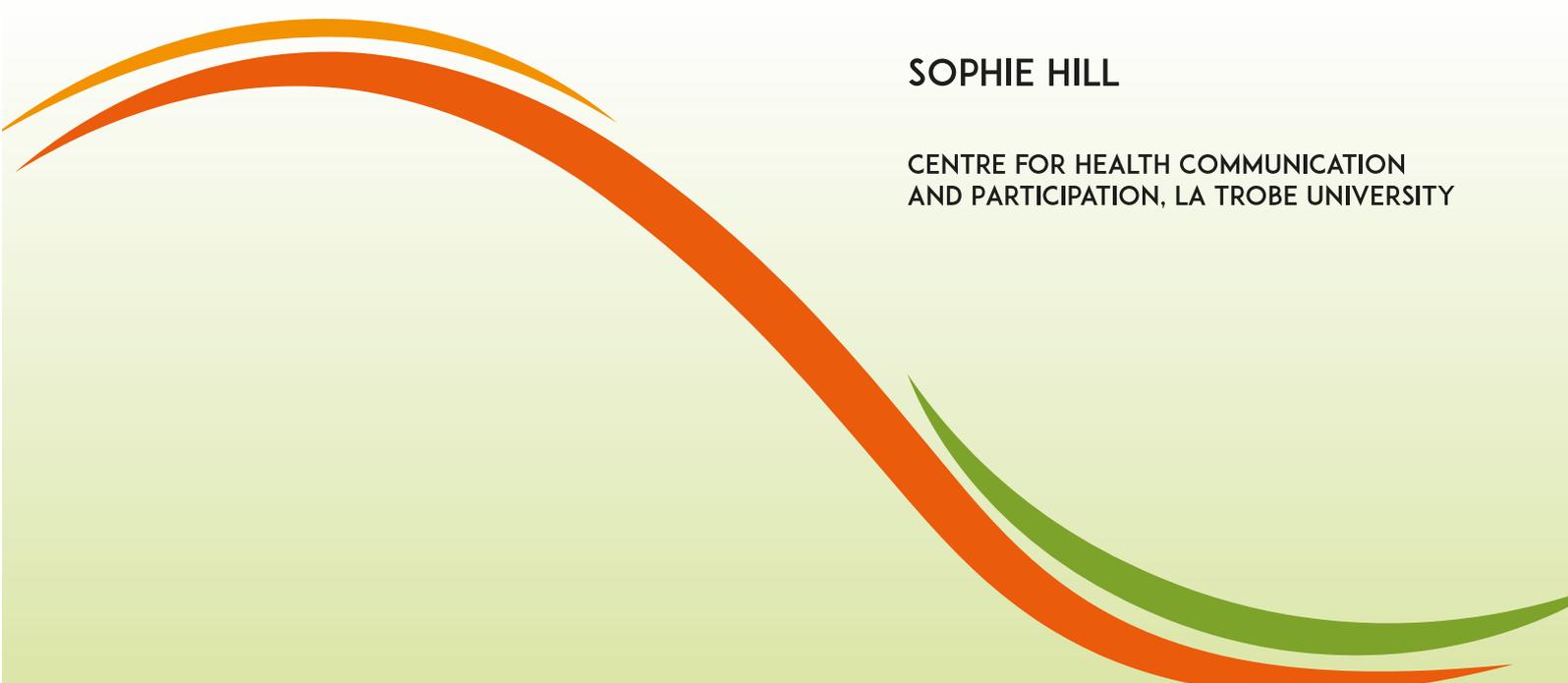


REPORT OF THE VICTORIAN 2014 CONSULTATION ON HEALTH LITERACY

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AUTHORSHIP

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EXECUTIVE SUMMARY

AUTHORSHIP

This report was prepared by Sophie Hill, Head, Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University, with input from Genevieve O'Neill on community networks, under the advice of the Health Information and Health Literacy Subcommittee of the Participation Advisory Committee of the Department of Health Victoria.

BACKGROUND AND CONSULTATION

Better health literacy improves access to a range of programs to help manage and maintain health, and achieve the best health outcomes possible.

To understand the gaps, barriers and enablers within the health system, the *Health Literacy: Enabling Communication and Participation in Health, Background Paper* (2013) was developed by the Department of Health Victoria.

The *Background Paper* outlined a series of questions related to key health literacy needs and priorities in healthcare for individual consumers, carers, communities, health professionals, healthcare organisations and systems. It was the basis for discussion in a state-wide consultation.

Consumers, carers, community members, and staff from health services, community organisations and the Department of Health were invited to provide feedback on the *Background Paper* in the consultation. In early 2014 there were seven workshops around Victoria and a call for submissions. The workshops were well attended (226 participants) and 13 submissions were received.

REPORT OF THE VICTORIAN 2014 CONSULTATION ON HEALTH LITERACY

This document is a report of the consultation on health literacy. It provides a summary of the issues raised. It also provides a synthesis of the advice from consultation participants informed by contemporary theories and evidence. The report contains recommendations for the Department of Health to consider. It outlines principles, criteria and advice on best practice to guide future implementation actions.

In August 2014 the Australian Commission for Safety and Quality in Health Care released the *National Statement on Health Literacy: Taking Action to Improve Safety and Quality*. The *Statement* outlines a number of areas and actions required to address health literacy in a coordinated way. The *Statement* was considerably informed by the *Background Paper* developed by the Department of Health.

RECOMMENDATIONS

It is intended the *Report of the Victorian 2014 Consultation in Health Literacy* will be one of the inputs to the development of the Department of Health's next Consumer Participation policy, which was evaluated in 2014. It presents 16 recommendations for improving the health literacy of Victorians. The Participation Advisory Committee has supported the progression of the recommendations contained in this report.

RECOMMENDATIONS

The report has 16 recommendations. They are presented in two ways.

First, they are listed below in the order they appear in Sections 1-3 of the report.

Second, in Section 4 they are reorganised under four overarching themes. These themes arose from the analysis and synthesis of the material and subsequent drafting of recommendations. This reorganisation aids discussion and consideration of the next steps. The overarching themes are:

1. Build the capacity of consumers, carers and community members to influence the health literacy agenda and outcomes
2. Enhance the communication capabilities of health professionals and services
3. Systematise the development and provision of health information
4. Implement policies and systems to improve Victorians' health literacy.

RECOMMENDATIONS SECTION 1: INDIVIDUAL CONSUMERS, CARERS AND COMMUNITIES

1. Definition of health literacy

The Department of Health Victoria should adopt the following revised definition of health literacy: Health literacy means people can obtain, understand and use the health information and services they need to make appropriate health decisions. Healthcare providers and the health system should provide information and improve interaction with individuals, communities and each other to respond to and improve health literacy.

2: Principles to underpin future health literacy actions

The following principles should be adopted as the basis of future action:

2a. Principles relevant to consumers, carers and community members

- Health literacy is an asset which can be built. The deficit approach to health literacy (i.e. one which sees it only as a problem with individual consumers) should be avoided
- Efforts to improve health literacy should have an equity focus and address those consumers and carers most in need but with approaches which are relevant to all people
- Strengthen the role of community members in supporting actions for improving health literacy in services, the community and Department of Health Victoria
- Support lifelong learning in the population in response to health needs and challenges at different life stages.

2b. Principles relevant to health professionals

- Communication and the exchange of information must be a central and not a peripheral feature of health culture, systems and services
- Support career-long learning of communication skills amongst health professionals.

2c. Principles relevant to healthcare organisations and systems

- Health literacy should be improved by people working in partnership at all levels. It is a shared concern of consumers, carers, community members, health professionals and health organisations
- Improving health literacy will require a shift in culture. Leadership will be needed for changes to be initiated and sustained
- Improving health literacy will require the development or enhancement of systems which support people or services to address health literacy.

3: State-wide training for community members on health literacy

There should be greater provision of state-wide health literacy training for community members. Training should cover the issue of health literacy and initiatives to improve it. Training should be available and tailored to people participating in health services at service or governance level, as well as for people who are participating in boards or advisory committees of community organisations.

4: Fostering networks amongst community members

Different mechanisms should be explored for increasing the connectedness of community members and to foster networks.

5: Enhancing the Better Health Channel

The Better Health Channel website should continue to be strengthened to be the authoritative and proactive source of health information. It should provide information in layered formats (i.e. levels of complexity) and recommend additional websites, with links to visual or audio materials. It should address misinformation and ensure that it is proactive on health promotion and illness prevention.

6: Education or training for the public on health literacy concepts

Community-based training initiatives could focus more on providing members of the public with strategies to improve their health literacy generally or in specific health encounters.

