

Health literacy, chronic conditions and enhancing server user outcomes: Lessons for practice

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Today's seminar

- ▶ Examine what health literacy is and why it's important
- ▶ Examine how health literacy is measured and become familiar with health literacy in Australia
- ▶ Explore the relationship between health literacy, disadvantage and chronic conditions
- ▶ Identify potential areas for improvement in personal and agency practice

What is health literacy?

Literacy

▶ **What is it?**

- ▶ Functional literacy is a measure of a person's ability to read basic text and write simple statements relevant to everyday life

▶ **Why do we care?**

- ▶ Those who are functionally literate are able to participate more fully in society and are able to exert a higher degree of control over everyday events
- ▶ Literacy levels have been shown to be consistently related to both primary health and public health outcomes

Health literacy

- ▶ **Coulter (2008) defines health literacy as:**
 - ▶ The ability to read, understand and act upon health information
 - ▶ Reading, understanding and having the competence to make health decisions
 - ▶ Essential for service user engagement - relevant to whole population
 - ▶ Critically important in tackling health inequalities that require targeted approaches
- ▶ **As such, health literacy is a social determinant of health, which has individual, organisational and structural dimensions and implications**

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Health literacy

- ▶ **Zarcadoolas and her colleagues take the idea further:**
 - ▶ Fundamental literacy, that refers to the ability to read, write, speak, and work with numbers
 - ▶ Scientific literacy, that refers to the skills and abilities to understand and use science and technology
 - ▶ Civil literacy, that refers to skills and abilities that enable citizens to recognise public issues and participate in civil society
 - ▶ Cultural literacy, that refers to the ability to recognise, understand, and use the collective beliefs, customs, and worldview, and social identity of diverse individuals to interpret and act on information

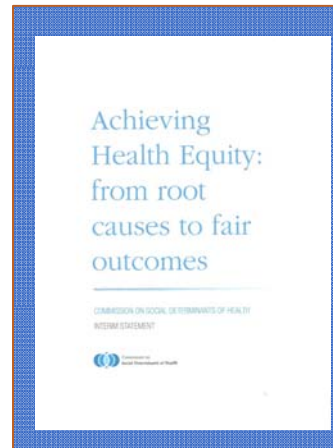
▶ Source: Zarcadoolas, Pleasant, & Greer (2005)

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Commission on the Social Determinants of Health

Education and the life-course

- ▶ “Removing the numerous barriers to achievement of primary education will be a crucial part of action on the social determinants of health”
- ▶ Literacy has “central role in health equity” in countries rich and poor



▶ Source: http://www.who.int/social_determinants/resources/interim_statement/en/index.html

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The Australian context

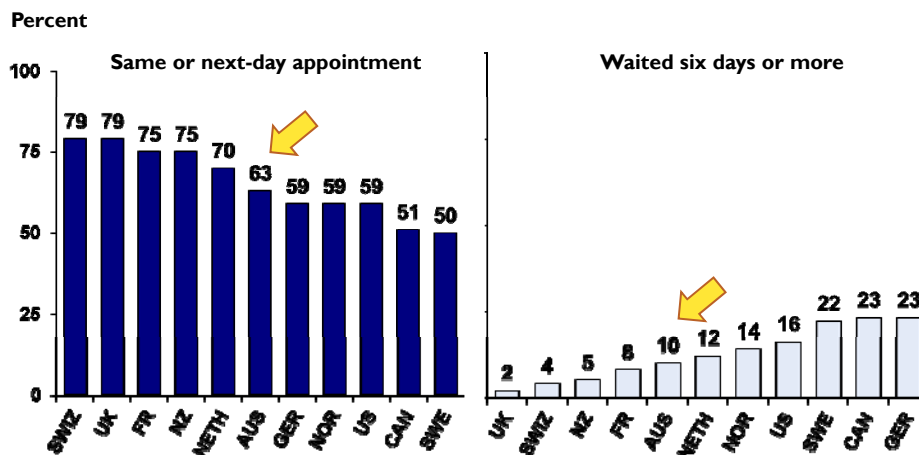
2011 Survey Profile of Sicker Adults

Percent	AUS	CAN	FR	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
Age 50 or older	57	50	54	60	57	54	60	58	63	62	56
Has two or more chronic conditions (out of eight)	44	41	34	42	34	34	35	26	37	45	53
Health care use in past two years:											
Hospitalised	54	37	51	43	40	50	46	48	54	48	40
Surgery	43	37	36	37	39	46	38	35	46	41	38
Saw four or more doctors	32	21	23	36	24	26	19	23	6	16	21
Taking four or more prescription medications regularly	28	30	26	24	31	27	29	30	24	35	37

Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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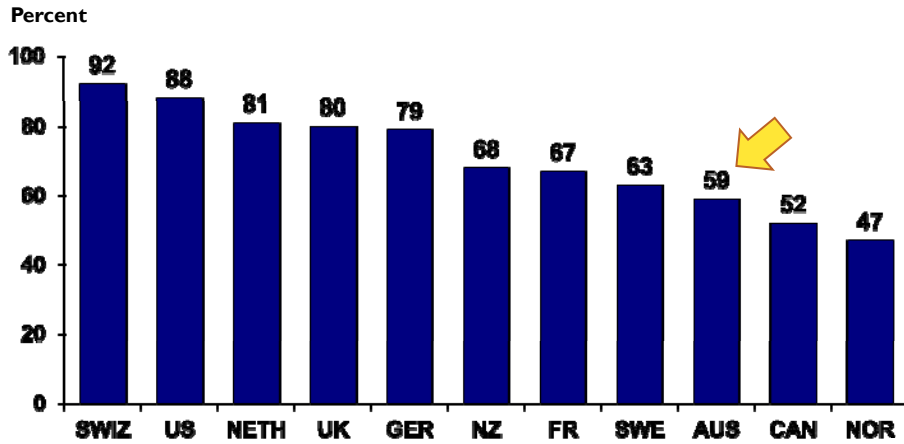
Access to doctor or nurse when sick or needed care



Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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Waited less than a month to see a specialist

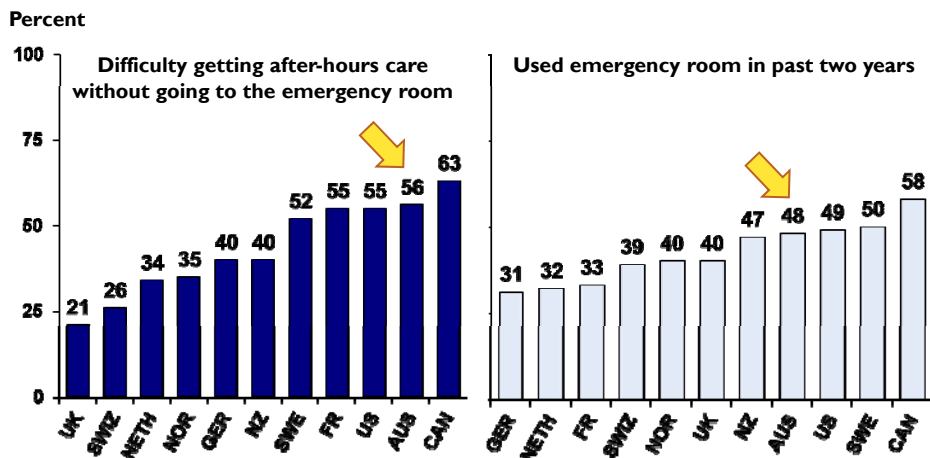


Base: Saw or needed to see a specialist in the past two years

Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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After-hours care & emergency room use



Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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Doctor-service user relationship & communication

Percent reported regular doctor always/often:	AUS	CAN	FR	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
Spends enough time with you	85	77	82	86	87	87	71	70	88	87	81
Encourages you to ask questions <u>and</u> explains things in a way that is easy to understand	69	59	53	64	54	67	31	41	77	77	71
Always/often to both	66	54	50	61	52	65	27	37	73	72	65

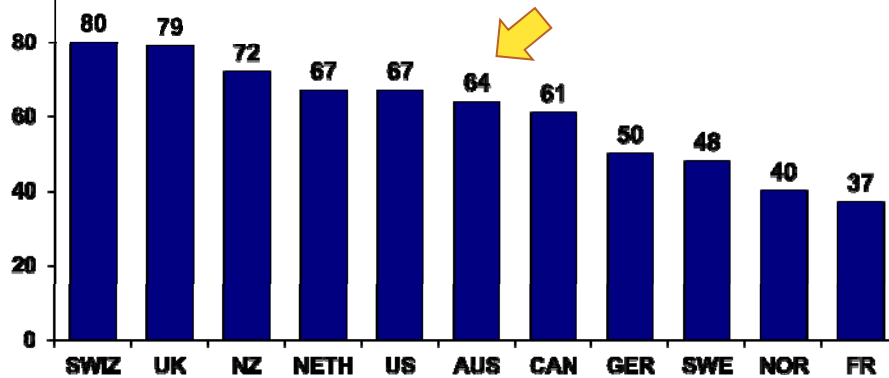
Base: Has a regular doctor/place of care

Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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Shared decision-making with specialists

Percent reporting positive shared decision-making experiences with specialists*

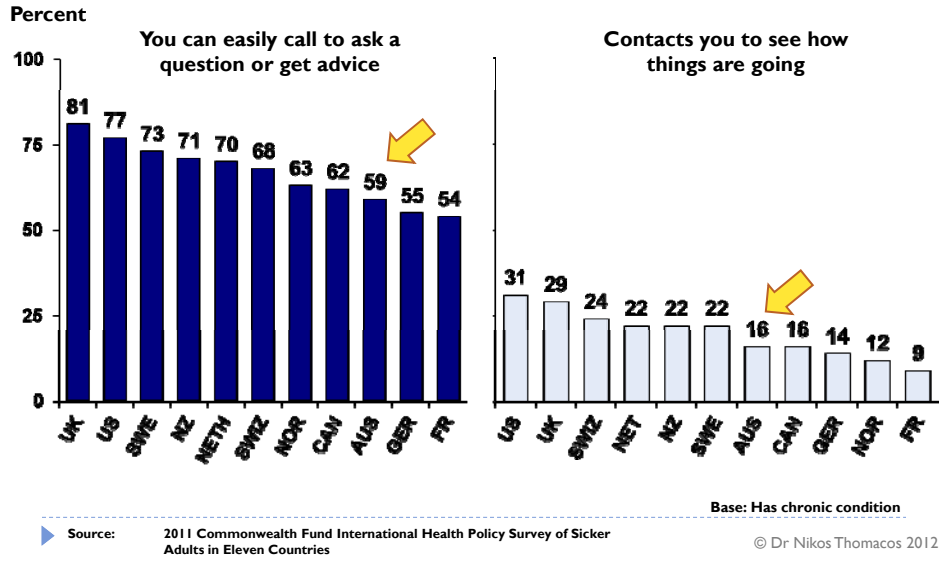


* Reported specialist always/often: 1) Gives opportunities to ask questions about recommended treatment; 2) Tells you about treatment choices; and 3) Involves you as much as you want in decisions about your care.
Base: Seen specialist in past two years

