

How could health information be improved? Recommended actions from the Victorian Consultation on Health Literacy

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Abstract

Objective. Health literacy is on the policy agenda. Accessible, high-quality health information is a major component of health literacy. Health information materials include print, electronic or other media-based information enabling people to understand health and make health-related decisions. The aim of the present study was to present the findings and recommended actions as they relate to health information of the Victorian Consultation on Health Literacy.

Methods. Notes and submissions from the 2014 Victorian Consultation workshops and submissions were analysed thematically and a report prepared with input from an advisory committee.

Results. Health information needs to improve and recommendations are grouped into two overarching themes. First, the quality of information needs to be increased and this can be done by developing a principle-based framework to inform updating guidance for information production, formulating standards to raise quality and improving the systems for delivering information to people. Second, there needs to be a focus on users of health information. Recommendation actions were for information that promoted active participation in health encounters, resources to encourage critical users of health information and increased availability of information tailored to population diversity.

Conclusion. A framework to improve health information would underpin the efforts to meet literacy needs in a more consistent way, improving standards and ultimately increasing the participation by consumers and carers in health decision making and self-management.

What is known about the topic? Health information is a critical component of the concept of health literacy. Poorer health literacy is associated with poorer health outcomes across a range of measures. Improving access to and the use of quality sources of health information is an important strategy for meeting the health literacy needs of the population. In recent years, health services and governments have taken a critical interest in improving health literacy.

What does this paper add? This article presents the findings of the Victorian Consultation on Health Literacy as they relate to needs, priorities and potential actions for improving health information. In the context of the National Statement for Health Literacy, health information should be a priority, given its centrality to the public's management of its own health and effective, standards-based, patient-centred clinical care. A framework to improve health information would underpin the efforts of government, services and consumer organisations to meet literacy needs in a more consistent way, improving standards and ultimately increasing the participation by consumers and carers in health decision making and self-management.

What are the implications for practitioners? The development and provision of health information materials needs to be systematised and supported by infrastructure, requiring leadership, cultural change, standards and skills development.

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Introduction

Health literacy is on the policy agenda. The National Statement on Health Literacy defines health literacy as comprising individual health literacy and a supportive health literacy environment.¹ Efforts in Australia and internationally to improve health

literacy^{2,3} are increasingly focusing on factors at different levels, from individual to societal, to ensure access to information that is understandable and facilitates health-related decisions and actions.^{1,3} Therefore, health information is a major component of health literacy.

In Victoria (Australia), health literacy was the focus of a Consultation on Health Literacy, initiated in 2014 by the Department of Health (now Department of Health and Human Services) and held in the context of a departmental evaluation of its consumer participation policy.⁴ In this article we report on the Consultation findings⁵ as they relate to health information. We outline the needs and priorities raised by those consulted, and the range of proposed actions to address shortcomings in access to and the use of quality health information. We discuss the recommended action areas within the context of Victorian and national developments.

Definition of health information

'Health information' is a poorly defined term with no clear bounds.^{2,6–8} It has been defined as 'any information that enables individuals to understand their health and make health-related decisions for themselves or their families'.⁷ Aligning our definition with national terminology,¹ 'health information' as discussed here refers to health information materials in different formats or media, including print, online or other health-related media (e.g. audio, signage). Therefore, this all-encompassing definition includes information for all health-related purposes: health promotion, protection, disease prevention, health care decision making and maintenance, as well as systems navigation.^{9–11} Interpersonal communication (i.e. where information is communicated verbally) is not discussed here because it emerged in the Consultation as a related yet necessarily distinct issue associated with recommendations to improve the communication skills of health professionals.⁵ However, the systems and process of making health information materials available to patients and carers is discussed.