7: Cultural responsiveness

Actions to promote health literacy must aim to overcome the disadvantages and barriers experienced by many groups and should accord with the Department of Health Victoria's policy on cultural responsiveness.

RECOMMENDATIONS SECTION 2: HEALTH PROFESSIONALS AND THE HEALTHCARE WORKFORCE

8: Consumer/carer focussed design principles for promoting good interpersonal communication

Services should adopt the following design principles as the basis of improving health literacy by improving interpersonal communication. Good communication from a consumer or carer perspective is:

- Being listened to
- Being encouraged to ask questions

- Communication without jargon
- Being able to understand the health professional
- Being understood culturally and linguistically
- Having the information to know what to do, when, and not being bombarded with information (verbal and/or written) at one instance
- Having health professionals check information needs as care progresses, taking into account health status and the needs of accompanying carers
- Being provided with consistent messages
- Being directed to reliable sources of additional information or support
- Having health services and professionals communicate effectively with each other about the consumer, carer or family.

9: Communication skills training for health professionals and healthcare workforce

There should be an expansion in, and promotion of, accredited communication skills training for health professionals and members of the healthcare workforce, taking into account the diversity of training needs, purposes and modalities.

RECOMMENDATIONS SECTION 3: HEALTHCARE ORGANISATIONS AND SYSTEMS

10: Health literacy and Consumer Participation policy

Health literacy actions should be integrated into the new Consumer Participation policy.

11: Health literacy systems-level infrastructure

It is recommended that actions to support health literacy:

- Build on existing policies, programs, infrastructure and resources, many of which may have a health literacy element
- Adopt a standards approach to written health information provision, communication skills and communication skills training so that improvements are uniform, tangible and measurable
- Foster efficient use of resources through the provision of open access, core resources and templates which can be tailored
- Promote the sharing of resources and the exchange of evidence, experience and best practice
- Increase opportunities for community members to play a skilled role in promoting the health literacy of others
- Foster partnerships and partnership models between community members, health professionals and health services at all levels
- Develop a stepped approach for health services to integrate health literacy initiatives into their systems
- Respond to the fact that population and health professional diversity is not currently recognised in health information or communication skills training.

12: Infrastructure to support improved provision of written health information

An appropriate website should be established for developers of written health information. This could include the following resources and features:

- Health information templates, and open source symbols, artwork and resources. This would include a library of brochures which can be tailored by health services (e.g. adding logo)
- Resources in multiple formats (e.g. written, audio, pictorial)
- A set of agreed definitions or uses for common terms, so that use and translation is standardised
- Audited and approved key documents, signage and instructions
- Information about online, open access training for health professionals on developing written health information
- Information about communication skills trainers and their expertise
- Evidence on health literacy initiatives, including evidence, case studies, and examples of good practice. The assessment of good practice should involve consumers, carers and health professionals
- Materials with no copyright (e.g. evaluation surveys)
- Information about other databases for service navigation.

13: Revision of the *Guide for Well-Written Health Information*

Guidance in the Communicating with Consumers Series, *Well-Written Health Information: A Guide* (2000), should be revised in collaboration with consumers, carers and health professionals. It will be necessary to provide guidance on how to develop written health information for health promotion.

14: Guidance on social media

Health services need better guidance on using social media to communicate health information to consumers, carers or the public. This includes guidance on how patient narratives could be used in websites.

15: Health information delivery within services

Health services could be encouraged to improve the delivery of written health information.

16: Audit the entry and exit documents associated with high-risk situations

An audit should be conducted of communication practices and of key healthcare entry and exit documents, focusing on common and high risk tasks. This should be performed with the aim of developing core competencies and standardised documents which can be tailored by all services.

INTRODUCTION

The Introduction explains the context for, and method of, the *Report of the Victorian 2014 Consultation on Health Literacy*. The Introduction also describes the preparation of this report.

This report was prepared by Sophie Hill under the advice of the Health Information and Health Literacy Subcommittee of the Participation Advisory Committee of the Department of Health Victoria. Members of the Health Information and Health Literacy Subcommittee are listed in Appendix 1.

BACKGROUND PAPER, 2013

Better health literacy improves access to a range of programs to help manage and maintain health, and achieve the best health outcomes possible.

To better understand the gaps, barriers and enablers within the health system, the *Health Literacy: Enabling Communication and Participation in Health, Background Paper* (2013) was developed by the Department of Health Victoria.

The *Background Paper* outlined a series of questions related to key health literacy needs and priorities in healthcare for individual consumers, carers, communities, health professionals, health organisations and systems. Its purpose was to obtain feedback on these questions. During early 2014 it was used as the basis for discussion in a state-wide consultation. Consumers, carers, community members, and staff from health services, community organisations and the Department of Health were invited to provide feedback.

CONSULTATION METHOD

The *Background Paper* was circulated for consultation and comment was sought via workshops around the state or by written submission to the Department of Health.

The objectives of the workshops were to:

1. Identify the perceptions, needs and priorities of different participants in the Victorian health system regarding health literacy and health information
2. Identify enablers and effective strategies to address health information and health literacy priorities
3. Develop a shared understanding of health literacy and its relationship to key policy frameworks and health outcomes
4. Establish key actions which address and improve health literacy in Victoria.

The scope of the consultation was set by the four questions of the *Background Paper*. Consumers, carers, community members, and staff from health services, community organisations and the Department of Health were invited to address these questions at workshops or in their submission.

Question 1: What does health literacy mean for you?

Question 2: What do you see as the key health literacy and health information needs and priorities for:

- Individual consumers, carers and diverse communities
- Health professionals and the workforce
- Healthcare organisations and systems?

Question 3: How are you and/or your organisation currently addressing health literacy and health information needs and priorities for:

- Individual consumers, carers and diverse communities
- Health professionals and the workforce
- Healthcare organisations and systems?

Question 4: What else could assist you or your organisation to address health literacy and health information issues?

Participants were asked to consider issues from varying perspectives.

Seven consultation workshops were held from February to April 2014. Workshops were held in:

1. Benalla for the Hume Region on 1 February 2014
2. Ararat for the Grampians Region on 5 March 2014
3. Melbourne for the Metropolitan Region health services, Department of Health, community services and agencies on 11 March 2014
4. Melbourne for the Metropolitan Region health services, Department of Health, community services and agencies on 18 March 2014
5. Traralgon for the Gippsland Region on 26 March 2014
6. Warrnambool for the Barwon South West Region on 3 April 2014
7. Bendigo for the Loddon Mallee Region on 8 April 2014.

The workshops were well attended (226 participants).

In the workshops health literacy was seen as a 'buzzword'. Many services and organisations had been examining the concept and how it was relevant for them or reviewing information and communication practices to find areas for improvement. Some services, working collaboratively with community agencies and researchers, had made a major investment in changes to promote health literacy. Many participants attended to learn from others.

Notes were taken by 3-6 people depending on the size of the workshop.

The opportunity to provide a written submission was taken by 13 organisations and individuals.

Overall, consultation participants were diverse and inclusive of a wide range of interests (Appendix 2).

REPORT OF THE VICTORIAN 2014 CONSULTATION ON HEALTH LITERACY

This document is a report of the consultation on health literacy. It builds on the work in the *Background Paper*, which made the case for health literacy as an enabling framework, allowing improvements to be made in areas of health communication and participation, health information, consumer participation and consumer-centred care.

The report provides a summary of the issues raised. It also provides a synthesis of the advice from consultation participants informed by contemporary theories and evidence. The report contains recommendations for the Department of Health to consider. It outlines principles, criteria and advice on best practice to guide future implementation actions.

PREPARATION AND ORGANISATION OF REPORT

The report was developed as follows: notes from all workshops and written submissions were analysed. The main issues and themes identified were grouped according to the three areas of focus outlined in the *Background Paper*:

Section 1: Individual consumers, carers and communities

Section 2: Health professionals and the workforce

Section 3: Healthcare organisations and systems.

In each of the Sections 1-3 there is a summary of the issues and priorities raised by workshop participants or in submissions, organised by common themes.

This is followed by recommendations. Some of the recommendations are followed by implementation considerations, and are highlighted. They are a synthesis of the main points from those consulted, informed by evidence and contemporary best practice or theory. They illustrate best practice or design criteria for new initiatives or for strengthening existing developments. The need for good ideas and best practice to be presented here arose from consultation participants asking that this report be practical in focus to aid future developments.

In Section 4, the report concludes with four overarching themes. The recommendations are reorganised by these themes to encourage discussion and consideration of next steps.

