iHealth:
supporting health by technology

Hans C. Ossebaard

iHEALTH: SUPPORTING HEALTH BY TECHNOLOGY

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This thesis was funded by the Strategic Research Program of the Dutch National Institute for Public Health and the Environment (RIVM).

Cover design: 'Scholar's rock'
by Giselle Banel [www.gisellebanel.nl] & Joost Hosman [www.byallmeans.nl]
Lay-out and print: Gildeprint Drukkerijen, The Netherlands

ISBN 978-90-365-3375-1
doi:10.3990/1.9789036533751

Dissertation, University of Twente

iHEALTH: SUPPORTING HEALTH BY TECHNOLOGY

PROEFSCHRIFT

ter verkrijging van
de graad van doctor aan de Universiteit Twente,
op gezag van de rector magnificus,
prof. dr. H. Brinksma,
volgens besluit van het College voor Promoties
in het openbaar te verdedigen
op vrijdag 15 juni 2012 om 12.45 uur

door

Hans Cornelis Ossebaard
geboren op 15 juni 1961
te Enschede.

Supervisor Professor Dr. E.R. Seydel and assistant-supervisor Dr. J.E.W.C. van Gemert-Pijnen have approved of this thesis.

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though on the sign is written
don't pluck these blossoms
it is useless against the wind
which cannot read

(Japanese poem)

Preface

Preface

In retrospect, 'knowledge' has been a *Leitmotiv* in my professional career. At the University of Utrecht (UU) I learned the Aristotelian truth that the best way to understand is to teach. Professor Dr. David Ingleby, head of the then Department of Developmental Psychology invited me to work with him and participate in research and education. From lecturing on topics such as developmental and clinical psychology, mental healthcare and critical psychiatry, I moved on to substance use and drugs addiction when Dr. Govert van de Wijngaart asked me to join his research team in 1993 and establish a CVO-Addiction Research Centre (Centrum voor Verslavingsonderzoek) at the Faculty of Social Sciences (UU). A successful grant application enabled us to develop a research program around the theme of substance use and dependency and to set up various educational tracks in this interesting and highly controversial field. Beside lecturing, I started researching and writing on a wide array of drug-related issues ranging from psychological perspectives (Burt et al., 1994; Alexander et al., 1998; Ossebaard, 1998a;) to prevention and treatment (Ossebaard, 1996a, 1999a; Ossebaard & Maalsté, 1997, 1999; Meeus et al., 1999; Hegger & Ossebaard, 2000; Rhodes et al., 2000) to policy perceptions (Ossebaard, 1996b; 1998b; 2000a; Ossebaard & Van de Wijngaart, 1998).
I particularly loved the serving art of reviewing books (cf. Ossebaard, 1996c, 2000b, 2000c; 2002) as a way to share knowledge, but I also engaged with more outwardly extrovert media as well, such as public lecturing, radio discussions and television interviews. Using these media was intended to reach an equally diverse audience of scientists, health professionals, youngsters, parents, policy-makers and drug users. And of course it was also meant to advance the CVO Addiction Research Centre (now called: 'CVO Research, Training, Consultancy') where friends and colleagues such as psychologists Richard Braam and Dick de Bruin, anthropologist Hans Verbraeck, psychotherapist Miriam Fris, and social scientist Nicole Maalsté, conducted high-profile research under the learned tutorage of dear Goof whose premature death in 2004 grieved all of us.

Via the academic and educational Dutch computer network SurfNet, I was introduced to the <proto-internet> in the beginning of the 1990s and it was quite impossible not to be impressed by its potential. The web of 'flat data', Web 1.0, was thriving. With friend and artist, Ingmar Spit, now an international game designer, we developed CVO's institutional website in 1996. It was one of the first websites of the university and it can still be accessed somewhere in the backstreets of the net. At the end of last century, I participated in an EC-funded research project to study the use of the Internet as a drug prevention tool called 'SYN-WEB: Synthetic drug prevention for young people through www-pages'. In collaboration with Dr. Nicholas Dorn from the British Institute for the Study of Drug Dependence, Dr. Teuvo Peltoniemi from the A-Clinic in Helsinki and several colleagues from Edex Kolektiboa (Bilbao, Spain), we developed and tested primordial, prototype websites for youngsters with regard to the use of the party-drug XTC (MDMA) (Schippers & Broekman 1998a; Ossebaard, 1999b). The bridge between substance use and technology was further substantiated through my program 'Digital Drugs: Psychoactive Technology' that aimed to study "(..) the impact of the use of new technologies (software, hardware, virtual reality, Internet) on human behavior and experience" (Schippers & Broekman, 1998b). In this research program, we studied the effects of a 'brain machine' on stress reduction among healthcare professionals and reported our findings accordingly (Ossebaard & Van Daalen, 1998).

When the Utrecht alma mater celebrated her 360th anniversary in 1996 I organized a movie series, a succession of lectures and an exhibition under the heading of 'Reis naar de roes' ('Tripping to get high' which was funded by the university's lustrum office, the City Council of Utrecht and the Foundation for Public Education on Science and Technology (Stichting Publieksvoorlichting over Wetenschap en Techniek). The urge to understand the universal human motivation to alter consciousness was central to this endeavor. The brain machine was part of the exposition were visitors could try it out and 'surf the brainwaves' while participating in a pilot-study (Ossebaard & Van Daalen, 1996). We were invited to open the National Science & Technology Week 1996 at the ceremonial Utrecht University academy building. On this occasion, Govert van de Wijngaart elucidated the relationship of human transformative experience and technology in a brilliant public lecture/performance. With director and performer, Norbert Stockheim, my soul mate who left for good in 2005, we developed an international cultural and intellectual context to share knowledge and understanding of the "cyberdelic experience" (Ossebaard, 1997). An in-depth report of the brain machine study is included in the present thesis because it so well matches the overall theme of how people use technologies for personal health management. Meanwhile, I took my educational, consultancy and research activities concerning drug-related themes and began focusing on them through the lens of my private firm INTOX.

At the Trimbos Institute (Netherlands institute of Mental Health and Addiction) I briefly led a national program on the prevention of alcohol and drug misuse for primary and secondary schools called 'The Healthy School and Drugs'('de Gezonde School en

Genotmiddelen'). The project and its partners, municipal medical and health services, prevention departments of regional addiction care services, schools, applied traditional means of communication: working books, videos, brochures, gadgets. The use of the Internet (for health information) was still limited among professionals and the public, but this was changing fast. Jellinek Prevention & Consultancy (Amsterdam), always at the forefront of innovative approaches to alcohol and drug prevention, invested in 'new media' for health communication at the end of the nineties. As web-editor, I took part in the development of Jellinek's online drug information and educational services.

The drive to acquire knowledge, create knowledge, share and disseminate knowledge with regard to health transposed to a more abstract level at the Dutch Ministry of Health, Welfare and Sports in The Hague. Early in 2001, the graceful and erudite Fons Vloemans MD, invited me to implement the requirements of New Public Management at the Department of Drug Policy, Mental Healthcare and Social Care. Knowledge management, information policy, accountability, policy information, performance indicators, ex ante evaluations replaced LSD-assisted therapy, Ecstasy, secret chiefs, neuro-hackers, back-loading, digital drugs and after-parties. The government invested substantially in ICT to improve the quality and availability of policy information and reduce the administrative load for companies, organizations and citizens. For the healthcare sector, this meant a sturdy effort to contribute to internal and external transparency and accountability based on functional registrations and databases. As an information officer, later policy advisor, I operated the interdepartmental VBTB-program ('Van Beleidsvoorbereiding tot Beleidsverantwoording'/'From Policy Budget to Accounting for Policy') for the field of mental health care, social care and addiction care. It was initially implemented under the aegis of the Ministry of Finance shortly beforehand. My portfolio included the development of the excellent psychiatric Case Registers, the production of the first sector-reports presenting performance information in mental health care, the innovative national illicit substances registration LCMR (Landelijke Centrale Middelen Registratie) and the national mental health monitor (NMG - Nationale Monitor Geestelijke gezondheid). I was also involved in the groundwork for the national online health and health care portal, a project emanating from a series of advisory reports on eHealth by the Council for Social Development (Raad voor de Maatschappelijke Ontwikkeling) and the Council for Public Health and Healthcare (Raad voor de Volksgezondheid en Zorg) against the background of health system transformation and new public management.

In 2005, I transferred to the RIVM, the national Institute for Public health and the Environment in Bilthoven, to work on the very same portal project that had been part of its assignment since 2004. The portal kiesBeter.nl was hosted and managed by the Center for Public health Forecasting, a well-reputed provider of health policy information to the Ministry of Health. As a product manager, I was primarily responsible for the availability and accessibility of medical information and information on the prevention of diseases. The democratic task to disclose knowledge to a general audience for decision making in health and healthcare matched well with my ambitions. However, I was missing my research activities and, shortly after, I wrote a research application in collaboration with epidemiologist Dr. Jeanne van Loon for the RIVM-Strategic Research Program. The subject matter was consumer health informatics, more or less tantamount to eHealth; until then, an unexplored field of study at RIVM. The thematic program that the proposal addressed was 'Risk Assessment, Perception and Consumer Behavior and Understanding led by geneticist Professor Dr. Harry van Steeg (Leiden University Medical Centre; Laboratory for Health Protection Research, RIVM).

I contacted Professor Dr. Erwin Seydel and his team at the University of Twente (UT) in my hometown Enschede. A former Dean of this University, he was now heading the IBR Research Institute for Social Sciences and Technology, chairing the department of Psychology and Health Communication at the faculty of Behavioral sciences, and member of the Scientific Council for Government Policy. My proposal for collaboration was in alignment with the university's ambitions with regard to the crossroads of health, technology and social sciences. I also engaged Dr. Gunther Eysenbach of the University of Toronto, pioneer in the field of eHealth, founder and editor-in-chief of the Journal of Medical Internet Research, to become a consultant to the project. The strategic relevance for RIVM was recognized and the application ('gettingBetter.nl', a paraphrase of the portal's name) was granted. In a non-descript railway station restaurant I met with Professor Dr. Erwin Seydel who agreed to adopt the collaborative project. He introduced me to Dr. Lisette van Gemert-Pijnen, the eHealth specialist within his team, who came to be responsible for the operational implementation of the research project and, as such, was my counter-part at the UT. As a start-up of the project, I organized a symposium (February 2007, RIVM) on consumer health informatics and prevention with Professor Dr. Erwin Seydel and Dr. Gunther Eysenbach as the keynote speakers. It took some time to find a suitable PhD-student to participate in the project, however, we were able to engage Saskia Kelders, MSc., (University of Groningen) at the end of the year and gettingBetter.nl took off.

The project reverberated at the University of Twente where Dr. Lisette van Gemert-Pijnen established the Center for eHealth Research and Disease Management in 2008, engaged Eysenbach as 'visiting professor', developed the Persuasive Health Technology program, and invited me to lecture in the field of eHealth. Every year we co-convened an international academic conference:

- 'Supporting Health by Technology I' (2008),
- 'Supporting Health by Technology II' (2009),
- 'Medicine 2.0™' (2010), and
- the 'eHealth symposium' at the biannual Medical Informatics conference (MIC, 2011).

These events attracted upbeat attention in the academic world (see, for example, Morris, 2011), in health care (circa one third of all visitors to the conferences were health care professionals), in policy (for example, at the Ministry's Chamber of Knowledge (Sept. 2010), in the press, et cetera. Furthermore, we contributed each year to a number of international conferences, thereby expanding our networks to share knowledge and information with regard to the role of technology in meeting the immense challenges in global health care such as ageing or increasing antimicrobial resistance.

The most prominent personal and academic outcomes of this research process, however, are the present thesis as well as the corresponding thesis of Saskia Kelders, MSc. They contain the major research papers that emanated from the gettingBetter.nl project. They also represent the collaboration between RIVM and the University of Twente in the field of consumer health informatics and eHealth. In addition, they indicate why such collaboration is necessary and what it can produce for the benefit of both parties' assignments. What do the investments and outcomes mean for RIVM's public health mission at this moment in time?

It is a given fact that the worldwide, disruptive increase in the use of information and communication technologies irrevocably affects all domains of life. Not in the least: the domain of (public) health, participatory health care and health research. As a tech-savvy country the Netherlands have always been at the forefront of this development: accessibility to, availability, connectivity and the use of digital technologies, such as the Internet or mobile phone, have been relatively (very) high. The IT infrastructures, as well as the economical and educational conditions are well-developed. This makes the country a perfect testing ground for using and evaluating these technologies in the face of the above-mentioned global health challenges.

The gettingBetter.nl project, which is the first RIVM project on the subject of eHealth and consumer health informatics, has kept RIVM abreast of developments that are of immediate concern for the institute's public health assignments. It provided RIVM with a visible, knowledge position with regard to an innovative area. This is important for RIVM's national and international credibility and reliability. The acquired knowledge and skills have already been used, are still being used and will go on being used for improving the online portal kiesBeter.nl and other public health information products, such as a forthcoming report on the risks of eHealth technology for the Healthcare Inspectorate in collaboration with the RIVM Centre for Pharmaceutical Affairs and Medical Technology. The project has helped to pave the way for several new RIVM initiatives in research, health, and risk communication (Ossebaard & Coutinho, 2011).

From the start, the research objective regarding (e-)Health literacy has been related to an international collaborative partnership of RIVM with a range of European bodies: the European Health Literacy Survey (HLS-EU) study, led by Professor Dr. Helmut Brand, the Institute of Public Health (lögd), Bielefeld, North Rhine-Westphalia in cooperation with the University of Zurich (Dr. Jen Wang). gettingBetter financially supported RIVM's participation in this project, which was the first European project team to work on health literacy. The HLS-EU steering group and national advisory boards introduced the issue of health literacy and the data and policy implications of HLS-EU to the first circle of key stakeholders. A model instrument was adapted and validated to measure core competencies for eHealth literacy. It is for the first time that data is collected on health literacy in European countries using a standard methodology. The preliminary outcomes on health literacy have been published by Sørensen et al. (2012), and specific analyses of Health literacy in respective countries will be published later this year. eHealth literacy will be highlighted in a separate study. RIVM involvement was realized by Dr. Mariël Droomers, later by Dr. Ellen Uitert of the RIVM Centre for Prevention and Health services Research. As of now, the project has co-produced the first Dutch national conference on Health Literacy (September, 2010) and co-founded a consortium to advance the case for health literacy in the Netherlands (2010). From HLS-EU we will learn about the necessity to adjust public health messaging to the level of health literacy observed in the general population which is hitherto unknown.

Such projects benefit from the national and international (academic) network that has been built up from the present project. The direct input from our partner, the University of Twente, has been very valuable, for instance with regard to the development of a 'roadmap' that enables researchers and health care professionals to ultimately increase the impact of eHealth technologies. Theoretically challenging, and applicable in the practice of public health, health care and research, this 'holistic framework' is currently in the process of being developed (Van Gemert-Pijnen et al. 2011). This project was initiated by Dr. Nicol Nijland (2011) and RIVM invested in its development to reconstruct it as a wiki.[1] We have presented and demonstrated the online wiki at the 4th congress on social media in health, medicine and biomedical science Medicine 2.0 at Stanford University (Van Gemert-Pijnen, Ossebaard & Nijland, 2011)[2]. We have further discussed it with our partners at the international conference on eHealth, Telemedicine, and Social Medicine eTELEMED in Valencia (Van Gemert-Pijnen et al. 2012). The wiki is in fact a collaborative toolkit composed of concepts from business modelling and human-centered design. It contains evidence-based knowledge as well as practical guidelines with regard to all stages of the development, design, implementation and evaluation of eHealth technologies. Due to its collaborative nature – other researchers contribute to it from their own experiences – using the dynamic wiki increases the chances for successful implementation and a measurable impact of these interventions. This is a substantial response to appropriate critique in recent years (cf. Atienza et al., 2010; Black et al., 2011) and a meticulous format to increase the impact of eHealth technology.

With regard to RIVM's statutory responsibilities in the prevention and control of infectious diseases, the model has been put to use in 'ePublic health: fresh approaches to infection prevention and control'; a strategic research project, proposed by the RIVM Centre for Infectious disease control in collaboration with UT (Ossebaard, Van Gemert-Pijnen & Beaujean, 2011; Ossebaard, Van Gemert-Pijnen & Seydel, 2011). Another example of related applied research and collaboration is the UT-led Eursafety project, a large-scale project for cross-border infection management. We have found international parties to further elaborate on the wiki; a pure form of action research.

With these activities, we believe we have contributed to the original aims of the RIVM strategic research program in general and the aims of gettingBetter.nl in particular. All these products, outcomes and processes add to the strategic and practical positioning of RIVM in the changing landscape of public health and information and communication technologies. RIVM is about risk detection and analysis as well as the integration of knowledge about health and environment. UT is about technology and people. Knowledge is what connects RIVM and the University; an indispensable tool to create information out of raw data. Knowledge is a technology, a bridge, a network, and an ambition. And a personal *Leitmotiv*, it seems.

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[1] www.ehealthwiki.org

[2] http://www.medicine20congress.com/ocs/index.php/med/med2011/paper/view/729

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Introduction to human health and technology

Health and technology

The present thesis is about supporting health through the use of technology. Traditionally, technology is associated with changing the world as it is (cf. Skolimowski, 1966). The philosophy of technology goes back to the roots of Western thought. Techne, or techné, which is etymologically derived from the Greek word τέχνη (ancient Greek: [tékʰnɛː], modern Greek: [ˈtexni]) is often translated as *craftsmanship*, *craft*, or *art*. It refers to the rational practice involved in making an object or accomplishing something to improve what is already in place. For the ancient Greeks, music and medicine, therefore, belonged to the same domain of *techne*. Throughout the ages, the meaning of the term has been more or less opposed to the realm of episteme - derived from ἐπιστήμη, the Greek word for *knowledge* or *science* - which concerns understanding the world as it is. But this practice (experience-based) versus theory (pure knowledge) schism is only superficial; both Aristotle and Plato refer to the necessity for practice to be informed by theoretical understanding and knowledge (cf. plato.stanford.edu/).

Without diving deeply into the philosophical relationship between technology and science, it is clear that the latter is about how things 'are', while the former is about how things 'ought to be' (Simon, 1969). Technology is "humanity at work" (Pitt, 1999) in all its beautiful and wicked ways, and if humans are at work they modify the world in order to improve the human condition, and ultimately to survive. In the same sense, technology has been conceived as 'applied science'. Since the nineteenth century all prominent thinkers have addressed this relationship between technology and humanity. The appreciation of the role and the meaning of technology varied between outright rejection and complete redemption. Fear of modernity has fed conservatism and a resistance to change. Anti-tech sentiments or anarcho-primitivism often reveal all too human worries about losing one's ground in a changing world. Yet on the other side of the spectrum, we find a true devotion to technology which even contains religious elements; as if technology could offer salvation for the troubles of mankind (Dery, 1996). Whatever the perspective, the urge to craft a better world has probably been an evolutionary drive since the birth of mankind. This can be observed in agricultural or industrial activity, in political or creative activity, in trade and in leisure, in medicine and in healthcare. Technology has often been viewed as a means to an end. An expression such as: "The availability of low-cost tablet computers facilitates bedside information retrieval by clinicians" shows how technology is conceived as a value-neutral tool that merely enables us to solve a problem (Kaplan, 2009). The opposite standpoint would be more determinist. For instance: "Implementing electronic patient records in this hospital will lead to lower patient mortality and higher patient safety.” Here, technology is supposed to irreversibly influence human behavior, or an organization, according to an autonomous logic leading to a specific outcome (Chandler, 1995). Both views ignore the complex interaction between humans and technology in real life settings. Society and technology mutually influence each other in often unpredictable chains of causation. Technologies emerge from social, cultural and economical relationships in specific settings. They ‘live’ in human practice and acquire meaning through the manner in which they are used and the context in which they are applied. A meaning that may change over time, since contexts change. And as much as humans and society are influenced by them, technologies are permanently influenced and shaped by human actions, needs and expectations (Van Lente, 2010; Verbeek, 2011). Such a ‘constructive’ perspective is taken in the present research. This position is quite common in contemporary philosophy of technology (cf. Floridi, 2011a) though mixed forms come about, for instance in the recent work of Kelly (2010) who advocates a teleological, evolutionary view on technology while acknowledging the social and historical conditions of its development.

It usually takes a while before a new technology is accepted, used or rejected. It took about twenty-five years for the bicycle to evolve from a useless thing for daredevils to its final dominant design; the safety bicycle as an indispensible means of transportation for men and women (Bijker, 1995). The domestication of the computer in the 1980s and the subsequent advent of the internet in the 1990s deeply affected the human-technology relationship. (Berker, Hartmann, Punie & Ward, 2006). The values created by technology increased and also diversified. The speed, the range and the impact of the developments in information and communication technologies (ICTs) in fact influenced all levels of human functioning. Some authors therefore speak of a Kuhnian ‘paradigm shift’; a fundamental change in our scientific and mental model of who we are and where we are (Fioridi, 2011b). Others talk about an information revolution that irreversibly changes the way we behave, feel, think and communicate, for better (Shirky, 2011) or for worse (Carr, 2010).

The existential role of information becomes clear when digital technology meets health (eHealth), and technology transcends the meaning of medical devices. In all domains of curative medicine, health care and disease prevention the power of ‘converging technologies’ can be observed. During the last decade, completely new concepts and innovative applications were introduced for diagnosis and treatment, for monitoring, or for self-management (Luijben & Kommer, 2010). These rapid changes are partly explained by convergence, i.e., simultaneous developments in different scientific disciplines such as biology, chemistry, nanotechnology, as well as computer, behavioral and material sciences. These have led to combinatory products that integrate several features or functions, which enables for instance early diagnostics, 'point-of-care' testing, or medical imaging. Together with applications in information and communication technologies (ICTs) this implies numerous novel opportunities and challenges for all people involved. At first glance, they affect where, when and how health care delivery takes place and both influence the quality of care and alter the traditional position of the health care consumer. They affect the lives of patients in that they enable new forms of participation, collaboration and interactivity, often alluded to with the terms Health 2.0 or participatory health (Van de Belt, 2010). Upon closer inspection, they also imply potential risks and ethical, social and financial challenges (Institute of Medicine, 2011). Both these perspectives will be addressed in this thesis.

What are the health issues within our 'technium', this complex, all-pervasive constellation of everything humanity has made (Kelly, 2010)? Global healthcare's major issues have been described extensively in scientific literature (cf. Hayashi et al, 2009). Their urgencies lie in the assumption that either in the short term the health care system will be inaccessible to large parts of the population or it will be too expensive to sustain with an acceptable quality of care. Faced with ageing, consumerism and a changing demand due to a rise in multi-morbid chronic diseases, health care delivery is in dire need of innovation (World Health Organization, 2010). Though the urgencies vary regionally between rising healthcare expenditures, demographic trends, the threat of infectious diseases, consumerism and the growth in multi-morbid diseases, the necessity for innovation can be considered a matter of fact.

This global state of affairs is reflected in regional situations. The following health trends have been identified. In the Netherlands three public health trends are important. The first is that life expectancy, a key indicator of public health, is increasing much faster than previously expected (Luijben & Kommer, 2010). In 2050 life expectancy at birth for females will be 88.1 years and for males 83.8 years. Life expectancy at the ages of 65 and 80 increased considerably as well, respectively 24.6 and 11.4 years (for females) and 21.1 and 9.5 years (for males). A second trend can be observed in the causes of death. From statistics that estimate the likelihood of dying from a specific disease, it appears that these chances decrease for all major causes of death.

The order of major illnesses, in terms of 'years lived with disability'[1] will remain the same until 2020. Anxiety (number 1), coronary heart diseases (2) and depression (3) will cause many 'years lived with disability', and also Diabetes type II (4) and stroke (5) will grow, as well as Arthritis (6) and Chronic Obstructed Lung Disease (7) (Hoeymans, Melse & Schoemaker, 2010). A third trend is that Dutch health care will become more specialized while its use will intensify. For instance, the number of medical specialists has tripled since 1960 and the density of pharmacists has increased with a factor 2.7. Growth is seen in the use of over-the-counter drugs and visits to specialists, dentists, and most notably physiotherapists. Hospital day-care has increased with 60% while the average duration of clinical admissions decreased from 14 to 7 days (1981-2005). Growth in health care use is made possible by an expansion of services from 6.5% (1970) to 13% (2008) of total Dutch employment. It is estimated that the volume of care increases until 2030 with approximately 3.4% a year, of which 1.1 percentage-point is explained by demographic developments. The parallel increase in expenditures amounts to 8% a year. Expenditures due to age-related diseases (Alzheimer disease, stroke) will increase with over 2.5% based on demography only. All this generates a growing demand for high-quality labour, but the working population decreases with an average of 0.2% a year (2007-2030). It is no surprise that the delivery of the necessary care with fewer resources is seen as a serious political challenge in the Netherlands (Luijben & Kommer, 2010). How can eHealth technology provide support?

Innovative solutions are needed to bridge this gap and to meet the increasingly complex demand for care: ageing leading to multi-morbidity leading to a higher volume and a higher variety of demand. De-hospitalization, organizing health care in regional networks of 2.0 collaborating professionals and patients is one future option (RVZ, 2011). A concentration of high complexity/low volume care is another. An effective contribution is the differentiation of care functions, for example, the nurse-practitioner or the physician's assistant. This differentiation is supported by new medical technologies. Technological developments have endorsed a shift in medical routine activities from secondary health care to primary health care and even to the home environment (Geertsma et al., 2007). This leads to a reduction in time and costs and an increase in the quality of life for patients.

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[1] YLD is an epidemiological measure composed of the duration of the disease and a weight factor that reflects the severity of the disease.

Potential savings due to implementing eHealth technologies and self-management were recently calculated in a collaborative report by the University of Maastricht and the research agency APE (Notenboom et al., 2012). Their financial estimations for five chronic diseases show that apart from gains in health and quality of life, small to substantial cost-reductions may be achieved. These can be attributed to a lower use of care, productivity gain (depression), medication compliance (diabetes), self-measurement (thrombosis), lower mortality or fewer admissions (heart failure, asthma). Costs savings (within the care sector) and labour savings (outside the care sector) tentatively amount to EUR 1 billion. More examples of possible cost reductions in different health care sectors in the Netherlands exist. Smit et al. (2011) extrapolate from analyses in addiction care and suggest that "(...) widespread introduction of eHealth technologies would help to substantially increase the efficiency of the Dutch health care system overall, with a more favorable cost-benefit ratio (...)." Riper et al. (2010) indicate promising cost-effectiveness studies and practices within the emerging field of e-Mental Health. Hermens & Vollenbroek-Hutten et al. (2012) point out the same for evidence of telemedicine applications in physical rehabilitation. A recent study shows that the use of assistive and sensor technologies enables elderly people to stay longer in their home environment and delay admission to a dementia care home, implying substantial cost savings (Nijhof, 2011a; b). Cost-effectiveness for prevention and public health is indicated by Zuure et al. (2011) who successfully set up a low-cost, internet-mediated, risk-based screening facility for the Hepatitis C virus that could be accessed by populations that were otherwise hard to reach. Van der Heijden, De Keizer, Spuls & Witkamp (2011) demonstrated that tele-dermatological consultation reduces referrals by the general practitioner to the dermatologist, and potentially improves both efficiency and quality of care for lower costs.

In spite of these Dutch examples from various health care areas, the volume of online health care services, telecare and other ICT applications is small and fragmented in the Netherlands. This is commonly attributed to financial and legal barriers, cultural, organizational and psychological factors, and the lack of standardization and available evidence on (cost-)effectiveness (cf. eHealth.nu). This is surprising for a country that is counted among the world leaders in e-participation (United Nations, 2012). After more than one decade, the potential of eHealth technology has still not been fully utilized while consumers increasingly wish to be involved in decision-making about health issues so that they can take more responsibility for their own health care (cf. Wentzel et al., 2012).

Consumer health informatics

Around the turn of the century, the scientific study of the blending of digital technology and health was called consumer health informatics, or telemedicine or e-health. To determine the scope of this new, horizontal discipline a great deal of academic discussion was devoted to definition issues. Many definitions were proposed to describe consumer health informatics (see e.g., Kaplan & Brennan, 2001; Houston & Ehrenberger, 2001). Lewis, Chang & Friedman (2005) cite an unpublished report of the United States General Accounting Office defining it in 1996 as:

> *"... the use of modern computers and telecommunications to support consumers in obtaining information, analyzing their unique health care needs and helping them make decisions.*

"A working group on consumer health informatics at the American Medical Informatics Association defined consumer health informatics as:

> *"... a form of medical information technology geared towards delivering better health-related decision-making based on the consumer's perspective. Through electronic technology, it provides a better outcome in terms of information exchange and communication between patients and health care providers" (Lewis et al., 2005).*

According to Eysenbach (2000) consumer health informatics is:

> *"... the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems."*

The latter definition is used in the description of 'gettingBetter.nl', the first project on consumer health informatics of the Dutch National Institute for Public Health and the Environment (RIVM), of which the present thesis is a result (RIVM, 2006).

As a government agency, the RIVM supports public authorities with knowledge and information in the field of public health, a task it has carried out for over one hundred years. This concerns a wide variety of subjects ranging from infectious diseases, radiation research, nutrition, quality of air and water, drugs, consumer safety, medical devices, health forecasting or nanotechnology. Since 2005 the institute has gradually taken on additional assignments with regard to prevention (i.e., population screening programmes), implementation of life style interventions, and health communication. The national health and healthcare portal kiesBeter.nl is an example of the latter. This platform provides online comparative health information to support transparency and choice for health care consumers.

The transformation from a positivist research institute into a knowledge institute requires new expertise. It was recognized that the institute's *Umfeld* was changing faster than ever before, particularly with regard to the socio-technological and epidemiological trends described above and with regard to the issue of public distrust (in politics, in finance, in science). This called for deeper and broader thinking about the implications of web-based and mobile technologies for public health and health care (Demon et al., 2012). Moreover, health and risk communication with a general audience requires a set of different skills and tools than those needed for professional communication, risk-management, knowledge integration or policy information. Social scientific knowledge *in casu* health psychology and communication sciences was sorely needed, as was further stipulated by the case of the somewhat unfortunate HPV vaccination campaign of 2009 (Ossebaard & Coutinho, 2011).

Therefore, the gettingBetter.nl project was funded by the strategic research program (2007-2011) of the RIVM[2]. It was carried out in close collaboration with the then IBR Institute for Social Sciences and Technology and the Center for eHealth Research and Disease Management at the University of Twente. The general aims of this project were thus formulated:

> *"- to generate knowledge and skills in the field of applied consumer health informatics;*
> *- to return on investment by delivering company-wide applicable results germane to (future) informational projects aimed at the general public; and*
> *- to contribute to the development of consumer health informatics and exchange key issues at a European c.q. international level"* (RIVM, 2006).

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[2] The strategic research program aims to furnish the RIVM with the expertise and quality that it requires, thus enabling it to undertake its duties for commissioners effectively both now and in the future. The objectives of the program are formally laid down in the the RIVM Act (1996) which arranges for the institution, responsibilities and assignment of the agency.