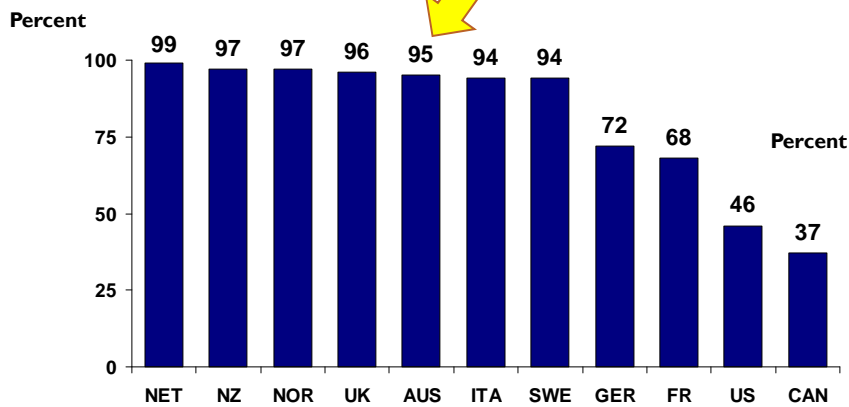
Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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Between doctor visits, has a health care professional who . . .



Electronic patient medical records



Source: 2009 Commonwealth Fund International Survey of Primary Care Physicians © Dr Nikos Thomacos 2012

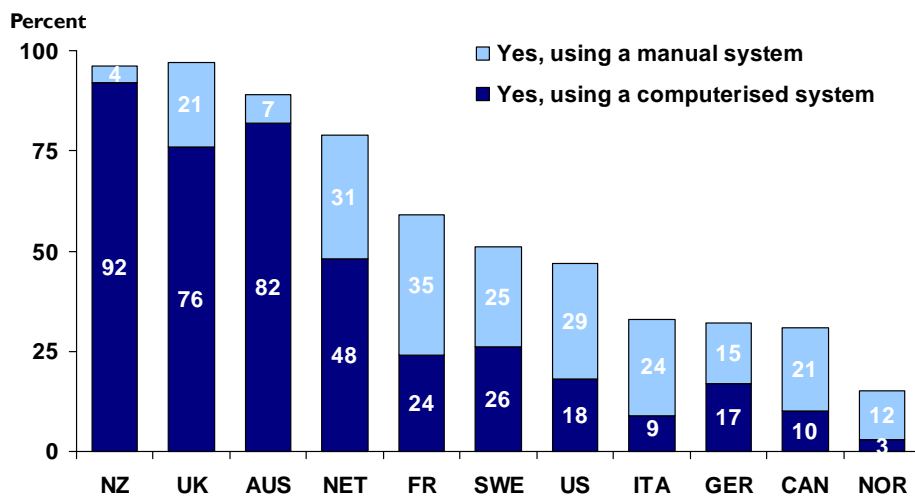
Computerised capacity to generate...

Percent report the COMPUTERISED capacity to generate:	AUS	CAN	FR	GER	ITA	NET	NZ	NOR	SWE	UK	US
List of patients by diagnosis	93	37	20	82	86	73	97	57	74	90	42
List of patients by lab result	88	23	15	56	76	62	84	49	67	85	29
List of patients who are due or overdue for tests/preventive care	95	22	19	65	76	69	96	32	41	89	29
List of all medications taken by an individual patient*	94	25	24	65	78	61	96	45	49	86	30

Source: 2009 Commonwealth Fund International Survey of Primary Care Physicians

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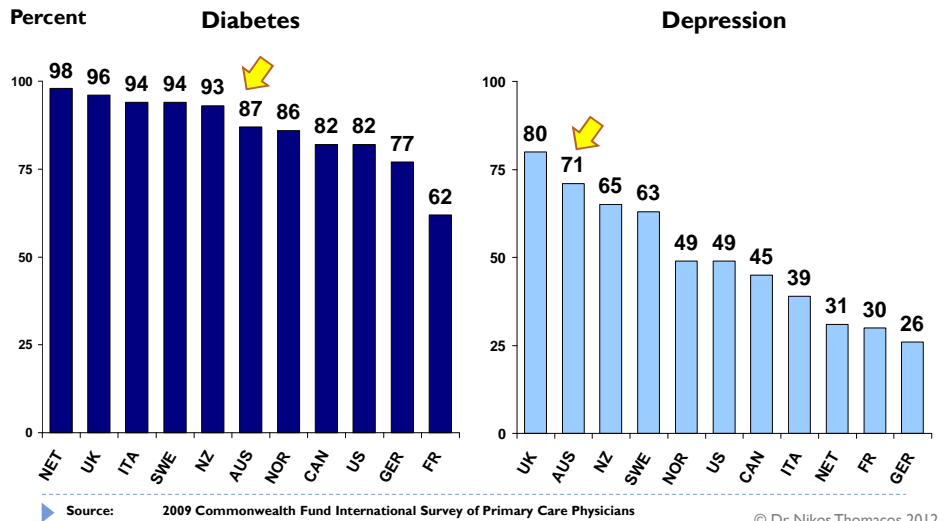
Follow up