NEXT STEPS

It is intended the *Report of the Victorian 2014 Consultation on Health Literacy* will be one of the inputs to the development of the Department of Health's next Consumer Participation policy, which was evaluated in 2014. The report presents 16 recommendations for improving the health literacy of Victorians. The Participation Advisory Committee has supported the progression of the recommendations contained in this report.

AUTHORSHIP

This report was prepared by Sophie Hill, Head, Centre for Health Communication and Participation, School of Psychology and Public Health, La Trobe University, with input from Genevieve O'Neill on community networks, under the advice of the Health Information and Health Literacy Subcommittee of the Participation Advisory Committee of the Department of Health Victoria.

SECTION 1: INDIVIDUAL CONSUMERS, CARERS AND COMMUNITIES

INTRODUCTION

Improving communication and information provision has become a health systems issue of considerable urgency. Consumers, carers, community members and health professionals all expressed similar anxiety about the problems they were facing. However the impact of the lack of attention to building health literacy was felt most keenly by consumers and carers.

In the section the following themes are covered:

- The definition of health literacy and principles to support further work in health literacy
- Ways of supporting community members to play a greater role in health literacy initiatives at service and community level
- Population considerations.

There are seven recommendations on the following themes:

1. Definition of health literacy
2. Principles to underpin future health literacy actions
3. State-wide training for community members on health literacy
4. Fostering networks amongst community members
5. Enhancing the Better Health Channel
6. Education or training for the public on health literacy concepts
7. Cultural responsiveness.

MAIN THEMES AND RECOMMENDATIONS

Health Literacy Definition

Participants at the workshops were asked to comment on the definition of health literacy in the *Background Paper*: 'the degree to which individuals can obtain, process and understand the health information and services they need to make appropriate health decisions. Healthcare providers and the health system can provide information and improve interaction with individuals, communities and each other to respond to and improve health literacy'.

Most were comfortable with it but wanted it revised to be more action-oriented and less 'conditional'.

Recommendation 1: Definition of health literacy

The Department of Health Victoria should adopt the following revised definition of health literacy: Health literacy means people can obtain, understand and use the health information and services they need to make appropriate health decisions. Healthcare providers and the health system should provide information and improve interaction with individuals, communities and each other to respond to and improve health literacy.

Principles

Workshop participants said that because health literacy is such a broad concept with relevance to many areas of health and healthcare delivery, it would be useful to start by having a set of principles to frame the recommendations for all parties. The principles should support a focus on empowerment, partnership and dialogue and not reinforce the relative powerlessness of consumers and carers.

Recommendation 2: Principles to underpin future health literacy actions

The following principles should be adopted as the basis of future action:

2a. Principles relevant to consumers, carers and community members

- Health literacy is an asset which can be built. The deficit approach to health literacy (i.e. one which sees it only as a problem with individual consumers) should be avoided
- Efforts to improve health literacy should have an equity focus and address those consumers and carers most in need but with approaches which are relevant to all people
- Strengthen the role of community members in supporting actions for improving health literacy in services, the community and Department of Health Victoria
- Support lifelong learning in the population in response to health needs and challenges at different life stages.

2b. Principles relevant to health professionals

- Communication and the exchange of information must be a central and not a peripheral feature of health culture, systems and services
- Support career-long learning of communication skills amongst health professionals.

2c. Principles relevant to healthcare organisations and systems

- Health literacy should be improved by people working in partnership at all levels. It is a shared concern of consumers, carers, community members, health professionals and health organisations
- Improving health literacy will require a shift in culture. Leadership will be needed for changes to be initiated and sustained
- Improving health literacy will require the development or enhancement of systems which support people or services to address health literacy.

Training for community members and their role in improving health literacy

Many community members are working in partnership with health services, community organisations and each other to achieve a better health system. The concept of partnership was well illustrated at the workshops where teams of community members and health professionals attended from their service contributing expertise and advice.

Community members were involved at all levels of the current Consumer Participation policy: helping consumers or carers at the individual level of care, as well as participating at the program or department level, at the health service organisational level and also in the Department of Health. Additionally many community members attended the workshops who were involved in community organisations, such as self-help groups and health foundations.

It was an overwhelming sentiment that community members could play a much greater role in helping the health system and Victorians improve health literacy, particularly as workloads for health professionals are increasing. Community members should be seen as potential leaders for health literacy.

Participants sought an increase in opportunities for community members to play a skilled role in promoting the health literacy of others. Numerous examples were given (see implementation considerations below).

At the workshops there were numerous examples of strategic or advocacy-oriented participation in health literacy-related initiatives but participants felt that much more could be done. Community members could play a much greater role in improving the health literacy of organisations and of individuals. One function mentioned frequently was the role of navigator (see Section 3). This role could encompass providing information and support on service availability, completing forms, following up or helping people ask questions.

Some rural health services needed more help in finding and involving community members, particularly those from disadvantaged groups.

In community agencies, members of the public are playing a key role in advisory committees, on boards and in training initiatives. Increasing their opportunities for training on health literacy would be popular and effective.

Community members involved in training consumers had used Skype to provide training to others at a distance and felt this could be further supported.

Some organisations had invested in new types of communication strategies to recruit more volunteers and these could provide a source of people who might be willing to read and comment on health information materials or be involved in training.

Recommendation 3: State-wide training for community members on health literacy

There should be greater provision of state-wide health literacy training for community members. Training should cover the issue of health literacy and initiatives to improve it. Training should be available and tailored to people participating in health services at service or governance level, as well as for people who are participating in boards or advisory committees of community organisations.

IMPLEMENTATION CONSIDERATIONS: Training for community members on health literacy

The following implementation considerations could guide the development of varying training programs. Information below may also be relevant to health services undertaking training of community members involved in health service committees.

- Purpose: Training should equip community members to participate meaningfully and effectively in supporting health literacy. Training could have core content but be tailored to different roles community members will inhabit and the different organisational settings in which they will participate (i.e. acute hospital, community health, or Victorian publicly-funded community agency).
 - Roles include: educators, advocates, navigators for patients or carers and being conduits for information, in addition to advisory or governance roles on committees. Consumers could be trained to obtain patient feedback.
- Content: Training should be based on content suitable to different roles and responsibilities.
 - Topics include: rights and legal obligations, privacy and confidentiality, governance, leadership, quality and safety, change management, health literacy concepts and practices, patient feedback systems and processes, support and entitlement systems for patients, quality sources of health information, health service and information databases, evidence and knowledge transfer, local and state-wide organisations relevant to health literacy, use of the Internet and social media issues, navigation models and issues, effective advocacy and networking, involving people from disadvantaged groups.
- Format: Face-to-face and online:
 - People, such as those in remote areas, need training which is more accessible. Training could include face-to-face sessions but other formats would also be valuable (e.g. using video or Skype). Once developed, some elements of training programs could then be provided free online.
- Standards: Accreditation for some training may be desirable.

Community members and networks

An area of need is to improve the connectedness of community members who are involved in health services or community organisations. This is particularly the case for connecting individuals involved in localised services or agencies with those involved in state or national organisations. Much of this connectedness only happens by people finding websites or through occasional events such as consumer participation conferences.

Improving connections between community participants would lead to a number of benefits, including: greater sharing of information; lessons or resources; and improved policy making for the Department of Health. It may also remove duplication: information resources for patients are being developed concurrently in services and in community organisations, which is wasteful.

Recommendation 4: Fostering networks amongst community members

Different mechanisms should be explored for increasing the connectedness of community members and to foster networks.

IMPLEMENTATION CONSIDERATIONS: Community members and networks

Supporting networks could include the following options:

- Supporting the extension of networks through social media
- E-newsletters to community members (sign-up basis)
- Establishing a 'clinical network' model for community members involved in Department of Health activities as a subcommittee of the Participation Advisory Committee.

Health literacy at population level

Improving health literacy should enable the management and improvement of health at an individual, family or community level. At a societal level, consumers and carers are encouraged to take more responsibility for their health. The health system could do more to make this an organising principle and assist them to achieve this. There was considerable discussion of the need for much more public information about preventing illness and promoting health at all ages, and specifically for people who are disadvantaged. Participants felt the Government could be more proactive given the downstream consequences on poverty, disadvantage and illness - and future demand for health services.

Participants wanted the Department of Health to be more proactive in mass media and social media, for example on issues such as alcohol or drug use. Participants in two rural workshops mentioned the challenges of addressing the culture around drinking at sporting events and said that improving people's understanding of the long-term consequences would be beneficial.

Health foundations were trying to fill the gap in information about staying healthy. One consumer group had successfully combined the provision of simple fact sheets with peer-based forums for people at key health stages (e.g. diagnosis).

