Acknowledgements

This framework has been informed and shaped by consumers, frontline staff and leaders across NSW Health. The CEC wishes to acknowledge their input, expertise and enthusiasm to create the framework, and their commitment to improving health literacy for patients, families and carers. Special thanks go to the Agency for Clinical Innovation (ACI)/CEC Consumer Council members, the CEC consumer advisor group, and the Health Literacy champions group, which is made up of interested clinicians across NSW and ACT Health. Staff at the CEC, ACI and ACSQHC are acknowledged with thanks.

All photos in this document have been used with permission. Photo of Blacktown Hospital courtyard (p9) courtesy of Blacktown and Mount Druitt Hospitals Expansion Project/Richard Glover; Photo of Mount Druitt Hospital Healing Garden (p11) courtesy of Blacktown and Mount Druitt Hospitals Expansion Project.
Foreword

At the Clinical Excellence Commission (CEC) we are striving for safer care, for every patient, every time. The four core values of the New South Wales (NSW) Health system – collaboration, openness, respect and empowerment – underpin everything we do. In working collaboratively, we acknowledge that every person working in the health system plays a valuable role in contributing to safe, reliable care and ensuring a positive experience of care for patients, their families and carers.

Improving health literacy, through simplifying information, checking-in to ensure understanding, making it easier for people to find their way around and supporting people to self-manage their health and well-being, is about truly partnering in care. The NSW Health Literacy Framework: a guide to action’s four priority areas illustrate that improving health literacy requires attention at all levels, from the individual to the system. We encourage you to work in partnership with your community, consumers and staff to engage in planned iterative cycles of improvement. We invite you to share your successes as we continue to build this resource over time.

Carrie Marr
Chief Executive

A/Prof Brian McCaughan AM
Board Chair
Enabling patients, families and carers to understand and manage their health is a key way to improve their quality of life and reduce the impact of disease. Identifying and removing barriers for them to become active partners in their health care is vital.

Low health literacy can lead to poor health outcomes, reduced access to care and poor management of long term conditions. Partnering with patients, families and carers to ensure understanding of their health can reduce personal, community and economic costs of care.

The importance of health literacy has been highlighted internationally and locally. In Australia, 60% of people have low health literacy. People who are aged, from culturally and linguistically diverse (CALD) backgrounds, and have lower socioeconomic status are more at risk of having low health literacy.

It is important to address health literacy across the whole health system. Delivering care which is safe, high quality and person centred must include addressing health literacy. Change is needed at both individual and organisational levels. Responsibility must lie with the leadership of organisations, but action needs to be taken at all levels.

A universal precautions approach is recommended for NSW Health. This means that all communications – written and spoken – should be in plain English.

This Health Literacy framework provides a guide to action. It defines priorities and the scope of the issue. It builds on the great work already done by frontline staff, leaders and managers across NSW Health to improve individual and organisational health literacy.

It is important to choose words carefully and ensure that language is simple but clear. In this framework, the word patient refers to any person accessing or using health services. It is acknowledged that other labels such as consumer, client, person with a mental health issue may apply in specific contexts.

Designed for the New South Wales (NSW) health system, adoption of the framework priorities by Local Health Districts (LHDs), Specialty Health Networks (SHNs) and Primary Health Networks (PHNs) will improve the health literacy responsiveness of health care facilities, enable patients to improve their health literacy and enhance staff capability.
The NSW Framework Priorities

There are four priorities outlined in this framework. The priorities aim to create sustainable system level change, and improve safety and quality of care.

**Recommendations for Action**

1. All NSW Health entities address the four priorities in the framework
2. LHDs, SHNs and PHNs use their existing safety, quality and clinical governance networks to develop a measurement, reporting and governance structure to monitor progress toward improving health literacy across the four priorities
3. LHDs, SHNs and PHNs self-assess their organisational health literacy responsiveness against the Ten Attributes of Health Literate Health Care Organisations and/or the Organisational Health Literacy Responsiveness (Org-HLR) Domains (see Appendix C)
4. LHDs, SHNs and PHNs provide an annual report about their progress toward becoming a more health literate organisation to their organisation’s peak safety and quality committee and National Standard 2 (Partnering with Consumers) committee.
PRIORITY 1: Patients, Families & Carers

All patients, their families and carers are active partners in their health care.

