Advancements in development and evaluation of health programs: Health literacy and Ophelia approach to improving impact and equity

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TPE, IReSP, Paris, 29th January 2015

What is this concept of Health Literacy?

What is health literacy?

The ability to understand, access and use health information.

- Social and cognitive skills to do these tasks
- Motivation and engagement in health-promoting and disease-management activities

It includes reading and writing, but it is much more than this

World Health Organization: **Health Promotion Glossary**. *Health Promotion International* 1998, **13**(4):349-364

By Howard K. Koh, Donald M. Berwick, Carolyn M. Clancy, Cynthia Baur, Cindy Brach, Linda M. Harris, and Eileen G. Zerhusen

New Federal Policy Initiatives To Boost Health Literacy Can Help The Nation Move Beyond The Cycle Of Costly 'Crisis Care'

DOI: 10.1377/hthaff.2011.1169 HEALTH AFFAIRS 31, NO. 2 (2012): -0 2012 Project HOPE--The People-to-People Health Foundation, Inc.

ABSTRACT Health literacy is the capacity to understand basic health information and make appropriate health decisions. Tens of millions of Americans have limited health literacy—a fact that poses major challenges for the delivery of high-quality care. Despite its importance, health literacy has until recently been relegated to the sidelines of health care improvement efforts aimed at increasing access, improving quality, and better managing costs. Recent federal policy initiatives, including the Affordable Care Act of 2010, the Department of Health and Human Services' National Action Plan to Improve Health Literacy, and the Plain Writing Act of 2010, have brought health literacy to a tipping point—that is, poised to make the transition from the margins to the mainstream. If public and private organizations make it a priority to become health literate, the nation's health literacy can be advanced to the point at which it will play a major role in improving health care and health for all Americans. Howard K. Koh, (Howard.Koh@ HHS.gov) is assistant secretary for health at the Department of Health and Human Services (HHS), in Washington, D.C.

Donald M. Berwick is the former administrator of the Centers for Medicare and Medicaid Services (CMS), in Washington, D.C.

Carolyn M. Clancy is director of the Agency for Healthcare Research and Quality (AHRQ), in Rockville, Maryland.

Cynthia Baur is senior adviser for health literacy, Office of the Associate Director for Communication, Centers for Disease Control and Prevention in Atlanta

Association studies



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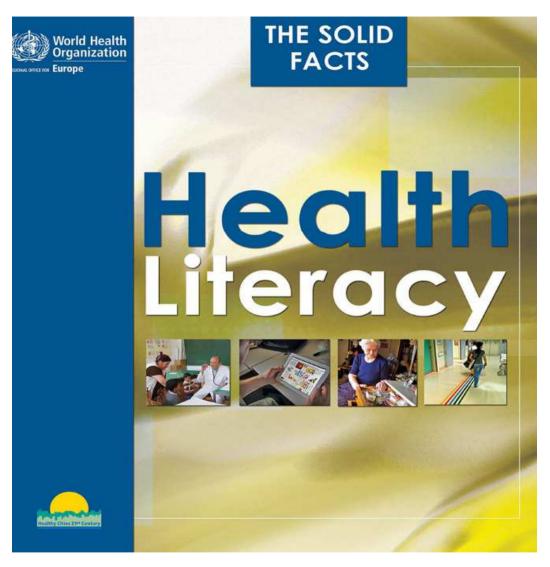
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Association studies: Low health literacy has been associated with...

- increased hospital admissions and readmissions [5-10]
- poorer medication adherence and increased adverse medication events [11-16]
- less participation in prevention activities [8, 17-21]
- higher prevalence of health risk factors [22, 23]
- poorer self-management of chronic diseases [23-28]
- and poorer disease outcomes [29, 30]
- less effective communication with health care professionals [31-33]
- increased health care costs [34-36]
- lower functional status [37]
- poorer overall health status[38, 39]
- increased mortality [40-42]

Extensive recent systematic review

- Berkman, N. D., S. L. Sheridan, et al. (2011). "Health literacy interventions and outcomes: an updated systematic review." *Evid Rep* <u>Technol Assess (Full Rep)(199): 1-941.</u>



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http://www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf

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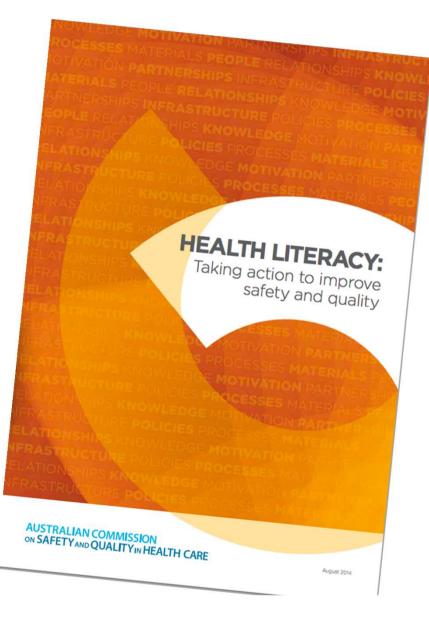
Making it Easy A Health Literacy Action Plan for Scotland





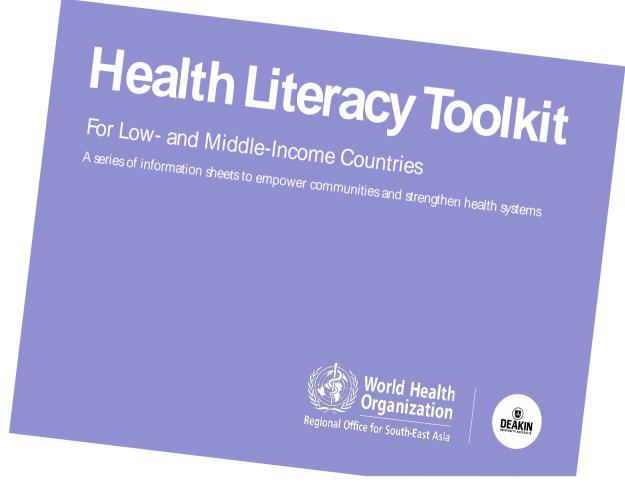
Australian national policy document

http://www.safetyandquality.gov.au/ourwork/patient-and-consumer-centredcare/health-literacy/



Health Literacy Toolkit for Low & Middle Income Countries

Publication: February 2015



Ophelia Toolkit

A step-by-step guide for identifying and responding to health literacy needs within local communities



A step-by-step guide through a process to identify the health literacy needs of a local community, and to develop and implement responses to those needs.

Also includes a range of practical tools and resources that can be used at each stage of the process.

A community of practice – to build and share knowledge across contexts



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A critical concept: health literacy is relative to the need for information



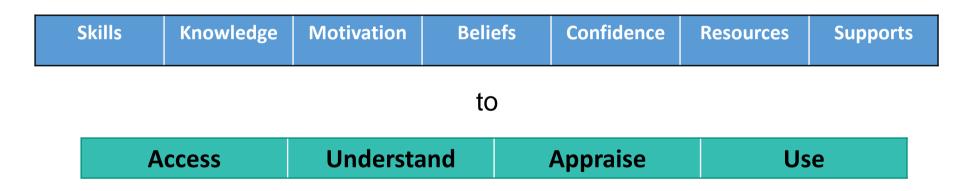
Source: Parker R. Measuring health literacy: what? So what? Now what? In Hernandez L, ed. Measures of health literacy: workshop summary, Roundtable on Health Literacy. Washington, DC, National Academies Press, 2009:91–98.

WHO regional office for Europe, 2013. Health literacy: The solid facts

...For example during the first few years of living with a chronic illness people often demonstrate large increases in **knowledge of health issues and health services** and a small increase in **health literacy** because their need for knowledge increases almost as fast as their knowledge.

Health literacy is...

the characteristics of the person + the things and supports they need



...information and services to make decisions

about their health and the health of their family and community



Health literacy responsiveness is...

the way in which services make

Information	Resources	Supports	Environments		
Available and Accessible					

to people with varying health literacy strengths and limitations



What is most important in determining health equity and outcomes?

