

“The impatient patient”

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Abstract. Modern Healthcare Systems that have embraced ICT and Internet technologies (referred to as Health 1.0) are evolving towards self management but from a clinical knowledge perspective. In contrast, from a user experience perspective, and using the latest web 2.0 technologies, the developing healthcare social networking communities (referred to as Health 2.0) are evolving towards becoming online medical portals.

The growing Grand Challenge for healthcare is therefore: how will health care services (Health 1.0) work together with user-generated health care (Health 2.0) in a consumer market place delivering self management services for a healthier lifestyle and medical compliance. What is foreseen is that the self care information tool of the future will be a combination between the patient’s observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.

This article deals with various aspects related to this Grand Challenge like the paradigm shift towards a needs-led and consumer-oriented healthcare, the role, supply and quality of information and the changing doctor-patient relationship.

1. Introduction

In 2002, the cumulative health spending of 24 Organisation for Economic Co-operation and Development (OECD) countries was \$2.7 trillion. Moreover, PricewaterhouseCoopers [1] estimates that health spending for OECD countries will more than triple to \$10 trillion by 2020. Healthcare organizations and governments around the world are urgently seeking solutions to temper costs while balancing the need to provide access to safe and high quality care. Yet, conventional approaches are failing, even in the most advanced nations of the world – throughout Europe, Asia, the Middle East, Australia, Canada and the United States.

According to the Royal Society report published on 8/12/06, low cost technology is the key to improve healthcare. Everyday technologies such as mobile phones and personal computers should not be overlooked in favour of large computer projects, such as the National Programme for IT (Connecting for Health), to improve the UK healthcare system. Furthermore the cost of telecommunications and computing power has dropped so dramatically that the potential finally exists to unite healthcare providers with patients and purchasers in a virtual seamless system with negligible costs. [3]

Preventive care, disease and lifestyle management programmes have much potential to enhance health status, reduce costs and introduce new cost sharing models but require support and integration across all the stakeholders for their benefits to be realised. A vision strategy needs to focus on investing multi-disciplinary research

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expertise and incorporating small-scale innovative technologies into an open platform for strategically important leading-edge developments across the wider spectrum of health, housing, social care and community safety by combining Information and Communication Technologies (ICTs) with that of care process optimisation and coordination for cost effective mass market self care management.

ICT has the potential to transform radically the delivery of healthcare to include prevention, well-being and disease avoidance and to address future health challenges. Whether they actually do so will depend on sufficiently accounting for the users' needs and the provision of adequate support and training after their introduction. The introduction of digital information systems offers the potential to deliver new interactive services to people at the point of need, in their own homes [2]. Tele-everything through television sets and other terminals will change the way patients are treated, operated on, monitored and counselled [3]. It is possible to store information and for users or carers to access it at convenient times. Urgent information triggered by alarms, changes in vital signs, or health status monitors can be transmitted and acted upon immediately. However, the best benefit to cost ratio will result from the deployment of the most appropriate solution for individual needs. Rather than being 'technology-driven', all solutions must be 'needs-led' and identify the most appropriate technology to fit. The single most important factor in realising the potential of ICTs for self care is the people who use them, both carers and patients. As seen from VoIP (Voice over Internet Protocol) the end users, the "consumers", will drive the adoption of new technologies and services in the mass retail market.

Since the patient/consumer is the primary source of information to be accepted, support systems for decision making must be integrated into everyday life. They must present the right information, in the right format, at the right time, without requiring special effort. In other words, they cannot impeach on day-to-day realities of living. They cannot require users to learn to use a series of disconnected computer systems and must not be at odds with doctors' concept of the medical record or sense of autonomy in decision-making.

The Grand Challenge is therefore: how will health care services (Health 1.0) work together with user-generated health care (Health 2.0) in a consumer market place delivering self management services for a healthier lifestyle and medical compliance. What is foreseen is that the self care information tool of the future will be a combination between the patient's observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.

The next three sections present an example of health 1.0, an overview of health 2.0 and whether the Internet is providing information or mis-information. Section 5 addresses the issues that consumerism will have on the conventional healthcare model and subsequent patient's expectations. Section 6 addresses the resulting doctor-patient relationship and section 7 presents the conclusions.

