Interventions and systems to promote health literacy: what is effective?

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OVERVIEW

1. What do we know about health literacy interventions – what is effective?

2. How do we integrate these into primary healthcare systems effectively?
IMPROVING HEALTH LITERACY

There is consistent good quality evidence to support strategies to improve outcomes for adults with low HL (Sheridan et al 2011, 2013)

a. Written health information

b. Prescription drug labels

c. Verbal communication

d. Risk communication

e. Shared decision making
INTERVENTIONS TO IMPROVING HEALTH LITERACY

There is good quality evidence showing improved outcomes for adults with low HL (Sheridan et al. 2011, 2013):

a. Written health information – use plain language guides
**HEALTH INFORMATION**

**Factors that improve understanding for adults with low literacy**

- Presenting essential information by itself or first
- Presenting numeric information in tables or pictographs not text
- Presenting numeric information in a logical order for evaluation (i.e., higher number is better)
- Presenting numerical information with a consistent denominator
- Using natural frequencies (1 out of 100) to help understand risks and benefits
- Adding video to verbal narratives to improve the salience of health states

## More information about

**Written communication**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Useful resources</th>
</tr>
</thead>
</table>
Plain Language Australia, Fortitude Valley, viewed 21 July, 2014, [www.plainlanguageaustralia.com](http://www.plainlanguageaustralia.com) |
IMPROVING HEALTH LITERACY

There is good quality evidence to support strategies to improve:

a. Written health information – use plain language guides

b. Prescription drug labels – use precise instructions
EFFECTIVE HEALTH COMMUNICATION

Prescription drug labels

- US study of 400 English speaking primary care patients, lower SES (Davies et al 2006)
  - 50% misunderstood commonly used prescription labels

- If instructions are precise and explicit understanding increased from 53% to 89% correct (Davies et al 2008)
EFFECTIVE HEALTH COMMUNICATION

**YES**
- take 1 at 6am and 1 at 6pm every day
- OR
- take 1 with breakfast and 1 with dinner

**NO**
- take twice daily
- OR
- take every 12 hours
IMPROVING HEALTH LITERACY

There is good quality evidence to support strategies to improve outcomes for adults with low HL (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
TEACH-BACK

What is teach-back?

- A way to make sure HCPs explain information clearly
- It asks a patient to explain in their own words what they need to know or need to do, in a caring way.
- A way to check understanding and if needed explain again
- Gives clinician immediate feedback on patient understanding
IMPROVING HEALTH LITERACY

There is good quality evidence to support strategies to improve:

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
Use natural frequencies or simple %

5 out of 100 women will experience side effects

or 5%
Of 100 women who take drug A

5 out of 100 women will experience side effects
RISK COMMUNICATION

Of 100 women who take drug A

5 out of 100 women will experience side effects or 5%...

NOT

20% less women will experience side effects

Trevena et al 2012
IMPROVING HEALTH LITERACY

There is good quality evidence to support strategies to improve outcomes for adults with low HL (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

e. Shared decision making – patient decision aids
SHARED DECISION MAKING

Measurement using the OPTION instrument

Glyn Elwyn • Adrian Edwards • Michel Wensing • Richard Grol
IMPACT OF SDM?

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
- Impact may be greatest in lower literacy/ socially disadvantaged patients

Stacy D et al Cochrane Review PtDAs (2014); Durand et al PLOS one (2014)
How well are we doing at implementing these into healthcare?
How well are we doing in implementing these into healthcare?

- Use of plain language materials
Systematic review: 126 written info CKD (Morony et al 2015)

- Readability (Flesh-Kincaid)

2/3 patients report they struggle to understand written information given to them (Payne 2002)

Results

- 77% beyond average recommended lexile score
- 66% beyond average readability score (grade 8 = 13-14 yrs)
- 95% beyond level for low literacy popn (grade 5 = 10 yo)
Sub-analysis of materials

- Printed health materials (n=26)
  - Diet and nutrition
  - Self-management
METHOD

Patient Education Materials Assessment Tool (PEMAT)