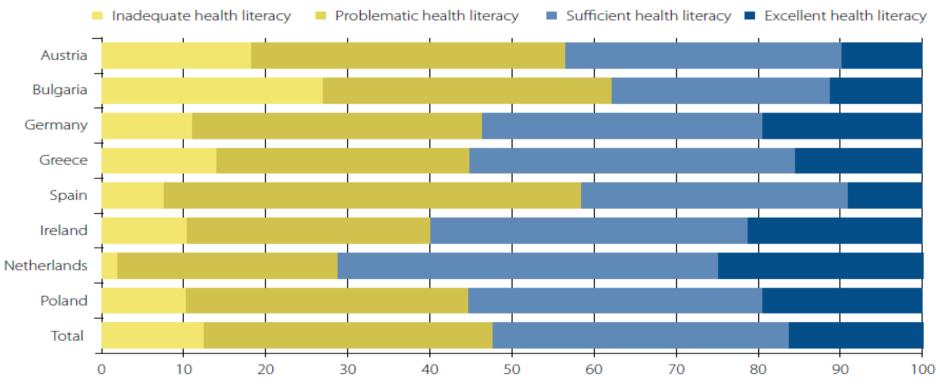
- 1. The health literacy of the individual?
- 2. The health literacy of the person in the family who cares for domestic issues like buying and cooking food?
- 3. The average health literacy of people in a family?
- 4. The average health literacy of the individual's peer group?
- 5. The health literacy of the 'highest status person' in the individuals age group?
- 6. The health literacy of village leaders?
- 7. The health literacy of health leaders? (e.g Health volunteers)
- 8. ...or... the **health literacy responsiveness** of healthcare system?

How has health literacy been measured?

- Mostly been assessed through measuring reading ability, comprehension and word recognition skills
- Tools used with patients:
 - 1. Rapid Estimate of Adult Literacy in Medicine (REALM)
 - 2. Test of Functional Health Literacy in Adults (TOFHLA)
 - 3. Newest Vital Sign (NVS)
- Audits and surveys
 - 4. Audit of written materials / health facilities (e.g. signage)
 - 5. National Literacy Surveys
- New / Modern scales
 - Health Literacy Questionnaire (HLQ)
 - Mainland French by Dr Xavier Debussche, La Réunion
 - Canadian French by Drs Maud-Christine Chouinard and Sylvie Lambert, Quebec
 - Health Literacy Survey Europe (HLS-EU)

Health literacy survey–European Union

Fig. 8. Percentage distributions of general health literacy for each country and the 7795 respondents



Percentages of General Health Literacy levels

Source: adapted from: Comparative report on health literacy in eight EU member states. The European Health Literacy Project 2009–2012. Maastricht, HLS-EU Consortium, 2012 (http://www.health-literacy.eu, accessed 15 May 2013).

Grounded development of questionnaires: Concept mapping

Structured conceptualisation process that captures the local wisdom of patients, practitioners and policy makers

1. Brainstorming session

- 2. Sorting and rating of statements
- 3. Multivariate analysis (multi-dimensional scaling and cluster analysis)

Seeding statement:

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

4. Interpretation of maps

Osborne et al. BMC Public Health 2013, 13:658 http://www.biomedoentral.com/1471-2458/13/658

HLQ development paper

To access this paper:

http://www.biomedcentral.com/1471-2458/13/658

>19,000 downloads

RESEARCH ARTICLE



Open Access

The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)

Richard H Osborne^{1*}, Roy W Batterham¹, Gerald R Elsworth¹, Melanie Hawkins¹ and Rachelle Buchbinder²

