

# NT PHN Health Literacy Strategy

OCTOBER 2018-2021

### Introduction

NT PHN's vision is to help Territorians enjoy their best health and wellbeing by building local partnerships, and directing resources towards an integrated, high quality health care system. A focus on health literacy – making it easier for people to navigate, understand, and use health information and services - will help to realise this vision.

"Reducing the demands placed on consumers by a complex health system is one way of making care more patient-centred and contributing to a safe and high quality health system".(1)

The NT PHN Health Literacy Strategy (the strategy) holistically supports

the achievement of the *NT PHN Strategic Plan 2018-2023* with the expectation that outcomes will aid all strategic goals, with a particular focus on Goal 1: To empower people to take control of their own health and wellbeing

### GOAL:

The primary goal of the strategy is to improve the health of Territorians by enhancing health literacy of consumers and health professionals across the Northern Territory.

#### **OBJECTIVES:**

To achieve this goal, the following objectives have been set:

- 1. Strengthen the health literacy environment created by NT PHN systems, policies, and practices;
- 2. Support consumers to make informed choices about their health and healthcare both directly and through improving healthcare providers' skills;
- 3. Create and sustain a health information library for validated accessible consumer information;
- 4. Improve collaboration and integration of health literacy activities across NT health system and organisations.

The strategy has been developed as a three year plan, with a proposed action plan included in Appendix 1 and 10 key performance indicators which could be used in monitoring the outcomes from the strategy and its activities in Appendix 2.

#### **HEALTH LITERACY**

The health care system is very complex, and many consumers have difficulty understanding and using

Improving health literacy involves reducing the complexity of information for consumers. An endocrinologist provides a continuing professional development session on advances in diabetes medication for GPs. As required by the strategy, the session includes a section on health literacy: how to discuss the benefits and risks of the new medications with consumers and ensure understanding, and resources that explain the medications visually.

currently available health information and health services. Health literacy is defined as how well people can obtain, communicate, process and understand health information and services to make appropriate health decisions for themselves and their families.(1) While general literacy (reading, writing, speaking and numeracy) is an important determinant of health and is necessary for individual health literacy, it is not sufficient to be able to manage complex health issues or to navigate health systems.(2)

The Australian Commission on Safety and Quality in Health Care separates health literacy into two components: individual health literacy and the health literacy environment.(1)

- Individual health literacy is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.
- The **health literacy environment** is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way in which people access, understand, appraise and apply health-related information and services.(1)

As NT PHN does not directly provide health care to individuals but is a funder and coordinator of health care delivery, the strategy focuses mostly on ways to improve the health literacy environment in the NT.

The strategy uses the term health consumer to refer to people who use health services, as well as their carers and families. A 'consumer' is someone who chooses and gets involved in decision making whereas traditionally a 'patient' is a person who receives care without necessarily taking part in decision making.(3)

### HEALTH LITERACY, LANGUAGE AND CULTURE

National statistics estimate that 41% of Australian adults have a level of health literacy that is adequate to understand and use day-to-day health information.(4) In the NT, this is around 37%. However health literacy must also be considered in the context of language and culture.(5) This is particularly important in the NT, where close to 30% of the population is Aboriginal, 27.5% of the population

Improving the health literacy environment involves reducing the complexity of the health system. A clinic undertakes a codesign process, inviting consumers to ring and ask for their results, make an appointment, and do walking interviews through the clinic.

Consumers are asked to complete common tasks such as "go and get this x-ray then come back and see me" and are asked to report back on what cues they used to complete the tasks, how they felt and how processes could be improved.

arrived in Australia in the last five years, and 42% of the population speak a language other than English at home.(6)

Depending on the context, language and cultural barriers may impact significantly on health literacy in a consultation between a consumer and a health professional.(7)

It is important to consider health literacy as a **dynamic concept** – the health literacy of an individual varies depending on the cultural, conceptual and linguistic demands of the context.(5)

Health literacy is dynamic. An Aboriginal consumer from Lajamanu who speaks Warlpiri at home, may have a high level of health literacy when speaking about diabetes management in Warlpiri with an Aboriginal Health Practitioner who is also from Lajamanu and is using culturally appropriate health information resources, but a low level of health literacy when speaking about the same topic with a non-Aboriginal GP from Darwin, due to the absence of shared language and cultural knowledge.

Other factors can also influence how a person's individual health literacy may fluctuate depending on context: being unwell, tired, stressed or in an unfamiliar place will affect a person's capacity to understand and act on information at a particular time.(1)

Therefore, this strategy uses a **universal precautions approach** to health literacy. This approach assumes that there are barriers to understanding for all consumers,(8) and considers it necessary to reduce the complexity of the health information and resources provided to everyone, through improving the health literacy environment.

### ALIGNMENT WITH NATIONAL AND TERRITORY PRIORITIES

Health policy at national and Territory levels calls for health literacy strategy at all levels of health care. The NT *PHN Health Literacy Strategy* has been developed in response to the recognition that health literacy is a key priority to provide higher quality, safer health care.

Health literacy policy	Document	Reference									
Commonwealth Initiatives	National Statement on Health Literacy,	"Strategies are needed both to build the capacity of people to understand the choices they have, make decisions about									
	Australian Commission on Safety and Quality in Health Care (ACSQHC)(9)	their health and health care; and to build the capacity of the health system to support and encourage this to occur."									
	National Aboriginal and Torres Strait Islander Health Plan 2013-2023(10)	Priorities include: individuals and communities to actively engage in decision making and control. "Health literacy is fundamental if people are to successfully manage their own health. A person's ability to make informed health-related choices is determined by their ability to understand health information and their ability to negotiate the health care system".									
	Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 (11)	Deliverables by 2018 include: "Existing local, regional, state and territory activity has been reviewed to assess health literacy and a coordinated strategy to address health literacy implemented"									
		Deliverables by 2023 include: "Health literacy has been included in policy development, planning, implementation and evaluation of programmes designed to reduce health and wellbeing disparities for Aboriginal and Torres Strait Islander peoples".									
	National Primary Health Care Strategic Framework (12)	Potential actions include: "Identify ways to address the social determinants of health – such as social status, geographic location, health literacy, housing, education, employment and access to health services – which contribute to poor health outcomes".									
	National Strategic	"A skilled workforce proficient in the use of									
	Framework for Chronic Conditions (13)	e-technologies, effective communication and in providing information and services to people who have varying levels of health literacy will help to overcome barriers and facilitate improved access to health services".									
	National Safety and Quality Health Standards, 2nd Edition,	Standard 2, Partnering with Consumers. Criteria include "Health literacy: health service organisations communicate with patients in a way that supports effective partnerships".									
	ACSQHC(14)										

