

Health Literacy: a fundamental element for generating equitable patient health outcomes

Richard Osborne

Professor of Public Health

Head, Public Health Innovation

Director, Population Health Strategic Research Centre

Deakin University, Melbourne,
Australia

E-sundhedsobservatoriets årskonference 9-10th Oct 2012



Outline

1. What is health literacy?
2. Why is it important?
3. How can it be used to make things better?



Without health literacy

- If a person does not have adequate health literacy, or the health worker is unaware of the person's health literacy level, we cannot generate person-centred care.



A **very bad** potential outcome...

- If you develop an e-health intervention/system and attempt to implement it without consideration of **the needs and capabilities of users**, and how they will participate in the whole system, you are at risk of inducing health inequalities.



A solution to low health literacy?

Self-management education interventions

	Type of intervention	Examples
Individual ↓	Face-to-face consultation	Flinders University model of clinician-administered support
	Telephone coaching	Coaching patients On Achieving Cardiovascular Health (COACH) program
	Internet individual course	New South Wales Arthritis Foundation course
	Internet group course	UK National Health Service's Expert Patients Programme online
	Group: ongoing cycle	Rehabilitation programs
	Group: formal/structured	Stanford University program
	Written information	Non-government organisation publications
Population	Television/multimedia, social marketing	Back pain beliefs campaign; Quit anti-smoking campaign

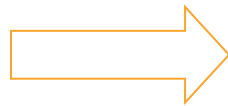


Concept mapping

Structured conceptualisation process grounded in the real world of individual

citizens, practitioners and policy makers

1. Brainstorming session



Seeding statement:

Thinking as broadly as possible, what would you want people who had done the course to say they had got out of it?

2. Sorting and rating of statements

3. Multivariate analysis (multi-dimensional scaling and cluster analysis)

4. Interpretation of maps



Components of the Health Education Impact Questionnaire (heiQ)

- From the patient, practitioner and policymaker perspective, what should self-management impact on?
 1. Positive and Active Engagement in Life
 2. Health-Directed Activities
 3. Skill and Technique Acquisition
 4. Constructive Attitudes and Approaches
 5. Self-Monitoring and Insight
 6. Health Service Navigation
 7. Social Integration and Support
 8. Emotional Distress



The Health Education Impact Questionnaire (heiQ): An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions

Richard H. Osborne^{a,*}, Gerald R. Elsworth^{b,1}, Kathryn Whitfield^{a,2}

^a Centre for Rheumatic Diseases, Department of Medicine, The University of Melbourne, Royal Melbourne Hospital, Parkville, Melbourne, Victoria 3050, Australia

^b Collaborative Institute for Research, Consulting and Learning in Evaluation, RMIT University, Melbourne, Victoria 3001, Australia

Received 6 August 2006; received in revised form 5 December 2006; accepted 10 December 2006

Abstract

Objective: This paper describes the development and validation of the Health Education Impact Questionnaire (heiQ). The aim was to develop a user-friendly, relevant, and psychometrically sound instrument for the comprehensive evaluation of patient education programs, which can be applied across a broad range of chronic conditions.

Methods: Item development for the heiQ was guided by a Program Logic Model, Concept Mapping, interviews with stakeholders and psychometric analyses. Construction ($N = 591$) and confirmatory ($N = 598$) samples were drawn from consumers of patient education programs and hospital outpatients. The properties of the heiQ were investigated using item response theory and structural equation modeling.

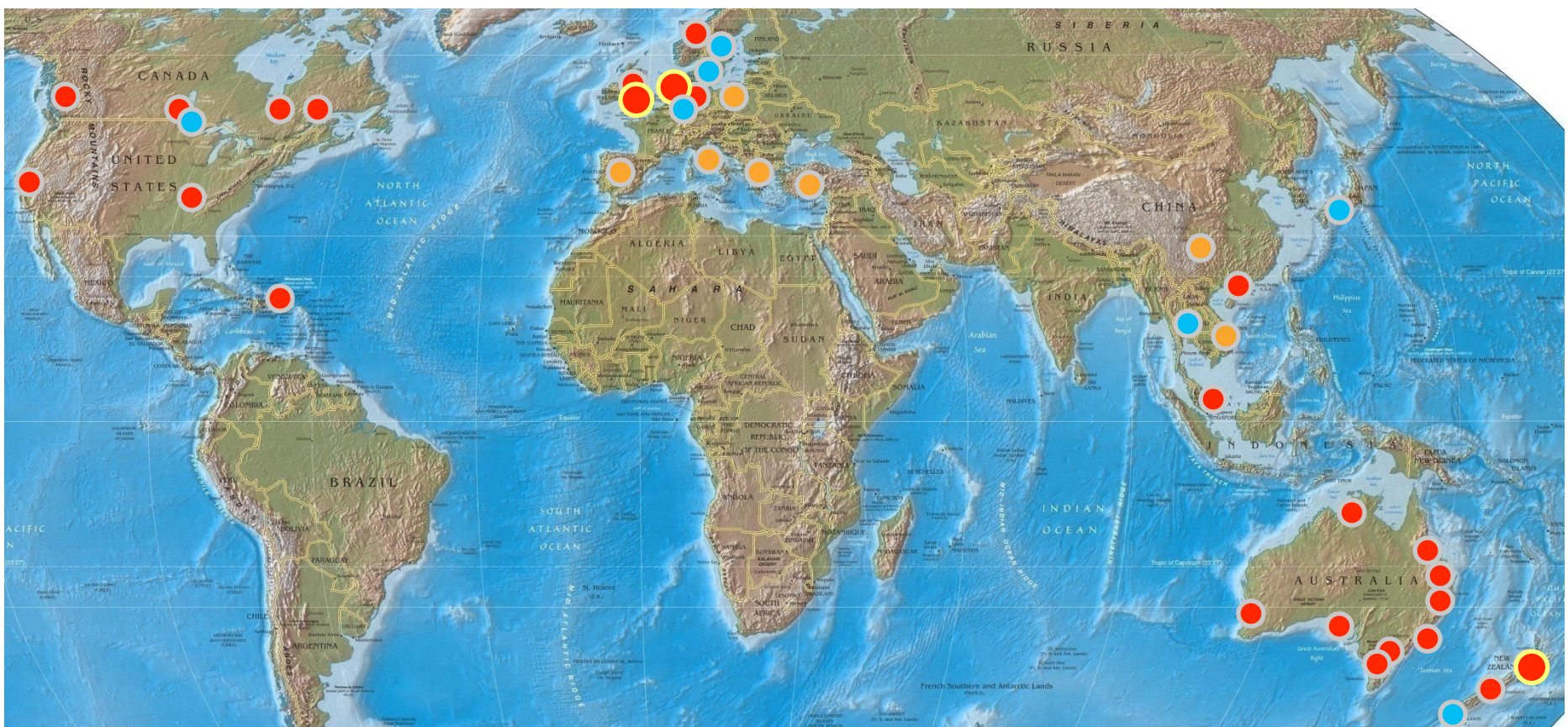
Results: Over 90 candidate items were generated, with 42 items selected for inclusion in the final scale. Eight independent dimensions were derived: Positive and Active Engagement in Life (five items, Cronbach's alpha (α) = 0.86); Health Directed Behavior (four items, α = 0.80); Skill and Technique Acquisition (five items, α = 0.81); Constructive Attitudes and Approaches (five items, α = 0.81); Self-Monitoring and Insight (seven items, α = 0.70); Health Service Navigation (five items, α = 0.82); Social Integration and Support (five items, α = 0.86); and Emotional Wellbeing (six items, α = 0.89).

Conclusion: The heiQ has high construct validity and is a reliable measure of a broad range of patient education program benefits.

Practice Implications: The heiQ will provide valuable information to clinicians, researchers, policymakers and other stakeholders about the value of patient education programs in chronic disease management.

The map displays the following distribution of colored dots across the world:

- Red Dots:** Located in Canada (two), the United States (two), the Caribbean Sea (one), Brazil (one), India (one), and Australia (four).
- Blue Dots:** Located in Canada (one), the United States (one), Europe (two), China (one), and New Zealand (one).
- Orange Dots:** Located in Europe (three), China (two), and Australia (one).
- Yellow Dots:** Located in Europe (two) and New Zealand (one).



Foundations of 'self-care' and 'self-management'

- "Command" over healthcare system (e.g., treatments, care providers)
- Access to opportunities to engage in healthy activities
- Confidence to take initiative
- Supportive environments to engage in and maintain healthy behaviours

Action planning, Problem-solving

- | | |
|---|--|
| 1. Positive and active engagement in life | 5. Health-directed activity |
| 2. Skill and technique acquisition | 6. Constructive attitudes and approaches |
| 3. Self-monitoring and insight | 7. Health service navigation |
| 4. Social integration and support | 8. Emotional wellbeing |

Faculties to distinguish correct/useful information from incorrect/unimportant information

Access to information about health and health professionals

Capacity to understand information about health

Capacity to identify / recognise health messages

Jordan JE, Briggs AM,
Brand C and Osborne RH
(2008) *Medical Journal of
Australia*. 189: 9-13



Health Literacy: several definitions

- “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)
- “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)
- “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 2011)



BBC Asia Edition

Bringing a local perspective to global news New from BBC.com

4 November 2011 Last updated at 09:10 GMT

103 [Share](#) [f](#) [t](#) [e](#) [p](#)

Poor patient literacy 'hampers healthcare'

[COMMENTS \(4\)](#)

By Dr Barry Parker

Medical and Dental Defence Union of Scotland

Patients aren't expected to understand medical jargon, but how do doctors ensure that those who lack basic reading skills get the right care? There has been a surge of written information in leaflets and online but, in this week's *Scrubbing Up*, Dr Barry Parker of the MDDUS, says doctors should not see those as substitutions for talking things through with patients.