The specific objectives for the project were:

> *"to investigate two major informational issues relevant to societal and technological trends: 1) information behavior of Dutch citizens: information seeking/searching behavior, background variables, motivational variables, deployment of image and sound, consumer health vocabulary (e-)health literacy, the emerging on-demand health consumer;*
> *2) information tools and services for citizens: support systems for a general public (idem for high risk and underserved populations; health disparities), evaluation methods, tailored health communication, search engines, integrating good examples, reaching the user (…)"* (RIVM, 2006).

The first line of study resulted, as mentioned above, in a series of peer-reviewed papers, lectures, research proposals, conferences as well as the present thesis. Results of the second line of study, conducted by S.M. Kelders, M.Sc., of the University of Twente, were simultaneously published in the academic press and will be part of her thesis in the late summer of 2012.

iHealth: persuasive health technology in context

The emphasis of our social scientific research is on the communicative, informational and transformative aspects of technology. Not so much technology itself but rather its application to collect, store, process, share, disseminate, enrich, design and organize information for the benefit of health and healthcare is our scope. The right information, to the right person, at the right time and in the right way to help make better health decisions and a better fit between patient, organization and technology. iHealth involves the use of information and communication technology (ICT) in health and care but emphasizes people instead of technology. "At the moment, the 'T' in Information Technology (IT) is pretty much solved. The real challenge for the future of healthcare is how do we get a grip on the 'I'." as is stated in a recent report (KPMG, 2012). Numerous study outcomes, practices and experiences have shown that a technology-driven approach disaffects users and results in low adherence, under-use and low uptake. iHealth takes this into account and engages users and their contexts from the start of development. It builds persuasive elements into health technology to support people in their different roles as patients, healthcare professionals, counselors, students, etc.). While eHealth will be a transitory concept in the progression towards embedded health technologies in care, *eHealth inside* as it were, the 'i' shall be the *quinta essentia*. It is impossible to separate information, technology and policy in networked systems such as health care and society. This shift from eHealth to iHealth implies that the latter is aware of the effect of technology on its own operations in the health care system as well as on its social and cultural relationship with patients and other stakeholders. To understand how this works within the complexity of health care, iHealth aims to create a real world setting, step-by-step, where innovation can succeed (see Fig.1) and combine an interpretive approach with conventional methods.

It is clear that we are social and informational organisms, or *inforgs*, as Fiordi (2011b) would say, especially since we breathe information through the lungs of digital technology. We are living in Castells' (1996) 'information age' where " (...) societies are increasingly structured around the bipolar opposition of the Net and the Self" and where information is an important production factor. For young people, the *digital natives* (Prensky, 2001; Palfrey & Gasser, 2010) "bathed in bits and bytes", this is a matter of fact. For older people, also referred to as *digital immigrants,* it is a matter of adapting to a new situation e.g., by adopting new skills and knowledge. For the first time in the Western world young people watch less television. They seem to prefer online activities to passively watching television (Shirky, 2011). This is an example of the inherent transformative capacity of technology, It also demonstrates why such a great part of thinking on the philosophy of technology takes the form of social-cultural critique.

Modern consumer information and communication technologies (ICTs) encapsulate all previous media. A cell phone is not just a phone, it is a pen and paper, a book, a newspaper, a library, a store, a calendar, a clock, a telegraph, a radio, a telephone, a camera, a tuning fork, a musical instrument, a television, a cinema, a recorder, a compass, a map, a game, a chat box, a musical instrument, and so forth. Moreover this medium is relatively cheap, it is ubiquitous and pervasive, it is valuable; it enables social interaction and participation, in real time and from many to many - it is even fashionable. These qualities explain the impact of information and communication technologies on all domains of our lives including health and well-being.

Technology's informational and communicational values with regard to health are central to the present thesis. iHealth is preferred to eHealth because the signifier 'electronic technology' is outweighed by the signified 'information'. It means to denote that the use of digital technologies in health affects the psychological and contextual realities because of altered modes of information and communication. The 'i' in 'iHealth technology' therefore does not stand for '*information*' only. It also stands for *'I'*, the self that attempts to bridge the gap to the 'Other' when, in whatever stadium of a disease process, there is a need to relate and to share experiences and knowledge. Technology can help to support this drive for togetherness when self-management is not sufficient to deal with the suffering that goes with the human condition. When the 'Other' is not physically present, technology enables a contact, a metaphorical touch. The 'i' also stands for the unambiguous *involvement* of the stakeholders in the health care environment when it comes to the human-centred design of smart health technology (Ziefle & Röcker, 2011). There is no point in developing technology without including the needs and wants of the intended users. The 'i' stands for the transformative *intervention* that every technology implies. There is no such thing as an a-technological intervention in health, just as there is no technology that does not affect the context and those engaged in it. 'iHealth' is not meant to be a neologism forever. The process of integrating information and communication technologies in the health arena will lead in the coming decade to new levels of academic discourse. It will also lead to new practices in health and health care, provided that an integrative approach is adopted. iHealth is contextual eHealth technology, is *eHealth* i*nside*. Its objective is to add value to the informational, transformational or communicative qualities of technology in health and health care. What could technology accomplish for people's health in specific situations? Does it deliver cure, care or prevention? Does it affect attitudes, cognitions or behaviors? Does it represent security, sustainability, convenience or safety? Does it provide information, knowledge, skills, training or education? Does it facilitate calm, tranquility, relaxation, quietness? Does it offer power, excitement, pleasure, enjoyment or fun? Does it help to reduce aggression, anger, panic, darkness, desolation? Does it facilitate interaction, comfort, engagement, participation, exposure, communication? All such values as well as the quest to design and provide what is needed, in a specific setting, in the most appropriate way, belong to the domain of iHealth.

While some studies have shown that web-based interventions can effectively influence (mental) health and health-related behavior, many other studies and systematic reviews report only limited effects or no effect at all (Verhoeven et al., 2007; Kelders et al., 2011). This is frequently attributed to non-adherence of users, referring to the fact that not all participants use, or keep using, an intervention in the intended way. A recent study by Kelders et al. (2012) indicates that adherence is largely explained by persuasive design characteristics. Design is important to understand the transformational power of eHealth technology. Its "effectiveness may be improved by optimizing the *design* of interventions, that is, the ways in which the content of an intervention is delivered" (Morrisson, L.G, Yardley, L., Powell, J. & Michie, S., 2012). This is why it is considered a key issue in the field of eHealth technology (Pagliari, 2007). Persuasive design aims to change the attitude or behavior of its users in a non-coercive manner (Fogg, 2002; Lockton et al., 2010). Information and communication technologies offer many modes to increase our capacities, they provide all sorts of experiences, or they present social interaction in the way Fogg schematized it in his well-known 'functional triad' of persuasive technology (id.). Oinas-Kukkonen et al. (2009) elaborated this and introduced the persuasive system design-model to classify the values of technology according to its main functions; primary task support, dialogue support, social support and credibility support. Concepts and methods from persuasive design have recently been applied to behavior change in the domain of health care, in particular with regard to eHealth interventions (Stevens, 2008; Cugelman et al, 2011; Letho & Oinas-Kukkonen, 2011).

In 'Grounding eHealth' (Nijland, 2011), a literature review and empirical work describe and analyze factors that influence the uptake and impact of eHealth technologies. This integrative approach is summarized in a roadmap that serves to improve, step-by-step, the design and development of iHealth technology with the ultimate goal of improving its uptake and impact (Fig. 1). Its components are extensively discussed in a view-point paper by Van Gemert et al. (2011).

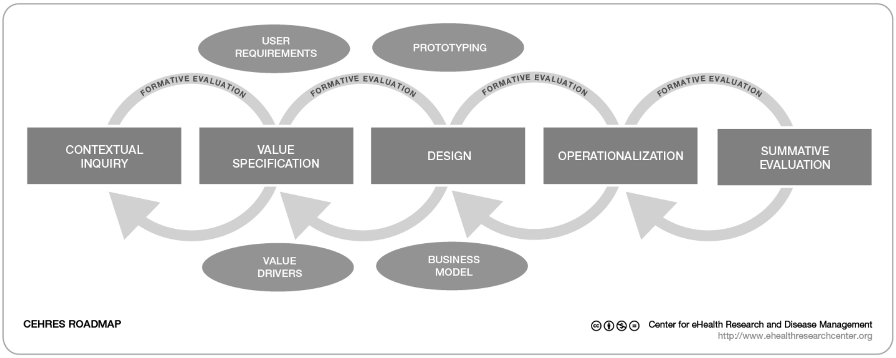

Figure 1. ceHRes Roadmap: persuasive eHealth technology in action (Van Gemert et al., 2011).

Part of the ‘holistic’ development approach of health technologies involves persuasive design. Persuasive design includes strategies and techniques that aim to facilitate a voluntary change in attitude and behavior (Fogg, 2002). Persuasive eHealth technology is conceived to be technology that is initially created to influence the health and wellbeing of people via persuasive design.

A holistic approach develops a social scientific perspective on the role of technology in health and health care. Persuasive eHealth technology development transcends an instrumental, a determinist or a functional approach towards technology as merely a product, a service or a stand-alone medical device. We recognize the social dynamics and significance of eHealth technologies and their potential for improving health care. Therefore, the central position of real people and their values are consequently accounted for. Creating a new technology often reveals the process of health care delivery, the flow of information, the roles of key-stakeholders and the factual financial organization. It also clarifies the interdependencies between technology, people, their socio-cultural environment, and the infrastructural organization of health care (Van Gemert et al., 2011). This is used to create a better fit between technological, human, and contextual factors. As long as this fit is sub-optimal, the uptake and impact of eHealth technologies will remain sub-optimal: at the very least poor and at best undecided. A holistic approach also emphasizes ”the importance of the whole and the interdependence of its parts.” (Van Gemert et al. 2011). This may relate to issues of finance, management and technology as well as design, implementation and evaluation. As a rule these are not analyzed in isolation.

Persuasive eHealth technology has been successfully applied in innovative projects in chronic care (diabetes, dementia, and chronic infectious diseases) and ePublic Health (Lyme disease, sexually transmitted diseases). From the collaboration between social sciences and technology, technology designs result that improve their uptake (acceptance, adherence) and impact (implementation) in the daily lives of end-users. For instance, with the aid of persuasive and narrative design techniques, certain forms of technology could be better attuned to client profiles and social situations. Rigid evaluations need to be conducted to establish the true value of this approach.

The other part of a ‘holistic’ development approach toward health technologies is *business modelling.* This is a formal procedure where stakeholders participate in the design *and* implementation of technology in order to determine its added value to health care practice. Stakeholders are all those that affect or are affected by the intervention in question. Depending on the specific context, stakeholders may be policy-makers, health care providers, employers, patients, informal carers, insurers and others. For the success of eHealth technology it is critical to understand the value needs of each stakeholder (Carr, Howells, Chang, Hirji & English, 2009). ‘Value’ may represent anything they consider important for an eHealth intervention to be developed and implemented. Value may be expressed in quantitative and qualitative terms. An example of the former is monetary value, an example of the latter may be safety. Business modelling entails the entire, collaborative effort of creating ‘value’. It is part of an integrative approach to eHealth technology to *a priori* establish what value technology should accomplish with regard to the practical needs of stakeholders. This way of ‘value specification’ helps to co-create and formulate a set of critical success factors that eventually will determine the degree of success when implementing the eHealth technology (Van Limburg et al., 2011).

Holistic development serves to improve health care processes in terms of safety, quality, equity and efficiency. The need to overcome the obstacles that stand in the way of the uptake of eHealth technologies has explicitly been recognized in international eHealth research (Atienza et al., 2007; Black et al., 2011; Mistry, 2012). An integrative approach to eHealth technology is construed here also as a strategy to reform health care by creating a social and technological infrastructure for participation and collaboration (Coiera, 2011). The present thesis exemplifies the lessons learnt from practice and research. It adds to and builds on concepts and insights from the holistic strategy that is currently developed at the University of Twente.

Scope and objectives

A social-scientific approach to the subject of supporting health through the use of technology connects the studies in this thesis. The technologies studied were planned to create added value, but did they actually achieve this and, if so, to what extent? What are the drawbacks of these technologies and what can be learned from experience in order to avoid them and eventually improve eHealth technology? The central research question, therefore, is about the added value of different eHealth technologies in terms of their informational, transformational or communicative qualities. What factors account for the uptake and impact of eHealth technologies and how could the *added value* of the interventions that were the subject of this study be increased? The successive studies operationalize the central question with regard to respective topics regarding health and information technologies. The approach underpinning the studies is characterized by the use of conventional and quantitative routines combined with interpretative and qualitative methods. A mixed-method design is used to optimize the collection and analysis of data and to provide a better understanding of the research problems from multiple perspectives (Creswell, Klassen, Plano Clark & Smith, 2011).

Chapter 1 is about conventional health technology. This study concerns an important determinant of mental health problems: stress and burn-out. It investigates an alternative method for enhancing relaxation and stress reduction among a group of health care professionals who have an increased risk of suffering from stress and burn-out. What would be the added value of this technology for people who are expected to have higher-than-average levels of stress and burn-out. The technology used is a 'brain wave synchronizer' that supposedly induces a relaxation response and other beneficial, psychological effects (cf. Huang & Charyton, 2008). In a multi-center, quasi-experiment, participants were exposed to audiovisual stimulation programmes during an eight-week period. The immediate effect of the exposure is measured in a repetitive pre-test/post-test design using Spielberger's State-Trait Anxiety Inventory. Subjective effects are self-reported in personal diaries. A long-term effect on burn-out is assessed using Maslach's Burn-out Inventory. The outcomes would serve to decide if wider employment of brain wave entrainment among different patients and professional populations was desirable.

Chapter 2 is about kiesBeter.nl, the national web-based health and care information portal for citizens and care-consumers. The portal represents a distinctive Web 1.0 approach[3] to providing health information. The study describes its policy context and evaluates the extent to which it meets its original objectives. The added values of the portal differ for citizens/patients and policymakers. For the latter, the added value originated from an ideological policy ambition to increase transparency in care in order to achieve a more competitive health care system. Another value incentive for the portal had been New Public management that attempts to create more professionalism in the public sector and to improve (financial) accountability. Several sources (a survey, a market monitor, direct feedback, web analytics) are analyzed to assess the portal's share of the health information market; the satisfaction of users; the public image and other parameters.

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[3] Web 1.0 denotes the first generation of internet development (circa 1990-2000) with a typical top-down approach to one-way presentation of static content (cf. O'Reilly, 2005).

The extent to which the portal has achieved its objectives (i.e., improved choice behavior, quality of care and cost reduction) is hard to appraise since these appeared to be stated in unverifiable terms. The added value is constructed through the informational and usability values of the portal which are perceived differently by different stakeholders.

Chapter 3 is about the how to increase the usability of web-based health information from a patient's point of view. Usability is the perceived ease-of-use of a tool, a system or an application. The focus is on the perception of patients for whom ease-of-use is an added value *per se*. It is an important issue in persuasive eHealth technology because of its correspondence with adherence. The main study objective is to examine what usability aspects of the portal kiesBeter.nl add value to user experience in terms of information seeking, self-management, decision-making, online health information and other variables. Participants were patients with three different long-term and their informal carers. In an innovative, mixed-method approach we combined assess usabilityrecommendations for new requirements, re-design and improvement.

Chapter 4 is about online decision- technology that helps patients to make informed choices about treatment options from a patient's perspective. The national health and health care portal kiesBeter.nl publishes a collection of patient decision aids developed in the Dutch Decision Aids implementation Programme, a 2004 initiative of the Netherlands Organization for Health Research and Development ZON-MW. In this study we examine the value added by the use of an online decision aid to the quality of the decision-making process. This is operationalized by measuring three decisional constructs: the stage of the decisional process, decisional conflict, and knowledge. Also acceptability and the degree of satisfaction with regard to the value of the decision aid was assessed. During a three-month study period, a convenience sample of visitors to a kiesBeter.nl decision aid for attention-deficit hyperactivity disorder (ADHD) was taken. Participants anonymously completed an online questionnaire before and after using the decision aid. The outcomes could lead to redesign and usability improvements.

Chapter 5 is about risk management in health care. Risk control obviously affects the important values of safety, trust, efficiency and perceived quality of care. What do we know about such risks with regard to the use of eHealth technology? The occurrence, frequency and magnitude of risks is likely to be related to its impact and uptake. In this exploratory study, we present an overview of risks associated with the use of eHealth applications and technologies in health care based on a quick scan of scientific literature, grey literature and relevant web-based sources. We also include recent authoritative reports that construe risks at a conceptual level. The outcomes were validated in a focus group of experts from health care, health care insurance companies, patients, policy-makers and researchers. The final results are used to inform the tasks of the Dutch Healthcare Inspectorate (IGZ) whose primary obligation is to promote public health through the effective enforcement of the quality of health services, prevention measures and medical products.

Chapter 6 is an intellectual contribution to the international academic discourse on the impact of eHealth interventions in global health care. It is generally agreed that eHealth technologies have the potential to help improve health processes and their safety, quality and efficiency on a worldwide basis. However, the successful realization of eHealth in daily practice lags behind expectations in all countries, irrespective of whether they have ample or few resources. Credibility is a value *sine qua non* for its contribution to health care innovation. The credibility of eHealth, in terms of trust in its innovative capacity, can and should be enhanced by improving interventions through a holistic approach and continuous medical education. This provides and preserves the values that are at stake for all of the relevant parties throughout the entire process from design right through to implementation in health care practice. It increases the odds for embedded eHealth interventions that are effective and sustainable in the long term.

In spite of their critical nature, the studies have lead to a constructive perspective on iHealth which is further elaborated in the last chapter. The outcomes have been used to foster the extension of the aforementioned framework to increase the uptake and impact of eHealth technologies and collaboration (Van Gemert-Pijnen, Ossebaard & Nijland, 2011). This framework is currently operationalized in a 'roadmap' that enables the evidence-based design, implementation and evaluation of eHealth interventions.

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Chapter 1

Conventional health tech

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Abstract

Stress and burnout are widely acknowledged as major causes of societal and individual problems in the Western world. In order to reduce material and immaterial expenses, increased efforts are made to enhance relaxation and stress reduction. Based on neuropsychological findings, alternative ways have been explored, one of them being the application of so-called brain wave synchronizers, which are said to induce a relaxation response by entraining alpha brain-wave activity (8–13 Hz) through audiovisual stimulation. A double blind, quasi-experiment was conducted among employees at a Dutch addiction care center to investigate the possible effects of two distinct brainmachine programs on burnout and anxiety. Subjects in both conditions showed a significant, immediate decrease in state anxiety as assessed by Spielberger's State-Trait Anxiety Inventory (STAI) and reported a range of subjective effects. However, a long-term effect on burnout, as measured with Maslach's Burnout Inventory (MBI-NL), could not be established. A long-term effect on anxiety (STAI), as investigated by interrupted time-series measurement, could not be established either. These and other findings suggest that the major claims with respect to these machines cannot hold over time, although pleasant short-term effects do occur. Individual differences in baseline responsivity, the stable character of burnout dimensions, or the ill-defined nature of relaxation, or a combination of these, may account for these results.

Introduction

Stress has become a much discussed concept. This may be due in large part to increasing evidence of its role in the origin and development of a range of somatic disorders such as diabetes, cardiovascular illnesses, and infections. It is also clear that stress is associated with psychosomatic complaints, depression, and anxiety (Van Eck, 1996). During the last few decades, The Netherlands, like most Western countries, has witnessed an enormous increase in unfitness and absenteeism at work due to psychological disorders related to stress. According to data of the independent National Institute for Statistical Information of The Netherlands (CBS), a mean 10% of the Dutch working population suffers from burnout, due to emotional exhaustion. Prevalence of work-related stress problems is particularly high among employees in the educational and catering sectors as well as the health and social welfare services (Centraal Bureau voor de Statistiek [CBS], 1998). Estimates of the societal cost of stress-related unfitness and absenteeism range from $2 to 20 billion/year. These tendencies have led to increased efforts to enhance the mental and physical health of employees. In The Netherlands, relaxation, stress reduction, and the "de-acceleration" (a term coined by Dr. Borst, Minister of Health, Welfare and Sports) of modern life have become the subject of public debate.

During the seventies, the concept of *burnout* emerged in the United States. It referred to work-related mental exhaustion. Burnout especially affects employees who work in "contactual professions," referring to their intense relationship with allegedly "difficult" populations. Examples include police officers, psychiatric nurses, workers in addiction treatment settings, and general practitioners. A characteristic feature is the strong entanglement of person and profession: one's personality is one's most important working tool (Schaufeli, Maslach, & Marek, 1993). Since the 1980s burnout entered the Dutch vocabulary. Today the association between job satisfaction, workload, absenteeism and burnout is widely acknowledged.

The search for ways that reduce work stress is breaking new ground. Neuropsychological studies have shown associations between brainwave activity and relaxation (Morse, 1993). The summarized activity of groups of neurons, or neural networks, is measurable as frequency patterns of the EEG. The increase in frequency corresponds with the rise in central nervous activation, and brain-wave activity tends to relate to certain psychophysiological conditions (Niedermeyer & Lopez da Silva, 1987). The different frequencies are generated from different locations in the brain and are distributed to several other areas. Apart from such natural, endogenous activity, brain waves may be induced through exogenous, sensory stimulation (Koukou, Lehmann, & Angst, 1980; Narici et al., 1990; Regan, 1972; Rockstroh, Elbert, Birbaumer, & Lutzenberger, 1982).

Photic stimulation (stimulation by rhythmic light impulses) is probably the most studied and most effective induction method. It entrains a “frequency following response” in cortical activity, meaning that the endogenous activity already present in this area synchronizes with the frequency offered. Since the 1930s, this phenomenon has been used to study epilepsy and has found many practical applications. Inducing alpha activity has been the main focus of interest due to its association with relaxation and its instrumental use for therapeutic purposes. Auditory stimulation has been studied as well (McCraty, Atkinson, Rein, & Watkins, 1996), although it is mostly combined with photic stimulation (Bridgewater, Sherry, & Marczynski, 1975). Not everyone naturally generates alpha activity. It is estimated that 10% show little or no activity in this bandwidth. Although most people show these frequencies with their eyes closed, a small percentage may produce 7–13 Hz with their eyes open. A relation might exist between one’s capacity to generate alpha or theta activity and the extent of hypnotizability. Compulsive or neurotic personalities are assumed to be less responsive to photic stimulation (cf. Morse, 1993).

Devices to induce brain-wave activity have been made available in the commercial market under the name of “brainmachines.” These typically deliver monotonous, staccato beeps through a pair of headphones, and short, monochrome light impulses are administered via a pair of goggles. The computer-generated audiovisual impulse patterns are especially designed to induce either a general or a specific relaxing effect in the alpha bandwidth. This is the frequency that is associated with relaxation, rest, or serenity, mental states that may otherwise be achieved through regular exercise or meditation (Brown, 1980). Young people may use brainmachines in a recreational and explorative way; for example, in the European rave scene, brainmachines can be found at raves to “chill out” or to experience altered states of consciousness by “digital drugs” (as they are sometimes -deceptively-called).

Empirical evidence exists for the assumption that sensory stimulation may be instrumental for relaxation. Morse (1993) cites several practical applications and positive results from obstetrics, where brain-wave synchronizers have been used to relieve pain during labor and delivery. He also mentions their use in anesthesiology and in the treatment of hypertension and migraine. Research in dental surgery (e.g., root canal procedures) showed considerable anxiety-and stress reduction among subjects experimentally exposed to a brain wave synchronizer. Through its use, patients suffering from chronic pain were able to improve their relaxation and decrease their preoccupation with pain. The attained relaxation has been established not only subjectively, but also by measuring changes in biological parameters such as blood pressure, heart rate, galvanic skin response, and neurotransmitter levels (Shealy et al., 1990). In general, negative side effects are not reported in subjects, if those possessing contraindications are excluded. These consist of the (family) presence of epilepsy, various heart conditions, the use of pacemakers, and the existence of certain psychiatric or neurological disorders.

Professional application of brainmachines marginally takes place in various treatment settings in order to reach the desired positive effects through relaxation. They have been used (experimentally) in the addiction services, in stress management, and in the treatment of headache and hypertension (cf. Bierman & Julien, 1997; Fahrion, Walters, Coyne, & Allen, 1992). Professionals working with brainmachines report positive anecdotal effects on stress, anxiety, and sleep disorders (Herreijgers, personal communication, Boumanhuis (Rotterdam Addiction Services), 1997), although scientific evidence for their efficacy is difficult to find. Available studies typically suffer from a lack of methodological rigor and scientific objectivity. From our own pilot work (Ossebaard & Van Daalen, 1996), it appeared that subjects reported significantly lower levels of state anxiety after using the brainmachine. Subjects stated they felt "better" and "more relaxed" as well. An earlier study by De Nicholas (1992) showed similar results. More substantial evidence for the potential of brainmachines may be derived from medical and psychological research concerning phototherapy, relaxation techniques (musical, subliminal, or hypnotic), and bioand neurofeedback methods (cf. Brockopp, 1984; Brown, 1977; Dodge, 1991; McCraty et al., 1996; Morse, 1993). Results of these and other studies legitimize the assumption that brainmachine sessions may actually have a stress-reducing effect. Dutch empirical evidence against this assumption entails an investigation of the influence of brain-wave synchronizers on sleep disorders among alcohol addicts (Bierman & Julien, 1997) and a study on memory and learning tasks among students (Groeneweg, Conrad, Wolters, & Wagenaar, 1995). In both studies unequivocal effects could not be found.

The present study assessed relaxation effects following a series of sessions with a brainwave synchronizer, among employees of a large Dutch addiction service center. Relaxation has been operationalized as a decrease in burnout and state anxiety scores as compared to pretest scores. These concepts respectively refer to a chronic, structural presence of work-related fatigue, and momentary, situational stress. It was hypothesized that after the intervention, all experimental subjects, on average, would feel more relaxed as expressed in (a) a significant decrease in mean scores on three burnout dimensions and (b) a significant decrease in mean scores on state anxiety. A second research question concerned a discriminative effect of exposure to a program that allegedly induced beta activity (13–25 Hz). Beta waves are associated with normal alertness and wakefulness. It was expected that after the intervention, the subjects in the alpha condition on the average would feel more relaxed than subjects in the beta condition, as expressed in (a) significantly lower mean scores on three burnout dimensions and (b) a significantly lower mean score on state anxiety. A nonintervention control group was included for comparison. No changes in burnout scores were expected for this condition.

Method

An experimental, double blind, matched design was the framework of this study. Synchro-Energizers (model 4X Satellite) were the brain-wave synchronizers employed.

Population

The study was conducted among 42 employees of a large addiction care center in an urban area in The Netherlands. They responded to a call for participation, supported by their employer, and were briefed on the research, both orally and in writing. They cooperated on a voluntary basis after signing an informed consent form. Furthermore, they were made aware that they could immediately end their participation if they wished so. There were 29 (69%) female and 13 (31%) male participants. Mean age of the subjects was 39.7 years (*SD* = 8.7); they were employed in the addiction services for an average of 7.7 years (*SD* = 4.4). The mean percentage of their working hours spent on direct client contacts was just over 46%. Half of them worked with clients over 45% of their time. Their stress levels (i.e., burnout scores, see below) corresponded to normative scores from people in other contactual professions, such as nurses and general practitioners, and were relatively high with regard to the general population.

The response from a written survey among 185 colleagues from the same center was used to comprise a control group, made up of 16 (64%) women and 9 (36%) men, mean age 38.3 years (*SD* = 6.4), working 7 years on average (*SD* = 4.2) in the addiction care sector. Over half of them worked a mean 40% (*SD* = 31.1) of their time with clients, half of them worked over 40% of their time with clients. No significant background differences existed between the control and the experimental groups.

Instruments

Burnout was assessed by the Dutch version of Maslach's Burnout Inventory (MBI-NL). The MBI is a valid and reliable instrument, possessing good psychometric qualities and as such it serves well to measure burnout. The 20-item, self-report questionnaire is especially appropriate for people working in contactual jobs (Schaufeli & Van Dierendonck, 1993).

It delivers three scores for the following dimensions: Emotional Exhaustion, Depersonalization and Personal Competence.

Emotional Exhaustion (EE) refers to the feeling of being "completely worn out," having used up all energy resources and not being able to recharge the batteries once more.

Depersonalization (D) entails feelings of estrangement expressed in a cold, cynical, and indifferent attitude towards the people one is working with (note that it does not involve the psychiatric definition of extreme alienation from oneself). The loss of Personal Competence (PC) involves the feeling of poor performance at work and related feelings of insufficiency (Schaufeli & Van Dierendonck, 1994).

Subjects indicate on a 6-point Likert type scale (never ...–regularly ...–daily) how often a statement applies to their working experience. For instance,

> "At the end of the day I feel empty" (EE);
> "I don't really care what happens to some of my clients" (D); or
> "I know how to adequately solve my client's problems" (PC).

To avoid any negative connotations, we renamed the MBI-NL as the "Work Perception Questionnaire" ("Werkbelevingslijst"), also adding a series of background variables.

The second instrument utilized was Spielberger's State-Trait Anxiety Inventory (STAI, Dutch version), in particular the part dealing with State Anxiety (Van der Ploeg et al., 1980). State anxiety is related to the immediate situation and the extent of a subject's relaxation. As such it discriminates from Trait Anxiety, which refers to a dispositional dimension. The self-report scale has a sufficient test–retest reliability, and it correlates well with several other instruments for stress assessment. Subjects indicate on a 4-point scale the extent (not at all ...– ...a lot) of relaxation at that very moment, as implied by questions like

> "I feel comfortable";
> "I am worried about nasty things that may occur"; or
> "I feel tense."

To investigate subjective experiences in a qualitative way, all participants were given a small diary and were requested to note any event they themselves related to their sessions, during the experimental 8-week period.

Procedure

Two weeks prior to the actual intervention, burnout among subjects was assessed by the MBI-NL. They were consequently matched on MBI scores and sex, and randomly assigned to the two experimental conditions. Two weeks after the experimental 8-week period, the MBI was again administered. The STAI was administered at four points during the experimental period, both immediately before and just after a session. In this way four differential STAI scores were collected for every subject.

In the first experimental condition, subjects engaged in two sessions a week, for 8 weeks, with the Synchro-Energizer standard program 4: "Deep relaxation and revitalization," a computer architecture designed to induce alpha brain-wave activity. It begins with a 5-min audiovisual stimulation at 30 Hz, followed by another at 10 Hz for 35 min. The second experimental condition consisted as well of a 40-min Synchro-Energizer session, twice a week, for of 8 weeks. This program was, however, especially designed to induce beta activity, beginning with a 5-min audiovisual stimulation at 30 Hz, followed by two more, at 25 Hz for 5 min and at 16 Hz for 30 min.

All sessions took place in quiet rooms and were accompanied by ambient music. Subjects reclined in a comfortable chair. A session leader was present to assist and to administer the STAI questionnaires four times before and after the sessions. Neither the session leaders nor the subjects were aware of the type of the experimental condition the participants were assigned to. The sessions occurred in the afternoon (during working hours) at three different locations. Attempts were made to keep other circumstances as identical as possible for the two experimental conditions.