	Health literacy: Taking action to improve quality and safety	"To address health literacy in a coordinated way in Australia, it is necessary to:
	ACSQHC(1)	Embed health literacy into high level systems and organisational policies and practices
		Ensure that health information is clear, focused and useable, and that interpersonal communication is effective
		Integrate health literacy into education for consumers and healthcare providers"
Territory Initiatives	Northern Territory Health Strategic Plan, 2018-2022 (15)	Commitments to service users and communities: "We will work with you, your family and your community to involve service users/community members in the design, delivery and evaluation of healthcare".
	Northern Territory Aboriginal Health Plan, 2015-2018(16)	Strategic direction 3: Deliver culturally secure and safe services.
		3.1 "Strengthening communication through use of interpreters, improved health literacy of Aboriginal consumers and clinicians and accessible written materials".
	Northern Territory Chronic Conditions Prevention and Management Strategy 2010- 2020 (17)	Key action area 1 objective: "Contribute to improving the social determinants of health impacting on chronic conditions through improving living conditions, food security, education, employment and health literacy".
	Chronic Conditions Prevention and Management Strategy 2010-2020 Implementation Plan 2017- 2020 (18)	Strategy 4.3: "Strengthen workforce training to enhance practice in self-management and health literacy".
	Northern Territory Health	Aims include:
	Promotion Framework (19)	"To increase community control over the determinants of health through collective efforts, community participation, empowerment, capacity building and increasing health literacy" through community engagement and advocacy.
		"To improve the health literacy of individuals, communities and organisations" through health education and skills development.

# Objective 1: Strengthen the health literacy environment created by NT PHN systems, policies, and practices

To ensure that the strategy is coordinated and sustainable, health literacy needs to be embedded in the systems and infrastructure of NT PHN. Organisational leadership and commitment are critical for its successful implementation and maintenance.

As such, sufficient funding will need to be allocated to the strategy, and the possibilities of innovative funding models to support the strategy and health literacy activities should be considered. Such models could include public-private partnerships or pooled funding across the NT health system. The funding of a newly created Health Literacy Officer role is essential to the strategy as this role will then have responsibility for much of its implementation as the primary change enabler.

To ensure success, all NT PHN employees will need to be supportive of the strategy. This will require change management processes from the organisational leadership as it will be a major change of focus for NT PHN. As part of this change management, education and training in health literacy and its role for each staff member will be imperative for both current and new staff at NT PHN and the activities will need to be embedded into strategy, policy, role descriptions and business planning.

NT PHN will need to redesign policies and procedures to support the implementation of this plan, and to ensure coordination and sustainability. These will include both policies and procedures addressing internal programs, as well as those addressing requirements of commissioning partners. External consumer engagements and communications will need to be strengthened and developed to allow for clear, consistent and impactful messaging around health literacy topics at both a national and local level.

NT PHN will be able to build on existing strengths – many things are already being done well from a health literacy perspective. Partnerships with consumers are essential for the development of better healthcare systems.(1) NT PHN's Community Advisory Council has a key role in providing strategic advice to the organisation, and has been involved in the design of the health literacy strategy and its resulting activities. The key to addressing health literacy within Aboriginal communities is ensuring that strategies build on Aboriginal understandings and perspectives, and use models of care that employ individuals who are trusted by the community.(20) The policy of NT PHN to prioritise Aboriginal Community Controlled Health Services (ACCHSs) in commissioning health care services for Aboriginal consumers should be strengthened and extended to health literacy programs.

### **ACTIVITIES**

- 1.1 Develop and implement a strategy for NT PHN to become a health literate organisation
- 1.2 Engage with NT PHN Community Advisory Council on health literacy strategy
- 1.3 Create a full time Health Literacy Officer role
- 1.4 Provide health literacy training to all new and current NT PHN employees and embed its importance in role descriptions
- 1.5 Require all new NT PHN projects and business activities to have a health literacy component
- 1.6 Ensure that all NT PHN commissioning partners use, develop and share health literacy tools
- 1.7 Prioritise Aboriginal Community Controlled Health Services (ACCHSs) in commissioning health literacy programs for Aboriginal consumers
- 1.8 Explore innovative funding arrangements for health literacy activities including public-private partnerships and pooled funding across the NT health system
- 1.9 Conduct organisational health literacy self-assessment regularly to assess progress

### ASSOCIATED IMPLEMENTATION KPIS

Staff importance score	ACCHSs health literacy	Consumer involvement	Commissioning
	programs score	score	partners health
			literacy score

# Objective 2: Support health consumers to make informed choices about their health and healthcare both directly and through improving healthcare providers' skills

Although health information is available from many sources, consumers rely on health professionals for the majority of information they need about health and healthcare.(21) However, research shows that people can only recall between 20 and 60 per cent of medical information given to them by health professionals immediately after a consultation, and approximately half of that recalled may be incorrect.(22) Health professionals with an understanding of health literacy, including the importance of communication, follow up and case management opportunities, are able to tailor health information to meet the needs and preferences of individual consumers.(1) This in turn can increase recall and consumer satisfaction, leading to more confidence, participation and effective decision making.

Goal 1 of NT PHN's strategic plan 2018- 2023 is to empower people to take control of their own health and wellbeing. An underpinning requirement of this empowerment is the ability to make choices depending on an individual's own circumstances and contexts. Providing consumers with timely, well constructed tools to understand their options is essential to this and will require a program of direct and indirect engagement with NT consumers as well as targeted engagement through clinic structures. Tools for self management, preventative health and wellbeing knowledge will need to be accessible in a variety of formats; when and as consumers need it.

