Health Literacy and Patient Centred Research

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+ growing Community of Practice
Outline

- What is health literacy?
- Why do we care about health literacy?
- Conceptualising health literacy
- Health literacy and patient-centred research
  - Important considerations
  - Potential benefits
Defining health literacy
What is literacy?

- Functional literacy is defined as a tangible set of **skills in reading and writing and the capacity to apply these skills in everyday situations**

- Literacy skills enable people to **better develop their knowledge and improve their potential to achieve personal goals.**

- Individuals are able to participate more fully in society and the economy.

Slide adapted from Nutbeam et al., 2013; https://www.slideshare.net/SaxInstitute/don-nutbeam-the-evolving-concept-of-heal
Literacy skills are significantly moderated by the context in which they are applied

- More accurate to talk about **literacies** for example:
  - Financial literacy,
  - Science literacy
  - Media literacy,
  - IT literacy (new literacy) and,
  - **Health literacy**

Slide adapted from Nutbeam et al., 2013; https://www.slideshare.net/SaxInstitute/don-nutbeam-the-evolving-concept-of-heal
What is *health* literacy?

- ...the cognitive and social skills that enable individuals to gain access to, understand and use information to make decisions about health\(^1\).

- Content and context specific

(Nutbeam, 1999)
Why do we care about health literacy?
Why do we care about health literacy?

1. Prevalence

60% of Australian adults lack functional health literacy skills (e.g. interpreting medicine dosage information).

(Australian Bureau of Statistics, 2008)
Why do we care about health literacy?

2. Impact on health

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

(AHRQ Systematic reviews: DeWalt et al 2004; Berkman et al 2011)
Why do we care about health literacy?

3. Social gradient

Lower levels of health literacy more common among the socially and economically disadvantaged.
Why do we care about health literacy?

4. Policy

National requirements of the Australian Commission for Safety and Quality in Healthcare (Standard 2)

NSW Health Pillar organisations (Agency for Clinical Innovation [ACI]; NSW Clinical Excellence Commission [CEC])

NSW Health Strategic Priorities 2017-18.
Why do we care about health literacy?
Conceptualising health literacy
Health literacy is determined by personal skills and context in which those skills are to be applied

Conceptualising health literacy

- Two different conceptualisations of health literacy

<table>
<thead>
<tr>
<th>Risk/ deficit approach</th>
<th>Asset approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Reifies health literacy as an individual deficit</td>
<td>• Health literacy is seen as a personal asset which offers consumers greater autonomy and control over healthcare decisions.</td>
</tr>
<tr>
<td>• Health literacy seen as a static patient characteristic that needs to be managed in the process of providing clinical care</td>
<td>• Health literacy seen to be a modifiable health determinant</td>
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Patient-Centred Research
Patient-centred Research

- **Patient involvement** refers to patients being active partners in research who contribute their experiences and perspectives across the stages of the research process – setting the research priorities, designing, conducting, reporting, and disseminating research. → *partnership*

- **Patient-centred research** generates evidence that helps patients and their caregivers communicate and make informed decisions about their health. Understanding their values, goals, and priorities are needed to inform patient-centred care. → *evidence*
Health literacy and patient centred research
Important considerations

1. NHMRC (2006) emphasises the diversity of consumer representatives

- Know the health literacy of your population
- Use multiple engagement strategies and approaches
- Purposively sampling for lower health literacy

Remember: 60% of Australian adults lack functional health literacy skills
Identifying those with lower health literacy

- There are a number of tools to measure and screen for health literacy, including:
  - Rapid Estimate of Adult Literacy in Medicine (REALM)
  - Short Test of Functional Health Literacy in Adults (S-TOFHLA)
  - Newest Vital Sign (NVS)
  - Chew et al., Screening Questions
  - Single Item Literacy Screener (SILS)
  - Health Literacy Questionnaire (HLQ)
Newest Vital Sign (NVS)

6 questions based on a nutritional (ice-cream) label

3-5 minutes

Not self-administered (presented verbally to patient)

3 categories:

- High likelihood of limited literacy
- Possibility of limited literacy
- Adequate literacy

Chew et al., Screening Questions

• “How confident are you filling out medical forms by yourself?”