MBI Questionnaires were sent to 185 colleagues of the subjects with the request to complete them anonymously under conditions of complete confidentiality. From the responses received (23%), a group was formed by matching independent variables (sex and age) and MBI scores with those for the two experimental groups. From this pool, a select sample was taken (n = 25; 9 male and 16 female persons) to compose a control group. An attempt to investigate the considerable nonresponse pool resulted in no substantial increase in the number of respondents. No intervention took place in the control group. After 10 weeks, the respondents received the MBI for the second and final time.

From the initial 42 participants (alpha condition n = 20; beta condition n = 22), those subjects who had participated in seven or more sessions were selected. An assumption made here was that at least seven sessions were required to cause any measurable effect, a premise that had been suggested by professionals experienced with brainmachines. These subjects (n = 25) appeared to be equally divided between the alpha condition (n = 13; 5 male and 8 female) and the beta condition (n = 12; 3 male and 9 female). They did not differ from those who participated in seven sessions or less. Thus, data analysis was limited to a selection of those subjects with the highest information density. The considerable dropout among participants (17 attended six or less sessions) could not be explained systematically and was therefore attributed to declining motivation and commitment during the long experimental period. Two persons decided to stop because of unpleasant experiences such as headache or nervousness. Each of them was assigned to a different condition. Both their MBI and STAI scores fell within the normal variance of the experimental groups.

Results

Burnout

Pretest MBI scores of the employees under study were comparable with normative scores from people in other contactual professions such as nurses or general practitioners. Analysis of variance revealed only small differences in burnout dimensions between the two experimental groups and the control group at their starting position, two weeks prior to commencing the experiment. Thus, the groups were composed in a homogeneous way. The postintervention scores in all three burnout dimensions revealed no significant differences between and within the groups (Table I).

Table I. Mean MBI Scores (*M*) and Standard Deviations (*SD*) of Experimental and Control Groups 2 Weeks Before (*t*(−2)) and 2 Weeks After (*t*(+10)) the Intervention

	EE *t*(−2)	EE *t*(+10)	PC *t*(−2)	PC *t*(+10)	D *t*(−2)	D *t*(+10)
Alpha (*n* = 13)	14.31 (7.54)	14.46 (6.19)	27.31 (3.96)	23.69^{**} (4.29)	6.69 (4.17)	7.31 (2.69)
Bèta (*n* = 12)	15.83 (8.23)	13.83^{*} (6.64)	27.08 (5.14)	27.08 (4.62)	7.58 (3.68)	7.42 (2.71)
Control (*n* = 25)	14.40 (7.67)	13.40 (6.51)	27.28 (5.24)	27.36 (5.45)	7.12 (4.25)	6.96 (3.55)

Note. EE: Emotional exhaustion; PC: Personal competence; D: Depersonalisation; *t*: start of intervention. Values in parentheses represent *SD*.

$^{*}p <.01$.

$^{**}p <.001$.

However, an interesting finding occurred with respect to the Personal Competence dimension in the alpha condition. Here, the postintervention scores were significantly lower compared to the preintervention scores and, additionally, were significantly lower than the scores for both the beta condition-and control groups. Subjects in the alpha condition thus reported feeling significantly less competent with regard to their job performance and their colleagues than before.

Unexpectedly, a small though significant decrease was observed in the Emotional Exhaustion dimension in the beta condition, whereas no significant changes occurred in the control condition. Weak interaction effects at specific dimensions did occur; however, they fell well below any level of significance and will not be further discussed here.

State Anxiety

State anxiety in both conditions significantly decreased immediately after each single session (Table II). A repeated-measures ANOVA showed neither significant differences in STAI scores between alpha-and beta conditions nor changes over time (before session: $F(3,15) = 1.013$ n.s.; after session: $F(3,15) = 0.926$ n.s.). There were no indications for long-term effects. Every next session where state anxiety was measured, subjects started at approximately the same level as before.

Table II. STAI Mean Scores, Before (Pre) and After (Post) Sessions

	Pre (*SD*)	Post (*SD*)	*t*	*df*	*p*
STAI 1 (pre) vs. STAI 1 (post)	42.16 (6.76)	33.40 (7.53)	−7.57	24	<.001
STAI 2 (pre) vs. STAI 2 (post)	38.82 (7.24)	33.00 (7.75)	−4.58	21	<.001
STAI 3 (pre) vs. STAI 3 (post)	38.50 (6.82)	34.08 (7.75)	−4.61	23	<.001
STAI 4 (pre) vs. STAI 4 (post)	39.55 (6.17)	31.86 (5.99)	−5.72	21	<.001

Diaries

From a qualitative content analysis of the diaries, it appeared that subjects attributed a range of subjective experiences to the brainmachine sessions. The perceived effects varied from almost psychedelic and cosmic experiences, via slumbering, to nervous irritation and headache. No systematic relations could be established between such reported effects and the test scores on both inventories.

Discussion

The results of this study suggest that brainmachines may cause immediate relaxation effects. Situational anxiety apparently decreased directly after the sessions and a qualitative content analysis of the diaries showed that subjects associated strong (after-) effects with the brain-wave synchronizer sessions. This implies a near-immediate, short-term effect related to the intervention. Various uncontrolled variables and artifacts probably played a role as well, such as the subject's expectancy or the hour of the day.

Relaxation effects were not exhibited for the burnout scores. The outcomes suggested that a decreasing influence on burnout dimensions was negligible in the long term. This is consistent with evidence that the stable and chronic character of burnout is difficult to change. From a meta-analysis of autocorrelates of burnout (Van Dam, 1997), it appears that the MBI dimensions show considerable stability when measured over an average time interval of 9.52 months (*SD* = 6.9).

This might have masked possible relaxation effects of the brain-wave synchronizer. The complex nature of burnout probably thwarts the efficacy of simple technologies such as brainmachines. This may be true for relaxation as well, which is an ill-defined concept in the sense that few instruments are available to objectively quantify it. Relaxation itself is made up of several biological, psychological, and social components. The established observation that relaxed subjects show increased alpha wave activity may have inspired the idea that the presence of alpha activity equals relaxation. This is a reductionist circularity that denies the intricate nature of relaxation.

From their study into the effects of a specific type of brainmachine, Rosenfeld, Reinhart, and Srivastava (1997) concluded that individual differences in responsivity may decisively determine the extent of entrainment. Persons with a low spontaneous (baseline) alpha activity appeared to respond stronger to alpha stimulation compared to subjects with a high baseline alpha activity. Such individual differences may have played a role in the present study. Entrainment might not have occurred in those subjects in the alpha condition whose feelings of Personal Competence had not decreased.

The decrease in Personal Competence in the alpha condition is noteworthy. Although speculative, it may be that those subjects who perceived an increased workload during the experimental period were more inclined to continue their participation in the study. Contraintuitively, from this study, it seems that alpha stimulation negatively affected feelings of Personal Competence and even burnout in general. If alpha stimulation would enhance relaxation, brainmachine sessions may not be a useful method to reduce burnout. Activation through beta stimulation might even be more appropriate with regard to the decrease of the Emotional Exhaustion dimension in the beta condition. Finally, the resultant small sample sizes for the experimental groups reduce the power of the study and may have masked a potential effect of the Synchro-Energizer.

In general, these outcomes undermine major claims concerning the (long-term) stress reduction effects of the brain-wave synchronizer. The added value of the brainmachine compared to other relaxation methods, such as listening to music, has not become clear. Other claims concerning alpha brain wave induction may need to be viewed with caution as well.

Acknowledgments

This study has been conducted in the frame of the 360th anniversary of Utrecht University and was cosponsored by the municipality of Utrecht. The author thanks Martin Hülscher and Roos van den Eeckhout (Synchro-Tech B.V., Amsterdam) who kindly made available 10 Synchro-Energizers for research objectives. He also thanks Dr. D. Brown for his advice.

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Chapter 2

National health and health care portal: health information 1.0

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Ossebaard HC, Van Gemert-Pijnen JEWC & Seydel ER. Technology for transparency: the case of the Dutch national health portal. Policy & Internet 4(2) 2012, art. 8

Abstract

Against a backdrop of New Public Management and healthcare system reform the Dutch Ministry of Health commissioned the National Institute for Public Health and the Environment (RIVM) to develop, host and manage an online public national health and care portal. The portal aims to facilitate consumer decision-making behavior in health and healthcare and to contribute to transparency in order to improve the quality of care and the general functioning of the health markets. This article describes the policy context and uses a multi-methods approach to evaluate the extent to which the portal, as an instrument of health policy, is meeting its original objectives. Since measurable ex ante objectives are lacking, ex post assessment of the portal's impact is not feasible. Instead, four qualitative and quantitative methods of user data collection -online survey, market monitoring, web analytics, and direct user feedback -are used to estimate the impact of the portal with regard to user behavior and online health information needs over time. The survey (N=267) renders bi-modal results that suggest that 40% of respondents feel more or less supported by the portal's information. The monitor (N=104) indicates a slightly skewed range in favor of female, educated and older visitors. A comparatively weak public image in terms of independence, reliability and usefulness contrasts an overall rating of 7 (1-10). From analyses of log files it appears that the portal attracts approximately 18,000 unique visitors/day (2010) while one in every two users visits at least medical information. Comparative choice information attracts fewer visitors; 33% visit comparative information on care providers, 6.4% visit information on insurances. Visitors stay less than 4 minutes, 15% of them return. Findability is high; 75% of visitors access the site via a search engine. Direct user feedback is not much used and a minority concerns comparative choice information. Mobile use is soaring. The portal reaches a fair share of the Dutch health information market in quantitative and qualitative terms. While its exact contribution to the functioning of the health markets in terms of transparency remains undecided it seems plausible that the portal's impact on choice behavior, choice awareness and empowerment is rather small.

Introduction

Accountability

Since the mid-1980s, much has been done to improve the legitimacy and efficiency of the use of public funds in the Netherlands. At first, political attention was directed at the eligibility of government expenditures. After that, attention centered more on auditing, regularity, and control. During the 1990s, the focus shifted again, and questions of the effectiveness, performance, and efficiency of public policy entered the debate (IOFEZ 2004).

The rationale behind this development was the Parliament's wish to improve the management of government organizations; they wanted management to become more output-directed and especially, more outcome-oriented, i.e., focused on the societal effects of policy measures. Improving government performance was seen as the main objective; that is, improving what is achieved, how it is achieved, and against what expenses. In order to achieve this, the government needed to clarify the relationship between the deployment of resources, products or services, and the desired outcomes (something which should be a basic assumption for policymaking, for policy implementation, and for policy evaluation). The Dutch Parliament was no longer satisfied with merely being informed about how the government budget was being allocated over various policy fields; the Parliament recognized that to maintain the long-term credibility of public policy it is also necessary to present taxpaying citizens with a clear demonstration of performance. The budgetary process was identified as the key to achieving this.

This innovation took form in the VBTB ("From Policy Budget to Accounting for Policy") program, implemented from 2000 under the responsibility of the Ministry of Finance. The general idea of the VBTB program was to make budget documents and the budgetary process much more policy oriented, basing them on formulations of verifiable goals for public policy, preferably in terms of social effects and outcomes. These general objectives were to be specified in terms of tangible products or services, sometimes also in terms of activities. The specific policy goals were to be evaluated, for example, by measuring performance indicators or by assessing the efficiency and efficacy of policy instruments ex ante (beforehand) as well as ex post (afterwards). This switch towards connecting financial information with information on intended (as well as achieved) policy objectives required a transparent presentation of more than just financial information in budgets and annual reports: it was expected that by linking together objectives, performance, and resources, departmental budgets and accounting would become more transparent and more closely related to policy goals (Ministry of Finance 1999). This underlying aspiration to encourage more professionalism in the public sector has been known since the 1980s as "New Public Management"; similar result-orientated management models were applied simultaneously in some Commonwealth and Scandinavian countries (Barzelay 2001).

In May 2000, the Dutch government presented a draft new-style budget to Parliament. The new approach was further consolidated in the early spring of 2001, when it was decided that all new legislation on budget increments must be based on accurate information on the desired effects and the costs of the instruments deployed. In the run up to the 2002 national budgets (the first newstyle budget documents), policy objectives were refined and information on both performance and desired societal effect was added in order validate the line items to some extent. During the process, the Dutch Court of Audit, an independent High Council of State, supplied the Ministries with advice on how to draft policy objectives and how to develop reliable indicators of management performance and policy effectiveness (Court of Audit 2007). The final evaluation at the end of 2004 (IOFEZ 2004) nevertheless reported that the twin objectives of the VBTB program, i.e., accessible budget documents and efficient policy, should actually be separated for each to be fully accomplished.

Health Policy

This general development towards public transparency and accountability at the level of the national administration converged with a similar trend in Dutch public health policy. Both trends reflected the government's response to a widely felt need to innovate policy and politics. Transparency was the buzzword in policy papers as well as in the national press. The alleged divide between national politics and the electorate was at the center of intense public debate. It was expected that the gap could be narrowed and trust would be restored by providing insight into the whys, whats, and wherefores of government policy. The Internet was to play an important role in operating this policy.

From the beginning of the 1990s reform of the Dutch healthcare system became a prominent issue in Dutch health policy (Helderman et al. 2005; Westert, Burgers, and Verkleij 2009). The main issue was how to curb the continuing and disquieting rise in healthcare expenditure, but corresponding trends such as an aging population, health consumerism, and epidemiological and technological developments also called for a national policy response. The introduction of managed competition for providers and insurers was considered by the government to provide an effective restraint on healthcare costs, while maintaining an acceptable level of accessibility as well as an increased quality of care. Transparency was also deemed essential for fair competition.

The enactment of the National Health Insurance Act in 2006 can be considered as a milestone in the transformation towards a privatized and compulsory health insurance scheme and increased individual financial responsibility (Ter Meulen and Maarse 2008). Its implementation was the first step in a reform process that was planned to last until at least 2012. The changes in roles for all stakeholders that took place were considerable: consumers and patients were to be provided with increased choice not just in selecting an appropriate health insurance policy but also in arrangements for cure, care, and prevention. Accordingly, much attention was paid to making comparative information available to the public regarding price and quality. Insurers were to negotiate the latter variables with healthcare providers; the new role of the government was basically to maintain the correct functioning of the health markets. Together with the traditionally strong legal position for patients and a gate-keeping position for primary care (GPs) this transformation to a type of social health insurance system drew the attention of an international academic audience (see Rosenau and Lako 2008; Leiber, Gress, and Manouguian 2010). Similar consumerist, choice-oriented approaches to the delivery of public services took place in France, Germany, and in other European countries at around the same time (Clarke et al. 2007; Schäfer et al. 2010; Woolf, Chan, and Harris 2005).

e-Transparency

Central to choice and competition in modern healthcare is the role of information and technology: their availability, their accessibility, and their reliability. In Europe and the United States, the public has shown an increasing interest in publicly released healthcare information (Cacace et al. 2011). The government's basic assumption is that all parties in the "health market" need the same comparative information on cost and quality if proper choices are to be made and competition is to work; this is "information by which consumers can make explicit comparisons between the performances of healthcare providers or health plans to make an informed choice" (Damman et al. 2010). The political discussion on accountability and transparency, inspired by New Public Management, motivated the decision by the Dutch Ministry of Health to initiate a web-based healthcare portal in 2000. This modest form of e-transparency was relatively new to the Netherlands. e-Transparency usually refers to access to data, processes, decisions, or actions of governments mediated by information and communication technology (ICT). An online information outlet on health and care could therefore be assumed to increase transparency and support consumer choice, as well as encourage and enable citizens to play a greater role in the development of a consumer-centered healthcare system.

The launch of the portal is not the only recent example of Dutch policymakers recognizing the implications of the Internet for public health policy.

Growing use of the Internet has affected a range of health policy measures, such as substantial government investments in ICTs in care and the development of a national electronic health record system since 2000. A series of influential studies by the Dutch Councils for Social Development (RMO 2000) and Public Health and Healthcare (RVZ 2000; 2002a–c) also recognized the importance and potential of the Internet for healthcare. These advisory reports generally endorsed the promotion of digital technologies in healthcare and health information, with the report on patients and the Internet (RVZ 2000) explicitly advising the launch of a web-based portal to provide impartial health information and to refer to other reliable (online) sources. These recommendations echoed the government memorandum "Choosing in care" ("Met zorg kiezen"; Ministry of Health 2001), which cited online availability and accessibility of reliable health information as indispensable to equip citizens to play their roles in the intended new demanddriven healthcare system. Well-informed consumers were assumed to be important contributors to the success of the transformation of the healthcare system. Since no third (private) market parties—for example, insurers, care providers or others—could be identified to fulfill the critical task of providing objective health information, the Ministry of Health took responsibility for solving this policy problem.

In 2000 the Dutch government announced the foundation of the first Dutch national health portal, and its launch in the year 2001.[1] The government discontinued this "Health booth" ("Gezondheidskiosk") project after a negative evaluation (AO 2003) but announced new efforts to work on a coherent informational infrastructure to support patients and consumers (Ministry of Health 2003). An international consultancy group was commissioned to investigate the demand for online health information among citizens and to advise on the requirements necessary for this ambition (CGE&Y 2004).

Hence in 2004 the National Institute for Public Health and the Environment (RIVM), an agency of the Dutch Ministry of Health, was commissioned to develop, host, and manage a new web-based healthcare portal, and to open telephone lines and physical outlets in local information centers.

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[1] This first attempt was discontinued, then relaunched in 2004.

These policy initiatives were explicitly supported at a European level (e.g., European Commission 2004; 2007). RIVM has statutory tasks in knowledge integration, policy information, and risk management; its main areas of research include public health and the environment.[2] The portal project can be seen as the government's policy instrument for improving understanding of the healthcare system by citizens through supporting transparency regarding products, quality, and costs of the system (Van Loon and Tolboom 2005).

e-Health Technology Use

The Dutch have been active Internet users for many years, and the accessibility, availability, and use of web-based and mobile technologies in the Netherlands are all high relative to other countries (Eurostat 2010). Back in 2007 the Netherlands Institute for Social Research reported that the Dutch can be considered "ecitizens"; the Internet for them is an important source of information, in particular with regard to health information (Steyaert and de Haan 2007). Today, over 90 percent of Dutch households have Internet access, and approximately 75 percent of Internet users are "online (almost) every day"; among younger people (under 25 years of age) this rises to 90 percent (CBS 2010). The ratio of the number of .nl domain names to the number of inhabitants is 1:4 (Hostnet 2011), and broadband penetration is nowhere higher—38.1 broadband subscribers for every 100 inhabitants (OECD 2010), while Dutch cell phone ownership is beyond the 100 percent mark. These figures are still increasing, especially with regard to social media tools (which can also be used for social and personal health objectives). With respect to global growth in health ICT, these sociotechnological conditions make the Netherlands an interesting test ground for a wide range of mobile and web-based interventions in health and care.

This article examines the extent to which the Dutch national health and care portal is meeting its original policy aspirations. It maps the significance of the portal for its customers by reviewing several methods of assessing their information needs. We first describe the portal and summarize some user metrics over time; we then evaluate the project as an instrument of public policy and discuss its future.

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[2] The RIVM Act (1996) arranges for the institution, responsibilities, and assignment of the agency. Section 5 of the Act implies the freedom of methodological approach and reporting of research activities. See: http://wetten.overheid.nl/BWBR0008289/geldigheidsdatum_26-06-2009. The institute has a track record in the field of collecting, validating, integrating, and presenting professional health information through various media. RIVM has produced online information since 1998 and invested in digital information and communication technologies. From 2004 onwards the institute took on new assignments in the field of public health communication.

The Dutch National Health Portal

kiesBeter.nl

The RIVM launched the Dutch national health portal, kiesBeter.nl (“Choose better”) in 2004, targeting a general, Dutch audience (over 16 years of age) of average educational background. A multi-channel model was adopted; not only the Internet but also conventional media such as telephone and helpdesks (in health centers and libraries) were chosen in order to serve the entire population. The portal provides a vast library of static flat data, accessible 24/7 via a standalone website (i.e., making use of “Web 1.0” technology). Users are able to access integrated, coherent, and comparative information on health, care and healthcare insurance services. The portal’s aim is to provide reliable answers to citizens’ personal questions on these topics; answers that would effectively improve their understanding of insurance companies and healthcare providers, and would inform their decisions on insurance and treatments. Five key values of the portal have been formulated by the agency as: customer-orientation, reliability (independence), simplicity, coherence, and comprehensiveness (Van der Graaf 2005). The project built an extensive national professional network to make it a collaborative enterprise.

From 2004 onwards, kiesBeter.nl gradually made available categories of dynamic, comparative information; the first being “display information” about the characteristics and services provided by individual healthcare providers, such as hospitals, physicians, nursing services, care and homecare facilities, and care for the mentally handicapped. This concerns factual up-to-date information about the providers’ coordinates, as well as names, addresses, geographical service regions, etc. It also includes attributes such as the type of provider (e.g., academic vs nonacademic vs peripheral), type of medical specialties available, facilities present, religious denomination, waiting times, and costs of services. The second type consists of information about the content and coverage of healthcare insurance policies and their prices as provided by the Association of Dutch Healthcare insurers. The third type of comparative information concerns the reimbursement of generic or brand medicines as collected from the Royal Dutch Pharmacists Association. The fourth type concerns the quality of healthcare services based on performance indicators. These indicators are generally derived from regular patient databases maintained by local or sectoral care providers for internal management, and external accountability and transparency. They represent relatively objective information on the medical and care performance of a healthcare sector or of an individual provider. Examples are the prevalence of decubitus in the nursing home population, the number of breast cancer surgeries performed by a specific hospital, professional routines in homecare, or the (presence of) guidelines to prevent healthcare-associated infections such as MRSA. The fifth type of comparative information concerns the quality of (aspects of) healthcare delivery as experienced by users. These indicators—for example, the Dutch Consumer Quality (CQ-) index, which is based on Consumer Assessment of Healthcare Providers and Systems (CAHPS)—are constructed from aggregated data collected by standardized population surveys among patients and care consumers. They are visualized, rated (0–5 stars, percentages, and numbers), and explained in so-called "quality cards." Examples are (dis)contentment with food or privacy, or (dis)satisfaction with medical examinations, information provision, or personal treatment.

Apart from these types of comparative information, the portal presents static information that needs no daily maintenance. An example of this is medical information on health complaints, diseases, medical examinations, and treatments; information on healthy living or on patient rights. A collection of decision aids is built into the portal as well. These have been developed according to international standards to support the decision-making process of patients, or their informal carers, with regard to treatment alternatives (Ossebaard et al. 2010). Each category of information is built onto the elementary portal in a modular way; from the portal's homepage visitors choose either dynamic or static material (http://www.kiesbeter.nl/algemeen/default.aspx; see Appendix 1). New updates of comparative information take place continuously, as well as improvements in interactive usability and design.

Content Selection

The portal project itself does not create content; its major task is the disclosure of information and knowledge for public, strictly noncommercial purposes. The way information is presented draws on existing literature on the subject and in-house studies in information-seeking behavior (Boot 2006a; 2006b), medical communication (Van den Broek 2006), and usability (Ossebaard, Seydel, and Van Gemert-Pijnen 2012). The portal's design is loosely based on principles derived from human-centered design (Maguire 2001; Norman and Draper 1986) in which the wants, needs, and limitations of end-users are accounted for at each stage of the developmental process.

The portal's selection of information is a staged process. The first stage is the expert assessment of public information needs, undertaken using a range of methods (Table 1). The next step is to establish the availability of the required information, followed by the actual selection based on criteria of quality, accessibility, reliability, pricing, and technical compliance. Subsequently, the delivery of information is secured via contracts, covenants, licenses, and other forms of legal agreement. After integration and editing, the content is finally produced in the technical and data infrastructure of the portal for public disclosure.

The portal is built in ASP.NET according to governmental Web guidelines[3] for the Dutch Quality Mark "no threshold.nl" ("drempelvrij.nl"), based on international standards of the World Wide Web Consortium (W3C), which aim to guarantee sustainable and accessible electronic information for functionally impaired users. The guidelines are generated by "e-Government for citizens," which is a program of the ICTU (ICT operational organization), and by the National Operational Program for better service and e-Government (NUP).

The ICTU foundation seeks to increase findability, accessibility, and availability (transparency) of government information. The NUP is an agreement (2008) between the Dutch administrative layers of national government, provinces, municipalities, and polder boards to further develop data exchange in order to improve electronic services for citizens and businesses. Both ICTU and NUP are funded by the Ministry of Domestic Affairs and the Ministry of General Affairs. Web guidelines are considered as a quality standard and are mandatory for government-funded websites. The portal has been in compliance with the international ethical HON Code of Conduct (http://www.hon.ch/home1.html) since 2006.

In 2011, the portal employs approximately 12 Full-time Equivalent professionals from various disciplinary backgrounds such as social scientists, communication experts, editors, technical developers, and data analysts. It is financed by the Ministry of Health at an average amount of EUR 4.6 million per year (2005–2010). The Ministry yearly approves of the portal's plans and may also propose to incorporate certain data or content such as information on the quality of care produced by the Dutch Health Care Inspectorate.

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[3] http://www.drempelvrij.nl/waarmerk-behalen/documenten-voor-inspectie.

Evaluation of the Health Portal

Assessments

The effectiveness and efficacy of the portal as a policy instrument have never been formally evaluated in quantifiable terms which, according to government regulations, should have occurred on a yearly basis (Ministry of Finance 2002). The principal objective of the portal as an instrument of health policy is:

> *"to equip citizens for a demand driven care sector by providing comprehensive, customer-oriented information on health, healthcare and health insurances" (Ministry of Health 2004).*

Such an ex ante formulation is hardly VBTB-proof, since it is impossible to assess ex post the extent to which citizens have actually been provided with information. Even if outcome measures or social effects had been determined in advance, "equipping citizens (…) by providing (…) information" is not exactly a verifiable objective. The mediating goal has not been defined and quantified either, for example in terms of what exactly constitutes the provision of "comprehensive, customer-oriented information on health" and what the cut-off point would be for success or failure.

> *An early mission statement reads:*
> *"{The Portal} provides citizens with insight into the choices they could make in healthcare and offers them relevant information to that end" (Van der Graaf 2005).*

The same drawbacks in definition apply here: i.e., that the intended mission is not measurable, as neither are the portal's achievements with regard to the overall policy objective of contributing to informed choice of citizens, transparency, and quality of care, and thus to the general functioning of the health markets.

Nonetheless, the portal's own data sources allow for an evaluation of its impact. Customer orientation, meeting the information needs of visitors, is a central aim of the portal and evaluative and research activities are built into the project's structure and developmental frame. A variety of methods allows for assessing user variables (Table 1). These data provide (permanently collected) information about the user experience, and are used to improve the portal and tune it to user needs. The data also provide some insight into the portal's success in operating in the online health information and policy environment (relating to the portal's original objectives).

Four of these data collection methods—web analytics, online surveys, market monitoring, and personal feedback—are described in more detail below.

Table 1. Assessing Information Behavior

Assessment methods	*Objective*	*Frequency*
1. Web analytics	Measure visitors' online behavior	Continuously
2. Online survey	Obtain evaluative users' information	Continuously
3. Market monitor	Collect and analyze data on the portal, its customers, competitors, and its wider context	Continuously
4. Personal feedback by email or phone	Collect direct user feedback, concerning technical or content issues	Continuously
5. Profiling on postal codes	Anonymously and randomly record Internet Protocol (IP-) addresses of visitors in real-time to relate to postal code databases in order to collect socialdemographic data of users	Occasionally
6. Online user testing	Users test new features via online questionnaire	Pre release
7. Audits	Establishing compliance to (international) ethical or legal standards and durability or accessibility guidelines	Occasionally
8. Literature reviews	Content and functional improvement	Occasionally
9. Expert panels	Generate professional feedback from stakeholders (care providers, patient organizations, information specialists)	Occasionally
10. Usability (lab) studies	Assess various parameters of usability	Pre release

Web Analytics

The health portal applies several methods of tracking, monitoring, and analyzing data to measure the behavior of online visitors. This includes analyses of log files and the automated generation of weekly "webanalytic" reports on visitors, click paths, page views, and other variables. The portal also uses tools for log file parsing, analysis, and reporting. Since the above-mentioned metrics do not permit the measurement of unique human visitors "page tagging" is applied. JavaScript is used to pass information about a rendered page and the visitor, such as the average number of pages a user visits, the average duration of the visit, or the number of mouse clicks per minute. Assigning cookies to the user allows for unique identification during a visit and in subsequent visits. The number of visitors is defined by kiesBeter as the sum of unique visitors per month.[4]

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[4] A "unique visitor" visits the site one or more times *within the same month* from a uniquely identifiable PC, mobile phone, or Internet-enabled device. If a query from this device is registered again *in another month*, this is counted as a visit of a new visitor.

Figure 1 shows the number of website visitors between 2006 and 2010. The number of visitors has risen each year to average approximately 4.9 million visitors in 2010. The highest number of visitors occurs in November when insurers publish their policy rates for the next year. The period between November and February is when people are allowed to adjust their policy or switch to another insurer, made possible since the enactment of the Health Insurance Act in 2006. Other temporary rises could be related to media campaigns (radio, magazines, newspapers) or accidental media attention for instance with regard to a specific disease.

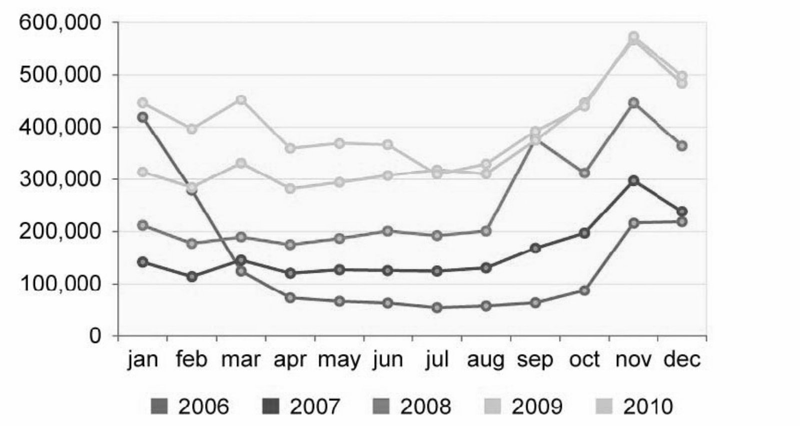

Figure 1. Unique Visitors per Month to kiesBeter.nl (2006–2010)

Non-comparative medical information, especially information on diseases and drugs, attracts approximately half of all the visitors, followed at a distance by comparative information on care providers and patient information. Use of comparative information on insurance has decreased from 11.9 percent (2007) to 6.4 percent (2010) of all visitors. The percentage of users of comparative information on healthcare providers has risen to almost 33 percent (2010). On average, 10 percent of the yearly growth in visitor numbers is explained by an increase in users seeking medical information. Mobile use of the portal is increasing every year, predominantly concerning the seeking of healthcare providers and information on drugs (Figure 2).

