

# Health literacy and patient portals

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## ABSTRACT

Health literacy has been described as the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Improving health literacy may serve to promote concordance with therapy, engage patients in their own health care, and improve health outcomes. Patient portal technology aims at enabling patients and families to have easy access to key information in their own medical records and to communicate with their health care providers electronically. However, there is a gap in our understanding of how portals will improve patient outcome. The authors believe patient portal technology presents an opportunity to improve patient concordance with prescribed therapy, if adequate support is provided to equip patients (and family/carers) with the knowledge needed to utilise the health information available via the portals. Research is needed to understand what a health consumer will use patient portals for and how to support a user to realise the technology's potential.

## What is health literacy?

The United States National Library of Medicine defines 'health literacy' as the 'degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions'.<sup>1</sup> This definition was adopted by the former New Zealand Guidelines Group (NZGG, now defunct) and by the New Zealand (NZ) Health Quality and Safety Commission (HQSC).<sup>2</sup> NZGG stated that a patients' health literacy skills include their ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy) and speak and listen effectively (oral literacy).<sup>2</sup> A NZ Ministry of Health 2010 report interprets health literacy as 'the skills people need to find their way to the right place in hospital, fill out medical and insurance forms, and communicate with their health providers'.<sup>3</sup> This report also shows that the majority of New Zealanders have limited health literacy, with less than half meeting the minimum health literacy requirements for making informed and appropriate health decisions. Furthermore, Māori have much poorer health literacy skills than non-Māori.<sup>3</sup> The inequality in terms of health literacy in some ethnic groups, including Māori and Pacific peoples, is also noted in *Cole's Medical Practice in New Zealand*, a guide for doctors pub-

lished by the Medical Council of New Zealand, which points out that low health literacy is one of the most important factors that adversely affect the health status of these groups.<sup>4</sup>

Similarly, a low level of population health literacy (>50% having low health literacy) has been reported across the Organisation for Economic Co-operation and Development (OECD) countries.<sup>5-8</sup> The relationship between a person's literacy level and their health management status is recognised internationally, particularly in terms of their adherence to evidence-based efficacious medications, health indicators, and ability to share in decision making.<sup>6,9</sup> Research has suggested that low literacy is associated with adverse health outcomes,<sup>10</sup> including poor medication adherence,<sup>11</sup> although a 2012 systematic review concluded that efforts to develop interventions to improve health literacy would not necessarily improve adherence to cardiovascular medications.<sup>12</sup> The complexity and difficulty in improving health literacy might be related to the fact that there are a range of factors influencing health literacy. These factors have been grouped into two categories:

1. the factors that determine one's health literacy skills and knowledge; and
2. the complexity of the health system's literacy demands (see Table 1).<sup>13</sup>

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In particular, the complexity of the health system and the technical language used by health professionals and in health information materials are well recognised as barriers to effective communication with health consumers.<sup>14</sup> However, it remains a challenge to develop and implement effective solutions to address this ‘health literacy’ problem. Research is needed to collect evidence on how to support the use of the best language by professionals and how to assist consumers in health literacy development. More research, especially with adequate representation of patients with low health literacy, is also needed to further define the relationship between health literacy and disease control/medication adherence,<sup>15</sup> and to understand why some people may improve with certain interventions.

## Patient portals

Patient portal technology is an electronic tool and is often accessed as websites; it aims at involving and enabling patients in their own health care. The technology provides patients (and families/carers) with easy access to their own medical records and supports electronic communications with their health care providers, such as their general practitioner (GP). A suite of portal functionalities are specified in the NZ National Health Information Technology (IT) Plan ‘allow[ing] people to communicate electronically with their GPs, make appointments, view their records, check their lists of medicines and renew prescriptions’. The Plan also set a 2014 target for 90% of the primary health organisation (PHO) eligible population to have a self-care portal available, with 10% having accessed the portal by the end of 2014.<sup>16</sup> However, this target appears not to have been met. Challenges in implementation of such initiatives are not unique. For instance, a recent review of the Australian personally controlled electronic health record (PCEHR) initiative reported slow adoption and utilisation of the technology, which is associated with issues regarding usability and perceived clinical value.<sup>17</sup> Domain experts have suggested that research is needed, especially involving those most affected by the NZ Plan—patients and general practices—to understand the experience of how the Plan is implemented and what a realistic timeframe for portal adoption might be.

A patient portal can be tethered to a primary care electronic medical record (EMR) system, providing access to key information in the EMR, such as diagnoses, allergies, medications and laboratory results. Narrative clinical notes, however, are out of the scope of most portals, possibly due to concerns over potential misinterpretation of clinicians’ ‘aide-mémoire’ notes and a lack of standardisation. There is also potential accessibility to secondary services’ EMR contents through patient portals, e.g. to access clinical letters and discharge summaries. Given the NZ target of rapid implementation of patient portals, increasing accessibility to health information via portals is expected, and a central question emerges, that of how portals will improve patient outcomes.

