Shared Decision Making and Health Literacy: opportunities and challenges

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DEMOCRATISING HEALTH

- The health environment has changed enormously and will continue to change
- Increasing use of internet to seek health information
- Increasing expectation that patients can access information online
- Todays health environment is increasingly complex
- Increasing requirement for self-management in chronic disease
- Explosion of health technology through mobile phones and Apps
- Implications for Shared Decision Making and Health Literacy
OVERVIEW

1. What is Shared Decision Making and why is it important?

2. What is Health Literacy and why does it matter?

3. How can we improve health literacy and SDM?

4. How can we integrate HL and SDM into health services in the future: opportunities and challenges?
SHARED DECISION MAKING

Measurement using the OPTION instrument

Glyn Elwyn • Adrian Edwards • Michel Wensing • Richard Grol
WHAT IS SHARED DECISION MAKING (SDM)?

SDM occurs when (Elwyn et al JGIM 2012):

- Patients are informed of the **benefits** and **harms** of different healthcare options using evidence
- Encouraged to express their preferences
- Encouraged to be involved in decision making to the extent that they desire
- Aim is to enable patients to make a decision consistent with their values and preferences
SHARED DECISION MAKING

- SDM described as ‘the pinnacle of patient-centred care’ (Barry NEJM 2012)
- Widely seen as an indicator of high quality healthcare 🌟
- Large scale efforts to implement SDM programs in US and UK
SUPPORTING SDM: tools and techniques

- Patient Decision Aid – booklet / video / audio / web-based form
- Coaching of patients / consumers
- Question prompt lists
- SDM training for HCPs

**ask the 3 Questions:**

1. What are my options? (One option will always be wait and watch.)
2. What are the possible benefits and harms of those options?
3. How likely are each of those benefits and harms to happen to me?
WHY IS SDM IMPORTANT?

Evidence from >130 RCTs that SDM results in better pt outcomes:

- Increased knowledge
- More realistic expectations of risks and benefits
- Reduced uncertainty in DM
- Increased participation in DM
- Reduced overuse of some procedures/interventions (eg. PSA testing, elective surgery, HRT) and reduced costs
- More ‘positive’ Dr-patient communication

Stacy D et al Cochrane Review PtDAs (2014)
SHARED DECISION MAKING

- Now integrated in legislation in US (eg. Affordable Care Act 2010, section 3504)
- UK - NHS Right Care Programme – ‘nothing about me without me’
SHARED DECISION MAKING:
What it means for patients

- Understanding evidence on options and outcomes:
  - Literacy and numeracy skills
- Ability and confidence to discuss options with HCP and weigh up benefits and harms
- Express individual values and preferences — discuss with HCP
- Participate in making a choice
- Find and locate patient decision aids and other support tools
- Have confidence to be involved in decision making with a HCP
- THIS REQUIRES HEALTH LITERACY!
OVERVIEW

1. What is Shared Decision Making and why is it important

2. What is Health Literacy and why does it matter?
WHAT IS HEALTH LITERACY?

‘The capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health’

(USDHHS 2000, US Healthy People 2010)
WHAT IS HEALTH LITERACY?

- ‘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….it means more than being able to read pamphlets….By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment.’

(WHO Nutbeam 1998)
MULTI LEVEL MODEL OF HEALTH LITERACY

Nutbeam (2000, 2008)

Critical HL
- Ability to analyse and act on information

Communicative/interactive HL
- Advanced cognitive & social skills

Functional HL
- Reading, writing, numeracy, oral skills
WHY DOES HEALTH LITERACY MATTER:
Low literacy and poor health

Association independent of all other known risk factors:
- Higher rates of chronic illness (e.g. CVD, diabetes, obesity)
- Higher rates of mortality (all cause)
- Higher hospitalisation rates and use of emergency services
- Lower rates of preventive services such as screening
- Poorer self management skills
- Greater medication errors
- Lower levels of knowledge about disease
- Lower ratings of satisfaction with doctor-patient communication
- Higher healthcare costs

(AHRQ DeWalt et al 2004; Berkman et al 2011)
LITERACY LEVELS IN AUSTRALIA ARE POOR

- Australian Adult Literacy and Life Skills survey 2006 (nationally rep sample adults aged 15-74 years):
  - 46% had ‘very poor’ or ‘marginal’ literacy skills (prose and document literacy)
  - 53% had ‘very poor’ or ‘marginal’ numeracy
  - 60% had ‘very poor’ or ‘marginal’ health literacy
INTERNATIONAL LITERACY LEVELS

- UK / US national surveys similar (Kutner et al 2006; OECD 2005):
  - 36-48% ‘limited’ / ‘inadequate’ health literacy.

