HEALTH
ISSUES
CENTRE
Victoria's Health Consumer Organisation

Submission on

'Consumers, the health system and health literacy: Taking action to improve safety and quality'

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EXECUTIVE SUMMARY

The importance of consumer engagement in health—both at the individual level and in the overall provision of health services—has been widely acknowledged in recent years. With this growing understanding has come a greater focus on the role of health literacy in achieving the best possible health outcomes.

Given that increased awareness, Health Issues Centre applauds the Commission's efforts to coordinate the approaches to health literacy within Australia and, specifically, we value the opportunity to comment on the current consultation paper.

The scope of health literacy is now generally accepted as encompassing more than the ability of consumers to read and understand health information. Thus, we endorse the Commission's broader definition which includes both 'individual health literacy' and 'the health literacy environment' in the discussion. We strongly support the notion that a consumer's ability to 'access, understand, appraise and apply health information' is significantly impacted by the health environment surrounding them ('the infrastructure, policies, processes, materials and relationships….') (ACSQHC 2013: 5).

However, we believe there are fundamental limitations to the current understanding of health literacy which we will outline in this paper and list below:

- **<u>Definitions:</u>**
  The term 'health literacy' focuses the issue squarely on the consumer and their perceived ability (or, more commonly discussed, inability) to interact effectively with the healthcare system. This focus on a 'consumer deficit model' assumes that up-skilling and motivating consumers will solve many of the system's difficulties. This definition, thus, greatly underestimates the obstacles that the healthcare system presents for consumers, while at the same time underestimating the responsibilities of health professionals and health services.

- **<u>Terminology:</u>**
  We acknowledge the attempts in the consultation paper to address the potential inaccuracy of the term 'health literacy' by splitting the discussion into 'individual health literacy' and 'health literacy environment'; however, this is not enough. It is necessary to shift to a more accurate term. We recommend a change of terminology from 'health literacy' to 'health engagement' or 'health communication and participation'. This would allow greater freedom to address the systemic issues preventing consumers from fully engaging with the health system.

- **<u>Patient centred care is the appropriate context:</u>**
  We believe that person and family centred care provides the best overall context for health literacy to succeed. Any discussion or plan for a national approach to health literacy needs to build on the foundation of person and family centred care which must be the aim of health services across Australia.

- **Consumers must be central to a coordinated approach:**
  All structuring of a coordinated approach to health literacy must consider how consumers will be involved in the thinking, planning, development, and embedding of any changes to health literacy. The concept of 'nothing about me without me' must be upheld in health literacy planning and coordination. This is not a point which is strongly made in the consultation paper.

- **Power relationships and human rights:**
  The importance of power relationships in the area of health literacy is not acknowledged in this paper. The feeling of 'powerlessness' is one of the most common themes found in patient experience and narrative. The impact of this powerlessness on the ability of consumers to access, understand, evaluate and apply health information—as well as navigating and accessing health services when and where they need them—should be explored and suitable recommendations put forward. This discussion needs to be framed within a human rights-based approach to health.

- **Education and training of consumers and health professionals:**
  Progress in improving health literacy will be made more quickly with a shift to understanding this as an area of dual responsibility. Both health professionals and consumers need support and training. The most effective approach to this will involve greater use of the skills, knowledge and experience of consumers, a much under-utilised resource. This paper provides an opportunity to endorse the value of consumer peer-training and consumer-delivered training for health professionals.

- **Positive reframing:**
  The overall health literacy discussion needs to be reframed in a more positive direction. Currently the debate focuses heavily on the lack of health literacy and the negative consequences of that lack, rather than looking at the potential gains to be achieved and a presentation of positive role models. This might consist of educational campaigns showcasing engaged consumers and the benefits for them and the healthcare system as a whole. Among many health professionals there remains scepticism, and often fear, of engaged and active health consumers (e.g., 'the professional patient', 'the expert consumer').

- **Target audience:**
  We suggest that thought needs to be given to whether or not health consumers are part of the target audience for this paper and any subsequent publications. If so, modification to language and content are required. If not, thinking needs to be done to determine how consumers will be involved in the consultation process.

- **Towards a policy framework**
  Part B outlines an approach to an integrated health literacy policy framework based on the principles outlined here.

