

Health literacy – a resource for improving health outcomes and reducing health inequalities

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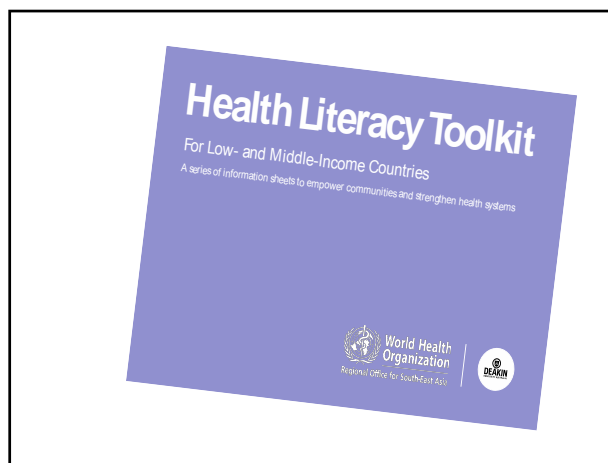
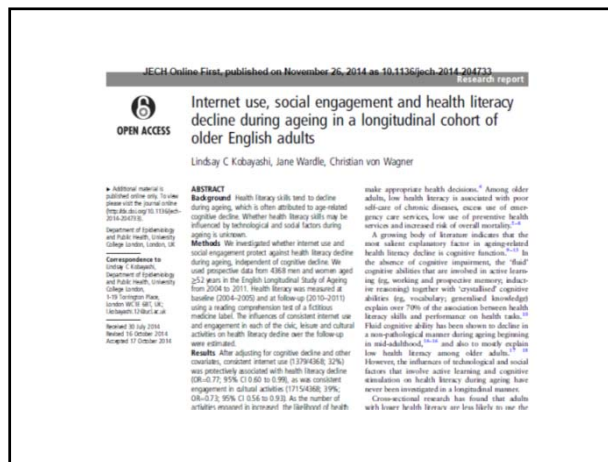
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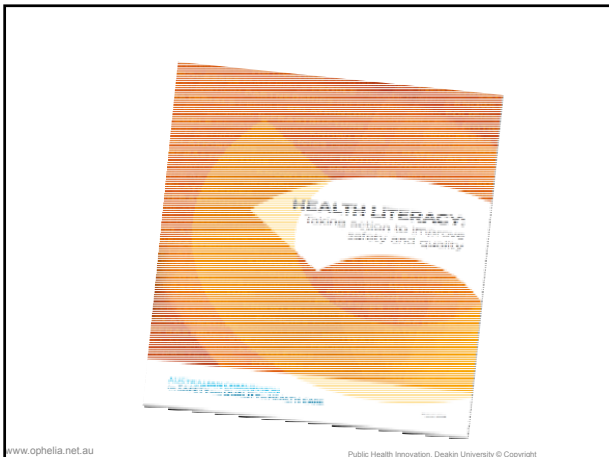


Overview

- Relevant background
 - Health service responsiveness
 - Measurement of health literacy
- Ophelia Victoria
- Health Literacy Response Framework

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The concept of health literacy exists:

- In academic journals
- In the media
- In health policy
- But how does it exist in a person's life?
- What is health literacy?
 - How can it be operationalised?
 - Can it be used to drive system-wide health improvements?
 - Can it be used to reduce health inequities?

Brief history of 'health literacy'

1974 - term health literacy first applied

1980s - debates on the definition of health literacy. Association studies between literacy and health outcomes

1990s - first generation health literacy measurement tools focused on literacy and numeracy. Institutionally endorsed definitions

2000s – causal models, intervention development and early intervention trials. Several systematic reviews

2007-2015 - sixfold increase in 'health literacy papers'. New multi-dimensional tools. Social aspects of health literacy more recognised

Two approaches to thinking about health literacy

1. Narrower approach:

- research oriented
- literal concept of 'literacy'
- focused on precise definition of the construct and distinguishing it from other constructs (e.g. patient activation)

2. Broader approach:

- practically oriented
- metaphorical concept of 'literacy' (like computer literacy or financial literacy)
- focused on being inclusive and identifying all the factors required for people to make effective decisions about health

Health literacy: several definitions

- 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)
- 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)
- 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 **ability** to make **sound health decisions** in the context of everyday life (Kickbusch, 2001)
- People's **competencies** to **access**, **understand**, **appraise** and **apply** information **to make health decisions** (Sorensen 2011)

Health literacy

Health literacy brings together many concepts that relate to what people need to make effective decisions about health for themselves, their families and their communities.

