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Empowering or misleading? Online health information provision challenges

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Abstract

Purpose – Patient empowerment (PE) is a key public health policy tool globally which is seen as unproblematic, but contains a number of unwarranted assumptions and unrecognised challenges to achieving effective implementation. Further, the theoretical foundations for understanding the impact of persuasive health communications on PE are weak. The purpose of this paper is to review these factors and to highlight major areas of concern.

Design/methodology/approach – First, the assumptions underpinning empowerment and the implicit theoretical foundations for active health information seeking behaviours are reviewed. This is then followed by a readability analysis of internet-based material relating to two general medical conditions, four chronic medical conditions and six patient information leaflets which was conducted to explore issues relation to the provision and readability of online health information.

Findings – The assumptions underpinning expectations of policy makers and health organisations regarding active health information seeking are shown to be problematic, with several potential impediments to effective PE implementation, including the fact that almost all of the online material reviewed is written in language too complex for the majority of the general public to comprehend, let alone act on.

Practical implications – Recommendations are made for guiding information seeking and a research agenda is outlined that would aid in strengthening theoretical underpinnings, expand knowledge and thereby help inform practice and policy debate regarding how PE can be improved.

Originality/value – This paper contributes to understanding of the challenges of effective health communication in the digital age by highlighting the need for a greater understanding of online health information seeking and the impact of limited health literacy and numeracy.

Keywords Digital literacy, Health literacy, Health information seeking, DTCA, DTC

Paper type Research paper

Introduction

Patient empowerment (PE) to make decisions regarding medical treatments and the management of chronic medical conditions is a cornerstone of a patient-centred approach to healthcare that began in the 1990s (Feste and Anderson, 1995). However, after two decades, there appears to still be a lack of understanding of the drivers of, and barriers to, PE (Prigge *et al.*, 2015). Given the “surfeit of health information from commercial and non-commercial sources” (Reyna *et al.*, 2009, p. 943), particularly from online sources, this paper therefore aims to review the theoretical assumptions behind PE and to explore the type and characteristics of online health information available, identifying areas of concern for PE implementation (Point 1).

The World Health Organisation supports involvement of healthcare system users in decision making, and patients’ influence rights have been strengthened in several



countries (Joosten *et al.*, 2008). The concept of active information seeking patients who are empowered to effectively manage their general health and well-being or chronic medical conditions (Black *et al.*, 2011) needs to be viewed in a holistic manner, incorporating medical professional support for, or resistance to PE and an understanding of all sources of potential information together with an analysis of how information from different sources is integrated and used in decision making under different levels of certainty regarding potential outcomes (Politi *et al.*, 2007).

Theories used in this sector should enable analysis of these issues and the prediction of the relative influence of different factors on PE. However, we show that current theoretical foundations are weak and require considerable development.

Literature review

Theoretical models

Two theoretical concepts may explain patient information seeking behaviours, particularly in the online environment. Uses and Gratification Theory suggests that people actively seek out information from specific media such as the internet to satisfy specific needs or achieve specific goals which may extend beyond information to encompass social and psychological needs (Hou and Shim, 2010). Unsatisfactory doctor-patient communications is a known predictor of post-consultation online information seeking (Li *et al.*, 2014; Tustin, 2010), however, the motivations for, and extent of online searches pre-consultation is not as well understood. While better knowledge of health issues prior to a consultation with a doctor is claimed to result in more productive visits (Lee, 2008), this appears to be dependent on the patient's ability to identify accurate and relevant information and to be able to relate it to their own personal situation. The readability analyses reported later in this paper will show that there are significant potential problems with this.

Doctors may view patients who have accessed online information pre-consultation as a burden due to the time needed to evaluate the information, correct misconceptions and modify unrealistic patient expectations, even if patients themselves feel empowered by their prior information gathering (Massey, 2013; Tustin, 2010). Consistent with the concept of Media Systems Dependency, online resources may be seen as more accessible than health professionals and the more they are used, the more dependent people become on them (Tustin, 2010). Thus Uses and Gratification Theory indicates that patients with unmet needs will seek alternative information sources; this seems most likely when anxieties are high and it is felt that questions have not been answered during a consultation (Bell *et al.*, 2011). Media systems dependency offers an explanation for a perception among patients that online sources enable more information to be accessed than is possible within a tightly time-constrained consultation; satisfaction with initial searchers will lead to increased reliance on those sources (Bowes *et al.*, 2012). However, if information is not available in a form patients can access, understand and apply, PE will be hampered, with negative consequences for both patient well-being and health system costs.

The weaknesses of the two concepts are that, while they offer broad descriptive facilities, they do not offer predictive capacity. It is likely that there are diverse patient segments with differing information acquisition strategies and resulting outcomes (Acosta-Deprez *et al.*, 2013; Prigge *et al.*, 2015). There is thus a clear need to understand the use of digital media such as the internet as a health information source across patient segments and to understand the consequences, both positive and negative, of information seeking behaviours using such sources for both the patient and the

medical practitioner. From this understanding, strategies to help medical practitioners respond effectively to patients who have gathered online health information can be developed. By strengthening theoretical underpinnings of this activity, strategies for maximising benefits and minimising potential negative impacts, guidance for policy decisions aimed at improving efficient and effective use of all resources can be achieved.