NT PHN has a major role in provision of continuing professional development for health professionals working in primary care and coordinates continuing professional development events, particularly on clinical topics. All continuing professional development sessions for health professionals should contain information on health literacy. For example, a session for GPs on diabetes management run by an endocrinologist should include a section on how to communicate the information to consumers and ensure understanding. Some health literacy training opportunities for health professionals already exist in the NT; NT PHN's role in these cases will be to facilitate engagement for health professionals. New workshops on health literacy for consumers with additional communication needs will need to be developed by NT PHN.

Another way to improve health literacy is to reduce the complexity of the health system. Empowering consumers to be involved in the design of health care services through codesign has been shown to reduce the complexity of health systems and improve outcomes. (23) NT PHN has a role in encouraging practice managers to employ codesign principles, using existing resources such as the Experience Based Codesign Toolkit.

Health professionals can also improve health literacy by assisting consumers to navigate the health system. However, the complexity and pace of health system reform can make this challenging for health professionals. NT PHN has a role in educating health professionals about the current state of health system reform and how it will affect consumers.

### **ACTIVITIES**

- 2.1 Develop a range of tools and resources for consumers to be active in their healthcare through prevention, self management and decision making
- 2.2 Ensure that all NT PHN continuing professional development sessions for health professionals include a health literacy component
- 2.3 Provide and support access to culturally competent health literacy training for health professionals, including training in teach-back, risk communication and the use of decision aids
- 2.4 Provide and support access to training for health professionals and other staff working in primary health care regarding locally available services to support people with additional communication needs, including interpreters, assisted hearing devices, relay systems and materials for people with visual impairment
- 2.5 Provide and support access to training and materials for practice/clinic managers in service co-design
- 2.6 Support health professionals to stay abreast of health system reforms

### ASSOCIATED IMPLEMENTATION KPIS

Health professional relevancy score	Interpreter use frequency
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# Objective 3: Create and sustain a NT health information library for validated consumer information

Consumer health information (educational pamphlets, posters, apps, etc.) is often unnecessarily complex, and there is evidence that the reading level of most health information is above the average adult's reading level.(24) Research has also shown that much health information cannot be understood by the people for whom it is intended, suggesting that assumptions about consumers' health literacy are inaccurate.(25) The high levels of linguistic and cultural diversity in the NT adds to this complexity.

Additionally, consumer health information in the NT can be difficult to access as it has been developed by different organisations and is spread across many different locations. Health professionals who are new to the NT and consumers are unlikely to be familiar with the range of different organisations who produce consumer health information here, e.g. Aboriginal Resource Development Services, Centre for Disease Control, Menzies School of Health Research, Northern Territory Government.

The solution is to have a process to validate health information that is easy to understand and to make validated resources accessible to health providers in a single online library. Validated information must use the universal precautions approach, to meet diverse needs. The library will be a standalone resource available to both health professionals and consumers but will also be able to link in with other NT PHN resources. It will be a repository for health information that is in plain English or translated, easy to read, understand and use, and has been tested by consumers representative of the group for whom it is intended. It will be complemented by a toolkit to create and improve consumer health information, including a readability/language tool, a consumer feedback tool, and a common language glossary so that resources use the same terms to describe the same concepts.

This will require substantial engagement with organisations across the NT health system that create health information, both to provide feedback on existing resources, and to provide tools and training on how to create new resources. It will also require substantial engagement with consumers to create the validation system and to test the resources. The consumer testing process will need to take into account the fact that some resources are very specific to local environments, particularly resources that are in languages other than English. To ensure sustainability of the health information library, the health literacy officer will take responsibility for ensuring the library and the information within it is up-to-date.

### **ACTIVITIES**

- 3.1 Develop a process for validating existing consumer health information including developing or adapting a readability/language tool, a consumer feedback tool, and a common language glossary
- 3.2 Conduct a consumer health information stocktake to identify consumer health information resources that are aimed at and/or provided to consumers in the NT, and engage with organisations across NT that create these resources
- 3.3 Develop a process for providing feedback to organisations regarding consumer health information resources
- 3.4 Test existing consumer health information using this process and provide feedback
- 3.5 Develop or adapt a toolkit for health professionals and organisations to create new consumer-friendly health resources, including a readability/language tool, a consumer feedback tool and a common language glossary
- 3.6 Develop an online library to support health professionals and consumers to search for validated consumer health information, and embed links to library in other NT PHN resources

### ASSOCIATED IMPLEMENTATION KPIS

Consumer friendly resource	Health information library use	Health information library use
proportion	frequency – health professionals	frequency - consumers

# Objective 4: improve collaboration and integration of health literacy activities across NT health system and organisations

Health literacy has been recognised as a priority by many health organisations in Australia, including in the NT, and there is much work happening to address health literacy. However, the work is disconnected and opportunities for shared learning are limited.(1) It is essential that this strategy involves other organisations and does not duplicate work being done by others. For a population the size of the NT, it is appropriate to have a single health literacy reference group with representatives from health services, organisations that produce consumer health information and consumers themselves. Good resources must be shared with all health professionals working in primary care in the NT. Supporting the integration of the NT health system also has the potential to reduce complexity for consumers thereby contributing to health literacy.

