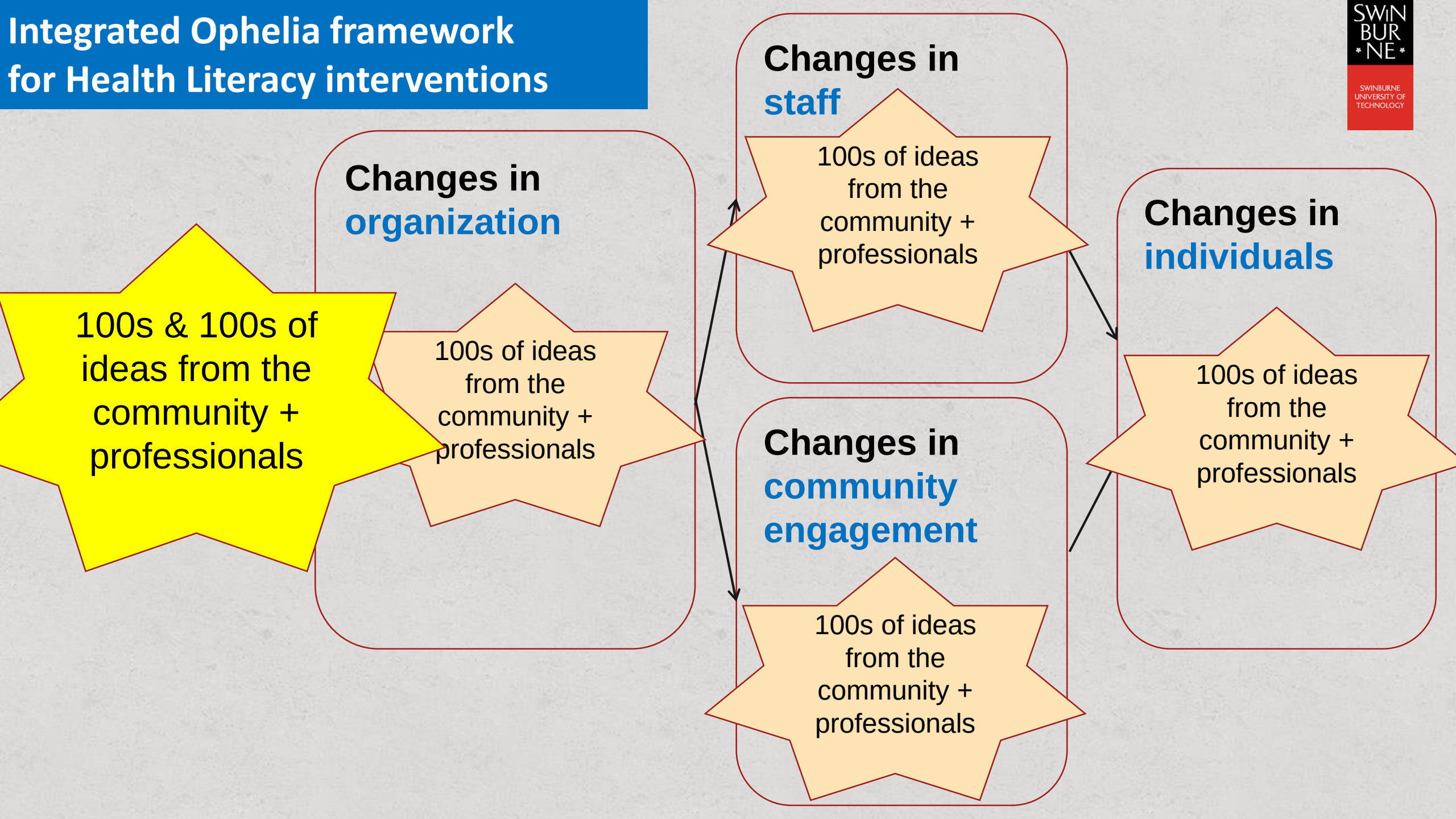
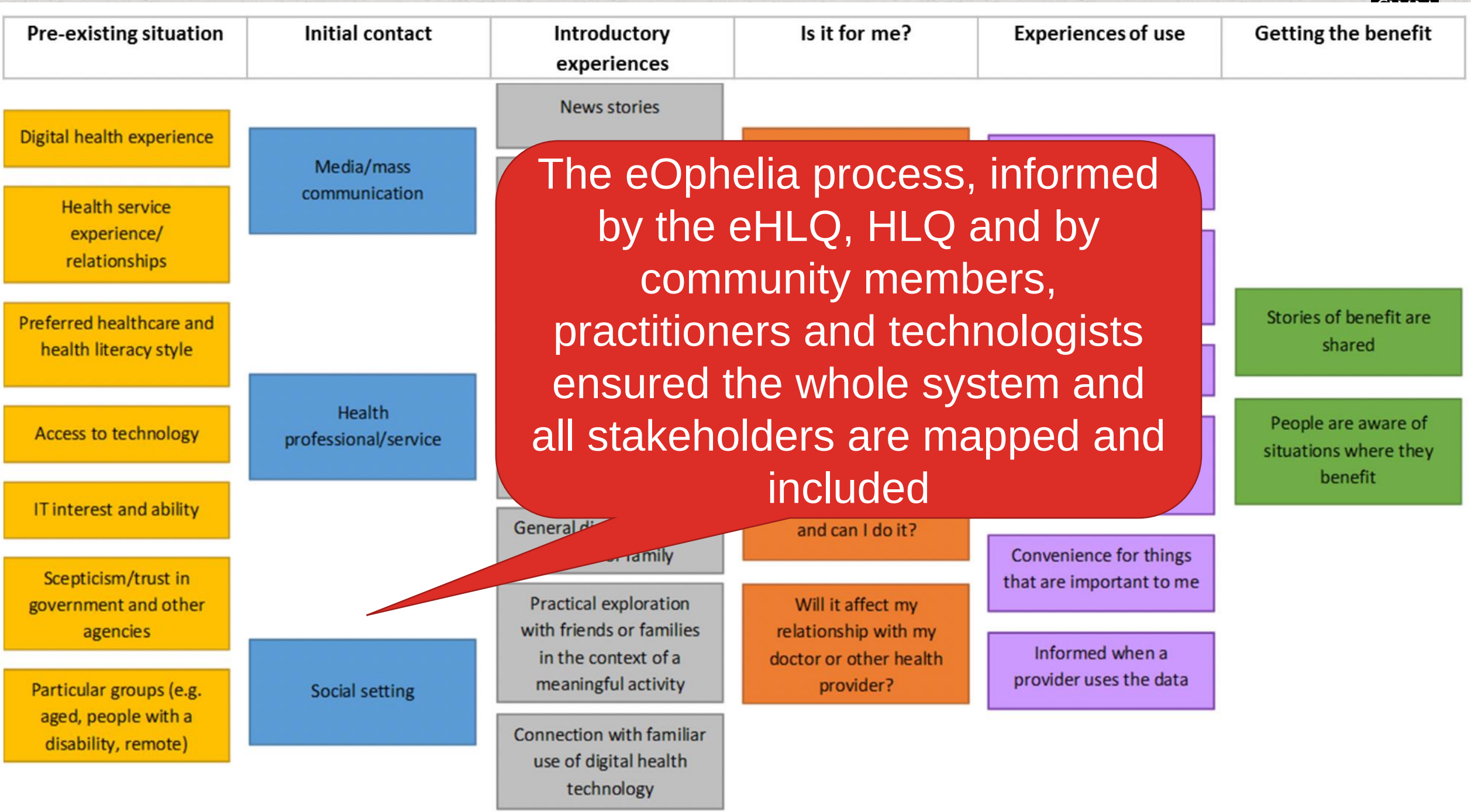
Integrated Ophelia framework for Health Literacy interventions