2. Health 1.0 and the need for change

The locus of power in health care is shifting: instead of the doctor acting as sole manager of patient care, a consumerist model has emerged in which patients and their doctors are partners in managing their care. A number of studies focus on whether the Internet can actually empower patients and enrich the patient-doctor relationship

[38,43]. On the other hand, there are many organisational and behavioral barriers to patients being involved in managing their healthcare [42] so a study should also address how the Internet model would affect these.

Public use of the Internet as a health care tool has grown dramatically in the past few years, and this trend is expected to continue. Obtaining information from the Web is often the basis for making health decisions and is thus an influential force. Of persons surveyed in 2000 by the Pew Internet & American Life Project, 41% said that the Internet affected their decisions about going to a doctor, treating an illness, or questioning their doctor. To obtain such information in the most optimal and safe way, Electronic Health Records (EHRs) should be structured in such a way that they can serve as the basis. [8]

“Medical knowledge is becoming increasingly specialised and there is an inevitable ‘competence gap’ between medical doctors and their patients. Through online information sources, citizens can to some extent bridge this ‘competence gap’ by informing themselves about disease prevention and healthy lifestyles, various health problems and treatment options. This can have an empowering effect and allow patients to exercise a certain degree of choice.” [7]

People are demanding the same easy access to advanced health care technology as is currently available to them when they do their banking or plan a vacation. The era of the "impatient patient" has arrived. Patients demand immediate, convenient access to a high level of personalised health care: they want it their way, and they want it now.

During the last years, a significant amount of money has been invested to evaluate monitoring via the Internet to home users worldwide. These types of studies, which will serve as important test cases for the possibility of e-technology to improve health outcomes have to be continued and extended during the following years by including long-term follow up and solid clinical measures. Furthermore, more research is needed utilizing larger samples over longer periods, controlled and randomised, in tandem with significant outcomes to support policy changes and buy-in efforts for implementation.

Several monitoring devices using the Internet have been developed to help patients manage their medical conditions at home. Research is needed regarding health outcomes, cost effectiveness, as well as the long-term acceptance of these devices by patients.

Breast cancer patients in an online education and support group had increased confidence in their doctors, as well as increased competence to deal with relevant, disease-related information. These patients were also more comfortable seeking information during a doctor office visit and were more comfortable participating in their own care. This study alone is minimal evidence to support changes in the patient-doctor relationship and more research is needed. [41]

According to an online poll, it was found that patients who use the Internet to look for health information are more likely to ask more specific and informed questions of their doctors and to comply with prescribed treatment plans. This was a survey and not a formal study. Further research is necessary to understand what effect the Internet age has on the patient-doctor relationship. For example, are patients more compliant with prescribed therapy because they discussed it more with their doctor or because they read it on the Web? [40]

The Internet offers an important opportunity for patients to become actively engaged in their own care. [8] During the pre-Internet era, medical information was published in medical textbooks and journals only, whereas patients can now gain access to citations of more than 12 million medical articles online. Indeed, many

patients are now helping to inform their doctors on the latest research and treatments. Doctors Gerber and Eiser postulate that the Internet age offers opportunities to improve the patient-doctor relationship by sharing the burden of responsibility for knowledge. They also underline the necessity for research to identify the effects on the patient-doctor relationship, as well as the effects on patient and doctor satisfaction and on health outcomes especially since healthguides² provides a common set of clinically based guidelines. [36]

New to the world of care and cure is the concept of the Expert Patient. The NHS website defines it as follows: “Expert patients are people living with a long-term health condition, who are able to take more control over their health by understanding and managing their conditions, leading to an improved quality of life.” [9] In his 2001 report, the UK chief medical officer Liam Donaldson, characterised them as people: “who enjoy good quality of life despite chronic disease; who have the confidence, skills, input and knowledge to play a central role in the management of life with chronic disease, and to minimise its impact on their day-to-day living.” [10]

However, these definitions focus on people with chronic diseases. Any patient, whatever their condition, should be able to become an expert patient. The way to achieve this is through information. [11] Through the proper information the citizen will be able to take more responsibility in the way they live and, once they become a patient, in the way they will be treated. “The greatest benefit could come in the future if patients could take on more responsibility for their bodies and minds... Doctors then may come to acknowledge... that doctoring is something of a joint venture between patient and healer, in which the doctor serves as a guide.”[12].