Abstract

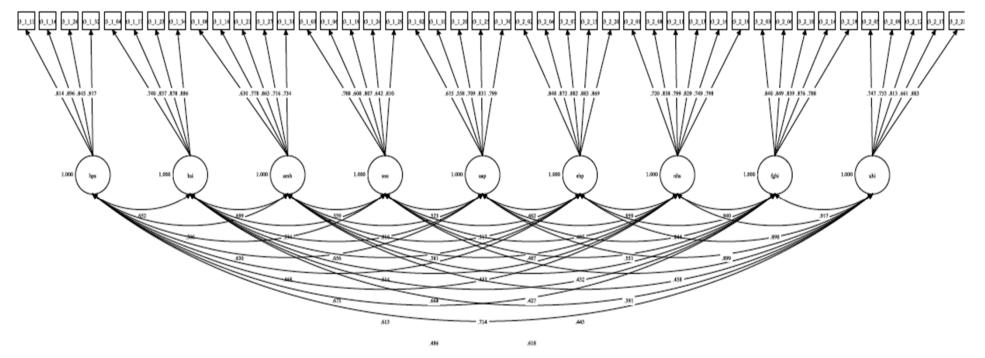
Background: Health literacy has become an increasingly important concept in public health. We sought to develop a comprehensive measure of health literacy capable of diagnosing health literacy needs across individuals and organisations by utilizing pespectives from the general population, patients, practitioners and policymakers. Methods: Using a validity-driven approach we undertook grounded consultations (workshops and interviews) to identify broad conceptually distinct domains. Questionnaire items were developed directly from the consultation data following a strict process aiming to capture the full range of experiences of people currently engaged in healthcare through to people in the general population. Psychometric analyses included confirmatory factor analysis (CFA) and item response theory. Cognitive interviews were used to ensure questions were understood as intended. Items were initially tested in a calibration sample from community health, home care and hospital settings (N=634) and then in a replication sample (N=405) comprising recent emergency department attendees. Results: Initially 91 items were generated across 6 scales with agree/disagree response options and 5 scales with difficulty in undertaking tasks response options. Cognitive testing revealed that most items were well understood and only some minor re-wording was required. Psychometric testing of the calibration sample identified 34 poorly performing or conceptually redundant items and they were removed resulting in 10 scales. These were then tested in a replication sample and refined to yield 9 final scales comprising 44 items. A 9-factor CFA model was fitted to these items with no cross-loadings or correlated residuals allowed. Given the very restricted nature of the model, the fit was quite satisfactory: x²_M sw/(866 d.f.) = 2927, p<0.000, CFI = 0.936, TLI = 0.930, RMSEA = 0.076, and WRMR = 1.698. Final scales included: Feeling understood and supported by healthcare providers; Having sufficient information to manage my health; Actively managing my health; Social support for health; Appraisal of health information; Ability to actively engage with healthcare providers; Navigating the healthcare system; Ability to find good health information; and Understand health information well enough to know what to do.

Condusions: The HLQ covers 9 conceptually distinct areas of health literacy to assess the needs and challenges of

The Health Literacy Questionnaire (HLQ)



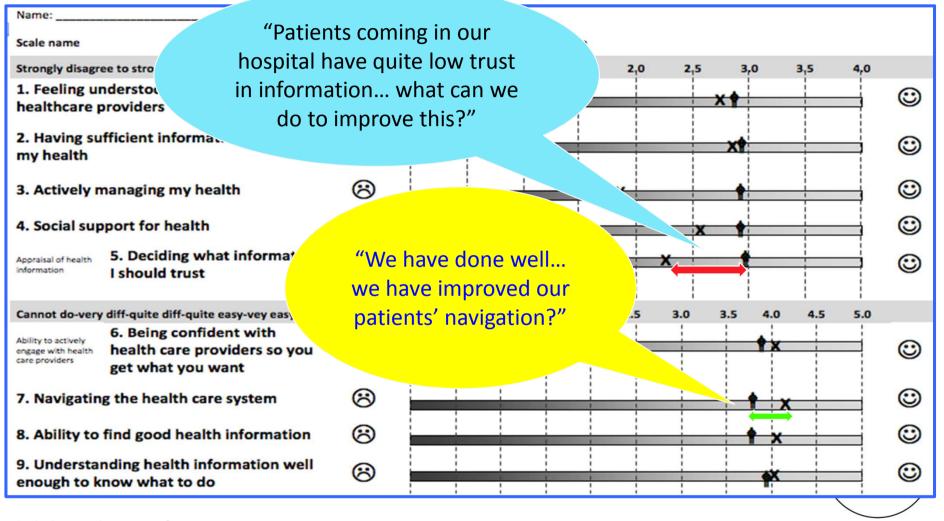
Psychometric properties of the English HLQ (and Danish, German, and Dutch) HLQ... very strong



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HLQ Organizational health literacy responsiveness feed back sheet

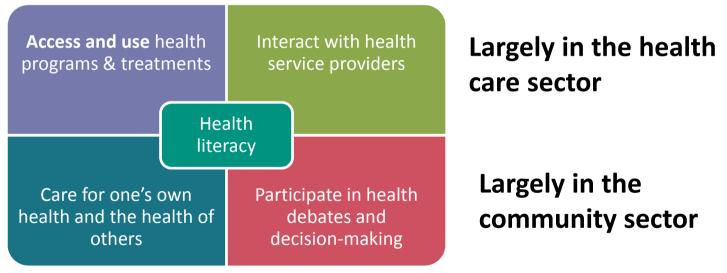


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Health Literacy...