People not only got information from health services associated with their specific issues but from the mass media, family and workplaces. Services, for example, are commonly contacted by consumers with questions after hearing or reading about new treatments. One suggestion was for the Department of Health to host a section on an appropriate website to address misinformation in the media so that health services could then refer to it.

The public did not have sufficient awareness of good health information websites and these could be promoted more actively by the Department of Health and by services. The features of what makes reliable health information also needed prominence.

Health organisations and services were also trying new ways of communicating with the public. New initiatives such as Google groups, open days, walk-ins and expos were mentioned as examples of successful ventures.

Recommendation 5: Enhancing the Better Health Channel

The Better Health Channel website should continue to be strengthened to be the authoritative and proactive source of health information. It should provide information in layered formats (i.e. levels of complexity) and recommend additional websites, with links to visual or audio materials. It should address misinformation and ensure that it is proactive on health promotion and illness prevention (see also Section 3 Recommendations 12-16 on health information).

Recommendation 6: Education or training for the public on health literacy concepts

Community-based training initiatives could focus more on providing members of the public with strategies to improve their health literacy generally or in specific health encounters.

Equity and diversity

The need to understand diversity in addressing health literacy was strongly argued. Diversity could encompass social, demographic, cultural and/or linguistic differences in consumers, carers and health professionals as well as physical or cognitive differences in consumers or carers. People with some conditions, such as mental health problems, could still feel stigmatised.

Who is vulnerable to poorer health literacy? Participants and submissions identified many groups who could be vulnerable, who faced difficulties in getting appropriate health information, or who faced barriers to good communication at health service level. Vulnerable groups identified were indigenous people, homeless people, older people from culturally and linguistically diverse backgrounds, people with gay, lesbian, bisexual or transgender identity, gay men from culturally and linguistically diverse backgrounds, people who are vision impaired or with other disabilities, people with mental health problems, and people with lower levels of education.

Consultation participants said there was too much reliance on providing people from culturally and linguistically diverse backgrounds with translated written health information as the main supplement to verbal communication. The complexity of communicating with people from diverse backgrounds meant a more considered response was needed. For instance people came from overseas with varying levels of education (high to low). English language may be learned but for some proficiency could diminish with ageing, the onset of conditions or the loss of memory. Knowledge and beliefs about health and healthcare varied amongst people and communities and had to be understood better for successful treatment or health maintenance. At the level of health organisations it was suggested that staff should identify who were their regular or high needs users and examine how to respond effectively.

In some communities a family-oriented approach was taken to health issues. For instance the family may be the point for information gathering in indigenous families. This has implications for information provision and also how health organisations respond when people present as patients (see also Section 3 Recommendation 12 and 15).

Recommendation 7: Cultural responsiveness

Actions to promote health literacy must aim to overcome the disadvantages and barriers experienced by many groups and should accord with the Department of Health Victoria's policy on cultural responsiveness.

More specific recommendations responding to aspects of diversity are found in Sections 2 and 3.

SECTION 2: HEALTH PROFESSIONALS AND THE HEALTHCARE WORKFORCE

INTRODUCTION

As highlighted by the *Background Paper*, addressing health literacy enabled better communication and the provision of appropriate information to consumers, carers and communities about how to manage and improve their health.

This section discusses the issue of interpersonal communication in the context of healthcare delivery. The issue of systems for improving the development and delivery of written health information is considered in Section 3.

The main issue identified by workshop participants and in submissions was the importance of interpersonal communication. This issue had two themes: communication from the perspective of consumers and carers; and communication from the perspective of health professionals and other health service staff. Considerable guidance on best practice relating to these themes was provided. The guidance has been synthesised into implementation considerations.

Building on recommendations in the previous section, there are two recommendations:

8. Consumer/carer focussed design principles for promoting good interpersonal communication
9. Communication skills training for health professionals and healthcare workforce

MAIN THEMES AND RECOMMENDATIONS

Communication from the perspective of consumers and carers

Communication facilitates access to health literacy. Participants asserted that health outcomes were improved if people had meaningful interpersonal interactions. From the perspective of consumers and carers the quality of interpersonal communication was a critical issue. Poor communication had an impact on consumers' or carers' *access* – access to knowledge and understanding, to being informed, to being able to participate or interact, to knowing what was happening or could happen. Failures in these areas led to adverse events or diminished people's chances to manage, maintain or improve their health, or to care for others. Poor interpersonal communication was undermining and for some people stigmatising.

Understanding, communication and trust were inter-related features which needed to be present to ensure good health management.

The topic of written health information was interwoven with the topic of interpersonal communication. However communication was viewed as central to health literacy and had primacy as an issue for most workshop participants. Written health information is addressed in Section 3.

In addition to the issue of interpersonal communication with health professionals is the issue of communication at the service level. For example staff such as receptionists played a critical role in welcoming people; informing them and helping them navigate current and future episodes. On this topic some noted that when 'greeting' patients or families, the written information provided was too

commonly in an 'Anglo' format (words or pictures) which bore no relation to the patient population the service was dealing with (see Section 1 Recommendation 7).

There needs to be much more encouragement of consumers or carers to speak up, ask questions and express views. Some services had initiated tools, training and systems to support this across the service.

Some people reported good experiences with new communication media. For instance a number of people in rural areas had been part of successful specialist consultations using video conferencing or by recording a consultation with a phone.

A separate issue is privacy in relation to better communication. Further work may be needed to explore the extent to which privacy issues are a barrier in situations when carers or friends are playing an active role in the care of the patient. It was said this is an issue for non-resident (and sometimes resident) carers of older or younger adults.

One other health-related issue mentioned was helping people know their rights for communicating their health status at work, particularly if there is the potential for stigma or discrimination associated with their new health status.

Recommendation 8: Consumer/carer focussed design principles for promoting good interpersonal communication

Services should adopt the following design principles as the basis of improving health literacy by improving interpersonal communication. Good communication from a consumer or carer perspective is:

- Being listened to
- Being encouraged to ask questions
- Communication without jargon
- Being able to understand the health professional
- Being understood culturally and linguistically
- Having the information to know what to do, when, and not being bombarded with information (verbal and/or written) at one instance
- Having health professionals check information needs as care progresses, taking into account health status and the needs of accompanying carers
- Being provided with consistent messages
- Being directed to reliable sources of additional information or support
- Having health services and professionals communicate effectively with each other about the consumer, carer or family.

IMPLEMENTATION CONSIDERATIONS: Using the consumer/carer design principles

The consumer/carer design principles could form the basis of developing training courses for health professionals. The principles could also inform service audits of communication skills, or measures to gather health service experience data from consumers and carers.

Health communication from the perspective of health professionals

Interpersonal communication for health professionals was seen as a major health literacy issue. It was a dominant theme in the workshops and submissions.

The complexity of many service settings and high patient demand, in conjunction with throughput funding models, has created very challenging work environments for health professionals.

Communication skills include being able to communicate respectfully and effectively with consumers and carers, as discussed above, but also communicate effectively in teams and with other health professionals. People used new terms to promote different approaches by health professionals such as 'choice architect' or 'listening health professional'.

The health literacy principles relating to health professionals from Recommendation 2, Section (b), are reproduced again for reference:

- Communication and the exchange of information must be a central and not a peripheral feature of health culture, systems and services
- Support career-long learning for communication skills amongst health professionals.

Clinicians new to the workforce want to learn more and interact with clients more effectively or sensitively but feel under-prepared because there was insufficient attention to communication issues during their university education. Training in communication skills for health professional was seen by participants as a major gap. This was the case not only at tertiary level, but throughout professional careers. New challenges perpetually arise in response to changing social expectations and changing socio-demographics.

The communication skills of health professionals whose first language was not English was raised several times and was a difficult issue to engage with without prejudice or stigma.

Some services had been training clinicians in the 'Teach-back' method, a useful strategy for clinicians to know that patients understand what has been communicated. Some services had also promoted Ask Me 3 (developed by the National Patient Safety Foundation of USA, see www.npsf.org/?page=askme3). One service presented literacy issues to its new medical staff and situated them in the context of managing risk. Beyond these initiatives, participants identified skills in listening, eliciting information and shared decision making as also important.

Various points on training needs were mentioned. Training should be continuous, implying it would cover a diversity of communication-related issues. Participants sought accredited training courses. A greater connection between communication skills and the National Safety and Quality Health Service Standards was also raised. Training needs to be available for ancillary staff such as receptionists, who play a critical role as gatekeepers and navigators. The principles of health literacy should also be embedded in all training, for example embedded into care planning training, as distinct from being a stand-alone form of training.