### **ACTIVITIES**

- 4.1 Support the design and delivery of policies, pathways and processes that reduce the complexity involved in navigating the health system
- 4.2 Commission health literacy programs that are designed and led by Aboriginal Community Controlled Health Services (ACCHSs)
- 4.3 Work with established health literacy groups in the NT and relevant stakeholders including consumers to establish a single health literacy reference group for the NT
- 4.4 Engage with and support existing initiatives that empower consumers to have more input into their healthcare, including Choosing Wisely, the Consumer Health Forum/Australian Hospital and Healthcare Association's experienced based codesign toolkit and national PHN consumer engagement campaigns
- 4.5 Work with Continuous Quality Improvement (CQI) teams to ensure integration of health literacy into formal processes

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**Collaboration score** 

### References

- 1. Australian Commission on Safety and Quality in Health Care. Health literacy: Taking action to improve safety and quality. Health Lit. 2013;96.
- 2. PHN North Coast. Northern NSW Health Literacy Framework [Internet]. 2016 [cited 2018 Feb 12]. Available from: https://ncphn.org.au/wp-content/uploads/2017/10/20160812-Health-Literacy-Framework-FINAL.pdf
- 3. Who is a health consumer? and other definitions · Getting started · Health Consumers NSW [Internet]. [cited 2018 Mar 19]. Available from: http://www.hcnsw.org.au/pages/who-is-a-health-consumer-and-other-definitions.html
- 4. Australian Bureau of Statistics. Health Literacy, Australia, 2006 [Internet]. 2008 [cited 2018 Mar 19]. Available from:

http://abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4233.0 Main%20 Features 22006? open document & tabname = Summary & prod no = 4233.0 & issue = 2006 & num = & view =

- 5. Lowell A, Schmitt D, Ah Chin W, Connors C. Provider health literacy, cultural and communication competence: towards an integrated approach in the Northern Territory. [Internet]. 2015. Available from: http://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/885/1/Health%20literacy%20communication%20and%20 cultural%20competence%20towards%20an%20integrated%20approach%20in%20Indigenous%20health%20care.pdf
- 6. 2016 Census QuickStats: Northern Territory [Internet]. [cited 2018 Mar 19]. Available from: http://www.censusdata.abs.gov.au/census\_services/getproduct/census/2016/quickstat/7?opendocument
- 7. Sudore RL, Landefeld CS, Pérez-Stable EJ, Bibbins-Domingo K, Williams BA, Schillinger D. Unraveling the relationship between literacy, language proficiency, and patient–physician communication,. Patient Educ Couns. 2009 Jun;75(3):398–402.
- 8. DeWalt D, Callahan L, Hawk V, Broucksou K, Hink A, Rudd R. Health Literacy Universal Precautions Toolkit. Agency for Healthcare Research and Quality; 2010.
- 9. Australian Commission on Safety and Quality in Health Care. National Statement on Health Literacy [Internet]. 2014 [cited 2018 Mar 19]. Available from: http://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-NationalStatement.pdf
- 10. Department of Health. National Aboriginal and Torres Strait Islander Health Plan, 2013-2023 [Internet]. Canberra: Australian Government; 2013 Jul [cited 2018 Mar 21]. Available from: http://www.health.gov.au/internet/main/publishing.nsf/Content/natsih-plan
- 11. Department of Health. Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 [Internet]. Canberra: Australian Government; 2015 [cited 2018 Apr 25]. Available from: http://www.health.gov.au/internet/main/publishing.nsf/Content/AC51639D3C8CD4ECCA257E8B00007AC5/\$File/DOH\_ImplementationPlan\_v3.pdf
- 12. Standing Council on Health. National Primary Health Care Strategic Framework [Internet]. Canberra: Australian Government; 2013 Apr [cited 2018 Apr 25]. Available from: http://www.health.gov.au/internet/main/publishing.nsf/content/6084A04118674329CA257BF0001A349E/\$File/NPHCfram e.pdf
- 13. Australian Health Ministers' Advisory Council. National Strategic Framework for Chronic Conditions [Internet]. Canberra: Australian Government; 2017 [cited 2018 Apr 25]. Available from:

 $https://www.health.gov.au/internet/main/publishing.nsf/Content/A0F1B6D61796CF3DCA257E4D001AD4C4/\\$File/National %20Strategic \%20Framework \%20 for \%20 Chronic \%20 Conditions.pdf$ 

- 14. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Sydney: ACSQHC; 2017.
- 15. Northern Territory Health. Northern Territory Health Strategic Plan, 2018-2022 [Internet]. Darwin: Northern Territory Government; 2018 [cited 2018 Apr 25]. Available from: http://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/2729/3/Northern%20Territory%20Health%20Strategic%2 OPlan.pdf
- 16. Northern Territory Health. Northern Territory Aboriginal Health Plan, 2015-2018 [Internet]. 2015. Available from: http://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/798/1/Northern%20Territory%20Aboriginal%20Health%2 OPlan%202015%20-%202018.pdf
- 17. Department of Health and Families. Northern Territory Chronic Conditions Prevention and Management Strategy 2010-2020 [Internet]. Darwin; 2009 [cited 2018 Apr 25]. Available from: http://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/535/1/Northern%20Territory%20Chronic%20Conditions% 20Prevention%20and%20Management%20Strategy%202010-2020.pdf
- 18. Department of Health. Chronic Conditions Prevention and Management Strategy 2010-2020, Implementation Plan 2017-2020 [Internet]. Darwin; 2018 [cited 2018 Apr 25]. Available from: http://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/2724/3/Chronic%20Conditions%20Strategy%20Implemen tation%20Plan%202017-2020.pdf
- 19. Department of Health. Northern Territory Health Promotion Framework [Internet]. Darwin: Northern Territory Government; 2013 [cited 2018 Apr 25]. Available from: http://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/881/1/Northern%20Territory%20Health%20Promotion%2 0Framework.pdf
- 20. Vass A, Mitchell A, Dhurrkay Y. Health literacy and Australian Indigenous peoples: an analysis of the role of language and worldview. Health Promot J Austr. 2011;22(1):33–7.
- 21. Gaglio B, Glasgow R, Bull S. Do patient preferences for health information vary by health literacy or numeracy? A qualitative assessment. J Health Commun. 2012;17(Suppl3):109–21.
- 22. Kessels RPC. Patients' memory for medical information. J R Soc Med. 2003 May;96(5):219–22.
- 23. Experience Based Co-Design Toolkit [Internet]. Australian Healthcare & Hospitals Association. 2017 [cited 2018 Mar 21]. Available from: http://ahha.asn.au/experience-based-co-design-toolkit
- 24. Rudd R, Moeykens B, Colton T. Health and literacy: a review of medical and public health literature. In: Comings J, Garner B, Smith C, editors. The Annual Review of Adult Learning and Literacy. San Francisco: Jossey-Bass; 2000.
- 25. Institute of Medicine. Health Literacy: a Prescription to End Confusion. Washington, DC: The National Academies Press; 2004.