Aims

- Patients are included in discussions and decisions about all aspects of their care
- Families and carers are included in discussions and decisions about care, to the extent the patient wishes
- Patients understand their treatment options
- Care is individualised, taking into account culture, mental state, patient preferences, age and disabilities including hearing and vision loss
- Patients, families and carers are made aware of their rights and responsibilities

What Can Health Leaders Do?

- Understand their patient population through data, and plan services with consumers to meet current and future needs
- Appoint patient navigators or key workers as contact people for patients, families and carers
- Ensure resources (print, audiovisual, website) are:
  - tested and approved by consumers from the target population
  - approved by their organisation for distribution
  - available in priority community languages
  - in accessible formats

“I need the health services to be my partner and be aware of my cultural background as this defines the way I receive and process information.”
What Can Health Staff Do?

- Involve patients, families and carers in all discussions about care and treatment, to the extent the patient wishes
- Ask every patient about their family, whether they are Aboriginal or Torres Strait Islander, and whether they have a carer or are a carer. Document this information
- Use interpreters when patients need assistance communicating in English or are Deaf
- When speaking to patients, confirm you understand them and they understand you by using a tool such as Teach-back⁴
- Ask patients with disabilities about aids they normally use e.g. communication boards and visual aids. Use them
- Pay special attention in high risk areas:
  - transfers of care, including discharge
  - medicine prescription and use
  - consent
- Conduct post admission follow up calls to ensure patients understand their care plan
- Refer patients to reputable resources (print, audiovisual and websites) for further information

In Northern NSW LHD, the health literacy project team helped to update Patient Information books at Grafton Base Hospital and Maclean District Hospitals to meet health literacy recommendations. The books give information about the hospital, services and how patients can be involved in their care. Consumers gave feedback into the books which are available in hard copy and on the website.
PRIORITY 2:
Staff

Staff communicate with patients, families and carers in ways they understand.

Aims
Our staff:

- understand the populations they serve and think about the context of the interaction for all patients, families and carers. They consider the additional challenges for people who are Aboriginal, CALD, mentally ill, disabled or marginalised
- understand the importance of health literacy
- provide care that meets the individual needs of patients
- understand their own biases and influence of their own culture
- partner with patients (and families/ carers as requested) to build self-management skills e.g. by using shared decision making
- confirm understanding at all points of contact

What Can Health Leaders Do?

- Arrange education for all staff at orientation and at other times about health literacy, working with interpreters and cultural competence.
- Ensure the consumer voice is present in education
- Make Plain English training available for staff and use it in all communications

*It is important that a patient has not only heard or read the information, but actually comprehends what is happening or about to happen.*
• Ensure staff participate in peer-to-peer learning and reflective practice
• Ensure patient resources are available, current, in a variety of formats and in languages that reflect local populations

What Can Health Staff Do?
• Examine data about the populations served/ not served in your unit/facility or organisation (see Appendix B)
• Ensure respectful and effective communication by using building rapport and listening to the patient
• Minimise use of jargon and acronyms. Explain technical terms
• Use communication techniques that increase the likelihood of being understood. Examples are: Chunk and Check; Teach-back; Plain English; Shared Decision Making

South Eastern Sydney LHD has developed an online learning module for clinical and non-clinical health workers explaining the value of the teach-back method and how to use it in practice. A Health Literacy and Teach-back podcast series has been developed by HETI (Health Education and Training Institute).
I am already stressed when I get to hospital. The last thing I need is to get lost on the way to my appointment.

Health Literacy Framework

Priorities

Environment

Health centres and facilities are easy to access and navigate.

Aims

• Facilities are culturally appropriate and welcoming
• Signs are clear and easy to understand, both inside and outside the facility or centre
• Patients and visitors can easily find their way from the nearest public transport or car park
• New and renovated buildings are designed to help people easily find their way
• Consumers are partners in design of new facilities and renovations
• Websites are easy to understand and navigate

What Can Health Leaders Do?