Whether the medical community looks forward to the advance of this paradigm shift, is uncertain. “The suspicion is that for many doctors, the expert patient of the imagination is the one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or, possibly worst of all, a treatment the doctor has never heard of, let alone personally prescribed.”[13]

3. User-generated healthcare (Health 2.0)

Five years ago, online content generated by individual web surfers was seen as something done by the technically gifted. Keeping a ‘blog’ was akin to being a computer coder. In recent years, there has been an incredible boom in user-generated content. Wikipedia is an online encyclopaedia written by thousands of global users. Even more recently, ‘social networking’ portals have become some of the most popular web sites, offering users a chance to connect to peers worldwide. For example, UK participation in social networking was revealed to be the highest in Europe, with 24.9 million unique visitors – 78% of the total adult online population – now belong to the UK’s social networking community. [39]

The boom in “user-generated content” is also addressing healthcare. Millions are now logging on to contribute information about topics stretching from aviation flu

² The Map of Medicine represents the state of the art in health 1.0. The map, intended for clinical use, is a web-based visual representation of evidence-based patient care journeys covering 28 medical specialties and 387 pathways. A patient version of the map, called Healthguides, is now being created by more than 500 doctors and nurses to give patients the same in-depth clinical information as used in the NHS, in easy to follow charts. <http://www.mapofmedicine.com/>

pandemics to the extraction of wisdom teeth. The “Economist” terms this *user-generated health care* or *Health 2.0*. (see also: [14]) The explosion of user-generated content in health care is in part the result of a broader internet trend; more and more people have broadband access and the tools for creating content and getting easier to use. But there are other drivers. Those with multiple chronic conditions, such as diabetes and depression, or lesser known diseases such as chronic fatigue syndrome, are anxious to get tips from others in similar situations.

Online support groups exist for almost every disease and condition, and discussion topics within each disease category are limitless. For example, diabetic patients who enjoy scuba diving can learn from fellow diabetic scuba divers how to cope with diabetes 50 feet (15.2 meters) below the water's surface. But just as important as the information exchanged in these e-discussions is the emotional support they provide. For each e-patient seeking a listening "ear," dozens of other patients offer encouragement. In turn, these words of solace are read by hundreds (and sometimes thousands) of other patients who read Internet message boards. This support may be recorded for future reference of patients, doctors, or health care planners.³

4. Internet and information or misinformation

Miss-use, misinformation and the sheer volume of health information are issues of concern. However, consumers concur that the upside outweighs the risk. Nearly one-third of the 100 Million Americans who looked for health information online say that they have been significantly helped. In contrast only 3% reported that online advice had caused serious harm. Furthermore, user-generated health content is in general accurate. A panel of neurology specialists judged that only 6% of content posted to the epilepsy support group of braintalk was factually wrong. In general with enough people online, misinformation is often quickly corrected

“In the early nineties, under the aegis of the United States National Information Infrastructure, the Internet facilitated the creation of an “information-for-all” environment. Despite the unstructured nature of its existence, the Internet has seen an unprecedented global growth in its role as a promoter of information solutions to the citizens of the world” wrote ICMCC’s co-founder Swamy Laxminarayan. [15]

Nowadays, information is available in abundance. Through publications, research communities, international projects, more and more people have access to information. Especially in the health area there is a need for it. “The number of people who have used the Internet to search for health-related information has increased markedly, (from 53% in 2005 to 71% currently). This brings the number of all U.S. adults who have ever searched for health information online to 160 million, from 136 million in 2006 and 117 million in 2005 — a 37 percent increase over two years. [...] Two thirds (66%) of adults online say that they have looked for information about health topics often (26%) or sometimes (40%), an increase of five percentage points from 2006 (61%).” [16]

However, there are risks involved. “In a large number of Web sites currently offering health information we cannot find credible and enforceable protection of

³ Some examples:

Patient opinion, <http://www.patientopinion.org.uk/>

I'm too young for this, <http://imtooyoungforthis.org/>

citizens from potential harm” [17] “Most studies (55 [70%]) concluded that quality is a problem on the Internet” [18]

People have a broad range of information preferences that may differ at different times and for different reasons. They may want more information than prescribers want to give—for example, about the possible side effects of a drug. They may place different interpretations on information about likely risks, and they may question the benefits of taking a drug when they are not greatly concerned by the medical “problem” that the treatment is meant to solve. They may well rate the practicalities of how to take a drug higher than the details of the inert components of the pills or the drug manufacturer’s address. [19]

The internet has given an enormous boost to the discussion about freedom of access to information and knowledge. Access to information and knowledge must be free, especially information originating from public and publicly controlled bodies. True however is that quite a large amount of the information available on the internet is non-information and non-knowledge. In such specific areas as health and care we will have to start the discussion about how to validate information such that even those who do not have the capacities to separate the wheat from the chaff can trust the information they want to access. “In a large number of Web sites currently offering health information we cannot find credible and enforceable protection of citizens from potential harm” [20]

Due to the way information is organised we will differentiate between scientific and non-scientific information as described in the following sections.