Active and empowered patients and electronic information

While enthusiastic support for the use of electronic technology to communicate health-related information is evident (Joosten *et al.*, 2008), risks associated with this strategy are generally not recognised and the cost-effectiveness of programs using electronic communications platforms has yet to be demonstrated (Black *et al.*, 2011). Support is largely due to a growing, but not universal, acceptance of active partnerships, as opposed to earlier paternalistic relationships between medical professionals and patients (Hou and Shim, 2010). While some doctors appear to welcome active information seeking by patients as leading to more productive consultations, others are reported as feeling their expertise is devalued and that they have lost control of information provision (Hughes *et al.*, 2008). Negative reception of patient-sourced information may lead to avoidance of the doctor in future and increased searching for information and other opinions (Bowes *et al.*, 2012). Statement such as “patients should be more active and effective managers of their health” (J. Greene and Hibbard, 2012, p. 520) appears to have been accepted uncritically: there is a growing body of literature relating to PE (see e.g. Schulz and Nakamoto, 2013b) and patient activation whereby patients “have the motivation, knowledge, skills and confidence to make effective decisions to manage their health” (J. Greene and Hibbard, 2012). While empowerment is growing in popularity as a concept, how it can be most effectively achieved remains under-researched (Calvillo *et al.*, 2013), with statements such as patients being “properly informed” by doctors open to interpretation and offering little guidance to processes or measurement. An implicit assumption behind PE is that it is unproblematic and medical professionals operationalise it. The impact of support for, vs resistance to, active patient involvement in treatment decisions remains under-researched.

Empowerment must also be viewed in the context of patients seeking information independent of medical professionals. “More people are posing health questions to google than to their doctors” (Kitchens *et al.*, 2014, p. 454). Almost half of those accessing internet-based information do not discuss the information obtained with their doctor, although this drops to less than 20 per cent for chronic conditions (Bartlett and Coulson, 2011). If the information obtained is high quality, people should be better informed and make better health-related decisions. Conversely, low-quality information may expose people to inaccurate or emotionally disturbing material, or lead to unnecessary or unwise health treatments (Hu *et al.*, 2012). It is suggested that increased reliance on the internet to disseminate health information will disadvantage some sections of the population due to a lack of ability to access, understand and effectively apply information (Bodie and Dutta, 2008; Kaphingst *et al.*, 2012). Health literacy and the related concept of health numeracy are discussed in later sections, however, while they are necessary for empowerment, they are not of themselves sufficient to achieve it: motivation and self-efficacy are also needed. Further, supporters of empowerment ignore the fact that not all patients want to be actively involved in medical decision (Lee *et al.*, 2010). There is thus a need to recognise that the expectation that patients will understand and apply health-related information may actually represent an unwelcome

burden to some patients or their caregivers (Reyna *et al.*, 2009). Organisations such as the WHO do not appear to have taken these issues into consideration in promoting the PE concept.

Another issue with the potential to adversely impact on PE is access to harmful information, particularly from online sources. Policy makers and health organisations appear to assume that all information available is of potential benefit to patients. Concerns regarding safety and ability to assess quality of online health information are noted in literature (Lau *et al.*, 2012), specifically regarding harmful health material targeted at consumers (e.g. pro-tobacco content in YouTube videos), public displays of unhealthy behaviours (e.g. self-harm and drug use), tainted public health messages (content counter to official public health messages) and psychological impacts from accessing inappropriate social media content (exposure to disturbing or offensive material without warning). Neither of the two theoretical models reviewed earlier offer adequate explanatory or predictive capacity to encompass the impact of positive vs negative relationships with medical professionals or access to information of dubious quality or value. Given the increasing use of online information sources, we therefore turn our attention to different sources of online health information, commencing with information from commercial sources.

Direct-to-consumer (DTC) promotion of medication

DTC involves the promotion of medication direct to the consumer, including advertising (DTCA) and other forms of promotional activity. It is particularly controversial in relation to prescription medicines as the promotion is to the patient, but the prescribing decision rests with a medical professional. Debate has raged for well over a decade regarding its effect on doctor-patient relationships, prescribing practices and patient outcomes (Eagle and Chamberlain, 2004). In 2010, the overall expenditure on prescription medicines was estimated at US\$307 billion (Fogel and Teichman, 2014). It is difficult to determine expenditure on DTC advertising of prescription medications: within the USA it was estimated at US\$4.8 billion in 2008 (Ahn *et al.*, 2014) but this figure does not include precise expenditure on digital media, which some estimate to be 4 per cent of overall expenditure (J.A. Greene and Kesselheim, 2010).

There are concerns that DTCA activity may be “hidden within disease awareness campaigns, ePharmacy web pages and online communities” (Gu *et al.*, 2011, p. 196) making expenditure estimates challenging. While DTC advertising of prescription medication is only formally permitted in the USA and New Zealand, electronic forms of DTC (e-DTC) enable consumers from other countries to access DTC material, including websites, advertisements and social media sites (Ahn *et al.*, 2014; Choi and Lee, 2007; Donohue *et al.*, 2007; Kornfield *et al.*, 2013). Specific concerns have been raised regarding the inadequacy of current DTC regulatory provisions regarding electronic/online DTC (e-DTC) (Gibson, 2014). However, no research has been conducted specifically on e-DTC’s actual effects on patient information seeking behaviours and interactions with health professionals. The ten largest global pharmaceutical companies are all active on social media such as Facebook, Twitter and sponsored blogs with eight also having YouTube channels (Collier, 2014).

