Health literacy in evaluation

Health Literacy can be very hard to measure. There are tools to measure an individual’s level of health literacy, and tools to assess an organisation’s approach to health literacy. There are also other indicators we can measure that give us an idea if health literacy has improved.

Individual health literacy

Over a hundred instruments measuring health literacy in adults exist. There are general and disease specific measures of health literacy, e.g. 6-item Cancer Health Literacy Test (CHLT-6) and Literacy Assessment for Diabetes (LAD).

We may want to measure health literacy to:
- Describe a population
- Explore the association between health literacy and health outcomes
- Plan and monitor effectiveness of interventions
- Target clinical communication
- See its effect as an independent contribution to health outcomes (over and above education and literacy)

Some of the most commonly used tools to measure general health literacy across populations and settings are detailed in Appendix 1.
For more tools, see:

- Health Literacy Toolshed, Boston University - Searchable database of health literacy measurement tools.

Should these measures be used in routine clinical settings?

In general, no. Some tools, like screening questions, may be more appropriate than performance based tools or longer measures in clinical settings. However, we recommend that you use Universal Precautions when communicating with people in clinical settings rather than any formal measures of health literacy. That is, not making any assumptions about what a person may or may not understand, and using best-practice health literacy strategies to communicate with everyone.

If you use these strategies, like using plain language, it helps everyone better understand their health, regardless of what health literacy level they may have. Strategies like teach-back to check for prior knowledge or understanding of particular topics, and asking people how they like to communicate and learn, allow us to tailor information to an individual without having to “test” them with one of these measurements.
Organisational health literacy

There are lots of recommendations for what a health literate organisation *should* do. To actually measure this concept is difficult.

One way you can do this is by checking how many criteria of a health literate organisation your service meets.

1. Use a tool (e.g. Checklist for becoming a health literate organisation) to review your organisation.
2. Create a plan of actions your organisation needs to take to meet more of the criteria.
3. Monitor your progress against this action plan as a way of tracking organisational health literacy improvement.

More organisational health literacy tools are in Appendix 2.

For a review of more tools to measure organisational health literacy, see: Bremer et al. Which criteria characterize a health literate health care organization? A Scoping review on organizational health literacy. BMC Health Services Research (2021) 21:664.

There are also specific tools to measure certain aspects of organisational health literacy, such as wayfinding to assess health service access and tools to assess if resources meet health literacy standards.

**Wayfinding**

Detailed instructions are found in the NSW Wayfinding for Healthcare Facilities guidelines. A wayfinding audit is also available on the NSW Health Quality Audit and Reporting System (QARS), called CEC_Wayfinding_for_Hospitals_and_Health_Services_October_2019

**Health literate resources**

You can use a tool like the Patient Education Materials Assessment Tool (PEMAT) to score resources. It assesses the understandability and actionability of print and audiovisual patient education materials. The Patient Education Materials Assessment Tool (PEMAT) and User's Guide is available from the Agency for Healthcare Research and Quality (ahrq.gov)

You can also see how individual resources stack up against guidelines or checklists for developing patient information. There are many of these available, like the Checklist for designing consumer-friendly health information developed by the Northern NSW Health Literacy Project. Many organisations have their own guidelines or processes for developing consumer information, such as Illawarra Shoalhaven, Western Sydney and Northern NSW Local Health Districts.
Other indicators related to health literacy

It’s not always practical or possible to measure health literacy. In these cases, we can use other indicators that are related to best-practice health literacy strategies or health outcomes to show improvements in health and care.

Other surveys
Other commonly used surveys that ask about patients’ experience of care can give us an idea of whether health professionals are using best-practice health literacy strategies. These surveys do not measure health literacy, but they do measure aspects of care that health literacy strategies aim to improve.