One in six people in the UK have a literacy level below that expected of an 11-year old.

This is alarming enough in terms of the ability to manage day-to-day activities, but problems may be even more widespread if we consider health literacy, which is an individual's ability to read, understand and use healthcare information to make decisions and follow instructions for treatment.

Literacy difficulties may stem from a variety of factors including conditions such as dyslexia, health problems, disrupted schooling or stresses acting as barriers to learning in childhood.

Unfortunately, stigma still surrounds adults who struggle to read and they are often too embarrassed to disclose any literacy difficulties, even in the confidential setting of a doctor's consulting room.

Scrubbing Up

'Shame on us nurses'

Alcohol limits
'confusing'

C-section myths
perpetuated

'Move child care'

Top Stories



Italian PM wins
confidence vote

Mass arrests at Occupy protests

'Ghost mountains mystery solved'

Fears grow over Iran nuclear plan

Obama 'assassination bid' charge

ADVERTISEMENT

Asia Edition

Bringing a local perspective to global news



New from BBC.com

Features & Analysis



Killing time

Do people want their TV much slower now?

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

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.

According to the Affordable Care Act of 2010, health literacy is the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions. An increasing

eracy is a dynamic systems issue,² reflecting the complexity of both the health information being presented and the health care system being navigated.³ As summarized by the Institute of Medicine, addressing the challenge of health literacy requires system-level changes for both health

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, Georgia.

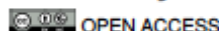
Cindy Brach is a senior health policy researcher at AHRQ.

Linda M. Harris is senior health communication and e-health adviser to the deputy assistant secretary for health, disease prevention, and health promotion at HHS, in



RESEARCH

Association between low functional health literacy and mortality in older adults: longitudinal cohort study



Sophie Bostock *research associate*, Andrew Steptoe *professor of psychology*

Department of Epidemiology and Public Health, University College London, London WC1E 6BT, UK

Abstract

Objective To investigate the association between low functional health literacy (ability to read and understand basic health related information) and mortality in older adults.

Design Population based longitudinal cohort study based on a stratified random sample of households.

Setting England.

Participants 7857 adults aged 52 or more who participated in the second wave (2004-5) of the English Longitudinal Study of Ageing and survived more than 12 months after interview. Participants completed a brief four item test of functional health literacy, which assessed understanding of written instructions for taking an aspirin tablet.

Main outcome measure Time to death, based on all cause mortality through October 2009.

Results Health literacy was categorised as high (maximum score, 67.2%), medium (one error, 20.3%), or low (more than one error, 12.5%). During follow-up (mean 5.3 years) 621 deaths occurred: 321 (6.1%) in the high health literacy category, 143 (9.0%) in the medium category, and 157 (16.0%) in the low category. After adjusting for personal characteristics, socioeconomic position, baseline health, and health behaviours, the hazard ratio for all cause mortality for participants with low health literacy was 1.40 (95% confidence interval 1.15 to 1.72) and with medium health literacy was 1.15 (0.94 to 1.41) compared with participants with high health literacy. Further adjustment for cognitive ability reduced the hazard ratio for low health literacy to 1.26 (1.02 to 1.55).

Conclusions A third of older adults in England have difficulties reading and understanding basic health related written information. Poorer understanding is associated with higher mortality. The limited health literacy capabilities within this population have implications for the design and delivery of health related services for older adults in England.

Introduction

Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make basic health decisions.”^{1,2} The World Health Organization and organisations responsible for public health in the United States and Canada have identified health literacy as an important determinant of population health.^{3,5} A rapidly growing body of research is exploring the gap between patients’ health literacy and the capabilities needed to effectively manage health.^{2,6} For example, lower health literacy is associated with less knowledge of chronic disease processes,⁷ poorer mental and physical health, limited use of preventive services, and higher rates of hospital admissions.⁸ Evidence for these associations emanates largely from the United States.⁹ In the United Kingdom, patients are increasingly expected to become active partners in their care, yet neither “health literacy” nor “literacy” is explicitly mentioned by the government in recent health strategies.^{10,11} Is health literacy an important determinant of health outcomes in the context of universal healthcare provision? We investigated the association between health literacy and mortality among older adults in England.

In this study we focus on functional health literacy—being able to apply reading skills and basic knowledge in a health context.¹² Health literacy, based on widely used measures of health related word recognition and comprehension, correlates strongly with general literacy^{13,14} but is assessed with greater health specific content.¹⁵ Health literacy is also associated with cognitive abilities, including processing speed and working memory.^{16,17} Low health literacy is predicted by older age, lower income, fewer education qualifications, and being from an ethnic minority group, yet the relation between health literacy and



“Health Literacy” is now in many parts of EU policy

- WHO Europe
 - Health 2020
 - Health Literacy – The solid facts
- European Commission
 - White Paper: Together for Health 2008-2013
 - Health for Growth for Citizens
- OECD
 - Agenda item in the Economic and Social Council.



What is the association between Health Literacy and Health Outcomes



Lower health literacy associated with:

- inadequate knowledge about health and healthcare system
- increased hospitalisation
- poor access and utilisation of health services
- People with lower health literacy ~ 1.5 to 3 times more likely to experience poor health event
- **Based on blunt measures of health literacy**

De Walt DA, et al. Literacy and health outcomes: a systematic review of the literature. J Gen Intern Med 2004;12:1228-39.



How has health literacy been measured?

- Mostly been assessed through measuring reading ability, comprehension and word recognition skills
- Key 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**)
- Key audits and surveys
 4. Audit of written materials / signage
 5. National Literacy Surveys



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;23:433-5.



Test of Functional Health Literacy in Adults: TOFHLA

Numeracy (17 items)

Abbocillin 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? _____

Newest vital sign (NVS)

Nutrition Facts			
Serving Size		½ cup	
Servings per container		4	
Amount per serving			
Calories	250	Fat Cal	120
			%DV
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, Water, 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.

Application of existing measures of health literacy

- Prevalence of low health literacy in Australia

*Barber M, Staples M, Osborne RH, Clerehan R, Elder C, Buchbinder R. Up to a quarter of the population may have suboptimal health literacy: a population-based survey. **Health Promotion International** 2009; 24:252-261.*



Prevalence of low health literacy

REALM	(N = 310)
Grade 4 or below may need low literacy materials; may not be able to read	6 (2%)
Grade 5-6 may need low literacy materials; may not be able to read	35 (11%)
Grade 7-8 may need low literacy materials; may not be able to read	269 (87%)

National survey (NAAL)
suggested that ~60% of
Australians have low
health literacy

TITLE	(N = 309)
Inadequate	8 (3%)
Marginal	13 (4%)
Adequate	288 (93%)

NVS	(N = 308)
0-1	22 (7%)
2-3	58 (19%)
4-6	228 (74%)

Will the real level of
health literacy please
stand up?

Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses

Joanne E. Jordan^{a,*}, Richard H. Osborne^{a,b}, Rachelle Buchbinder^{c,d}

^aDepartment of Medicine, Centre for Rheumatic Diseases, The Royal Melbourne Hospital, The University of Melbourne, Parkville, Victoria, Australia

^bPublic Health Research and Evaluation and Policy Cluster, School of Health and Social Development, Deakin University, Melbourne, Victoria, Australia

^cMonash Department of Clinical Epidemiology at Cabrini Hospital, Monash University, Victoria, Australia

^dDepartment of Epidemiology and Preventive Medicine, School of Public Health and Preventive Medicine, Monash University, Cabrini Medical Centre, Victoria, Australia

Accepted 13 April 2010

Abstract

Objective: Health literacy is defined as an individual's ability to understand and use health information. The purpose of this study was to evaluate the validity and reliability of health literacy indices and to determine whether they measure the same construct.

The definition of Health Literacy: does not match what current tools measure!

Tests fail to meet fundamental measurement criteria

The 'cutting edge' of Health Literacy Approaches

- Health Literacy Survey – Europe (HLS-EU)
 - Europe
- Health Literacy Questionnaire (HLQ)
 - Australia
- e-Health Literacy Questionnaire
 - Denmark/Australia
- National Health Literacy Assessment for Children
 - Taiwan (Prof Annie Chieh-Hsing Liu)
- National Health Literacy Project
 - Thailand



Health literacy survey – European Union



Kristine Sørensen et al

Prof. Brand Maastricht University, the Netherlands

Prof. Agrafiotis National School of Public Health, Greece

Dr. Doyle University College of Dublin, National University of Ireland,

Prof. Pelikan Ludwig Boltzmann Gesellschaft GmbH, Austria

Prof. Slonska Instytut Kardiologii, Poland

Dr. Falcon University of Murcia, Spain

Prof. Tchamov Medical University - Sofia, Bulgaria

Dr. Droomers National Institute of Public Health and the Environment, The Netherlands

Dr. Mensing Landesinstitut für Gesundheit und Arbeit des Landes Nordrhein-Westfalen