In the two countries where DTC of prescription medicines is allowed, DTC in traditional media has been criticised as leading to increased financial burdens on the health system through “disease mongering” (Kochen and Córdoba, 2013, p. 27) or “selling sickness” (Moynihan *et al.*, 2002, p. 886). It is claimed that DTC fundamentally changes the doctor-patient relationship (Spurgeon, 1999), including reports of patients

requesting (McKinlay *et al.*, 2014), or even insisting on being prescribed advertised medication (Mehta and Purvis, 2003). “Lifestyle medicines” (Gilbert *et al.*, 2000, p. 1341), such as medicines for erectile dysfunctions, obesity, lipid lowering agents and proton pump inhibitors have been found to be advertised particularly heavily and requested frequently (Egger *et al.*, 2009).

Conversely, some positive effects of DTC have also been acknowledged, such as encouraging discussions with GPs about specific health problems (Finlayson, 2005) and increased patient confidence when talking about illnesses with a health care provider and actively seeking help (Myers *et al.*, 2011). There are several factors where different studies claim positive and negative impacts, leading to the observation that DTC “is both beneficial and detrimental to the public health” (Ventola, 2011, p. 669). Table I summarises the main claims and counter claims made in the academic literature. The contradictory claims are largely due to problems in generalising from individual studies that focus on specific medication or medical conditions: there are likely to be multiple segments and multiple cost-benefit outcomes.

Despite these contradicting findings and potential implications for health policy and communication regulation, there is, to date, relatively little research specifically addressing the extent and impact of online DTC (e-DTC), as an individual information source and its use in combination with other sources of medical information, given that online campaigns are accessible, though not regulated through traditional DTC-advertising regulations, globally. Again, the two theoretical models are inadequate to analyse or predict the impact of e-DTC on PE. We now focus on online information sources that are beyond the control of policy maker-related organisations, i.e. social media.

Social media

Recent US studies suggest between 9 and 12 per cent of people but almost 40 per cent of patients with chronic diseases have participated in one or more of the over 12,000 online support groups available (Bartlett and Coulson, 2011; Hu *et al.*, 2012). Social media is claimed to raise awareness of health issues, improve access to information and empower individuals to manage their health. It also provides a platform for health

Claim re positive effects (Ahn *et al.*, 2014; Ball *et al.*, 2014; Donohue *et al.*, 2007; Liu and Gupta, 2011)

Claim re negative effects (Dave and Saffer, 2012; Gibson, 2014; Kornfield *et al.*, 2013)

Averts under use of medications

Consumers seek unnecessary drugs and ignore alternative treatment options

Motivates consumers to actively interact with doctors. Strengthens doctor-patient relationships and adherence to prescribed medication regimen
Improves acceptance of stigmatised health conditions

Negatively impacts on doctor-patient interactions and relationships, including placing pressure on doctors to prescribe specific medication

Encourages consumers to recognise symptoms and seek medical advice

Increases stigma of conditions such as mental illness

Educates and empowers

Leads to inaccurate self-diagnosis

Fails to provide balanced information of range of treatments available, misinforms and over-emphasises drug benefits

Encourages competition and lowers prices; cost effective in terms of life-years saved

Inflates healthcare costs

Table I.

Contradictory claims made in relation to the impact of DTC

interventions targeting populations that may otherwise be hard to reach (Mowlabocus *et al.*, 2014). When dealing with specific medical conditions, social media may be used to locate others with similar conditions, thereby gaining support and a sense of belonging (Mano, 2014). While there are obvious benefits, there are also potential disadvantages. For example, misinterpretation of messages may occur and a lack of strong ties to other participants may mean that misunderstandings may not be corrected (Bartlett and Coulson, 2011). Online discussion groups have been shown to lead to a “nocebo” effect (Mao *et al.*, 2013) where knowing of a side effect through reading online postings within virtual communities will likely make an individual attribute the side effect to a therapy, leading to discontinuation of or refusal to commence medication. A further concern is that some social media sites have input from bloggers who appear to be independent but who are actually paid or sponsored by pharmaceutical companies (Gibson, 2014).

Thus, social media, like DTC, can be seen as having both positive and negative potential impacts. These can be summarised as follows (Table II). Trust of internet-sourced material for health information has been shown unsurprisingly to predict online health information seeking (Miller and Bell, 2012). The problem is not a lack of information but rather knowing what information to trust (Kravitz and Bell, 2013) and being aware of potential negatives such as loss of privacy and internet scams (Monteith *et al.*, 2013). An “abundance of health information does not always translate into informed choices” (Ivanitskaya *et al.*, 2006, p. 4) The most effective ways to integrate patient use of web-based information into health care practice and the role of medical professionals in guiding searches to relevant and credible sources is un-researched (Schulz and Nakamoto, 2013a) as is the potential role of the pharmaceutical industry. In expanding existing theoretical models or developing new models, these factors must be explored and their influence incorporated. This will require sophisticated analytical techniques, such as structural equation modelling rather than purely descriptive techniques.