• Possible responses:
  • 0-Extremely
  • 1-Quite a bit
  • 2-Somewhat
  • 3-A little bit
  • 4-Not at all

• Higher scores reflect greater problems with reading
Identifying those with lower health literacy


Identifying those with lower health literacy

- **Health Literacy Toolshed**: [https://healthliteracy.bu.edu/](https://healthliteracy.bu.edu/)
Important considerations

2. Supporting consumers (with lower health literacy) to be involved
   a. A risk approach

Image source: [https://www.keepcalm-o-matic.co.uk/p/keep-calm-and-use-universal-precautions/](https://www.keepcalm-o-matic.co.uk/p/keep-calm-and-use-universal-precautions/)
Supporting consumers to be involved: A risk approach

- Communication with consumers should be guided by best-practice health literacy principles.

Priority-setting ➔ Designing ➔ Conducting ➔ Reporting ➔ Disseminating

Verbal and written communication!
Written information

- Readability scores
- Patient Education Materials Assessment Tool (PEMAT)
- Suitability Assessment of Materials (SAM)
- Universal Precautions (Toolkit)
Written information

- Toolkit to Make Written Materials Clear and Effective

- Health Literacy Online: A Guide for Simplifying the User Experience

- Simply Put: A guide for creating easy-to-understand materials

- Everyday Words for Public Health Communication
<table>
<thead>
<tr>
<th>Item #</th>
<th>Item</th>
<th>Response Options</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topic: Content</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>The material makes its purpose completely evident.</td>
<td>Disagree=0, Agree=1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>The material explains terms clearly.</td>
<td>Disagree=0, Agree=1</td>
<td></td>
</tr>
<tr>
<td>Topic: Word Choice &amp; Style</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>The material uses common, everyday language.</td>
<td>Disagree=0, Agree=1</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Medical terms are used only to familiarize audience with the terms.</td>
<td>Disagree=0, Agree=1</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>The material uses the active voice.</td>
<td>Disagree=0, Agree=1</td>
<td></td>
</tr>
<tr>
<td>Topic: Organization</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>The material breaks or “chunks” information into short sections.</td>
<td>Disagree=0, Agree=1, Very short material*=N/A</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>The material’s sections have informative headers.</td>
<td>Disagree=0, Agree=1, Very short material*=N/A</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>The material presents information in a logical sequence.</td>
<td>Disagree=0, Agree=1</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>The material provides a summary.</td>
<td>Disagree=0, Agree=1, Very short material*=N/A</td>
<td></td>
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</table>
Verbal communication


  - Repeat content nouns and verbs across sentences. Don’t aim for diverse vocabulary for its own sake (low lexical diversity).

  - Give listener’s “advance organizers” to help them predict what information will follow.

  - Use internal summaries.

Verbal communication

- Teachback
  - Iteratively asking the patient to summarise or restate the important points in a consultation using their own words
  - Impact greatest for those with low health literacy (Morony et al., forthcoming)

Important considerations

2. Supporting consumers (with lower health literacy) to be involved
   b. Training and skill building

Supporting consumers to be involved: An asset approach

- National Framework for Consumer Involvement in Cancer Control\(^1\)
  - Consumers receive training specific to the area of participation and involvement.

  - Training and mentoring of consumers is essential if consumers are to acquire the levels of expertise required for their roles.

  - Opportunities that enable consumers to develop expertise in areas of interest...are considered a necessary component of effective consumer engagement.