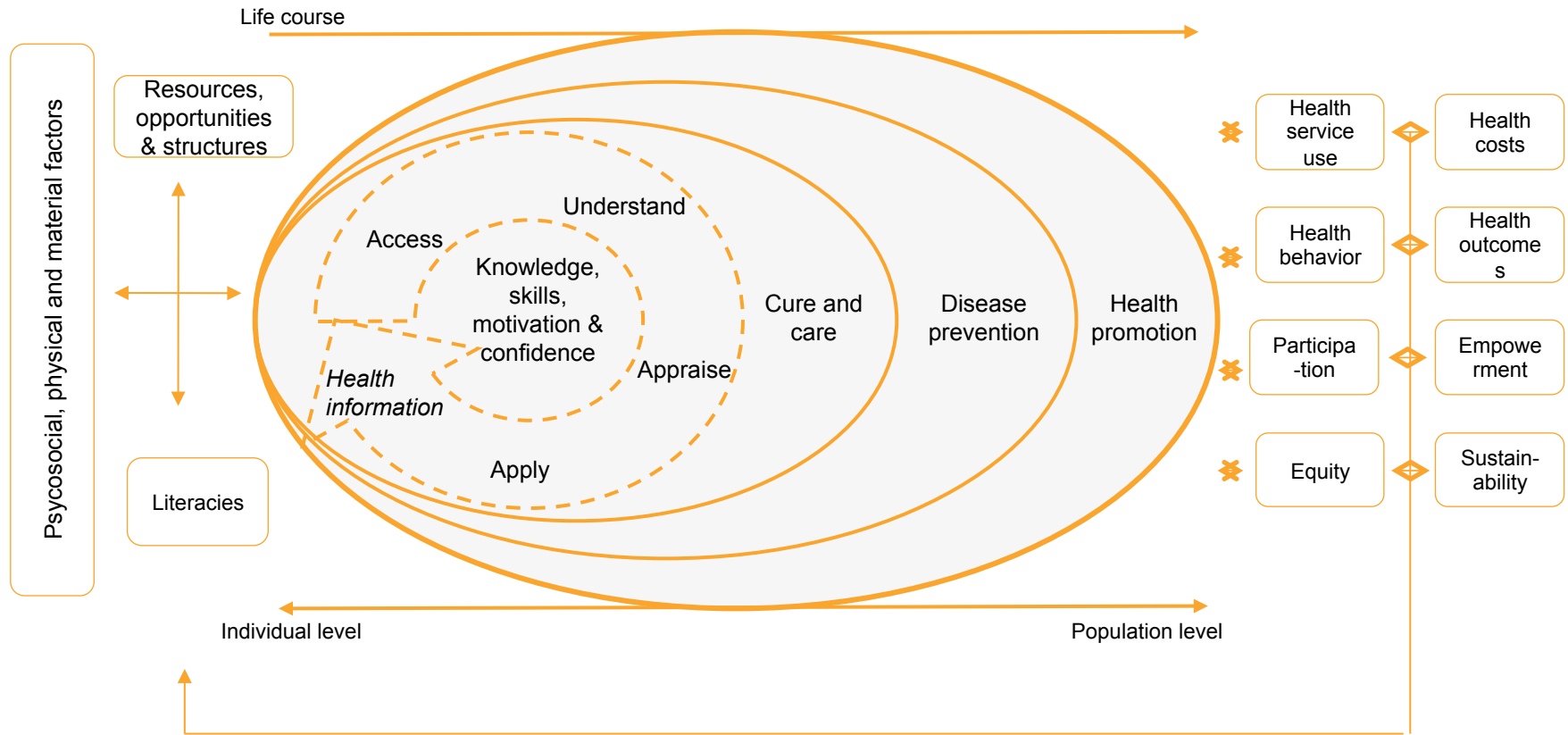
+ collaborating partners

+ technical advisors

Supported by the European Agency for
Health and Consumers



HLS-EU Conceptual model



Health literacy matrix	Access/ obtain	Understand	Appraise	Apply
Cure & Care	How easily do you find information on the following medical issues?... Cancers, resp. diseases etc.	How easily do you understand the content of the leaflets that come with medications?	Do you consider advantages and disadvantages of treatment options?	How often do you follow your doctor's advice ?
Disease prevention	How easily do you find information on the following risk factors?... tobacco, alcohol etc.			
Health promotion	How easily do you find information on the following health enhancing factors?... Nutrition and diet, exercise etc.			

What really is health literacy?



Health Literacy: several definitions

- “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)
- “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)
- “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 2011)



Development of the Health Literacy Questionnaire (HLQ)



Steps in instrument development

- 1. Purpose and conceptualisation**
- 2. Draft item development** – strict item writing rules, cognitive interviews
- 3. Administration to a ‘construction sample’** – 600+
- 4. Psychometric analysis and refinement** – structural equation modelling
+ Rasch analysis
- 5. Administration to a ‘validation sample’** – 400+
- 6. Finalization of the tool**
- 7. Develop a web of evidence of the value of the tool in target settings**



If one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there.

Søren Kierkegaard: “Synspunktet for min Forfatter-Virksomhed. En ligefrem Meddelelse, Rapport til Historien”, C.A. Reitzels Forlag, 1859.



The quest to develop a measure of health literacy that serves patients, practitioners, policymakers (2006 – 2012)

- Maximum heterogeneity
- Interviews and Concept Mapping workshops:
 - Individuals who had taken part in a chronic disease self-management program (n=20)
 - General population (n=14)
 - Individuals who recently presented to the Hospital Emergency Department (n=14)
- International workshop consultation (Borneo)
 - Expert clinicians (n=15)
 - Expert patients (n=12)
 - Community services managers/policymakers (n=10)
- Many other people across fields



Concept mapping

Structured conceptualisation process grounded in the real world of individual

citizens, practitioners and policymakers

1. Brainstorming session

2. Sorting and rating of statements

3. Multivariate analysis (multi-dimensional scaling and cluster analysis)

4. Interpretation of maps



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 in order to get and to use all of the information they need?

Person-centred health literacy

Strongly Agree—Strongly disagree

1. Healthcare provider support

- I have at least one healthcare provider who knows me well
- I can rely on at least one healthcare provider

2. Having sufficient information

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

3. Actively managing health

- I spend quite a lot of time actively managing my health
- There are things that I do regularly to become more healthy

4. Social support

- When I feel ill, the people I know can help me understand what I need
- I have at least one person I can go to for advice or support when I have a medical problem

5. Critical appraisal

- When I see new information about health, I check up on whether it is true or not
- I compare health information from different sources. When I see new information about health, I check up on whether it is true or not

Cannot do—Very easy

6. Active engagement with healthcare providers

- Feel able to discuss my concerns with a healthcare provider
- Discuss my concerns with healthcare providers until you feel satisfied

7. Understanding the healthcare system

- Know what is the best care for you
- Know which healthcare provider you need to see

8. Ability to find good health information

- Get health information in words you understand
- Find information about health problems

9. Reading & understanding health information

- Read and understand all the information on medication labels
- Understand what healthcare providers are asking you to do

10. Beliefs and values

A quote from Primary Care...

*“Richard... these are the things that doctors **hate most** about their patients”*

Now available in Danish language

Breadth and depth

- Each scale is an independent questionnaire and has items that measure a wide range of Health Literacy needs



WDIDOMM?

What Do I Do On Monday Morning?



WDIDOMM health literacy questionnaire

Strongly Agree—Strongly disagree

1. Healthcare provider support

- I have at least one healthcare provider who knows me well
- I can rely on at least one healthcare provider

2. Having sufficient information

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

3. Actively managing health

- I spend quite a lot of time actively managing my health
- There are things that I do regularly to make myself more healthy

4. Social support

- When I feel ill, the people around me really understand what I am going through
- I have at least one person who can come to medical appointments with me

5. Critical appraisal

- When I see new information about health, I check up on whether it is true or not
- I compare health information from different sources When I see new information about health, I check up on whether it is true or no

Cannot do—Very easy

6. Active engagement with healthcare providers

- Feel able to discuss your health concerns with a healthcare provider
- 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
- Find information about health problems

9. Reading & understanding health information

- Read and understand all the information on medication labels
- Understand what healthcare providers are asking you to do

10. Beliefs and values

Getting sick is part of getting old



Applications of a comprehensive measure of health literacy

Obtain a **profile** of an organisation's health literacy challenge

1. Healthcare provider support

2. Having sufficient information

3. Actively managing health

9. Reading & understand health information

4. Social support

8. Ability to find good information

7. Navigating the healthcare system

6. Active engagement with providers

5. Critical appraisal

Applications of a comprehensive measure of health literacy

Obtain a **profile** of an individual's health literacy
To support clinical practice