Bureau of Health Information (BHI) patient survey
There are multiple patient surveys, which ask questions like:

- Did the health professionals explain things in a way you could understand?
- During your stay in hospital, how much information about your condition or treatment was given to you?
- Did the health professionals listen carefully to any views or concerns you had?
- Were you involved, as much as you wanted to be, in decisions about your care and treatment?
- Thinking about when you left hospital, were you given enough information about how to manage your care at home?

There are many more relevant questions. You can download the results of these surveys for the state, broken down by Local Health District and hospital, or use the Bureau of Health Information Data portal to search for results.

Patient Reported Measures (PRMS)
Patient Reported Experience and Outcomes Measures (PREMs and PROMs) can be used within services. There are disease specific measures and more general measures, such as Inpatient and Outpatient PREMs. These include questions like:

- Did the health professionals explain things in a way you could understand?
- I was involved as much as I wanted in making decisions about my treatment and care
- Have you been given enough information about how to manage your care at home?

Measures and more information can be found on the Resources for clinicians and patients page from the NSW Agency for Clinical Innovation.

Measuring behaviour change through process or output indicators
1. Consider the health literacy barrier you are trying to address
2. Measure the change in the behaviour associated with that specific barrier (either a consumer or an organisational/health professional behaviour change). E.g.:
   - each patient offered smoking cessation advice has a quit smoking plan documented
- no show rates for clinic decrease after implementing actions to improve access
- registration for program increases after implementing actions to improve understanding of registration process
- Changes in self-reported use of teach-back by healthcare workers over time.
- Changes in client knowledge about their condition, before and after teach-back is used.
- Decreases in readmission rates for issues where client understanding of self-management is paramount.
- Peer observation of how individual staff use teach-back.
- Chart audit to see how many times teach-back is being documented.
- Changes in satisfaction surveys of clients or caregivers.

While none of these examples measure health literacy specifically, by showing improvements in these areas you are showing improvements in health outcomes and health behaviours that evidence tells us are supported by better health literacy. Due to other confounding factors, you won’t be able to contribute any change in these behaviours solely to health literacy improvements.
Appendix 1. Common tools to measure individual health literacy

This information is based off The Health Literacy Hub Presentation “Measuring Health Literacy” by Dr Danielle Muscat and Julie Ayre.