### Appendix 1: Proposed Action Plan

### within 6 months

Key activity	Steps to undertake
1.1 Develop and implement a strategy for NT PHN to become a health literate organisation  1.2 Engage with NT PHN Community Advisory Council on health literacy strategy and key activities	<ul> <li>Develop a strategy to address health literacy with effective communication and consumer health information as core components</li> <li>Allocate appropriate funding to the implementation of the strategy</li> <li>NT PHN CEO and Board to endorse the strategy</li> <li>Consult with NT PHN Community Advisory Council for input to health literacy strategy</li> </ul>
1.3 Create a full time Health Literacy Officer role  1.4 Provide health literacy training to all new and current NT PHN employees and embed its importance in role descriptions	<ul> <li>Allocate funding for Health Literacy Officer to have responsibility for health literacy activities including implementation and ongoing upkeep of the health information library</li> <li>Recruit to position</li> <li>Candidate commences position and is trained</li> <li>Health literacy training added to cultural competency training component of orientation for new staff</li> <li>Three health literacy training sessions are held for current staff as part of standard staff education</li> <li>Include how health literacy included in role in 100%</li> </ul>
4.1 Support the design and delivery of policies, pathways and processes that reduce the complexity involved in navigating the health system  4.2 Commission health literacy programs	<ul> <li>new job descriptions advertised</li> <li>Ensure the rollout of HealthPathways, designed to assist with navigation between primary and secondary or tertiary care services</li> <li>Contract Aboriginal specific health literacy programs</li> </ul>
that are designed and led by ACCHSs  4.4 Engage with and support existing initiatives that empower consumers to have more input into their healthcare	through ACCHSs in accordance with the NT PHN Commissioning Policy  • Engage with and promote Choosing Wisely campaign that aims to increase health literacy and empower consumers

### within 12 months

Key activity	Steps to undertake
1.5 Require all new NT PHN projects and business activities to include health literacy component	Alter Project Planning Document templates to include health literacy component
1.6 Ensure that all NT PHN commissioning partners use, develop and share health literacy tools	<ul> <li>Alter NT PHN Commissioning Policy to include health literacy as an NT PHN commissioning principle</li> <li>Alter NT PHN Commissioning Procedure to include health literacy in NT PHN's Procurement Approaches (4.2.1)</li> </ul>
1.7 Prioritise Aboriginal Community Controlled Health Services (ACCHSs) in commissioning health literacy programs for Aboriginal consumers	Contract Aboriginal specific health literacy programs through ACCHSs in accordance with NT PHN Commissioning Policy
1.8 Explore innovative funding arrangements for health literacy activities including public-private partnerships and pooled funding across the NT health system	<ul> <li>Explore the possibility of public-private partnerships to fund health literacy activities, including partnerships with e.g. banks</li> <li>Explore the possibility of pooled funding across the NT health system to fund health literacy activities</li> </ul>
2.2 Ensure that all NT PHN continuing professional development sessions for health professionals include a health literacy component	<ul> <li>Require all presenters at NT PHN continuing professional development events to include a section on health literacy</li> <li>Supply presenters with information on health literacy and examples of how to include it in their presentations at continuing professional development events</li> </ul>
2.3 Provide and support access to culturally competent health literacy training for health professionals, including training in teach-back, risk communication and the use of decision aids	<ul> <li>Engage Poche Centre to provide annual health literacy training sessions in each region for health professionals working in Aboriginal health</li> <li>Engage health professionals with health literacy and interpersonal communication resources that already exist, including SA Health and NorthWest Melbourne PHN's resources</li> </ul>
2.6 Support health professionals to stay abreast of health system reforms	<ul> <li>Deliver health system reform update at each Pop Up PHN event in each region</li> <li>Distribute filmed session from appropriate NTPHN events to health professionals who are unable to attend</li> </ul>
4.3 Work with established health literacy groups in the NT and relevant stakeholders	<ul> <li>Meet with representatives from TEHS Health Literacy Committee, other established health literacy groups, and stakeholders including ACCHSs or AMSANT and organisations that produce consumer health</li> </ul>

including consumers to establish a single health literacy reference group for the NT	<ul> <li>information in the NT, to establish a single reference group for health literacy</li> <li>Draw up terms of reference for this group</li> </ul>
4.5 Work with continuous quality improvement (CQI) teams to ensure integration of health literacy into formal processes	<ul> <li>Engage with Aboriginal Health CQI team at AMSANT to determine if health literacy already a component of System Assessment Tool, and other opportunities to include health literacy in CQI processes</li> <li>Ensure health literacy a major component of CQI program for mainstream primary care (currently under development)</li> </ul>

