

Consumer e-health: an overview of research evidence and implications for future policy

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Abstract

Consumer e-health is rapidly becoming a fundamental component of healthcare. However, to date only provisional steps have been taken to increase our understanding of how consumers engage with e-health. This study, an interpretive review, assessed the evidence about consumer use of e-health and identified five categories that encompass consumer e-health: (i) peer-to-peer online support groups; (ii) self-management/self-monitoring applications; (iii) decision aids; (iv) the personal health record; and (v) Internet use. Our findings reveal that e-health offers consumers many possibilities and potential benefits, although there appears to be apprehension concerning the efficacy of some interventions and barriers relating to the trustworthiness of Internet-acquired information. It is imperative that policy initiatives address these issues to ensure that consumer e-health services can be effectively, efficiently, and safely accessed.

Keywords (MeSH): *Consumer Participation; Patient Participation; Health Policy; Healthcare Delivery; Internet; Medical Informatics; Health Records, Personal*

Introduction

In October 2010, the Australian Minister for Health and Ageing, Nicola Roxon, announced an investment of AUD\$466.7 million for major e-health developments, including the introduction of personally controlled electronic health records (PCEHRs). PCEHRs are projected to lead to the seamless exchange of information such as hospital discharge summaries, referrals and medication lists (Department of Health and Ageing 2010). This represents a potentially major step for the implementation of information and communication technologies (ICT) in Australian healthcare, a sector that has long lagged behind other areas of the Australian economy in the employment of computerised systems (Pearce & Haikerwal 2010).

The uptake and diffusion of ICT remains a significant challenge for governments, health managers, healthcare practitioners and system developers. The stakes involved in health ICT implementation are high (Westbrook & Braithwaite 2010) and there are significant financial, clinical and organisational risks involved (Karsh et al. 2010). The National Programme for Information Technology in England's National Health Service (NHS) was established in 2005 to provide integrated electronic records that included a nationally stored summary care record (SCR). The evaluation of the SCR reported that its adoption was slow, labour intensive and technically challenging, and was unable to show any direct evidence of improved safety (Greenhalgh et al. 2010). The NHS experience has prompted an important discussion with widespread international ramifications about the future, particularly regarding what does and does not constitute the promise of a viable and sustainable national e-health strategy (Coiera 2011).

The increasingly prevalent availability of interactive consumer health information, especially through the

Internet, is reflective of major developments providing consumers with the means to take on more responsibility for their own health (Eysenbach, Sa & Diepgen 1999; Jadad 1999). Often described as 'consumer empowerment', this trend represents an endeavour to enhance an individual's ability to satisfy their own needs and control their own lives (Gibson 1991). According to Curran and Curran (2005), consumers are no longer deemed to be submissive contributors to their wellbeing but are now expected to be active participants in their healthcare, with the ability to choose the degree of control they wish to exercise over care decisions that affect their health. Yet there have been surprisingly few studies that have drawn together and reviewed the evidence concerning a range of health information technology applications, particularly those related to the management of chronic diseases such as cardiovascular disease and diabetes. To date, only tentative steps have been made to increase our understanding of how consumers actually engage with e-health and the circumstances in which they do so (Goldzweig et al. 2009; Nettleton & Hanlon 2006; Chaudhry et al. 2006).

In view of this situation, we set out to undertake an interpretative review of the consumer health literature to examine existing evidence about the use of e-health, the circumstances in which it is used, and the policies and community implications involved with its diffusion. Our aims were to: (a) identify the different types of e-health applications and their role in promoting consumer involvement; and (b) consider the policy implications for the development and diffusion of e-health applications across the healthcare spectrum.

Method

To provide an holistic view of the literature relevant to this interpretive review, we drew upon a diverse range of

evidence (Dixon-Woods et al. 2005; Pawson et al. 2005). We began our search by exploring a number of databases including: Cochrane; Medline; Embase; and Google Scholar. We also searched key medical and informatics journals including: *British Medical Journal*; *Journal of the American Medical Association*; *Journal of the American Medical Informatics Association*; and *Journal of Medical Internet Research*. Keywords such as consumers, patients, information, health, technology, and chronic disease were used in various combinations when searching these databases. The search was conducted iteratively throughout November 2008 to January 2009. During the initial searches, we primarily aimed to identify key articles in the form of systematic reviews that would lead us to additional citations, thereby directing our subsequent searches for additional sources of knowledge. The next step was to focus on evidence related to chronic disease, particularly cardiovascular disease and diabetes, which was chosen as a means of providing examples to examine the impact of the uses of consumer e-health applications. Selection of literature was based on a series of criteria including relevance, quality, informational value, applicability and validity. The literature was summarised and categorised into emergent themes in order to consolidate the presentation of our findings.

Results

Following a search of the literature, we identified the following five broad categories that encompassed the field of consumer e-health: i) peer-to-peer online support groups and health related virtual communities; ii) self-management/self-monitoring applications; iii) decision aids; iv) the personal health record; and v) Internet use. Each of these categories is presented below in addition to instances in which they have been utilised, their purpose, and benefits/disadvantages identified through their increasing use by consumers. Table I provides a comparative summary of consumer e-health applications, incorporating their definition, description of purpose, strengths and weaknesses.