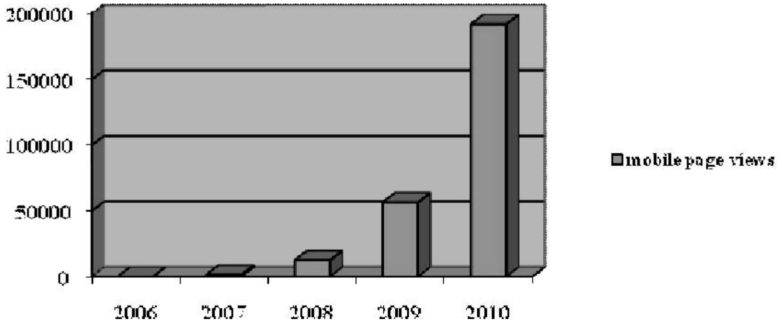

Figure 2. Mobile Page Views (2006–2010)

In recent years, about three quarters of the website's visitors have entered the portal via a search engine, 10 percent have entered the site directly, and 10 percent by referrals. Internet Explorer is the most commonly used browser (two thirds), followed by Mozilla Firefox (about 5 percent), Safari (5 percent), and Google Chrome (4 percent). Referring sites differ according to the news of the day. The average visiting time is 3.7 minutes (2010), compared with 5.7 minutes in 2009. Approximately 15 percent of the visitors return to the portal within the same month.

Use of social networking media such as Twitter, LinkedIn, and Facebook since 2009 has allowed for marketing of the portal and pro-active communication with its audience, including healthcare intermediaries. Employees of the portal contribute to health forums, respond to health blogs or engage in other forms of participatory health since 2010. These activities have amplified the online presence of the portal. Findability of the portal is high, and has increased considerably since achieving full compliance with national Web guidelines. The portal's Google's pagerank has been stable over the last few years at 7/10, primarily indicating linking from other high-rated sites to the portal and thus a measure for relative importance and appreciation. Other portals with a similar pagerank are Schiphol Amsterdam airport (www.schiphol.nl) or the national railways (www.ns.nl). Compared to other Dutch portals that offer consumer health information kiesBeter is highest in pagerank. But the commercial portal Gezondheidsplein.nl attracts slightly more visitors and is apparently much better known (Colijn 2011).

Online Survey

Web-based surveys can be used to collect qualitative information from website visitors. One serious downside of these is that a non-random sample of visitors cannot be controlled for representativeness and bias, and online surveys seem to attract either enthusiastic or disappointed users. However, the advantages of online surveys (that they are fast, cheap, simple, and indicative) are nonetheless compelling, and a short survey has been online since the launch of the portal. Visitors to the portal are invited to fill out a semi-structured online questionnaire asking about the reason of the visit, the referring site, the portal's design, information quality, ease of use, etc. Some items are "open questions" to invite commentary.

We look at three issues vital to choice behavior and provision of information to citizens. Table 2 shows reasons why people visit the portal, which is mainly for personal reasons.

Table 2. Reasons for Visiting the Portal (2010)

For what reason did you visit kiesBeter? (N=267)	
For myself	58.1
For someone else	23
For my job	16.5
For my school	2.4
	100%

Tables 3 and 4 illustrate the outcomes of two respective issues that are important for the portal's objectives. [5] About half of the respondents find or now know where to find the information they need while the other half do not, and keep on searching or give up.

Table 3. Finding the Information Sought for (2010)

Did you find what you were looking for? (N=267)	
Yes, I did	40.50
No, but now I know where I can find it	8.25
No, I keep on searching	29.25
No, I give up	21.50
	100%*

**Round-off difference.*

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[5] The year 2010 is representative for the preceding years.

While almost 40 percent of the respondents are felt helped by the information found on kiesBeter.nl (Table 4), the remaining respondents (almost 60 percent) did not feel supported in their decision-making. Over three quarters of respondents feel that the information did not, or did “just a little”, support their decision making. Overall judgment of survey respondents is reflected in these outcomes. If asked to assess the portal on a 1–10 Likert-type scale respondents rate the portal an average 5.6 (2010).

Table 4. Decision Support (2010)

Did the information support your decision? (N=267)	
Yes, certainly	22.75
Just a little	18.5
No	58.75
	100%

Market Monitor

The international marketing and data collection firm TNS-NIPO surveys quarterly an online panel (*N*=600) representative of the Dutch population. Respondents who have visited the portal (*N*=104; 2010) are overrepresented in the 50–65 years age class, while the 25–40 years class is representative as compared with the total Dutch population. More female visitors (58 percent) relative to the Dutch population visit the portal, while the general educational level is higher than average. They are likely to live in the urbanized western part of the country or the eastern, rural region. From the panel data it can also be derived that over the years (2008–2010) the brand name awareness is 1 percent while 15–20 percent recognize the brand name if aided by the question: “Do you know kiesBeter?” The portal’s image in terms of independence, reliability, and usefulness is rated slightly below average (3.2 on a 1–5 Likert-type scale) in comparison to three competing commercial consumer health portals (Gezondheidsplein.nl; Gezondheidsnet.nl; Gezondheid.nl). This is also the case when the portal is compared to the health insurance comparison websites Independer.nl and Consumentenbond.nl. Panelists rate the portal an overall 7 on a 1–10 Likert-type scale (*N*=600; 2010).

Personal Feedback by Email or Phone

Between 2006 and 2010, portal visitors were able to contact a customer helpdesk by email, web-chat, or telephone in the case of technical problems or information needs not otherwise met. Trained staff at the portal’s helpdesk answered incoming questions during office hours (medical advice was not given). In 2010, fewer than 300 contacts a month were recorded, of which approximately 60 percent took place by email. About

32 percent of these emails were from private individuals while 55 percent were sent by health professionals. Phone calls were made in 54 percent of cases by private persons and in 42 percent by professionals. By far, the largest part of all questions (approximately 35 percent, *N*=1,200 contacts) concerned requests to add a link, to adapt information, or to help find a specific subject. Subjects relating to healthcare providers (quality comparisons) and insurance (November–December) came next, with over 400 contacts made in 2010.

Summary of Results

Since verifiable, operational objectives are lacking, an ex post assessment of the portal's impact as a policy instrument is not possible. However, the portal's own data sources allow for estimation of the extent to which it meets the original aspirations. KiesBeter.nl reaches a fair share of the Dutch health information market, attaining a high Google pagerank (7) with a relatively small marketing budget of 11.4 percent (about 524,000 euros annually, averaged over 2005–2010). The service is used by some 18,000 visitors a day, the majority (58 percent) of whom are female. The information is appreciated by many (mark 5.6 or 7). They seek information for themselves or for others. The portal's brand name is familiar to almost 18 percent of the Dutch (2010). Its image in terms of independence, reliability, and usefulness is average. Still it ranks third among comparable websites that provide health information and second in terms of number of visitors. Half of the respondents rate the information provided as "useful." In less than four minutes almost 50 percent find what was looked for or know now where to find it. Just over 40 percent feel more or less supported by the information. The average user is more likely to be female and higher educated than average, aged either between 50 and 64 or 25 and 39 years. Use of comparative information is relatively low and is restricted for the better part to care providers. Medical information is used by half of all visitors, who stay less than four minutes on average. The customer helpdesk is little used by non-professionals and for the bigger part not for choice information. Mobile usage is relatively booming. Though many Dutch citizens are using the online health information (over 60,000 pages in total) provided by kiesBeter.nl since 2004, the impact of use on their choice behavior, awareness, or empowerment seems small, as far as this can be estimated based on available user data.

Discussion

In the period preceding the decision to establish an Internet portal to support the transformation to a customer-centered healthcare system, the Dutch government was under pressure to be more open and transparent with regard to the spending of public money. New Public Management was a pervasive approach to publicly account for the performance of governmental bodies, and the effectiveness and efficacy of the policy instruments used to solve a specific societal or policy problem. As a policy instrument the portal is however not at all defined in measurable terms; no verifiable objectives are stated to evaluate its performance with regard to policy goals and money, effectiveness, or efficiency. The Dutch Ministry of Health is known for poor performance in terms of accountability (Court of Audit 2011). But from the evaluation of VBTB (IOFEZ 2004) it also appears that government's objectives, performance, or outcome measures often cannot be quantified. This may well have been the case for kiesBeter.nl, since it is hardly feasible to reliably measure its impact on psychological (motivation, cognition) or behavioral (information seeking, choice) variables in the general population.

The all-encompassing impact of the Internet on social, economic, and political life and its implications for policymaking have been recognized by the Dutch Ministry of Health: an array of projects have been initiated to enhance the use of ICT to improve healthcare outcomes, healthcare organization, quality of care, and accountability. As a policy instrument of the Ministry of Health the health portal kiesBeter ("Choose better") was intended to influence consumer and patient choice behavior. Participation of well-informed citizens should endorse the new healthcare system in that an improved information position for consumers on the health market would allow for competitive elements. This instrument involved a mixture of all four public policy tools as suggested by Hood and Margetts (2007): nodality, authority, treasure, and organizational capacity. In terms of health policy, nodality is the government's ability to be "nodal" to digital networks and to operate successfully in a networked society as to the collection and dissemination of health information. Authority denotes the capacity to exercise governmental health policy regulation and to influence the state–citizen relationship. Treasure indicates the monetary effects of e-government with regard to health, healthcare, or health insurances. Organizational capacity is the ability to use Internet technology to interact with various stakeholders in the field of health and healthcare. The presence of these tools, however, guarantees no successful implementation in terms of changed information behavior, greater transparency, or improved market mechanisms.

The use of Internet for health information has undoubtedly shifted traditional patterns of consumer health information use, physician–patient relationship, health services delivery, and healthcare policy (Dutta-Bergman 2006). But choice behavior is not as one dimensional as was often (wishfully) thought from a policy perspective (Adams 2008). Making choices in health and healthcare is an extremely complex individual behavior that is influenced by a range of factors. In the case of the kiesBeter.nl its precise influence on choice behavior, awareness, or empowerment of citizens seems small. The integrated outcomes of the multi-methods approach in the present study reflect this conclusion. Comparative information is less used than medical information except for a seasonal increase when insurance policies are compared around November– December each year. The portal's impact on quality of care, transparency, and general functioning of the health markets should be correspondingly low. Current insights from social sciences and neurology suggest that such choices are not so much based on rationality but rather on emotional, moral, or social grounds. Recently the "libertarian paternalist" concept of "choice architecture" has been advanced as a policy instrument to influence people "to do the right thing" (Thaler and Sunstein 2008). The Dutch Scientific Council for Government Policy endorsed these notions for public policy through an advisory study (Tiemeijer, Thomas, and Prast 2009) that received quite a lot of approval in national policy circles.

Could a health portal be part of such an overall choice architecture? kiesBeter.nl implemented elements from persuasive technology (Fogg 2003) such as feedback options on every page that allows for direct and easy judgment, suggestions, or error report. More advanced methods of user behavior assessment are currently brought into market monitoring tools to better and more directly construct visitors' profiles. But new methods are needed to determine how these visitors actually use the portal's comparative information in their decision-making process, and what exactly makes them return or drop out. Persuasive design deserves more attention to create a relationship with visitors and to improve stickiness. An initial impetus to this is the "roadmap" developed by the research group at the Center for eHealth Research, University of Twente. Based on a review of 16 e-health frameworks, it intends to avoid documented pitfalls while capitalizing on several identified working principles from business modeling and human-centered design (Van Gemert-Pijnen et al. 2011). The roadmap, recently published as a wiki (www.ehealthwiki.org), would enable a systematic evaluation to assess the cost–benefit relation of kiesBeter as a policy instrument, its impact on user behavior, and its potential for improvement.

It was widely expected that performance information for patients and consumers would play a key role in further developing the market-based reforms recently introduced in the

Netherlands. But evidence about the impact of (quality) information systems is limited. There is some support for a correspondence between public reporting of performance data and improvement in quality of care (Cutler, Huckman, and Landrum 2004; Werner, Konetzka, and Kruse 2009; Werner and Bradlow 2010). But concern exists among all stakeholders about the slow pace of making quality information available and about the usefulness (for patients) of complex and hard-to-interpret data, of which the validity and reliability may also be questioned (Cacace et al. 2011).

Recently, more and more scholars doubt if transparency in its traditional form and even more in its computer-mediated form ("e-transparancy") should be a completely desirable objective for public administration. On the contrary, it may lead to increased hopes (and greater disappointment), information over-kill, and uncertainty. Data transparency with regard to performance indicators of healthcare providers is known to be controversial: not only because indicators can easily be misinterpreted by lay people due to bad explication or lack of presentation, but also because they can be manipulated (Bannister and Connolly 2011). Moreover, a recent analysis by the Dutch Scientific Council for Government Policy observes growing concern with regard to digital technology and the poorly understood responsibilities of government regarding the information society (WRR 2011; Broeders, Cuijpers, and Prins 2011). The "orphaned" transparency and accountability should receive a "parent" again: an owner and an address. This illustrates the Council's view on a paradigm shift from e-government to igovernment, implying that the latter is aware of the effect of technology on its own functioning as well as on its relationship with the citizen. To understand how this works within the complexity of contemporary health and to learn from past experience some authors suggest a more interpretative approach that would be more useful at the level of policymaking than conventional evaluations of e-health programs (Greenhalgh et al. 2011).

Though reliable data on Internet use for health information purposes is limited, it is recognized that use varies by social economic status, age, and gender (Gilmour 2007). Disparities in Internet access and usage reflect existing health disparities. A minority use the Internet to actually compare healthcare providers, insurance policies, or prices. This is reflected in the figures presented in this study. Most Dutch people (42 percent) still rely on their GP when seeking advice on hospital quality or other choices in care (Schäfer et al. 2010). Other offline sources follow such as friends and relatives (11 percent), and brochures or booklets (8 percent). Even though this is changing because of improved usability, social media, and use of persuasive technologies (Kelders et al. 2011) only 7.5 percent would seek information immediately from a hospital's website while just 3 percent would use the Internet (Schäfer et al. 2010). Boot and Meijman (2010) suggest people have at least five drivers for seeking online health information, which are not strictly reflective or deliberate. Their findings implicate that online information providers should address not only rational knowledge-related motivations but also speak to social, emotional, or psychological urges. They should also give account of the information epistemology of users as they interpret and re-contextualize health information to make sense of it (Mager 2009).

Amidst a "chaotic media" landscape a trusted medium such as a government-funded health portal may remain a public responsibility. However, there is debate on whether the government is all-the-way responsible for the operational realization of specific information on health and healthcare. There are limitations on the government's responsibility for the functioning of the information society. Technical and social developments suggest that a logical data structure would be a more appropriate alternative. This would allow stakeholders to derive specific information for their target groups more efficiently. It refers to open governance initiatives such as the exemplary community health data initiative of the U.S. Department of Health & Human Services (U.S. Department of HHS 2010). It also aligns with the conclusion that digital technology and interconnected information flows change government fundamentally. These imply a truly new role for i-government (Broeders, Cuijpers, and Prins 2011).

A Letter to the Parliament (Ministry of Health 2011) restates the right of citizens to quality care and acknowledges that transparency in quality is lacking. A still to be established healthcare quality institute was announced to improve transparency for citizens, professionals, insurers, and the Healthcare Inspectorate. The expectation is that if quality of care is rewarded it will improve throughout the healthcare system. KiesBeter.nl is appointed as one of the organizations that will be integrated into this institute to provide comparative quality information. This policy proposal may indeed create new conditions for innovative and transparent health policy.

Appendix 1. Screenshot of kiesBeter.nl (2011)

Bij sommige medicijnen wilt u weten of ze pijn doen in uw portemonnee

Betrouwbare informatie van de overheid. Alles over zorg en gezondheid.

Lees verder

- Lees: veelgestelde vragen
- Bezoek: kB-informatiepunt
- E-mail: info@kiesbeter.nl
- Volg: Facebook of Twitter

Geen zorgverzekering? Nu afsluiten, geen boete!

Medische informatie

Ziekte en gezondheid, medicijn en behandeling.

Patiënteninformatie

Zoek patiënteninformatie en patiëntenorganisaties.

Zorgverleners

Vind en vergelijk zorg bij u in de buurt.

Zorgverzekeringen

Vind de zorgpolis die het beste bij u past.

Laatste nieuws

28 juni 2011

Cholesterol belangrijkste risicofactor hartaanval

Een gezonde leefwijze en vooral een goed cholesterolgehalte helpt hartaanvallen te voorkomen. Dat blijkt uit een langdurig onderzoek in Engeland.

Lees verder

24 juni 2011

Nieuwe internetportal voor chronisch zieken

Eén plek waar zowel informatie over diabetes als over hart- en vaatziekten te vinden is. Dat biedt het nieuwe internetportal www.mijnzorgpagina.nl.

Dossiers

Actueel: hooikoorts

Hooikoorts is een allergie. De allergische reactie ontstaat als iemand in contact komt met stuifmeelkorrels (pollen). Klachten zijn onder meer niezen en jeukende ogen.

Lees verder

Actueel: tekenbeten

Teken zijn kleine parasieten die zich vastbijten in de huid van mens of dier. Een beet kan soms de ziekte van Lyme veroorzaken. Met simpele maatregelen kunt u dit voorkomen.

Lees verder

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WRR Scientific Council for Government Policy [Wetenschappelijke Raad voor het Regeringsbeleid]. 2011. *iOverheid {iGovernment}.* Amsterdam: Amsterdam University Press.

Chapter 3

National health and health care portal: usability

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Ossebaard HC, Seydel ER & Van Gemert-Pijnen JEWC. On Line Usability and Patients with Long-term Conditions. A mixed-method approach. Int J Med Informatics 81(6) 2012, p. 374-387

Abstract

Background: To improve the information position of health care consumers and to facilitate decision-making behavior in health the Dutch ministry of Health commissioned theNational Institute for Public Health and the Environment to develop, host and manage apublic national health and care portal (www.kiesbeter.nl) on the Internet. The portal is usedby over 4 million visitors in 2010. Among them, an increasing amount of patients that usethe portal for information and decision making on medical issues, healthy living, healthcare providers and other topics.

Objective: First objective is to examine what usability aspects of the portal kiesBeter.nl matterfor chronic patients and their informal carers with regard to information seeking, selfmanagement, decision making, on line health information and other variables. Secondobjective is to make evidence-based practical recommendations for usability improvement.

Methods: An innovative combination of techniques (semi-structured interviews; eHealth Literacy scale; scenario-based study using think-aloud protocol and screen capture software; focus group) is used to study usability and on line information seeking behavior in a non random judgment sample of three groups of patients (N = 21) with long-term medical conditions(arthritis, asthma and diabetes).

Results: The search strategy mostly used (65%) by the relatively well-educated subjects 'orienteering'. Users with long-term conditions and their carers expect tailored support froma national health portal, to help them navigate, search and find the detailed informationthey need. They encounter serious problems with these usability issues some of whichare disease-specific. Patients indicate a need for personalized information. They report lowimpact on self-management and decision making. Overall judgment of usability is rated 7on a Likert type 0-10 scale. Based on the outcomes recommendations could be formulated. These have led to major adaptations to improve usability.

Introduction

Against a backdrop of health care system reform the Dutch ministry of Health commissioned the National Institute for Public Health and the Environment (RIVM) in 2004 to develop, host and manage a public national health and care portal (www.kiesbeter.nl) on the Internet. Its objectives are to improve the information position of consumers and to enable citizens to make informed decisions in health, health care and health insurance. The portal seeks to provide reliable, independent and coherent information on a range of health care related topics. These are categorized in subdirectories onfor instance mental health, prevention, drugs, medical information, care providers or health insurances. The amount of visitors has gradually increased from one million unique visitors in the year 2006 to well over four million visitors in 2010 (Fig. 1).

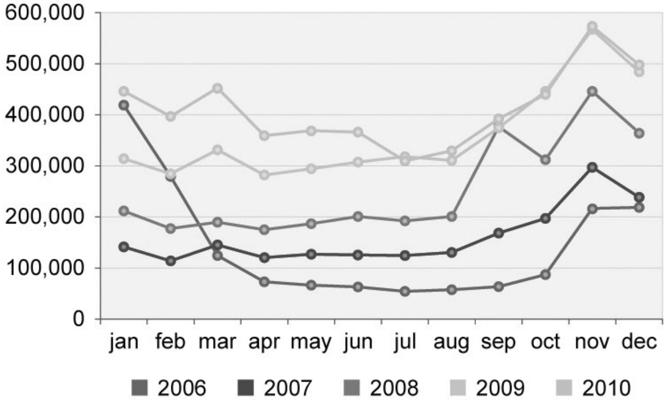

Figure 1. Unique visitors per month 2006-2010 kiesBeter.nl [1].

Accessibility, availability and use of Internet in the Netherlands are high relative to other Western countries. The authoritative Netherlands Institute for Social Research (SCP) reports already in 2007 that the Dutch have become “e-citizens” for whom the Internet is an important source of information, also with regard to health information [2].

As of today over 90% of Dutch households have internet access and approximately 75% of users are “online (almost) every day”. Among younger people (<25 years) this is 90% [3]. With respect to global growth in health information and communication technology, these sociotechnological conditions make the country an interesting test ground for a wide range of mobile and web-based interventions in health and care.

These interventions can only be effective if users actually use them and keep on doing so. Usability is an approach to product development that incorporates direct user feedback throughout the development process. It is about making systems easy to use and matching them to user needs and requirements. In this way adherence can increase while attrition can be prevented [4]. Definitions of usability often refer to perceived ease of use defined as "the degree to which a person believes that using a particular system would be free of effort" [5]. Venkatesh et al. [6] construct usability as "effort expectancy", the degree of ease associated with the use of a (new) technology. Together with usefulness ("performance expectancy") they influence the intention to use and actual usage. Recent research [7,8] adds users' characteristics as well as an accurate fit between human, organizational and technological factors as most important predictors of usage and effectiveness. With regard to health information technologies past research [9] has shown that the impact of eHealth interventions relies to a considerable degree on the usability of the technologies used. In a review of 180 usability studies Hornbaek [10] differentiates between objective (for instance: click paths) and subjective indices (for instance: perceptions) to measure usability. Usability issues are associated with "non usage attrition" [4] and other behaviors that influence the actual usage and impact of eHealth services [11]. Many studies emphasize the value of considering users' perspectives; how they interact with technology and healthcare systems [12,13].

Usability has become crucial for human-centered design in eHealth technology [14]. This is because of its importance for the prevention of the abovementioned 'non usage attrition', its relevance to the improvement of adherence and effectiveness [15] and since it epitomizes the widely acclaimed client-centeredness [16].

Client-centeredness is an essential value to the kiesBeter portal [17]. From its inception usability studies have been conducted in order to facilitate information seeking and to increase the attraction for users and thus their willingness-to-return. As a rule these studies are done before every single release of major modifications in design, navigation or content. Though kiesBeter is no patients' portal, 'chronic' patients presumably form an increasing part of its audience. This assumption is based on recent Dutch epidemiological findings that prevalence of most chronic diseases and multi-morbidity is rising over the years [18]. People with chronic disease have multiple and dynamic needs, including information needs about their condition and the various treatment options; support with making decisions; social support or support with maintaining behavior change. Online applications have shown to positively affect these patients in this regard. From a systematic review of 24 RCTs, Murray et al. conclude that such applications improve users' knowledge, social support, health behaviors and clinical outcomes [19]. Respecting and responding to users' preferences implies exploring and studying these [20]. To examine the portal's usability for patients, we therefore conducted a detailed study among chronic patients and their fellows or 'informal carers'. We observed their information-seeking behavior using the site in real-time and as realistic as possible in order to discover how well it meets their expectations, needs and demands with regard to a series of usability issues. The main research questions are:

- what search strategies and which functionalities are mostly used;
- what are the needs and expectations with respect to usability and information-seeking of patients with a long-termcondition;
- what would be their judgment on the portal's usability with regard to its suitability for their information needs in relation to decision making and self-management;
- is it possible to make evidence-based, practical recommendations for usability improvement.

Building on recent insights in usability research [21] we have used a mixed-methods approach wherein we combine different techniques that complement one another to examine usability from the patients' point of view. Their unique collective application is thought to be more powerful. We hereby expect to contribute to the growing body of information seeking research.

Methods

Subjects

Three high-prevalent, long-term conditions that bring along a variety of health complaints were selected; arthritis, asthma and diabetes. To collect participants a non random judgment sample was taken via recruitment on patient websites, online platforms, and by personal communication. Five patients plus two informal carers (such as husbands, daughters or parents) per disease were arbitrarily chosen. Nine men and twelve women, age range 23-67 years took part in the study. Fig. 2 shows their background characteristics. Over half of them have a higher education while nine respondents have a medium education and two a low education. The overall educational level is not representative of the Dutch national educational distribution. Mean age of the arthritis group is highest; their average educational level is lowest. Mean age of the asthma group is lowest and their average educational level is highest. Most patients (N = 18) have their condition for over 5 years. During the research sessions none of them showed insurmountable problems

with regard to task performance even though some have severe disabilities, e.g., due to arthritis. They were found to cope with their physical restraints for example by using keyboard short cuts instead of using the mouse. Small incidents (e.g., hypoglucosis) could be dealt with during sessions for instance by inserting a break.
A medical-ethical assessment was not required according to Dutch law (WMO: Medical research involving human subjects). The study was conducted in concordance with the protocol of the Declaration of Helsinki (World Medical Association). Participants gave their a priori consent after having been informed on all aspects of the study. They received no reimbursements for their participation.

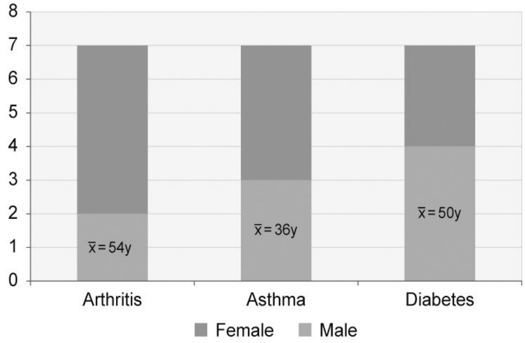

Figure 2. Background variables: disease, mean age, sex (N=21).

Design

Subjects were interviewed, observed and tested in 90-min sessions in their home environment or at the research facility in the presence of one investigator. In short interviews their background variables were recorded and their eHealth literacy was measured using the eHealth literacy scale [22]. The remaining 45 min were used to study usability with a combination of methods. While subjects completed nine scenarios at the website under study, their performance was registered by software that records sound and screen action. After this, subjects were interviewed with regard to usability, information seeking and empowerment issues they encountered. The outcomes were ultimately validated in a focus group setting leading to a series of practical recommendations with regard to usability.

eHealth literacy scale, NL version

The eHealth Literacy Scale (eHEALS) is a 10-item self-report instrument developed by Norman and Skinner [22] measuring perceived knowledge, ease and skills of users to find, evaluate and apply electronic health information. It has shown to have satisfying psychometric properties as a tool for assessing consumer comfort and skill in using information technology for health. We have translated the scale for the purpose of our study. This version was later validated and adapted for The Netherlands by Van Deursen and Van Dijk [23]. The eHEALS outcomes were used as a background variable since a low or high eHealth literacy may affect usability outcomes and must be controlled for. Appendix A contains the English version of the eHEALS.

Scenarios and think-aloud protocol

The core of the study is a 45-min set-up wherein subjects perform different scenarios using the website under study (see Appendix B for a screenshot of its Home page). A scenario is cognitive task that concerns information seeking. For example:

> "Your annual diabetes check takes place within duetime. You'd like to know what exactly will be measured and examined. Please find this information at www.kiesbeter.nl", or: "You are curious if arthritis can be observed on an X-ray image. Figure out if this is the case".

The scenario-method provides insight into difficulties subjects may experience while performing the task. These were translated into technical or functional requirements.
For each patient group nine scenarios were developed. This was assumed to be feasible in terms of attention span and time. In a pre-study we conducted 'cognitive walkthroughs' to locate possible search paths and hindrances and to account for equal complexity [24]. All steps a respondent took to complete a scenario, using mouse and keyboard to activate functionalities within a limited time, were tracked and recorded. Such an action ended if the participant gave up searching with or without success. The shortest click paths were discerned from less efficient routes. This led to refinement in the eventual scenarios used. The constructed scenarios typically entailed tasks to search and find types of information and to evaluate these tasks. They were based on disease-specific information and the supposed information needs of patients and their carers.

Scenarios were alternately ‘directed’ or ‘semi-directed’ to account for different styles of searching as proposed by Marchionini [25]. A directed scenario asks for specific information:

> “You are living in Eindhoven and you want to make an appointment for a regular check-up of your diabetes condition. Find out the nearest hospital where medical examinations (feet, blood, eyes, etc.) are done in one day”.

A semi-directed scenario is a more open-ended task that allows for several solutions, for example:

> “Next week you will visit your lung specialist. Her assistant indicated that some additional clinical examinations have been scheduled. Look for information on clinical examinations of asthma-patients”.

Carers received the same scenarios, though worded from their specific perspective:

> “Next week, your partner will visit his lung specialist (etc.)”.

The order of the nine scenarios was chosen with regard to the most important topics to be covered with regard to both their relevance to choice-behavior of patients and the limited time slot. These main topics concerned ‘medical information’ (three scenarios), ‘care providers’ (two), ‘drugs’ (one) and ‘health insurances’ (one). Less important topics were ‘healthy living’ (one) and ‘patient rights’ (one). See Appendix C for an example of a typical scenario.

Participants were instructed to ‘think aloud’ while completing a scenario meaning that they accompany their actions with spoken comments on why and what they do. The think-aloud method is originally developed to study short-term memory (STM) processes. Ericsson and Simon, op. cit. Krahmer and Ummelen [26] constructed a concurrent think-aloudprotocol for usability testing. Deviating from their method we allowed respondents to talk to the investigator. This supposedly disturbs the stream-of-thoughts in STM while activating the long-term memory and additional cognitive processing for communication, listening, responding, etc. However to us this seemed less important than encouraging participants to keep thinking aloud, motivating them and avoiding unnatural communication, as maintained also by Boren and Ramey [27].

The execution of the scenarios was audiovisually recorded using screen-capture software (FastStone Capture 6.3TM) to enable analysis of navigation and verbalizations. The software registered the verbal expressions of participants and generated a video of their on-screen action. From the recordings all navigational actions and verbal 'think-aloud' expressions were later coded per scenario by two independent raters. Coding was done according to descriptive characteristics such as duration (seconds to complete a scenario, or until respondents indicates to stop), use of clickable elements (e.g., clicking, box checking, entering, back-spacing, etc.) and results. Results fell into four categories: success (respondents gives the right answer within time), perceived success (but in fact a failure), perceived failure (but in fact a success), or discontinuation (respondent gives up). Any sequence of actions adds up to a 'strategy'. Search strategies and their combinations were operationalized in terms of orienteering and teleporting [28]. The first implies a gradual process starting from a wide perspective (e.g., a web site's menu structure) narrowing down to more specific steps. Teleporting is a more targeted strategy, e.g., using the free search functionality or direct internal/external hyperlinks to find the information in the quickest way.

Verbal expressions, remarks, sayings, phrases, statements et cetera were coded according to six specific well-described categories; lay out, navigation, content, acceptance, satisfaction and empowerment. These main categories were derived from literature on usability, information behavior and patient empowerment [29-32]. Most categories were divided into subcategories to allow for analysis of specific verbal content.