Pre-existing situation
Initial contact
Introductory experiences
Is it for me?
Experiences of use
Getting the benefit
Digital health experience
Health service experience/ relationships
Preferred healthcare and health literacy style
Access to technology
IT interest and ability
Scepticism/trust in government and other agencies
Particular groups (e.g. aged, people with a disability, remote)
Media/mass communication
Health professional/service
Social setting
News stories
Practical exploration with friends or families in the context of a meaningful activity
Connection with familiar use of digital health technology
and can I do it?
Will it affect my relationship with my doctor or other health provider?
Convenience for things that are important to me
Informed when a provider uses the data
Stories of benefit are shared
People are aware of situations where they benefit
The eOphelia process, informed by the eHLQ, HLQ and by community members, practitioners and technologists ensured the whole system and all stakeholders are mapped and included

The Positive Deviant and Gold Mining

Two of the most important resources for developing new approaches to ‘leave no-one behind’ are:

- People in your target group who are doing very well despite sharing many similar circumstances to those who are being left behind
- Health workers, volunteers or community leaders who work with your target group and who achieve high levels of success with people that are often left behind

Gold Mining

The Ophelia "BreastScreen Victoria" Project

Improving awareness and participation among Aboriginal, Arabic and Italian women

Caring about Women

BreastScreen Victoria

Ophelia: finding and building on current good practices [and using existing expertise]

Communities of practice, quality improvement collaboratives

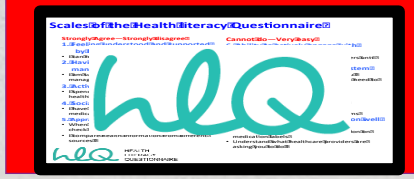
Realist program design and evaluation

Intervention mapping

Health service settings: participatory service development and quality improvement (e.g. 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