Peer-to-peer online support groups/health related virtual communities

Online support groups can be referred to as forums where individuals who share similar health concerns congregate 'virtually' to disclose experiences, pass on and acquire information, and offer emotional support and reassurance (Bane, Haymaker & Zinchuk 2005). These virtual communities work like a social network and are facilitated by electronic media, primarily through various Internet applications, including mailing lists, newsgroups, bulletin boards, web-based discussion forums and live chat rooms (Eysenbach et al. 2004). To some extent, their growth is a consequence of the desire, felt by many consumers, to become more active participants in the management of their health (White & Dorman 2001). The possibility for individuals within online support groups to share experiences and provide emotional support to one another has

also facilitated their growth (Eysenbach et al. 2004). The ability to immediately interact with individuals experiencing similar conditions, from anywhere in the world, has considerable potential. Heightened empowerment, better health outcomes, feelings of unity, and a reduction in societal loneliness are among the most evident benefits (White & Dorman 2001). Furthermore, the anonymity provided by online support groups enhances the potential for self-disclosure, as well as promoting honesty and understanding among individuals (White & Dorman 2001). In this way, they encourage and offer members the opportunity to help each other (Ferguson & Kelly 1999).

While online support groups and health related virtual communities have the potential to support individuals in coping with chronic illnesses, some research findings have drawn attention to the potential problems with such groups. The absence of visual, oral and contextual signals can potentially lead to online messages that are misunderstood upon being read, which adds to the comparative impersonal and remote features of online communication (Parks & Floyd 1996). Considering healthcare practitioners fail to assist and/or oversee the nature and content of most online support groups, opportunities present themselves for the development of imprecise, dangerous or erroneous medical information (Winzelberg 1997; Dickerson, Flaig & Kennedy 2000). Hardey (2002) describes incidents where unidentified online sources have inadvertently or advertently become creators of untrustworthy health information and unregulated distributors of healthcare.

A systematic review carried out by Eysenbach et al. (2004) assessed online peer-to-peer support groups. It revealed that most of the 45 publications included in the review failed to show any significant effect. However, the review also found no evidence to support concerns in regard to online health communities harming individuals who take part in them. The authors pointed out that because most peer-to-peer online communities have been evaluated only in combination with other interventions, possible effects may have been confounded by co-interventions (Eysenbach et al. 2004). A more recent review by Demiris (2006), comprising 47 studies, considered the moral, legal and technological factors concerned with the use of virtual communities in healthcare. The author concluded that while virtual communities have the capability to empower consumers and improve the management of care services, there is a lack of adequate methodical evidence regarding their effect on patient health outcomes or patient empowerment.

Self-management and self-monitoring

As individuals today are increasingly living with complex chronic conditions and are at high risk of poor health outcomes, encouragement for self-management programs is gradually increasing (Bayliss et al. 2007). Self-management programs stress the importance of the patient in taking on responsibility for managing their illness (Lorig et al. 2001). Self-management entails: collabora-

Table 1: Comparative summary of consumer e-health applications incorporating definition, description of purpose, strengths and weaknesses

CATEGORY	DEFINITION	PURPOSES	STRENGTHS	WEAKNESSES
Peer-to-Peer Online Support Groups / Health Related Virtual Communities	Online environment where individuals who share similar health concerns meet virtually (Bane et al. 2005). Acts like a social network (Eysenbach et al. 2004).	To disclose experiences, pass on and acquire information, and offer emotional support and reassurance (Bane et al. 2005).	(i) Heightened empowerment; improved health outcomes; feelings of unity; reduction in societal loneliness (White & Dorman 2001). (ii) Anonymity enhances the potential for self-disclosure and promotes honesty and understanding among individuals (White & Dorman 2001).	(i) Absence of visual, oral and contextual signals can lead to misunderstandings of messages (Parks & Floyd 1996). (ii) Impersonal and remote features of online communication (Parks & Floyd 1996). (iii) Potential for the development of imprecise, dangerous or erroneous medical information (Witzelberg 1997; Dickerson et al. 2000).
Self-Management / Self-Monitoring	Self-management: Importance placed on the patient to have a central role in managing their illness (Lorig et al. 2001). Self-monitoring: Utilisation of a monitoring system.	Self-management: Collaboratively assisting patients and their families to obtain the skills and assurance required to deal with their chronic illness (Glasziou et al. 2005). Self-monitoring: Entails the intermittent measurement that controls the management of a chronic or persistent condition (Glasziou et al. 2005).	Self-management: (i) Improvements in quality of life, risk behaviours and physiological determinants of illness (Harris et al. 2008). Self-monitoring: (i) Feasible and acceptable to patients, nurses and practitioners in general practice; Potential to facilitate improvement in awareness and adherence to guidelines (Cappuccio et al. 2004; Glasziou et al. 2005). (ii) Measurements for the practitioner between appointments; better selection of treatments based on individual response (Lowy 1998; Bodenheimer et al. 2002).	Self-management: No weaknesses reported. Self-monitoring: (i) Feelings of detachment in that the patient takes on more of a passive role (Mort et al. 2009). (ii) Elevated levels of distress, worry/anxiety and depressive symptoms (Franciosi et al. 2001; Simon et al. 2008). (iii) Apprehension or adjustment of treatment by the patient (Stergiou et al. 2004).
Decision Aids	Facilitate individuals in making specific decisions through the presentation of information on the options and outcomes relevant to the individual's particular health condition (O'Connor et al. 2003).	Appropriate treatment alternatives are depicted through various formats which outline the possible benefits and risks specific to the patient's condition (Woolf et al. 2005; Sarfati et al. 1998; Edwards et al. 1999).	(i) Enhancement of knowledge and agreement between values and choices; realistic expectations are met; decrease in decisional conflict; encourage patients to become more active participants in decision making (O'Connor et al. 2003). (ii) Successful in informing patients about alternative choices in treatment (Barry 2002).	(i) Nonverbal prompts to convey information fails to identify the needs and requirements of the individual (O'Connor et al. 2003; Billings 2004).
Personal Health Record	Electronic tool that allows individuals to access, coordinate and control parts of their health information (Markle Foundation 2003).	Combine data, knowledge and software tools which motivate individuals to become more involved in their health care (Tang et al. 2006; Richards 2007).	Potential strengths include (i) Assist the understanding of instructions from the practitioner; prevent medical mistakes; greater control over one's care; improve questions put forward to practitioners; change self-care of individuals (Markle Foundation 2003). (ii) Reduction in geographical barriers to patient care (Richards 2007).	(i) Concerns have arisen regarding their value, privacy and security (Markle Foundation 2003).
Internet Use	Health information acquired by consumers from the World Wide Web (Eysenbach 2000).	With its simplicity of web browsing and 24 hour accessibility, the use of the Internet to acquire health information is increasing (Calabretta 2002).	(i) Possibility for consumers to become more knowledgeable once information was obtained from the Internet (Sommerhalder et al. 2009). (ii) Feelings of increased competence and confidence of the consumer (Lemire et al. 2008).	(i) Concerns regarding the quality, quantity, completeness and accuracy of health information on the Internet (Adhmad et al. 2006; Eysenbach et al. 2002).

