

## Patient 2.0 Empowerment

Lodewijk Bos, Andy Marsh, Denis Carroll, Sanjeev Gupta, Mike Rees

**Abstract**—The authors want to show the implication of interactive ICT on patient empowerment, through an overview of some of the key aspects - EHR, telecare and patient networks - all this within the context of recent Health 2.0 developments. Definitions will be given of both Health 2.0 and Patient 2.0 Empowerment.

### I. INTRODUCTION: PATIENT EMPOWERMENT

For years patient empowerment has been subject of thinking and research. First discussions started in the mid 1990s [1]. As recently as 2004, Salmon and Hall published a very interesting study on the subject [2] from which we give some quotes: “Although it has not yet surveyed the full range of such innovations, the results of intensive study of several that affect important areas of routine patient care are incompatible with the assumption that patients generally seek empowerment or that it routinely serves their interests.” (p.53); “The accounts of patients' perspective that are currently available suggest that patients do not generally embrace empowerment. In emphasizing research into how to empower patients at the expense of research into what patients feel like when they have been 'empowered', medicine paradoxically continues the tradition of assuming that 'doctor knows best'. Unless the balance of research is reversed, academic and political statements that 'patient empowerment... has put patients in charge of their medical destiny', or that 'by offering choice, patients will be given the chance to control their own destiny', will continue to construct a framework for clinical care that obfuscates rather illuminates patients' needs.” (p.55)

Real definitions of patient empowerment are hard to find. “The term “patient empowerment” describes a situation that citizens are encouraged to take an active part in their own health management. Patient empowerment is considered as a philosophy of health care that proceeds from the perspective that optimal outcomes of health care interventions are achieved when patients become active participants in the health care process. It makes emphasis in the importance of

individual involvement in health decision making.” [3]

It's only with recent developments in the application of Internet, more specific Web 2.0, that patient empowerment becomes a feasible reality. To mark this shift, we introduce the term Patient 2.0 Empowerment.

However, it is hard to find a definition of what Web 2.0 really is. At the basis of the whole conceptual discussion about Web 2.0 is O'Reilly's article from 2005 [4]. His starting concept is: *The Web as a platform*. In the course of the article he adds a couple of useful other concepts: *the power of the web to harness collective intelligence; users add value; innovation in assembly*.

Let's assume here, that the same elements are essential for Health 2.0. In fact we are then talking about Electronic Health Records (EHRs) and the information supply that is their consequence, telecare and patient networks. These elements will be covered in the following chapters after we dealt in more detail with the concept of Health 2.0, in the next chapter.

### II. HEALTH 2.0

“Health 2.0 is the transition to personal, participatory health care. Everyone is invited to see what is happening in their own care and in the health care system in general, to add their ideas, and to make it better every day.” [5]. That is the definition Ted Eyton delivered at the time we started writing this paper.

Most attempts at definitions we came across were not more than (overviews of) descriptions [6],[7]. Interesting is the pre-requisites mentioned at the Health 2.0 organization website: [8]

1. Begin by defining Health 2.0
2. Realize that Health 2.0 is all about Patient Empowered (not the misnomer "Consumer Directed") Healthcare whereby patients have the information they need to be able to make rational healthcare decisions (transparency of information) based on value (outcomes over price). In the Health 2.0 paradigm, everyone in the healthcare process is focused on increasing value for the patient.
3. Realize that Health 2.0 is absolutely reliant on interoperability of health information. Everything from the Personal Health Record (PHR), to the Clinic Health Record (CHR), to the Enterprise Health Record (EHR), to the National Health Record (NHR) must be based on standards, be seamlessly transitioned between environments per standardized security and privacy protocols, and be

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Lodewijk Bos is President of the International Council on Medical & Care Computetics (phone: +31.30.2311038; fax: +31.30.2321967; e-mail: lobos@icmcc.org).

Andy Marsh is vice-president of ICMCC, CEO of VMWSolutions (e-mail: [andy\\_marshall@vmwsolutions.com](mailto:andy_marshall@vmwsolutions.com)) and visiting Professor at the University of Westminster.