- 17 “understandability” items
  - Content Organization
  - Word choice/style Layout / design
  - Visual aids Use of numbers

- 7 “Actionability” items

- Further analysis of images
What we found

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protein</td>
<td>Sodium</td>
</tr>
<tr>
<td>Potassium</td>
<td></td>
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</tbody>
</table>

To work with a renal dietitian, you need to ensure that your diet is balanced and suitable for your condition. Ask your doctor to refer you to a renal dietitian. Work with your renal dietitian to figure out the right diet plan for you.
To work because recommend activity body Protein dietitian sodium, Now friendly” heart up should, D. Follow a kidney-friendly diet
When your kidneys are not working as well as they should, nutrients from what ... doctor to refer you to a renal dietitian. Work with your renal dietitian to figure out the right diet plan for you.

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Helpful Foods" /></td>
<td><img src="image2.png" alt="Unhelpful Food" /></td>
</tr>
</tbody>
</table>

**Result of Image Evaluation**

**What we found**
How well are we doing in implementing these into healthcare?

- Use of plain language materials X
- Prescription drug labels X
- Teach-back X
- Risk communication formats X
- Shared decision making X
How well are we doing at implementing these into healthcare?
10 years of health literacy intervention research

1. Risk communication graphics / formats for low literacy adults: (McCaffery et al MDM 2009)
2. Decision aid for bowel cancer screening for adults with low literacy and low education (Smith et al BMJ 2010)
3. Health literacy program for adults with low literacy and numeracy attending TAFE (McCaffery et al BMC 2016).
4. SDM program for adults with low literacy and numeracy (Muscat et al – in progress)
5. RCT of a ‘teach back’ intervention in a telephone health information support line (Usyd and Health Direct) in progress.
6. Improving health literacy in pregnant women – pilot study
2. How do we implement these into healthcare – primary healthcare?
How do we create health literate health systems?

Communicates clearly what health plans cover, and what services consumers have to pay for.

 Designs and distributes health information that is easy to understand and use.

 Involves consumers, e.g.: in testing health information.

 Ensures easy access in navigating systems, sites and information.

Meets the needs of all consumers.

Has Leadership that makes literacy integral to its mission and operations.

Uses health literacy strategies in interpersonal communication.

Integrates health literacy into organisational, clinical and quality improvement planning and evaluation.

Targets high risk situations, e.g.: communications about medicines.

Prepares and skills the workforce for becoming a health literate organisation.

Adapted from 'Ten Attributes of Health Literate Health Care Organisations' model, Institute of Medicine, 2012)
How do we create health literate health systems?

1. Universal Precautions Approach
   - Health literacy universal precautions toolkit - AHRQ 2010 [www.ncbihealthliteracy.org/toolkit](http://www.ncbihealthliteracy.org/toolkit)
   - Deliver care as if every patient has low HL

2. Ophelia – needs assessment + intervention development: [www.ophelia.net.au](http://www.ophelia.net.au)


Centre for Research Excellence 2016-2021: EBM+SDM in General Practice – focus on SDM for vulnerable populations

<table>
<thead>
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<th>Application ID: APP1106452</th>
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<tbody>
<tr>
<td><strong>Title:</strong> Testing, Translation and Uptake of Evidence in General Practice: A systems approach to rapid translation</td>
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**Chief Investigators**

<table>
<thead>
<tr>
<th>CI-A</th>
<th>Professor Paul Glasziou</th>
<th>Centre for Research in EBP, Bond University</th>
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<tbody>
<tr>
<td>CI-B</td>
<td>A/Professor Lyndal Trevena</td>
<td>Public Health, University of Sydney</td>
</tr>
<tr>
<td>CI-C</td>
<td>A/Professor Tammy Hoffmann</td>
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</tr>
<tr>
<td>CI-H</td>
<td>Professor France Légaré</td>
<td>University of Laval, Canada</td>
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</table>
Laboratory of general practices
Automated tools for developing evidence summaries and decision aids...