<table>
<thead>
<tr>
<th>Name</th>
<th>Type of assessment</th>
<th>Aspect of health literacy assessed</th>
<th>Validity and reliability Settings used in</th>
<th>What does the participant have to do?</th>
<th>How is it scored?</th>
<th>Cost</th>
<th>Administration</th>
</tr>
</thead>
</table>
| **Screening questions for limited health literacy**  
Chew et al., 2008 | Screening  
Self-reported | Identify adults in need of help with printed health material | • Performs reasonably well in detecting “limited/marginal” health literacy.  
• Does not perform well in detecting “marginal” health literacy  
• Suitable for clinical practice and research  
• May not be sensitive enough to detect change in health literacy or associations with outcomes | 1."How often do you have someone help you read hospital materials?“  
2."How confident are you filling out medical forms by yourself?“  
3. "How often do you have problems learning about your medical condition because of difficulty understanding written information?" | Higher scores reflect greater problems with reading.  
Categories:  
• 1.Limited/marginal (corresponds to <9th grade reading level on the REALM)  
• 2. Adequate | Easy to use and administer  
Less than 1 min  
Self-administered |
| **Single Item Literacy Screener (SILS)**  
Source: Morris et al. BMC Fam Practice (2006) 7:1 | Screening  
Self-reported | • Performs reasonably well in detecting limited health literacy  
• Does not perform well in detecting marginal health literacy (sensitivity of 34%)  
• May not be sensitive enough to detect change in 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 pharmacy?” | Scores greater than 2 indicate some difficulty with reading printed health related material.  
Categories: | Free  
Less than 1 min  
Self-administered |
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<tbody>
<tr>
<td><strong>Rapid Estimate of Adult Literacy in Medicine (REALM)</strong>&lt;br&gt;Source: Davis et al. Family Medicine (1991) 23:6</td>
<td>Measurement tool&lt;br&gt;Performance based (“test”)</td>
<td>Functional health literacy only</td>
<td>• Established reliability and validity&lt;br&gt;• Only identifies those with reading levels below grade 9</td>
<td>66 word recognition and pronunciation test&lt;br&gt;Asks patients to read medical words aloud&lt;br&gt;There is a short version with 7 medical terms.</td>
<td>4 categories of scores:&lt;br&gt;• ≤3rd grade&lt;br&gt;• 4-6th grade&lt;br&gt;• 7-8th grade&lt;br&gt;• high school</td>
<td>Free</td>
<td>1-2 minutes to complete&lt;br&gt;Not self-administered</td>
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<tr>
<td><strong>Test of Functional Health Literacy in Adults (TOFHLA)</strong>&lt;br&gt;Source: Parker et al. JGIM (1995) 10:10</td>
<td>Measurement tool&lt;br&gt;Performance based (“test”)</td>
<td>Functional health literacy only</td>
<td>Part 1: 17 item numeracy test – assesses ability to use numerical skills to comprehend directions (e.g. medication instructions).&lt;br&gt;Part 2: 50 item reading comprehension test – patients have to fill in the blanks with one of four options in a medical-related sentence.</td>
<td>Different reading levels:&lt;br&gt;• 4th grade level&lt;br&gt;• 10th grade level&lt;br&gt;• 19th grade level.</td>
<td>Licence required</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>S-TOFHLA</strong></td>
<td>Measurement tool</td>
<td>Functional health literacy only</td>
<td>• Established reliability and validity in English</td>
<td>Two reading passages only</td>
<td>3 categories:&lt;br&gt;• Limited&lt;br&gt;• Marginal</td>
<td>Licence required</td>
<td>7 minutes&lt;br&gt;Self-administered</td>
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<tr>
<td>Name</td>
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| Newest Vital Sign | Measurement tool | Functional health literacy only | • Established reliability and validity in English  
• Reliability and validity poorer in other languages (Spanish)  
• May misclassify patients with adequate health literacy, and overestimate the percentage of patients with limited literacy | 6 questions based on a nutritional (ice cream) label | 3 categories:  
• High likelihood of limited literacy  
• Possibility of limited literacy  
• Adequate literacy | Free | Not self administered (presented verbally to patient) |
| Health Literacy Questionnaire (HLQ) | Measurement Self-reported | Multi-dimensional tool health literacy strengths and limitations of individuals and populations across 9 domains (goes beyond functional skills) | • Validity studies completed  
• Used by the Australian Bureau of Statistics to measure health literacy in the Australian population  
• Can be used to inform health literacy interventions  
• Able to detect change in health literacy | 44 item questionnaire over 9 domains:  
1. Feeling understood and supported by health care providers  
2. Having sufficient information to manage my health  
3. Actively managing my health  
4. Social support for health  
5. Appraisal of health information  
6. Ability to actively engage with health care providers  
7. Navigating the health care system  
8. Ability to find good health information | 9 scale scores  
These **cannot** be averaged into one score. | Licence required (but may be free for NSW Health staff) | 7 - 45 minutes  
Self or verbally administered on paper or online  
Available in multiple languages |
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</table>
| **Conversational Health Literacy Assessment Tool (CHAT)** | Screening, Self-reported | Used to help identify health literacy needs, barriers and challenges that may be preventing patients from managing and maintaining their health | • Not a measure  
• CHAT can be used as part of your existing intake and assessment procedures to gather a broader perspective of a patient’s health literacy level.  
• You can also choose to use CHAT as part of discharge planning to help tailor any follow-up care required to the patient’s individual health literacy needs | 1. Supportive professional relationships  
• Who do you usually see to help you look after your health?  
• How difficult is it for you to speak with [that provider] about your health?  
2. Supportive personal relationships  
• Aside from healthcare providers, who else do you talk with about your health?  
• How comfortable are you to ask [that person] for help if you need it?  
3. Health information access and comprehension  
• Where else do you get health information that you trust?  
• How difficult is it for you to understand information about your health?  
4. Current health behaviours  
• What do you do to look after your health on a daily basis? | CHAT questions are not intended to be delivered as a checklist. They help you to shape an open conversation around the literacy themes. | Free | Not self-administered, meant to be a conversation with patient  
Administration time depends on number of questions asked |
### E-health literacy tools