...influences how people make health decisions, and what decisions they make, and it impacts how effectively people:



Sources: Informed by Paasche-Orlow and Wolf, 2007 and Nutbeam 2000

Importance of addressing health literacy

If we can improve health literacy, and/or the responsiveness of organisations to health literacy issues we can:

Improve health

Reduce inequities

• The way this works is by:

Improving the effectiveness of people's engagement with health information and services, which in turn...

Improves the ability to make effective health decisions and the quality of those decisions, which in turn...

Enhances people's engagement with healthy behaviours, and disease screening, treatment and management

ophelia

A global initiative to Optimise Health Literacy and Access to health information and services

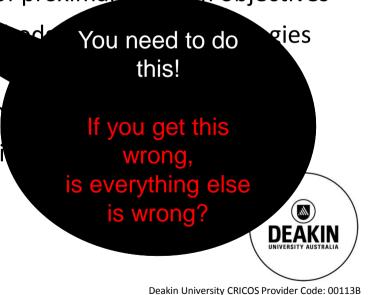


We are building a health literacy response framework

Intervention development

(intervention mapping)

- 1. Needs assessment (fine grained health literacy needs: e.g., HLQ, ISHA-Q)
 - Needs of consumers / patients
 - Needs of system (practitioners, planners/managers, policymakers)
- 2. From the needs assessment to create matrix of proximal program objectives
- 3. From the target users, select intervention and suggestions
- 4. Co-design and plan interventions with all stakeh
- 5. Prioritisation, adoption and implementation of i
- 6. Monitoring and program evaluation.



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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



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 Batterham¹, Rachelle Buchbinder^{2,3}, Alison Beauchamp^{1,3}, Sarity Dodson¹, Gerald R Elsworth¹ 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 communitiesbased 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 cocreation 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 outcomesoriented 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-climensional 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.

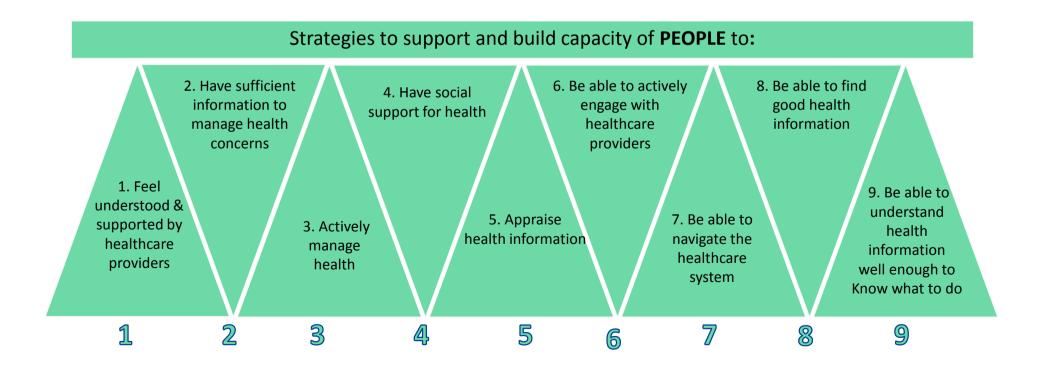
Discussion: There have been few attempts to assist agencies to identify, and respond, in a planned way, to the varied health literacy needs of their clients. This project will assess the potential for targeted, locally-developed health literacy interventions to improve access, equity and outcomes.

Keywords: Health literacy, Equity, Chronic illness, Access, Implementation, Intervention development, Intervention mapping, Participatory research, Health Literacy Questionnaire (HLQ), Co-creation

Health Literacy Response Framework

There are potentially 1000s of strategies that are (or can) be used by health workers in direct contact with patients

• These impact one or more of the following areas / HLQ domains:



Average age	Average Number Cond	1. Fee understo & suppor by healthca provide	ood ted are	nt n to ealth		act	/ na	e f	un inf well	Be able to derstand health ormation enough to what to do
A.	₹ S	1	2	3	4	5	6	7	8	9
54	2.5	3.96	3.82	3.80	98.E	3.63	4.51	4 48	4 23	4.43
69	2.2	4.00	3.95	3.68	3.88	2.64	4.88	4.40	3.68	3.88
64	2.4	3.59	3.23	2.96	3.40	2.89	4.70	4.64	4.31	4.77
70	3.5	3.28	3.28	3.30	3.54	3.08	4.30	4.08	4.12	4.04
56	5 3.3	3.81	3.25	3.60	2.20	3.75	4.35	3.75	4.10	4.25
67	7 20	3.75	3.50	3.40	2.50	2.00	4.50	4 33	2.50	4.40
66	5 3.0	3.18	2.93	2.81	2.88	2.76	4.00	3.94	3.90	3.94
		0.00	0.01	0.00	0.00	0.00	1.01	0.00	0.10	0.00
68	3.8	3.65	3.50	2.64	3.12	2.80	4.40	4.03	3.16	2.44
65	5 4.3	3.02	2.93	2.76	2.78	2.69	3.80	3.58	3.51	3.02
47	7 3.0	3.16	2.70	2.49	2.71	2.13	3.55	3.52	3.47	3.95
57	3.6	2.78	2.11	2.98	2.33	2.58	3.18	2.87	2.91	3.69
62			2.67	2.58	2.93	2.31	3.27	3.04	2.31	2.78
45		and the second	1.00	1.00	1.00	1.00	1.80	1.83	2.80	4.20

Box 1. Vignettes representing potential health literacy profiles derived from the nine dimensions of the Health Literacy Questionnaire

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

Vignette 1. Doesn't really understand what to do, but would trust their doctor

Giovanni is a 73 year old Italian man whose wife died 3 years ago. He now lives alone. Giovanni has type 2 diabetes and arthritis, and was recently diagnosed with heart failure. Although he trusts everything the doctor tells him and tries to follow instructions (scale 1), he gets very confused about how to manage all his new heart failure medications, and his fluid restriction (scales 2 and 9). He never feels certain that he is actually doing the right thing. He doesn't feel right about asking questions of the doctor (scale 6) because he was brought up to never question what a doctor says. He doesn't really look for information elsewhere either (scale 8). His daughter helps when she can (scale 4), but she doesn't always have the knowledge to explain things to him. The doctor referred him to a lifestyle education program at the community health center, but a lot of the information seemed very complicated, and because it doesn't come from his doctor, Giovanni doesn't try to take it all in.

1. Feeling anderstood and supported by healthcare providers	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability of actively engage with health care providers	7. Navigating the health system	8. Ability to find good health information	9. Understanding health information well enough to know what to do
Extremely low	Low	High	Very low	Low	Low	Moderate	Moderate	Very high

Vignette 2. Reasonable capacity and confidence, but only moderate engagement and support

Jean is a 73 year old woman with osteoarthritis and type 1 diabetes who is receiving some cleaning services from the council. She has been with the same doctor for ten years and trusts his advice. Recently, however, her doctor has partially retired and now she often needs to see doctors in the practice that she doesn't really know. Sometimes she thinks they are telling her different things. She isn't always honest with the doctors as she knows she isn't doing all the things that they recommend. Recently one of the doctors really told her off and now she feels scared about going unless she can see her old doctor (scale 1). She has a reasonable amount of knowledge of medical terms and can read and understand information that she receives (scale 9)- it's just that most information that she receives is not as practical as she is looking for (scale 2). Her main concern is how her osteoa impacts her mobility. She knows that if she lost some weight, it would help but she has never been able to achie te trying many diets that she has come across. She doesn't like talking to people out her problems bec are tired of hearing about them and It (scale 4). often judge her because she is

How do you work with people like this so they have the best chance of getting and maintaining good health? "15% of the people coming to your service have a health literacy needs profile like this"

In what way does your organisation meet these needs?

Health Literacy Response Framework - patient level responses

Strategies to support and build capacity of **patients** to:

Theme	Sub-themes
Build trust	Responsive to need, ensure consideration is given to: Duration of involvement; consistency of
	contact person; reliability; involvement of family/carers; rapport; honesty & transparency;
	persistence; planning of contacts; amount of time allowed for contacts; delivering something of use
	to consumer
Provide patient centered	Ensure: a focus on patient goals; flexible mode of service delivery – out of hours, outreach,
care	telephone, internet etc; service matched to need; identification of barriers to engagement
Coordinate care	Facilitating access and links with GP; Coordination of care between healthcare providers