### within 18 months

Key activity	Steps to undertake
1.2 Engage with NT PHN Community Advisory Council on health literacy strategy and key activities  3.1 Develop a process for validating existing consumer health information as "consumer friendly", including developing or adapting a readability/language tool and a consumer feedback tool, and developing a common language glossary to be used in	<ul> <li>Consult with NT PHN Community Advisory Council on best approach to validating consumer health information for health information library</li> <li>Consult with NT PHN Community Advisory Council on toolkit for creating new consumer-friendly health resources</li> <li>Develop or adapt a tool to test available consumer health information resources for reading level and suitability</li> <li>Develop or adapt a consumer testing tool to validate consumer health information resources</li> <li>Develop a glossary of health information language that is widely understood by consumers of all abilities, to use in consumer health information</li> </ul>
consumer health information  3.2 Conduct a consumer health information stocktake to identify consumer health information resources that are aimed at and/or provided to consumers in the NT, and engage with organisations across NT that create these resources  3.3 Develop a process for providing feedback to organisations regarding consumer health information resources	<ul> <li>Engage with organisations across NT to identify available consumer health information resources</li> <li>Engage with organisations across NT to obtain permission to test resources and include in health information library if pass testing</li> <li>Consult with NT PHN Clinical Advisory Council to identify additional frequently used consumer health information resources</li> <li>Develop a process to provide feedback on resources that do not pass testing and how to improve them</li> </ul>
3.5 Develop or adapt a toolkit for health professionals and organisations to create new consumer-friendly health resources, including the common language glossary  4.1 Support the design and delivery of policies, pathways and processes that reduce the complexity involved in navigating the health system	<ul> <li>Adapt step-by-step consumer health information writing guidelines (Health Direct Australia, Illawarra Shoalhaven Local Health District, Northern NSW PHN)</li> <li>Adapt consumer health information templates (Illawarra Shoalhaven Local Health District)</li> <li>Develop guidelines on how to get information translated if necessary (potential partnerships with iTalk, ARDS)</li> <li>Include consumer testing tool from 3.1 in toolkit</li> <li>Include common language glossary from 3.1 in toolkit</li> <li>Ensure the development of health information library has input and engagement from organisations around the NT that create consumer health information</li> </ul>

### within 24 months

Key activity	Steps to undertake
1.5 Require all new NT PHN projects and business activities to include health literacy component	100% of all newly approved NT PHN projects and business activities to include health literacy component
1.6 Ensure that all NT PHN commissioning partners use, develop and share health literacy tools	50% of all new commissioning partners or re- commissioned partners use health literacy tools
<ul> <li>2.3 Provide and support access to culturally competent health literacy training for health professionals, including training in teach-back, risk communication and the use of decision aids</li> <li>2.5 Provide and support access to training</li> </ul>	<ul> <li>Develop/commission health literacy training for health professionals that includes tips for communicating clearly, teach-back method, encouraging questions, risk communication and the use of decision aids</li> <li>Deliver the workshop annually in each region</li> <li>Engage practice manager with service co-design</li> </ul>
and materials for practice/clinic managers in service co-design	resources that already exist (Consumer Health Forum/Australian Hospitals and Healthcare Association Experience Based Co-design Toolkit)
3.4 Test consumer health information resources using process for validating as "consumer friendly" and provide feedback to organisations	<ul> <li>Test twenty consumer health information resources that were identified in stocktake (3.2)</li> <li>Test using both readability tool and consumer testing tool developed in 3.1</li> <li>Provide feedback to organisations using process developed in 3.3</li> </ul>
4.4 Engage with and support existing initiatives that empower consumers to have more input into their healthcare	<ul> <li>Promote and provide training for the Consumer Health Forum/Australian Hospitals and Healthcare Association Experienced Based Codesign Toolkit, as per 2.3</li> </ul>

### within 30 months

Key activity	Steps to undertake
2.4 Provide and support access to training for health professionals regarding locally available services to support people with additional communication needs, including interpreters, FM systems, relay systems and materials for people with visual impairment	<ul> <li>Develop training session on locally available supports for people with additional communication needs</li> <li>Deliver training session annually in each region</li> </ul>
3.4 Test consumer health information resources using process for validating as "consumer friendly" and provide feedback to organisations	<ul> <li>Test another twenty consumer health information resources that were identified in stocktake (3.2)</li> <li>Test using both readability tool and consumer testing tool developed in 3.1</li> <li>Provide feedback to organisations using process developed in 3.3</li> </ul>
3.6 Develop an online health information library to support health professionals and consumers to search for validated consumer health information, and embed links to library in other NT PHN resources	<ul> <li>Design an online library to allow health professionals and consumers to search for and access validated consumer health information resources</li> <li>Embed links to library in HealthPathways</li> <li>Health professionals and consumers to test site and links before go live</li> <li>Market online health information library to NT health professionals and consumers</li> </ul>
3.5 Develop or adapt a toolkit for health professionals and organisations to create new consumer-friendly health resources	<ul> <li>Upload toolkit to online health information library</li> <li>Market toolkit as part of online health information library</li> <li>Provide and support access to training in how to use the toolkit to create consumer health information</li> </ul>

### within 36 months

Key activity	Steps to undertake
1.6 Ensure that all NT PHN commissioning partners use, develop and share health literacy tools	100% of all new commissioning partners or re- commissioned partners use health literacy tools
1.9 Conduct organisational health literacy self-assessment to assess progress	<ul> <li>Use Enliven Organisational Health Literacy Self- assessment Resource to assess how NT PHN is progressing as health literate organisation</li> </ul>
3.3 Develop a process for providing feedback to organisations regarding consumer health information resources	<ul> <li>Provide six monthly feedback to organisations as to how frequently their resources are accessed via the online health information library</li> </ul>
3.4 Test consumer health information resources using process for validating as "consumer friendly" and provide feedback to organisations	<ul> <li>Test another twenty consumer health information resources that were identified in stocktake (3.2)</li> <li>Test using both readability tool and consumer testing tool developed in 3.1</li> <li>Provide feedback to organisations using process developed in 3.3</li> </ul>
3.6 Develop an online library to support health professionals and consumers to search for validated consumer health information, and embed links to library in other NT PHN resources	<ul> <li>Review data on health professional use of online health information library three monthly</li> <li>Review data on consumer use of online health information library three monthly</li> <li>Continue to add validated consumer health information resources to the library in an ongoing fashion, and ensure resources are up-to-date</li> </ul>

### **Appendix 2: Key Performance Indicators**

KPIs for Objective 1: Strengthen health literacy environments to enhance NT PHN systems, policies and practices