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<tr>
<th>Health literacy tool</th>
<th>Description and Outcomes assessed</th>
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<tr>
<td><strong>eHealth Literacy Scale (eHEALS) (2006)</strong></td>
<td>• 8-item measure of eHealth literacy developed to measure consumers’ combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems</td>
</tr>
</tbody>
</table>
| **eHealth Literacy Questionnaire (eHLQ) (2018)** | • Provides insight into users’ perceptions and experiences of digital health solutions  
• Helps us understand why implementations work or fail  
• Has 7 scales that cover the dimensions of the eHealth Literacy Framework  
• Has been translated into at least 4 languages, with others in progress |
## Appendix 2. Organisational health literacy tools

### Organisation-wide tools

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<tr>
<th>Health literacy tool</th>
<th>Description and Outcomes assessed</th>
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• Practical checklist to check your organisational health literacy based on the ten attributes of a health literate organisation, including ideas for improvement.                                                             |
| **10 Attributes of a Health Literate Organisation** (2012)                          | • Developed by the American Institute of Medicine.  
• Describes 10 attributes of health care organizations that make it easier for people to navigate, understand, and use information and services to take care of their health. Most of the other tools are based on this. |
| **Organisational Health Literacy Responsiveness (Org-HLR) self-assessment tool** (2018) | • Developed as part of the Ophelia process.  
• Helps organisations assess strengths and areas for further development in relation to systems, processes and practices.  
• Suits all organisations that play a role in providing health and health-related information, services and programs to individuals and communities. |
| **AHRQ Universal Precautions Toolkit** (2015)                                       | • Developed by the Agency for Healthcare research and Quality.  
• Toolkit can help primary care practices reduce the complexity of health care, increase patient understanding of health information, and enhance support for patients of all health literacy levels.  
• 175 page document – takes a long time to complete. |
| **The health literate health care organization 10 item questionnaire (HLHO-10)** (2015) | • Ten items were developed to represent the ten attributes of HLHO (HLHO-10).  
• It provides a useful tool to assess the degree to which health care organizations help patients to navigate, understand, and use information and services. |
• Agency Self-Assessment Checklist.  
• 56 page document |
| **Enliven Organisational Health Literacy Self-Assessment resource**                 | • Based on 10 attributes.  
• 36 pages |
| **Making Health Literacy Real: The beginnings of my organization’s plan for action** | • CDC template to develop organisation action plan. |
• 21 pages.  
• Good concise version that provides practical examples of actions organisations can take to address each of the ten attributes and resources to support actions. |
• Approach for analyzing literacy-related barriers to healthcare access and navigation. |
## Health literacy practice assessments

<table>
<thead>
<tr>
<th>Health literacy tool</th>
<th>Description and Outcomes assessed</th>
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</table>
| **Health Literate Primary Care Practice screener (HLPC)** (2015) | • Developed in Germany  
• HLPC is a 4-item screener  
• Provides insights in the extent of the utilization of health literacy strategies in primary care practices. |
| **health literacy-sensitivity of communication (HL-COM)** (2017) | • Developed in Germany  
• The instrument measures an important aspect of organizational HL; i.e., the degree of health literacy-sensitivity of communication  
• The instrument might be used to measure attributes of health-literate health care organizations or to evaluate communication skills trainings for physicians or other health professionals from the patient's perspective. |
| **Teach-back checklist** (2018)                           | • A checklist to monitor teach-back proficiency of health professionals.                                                                                         |