To feel
 understood &
 supported by
 providers

Health Literacy Response Framework - Patient level responses

1. To feel understood & supported by	Building trust
healthcare providers	Patient centered
	Care coordination

Emerging evidence

Type of intervention	Authors	Main components of intervention	Outcomes as reported by authors
Client-centred	Lewin et al, 2001	Cochrane review of 17 interventions – clinician-based interventions included training in pt. communication and using pt-centred approaches , reflective evaluation of their practice, checklists. Patient-based interventions included role play, group- based discussion or education, training in MI and other	The majority of interventions were successful in increasing pt-centred approaches in consultations, and in patient satisfaction with care
		communication skills	



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Consumer leve		ng the health literacy of those makin siveness of services, environments a		Measurable indicators of health literacy and health literacy responsiveness
	Coordinate care	Provide client centered content, approaches & contact types	Build trust	1. To feel understood & supported by providers
Provide Information from trusted sources	Provide accessible information	Provide tailored and responsive education	Provide proactive education	2. To have sufficient information to manage health concerns
	Support capacity building	Support planning for action	Support agenda setting	3. To actively manage health
	,	Support addressing barriers to support for health	Support establishment of new supports for health	4. To have social support for health
	Support appraisal of conflicting information	Support prioritisation of information	Support interpretation of health information	5. To appraise health information
	,	Provide resources to support active engagement	Support development of assertiveness and communication skills	6. To be able to actively engage with providers
		Provide support and advocacy for service navigation	Support development of knowledge/skills for service navigation	7. To be able to navigate the healthcare system
			Support development of knowledge/skills for sourcing reliable info	8. To be able to find good health information
Provide readable information resources	Check understanding	Provide information in a graded manner	Tallor Information to consumers learning styles and needs	9. To be able to understand health information well enough to know what to do

Development of the Health Literacy Response Framework (HL-RF)

77 practitioners, 9 organisations, 200+ intervention ideas

Local stakeholders generate insights into:

- The health literacy strengths and challenges of consumers, and;
- Potential strategies for optimising health literacy and improving organisational responsiveness

Thematic analysis of intervention ideas, and matching of themes to HL Identification of mechanisms by which interventions influence HL Identification of provider, organisational and higher order requirements

Health Literacy Response Framework

REGIONAL/STATE LEVEL: strategies to optimise service coverage and integration

ORGANISATION LEVEL: Organisational strategies to influence the culture, and improve the accessibility, efficiency and equity of services

PRACTITIONER LEVEL: Strategies to support and build capacity of **practitioners / staff**

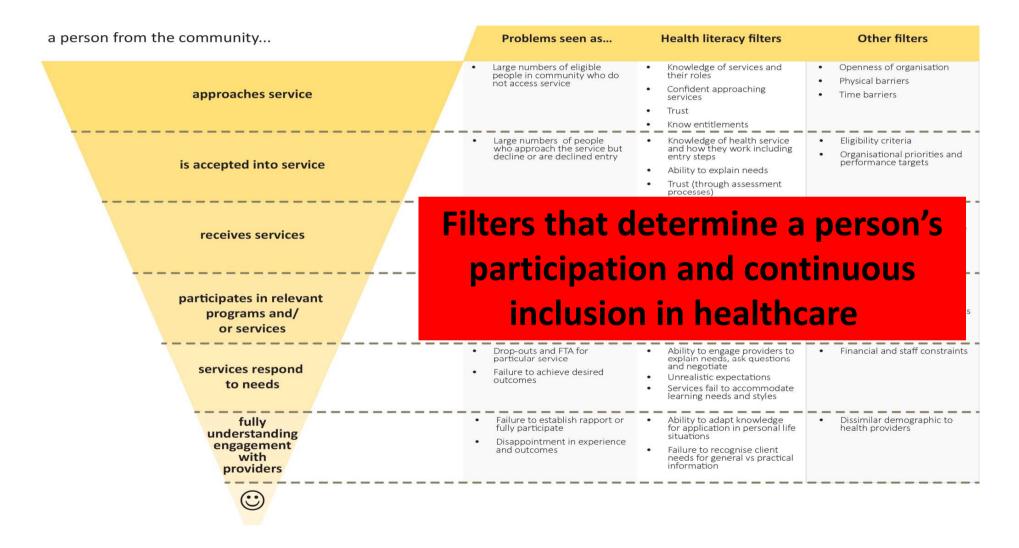
PERSON LEVEL: Strategies to support and build capacity of **consumers / patients / community groups**

