AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

HEALTH LITERACY STOCKTAKE

Consultation Report

September 2012

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Introduction

The Commission

The Australian Commission on Safety and Quality in Health Care (the Commission) was initially established in 2006 by the Australian, State and Territory governments. It commenced as an independent, statutory authority on 1 July 2011. The role of the Commission is to lead and coordinate improvements in safety and quality in health care in Australia by identifying issues and policy directions, and recommending priority areas for action.

The Commission's functions and responsibilities are described in the *National Health Reform Act 2011* and the National Health Reform Agreement. These include:

- formulating standards, guidelines and indicators relating to healthcare safety and quality matters
- advising health ministers on national clinical standards
- promoting, supporting and encouraging the implementation of these standards and related guidelines and indicators
- monitoring the implementation and impact of these standards
- promoting, supporting and encouraging the implementation of programs and initiatives relating to healthcare safety and quality matters
- formulating model national schemes that provide for the accreditation of organisations that provide healthcare services and relate to healthcare safety and quality matters
- collecting analysing, interpreting and disseminating information relating to healthcare safety and quality matters
- publishing reports and papers relating to healthcare safety and quality matters.

Health literacy

Literacy was a term once used to describe only the ability to read and write. The modern meaning of literacy is considerably different. While the skills of reading and writing still feature heavily, it is now used to describe how these skills of reading and writing are used to participate in society and in everyday living. Although there is no widely accepted definition for literacy, it is widely accepted that poor literacy has substantial social and economic influences and that those with low literacy have poorer health outcomes.[1]

The concept of health literacy is the junction between literacy, health and health care. It is defined as the 'degree to which individuals can obtain, process and understand the basic health information and services they need to make appropriate health decisions'.[2]

This definition belies the complex interactions that occur between consumers, health information and health service providers. Health literacy involves consumers and their individual health literacy skill level, health services and the how they are structured, and how health service providers communicate and provide information. Health literacy also involves consumers interacting with health information in a variety of forms and mediums.

One model of health literacy identifies three types of health literacy: functional health literacy, interactive health literacy and critical health literacy.[1] Functional health literacy is based on traditional literacy skills such as reading and writing and improving individual knowledge through communication of health information. Interactive health literacy involves the

development of skills to act on knowledge independently and personal capacity development. Critical health literacy is the development of skills to support both social and political action, and individual action.

Studies into health literacy have resulted in differing views and perspectives of it's component parts. Ultimately, the many and varied interactions in which consumers obtain, process and understand health information influences how consumers make decisions about their healthcare and their health outcomes.

There is strong evidence linking low health literacy and poorer outcomes for patients.[3] People with inadequate health literacy have poorer levels of knowledge and understanding about their condition, are less likely to attend appointments, are less adherent to medication regimens and health behaviour advice, make more medication errors and perform worse at self care activities.[4] What decisions consumers make about health and health care services occur both within and outside of the health care system. Improving health literacy is a challenge that extends beyond the health care system.

Given these links between low literacy and patient outcomes, it is concerning that a study by the Australian Bureau of Statistics in 2006 found that approximately 60 per cent of adult Australians have poor health literacy and are not able to effectively exercise their 'choice' or 'voice' when it comes to making health care decisions.[5] A similar picture is seen internationally. In 2006 the US Department of Education released a report outlining health literacy in America based on the results of the 2003 National Assessment of Adult Literacy. This was the first national assessment of the health literacy in the US and showed that low health literacy was a widespread issue.[6] Similarly, a 2007 report by the Canadian Council on Learning Report found low health literacy is an important issue for Canada based on results of the 2003 International Adult Literacy and Skills Survey.[7]

A growing awareness and understanding of health literacy has led to a subsequent increase in initiatives aimed at both improving consumer health literacy skill and reducing health literacy barriers within health care systems. There has been an increase in interest in this area within Australia and internationally. In the USA and Canada national policies and programs have been developed to foster a greater coordination of efforts to address health literacy.[6-7]

Health literacy and safety and quality in Australia

Health literacy is part of Australia's national approach to safety and quality that has been endorsed by Health Ministers. This approach is set out in the Australian Safety and Quality Framework for Health Care and the Australian Safety and Quality Goals for Health Care. It is also included in the National Safety and Quality Health Service Standards.

The Australian Safety and Quality Framework for Health Care (the Framework) describes a vision for safe and high quality care, and the actions needed to achieve this vision. The Framework specifies three core principles for safe and high-quality care. These are that care is consumer centred, organised for safety and driven by information. One of the actions within the Framework is to improve health literacy.