Effects and importance of health information

Health information is critical to the health of the population and to effective health care. Health information, as a core component of health literacy, is commonly viewed as one way of reducing health disparities.^{2,11,12} Low health literacy is associated with poorer outcomes across a range of health status and usage measures, with higher costs for individuals and society as the result.^{2,11,13} Victorian research confirms this association.¹⁴

Health information is an intervention and its effect is discernible across a wide body of research. Quality health information promotes involvement in decision making, has a positive effect on health behaviours, enhances knowledge and recall and improves the health care experience.^{8,15} Health information tailored for populations with lower health literacy, such as materials featuring images or interactive software, have been found to have positive effects on consumers' knowledge acquisition and comprehension.¹⁶ Health information is essential to informed consent interventions¹⁷ and is an essential component of many other more complex interventions, such as decision aids,¹⁸ personalised care planning¹⁹ and a wide range of interventions for safe and effective medicine use.²⁰

Health information is a central element to national and Victorian health policy and service improvement frameworks, including the National Safety and Quality Health Service (NSQHS) Standards²¹ and Victoria's Health 2040²² blueprint for system change for person-centred health care and evaluation

of its existing consumer participation policy.⁴ Evaluators KPMG concluded that 'well written health information, web-based information sources, virtual support, and tailored information for groups with low levels of health literacy'²³ underpin a recommendation for strengthening involvement of consumers, carers and community members, as well as being related to recommendations on responsiveness to diversity and ongoing learning.

Therefore, quality health information is crucial to enabling the participation of consumers and carers. It is a critical component of efforts to improve health outcomes through a national digital platform for health information, navigation advice and help-lines,²⁴ to meet national goals in patient-centred care,²⁵ to promote equitable access to effective treatments²⁶ or to address misinformation.²⁷ It is central to rights,^{28,29} as well as actions for redress.³⁰

A nationwide stocktake of health literacy initiatives revealed 47% focused on health information,³¹ part of a surging interest in health literacy, signalled by the introduction of the National Statement on Health Literacy.¹

It is therefore timely to present the issues with health information from one state and consider the implications of recommended actions for improvement.

Methods

In 2013, the Department of Health Victoria released a background paper¹¹ to stimulate thinking about the gaps, barriers and enablers for health literacy within the health system, focusing on the role of publicly funded health services. This background paper outlined a series of questions related to key health literacy needs and priorities for individual consumers, carers, communities, health professionals, health organisations and systems. During 2014, it was used as the basis for a consultation, with workshops around the state and a call for submissions. Workshop notes and submissions were analysed thematically and a report with recommendations was prepared with input from an advisory committee (for more detail, see the report⁵).

Results

Consultation participants commented on a health literacy definition¹¹ and requested more action-orientation. The result (emphasis added) was:

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.⁵

Achieving these goals would be met if initiatives were informed by a comprehensive set of principles (see Table 1). Those most relevant to improving health information are Principles 1 and 3. Principle 1, relevant to consumers, carers and community members, specifically frames health literacy as an asset to build and emphasises the importance of an equity approach within a context of meeting all needs. Regarding Principle 3, relevant to healthcare organisations and systems, attention was drawn to the need for leadership to promote a shift in culture (i.e. towards greater recognition of the importance of health information) and

Table 1. Principles to underpin future health literacy actions

The Victorian consultation report⁵ recommended the following principles should be adopted as the basis of future action

Principles relevant to consumers, carers and community members
<ul style="list-style-type: none"> • Health literacy is an asset that can be built; the deficit approach to health literacy (i.e. one that 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 that 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 and Human Services Victoria • Support life-long learning in the population in response to health needs and challenges at different life stages
Principles relevant to health professionals
<ul style="list-style-type: none"> • Communication and the exchange of information must be a central, not a peripheral, feature of health culture, systems and services • Support career-long learning of communication skills among health professionals
Principles relevant to healthcare organisations and systems
<ul style="list-style-type: none"> • 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 that support people or services to address health literacy

for the development or enhancement of systems to support change.

The principles, it was argued, should be used to inform new initiatives or the modification of existing systems when responding to the range of problems that consumers or services were facing. Various, often contradictory, problems were described by consultation participants, such as: health information in the public realm is of highly variable quality; the public is bombarded by health information, but there was little public education on how to discern reliable sources; and masses of written information are prepared by, or required in, health services, but the information is often inaccessible to those most in need. Without a coherent and overarching approach, it was felt by consultation participants that the more intractable problems would continue, gaps would remain unaddressed and initiatives would continue to be localised and often duplicative. Therefore, health information needed to improve in order to improve the health literacy of people and to have health-literate systems and services, and actions for improvement had to be developed within a principle-based framework.