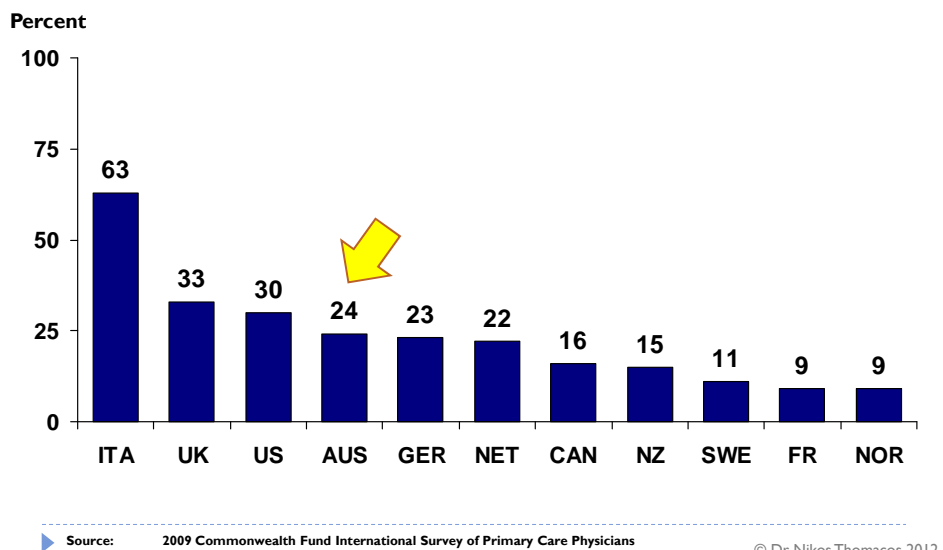
Source: 2009 Commonwealth Fund International Survey of Primary Care Physicians

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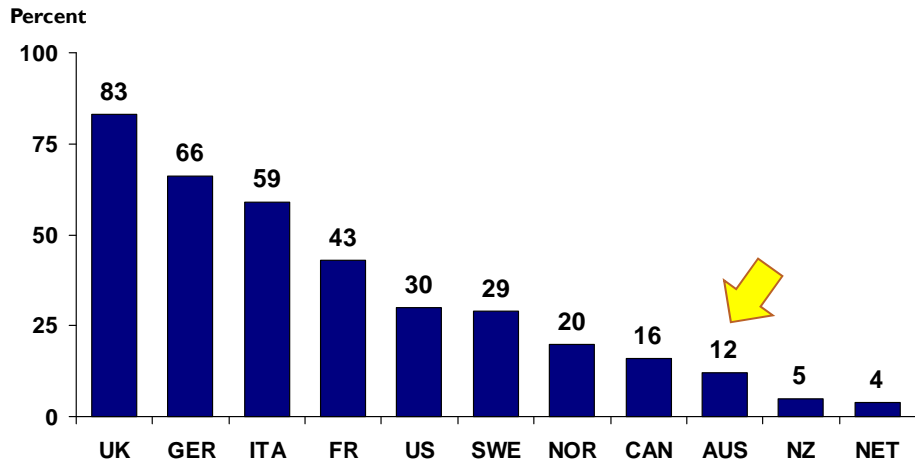
Use of written treatment guidelines



Routine provision of written information



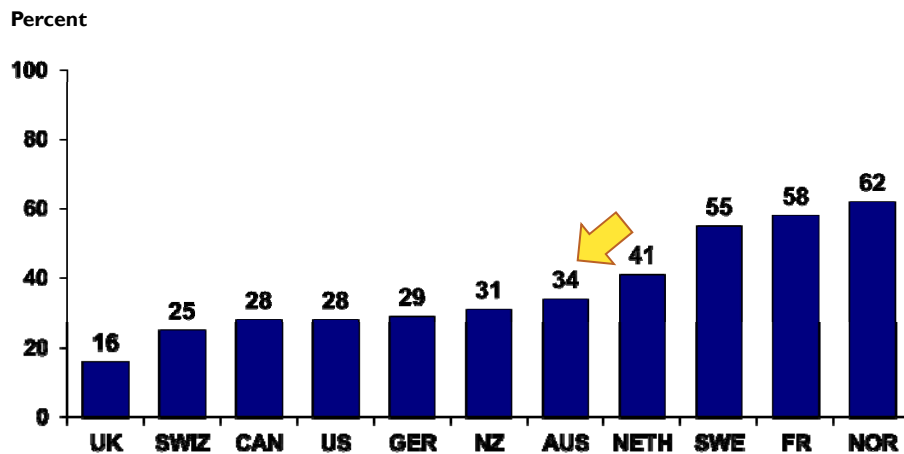
Routine provision of a written list of all medications



Source: 2009 Commonwealth Fund International Survey of Primary Care Physicians

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Pharmacist or doctor did not review & discuss prescriptions in past year



Base: Taking two or more prescriptions.

Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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Gaps in hospital or surgery discharge in past two years

Percent did NOT	AUS	CAN	FR	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
Receive instructions about symptoms and when to seek further care	16	16	33	23	22	17	29	27	13	11	7
Know who to contact for questions about condition or treatment	12	11	20	9	9	10	13	16	9	5	6
Receive written plan for care after discharge	30	27	33	26	44	31	44	46	28	19	7
Have arrangements made for follow-up visits	31	26	47	47	22	31	38	36	32	12	16
Receive clear instructions about what medicines to be taking	15	11	27	15	20	11	19	14	14	9	5

Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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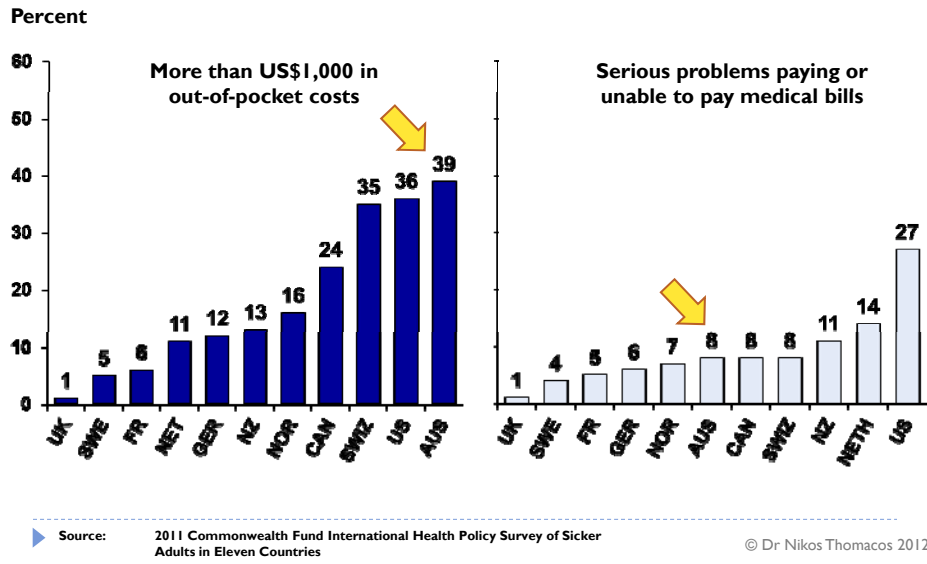
Cost-related access problems – past year

Percent	AUS	CAN	FR	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
Did not fill prescription or skipped doses	16	15	11	14	8	12	7	7	9	4	30
Had a medical problem but did not visit doctor	17	7	10	12	7	18	8	6	11	7	29
Skipped test, treatment, or follow-up	19	7	9	13	8	15	7	4	11	4	31
Yes to at least one of the above	30	20	19	22	15	26	14	11	18	11	42

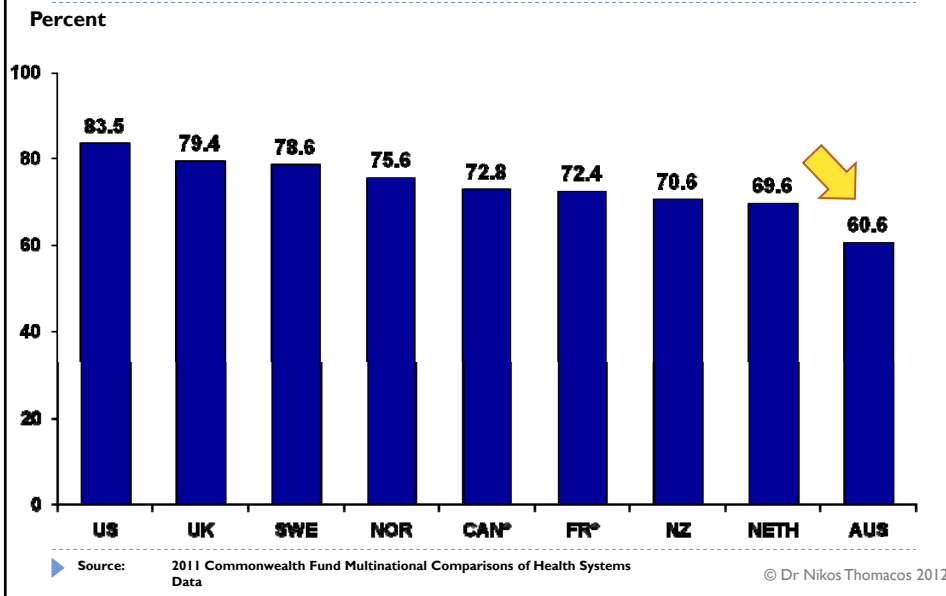
Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries

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Out-of-pocket spending & problems paying medical bills in past year



Cervical Cancer Screening Rates, 2006 Women Aged 20–69



Service user engagement in care management for chronic condition

Percent reported professional in past year has:	AUS	CAN	FR	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
Discussed your main goals/priorities	63	67	42	59	67	62	51	36	81	78	76
Helped make treatment plan you could carry out in daily life	61	63	53	49	52	58	41	40	74	80	71
Given clear instructions on symptoms and when to seek care	66	66	56	64	64	63	44	49	84	80	75
Yes to all three	48	49	30	41	42	45	23	22	67	69	58

Base: Has chronic condition

Source: 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in Eleven Countries © Dr Nikos Thomacos 2012

Why is health literacy important?