4.1. Scientific information

With the growing need to be informed, the citizen demonstrates more interest in scientifically based information. “In 2005, the criteria perceived as the most important indicators of quality and usefulness for health Web sites among non-professional and professional groups of users: (1) availability of information, (2) ease of finding information/navigation, (3) trustworthiness/credibility and (4) accuracy of information. Both non-professional and professional users, in Europe and the USA, favor academic/university sites (89.4%, n=1403) and sites sponsored by medical journals (88.9%, n=1394), closely followed by government agencies (86.1%, n=1395). We have also observed that a significant number of Web users, about 25% of a sample of 1,386 persons from all over the world, lack confidence in sites sponsored by pharmaceutical manufacturers and commercial, mainstream media organizations.” [2,6]

“Medical knowledge is becoming increasingly specialised and there is an inevitable ‘competence gap’ between medical doctors and their patients. Through online information sources, citizens can to some extent bridge this ‘competence gap’ by informing themselves about disease prevention and healthy lifestyles, various health problems and treatment options. This can have an empowering effect and allow patients to exercise a certain degree of choice.” [7]

Although the number of so-called open source journals and publications increases, many of the scientific publications are available only at relatively high subscription costs. However, there are a number of international initiatives to make these publications freely available.

- The *HINARI* [22] program, set up by WHO together with major publishers, enables developing countries to gain access to one of the world's largest collections of biomedical and health literature.

- *INASP Health* [23] works towards a future where all healthcare providers, researchers, educators and policymakers can access and contribute information and knowledge for better health and healthcare worldwide.
- *HTAi* [24] (Health Technology Assessment International) focuses uniquely on health technology assessment (HTA) and provides the key forum for all those from the worlds of health care, academia and business interested in the science, development and application of HTA.
- The *EAHIL* [25] (European Association for Health Information and Libraries) wants to improve library services to the health professions by cooperation and shared experience across national boundaries.

These organisations aim at professionals only, either worldwide or in developing countries. We think that these facilities should also be available to patients. The expert patient is a relatively new phenomenon that will become more and more common in the next couple of years. By creating this information portal, we will help them to become an expert patient based on coordinated access. (see also 4.2)

4.2. Non-scientific information

General health information sites should be on a national level, as much of the information about diseases, treatments and quality and location has a strong national orientation. We should aim at making the information on these national sites also accessible to people from other countries. Especially in Europe this is necessary, due to on the one hand holiday traveling, on the other hand the European rule, that patients are free to seek medical assistance outside their own country.

Fundamentally these sites are not only about diseases but about health, informing not only patients but also citizens in general. Well being is becoming increasingly important and we should supply citizens with information on what is nowadays called complimentary and alternative medicine, offering alternatives to our own, reparative medical tradition.

The amount and complexity of information must be tailored to the perceived needs of a patient. Access to further information should be facilitated, and patients helped in interpreting the data. The internet has greatly expanded the availability of information, but this is often disjointed, incomplete, apparently conflicting, and not aimed at a general audience. The use of information from the web varies considerably across socioeconomic groups. Therefore, to improve access to information, it should in future be provided in a variety of formats—spoken, written, and pictorial. [26]

Another essential aspect is the independence of such portals/platforms. It is with full agreement that we quote here James Kennedy, a British GP: “I would like to see the establishment of a specialised and rigorous “information source” independent of both the health service and pharmaceutical industry. It would act as a quality controller for information from a variety of sources—research communities in universities, specialist professional bodies, and pharmaceutical companies. Such a trusted resource could monitor, assess, and interpret the research evidence in each clinical area and become an authoritative, but not exclusive, information provider for clinicians and the public. It could also be invited to develop and test methods for information dissemination.” [26] How accurate Kennedy’s observation is, follows from a study by Joergensen et al.: “the information presented to women on websites by professional advocacy groups and governmental organisations was selective and biased and failed to mention major harms. Websites from consumer groups were more

balanced and comprehensive than sites by professional advocacy groups and governmental organizations.”[27]