The Australian Safety and Quality Goals (the Goals) set out important safety and quality challenges for Australia that would benefit from a coordinated national approach to improvement. Goal 3 is: Partnering with Consumers – that there are effective partnerships between consumers and health care providers and organisations at all levels of healthcare provision, planning and evaluation. Within this Goal, one of the areas for proposed action is the design and delivery of health care services in a way that reduces barriers to health literacy.

The National Safety and Quality Health Service Standards (the NSQHS Standards) have been developed to drive safety and quality improvement, and improve the quality of health service provision in Australia. The NSQHS Standards provide a nationally consistent statement of the level of care patients and consumers should be able to expect from health services. Although health literacy is not explicitly mentioned in the NSQHS Standards, items and actions in the NSQHS Standards require the provision of information and services in a way that is appropriate for and understood by patients, families and carers. Examples of such actions include:

- 1.18.3: Mechanisms are in place to align the information provided to patients with their capacity to understand
- 3.19.2: Patient infection prevention and control information is evaluated to determine if it meets the needs of the target audience
- 7.10.1: Information on blood and blood products is provided to patients and their carers in a format that is understood and meaningful.

Health Literacy Stocktake

As part of its work to improve safety and quality the Commission is now including activities to reduce barriers related to poor health literacy in its work plan. To inform future work and to support the directions set out in the Framework, the NSQHS Standards and the Goals the Commission sought to build a comprehensive picture of health literacy activity in Australia. The Health Literacy Stocktake consultation process was the mechanism to collect information about initiatives within Australia aimed at improving health literacy.

The Stocktake was undertaken by the Commission from early December 2011 to 30 March 2012. A consultation process was held and involved inviting a range of stakeholders to provide submissions. The invitation to participate was widely circulated. Letters were sent to 75 key stakeholders directly and an open invitation for submissions was issued via the Commission's web site. The invitation was also distributed using the Commission's emailing databases. Health services and organisations, professional bodies and member organisations, consumer groups, government agencies, safety and quality organisations, research groups and universities were invited to participate.

Respondents could respond using the following methods:

- online survey via Survey Monkey
- email using a reporting template (MS word document) provided via the Commission's web site
- written submissions to the Commission.

The Commission invited submissions about initiatives that had a deliberate and explicit focus on health literacy and involved developing materials and strategies that specifically address health literacy barriers or aim to strengthen health literacy of individuals. Key information sought included a description of the initiative including:

- methodology
- target audience
- project timeframe
- evaluation
- links to web resources where available, and

- sustainability and funding information.

Overall, 66 submissions were received. Many respondents reported multiple health literacy initiatives. Consequently, there were over 220 discrete health literacy initiatives reported.

Types of respondents

There were a wide range of organisation types represented in the Stocktake and many organisations described partnerships with other organisations on health literacy initiatives. Submissions were also received from organisations outside the health care sector, including the education sector and local government.

A list of organisations that provided submissions can be found at Appendix A and the following table illustrates the type of organisations represented in the Stocktake.

Table 1: Number of submissions by source type

Type of organisation	Number of submissions	Proportion of overall submissions
Professional or member organisations including associations	6	9%
Researcher, university or health information development organisation	16	24%
Safety and quality organisations	2	3%
Government departments or agencies	11	17%
Professional colleges	5	8%
Health service or organisation	20	30%
Consumer organisation	4	6%
Local government or council	2	3%
Total	**66**	**100%**

The consultation report

This consultation report provides a summary of the Stocktake process and the key findings of how health literacy initiatives are being carried out in the Australian health care system. The discussion identifies some areas for future work based on the findings of the Stocktake process.

Part One:
Overall findings

Overall, the Stocktake showed investment in health literacy initiatives from a broad range of stakeholders at different levels of the health care system in Australia. The Stocktake presented a host of innovative and collaborative approaches to improving and understanding health literacy. It should be noted however, that the nature of the process used for the Stocktake means that the results do not represent all health literacy activity occurring within Australia. The Stocktake provides an indicator of the kinds of activities which are occurring and the extent to which these activities are connected, coordinated and related.