- Health literacy is about health information and participation
- Health literacy needs to be considered in a person centred health care approach
- Health literacy concerns issues of power sharing and human rights
- Health literacy should be considered in a positive framing and not as a ‘consumer deficit ‘

It proposed that health literacy policy should have as its aim better health outcomes though active consumer participation in health where informed consumers are empowered to make decisions about their health, knowing that however they obtain the information they need, they will be respected participants in health decisions, supported in their information needs and rights to decision making by policies, regulations, system design, health services and individual clinicians.

CONSUMER INVOLVEMENT IN OUR SUBMISSION

Health Issues Centre aims to represent the voice of consumers in health issues across Victoria. The organisation promotes improvements to the health care system from the perspectives of consumers, with an emphasis on equity, as well as promoting and providing expertise on consumer participation in health. It is through this lens that we are responding to the Commission's consultation paper on health literacy.

In preparing our response, we asked a small group of experienced consumer representatives to read the submission and attend a two-hour discussion session. The results of that session are summarized in this document; we have on all occasions attempted to represent the voice of these consumers in our response. This submission is also influenced by the organisation's thirty years of experience and expertise of addressing health consumer issues.

RESPONSE

Definitions:
The health literacy debate remains heavily focused on the level of literacy required by an individual to enter or participate in the health system. This premise ultimately places the responsibility (and often the blame) on the consumer rather than equally addressing the systemic issues that prevent full participation by consumers.

There are several clear difficulties with such an approach. First, the 'consumer deficit model' makes the assumption that the solution lies in simply providing education and motivation to consumers. Yet even the most well-educated and motivated consumers are still very often not empowered to make decisions within the clinical setting; they are regularly (usually inadvertently) deprived of key information; they generally lack the in-depth knowledge of the health systems processes to advocate effectively. Thus, they are left woefully lacking in their engagement with the health system.

Second, in focusing heavily on the consumers' responsibilities, the debate largely views the role of health services as needing to overcome the inadequacies of consumers, such as: their lack of formal or health education, lack of English language skills, poor motivation, etc. Yet, from the view of consumers, there are often many inadequacies on the part of health services. For example, failure to translate information for CALD groups; education materials presented in convoluted, jargon-heavy language; health services offered in an uncoordinated manner; or insensitive or unprofessional face-to-face communication.

Our recommendation is for a clear shift away from the 'consumer deficit' understanding of health literacy.

Terminology:
One approach for addressing the problems inherent in the definition of the term 'health literacy' is to move to a more accurate term. Given the international use of the current terminology we recognize the somewhat radical nature of such a suggestion. However, the view from our consumers is that the term 'health literacy' limits the discussion unnecessarily.

As stated in the consultation paper, ‘there is currently no consensus about the definition of, or conceptual framework for, health literacy’. The word ‘literacy’ means, by definition, the ability to read and write. In the context of health, the scope of this term has been stretched, squeezed and reshaped to try to cover all of the factors that affect the way consumers relate to the health system and the resulting outcomes (ACSQHC 2013: 11).

The consultation paper attempts to address the limitations of the term by dividing the discussion into ‘individual health literacy’ and ‘health literacy environment’. This is a step in the right direction, but ultimately any conversation that focuses on ‘literacy’ is fundamentally about the abilities of the health consumer to read and digest health information. If the goal is full participation by consumers, and if we know that the obstacles to this are multi-faceted and rest with consumers and health services alike (as well as the system), the name must reflect this.

Our recommendation is to consider a term such as ‘health engagement’ or ‘health communication and participation’. This would allow greater freedom to address the variety of issues preventing consumers from fully engaging with the health system.

Patient centred care is the appropriate context:
As we have already stated, we believe that health literacy is a complex issue which is influenced by many factors. Thus, it needs to be situated within a model of healthcare which can lay the groundwork for patient engagement. Person/patient/consumer and family centred care does just that.

While patient centred care was mentioned in the consultation paper as a related concept (ACSQHC 2013: 9), we recommend that this be taken much further, establishing patient/person and family centred care as the best context in which to progress issues of health literacy.

The four key principles of patient/person and family centred care are: respect and dignity, information sharing, participation and collaboration. These principles set out an approach to healthcare which fits perfectly with the aims of health literacy; it is important that they be included in a final version of the paper.