At a population level, the Department of Health and Human Service's 'Better Health Channel' website (<https://www.betterhealth.vic.gov.au/>, accessed 6 May 2016) was seen as the most important vehicle for obtaining accessible and authoritative health information. Therefore, continuing to strengthen the site was a recommendation. Key topic areas where the site should have a strong presence included information for preventing illness, information about how to engage in health encounters in an active way and to make treatment choices and information to assist with navigating the health system. Recognising that needs may vary from straightforward to more in-depth, it was suggested information could be presented in layered formats, with recommendations to other quality sites and links to audiovisual or pictorial materials where possible.

Consultation participants, particularly health services, also wanted the health department to be an active presence in mass and

social media; for example, to address misinformation and countering the promotion of non-effective treatments or to strengthen health promotion messaging in key problem areas.

The issue of building people's knowledge and ability to find and appraise quality sources was also picked up in recommendations for training programs in health literacy for community members. There are many people involved in health services and community organisations in volunteer roles. Participants said they were aware of the pressures on health professionals and wanted to be skilled in contributing and assisting others, such as helping people navigate a health service or find relevant services.

One issue was the need for a standards approach to address two inter-related problems: (1) the proliferation of health information producers at service level, many without the skills for the task; and (2) the diversity and complexity of population needs. It was argued that a change was needed to the pervasive attitude that writing health information was something anyone in a health service could do. Developing good-quality health information requires expertise to meet the needs of multiple audiences as well as systems to keep up to date. A related issue is the need to address the gap in straightforward and accessible health information and to recognise that people can become experts in their condition, which may lead to higher expectations for more detailed information.

Health services around Victoria were introducing health information policies and reviewing procedures for developing health information generated within the service. For example, some had invested in building up sophisticated service-wide systems for developing most written health information required, involving a team of staff and community members. Others had adopted a 'train the trainer' approach. Participants said these new approaches created expertise and raised standards.

However, not all could operate in this way, particularly smaller rural services, so centralised systems (e.g. at state level) were recommended for the provision of written health information or templates for high-need topics. This would mean health

information that met prespecified criteria could be produced, enabling translation, production in different media or adaptation for specific service configurations or populations served. This approach was supported because it also reduced the wasteful and duplicative production of information on the same topics within and across services. Victoria already has a program of providing written health information brochures for common medical procedures. Feedback from the workshops suggests that this model may provide a good approach that could be extended to other areas.

Another problematic area was the intersection of the delivery of printed health information to individual patients (or families) with the movement of those patients through the health service. The compounding factors include time pressures on clinicians, and associated throughput targets, as well as the potentially large number of staff, departments or campuses involved in any one treatment episode. A commonly mentioned problem was the overloading of patients with printed materials at one point in the patient's journey. Workshop participants said that this may not be the point where health condition and treatment-related information could be absorbed or future service navigation information be usefully provided or anticipated. Compounding this was the failure of much information to be written in a way that encouraged questions, gave prompts or provided follow-up contacts or reliable sources of information. This meant it was not only hard to absorb, but also that it did not encourage patient participation in care or assist carers with navigating the maze.

One recommendation to address this problem was for an audit of common 'entry' and 'exit' documents where the costs or risks associated with misunderstanding are high. Examples of such documents include procedural preparation, informed consent and discharge advice. An audit may have the potential of leading to accepted standards for key documents and agreement on core information topics and formats for different patient groups (e.g. sight impaired). It may also lead to examination of the processes by which information is made available to patients and the discussion that accompanies these transactions.

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 or media (e.g. culturally appropriate, easy-to-read, pictorial, Braille, audio, multimedia). As a consequence, services wanted more advice on how to decide which different formats or media to invest in.