It had initially been anticipated that information about health literacy activities collected through the Stocktake could be classified into existing models of health literacy, such as improving functional health literacy, interactive health literacy and critical literacy. However, the information received through the Stocktake process generally did not identify the type of literacy that was being targeted. Rather, the details of the submissions, and the focus for much of the analysis that follows in this report, is on the type of strategies that are being used to improve health literacy in Australia. Definitions and theoretical approaches to health literacy were rarely described in the submissions. Where they were noted, they varied considerably and generally a broad interpretation of the concept of health literacy was taken by respondents.

While the majority of initiatives were from within the health care system, submissions were also received from outside health care, including local government organisations and from some state government education organisations. The broad range of stakeholders responding to the Stocktake and the number of partnerships between organisations shows health literacy as a broad societal issue.

Health literacy in Australia

The Stocktake process was aimed at better understanding the health literacy landscape in Australia including identifying the type of actions which are being taken to improve health literacy.

The spread of the submissions received showed that there is some level of activity around health literacy occurring in all states and territories in Australia. Most initiatives are occurring at the health service level, although a small number of submissions demonstrated action around health literacy at the Commonwealth and state or territory government level.

The variation in the types of initiatives reported in the Stocktake demonstrated the range of strategies being undertaken to improve health literacy and reduce health literacy related barriers. There were a number of submissions reporting research projects related to health literacy, showing an ongoing interest in understanding and exploring the complexities of this issue. Many partnerships and collaborative initiatives were described, particularly between health services and research organisations.

Target audience

Respondents were asked to describe the target audience of their health literacy initiative. The submissions received showed a range of target audiences from whole of population health promotion initiatives to initiatives aimed at particular at-risk groups. There were also initiatives reported that targeted health care workers to build their capacity to address health literacy issues.

There was a particularly strong focus on initiatives which developed or adapted information materials for culturally and linguistically diverse populations including the translation of material into multiple languages.

Timeframe, evaluation and sustainability

There was great variability in the timeframes, evaluation and sustainability reporting in the Stocktake and in many cases, evaluation and sustainability were not reported. Many submissions described ongoing projects such as web-based resources that are updated regularly, as well as one-off projects for resources that have been developed and continue to be distributed. One-off projects were particularly common for initiatives involving the development of information material.

For initiatives based on the provision of education programs and the provision of support services, the timeframe of projects was reliant on future sources of funding, and in many cases the sustainability of the initiative was influenced by ongoing funding constraints.

Varying approaches to improving health literacy

Traditionally, the approach to improving health literacy has been targeted at improving the skill of the individual, through, for example, improvement of information materials adapted for a specific audience or through education programs.

Recently attention has turned to what actions health services can take with initiatives to examine and reduce health literacy demands placed on consumers accessing the health care system. Examples include modifying the environment and how information is presented, such as changes to signage and service processes.

Both of these approaches were described in submissions received in the Stocktake. In addition, there was a large proportion of research initiatives and initiatives for the dissemination of information about health literacy.

Part Two:
Exploring Australian health literacy initiatives

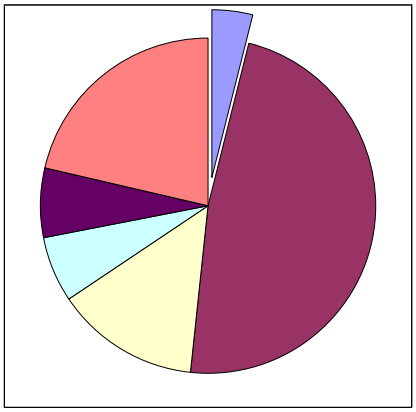
The variability in the type, complexity and detail presented in the Stocktake meant that it was a challenge collate and compare health literacy initiatives, however there were common approaches that emerged. The six approaches discussed in this section are noted below, together with the overall proportion of the total initiatives for which this approach was dominant. A total of 229 different health literacy initiatives were considered in this analysis.

- *Policy or framework approach:* initiatives focused on a policy or framework for improving health literacy. These initiatives were provided by respondents at different levels of the health care system. Approximately four per cent of initiatives took this approach.
- *Health information:* initiatives involving the development and communication of health information. Approximately 47 per cent of initiatives reported were focused on health information.
- *Improvement of individual health literacy skill:* initiatives aimed at improving the health literacy skill of individuals through education or support programs. Approximately 14 per cent of initiatives reported took this approach.
- *Health literacy environment:* initiatives aimed at modifying the health service environment to reduce health literacy barriers. Approximately seven per cent of initiatives reported took this approach.
- *Workforce training and capacity building:* initiatives that target the workforce to take action to improve health literacy, generally through training. Approximately seven per cent of initiatives reported took this approach.
- *Research and knowledge sharing:* initiatives focused on health literacy research or initiatives for sharing information about health literacy. Approximately 21 percept of initiatives reported involved this approach.