Summary: Ophelia Process to build a Health Literacy Response Framework





The Health Literacy Access Framework Batterham et al http://www.biomedcentral.com/1471-2458/14/694/about



Examples of Ophelia Interventions

Site & target client group	Aim	Intervention
Regional HARP programAll HARP clients	To support HARP clinicians to provide effective client education on health service navigation and engagement	 Screen client learning preferences so education can be tailored appropriately; Develop client-focused health appointment plans; Use teach-back in patient education.
 Rural CHC (120km from CBD) Clients with chronic disease (esp. those with limited access) 	To build community capacity to navigate online health information	 Deliver online navigation training within existing computer course at community house in low SES area; Deliver a video education session via the CHC website; Deliver presentations at CHC groups to provide key messages about online health information.
 Metro City Council HACC program Clients not engaging with GPs 	To facilitate an open exchange between consumers and their GP	 Screen for client-GP engagement issues; Provide guidance to clients on strategies to engage with their GP; Provide information to GPs regarding guidance offered to their clients.

Site & target client group	Aim	Intervention
 Metro CHC Clients with chronic disease who access the service for episodic care only 	To support clients to move from episodic to ongoing care where appropriate	 Implement a referral pathway between on-site dental service and primary health care services within the CHC; Begin to develop a health literacy policy on service access.
 Rural CHC (250km from CBD) Community members from more remote and rural areas 	To build community health literacy knowledge and capacity by supporting CHC volunteers to act as health mentors for their rural community	 Volunteers who run existing CHC group programs in their local rural community deliver health literacy messages and resources; Volunteers attending clients' homes as part of the 'friendly visitors' program deliver guidance on the above topics; Integrate additional training in health literacy as part of the volunteer induction program for interested volunteers.
 Metro City Council HACC program (low SES area) Socially isolated clients with limited mobility 	To develop a mentorship program whereby community volunteers are trained to act as health mentors	 Utilise mentors to support clients in a gentle exercise program in a group setting; Utilise mentors to support clients in a gentle exercise program at home.

Site & target client group	Aim	Intervention
 Outer metro CHC (low SES area) Clients with chronic disease 	To improve care coordination and self- management of health conditions in District Nursing and other CHC clients	 Care Coordination within District Nursing Team; Use of a patient diary as a tool to assist clients to manage their appointments, communicate with providers and plan and monitor the progress of their health goals.
 Community nursing service across Melbourne Clients with diabetes 	To support clinicians to improve the quality and consistency of diabetes education for clients	 Use of a diabetes education checklist to ensure effective delivery of key educational messages; Use of the teach back method by nurses providing diabetes education; Use of an online library of diabetes education resources for nurses to use when educating patients.
 Metro HARP program All HARP clients 	To support clients to navigate health appointments and to manage perceived health crises appropriately	 Provide tailored and focused education and support based on episodes of health crises; Develop client-focused health appointment plans; Use teach-back in patient education.

Ophelia website

Launch: 2015

www.ophelia.net.au

The Ophelia website will be used by registered organisations to:

- -Share experiences and ideas through a community of practice
- -Share health literacy tools and resources
- -Share details of health literacy interventions being tested or applied
- -Administer the Health Literacy Questionnaire (HLQ)
- -View and download Health Literacy Questionnaire (HLQ) results



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Ophelia Toolkit

Ophelia Toolkit

A step-by-step guide for identifying and responding to health literacy needs within local communities



A step-by-step guide through a process to identify the health literacy needs of a local community, and to develop and implement responses to those needs.

Also includes a range of practical tools and resources that can be used at each stage of the process.

A community practice – a 'wiki' to build and share knowledge across contexts



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Conclusion

- Health literacy
 - Key enablement and empowerment element for patients, clinicians & organisations
- Health literacy responsiveness
 - Indicator of the quality of health service provision and systematic production / prevention of health inequalities
- Can you do TPE properly without understanding the health literacy profile of patients?
 - Probably not, sometimes, always... it depends
- Great practitioners already to great 'health literacy responsiveness'
 - But poor/untrained/novice practitioners probably don't
- We need systematic processes to uncover excellent practice in different contexts, based on clear understanding of health literacy profiles in all contexts
 - This will improve therapeutic outcomes and reduce social inequalities in health

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Thank you

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