tively assisting patients and their families to obtain the skills and assurance required to deal with their chronic illness; regularly evaluating successes and barriers that accompany self-management; and supplying individuals with devices to aid self-management. Self-monitoring implies similar concepts to that of self-management. It can be distinguished by its utilisation of a monitoring system, which entails the intermittent measurement that controls the management of a chronic or persistent condition (Glasziou, Erwig & Mant 2005). With the establishment and legalisation of innovative electronic devices, self-monitoring of certain conditions, such as blood pressure and blood glucose measurements, is becoming increasingly popular with both practitioners and patients, and is broadly acknowledged to be an essential component of continuous patient care (Chobanian et al. 2003). Motivation, greater availability of reliable devices for self-monitoring, measurements for the practitioner between appointments, and a better selection of treatments based on individual response, are all aspects that contribute to the more frequent use and popularity of self-monitoring (Lowy 1998; Bodenheimer, Wagner & Grumbach 2002).

Research literature identified in the area of self-management predominantly suggests that such programs generate at least some improvements in the health status of individuals with chronic disease. A systematic review, undertaken by Zwar et al. (2006), confirmed that self-management support was effective for a range of chronic illnesses and was most notably successful in patients with diabetes, heart disease and hypertension. Quality of life, risk behaviours, and physiological determinants of illness were all enhanced among patients with diabetes through implementing self-management support (Harris et al. 2008). A systematic review was carried out to determine the value of interventions for chronically ill patients in primary care (Dennis et al. 2008). Based upon an analysis of 141 studies and 23 systematic reviews, the authors concluded that self-management interventions were successful in enhancing patient outcomes, specifically in patients with diabetes and hypertension. Literature that examined the use of self-monitoring, particularly in relation to blood pressure monitoring, demonstrated that self-monitoring is feasible and acceptable to patients, nurses and practitioners in general practice, and may facilitate improvement in awareness and adherence to guidelines (Cappuccio et al. 2004; Glasziou, Irwig & Mant 2005).

There are also some limitations to these approaches. Self-monitoring systems are commonly considered to produce a sense of empowerment within patients. Alongside this, however, it has been found that systems have created feelings of detachment in that the patient takes on more of a passive role (Mort, Finch & May 2009). A quantitative study that investigated the impact of self-monitoring in Type II diabetic patients found that blood glucose self-monitoring among non-insulin-treated patients can have a harmful outcome on quality of life,

with elevated levels of distress, worry and depressive symptoms (Franciosi et al. 2001). Similar results were found in a study conducted by Simon et al. (2008), in which a health economic analysis of self-monitoring of blood glucose among non-insulin-treated Type II diabetic individuals was carried out prospectively. The authors found that self-monitoring of blood glucose within the above mentioned group of patients had a negative impact on quality of life, and to some extent was associated with increased levels of anxiety and depression. In some cases there may be patients who are not suitable for self-monitoring as it may result in apprehension or adjustment of treatment by the patient (Stergiou et al., 2004). Verberk et al. (2005) recommend that self-monitoring should be discouraged when it causes harmful effects on quality of life or induces self-modification of treatment regimes.

Decision aids

Decision aids are interventions that are intended to facilitate individuals in making specific and contemplative decisions through the presentation of information on the options and outcomes applicable to the individual's particular health condition (O'Connor et al. 2003). Images, diagrams, charts and figures presented through formats such as pamphlets, booklets and, more recently, interactive compact disc and computer based systems, depict appropriate treatment alternatives while outlining the associated benefits and risks specific to the patient's condition (Woolf et al. 2005; Sarfati et al. 1998; Edwards, Alwyn & Gwyn 1999).