Aim: to make it really easy for GPs and patients to access well designed, up-to-date evidence and decision aids
4. Monitor knowledge use
(GPs tested in practice, placed on intranet)

Knowledge creation

Primary studies

Systematic reviews

Practice guidelines
Care pathways
Decision aids

5. Evaluate Outcomes
(Use by GPs and Patients)

6. Sustain knowledge use

3b. Adapt knowledge
(Patient instruction sheet, sleep diaries, consultation flow)

3a. Adapt knowledge
(Questions? Sent to study authors)

1. Identify problem
(e.g. dangers of benzodiazepine; value of behavioural ‘prescription’ for insomnia)

2. Identify, review, select knowledge
(Systematic review of behavioural interventions for insomnia; GP-based trial)
An example in practice: Illawarra Shoalhaven Primary Health Care Network

Illawarra Shoalhaven Local Health District

Health Literacy Framework 2012 - 2015

A Plan for Becoming a Health Literate Organisation

What we wanted to achieve?

We wanted to:

1. Embed health literacy into high-level systems and organisational policies and practices

2. Integrate health literacy into our planning and evaluation for clinical and quality improvement

3. Have plain English health information that is easy to read, understand and use

4. Partner with consumers in the evaluation of health information and access and navigation of services

5. Have effective and evidence based health literacy strategies in interpersonal communication
So what was the path we took?

To address health literacy in a coordinated way we:

- Conducted an extensive literature review and a gap analysis to identify best practice and key strategies for addressing health literacy
- Conducted a pilot project with Drug & Alcohol to test a model for the development of plain English consumer information
- Developed ISLHD Health Literacy Framework with five key goals
- Embedded health literacy in ISLHD Safety and Quality Plan
Key Strategies of ISLHD Health Literacy Framework

- Patient Information Portal (PIP)
- Plain language consumer information
- Systems and Resources to drive and support change
- Health Literacy Ambassador Program
- Access and way-finding
- Education programs (teach-back)

Becoming a health literate organisation
Key Strategies of ISLHD Health Literacy Framework

- Resources to drive and support health literacy at a District level (Patient Information Coordinator)
- A new way of doing business - governance for consumer information
- ISLHD Procedure for Plain English Consumer Information & guidelines

- HLAs support staff to produce plain English patient information
- Training and on-going support provided by Patient Information Coordinator
- Common Goal = stock-take of all consumer information used by individual services to identify priority information for plain English review and consumer testing.

Health literacy information provided to:
- all new staff at general orientation
- 4th year medicine students

- Health Literacy training resource available on PIP including teach-back training package

PIP –
- Intranet site for staff to find plain English and translated consumer information
- Tools to help staff develop plain English consumer resources,
- Information about health literacy and teach-back information
- Multi-lingual Grants Program

- ACCESSAbility Hospital Way-Finding Program
- Welcome to Wollongong Hospital Tours for refugees and newly arrived migrants
- Joint staff / consumer way-finding committee (new TWH development)
Health literate health systems......
Thank you

kirsten.mccaffery@sydney.edu.au
Thank you

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RISK INCREASING INEQUALITIES

- 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 literate as information rich with access to choice

Lower health literate as information poor & little access to choice
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!
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%
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
**What is cancer screening?**

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).

---

**What increases your risk of getting bowel cancer?**

**Risk Factors**

- **Age**: bowel cancer is more common as you get older.
- **Gender**: bowel cancer is a little more common in men.
- **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.

e.g. For screening:

<table>
<thead>
<tr>
<th>Against screening</th>
<th>Unsure</th>
<th>For screening</th>
</tr>
</thead>
</table>

e.g. Against screening:

<table>
<thead>
<tr>
<th>Against screening</th>
<th>Unsure</th>
<th>For screening</th>
</tr>
</thead>
</table>

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?

