# How information about other people's personal experiences on the internet can help with healthcare decision-making and recovery:

# A literature review

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# Executive Summary

## Purpose

The purpose of this snapshot review was to review qualitative literature on how stories about individual experiences of health and illness available on the internet may inform health care decisions and aid people in their everyday negotiation of a chronic condition or injury. This objective of this report is to answer the following two questions:

> ➢ How might people's stories of health and illness on the internet help peopl[e] more informed decisions about their own health care?

> ➢ How might telling and sharing stories with others about health and illness experiences, and accessing people's stories of health and illness assist recovery?

## Methods

Key health and social sciences databases were systematically searched for qu[alitative] research published between 2005 - 2012. The following search terms wer[e] qualitative, chronic illness or injury, personal experiences, experiential expe[riences,] subjective experiences, storytelling, decision making, recovery, behaviour narratives, health narratives, benefits, e-health, Internet, web and online. This yiel[ded] articles. Following detailed assessment, 52 relevant papers were included in this rev[iew.]

## Main findings

Current research on patients' health and information seeking has identified the internet as an increasingly important resource. Patients particularly value other people's stories of their health and illness experiences typically found on internet websites, discussion groups or social media sites, and differentiate between this kind of information and clinical / biomedical information.

The report's key findings are as follows:

*Limited but growing evidence base*

> ➢ There is limited but developing research on the health and illness experiences and outcomes of patients' who access information online. Direct measurement of the benefits of web-based stories of people's health and illness experiences on health outcomes or decision-making is difficult. However the existing evidence on sharing stories on health and illness experiences suggests that stories improve people's understanding of their own situation and can positively influence patient thinking and behaviour.

*Chronic conditions and the search for health information online*

> ➢ Patients are seeking more information regarding chronic conditions online, particularly personal accounts of experiences of such conditions. They

regard this as complementary to clinical / biomedical information and treatment.

*The therapeutic benefits of stories*

Telling stories about health and illness experiences can help patients make sense of these experiences and provide an outlet for their emotions, which in turn can strengthen their sense of agency, promote resilience, and alleviate distress.

➢ Hearing stories about other patients' experiences is also helpful in reducing feelings of isolation, promoting a sense of empathy towards and connection with others, offering different ways of thinking about one's own experiences, and providing encouragement or a sense of hope for the future.

*Personal stories and healthcare decision-making*

➢ Patients value health and illness experience based information because it highlights the real experience of living with a chronic condition in way that clinical information cannot.

➢ Other patients' stories of their experiences can help with decision making in relation to both treatment and everyday life challenges, and can also help alleviate the distress, isolation and anxiety people may feel as a result of living with a chronic condition.

➢ Personal stories of health and illness experiences on the internet help expand patients' knowledge of their condition which in turn may aid patient-Healthcare Professional (HCP) communication and promote better use of medical resources. Better informed patients make more informed health care decisions and are more likely to improve their quality of life than patients who are less informed.

➢ HCPs and policymakers recognise the benefits of better informed patients and are beginning to use the internet to improve self-management of chronic conditions and improve health outcomes for patients.

*How and why patients search for health and illness information online*

➢ The internet is valued as a source of health and illness experience information because it is available when needed, can be accessed by people from a wide range of backgrounds, and provides anonymity.

➢ Different groups (e.g. men, women, young people, people living in rural areas, older people) have different motivations for using the internet for searching for health and illness information.

➢ Patients can be wary of information found online for reasons of volume and quality, fearing they may be overwhelmed or misinformed. Websites supported by reputable organisations or recommended by HCPs alleviate some of these concerns.

*The potential effects of online databases of patient experiences*

➢ Internet-based personal experiences of health and illness, especially those incorporating visual content such as video-recordings, are seen as valuable addition to health care information from doctors, fact sheets, brochures or medical websites.

➢ Rigorous, evidence-based and systematically derived online sources of

personal experiences of health and illness can support and enhance people's health care and ability to self-manage their condition in line with the objectives of the Australian Government's Chronic Disease Strategic Plan.