Denis Carroll is vice-president of ICMCC and head of KTP at University of Westminster (e-mail: [D.C.Carroll@westminster.ac.uk](mailto:D.C.Carroll@westminster.ac.uk)).

Sanjeev Gupta, Head of Service Delivery, Commissioning Support Services (NHS), Email: [sanjeev.gupta@risible.co.uk](mailto:sanjeev.gupta@risible.co.uk)

Mike Rees, Principle Lecturer, University of Westminster, email [reesm@westminster.ac.uk](mailto:reesm@westminster.ac.uk)

accessible anytime from anywhere.

4. Undergirding this foundation of information, the Four Cornerstones (Connectivity, Price, Quality, and Incentives) of the Value Driven Healthcare movement begin to create a virtuous cycle of innovation and reform. Transparency serves as a key catalyst in this process by creating positive sum competition that can deliver better outcomes at a lower cost.
5. As more information becomes available as a result of increased transparency, there will be a wave of innovation at all points along the full cycle of care [...], which includes phases where health care service providers Educate, Prevent, Diagnose, Prepare, Intervene, Recover, Monitor, and Manage the various disease states. Measuring someone's HgA1c or Ejection Fraction does not tell you how effective their diabetic or cardiovascular treatments have been. You need to factor in the care provided over the full cycle of care to appropriately determine value.
6. An increased amount of personal health and outcomes information will create an ongoing role for infomediaries and related services providers to add value at each stage of the full cycle of care. These value added Health Advisory Services (more later) will offered by hundreds of companies, in thousands of forms, to millions of people who are can benefit from the remixing of medically related information. It is easy to see how the new Web 2.0 framework, with its inherent social networking and collaboration tools, will make this "long tail" of medicine a "value"able venture. [8]

Another aspect to be mentioned is the term "patient-centric" used in many of the discussion on the developments in health and care. In many occasions that term is used in a one-way-street sense, professionals declare the patient to be in the centre, often "to the extent that they can regard patients as empowered, they can regard themselves as being freed from a degree of responsibility for them" (p.55) [Salmon], however denying the patient real active and responsible involvement.

The definition by Eytan caused a small discussion scattered over three web blogs in parallel (one of the drawbacks of Web 2.0) [9]. We phrased, as a consequence of that discussion, the following definition:

**Health 2.0 defines the combination of health data and health information with (patient) experience through the use of ICT, enabling the citizen to become an active and responsible partner in his/her own health and care pathway.** [10]

### III. EHR

Essential in patient empowerment is the access to

information. The internet delivers information in abundance. In a recently published article the authors covered the most important aspects about (mis)information on the internet [11]. An important development is the fact that the consumer is actively searching for information: "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%)." [12]

To achieve true patient empowerment, a bi-directional contact between patient and clinician is necessary: "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, 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." [13]

To ensure supply of information that is at the same time relevant, trustworthy and comprehensible, we will have to deliver the appropriate search input to the patient. Simply Googling "obesity" does certainly not bring you a guaranteed high quality result. The authors hold the view that through properly standardising and coding (SNOMED CT, ICD10, etc) elements contained in Electronic Health Records could and should be used for the input of search data.

*Access to relevant and adequate information is the first step to patient empowerment.*

Of course this will cause major paradigm shifts in the patient-doctor relationship. Litigation is one aspect: “The need to provide clinical care of the highest quality is an imperative and if the patient wants an alternative approach this can be a significant inhibitor to allowing the patient the control they desire. The capacity of health record systems to record both the advice provided to the patient, and the explanation of potential repercussions of patient decisions, along with the patient’s acknowledgement of these details offers the potential to more clearly define the patient’s responsibility for choices made about care. These discussions could and should have occurred in the past, but appear to have been rare.” [14]

Many different concepts of EHRs exist, the most important conceptual difference being PHR (Personal Health Record) vs EHR: “EHR systems function to serve the information needs of health care professionals, PHR systems capture health data entered by individuals and provide information related to the care of those individuals” [15]. Recently Mandl and Kohane added the personally controlled health records (PCHRs) [16].