<table>
<thead>
<tr>
<th>Against screening</th>
<th>Unsure</th>
<th>For screening</th>
</tr>
</thead>
</table>

Lowering your risk of bowel cancer by screening

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

<table>
<thead>
<tr>
<th>Against screening</th>
<th>Unsure</th>
<th>For screening</th>
</tr>
</thead>
</table>

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
PRELIMINARY RESULTS – immediate assessment

<table>
<thead>
<tr>
<th>Shared Decision Making</th>
<th>Score range</th>
<th>Intervention vs standard LLN</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM knowledge (0-15)</td>
<td></td>
<td>11.7 vs 11.1</td>
<td>P=0.3</td>
</tr>
<tr>
<td>Recall of SDM questions (intervention only)</td>
<td></td>
<td></td>
<td>Comparable with higher literacy sample Shepherd et al (2016)</td>
</tr>
<tr>
<td>Q1</td>
<td>Q2</td>
<td>Q3</td>
<td>All 3</td>
</tr>
<tr>
<td></td>
<td>77%</td>
<td>66%</td>
<td>59%</td>
</tr>
<tr>
<td>Topics important to discuss with doctor</td>
<td>Options</td>
<td>Benefits &amp; Harms Likelihood</td>
<td>53% vs 1%</td>
</tr>
<tr>
<td></td>
<td>53%</td>
<td>49%</td>
<td>37%</td>
</tr>
<tr>
<td></td>
<td>vs 3%</td>
<td>vs 1%</td>
<td>vs 1%</td>
</tr>
</tbody>
</table>

Findings adjusted for clustering, and baseline health literacy score (using NVS). Randomised participants only
Inclusion criteria:
Direct measure of HL/L
Quantitative studies
English; 1966-2011

Databases: Medline, CINAHL, PsychINFO, ERIC, Cochrane

Process: Related abstracts review and quality assessment by 2 reviewers, AHRQ criteria.

Articles incl in AHRQ 2004 or 2011 review n=214

Total abstracts reviewed n=763

Abstracts excluded as unrelated n=763

Abstracts excl as unrelated n=707

Dually reviewed abstracts n=56

Full text articles reviewed n=25

Articles incl in review n=18
Cross sectional n =17; intervention n=1

Articles excluded fr in AHRQ 2011 as no direct HL/L measure or no outcomes of interest n=549

Abstracts excluded: 3 reviews; 4 no HL/L measure; 20 no outcome of interest; 1 abstract only; 1 unobtainable, 1 developing country

Full text articles excluded: 2 no HL/L measure; 2 no outcome of interest; 2 intv studies not stratified by HL/L

0 articles of poor quality
RESULTS: knowledge and understanding

- Lower HL associated with lower patient understanding/knowledge in 14/16 studies (Dewalt et al 2004).
- Interventions studies suggested strategies to improve understanding (14 studies relevant to PtDAs) (Berkman et al 2001; Sheridan et al 2011)
RESULTS: knowledge and understanding

- Lower HL strongly associated with lower patient understanding/knowledge in 14/16 studies (Dewalt et al 2004).
- Interventions studies suggested strategies to improve understanding (14 studies relevant to PtDAs) (Berkman et al 2001; Sheridan et al 2011)

### Practical design strategies to improve understanding

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present essential information first</td>
<td>Peters et al 2007</td>
</tr>
<tr>
<td>Present numerical information in tables or pictographs</td>
<td>Galesic et al 2009; Garcia-Retamero 2009</td>
</tr>
<tr>
<td>Present numerical information so the higher number is better</td>
<td>Peters et al 2007</td>
</tr>
<tr>
<td>Present numerical information with a consistent denominator</td>
<td>Garcia-Retamero 2009</td>
</tr>
<tr>
<td>Use natural frequencies</td>
<td>Galesic et al 2009b</td>
</tr>
</tbody>
</table>
RESULTS: values clarity

- No studies examined HL and values clarity directly
- 4 studies: HL and decisional uncertainty, regret, confidence. 1 intervention study
RESULTS: values clarity

- No studies examined HL and values clarity directly
- 4 studies: HL and decisional uncertainty, regret, confidence. 1 intervention study

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Studies</th>
<th>Summary of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decisional uncertainty</td>
<td>2</td>
<td>Lower HL associated with higher uncertainty and decisional regret.</td>
</tr>
<tr>
<td>Decisional regret</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidence in decision making</td>
<td>2</td>
<td>Effect unclear.</td>
</tr>
<tr>
<td>Intervention studies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decisional uncertainty</td>
<td>1</td>
<td>Patient videos increased the salience of health states reduced decisional uncertainty. Strongest effect in lower HL patients.</td>
</tr>
</tbody>
</table>
RESULTS: patient involvement communication