1. Healthcare
provider
support

2. Having
sufficient
information

3. Actively
managing
health

9. Reading &
understand
health
information

4. Social
support

8. Ability to find
good
information

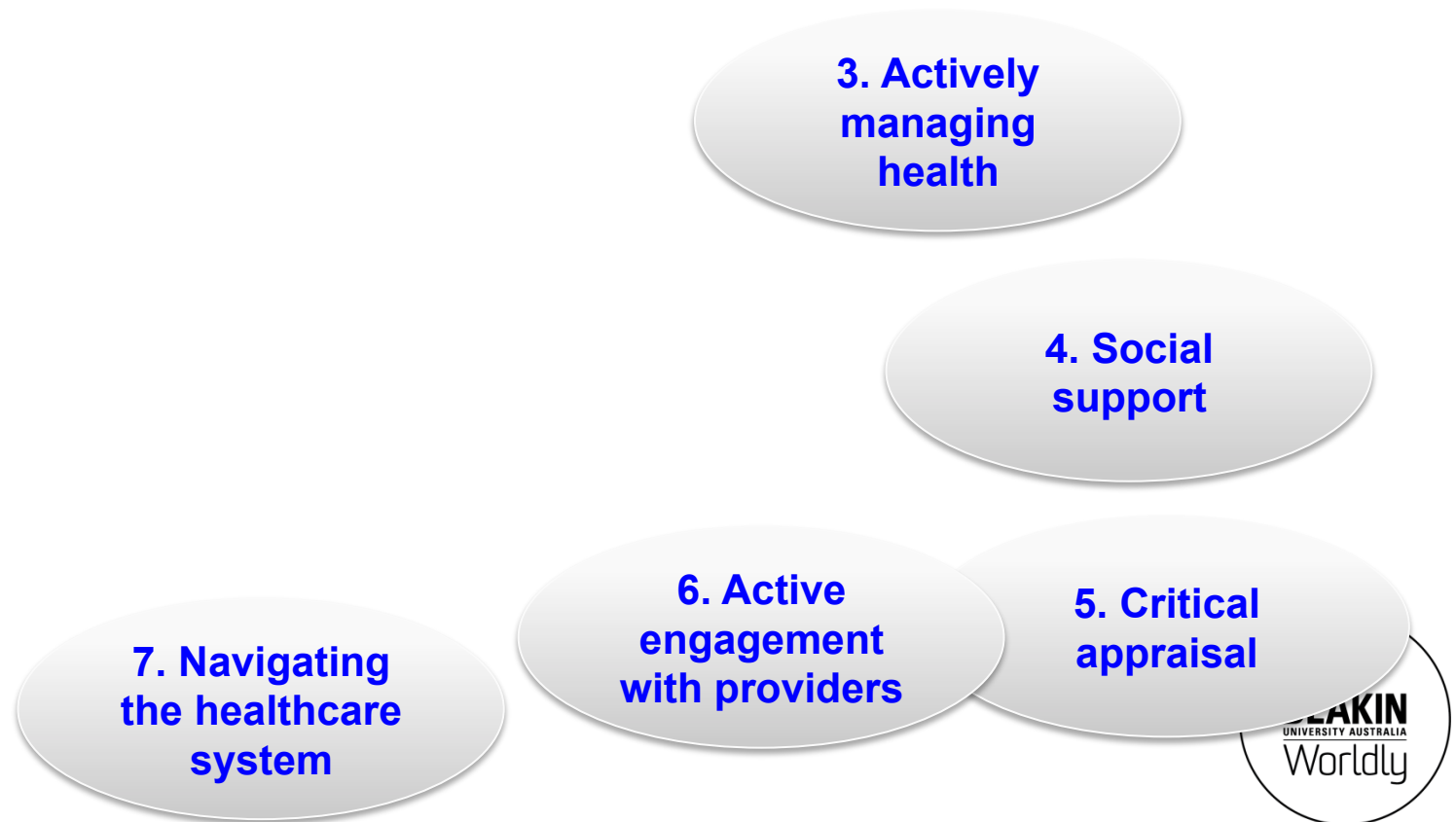
7. Navigating
the healthcare
system

6. Active
engagement
with providers

5. Critical
appraisal

Applications of a comprehensive measure of health literacy

Evaluation of an intervention aimed to empower a disadvantaged group in their self-management



Applications of a comprehensive measure of health literacy

Evaluation of a training program to improve clinician's ability to apply patient-centred care

**1. Healthcare
provider
support**

**2. Having
sufficient
information**

**8. Ability to find
good
information**

**7. Navigating
the healthcare
system**

**6. Active
engagement
with providers**



Applications of a comprehensive measure of health literacy

Obtain a **profile** of intended and unintended effect of EPITAL

1. Healthcare provider support

2. Having sufficient information

3. Actively managing health

9. Reading & understand health information

4. Social support

8. Ability to find good information

7. Navigating the healthcare system

6. Active engagement with providers

5. Critical appraisal

Applications of a comprehensive measure of health literacy

To understand the needs of citizens through surveys of target populations

We must understand **needs** so that the interventions we develop can meet these needs

1. Healthcare provider support

2

3. Actively managing health

4. Social support

8. Ability to find good information

5. Critical appraisal

Active engagement with healthcare providers

Engaging with the healthcare system

Health literacy **needs assessment**

Question asked:

Response:

Applications of a comprehensive measure of health literacy

Obtain a **profile** of an organisation's health literacy challenge



What are the capabilities and resources of an individual?
What challenges are they experiencing?

Tailoring of interventions to the level of health literacy of the target groups

Applications of a comprehensive measure of health literacy

Obtain a **profile** of an organisation's health literacy challenge



Who are our patients / citizens?
How do they respond to our services & education?

Service re-organisation to be responsive to diverse patient needs

Is the Health Literacy Questionnaire suitable to understand and evaluate e-health?



Harold and Bert looking for socks and underpants online.



e-health literacy?

- Exciting new work done by:
 - Ole Nørgaard (PhD Scholar)
 - Associate Professor Lars Kayser
 - Professor Richard Osborne
 - and others
- Centre for Human Centred Computing, Copenhagen University.



Concept mapping

Structured conceptualisation process grounded in the real world of individual

citizens, practitioners and policymakers

1. Brainstorming session

2. Sorting and rating of statements

3. Multivariate analysis (multi-dimensional scaling and cluster analysis)

4. Interpretation of maps



Seeding statement:

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

Spørgsmål

- Tag udgangspunkt i dine erfaringer omkring dit eget og/eller din families helbred. Hvad skal man kunne for at anvende digitalt baserede tilbud i sundhedssektoren?
 - Med *sundhedssektoren* tænker vi meget bredt. Dvs. alle steder, hvor der foregår behandling, genoptræning, forebyggelse eller sundhedsfremme, og på alle niveauer – hos praktiserende læger, i kommunen, på sygehusene, via staten eller hos private virksomheder.
 - *Digitalt baserede tilbud* omfatter alle former for tilbud, hvor digitale teknologier anvendes. Det er altså ikke udelukkende, hvor den traditionelle computer bruges.



Preliminary results: e-health literacy

1. Physical access to digital services that work

High: Have access to IT systems (computers and other digital media) that the users trust to be working *when* they need it and *as* they expect it to work.

2. Digital services that suit individual needs

High: Have access to digital services that are adjusted to the specific needs and preferences of the users. This includes adjustment of devices and interfaces to be used by people with physical and mental disabilities.

3. Feel motivated in to engage with IT as will be beneficial

High: Feel that engaging in the use of IT will help them in managing their health more effectively than by other means.

4. Know how to engage with information and systems

High: Know how to find, understand and use information by using IT systems.

5. Feel safely in control of data and system

High: 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 relevant (own doctor, own nurse etc.).

6. Work with information – reading, writing, understanding and remembering

High: Able to read, write, remember, apply basic numerical concepts and understand context-specific language (e.g. health, IT or English).

7. Knowing about one's own health

High: 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.

Preliminary results: e-health literacy

- 1. Physical access to digital services that work**
- 2. Digital services that suit individual needs**
- 3. Feel motivated in to engage with IT as will be beneficial**
- 4. Know how to engage with information and systems**
- 5. Feel safely in control of data and system**
- 6. Work with information – reading, writing, understanding and remembering**
- 7. Knowing about one's own health**



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**

- This is where you come in...



You are all invited...

To help with the validation of the e-health literacy tool
To use the Health Literacy Questionnaire (Danish)

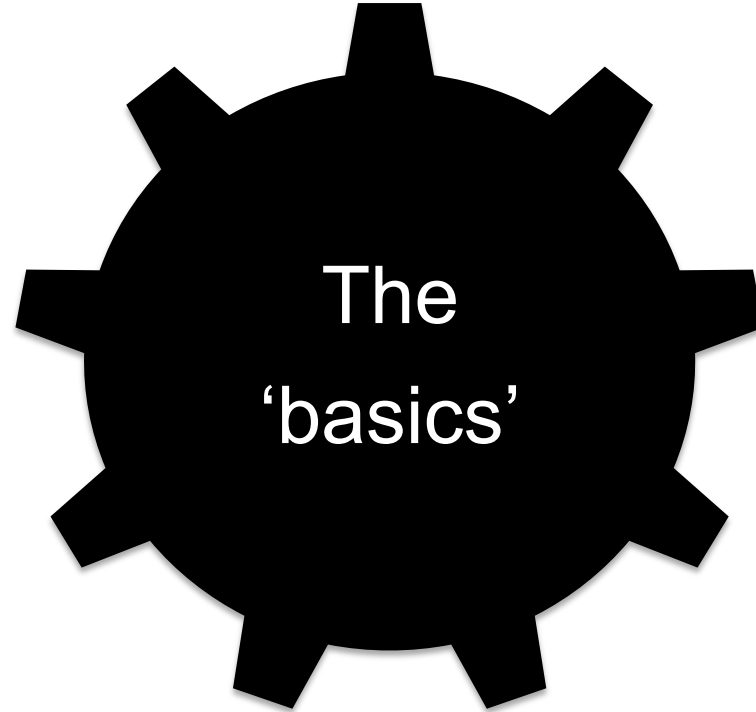
Further information:

- Ole Nørgaard
- onf@sund.ku.dk



Does Health Literacy make a Citizen's world go around?

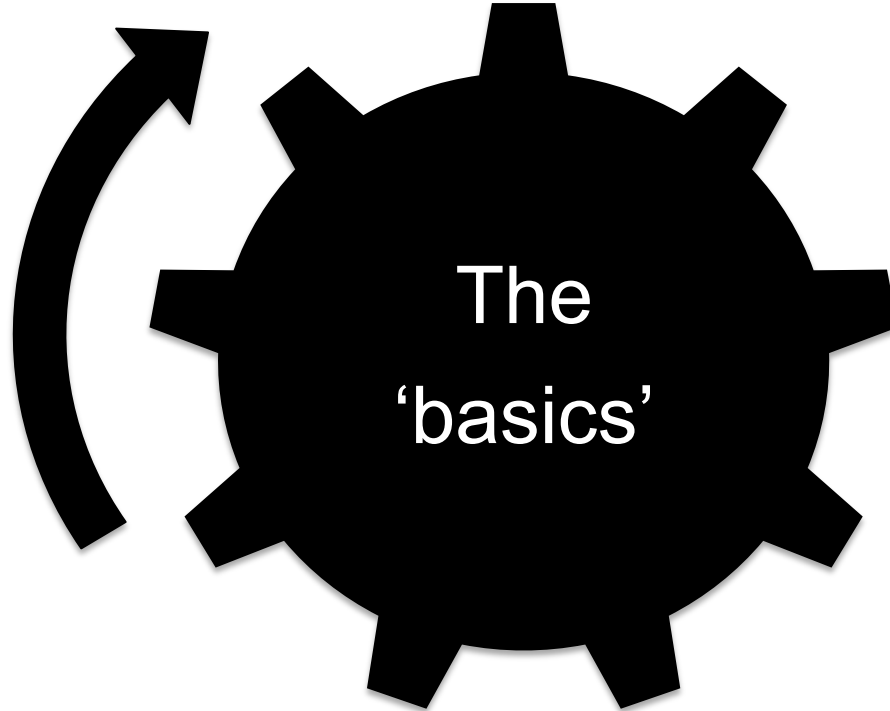




- Housing
- Resources
- Support
- Wellbeing
- Advice
- Coaching
- Other

Does Health Literacy make a
Citizen's world go around?