Poor or marginal health literacy

- ▶ Poorer physical and mental health, and result in individuals being more likely to report their health as poor or very poor (ABS, 2006; Institute of Medicine, 2004)
- ▶ Women with poor health literacy are also less likely to engage in screening and prevention interventions such as pap smears and mammograms (Lindau & Leitsch, 2006)
- ▶ Both men and women with poor health literacy have fewer flu immunisations (Cho, Plunkett, Wolf, Simon, & Grobman, 2007; Giordano et al., 2008; Guerra, Dominguez, & Shea, 2005)

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Poor or marginal health literacy

- ▶ People with poor or marginal health literacy are also:
 - ▶ More likely to present later with cancer (Donelle, Arocha, & Hoffman-Goetz, 2008; Westin et al., 2008)
 - ▶ More likely to engage in unhealthy behaviours (Carmona, 2005; Howard, Sentell, & Gazmararian, 2006; von Wagner, Knight, Steptoe, & Wardle, 2007)
 - ▶ Less likely to be effectively engaged by health promotion activities and programs (Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005; Parker, & Nurss, 1996)
- ▶ U.K. study (von Wagner et al., 2007), found poor health literacy was associated with poorer eating and diet-related behaviours - small increase in health literacy was associated with a significant increase in healthy eating, not-smoking, and exercising once a week (but this last finding was not significant)

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Health literacy in Australia

Health literacy in Australia

- ▶ The ABS measures health literacy using the Adult Literacy and Life Skills Survey (ALLS), an OECD measure used in over a dozen other countries. The survey was administered most recently in Australia in 2002 and 2006
- ▶ The ALLS is comprised of four measures of literacy that collectively contribute to an overall measure of health literacy
- ▶ The ALLS contains 191 health-related items across five domains:
 - ▶ Health promotion (60 items)
 - ▶ Health protection (64 items)
 - ▶ Disease prevention (18 items)
 - ▶ Health care maintenance (16 items)
 - ▶ System navigation (32 items)

Health literacy in Australia

These four domains that make up the ALLS are:

- ▶ **Prose literacy:** Represents individuals' ability to understand and use information from various kinds of narrative texts, including texts from newspapers, magazines and brochures
- ▶ **Document literacy:** Represents the knowledge and skills individuals require to locate and use information contained in various formats including job applications, payroll forms, transportation schedules, maps, tables and charts
- ▶ **Numeracy:** Represents the knowledge and skills individuals use to manage and deal with the mathematical demands of diverse situations
- ▶ **Problem solving:** Represents goal-directed thinking and action in situations for which no routine solution is available

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Health literacy in Australia

- ▶ The 2006 data showed that approximately 40% of all Australians have 'adequate' levels of general and health literacy, while 60% have less than adequate levels of literacy and health literacy
- ▶ Just 6% of the Australian population have high health literacy levels.
- ▶ The data also suggest that approximately 46% of Australians aged 15 to 74 years achieved less than 'adequate' scores for the prose domain, 47% for the document domain, 53% for the numeracy domain, and 70% for the problem solving domain

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At-risk populations - CALD

- ▶ For people from a CALD background, the data suggest that 33% overseas-born Australians enjoy adequate health literacy compared to 43% of Australian-born people
- ▶ When examined further, the percentage of overseas-born Australians with adequate levels of health literacy drops to 27% for those who have arrived in Australia within the past five years
- ▶ When English is not the first language spoken the percentage of people with adequate health literacy decreases to 26%. This compares to 44% of people whose first language is English

▶ Source: Thomacos & Keleher (2009)

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At-risk populations – Older people

- ▶ For older people, the data again evidence poor levels of health literacy, especially for people over the age of 65; with only 17% of people aged 65-74 possessing adequate health literacy
- ▶ For older adults aged 60-64 the percentage demonstrating adequate health literacy rises to 29%, and for older adults aged 55-59 the percentage demonstrating adequate health literacy is 34%
- ▶ Evidencing an inverse relationship between age and level of health literacy, increased adequacy of health literacy is associated with decreasing age

▶ Source: Thomacos & Keleher (2009)

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At-risk populations – Low SES

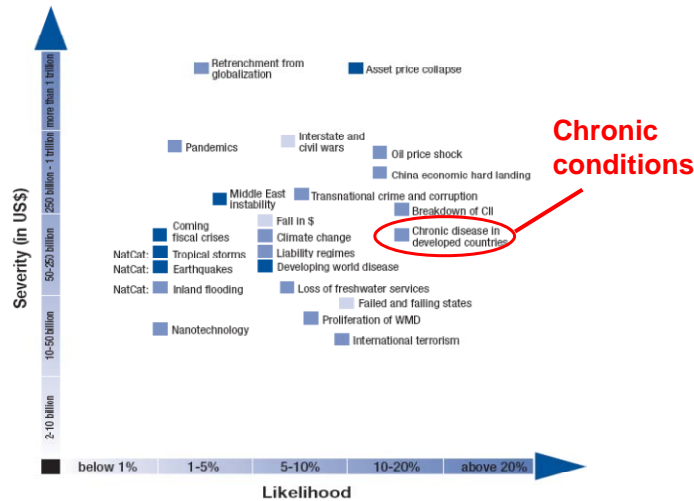
- ▶ In respect to socio-economic status, the data once more evidence a clear relationship
- ▶ In this case, high socio-economic disadvantage (i.e. lower socio-economic status) is associated with poorer health literacy
- ▶ For people in the bottom 20% (i.e. the lowest quintile – that is those most socio-economically disadvantaged), only 26% enjoy adequate health literacy
- ▶ This compares to 55% in the highest 20% (i.e. the highest quintile – that is those least socio-economically disadvantaged)

▶ Source: Thomacos & Keleher (2009)

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Health literacy & chronic conditions

Why focus on chronic conditions?



Source: Ratzen (n.d.)