Social capital

The social context of health information seeking and decision making, including social and cultural factors in individual homes, work environments (Nutbeam, 2008) and in

Benefits	Limitations
Increases interactions with others	Lack of reliability/quality concerns
More available, shared and tailored information	Lack of confidentiality and privacy
Increased accessibility and widening access	Users often unaware of the risks of disclosing personal information online
Peer, social and emotional support	Risks associated with communicating harmful or incorrect advice using social media
Public health surveillance	Information overload
Potential to influence health policy	Not sure how to correctly apply information found on line to personal health situation
	Certain social media technologies may be more effective in behaviour change than others
	Adverse health consequences
	Negative health behaviours

Table II.
Benefits and limitations of using social media for health communication: general public and patients

Source: Moorhead *et al.* (2013, pp. 35-36)

the wider communities in which both of the former are situated has been under-researched and recent research suggests social capital may offer a useful framework for examining these influences. Social capital is “actual or potential resources that result from social connections and senses of reciprocity and trust, which, when mobilised, can bring about outcomes at the individual and collective level” (Beaudoin and Tao, 2007, p. 587). Interest in the concept within the health sector is relatively recent, but research has indicated that social capital can influence health outcomes as social networks enable information and resource sharing and support (Lewis and Martinez, 2014). Close ties positively are associated with communication efficacy which then is associated with information seeking, however, the relative impact of information from interpersonal vs mediated sources requires further investigation (Chen *et al.*, 2015; Lewis and Martinez, 2014). While social capital is widely discussed, its precise meaning, dimensions and mechanisms are unclear. This is due, in part, to the fact that the concept is, in spite of a large body of literature on the subject, difficult to define due to multiple definitions stemming from disparate disciplinary approaches including economics, political science, sociology and anthropology and other social sciences. This diverse disciplinary interest has resulted in a lack of standardised measurement instruments (Gaag and Webber, 2008) or empirical data across all aspects of society in which social capital (however, defined) may have a role (Sabatini, 2009).

Social capital can be categorised into three subsets, bonding, bridging and linking. Bonding social capital focuses on homogeneous groupings, “such as religious, cultural, professional, racial, or ethnic groups” (Ebi and Semenza, 2008, p. 502): ties are generally close. Bridging social capital focuses on the connections between socially heterogeneous groups and linking social capital on the connections between people at different levels of power and influence although the latter is sometimes subsumed into bridging capital (Murayama *et al.*, 2012). While bridging ties may be weaker, they enable useful transfers of information (Lewis and Martinez, 2014). Effective social capital enables a wider range of information sources and faster information flow and is linked to digital literacy and inequalities as social and digital connectivity are inter related (Chen *et al.*, 2015). Authors’ comparison of effects across studies is hampered by inconsistent operationalisation of the social capital construct (Iwase *et al.*, 2012).

Thus considerably more work will be required to determine how social capital can be conceptualised before it is able to be added to the range of other factors already noted as warranting inclusion in more powerful theoretical models that can explain and predict the impact of the increasingly complex range of factors potentially impacting effective PE implementation.

Some potential barriers to PE are more easily examined. We therefore now turn our attention to a fundamental barrier to PE, i.e. limitations within significant percentages of the population relating to access to information and its comprehension.

Health literacy, numeracy, digital literacy and digital divides

The percentage of the US population that seek health information online is at least 60 per cent (Kitchens *et al.*, 2014), and possibly over 70 per cent (Pew Research Internet Project, 2013). Similar figures are recorded for Canada (Gibson, 2014). It is not unreasonable to assume that percentages would be high in most other developed countries. The range of competencies, including health literacy, needed to evaluate the quality of health information, conduct effective information searches and evaluate the quality and trustworthiness of information sources has been underestimated for more than a decade (Ivanitskaya *et al.*, 2006).

Health literacy

Health literacy at its simplest is defined as: “individuals’ knowledge and skills to deal successfully with matters of health and illness” (Abel *et al.*, 2014, p. 1). A more complex definition drawn originally from the US Department of Health and Human Services Healthy People 2010 report is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Britt and Hatten, 2013, p. 2).

There is a relationship between health literacy skills and health outcomes and evidence in several studies that health literacy levels are suboptimal and disparities in literacy are increasing (Bodie and Dutta, 2008). The 2011 European Health Literacy survey found almost half of Europeans to have limited health literacy (HLS-EU Consortium, 2011); similar levels have been identified in North America (Manafò and Wong, 2012). Those with low literacy incur higher health care costs, use more inpatient and emergency department services and tend to have inefficient mixes of health care services (Eichler *et al.*, 2009). They will also struggle to understand, or potentially misinterpret information, including DTC advertisements (Mackert and Love, 2011).

E-health literacy is defined as the “ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” (Chen and Lee, 2014, p. 104). It is complex, being impacted by: traditional literacy and numeracy, health literacy, computer literacy, media literacy, science literacy and information literacy (Norman and Skinner, 2006). Communication capital, i.e. the ability to discuss problems with family, friends, colleagues or wider community members is suggested as an additional dimension (Jeffres *et al.*, 2013) although this concept has not been operationalised or tested.

It is suggested that e-Health levels will change as technology changes (Collins *et al.*, 2012). Health literacy overall is also not static, being context specific, with different knowledge and skills needed to prevent disease and maintain a healthy lifestyle vs the knowledge and skills needed to successfully navigate health services (Abel *et al.*, 2014). There are known socio-economic differences in digital literacy (specific skills and wider competencies impacting on both time online and tasks carried out; Castaño-Muñoz, 2010).

Cross-country studies conducted by the OECD and other organisations identify five different levels of literacy. Level 3 is regarded as the “minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy” (Australian Bureau of Statistics, 2006/2008, p. 1). Recent OECD data, shown in Table III, indicates that a significant percentage of people across a range of OECD countries do not reach this level, imposing a barrier to the comprehension and application of health-related information for PE.