It’s our view that whatever the name of the record will be, it should be a “*container of links to all medical information about the citizen stored at hospitals, GP practices, pharmacies, independent lab and exam facilities, etc., together with the input from devices, paramedics. The citizen must be able to add his input (comments, over-the-counter-drug use, lifestyle, etc.), to make corrections as well as to decide who is going to see which part of his data and if/how his de-identified data will be used.*” [17].

#### IV. TELE CARE

Telecare is the application of Information and Communication Technologies in health and care encompassing curative, preventive and promotional aspects, as well as the interaction between doctor and patient.

In Patient 2.0 Empowerment telecare is expected to play a major role. The rapid development of mobile and wearable devices to monitor the citizen’s condition and life style makes telecare more available and triggers speedy adoption by health and care providers. “After two decades of pioneering work from around 1975 to 1995, followed by a decade of transition with early adopters using telematics applications to improve their daily work in health and social care in limited scenarios, telemedicine has then clearly started to become an important issue for implementation, operational deployment of services and a promising market for industry.” [18], with the following important observation: “A shift from telemedicine applications as stand-alone, added-value component driven by the paradigm of technology-push, toward eHealth services emerging as one-of-many features in digital medical work environments driven by the paradigm of demand-pull.” (p.6)

“I think telemedicine, e-health, and medical informatics are all interrelated and fit together like pieces of a puzzle.

We will eventually all go to electronic medical records, which will help link these components even more closely. [...] Regarding home healthcare, so much of what people used to do outside the home for healthcare is being done in the home. Telemonitoring devices are making it easier for healthcare providers to evaluate their patients’ status without an office visit, and the data-monitoring centers can alert the clinician to significant changes in health status, making early intervention much more probable. Tele-home healthcare is the way of the future and will become more ubiquitous—extending from the home to work and play environments as well. [...] But whether it progresses to bringing healthcare prevention into the home on a large scale—where we all would have these devices in our homes to measure our blood pressure or blood glucose levels—is not clear. Will that be what people want? At what point might it become too much information, for example. And will the patient need to or want to have access to all of the data generated by daily monitoring? These are questions that still need to be addressed.” [19]

However, research seems to indicate that in one of the primary target groups, the elderly, the satisfaction with telecare, compared to daycare centers or nursing homes, is significantly higher. [20]

The application of telecare will be accelerated considerably by recent developments in mobile phone applications. These developments span a large area, ranging from distant patient monitoring [21], aging services [22], diagnosis [23] to consultation assistance in rural areas [24]. For an overview of recent publication of the use of cell phones see [25].

#### V. PATIENT NETWORKS

In our definition of Health 2.0 the word experience plays a primordial role, as it is the essence of the 2.0 version of any development.

For patient empowerment, experience and the exchange thereof is crucial. Online networks are important platforms to achieve this. “Online self-helpers, [...] will typically know only about their own disease, but some will have an impressive and up-to-date knowledge of the best sources, centers, treatments, research, and specialists for this condition. A smart, motivated, and experienced self-helper with hemophilia, narcolepsy, hemochromatosis or any number of rare genetic conditions may well know more about current research and treatments for their disease than their own primary practitioner. And when it comes to aspects illness that some clinicians may consider secondary—e.g., practical coping tips and the psychological and social aspects of living with the condition—some experienced self-helpers can provide other patients with particularly helpful advice.” [26]

“The new Web sites facilitate the exchange of health information and personal stories in a way that transcends both medical textbooks and chatting with a friend on the

phone - yet offers some of the benefits of both. Consumers are quickly adopting such social networks; one in three Americans used some form of social media online for health in 2007.” [7]

Patient networks, through information and experience from others, can help in both primary and secondary aspects of patient empowerment, resp. the decision making process (primary), and assistance in dealing with aspects like the consequences of those decisions or choices made in a citizen's health or care pathway (secondary).