- 13 studies examined outcomes incl: patient activation, desire for participation, participation and communication quality
RESULTS: patient involvement/ communication

- 13 studies examined outcomes incl: patient activation, desire for participation, participation and communication quality

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Studies</th>
<th>Summary of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferences for participation in dec making</td>
<td>3</td>
<td>Lower preference for involvement among lower HL pts</td>
</tr>
<tr>
<td>Patient activation</td>
<td>1</td>
<td>Less patient activation assoc with lower numeracy not HL</td>
</tr>
<tr>
<td>Question asking</td>
<td>2</td>
<td>Less question asking among those with lower HL. More clarification questions (indicating lack of understanding)</td>
</tr>
<tr>
<td>Level of involvement</td>
<td>2</td>
<td>Lower HL reported less involvement. Less ‘mutuality’ observed between doctors and lower HL pts</td>
</tr>
<tr>
<td>Communication quality / Patient centered care</td>
<td>6</td>
<td>Less PCC among lower HL pts in 5 studies. 1 study reported effects varied by how numeracy was measured.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Effects on communication quality (satisfaction and perceived quality) varied.</td>
</tr>
</tbody>
</table>
SUMMARY

- Patients with lower health literacy had:
  - Lower comprehension/understanding
  - Higher decisional uncertainty and regret,
  - Less involvement in DM and less PCC

- Interventions studies suggests:
  - Ways to improve understanding in PtDAs
  - 1 study reduced decisional uncertainty using patient videos (Volandes et al 2009)
REVIEW 2

Specific Patient Decision Aid Literature

To what extent do existing PtDAs and PtDA trials address issues of health literacy?
REVIEW 2: METHODS

Methods

1. Systematically reviewed PtDAs published in latest Cochrane review (Stacey et al 2011).
2. Updated their review to include articles published to the end of 2010

[Led by Margaret Holmes-Rovner]
METHODS

- 3 researchers developed criteria based on IPDAS 2006 guidelines
- 5 new criteria added
- PtDAs rated by individual reviewers
- Inter-rater reliability performed on a random 13% of studies with 94.4% agreement.
### Original IPDAS 2006 health literacy criteria

| 1. | Is the PtDA written at a level that can be understood by the majority of the patients in the target group? |
| 2. | Is the PtDA written at a grade 8 /equivalent or less according to readability scores? |
| 3. | Does the PtDA provide ways to help patients understand information other than written text? |

**Response options:**
- Present = P
- Absent = A
- Unknown = UK
# Rating criteria for PtDAs and PtDA trial

## Original IPDAS 2006 health literacy criteria

1. Is the PtDA written at a level that can be understood by the majority of the patients in the target group?

2. Is the PtDA written at a grade 8 /equivalent or less according to readability scores?

3. Does the PtDA provide ways to help patients understand information other than written text?

## PtDA Trial Design Criteria

4. Was the DA web-based?

5. Were study groups stratified by health literacy/ literacy?

6. Were study groups stratified by education?

7. Were low health literacy/ literacy groups over-sampled?

8. Were any conclusions drawn regarding low health literacy

<table>
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<th>Response options:</th>
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<tbody>
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<tr>
<td>Unknown = UK</td>
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</tbody>
</table>
RESULTS

Out of 97 PtDA trials

- 5 reported a reading level ≤ grade 8
- 2 followed health literacy criteria but did not state which
- 7 recruited ‘lower literacy’ patients based on educational level
RESULTS

- Multi media used by many but difficult to evaluate whether they addressed health literacy

- Only 3 RCTs of PtDAs among lower health literacy / education adults
  - 2 showed increased knowledge in lower literacy adults (Trevena et al 2008; Smith et al 2010)
  - 1 showed increased informed choice (Smith et al 2010)
  - 2 show lower decisional conflict (Volk et al 2008; Smith et al 2010)
SUMMARY