O'Connor et al. (2003) conducted a systematic review of 55 randomised controlled trials, which evaluated 51 separate decision aids, all encompassing a variety of formats. Their findings verified that decision aids substantially enhanced knowledge and agreement between values and choices; led to more realistic expectations; decreased decisional conflict; decreased the percentage of people who continued to be in doubt post intervention; and encouraged patients to become more active participants in decision making without increasing their anxiety. Likewise, Barry (2002) asserts that decision aids appear to be successful in informing patients about alternative choices in treatment.

However, the use of decision aids also possesses a number of drawbacks. By using nonverbal prompts to convey facts, values and advice, the decision aid is insensitive to the needs and requirements of the individual patient. The present era of decision aids and software tools cannot entirely house the patient's information needs (O'Connor et al. 2003; Billings 2004). These information requirements may include relevant data from the individual's medical record such as the patient's risk factors, family and personal medical history and attempted treatments in the past. Such crucial information can help determine the best choice for an individual, but are currently only available to the patient's healthcare practitioner (Woolf et al. 2005).

Personal health record (PHR)

In recent years, there has been a particular surge in interest surrounding the implementation of Personal Health Record (PHR) systems for consumers (Tang et al. 2006). PHRs can be broadly described as a set of electronic tools that allow consumers to access, coordinate, and control appropriate parts of their health information (Markle Foundation 2003). PHRs combine not only data, but knowledge and software tools, which motivate patients to become more involved in their healthcare (Tang et al. 2006; Richards 2007). A PHR should typically present a comprehensive and precise review of the health and medical history of the individual patient through the collection of information from a variety of sources. Since it is retained, maintained and controlled by the consumer, the PHR positions the consumer at the core of the healthcare process, potentially fostering personal empowerment and facilitating self-management, shared decision making and better clinical outcomes (Tang et al. 2006; Richards 2007). The PHR differs from the electronic health record (EHR) in that it is not limited to a distinct organisation or a particular healthcare provider. In contrast, the EHR seldom includes information provided by the patient, and is usually owned by and limited to the information compiled by one practitioner or health service (Markle Foundation 2003).

Research has verified that consumers do have an interest in owning a PHR, mostly through their aspiration to actively and collaboratively engage in their healthcare. In 2003, a national online survey of 1,246 US households, conducted by the Personal Health Working Group of the Markle Foundation, was carried out in order to determine, amongst other things, what factors are of greatest interest if the PHR was currently available. It reported that individuals with chronic illnesses, frequent healthcare users and those caring for older patients had the greatest interest in owning a PHR. When asked about the potential benefits of having a PHR, 71% of respondents stated that PHRs would facilitate their understanding of instructions from the practitioner; 65% confirmed that they would prevent medical mistakes; 64% acknowledged possibly having more control over their care; 62% affirmed that a PHR would improve the questions put forward to practitioners; and 60% thought it would change how respondents took care of themselves (Markle Foundation 2003). Similarly, a group of authors in the US undertook a survey of 104 participants in order to gain insight into patient information needs and experiences of those who had observed their health records. The authors found that: 81% percent of participants viewed their record in order to 'have detailed information about one's health'; 81% to 'take a more active role in managing their own health'; and 80% retrieved the document 'to have a copy for one's own record.' (Keselman et al. 2007: 401). A review by Tang et al. (2006) revealed that patients are offered greater access to a broad selection of reliable health information and knowledge as a result of PHRs. Furthermore, geographical barriers to patient care may

be diminished, especially in disjointed health systems, therefore enhancing continuity of care and efficiency (Richards, 2007).

Despite some of the extensive enthusiasm for PHRs, their uptake has been slow and concerns have arisen regarding their value, privacy and security. In order to retain one's privacy, appropriate systems need to be in place that will permit individuals to identify which elements of their PHR can be shared with specific practitioners and/or health services (Markle Foundation 2003). In addition, the PHR must be readily accessible despite having robust security in place. If the PHR were to become integrated with an EHR, the user's verification is very important (Tang et al. 2006). The integration of PHRs with EHRs offers greater advantages than stand-alone systems, by way of strengthening consumers' ability to manage their own care. Essentially, integrated PHRs may not only change the way that healthcare is distributed, but they can also influence the patients' behaviour (Tang & Lansky 2005).

Internet use

The increased availability of health information during the past years, most notably accessed through the Internet (Eysenbach 2000), has facilitated a change in traditional roles for patients and practitioners, with an escalation in the number of patients bringing health information obtained from the Internet into consultations (Dickerson et al. 2004). With its simplicity of web browsing and 24-hour accessibility, the ever-increasing use of the Internet ultimately facilitates the growth of health consumerism (Calabretta 2002).

Various studies regarding consumer informatics maintain that consumers are increasingly employing the Internet to autonomously and proactively manage their healthcare. Ferguson (2000: 1130) reported on the results of a Harris Poll undertaken in the US in August 2000, which found that 'those who visit health-related sites are, on average, older than other users of the Internet, and people over 65, who require the most medical care, are increasing their use of online services faster than any other age group.' In 2001, a study to determine the rate of Internet use for health related purposes by consumers in Switzerland, showed that 30% of consumers who had Internet access used it to acquire health related information (Jeannot et al. 2004). A similar study was performed over an 18-month period, between 2005 and 2007, across seven European countries to determine utilisation of the Internet for health related topics. Results confirmed that in 2005, approximately 42.3% of the population used the Internet for the purpose of locating health related information. This number increased by almost 10%, with approximately 52.2% of the population retrieving health information via the Internet in 2007. It was evident that in all seven countries included in the study, there was a considerable increase in the utilisation of the Internet for health related purposes (Kummervold et al. 2008).