'Navigation' for instance, was divided into subcategories such as page design; labels and headers; user input, site-wide search options; loading speed and Help-options.

Expressions with regard to 'Content' were divided into six categories (understandability, comprehensiveness, accurateness, relevance, images, and external links) of which two were divided in sub-subcategories. Lay-out, for example, was divided into only three subcategories: expressions on general features of design; expressions with regard to the use of color; and expressions on readability (font size, type of font, etc.). 'Acceptance' was composed of subcategories that referred to reliability/credibility of the site, to a clear statement on the sources of supply and objectives of the site, and its perceived up-to-dateness. 'Satisfaction' was made up of willingness-to-return, general appreciation and if respondents would recommend the site.

The expressions, including post-scenario remarks, were coded according to these (sub) categories and received, if relevant, marks for a positive (+), a neutral (+/-) or a negative (-) judgment and were entered into a codebook for descriptive statistical analysis with SPSS 17 (Statistical Package for the Social Sciences).

Interviews

Immediately after each scenario evaluative questions were asked with regard to navigation and content (see Table 1):

After finishing all scenarios a semi-structured interview was taken. It was based on the validated and standardized Dutch Website Evaluation Questionnaire WEQ [31], to find out about the subjects' experience of the portal's usability. The WEQ measures usability and quality dimensions of informational, governmental websites such as navigation, content, lay-out, user-satisfaction and user-acceptance. Empowerment issues were raised only with patients, not with their informal carers. The topics were derived from Van Uden-Kraan et al. [33] and involved knowledge, self-confidence towards health care professionals, coping skills, expectations, decision making and self-management. A final judgment mark on a Likert-type scale (0-10) was obtained as well as eventual remarks and wishes regarding the portal. The interviews were recorded and written out *ad verbatim* to be coded, as to intrinsic elements of content, for analysis.

Table 1. Post scenario questions.

Category	*Post-scenario question*
1. Navigation	Was it easy to find for you?
2. Content	Do you understand the information?
	Do you find it complete?
	Do you find it accurate?
	Do you find it relevant?

Focus group

The results that emerged from the scenario study and the interviews were finally tested in a focus group session at the research facility, led by two investigators. The aim of the focus group was to establish to what extent the outcomes align with the experience of the participants and to find out if any issues are missing. Only the main results were tested against their experiences and opinions. These were systematically treated per topic (medical information, care providers, etc.) using a digital online 'smart board' on the wall with the website projected onto it. The 2-h session was recorded and written out *ad verbatim* to be coded for analysis.

Data analysis

All screen-capture recordings of navigational muse and keyboard actions and all verbal 'think-aloud' expressions were written out, coded and allotted to specified subcategories of information seeking and usability. All recorded interviews were written out *ad verbatim* and (para-)coded for labeling into semantic units. Coding was independently done by two junior investigators. All coded actions and expressions were entered into an SPSS data matrix to enable frequency analyses. A summarized codebook is available as supplementary material to this article.

Results

eHealth literacy scale

Most respondents believe they have the skills and interest to use on line health information and 90% would appreciate the use of the Internet for health-related decisions. However only 40% believe the information on the net is reliable enough to use for personal health decisions. All participants report to have ample Internet experience and they use it on a daily basis. They report to be able to search and find health information and to be able to discriminate between high and low quality information. Their familiarity with the portal kiesBeter.nl is negligible.

Scenarios and think-aloud protocol

From the scenario study and the applied think-aloud protocol the following main results are derived.

Search strategies

From the analysis it appears that 'orienteering' is the search strategy most subjects used: of all recorded occurring actions that make up a strategy 65% concern primarily menu functionalities to complete a scenario (Table 2). Of the occurring action, only 16% add up to a 'teleporting' strategy while in a minority of cases combinations are identified. An OTO sequence, for example, indicates an action sequence where initially particular menu-options (O: Orienteering) are activated alternated by using targeted search-options (T: Teleporting) and followed by, again, using options from the menu-structure (O: Orienteering). Orienteering is less efficient than teleporting since is requires much more actions. Both strategies are nonetheless equally effective since they deliver approximately the same success ratio. Success ratio is here defined as the amount of respondents giving the right answer within time divided by the respondents who completed a scenario within time. Most functionalities the portal offers are used. Exceptions are the under-used hyperlinks in the sub-menu at the right edge of the screen, and the advanced search options that appear at the right side of the page.

Table 2. Search strategies used: Orienteering (O), Teleporting (T) and combinations.

Strategy	Occurrence	%
O	88	65%
T	22	16%
OT	11	8%
OTO	7	5%
TO	5	4%
OTOT	1	1%
TOTO	1	1%
Total	*135*	*100%*

Most participants do not finish all nine scenarios within the 45 min time frame (Table 3). The last scenarios being the least completed; e.g., the ninth scenario on Patients' rights was completed by only 24% of participants. Of those who did, all did so successfully. In Table 3 the three scenarios on Medical information have been aggregated; the two on Care providers have been left segregated because they differ considerably in the way the requested information could be found.

Success ratio and directness vary over different information topics, e.g., care providers or health insurances (see Table 3). The three, aggregated, scenarios on medical information, are completed by 81% of the subjects of which 60% did so successfully. For example the second scenario on care providers (general practitioners/GPs) was carried out by all 21 subjects (100%) of which 15 (71%) found the right information in time. The sixth scenario on Health insurances delivered the lowest success ratio; out of 21 subjects 15 (71%) finished it, butonly 5 (33%) did so accurately.

The asthma-group (lowest average age, highest average education) finished most scenarios while having the highest success ratio. The arthritis group (highest average age, lowest average education) finished the least scenarios while having the lowest success ratio.

Table 3. Percentage of subjects completing scenarios and success ratio.

Scenario (scenario sequence)	% of subjects who completed a scenario	success ratio
Medical information (sc. 1, 3, en 7)	81%	60%
Care providers - GPs (sc. 2)	100%	71%
Care providers - Hospitals (sc. 4)	90%	79%
Drugs (sc. 5)	90%	89%
Health insurances (sc. 6)	71%	33%
Health living (sc. 8)	29%	100%
Patients' rights (sc. 9)	24%	100%

Think aloud protocol

We scored positive, neutral and negative expressions within each of the (sub)categories and analyzed their content. Table 4 shows the amount of positive, neutral and negative expressions per category recorded during scenario sessions. Of all expressions (677) recorded during the scenarios 41.5% are positive and affirmative with respect to usability and behavior categories, 57.6% are negative and unenthusiastic, while less than 1% are of a neutral character (Table 4). Most expressions concern Navigation (80.6%) followed at a great distance by comments on Content (18%). Most negative comments are made with regard to Content (64.8%) and by Navigation (56%).

Table 4. Expressions recorded during scenarios, per usability category.

Usability / behavior category	+	(+)%[a]	-	(-)%[a]	+/-	(+/-) %[a]	Total	% of total amount 'think aloud' expressions (N=677)[b]
Navigation	235	43.0%	306	56.0%	5	0.9%	546	80.6%
Content	42	34.4%	79	64.8%	1	0.8%	122	18.0%
Lay out	2	50.0%	2	50.0%	0	0.0%	4	0.6%
Acceptance	0	0.0%	2	100.0%	0	0.0%	2	0.3%
Satisfaction	1	50.0%	1	50.0%	0	0.0%	2	0.3%
Empowerment	1	100.0%	0	0.0%	0	0.0%	1	0.1%
Total	*281*	*41.5%*	*390*	*57.6%*	*6*	*0.9%*	*677*	*100%*

\+ = positive; - = negative; +/- = neutral
a = Percentage of all expressions within the category
b = Percentage expressions of all expressions, concerning the category

Interviews

We scored positive, neutral and negative expressions from the two post-scenario questions and the WEQ-based interviews within each of the (sub)categories and analyzed their content. Table 5 shows the amount of positive, neutral and negativeexpressions per category. Of all expressions (1013) 61.2% arepositive and affirmative with respect to usability categories, 35.5% are negative and unenthusiastic, while just over 3% are of a neutral character. Most verbal expressions concern Content (46.7%) followed closely by remarks on Navigation (33.4%).

Interviews bring out relatively (much) more positive comments on Content (74%), followed by Satisfaction (67.3%) and Acceptance (60.4%) and Lay out (55.3%). Only 6.4% of all expressions in interviews concern Empowerment, operationalized as the feeling of control and coping with regard to the patient's condition (self-management). Of these 65 recordings the majority (76.9%) is negative or neutral. Relatively few expressions during interviews fall into the categories Satisfaction and Acceptance, but of those that do

(97; 9.5%) respectively 67.3 and 60.4% are affirmative as to the respective components of these categories. On a 10-point Likert-typescale, part of Satisfaction, the site was finally rated a 7.0 on average (range 4-8). High-raters mention the information quality and the appearance of the site. Low-raters mention the superficiality of the information and the poor findability.

Table 5. Expressions recorded during interviews, per usability category.

Usability / behavior category	+	(+)%[a]	-	(-)%[a]	+/-	(+/-)%[a]	Total	% of total amount interview expressions (N=1013)[b]
Content	350	74.0%	111	23.5%	12	2.5%	473	46.7%
Navigation	174	51.5%	160	47.3%	4	1.2%	338	33.4%
Satisfaction[c]	33	67.3%	16	32.7%	0	0.0%	49	4.8%
Acceptance	29	60.4%	10	20.8%	9	18.8%	48	4.7%
Lay out	21	55.3%	17	44.7%	0	0.0%	38	3.8%
Empowerment	15	23.1%	44	67.7%	6	9.2%	65	6.4%
Total	*620*	*61.2%*	*360*	*35.5%*	*32*	*3.2%*	*1013*	*100%*

\+ = positive; - = negative; +/- = neutral

a = Percentage of all expressions within the category

b = Percentage expressions of all expressions, concerning the category

c = Ex judgment of website

Examining the outcomes in more detail

A closer look at the data summarized in Tables 3 and 4 reveals more on how patients view information seeking issues. We concentrate on the major issues of Navigation and Content. 'Thinking aloud' during scenario sessions on Navigation shows negative quotations in 56% of all verbal expressions while in interviews this somewhat less: 47.3%. When taking together all expressions on Navigation, 52.7% is negative. If we look at its subcategories we see that general aspects of navigation and site-wide search options account for this.

Post-scenario expressions are generally more positive. Some subjects completed few scenario's within the time given but "(. . .) *I think that if I take a few hours and I need something specificI might have found it anyway*" {arthritis-carer 2}.

If we consider expressions on Navigation per scenario we see that especially the one on health insurances (sc. 6) causes problems in terms of failure to complete it. All expressions while thinking aloud are negative about this topic where the portal offers comparative, complex information on health insurances policies. Expressions on Care providers (scenarios 2 and 4), Medical Information (1, 3, 7) and Drugs (5) are somewhat more positive but closer analysis results in 57 final recommendations for improvement concerning Navigation (see supplementary material for a synopsis). These range from consistency in search paths, presentation of search results, transparency, labeling, heading, positioning of hyperlinks, cross references, and speed to the removal of under-used options.

The second major issue is Content. Here as well we observe far more negative expressions during scenario sessions (64.8%) compared to 23.5% of expressions during interviews where most expressions (46.7%) concern precisely Content. This category was divided into six subcategories: understandability, completeness, accuracy, relevance, images, and hyperlinks.

Understandability was generally appreciated by most respondents. But among diabetes patients problems are observed with understanding and relevance of information. Positive expressions on completeness regard the amount and the scope of information presented. Negative references concern the incidental use of 'difficult' terms ('protocol', 'restitution') and insufficiencies in the medical information about the patient's own disease, e.g., the genetics of arthritis, special medical examinations for asthma, or alcohol use and people with diabetics. Most patients indicate that though the general medical information is accurate it is hardly relevant, since they are used to deal with specific and detailed information due to their chronic condition. Images elicit both mixed responses of positive, neutral and negative nature. Some patients would see more hyperlinks to other sites of interest.

In the interviews respondents express themselves generally less negative as compared to their verbalizations during scenarios: 35.5 vs. 57.6%. In the interviews not only much more expressions are recorded, but also more semantic differentiation could be observed. While evaluating Content the interviewed patients rate it almost twice as much positive (74%) than they did during sessions (34.4%). They refer to the understandability and accuracy of it though they make reservations with regard to medical jargon and the lacuna in certain parts of medical information that restrict the overall usefulness.

Comparing aggregated verbal expressions from scenario sessions (Table 4) with verbal expressions from interview sessions (Table 5) shows conspicuous differences; most 'think aloud' expressions (80.6%) fall into the Navigation category while the record of interview expression shows a partition between mainly Content (46.7%) and Navigation (33.4%). If verbalizations from scenarios and interviews on Navigation are taken together, only 48.3% are positive.

Of these recordings that match the category of Empowerment a majority (76.9%) is negative or neutral. Examined more closely this is because respondents do not think the portal contributes to knowledge about their condition (64.7%). They feel others, recently diagnosed, would better benefit from the information. And 60% of expressions articulate no support of the site's information for their contact with their GP or other care providers; over 72% indicate no support for selfmanaging their disease; *"(. . .) but it don't say what to do about it. Dust mites. If you're allergic you could buy, for example, a bed with a mattress that protects against dust mites. That would helpme deal with my condition. Or: 'Don't forget to take your asthma-spray with you'"* [asthma patient 3]. The information hardly helps to have realistic expectations about the course of their condition or to support decision making. Some however indicate that their experience with the portal may be too limited for balanced judgment on such Empowerment issues: *"(. . .). Maybe, yes. I find the tasks that I had to do. . ., too narrow. I can't say now if that would be possible or not"* [arthritis patient4].

If we examine the verbal expressions about Lay-out, these tend to be somewhat more affirmative in the interviews (Table 5) and almost non-existent in scenario sessions (Table 4). Lay-out is divided into three subcategories: (L1) containing expressions on general features of design; (L2) including expressions with regard to the use of color; and (L3) containing expressions on readability (font size, type of font, etc.). For each of these subcategories positive and negativeexpressions are recorded.

Table 6 illustrates the semantic profile that emerges from a closer look. Especially readability, font size in particular, is seriously disapproved of. This was the case for the relatively aged arthritis patients and their carers: *"It is really quite small. People with arthritis are mostly old people who have trouble reading small print"* [arthritis patient 2]. It was also the case for diabetes patients who more than likely have come across ocular problems in their lives.

Table 6. Verbal expressions from scenarios and interviews layed-out in subcategories.

Usability					
Subcategory Lay-out	+	(+) %[a]	-	(-) %[b]	total
(L1) General features of design	16	64.0%	9	36.0%	25
(L2) Use of colour	6	85.7%	1	14.3%	7
(L3) Readability	1	10.0%	9	90.0%	10
total	23	54.8%	19	45.2%	42

+ = positive verbal expressions; - = negative verbal expressions

[a] percentage positive expressions of total amount of expressions within subcategory Lay-out.

[b] percentage negative expressions of total amount of expressions within subcategory Lay-out

Screen-capture recordings and interviews were written out and codified independently by two junior investigators. A sufficient inter-rater reliability was determined by calculating Krippendorff's alpha ($\alpha = .83$), a general measure to assess agreement between raters. We observed no substantial differences in performance between subjects tested in their home environment (N = 6) and those participating at the research facility (N = 15).

Focus group

After the primary data collection and analyses the outcomes form the scenario study and the interviews have been subjected to a small focus group facilitated by two investigators. Participants were randomly selected from those who agreed to a follow-up session. Eight respondents were contacted by phone; four could not participate at the given date or were not motivated to join. Four patients eventually took part in the group. The outcomes are presented to the focus group per topic and then discussed with regard to the usability categories (lay out, navigation, content, acceptance et cetera). Participants were requested to generate an improvement hierarchy based on their responses to the outcomes. It appears that they often disagree and sometimes contradict themselves. They however agreed on six general recommendations regarding information seeking issues, these are summarized in Table 7.

Participants indicated that all these issues have equal priority, and that an improvement on one issue would not be enough. More elaborated outcomes on major and minor issues of the focus group are generally congruent with earlier findings from within this study.

Table 7. Main issues raised in focus group.

General recommendations on information seeking
Bring left-edge menu and right-edge menu together and relate it to the main page content
Simplify the portal
Make navigating more consistent and improve findability
Make headers in tune with the text content
Improve general search options
Remove redundancies in lay out, functionalities and content (double links and overlapping information

Conclusions

Participants are relatively well-educated. Also their eHealth literacy level is relatively high. The latter does not seem to correspond with successfully completing an online health information scenario. In our study age and education do correspond with online performance and success ratio. Participants' main search strategy is clearly orienteering; narrowing down from the given menu option to find the information searched for. This less-efficient method is as effective as other strategies. No specific preferences for menu search options are observed, though right-edged menu options are not muchused.

Navigation is obviously the major usability issue for the participating patients, followed by Content. During scenarios 56% of expressions that relate to this issue are negative, during interviews this is 23.5%. Most verbal expressions in the interviews concern Content, followed closely Navigation. Scenarios elicit relatively more negative comments on Content (64.8%) followed by Navigation (56%). Content is appreciated by the patients who nonetheless indicate they need tailored, if not personalized, and in-depth information instead of general information.

If verbalizations from scenarios and interviews are taken together, 48.3% are positive on Navigation. Of all expressions recorded during the scenarios 41.5% are positive and affirmative with respect to usability and behavioral categories, 57.6% are negative and unenthusiastic. During interviews about 2/3 of all verbalizations are positive and affirmative with respect to usability categories while roughly 1/3 are negative and unenthusiastic. Of the few recordings regarding matters of Empowerment, including decision making and self-management, a minority is positive. Subjects view lay-out issues positively with regard to design but they are unfavorable towards readability. Patients expect high quality Content and unhampered Navigation but this is not what they experience. Nevertheless the overall judgment mark (7 on a 1-10 point scale) on what the health portal has to offer corresponds with a comparable level of Acceptance. Most of these findings were confirmed in the focus group session. Most could be formulated into recommendations.

Discussion

The present non random judgment sample does not allow for generalization to a wider population. From usability literature we know however that a small sample size may actually generate valid and valuable information on the majority of usability issues [13].

The applied mixed-methods approach demonstrates this. Future studies cannot do without a combination of methods. They cannot do without giving account of the patient's perspective either. The eHealth literacy level of participants is slightly higher compared to general levels found in a general population [23]. It is likely that the observed level of eHealth literacy did not interfere with their information seeking behavior and its outcomes, which might have been be the case if low eHealth literacy levels are measured. May be the eHealth literacy scale itself is a poor predictor ofactual performance.

Based on their self-reported digital skills and their educational level a teleporting strategy rather than orienteering could have been expected. Using the menu-structure to navigate through the site and find what you look for needs more actions than strictly necessary and is thus is a relatively inefficient method. Apart from personal preferences for orienteering the use of the less efficient method of orienteering may have been induced by the scenario itself. The semi-structured browsing tasks direct subjects to find information about some subject instead of searching the answer to a specific question. The site's design may explain the preference as well; its menu functionalities probably dominate the general free search function in both space and position and thereby facilitate orienteering. The under-used elements of the sub-menu at the right edge of the screen, and the advanced search options that appear at the right side of the page attract little visual attention probably because of their dexterous location, a finding known from eye-tracking studies in human-computer interaction and usability research [34,35]. It is well known that chronic patients have learnt to cope with their restraints in daily life and know their limitations. In terms of digital skills this was demonstrated by patients using all kinds of shortcuts to avoid use of the mouse. Others found the screen font-size too small but nevertheless dealt with that and perform the tasks.

In terms of the major usability issues participants are initially disappointed by respectively suboptimal Navigation and Content that is not tailored to their needs. In subsequent interviews however they rate the latter twice as high as during scenario sessions and express themselves more positive as to all other usability categories as well. For instance Content is evaluated positively on the average. Educational level and knowledge level as a chronic patient help to explain this.

Differences between expressions from scenario sessions (uni-dimensional: navigation) with verbal expressions from interview sessions (bi-dimensional: content and navigation) may have several causes. They might reflect the attention that was given during interviews to content and navigation or the fact that while completing scenarios primarily navigational problems occur - which are expressed accordingly.

Respondents verbalize less negatively in interviews as compared to their expressions in scenarios. The difference may have been caused by high expectations during scenarios and typical internet behavior ruled by the universal 'principle of least effort' [36]. In interviews respondents are apt to cognitively reconstruct their information seeking behavior as logical; leaving out the strain of the moment, compensating for their own shortcomings, introducing more contexts or find a socially desirable insert. It is a common form of response bias in social research that people tend to be more positive in interviews than would be justified regarding the problemsthey actually ran into. During scenario sessions such problemsare more vivid and present than in a post hoc interview andthey are verbalized accordingly. The focus-group allowed forcontradictions and similarities but its size and composition ofmotivated participants limit its significance.

Lay-out is evaluated positively, apart from 'readability': "Itlooks professional; I see no advertisements and no fancy colors. It's not amateuristic or too flashy. He just gives factual information. I get the idea that it's being maintained somehow" [asthma patient 1]. This is probably explained by the portal's design which is in agreement with the non-expressive aesthetic dimension of online user perception that La Vie and Tractinsky call "classical" [37]. This relates to clean and orderly design, ultimately referring to pleasant user perceptions of the site's usability such as ease of use.

From a closer examination we conclude that these relatively well-educated users with long-term conditions and their carers expect support from a governmental website, to help them navigate, search and find the information they need. Adapted to their long-term condition patients expect tailored and in-depth information instead of general information, a finding known from other studies [13,38]. In that respect their Acceptance of the portal as expressed in the interviews is beyond expectation. Though their general health-related information needs may occasionally be met by a generic portal such as kiesBeter.nl, their specific disease-related needs may only be met in specialized websites. Meanwhile their distrust is remarkable: only 40% would rely on online information for personal health decisions. As a tool for empowerment and decision making the portal is of little use to most participants. More personal experience with this portal would probably alter this. It remains impossible to develop a 'one sizefits all' portal. Many specialized patient sites arise in response to specific information needs, and the role of participative applications increases.

For an online health information portal this study's outcomes are serious, especially since user-orientation is central to this public enterprise. Therefore many recommendations from the present study have been implemented (see Supplementary material). To maintain adherence and willingness-to-return the introduction of more persuasive interaction is a condition sine qua non [15,39]. Tailoring information to users' needs is another [40]. At the same time users will keep on assembling information from the web and make sense of it in their own context [41]. Patients do not differ from other users in their sensemaking practices and have similar needs of personalized and contextualized information [42]. Efforts to increase usability need permanent and strong involvement of all stakeholders involved in the development and implementation process of an online portal [43].

Otherwise a general health portal is just not a sufficiently appropriate source of information for health care consumers with long-term conditions.

Acknowledgements

This article is the second in a series of research reports on consumer health informatics in the Netherlands, funded by the RIVM Strategic Research Program. We thank Ms. M. Zuidema MSc and Ms. M. Bakker MSc for their respective contributions to the present study.

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Appendix A

eHealth literacy scale (eHEALS; Norman & Skinner, 2006)

I would like to ask you for your opinion and about your experience using the Internet for health information. For each statement, tell me which response best reflects your opinion and experience *right now.*

1. How **useful** do you feel the Internet is in helping you in making decisions about your health?

☐1	☐2	☐3	☐4	☐5
Not useful at all	Not useful	Unsure	Useful	Very Useful

2. How **important** is it for you to be able to access health resources on the Internet?

☐1	☐2	☐3	☐4	☐5
Not important at all	Not important	Unsure	Important	Very important

3. I know **what** health resources are available on the Internet

1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

4. I know **where** to find helpful health resources on the Internet

1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

5. I know **how** to find helpful health resources on the Internet

1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

6. I know **how to use** the Internet to answer my questions about health

1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

7. I know how to use **the health information** I find on the Internet to help me

1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

8. I have the skills I need to **evaluate** the health resources I find on the Internet

1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

9. I can tell **high quality** health resources from **low quality** health resources on the Internet

1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

10. I feel **confident** in using information from the Internet to make health decisions

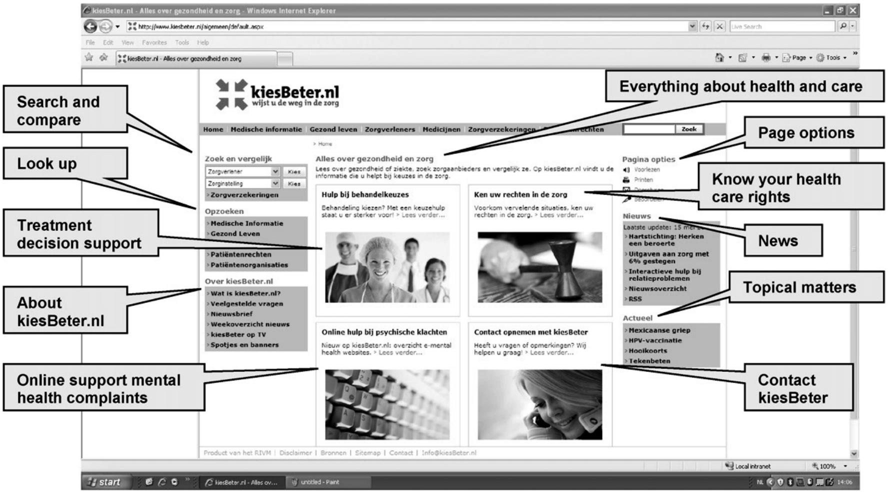
1) ☐ Strongly Disagree
2) ☐ Disagree
3) ☐ Undecided
4) ☐ Agree
5) ☐ Strongly Agree

Thank you!

** Note: Questions #1 and #2 are recommended as supplementary items for use with the eHEALS to understand consumer's interest in using eHealth in general. These items are not a formal part of the eHealth Literacy scale, which comprises questions #3-10.*

Appendix B

Screenshot HOME page kiesBeter.nl at the time of the study



Alles over gezondheid en zorg

Lees over gezondheid of ziekte, zoek zorgaanbieders en vergelijk ze. Op kiesBeter.nl vindt u de informatie die u helpt bij keuzes in de zorg.

Hulp bij behandelkeuzes

Behandeling kiezen? Met een keuzehulp staat u er sterker voor! > Lees verder...

Ken uw rechten in de zorg

Voorkom vervelende situaties, ken uw rechten in de zorg. > Lees verder...

Online hulp bij psychische klachten

Nieuw op kiesBeter.nl: overzicht e-mental health websites. > Lees verder...

Contact opnemen met kiesBeter

Heeft u vragen of opmerkingen? Wij helpen u graag! > Lees verder...

Laatste update: 15 mei

Appendix C

Example scenario for asthma patients

{Medical information}

1. You just learnt that new clothes may cause an asthma attack. You want to know if there are more factors triggering such an attack. Seek information about which stimuli specifically trigger asthmatic lungs.

{Care providers}

2. Your GP wants to refer you to a physiotherapist for lung-reinforcement. You live at Papaverstraat 51, 1446 EL in Purmerend. Look for the nearest physiotherapist.

{Medical information}

3. Next week you will visit your lung specialist. Her assistant indicated that some additional clinical examinations have been scheduled. Look for information on clinical examinations of asthma-patients.

{Care providers}

4. You are moving to Nijmegen and want to know where the nearest hospital is. Check for nearby hospitals that specialize in asthma-care.

{Drugs}

5. Your doctor prescribes theophylline. Find information about what kind of drug this is.

{Health insurances}

6. This year you want to change your healthcare insurance policy. You hesitate between a policy at X or one at Y's. Since you benefit from homeopathic treatment you wish to have this reimbursed for €250 a year. Look for the cheapest insurer to cover this.

{Medical information}

7. While exercising you experience a lack of oxygen. Search for information on how to deal with this.

{Healthy Living}

8. Your doctor advises you to get the seasonal influenza vaccination. You doubt if you want to keep on doing this. Look for information on influenza vaccination and asthma.

{Patients rights}

9. You want to contact an asthma patient organization. How would you do that?

Appendix D

Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.ijmedinf.2011.12.010.

Chapter 4

National health and health care portal: decision support technology

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Ossebaard HC, Van Gemert-Pijnen JEWC, Sorbi MJ & Seydel ER. A study of a Dutch on line decision aid for parents of children with ADHD. J Telemed Telecare 16(1) 2010, p. 15-19

Summary

During a three-month study period, visitors to an online decision aid (DA) for attention deficit hyperactivity disorder (ADHD) were invited to complete an online questionnaire before and after working through the DA. Some 75,000 unique visitors found their way to the page on DAs, although fewer than 1 in 10 visited the DA for ADHD, staying there for about six minutes on average and using 8–9 clicks to navigate. A total of 195 people completed the first questionnaire (a response rate of about 3%). Only 12 of the respondents to the first questionnaire (6%) completed the second questionnaire. There was no significant effect of the DA as measured by three decisional outcome measures. Respondents moderately appreciated the information received. Even though the DA was constructed according to evidence-based guidelines and International Patient Decision Aids Standards wherein expert and patient involvement are assured, these preliminary results suggest that the online DA for ADHD needs further work to support the decision-making process of parents with regard to the most appropriate treatment for their child.

Introduction

Since the 1990s, reform of the Dutch health-care system has been a prominent matter in Dutch health policy.[1] Competition and choice became guiding principles for change. The main rationale had been the continuing rise in health expenditures in combination with demographic trends and technological developments, i.e. increasing diagnostic and curative possibilities. A more consumerist, choice-oriented approach to the delivery of public services took place in other Western countries as well.[2] The enactment of the National Health Insurance Act in 2006 brought about a shift towards privatized health insurances and there were major changes in the rules and regulations concerning health care in the Netherlands. For consumers and patients this implied the possibility of increased choice in arrangements for cure, care and prevention.

The role of information with regard to choice and competition in health care is essential. All parties in the health 'market' need the same (comparative) information on cost and quality if proper choices are to be made and competition is going to work.[3] The Dutch Ministry of Health therefore initiated a health-care portal on the Internet.

The National Institute for Public Health and the Environment (RIVM) was requested to develop a new portal on the Internet and to open telephone lines and help desks in local information centres. The portal was dubbed kiesBeter.nl ('make better choices') and aimed at a general Dutch audience (over 16 years old) of average educational background. The portal has been available since 2004. Consumers have access to integrated, independent and reliable information on health, care and health-care insurance services. In 2004 the Netherlands Organisation for Health Research and Development initiated the Dutch Decision Aids implementation Programme (D-DAP).[4] Decision support technology assists patients in making informed choices about treatment options, including the in *dubiis abstine* decision (in case of doubt, abstain from intervening), from a patients' perspective. The information is based on evidence-based medical guidelines. Decision aids therefore support the decision-making process, empower patients and supplement patient-clinician interactions. DAs thus fit into the model of shared decision-making where the care provider and care consumer aim for mutual agreement and effort with regard to medical decisions[5] thus contributing to patient empowerment. From a meta-analysis by O'Connor *et al.*[6] it appears that DAs are effective with regard to improved knowledge, realistic expectations as to the benefits and risks of treatment options, patient participation in the decision-making process and decreasing decisional conflict.