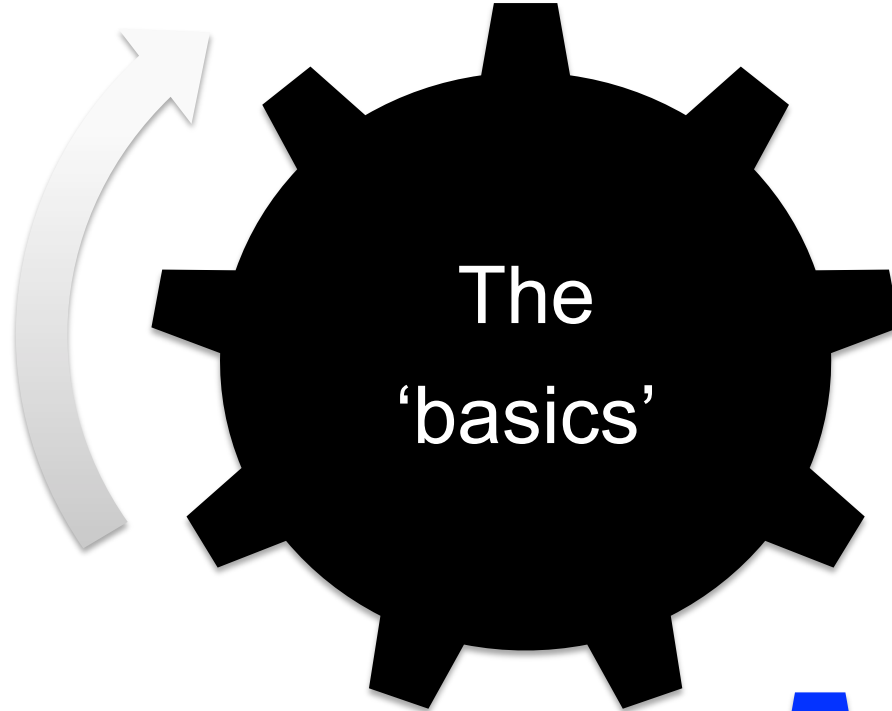




- Housing
- Resources
- Support
- Wellbeing
- Advice
- Coaching
- Other

Does Health Literacy make a
Citizen's world go around?