As consumers are increasingly and successively acquiring health information via the Internet, studies have reported that a number of consumers are using consultations to understand and substantiate their Internet-acquired health related information. This was highlighted by a telephone survey of health Internet users ($n=406$), which was conducted in Australia and New Zealand in 2006-2007 by Gauld (2011). The study aimed to understand the employment of information technology and Internet use. It reported that 52% of Internet users pursued medical advice combined with their Internet searches, 40% referred to the Internet preceding their medical consultation and 50% discussed documentation with their practitioner, which they had obtained from the Internet. Of these Internet users, 15% believed that their practitioner felt uncomfortable with this, 46% affirmed it improved their relationship with their practitioner, and over 80% were of the opinion that it enhanced their comprehension of the Internet-acquired information, as well as their treatment plan in general. A qualitative study was carried out where patients made use of their consultation time to discuss and analyse health related Internet information with their practitioner (Sommerhalder et al. 2009). Practitioners in the study believed that patients who had obtained information via the Internet were significantly more knowledgeable in terms of health related issues than patients who were not Internet-informed. Sommerhalder et al. (2009) suggested that collaboratively validating and deliberating over Internet-acquired information with their practitioner enabled individuals to tailor their information to fit their personal situation and thus lead to patient empowerment. Lemire, Sicotte & Paré (2008) found that, as a result of retrieving online health information from a specific website, Internet users felt increased competence and confidence.

A driving force behind the requirement for online health information is the lack of information that should be obtained without difficulty from the practitioner. According to some authors, many consumers state that the health information and advice that they locate online is more comprehensive and useful than the information they receive from their practitioners (Ferguson & Kelly 1999; Ferguson 2002). However, there is also evidence pointing to the potential disadvantages of using the Internet as a source of health information. These include concerns about the quality and quantity of health information on the Internet. In addition, it has become evident that the credentials of health websites are often not assessed by the individuals, and the way in which individuals search for health information varies widely (Eysenbach & Köhler 2002). Gauld (2011) reported that 90% of respondents believed that health information obtained over the Internet was trustworthy, yet only 35% consistently checked the credentials of the web site providers. A qualitative study carried out in Germany by Eysenbach and Köhler (2002) found that many of their study participants believed that they had checked

credentials, but only a small number actually did so in a systematic manner. A qualitative study carried out in Canada by Ahmad et al. (2006) reported that the practitioners in their study were certain that health related Internet information was often incorrect, possibly leading to harmful self-diagnoses or self-treatment. In 2002, a systematic review assessed the quality of health information available to consumers via the Internet (Eysenbach et al. 2002). A total of 79 studies were included in the review, which assessed 5,941 health related websites, 1,329 web pages and 408 evaluation results for 86 distinct quality criteria. The authors reported that 70% of studies found that the quality of information on the Internet was problematic; 22% of studies remained impartial; and only 9% of studies achieved a positive assessment regarding quality. Significant factors relating to quality centered around a lack of completeness and inaccuracy of information on the Internet.

Discussion

The growth of consumer based e-health applications has been heralded as part of a new paradigm in healthcare delivery with the potential to transform the present paternalistic model of healthcare toward one that is responsive to consumer needs and treats each individual as a co-pilot in a life-long healthcare process (Tang & Lansky 2005; Wilson 2009). Yet despite the interest and significant investments in promoting the uptake of consumer e-health solutions, there remains a major gap between the promise and reality of e-health delivery (Black et al. 2011). This review identified five areas where e-health applications have contributed to the shaping of consumer healthcare provision: i) peer-to-peer online support groups and health related virtual communities; ii) self-management/self-monitoring applications; iii) decision aids; iv) the personal health record; and v) the Internet. While these areas have grown and developed separately, they are by no means mutually exclusive. In the future, they are likely to merge, perhaps as part of an all embracing personal health record that allows consumers to enter their own health information, share and access information and knowledge, and engage with others, alongside managing their own healthcare (Kaelber et al. 2008).

An increasingly significant characteristic that has emerged through the use of e-health applications is the rise in consumer empowerment. In today's society, these applications are growing to become more customary that, in turn, reinforces the expectation that consumers will not only take on a more active and self-managing role, but will also be able to manage parts of their healthcare remotely (NHS Confederation 2011). As our findings clearly indicate, consumers encourage and offer support to one another, acquire skills and confidence required to deal with their illness, and welcome more responsibility for managing their own health. Evidence-based tools are also available that allow consumers to access and control parts of their health information. Additionally,

an ever increasing number of consumers are searching for information prior to consultation with healthcare practitioners. Healthcare practitioners are likely to face challenges, however, in providing education to consumers about the reliability of information found on the Internet. These challenges could be confronted by practitioners by way of 'Internet prescription', a term used by Gerber & Eiser (2001), whereby the consumer can be directed to certified Internet resources that offer trustworthy and correct information. However, this is dependent on the practitioner being familiar with where to find the appropriate information on the Internet. In addition, Eysenbach (2003) proposed that practitioners could instruct consumers on how to 'filter' the information that they came across, providing the practitioners themselves were knowledgeable on how to do this.