- High % adults struggle to understand routine / ‘every day’ written information
Individual health literacy

Health literacy environment
Individual skills, knowledge, capacity, motivation

Health system policies, processes, materials, relationships
Individual HL 60% ‘inadequate’ HL
**PROBLEM**

Individual HL

60% ‘inadequate’ HL

HL environment

60-80% of health info too complex
**SDM AND HEALTH LITERACY SKILLS**

1. Understanding healthcare options and outcomes
2. Consider values/prefs, communicate with HCP
3. Weighing up options to make & implement a choice

- **Functional HL**
  - Reading, writing, numeracy, oral skills
- **Communicative/interactive HL**
  - Advanced cognitive & social skills
- **Critical HL**
  - Ability to analyse and act on information
A MODEL OF HEALTH LITERACY

SDM is the pinnacle of health literacy
RISK INCREASING INEQUALITIES

health literate as information rich with access to choice

Lower health literate as information poor & little access to choice

- Lower health literacy patients are over-represented in the health system — poorer health and health outcomes
- Clinicians report they find communication challenging with lower literacy patients
HEALTH LITERACY

“There is potential not only to improve the safety and quality of health care, but also to reduce health disparities and increase equity”

OVERVIEW

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3. How can we improve health literacy and SDM?

4. Opportunities and challenges for health services
SDM FOR ADULTS WITH LOW HEALTH LITERACY

Development and evaluation of a decision aid for adults with low education and literacy

A decision aid to support informed choices about bowel cancer screening among adults with low education: randomised controlled trial

Sian K Smith, postdoctoral research fellow, Lyndal Trevena, associate professor, Judy M Simpson, professor of biostatistics, Alexandra Barratt, associate professor in epidemiology, Don Nutbeam, professor of public health, Kirsten J McCaffery, senior research fellow

ABSTRACT
Objective To determine whether a decision aid designed for adults with low education and literacy can support the decision aid group (2.2% difference, 15% to 39%; P=0.001). More participants in the decision aid group had no decisional conflict about the screening decision.

Information needs and preferences of low and high literacy consumers for decisions about colorectal cancer screening: utilizing a linguistic model

Sian K Smith BSc (Hons), Lyndal Trevena MBBS (Hons) MPhIL PhD, Don Nutbeam BEd MA PhD FFPHM, Alexandra Barratt MBBS (Hons) PhD FAFPHM, and Kirsten J McCaffery BSc (Hons) PhD

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Exploring patient involvement in healthcare decision making across different education and functional health literacy groups

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b Office of the Vice Chancellor, University of Southampton, Southampton, UK
The University of Sydney

**SDM for adults with low literacy**

**Decision Aid RCT n=585**

*RCT Smith et al BMJ 2010,*

*Predictors informed choice*

*Smith et al MDM 2011*

Qualitative fol up:

*Smith et al PEC 2012*
* No formal educ qualifications, intermediate school certificate, technical/trade qualification

Community sample: adults 55-64 years, n= 585
Lower education levels*

Decision Aid
FOBT kit

Control:
Govt screening booklet
FOBT kit

Knowledge
Involvement in decision making
Psychosocial outcomes
Informed choice

Screening behaviour (FOBT completion)

HIGH uptake >80%

HIGH follow-up >90%

2 weeks

3 months
DECISION AID DEVELOPMENT

- Plain language (grade 8 reading age),
- Structure and design guided by a linguistic model (Clerehan et al 2005)
- Meaningful illustrations to convey key messages
- Sign posting
- Colour coding
- Glossary for key words
- Numeric information presented as absolute frequencies in population diagrams
- Rigorous piloting and testing
Cancer screening means looking for early signs of cancer or pre-cancer, in people who are well and have no symptoms.

If cancer or pre-cancer is found at an early stage it can be treated more easily.

There are different types of screening tests to find early signs of different cancers. For example, mammograms to screen for breast cancer, Pap smears to screen for cervical cancer and prostate specific antigen (PSA) to screen for prostate cancer.

This booklet is about screening for bowel cancer with Faecal Occult Blood Testing (FOBT).

Your age: bowel cancer is more common as you get older.

Your gender: bowel cancer is a little more common in men.

Your family history: bowel cancer is twice as likely to occur in women and men who have at least one family member with bowel cancer. See page 5 to find out your family history group or ask your doctor.