In the longer term, these networks can have an empowerment aspect on a different level, medical research. “The prospect of research-oriented online support groups offers a number of appealing scenarios. Patient groups could design and conduct their own studies, collecting their own data, analyzing their results, and publishing their results. They could provide researchers with access to perfectly targeted study populations at little or no cost. But whatever role they play, once they become active players in medical research, patient groups will demand a voice in deciding what should be studied and how that research will be conducted. And while such e-patient initiatives may encounter some resistance, in the end it seems likely that the financially-strapped medical research establishment will come to consider such e-patient research an offer it can't afford to refuse.” [27]

## VI. PATIENT 2.0 EMPOWERMENT

The Eytan definition assumes Health 2.0 to be a transition. This concept is confirmed by McCabe Gorman and den Braber [28]. However, to enable ICT related health developments to move on and develop (neXthealth) [28], a secure foundation has to be laid. Therefore it is our view that Health 2.0 will not be a concept of transition, but one of the main pillars for the interactive use of ICT in health and care.

As it will give data and information a much needed citizen-related context, the application of experience is primordial and will help to make health ICT sustainable.

*Patient 2.0 Empowerment is the active participation of the citizen in his or her health and care pathway with the interactive use of Information and Communication Technologies.*

## REFERENCES

- [1] Saltman RB, Patient choice and patient empowerment in northern European health systems: a conceptual framework, *Int J Health Serv.* 1994;24(2):201-29
- [2] Peter Salmon, and George M Hall, Patient empowerment or the emperor's new clothes, *J R Soc Med.* 2004 February; 97(2): 53-56, available: <http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1079288&blobtype=pdf>
- [3] José Luis Monteagudo and Oscar Moreno, Patient empowerment opportunities with eHealth, eHealth ERA Report on Priority Topic Cluster Two and recommendations, March 2007, available: [http://ec.europa.eu/information\\_society/newsroom/cf/document.cfm?action=display&doc\\_id=320](http://ec.europa.eu/information_society/newsroom/cf/document.cfm?action=display&doc_id=320)
- [4] Tim O'Reilly, What is Web 2.0 - Design Patterns and Business Models for the Next Generation of Software, 09/30/2005, available: <http://www.oreillynet.com/pub/a/oreilly/tim/news/2005/09/30/what-is-web-20.html>
- [5] Ted Eytan, My Definition of Health 2.0 : The Transition to Personal, Participatory Health Care, available: <http://www.tedeytan.com/2008/05/02/889>
- [6] Joseph Conn, Health 2.0: The next generation of Web enterprises, *Modern Healthcare*, 11 December 2007, available: <http://articles.icmcc.org/wpc/tag/health-2.0>
- [7] Jane Sarasohn Kahn, The Wisdom of Patients - Social Media In Health Care, THINK Health for California Healthcare Foundation, April 2008, available: <http://www.chcf.org/documents/chronicdisease/HealthCareSocialMedia.pdf>
- [8] Scott Shreeve's Definition, Health 2.0 Organization, available: [http://health20.org/wiki/Health\\_2.0\\_Definition#Shreeve.27s\\_Definition](http://health20.org/wiki/Health_2.0_Definition#Shreeve.27s_Definition)
- [9] Ted Eytan, My Definition of Health 2.0 : The Transition to Personal, Participatory Health Care, 2 May 2008, available: <http://www.tedeytan.com/2008/05/02/889>  
e-patients.net, Participate in defining "Health 2.0", 6 May 2008, available: [http://www.e-patients.net/archives/2008/05/participate\\_in.html](http://www.e-patients.net/archives/2008/05/participate_in.html)  