Longer term issues associated with improving communication skills training were raised. It was suggested the Department of Health could work with peak health service bodies, consumer groups, clinical colleges and clinical networks to examine existing training courses for gaps in content and availability. The Department of Health could also request Victorian tertiary institutions to review the

purpose, content and format of communication skills subjects in undergraduate and postgraduate courses, and report back to the Department of Health on areas for improvement. Furthermore the Department of Health could examine the issue of competencies for clinical communication in conjunction with the relevant national agencies. This would enable health services to integrate communication competencies into standard Position Descriptions. Finally, the Department of Health may wish to examine how to address the longer term issues raised above, in consultation with the Australian Commission for Safety and Quality in Health Care, the Australian Health Practitioner Regulation Agency, as well as with Victorian tertiary educational institutions.

Recommendation 9: Communication skills training for health professionals and healthcare workforce

There should be an expansion in, and promotion of, accredited communication skills training for health professionals and members of the healthcare workforce, taking into account the diversity of training needs, purposes and modalities.

IMPLEMENTATION CONSIDERATIONS: Addressing diverse needs in developing communication skills training

There was much discussion on what constituted good communication and distilled are the following key features. These could form the basis of communication skills courses which would be designed to respond to different needs.

- Who is the target?
 - Undergraduate
 - Postgraduate
 - Clinicians who are new to the workforce, who need to acquire new skills or refresh their language or skills
 - Clinicians in specific roles which require additional training
 - General staff in health services who interact with consumers or carers
 - Management and board members.

- What is the purpose?
 - General education
 - Specific knowledge or skills
 - Refresher
 - Mandatory requirements.

(continued next page)

IMPLEMENTATION CONSIDERATIONS (*continued*)

- What should be covered?
 - *Learning about different needs:*
 - Awareness and understanding of social, cultural and linguistic issues
 - How consumer and carer needs and communication preferences vary
 - Consumer/carer communication design principles (see Sec. 2 Rec. 8)
 - Communicating with people with varying forms of disability
 - Understanding issues of gender, sexuality, age, loss, death and dying, law and health.
 - *Learning different communication skills:*
 - Using strategies to help people remember or record discussion
 - Basic communication principles and styles
 - Discussing information brought by the consumer (e.g. from the Internet)
 - Discussing evidence
 - Communicating simply and effectively
 - Listening and eliciting questions
 - Shared decision making
 - Communicating bad news
 - High risk situations.
 - *Service-specific topics:*
 - Patient rights
 - Privacy and carers
 - Consumer participation
 - Learning how to write in Easy English
 - Using email or videoconferencing
 - Effective communication in teams, across departments or services
 - Communication in challenging situations or dynamic environments
 - Provision of interpreters
 - Using health service navigators
 - Health treatment-specific (e.g. palliative care, post-surgical)
 - Referral to other services, support or information.
- Format:
 - Face-to-face
 - Online and open access
 - Involving consumers or carers as trainers
 - Using actors for simulation training in complex or difficult situations
 - Using multidisciplinary teams of students to co-teach fellow students or staff.

SECTION 3: HEALTHCARE ORGANISATIONS AND SYSTEMS

INTRODUCTION

For healthcare organisations and systems, embedding health literacy considerations into organisational processes and policies should be aimed at facilitating responsive healthcare provision and improving health outcomes.

This section covers:

- Policy development and systems-level implementation of health literacy initiatives
- The content and delivery of written health information, including social media
- Initiatives being taken at health service level to improve communication
- Navigation
- High risk contexts
- Equity and diversity issues
- Community organisations and networks
- Evaluation.

Section 3 contains seven recommendations building on the recommendations in Sections 1 and 2, as well as containing a range of ideas and best practice for services to consider implementing. The recommendations are:

10. Health literacy and Consumer Participation policy
11. Health literacy systems-level infrastructure
12. Infrastructure to support improved provision of written health information
13. Revision of the *Well-Written Health Information: A Guide*
14. Guidance on social media
15. Health information delivery to consumers and carers within services
16. Audit entry and exit documents associated with high-risk situations.

MAIN THEMES AND RECOMMENDATIONS

Leadership and cultural change for policy development

Many health services had taken a proactive approach to investigating health literacy problems and had already implemented changes. These ranged from simple strategies to complex whole-of-organisation changes supported by the senior executive. Organisations in the community had also been involved in a wide range of initiatives: training, raising awareness or collecting narratives of problems and impacts. This level of activity provides an excellent base on which to build further improvements.

The Department of Health Victoria should continue to advocate for health literacy across health services, as well as to other government departments, national bodies and community-based agencies. Advocacy should also continue within the Department of Health itself. This leadership role

could incorporate integrating health literacy actions into the new Consumer Participation policy after consideration of the recommendations in this report.

The health literacy principles relating to healthcare organisations and systems from Recommendation 2, Section (c), are reproduced again for reference:

- Health literacy should be improved by people working in partnership at all levels. It is a shared concern of consumers, carers, community members, health professionals and health organisations
- Improving health literacy will require a shift in culture. Leadership will be needed for changes to be initiated and sustained
- Improving health literacy will require the development or enhancement of systems which support people or services to address health literacy.

There was considerable discussion in the workshops of how centralised systems and resources could help healthcare services improve their services in a more consistent way.

A health literacy approach must be integrated into existing policies, standards and requirements. A prescriptive policy was discouraged. It was suggested it would be more effective to pull together strategies, toolkits and good ideas and link these to existing requirements. This was particularly the case for services or regions which had invested in major health literacy initiatives which were well underway. There was a strong endorsement of centralised tools, open source documents and key templates which could be tailored by services, as well as endorsement of resources, training and navigation assistance for consumers and carers.

Whilst a prescriptive approach was discouraged, people stated that without executive support (at Department of Health or health service level) it was difficult to make more than piecemeal changes. For systems to change executive endorsement was needed in addition to resources. Therefore it was suggested that the Department of Health could encourage services to embed health literacy in their strategic and operational plans with a high correlation with accreditation requirements.

There was discussion on how the National Safety and Quality Health Service Standards could integrate health literacy more effectively so accreditation could become a driving force of health literacy actions. Examples raised included having communication skills training as part of accreditation.

Several health services and community agencies argued effective communication in consultations was hindered by activity-based funding with specified throughput targets. These targets existed irrespective of the degree of complexity of patient or family issues. Participants stated it was difficult to build up trust if funding only allowed a short period for consultation. Adding more health literacy items to already lengthy screening checklists was not supported.

Services noted the increasing time and cost associated with training new staff for a suite of policy requirements. Adding another health literacy training module was not favoured. Instead participants argued for the integration of health literacy concepts and practices into various existing training programs. There was overall support for much greater availability of, and requirements for, communication skills training for health professionals throughout their career (see Section 2).

In relation to the cost of training staff in health services on health literacy, at one workshop the proposal was made that induction training could be funded separately by a central fund (and not by the health service from operating costs). Thus in a two week induction period all training needs for new staff could be addressed. After the two week training the health service would resume the cost of salary.

Three-year program funding cycles could lead to uncertainty with staffing, workforce instability and loss of local expertise. Participating health professionals argued this impacted on health literacy. One area where local knowledge was critical was service access criteria. The lack of publicly available information on access criteria meant services would refer onto others, only to find clients could not receive care. Criteria were often not readily identifiable.

Building on the points covered in Section 2, in relation to health professional communication training it was suggested the Department of Health may wish to coordinate with the Australian Health Practitioner Regulation Agency on how health literacy elements could be integrated into core Positions Descriptions.

Recommendation 10: Health literacy and Consumer Participation policy

Health literacy actions should be integrated into the new Consumer Participation policy.

Recommendation 11: Health literacy systems-level infrastructure

It is recommended that actions to support health literacy:

- Build on existing policies, programs, infrastructure and resources, many of which may have a health literacy element
- Adopt a standards approach to written health information provision, communication skills and communication skills training so that improvements are uniform, tangible and measurable
- Foster efficient use of resources through the provision of open access, core resources and templates which can be tailored
- Promote the sharing of resources and the exchange of evidence, experience and best practice
- Increase opportunities for community members to play a skilled role in promoting the health literacy of others
- Foster partnerships and partnership models between community members, health professionals and health services at all levels
- Develop a stepped approach for health services to integrate health literacy initiatives into their systems
- Respond to the fact that population and health professional diversity is not currently recognised in health information or communication skills training.

Written health information provision

Many consumers and carers reported they experienced the contradictory pressures of information scarcity and information overload. Participants argued that reform was needed of the provision of written health information through a multi-level 'health systems' response. It seemed surprising but respondents identified information to stay healthy as one of the major gaps.