It is important to note that many initiatives addressed more than one category. In this analysis the dominant category for each initiative has been identified, and each initiative has been counted only once in this category. Examples from the submissions have been included in each section to illustrate the variety of approaches and strategies used.

Policy or framework approach

Some submissions described policy or framework documents outlining a strategic approach to improving health literacy. This was reported by some state and territory governments and some health service organisations. Generally, these overarching documents incorporated a range of strategies organised into systematic, coordinated and focused approaches to addressing health literacy to be applied at different levels of the health system. There were also submissions that described a broader policy document within which health literacy was an element. Approximately four percent of the total initiatives reported could be described as taking a policy or framework approach.



Submission 46: Department of Health and Human Services Tasmania - Communication and Health Literacy Action Plan

This Action Plan describes a government level approach to improve health literacy in Tasmania.

The key principles identified in the Action Plan are:

- 'Clients have a right to information: it is our responsibility to communicate effectively.
- Clients have a right to be involved in decision-making about their health and wellbeing.
- Improving health literacy is a shared responsibility, especially across the health and education sectors.
- Improving communication and health literacy requires small contributions from many.
- Consistency of messages in important, and supported by evidence-informed practice.'

Through the Action Plan, the Department of Health and Human Services aims to foster:

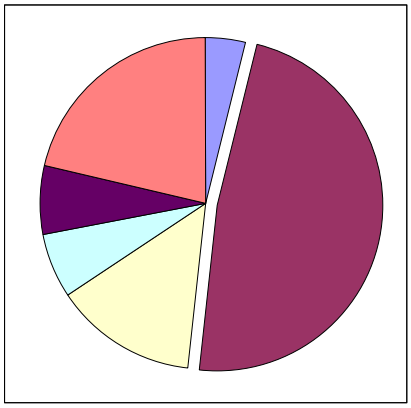
- healthcare and human services staff skills and resources and capacity to communicate effectively with people who use their services.
- a reduction in literacy-related barriers for people accessing their services.
- a more health-literate population in Tasmania by working in partnership with the education sector and others.

Beneath these three overarching strategies, the Department of Health and Human Services Tasmania has identified 15 specific initiatives to achieve their objectives.

Additional information about the Action Plan can be found at the Department of Health and Human Services web site:
www.dhhs.tas.gov.au/about_the_department/your_care_your_say/health_literacy

Health information

The development and provision of information to individuals is central to health literacy. Around 47 per cent of the initiatives reported the development of new information materials or modification of existing information for a target audience. There was an assortment of examples provided ranging from printed resources and fact sheets, DVDs and web-based resources, to health promotion campaigns using multiple communication methods.



The process for developing information differed between submissions. A large proportion of initiatives were based on the development of information designed for a target audience, typically developed or written by health service staff and subject experts. The process of development includes identification of a knowledge gap within the target audience and the development and dissemination of information resources to address the knowledge gap and improve health literacy.

A smaller proportion of initiatives reported developing new, or adapting existing information for the target audience, again typically by health service staff or subject experts, and then subsequently consulting or testing the information with the target audience for appropriateness, suitability and understanding. This generally occurred through survey, representative focus group style testing, or general feedback from the target audience.

There were a small number of submissions that reported taking an additional step and involving the target audience in the identification of what information is required, and then in the subsequent development and testing of the information.

Submission 42: NSW Council for Intellectual Disability – Healthier Lives fact sheets

The NSW Council for Intellectual Disability developed Healthier Lives fact sheets: one easy read set of fact sheets targeted at people with intellectual disability and another standard English set targeted at a broader audience such as families, disability workers and other professionals.

The easy read set of fact sheets was developed by a participation worker in collaboration with a group of people with intellectual disability and using advice from health professionals. An illustrator was also contracted for the fact sheets.

The standard English set was developed by writers with plain English writing skills and knowledge of the intellectual disability sector. The topics for the fact sheets were developed with advice from two parents and three doctors who specialise in the health of people with intellectual disability. The fact sheets contained input from, and were reviewed by a range of experts. Three of the fact sheets were tested with 25 family members and disability workers.

The fact sheets are primarily a web resource but are available in hard copy also. The NSW Council for Intellectual Disability reported positive feedback in response to the fact sheets and the web site for the fact sheets received approximately 40,000 web site hits in the first year.