• Provide culturally appropriate spaces for Aboriginal people
• Use signs that are easy to understand by your population, using words that people know. Use images and other languages where appropriate
• Understand the consumer experience by regular consumer audits or walking interviews inside and outside the facility or centre
• Think about access for the aged, people with disabilities and parents with prams
• Have a well signposted and staffed information desk with maps and directions available in community languages
• Train volunteer guides to take patients and visitors to their destinations
• Ensure consumers have the opportunity to contribute to new designs and renovations
• Seek community feedback on your website and act on it

What Can Health Staff Do?
• Understand their patient population and have plans in place to meet their needs (see Appendix B)
• Ask their patients about any access issues
• Alert their managers of any issues

What is Already Being Done?
Illawarra Shoalhaven LHD raises awareness of health literacy for staff and people from CALD backgrounds by hosting hospital tours for adult students.
Blacktown Hospital trains volunteers as wayfinders. They wear bright purple vests and take patients and visitors to their destinations in the hospital.
Health literacy is all to do with communication. It needs to be right at the top of everything. There must be a plan and there needs to be training.

**PRIORITY 4: Health System**

Our health systems are built to be sustainable and reliable for every patient, every time.

**Aims**
- Leaders openly commit to improving health literacy
- Understand the populations we serve, and design and deliver services to address their specific needs in culturally appropriate ways
- Routinely partner with consumers who actively contribute to decisions in our organisations
- Understand and act on the requirements for health literacy in the [National Standards](#)
- Take a universal precautions approach to health literacy
- Be mindful of the importance of clear communication at all times, especially in high risk situations such as transfers of care, medication management and consent. Confirm patient understanding by using a tool such as [Teach-back](#)

**What Can Health Leaders Do?**
- Conduct an organisational self-assessment by using the following evidence-based health literacy measurement tools (see Appendix C):
  - Organisational Health Literacy Responsiveness Framework
  - Ten Attributes of Health Literate Health Care Organisations
• Develop a system for producing health literate print, audiovisual, website and social media content that:
  – tests for [readability level](#) on documents
  – aims for grade 6-8 readability level
  – involves consumer consultation and testing
• Take a [quality improvement](#) approach to addressing health literacy factors in incident, adverse outcome and complaints data, and in patient and staff feedback
• Create a consumer engagement framework for your district

What Can Health Staff Do?
• Consider target populations and ensure:
  – patient information is available in appropriate languages and formats
  – consent documentation can be understood
  – health promotion material can be understood
• Partner with consumers to improve services
• Participate in awareness raising activities such as [Drop the Jargon day](#)

What is Already Being Done?
Northern NSW LHD has a Health Literacy Officer who works with the LHD and the Primary Health Network (PHN). The aim is to enable better health literacy for staff and community members through education. More than 1000 health professionals have been trained over two years. A comprehensive [website](#) provides tools for improvement.

Western Sydney LHD’s [Health Literacy Hub](#) provides access to a wide range of educational materials and programs, practical tools and advice on health literacy.
Health Literacy in Aboriginal Communities

Aims

- Create an Australian health system that is free of racism and inequality, and where all Aboriginal people have access to health services that are effective, safe, high quality, appropriate and affordable
- Understand, respect, honour and celebrate Aboriginal cultures, heritage and identity
- Provide respectful, responsive and culturally sensitive services

- Ensure Aboriginal Cultural training is available for all staff e.g. Respecting the Difference
- Ensure that Aboriginal people are represented in service planning, consultations and in workforce
- Ensure that Aboriginal Impact Statements are completed for all policies, programs and projects

What Can Health Staff Do?

- Ask every patient whether they are Aboriginal or Torres Strait Islander. Document this information
- Include families and carers in discussions and decisions about care, to the extent the patient wishes
- Ask patients if they would like contact with the Aboriginal Liaison Officers or Aboriginal Health Workers
- Complete Respecting the Difference Aboriginal Cultural training – eLearning and face-to-face
- Complete Aboriginal impact statements for any projects you are doing

Social indicators for Aboriginal people, including health indicators, remain the lowest of all Australian groups.

Understanding the impacts of past injustice and striving to eliminate discriminatory practices are important factors in improving social outcomes for Aboriginal Australians.
Evaluation and Measurement

Evaluation, reporting and measurement is important to ensure that changes are carried out, lead to improvement and provide a source of feedback and learning. It is necessary to plan your measurement requirements and what you want or need to demonstrate, and to whom.

The Clinical Excellence Commission (CEC) recommends that overall responsibility for implementing health literacy improvements should sit at a senior executive level within the LHD/SHN/PHN. Governance is needed to ensure that changes occur at all levels of organisations – at individual service and unit level as well as more broadly. Committees set up to monitor progress toward National Standard 2 may be well suited to this governance role, as health literacy is part of Standard 2 (Partnering with Consumers). The model used in Illawarra Shoalhaven LHD may be valuable to other districts. Their Health Literacy Ambassador (HLA) Program trains staff to be HLAs and advocate for change across the organisation, supporting staff to learn and use health literacy strategies in routine practice and service delivery.