Indicator	Staff importance	ACCHSs health	Consumer	Commissioning
name	score	literacy programs	involvement score	partners health
		score		literacy score
Key performance question	To what extent do	To what extent has	To what extent has	To what extent
	NT PHN staff	NT PHN prioritised	NT PHN consulted	has NT PHN
	consider health	Aboriginal	with and involved	encouraged its
	literacy to be part of	Community	consumers in its	partners to
	NT PHN core	Controlled Health	health literacy	become health
	business?	Services (ACCHSs) in	activities?	literate
		health literacy		organisations?
		activities for		
		Aboriginal		
		consumers?		
How will and won't this	The indicator will be	This indicator will be	This indicator will be	This indicator
indicator be used?	used to assess and	used to assess and	used to assess and	will be used to
	report internally on	report on the	report on how NT	assess whether
	staff acceptance and	proportion of health	PHN is involving the	NT PHN is
	understanding of	literacy programs	Community Advisory	following its
	health literacy as	commissioned by NT	Council in its health	updated
	part of core	PHN that are	literacy strategy	Commissioning
	business. It will not	delivered by ACCHSs.	development and	Policy and
	be used to assess	It will not be used to	implementation. It	Procedures in
	the knowledge or	assess the health	will not be used to	requiring
	understanding of	literacy of ACCHSs.	gather feedback on	commissioning
	individuals.		the level of	partners to use
			consultation on any	health literacy
			other topic.	tools. It will not
				be used by the
				procurement
				team to
				evaluate
				commissioning
				partners.

Data collection method	The data will be	The data for the	The data will be	The data will be
Data collection method	collected using a	ACCHSs health	collected using a	collected from a
	short anonymous	literacy programs	short, written	retrospective
	email-based survey.	metric is collected as	·	audit of
	eman-based survey.		questionnaire.	awarded
		part of		
A + /f   - /   -	0	commissioning work.	0	tenders.
Assessment/formula/scale	On a scale of 1-10,	Of the health literacy	On a scale of 1-5,	Of the awarded
	how important is	contracts for	has the NT PHN	tenders, what
	health literacy in	Aboriginal	sufficiently involved	percentage of
	your job at NT PHN?	consumers that have	and responded to	new
	Take the average of	been awarded, what	feedback from the	commissioning
	all responses out of	percentage of these	Community Advisory	partners and
	10, and report as a	have been awarded	Council with regards	recommissioned
	percentage.	to ACCHSs?	to health literacy	partners show
			planning and	evidence of
			activities? Report as	using or
			a number.	developing
				health literacy
				tools?
Target	70 per cent by end	80 per cent by end	4 by end of third	50 per cent by
	of third year of	of third year of	year of strategy.	second year of
	strategy.	strategy.		strategy. 100
				per cent by
				third year of
				strategy.
Source of data	All current NT PHN	These data area	Community Advisory	These data will
	staff, including CEO,	already collected by	Council to complete	be collected by
	Board and Senior	the procurement	the survey at their	the
	Executive Members.	team	scheduled meeting.	procurement
				team
Data collection frequency	Six monthly	Twelve monthly	Twelve monthly	Twelve monthly
	(including baseline)			
Reporting frequency	Six monthly	Twelve monthly	Twelve monthly	Twelve monthly
Data collection	Health literacy	Procurement team	Community Council	Procurement
	officer		Liaison Officer	team
How much will it cost?	The costs are low	The costs of	The costs of	The costs of
	given the availability	producing this	producing this	producing this
	of cheap/free email-	metric are low as the	metric are low as the	metric are low

		d-4 10	determine the termine	1
	based survey	data are readily	data can be obtained	because once
	programs.	available.	from meetings that	the
			are already	Commissioning
			scheduled.	Policy and
				Procedure are
				changed, the
				data should be
				regularly
				collected.
How complete is this	It provides a nice	It provides an	It provides a nice	It provides a
indicator?	simple number, but	indication of the	simple number, but	yes/no
	it should be	commitment to	it should be	indication of
	supplemented with	consumer input into	supplemented with	whether
	unstructured	health literacy but	unstructured	commissioning
	feedback (also	awarding these	feedback.	partners are
	obtained from the	programs to ACCHSs		engaging with
	survey) such as:	does not tell us how		health literacy
	"how does health	much consumer		but it does not
	literacy impact your	input there is.		tell us how
	job?".			much or how
				little partners
				are doing in this
				field.
Sources of bias or possible	Staff could feel that	Other organisations		Commissioning
unintended consequences	they are being	that are not ACCHSs		partners could
	assessed individually	but that have used		view this as a
	(this could be	codesign principles		"box-checking
	countered to some	effectively would not		exercise" to
	extent by assuring	be captured by this		meet the
	staff it is anonymous	metric.		requirements of
	and that only the			tenders without
	average score will be			truly engaging
	used).			with health
	Only staff interested			literacy.
	in health literacy			,-
	might reply,			
	meaning that the			
	results have a			
	results have a			

response bias.	
Multiple reminders	
via email can help	
increase response	
rates.	
Staff might respond	
that it is important	
because they feel	
that this is the	
correct answer.	

### KPIs for Objective 2: support health professionals to empower consumers to make informed choices about their health and healthcare

Key performance question	To what extent do health professionals	To what extent do health professionals
	understand health literacy and their	use communication aids to assist those
	role in it?	with additional communication needs?
How will and won't this	The indicator will be used to assess and	This indicator will be used to assess and
indicator be used?	report internally on how effective NT	report on how frequently health
	PHN has been in supporting health	professionals use interpreters and if this
	professionals to improve their health	is increasing.
	literacy.	
Indicator name	Health professional relevancy score	Interpreter use frequency
Data collection method	The data will be collected using a short	The data will be collected as raw whole
	anonymous evaluation.	numbers of interpreters used for
		consultations in primary care.
Assessment/formula/scale	On a scale of 1-10, how relevant was	How frequently have interpreters been
	the health literacy workshop to your	used by health professionals in primary
	day-to-day job? Take the average of all	care situations in the NT?
	responses out of 10, and report as a	
	percentage.	
Target	70 per cent by end of third year of	An increase of 5 per cent year on year.
	strategy.	
Source of data	All health professionals who have	Translation and Interpreter Service,
	attended an NT PHN health literacy or	Aboriginal Interpreter Service.
	communication training session, at the	
	conclusion of the training session.	
Data collection frequency	Twelve monthly	Twelve monthly, including baseline
Reporting frequency	Twelve monthly	Twelve monthly
Data collection	Health literacy officer	Health literacy officer
How much will it cost?	The costs are low as evaluations are	It is unclear whether the TIS or AIS
	routinely done at the conclusion of	would impose a cost for providing these
	training sessions.	data.
How complete is this	It provides a nice simple number, but it	It only provides a trend, but does not
indicator?	should be supplemented with	provide calculated interpreter need,
	unstructured feedback (also obtained	which could be increasing or decreasing
	from the evaluation) such as: "Are there	with demographic changes.