Ted Eytan, e-patients: Participate in defining "Health 2.0", 7 May 2008, available: <http://www.tedeytan.com/2008/05/07/917>
- [10] Lodewijk Bos, Health 2.0: Definition, ICMCC blog, 12 May 2008, available: <http://blog.icmcc.org/?p=2254>
- [11] L. Bos, A. Marsh, D. Carroll, The Impatient Patient, *Medical and care Compunetics* 5, L. Bos et al, (eds), IOSPress 2008, pp. 1-13
- [12] The Harris Poll® #76, July 31, 2007, available: [http://www.harrisinteractive.com/harris\\_poll/index.asp?PID=792](http://www.harrisinteractive.com/harris_poll/index.asp?PID=792)
- [13] 9th "Health on the Net Survey of Health and Medical Internet Use" <http://www.hon.ch/Survey/Survey2005/res.html>
- [14] Heather Grain, Changes in Doctor-Patient Relationships for Realizing the Personal Health Paradigm, *Medical and care Compunetics* 5, L. Bos et al, (eds), IOSPress 2008, pp. 373-378
- [15] 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, available: <http://www.jamia.org/cgi/content/full/13/2/121>
- [16] Kenneth D. Mandl and Isaac S. Kohane, Tectonic Shifts in the Health Information Economy, *NEJM*, Volume 358:1732-1737, April 17, 2008, Number 16, available: <http://content.nejm.org/cgi/content/full/358/16/1732>
- [17] Lodewijk Bos, EHR – Patient Managed?, ICMCC Blog, 6 May 2008, available: <http://blog.icmcc.org/?p=2197>
- [18] Sustainable Telemedicine: paradigms for future-proof healthcare, EHTEL Report, March 2008, available: <http://www.ehtel.org/SHBlob.asp?WCI=ShowD&F=english%2Fdti81865%2FEHTEL+Briefing+Paper+Sustainable+Telemedicine.pdf>
- [19] Vicki Glaser, Telethinking With Elizabeth A. Krupinski, *Telemedicine and e-Health*, March 1, 2008, 14(2): 117-121, doi:10.1089/tmj.2008.9987, available: <http://www.liebertonline.com/doi/pdfplus/10.1089/tmj.2008.9987>
- [20] Maria L. Onor et al, Effectiveness of Telecare in Elderly Populations– A Comparison of Three Settings, *Telemedicine and e-Health*, March 1, 2008, 14(2): 164-169, doi:10.1089/tmj.2007.0028, abstract available: <http://www.liebertonline.com/doi/abs/10.1089/tmj.2007.0028>
- [21] Kevin D. Blanchet, Remote Patient Monitoring, *Telemedicine and e-Health*, March 1, 2008, 14(2): 127-130, doi:10.1089/tmj.2008.9989, available: <http://www.liebertonline.com/doi/pdfplus/10.1089/tmj.2008.9989>
- [22] Majd Alwan, Devon Wiley, Jeremy Nobel, The State of Technology in Aging Services, Center for Aging Services Technology (CAST), March 2007, available: [http://www.agingtech.org/documents/bscf\\_state\\_technology\\_phase1.pdf](http://www.agingtech.org/documents/bscf_state_technology_phase1.pdf)
- [23] Christop Ebner et al., Mobile teledermatology: a feasibility study of 58 subjects using mobile phones, *Journal of Telemedicine and Telecare*,

Volume 14, Number 1, January 2008 , pp. 2-7(6), abstract available:  
<http://www.ingentaconnect.com/content/rsm/jtt/2008/00000014/0000001/art00002>

- [24] Balin, Surya; Singh, Amar Jeet, Mobile phone consultation for community health care in rural north India, *Journal of Telemedicine and Telecare*, Volume 13, Number 8, December 2007 , pp. 421-424(4), abstract available:  
<http://www.ingentaconnect.com/content/rsm/jtt/2007/00000013/0000008/art00010>
- [25] ICMCC News Page, <http://articles.icmcc.org/wpc/tag/cellphone>
- [26] Ferguson T., Can Useful and Reliable Online Health Resources be Produced by 'Medically Unqualified' Persons?, *The Ferguson Report*, Number 5, July 1999,  
<http://www.fergusonreport.com/articles/fr079902.htm>
- [27] Ferguson, T., e-Patients as Medical Researchers, *The Ferguson Report*, Number 9, September 2002,  
<http://www.fergusonreport.com/articles/fr00903.htm>
- [28] Jen McCabe Gorman and Maarten den Braber, *Semantic Web Sparks Evolution of Health 2.0 – A Road Map to Consumer-Centric Healthcare*, to be published