Our review identified a number of gaps in the literature. In particular, our findings pointed to areas where there is a paucity of evidence regarding improvements in health outcomes (peer-to-peer online support groups), concerns about the efficacy and effectiveness of some interventions (decision aids) or even barriers related to the trustworthiness of information (Internet use). Taken together, these challenges and barriers will require major policy changes that take into account the costs involved in establishing widespread consumer based applications, satisfy the complex privacy and confidentiality concerns regarding the spread of information, and are designed to optimise accessibility and communication (Kahn, Aulakh & Bosworth 2009). It is important that these challenges are addressed, with regards to the development and implementation of the Australian government's plans to provide a personally controlled electronic health record that will provide consumers access to their own information and allow them to consent over who does or does not see it (Dearne 2011). It must be acknowledged that policy development is a process that seeks to balance the needs and interests of a range of stakeholders. This is evident in a report by the NHS Confederation (2011), which stated that difficulties arise when designing e-health applications as they must appeal to all stakeholders involved including commissioners, practitioners and consumers. As it is the consumer who ultimately benefits, it is essential that their voice not be lost in deliberations that will necessarily include financial, clinical and organisational considerations.

Developing effective policy for consumer based e-health services must take into account the range of environments in which activity occurs, as well as the dynamic nature of the technology itself. Given the rapid rate of technological change there is a need to ensure that policy remains technologically relevant (Curtis 2008). Additionally, e-health services, particularly peer-to-peer online support groups/health related virtual communities and Internet information, may originate within Australia or be based overseas. Thus, many e-health services are outside Australia's jurisdiction and are therefore difficult to directly monitor and/or control. Those services that are

based overseas will add an additional complexity, which suggests that effective policy development will need to approach those issues from several standpoints. As with existing privacy initiatives, state and federal governments will need to take a lead role, providing an overarching framework within which government and private organisations may operate.

Conclusion

e-Health applications are increasingly becoming an integral part of the healthcare environment. While the uptake and dissemination of these services still remain a considerable challenge, evidence suggests that consumers are willing to adopt e-health applications due to their many potential benefits. e-Health offers many opportunities by way of support groups, chronic disease self-monitoring and wide-ranging access to sources of rich information from anywhere in the world, which in turn will assist consumers in making more informed decisions regarding their healthcare. Nonetheless, policy measures need to ensure that consumers and service providers are discerning and critical in their use of e-health services, such as the applications presented in this review. Such policies should also highlight the necessity to educate consumers. Policy initiatives will need to provide a comprehensive framework, which will ensure that these broad-ranging consumer e-health services can be effectively, efficiently, and safely accessed.

References

- Ahmad, F., Hudak, P., Bercovitz, K., Hollenberg, E. and Levinson, W. (2006). Are physicians ready for patients with Internet-based health information? *Journal of Medical Internet Research* 8(3): e22.
- Bane, C., Haymaker, C. and Zinchuk, J. (2005). Social support as a moderator of the big-fish-in-a-little-pond effect in online self-help support groups. *Journal of Applied Behavioural Research* 10(4): 239-261.
- Barry, M. (2002). Health decision aids to facilitate shared decision making in office practice. *Annals of Internal Medicine* 136(2): 127-135.
- Bayliss, E., Bosworth, H., Noel, P., Wolff, J., Damush, T. and McIver, L. (2007). Supporting self-management for patients with complex medical needs: recommendations of a working group. *Chronic Illness* 3(2): 167-175.
- Billings, J. (2004). Promoting the dissemination of decision aids: an odyssey in a dysfunctional health care financing system. *Health Affairs Web Exclusives*, VAR – 128-132.
- Black, A. D., Car, J., Pagliari, C., Anandan, C., Cresswell, K., Bokun, T., McKinstry, B., Procter, R., Majeed, A. and Sheikh, A. (2011). The impact of ehealth on the quality and safety of health care: a systematic overview. *Public Library of Science Medicine* 8(1): e1000387.
- Bodenheimer, T., Wagner, E. and Grumbach, K. (2002). Improving primary care for patients with chronic illness. *Journal of the American Medical Association* 288(14): 1775-1779.
- Calabretta, N. (2002). Consumer-driven, patient-centered health care in the age of electronic information. *Journal of the Medical Library Association* 90(1): 32-37.
- Cappuccio, F., Kerry, S., Forbes, L. and Donald, A. (2004). Blood pressure control by home monitoring: meta-analysis of randomised trials. *British Medical Journal* 329(7458): 145.