Note: Although diet is important for your general health, whether it affects your risk of bowel cancer is unclear.
Risk information for men with a weak family history of bowel cancer: bowel cancer mortality with and without FOBT screening.

How does the screening test help men with a weak family history?

Of 1000 men your age (55-64) with a WEAK FAMILY HISTORY who DO NOT HAVE SCREENING, over the next 10 years:

- 5 may die of bowel cancer without screening over the next 10 years

Of 1000 men your age (55-64) with WEAK FAMILY HISTORY who DO HAVE SCREENING, over the next 10 years:

- 4 may die of bowel cancer with screening over the next 10 years

In other words, 1 less man dies from bowel cancer with regular screening.
I'm just picturing half of the Enmore theatre. Nine people in there have bowel cancer. That's the way I look at it…

Participant 11, male, age 55, lower literacy
Personal worksheet for women with no family history of bowel cancer to help clarify their values about the possible outcomes of screening

Your Personal Worksheet
No Family History

Think about how each point makes you feel about bowel cancer screening with FOBT.

Circle the thumbs to show how each point makes you feel about screening.

- For screening
  - Against screening
  - Unsure
  - For screening

E.g. Against screening

Think about your current risk of bowel cancer
Your risk of dying from bowel cancer over the next 10 years without screening is about 2 in 1000 (see pages 12–13). How does this make you feel about screening?

- Against screening
- Unsure
- For screening

Lowering your risk of bowel cancer by screening
Having a screening test every 2 years over the next 10 years does not affect your chances of dying from bowel cancer (see pages 12–13). How does this make you feel about screening?

- Against screening
- Unsure
- For screening

Think about the possible screening test outcomes
Bowel cancer screening will tell a large number of people that their risk of bowel cancer is low. It may not find all cancers and some people will have follow-up procedures (colonoscopy) that do not really need. There are also some rare risks linked to having a colonoscopy (see page 9 and 15). How does this make you feel about screening?

- Against screening
- Unsure
- For screening

Doing the bowel cancer test at home
Some people find the test a bit unpleasant but it is simple to do and is designed to be done in the privacy of your own home. How does this make you feel about screening?

- Against screening
- Unsure
- For screening

Other things important to you
Write down any other things that are important to your decision.

How does this make you feel about bowel cancer screening?

- Against screening
- Unsure
- For screening

Making your decision about the bowel cancer screening test
Thinking about all the points above, how are you feeling about the screening test?
- Yes, I want to do the test
- No, I do not want to do the test
- I am unsure about whether I want to do the test
TRIAL RESULTS

PtDA had a significant effect on primary and secondary outcomes:

1. **Screening knowledge:** 38% (95%CI 30,45) increase in PtDA arm (P<0.001).

2. **Informed choice:** 22% (95%CI 15,29) increase in PtDA arm (P<0.001).

3. **Decisional conflict and preferences for SDM:** Reduced uncertainty in DM (P=0.03), increased preferences for SDM (P=0.04).
QUESTION PROMPT LISTS FOR ADULTS WITH LOW EDUCATION AND LITERACY

- **Ask Share Know:** Question prompt list for patients to use with doctors/HCPs to elicit evidence-based Shared Decision Making consultations.

- Effective in study with simulated patients and in family planning.

- No research with adults with low education and literacy.

www.askshareknow.com.au
TAFE HEALTH LITERACY TRIAL

Basic literacy and numeracy students  n=319

Pre-assessment

Control Group
(Existing literacy program)

Intervention Group
(New health literacy program – including SDM module)

Post-assessment

6 month follow-up
KEY FINDINGS

- Recall was equivalent to study with general population (78% recalled at least 1 question).
- Intervention students more likely to consider options, benefits, harms and likelihood important to discuss with HCPs (vs process Qs) p<0.001).
- Perceived the questions to be useful once they understood their meaning.
- 6 month follow up recall approx. 40% for each Q

<table>
<thead>
<tr>
<th>Table 1 AskShareKnow question recall at immediate follow-up</th>
<th>n (%)</th>
</tr>
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<tbody>
<tr>
<td>Q1: What are my options?</td>
<td>84 (77.1)</td>
</tr>
<tr>
<td>Q2: What are the benefits and harms of those options?</td>
<td>72 (66.1)</td>
</tr>
<tr>
<td>Q3: How likely are each of those benefits and harms to happen to me?</td>
<td>65 (59.6)</td>
</tr>
<tr>
<td>All 3 questions</td>
<td>59 (54.1)</td>
</tr>
<tr>
<td>At least 1 question</td>
<td>85 (78.0)</td>
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IMPROVING HEALTH LITERACY & SDM