Health numeracy

Closely linked to health literacy, and often regarded as a subset of it, is the concept of health numeracy – the ability to access, understand and apply numerical data in health decisions (Ancker and Kaufman, 2007). Numeric information covers disease risks, potential outcomes of undertaking disease prevention behaviours and the risks vs benefits of specific medications or medical procedures, with the assumption that understanding of this material is unproblematic and leads to informed decisions and behaviours (Lipkus and Peters, 2009). Table IV indicates that similar problems exist in relation to numeracy as for literacy with similar implications for the achievement of effective PE.

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	Below level 1 %	Level 1 %	Level 2 %	Level 3 %	Level 4 %	Level 5 %	Missing %
Australia	3.1	9.4	29.2	39.4	15.7	1.3	1.9
Germany	3.3	14.2	33.9	36.4	10.2	0.5	1.5
Japan	0.6	4.3	22.8	48.6	21.4	1.2	1.2
Norway	3.0	9.3	30.2	41.6	13.1	0.6	2.2
Poland	3.9	14.8	36.5	35.0	9.0	0.7	0.0
USA	3.9	13.6	32.6	34.2	10.9	0.6	4.2
England	3.3	13.1	33.1	36.0	12.4	0.8	1.4
Russian Federation	1.6	11.5	34.9	41.2	10.4	0.4	0.0

Notes: Level descriptors: below Level 1: basic vocabulary knowledge only; Level 1: read relatively short digital or print texts to locate a single piece of information; Level 2: match text and information, may require paraphrasing or low-level inferences; Level 3: read dense or lengthy text, identify, interpret or evaluate one or more pieces of information, disregard irrelevant or inappropriate content; Level 4: integrate, interpret or synthesise information from complex or lengthy texts, interpret or evaluate subtle evidence-claims or persuasive discourse; Level 5: search for and integrate information across multiple dense texts, construct synthesis of similar and contrasting ideas or evaluate evidence-based argument, make high-level inferences. Adults in the missing category were not able to provide enough background information to impute proficiency scores because of language difficulties, learning or mental disabilities

Source: Organisation for Economic Cooperation and Development (OECD) (2013; Table 2.1)

Table III.
Percentage of adults scoring at each proficiency level in literacy national entities

	Below level 1 %	Level 1 %	Level 2 %	Level 3 %	Level 4 %	Level 5 %	Missing %
Australia	5.7	14.4	32.1	32.6	11.7	1.5	1.9
Germany	4.5	13.9	31.0	34.9	13.0	1.2	1.5
Japan	1.2	7.0	28.1	43.7	17.3	1.5	1.2
Norway	4.3	10.2	28.4	37.4	15.7	1.7	2.2
Poland	5.9	17.6	37.7	30.5	7.7	0.7	0.0
USA	9.1	19.6	32.6	25.9	7.8	0.7	4.2
England	6.4	17.8	33.3	29.8	10.4	0.9	1.4
Russian Federation	2.0	12.1	39.7	38.1	7.7	0.3	0.0

Notes: Level descriptors: below Level 1: counting, sorting, basic arithmetic with whole numbers; Level 1: perform simple, one-step concrete tasks including simple percentages, simple graphical or spatial representations; Level 2: perform task that require identifying and acting on mathematical information in common contexts; Level 3: perform task that require an understanding of mathematical information in contexts that are not always familiar and are presented in more complex ways; Level 4: perform tasks that may be complex, abstract or embedded in unfamiliar contexts: multiple steps requiring selection of appropriate problem solving; Level 5: understand complex representations and abstract and formal mathematical and statistical ideas, sometimes embedded in complex texts. Adults in the missing category were not able to provide enough background information to impute proficiency scores because of language difficulties, learning or mental disabilities

Source: OECD (2013; Table A2.5)

Table IV.
Percentage of adults scoring at each proficiency level in numeracy national entities

As with literacy, there are concerns that low numeracy skills may adversely impact on health decisions and outcomes: “low numeracy is pervasive and constrains informed patient choice, reduces medication compliance, impedes access to treatments, impairs risk communication (limiting prevention efforts among those most vulnerable

to health problems), and, based on the scant research conducted on outcomes, appears to adversely affect medical outcomes” (Reyna *et al.*, 2009, p. 2). It has been noted that almost 40 per cent of patients in a cancer screening study “reported that they found it hard or very hard to understand medical statistics” (Kiechle *et al.*, 2015). Further, 16 per cent of a highly educated sample could not correctly answer questions relating to risk magnitude (Peters *et al.*, 2007). In spite of this knowledge, practical solutions are not debated in the literature.

The same OECD study from which numeracy data was obtained shows that similar problems are evident in regard to numeracy, with implications for understanding factors such as correct medication dosages and that the problem is even greater in relation to problem-solving ability in technology-rich environments.

Earlier data from the Australian Bureau of Statistics indicated that, while literacy problems impacted some 40 per cent of the population to some degree, the ability to use information to solve problems was a much more widespread problem, with up to 70 per cent of the population having problems with problem solving, defined as goal-directed thinking and action in situations for which no routine solution is available (Australian Bureau of Statistics, 2006/2008). Unfortunately, these types of data are not available for other countries, but it is not unreasonable to assume that similar challenges exist across national borders.

The increase in online information in the expectation that people will be able to use it effectively is somewhat concerning, given the 2006 Australian findings and recent OECD findings, shown in Table V, regarding proficiency in problem solving in technology-rich environments which is defined as: “using digital technology, communications tools and networks to acquire and evaluate information, communicate with others and perform practical tasks” (Organisation for Economic Cooperation and Development (OECD), 2012, p. 5). It is suggested that an increasing reliance on internet-based technology will widen these disparities (Dutta-Bergman, 2005); high levels of health/e-health literacy may be an enabler, but low levels will be a barrier (Hu *et al.*, 2012).