D-DAP was part of a wider research and development schedule supported by the Dutch government and designed to provide health-care consumers with tools to strengthen their position in a demand-driven health-care system. All DAs within the D-DAP were developed according to the International Patient Decision Aid Standards,[7] based on a theoretical framework[8] and subject to a production and validation process involving experts in medical decisionmaking, researchers, health professionals and patients.[4] They are made available through the national health portal. As such they are constructed using ASP.NET according to government guidelines and W3C standards with regard to accessibility and sustainability. Currently there are 17 DAs available online, four of which concern mental health problems such as depression, anxiety disorders and attention deficit hyperactivity disorder (ADHD) among children.

Recent approaches in decision support technology research have evaluated either the outcome decision or the decision-making process itself.[9] In the present study we took the latter approach with regard to the decision-making process of parents or caretakers and their care providers on the treatment of ADHD among children. Extrapolated from foreign studies it is estimated that 3–5% of Dutch children (under 16 years old) suffer from ADHD.[10–12] Some 60,000–100,000 children (5–14 years old) meet the criteria for this diagnosis. It is further estimated that 40,000 children need treatment for ADHD.[10]

Three aspects of decision-making were investigated in the present study: the stage of decision-making, decisional conflict and the knowledge of parents who are looking for a treatment for their ADHD-diagnosed child. The acceptability of the DA for parents was also measured.

Methods

The study entailed a pre-/post-test design using an online survey of visitors of the DA for ADHD. The log-on screen of the general DA starting page is shown in Figure 1. Visitors who clicked on the link about DAs for ADHD were directed to a page where they were asked to complete a questionnaire before and after completing the DA. Visitors could decide to carry on using the DA or – by default – to participate in the study anonymously (Figure 2).

If they decided on the latter, then a new window opened and they were referred to the first online questionnaire (Q1). When respondents had completed it they could navigate through the DA on ADHD at their own pace. Once finished they were referred to the second questionnaire (Q2).

Keuzehulpen

Een keuzehulp helpt u bij het kiezen van een behandeling voor een ziekte, klacht of aandoening die het meest geschikt voor u is.

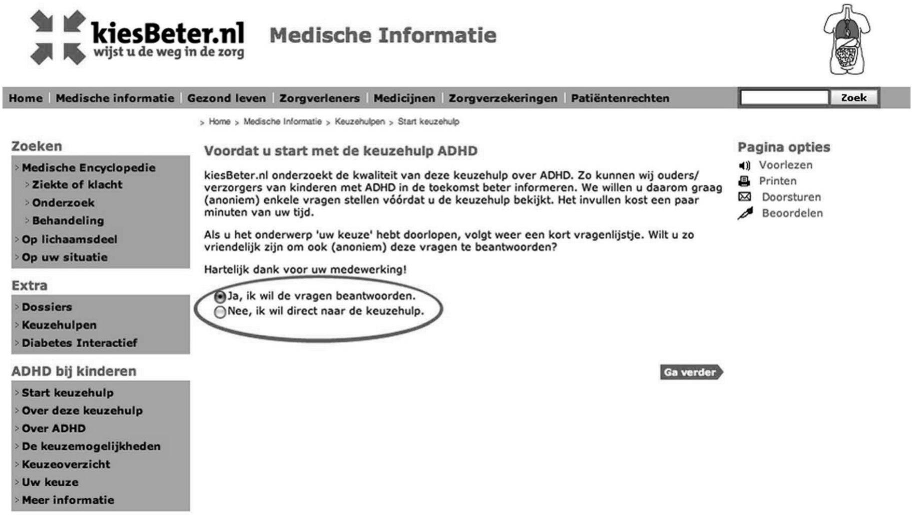
Er zijn keuzehulpen voor:

- ADHD bij kinderen
- Angststoornissen bij volwassenen
- Amandelen
- Borstkanker
- Depressie
- Depressie bij Turkse en Marrokaanse Nederlanders
- Diabetes
- Hart-en vaatziekten
- Hernia in de onderrug
- Klaplong
- Overgangsklachten
- Prenataal screening Downsyndroom
- Testen op prostaatkanker
- Trommelvliesbuisjes
- Verhoogde kans op hart-en vaatziekten

In de toekomst worden meer keuzehulpen toegevoegd:

- Anticonceptie
- Pijn bij bevallen

Figure 1 The log-on screen of the general DA ('Keuzehulpen') starting page



Voordat u start met de keuzehulp ADHD

kiesBeter.nl onderzoekt de kwaliteit van deze keuzehulp over ADHD. Zo kunnen wij ouders/verzorgers van kinderen met ADHD in de toekomst beter informeren. We willen u daarom graag (anoniem) enkele vragen stellen vóórdat u de keuzehulp bekijkt. Het invullen kost een paar minuten van uw tijd.

Als u het onderwerp 'uw keuze' hebt doorlopen, volgt weer een kort vragenlijstje. Wilt u zo vriendelijk zijn om ook (anoniem) deze vragen te beantwoorden?

Hartelijk dank voor uw medewerking!

● Ja, ik wil de vragen beantwoorden.
○ Nee, ik wil direct naar de keuzehulp.

Figure 2 Intermediate page for the DA on ADHD among children ('keuzehulp ADHD')

The convenience sample was taken from parents or caretakers of children (6–18 years old) recently diagnosed with ADHD. They were either referred by schools or by care providers, or found the DA by referrals from websites on ADHD or via search engines.
The data in the present study were collected during a three-month period.

Questionnaires

The first questionnaire started with basic background variables and two exclusion questions about ADHD actually and recently being assessed and about the respondents' experience with the present DA. The semi-structured questionnaires were constructed using O'Connor's work and manuals,[13-15] as well as expert opinion (P Stalmeier, personal communication).

Five valid and relevant constructs were measured in the two questionnaires in order to establish an effect of using the DA. The first is the stage of the decisional process, to determine how far respondents are in deciding about the treatment options for the child in question (e.g. 'Several treatments are available for children with ADHD. Have you thought about a treatment for your child?' with a response on a five-point Likert-type scale). The second is decisional conflict meaning the extent of uncertainty the respondent experiences about making a decision (e.g. 'I know the advantages of every treatment' with a response on a five-point Likert-type scale). The third is knowledge ('Would you please rate your knowledge on ADHD and its treatment possibilities' with a response on a 1–10 numerical scale) as assessed by the respondents themselves. Apart from these decisional constructs, two other features were measured: acceptability, the degree of satisfaction with the (amount of) information and preparation, the extent to which respondents feel the DA contributed to a better preparation for the doctor's visit and for deciding.

The instruments were pre-tested by representative testers in an online environment.

Results

The portal (http://www.kiesBeter.nl) attracted approximately 900,000 unique visitors during the three-month study period. (A unique visitor is usually defined as a visitor logging on from a single IP address and not returning within 24 hours). About one-third of them visited the subsite on medical information. About one-quarter of these, some 75,000 unique visitors, found their way to the DAs (Figure 3). Fewer than 1 in 10 DA visitors visited the DA on ADHD, staying there for about six minutes on average and using 8–9 clicks to navigate (Figure 4). Thus in the 3 months of the study, about 7500 people visited the ADHD page.

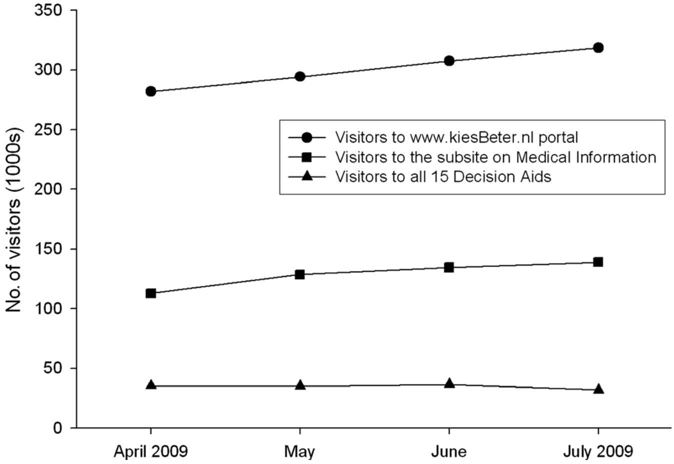


Figure 3 Numbers of unique visitors to the health portal, to the medical information subsite and to all DAs during a four month period.

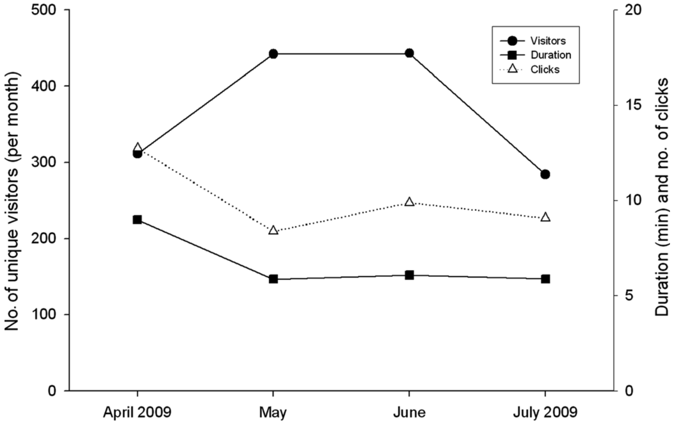


Figure 4 Number of unique visitors to the DA, duration of visit and number of clicks

A total of 195 people completed the first questionnaire (a response rate of about 3%). Only 12 of the respondents to the first questionnaire (6%) completed the second questionnaire (Table 1). Most of them were female, about 38 years of age and of more than average educational background. The children concerned were 6–10 years of age.

Table 1. Background and dependent variables for respondents completing each questionnaire

		Mean values **Q_1 (*n*=195)**	**Mean values** **Q_2 (*n*=12)**
Background variables			
Sex	No. of males (%)	50 (26)	2 (17)
	No. of females (%)	145 (74)	10 (83)
Age	Male (years)	41(6)	39 (4)
	Female (years)	39 (5)	39(3)
	Child concerned (years)	9 (3)	8 (2)
Educational level[a] (SD)		4.7 (1.5)	4.8 (1.8)
Dependent variables			
Stage of decisional process[b]		2.4 (1.1)	2.6 (1.1)
Decisional conflict[c]		68 (26)	55 (30)
Knowledge[d]		6.2 (1.9)	6.5 (1.9)

[a] Educational level was the highest education completed by the respondent, ranging from 1 (primary school) to 7 (academic education)

[b] Stage of the decisional process measured how far respondents were in deciding about the treatment options for the child, on a five-point Likert-type scale ranging from 1 = at the very beginning of the decision-making process ('I haven't given it a thought") to 5 = the end of the process ("I have chosen a treatment for my child and I feel confident about it").

[c] Decisional conflict measured the extent of uncertainty that the respondent experienced about making a decision. The scale was composed of three subscales (Uninformed [3 items, e.g. "I know from which treatment options I can choose"], Values [2 items, e.g. "It is clear to me which advantages are most important for me"] and Uncertainty [2 items, e.g. "I know the disadvantages of every treatment option"] all with five-point Likert-type answers. The scores were aggrgated and recoded on a 0-100 scale where 0=no decisional conflict and 100=full decisional conflict.

[d] Knowledge was measured by self-rating on a10-point scale ("Would you please rate your knowledge on ADHD and its treatment possibilities")

For respondents (*n* = 12) completing both questionnaires, there were no significant differences between them with regard to the stage of decisional process, decisional conflict and knowledge (Table 2). There appeared to be a small, non-significant increase in both decisional conflict and the self-report on knowledge, as well as a small, non-significant decrease of the stage of decision making of the respondents.

The respondents' answers indicated that the DA contributed to better preparation for decisions and facilitated decision-making (63%). Satisfaction with the information received through the DA was moderate, and 60% felt that the information was too limited. The overall acceptability of the DA on ADHD was average (i.e. approximately midway between unacceptable at the one end of a Likert-type scale and complete acceptance at the other).

Table 2. Mean values of the dependent variables from those respondents who completed both questionnaires

	Mean Q_1 (*n*=12)	Mean Q_2 (*n*=12)	z-value	p-value
Stage of decisional process (SD)	2.6 (1.1)	2.2 (0.7)	-1.4	.16
Decisional conflict (SD)	55 (30)	57 (27)	-0.1	.94
Knowledge (SD)	6.5 (1.9)	6.7 (1.5)	-0.1	.89

Coherence, as determined by the correlation coefficient between the three dependent variables appeared to be average to strong (Table 3).

There was moderate correlation between decisional conflict and stage of decisional process, and between decisional conflict and knowledge of ADHD. There was a strong correlation between the stage of decisional process and knowledge. Higher decisional conflict implies that respondents are in the first stages of their decision-making process, and that they possess relatively little knowledge about ADHD and treatment options. When respondents progress in their decision-making process their knowledge of ADHD increases.

Consistency, reliability and internal validity of the constructs built into the questionnaires as measured with Cronbach's alpha appeared to be high (data not reported).

Table 3. Correlation coefficients between the three dependent variables (N=195)

	Decisional conflict	Knowledge
Stage of decisional process	-0.62*	1.00**
Knowledge	-0.62*	-

* p < .05; **p< .01

Discussion

In the present study, the DA on ADHD did not seem to influence transitions of respondents to another stage in their decision-making process. The respondents indicated more decisional conflict and increase of knowledge, although at a non-significant level. They rated the acceptability of the DA, in terms of satisfaction and information needs, at an average level. The observation that most respondents (94%) did not complete both questionnaires suggests that the navigational flow and usability of the online DA may have been too complicated.

These outcomes concern the group of respondents and cannot be generalized. The present study is still ongoing and a substantial increase in respondents may change the strength and direction of the effect. These preliminary results are nonetheless important with regard to the DA on ADHD. It appears that the basic objectives are not sufficiently met. Development of decision support technology is in its initial stage in the Netherlands, although serious steps have been taken that are widely supported by scientific, professional and patients' organizations. Little research has been done with regard to its effectiveness. The emphasis has been on the scientific underpinning of both content and process, while underestimating the importance of the online userexperience. Improvement may be reached by increasing the usability of the DA and its acceptability by users.

Acknowledgments

We thank I.C.J. van Miert, V. Siemers Reiter and F.L.M. Taken (Utrecht University) for their work on data collection, J.J. Colijn (RIVM) for her valuable input and P. Stalmeijer (Radboud University Nijmegen) for his advice.

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Chapter 5

eHealth technological risks

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Ossebaard HC, Geertsma RE & Van Gemert-Pijnen JEWC. Health Technology Trust: Undeserved or Justified? In: Van Gemert-Pijnen JEWC, Ossebaard HC, Smedberg A, Wynchank S & P Giacomelli (Eds.) Proceedings 4th International Conference on eHealth, Telemedicine, and Social Medicine eTELEMED 2012, p. 134-142. Valencia, Spain. Washington: IEEE Computer Society, ISBN 978-1-61208-179-3.

Abstract

Challenges for global health care are considerable. Increasing healthcare expenditures, ageing, the rise of chronic diseases and the public health threat of infectious diseases give reason to worldwide concern. Many believe eHealth technologies to contribute to the solution of these issues and to the necessary innovation of healthcare systems. Is the widespread trust among public administrations, care professionals, researchers and the general public justified? The present paper aims to assess the risks of eHealth technologies for both patient safety and quality of care. A quick-scan of scientific literature was performed to collect publications on risks associated with the use of eHealth applications in cure and care. Only randomized controlled trials (RCTs) were included. Data-management issues were excluded. Of 340 identified publications, 17 met the inclusion criteria. Human, technological or organizational risks appear to be no subject of RCTs. But they come into view en marge implementations. As such, the selected studies suggest there is evidence for risks caused by the use of eHealth in healthcare which can negatively affect the quality of care and the safety of patients. A realistic reconsideration of the implementation of eHealth interventions is recommended. The ceHRes roadmap is an evidence-based guideline to systematically avoid or minimize these risks.

Introduction

Challenges for global health care have been documented extensively. Most countries face a serious increase in healthcare expenditures that corresponds to ageing, a growth in multi-morbid chronic illnesses, the menace of infectious diseases, consumerism or other dynamics [1, 2]. eHealth technologies have frequently been hailed as a panacea for these challenges. These technologies have proven their potential to contribute to the increase of (cost-) effectiveness and efficiency of care, the improvement of the quality of care, the empowerment of consumers, system transparency, and eventually to the reduction of health care costs [3-7]. But expectations have recently been mitigated due to the publication of studies that emphasize the complex nature of innovation in healthcare and the lack of rigid evidence for impact of eHealth technologies on health care outcomes thus far [8, 9]. Moreover, the application of eHealth technologies in healthcare may introduce risks for patient safety and quality of care [10-12]. Nonetheless, trust in information and communication technologies (ICT) seems to remain unaffected by these moderating results. This is remarkable against a backdrop of widespread declining trust in the legal system, in politics, finance, science and other public domains [13, 14]. Public administrations, care professionals, researchers and the general public are generally trustful and overly optimistic about the 'a-political' power of digital technology in virtually all public and personal domains [15, 16]. Investments in ICT are rarely withdrawn because of identified or alleged risks for patient safety or for the quality of care. Where interpersonal trust is an attitude towards others whom we hope will be trustworthy, institutional trust refers to institutions or systems (i.e. the government or the administration of justice) and their trustworthiness [17]. The value of institutional trust lies in its opportunities for cooperation, knowledge, autonomy and other 'social goods' that contribute to the foundations of society [18]. In the case of eHealth technology the question if trust is warranted is socially important as well. Is it plausible, justified and well-grounded to trust technologies that are designed to advance health, safety and care? Are these systems trustworthy themselves? Is adherence related to trust? Trust in and trustworthiness of eHealth interventions are obviously affected by (perceived) risks and lack of knowledge in the long run. Over the last decades studies of risk (and technology) have grown into a major interdisciplinary field of research. Risk researcher Hansson states "When there is a risk, there must be something that is unknown or has an unknown outcome. Therefore, knowledge about risk is knowledge about lack of knowledge. This combination of knowledge and lack thereof contributes to making issues of risk complicated from an epistemological point of view" [19]. Since epistemology is not our focus here we will apply a an internationally accepted definition for risk i.e. “the combination of the probability of occurrence of harm and the severity of that harm” [20]. This definition is also used in the international standard for risk management of medical devices [21] which is the regulatory sector in which part of the eHealth technologies can be classified.

In a recently published study we have reported on flaws and drawbacks of eHealth technologies [22]. This study was based on a comprehensive analysis of eventually sixteen frameworks regarding the development and implementation of eHealth interventions over the last decade (2000-2010). The reported drawbacks may legitimately be conceived as risks since they imply equivalent and immediate hazards for the patient’s safety or the quality of care. Therefore we think it relevant for the present study to provide a short summary of these findings. Table I shows a summary of these risks phrased in conceptual terms.

Table I. Risks derived from previous research*

Conceptual risk	Description
eHealth technology development as an expert-driven process	If project management fails to arrange stakeholder participation in the full development process risks for rejection by (end-)users increase.
eHealth technology development ignores evaluation	If the development is viewed as a linear, fixed and static process instead of a iterative, longitudinal research activity risks of suboptimal outcomes increase.
Implementation of eHealth technology as a post-design activity	If conditions for implementation are not properly accounted for right from the start in all subsequent stages stakeholders may drop out.
eHt development does not affect organization of healthcare	If it is ignored that eHealth technologies intervene with traditional care characteristics and infrastructure unexpected effects cause stakeholders to abandon.
eH technologies as instrumental, determinist applications	If eH interventions ignore users. needs for affective, persuasive communication and information technologies for motivation, self management and support, they drop-out..
eH research fails to integrate mixed-methods and data triangulation	If conventional research methods keep falling short of assessing the added value for healthcare in terms of process (usage, adherence) and outcome variables (behavioral, clinical outcomes; costs) societal and scientific refutation follows.

* Van Gemert-Pijnen et al., 2011 [22]

Precisely the opposites of factors that improve the uptake and impact of eHealth technologies constitute risk for both patient safety and quality of care; they increase the probability of occurrence of harm and the severity of that harm. For further reading we refer to the abovementioned review.
In the present study we seek to validate these outcomes by assessing the nature and prevalence of any risk to patients' safety and quality of care that may be associated with eHealth applications, as established in randomized controlled trials. These interventions include web-based and mobile applications for caregivers, patients and their relatives within a treatment relationship as well as technology regarding quality in healthcare. This provides an inventory of documented risks that impact on quality of care and the patients' well-being. Increasing use of eHealth technology is one of the major developments in today's healthcare [23]. The opportunities of web-based and mobile eHealth technologies should therefore remain central to the global health discourse. At the same time it is required to explore the risks of these technological advancements.

Literature scan

The present desk research involves a literature scan to exploratory assess only those risks that are reliably documented in the scientific literature. The scan is restricted to publications regarding risks that affect the quality of healthcare and the patients' safety. The public health domain is excluded. Issues concerning security of data-transmission, storage, encryption, standardization, data-management and privacy are not included to avoid overlap and redundancy [24]. The search is limited to randomized controlled trials (RCT) to allow for comparisons. No systematic review was performed.

The bibliographic database SciVerse Scopus was searched because of its broad content coverage including 100% coverage of Medline titles and over 16.000 peer-reviewed academic journals. The used search query combined the topic 'eHealth' with search terms regarding risk, healthcare-setting and study design. The complete query can be found in Appendix I. One author reviewed the titles and abstracts of the identified publications to decide whether they should be examined in full detail. Inclusion criteria are: (1) the article deals with an eHealth application and/or (2) deals with risks for (3) quality of care in general and/or patients' safety resulting from the use of the application. Articles describing such risks merely as unintended outcomes were included as long as these risks affect quality of care and/or patients' safety. Articles whose titles contained outcome-measures or evaluation criteria of an eHealth program were included as well. If risks or limitations where explicitly mentioned in the abstract, the article was included. Furthermore (4) articles had to be RCTs published (5) between 2000-2011. Finally (6) only articles written in the German and English language were scanned. An overview of the inclusion criteria is presented in Table II. The study selection process is included in Appendix II.

Table II. Inclusion criteria for the study selection process

Inclusion criteria
1. eHealth application
2a. in Title: outcome-measure and/or evaluation and/or risk
2b.in Abstract: risk and/or limitation found
3. Quality of care and/or patients' safety/well being
4. Design: Randomized controlled trial
5. Publication year: between 2000 – 2011
6. Language: German or English

Identified risks were structured according to a multi-level approach covering risks dealing with either human factors (patient), technology factors or organizational factors, referring to the framework for health information systems evaluation as proposed by Yusof et al. [25].

Outcomes

Study characteristics

The search was performed in SciVerse Scopus in July 2011 delivering initially 340 potentially relevant publications. Of these, 17 were eventually included after the selection procedure described sub II.

Multi-level risks assessment

Human, technological or organizational risks appear to be no primary subject of the RCTs identified in the search. However they emerge as secondary effects or unintended outcomes of eHealth technology implementations. Identified risks have been structured with regard to their primary occurrence at a human level, a technological level and organizational level.

1) Risks concerning Human factors

Masa et al. [26] compared conventional spirometry to online spirometry with regard to outcome measures like forced vital capacity, quality criteria (acceptability, repeatability) and the number of maneuvers and time spent on both of the two procedures. They found that the number of spirometric maneuvers needed to meet quality criteria was somewhat higher in the online mode as compared to conventional spirometry. Online spirometry also took more time for patients (mean differences of 0.5 additional maneuvers and 0.7 minutes more). Higher time-consumption may also negatively affect the remote technician instructing the patient while the latter uses the spirometer. The spirometric values achieved online were very similar to the values achieved by conventional spirometry.

Some eHealth applications appear to be more beneficial for specific patient groups. Bujnowska-Fedak et al. [27] tested a tele-homecare application for monitoring diabetes. Older and higher educated patients, spending a lot of the time at home and having acquired diabetes recently, benefited most from the application. A positive association was found between educational level and ability to use the tele-monitoring system without assistance. Spijkerman et al. [28] evaluated a web-based alcohol-intervention without (group 1) and with (group 2) feedback compared to a control group in order to reduce drinking behavior in 15-20yrs. old Dutch binge-drinkers. They found that the intervention may be effective in reducing weekly alcohol use and may also encourage moderate drinking behavior in male participants over a period of 1-3 months. The intervention seemed mainly effective in males while for females a small adverse effect was found. Women following intervention group 1 were less likely to engage in moderate drinking and had increased weekly drinking a little, although significantly ($p=.06$; 1.6 more drinks/week), at one month follow-up. Zimmerman et al. [29] performed a secondary analysis on data from an RCT on a symptom-management intervention for elderly patients during recovery after coronary artery bypass surgery. They found that the intervention had more impact on women than on men for symptoms such as fatigue, depression, sleeping problems and pain. Regarding measures of physical functioning no gender differences were found. Cruz-Correira et al. [30] tested adherence to a web-based asthma self-management tool in comparison to a paper-based diary. The tool was designed to collect and store patient data and provide feedback to both patient and doctor about the former's condition in order to support medical decision making. Patients. adherence to the web-based application was lower than in the control group. Willems et al. [31] tested a home monitor self-management program for patients with asthma where data such as spirometry results, medication use or symptoms were recorded. They found a low compliance of participants with the intervention protocol. Participants in the intervention group recorded in average less PEF tests (peak expiratory flow; lung function data): 1.5 per day versus the required number in the protocol of 2 tests per day. Verheijden et al [32] tested a web-based tool for nutrition counseling and social support for patients with increased cardiovascular risk in comparison to a control group receiving conventional care. The authors found that the uptake of the application in the intervention group was low (33%) with most participants using the tool only once during the 8 months study period. Patients properly using the intervention were significantly younger than those who did not. Morland et al. [33] compared an anger management group therapy for veterans delivered face-to-face versus via videoconferencing. Group therapy via videoconferencing teleconferencing seemed effective to treat anger symptoms in veterans. While no differences could be found between the two groups regarding attendance or homework completion, the control group reported a significant higher overall group therapeutic alliance than the intervention group. Postel et al. [34] evaluated an eTherapy program for problem drinkers, where therapist and patient communicated online to reach a reduction of alcohol use, as compared to a control group receiving regular information by email. While effective for complying participants, they found high drop-out rates in the eTherapy group though quitting the program did not automatically mean that the participant had also relapsed or increased alcohol consumption. Ruffin et al. [35] tested a web-based application where participants received tailored health messages after giving information about family history of six common diseases. In the intervention group the authors found modest improvements in self-reported physical activity and fruit and vegetable intake. But participants also showed a decreased cholesterol-screening intention as compared to the control group who received standard health messaging.

In summary, higher time consumption, unintended adverse effects, and selective benefits differing for sex, education, age and other variables are the risks observed on the side of the human (end-)user. Frequently adherence (or compliance, drop-out, alliance, up-take) is mentioned and associated with a negative impact on the intended effect of an intervention.

2) Risks concerning Technology

Evaluating a tele-homecare application for monitoring diabetes Bujnowska-Fedak et al. [27] observe usability problems among participants; 41% of them (patients with type 2 diabetes) were unable to use the system for glucose-monitoring needing permanent assistance. Patients who could easily use the application derived a greater impact from its use. Nguyen et al. [36] evaluated an internet-based self-management program for

COPD patients but discontinued before the sample target was reached due to technical and usability problems with the application. Participants stated at the exit interview that decreased accessibility, slow loading of the application, and security concerns prevented them from using the website more frequently. Participants reporting usability problems had to complete (too) many actions on a PDA-device before being able to submit an exercise or symptom entry. Other problems dealt with limited wireless coverage of the PDA. The technical problems decreased participants' engagement with the tools. Decreased engagement was associated with the number of web log-ins and the exercise and symptom entered via the website and/or the PDA. While evaluating a web-based asthma self-management tool Cruz-Correira et al. [30] found nine patients reporting problems (19 in total) related to the use of a web-based self-management tool. Most problems concerned the internet connection and the graphical user interface. Two of the patients could not even use the application because of technical problems. Demaerschalk et al. [37] tested the efficacy of a telemedicine application (vs. telephone-only consultation) for the quality of decision making regarding acute stroke. They found technical issues in 74% of telemedicine consultations versus none in telephone consultations. The observed technical problems did not prevent the determination of treatment decision but some did influence the time necessary to treatment decision-making. Jansà et al. [38] used a telecare-application for type 1 diabetes patients having poor metabolic control to send glycaemia values to the diabetes team. They found that 30% of team-patient appointments were longer than expected (1h vs. 0.5h) due to technical problems with the application. Technical problems concerned the inability to send results of counseling caused by problems with the application itself, the server or internet-access. Using a telemanagement application for diabetes patients Biermann et al. [39] found that 15% of the participants had difficulties in handling the application, the consequences of which were not elaborated. In a study of an asthma self-management telemonitoring program by Willems et al. [31] 1/3 of participants experienced technical problems, mostly with malfunctioning devices. Practitioners had to contact patients e.g., regarding a missed data transfer leading to logistical problems.

In summary, a variety of issues have been reported at the technology level affecting patient safety or quality of care. They range from usability problems and security issues to problem with accessing the server or malfunctioning devices.

3) Risks concerning Organization

Copeland et al. [40] tested whether a telemedicine self-management intervention for congestive heart failure (CHF) patients could be effective in terms of improving physical and mental health-related quality of life and cost-effectiveness as compared to a control group receiving usual care. They could not find substantial differences between groups, but overall costs related to CHF were higher for the intervention group. The authors state that this might be related to the intervention encouraging medical service utilization by facilitating access to care.

One tele-management application for diabetics allows patients to measure their blood-glucose values and send it to their care provider [39]. Though time-saving for patients, use of the application lead to 20% more time investment (50 vs. 43 min. per month over a 4-month period, and 43 vs. 34 min. per month over an 8-month period) on the side of the care provider compared to conventional care. The higher time expenditure did not reflect time necessary to manage the application itself: it was due to more access to the provider, so that patients tended to call more often. Montori et al. [41] also found a comparable risk concerning time-consumption. They tested a telecare-application for data-transmission for type 1 diabetes patients. The nurses needed more time reviewing glucometer data (76 min. vs. 12 min.) and giving the patient feedback (68 minutes vs. 18 minutes) in the telecare condition as compared to the control group. The authors found more nurse feedback time to be significantly associated with more changes in insulin doses; more changes of doses thus appeared in the telecare group.

Strayer et al. [42] tested a personal digital assistant (PDA) as a tool for improving Smoking Cessation Counseling (SCC) against a paper-based reminder tool. In semi-structured interviews medical students providing SCC reported that they felt barriers for using the PDA in practice such as a lack of time or a lack of training. Also they felt uncomfortable to use the PDA in the presence of patients. The PDA tool did not increase key SCC behaviors of the participants of the intervention group as compared with the paper-based reminder.

In summary, increased time consumption, barriers for proper use and financial issues are the risks observed at the organizational level.

Conclusion

RCTs of the immediate risk of eHealth technology for patients. safety or quality of care have not been found. Risks emerge as unintended, secondary outcomes in the margin of studies aiming to evaluate the effectiveness of eHealth interventions. The selected studies suggest nonetheless evidence for risks at all three levels of the multi-level approach applied. Ten studies mention risks concerning the patient at the human level, especially where adherence issues lead to suboptimal use of an intervention and corresponding low effectiveness. But also adverse effects were reported, as well as the fact that not all patient groups can equally benefit from an eHealth intervention. Issues at a technological level were found in seven studies, revealing considerable rates of usability problems, limited access or other technical problems. Organizational issues were found with regard to higher use of resources (time, money, staff) affecting quality of care in two studies. Table III shows the level and nature of the risks observed in our study.