Undertaking an assessment of your organisation against the Organisational Health Literacy Response Tool11 and/or the Ten Attributes of a Health Literate Organisation12 will indicate the areas to focus on (See Appendix C). These tools can identify strengths and areas for improvement, and guide your development toward becoming a more health literate organisation. Other tools such as the walking interview tool which have been mentioned in this framework can also be used.

The CEC recommends that, before commencing any change, senior executive and the clinical governance units liaise with individual services and units, and consumers, to formulate the measures to use, the process for data collection and the allocation of responsibility for the measurement activities.
Glossary

Aboriginal
The term which describes the original inhabitants of Australia. Aboriginal, when used in this document, is inclusive of the terms Aboriginal and/or Torres Strait Islander and/or Indigenous peoples.

Carer
A carer is someone who provides personal care, support and assistance to another individual who is in need of support due to disability, medical condition (including terminal or chronic illness and mental illness), or who is frail and/or aged.

Chronic conditions
Health conditions which are long lasting and have persistent effects.

Chunk and Check
Involves breaking larger pieces of information into bite sized bits and checking if each piece has been understood correctly.

Consumer
A person who currently uses health services, as well as their family and carers. Includes people who have used a health service in the past or who could potentially use one in the future.

Consumer partnership
Planned engagement with consumers that supports the design, delivery and evaluation of health services provided or coordinated by the organisation.

Consumer advisor or representative
Members of the public with an interest in supporting and improving the public health care system. They have personal experience of the health services, either as a patient, family member or carer. They provide valuable insights and ideas about how to improve the patient experience and outcomes.

Health literacy
People’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course. Health literacy has both organisational and individual components.

Health professional
People who have a degree or training in a health related field. This includes doctors, nurses, and allied health staff.

Patient
Any person accessing health care in a hospital or community setting. In this document, the word patient is used to include client, consumers and other similar terms.

Person/Patient centred care
Care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions.

Plain English
A communication is in Plain English if its wording, structure and design are so clear that the intended audience can easily find what they need, understand what they find, and use that information.

Social determinants of health
These are factors such as employment, housing, education and social support that can work to strengthen or destabilise the health of people and their communities.

Sustainable
Designed to last and be maintained at a certain level.

Teach-back
A simple but effective tool to check understanding of spoken communications.

Universal precautions
The steps that are taken when it is assumed that all patients may have difficulty understanding health information and accessing health services. They involve simplifying information, making it easier for people to find their way around, supporting people to self-manage their health.
References


2. Australian Commission on Safety and Quality in Health Care www.safetyandquality.gov.au


17. Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. 9th Global Conference on Health Promotion Shanghai: 21-24 November, 2016. Available from: www.who.int%2Fhealthpromotion%2Fconferences%2F9gchp%2Fshanghai-declaration.pdf%3Fua%3D1&usg=AOvVaw01X5B68_kS1W8txBifJKTU


**Additional Reading**


A business case may be needed to obtain the support of your leadership and/or to obtain funds for an improvement project. The following statements can be used to make or strengthen your case:

**Quality and Safety**
- People with low functional health literacy may have less knowledge about their health conditions and treatments, poorer overall health status, and higher rates of hospitalisation\(^{14}\)
- Studies report an association between low health literacy and a person’s ability to take part in decision making, to adhere to recommended treatments, to implement health promoting behaviours, and to engage with preventative health services\(^{16}\)

**Equity and access**
- In 2006, the ABS found that 60% of people in Australia have low health literacy\(^{1}\)
- To run a health system that is truly inclusive, consumers need to understand their care and be able to speak the same ‘language’ as the clinicians
- Failing to address low health literacy can result in inequity and disempowerment\(^{1}\)
- People with low socioeconomic status, diverse backgrounds and the aged have lower health literacy\(^{3}\)
- The Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development recognises health literacy as a critical determinant of health\(^{17}\)