	Below level 1 %	Level 1 %	Level 2 %	Level 3 %	No computer experience %	Opted out of computer based assessment %	Failed ICT core %	Missing %
Australia	9.2	28.9	31.8	6.2	4.0	13.7	3.5	2.7
Germany	14.4	30.5	29.2	6.8	7.9	6.1	3.7	1.5
Japan	7.6	19.7	26.3	8.3	10.2	15.9	10.7	1.3
Norway	11.4	31.8	34.9	6.1	1.6	6.7	5.2	2.2
Poland	12.0	19.0	15.4	3.8	19.5	23.8	6.5	0.0
USA	15.8	33.1	26.0	5.1	5.2	6.3	4.1	4.3
England	15.1	33.8	29.3	5.7	4.1	4.6	5.8	1.6
Russian Federation	14.9	25.6	20.4	5.5	18.3	12.8	2.5	0.0

Notes: Level descriptors: below Level 1: perform one simple technology function only; Level 1: use of widely available and familiar technology applications: simple reasoning; Level 2: use of both generic and more specific technology applications. Some integration and inferential reasoning may be needed; Level 3: tasks require evaluating relevance and reliability of information. Integration and inferential reasoning may be needed to a large extent. Adults in the missing category were not able to provide enough background information to impute proficiency scores because of language difficulties, learning or mental disabilities

Source: OECD (2013; Table 2.10a)

Table V.
Percentage of adults scoring at each proficiency level in problem solving in technology-rich environments

Research question

Given the barriers identified in relation to literacy and numeracy discussed in the preceding sections, we therefore set the following research question for a readability analysis:

RQ1. Are health information materials readily available online or through medical professions written at a level that would enable the majority of the population to readily understand them? (Point 3).

The OECD data reported in the earlier tables does not link to any form of measurement tool that enables information to be assessed against the levels identified in their reports. We therefore used a different methodology to obtain a measure of likely readability.

Readability analysis: specific aim and methodology

Part A: online information – methodology: we used Google to search for two health and well-being topics, i.e. diet and exercise, then four of the most common chronic disorders, then analysed the first five results obtained for each using the SMOG readability index. This index indicates the years of formal education necessary to be able to comprehend material and was selected because it has been repeatedly validated, and because of its proven accuracy, correlation with other readability formulae and subsequent widespread use in the academic literature, primarily in the health field ([Mumford, 1997](#); [Wallace and Lemon, 2004](#)). It has been described as “the gold standard readability measure” ([Fitzsimmons *et al.*, 2010](#), p. 294). The method used for the SMOG calculations followed the methodology in the literature ([Aldridge, 2004](#)). SMOG calculations can be calculated manually, however, the originator ([McLaughlin, 1969](#)) of the SMOG formula has also provided an (undated) internet-based version of the calculator at www.harrymclaughlin.com/SMOG.htm. Thus, we compared the manually calculated results with those derived from the internet version and found no difference between them. This calculation measures only the likely reading level in terms of years of formal education required for comprehension of the material and not other aspects such as suitability of material for patient needs which could be assessed using other tools such as the readability assessment instrument ([Adkins *et al.*, 2001](#)) or the suitability assessment of materials measurement ([Doak *et al.*, 1985](#)). Excluded were: dictionary definitions, sales-based sites such as for herbal weight loss or asthma relief products, sites that duplicated information such as Australian state and federal sites. In this latter instance, only the first site was used, whether state or federal in origin. Sites in languages other than English (which only occurred for one diabetes medication) and online pharmacies offering medication without prescription were also excluded.

Reading is a skill like any other and the average adult reading skill level will fall by 3-5 grades below the level expected at the completion of formal education. Thus an adult who left school after 12 years of formal education but who does not maintain their reading skills can be expected to have a reading skill level of 7-9 ([Kemp and Eagle, 2008](#)). To be readily comprehended by the majority of people, we therefore would expect that the material analysed would return readability scores within the 7-9 range. We will show that this is not in fact the case for the vast majority of the sites. As the following tables indicate, all but two of the sites examined (WebMD in Table VI and NHBLI in Table IX) contain material written well above the average person’s ability to understand it.

It is interesting to note that Wikipedia sites in Tables VI-VIII contain material that requires at least some tertiary education, and for physical exercise in Table VI, to post graduate level. It is of further concern that several government-funded organisations’ material and that from drug information sites also present material that requires