At health service level there are many issues. The current approach is not streamlined, highly duplicative and produces masses of information. Much of this information is not accessible to consumers or carers, or does not meet people's needs. The criticisms of the current situation were informed by audits undertaken by several health services. Repeatedly the question was raised: if health information topics are broadly the same at each health service, why is it not produced or provided centrally by people with the expertise? In this context the new initiative, Patient Information brochures for Common Medical Procedures, commissioned by the Department of Health to provide a centralised set of resources for common procedures, was seen as potential for improvement.

A new attitude is required for the development of written health information. It must no longer be seen as something which anyone can do. Developing written forms of health information requires expertise, good organisation and systems. It is unrealistic to expect that every service could manage this within its own staff and resources. Some services had developed sophisticated, service-wide systems - involving community members and staff - for developing all-written health information. This built expertise and raised standards. However some participants felt it was a substantial burden on smaller services to require their community members to read all health information to check its accessibility as part of accreditation. This is also highly duplicative.

In this context a need was expressed repeatedly for agreed or standardised resources or templates, ideally held by a central website, which services could then tailor, for example adding logo and contact information. This could also assist with extending the range and quality of translated materials.

It was noted that externally-provided training programs (i.e. training to prepare written health information) may be expensive. Some services were adopting a 'train the trainer' approach to ensure skills were spread amongst a wider group of staff. This approach was also needed due to the turnover of healthcare staff, making training an expensive requirement. There were difficulties in knowing about available training courses (e.g. writing in Easy English) or good initiatives and resources.

Strategies to bring up the quality of key written documents (e.g. informed consent) need attention. These could be aided by the Department of Health publishing examples or templates of key documents on its website. In developing new resources it was suggested health services could send in examples and a committee of health information specialists, health professionals, consumers and carers could provide advice on what was considered best practice. New materials could also be tested in a focus group of consumers and carers.

The challenge for health services of responding effectively to people's different health information needs was underscored by the lack of health information materials in more suitable formats (e.g. easy-to-read, pictorial, Braille, audio, multimedia). Services wanted more advice on how to decide which different media or formats to invest in.

All the issues above are magnified for translated materials. The following points were made:

- Using multimedia to provide information, for example in DVD format, could help to overcome the barriers related to educational level

- Some services had developed standards for how to translate materials.

Recommendation 12: Infrastructure to support improved provision of written health information

An appropriate website should be established for developers of written health information. This could include the following resources and features:

- Health information templates, and open source symbols, artwork and resources. This would include a library of brochures which can be tailored by health services (e.g. adding logo)
- Resources in multiple formats (e.g. written, audio, pictorial)
- A set of agreed definitions or uses for common terms, so that use and translation is standardised
- Audited and approved key documents, signage and instructions
- Information about online, open access training for health professionals on developing written health information
- Information about communication skills trainers and their expertise
- Evidence on health literacy initiatives, including evidence, case studies, and examples of good practice. The assessment of good practice should involve consumers, carers and health professionals
- Materials with no copyright (e.g. evaluation surveys)
- Information about other databases for service navigation.

See also Section 3 Recommendations 13-16.

The content of written health information

In Section 2 it was noted while interpersonal communication has primacy amongst participants, it was said communication should be supported by good quality written health information. The discussion above addressed the issues associated with the provision of health information and this section addresses the issue of content.

There were a range of issues with the quality of health information content. The most important gap to fill is straightforward and easy to understand information. However it was also noted care should be taken not to 'dumb down' health information but have a system that optimises people's awareness and knowledge.

There were various problems associated with health information content:

- Too much health information used jargon or technical terms and was not straightforward or easy to understand
- There was a lack of information encouraging consumers or carers to ask questions or to be active in their decision making. Written information needs to be more active in orientation (i.e. what will happen next, what to do next, what to do if problems emerge)
- It was difficult to find information about health and services that is up to date, authoritative and combined simplicity with referral to other sources, or which layered information to present more complex information for those who wanted it

- Rapidly changing treatment choices and technologies made the task of keeping the content up to date harder
- Messages cannot always be ‘simple’ because some conditions require skills to self-manage
- Up to date information for people with rare conditions was a gap.

Health services and health professionals need to have information sources to recommend to patients and families who want more detail. The role of the Better Health Channel as a health information provider was endorsed but it was suggested it could play a more concerted role in referring people to other quality information sources. This would mean health services could then concentrate on providing the simpler material but referring people onto a website with more links to detailed material.

One strong theme was that the 2000 report in the Communicating with Consumers Series, titled *Well-Written Health Information: A Guide*, needs to be updated and revised. The guidance could be simpler and take into account the different purposes and modalities of health information. A decision aid is different to a condition-specific information pamphlet, and these differences can be important to clarify.

Updated guidance is needed for developers of health promotion information. Other gaps were information that was easy to act on, information that encouraged consumers to ask question and be involved in decision making.

In revising the *Guide*, more attention needs to be paid to spelling out the different ways community members could be involved in shaping the information content, rather than purely commenting on the language and terminology.

A major challenge is the diversity of target audiences. Health information has to take into account the reader’s age, disability, gender and language. More thought needs to go into understanding the needs of specific audiences in terms of how to prepare relevant content. For example, in the context of health literacy, participants said that it was risky to assume that everyone knew the basics about the body and how it worked – and this sometimes needed to be included in key documents, depending on the audience.

Women’s health agencies identified topics where information was regularly needed: preventing violence against women, information and support for women who are the victims of violence, sexual and reproductive health, diet and nutrition, and parenting.

13: Revision of the Guide for Well-Written Health Information

Guidance in the Communicating with Consumers Series, *Well-Written Health Information: A Guide* (2000), should be revised in collaboration with consumers, carers and health professionals. It will be necessary to provide guidance on how to develop written health information for health promotion.

IMPLEMENTATION CONSIDERATIONS: Written health information content

Drawing together advice from community members and experts in translation, the following is a list of questions or prompts which could inform services in the development of varying written resources, as well as inform the revision of the *Guide*:

Purpose:

- What is the goal of the information material?
- What are the key features linked to that goal that should be covered (e.g. information to enable involvement in decision making, or educational material for self-management)?

Content:

- What does the clinician want to communicate?
 - What information has to be communicated or learned?
 - Why?
 - What is the patient or family required to know or do?
 - What are people's rights and entitlements?
- What do patients or carers want to know?
- Who is the target: patient, carer and/or family? After these categories, consider other important differences such as gender, age, disability, nature of condition
- What are additional, reliable sources?
- Who are the follow-up contacts?
- Sample questions for consumers
- Could provide narrative or selected patient experience information
- Date and authorship.

Social media and new communication media

Some consultation participants said their service needed assistance with social media as a way of providing and seeking information. Issues included: how far to go with platforms such as Facebook or Twitter; how to increase the social media expertise of staff or consumer advocates; and how to ensure social media confidentiality. It was said young people may be more likely to seek out information from their peers. Social media was important in this context.

If no suitable guidance exists for health services on using social media for consumers and carers it should be developed. This should include guidance on how to include patient narratives or experience data on service websites.

Recommendation 14: Guidance on social media

Health services need better guidance on using social media to communicate health information to consumers, carers or the public. This includes guidance on how patient narratives could be used in websites.

Delivering written health information to people

As stated previously a primary issue was that interpersonal communication is the key to health literacy, but needs to be supported by the effective delivery of written health information to people. Both strands were undermined by the pressures of time – meaning the consumer or carer was often overloaded with both verbal and written information at a single point.

This issue would benefit from more investigation because to address it requires services to examine the main points at which patients or carers are handed written information. Services may need to develop a better delivery strategy. High risk areas are one place to start, for example preparatory information for procedures, informed consent, discharge, service coordination and transition (see also Section 3 Recommendation 16).

Some services had reviewed the process by which information was distributed to people and noted that reaching out to the family members as well as the patient could be important because this increased the number of people who knew what was happening.

More attention should be given to why health information is being provided. This also has relevance for how the content is developed.

Recommendation 15: Health information delivery within services

Health services could be encouraged to improve the delivery of written health information.

Health services supporting improved communication between health professionals

Services could ensure that their organisation promotes health literacy through supporting better communication between health professionals, as well as between health professionals and consumers and carers. This was because health literacy was also perceived as an access issue for staff (i.e. enabling clinicians to communicate more easily and effectively with each other). At several workshops participants discussed the importance of systems and training to encourage health professionals to communicate more effectively with each other as a major strand of supporting health literacy to benefit patients.