- There is good quality evidence to support strategies to improve communication for patients with lower health literacy (Sheridan et al 2011, 2013):
  
  a. Written health information – use plain language guides
  
  b. Prescription drug labels – use precise instructions
  
  c. Verbal communication – use ‘teach back’ method
  
  d. Risk communication – using formats which aid understanding

- Effective strategies to increase SDM: decision aids, QPLs, clinician training, coaching (eg. Stacey et al 2014)
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## CREATE A HEALTH LITERATE ORGANISATION

### A health literate organisation

<table>
<thead>
<tr>
<th>Has leadership that makes HL integral to its mission, structure and operation</th>
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<tbody>
<tr>
<td>• Assign responsibility to an individual or group</td>
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<td>• Make clear, effective communication a priority across all levels of the organisation</td>
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<tr>
<th>Integrates HL into planning, evaluation, patient safety and quality improvement</th>
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<tbody>
<tr>
<td>• Audit the HL environment in the annual audit program</td>
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<tr>
<td>• Ensure safety and quality initiatives reflect HL</td>
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<tr>
<th>Prepare workforce to be HL and monitor progress</th>
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<tr>
<td>• Incorporate HL training into all staff training</td>
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<th>Include populations served by the organisation in the design and evaluation of health information and services</th>
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<tbody>
<tr>
<td>• Include consumers in governance processes</td>
</tr>
<tr>
<td>• Collaborate with members of the target community in design and testing</td>
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</table>
### CREATE A HEALTH LITERATE ORGANISATION

**SDM**

<table>
<thead>
<tr>
<th>A health literate organisation</th>
<th>Examples of actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet the needs of populations with a range of literacy levels while avoiding stigmatisation</td>
<td>• Adopt a universal precautions approach</td>
</tr>
<tr>
<td></td>
<td>• Provide alternatives to written info where possible</td>
</tr>
<tr>
<td></td>
<td>• Create environments that do not place a high literacy burden</td>
</tr>
<tr>
<td>Use HL strategies in communication that confirms understanding at all points of contact</td>
<td>• Foster a culture that checks for understanding at all points of contact</td>
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<tr>
<td></td>
<td>• Plan for and provide language assistance</td>
</tr>
<tr>
<td></td>
<td>• Treat communication failure as a patient safety issue</td>
</tr>
<tr>
<td>Provide easy access to health information and services and navigation assistance</td>
<td>• Use easy to understand language, symbols and signs</td>
</tr>
<tr>
<td></td>
<td>• Ensure understanding among consumers with low literacy levels</td>
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## CREATE A HEALTH LITERATE ORGANISATION

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| Designs print and audio visual info that is easy to understand and ACT ON | • Use materials that reflect HL principles  
• Use materials appropriate for consumers with low HL  
• Test consumer information with the target audience |
| Address HL in high risk situations incl communication about medicine, care transition | • Identify high risk situations and plan to ensure safe clear communication |
| Communicate what health insurance plans will cover and where individuals have to pay for services | • Make clear when out of pocket costs will need to be paid. |

C Brach, D Keller, L Hernandez, C Baur, R Parker, B Dreyer et al. Ten attributes of health literate health care organizations. Institute of Medicine, Washington DC, 2012, viewed 22 July 2014,
CHALLENGES AND OPPORTUNITIES

1. Increase patient access to decision support tools
2. Bring technology, evidence and decision tools to the fingertips of clinicians.
3. Give patients confidence and permission to ask questions and be involved in decisions.
4. Give clinicians the skills to practice SDM with their patients.
CHALLENGES AND OPPORTUNITIES

1. Increase patient access to decision support tools.
2. Bring technology, evidence, and decision tools to the fingertips of clinicians.
3. Give patients confidence and permission to ask questions and be involved in decisions.
4. Give clinicians the skills to practice SDM with their patients.

Potential for benefit is considerable, but requires investment in systems, technology and training.
Health services in the future

Systems and technology

Evidence + decision support

Patient

Clinician

Consultation

Training, skills development and culture change
DEMOCRATISING HEALTH

- Stop wasting valuable health $$ on low value tests and treatments with little evidence of benefit.
- Invest in skills development and technology to support evidence-based shared decision making
- Create systems that support and reward this
Shared Decision Making and Health Literacy: opportunities and challenges

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