Health literacy is...

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

Skills	Knowledge	Motivation	Beliefs	Confidence	Resources	Supports
--------	-----------	------------	---------	------------	-----------	----------

to

Access	Understand	Appraise	Use
--------	------------	----------	-----

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

Health literacy is...

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

Every one will be different in what they need

skills & knowledge

motivation & beliefs

confidence

resources & supports

what they need

Health literacy is...

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

Every one will be different in what they need and what they have.....

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Health literacy responsiveness is....

the way in which healthcare services make

information	resources	supports	environments
-------------	-----------	----------	--------------

accessible

to people with **varying** health literacy strengths and limitations
(accessible = **approachable, acceptable, available, affordable, appropriate**)

Health service responsiveness and access to healthcare

People engage with services by....

Health literacy responsiveness is....
the way in which healthcare services make

accessible

to people with **varying** health literacy strengths and limitations
(accessible = **approachable, acceptable, available, affordable, appropriate**)

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Health service responsiveness and access to healthcare

People engage with services by....

Problem seen as....	Examples of health literacy barriers
Approaching a health service	<ul style="list-style-type: none"> • Little knowledge about entitlement to service • Lack of confidence
Receiving a service	
Service is responsive to needs	
Fully engages with providers/fully understands own health needs	

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Health service responsiveness and access to healthcare

People engage with services by....

Problem seen as....	Examples of health literacy barriers
Approaching a health service	<ul style="list-style-type: none"> • Little knowledge about entitlement to service • Lack of confidence
Receiving a service	<ul style="list-style-type: none"> • Limited knowledge of how the service works • Difficulty explaining needs to intake workers
Service is responsive to needs	
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Service is responsive to needs	<ul style="list-style-type: none"> • Services don't tailor what they do to individual patients' learning needs or styles
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Health service responsiveness and access to healthcare

People engage with services by....

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Service is responsive to needs	<ul style="list-style-type: none"> • Services don't tailor what they do to individual patients' learning needs or styles
Fully engages with providers/fully understands own health needs	<ul style="list-style-type: none"> • Providers unaware that patients are not able to put knowledge into practice – may lead to frustration and lack of trust

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Health service responsiveness and access to healthcare

People engage with services by....

Problem seen as....	Examples of health literacy barriers
Approaching a health service	<ul style="list-style-type: none"> • Little knowledge about entitlement to service • Lack of confidence
Receiving a service	<ul style="list-style-type: none"> • Limited knowledge of how the service works
Service is responsive to needs	<ul style="list-style-type: none"> • Fewer people reach these last levels • Most likely to be those with higher health literacy and higher socioeconomic status
Fully engages with providers/fully understands own health needs	<ul style="list-style-type: none"> • This creates inequity.....access is therefore an equity issue

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Measurement of health literacy

Low health literacy has been associated with.....

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

Extensive systematic review

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

but....

- Numerous studies had methodological weaknesses including inadequate consideration of possible confounders
- Most use the REALM, TOFHLA or NVS, 'unidimensional' measures

Rapid Estimate of Adult Literacy in Medicine: REALM

66 words

List 1

fat
flu
pill
dose
eye
stress
smear
nerves
germs
-
-

List 2

fatigue
pelvic
jaundice
infection
exercise
behaviour
prescription
notify
gallbladder
-
-

List 3

allergic
menstrual
testicle
colitis
emergency
medication
occupation
sexually
alcoholism
-
-

Davis TC, et al. Rapid estimate of literacy levels of adult primary care patients. Fam Med 1991;23:435-5.