Organisation	URL	SMOG	Empowering or misleading?	
<i>General health and well-being: diet</i>				
Impromy	http://impromy.com/?gclid=CIOEvdmh4MECFY0svQodDrUA7w	14.91	1011	
Web MD	www.webmd.com/diet/features/what-your-parents-got-wrong-about-food	9.04		
Body+soul	www.bodyandsoul.com.au/weight+loss/diets/	11.2		
Body trim	www.bodytrim.com.au/diet	12.53		
Wikipedia	http://en.wikipedia.org/wiki/Diet_(nutrition)	13.46		
The 5.2 fast diet	http://thefastdiet.co.uk/	9.95		
<i>General health and well-being: exercise</i>				
Wikipedia	http://en.wikipedia.org/wiki/Physical_exercise	15.68		Table VI. SMOG analysis for general health and well-being internet-based material
Mayo clinic	www.mayoclinic.org/healthy-living/fitness/in-depth/exercise/art-20048389	12.07		
Web MD	www.webmd.com/fitness-exercise/	11.0		
Better health channel	www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Depression_and_exercise	14.62		
About health	http://exercise.about.com/cs/cardioworkouts/a/burn300calories.htm	12.41		
<hr/>				
Organisation	URL	SMOG		
<i>Chronic medical condition: diabetes</i>				
Health Direct Australia	www.healthdirect.gov.au/diabetes?gclid=CJ-bvb255MECFVcDvAodrkkAdQ	12.30	Table VII. SMOG analysis for general and specific medication-focused internet-based material for diabetes	
Wikipedia	http://en.wikipedia.org/wiki/Diabetes_mellitus	13.05		
Diabetes Australia	www.ndss.com.au/en/About-Diabetes/	13.14		
About.com	http://index.about.com/index?gclid=CNjc8bG85MECFRUJvAodH74Aag&am=broad&q=information+about+diabetes&an=google_s&askid=8a623177-5e3e-4891-9676-d5558de07725-0-ab_gsb&dqi=&qsrc=999&ad=semD&o=5946&l=sem	11.93		
American Diabetes Asn	www.diabetes.org/	13.91		
<i>Diabetes-specific drugs</i>				
Better Health: Diabex	www.betterhealth.vic.gov.au/bhcv2/bhcmcd.nsf/pages/afcdiabe/\$File/afcdiabe.pdf	13.51		
Virtual Medical Centre: Diabex	www.myvmc.com/drugs/diabex/	12.21		
Livestrong: Diabex side effects	www.livestrong.com/article/252403-side-effects-of-diabex/	11.18		
Gp2u: Diabex product information	https://gp2u.com.au/static/pdf/D/DIABEX_XR-PI.pdf	13.39		
My Virtual Medical Centre: Glucohexal	www.myvmc.com/drugs/glucohexal/	14.10		

tertiary education. This probably reflects the education level of those providing the material rather than the intended users of it but indicates the need for the providers of this type of information to be more attuned to the abilities of the intended recipients of the material (Tables IX and X).

Part B: we then analysed a range of standard patient information leaflets available from a general medical practice and obtained similar findings to the internet-based material as shown in Table XI. While the readability scores are lower than the internet-based material, a significant percentage of the population are likely to still struggle with comprehension of this material. Once again, this is a potential barrier to effective PE.

MIP
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1012

Table VIII.
SMOG analysis for
general and specific
medication-focused
internet-based
material for asthma

Organisation	URL	SMOG
<i>Chronic medical condition: asthma</i>		
Health Direct Australia	www.healthdirect.gov.au/asthma?gclid=CKihsIK_5MECFQoDvAodySIAbA	11.37
Wikipedia	http://en.wikipedia.org/wiki/Asthma	14.51
Royal Children's Hospital	www.rch.org.au/clinicalguide/guideline_index/Asthma_Acute/	17.04
Royal Children's Hospital: Parent's handout	www.rch.org.au/kidsinfo/fact_sheets/Asthma/	10.14
National Heart, Lung and Blood Institute	www.nhlbi.nih.gov/health/health-topics/topics/asthma/	7.95
<i>Asthma-specific drugs</i>		
Drugs.com: Ventolin	www.drugs.com/ventolin.html	11.39
GlaxoSmith Kline: Ventolin	www.gsk.com.au/products_prescription-medicines_detail.aspx?view=29	11.07
Better Health: Bricanyl	www.betterhealth.vic.gov.au/bhcv2/bhcmcd.nsf/pages/apcbrici/\$File/apcbrici.pdf	13.52
Medicine.Net.com	www.medicinenet.com/terbutaline/article.htm	12.32
Netdoctor.co.uk: Bricanyl	www.netdoctor.co.uk/allergy-and-asthma/medicines/bricanyl.html	12.00

Organisation	URL	SMOG
<i>Chronic medical condition: coronary heart disease</i>		
Health Direct	www.healthdirect.gov.au/coronary-heart-disease-and-atherosclerosis?gclid=Cj0KEQjw-tSrBRck8bzDiO_gbwBEiQAK-D31YjdFWV689JqarJP5opMZ2F29qWg0_3XNUfswyAL7pMaAr dh8P8HAQ	14.94
Heart Foundation	www.heartfoundation.org.au/Pages/default.aspx?gclid=Cj0KEQjw-tSrBRck8bzDiO_gbwBEiQAK-D31cVPp0kZ6Z6z7wyYYK1P6dc bL17jKYoNdy0WtLE5RyMaApUP8P8HAQ	12.78
Heart Research Institute	www.hri.org.au/Page.aspx?pid=351	13.17
US National Heart, Lung, and Blood Institute	www.nhlbi.nih.gov/health/health-topics/topics/cad	10.10
Wikipedia	http://en.wikipedia.org/wiki/Coronary_artery_disease	11.98
<i>Heart disease – specific drugs</i>		
Web MD ACE Inhibitors	www.webmd.com/heart-disease/tc/coronary-artery-disease-medications	11.30
Mayo Clinic Cholesterol - modifying medication	www.mayoclinic.org/diseases-conditions/coronary-artery-disease/basics/treatment/con-20032038	13.06
NHS Choices Antiplatelets low dose aspirin	www.nhs.uk/conditions/Anti-platelets-aspirin-low-dose-/Pages/Introduction.aspx	14.87
Antiplatelets clopidogrel	www.nhs.uk/conditions/Anti-platelets-clopidogrel/Pages/Introduction.aspx	13.41
Drugs.com Norvasc	www.drugs.com/condition/coronary-artery-disease.html	10.52
Medicine.Net Betablockers	www.medicinenet.com/beta_blockers/article.htm	15.09
Mayoclinic Betablockers	www.mayoclinic.org/diseases-conditions/high-blood-cholesterol/in-depth/statins/art-20045772	11.47