## How will portals improve patient outcomes?

Experience at Kaiser Permanente suggests an association between the use of secure patient-doctor email messaging via patient portals and improved care effectiveness.<sup>18</sup> However, there is a gap in our understanding of how portals improve patient outcomes. Studies are needed to gather evidence on:

1. the extent to which each of the (potential) portal features has an impact on patients, in terms of their health beliefs, attitudes, behaviours and outcomes;
2. how and why portals have an impact on some patients and not others;

Table 1. Factors influencing health literacy\*

Factors that determine the individual's health literacy skills and knowledge
<p>These include:</p> <ul style="list-style-type: none"> <li>• familiarity with the health topic and the health system</li> <li>• available time and resources</li> <li>• stress levels</li> <li>• confidence levels</li> <li>• attitudes, values and beliefs</li> </ul>
Complexity of the health system's literacy demands
<p>Particularly important factors include:</p> <ul style="list-style-type: none"> <li>• how services are designed and delivered</li> <li>• organisational and funding processes</li> <li>• complexity of the health issue</li> <li>• communication skills of the health workforce</li> <li>• complex documents (e.g. forms, letters, labels, and instructions)</li> </ul>

\* Adapted from: Improving health literacy<sup>13</sup>

3. which patient information needs are being addressed by portals and which are not; and
4. how to ensure portals address health inequalities.

The expectations of patient portals appear to be built upon an assumption that providing more information to patients will lead to better outcomes. The authors believe that there is a missing ‘link’ in this assumption—that is the patient’s capacity to understand the health information available via portals in order to make appropriate health decisions; in other words, the health literacy level of the patient.

**Many complex factors affect health outcomes, but there is evidence suggesting that a supported and informed patient demonstrates better adherence to therapy and positive behaviour change, leading to improved health outcomes**

#### *Applying the health belief model*

There are well-recognised limitations of the health belief model (HBM),<sup>19,20</sup> including its disregard of a patient’s emotions and personal beliefs. Nevertheless, it provides a useful framework for considering the potential of patient portals. Applying HBM, a patient’s knowledge, cues to action (e.g. education) and self-efficacy all affect the patient’s perception (e.g. on disease susceptibility and seriousness, treatment benefits, and barriers to behavioural change), and therefore affect their health behaviour. For instance, the health literacy level of a patient with diabetes indicates their ease in gaining knowledge about the disease, their medications, and lifestyle changes recommended by their GP to manage their diabetes. This, in turn, modifies the patient’s perception of whether and how they are able to manage the disease, and subsequently will impact on their health behaviours, such as dietary management and medication adherence. Accordingly, the HBM constructs need to be considered when designing and implementing patient portals in order to realise the technology’s potential to enable patients in health decision making and behaviour

change. In particular, the authors believe that patient portals present an opportunity to improve patient concordance with prescribed therapy, if adequate support for patients is provided to equip them with the knowledge needed to utilise the health information available via portals. In other words, the key to patient portals’ success is health literacy.

#### **Potential benefits**

Many complex factors affect health outcomes, but there is evidence suggesting that a supported and informed patient demonstrates better adherence to therapy<sup>21</sup> and positive behaviour change,<sup>22</sup> leading to improved health outcomes. By providing information and communication support, and potentially decision support, patient portals may help patients gain the needed knowledge to make appropriate health decisions. The portal technology may also help engage and enable families and carers, especially via its ability to enable access to medical records by an authorised proxy for a patient. In NZ, patients have rights to see their medical records, and they are the owner of these records. Health care providers exercise the custodianship of official medical records and are responsible for maintaining the accuracy of records. There are contentious and challenging issues in patient health records (including portals) management related to the medicolegal ramifications of portals that are owned and managed by patients. However, the authors believe patient portals may play an important role in supporting patients and families/carers. Patient portals also have the potential to support patients in health literacy improvement initiatives given their capability to facilitate easy access to information, such as problem and medication lists, and to support asynchronous communications between patients and their health care providers. The technology has the potential to support both proactive patients and prepared clinicians as described in Wagner’s chronic care model.<sup>23</sup>

#### **Future research directions**

Research is needed to understand what a NZ health consumer will use patient portals for and how to support a user in order to realise the technology’s potential. An interview study with 10

early adopters of a patient portal available in NZ found that reasons for using the portal functions included interaction with their GP (e.g. ordering a repeat prescription), and reviewing information, such as laboratory results and medication lists.<sup>24</sup> Studies are needed to understand how patient portals can support patients and families/carers, and improve health outcome, particularly addressing the issue of health literacy. Specifically, how will portals work and for whom? And what will improve the usability and value of portals, especially for those with low health literacy and those failing to access or benefit from health services?

### Realising the potential of patient portals

The New Zealand National Health IT Plan has indicated a rapid implementation strategy for patient portals. Central to giving patients easy access to health information via portals are a series of unanswered questions, including:

- Will a patient understand the information?
- Will they act upon the information appropriately?
- What will patients use portals for?
- How will portals improve patient outcomes?

It is the authors' opinion that patient portal technology presents an opportunity to improve patient concordance with prescribed therapy, if adequate support is provided to equip patients with the knowledge needed to utilise the health information available via the portals. Research is needed to gather evidence on how to best realise patient portal technology's potential.

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**COMPETING INTERESTS**  
None declared.