The patient-centred approaches provides a clear cultural shift away from system-centred services to those that revolve around the needs of the patient/person and family, working together with the consumers to provide the best quality, safety and outcomes possible. As mentioned in the consultation paper, worldwide evidence is indeed building about the strength of patient/person and family centred care as a means to safer healthcare and more satisfied patients.

Our recommendation is that patient/person and family centred care is endorsed as the appropriate approach for progressing health literacy.

Consumers must be central to any coordinated approach:
We strongly support the Commission’s emphasis on developing a coordinated approach to health literacy across Australia. A national approach, such as the National Action Plan to Improve Health Literacy developed by the US Department of Health and

Human Services, could provide the impetus and clarity that has been lacking across the somewhat muddied waters of health literacy(ACSQHC 2013: 19).

However, and this is an absolutely vital point from our perspective, consumers need to be at the heart of any coordinated national approach. In our opinion, running a series of state-based focus or consultation groups with consumers is not sufficient. It requires, instead, that consumers be embedded in the decision-making process (the committees, boards, etc.). They need to be involved in the thinking, planning, development and roll-out of a national health literacy framework/plan. Without this consistent, clear consumer input throughout the process, the plan will be less appropriate, effective and consumer-centred than it should be.

Our recommendation is for a very strong consumer presence across all aspects of a coordinated approach to health literacy.

Power relationships and human rights:

The relevance of power in healthcare relationships is often quoted as an important issue for consumers, but rarely by health professionals (unless they are referring to power and hierarchy issues within the profession). A feeling of powerlessness could be described as endemic among consumers within the health system. ‘Empowerment’ and a human rights-based approach to health need to be key concepts linked to health literacy.

The issue of power relationships links back to our initial point in this document about the definition and understanding of health literacy and the roles and responsibilities of both consumers and health professionals in bringing about tangible improvements. In order to progress health literacy, any foundational document needs to acknowledge the imbalance of power in healthcare relationships and embrace the human rights-based approach to health, which aims to address this imbalance.

Unfortunately, for most consumers, even when they have been given full information and developed their health literacy to a high level, they are still generally not empowered to make many decisions about their care within the clinical setting. While there may sometimes be good reasons for this, there are also times when this disempowerment is largely the result of traditional systems and approaches to medicine which are not based on a partnership/patient centred model.

We recommend that formal attempts to address this disempowerment need to be built into any national framework for health literacy.

Education and training of consumers and health professionals:

Health Issues Centre strongly agrees with the consultation paper’s emphasis on the need to provide education and training in health literacy to both consumers and health professionals (ACSQHC 2013: 34-38). We particularly agree with the paper’s broad perspective on the need to train all members of the health service staff—such as executives, managers, receptionists and ward clerks—about health literacy and the value in providing an environment that is patient centred and accessible to patients in every way.

We support embedding health literacy across a variety of education media and would especially support a greater emphasis on training in self-advocacy. Significant progress could be made by embedding simple concepts across society, such as: bringing questions to appointments with health professionals, learning to keep track of your medications, it’s okay to ask for a second opinion, bring a friend or family member to support you with a new diagnosis.

Traditionally, training consumers in health literacy has been viewed as largely the responsibility of health professionals. We argue that improving health literacy needs to be a coordinated effort between diverse sectors of society, including the education system, media and the health sector. Furthermore, we advocate for an increased exploration of the benefits of peer education. As peer support networks grow, and evidence builds for the value of peer support in improving health outcomes (such as in self-management initiatives and mental health peer work models), this is an obvious direction to pursue.

With regards to training health professionals in understanding the core concepts of health literacy and their critical role in its success, we support a consumer-led education and training program for health professionals. Consumers see the patient experience through a different lens and are able to bring ‘insider knowledge’ to the issues and obstacles to improving health literacy. Their perspective on the importance of issues like interpersonal and communications skills would be of tremendous benefit for training programs.

We also strongly advocate for the involvement of consumers in the development or review of existing health information. There is Cochrane level evidence that involving consumers in the development of health information results in better, more user-friendly health information (Nilsen, et al 2012). Involving consumers in the development and design of information about health services, health service directories and websites may prove extremely beneficial.

We recommend the exploration of peer training for consumers in health literacy. We also recommend strong consumer involvement in the design, delivery and evaluation of health literacy training for staff (clinical and non-clinical) at all levels of health services, and in the development and design of health information.