Community settings: participatory community development/ participatory research (e.g. ABCD)

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

Cycling between bottom-up and top-down planning

Can we ensure that the interventions we select or develop are not…

- Weak
- Only suitable for easy to find ‘average’ patients / highly empowered people
- Hard to implement in the real world
- Disappear when the ‘project’ stops

Projects can “look good”, have fashionable theory, be trendy, be pushed by a powerful person/impressive funding…

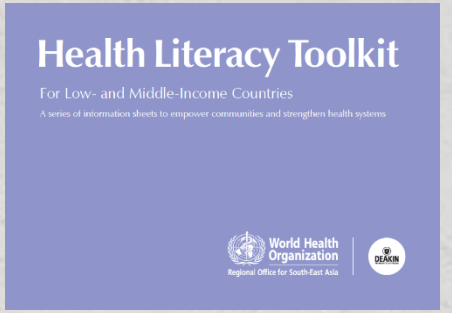
– **but are not really wanted, not scalable, and not sustainable**

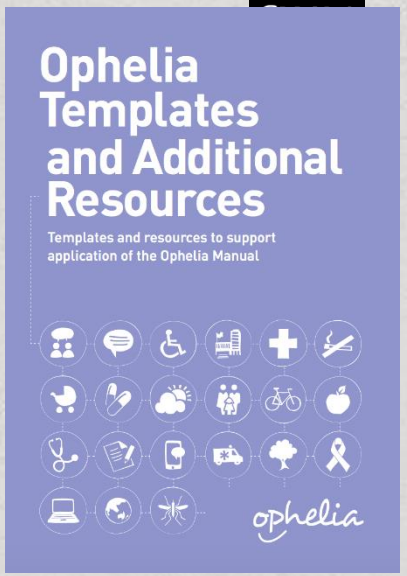
Considerations for setting up a National Health Literacy Demonstration Project (NHLDP)

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

WHO GLOBAL COORDINATION MECHANISM ON NCDs

#beatNCDs #gcmncd





"The WHO European Action Network on Health Literacy for Prevention and Control of NCD"

Was launched by Portuguese Government and Russian Federation in January 17-18, 2019

Flagship WHO Projects (GCM/NCD):
China, Egypt, Myanmar

Also underway:

EU: - Portugal, Slovakia, Denmark, Norway, Netherlands, France, Ireland

Elsewhere: Australia (x2), Philippines (x3), Thailand (prisons), Mali, Benin, Brunei, Thailand,

Emerging: Canada, England, Scotland etc

http://www.who.int/global-coordination-mechanism/activities/working-groups/wg-february-2018/en/

Current issue

Download current issue

Highlights

Electronic health information system implementation in outpatient and inpatient healthcare facilities of Armenia

Development of Internet technologies for health care in the Russian Federation

Read more

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REPORT

Acting together – WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region

Mark Matthijs Bakker[1]*, Polina Putrik[1]*, Anna Aaby[2], Xavier Debussche[3], Janis Morrissey[4], Christine Råheim Borge[5], Dulce Nascimento do Ó[6], Peter Kolarčik[7], Roy Batterham[8], Richard H. Osborne[8], Helle Terkildsen Maindal[2]

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[4]Irish Heart Foundation, Dublin, Ireland

[5]Lovisenberg Diaconal Hospital, Oslo, Norway

[6]Portuguese Diabetes Association, Lisbon, Portugal

[7]Department of Health Psychology, P.J. Šafárik University, Košice, Slovakia

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Corresponding author: Mark Matthijs Bakker (email: mark.bakker@mumc.nl).

ABSTRACT

The burden of noncommunicable diseases (NCDs) is increasing worldwide with the European Region of no exception. This poses economic and social challenges, which contribute to persisting health inequities. Sustainable Development Goal (SDG) target 3.4 specifically focuses on reducing premature mortality from NCDs by a third through prevention and treatment, and promoting mental health and well-being. The promising role of health literacy is increasingly recognized in relation to the prevention and treatment of NCDs throughout the life course. In support of this, WHO has initiated National Health Literacy Demonstration Projects (NHLDPs) in the European Region to generate evidence and accelerate NCD intervention development. The current European NHLDPs use the OPtimising HEalth LIteracy and Access (Ophelia) approach. This manuscript presents the methods, aims, status and preliminary outcomes of the seven flagship European NHLDPs, which cover a broad scope of settings (such as schools, hospitals and communities), health conditions (such as cardiovascular disease, renal failure and chronic obstructive pulmonary disease) and life stages. While the long-term impact of these NHLDPs on the NCD curve is too early to predict, the processes of engagement and action in each of the projects are promising.

Thank you

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