## Conclusion

The health and mental health needs of those living with chronic conditions or injury are complex. Current research on patients' growing use of the internet to search for health information suggests that information based on other people's experiences of living with a chronic condition may help patients make more informed decisions regarding their health and alleviate distress, an important step on the path to recovery. Health and illness experiences, in the form of online stories, provide insight into living with a chronic condition or injury, not just for patients but their HCPs, carers, family, friends, service providers and policymakers. Stories highlight the various strategies that others use to negotiate their everyday life and approach the future, sources of information, alternative health services and activities that others have found helpful or enjoyable. They can also expand patients' understanding of their condition, which may promote better self-management.

Well-presented stories can inspire, engage and improve individual lives and promote health in an emotionally meaningful way. More formal health information in traditional forms, such as print information and medical advice given by HCPs, remain important. However, health information based on the experiences of those with a particular health condition is above all valuable for providing insight into living with a chronic condition or injury, the complexities inherent in decisions about health and other aspects of their lives, and self-management. An online database of people's stories of health and illness experiences (such as the UK's healthtalkonline.org) has the potential to improve communication between HCPs and patients, building more cooperative and collaborative relationships. This review finds that HCPs and policymakers are recognising the potential of the internet and are using it to i) find out what is important to patients and the public and ii) to aid patient understanding of their condition.

# Background

The Transport Accident Commission (TAC) commissioned this snapshot review of qualitative literature exploring how information about other people's personal health and illness experiences on the internet can help with health care decision-making and recovery. The review was conducted by researchers in the Health and Illness Experiences Research Programme, PSI, Faculty of Arts, at Monash University.

## Aim

Internet access has meant that people and patients, in particular, are searching for health and illness-related information online in increasing numbers. There is evidence that people differentiate between clinical or biomedical information and information based on fellow patients' health and illness experiences. Other people's experiences are an increasingly appreciated form of information used by patients to aid health care decision-making. This snapshot literature review explores the benefits of accessing other patients' experiences of health and illness on the internet, and the potential impact of this information on patients' management of chronic conditions or injury and health outcomes. Two questions are explored:

➢ How might people's stories of health and illness on the internet help people make more informed decisions about their own health care?

➢ How might telling and sharing stories with others about health and illness experiences, and accessing people's stories of health and illness assist recovery?

## Method

There is little published evidence on the impact of patients' experiences of encountering and engaging with others' stories of health and illness on the internet. The scientific basis needs strengthening. This review therefore focuses on the qualitative research in this area to explore the potential impact of online patients' experiences.

A search of various health and social sciences databases was conducted to identify relevant literature published between 2005 and 2012. Databases consulted included: Medline, Psychinfo, Sociological Abstracts, Web of Science, CSA Illimunia, CINAHL, and SAGE online. Further articles were identified using Google Scholar and reference lists in papers reviewed. A few key articles published prior to 2005 have been included. Search terms used to identify literature included: qualitative, chronic illness or injury, personal experiences, experiential experiences, subjective experiences, storytelling, decision making, recovery, behaviour change, narratives, health narratives, benefits, e-health, Internet, web and online. Initial searches identified 132 potentially relevant articles. After further assessment, 52 articles were identified as relevant and subsequently included in the review. The study design,

results and conclusions were summarised for each article and a review of the findings, organised around six main themes, is provided below.

# Results

## Limited but Growing Evidence Base

It is important to note at the outset of this review that research is still developing on the impact on patients' healthcare decision-making and recovery, of sharing their health and illness experience stories, and accessing the experiences of other people online. This is primarily because internet-based experiential accounts of personal health and illness experiences are both a relatively new phenomenon and one that has rapidly expanded in recent years. Much of the published literature has been concerned with the accuracy of information provided in such online resources, instead of exploring how this information affects patients or what they do with it.[13] In addition, and not least because of the way in which people tend to use and integrate information from numerous websites, direct health outcomes are difficult to measure.[14] Nonetheless, existing studies focusing on searching for health information online and stories of people's health and illness experiences have reported potential positive impacts. [2, 15]

A forthcoming paper[2] by Ziebland and Wyke reviews the published literature in the social and health sciences on the potential impact of online health experiences and is a useful guide to the mechanisms through which online patient experiences can potentially affect health. The authors identify these as being: being informed; feeling supported; maintaining relationships; using health services; learning to tell one's own story; visualising illness; and changing behaviour. In all of these domains, Ziebland and Wyke note the possibility of potential harms as well as benefits. However the authors argue that sharing personal experiences of health and illness on-line will remain central to e-health due to 'the value of first person accounts, the appeal and memorability of stories, and the need to make contact with peers'. Importantly, they also note that this is particularly the case for patients with a chronic condition, some of the reasons for which are discussed in the next section.