More information can be found at the NSW Council for Intellectual Disability web site: www.nsw.cid.org.au

Submission 53: Centre for Culture, Ethnicity & Health – Radio campaign for the Arabic, Cantonese and Mandarin speaking communities in Melbourne to increase awareness about maternal and child health, reading and story telling and nutrition and diet

The Centre for Culture, Ethnicity & Health (CEH) were funded to develop key messages for community radio to increase awareness of maternal and child health, reading and story telling and nutrition and diet. This project was carried out over 12 months.

The CEH conducted focus groups with families of children in the 0 – 6 age group from Arabic and Chinese background to develop the campaign. Following the focus groups and consultation process six radio scripts were developed; two about maternal and child health, two about nutrition and diet and two about reading and storytelling.

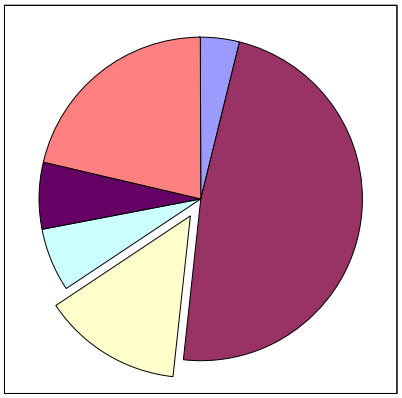
The messages were tested with the target audience: they were read to parents from Chinese- and Arabic-speaking backgrounds using qualified interpreters. This process highlighted confusion in the messages and let to the advertisements being re-scripted and presented as a conversation with a mother and grandmother, in line with cultural practices of role modelling within these communities.

An evaluation was conducted on the project which found that:

- advertisements for parents of culturally and linguistically diverse parents should be focus-tested with the target audience prior to implementation
- advertisements should be relevant to the cultural practices and lifestyles of the audience
- if advertisements are translated from English, verify the integrity of the translations with a focus group and check the key messages have been conveyed appropriately
- radio and print advertising should be supplemented with editorial coverage and interviews to maximise exposure to the message. Spokespersons from the target audience community can be selected and given media training as media spokespersons.

This submission can be found at the Commission's web site: www.safetyandquality.gov.au

Improvement of individual health literacy skill



Health literacy is commonly viewed from the perspective of the individual's skills and capacities. Much research is centred around an individual's functional literacy skills such as reading, writing and numeracy. This is also the basis for many health literacy measurement tools (for example the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA)).

Accordingly, a substantial number of the initiatives reported in the Stocktake were aimed at improving health literacy skill of individuals through some form of education or support program. This type of health literacy initiative accounted for approximately 14 per cent of the initiatives reported. These initiatives are closely linked to information initiatives as they involve the provision of information to consumers through education. These initiatives involved structured education programs, specifically targeted information sessions or the provision of support services to educate consumers.

Examples of different methods of consumer education to improve health literacy skill presented in the Stocktake include:

- the inclusion of health literacy into school curricula in partnership with organisations from the education sector
- self-management courses or programs. There was a particular focus for consumers with chronic disease or ongoing health conditions
- education programs and dedicated support services for consumers with a specific health condition. Examples include training programs or one-off training sessions, a dedicated telephone service or other support services for individuals from a targeted population. Some initiatives reported the provision of education aimed at explicitly increasing knowledge about health literacy.

Submission 60: ACT Health Directorate - Living a Healthy Life with Long Term Conditions

The ACT Health Directorate offers ACT residents with a long term condition a six week course to learn how to self-manage their condition including fatigue management, communicating with health professions and how to navigate the health system.

The course is conducted by a health professional and a person with a long-term condition who has completed leader training.

More information can be found at the ACT Health web site: www.health.act.gov.au/c/health?a=&did=11025168

Submission 59: Kingston City Council – Heatwave Strategy

The Kingston City Council identified heatwaves as a significant public health issue and in 2011/12 implemented the Heatwave Strategy to raise awareness and target specific vulnerable and at-risk groups in the City of Kingston community.