4.3. Literacy

To be able to access and understand the available information, a certain level of eHealth literacy is desirable if not mandatory. “eHealth literacy is influenced by a person’s presenting health issue, educational background, health status at the time of the eHealth encounter, motivation for seeking the information, and the technologies used. Like other literacies, eHealth literacy is not static; rather, it is a process-oriented skill that evolves over time as new technologies are introduced and the personal, social, and environmental contexts change. Like other literacy types, eHealth literacy is a discursive practice that endeavors to uncover the ways in which meaning is produced and inherently organises ways of thinking and acting. It aims to empower individuals and enable them to fully participate in health decisions informed by eHealth resources.” [32] Norman et al. define 6 components of the eHealth literacy model: traditional, information, media, health, computer and scientific literacy [32].

5. Healthcare as a consumer commodity

The availability of easily accessible information will be at the heart of any consumer driven healthcare information retrieval system. Consumers will also assume greater responsibility for choosing their health benefits and providers. Online Health plan products will guide decision making based on healthcare needs and budgets to allow employers and/or employees to choose from a variety of benefits and identify the best alternative for each situation. Recent research shows that the use of telecare has additional social benefits [28]. Consumers will have greater financial responsibility in both purchases and care. Consumers will become active participants and control care decisions and help manage their health. As the number of people with chronic conditions grows, health plans will need to step up even more as the primary sponsors of voluntary disease and health management programmes. Consumers will expect medical devices to be familiar, friendly, interoperable and have easy to use processes for data capture. Consumers will require easy to use appropriate knowledge management tools to assess the generated knowledge and integrating this knowledge to the knowledge gained from the patient’s clinical history.

Since the evolving healthcare model is addressing the consumer market on a mass scale a number of underlying issues have to be taken into consideration including organisational (remote monitoring implications), cost-benefit (are indirect costs included), elderly (are the services useable), teenager (are they catered for), carer (what is the learning curve), durability (robustness, maintainability), usability (do the solutions work in real life), user experience (also risk groups) [37]. In addition, networks of medical doctors enabling easy communication amongst themselves about problems with patients, questions about diagnostics or treatments, in short, exchanging information and knowledge will become of immense importance. Most of this communication can be done almost real time due to the internet. Within the networks doctors can share detailed information in the form of email attachments, be it laboratory results, images or their own observations. [30]

Contrary to previous times, knowledge has become more and more specialised. Therefore, cooperation networks have become a necessity. A doctor depends on X-ray technology or MRI scans to make a diagnosis, he needs cooperation with surgeons or physiotherapists to enable improvement of his patient's condition. Once again, contact between members of those cooperation networks can become instantaneous, independent of location. Via broadband facilities, colleagues can be visually contacted for advice and/or assistance.

With the most recent telecommunication developments, they can invite colleagues to observe operations real time or even take part in them, no matter what the distance is between them. They can build communities that hardly suffer from the ancient communication problems, being distance in time and place.

Pagliari et al [31, table 1] give an overview of the "Professional Clinical Informatics" issues that dominate e-health:

- Decision aids for practitioners (e.g., prompts, reminders, care pathways, guidelines)
- Clinical management tools (e.g., electronic health records [EHRs/EPRs], audit tools)
- Educational aids (guidelines, medical teaching)
- Electronic clinical communications tools (e.g., e-referral, e-booking, e-discharge correspondence, clinical email/second opinion, laboratory test requesting/results reporting, e-shared care)
- Electronic networks (NHS-Net and disease specific clinical networking systems)
- Discipline/disease specific tools (e.g., diabetes informatics)
- Telemedicine applications (for interprofessional communication, patient communication and remote consultation)
- Subfields (e.g., nursing & primary care informatics)

Healthcare is primarily a people and location business. Rigid clinical roles, cultures and structures are detrimental to sustainable health systems. Technology is eliminating some jobs and creating new ones in informatics and pharmacogenomics. It is also opening up the possibility for more care to be delivered in outpatient clinics, offices and even homes but this is also has consequences on the doctor-patient relationship.

6. The consumer-driven Doctor-Patient relationship

Hospitals traditionally have required patients and doctors to come to them. Most hospitals were built on an inpatient model that has been expanded, remodelled and altered into consumer-unfriendly labyrinths. That original model is changing. Patients and doctors are finding other avenues for care provision that are more convenient, and technology ensures that caregivers connect to the best and brightest doctors globally.