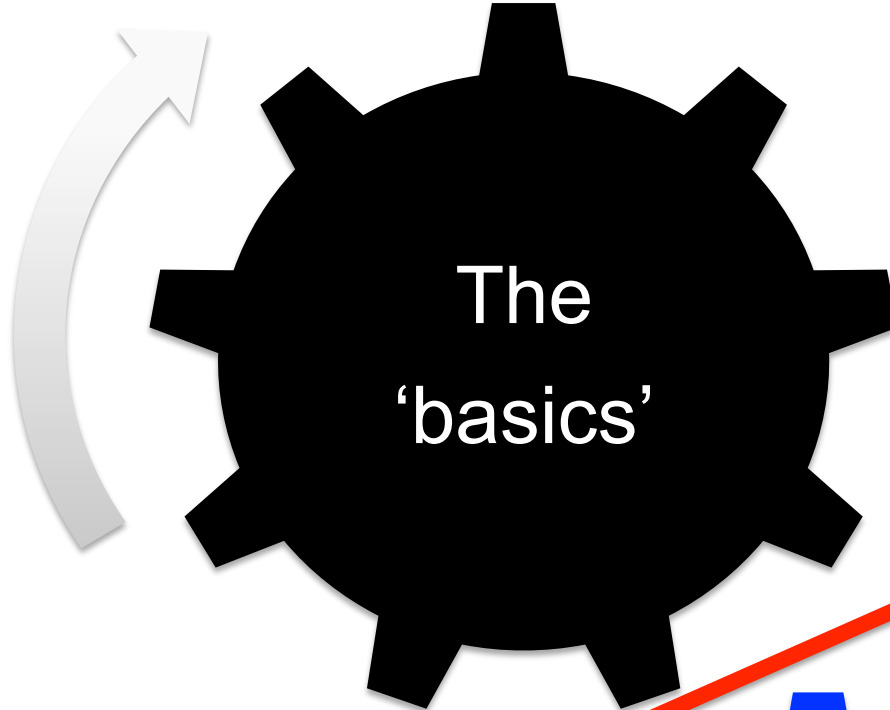


- Housing
- Resources
- Support
- Wellbeing
- Advice
- Coaching
- Other

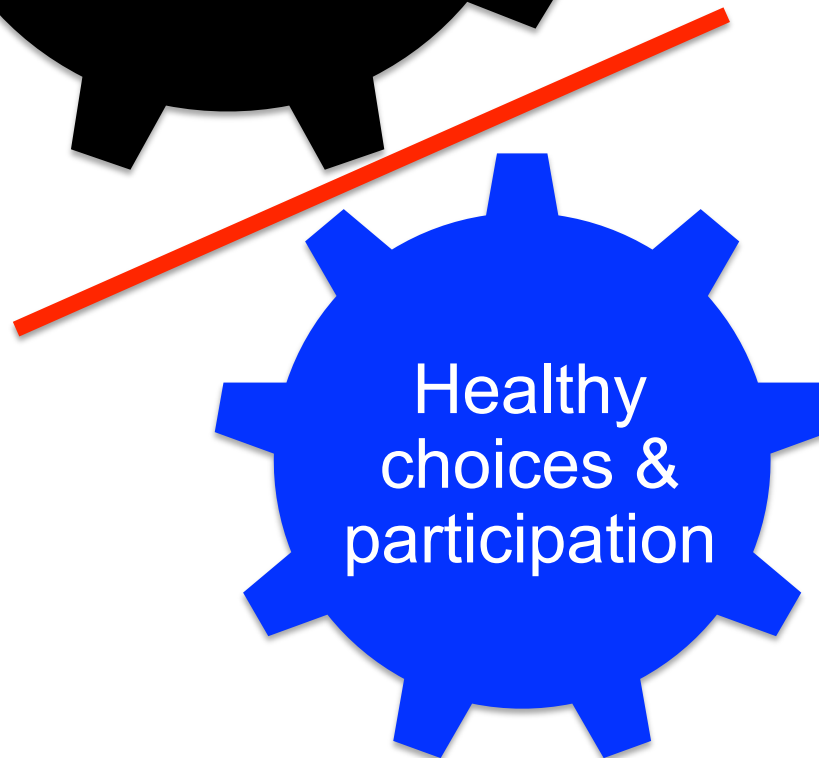


- Informed
- Enabled
- Healthy
productive
lives



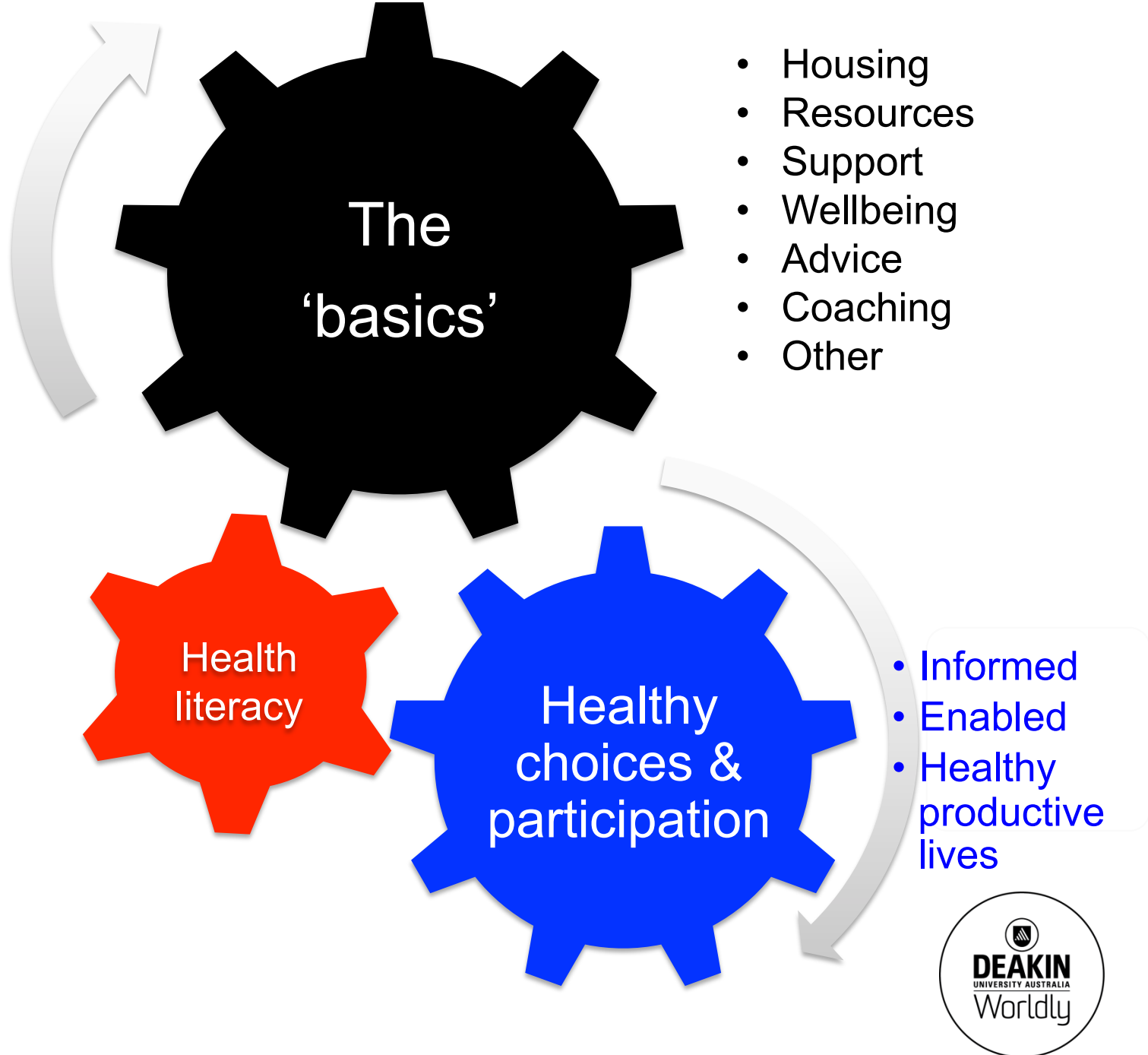


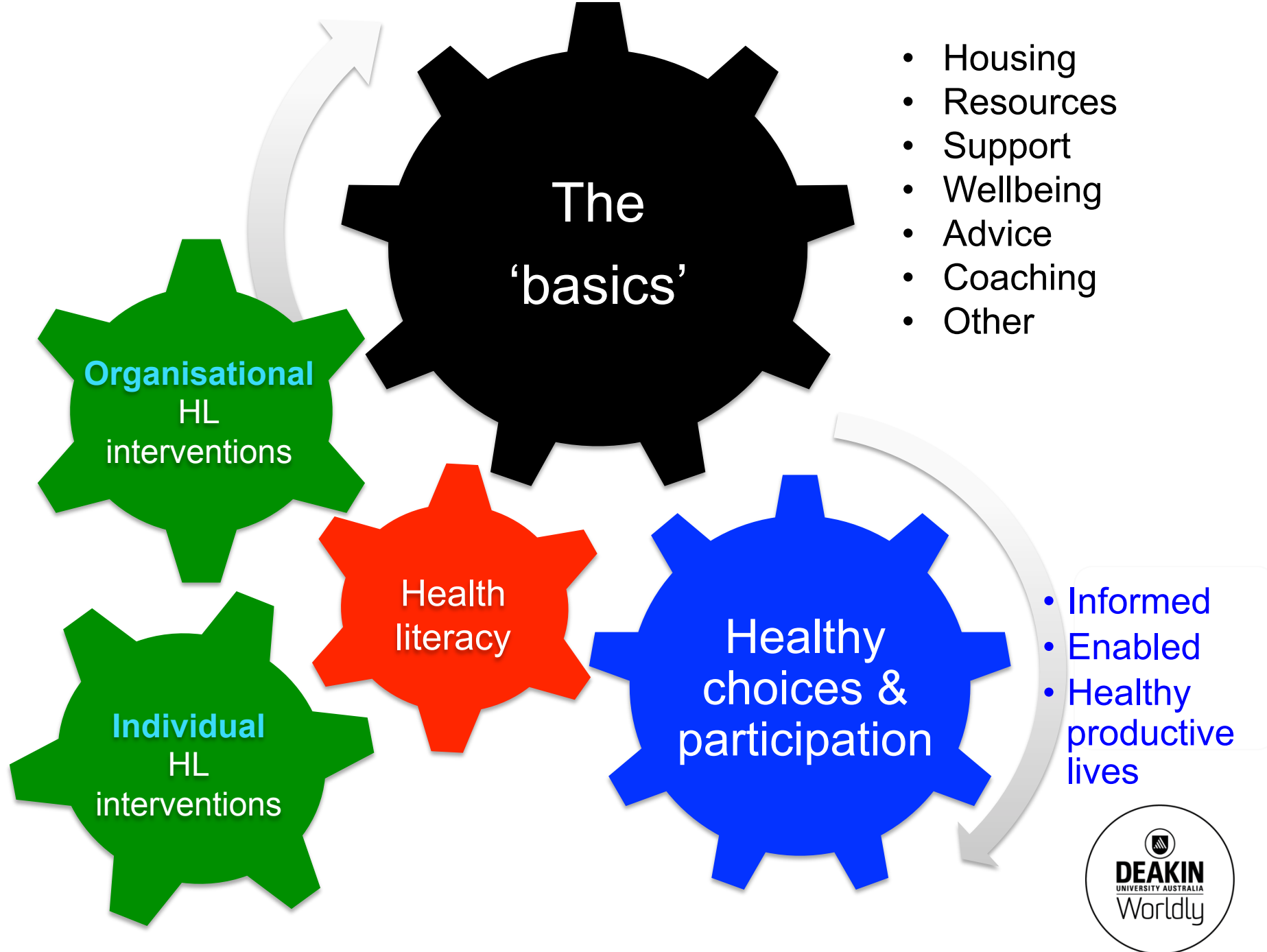
- Housing
- Resources
- Support
- Wellbeing
- Advice
- Coaching
- Other



- Informed
- Enabled
- Healthy
productive
lives







- Measurement is not enough!
- What health literacy interventions should I put in place?



WDIDOMM?

What Do I Do On Monday Morning?



Applications of the health literacy questionnaire(s)

- Needs assessment
 - Who are our citizens?
- Benchmarking
 - Do people leave our health services with higher health literacy compared with when they enter?
- Understand mechanisms
 - Who complies with treatment / e-health intervention and why?
- Outcomes assessment
 - Have your participants received proximal benefits?
 - Does low health literacy kill people?



Development of the Victorian Health Literacy Response Framework

Australian Research Council (ARC)

Linkage Grant (2012-2015)

- **Chief Investigators**

- Prof Richard Osborne
- Prof Rachelle Buchbinder
- Dr Alison Beauchamp

- **Associate Investigators**

- Roy Batterham
- Dr Sarity Dodson
- Prof Gerald Elsworth

- **Partner – Victorian Government**

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

- **PhD Scholars wanted**



Health literacy **needs assessment**

Question asked:

Response:

Applications of a comprehensive measure of health literacy

Obtain a **profile** of an organisation's health literacy challenge



Patient level: What are the capabilities and resources of an individual?
How do you help them?

Tailoring of interventions to the level of health literacy of the target groups

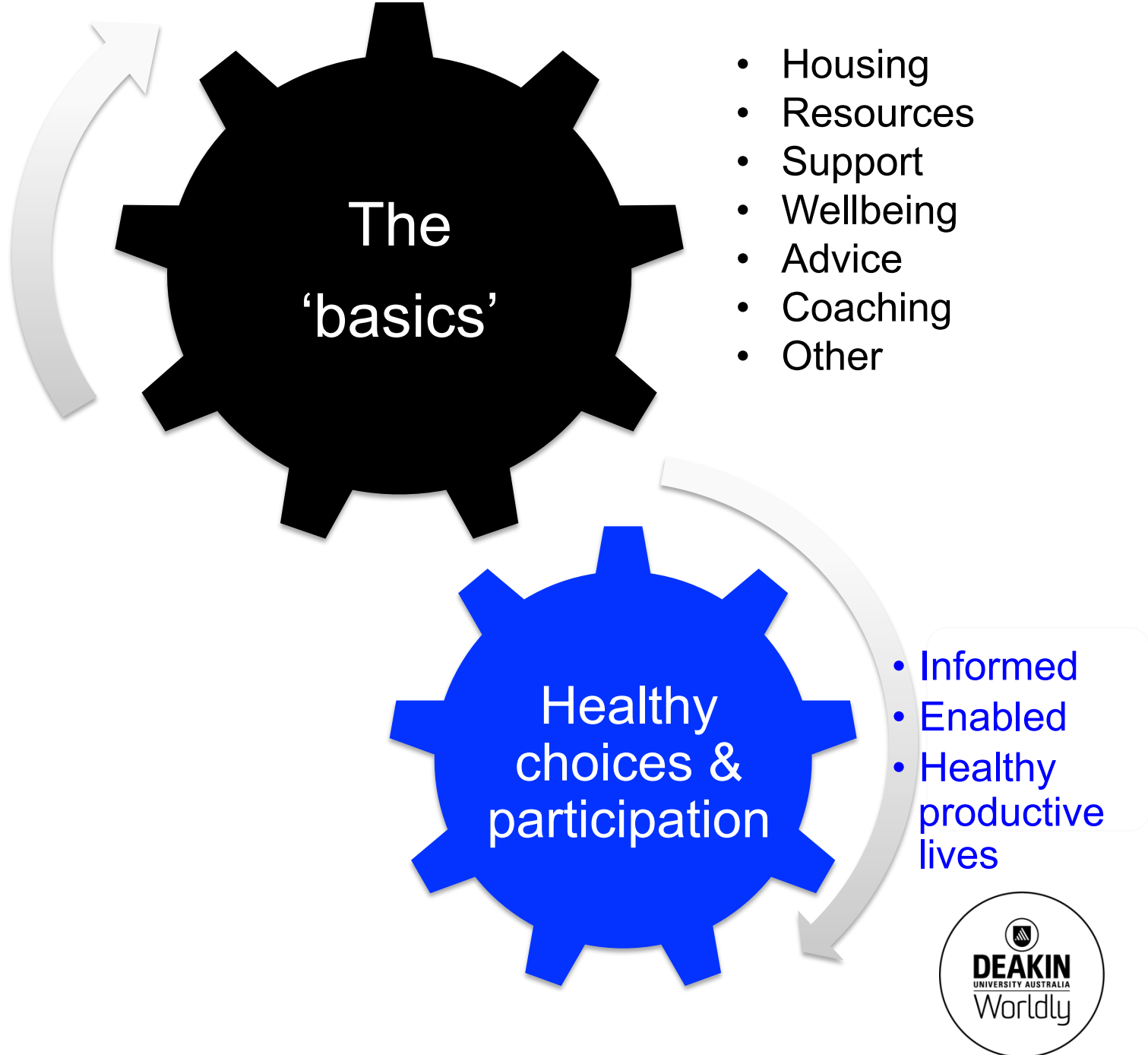
Applications of a comprehensive measure of health literacy