	other ways that NT PHN could support	It does not take into account informal	
	you in improving your health literacy?"	interpreters who may be used at times	
	Although health professionals may feel	such as Aboriginal Health Practitioners	
	that health literacy is relevant, they may or relatives, however the use of		
	not have the time or ability to put the	informal interpreters is not best	
	concepts that have been learned into	practice.	
	day-to-day use.		
Sources of bias or possible	Those health professionals who already	Increased use of interpreters could be	
unintended consequences	consider health literacy to be relevant	mistaken for the only way to address	
	are more likely to attend health literacy	health literacy and other techniques	
	training, and more likely to complete	could be ignored.	
	the evaluation.		

### KPIs for Objective 3: create and sustain a health information library for validated consumer health information

Key performance question	How much of the	How useful is the health	How useful is the health
, personance queens	consumer health	information library to	information library to
	information available in	health professionals?	consumers?
	the NT is appropriate for	neutin professionals.	consumers.
	the consumers it is		
	intended for?		
		<del></del>	<del></del>
How will and won't this	The indicator will be used	This indicator will be used	This indicator will be used
indicator be used?	to assess and report on	to assess and report on	to assess and report on
	the proportion of	how much the health	how much the health
	consumer health	information library is	information library is
	information that is	used by health	used by consumers.
	validated as "consumer	professionals.	
	friendly" using the		
	readability and consumer		
	tools. It will give an		
	indication of how		
	organisations are		
	improving in this way and		
	if the tools and education		
	provided are assisting in		
	this.		
Indicator name	Consumer friendly	Health information	Health information
	resource proportion	library use frequency –	library use frequency -
		health professionals	consumers
Data collection method	The data will be collected	Frequency of visits to	Frequency of visits to
	from the stocktake and	health information library	health information library
	testing process that is	site by those who select	site by those who select
	outlined in the proposed	"health professional" on a	"consumer" on a popup
	action plan.	popup which appears on	which appears on entry to
		entry to the library	the library
Assessment/formula/scale	What proportion of	How frequently is the	How frequently is the
	consumer health	health information library	health information library
		·	, i
	resources tested, out of	visited by health	visited by consumers in
	resources tested, out of those identified, pass	professionals in the NT?	the NT?

	both the readability and		
	consumer testing tools?		
Targets and performance	60 per cent by end of	300 visits per month by	100 visits per month by
thresholds	third year of strategy	end of third year of	end of third year of
		strategy.	strategy.
Source of data	Consumer health	Number of page visits to	Number of page visits to
	resources identified	the homepage of the	the homepage of the
	through the stocktake,	library where the user has	library where the user has
	new consumer health	selected "health	selected "consumer" per
	resources that are sent to	professional" per month.	month.
	the health information		
	library to be added.		
Data collection frequency	Six monthly commencing	Monthly commencing	Monthly commencing
	after stocktake is	after go live of health	after go live of health
	complete.	information library.	information library.
Reporting frequency	Annually	Six monthly	Six monthly
Data collection	Health literacy officer	IT officer	IT officer
How much will it cost?	The costs are low given	The costs are low as these	The costs are low as these
	the work will be being	data will be readily	data will be readily
	completed as part of the	available.	available.
	strategy and therefore		
	the data are readily		
	available.		
How complete is this	It provides a nice simple	It provides an indication	It provides an indication
indicator?	number, but relies on	of visits to the homepage	of visits to the homepage
	valid consumer testing	but not of whether	but not of whether
	and readability tools.	resources are being	resources are being
		downloaded and used	downloaded and used
		with consumers.	with consumers.
Sources of bias or possible	Going forward after the	Those who use the library	Those consumers who
unintended consequences	stocktake testing has	may use it a lot, while	use the library may use it
	been completed, only	many health	a lot, while many
	those that are sent to the	professionals may not use	consumers may not use it
	health literacy officer to	it at all, causing a skewed	at all, causing a skewed
	be added will be tested.	picture.	picture.
	This will introduce		
	selection bias.		

## KPIs for Objective 4: improve collaboration and integration of health literacy activities across NT health system and organisations

Key performance question	Is NT PHN working collaboratively on health literacy
	with other organisations in the NT?
How will and won't this indicator be used?	This indicator will be used to allow other
	organisations working on health literacy in the NT to
	assess how well NT PHN is doing in terms of
	communication and collaboration.
Indicator name	Collaboration score
Data collection method	The data will be collected using a short anonymous
	email-based survey.
Assessment/formula/scale	On a scale of 1-10, how well is NT PHN
	communicating and collaborating in its work on
	health literacy? Take the average of all responses
	out of 10, and report as a percentage.
Targets and performance thresholds	70 per cent by end of three year strategy.
Source of data	Key health literacy contacts at organisations
	involved in health literacy activities, including
	AMSANT, TEHS, CDU, ARDS, Menzies, Poche Centre.
Data collection frequency	Twelve monthly
Reporting frequency	Twelve monthly
Data collection	Health literacy officer's supervisor
How much will it cost?	The costs are low given the availability of cheap/free
	email-based survey programs.
How complete is this indicator?	It provides a nice simple number, but it should be
	supplemented with unstructured feedback (also
	obtained from the survey).
	Some collaborations might be working very well, and
	others not so well, and an average will not allow this
	to be seen adequately.
Sources of bias or possible unintended	Key contacts could feel that they are being assessed
consequences	individually and that the information will be fed back
	to their seniors (this could be countered to some
	extent by assuring staff it is anonymous and that
	only the average score will be used).
	Those organisations that are not already
	collaborating will not be given a chance to respond.