Moreover, there is growing evidence that the current health systems of nations around the world will be unsustainable if unchanged over the next 15 years. Globally, healthcare is threatened by a confluence of powerful trends – increasing demand, rising costs, uneven quality, misaligned incentives. If ignored, they will overwhelm health systems, creating massive financial burdens for individual countries and devastating health problems for the individuals who live in them.

ICT is an important enabler in resolving healthcare issues such as integrating care and improving information sharing, when there is system wide and organisational commitment and investment. But IT is not a solution in and of itself. Of equal importance is improving patient safety and restoring patient trust.

There is also a significant, bi-directional influence on the patient-clinician relationship. "54% of patient-type respondents have discussed the results of their Internet searches with their care providers (n=533). Our results are confirmed by a recent study, from Harris Interactive [33], reporting that a majority (57%) of American adults, who have gone online to get health information, say that they have discussed this information with their doctor at least once. We report, among those who discussed the results of their Internet searches with their care providers, 95.8% (n=334) enjoy obtaining health information from the Internet and some 78.3% said ensuing discussions with their care provider were helpful because it improved doctor-patient communication, a huge increase of 40% compared to 2002 (38.3%, n=796). Most patient-respondents (88.2%) agreed that seeking health information on the Internet improves the quality of consultation with their physician. More than half (53%) of them use the Internet to seek a second opinion about a medical diagnosis. It is important to note that the majority of patient-respondents (90%) said that health care providers should suggest trustworthy online sources of health information. As the other player in the patient-physician relationship, health professionals had a receptive and positive attitude toward this behaviour, professionals' responses to these questions confirm previous patient-respondent results. Like patient respondents, medical professionals agreed by 77% that patient health information seeking on the Internet improves the quality of patient consultation." [34] Doctors can be essential in that they can "prescribe" information to the patient. [35] [36]

Prescribing doctors have a key role in ensuring patients have adequate access to information and helping them to interpret this information. Health services are responsible for ensuring the information exists and is reliable and accessible. Pharmaceutical companies have the greatest repository of data on their drugs, but their impartiality may be questioned. Special interest groups (charities, pressure groups) may have their own agendas to protect. Doctors, particularly general practitioners (who often can build on long term relationships with patients), must take a lead in information sharing with patients. There will be understandable concerns about the need for yet more time for yet more clinical tasks. It seems logical, however, to argue that early engagement of patients in decision making about treatment should prevent much subsequent morbidity and confusion and may, even in the short to medium term, save time as well as improve outcomes. [26]

When patients assume a greater role in acquiring medical knowledge, there must be a corresponding change in the doctor's role as treatment decision-maker. Additional dynamics are likely to result from different doctor behaviors, including embracing, avoiding, or disregarding Internet-derived information. To better define this variable, surveys and observational studies are needed that will elicit doctor attitudes toward Internet health information and their corresponding patient-doctor relationships. In addition, research is needed to evaluate the barriers to doctor implementation of information technology. In Canada, researchers have administered a new survey instrument to stratify primary care doctors into different levels of information technology usage. This approach may allow for specifically tailored strategies to be used in implementation. [36]

With the advent of user-generated health care, studies need to focus on defining steps towards sustainability by understanding its impact on global healthcare trends and how it will influence future health spending. “solution drivers” need to be identified within the control of executives and administrators, where health leaders can take action and effect change, serving as a call to action for healthcare organisations to look beyond their own boundaries to tackle the complex challenges of integrating user-generated health care and its sustainability impact.

In our view, the following is needed:

- *A common vision and strategy* to balance public versus private interests in building an infrastructure and in providing basic health benefits within the context of societal priorities.
- *Better use of technology* and interoperable electronic networks to accelerate integration, standardisation, and knowledge transfer of administrative and clinical information.
- *Incentive systems* that ensure and manage access to care while supporting accountability and responsibility for healthcare decisions.
- *Defined and adopted clinical standards* need to be established with mechanisms for accountability and enhanced transparency, thereby building consumer trust.
- *Optimised resource allocation* that appropriately satisfies competing demands on systems to control costs while providing sufficient access to care for the most people.

Innovation, technology and process changes are a means to continuously improve treatment, efficiency, outcomes and governance but these must be taken into context of *flexible care settings* and *expanded clinical roles* that provide avenues for care that are centred on the needs of the patient.