\(^1\)Cancer Australia and Cancer Voices Australia, 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.
Facilitation Skills

Subject-specific knowledge:
- Research Methods
- Project management
- Reflection
- PPI involvement
- Interpersonal & communication processes
- Team working skills
- Support mechanisms

Educational expertise:
- Group facilitation
- Management of the learning environment
- Teaching & learning approaches
- Student support

Context:
- PPI Involvement
  - Local & National policy context
  - The benefits to engagement
  - Methods of engagement

Core: Research Methods
- Developing a research idea
- Reviewing the literature
- Developing the project team: roles & responsibilities
- Participant recruitment: ethical considerations
- Data collection & analysis
- Dissemination: Reporting the findings
- Applying for funding

External: Support
- Peer support
- Buddy systems
- Tutorials
- Coaching
- Mentorship
- Supervision
- Practical resources

Internal: Reflection
- Personal development planning
- Interpersonal skills
- Coping strategies
- Presentational skills
- Personal resources
- Knowledge & expertise

Collective: Team work
- Project Management
- Roles & responsibilities
- Communication skills
- Task allocation

Important considerations

2. Supporting consumers (with lower health literacy) to be involved
   c. Addressing power imbalances

- Adults with lower literacy are more likely to perceive a greater power imbalance
- Ask fewer questions (during consultations)

...compared to higher literacy patients (Katz et al., 2007).
Important considerations

3. Benefits

- Patient/consumer involvement can result in products that meet the needs of target populations (ACI, 2015)

- Information was more relevant, ‘readable’ and understandable when consumers were involved than when clinicians produced written materials alone (Nilsen et al., 2006).
Integrating health literacy principles and consumer engagement

- Case study 1: Development of mass communication for Medicaid beneficiaries (Neuhauser et al., 2009)

  - Aim: To support highly vulnerable populations participating in Medicaid to make complex choices to select a health plan given that only 25% made active, informed choices.

  - Methods:
    • Identified and engaged user subgroups; established an 24-member advisory group
    • Conducted focus groups and interviews with purposive sampling
    • Developed a guidebook; set health literacy standards and performed usability and readability testing
    • Adapted final ‘guidebook’ into 13 languages
Integrating health literacy principles and consumer engagement

- Case study 1: Development of mass communication for Medicaid beneficiaries (Neuhauser et al., 2009)

  - Results of an RCT:

    - Intervention participants showed gains in knowledge, positive attitudes, and intentions to enroll in Medicaid managed care that were statistically significant compared with control participants.

    - Nearly all (97.9 percent) participants found the guidebook somewhat or very useful.
Health literacy and consumer engagement

- Case study 2: Designing infographics for community members with varying levels of health literacy (Arcia et al., 2016)
  
  - Aim: To identify best practices for health information visualisations

  - Methods:
    - Purposively sampled consumers based on language and health literacy (adequate, marginal, inadequate)
      - Chew et al., 2008 single item health literacy screener
    - Iterative infographic refinement process

  - Results:
    - Identified infographics that will be meaningful, culturally relevant, and actionable for future testing in research studies.
Health literacy and consumer engagement

Case study 3: The experience of teenage pregnancy (cited by Parkes et al., 2014)

- **Aim:** To explore the experience of teenage pregnancy
- **Methods:**
  - Six young mothers and their youth worker were trained in how to design an interview schedule and conduct focus groups with their peers.
  - With the support of the research team, trainees then conducted focus groups with other young mothers, young offenders and Children Looked After.
  - The groups were facilitated in pairs of teenagers who had been trained by the research team.
Health literacy and consumer engagement

Case study 3: The experience of teenage pregnancy (cited by Parkes et al., 2014)

- Results:
  - Consumers’ advice and experience enhanced the wording of the focus group schedules
  - Consumers were very successful in building rapport with participants who were of a similar age.
Summary

- High proportion of people with lower health literacy → support diversity in consumer participation
  - Target and tailor communication
  - Training and skill-development

- Established evidence for impact of including diverse range of patients/consumers in the research process.