Newest vital sign (NVS)

Nutrition Facts		% DV
Serving Size		4
Servings per container		
Amount per serving		
Calories	250	Fat Cal 120
Total Fat 13g		20%
Sat Fat 9g		40%
Cholesterol 28mg		12%
Sodium 55mg		2%
Total Carbohydrate 30g		12%
Dietary Fiber 2g		
Sugars 23g		
Protein 4g		8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Vanilla, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

QUESTIONS

1. If you eat the entire container, how many calories will you eat?

Answer: 1,000

Weiss BD, et al. Quick assessment of literacy in primary care: the newest vital sign. *Ann Fam Med* 2005;3:51-22.

Test of Functional Health Literacy in Adults: TOFHLA

Numeracy (17 items)

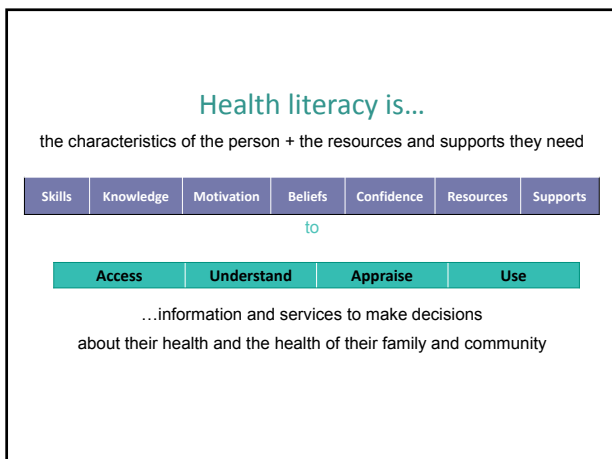
Abocillin VK Tablets 250mg 50
Take ONE tablet by mouth four times a day

Mr Ian Garfield nil Rpts
16/04/06 Dr Michael Lubin FF941858
\$11.53

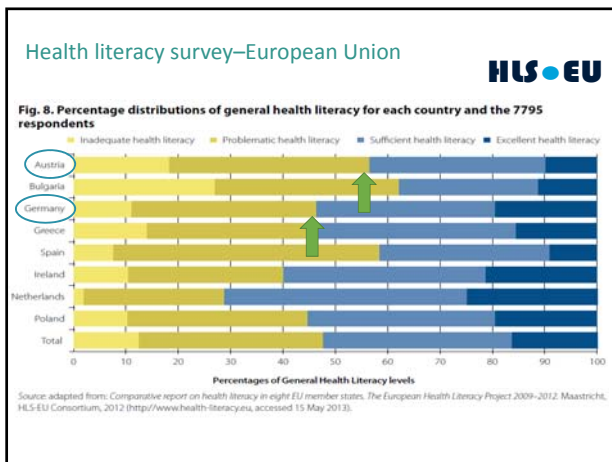
Q1. If you take your first tablet at 7.00am, when should you take the next one? _____

Q2. And the next one after that? _____

Parker RM, et al. The Test of Functional Health Literacy in Adults: a new instrument for measuring patients' literacy skills. J Gen Intern Med 1996;537-41.



- ### Some new multidimensional approaches to health literacy measurement
- Health Literacy Questionnaire (HLQ)
 - Western culture / developed countries (Australia)
 - Information and Support for Health Actions Questionnaire (ISHA-Q)
 - communal cultures/ LMICs (Thailand)
 - European Health Literacy Survey (HLS-EU)
 - measurement of populations
 - National Health Literacy Assessment for Children
 - Taiwan
 - Functional, Communicative and Critical HL in diabetes scale; All Aspects of Health Literacy Scale (AAHLS)



Grounded development of questionnaires:

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

Seeding statement: *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?*

1. Brainstorming session

2. Sorting and rating of statements

3. Multivariate analysis

4. Interpretation of maps

A multi-dimensional health literacy tool

HLQ Health Literacy Questionnaire

Scales:	Example Questions:
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 spend quite a lot of time actively managing my health
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	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	Understand what healthcare providers are asking you to do