Notwithstanding the improvements that had been made, the failure to use interpreters was mentioned in several workshops and in one rural workshop it was stated that use was 'rarely promoted'. Health staff should be more aware that in specific communities certain members may control information given to other parties, and so the role of a professional interpreter was critical. Furthermore Aboriginal health workers played a critical role as intermediaries, 'translating' health information into understandable terms.

At the service level there was a range of local initiatives which supported health literacy across the service. Examples were:

- Promoting the use of Ask Me 3 (<http://www.npsf.org/?page=askme3>) or similar prompts to encourage patients or carers to find out more
- Providing new staff with an orientation session which situated health literacy within a risk management context – in recognition of the adverse consequences of communication failures. The service had also developed ‘Five ways to make your words count’ which was a resource provided to all new doctors
- Training staff in the ‘Teach-back’ method
- Organising conference calls with patients or carers and clinicians to overcome distance and availability
- ‘Walk-arounds’ or hospitals tours for people from the community. These could be transformational interventions because they give health professionals direct access to the issues and concerns of the community. This helps clinicians to understand the perspectives and experiences of patients or carers. Exposure to people on tours means staff can recognise ‘frequently asked questions’. This can help them identify key issues or where existing information was missing the mark. It can also benefit community members because it is a less intimidating environment for asking questions
- Having plain English champions at all service sites, or SCOPE-trained staff (<http://www.scopevic.org.au/index.php/site/home>)
- Using the SMOG readability formula to review and change key documents (<http://www.readabilityformulas.com/smog-readability-formula.php>)
- Participating in the OPHELIA Project led by Deakin University to research and develop new interventions to address health literacy needs <http://www.deakin.edu.au/health/research/phi/OPHELIA.php>
- A community collaboration in partnership with Monash University which produced the Enliven Organisational Health Literacy Self-Assessment Tool, in addition to health literacy resources tailored to general practice, allied health and practice nurses (<http://www.enliven.org.au/library.html>)
- Introducing group consultations for men with cancer with the hope that some support groups may emerge organically
- Enabling staff to attend health literacy-specific training (e.g. as provided by the Centre for Culture, Ethnicity and Health, <http://ceh.org.au/training/health-literacy-course->).

Various areas where health services could take action include the following examples:

- Increase content about communication issues in orientation programs for new staff
- Review needs for communication skills training in order to identify where clinical staff feel under-prepared
- Review English-language speaking skills of newly arrived doctors and nurses to see if booster courses are needed
- Integrate training for communication skills into training programs for clinical and ancillary staff
- Promote awareness of online or open access training courses
- Examine strategies for improving communication with vulnerable clients.

Synthesising advice from participating services, a health literacy-promoting organisation or environment for health professionals is one where:

- There is good communication between health professionals
- Team work is promoted and supported, and different qualifications are respected
- Communication skills training is available
- There is appropriate provision and use of interpreters at all times
- Communication tools and varied information resources are readily available.

Helping consumers, carers and health professionals navigate the health system

Participants stated the health system is becoming complex to navigate. People need to occupy specialised roles as navigators or experts on service availability in order to facilitate timely access to services. Participants used 'navigation' as a concept which they applied to assistance with physical movement around a service, and provision of information for staff and patients on services, entitlements and sources of support. It was also used to apply to a liaison role between the patient and family/carers and health and social services.

The role of service navigator could be occupied by health professionals, as well as consumer or carer advocates. Some argued this should become a designated role for health professionals so that other professionals in the service knew who to contact. Health services should consider whether health navigation becomes a more formal staff role, with associated training and recognition.

As described in Section 1, community members are already playing a critical role in assisting consumers navigate services and training for them was requested.

Various databases supported service navigation but participants noted the patchy awareness of these and wanted more information on how to make best use of database content. Resources mentioned included:

- National Health Services Directory (<http://www.nhsd.com.au/about-us>), and the Victorian website, Connecting Care in Victoria (<https://www.connectingcare.com/>)
- Health Translations (<http://www.healthtranslations.vic.gov.au/>)
- The National Health and Medical Research Council Clinical Practice Guidelines Portal (<https://www.clinicalguidelines.gov.au/>)
- The Cochrane Library (www.thecochranelibrary.com).

Refer to Section 1 Recommendation 3 regarding training for community members in health service navigation roles.

Refer to Recommendation 12 above for better promotion of existing navigation aids and databases.

Communication in high risk contexts

There are various contexts where communication is critical to safety and quality. High risk situations included discharge, transition between services, informed consent or information provision post-surgery. A number of poor experiences were presented involving vulnerable people.

These situations are common to many health services and it was argued that key communication processes and documents should be standardised across services, with examples of best practice made available.

Communication in emergency departments was also mentioned as a challenging area. For instance one service said that people called an ambulance thinking they could get into hospital more quickly but this then tied up ambulances and crews. There could be confusion about the requirement for maintaining a resuscitation bed - often empty - upsetting patients who were waiting. Some participants suggested that these issues could be overcome by having someone in the emergency department checking for questions and providing explanation, such as a community volunteer.

Recommendation 16: Audit the entry and exit documents associated with high-risk situations

An audit should be conducted of communication practices and of key healthcare entry and exit documents, focusing on common and high risk tasks. This should be performed with the aim of developing core competencies and standardised documents which can be tailored by all services.

Equity and diversity at service level

Concern was expressed that currently more attention is paid to responding to the health information needs of those who can communicate well, who are already well-read and who can act more easily on health information. People who face barriers in reading or being understood do not have their needs met. Furthermore inadequate information was collected about the carer, such as primary language of the carer, and this could impact adversely on subsequent communications.

Participants noted that addressing health literacy challenges will require that health services:

- Work in partnership with their community members
- Understand who are the users of their services and what barriers they face
- Identify who is most in need and consider how to prioritise actions
- Identify how the service will meet the needs and formulate a change strategy
- Communicate with or link to relevant external community organisations.

Other stakeholders: community organisations and networks

The consultations were attended by many people with an interest in health literacy but who were not part of the Victorian publicly-funded system.

This included people from:

- Agencies such as Medicare Locals (to become Primary Care Networks)
- Non-government agencies, such as health or disability groups or foundations
- Educational institutions which train health professionals at a tertiary level
- Other government departments (e.g. Education)
- National bodies, such as Australian Commission for Safety and Quality in Health Care, the Australian Health Practitioner Regulation Agency, and the Australian Government Department of Health.

The following section therefore addresses the issues raised by these parties, where not elsewhere discussed, and makes suggestions for closer collaboration.

Organisations in the community are playing a critical role in addressing different aspects of health literacy and health information but this is a very under-developed area in terms of policy and coordination. Organisations include the publicly-funded Primary Care Partnerships (PCPs), but also nationally-funded Medicare Locals, health- or disease-specific non-government organisations and smaller community agencies. All were keen to play a greater role in improving health literacy.

These organisations could be enlisted to support initiatives at the state-wide or service level by forming better connections between their activities and services, between each other, and into state-level policy and advisory structures. Links to general practice are particularly critical. For example there was a lot of discussion around the role of GPs, given the fundamental role they play at the primary care level. They were considered a 'trusted source' of information but for some community health services, effective linkages had proved problematic.

Community organisations are perfectly placed to share resources and evidence-based research on health literacy. Most have regular newsletters with a broad readership of health professionals, program officers and other community agency employees.

Many Medicare Locals and PCPs are already doing work on health literacy, including developing tools to assist health professionals and health services become more health literate. Each of these organisations could potentially work together or develop working groups, share their knowledge and discuss enablers and barriers to incorporating health literacy-related material. Of considerable importance is for these organisations to work together to prevent duplication of tools and resources, which was a concern.

One of the main roles of organisations at this level is training. Medicare Locals, for example, focus a lot of resources into providing accredited Continuing Professional Development. These agencies could start incorporating health literacy tools, like Ask Me 3 or the 'Teach-back' method, into each training session provided.

Training which is more accessible for people outside metropolitan areas is needed. This includes online modes (e.g. using video or Skype-based teleconferencing).

Community members involved in PCPs, Medicare Locals or non-government agencies could be asked to assist in identifying gaps, commenting on health information or volunteering for various roles. For instance a number of Medicare Locals had developed initiatives to gather the names of people who wanted to volunteer or had assembled resources to aid service navigation.

Coordinating mechanisms could include widening the membership of policy advisory committees, supporting better coordination between agencies in the community sector through regular meetings, or facilitating communication between agencies such as PCPs and state or national non-government agencies.