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Knowledge & comprehension

Hypertension and diabetes

- ▶ 402 patients with hypertension and 114 patients with diabetes at two urban public hospitals in the U.S.A.
- ▶ Knowledge questionnaire: normal and levels, lifestyle modifications, drugs, symptoms and complications
- ▶ TOFHLA - 49% and 44%, respectively, had poor or inadequate health literacy
- ▶ Health literacy was strongly associated with knowledge of illness

Source: Williams, Baker, Parker et al (1998)

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Knowledge & comprehension

Patients with poor or inadequate health literacy were less likely to know:

- ▶ Blood pressure of 130/80 is normal ($p < 0.001$)
- ▶ Blood pressure of 160/100 is high ($p < 0.001$)
- ▶ Exercise lowers BP ($p < 0.001$)
- ▶ Canned vegetables are high in salt ($p = 0.001$)
- ▶ Losing weight lowers BP ($p < 0.001$)
- ▶ Normal blood glucose level is between 70-140 ($p = 0.003$)
- ▶ If you feel shaky, sweaty and hungry, it usually means your blood glucose is low ($p = 0.001$)

▶ Source: Williams, Baker, Parker et al (1998)

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Lack of understanding & use of preventive health services

Vaccines/Mammogram/Pap in older patients

- ▶ 2,722 Medicare patients age 65-79 in an HMO in 4 cities
- ▶ STOHFLA
- ▶ After adjustment for socio-demographic variables and health status, greater numbers of patients with poor or inadequate literacy had:
 - ▶ Never had influenza vaccination ($p = 0.000$)
 - ▶ Not had a mammogram in the previous 2 years ($p = 0.17$)
 - ▶ Never had a pap smear ($p = 0.002$)

▶ Source: Scott, Gazmararian, Williams, & Baker (2002)

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Poorer health status

Type II diabetes

- ▶ 408 participants
- ▶ STOFHLA, hemoglobin A1C levels and complications of diabetes
- ▶ Patients with poor or inadequate health literacy were less likely to have tight glycemic control (hemoglobin A1C <7.2; $p=0.05$) and more likely to have poor glycemic control (hemoglobin A1C >9.5%, $p=0.02$)
- ▶ For each one point decrement in STOFHLA score, the hemoglobin A1C value increased by 0.02 ($p=0.02$)

▶ Source: Schillinger, Grumbach, Piette, et al (2002)

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Poorer health status

Prostate Cancer

- ▶ 212 men at a prostate cancer clinic
- ▶ REALM
- ▶ Poorer health literate men were more likely to have advanced stage prostate cancer at presentation than those with higher reading abilities ($p=0.02$) even after adjusting for race, age and study site.

▶ Source: Bennett, Ferreira, Davis, et al. (1998)

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Increased hospitalisations

- ▶ 958 low-income patients at EDs and walk-in clinics
- ▶ TOFHLA
- ▶ Hospital information system used to retrospectively determine number of hospitalisations and visits to walk-in clinic in the previous 2-year period
- ▶ Patients with poor or inadequate health literacy were twice as likely to be hospitalised compared with those who with marginal or adequate health literacy (31.5%, 16.4% and 14.9%, respectively, $p < 0.001$), even after adjusting for health status and various socio-demographic indicators.

▶ Source: Baker, Parker, Williams, et al. (1998)

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Sources of health information

Percentage of adults with below basic or basic health literacy (i.e. poor or inadequate health literacy who get little or no health information from the following sources

Source	Below basic	Basic
Internet	85%	70%
Magazines	64%	47%
Books or Brochures	62%	45%
Newspapers	59%	51%
Family or Friends	47%	40%
Healthcare Providers	35%	30%
Radio or TV	33%	29%

▶ Source: National Center for Education Statistics, Institute for Education Sciences

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From a systems viewpoint

The Extended Chronic Care Model

- ▶ Developed by Barr and her colleagues (2002) to address some of the original model's shortcomings
- ▶ Used in B.C. to inform population health-informed service delivery planning, delivery, and evaluation
- ▶ Incorporates service delivery partnerships, policy development, and the determinants of health



Source: Barr et al., (2002). Available at: http://www.health.gov.bc.ca/cdm/cdmnbc/chronic_care_model.html

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From a practice viewpoint

- ▶ The following are believed to contribute to chronic condition self-management process:
 - ▶ Having knowledge of the condition and/or its management
 - ▶ Adopting a self-management care plan agreed and negotiated in partnership with health professionals, significant others and/or carers and other supporters
 - ▶ Actively sharing in decision-making with health professionals, significant others and/or carers and other supporters
 - ▶ Monitoring and managing signs and symptoms of the condition
 - ▶ Managing the impact of the condition on physical, emotional, occupational and social functioning
 - ▶ Adopting lifestyles that address risk factors and promote health by focusing on prevention and early intervention
 - ▶ Having access to, and confidence in the ability to use support services

Source: NHPAC (2006)

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What can we do?

- ▶ Recognise that the issue exists: be aware of the prevalence and consequences
- ▶ Identify vulnerable individuals in your practice
- ▶ Realign and reconfigure case management and/or care coordination so that it is meaningful and relevant for service users with poor or inadequate health literacy
- ▶ Assist those with reading difficulties:
 - ▶ Verify understanding by asking service users to repeat instructions back to you
 - ▶ Verify they are taking their medications as prescribed
 - ▶ Use low-literacy educational materials or approaches

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Should we therefore test for health literacy?

What the literature suggests

- ▶ The literature reports a range of methods and tools for assessing health literacy that have been tested with specific service user groups as well as the general population
- ▶ Population-based surveys conducted in Australia by and in other countries comparable to Australia (e.g. Canada, USA, etc.) have established reliable profiles of general and health literacy across the population
- ▶ There is fair evidence to suggest that possible harm outweighs any current benefits; therefore, clinical screening for literacy should not be recommended at this time (Paasche-Orlow & Wolf, 2007, 2008)

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Suggested approaches to testing

- ▶ Simple strategies are available as an alternative, and should be made routine (Morris, MacLean, Chew, & Littenberg, 2006)
- ▶ One approach, advocated by Morris and her colleagues (Morris et al., 2006), suggests the use of a single item/question to assess service users' health literacy

“How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or chemist?”