HLQ Health Literacy Questionnaire

This paper describes the development and validation of the HLQ

To access this paper:

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

HLQ Health Literacy Questionnaire

Profiles can be used to:
Explore individual client strengths and limitations

The HLQ has nine individual scales (each scored separately)

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

Provides a **profile** of a person's health literacy strengths and needs

AND / OR
Strengths and limitations of groups of clients within a service / community

Example of a group of clients (using **cluster analysis** to group people with similar health literacy profiles together)

% of sample in each cluster	Range 1-4					Range 1-5			
	Health provider support	Have enough info	Actively manage health	Social support	Appraise health info	Active engage with HP	Navigate health services	Find good health info	Understand health info for action
22%	3.68	3.45	3.40	3.50	3.16	4.55	4.40	4.26	4.46
24%	3.17	3.01	2.93	2.98	2.76	4.10	4.00	3.83	4.00
20%	3.35	2.91	3.08	3.12	2.84	3.74	3.47	2.96	2.83
20%	2.72	2.49	2.74	2.54	2.43	3.44	3.32	3.31	3.71
14%	2.83	2.39	2.70	2.68	2.23	2.38	2.19	1.94	2.24

1. Feels understood & supported by HCP	2. Having sufficient information to manage health	3. Actively managing health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with HCP	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information to know what to do
2.56	2.73	2.88	2.85	2.22	3.45	3.28	3.34	3.48

HLQ data can be combined with demographic and interview data to develop a 'vignette' about what it's like to live with that health literacy profile

Simon is a 51 year old man who works as a painter for a large company. He is finding the work harder as he gets older, mostly because of the back pain he has had for years. He drinks and smokes a lot and is starting to lose his breath when climbing ladders. He feels quite down about his worsening health but just sees it as part of getting older. His father died of heart disease at age 60, so Simon half expects the same thing to happen to him. He's aware that he should take steps to stop smoking and drinking (**scale 3**) but doesn't know where to go to for help (**scale 7**). When he tried to cut down last year, all his mates just laughed at him (**scale 4**). He doesn't really trust doctors anyway (**scale 1**); he's been telling them about his back pain for years but they haven't done anything about it.

The Ophelia Approach

What is the Ophelia Approach?

- A way of identifying health literacy needs, and then developing and testing potential solutions
- Allows easy application of evidence-based health promotion approaches to the field of health literacy

Ophelia means
Optimizing
Health
Literacy and
Access to health information and services

Health literacy intervention development

- Problem**
 - I **can not** 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 do each day
- Solution**
 - Use data from 'usual' patients
 - Work with the best frontline practitioners and managers and capture their experiential knowledge and wisdom

Allowing local wisdom to emerge

1. Feels understood & supported by HCP	2. Having sufficient information to manage health	3. Actively managing health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with HCP	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information to know what to do
2.56	2.73	2.88	2.85	2.22	3.45	3.28	3.34	3.48

Simon is a 51 year old man who works as a painter for a large company. He is finding the work more difficult as he gets older, mostly because of the back pain he has had for years. He drinks and smokes a lot and has noticed that he's starting to lose his breath when climbing ladders. He feels quite depressed about his worsening health but just sees it as part of getting older. His father died of heart disease at age 60, so Simon half expects the same thing to happen to him. He's aware that he should take steps to stop smoking and drinking (**scale 3**) but doesn't know where to go to for help (**scale 7**). When he tried to cut down last year, all his mates just laughed at him (**scale 4**). He doesn't really trust doctors anyway (**scale 1**); he's been telling them about his back pain but they haven't done

How can/do you work with people like this to give them 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 could your organisation meet these needs?

Advantages of working with practitioners

- Years of experience and tacit knowledge are important resources
 - knowledge of local situations
 - knowledge of people
- Able to respond to issues not covered by the literature
- Likely to be implementable
- Don't need to achieve subsequent buy-in
 - Don't need to convince them it's a good idea... it's their idea!