Learning from each other and evaluation

If people are asked to give feedback on what is wrong with a service or the system, it is important to tell them what has been done in response to their feedback and why. Participants endorsed the valuable process of asking patients, carers and community members about the problems associated with health literacy and then acting on them together. More research is needed on what patients and families want in order for them to be health literate.

Health service personnel said they needed more advice on how to evaluate their initiatives. It was suggested that partnerships with universities from the beginning would aid this process. Several important collaborations with universities were described. There was support for more promotion and dissemination of information about the evidence base of strategies.

After the introduction of a policy, it was noted that it is valuable to continue to provide educational and exchange opportunities for health professionals and community members in regions. This helps to embed and build initiatives and share information about effective strategies.

SECTION 4: CONCLUSION

Health literacy is a multi-faceted concept. Consultation participants highlighted issues across a wide range of areas and proposed numerous opportunities and strategies for change. From analysis and synthesis of the raw material, and subsequent drafting of recommendations, four overarching themes emerged. The 16 recommendations have been reorganised according to these themes to aid discussion and consideration of the next steps.

I. BUILD THE CAPACITY OF CONSUMERS, CARERS AND COMMUNITY MEMBERS TO INFLUENCE THE HEALTH LITERACY AGENDA AND OUTCOMES

Recommendations relevant to this theme are:

State-wide training for community members on health literacy

There should be greater provision of state-wide health literacy training for community members. Training should cover the issue of health literacy and initiatives to improve it. Training should be available and tailored to people participating in health services at service or governance level, as well as for people who are participating in boards or advisory committees of community organisations.

Fostering networks amongst community members

Different mechanisms should be explored for increasing the connectedness of community members and to foster networks.

Education or training for the public on health literacy concepts

Community-based training initiatives could focus more on providing members of the public with strategies to improve their health literacy generally or in specific health encounters.

II. ENHANCE THE COMMUNICATION CAPABILITIES OF HEALTH PROFESSIONALS AND SERVICES

Recommendations relevant to this theme are:

Consumer/carer focussed design principles for promoting good interpersonal communication

Services should adopt the following design principles as the basis of improving health literacy by improving interpersonal communication. Good communication from a consumer or carer perspective is:

- Being listened to
- Being encouraged to ask questions
- Communication without jargon
- Being able to understand the health professional
- Being understood culturally and linguistically
- Having the information to know what to do, when, and not being bombarded with information (verbal and/or written) at one instance

- Having health professionals check information needs as care progresses, taking into account health status and the needs of accompanying carers
- Being provided with consistent messages
- Being directed to reliable sources of additional information or support
- Having health services and professionals communicate effectively with each other about the consumer, carer or family.

Communication skills training for health professionals and healthcare workforce

There should be an expansion in, and promotion of, accredited communication skills training for health professionals and members of the healthcare workforce, taking into account the diversity of training needs, purposes and modalities.

III. SYSTEMATISE THE DEVELOPMENT AND PROVISION OF HEALTH INFORMATION

Recommendations relevant to this theme are:

Enhancing the Better Health Channel

The Better Health Channel website should continue to be strengthened to be the authoritative and proactive source of health information. It should provide information in layered formats (i.e. levels of complexity) and recommend additional websites, with links to visual or audio materials. It should address misinformation and ensure that it is proactive on health promotion and illness prevention.

Infrastructure to support improved provision of written health information

An appropriate website should be established for developers of written health information. This could include the following resources and features:

- Health information templates, and open source symbols, artwork and resources. This would include a library of brochures which can be tailored by health services (e.g. adding logo)
- Resources in multiple formats (e.g. written, audio, pictorial)
- A set of agreed definitions or uses for common terms, so that use and translation is standardised
- Audited and approved key documents, signage and instructions
- Information about online, open access training for health professionals on developing written health information
- Information about communication skills trainers and their expertise
- Evidence on health literacy initiatives, including evidence, case studies, and examples of good practice. The assessment of good practice should involve consumers, carers and health professionals
- Materials with no copyright (e.g. evaluation surveys)
- Information about other databases for service navigation.

Revision of the Guide for Well-Written Health Information

Guidance in the Communicating with Consumers Series, *Well-Written Health Information: A Guide* (2000), should be revised in collaboration with consumers, carers and health professionals. It will be necessary to provide guidance on how to develop written health information for health promotion.

Guidance on social media

Health services need better guidance on using social media to communicate health information to consumers, carers or the public. This includes guidance on how patient narratives could be used in websites.

Health information delivery within services

Health services could be encouraged to improve the delivery of written health information.

Audit the entry and exit documents associated with high-risk situations

An audit should be conducted of communication practices and of key healthcare entry and exit documents, focusing on common and high risk tasks. This should be performed with the aim of developing core competencies and standardised documents which can be tailored by all services.

IV. IMPLEMENT POLICIES AND SYSTEMS TO IMPROVE VICTORIANS' HEALTH LITERACY

Recommendations relevant to this theme are:

Definition of health literacy

The Department of Health Victoria should adopt the following revised definition of health literacy: Health literacy means people can obtain, understand and use the health information and services they need to make appropriate health decisions. Healthcare providers and the health system should provide information and improve interaction with individuals, communities and each other to respond to and improve health literacy.

Principles to underpin future health literacy actions

The following principles should be adopted as the basis of future action:

a. Principles relevant to consumers, carers and community members

- Health literacy is an asset which can be built. The deficit approach to health literacy (i.e. one which sees it only as a problem with individual consumers) should be avoided
- Efforts to improve health literacy should have an equity focus and address those consumers and carers most in need but with approaches which are relevant to all people
- Strengthen the role of community members in supporting actions for improving health literacy in services, the community and Department of Health Victoria
- Support lifelong learning in the population in response to health needs and challenges at different life stages.

b. Principles relevant to health professionals

- Communication and the exchange of information must be a central and not a peripheral feature of health culture, systems and services
- Support career-long learning of communication skills amongst health professionals.

c. Principles relevant to healthcare organisations and systems

- Health literacy should be improved by people working in partnership at all levels. It is a shared concern of consumers, carers, community members, health professionals and health organisations
- Improving health literacy will require a shift in culture. Leadership will be needed for changes to be initiated and sustained
- Improving health literacy will require the development or enhancement of systems which support people or services to address health literacy.

Cultural responsiveness

Actions to promote health literacy must aim to overcome the disadvantages and barriers experienced by many groups and should accord with the Department of Health Victoria's policy on cultural responsiveness.

Health literacy and Consumer Participation policy

Health literacy actions should be integrated into the new Consumer Participation policy.

Health literacy systems-level infrastructure

It is recommended that actions to support health literacy:

- Build on existing policies, programs, infrastructure and resources, many of which may have a health literacy element
- Adopt a standards approach to written health information provision, communication skills and communication skills training so that improvements are uniform, tangible and measurable
- Foster efficient use of resources through the provision of open access, core resources and templates which can be tailored
- Promote the sharing of resources and the exchange of evidence, experience and best practice
- Increase opportunities for community members to play a skilled role in promoting the health literacy of others
- Foster partnerships and partnership models between community members, health professionals and health services at all levels
- Develop a stepped approach for health services to integrate health literacy initiatives into their systems
- Respond to the fact that population and health professional diversity is not currently recognised in health information or communication skills training.

APPENDIX 1: HEALTH INFORMATION AND HEALTH LITERACY SUBCOMMITTEE MEMBERSHIP

Members of the Health Information and Health Literacy Subcommittee, a subcommittee of the Participation Advisory Committee included: consumers; health services staff; and Department Health Victoria staff from across acute health, community health and aged care, Aboriginal health, and the Better Health Channel.

Members were: Sophie Hill; Darren Clinch; Cath Harmer; Tanya Hendry; Catherine Herman; Lidia Horvat; Maureen Johnson; Kirsten Phillips; Jayne Power; Natalie Ross; Evelyn Webster.

A copy of *Health Literacy: Enabling Communication and Participation in Health, Background Paper* (2013), can be found at: <http://docs.health.vic.gov.au/docs/doc/Health-literacy-enabling-communication-and-participation-in-health>.

APPENDIX 2: CONSULTATION PARTICIPANTS

Consultation participants were diverse and inclusive of:

- Individual consumers, carers and community members
- Consumer representatives and members of Community Advisory Committees
- Consumer groups
- Health services
- Health professionals and other staff members
- Community health centres
- Non-government organisations, agencies and foundations
- Ethno-specific organisations
- Health specific condition organisations
- Department of Health Victoria and other government departments
- Victorian Aboriginal Community Controlled Health Organisations
- Medicare Locals (to become Primary Care Networks)
- Primary Care Partnerships
- Educational institutions.