- Chaudhry, B., Wang, J., Wu, S., Maglione, M., Mojica, W., Roth, E., Morton, S. C. and Shekelle, P. G. (2006). Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. *Annals of Internal Medicine* 144(10): 742-752.
- Chobanian, A., Bakris, G., Black, H., Cushman, W., Green, L., Izzo, J., Jr., Jones, D., Materson, B., Oparil, S., Wright, J., Jr. and Roccella, E. (2003). The seventh report of the joint national committee on prevention, detection, evaluation, and treatment of high blood pressure: the JNC 7 report. *Journal of the American Medical Association* 289(19): 2560-2571.
- Coiera, E. (2011). Do we need a national electronic summary care record? *The Medical Journal of Australia* 194(2): 1-3.
- Curran, M. and Curran, K. (2005). The e-health revolution: competitive options for nurse practitioners as local providers. *Journal of the American Academy of Nurse Practitioners* 17(12): 495-498.
- Curtis, K. (2008). Speech to Privacy Connections breakfast and launch of the Australian Privacy Awards and the Australian Privacy Medal. Sheraton at the Park Hotel, Sydney.
- Dearne, K. (2011). Roxon sells her vision of handing power to patients *The Australian*, 12 April
- Demiris, G. (2006). The diffusion of virtual communities in health care: concepts and challenges. *Patient Education and Counseling* 62(2): 178-188.
- Dennis, S., Zwar, N., Griffiths, R., Roland, M., Hasan, I., Davies, G. and Harris, M. (2008). Chronic disease management in primary care: from evidence to policy. *Medical Journal of Australia* 188(8): S53-S56.
- Department of Health and Ageing. (2010). The Hon Nicola Roxon MP, Minister for Health and Ageing. Media release, 28 October 2010, E-Health Conference - Revolutionising Australia's Health Care. Available at: <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/content/home> (accessed: 10 January 2011).
- Dickerson, S., Flaig, D. and Kennedy, M. (2000). Therapeutic connection: help seeking on the Internet for persons with implantable cardioverter defibrillators. *Heart & Lung: The Journal of Acute and Critical Care* 29(4): 248-255.
- Dickerson, S., Reinhart, A. M., Feeley, T. H., Bidani, R., Rich, E., Garg, V. K. and Hershey, C. O. (2004). Patient Internet use for health information at three urban primary care clinics. *Journal of the American Medical Informatics Association* 11(6): 499-504.
- Dixon-Woods, M., Agarwal, S., Jones, D., Young, B. and Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research & Policy* 10(1): 45-53.
- Edwards, A., Elwyn, G. and Gwyn, R. (1999). General practice registrar responses to the use of different risk communication tools in simulated consultations: a focus group study. *British Medical Journal* 319(7212): 749-752.
- Eysenbach, G. (2000). Recent advances: consumer health informatics. *British Medical Journal* 320(7251): 1713-1716.
- Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA: A Cancer Journal for Clinicians* 53(6): 356-371.
- Eysenbach, G. and Köhler, C. (2002). How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal* 324(7337): 573-577.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. and Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *British Medical Journal* 328(7449): 1166-70.
- Eysenbach, G., Powell, J., Kuss, O. and Sa, E.-R. (2002). Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. *Journal of the American Medical Association* 287(20): 2691-2700.
- Eysenbach, G., Sa, E. and Diepgen, T. (1999). Shopping around the Internet today and tomorrow: towards the millennium of cybermedicine. *British Medical Journal* 319(7220): 1294.
- Ferguson, T. (2000). Online patient-helpers and physicians working together: a new partnership for high quality health care. *British Medical Journal* 321(7269): 1129-1132.
- Ferguson, T. (2002). From patients to end users. *British Medical Journal* 324(7337): 555-556.
- Ferguson, T. and Kelly, B. (1999). *E-patients prefer e-groups to doctors for 10 of 12 aspects of health care*. The Ferguson Report. Available at: <http://www.fergusonreport.com/articles/fr039905.htm> (accessed 10th November 2008).
- Franciosi, M., Pellegrini, F., De Berardis, G., Belfiglio, M., Cavaliere, D., Di Nardo, B., Greenfield, S., Kaplan, S., Sacco, M., Tognoni, G., Valentini, M. and Nicolucci, A. (2001). The impact of blood glucose self-monitoring on metabolic control and quality of life in type 2 diabetic patients. *Diabetes Care* 24:1870-1877.
- Gauld, R. (2011). Factors associated with e-mail and Internet use for health information and communications among Australians and New Zealanders. *Social Science Computer Review* 29(1): 161-171.
- Gerber, B. and Eiser, A. (2001). The patient-physician relationship in the Internet age: future prospects and the research agenda. *Journal of Medical Internet Research* 3(2): 15.
- Gibson, C. (1991). A concept analysis of empowerment. *Journal of Advanced Nursing* 16(3): 354-61.
- Glasziou, P., Irwig, L. and Mant, D. (2005). Monitoring in chronic disease: a rational approach. *British Medical Journal* 330(7492): 644-648.
- Goldzweig, C., Towfigh, A., Maglione, M. and Shekelle, P. (2009). Costs and benefits of health information technology: new trends from the literature. *Health Affairs* 28(2): 282-293.
- Greenhalgh, T., Stramer, K., Bratan, T., Byrne, E., Russell, J. and Potts, H. (2010). Adoption and non-adoption of a shared electronic summary record in England: a mixed-method case study. *British Medical Journal* 340: c3111.
- Hardey, M. (2002). "The story of my illness": personal accounts of illness on the Internet. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 6(1): 31-46.
- Harris, M., Williams, A., Dennis, S., Zwar, N. and Davies, G. (2008). Chronic disease self-management: implementation with and within Australian general practice. *Medical Journal of Australia* 189(10): S17-S20.
- Jadad, A. (1999). Promoting partnerships: challenges for the Internet age. *British Medical Journal* 319(7212): 761-764.
- Jeannot, J., Froehlich, F., Wietlisbach, V., Burnard, B., Terraz, O. and Vader, J. (2004). Patient use of the Internet for health care information in Switzerland. *Swiss Medical Weekly* 134(21-22): 307-12.
- Kaelber, D., Jha, A., Johnston, D., Middleton, B. and Bates, D. (2008). A research agenda for personal health records (PHRs). *Journal of the American Medical Informatics Association* 15(6): 729-736.
- Kahn, J., Aulakh, V. and Bosworth, A. (2009). Personal health records: what it takes: characteristics of the ideal personal health record. *Health Affairs* 28(2): 2369-376.
- Karsh, B., Weinger, M., Abbott, P. and Wears, R. (2010). Health information technology: fallacies and sober realities. *Journal of the American Medical Informatics Association* 17(6): 617.
- Keselman, A., Slaughter, L., Smith, C., Kim, H., Divita, G., Browne, A., Tsai, C. and Zeng-Treitler, Q. (2007). Towards consumer-friendly PHRs: patients' experience with reviewing their health records. *American Medical Informatics Association 2007 Symposium Proceedings* 2007: 399-403.
- Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. and Wangberg, S. (2008). e-Health trends in Europe 2005-2007: a population-based survey. *Journal of Medical Internet Research* 10(4): e42.
- Lemire, M., Sicotte, C. and Paré, G. (2008). Internet use and the logics of personal empowerment in health. *Health Policy* 88(1): 130-140.
- Lorig, K., Sobel, D., Ritter, P., Laurent, D. and Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice* 4(6): 256-62.