## Chronic Conditions and the Search for Health Information Online

The onset and diagnosis of a chronic condition, or the experience of injury and recurring pain, can cause emotional distress and impact on a patient's social relationships. It can test their capacity to cope with everyday life and deal with their condition. Feelings of helplessness and isolation, difficulties completing everyday tasks, or the experience of daily pain, can increase the levels of distress experienced as a result of injury or a chronic condition and heighten the need for information.[1-4] Research demonstrates that people are increasingly searching for information regarding health and illness online in the active pursuit of health. Kivits *et al.*[5] argue that people's use of the internet to manage their everyday health, and improve their

quality of life, indicates that the internet is a tool for improving health rather than just another source of information.

**The Therapeutic Benefits of Stories**

Chronic illness affects everyday competencies, which in turn can make the future unpredictable and lead to feelings of insecurity and isolation. Storytelling builds resilience through active engagement with what has occurred, and brings the individual's future into view. Meaningful stories can mobilise people toward improving their quality of life,[4] not only for those accessing them but also those constructing them. Sharing the experience of health and illness through personal stories is valued since other people's experiences often resonate with one's own. This generates a sense of empathy and solidarity with others in a similar situation. By sharing stories people may transform their experience of illness, with possible actions becoming apparent within other people's stories.[35, 50] Personal stories build personal understanding of the condition,[30] and aid emotional adjustment to altered circumstances.[40]

Telling a story can confer or recover a patient's sense of agency[44] by forcing the individual to make sense of and reorganise a series of events into a coherent whole.[12, 45] Hussain[46] notes that the quality of human life depends largely on the ability to cope with adversity. In the case of a chronic condition or injury, storytelling enables people to gain a clearer perspective over seemingly chaotic circumstances. The construction of meaningful stories can build resilience, decrease levels of distress, and improve overall wellbeing.[12, 45] Research into storytelling in relation to specific illness experiences has found that storytelling is especially beneficial for those who have experienced stints in intensive care,[47] and those who have experienced cancer.[48] The effect of reinterpreting cancer experiences was evident in reduced levels of stress and anxiety, and improved personal relationships. Another study[49] required people to write about their experiences and participate in an online discussion group.  Exploring one's feelings through writing helped people organize and express their emotions, while accessing other people's stories enabled people to overcome their sense of isolation and suffering, and to 'move on' from difficult experiences. Therapeutic benefits were thus derived not only from the telling of one's story, but also from accessing other people's stories. It also equips patients to construct their own story about their condition or injury, as hearing other people's stories expands their emotional vocabulary[2],  and can offer encouragement and inspiration.[2]

Whilst negative stories can overwhelm patients, they also provide insight into living with a chronic condition or injury and can help patients to see that their emotional experiences and struggles are similar to those of others.[29] Early on in an illness or following an injury, people can feel very isolated, and recognising that others have experienced or are experiencing similar problems can diminish this sense of isolation.[3, 11, 16, 29, 40] Accessing personal stories also provides an alternative source of support which may be lacking in personal relationships.[32] Although tangible health

benefits are difficult to measure,[2] active information seeking and utilization of internet resources may facilitate a more informative, inclusive and participatory interaction with Health Care Professionals (HCPs) and promote personal health.[11, 14]

**Personal Stories and Healthcare Decision-making**

Clinical or biomedical information is qualitatively different to personal experiences; and is largely concerned with physical, biological, chemical and/or treatment aspects of a person's condition.[17, 19, 28] By contrast, personal information in the form of stories about people's thoughts and feelings highlights the 'real life experiences' of health and illness.[16] Patients feel that decisions concerning their treatment or rehabilitation are 'made real',[17] and that the emotional consequences become evident[18-19, 35] in these kinds of narratives. Medical jargon can be inaccessible[20] or too abstract,[15] and may not adequately reflect what it is like to live with a chronic condition or injury on a daily basis. People place great value on health and illness information based on personal experiences as well as the advice of family and friends,[21] preferring information that is personally meaningful to information that is abstract and impersonal.[22]