**Inclusiveness**
- Inadequate health literacy in Australia is greatest for those with chronic conditions. Poor health literacy has adverse effects on health outcomes, with less capacity to self-manage care and to follow medication guidance\(^{18}\)
- Improving health literacy will mean that far more people would have a capacity to self-manage chronic conditions, make informed end of life decisions, and be able to solicit and interpret information from clinicians\(^{1}\)
- The diversity of our NSW population creates challenges for communication, which can be addressed through better organisational health literacy
- Even highly educated individuals may find health systems too complicated to understand, especially when a health condition makes them more vulnerable\(^{1}\)

**Financial**
- International organisations such as the WHO attribute insufficient health literacy to increased financial costs (3-5% of health budget)\(^{3}\)
- Increasing health literacy is likely to reduce health costs through the prevention of illness and chronic disease\(^{19}\)

**Accreditation**
- The ACSQHC National Standards (version 2) have included health literacy for the first time within the Partnering with Consumers section
- Addressing the priorities in this framework will ensure you meet the requirements for health literacy in the National Standards
APPENDIX B: Identifying Your Context

You may find this tool useful as a starting point for your discussions. It can serve to better understand your population and determine if your existing priorities match your patients’ needs. Fill in wherever needed e.g. at hospital, service or unit level. Data sources can be: census population data, Ministry of Health data or hospital level data. Decide how often to update your data. Add details into the shaded boxes. Add extra questions in the empty boxes as required.

<table>
<thead>
<tr>
<th>Your Activity</th>
<th>How many people seen last year</th>
<th>Main types of problem or issue seen</th>
<th>Main age groups seen</th>
<th>Number of Aboriginal people seen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Your Community profile</th>
<th>Main countries of birth</th>
<th>Main languages spoken</th>
<th>Main languages of interpreter usage</th>
<th>Number of refugees/ new migrants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
</tr>
<tr>
<td>Aboriginal population</td>
<td>Socio-economic profile</td>
<td>Disability profile</td>
<td>LGBTQI profile</td>
<td></td>
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<tr>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td></td>
</tr>
<tr>
<td>Homeless profile</td>
<td>Age profile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Response</td>
<td>Response</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication</th>
<th>Number of complaints/ compliments</th>
<th>Main complaint/ compliment type</th>
<th>Main complaint/ compliment location</th>
<th>Main feedback received from patients, families and carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Harm/errors</th>
<th>Most common types of harm/errors</th>
<th>Where harm/errors occur most</th>
<th>% incidents where communication was a major factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
<td>Response</td>
<td>Response</td>
<td>Response</td>
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</tbody>
</table>

Ask:
- Are we missing anything? Are we addressing our whole community?
- How well do we understand our population?
- What are our opportunities to improve?
APPENDIX C: Assessing Health Literacy Responsiveness

<table>
<thead>
<tr>
<th>Organisational Health Literacy Responsiveness (Org-HLR) Domains</th>
<th>Ten Attributes of Health Literate Health Care Organisations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy and funding mandate</td>
<td>Has leadership that makes health literacy integral to the mission, structure and operations of the health care organisation</td>
</tr>
<tr>
<td>Leadership and culture</td>
<td>Integrates health literacy into planning, evaluation measures, patient safety and quality improvement</td>
</tr>
<tr>
<td>Systems, processes and policies</td>
<td>Meets the needs of populations with a range of health literacy skills while avoiding stigmatisation</td>
</tr>
<tr>
<td></td>
<td>Addresses health literacy in high-risk situations, including care transitions and information about medicines</td>
</tr>
<tr>
<td>Access to programs and services</td>
<td>Provides easy access to health information and services, and navigation assistance</td>
</tr>
<tr>
<td>Community engagement and partnerships</td>
<td>Includes populations served by the organisation in the design, implementation and evaluation of health information and services</td>
</tr>
<tr>
<td>Communication with consumers</td>
<td>Uses health literacy strategies in interpersonal communication, and confirms understanding at all points of contact</td>
</tr>
<tr>
<td></td>
<td>Designs and distributes print, audio visual and social media content that is easy to understand and act on</td>
</tr>
<tr>
<td></td>
<td>Communicates clearly about what is covered by health plans and what individuals will have to pay for services</td>
</tr>
<tr>
<td>Workforce</td>
<td>Prepares the workforce to be health literate, and monitors progress</td>
</tr>
</tbody>
</table>

Consider how well your organisation meets these domains and attributes by reflecting on your organisation’s activity. Determine your own goals, or access the Org-HLR self-rating tool.