Table IX.
SMOG analysis for
coronary heart
disease

It is therefore evident that the majority of the material analysed both from internet-based and more “traditional” sources is written in language far too complex for the average person to understand and thus act on, thus presenting a major impediment to the achievement of effective PE. Given that PE is, as we noted earlier, a public policy

Organisation	URL	SMOG	Empowering or misleading?	
<i>Chronic medical condition: Alzheimer's disease</i>				
Health Direct	www.healthdirect.gov.au/alzheimers-disease?gclid=Cj0KEQjw-tSrBRck8bzDiO_gbwBEiQAK-D31dz5ieWx21uno9AcAHQAN4qC7jBaFFxMoC03-9kUkuMaAiTm8P8HAQ	14.55	1013	
Fight Dementia.org	https://fightdementia.org.au/about-dementia-and-memory-loss/about-dementia/types-of-dementia/alzheimers-disease	13.84		
Wikipedia	http://en.wikipedia.org/wiki/Alzheimer's_disease	13.39		
National Institute on Aging	www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet	13.17		
Better Health Channel	www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Dementia_-_Alzheimer's_disease	14.33		
<i>Alzheimer-specific drugs</i>				
National Institute on Aging	www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet	15.25		
Donepezil (Aricept)	www.aricept.com/	13.49		
Galantamine (Razadyne)	www.nlm.nih.gov/medlineplus/druginfo/meds/a699058.html	10.16		
Rivastigmine (Exelon)	www.rxlist.com/exelon-drug.htm	13.02		
Namenda (memantine HCl)	www.namenda.com/	13.09		

Table X.
SMOG analysis for Alzheimer's disease

Organisation	Leaflet title	SMOG	
<i>Chronic medical condition</i>			
National Diabetes Support Service	Live well with diabetes join the NDSS leaflet	13.83	Table XI. SMOG analysis for Australian patient information leaflets
National Diabetes Support Service	Living well with diabetes	9.51	
Townsville Health Service District	"More About Diabetes" group	12.87	
Asthma Australia	Asthma care	9.79	
Boehringer Ingelheim Pharmaceuticals	Managing COPD with SPIRIVA	11.31	
Pfizer/Quit Victoria (joint initiative with several health organisations)	Champix can help you quit smoking	11.06	

strategy and that a large amount of material originates from sources either directly or indirectly funded by government, this issue could be readily addressed.

Discussion and conclusions

The concept of effective PE faces multiple challenges, particularly in relation to information provision, comprehension and use. The concept, together with its potential barriers and enablers, needs to be mapped in much more detail than has been achieved to date. As part of this, sophisticated analytical research is needed in a number of areas in order to expand and considerably strengthen the currently weak theoretical foundations in the area. As we notes earlier, Uses and Gratification Theory indicates that if patients do not gain information that meets their needs, they will seek information from other sources. What is not known is what these sources might then be, and how information from combinations of sources are used and with what outcomes for PE and ultimately for the patients themselves. Given that the resources reviewed are unlikely to meet the needs of a significant percentage of populations, this issue should be explored as a priority.

As part of this, persuasive health communications should be viewed holistically rather than focusing on individual sectors such as DTC/DTCA, with a greater

understanding of the social and cultural factors that impact on whether, how and from what sources information is sought, interpreted and acted upon. Coupled with this should be a focus on the implications of literacy limitations and the implications for user comprehension together with how existing information can be revised, or alternative sources provided. It is important for all sectors of the health information community, from pharmaceutical companies through to health care providers and those managing online support groups and policy makers to recognise these challenges and to integrate patient use of web-based information into optimum health decision making and to recognise the role and relative importance of all information sources.

Limitations of this study

Only a small range of medical conditions and websites were analysed, however, as these were the first to be listed during the search processes, it is likely that they will be visited first by those seeking information. A wider range of sites may also have identified “alternative” treatment options.

It would also have been desirable to have linked the OECD data directly to readability but no measurement tool exists for this. We believe that the use of the widely used and well-validated SMOG index is an appropriate alternative.

Directions for future research

This research will be extended to include a wider range of medical conditions and of potential information sources, including online discussion and support groups, including social networking sites as well as phone apps. It will also seek to identify the combination of media channels used to gain information about treatment options by patients, with a specific emphasis on new and social media forms, and assess the extent to which these channels influence patients’ interactions with health professionals and, ultimately, health decisions as well as satisfaction and health outcome measures.

Further avenues for future research include evaluation of differences in behaviour and information seeking based on health literacy and education levels, consistent with van Deursen and Van Dijk (2014) observation that accessing of information sources on the internet is mediated by education and socio-economic factors. Following on from this, potentially fruitful research should explore how recipients of internet-based information react towards information written at a level different to their personal health literacy level. This will be followed by exploration of how differing formats of both text-based and numerical information impact on comprehension and application to health decisions across population segments and different levels of certainty/uncertainty regarding potential decision outcomes.

In addition, dialogue with those providing health information resources would be useful in order to test the impact of changes in readability on patient outcomes.

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