People who live with chronic conditions are faced with daily challenges in terms of coping, adjustment, treatment and self-management which require decisions on various courses of action at different times.[23] People who have recently received a new diagnosis, or face health related decisions often want information on how other people have experienced a similar situation.[2 18,14] The nature of the health issue, and the type of decision affects the type of information (facts and figures or health experiences) that people value. A recent landmark study[17] found that people caring for someone with dementia, or making decisions about antenatal screening, particularly prized personal experiences of health and illness, while those facing treatment decisions in lymphoma reported that biomedical information was more important to them than other patients' experiences.

Accessing online information about health and illness experiences not only has the potential to produce better health outcomes, but may also ensure more effective use of medical resources and services. Policymakers and HCPs alike are beginning to realise the benefits of better informed patients, and of online health information based on personal experiences.[32] There is emerging evidence that HCPs are starting to recommend online resources they consider helpful to their patients, as it aids in patient understanding and enables HCPs to focus on important aspects of treatment.[1] Patients often feel that there is insufficient time to discuss every aspect of their condition and treatment during an appointment with their HCP.[25-26] Accessing stories of other people's personal health and illness, patients are able to compare and contrast their health experiences with those of others in similar circumstances. This may limit unnecessary visits to the doctor and promote better self-management.[10, 33]

Patients are wary of accessing too many negative stories and are concerned about the accuracy of online information, and tend to be discerning when accessing information online.[7, 16, 24, 29] Information available online can allow patients to explore aspects of their condition or treatment that they have not understood within the clinical encounter.[18, 24]

## How and Why Patients Search for Health and Illness Information Online

Research shows that health information available online is especially helpful because it is available when needed, can be revisited, and can be accessed by people from a wide range of socio-economic backgrounds, although the lack of internet access for some people remains an issue.[38] The anonymity of the internet is appreciated by all social groups.[10, 15, 29] Anonymity is especially valued when searching for information regarding stigmatising conditions, such as mental illness,[38-39] or potentially sensitive or embarrassing topics.[1, 10, 15, 25, 40]

Social interaction can be difficult for people experiencing chronic conditions. For example, Sandaunet[23] found that while women with breast cancer generally found aspects of an online discussion group beneficial, they tended to avoid talking about difficult aspects of their condition for fear of being seen as overly pessimistic, or for fear of bringing the group down. Support groups for people with degenerative conditions are also problematic for those who have been recently diagnosed. Face-to-face interaction with people in more advanced stages of the condition can be confronting as they represent a possible future for people who have just received a diagnosis.[43] A web-based resource of people's stories may avoid such problems and allow people to search for support when they are ready. As Manzanderani et al.[43] suggest, this apprehension decreases over time and people's stories become important for their insight into living with a chronic condition.[3, 32] Web-based stories offer insight into living with a chronic condition, and avoid the potential problems of direct social interaction related to one's health condition.

The literature reviewed also shows that how individuals use the internet and search for this information is influenced by factors such as age, gender and geographical location. Overall, women are more likely than men to research health conditions on the internet[1], but compared with other groups, men[1] and young people[15] are more likely to use the internet to search for sensitive health-related information. Possibly due to their familiarity with the risks associated with the internet, young people are wary of online discussion groups. One study found that young people felt that an online database of people's stories of health and illness would overcome such problems.[15] Younger people in general tend to favour web-based health information, particularly personal stories, since they consider them to be more relevant and accessible than abstract medical information.[15] People located in isolated rural areas may be more reliant on web-based health resources than their city counterparts due to a scarcity of services or the great distance they have to travel to medical appointments.[33] Research indicates that older people continue to rely more on their HCPs for the standard diagnostic and/or treatment processes. However, they use

the internet to prepare themselves for doctor's appointments and to supplement their knowledge so they can be more active in their health care management.[27] Older people with chronic health issues are one of the fastest growing groups of internet users.[2]