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
- Gerald Elsworth

Partner – Victorian Government

- Home and Community Care (HACC)
- Primary Health
- Hospital Admissions Risk Program (HARP)

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Ophelia - aims

- Ophelia aims to improve health outcomes and reduce health inequalities for people with long-term conditions, by
 - Empowering health/community services and service providers to optimise the health literacy of their clients and community, by
 - Improving their responsiveness to clients with varying health literacy strengths and needs

Phase 1
Identify health literacy strengths and limitations of local community

- Health literacy data collected using HLQ and qualitative techniques
- Data are analysed and presented to stakeholders for discussion
- Effective local practices and innovative intervention ideas are identified

Phase 2
Co-creation of health literacy interventions

- Local stakeholders make decisions about priorities for action
- Interventions with potential to respond to local health literacy needs or improve information and service accessibility are designed

Phase 3
Implementation, evaluation and ongoing improvement

- Health literacy interventions applied as quality improvement cycles
- Organisations actively improve effectiveness, uptake and sustainability of interventions

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Ophelia Victoria - methods

- Healthcare services from 4 diverse regions invited to apply:
 - community health centres, municipal councils, home nursing and hospital admission risk programs (9 sites in total)
- n=813 clients from nine sites provided HLQ and demographic data
- Semi-structured interviews with 4-6 clients at each site
 - stories behind the HLQ scores to inform vignettes
- 3-hour workshops with clinicians and managers at each site

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Expanding Health Literacy
and Health Skills

Demographic data for overall sample (n=813)		
	n (%)	Missing data (n)
Female	505 (63%)	10
Age ≥65yrs	607 (77%)	25
Lives Alone	337 (43%)	35
Lower education	376 (48%)	30
Born in Australia	541 (67%)	8
English spoken at home	723 (91%)	17
>4 chronic conditions	276 (34%)	23
Health Insurance	298 (38%)	19
Assisted with HLQ	291 (37%)	18

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Expanding Health Literacy
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Results –intervention ideas

- Cluster analysis revealed a wide range of health literacy profiles for each site
- Over 200 intervention ideas generated at feedback workshops
- Following the workshops, intervention ideas were:
 - Refined collaboratively using modified program logic models
 - Processes were pilot tested using quality cycles
 - Interventions ‘rolled out’ more broadly within each service

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‘Focus’ of intervention	Examples
Client	<ul style="list-style-type: none"> Improving skills in appraisal of information (e.g. computer courses in a disadvantaged area) Providing resources for clients to better engage with doctors
Practitioner	<ul style="list-style-type: none"> Enhanced skills for education of clients (e.g. identification of clients’ preferred learning styles) Strategies to help clients operationalise care plans (e.g. teach-back)
Organisation	<ul style="list-style-type: none"> Service access policies (e.g. directing clients with chronic disease from ‘one-off’ visits to an ongoing model of care) Nurse ‘care coordination’ in rural community health centre Training volunteers and peers to deliver health literacy messages (e.g., delivered by volunteers in rural programs)
Inter-agency	<ul style="list-style-type: none"> Engaging other organisations for mutual benefit (e.g. training members of the local Country Women’s Association as ‘health coaches’ for older community members to support falls prevention)

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and Health Skills

Evaluation of Ophelia Victoria projects occurred across multiple ‘levels’

- What changes occurred:
 - For the clients?
 - At individual clinician level?
 - At an organisational-level?
 - Were there any ‘ripple’ effects that could be measured more widely in the community?