- Only 3 RCTs of PtDAs among lower literacy adults

- In over 90% of trials neither the reading level of PtDA nor reading needs of patients was reported

- But where health literacy was addressed – results encouraging with improvements in knowledge, informed choice and decisional conflict
CONCLUSION

- Not nearly enough attention paid to health literacy in PtDA literature

- Lower HL patients are particularly disadvantaged in health decision making: poorer understanding, higher decisional uncertainty and regret, less PCC and less involved

- Some evidence available to support improved PtDA design for lower literacy patients

- But we know little about value clarification and supporting involvement in decision making - more research here especially is needed
MAIN LIMITATIONS

Review 1

- Inclusion and exclusion of articles was based on a single assessment but articles closest to review subject and article quality reviewed by 2 authors
- Excluded studies using education as a proxy for health literacy

Review 2

- Did not assess PtDA development papers – only papers reporting main trial
- Some review criteria were difficult to implement
RECOMMENDATIONS

1. Follow good HL principles: state what principles were followed and how they were implemented

2. Recruit where possible adequate numbers of lower HL adults to permit analyses in this population

3. Assess HL and numeracy in samples by direct measurement (e.g. TOHFLA, REALM or NVS)

4. If 2 and 3 not possible - test or pilot the PtDA in samples with lower HL defined education (high school equivalent or less) – still under debate in our group
Health Decision Making is difficult

- Information is new, situation novel
- Language is complex & unfamiliar (jargon)
- Risks & benefits difficult to understand
- Situation often emotional – can be serious physical, QoL, social, work consequences
- Implications for family
- May be /feel time pressured
Different styles of health decision making
Different styles of health decision making

1. Traditional – clinician / provider directed or persuasive
2. Nudge – manipulating choice architecture

MAKE CHOICES A BIT EASIER (OR HARDER)

“In seven weeks, New York Googlers consumed 3.1 million fewer calories from M&Ms”

The Google Diet: Search Giant Overhauled Its Eating Options to 'Nudge' Healthy Choices

By JUJU CHANG and MARY MARSH
Jan. 25, 2013
3. Informed or Shared Decision Making
What is Shared Decision Making?

- 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.

‘**Pinnacle of patient-centred care’** Prof M Barry, NEJM 2012

Elwyn et al JGIM 2012
Different styles of DM appropriate in different contexts
Decision making is hard work

How can we make it easier?
How can we help people make ‘good’ health decisions?
What are the barriers – what are the facilitators......
Decision Making is not rational and prone to bias

• Overconfidence bias
Believing too much in your own ability to make good decisions

• Anchoring bias
Using first received information to make subsequent judgements

• Confirmation bias
Selecting and using only facts that support our decision

• Availability bias
Overemphasizing information that is readily at hand: recent or vivid

• Ambiguity effect - Tendency to avoid uncertainty
Health literacy: major barrier to effective health decision making
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)
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
1. Individual skills and capacities

Individual skills, knowledge, capacity, motivation

2. Health literacy environment

Health system policies, processes, materials, relationships
Individual skills, knowledge, capacity, motivation
LITERACY LEVELS IN AUSTRALIA

- 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

- High % adults struggle to understand routine / ‘every day’ written information
2. Health literacy environment

Health system policies, processes, materials, relationships
2. Health literacy environment

Health system policies, processes, materials, relationships
Of 100 women who take drug A, 5 out of 100 women will experience side effects or 5%....

Yet recommended formats RARELY used.

20% less women will experience side effects

Trevena et al 2012
Individual skills and capacities

46-60% inadequate literacy

Health literacy environment

Health information: 60-95% inappropriate for average or low literacy popns
Why does health literacy matter?

Low literacy / health literacy associated with poor health 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

(AHRQ Systematic reviews: DeWalt et al 2004; Berkman et al 2011)
Why does health literacy matter?

Accurate understanding of Tx recommendations varied from 0 - 68.3%, mean 45.4%, (SD 21.5)

Adherence greater for patient perception of Tx than actual recommendation

45.4% vs 62.4%; difference 17%; p<0.009
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
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
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’