One negative aspect of searching for health and illness related content online is that the amount of information has increased exponentially in the form of dedicated websites, personal blogs, You Tube, discussion groups, peg boards and even Facebook pages. Many individuals fear being overwhelmed by the sheer volume of information [5, 7, 38, 41], citing trust[16, 34, 7]and the credibility of information[7] as major concerns. However, in qualitative research interviews they often suggest that it is *other people* who might be misled, while they themselves are savvy, approach online information with a degree of scepticism and assess information accordingly.[25, 42] By sourcing health information relevant to their needs,[7, 14, 35] utilising health information related websites they deem reputable,[9] and accessing websites recommended by HCPs or friends,[1, 7] people avoid these perceived problems of lack of credibility or trustworthiness.

## The Potential Effects of Online Databases of Patient Experiences

Stories of health and illness experiences available online enable people to think differently about their health, and how they might improve it, outside of formal health settings. This can lead people to undertake health improvement activities they had not previously considered or thought were beyond their reach,[41] build resilience, and reduce anxiety and stress experienced as a result of living with a chronic condition.[4, 22, 48] Other people's stories can encourage patients to undertake health-promoting activities through highlighting the possibility of thinking and acting differently in relation to their condition or injury, treatment and relationship with HCPs. Becoming an active agent in improving their own health opens patients up to the possibility of improving their lives.[11, 47, 50] Rigorous, evidence-based and systematically derived online sources of personal experiences of health and illness can support and enhance people's health care. The Australian Government's Chronic Disease Strategic Plan[51] explicitly states support for empowering and enabling people with chronic conditions to actively self-manage their conditions

In summary, from the limited evidence available, the internet has opened up new avenues for treatment, and can equip  patients to become actively involved in improving their everyday lives. Patients' stories found online help to inform and support other patients, empowering them and fostering a sense of control.[52]

# Conclusion / Recommendations

Research suggests that patient experiences of health and illness available in the form of stories are not only valued by patients for their insight but may also improve health outcomes. While conclusive evidence in this area is still limited[2] and poses several methodological challenges,[14] existing studies suggest that other people's stories help inform patients in a personally meaningful way (see also www.ipexonline.org). Personal stories are able to create a sense of empathy and solidarity among people with similar experiences, and overcome feelings of isolation. People who have only recently been injured, or learned they have a serious illness, or are facing a health related decision, report that the stories of others who have been through the same experience can inform them about the difficulties inherent in decisions related to use of health services, treatment options and, adjustment in everyday life. Stories about other people's experiences of health and illness have the potential to provide insight, build resilience and help people to cope.

Through becoming aware of how others with similar experiences face everyday life and the future, patients are able to compare and contrast their experiences. Stories reveal the different strategies that others have used to improve their daily lives, highlight things that they have struggled with, and draw attention to the support available to resume work and enjoyable activities. For patients accessing such stories, an important element is the possibility of thinking differently about their situation. Implicitly such stories expose patients to the possibility of transforming their lives in a positive way in spite of their condition. Although clinical or biomedical forms of health information continue to be an important resource for making informed decisions, patients are using the internet to seek other people's experiences of health and illness, particularly when facing a new diagnosis or altered health circumstances. They can alert people to the possibility of seeking a second opinion, challenging doctors where necessary, and hearing about experiences of complementary approaches and life style changes. Due to their insights into living with a chronic condition or injury, people's stories offer more than emotional support. They create a space for patients to think and act differently about their condition, treatment and engagement with HCPs, possibly towards improving their health and everyday life.

Improving patients' experiences has been recognised as a key goal of healthcare (e.g. in the UK the patient's experience has been described in policy documents as the 'final arbiter' of everything the National Health Service does). The internet is a rich and developing pool of information about people's experiences of health and illness, which can be harnessed for numerous purposes. Policymakers and HCPs have recognised the benefits of more informed patients, and are actively constructing resources to support and educate patients. HCPs in training can learn about what is important to patients by looking at online resources. Online accounts of patients experiences can also help service providers to monitor, improve and develop services.

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