Positive reframing

Our response has already outlined the need for a re-defining of the issues and terminology of health literacy. In speaking of ‘positive reframing’ we are referring to the need to bring about a cultural shift—among health professionals—but also in the wider society that highlights the benefits of consumer involvement in healthcare.

Among health professionals there is, thankfully, a growing acknowledgement that health literacy is essential for achieving the best outcomes. With that, is coming a greater acceptance of the importance of consumer involvement and knowledge at the individual level. Though, it must be said, there remains significant concern in areas such as consumers accessing information about health issues and conditions from the internet. The reality is that consumers *do* and *will* search for information on their own; the most useful thing is for health professionals to advice and direct that search (e.g., by directing consumers toward good sites and away from non-evidence-based ones, and by encouraging them to seek help with interpreting the information). There is also still an unwillingness to embrace consumer involvement at the organisational level; that is, the involvement of consumers in the governance, planning, design and delivery of services.

Society-wide there has not been a strong campaign or educational movement to emphasise the value of becoming involved in and knowledgeable about your health. There has been great progress in the area of health promotion (risks of smoking, benefits of exercise and healthy diet); this needs to be extended to include self-advocacy and involvement in one's interactions with the health system.

We recommend a strong push toward a positive message campaign promoting consumer involvement in health.

Target audience:

Our final point here relates to the target audience for this paper and subsequent publications. Our assumption is that this paper was not targeted at health consumers. If consumers are meant to be part of the target audience for future, related publications, we believe that the language and use of health-related jargon and terminology need to be modified significantly. If consumers are not part of the target audience, then we recommend that serious thought be given to how consumers will be reached for consultation and involvement in the ongoing process. If consumers are not consulted throughout the development of a coordinated approach to health literacy, we believe that the result will be disappointing for the advancement of health literacy in Australia.

PART B “IF PEOPLE WERE MORE HEALTH LITERATE…..” TOWARDS DEVELOPING A HEALTH LITERACY POLICY FRAMEWORK

While we appreciate the efforts of the discussion paper to move away from the ‘consumer deficit’ concept of health literacy by distinguishing individual health literacy and the health literacy environment, we think it would be useful to use a type of program logic approach to map out the key policy component of health literacy, see where there are supporting policies and initiatives and where the gaps are, and basically see the issues on a policy map which needs to be completed. This provides a more integrated approach to considering health literacy rather than trying to balance separate issues of individual and system health literacy. We have outlined a preliminary sketch of what this could look like as a trial of the concept.

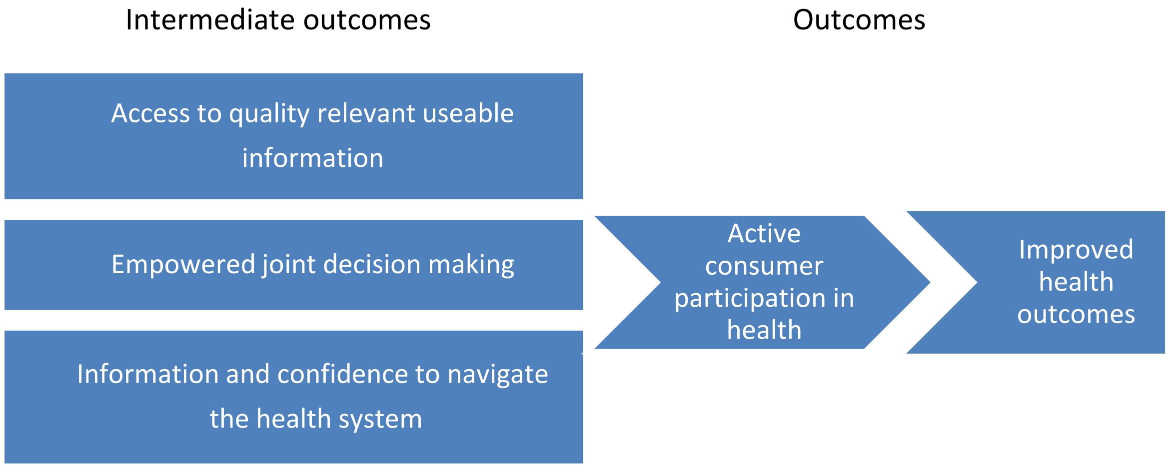
In the first instance one would look at what are the outcomes (including intermediate outcomes) that we are trying to achieve through health literacy. This is mapped out below. This is an approach to health literacy based on consumer perspectives. Health services often voice alternative desired outcomes, eg better health literacy will mean fewer consumers using Emergency Departments for primary health care type services.