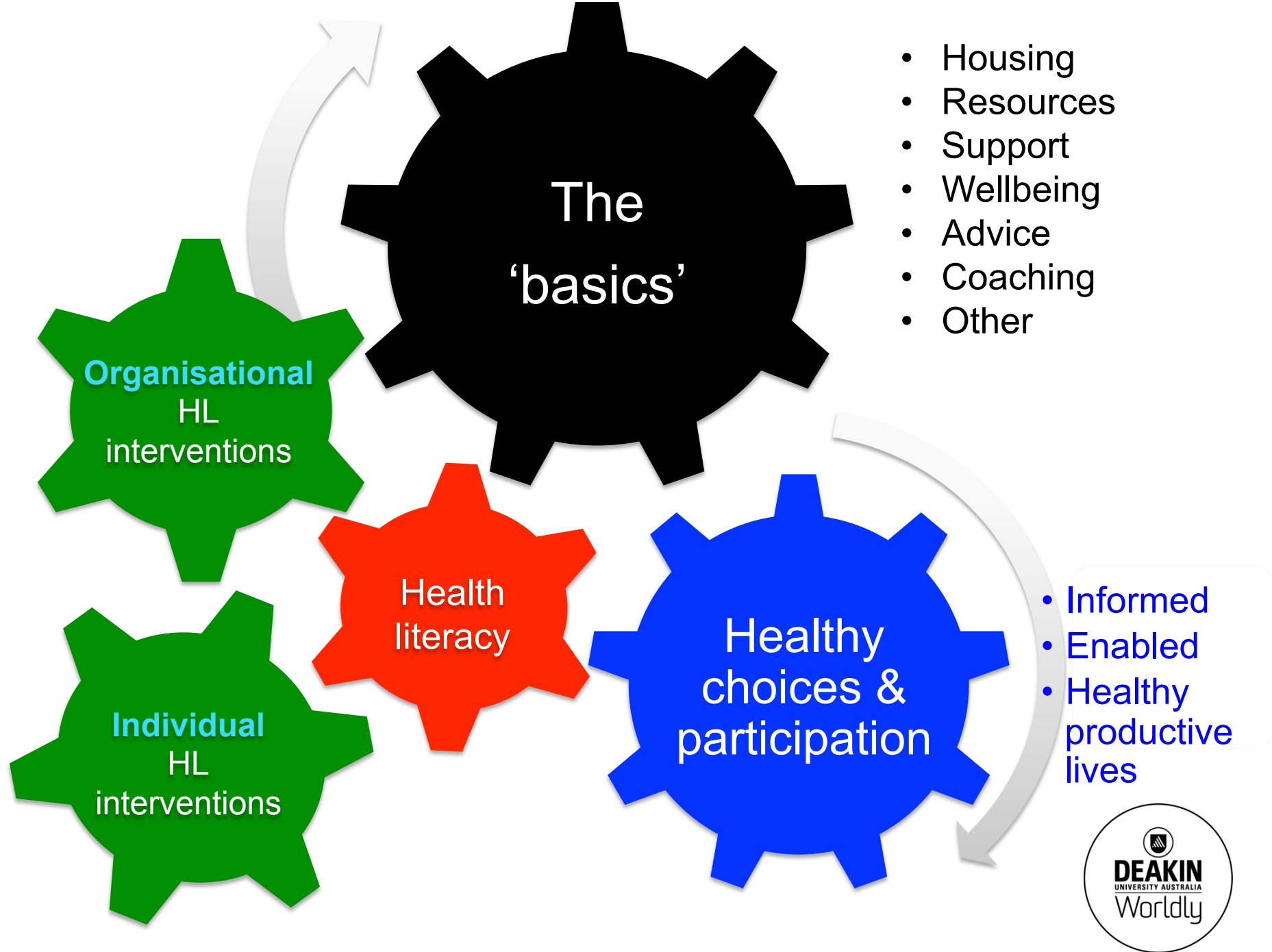
Obtain a **profile** of an organisation's health literacy challenge



Organisation level: Who are our patients / citizens?
What services are needed, how can services be reorganised?

Service re-organisation to be responsive to diverse patient needs





What about children?

The new person

Strongly Agree—Strongly Disagree

1. Healthcare navigation

I have at least one health provider who knows me well

Perceived information adequacy

I have the information I need to manage my health properly

Responsibility for health

I have goals about health and fitness

Health focused

Health is important to me

Social support

If I need help, I have plenty of people I can rely on

6. Critical appraisal

I know which places provide health information that I can trust

But can health education improve health literacy in children?

Equitable health outcomes / informed and empowered adults

These are the skills we need our children to have as they enter adulthood

Health promotion: evidence pathway in schools (Taiwan)

↓ Education

- Distribution and quality of school health education

↓ Health literacy

- National survey (n=162,000)

↓ Risk factor survey

- National surveys

↓ Health status

- National surveys

Need to demonstrate causal links, i.e., change over time.

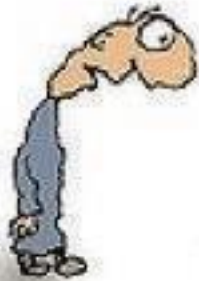
Data can then inform practice and policy



How well does your e-health intervention fit with a citizen's life?



what are
you doing?



I'm using
my device...



What is
your device?



My device is
the sky.



Does your device have
many applications?



Yes. It has sun,
moon, clouds
and birds.



And do you have
to recharge your device
very often?



I don't ever have
to recharge my device.
It recharges me.



Leung

3 steps for implementation

1

Product
design

2

Miracle

3

“Scaled up” and
implemented

Designing an intervention for successful **embedding**

Increasing implementation success



**Massive
organisational
barriers**

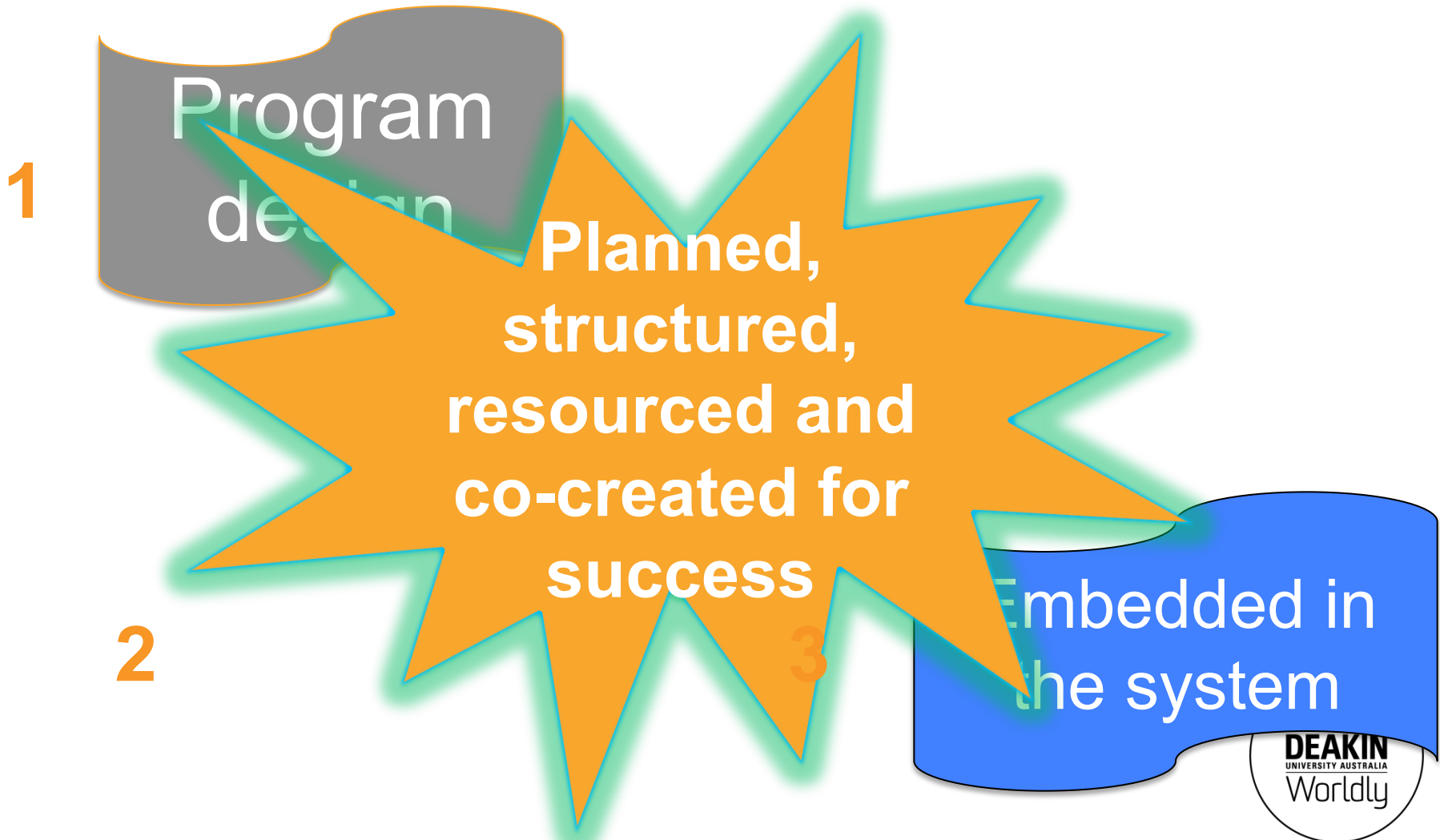
**High need for the innovation and
high readiness for change**

**Complete
Routinisation**

**Very little obvious benefit
from the innovation**

**The innovation is so good it is
'sucked' into practice**

3 steps for implementation



HOW TO GET THERE

(How to implement)

Go to the end of the path until you get to the gate.