7. Conclusion

Modern Healthcare Systems that have embraced Internet technologies (referred to as Health 1.0) are evolving towards self management from a clinical knowledge perspective. In contrast, patients are using the latest web 2.0 technologies and developing healthcare social networking communities (referred to as Health 2.0) which are evolving towards becoming online medical portals. The developing Grand Challenge in healthcare is therefore how Health 1.0 will work together with Health 2.0 in a consumer market place to deliver personalised self management services.

The locus of power in health care is shifting: instead of the doctor acting as sole manager of patient care, a consumerist model has emerged in which patients and their doctors are partners in managing their care. The self care information tool of the future will be a combination between the patients observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.

Consumers will assume greater responsibility for choosing their health benefits and providers. Moreover, the availability of easily accessible information will be at the core of any consumer driven healthcare model. However, whether the Internet can actually empower patients and enrich the patient-doctor relationship is still undecided. Furthermore, with the advent of user-generated health care its impact on global

healthcare trends and influence on future health spending needs to be understood in order to tackle the complex challenges of integrating user-generated health care and its sustainability impact.

8. References

- [1] "HEALTHCAST 2020: Creating a sustainable future", PricewaterhouseCoopers, December, 2006.
- [2] "Healthcare and Smart housing technologies", Report of a DTI International Technology Services mission to Japan, 14-18 February 2000.
- [3] Digital healthcare: the impact of information and communication technologies on health and healthcare, Royal Society 2006, <http://www.royalsoc.ac.uk/news.asp?id=5690>.
- [4] ETSI Report 2005: "Human Factors (HF) in Telecare services: Issues and recommendations for user aspects", ETSI DTR 102 415 (2005-06-15). Available from <http://portal.etsi.org/stfs/hf/STF264.asp>
- [5] The MATCH projects focus on a number of perspectives: manufacturers, regulators and users. Project 3 in particular is about engaging with users. See <http://www.match.ac.uk>
- [6] 9th "Health on the Net Survey of Health and Medical Internet Use" <http://www.hon.ch/Survey/Survey2005/res.html>
- [7] Health and ageing in the knowledge society: employment, social cohesion and e-health potential. Working document of the high level group on employment and social dimension of the information society (esdis) 2006 http://ec.europa.eu/employment_social/knowledge_society/docs/healthinks_20060429_esdis.pdf
- [8] L. Bos, Medical and Care Compunetics the Future of Patient-Related ICT, Medical and Care Compunetics 4, L. Bos et al, IOSPress 2007, pp. 3-17, <http://www.icmcc.org/pdf/bosios2007.pdf>
- [9] Experts Patient Programme, <http://www.expertpatients.nhs.uk/what.shtml> (accessed July 26, 2006)
- [10] The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century, UK Department of Health, 2001. <http://www.dh.gov.uk/assetRoot/04/01/85/78/04018578.pdf>
- [11] Trevor Jones, Foreword to the Expert Patient, The Association of the British Pharmaceutical Industry, http://www.abpi.org.uk/publications/publication_details/expert_patient/foreword.asp
- [12] Glin Bennet, Patients and their doctors : the journey through medical care, 1979
- [13] Joanne Shaw, Mary Baker, "Expert patient"—dream or nightmare?, editorial, *BMJ* 2004;328:723-724, <http://bmj.bmjournals.com/cgi/content/full/328/7442/723>
- [14] Joseph Conn, Health 2.0: The next generation of Web enterprises, *Modern Healthcare*, December 2007, <http://www.modernhealthcare.com/apps/pbcs.dll/article?AID=/20071211/FREE/312110003/>
- [15] Swamy Laxminarayan, Foreword, *Clinical Knowledge Management, Opportunities and challenges*, R. Bali, 2005.
- [16] The Harris Poll® #76, July 31, 2007, http://www.harrisinteractive.com/harris_poll/index.asp?PID=792
- [17] A. Risk, J. Dzenowagis, Review of internet health information quality initiatives, *J. Med. Int. Res.* 3 (4) (2001) e28, <http://www.jmir.org/2001/4/e28/>.
- [18] Gunther Eysenbach, MD; John Powell, MSc, MRCPsych, MFPHM; Oliver Kuss, PhD; Eun-Ryoung Sa, MS, Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web A Systematic Review *JAMA*. 2002;287:2691-2700 <http://jama.ama-assn.org/cgi/content/full/287/20/2691>
- [19] Ask the patients—they may want to know more than you think David Dickinson, D K Theo Raynor *BMJ* 2003;327:861-4
- [20] A. Risk, J. Dzenowagis, Review of internet health information quality initiatives, *J. Med. Int. Res.* 3 (4) (2001) e28, <http://www.jmir.org/2001/4/e28/>
- [21] 9th "Health on the Net Survey of Health and Medical Internet Use" <http://www.hon.ch/Survey/Survey2005/res.html>
- [22] <http://www.who.int/hinari/en/>
- [23] <http://www.inasp.info/health/index.shtml>
- [24] <http://www.htai.org/>
- [25] <http://www.eahil.net/index.htm>
- [26] "Doc, tell me what I need to know"- a doctor's perspective, James G. Kennedy, *BMJ* 2003, 327; 862:863
- [27] Presentation on websites of possible benefits and harms from screening for breast cancer: cross sectional study, Karsten Juhl Jørgensen, Peter C Gøtzsche, *BMJ* 2004;328:148ff, doi:10.1136/bmj.328.7432.148