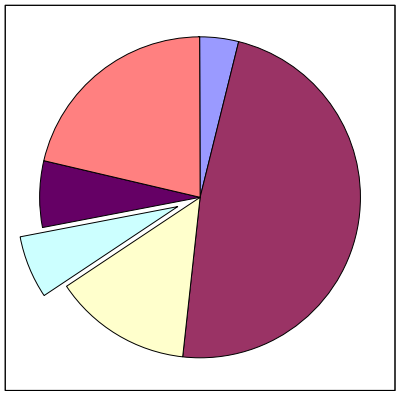
The strategy included the following objectives and actions:

- increase public awareness of the health risks caused by heatwaves using activities such as posters, articles and media releases
- increase public knowledge of preventive measures to decrease the health risks associated with heatwaves using activities such as emails and posters
- distribute heatwave resources, including cool neck ties, posters and handheld fans with indentified groups in the community
- hold information sessions with identified groups in the community
- mail out reminders and resources to at-risk groups during a heatwave.

The Kingston City Council undertook an evaluation of the Heatwave Strategy using a range of quantitative and qualitative methods and discussed barriers to the implementation of the strategy. Overall, the Kingston City Council found the Heatwave Strategy was positive and improved the health literacy of target groups and wider Kingston community. Kingston City Council noted many of the methods used in this strategy are transferrable to the implementation of future strategies.

This submission can be found at the Commission's web site: www.safetyandquality.gov.au

Health literacy environment



This type of initiative is aimed at reducing health literacy barriers in the health service environment. It includes modification of physical aspects of the health service or modification of processes to improve ease of navigating and accessing the health service for consumers. This approach considers health literacy from the perspective of what action a health service can take to reduce the health literacy demands placed on consumers within the physical environment. This is an emerging approach to addressing health literacy, taking the focus away from the individual and their capacity, and putting the onus on health services to take action to make the health service more accessible to consumers with low health literacy. Approximately seven per cent of submissions reported undertaking this type of initiative.

Submission 30: Penola War Memorial Hospital Country Health SA Local Health Network Lower South East Health Service - First Impressions Activities

The Penola War Memorial Hospital has developed the First Impressions Activities to consider some of the characteristics of the hospital that help or hinder the ability of a patient or visitor to make their way around the hospital.

It consists of three activities that look at first impressions of patients and visitors through different activities: a phone call, a visit to the web site and a walking interview. The instructions for these activities are described below.

1. Telephone
    - Look for the hospital phone number in the phone book and internet. Call the main telephone number of the hospital and ask for advice on how to get to the hospital by car. Choose different times of the day and evening to get different situations. Use the First Impressions Telephone tool to report findings and recommendations.
2. Web site
    - Use a search engine to locate the hospital's web site. Use the First Impressions Web site tool to report findings and recommendations
3. Walking Interview
    - The walking interview involves the completion of a series of stages where an Observer is asked to share their observations and impressions about the hospital with a Guide as they move through different locations and complete different tasks. The Observer is asked to complete tasks such as 'Find the Entrance to Accident and Emergency', and is asked to report back on what they have noticed, how they feel and what signs or cues they used to complete the task. The Guide completes a written report using the information provided by the Observer and using the Walking Interview tool.

The feedback is then provided back to the Director of Nursing, the Leadership Group and

the Health Advisory Council.

This submission can be found at the Commission's web site: www.safetyandquality.gov.au

Submission 47: Goulburn Valley Health - Hospital Orientation and Health Information Tours for Migrants and Refugees

In 2010, Goulburn Valley Health Shepparton undertook a pilot program providing tours of the hospital for small groups of English language students from the Migrant Education Centre at Goulburn Ovens Institute of TAFE. The purpose of the tours was to:

1. Familiarise community members with the hospital and how to find their way around.
2. Introduce key take home messages at stop-off points around the hospital including pharmacy, pathology, imaging and emergency department. The stop-off areas were chosen based on feedback from community members through a survey conducted by the Ethnic Council of Shepparton and concerns raised by staff regarding patients not following pre-test instructions.

The pilot was evaluated, and in 2011 and 2012 the program was expanded to include:

- the addition of outpatients clinics and the Sanctuary (a sacred place in the hospital available to people from all faiths) to the tour
- tours for multicultural support workers and settlement support service staff with the aim of enabling them to better assist refugee and migrant families to access hospital services
- a structured program of tours for targeted community groups to ensure interpreting needs are more easily met.