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Evaluation of Ophelia Victoria projects

- Examples include:
 - Relevant scales of the HLQ (pre and post intervention)
 - Interviews with clients about e.g. the impact of the intervention in their everyday life
 - Interviews with clinicians about the way in which they communicate with or understand clients, or other changes to their practice
 - Disease-specific questionnaires related to knowledge or self-management skills
 - Number and type of service referrals

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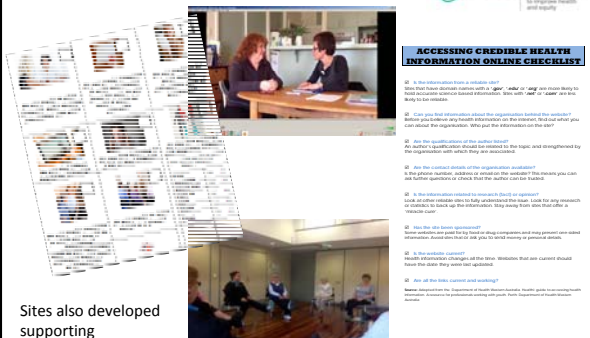
Intervention to train volunteers as health mentors in their local communities + develop supporting resources (questions for good health, video, links to reputable websites)

HLQ data (10 volunteers and 13 clients agreed to evaluation)	Have sufficient information to manage my health (scale 2)	Appraisal of health information (scale 5)	Actively engage with healthcare providers (scale 6)
	Mean (SD)	Mean (SD)	Mean (SD)
Pre intervention	2.95 (0.49)	2.89 (0.49)	4.03 (0.50)
Post Intervention	3.22 (0.50)	3.07 (0.29)	4.34 (0.61)
Effect size for difference (95% CI)	0.56 (-0.09,1.20)	0.52 (-0.13, 1.16)	0.56 (-0.11, 1.22)


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Interviews with mentors and clients were also conducted

- Community members = multiple stories of positive outcomes reported, e.g. asking more questions and feeling more prepared for GP visits.
- Volunteers = responses indicated a sense of feeling useful, alongside pride and achievement from participating in a health promoting project.
- Responses indicated a ripple effect in terms of clinicians, volunteers and clients spreading the study's message within existing circles.





Sites also developed supporting resources and programs



What next?

- Overall Ophelia evaluation – what were the organisational impacts?
- Realist analysis – what worked for whom under what circumstances?
- Development of a Health Literacy Response Framework



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

77 practitioners, 9 organisations, 200+ intervention ideas


Local stakeholders generate insights into:

1. The health literacy strengths & challenges of patients, and;
2. Potential strategies for optimising health literacy and improving organisational responsiveness

Thematic analysis of intervention ideas, and matching of themes to health literacy needs

Identification of mechanisms by which interventions influence health literacy

Identification of provider, organisational and higher order requirements




Health Literacy Response Framework - patient level responses

Strategies to support and build capacity of patients to:

1. To feel understood & supported by providers

Theme	Sub-themes
Build trust	Responsive to need, ensure consideration is given to: Duration of involvement; consistency of contact person; reliability; involvement of family/careers; rapport; honesty & transparency; persistence; planning of contacts; amount of time allowed for contacts; delivering something of use to consumer
Provide patient centered care	Ensure: a focus on patient goals; flexible mode of service delivery – out of hours, outreach, 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