Table III. Observed Risks

Risk level	**Description**
Human level	Adherence (or compliance, drop-out, alliance, up-take)
	Unintended adverse effects
	Selective patient benefits (sex, education, age and other variables)
Technology level	Usability problems
	Access
	Security issues
	Malfunctioning devices
Organizational level	Higher time consumption
	Barriers for proper use
	Higher costs

In some cases the causes of the risks were qualified as study (design) artifacts. In many instances the consequences have not been elaborated.

Discussion

Risk is a complicated epistemological issue that refers to a lack of knowledge along subjective and objective dimensions. Trust is an important social good. But trust is risky. The observed lack of academic interest for risk assessment in eHealth technology should be a matter of concern. Patient safety and quality of care deserve a high level of risk awareness when it comes to new technologies. At present risks emerge in the margin of RCTs in eHealth. They are conceived as problems, issues, disadvantages, costs or other designations that one way or another affect human, technological or organizational functioning in a detrimental manner.

Though both quantity and quality of the reported issues do not seem disturbing at first glance, a wider search would almost certainly deliver a more disquieting range and diversity of risks. Given the outcome of our study that none of the RCTs were designed to study risks, we must conclude that they do in fact not represent the studies with the highest evidence level related to our research question. Therefore, a follow-up search, including review articles, controlled clinical trials, and perhaps also observational studies should be performed. Furthermore, in databases such as MAUDE (Manufacturer and User Facility Device) of the U.S. Food and Drug Administration, in grey literature, articles in professional magazines and other (online) sources of different organizational, consumer and academic nature a variety of incidents involving risks have been recorded[1]. While often viewed as avoidable or improvable intervention flaws or explained as study (design) artifacts they should not be played down. Their presumed prevalence and incidence give rise to reconsideration when it comes to exploring the opportunities of web-based and mobile eHealth technologies for global healthcare innovation.

This reconsideration implies the need for extensive research that explicitly focuses on establishing the volume and nature of such risks. It also implies an improved way of monitoring to advance transparency in the reporting of risk prevalence and safety incidents. Finally it implies a higher level of healthcare risk management, continuity of care and understanding of how risks affect patients through risk identification, operating ways to avoid or moderate risks and developing contingency plans when risks cannot be prevented or avoided.

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[1] Risk analyses of these and other sources will be published in 2012.

The results of the present scan are in accordance with outcomes from the ceHRes study that covers over a decade of eHealth technological development [22]. The 'conceptual' risks (Table I) represent the same categories of risks that result from the literature study. For instance expert-driven eHealth interventions that neglect the essential role of patients lead to adherence issues mentioned sub B1). Or disregarding conditions for implementation imply underestimating issues such as time-consumption mentioned sub B3). To minimize and avoid such risks a 'Roadmap' has been developed to design, develop, implement and evaluate eHealth interventions (see Appendix III). It uses concepts and techniques from business modeling and human centered design [43]. The roadmap serves as a guideline to collaboratively improve the impact and uptake of eHealth technologies. For this purpose it is published as a wiki (ehealthresearchcenter.org/wiki/).

For now the ubiquitous trust in technology seems unjustified and needs to be put in perspective to be deserved. We have the instruments and the knowledge to reconsider the implementation of eHealth to achieve this. Until then present stakeholders should be aware to minimize such risks ex ante. But at the end of the day it is the acceptability of a risk that determines the necessary course of action.

Acknowledgments

Under its 2011 Work plan (Domain Drugs and Medical technology; theme: information- and communication technology), the Dutch Health Care Inspectorate commissioned the National Institute for Public Health and the Environment (RIVM) to conduct this study of which we here present the first outcomes. It was carried out in collaboration between the Centre for Biological Medicines and Medical Technology and the Centre for Public Health Forecasting (RIVM), the Center for eHealth Research (IBR Institute for Social sciences and Technology, University of Twente). We thank ms. Fabiola Mueller for her work in data collection and mr. Adrie de Bruijn for his input in discussions about the subject of this study.

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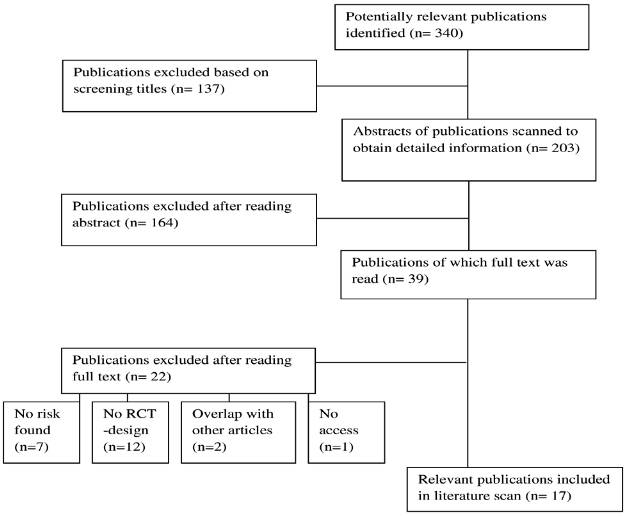
Appendix I

Search query used in SciVerse Scopus

(TITLE-ABS-KEY(ehealth OR e-health OR “e health” OR etherapy OR e-therapy OR “e therapy” OR emental OR e-mental OR “e mental” OR telemedicine OR telecare OR teleconsult OR telemonitoring OR telehealth OR teleconference OR “health information technology” OR “web based”) OR TITLE-ABS-KEY(“internet based” OR “web application” OR domotica OR ìpersonal digital assistantî OR ìpdaî) AND TITLE-ABS-KEY(risk OR risks OR danger* OR threat OR threats OR limitation* OR barrier* OR problem* OR concern* OR challenge OR challenges OR ìadverse effect*î OR quality OR drawback OR drawbacks) AND TITLE-ABS-KEY(health OR care OR ìhealthcareî OR healthcare) AND TITLE-ABS-KEY(“randomized clinical trial*” OR “randomised clinical trial*” OR “randomized controlled trial*” OR “randomised controlled trial*” OR rct OR “RCTs” OR experimental)) AND PUBYEAR AFT 1999 AND PUBYEAR BEF 2012 AND (LIMIT-TO(LANGUAGE, “English”) OR LIMIT-TO(LANGUAGE, “German”))

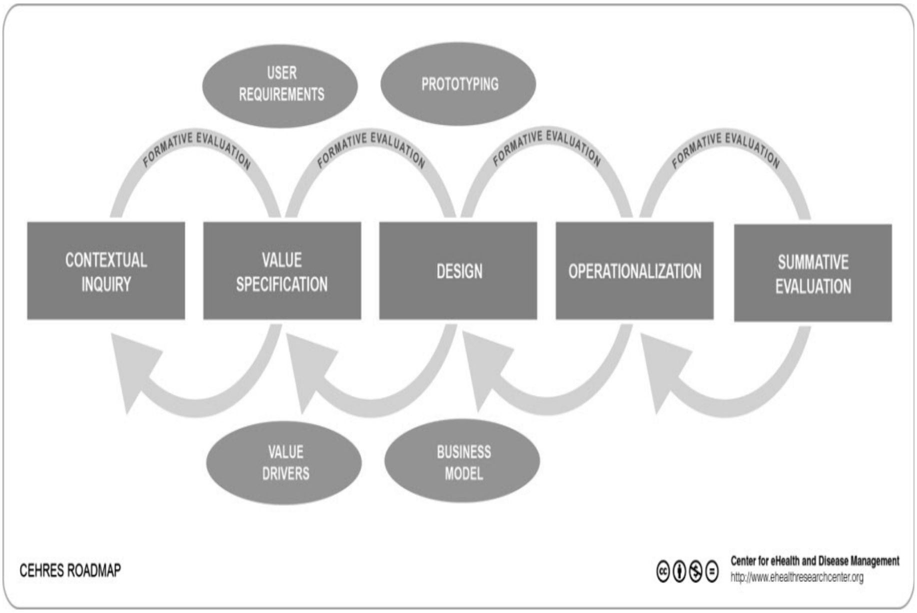
Appendix II

Study selection process



Appendix III

ceHRes Roadmap to improve the impact of eHealth interventions



Chapter 6

eHealth credibility

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Van Gemert-Pijnen JEWC, Wynchank S, Covvey, HD and Ossebaard HC Improving credibility of electronic health technologies Bull World Health Organ 2012; 90:323-323A.

Abstract

eHealth technologies have the potential to help improve health processes and their safety, quality and efficiency on a global basis. However, the successful realization of eHealth in daily practice lags behind expectations in high and low resource countries. The credibility of eHealth can and should be enhanced by improving interventions through a holistic approach and continuous medical education.

Geissbuhler & Al-Shorbaji's [1] call for papers represents a watershed in the development of eHealth interventions. Global healthcare delivery is in need of innovation [2]. Although degrees of urgency vary regionally in the face of rising healthcare expenditures, demographic trends, the threat of infectious diseases, consumerism and the growth in multi-morbid diseases, the necessity for innovation is an undisputable fact. eHealth technologies have often been hailed as a panacea for these challenges. The World Health Assembly's resolution of 2005 acknowledged eHealth's potential to enhance health systems and to improve the safety, quality and efficiency of care [3]. eHealth should, furthermore, improve health equity as a consequence of its ability to ease access to information and health services. However, the successful realization of eHealth in daily practice lags behind expectations. Studies confirm the complex nature of healthcare innovation and the lack of rigid evidence of the effects of eHealth technologies on health care [4]. Why is this so and what we can do about the cynicism regarding eHealth today?

Definitions of eHealth have been around since 1999 [5], a time-frame characteristic of conceptualizing any new field of health interventions. Here we would like to address how the classic approach to eHealth development has affected its credibility in both high and low resource countries. The classic model of eHealth development can be characterized as a technology-driven approach, viewing eHealth merely as a technological intervention. This has led to the design of stand-alone devices and applications. In daily practice, these proved difficult to implement as they ignored the complex interactions of humans, human health, health care and technology. The classic eHealth model also slowed the diffusion of innovations into care. Innovation requires investment in education and training, focusing on *how* and *why* technology can ensure better, more efficient health care, rather than concentrating on specific applications. Innovation also means developing better approaches to reimbursement, instituting new governance that, for example, emphasizes patient engagement, self-management and home-care, while respecting how technology influences professionals' and patients' personal routines. again neglected matters. The fallacy that implementing eHealth is a one-step process and not a continuous one forces organizations to budget for development and implementation and maybe a little maintenance. But then the input flags and the organizations expect nothing but benefits. A consequence is often financial disaster (due to precipitous action, unsustainability and unachievable deadlines), resistance to further change, unused or misused technologies, and stakeholder dissatisfaction because expectations were never really met [6]. No wonder many evaluations are disappointing, let alone that classic evaluation methods (like RCTs) are, in fact, inappropriate for assessing eHealth interventions.

The suboptimal impact of eHealth and the rapid proliferation of emerging technologies demanded a new approach, defying the classic eHealth model. A new ëholistic' view considers eHealth as a way to reform health care by creating an infrastructure for participation [7]. This social and technological infrastructure displaces traditional division of labour and the time/place-dependent delivery modalities. Contemporary eHealth grounds itself in strategic, innovative and multidisciplinary approaches that enable the reinvention of health care. It makes new approaches to management, human resources utilization and thinking about how to better deal with complexity in global healthcare.

Based on experience and research, we have constructed a holistic perspective on what is needed in the international evidence base to crank up eHealth's credibility:

- To achieve optimal levels of healthcare delivery we must focus on the integration of traditional care with IT-based care, and addressing policy barriers. Doing this, we will see how to avoid waste (duplicated administration, high costs and high drop-out) and how to enable the transformation from high-cost hospital care to low-cost primary/ community care and prevention.
- To achieve high quality, patient safety and efficacy of care, we must focus on persuasive eHealth systems that increase adherence and reduce costs for people with complex health and social care needs. We must also develop and implement eHealth curricula for medical and nursing schools, facilitate ëcontinuing medical education' and tele-learning, and increase interdisciplinary collaboration in health informatics programs [8].
- To enable accessible care, we must focus on transparency and accountability, implement adequate business models for eHealth and develop and use process, productivity and outcome indicators.
- To realize evidence-based eHealth interventions, we must collaborate internationally (e.g., eHealthwiki.org) to evaluate the process, outcome and financial impacts of eHealth- interventions thereby providing evidence-based indicators that can guide investment in eHealth.

These are the main elements for the eHealth evidence base to restore credibility. Further evidence for the credibility of eHealth arises from experience in developing countries. There the emphasis is on eHealth projects to aid public health services for the many socio-economically deprived persons living in remote rural areas with poor infrastructure, often far any medical service. Such health services are usually village clinics run by nurse-practitioners. Tele-consultations save transportation costs and providing other clear benefits, including gaining experience from repeated tele-medical consultations with specialists and other healthcare professionals related to common pathologies. HIV/AIDS-telededermatology is a good example of this. Over 90% of AIDS patients have skin problems that are often the infection's first manifestation; their nature and degree can allow determination of the infection-stage. In South Africa, with one of the world's largest pools of infected persons, increasing teledermatological experience has resulted in competent, referral-free local management of many HIV-associated skin problems [9]. There are also numerous examples of successful, conventional tele-education programs for healthcare workers in developing countries [10]. Both these practices have enhanced the credibility of eHealth in developing countries, augmented by the impacts seen with telesurveillance.

On the other hand, the implementation in developing countries of eHealth technologies designed for developed countries has entailed multiple problems due to the mismatch of the local infrastructure, habits and rituals in developing countries. Therefore, it is essential that local users develop eHealth interventions. Especially when projects are aimed at disease management (e.g., in China, Brasil and India), the health system should be transformed from being ëdisease-centered' to 'people-centered'; and the core of health services should be changed from ëinstitutional care' to 'community and home-based care'. Obviously, eHealth technologies that mesh with community and home care should be explored and used congruently. This significant transformation requires corresponding changes in operations, clinical thinking and treatment. More medical staff should work in the community, health finances should be supportive of the community and home-based care, medical staff should be trained in other formats of care treatment, and policy, administration and operation should be re-engineered accordingly.

Innovations, even disruptive ones, take time to diffuse. But recess is over and we must recapitulate the lessons learnt. A *holistic approach* is needed, wherein all stages of development are evidence-based using sound knowledge to achieve technologies that are people-centered, fit-for-context and that have added-value for all stakeholders. A holistic view involves a focus on how people live their lives within their own environments, a focus on the persuasive capabilities of technology to support this and a concentration on stakeholders' needs and interest in improving their care. Peoples' needs must be a principal concern, as is clarity regarding financial responsibility for subsequent interventions. The recent debate on a new definition of health [11] emphasizes the value of self-management in the 21st century. Health: This is precisely what eHealth interventions can support. eHealth should be appraised in terms of meaning, responsibility, participation and sustainability. Not *more* research necessarily, but rather *better* research, is crucial.

Technological and social innovation can go hand-in-hand and the capacity for innovation is growing in some developing countries. This, together with local public-private R&D partnerships, may represent the only sustainable means of improving health systems' effectiveness in developing nations [12]. The potential of eHealth is far from being realized, but its proven successes justify faith. However today's requirements are that eHealth's credibility and its ability to enable and track change need to be increased and substantiated to support the six-point WHO agenda [13].

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Discussion

In the Preface to a recent report published by the United States Institute of Medicine, Mr. Gail Warden, Chair of the Committee on Patient Safety and Health Information Technology, writes:

> *"Technology - which has the potential to improve quality and safety of care as well as reduce costs - is rapidly evolving, changing the way we deliver health care. At the same time, health care reform is reshaping the health care landscape. As Sir Cyril Chantler of the Kings Fund said,*
>
> > *"Medicine used to be simple, ineffective, and relatively safe. Now it is complex, effective, and potentially dangerous."*
>
> *More and more cognitive overload requires a symbiotic relationship between human cognition and computer support. It is this very difficult transition we are facing in ensuring safety in health care. Caught in the middle are the patients - the ultimate recipients of care."*
> (IOM, p. ix, Aug. 2011)

Although health care conditions in Europe differ greatly from those in the United States, a comparable transition is taking place in the Netherlands (Schäfer et al., 2010). The aim should indeed be a safe and patient-centered health care system that is effective, efficient and equitable. Agreement exists on the necessity of redesigning the health care system and the role of technology in this process (Smith, 2008). The Netherlands is one of the most 'tech-savvy' countries of the world when it comes to IT-infrastructure, availability, connectivity, adoption, use, and other parameters of technology acceptance. As such it is an ideal testing ground for technological innovation in health, health care and public health. However, health care ICT expenditures are relatively low compared to other industries (Idenburg & Van Schaik, 2010). Innovation in health care is nonetheless driven by eHealth technologies. The ways in which users interact with these technologies will eventually determine the success of this transformation.

The studies conducted for this thesis reveal some major issues that are relevant to social scientific research into how technology can support health care innovation and human health. To summarize what has been found we return to our central question about the added value of different eHealth technologies in terms of their informational, transformational or communicational qualities. What factors account for uptake and impact of eHealth technologies and how could value of the interventions that were studied be increased?

A *sine qua non* for the uptake and impact of technology are the values technology represents within the ecosystem of stakeholders. The issue of value creation is the premier starting point for any eHealth technology implementation. In terms of business modeling, the added value is identified at an early stage by aggregating " all value needs bottom-up from the stakeholders, and, through dialogue, (…) co-create a fit between all the values that will become the overall expected value of the eHealth technology" (Van Limburg et al. 2011, p.5). This is a process of sense-making. The respective studies in this thesis show that this vital condition is often not sufficiently fulfilled. It is precisely this issue that should be the main target for improvement for the technologies in this thesis: a systematical, recurring process of stakeholder-focused and value-driven re-design to increase effectiveness and sustainability. This sensitive and complicated venture is worth undertaking. The value-creating process, embedded in both human-centred design and business modeling, is a relatively novel approach the necessity of which is demonstated by the findings in this thesis. In spite of their critical nature, the different studies carried out have led to a constructive perspective on contextual eHealth technologies which is elaborated further in the last chapter. What do the outcomes mean for iHealth practice, policy and research?

1. The experimental study with regard to the 'brain machine' illustrates that if a complex concept such as stress or relaxation is operationalized for study, some important features are lost. In order to study a phenomenon a certain amount of reductionism is unavoidable, but this implies a simplification that renders results that are not useful in practice. A technology cannot be reduced to a causal factor that automatically induces relaxation or reduces stress. This determinist claim for better health had to be rejected in this study. The capacities of this specific, new technology to help people relax are most likely either overstated or biased. Relaxation is not the same as the presence of alpha waves as registered by EEG. There are most likely interpersonal differences with respect to (the stability of) burn-out dimensions, or the baseline responsiveness to audiovisual 'entrainment'. Technology characteristically interacts with people's psychological, social and biological make-up, their daily lives, the setting in which it is used. Their expectations are projected onto it; we perceive what we expect to perceive. This is why some repondents felt nervous and uneasy while others felt high-minded and relaxed. The considerable drop-out in the quasi-experiment may be attributed to low motivation caused by non-fulfillment of the expectation. End-users were expecting a transformative value of this new technology in terms of relaxation, distraction or stress reduction: without much ado they hoped to accomplish this during working hours. Realization of this value was not achieved in their view. On average, it generates little or no added-value in terms of information or

transformation.. The 'brain machine' is an example of technology that was developed *without* the end-user in mind. The outcomes suggest that the major claims with respect to specific, relaxing qualities attributed to this technology cannot stand the test of time, although pleasant short-term effects do occur.

The introduction of new technologies in health is usually embedded in a process of domestication. Domestication is a concept from the sociology of technology, and from media and communication studies, that is used to describe and analyse the acceptance, rejection and use of new technologies. It refers to what happens when new and 'strange' technologies are introduced. They have to be 'tamed', i.e., "(..) they have to be integrated into the structures, daily routines and values of users and their environments" (Berker, Hartmann, Punie & Ward, 2006; p. 3). If this daily interaction works out succesfully these technologies become part of everyday life as functional and/or symbolic tools. Such a domestication process is almost always open-ended. It is not certain that a given technology will be adeopted or in what form it will be accepted. It takes time to make sense, i.e., to identify the values that matter. In households, in everyday life or in the streets this has its own dynamic, but in health care the process can be managed to a certain extent. In health care an environment is created that is mediated by technologies. When these are adapted to meet the changing needs of users, the constitution of the health care organization or the care setting domestication can be followed by re-domestication or even de-domestication. This also depends on the maturity of the technology itself. Now that 'perpetual beta' seems to be the customary standard in technology development, it must be acknowledged that technologies have to be in use for some time to remove or reduce initial errors. This is a necessary condition for acceptance and adoption, especially for critical technologies in health and health care (Wears & Berg, 2005). The rate of new breakthrough advances in eHealth is still very high with rapid and diverse innovations. In order to mature a substantially longer time horizon should be expected to achieve use meaningful of eHealth technologies. This would create more room for value creation in terms of information, communication and transformation and contribute to a better uptake of technology.

The domestic environment is increasingly mediated by technology as well. For eHealth technology implementation, domestication is a process that must be taken into account, especially as "health care is going home" (Landers, 2010). If this is managed carefully from the perspective of patients and other stakeholders it will result in a comfortable and trustworthy usage of iHealth, i.e. persuasive and contextualized eHealth technology.

If not, it will be regarded as a lifeless, unresponsive, difficult ‘thing’ causing stress, discomfort and ultimately non-compliance.

2. The introduction of the health care portal was a top-down, large-scale policy decision that was hardly informed at all by the intended end-users. It is theoretically plausible that this explains why the majority of users do not feel supported in their decision-making process, only half of them find the information ‘useful’ and 50% do not find the information sought for. The overall impact of use on their choice behavior, awareness, or empowerment most probably remains small. In the case of decision technology we see that while patient groups were involved in the development of content for the decision aids, this did not lead to the intended user-friendliness, on the contrary it led to a dramatic attrition and hardly any added value in terms of tailored-information or empowerment. This is also due to the proto-professionalization of patients that took part in the pre-test period. Nevertheless of overriding importance is the absence of co-creation during the technical construction of the decision aids and the choice to position them outside the setting of a doctor-patient relationship onto a public portal.

eHealth technology, such as a web-based solution to communicate comparative health information to an audience of laymen, is a long-term, costly endeavour. Increasing adherence and health impact of online applications remains a matter of permanent concern (Schneider, Van Osch, & De Vries, 2012). To improve adherence, persuasive elements should be introduced to construct a choice architecture that affects complex choice behaviour. In our studies we have tried to find out about this. What defines the added value for users is the ease and effectivity of online decision-making support in health and health care. This could be improved and informed by repetitive, usability research. The roles of patients have changed and will further change under the conditions of managed competion in the Dutch health care system. Today, they are supposed to seek information on health insurers and care providers and weigh up and compare the results with regard to their preferences. We still have a long way to go to understand how this works. Qualitative, interpretative research on how people actually use technology to support their decision-making would provide further meaning and signficance to quantitative data and should be endorsed (cf. Greenhalgh & Swinglehurst, 2011).

To account for the efficacy and effectiveness of a health policy instrument such as kiesBeter.nl, objectives must be quantified in measurable terms. In the case of kiesBeter.nl, which was originally launched to influence complex behavioral and cognitive variables, this might have been possible if objectives had been formulated in more modest terms. If online quality information is not available, if it is insufficiently represented, or if it is produced in a questionable way, transparency cannot be realized. Transparency as it is currently promoted might not even be such a desirable value. Recent research among citizens reveals that the majority (60%) would not themselves seek out a hospital or medical specialist if they were referred to one by their GP (Reitsma, Brabers & De Jong, 2012). The main reason they gave for this is that they already knew were to go. Nevertheless, many people find it difficult to choose; they do not know what should guide their choice, where to get information, how to weigh up the information they receive, or how to judge its reliability. And so they rely on their GP for advice, or on their past experience with a specialist/hospital, or they simply chose the nearest option. Of the 40% that indicate they seek out information themselves, most (55%) use their GP as their primary source, followed by friends and relatives (43%), or their health insurer (23%). Their final stage of decision-making is also supported by these sources, much more than online sources with (comparative) choice information such as kiesBeter.nl (16%). This suggests that the active, comparing and selecting health care consumer is not (yet) a full-blown reality in the Netherlands. The impact of his or her choice behavior on competition and prices in health care will be negligible. Value creation for health care consumers requires further research. Transparency seems to be a top-down transferred value. But things take time, as is evident from the stakeholder-driven implementation of the Consumer Quality Index (Hopman, De Boer & Rademakers, 2011). Quality information and transparency is only useful if they have an owner and an address to serve the relationship with customers, consumers or citizens. It is a matter of public interest to provide objective information about the quality of care. iHealth technology can contribute to its accessible disclosure.

3. Independent of developments in eHealth technology, usability remains the number one subject in mediating iHealth technology. It is concerns the closeness of the match between users, technology and the environment. Its importance cannot be overestimated. It is the psychological value of user-experience and user-perception that counts in the relationship with an individual customer. People-centered approaches are therefore the only way to continuously improve usability in order to avoid drop-out and to encourage adherence. There is no point in designing technology that is underused. The informational and usability needs of patients in our study can actually only be met in a personalized and interactive way. In health care and consumer health informatics, the patients' perspective is indispensable for usability and attention for this should be a continuous concern. If not, the 'law of attrition' (Eysenbach, 2005) applies and the willingness-to-return decreases, as is illustrated by our study of the decision aid for ADHD. This is not a new finding, but it needs to be emphasized.

Online decision technology is in its infancy in the Netherlands despite its potential to support patients' decision-making as part of a wider process to advance shared decision-making (SDM). This is an approach whereby health care professionals and their patients communicate seriously when it comes to medical decision-making. For that they draw on medical guidelines and fully respect the patient's perspective and autonomy (Charles, Gafni, & Whelan, 1999). This transformative process is of increasing importance; see for example the influential Salzburg Statement on SDM (British Medical Journal, 2011), the call in an Editorial of *The Lancet* (2011) to take this seriously, or a recent output by the Dutch Council for Public Health and Health Care to recognize SDM as a standard for 'good care' (cf. RVZ, 2012). Decision aids can tentatively be assumed to contribute to adherence to drug treatment and life-style interventions (Stalmeier, 2011). But many questions remain unanswered as to how the process of decision-making actually takes place. It may be fuzzy, even irrational, calculated, ethical or social in nature. But at the end of the day we still do not understand the process sufficiently. Although patient decision-making can be supported in a variety of other ways, the importance of iHealth technology is obvious. The seventeen online decision aids that are currently being disclosed on the national health portal kiesbeter.nl have gradually been improved using the outcomes of usability research. They are increasingly being accessed via mobile devices. However, they run the risk of becoming orphaned when the portal has a different role assigned to it in 2013. As of now there is no funding available to produce new decision aids, nor for up-dating the content and solving the usability issues of the existing ones. Online patient decision aids should be therefore adopted by health insurers and the use of decision aids should be embedded in medical education and training and in health care delivery itself. But a clear implementation and research agenda is still missing for SDM (Van der Weijden et al., 2011). The recently launched Dutch Platform for SDM should be able to respond to this and preserve and extend the current body of empirical knowledge on the devlopment of decision aids in the Netherlands.

4. An urgent issue in patient safety and quality of care is the management and control of risks. These concern in fact the premier values of health care for all stakeholders. It is increasingly brought to the forefront of discussions on innovation and technology. Now that information and communication technologies merge with medical technologies, risk management in all phases of a technology's life-cycle and in all phases of the care process, deserves greater attention. From our study it appears that we know more about the nature of risks than about the frequency and scale of their occurrence. We know what may happen, and what has happened, at the level of human action, at the level of technology itself and

at the organizational level. But we hardly know anything about how often it happens, what the magnitude is and what the precise consequences are at different levels. A recent assessment by the Dutch Health Care Inspectorate adds to this the risks posed to patient care which are related to one prominent area of eHealth technologies: namely, the use of ICT to transfer patient information (IGZ, 2011). The most severe risks seem to be caused at nodes in the networks of information exchange between various health care providers, irrespective of whether or not they rely on ICT applications. Patient information is often incomplete or not available at the right moment for the right persons in the health care chain. Though a shared value, trust in technology is not self-evident in these respects. Since health care providers offer more and more technological solutions, increasingly also for the purpose of self-management and for the home environment, risk management should be formally controlled to avoid non-adherence and categorical unsafety. This could be done by constructing one or more new quality indicators for eHealth technology for the basic set of quality indicators that is applied by the Healthcare Inspectorate and other stakeholders to systematically assess and control risks in hospital care. Over the years this has proven to be an effective way to reduce risks and improve risk control in practice (IGZ, 2012). Medical education should contain horizontal tracks that promote risk management as part and parcel of a professional attitude and core competence.

Reducing risk is the other side of promoting positive health outcomes. New initiatives to assess and reduce risk in health care should engage patients and use solutions offered by participative health care. With regard to iHealth technologies, the ceHRes roadmap in combination with the international standard for risk management of medical devices EN ISO 14971 (EN ISO 14971; 2009) provides in-depth opportunities for improving patient safety. Here, a holistic approach means that "Safety analyses should not look for a single cause of problems but should consider the system as a whole when looking for ways to make a safer system" (IOM, 2011). Safety is the product of the larger socio-technical system and emerges from the interaction between different parts of this larger system. The ceHRes roadmap takes these relationships into account. It ensures that if safety is identified as a common value of all stakeholders, then it is built-in from the very start of the development process. Safety should be an added value of technology. Risk management is not new. It is applied in many other industries and has already been introduced into the health care system, but its urgency needs to be underscored. It is the holistic approach that is innovative: it allows all stakeholders (industry representatives, health care providers, patients, health officials from different authorities) to take on their own responsibility for improving interoperability and standardization, communication and transparency. This means transparency with regard to the ocurrence of incidents and monitoring the introduction and implementation of eHealth technologies. The existing infrastructure for reporting incidents, complications or complaints should be developed further in order to improve routine use. This is apparently also a question of professional attitude and legal protection; to err is all too human. This is a topic for continuous medical education and training.

5. Consumer health informatics often refers to curative medicine, to health care and, to a lesser extent, to prevention and public health. This is nevertheless an area where benefits have been demonstrated in low resource countries more obviously than in the developing countries. But the need to innovate preventative measures to promote good health and improve morbidity and mortality in the population of developed countries is clear in view of demographic trends, trends in the prevalence and incidence of (chronic) diseases, developments in technology, the unpredictable course of infectious diseases in the population as well as the control of health care associated infections. ePublic health concerns the way in which information and communication technologies can be applied to the sector of public health (Ossebaard, Van Gemert-Pijnen & Seydel, 2011). An innovative approach is offered by 'infodemiology'; a notion devised by Eysenbach (2009) who defined it as "the science of distribution and determinants of information in an electronic medium, specifically the internet, or in a population, with the aim to inform public health and public policy." The value of infodemiology to inform public health and public policy should be explored further. For example, with regard to the usefulness and robustness of analyses of queries from online search engines to predict outbreaks of diseases; the monitoring of peoples' status updates in social media for syndromic surveillance; the detection and estimation of disparities in health information availability; (e-)health marketing; crowdsourced health research studies, the measurement of information diffusion and knowledge translation; the tracking of the effectiveness of health marketing campaigns; buzz-monitoring or the impact of health record banks on the validity, reliability and stability of databases and the models they feed. The RIVM is developing several research activities in this field (Ossebaard & Coutinho, 2011). But a concerted policy effort would bring more unity and capacity to the patchwork of fragmented practices and home-grown interventions that currently characterizes ePublic health in the Netherlands.