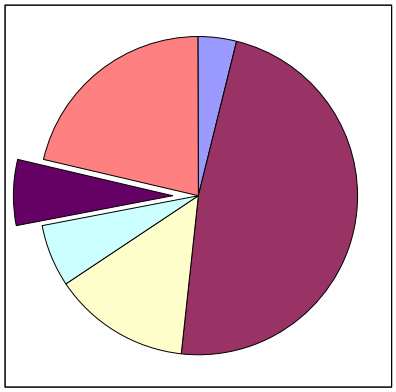
The tour includes information about interpreter services, use of mobile phones, confidentiality and an overview of campus entries and walkways, car parking, public transport, signage, information directory boards and the recognition and roles of Customer Service Officers and Volunteer Guides.

This submission can be found at the Commission's web site: www.safetyandquality.gov.au

Workforce training and capacity building

This type of initiative focuses on the delivery of workforce training and capacity development for health care professionals and other support workers to take action in improving health literacy.

Submissions described formalised education packages and seminars to raise awareness of health literacy issues and improve communication, as well as resources and tools aimed at providing support and aid in decision making. Approximately seven per cent of submissions had a training focus.



Submissions 19 and 33: Eastern Health Clinical School, Monash University and funded by the Department of Health and Ageing - Health literacy in pharmacy project

As part of the Fifth Community Pharmacy Agreement Research and Development Program – Health Literacy Research Project, a consortium of experienced pharmacists and other academics from Monash University, Sydney University, Queensland University and Curtin University with the Pharmaceutical Society of Australia (Victorian Branch) will design an innovative, accessible, manageable and evidence-based education package in health literacy for community pharmacies.

A train-the-trainer approach will be used to prepare pharmacists to deliver training to other pharmacists and pharmacy assistants in the workplace. It will be supported by online resources.

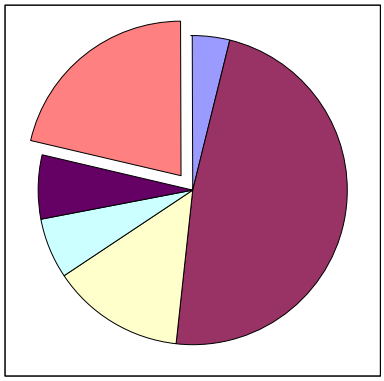
The purpose of the project is to develop, pilot and refine the educational package around health literacy to enable them to better tailor information to consumers.

This submission can be found at the Commission's web site: www.safetyandquality.gov.au

Research and knowledge sharing

There were many initiatives reported in the Stocktake related to research and a range of research topics were described. The following were particularly featured:

- measurement of health literacy and functional literacy
- effectiveness of decision support tools
- effectiveness of information resources provided to consumers.



In addition, some submissions reported initiatives for sharing health literacy research and information. Approximately 20 per cent of the initiatives described involved research and information sharing activities.

Submission 8: University of Sydney – Development and evaluation of a bowel cancer screening decision aid for adults with lower education and literacy

The University of Sydney reported an initiative to develop and evaluate a decision aid intervention specifically designed to support informed choice and involvement in decisions about faecal occult blood testing (a self-sampling screening test for bowel cancer) for populations with lower education and literacy.

The initiative used a combination of qualitative and quantitative methods and methodologies. The research was carried out in three key stages:

1. Development and pilot testing of a bowel cancer screening decision aid for adults with lower education and literacy. This was completed through in-depth interviewing and survey work to identify information needs and design preferences and examine the acceptability of the tool.
2. Exploratory research to gain an insight into the meaning that different education and literacy groups attach to their experiences and understandings of involvement in health care decision-making.
3. Formal evaluation of the decision aid using a randomised trial design with a sample of adults with lower educational attainment.

The initiative was targeted at adults aged between 55 – 64 years with lower levels of education and literacy making decisions about the faecal occult blood test to screen for bowel cancer. The initiative found that participants in the decision aid group had higher levels of knowledge about the outcomes of screening, were less positive about doing the faecal occult blood test and were less likely to have completed it than the controls. The proportion of participants making an informed choice was 22 per cent higher in the decision aid groups. Although most participants made the screening decision on their own, decision aid participants were 2.5 times more likely to share or prefer to share the decision with their doctor. More decision aid participants had no decisional conflict about the screening decision compared with the controls.

This submission can be found at the Commission's web site: www.safetyandquality.gov.au

Submission 11: Primary Health Care Research and Information Service - Conference Abstracts, PHC RIS round up

The Primary Health Care Research and Information Service (PHC RIS) did not conduct any specific health literacy initiatives, however they described resources for sharing knowledge and information about health literacy activity as follows:

1. the PHC RIS ROAR database containing information about relevant projects and researchers
2. conference abstracts about health literacy presented at the PHC conference
3. overview or summary of research about primary health care health literacy in the 'Research ROUNDup'

This submission can be found on the Commission's web site:

www.safetyandquality.gov.au.