While the various academic attempts to define health literacy are infinitely nuanced in different ways, we might think about what a health literacy policy definition might look like. It might look like this. Health literacy policy has as its aim better health outcomes though active consumer participation in health where informed consumers are empowered to make decisions about their health, knowing that however they obtain the information they need, they will be respected participants in health decisions, supported in their information needs and rights to decision making by policies, regulations, system design, health services and individual clinicians.

This mapping of outcomes is based on the principles outlined in our submission:

- Health literacy is about health information and participation
- Health literacy needs to be considered in a person centred health care approach
- Health literacy concerns issues of power sharing and human rights
- Health literacy should be considered in a positive framing and not as a ‘consumer deficit ‘

Figure 1 Health literacy outcomes



The next step is to think about activities required to achieve this. This list is indicative rather than comprehensive.

Figure 2 Health literacy enabling activities

Availability of good quality health information*	Development processes Ongoing review processes Different formats and levels of information Methods of access Positive approach to internet information finding Access to guidance on good search approaches and reliable sites Translated and disability friendly materials
Support for shared decision making	Involvement in decision making Health information support for decision making Confident consumers aware and supported in own rights Communication that support joint decision making Communication that understands consumer's Information requirement and communicates accordingly (literacy, special requirements, etc) Access to second opinions Public campaigns to increase awareness
Supportive environments	Person and family centred care Cultural competence Investments in availability of health information On-site health information resources and spaces Understanding of different ways consumers access and use health information used to design health information - these may include oral and community based approaches Positive public education messages about the benefits of health information and participation in health

	Person centred informed consent focused on the informed consumer not the signature Use of health literacy surveys to co-design health service health literacy related programs (see Appendix 1)
Navigating health care	Accessible health care Simplified access to health to make navigation simple and person- not system-centred Personally controlled electronic health records

* Criteria for developing, appraising and adopting consumer health information need to be based on criteria that include its evidence base, its information relevance to consumers and the involvement of consumers in developing the information (and not just asked to comment on the final draft). This gives consumers the type of information that allows them to make decisions. Much consumer health information is simply not like this. It translates information about the topic into various version of lay language. It is essentially information about conditions or treatments, not information that informs consumers about their choices and decisions.

What resources are required to enable this?

Serious investment in health information, funding, people and time

Resourcing consumer organisations to promote health information and participatory approaches and to support and provide training for consumers

A framework and strategy to develop more coordinated approaches to the development of quality consumer information across the variety of levels, purpose, formats and modes of access

Requisite education and training of health professionals in person and family centred health care and participatory health care, including consumer lead training. This includes training and education in communication and interpersonal skills that supports shared decision making

Deep consumer involvement in developing health literacy policies, frameworks and initiatives at all levels from initiation to evaluation and resourcing of this

APPENDIX A WHAT DO CONSUMERS THINK IS HEALTH LITERACY

Richard Osborne and colleagues (2013) undertook research with consumers on what they identified as health literacy from consumers' points of view.

This includes:

- Feeling understood and supported by healthcare providers;
- Having sufficient information to manage my health;
- Actively managing my health;
- Social support for health;
- Appraisal of health information;
- Ability to actively engage with healthcare providers;
- Navigating the healthcare system;
- Ability to find good health information; and
- Understand health information well enough to know what to do.

This was used to develop health literacy survey which is the basis of the Ophelia project, a three year Victorian initiative that aims to identify and test interventions to address health literacy needs in people attending a broad range of Victorian agencies. It is funded by the Australian Research Council, in partnership with the Victorian Department of Health and Monash University.

Ophelia provides organisations with a structured approach to recognise, understand and respond to the health literacy needs of members of their community. The project's aims are to improving health outcomes and reducing health inequalities.

Ophelia measures the different needs of clients/consumers using the Health Literacy Questionnaire, which captures client's experience, views and capabilities across nine dimensions. This is followed by the collaborative development and testing of new interventions to tackle health literacy issues at the practitioner and service level.

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