Ageing leads to multi-morbidity which, in turn, leads to a higher volume and a higher variety of demand. To successfully address this changing demand, the landscape of care will have to adapt and many proposals and practices illustrate the feasability of this large and complex transformation (Van der Klauw & Flim, 2011). Today's favourable European political climate can certainly bring us closer to realising this. In 2004, the European Council endorsed the 'eHealth Action Plan', which was the first formal commitment of the Member States to cooperate more closely in the area of eHealth. It was evaluated satisfactorily in many respects (Kotsiopoulos & Whitehouse, 2011; Stroetmann et al., 2011). In 2012, a second eHealth Action Plan followed. It was launched by the European Commission and builds on the outcomes and addresses new issues, especially in view of the current economic crisis. The European Union (EU) expects that investment in innovation will help to overcome today's economic recession, and the European Commission believes that eHealth is an appropriate market for innovative solutions. eHealth is already part of the EU's Digital Agenda that focuses on technology applications to reduce energy consumption, to support healthy ageing, to improve health services and to deliver better public services (e-government). In its 'Europe 2020 Strategy' the European Commission appointed 'smart growth' as a key target domain to be reached by 2020. Here, 'European Innovation Partnerships', as in the field of 'active and healthy ageing', have been identified for so-called Flagship Initiatives that aim to boost economic growth and jobs. But it is a long journey from the international policy level to the work floor. At this ground-floor level some of the main obstacles standing in the way of up-scaling are often mentioned. The Netherlands Court of Audit (Algemene Rekenkamer, 2009) reports a lack of financial incentives for innovations such as telecare, as well as legal obstacles, a lack of standardization and a lack of stakeholder support for the use of ICT in care. A recent report on global health care transformation and the role of eHealth innovations arrived at similar conclusions (KPMG, 2012). From a survey among leaders in health care (N= 39) it appears that the top three perceived barriers to eHealth implementation are (still) money (34%), attitudes amongst medical professionals (29%) and poor change management (21%). The report also indicates that whilst some attempts to drive eHealth have been successful, many lost momentum after the pilot phase. Some within the profession suggest that they have 'technology anxiety' with 63% arguing there is a need to build confidence in eHealth applications and 29% suggesting data safety as a concern. It is also clear that the healthcare profession needs to be better informed about the advantages of eHealth, with 21% stating that there is currently a failure to showcase success, 26% suggesting that a shortage of staff members drives eHealth, and 47% claiming that consumers are the ones that drive the eHealth transformation. Almost 60%

of the healthcare executives interviewed said that the top two drivers for eHealth will be patient expectation (61%) and an increase in efficiency (58%). To create change in the healthcare system, through telehealth or telemedicine, the report cites three conditions as being essential for success: crowd-accelerated innovation, collaborative alignment and creative dislocation. These outcomes and the proposed solutions allign seamlessly with the findings that have led to the construction of the ceHRes-roadmap (see Introduction). What is needed is an embedded design approach that is not just expert-driven, not just about engineering, not just medical, clinical or psychological, but an approach that strives to integrate social sciences and engineering into a practical process-model for iHealth technology. The foundations of this approach are laid down in the roadmap.

The studies have their limitations with regard to their design and methods used, mostly stemming from limited financial resources. In general we have worked with small, non-random samples which reduces the overall power and reliability of the study. Attrition has been a serious drawback as well. Furthermore the studies were limited to evaluations of already designed technologies, and took place within a short time frame.

From the first Chapter we recapitulate that technology characteristically interacts with people's psychological, social and biological make-up, their daily lives, and the setting in which it is used. This implies the careful involvement of such variables in development, implementation and research. Domestication and maturing are processes that must be taken into account when developing and implementing health technology interventions. With regard to web-based health information (Chapter 2) it is clear that to account for the efficacy and effectiveness of a health policy instrument such as kiesBeter.nl, objectives must be quantified in measurable terms. Qualitative, interpretative research on how people actually use technology to support their decision-making in health care would provide further meaning and signficance to quantitative data and should be endorsed. Value creation for health care consumers requires further qualitative research to inform how this fundamental process take place among individuals and groups.

Decision support technology (Chapter 3 and 4) could greatly benefit from people-centered approaches that are the main avenue for avoiding drop-out and encouraging adherence. Solving usability issues is the first priority. Online patient decision aids should be adopted by health insurers to gurantee their availability. The application of these tools should be embedded in medical training and in health care delivery.

Chapter 5 implies that trust in technology is not a self-evident value. Safety is the product of the larger socio-technical system and emerges from the interaction between different parts of this larger system. Risk management for eHealth technology should be adopted in the basic set of quality indicators as applied by the Healthcare Inspectorate. Using the existing infrastructure for reporting incidents should be encouraged in order to improve routine use through establishing shared professional values.

The credibility of eHealth technologies is to be restored (Chapter 6). A concerted policy effort would bring more unity and capacity to the patchwork of fragmented practices that currently characterizes ePublic health in the Netherlands (and abroad). The value of infodemiology to inform public health and public policy should be explored by applying its methods to assess their worth for research and practice in public health.

There are some opportunities and challenges for future research that spring from this work. The field of iHealth needs research into persuasive design techniques to advance our understanding of how technology can robustly motivate healthy behaviors and meet the needs of users. Outcomes would have wide range of useful application in (public) health. Pragmatic evaluations of interventions could provide more quantitative data about *outcomes* at the level of end-users, clients or patients. Ethnographic methods in the 'natural' context of users, such as observations, informal interviews, screen capturing or think-aloud protocols, could deliver data on the *process* of decision making or behaviour change supported by technology. Research is needed on *how* technology works within innovation-management to improve the infrastructure of health care provision. Health care and patients could benefit from online decision aids once they are light-weighted, easy-to-use and can be applied to many more health complaints and illnesses. Developing them is a matter of co-creation and research. iHealth could further contribute to presenting comparative choice information on choice in health care to enhance their use and support the new roles of health care consumers. All such developments require the sensible integration of business modelling, which is a pioneering field of research and practice itself. The relevance of eHealth as a concept will diminish in the coming decade. Without a doubt 'eHealth inside' will become the norm, indicating that information and communication technologies are fully embedded in the health care process.

The chapters of this thesis exemplify these lessons from practice and research, and advance a holistic strategy to overcome obstacles, restore trust, and reinforce the credibility of eHealth technologies. This is necessary to meet the justified demands for a better impact, and a higher uptake and return-on-investment (Van Gemert et al., 2011). These lessons are interrelated in that they draw attention to the importance of persuasive health technology design. They have led us to the additional development of an applicable roadmap for iHealth technology advancement based on persuasive health technology and a managerial business modelling routine. This framework has been operationalized in a ‘roadmap’ that enables an evidence-based design, implementation and evaluation of eHealth interventions. To disseminate, implement and improve this tool it is currently published as a wiki for collaborative development (Van Gemert-Pijnen, Ossebaard, & Nijland, 2011). A research pilot to utilize and evaluate the wiki in practice is underway with partners from South Africa (Telemedicine and mHealth, Medical Research Council, Cape Town; Stellenbosch University), Norway (Telemedicine Center, Tromsø), Sweden (Department of Computer and Systems Sciences, Stockholm University) and Canada (University of Waterloo Institute of Health Informatics). This enterprise is co-funded by the strategic research program of RIVM. We expect it will contribute to a people-centered health care system that is able to face the challenges of our time whilst avoiding the pitfalls of the past.

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Samenvatting
(summary in Dutch)

Dit proefschrift gaat over hoe mensen omgaan met technologie waar het hun gezondheid betreft. Het onderzoek spitst zich toe op informatie- en communicatietechnologie zoals die de laatste tien jaar sterk is doorgedrongen in ons dagelijks leven. Veel factoren spelen een rol in de wisselwerking tussen deze technologie en de mens die haar gebruikt. Enkele daarvan hebben we onderzocht in verschillende studies.

De onderzochte technologieën zijn bedoeld om 'waarde' toe te voegen aan wat hun gebruikers nodig hebben op het gebied van gezondheid en zorg. De centrale onderzoeksvraag van dit proefschrift betreft dan ook de waarden die deze gezondheidstechnologieën toevoegen in termen van informatie, verandering en communicatie. Hebben ze werkelijk waarde toegevoegd, welke waarden, en in welke mate? Welke factoren bevorderen of belemmeren de acceptatie en het gebruik? Zijn er onbedoelde nadelen gevonden? Kan de toegevoegde waarde ook vermeerderd worden? Wat kunnen we van deze en andere ervaringen leren om dergelijke technologieën te verbeteren en de gezondheidszorg te vernieuwen? Deze en andere, van de centrale onderzoeksvraag afgeleide, vragen komen in de studies aan de orde. Wat de studies naast hun inhoudelijke verwantschap verbindt, is de sociaal-wetenschappelijke benadering van het onderwerp. Daarin hebben we gebruik gemaakt van traditionele en kwantificerende methoden in combinatie met meer interpretatieve en kwalitatieve methoden. Dat wordt wel een 'mixed-methods design' genoemd, bedoeld om de verzameling van gegevens te verbeteren en tot een beter begrip van de onderzoeksproblemen te komen.

In de Inleiding tot de artikelen wordt een aantal begrippen geïntroduceerd of toegelicht en wordt de onderzoeksvraag beschreven. Om te beginnen het begrip *technologie*. Daarover wordt al sinds mensenheugenis nagedacht; wat is het eigenlijk, hoe verhoudt zij zich tot wetenschap, wat doen wij er mee, en hoe beïnvloedt zij ons? Waar wetenschap vooral gaat om het begrijpen van de wereld, gaat technologie om het aanpassen daarvan. 'Iets maken' om te verbeteren wat er al is. De oude Grieken rekenden technologie dan ook tot hetzelfde domein als de geneeskunde of de muziek. Ook daar gaat het om de kunst het bestaan te veraangenamen. Vanuit een meer evolutionair perspectief kan zelfs worden gesteld dat de mens met technologie, hoe eenvoudig of hoe ingewikkeld ook, zichzelf of zijn omgeving zo aanpast dat zijn overlevingskansen (dat wil zeggen: de kansen op gezonde nakomelingen) verbeteren.

De snelheid, het bereik en de invloed van technologieën op het dagelijks leven zijn onmiskenbaar toegenomen. Dat is nergens zo zichtbaar als op het vlak van de informatie- en communicatietechnologie. Nog nooit was ingewikkelde technologie zo goedkoop, beschikbaar, modieus en alomtegenwoordig. Nog nooit kon informatie zó onmiddellijk, door zóvelen, verspreid en gedeeld worden – op het moment zèlf. Dat beïnvloedt ons gedrag, ons denken, voelen, en communiceren op een ingrijpende manier. Vooral de tweede generatie internet applicaties (Web 2.0) heeft het debat daarover op een ander plan gebracht. Voor wat betreft gezondheid en zorg kan de huidige mobiele en internettechnologie de zorg ingrijpend vernieuwen en verbeteren. Juist omdat patiënten, hun familieleden en zorgverleners veel meer mogelijkheden hebben om met elkaar te communiceren en samen te werken. Daartoe moet nog wel het een en ander veranderen. In de houding van alle betrokkenen, in de vergoeding en in de organisatie van de zorg.

Gezondheid is een belangrijke, universele waarde. Gezondheid hangt samen met welvaart, voorspoed en geluk. Wereldwijd proberen we daarom ziekten te voorkomen, te genezen en gezondheid te bevorderen. Op dit moment zijn er grote uitdagingen op dit gebied. Hoe gaan we die oplossen: de gevolgen vergrijzing, de toename van chronische ziekten, de hoge kosten van de zorg, de internationale 'onzichtbare vijand' van de infectieziekten enzovoorts. Voor al deze problemen wordt gedacht dat technologie kan bijdragen aan een oplossing.

De laatste tien jaar zijn er op het gebied van medische technologie belangrijke vernieuwingen geweest. Deze hebben bijgedragen aan een betere en eerdere diagnostiek, aan betere behandeling, aan betere zelfzorg en het beter kunnen volgen van het ziektebeloop. In samenhang daarmee worden ook de mogelijkheden die informatie- en communicatietechnologie bieden voor gezondheid en gezondheidszorg de laatste jaren intensief bestudeerd. Dat wordt wel *eHealth* genoemd, waarbij de 'e' staat voor 'elektronisch' waarmee dan digitale apparatuur wordt bedoeld, die het contact tussen dokter - patiënt, dokter - dokter of patiënt - patiënt bewerkstelligt. Hoewel er geen eensluidende definitie van eHealth bestaat, zijn er inmiddels talloze studies, ook in Nederland, die laten zien dat eHealth kan bijdragen aan efficiëntie, (kosten-)effectiviteit, kwaliteit van zorg en tevredenheid van patiënten. Toch is eHealth, ondanks de hooggespannen verwachtingen, nog lang niet volledig opgenomen in de zorg. Er zijn allerlei financiële en wettelijke belemmeringen, maar ook psychologische, organisatorische en culturele oorzaken die dat in de weg staan. Bovendien is er een gebrek aan standaardisatie en interoperabiliteit. Vooral is er gebrek aan degelijk, wetenschappelijk bewijs voor langdurig effect.

Het RIVM (Rijksinstituut voor Volksgezondheid en Milieu) voorziet de autoriteiten van wetenschappelijke kennis en informatie op het gebied van de volksgezondheid en het milieu. Die zijn nodig om beleid te kunnen voorbereiden, uit te voeren en te evalueren. Sinds 2005 heeft het RIVM er taken bij gekregen op het gebied van het voorkomen van ziekten en gezondheidscommunicatie. Een voorbeeld daarvan is de portal kiesBeter.nl die is opgericht om burgers betrouwbare informatie te verschaffen waarmee zij keuzes kunnen maken in de gezondheidszorg. Als kennisinstituut heeft het RIVM te maken met maatschappelijke veranderingen zoals de bovengenoemde opkomst van informatie- en communicatietechnologie. Daarom investeert het in onderzoek naar eHealth. Dat heeft onder meer geresulteerd in (de studies in) dit proefschrift, en ook dat van Saskia Kelders - later in 2012.

In dit proefschrift staan verschillende onderzoeken naar d'e kenmerken van technologie die te maken hebben met informatie, communicatie en verandering. Het gaat niet zozeer om de technologie zelf maar om wat zij betekent voor het verzamelen, opslaan, verwerken, delen, verspreiden, verrijken, begrijpen, ontwerpen en organiseren van informatie. De 'i' van informatie is eigenlijk belangrijker dan de 'e' van elektronisch, vandaar dat we voorstellen om voortaan van iHealth te spreken. eHealth zal een overgangsbegrip blijken te zijn, een tijdelijke aanduiding op weg naar *eHealth inside*; de volledige inbedding van informatie- en communicatietechnologie in de zorg. In iHealth staat *informatie* centraal, en de manier waarop geprobeerd wordt technologie te ontwerpen mèt de mensen die haar gaan gebruiken. Technologie die hen werkelijk in staat stelt en aanspoort om op hen toegespitste informatie voor hun gezondheid te gebruiken, in hun situatie. Daarbij proberen we de valkuilen te vermijden van eerdere ontwerpen, waarvan gebleken is dat die onvoldoende werden gebruikt. Deelname aan dat ontwerpproces van de 'eindgebruikers' is daarbij van groot belang. Het gaat ten slotte om de *'waarden'* die deze informatie en communicatie toevoegen aan wat - bijvoorbeeld - patiënten nodig hebben om hun gezondheid in eigen hand te houden. Of om wat zorgverleners nodig hebben aan 'toegevoegde waarde' die hen in staat stelt hun werk effectief, efficiënt, en naar tevredenheid uit te kunnen voeren.

Als die waarden goed kunnen worden vastgesteld, begrepen en benut worden, dan is de kans groot dat het effect van eHealth meetbaar toeneemt. Om dat te bereiken is aan het Center for eHealth Research and Disease management van de Universiteit Twente een *roadmap* (een richtlijn) ontwikkeld, op basis van uitgebreid literatuuronderzoek en proefondervindelijk onderzoek. Daarin wordt per fase beschreven hoe het ontwerpen èn het invoeren van eHealth het best kan plaatsvinden, en welke methoden en technieken van belang zijn om tot een succesvol resultaat te komen. Een overtuigend en aantrekkelijk ontwerp van technologie, zorgvuldige aandacht voor de waarden van alle betrokkenen en een centrale plaats voor de gebruikers zijn kenmerkend voor de *roadmap*[1]. In de sociaal-wetenschappelijke benadering van hoe mensen technologie gebruiken voor hun gezondheid (dit proefschrift) staan waarden eveneens centraal. In de verschillende studies gaat het steeds om wat de *toegevoegde waarde* is van een technologie in termen van informatie, communicatie en verandering.

Hoofdstuk 1 gaat over een technologie (een zogeheten 'brain machine') die onder meer zou helpen bij het bereiken van ontspanning en het verminderen van stress. De brain machine geeft door middel van een bril korte lichtflitsen af en tegelijkertijd via een hoofdtelefoon geluidsimpulsen. Deze voorgeprogrammeerde patronen van licht en geluid, zouden de hersengolven 'meetrekken' in een frequentie die ook tijdens ontspanning kan worden gemeten. We hebben dit onderzocht door mensen met een belastend beroep (die dus naar verwachting veel stress ervaren) acht weken lang, twee keer per week, bloot te stellen aan programma's van de brain machine. Voór en ná deze periode hebben we bij hen de mate van overbelasting gemeten met een daarvoor ontworpen vragenlijst (Maslach's Burn-out Inventory). Daarnaast hebben we, op vier momenten, vóór en ná een sessie, hun mate van ontspannenheid in kaart gebracht met een vragenlijst die dat goed meet (Spielberger's State-Trait Anxiety Inventory). Ten slotte hebben we de deelnemers gevraagd hun ervaringen bij te houden in een dagboekje. We vonden geen lange termijn effect van enige betekenis. We vonden wel korte-termijn effecten op ontspanning, hoewel die niet eenduidig konden worden toegeschreven aan de brain machine. 'Ontspanning' is een complex begrip dat niet zomaar door middel van een apparaat is te bereiken.

Hoofdstuk 2 gaat over de gezondheids- en zorgportal kiesBeter.nl. Deze is opgericht om burgers te helpen bij het maken van keuzes in de gezondheidszorg. Daartoe publiceert de website betrouwbare informatie over kwaliteit van de zorg, over zorgverleners, over (het voorkomen, behandelen, vaststellen van) ziekten, over medicijnen, over zorgverzekeringen enzovoorts. Deze studie beschrijft enerzijds de geschiedenis van de portal en met welke doelen het Ministerie van Volksgezondheid een portal als een beleidsinstrument heeft ingezet. Anderzijds probeert de studie vast te stellen in welke mate deze doelen zijn bereikt.

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[1] Om de *roadmap* in de praktijk te gebruiken, te onderzoeken en verder te ontwikkelen is hij als een soort gereedschapskist online gezet op www.ehealthwiki.org

Het blijkt dat de doelen van kiesBeter, zoals beschreven in verschillende beleiddocumenten, maar moeilijk zijn te meten. We hebben verschillende bronnen gebruikt, waaronder de op de server vastgelegde raadplegingen van de portal (de *logfiles*), een online vragenlijst over de portal, een 'markt-monitor' en de directe reacties van gebruikers via e-mail of telefoon. We kunnen daardoor toch bij benadering vaststellen dat kiesBeter in elk geval een aanzienlijk deel bereikt van haar doelgroep (18.000 verschillende bezoekers per dag in 2010). Maar betrekkelijk veel mensen voelen zich niet echt ondersteund voor wat betreft hun beslissingen, zij vinden de informatie niet zo nuttig als ze die al weten te vinden. Zij vinden hun waarden niet duidelijk terug in de portal. Het effect van het beleidsinstrument op keuzegedrag is waarschijnlijk dan ook gering evenals de beoogde functie van de portal voor een beter werkende gezondheidszorg.

Hoofdstuk 3 gaat eveneens over kiesBeter.nl en wel over *usability* zoals ervaren door patiënten met langdurige ziekten (reuma, astma, diabetes). *Usability* is al langere tijd een erg belangrijk begrip in de informatie- en communicatietechnologie. Het duidt op de gebruiksvriendelijkheid van een apparaat, een toepassing of een (computer) systeem voor een individuele gebruiker in zijn/haar specifieke situatie. Nadat we hun achtergrondgegevens hebben vastgelegd, brachten we de ervaring van de deelnemende patiënten met verschillende methoden in kaart. We hebben hen taken laten uitvoeren op kiesBeter.nl, bijvoorbeeld door hen bepaalde informatie te laten opzoeken en daarbij hardop te denken. Daarvan werden geluidsopnames gemaakt. Tegelijkertijd werden ook hun handelingen op het scherm geregistreerd met speciale software. We hebben hen geïnterviewd en met een klein aantal hebben we alle resultaten nog eens besproken in een zogenaamde focusgroep. Stelselmatig zijn we alle uitkomsten nagegaan waarna bleek dat kiesBeter volgens deze patiënten nog veel te wensen overliet als het gaat om informatie zoeken en vinden, om hulp bij hun besluitvorming en bij zelfzorg, om de inhoud van de informatie zelf en om andere kenmerken van de waarde die *usability* vertegenwoordigt. Met deze resultaten zijn aanbevelingen geformuleerd die door kiesBeter grotendeels zijn overgenomen en toegepast.

Hoofdstuk 4 gaat over keuzehulpen. Dat zijn toepassingen die onder meer op kiesBeter worden gepubliceerd en die bedoeld zijn om mensen te ondersteunen bij het kiezen van een behandeling die bij hen past. In dit geval gaat het om een keuzehulp die ouders helpt bij de beslissing over welke behandeling goed is voor hun kind met ADHD. Deze is ontworpen door het Trimbos Instituut volgens internationale standaarden, en is gebouwd door het team van kiesBeter. We hebben het effect van de keuzehulp op de kwaliteit van het beslissingproces onderzocht. De bezoekers van de keuzehulp vroegen we om vooraf een voor dit doel ontworpen vragenlijst anoniem te in te vullen en na afloop van het doorlopen van de keuzehulp, een tweede vragenlijst. Zo konden we nagaan wat het effect van de keuzehulp was op de fasen van het besluitvormingsproces, op het oplossen van een conflict in de besluitvorming, op het kennisniveau, op tevredenheid en op aanvaardbaarheid van de keuzehulp. Tijdens de drie maanden waarin we de gegevens verzamelden bleek dat maar erg weinig mensen de tweede vragenlijst invulden. Voor degenen die dat wèl deden was de keuzehulp nauwelijks behulpzaam. Aan waarden als aanvaardbaarheid, tevredenheid, bevredigde informatiebehoefte werd slechts matig voldaan. Deze resultaten hebben tot verscheidene aanpassingen geleid aan de keuzehulpen op kiesBeter.

Hoofdstuk 5 gaat over een onderwerp dat nog weinig belicht is: de risico's van eHealth technologieën. De beheersing van dergelijke risico's voor patiënten vertegenwoordigt belangrijke waarden als vertrouwen, veiligheid en kwaliteit van zorg. Wat weten we eigenlijk van de aard en omvang van deze risico's? We hebben een verkenning uitgevoerd door in de wetenschappelijke literatuur te zoeken naar klinische studies hierover. Onderzoek naar studies die over de opslag, verzending, vertrouwelijkheid en veiligheid van gegevens gaan, hebben we niet meegenomen om overlap te vermijden. Ook hebben we 'grijze literatuur' onderzocht, dat zijn minder toegankelijke studies, databases en websites van relevante organisaties. De uitkomsten hebben we vervolgens besproken in een focusgroep bestaand uit deskundigen uit de industrie, de zorg, de overheid, de wetenschap, de patiëntenbeweging en uit de verzekeringswereld. We concluderen dat er geen klinische studies voorhanden zijn. Het is ook moeilijk om risico's direct te onderzoeken, dat zou onethisch kunnen zijn. We concluderen verder dat we over de aard van risico's rond eHealth technologie wel het een en ander weten: er gaat van alles mis of kan van alles mis gaan door menselijk functioneren, door gebreken in de organisatie of het falen van de technologie zelf. Maar over de schaal waarop dit gebeurt, en hoe vaak, en wat de gevolgen zijn van deze gebeurtenissen weten we nagenoeg niets. Dat komt overeen met resultaten van (internationaal) gezaghebbende studies die ongeveer tegelijk verschenen met onze rapportage. Op grond van deze studie hebben we de Inspectie voor de Volksgezondheid aanbevelingen gedaan om tot meer aandacht voor risico-management in eHealth op te roepen, om meer onderzoek op dit gebied te laten verrichten en te overwegen of de instelling van een systeem voor melding en documentatie van dergelijke risico's zinvol zou zijn.

Hoofdstuk 6 is een intellectuele bijdrage aan het debat over hoe eHealth technologie beter kan bijdragen aan het oplossen van problemen in de volksgezondheid en de gezondheidszorg waar de wereld mee te maken heeft. Op grond van onze kennis en ervaring betogen we dat de waarde 'geloofwaardigheid' versterkt moet worden. Dat kan door middel van een 'holistische' benadering die ook in de eerder genoemde *roadmap* is terug te vinden. Dat betekent in wezen dat alle betrokkenen een evenwaardige, praktische en stelselmatige inbreng hebben in het ontwerpen, ontwikkelen, uitvoeren en onderzoeken van eHealth technologie. Dan is de kans op een duurzaam 'waardevolle' en effectieve bijdrage aan gezondheid en gezondheidszorg het grootst. Zo een benadering kan het beste worden ingebed in een gezondheidbeleid dat door alle betrokken partijen, vooral ook met patiënten, wordt vormgegeven.

Ondanks hun kritische aard hebben de studies geleid tot een opbouwend gezichtspunt over eHealth. iHealth is te beschouwen als de volgende fase van de eerder aan de Universiteit Twente ontworpen *roadmap* en houdt beloften in voor de toekomst. De afzonderlijke studies hebben zo hun beperkingen. Toch denken we dat ze kunnen bijdragen aan een beter begrip van wat nodig is om technologie zodanig te ontwerpen dat zij de waarden aanspreekt van haar gebruikers, en daardoor meer effect heeft. Niet alleen voor de gebruikers (patiënten), maar ook voor de zorgorganisatie.

Toekomstig onderzoek zou zich moeten richten op hoe technologie kan worden ingezet voor het bevorderen van gezond gedrag. Hoe maken we technologie zo aantrekkelijk en passend bij iemands situatie dat een gebruiker niet voortijdig afhaakt, zoals nog te vaak gebeurt? Hoe kan technologie helpen om de zo noodzakelijke vernieuwing van de gezondheidszorg te ondersteunen? Hoe kan de volksgezondheid meer baat hebben bij informatie- en communicatietechnologie? Daarvoor is onderzoek nodig waarin de gebruiker en zijn sociale situatie een belangrijke plaats innemen. Hoe pakken we dat aan? Een holistische benadering van dergelijke vragen is op dit moment de beste garantie voor een succesvolle overgang naar *eHealth inside*.

Acknowledgments

This thesis and the one by drs. Saskia Kelders (appearing in the late summer of 2012) are the major academic outcomes of the gettingBetter.nl project, funded by a grant of the strategic research program (2007-2011) of the Dutch National Institute for Public Health and the Environment (RIVM) in collaboration with the University of Twente.

My professional and personal lives were never divided too much. The people I enjoyed working with, usually have the same sort of passionate *plaisir de métier*. I am grateful and indebted to them for sharing this with me!

I thank Professor Dr. David Ingleby for providing me with the opportunity to develop and grow in scientific activity and distantly but wisely coached me in this formative and turbulent period in the beginning of the 1990s.
I thank Dr. Govert van de Wijngaart† for his teachings in the science of life and his enduring companionship.
I thank mr. Fons Vloemans MD, for elegantly engaging me at the Ministry of Health and his intelligent and thoughtful dedication to people and the public cause.
I thank Professor Dr. Harry van Steeg for his personal trust in me and his unconventional approach to the serious game of science.
I thank Professor Dr. Hans van Oers, head of the RIVM Centre for Public Health Forecasting, for his willingness to facilitate me in conducting research and his encouragement.
I thank Dr. Jeanne van Loon and Dr. Jos van Sonderen, respective project leaders of the health portal kiesBeter.nl for their support.

I thank Professor Dr. Erwin Seydel for accepting to supervise me and for his dedication and enigmatic and eloquent high-level conversations on science and life.
I thank drs. Saskia Kelders for her commitment to our co-creational project in eHealth.

I thank Dr. Gerben ter Riet MD, my dear old friend who never let me down, for being my high-class para-nimph.
I thank Drs. Annemarie van Rijn my best ex-room-mate ever for her comradeship, engagement and para-nimphomania.

I thank my dear colleagues at kiesBeter.nl and the RIVM, and as well as my collegues at the Department of Psychology, Health and Technology (University of Twente) for their professional and personal commitment.

And evidently, I thank my assistant-supervisor Dr. Lisette van Gemert-Pijnen for her support in successfully finishing (the first part) our mutual project. She is mentioned earlier as my “counterpart” but she rather has become an friend with whom I trust to develop much more interesting research at the cross-roads of health, technology, social sciences and life.

I thank my family and friends for linking-in, meeting-up and staying tuned – there is nothing as good as sharing the same table with you. The table is a source.

There have been many moments in my life when I felt indebted to my parents Han Ossebaard† and Heleen den Hollander† who, for the meantime, have been away for most of my days. This is one such moment. With their parental dedication they provided the vital conditions for my development from childhood onwards. They have kindled my curiousness. And they would have been proud, for sure.

As proud as I am today of my sons Merlijn, Felix en Storm.
I am so very happy to share my life with them and, since 2011, with Milla.
I hope you will feel as inspired by me as I am by you.

Giselle, where were you for so long; I feel blessed to have met you.

Appendix

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Statements

belonging to the doctoral dissertation

iHEALTH: SUPPORTING HEALTH BY TECHNOLOGY

Hans C. Ossebaard

1. iHealth = persuasive health technology in context.
2. eHealth credibility increases with the extent of people-centeredness.
3. Usability is not merely a key characteristic of a tool, rather it is the closeness of the match between humans, technology and the environment.
4. Digital decision-support technology deserves serious and permanent attention in health policy.

5. The relevance of the transitory concept of 'eHealth' will diminish in the next decade as a completely integrated system of eHealth technologies eventually becomes the norm: *'eHealth inside'.*
6. Feyerabend's *tutto fa brodo* is the modest recognition of rational science as a human endeavor.
7. Risk is a lack of knowledge.
8. The recent Dutch initiative to replace the 1947 WHO definition of health complies qua content perfectly with the potential of eHealth technology.

9. Probability never sleeps.
10. Alles geeft niks (untranslatable).