More information can also be found at the PHC RIS web site:

www.phcris.org.au/

Part Three:
Discussion and future directions

The Commission undertook the Health Literacy Stocktake to gain a better understanding of the approaches being taken to address health literacy in Australia. This aim has been achieved, and the information obtained through the Stocktake illustrates the range of strategies and approaches that are currently being used to improve health literacy, and reduce barriers related to health literacy. These strategies encompass:

- development of policies or frameworks
- provision of health information
- improving the skills of individuals
- examining or changing the health service environment
- training the health workforce
- researching and sharing knowledge about health literacy.

These different approaches reflect the need for a multi-factorial approach to improving health literacy. Traditionally approaches to improving health literacy have focused on the skills of individual patients or consumers, the Stocktake shows strategies that look at the way health services operate and the way in which healthcare providers work are becoming more common.

From the submissions received in the Stocktake, it would appear that the approach to improving health literacy in Australia is largely fragmented and is currently not coordinated or led at a national level. The submissions received showed that action is being taken in a variety of settings, using a range of different strategies across Australia, with many pockets of excellence and innovation. However most initiatives are being undertaken at the individual health service level with limited capacity for diffusion of the innovations which occur.

The response to the Stocktake showed interest from stakeholders in understanding and addressing barriers to health literacy within the healthcare system. Yet, there was also a clear message that due to a range of factors, the lessons learnt from the work being undertaken were not always able to be shared. Coordination and collaboration appeared to be limited, which may be a result of limited national guidance and leadership on the issue.

Internationally, particularly in the USA[6] and Canada,[7] there has been movement towards greater coordination and focus on improving health literacy at the national level. Both countries have overarching strategic documents outlining action to be taken to take on improving health literacy nationally. These strategies offer broad applicability to the Australian health care system. The Commission will use the information from the Stocktake, indicating the need for better national coordination, to inform its future work in this area.

Appendix A:
List of Submissions

No	Respondent
1	Ballarat Health Services
2	University of Melbourne
3	Central Victoria General Practice Network
4	Murray-Plains Division of General Practice
5	St John of God Health Care
6	University of Tasmania
7	University of Tasmania
8	University of Sydney
9	University of Sydney
10	University of Sydney
11	Primary Health Care Research and Information Service
12	National Health Call Centre Network Ltd
13	University of Tasmania
14	Clinical Excellence Commission
15	Monash University
16	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
17	Office of Safety and Quality in Health Care (WA Health)
18	Canterbury Hospital Maternity Unit
19	Department of Health and Ageing
20	Royal Australian College of Surgeons
21	Royal Australian and New Zealand College of Radiologists
22	Western Region Health Centre
23	National Health and Medical Research Council
24	Djewrriwarrh Health Services
25	Victorian Department of Education and Early Childhood Development
26	Eastern Health
27	Specialist Management Services
28	Doutta Galla Health Services
29	Women with Disabilities Victoria
30	Penola War Memorial Hospital
31	Womens Health Loddon Mall'ee
32	DES Action Australia
33	Eastern Health Clinical School, Monash University
34	Royal Australasian College of Physicians
35	ISIS Primary Care
36	Ethnic Communities' Council of Victoria
37	Melton Shire Council
38	Royal District Nursing Service
39	Eastern Health
40	HealthWest
41	Deakin University
42	NSW Council for Intellectual Disability
43	Eastern Health
44	HCF

No	Respondent
45	Health Issues Centre
46	Department of Health and Human Services (Tas)
47	Goulburn Valley Health
48	Australian General Practice Network
49	Kimberley Aged and Community Services (WA Health)
50	Patient Safety and Quality Unit (SA Health)
51	Consumers Health Forum of Australia
52	Department of Health and Human Services (Tas) - Part 2
53	Centre for Culture, Ethnicity and Health
54	Australian Dental Association
55	Australian Health Practitioner Regulation Agency
56	Dietitians Association of Australia
57	North Shore and Central Coast Area Health Service
58	Royal College of Pathologists of Australasia
59	Kingston City Council
60	ACT Health
61	Royal Women's Hospital (Vic)
62	Northern NSW Local Health District
63	Deakin University
64	Illawarra Shoalhaven Local Health District
65	Department of Health Victoria
66	SA Health

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