Go through the gate and head straight out towards the horizon.



Keep going towards the horizon.



Sit down and have a rest every now and again.



But keep on going. Just keep on with it.



Keep on going as far as you can. That's how you get there



Leunig, H. (1990) The Travelling Leunig. Ringwood; Penguin.

The Health Literacy Questionnaire (HLQ)

- ✓ **Purpose and conceptualisation** – grounded approach based on widespread consultation, concept mapping
- ✓ **Draft item development** – strict item writing rules, Blooms taxonomy, cognitive interviews
 - 5 years of effort!
- ✓ **Administration to a ‘construction sample’** – 500 people across target population, 92 draft items, psychometric analysis and refinement
- ✓ **Administration to a ‘validation sample’** – 400 target population, 52 items, conformation of psychometric structure
- ✓ **Finalization of the tool**
- ✓ **Translation to Danish**

Develop a web of evidence of the value of the tool in target settings

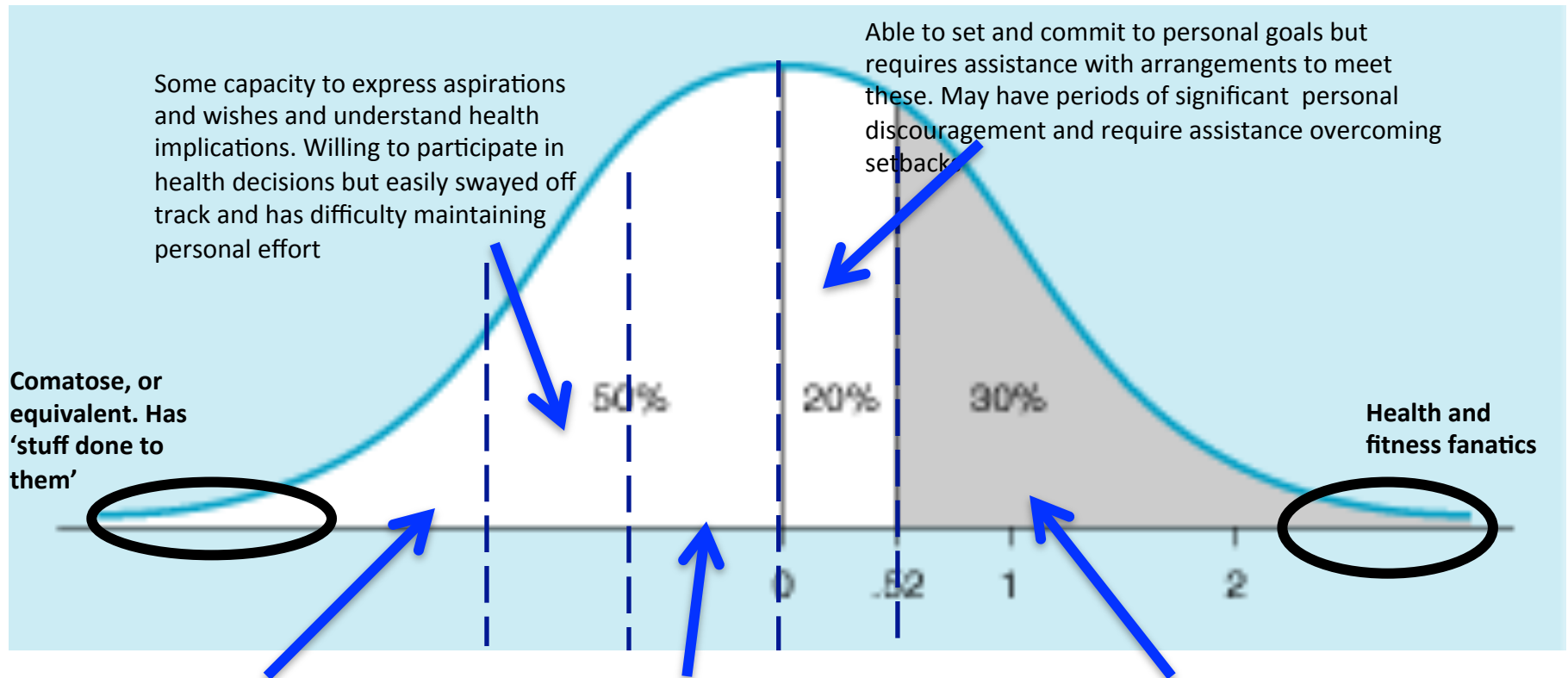
[with your help, the Danish e-health literacy tool is coming soon!]

Why is health literacy important?

1. Clinicians need to know a person's capacity to process and understand health information to be able to communicate with them effectively
2. Policymakers and health service managers need to understand the community's capacity to gain access to and understand health information to be able to set appropriate policies and provide appropriate resources
3. Researchers need to understand these issues to make correct judgments about research methods, processes, findings etc
4. Health literacy is a fundamental element of self-care, and should be considered when developing and evaluating interventions
5. We cannot provide complete health education without understanding health literacy
6. Our interventions will induce social inequalities in health if we don't include the insights of health literacy
 - A predictor of quality of entry points, participation, outcomes, equity



Conceptualising 'self-management' – its not yes or no, it's a continuum (Roy Batterham 2008)



Very little understanding of what is done to them and no emotional buy in or commitment. Cooperation ad hoc and reactive if at all.

Able to express wishes and preferences and understands how health services and personal actions can contribute to these. Actively participates in health service decisions and cooperates to the best of their ability. Piecemeal approach to personal health care actions

Stanford or Flinders 'self manager'. Able to set goals and commit to them and take initiative in accessing the means to achieve them)



Self-management: it's not “yes” or “no” (Roy Batterham 2010)

Level of self management	Strategies
5 (Classic ‘self manager’) Largely independent in looking after health at least between acute health episodes. Some regular health improvement activities. Initiates engagement with health and related providers when necessary or when they consider it beneficial.	<ul style="list-style-type: none"> • Classic health education
4 (Supported ‘self manager’) Able to set and commit to personal goals but requires assistance with arrangements to meet these. May have periods of significant personal discouragement and require assistance to overcome setbacks.	<ul style="list-style-type: none"> • Health education, • Referral • Some monitoring • ‘Coaching’ • Linkage to services, • Relapse planning
3 (Prompted ‘self manager’) Able to express wishes and preferences and understands how health services and personal actions can contribute to these. Actively participates in health service decisions and cooperates to the best of their ability. Piecemeal approach to personal health care actions.	<ul style="list-style-type: none"> • Coaching • Organise environmental stimuli • Assist to establish routines • Work with families
2 (Reactive co-operator) Some capacity to express aspirations and wishes and understand health implications. Willing to participate in health decisions but easily swayed off track and has difficulty maintaining personal effort.	<ul style="list-style-type: none"> • Assist to establish routines • Address crises • Address mental health conditions • Assist families
1 (Non-co-operator) Very little understanding of what is done to them and no emotional buy-in or commitment. Cooperation is piecemeal and reactive if given at all.	<ul style="list-style-type: none"> • Find something they ‘love’ to do • Ensure crisis needs are met • Ensure that any mental health conditions are treated • Assist families or carers • Try to establish a relationship with one or two care providers

Without health literacy

- If a person does not have adequate health literacy, or the health worker is unaware of the person's health literacy level, we cannot generate person-centred care.



With health literacy

- If a person does not have adequate health literacy **and** the health worker **is aware** of the person's health literacy level, we **can** generate person-centred care.



A **very bad** potential outcome...

- If you develop an e-health intervention/system and attempt to implement it without consideration of **the needs and capabilities of users**, and how they will participate in the whole system, you are at risk of inducing health inequalities.



A **good** potential outcome...

- If you **engage citizens** to develop an e-health intervention/system and attempt to implement it **with full consideration** of **the needs and capabilities of users**, and how they will participate in the whole system, you are **likely to force health equality and improve health outcomes**.
- It will have been co-created
- It will be fit for purpose



Do we have the solutions for
chronic disease management?



Chronic disease management



Health
Professionals



Chronic disease management

Health care

Self-management
+/- carer & family
+/- community



Foundations of 'self-care' and 'self-management'

- "Command" over healthcare system (e.g., treatments, care providers)
- Access to opportunities to engage in healthy activities
- Confidence to take initiative
- Supportive environments to engage in and maintain healthy behaviours

Action planning, Problem-solving

Positive and active engagement in life
Skill and technique acquisition
Self-monitoring and insight
Social integration and support

Health-directed activity
Constructive attitudes and approaches
Health service navigation
Emotional wellbeing

Faculties to distinguish correct useful information from incorrect/unimportant information

Access to information about health and health professionals

Capacity to understand information about health

Capacity to identify / recognise health messages

Health
literacy
competencies

Jordan JE, Briggs AM,
Brand C and Osborne RH
(2008) *Medical Journal of
Australia*. 189: 9-13



Thank you

Richard.Osborne@deakin.edu.au