Similarly, some services wanted 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 health service websites. Some were experimenting with new ways of communicating with the public (e.g. starting Google groups). It was suggested that meso-level health organisations could work with health services and government to develop guidance on issues such as using social media or user content.

In the context of raising standards and providing guidance, participants recommended the seminal Victorian 2000 Guide on how to prepare health information³² be updated and revised to take account of newer modalities of information, address gaps and to promote codesign by consumers.

Discussion

Two overarching themes determined the scope of recommended actions for improving health information. The first focuses on raising the quality of information by developing a principle-based framework to inform: updating guidance for central or service-based information production, the formulation of standards to raise quality and improving the systems for delivering information to people. The second focuses on users of health information, with recommendations for information that promotes active participation in health encounters, resources to encourage critical users of health information and increased availability of information formats and media tailored to diverse population needs.

The development of standards for health information is challenging and may require collaborative leadership, such as that taken by the Australian Commission on Safety and Quality in Health Care on the overarching issue of health literacy. Consultation participants wanted to see links between any new standards for health literacy-related initiatives with NSQHS Standards and accreditation requirements so that improvements are consistently applied and benefits measurable.

The systematising of health information production and the formulation of standards for the different purposes of health information (described above), and the different types, content, format, media and delivery of information interventions³³ would be a major policy initiative replete with questions around scope and priorities. However, without standards or a guidance-based framework, improvements will continue to happen in an *ad hoc* way and the current level of costly duplication will continue, while smaller organisations or particular populations of patients could be disadvantaged or neglected.³⁴ The implication of developing standards and guidance is that locally developed solutions become more feasible (i.e. at service level) as the parameters are clearer.^{35,36}

A focus on standards (and the skills for preparing health information) may indirectly benefit non-governmental organisations, which are major providers of health information.⁸ Furthermore, a standards approach could be used concurrently to inform training programs for community members (e.g. building skills in recognising what makes quality information) and may address some elements of the emerging issue of health literacy competencies for health professionals.^{37,38} Other health systems have taken this approach³⁹ and, increasingly, health communication interventions are evolving to meet standards,⁴⁰ so lessons from these experiences could inform the approach adopted in Australia.

The second theme, having a more responsive approach to the diverse needs of users of health information, will also be a challenging one to address because there may be tensions between adopting an approach that meets the need for more accessible information for various populations not well served at present and the sometimes competing need (certainly at a service level) for providing more detailed information than currently happens. Participants wanted the gap of more accessible information filled, but they also wanted information to encourage more active participation by consumers.

These aims do not always have to compete. For example, there has been a rapid development in the complex functionality of health information sites. Sites are evolving to meet various

information needs by layering health information complexity and linking to alternatives to print, decision making resources, service directories, patient records or discussion forums.

Nationally and in Victoria, governments have invested in health websites^{24,41} or in tools to help services write clear health information or to involve consumers in developing the information.^{42,43} Sites play an important role across the board for health issues, but particularly for health access and navigation issues for people from low socioeconomic communities.⁴⁴ User-generated content is now appearing on non-government health organisations sites (See Stroke Foundation, EnableMe, <https://enableme.org.au/>, accessed 6 May 2016).

Consumer participation in the design, production, implementation and evaluation of health information is one attribute of a health-literate organisation⁴⁵ and of increasing interest to those supporting co-design models.

This article has presented the findings from a Victorian consultation and the issues may vary in importance to those in other states and territories. It is possible that different issues would have emerged with another consultation method, but the aim was to address this with efforts to ensure wide participation by population groups and organisations in both the consultation and on the advisory committee; in addition, multiple drafts of the consultation report were read by committee members.⁵ The emphasis on health information materials is an arbitrary distinction in some situations, but the experience of the consultation was that health literacy is a huge concept overlapping with other concepts¹¹ and it was sometimes hard to get agreement on where to start. It is hoped that a focus on one key component, health information, may enable action to be taken.

Conclusion

A framework to improve health information would underpin the efforts of government, services and consumer organisations to meet literacy needs in a more consistent way, improving standards and ultimately increasing the participation by consumers and carers in health decision making and self-management.

Competing interests

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