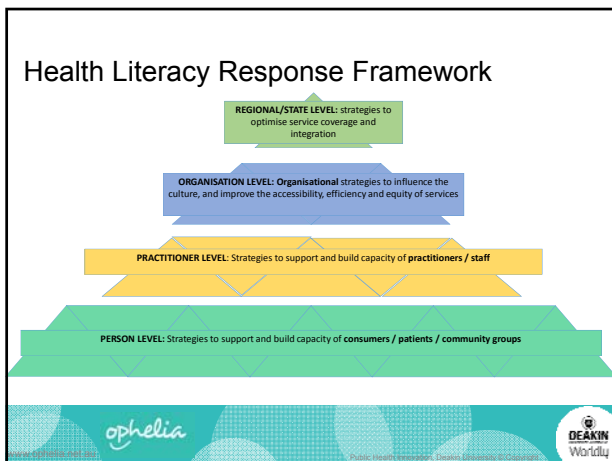
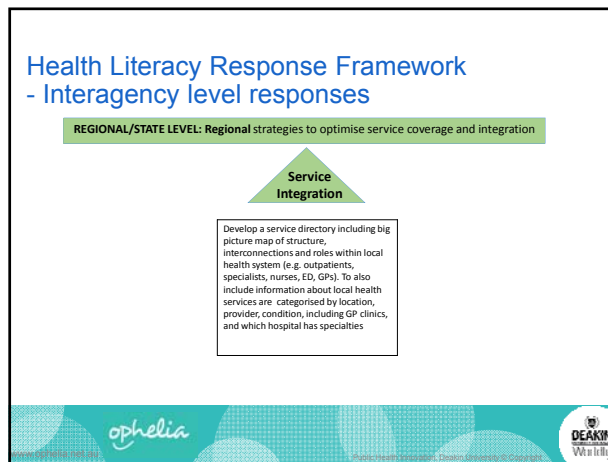
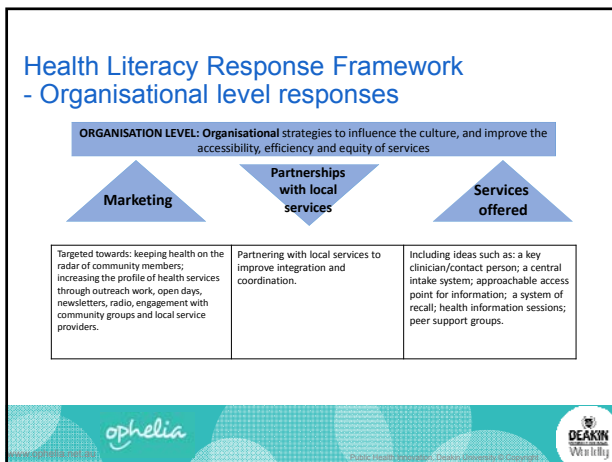
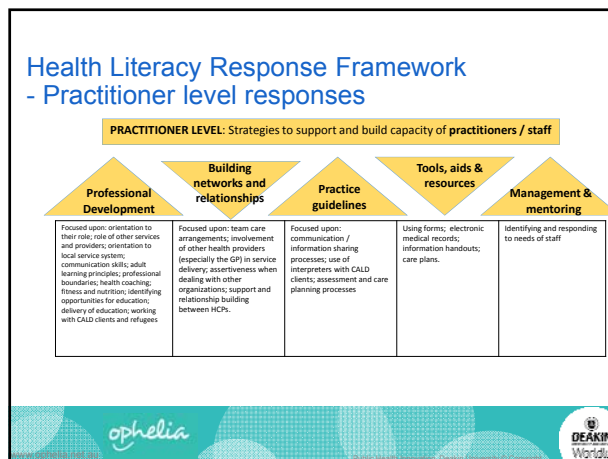
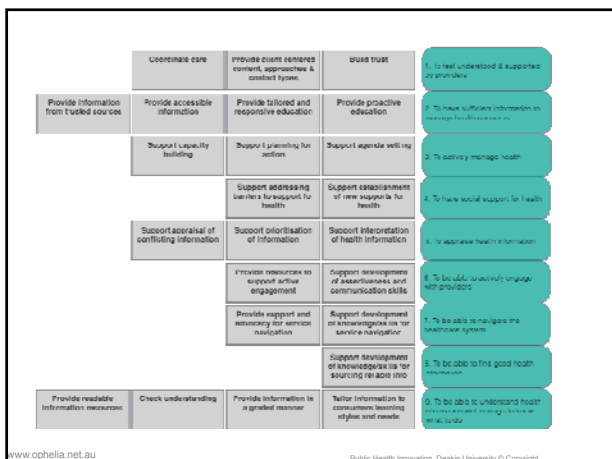
Health Literacy Response Framework - Patient level responses

1. To feel understood & supported by healthcare providers	<ul style="list-style-type: none"> Building trust Patient centered Care coordination
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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 communication skills	The majority of interventions were successful in increasing pt-centred approaches in consultations, and in patient satisfaction with care





Ophelia Toolkit



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

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

Thank you!

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