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Suggested approaches to testing

- ▶ Aside from this specific approach, alternative (but similar) strategies exist
- ▶ These include asking service users for clarification of what has been discussed with them, asking them to repeat back what they understand, and checking if service users find written information provided to be useful or clear to them, or whether they would like further explanation of the contents of the information and/or literature provided (Chew, Bradley, & Boyko, 2004; Wallace, Rogers, Roskos, Holiday, & Weiss, 2006)

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The Chew approach to testing

Chew and her colleagues (Chew, Bradley, & Boyko, 2004) suggest asking 3 questions:

- 1) How often do you have someone help you read written materials regarding your health condition(s)?
- 2) How often do you have problems learning about your health condition(s) because of difficulty understanding written information?
- 3) How confident are you filling out medical forms by yourself?

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So, where to from here?

Four critical domains

- ▶ My practice
- ▶ My organisation
- ▶ The broader service sector
- ▶ The community

Teach-back is...

- ▶ Asking service users to repeat in their own words what they need to know or do, in a non-shaming way
- ▶ It is not testing service users; rather, how well you explained a concept
- ▶ A chance to check for understanding and, if necessary, re-teach the information
- ▶ And it is supported by evidence:
 - ▶ Asking that service users to recall and restate what they have been told is one of 11 top service user safety practices based on the strength of scientific evidence (AHRQ, 2001)
 - ▶ “Physicians’ application of interactive communication to assess recall or comprehension was associated with better glycemic control for diabetic patients” (Schillinger, 2003)

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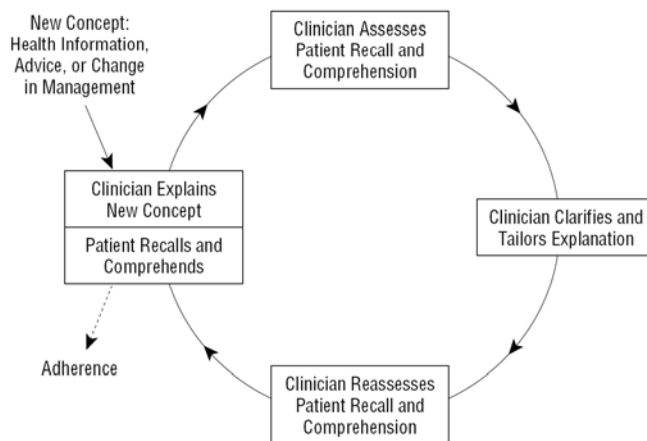
Examples of asking for a teach-back

Ask service users to demonstrate understanding, using their own words:

- ▶ “I want to be sure I explained everything clearly. Can you please explain it back to me so I can be sure I did?”
- ▶ “What will you tell your husband about the changes we made to your blood pressure medicines today?”
- ▶ “We’ve gone over a lot of information, a lot of things you can do to get more exercise in your day. In your own words, please review what we talked about. How will you make it work at home?”

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Teach-back: Closing the loop



Source: Schillinger et al. (2006)

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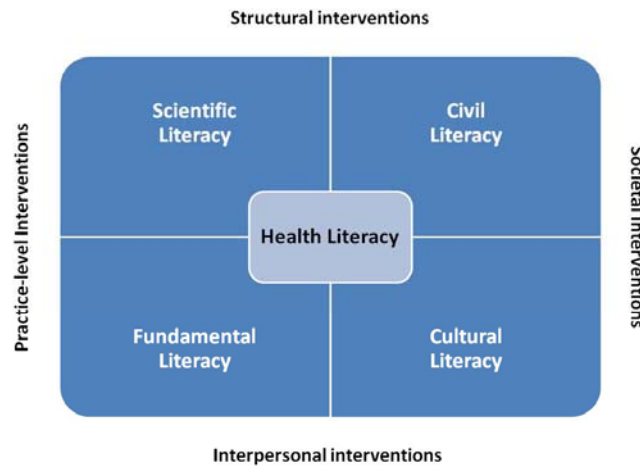
Making it happen in your organisation

- ▶ Health literacy can be enhanced by improving service user interactions with health care professionals and agencies
- ▶ Health literacy can be enhanced and developed by improving the usability of health services
- ▶ Health literacy can be enhanced and developed by improving access to accurate and appropriate health information
- ▶ Health literacy can be enhanced and developed by building the knowledge needed to improve the health care workforce's thinking, decision-making, and practice
- ▶ Health literacy can be enhanced and developed by operationalising an integrated model of health literacy

Source: Thomacos & Keleher (2009)

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Bringing it together



▶ Source: Thomacos & Keleher (2009)

Concluding thoughts

- ▶ Health literacy is fundamentally dependent upon levels of basic literacy
- ▶ Developing self-confidence and self-agency to act on knowledge as well as the ability to support others demands the incorporation of adult learning principles and health promotion concepts into all of our work
- ▶ Promoting greater health literacy and well informed, independent decision-making requires recognition of social and environmental context to decision-making, enabling individuals to address not only the social, but also the structural barriers to health and well-being
- ▶ Simply making things 'simpler' will not on its own address the challenges posed by 'poor' health literacy

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Thank you

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