- Lowy, C. (1998). A memorable patient: home glucose monitoring, who started it? *British Medical Journal* 316(7142): 1467.
- Markle Foundation. (2003). Connecting for health, a public-private collaborative: the personal health working group. Final report. Available at: http://www.connectingforhealth.org/resources/final_phwg_report1.pdf.
- Mort, M., Finch, T. and May, C. (2009). Making and unmaking telepatients. *Science, Technology & Human Values* 34(1): 9-33.
- Nettleton, S. and Hanlon, G. (2006). 'Pathways to the doctor' in the information age: the role of ICTs in contemporary lay referral systems. In: Webster, A. (ed.) *New Technologies in Health Care Challenge, Change and Innovation*. Hampshire, Palgrave Macmillan.
- NHS Confederation (2011). Remote control: the patient-practitioner relationship in a digital age.
- O'Connor, A., Bennett, C., Stacey, D., Col, N., Eden, K., Entwistle, V., Fiset, V., Holmes-Rovner, M., Khangura, S., Llewellyn-Thomas, H. and Rovner, D. (2003). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* (2): CD001431.
- Parks, M. and Floyd, K. (1996). Making friends in cyberspace. *Journal of Computer-Mediated Communication* 1(4): 80-97.
- Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K. (2005). Realist review - a new method of systematic review designed for complex policy interventions. *Journal of Health Services Research Policy* 10(Supplement 1): 21-34.
- Pearce, C. and Haikerwal, M. (2010). e-Health in Australia: time to plunge into the 21st Century. *The Medical Journal of Australia* 193(7): 397-398.
- Richards, T. (2007). My illness, my record. *British Medical Journal* 334(7592): 510.
- Sarfati, D., Howden-Chapman, P., Woodward, A. and Salmond, C. (1998). Does the frame affect the picture? A study into how attitudes to screening for cancer are affected by the way benefits are expressed. *Journal of Medical Screening* 5(3): 137-140.
- Simon, J., Gray, A., Clarke, P., Wade, A., Neil, A. and Farmer, A. (2008). Cost effectiveness of self monitoring of blood glucose in patients with non-insulin treated type 2 diabetes: economic evaluation of data from the DiGEM trial. *British Medical Journal* 336(7654): 1177-1180.
- Sommerhalder, K., Abraham, A., Zufferey, M., Barth, J. and Abel, T. (2009). Internet information and medical consultations: experiences from patients' and physicians' perspectives. *Patient Education and Counseling* 77(2): 266-271.
- Stergiou, G., Mengden, T., Padfield, P., Parati, G. and O'Brien, E. (2004). Self monitoring of blood pressure at home. *British Medical Journal* 329(7471): 870-871.
- Tang, P., Ash, J., Bates, D., Overhage, J. and Sands, D. (2006). Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association* 13(2): 121-126.
- Tang, P. and Lansky, D. (2005). The missing link: bridging the patient-provider health information gap. *Health Affairs* 24(5): 1290-1295.
- Verberk, W., Kroon, A., Kessels, A. and de Leeuw, P. (2005). Home blood pressure measurement: a systematic review. *Journal of the American College of Cardiology* 46(5): 743-751.
- Westbrook, J. I. and Braithwaite, J. (2010). Will information and communication technology disrupt the health system and deliver on its promise? *Medical Journal of Australia* 193(7): 399-400.
- White, M. and Dorman, S. (2001). Receiving social support online: implications for health education. *Health Education Research* 16(6): 693-707.
- Wilson, E. (2009). *Patient-centered e-health*. New York, Medical Information Science Reference.
- Winzelberg, A. (1997). The analysis of an electronic support group for individuals with eating disorders. *Computers in Human Behaviour* 13(3): 393-407.
- Woolf, S., Chan, E., Harris, R., Sheridan, S., Braddock, C., III., Kaplan, R., Krist, A., O'Connor, A. and Tunis, S. (2005). Promoting informed choice: transforming health care to dispense knowledge for decision making. *Annals of Internal Medicine* 143(4): 293-300.
- Zwar, N., Harris, M., Griffiths, R., Roland, M., Dennis, S., Powell Davies, G. and Hasan, I. (2006). A systematic review of chronic disease management.: Research Centre for Primary Health Care and Equity, School of Public Health and Community Medicine, UNSW.

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