- [28] Brownsell, Simon; Blackburn, Steven; Hawley, Mark S., An evaluation of second and third generation telecare services in older people's housing, *Journal of Telemedicine and Telecare*, Volume 14, Number 1, January 2008, pp. 8-12(5)
- [29] B.R.M. MANNING, J. McCANN, S. BENTON, J. BOUGOURD, Active Ageing: Independence through Technology Assisted Health Optimisation, *Medical and Care Compunetics* 5, IOSPress 2008
- [30] J. Verhoef, P.J.Toussaint, T.P.M. Vliet Vlieland, J.H.M. Zwetsloot-Schonk, The impact of structuring multidisciplinary team conferences mediated by ICT in the treatment of patients with rheumatic diseases, in: *Medical and Care Compunetics* 1, L. Bos et al., 2004
- [31] Pagliari C, Sloan D, Gregor P, Sullivan F, Detmer D, Kahan JP, Oortwijn W, MacGillivray S, What Is eHealth (4): A Scoping Exercise to Map the Field *J Med Internet Res* 2005;7(1):e9, <http://www.jmir.org/2005/1/e9/>
- [32] Norman CD, Skinner HA, eHealth Literacy: Essential Skills for Consumer Health in a Networked World, *J Med Internet Res* 2006;8(2):e9, <http://www.jmir.org/2006/2/e9/>
- [33] Number of "Cyberchondriacs" – U.S. Adults Who Go Online for Health Information – Increases to Estimated 117 Million, David Kran, Harris Interactive, *HealthCare News*, 2005, http://www.harrisinteractive.com/news/newsletters/healthnews/HL_HealthCareNews2005Vol5_Iss08.pdf
- [34] 9th "Health on the Net Survey of Health and Medical Internet Use" <http://www.hon.ch/Survey/Survey2005/res.html>
- [35] Donald W. Kemper, Molly Mettler, *Information Therapy*, 2002; www.healthwise.org
- [36] Gerber BS, Eiser AR, The Patient-Physician Relationship in the Internet, *J Med Internet Res* 2001;3(2):e15, <http://www.jmir.org/2001/2/e15/>
- [37] Diagnostic, Monitoring and Assistive Tools, Devices, Technologies and Equipment to Support Self Care, Full review report, Department of Health, UK, August 2005.
- [38] S Shoor, KR Lorig, Self-Care and the Doctor-Patient Relationship, *Medical Care*. 40(4) Supplement:II-40-II-44, April 2002
- [39] <http://www.bigmouthmedia.com/live/articles/social-networking-sites-are-uk-hit.asp/4155/>
- [40] Ahmad,F, HudaK.P.L, BercovitZ.K, Hollenberg. E, Levinson,W. Are Physicians Ready for Patients With Internet-Based Health Information? (*J Med Internet Res* 2006;8(3):e22) doi:10.2196/jmir.8.3.e22
- [41] <http://www.health.am/cr/more/online-information-may-improve-cancer-patients/>
- [42] P. C. Tang, J. S. Ash, D. W. Bates, J. M. Overhage, D. Z. Sands, Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption, *J Am Med Inform Assoc*. 2006;13:121-126. DOI 10.1197/jamia.M2025, <http://www.jamia.org/cgi/content/full/13/2/121>
- [43] Frauke Sinclair, In Need of TLC? A Doctor-Patient Relationship Fit for the Future, Scottish Council Foundation, 2007, <http://www.scottishcouncilfoundation.org/page.php?id=25>