

Health Information on the Internet

State of the Art and Analysis

E-Health is often understood as a means of optimizing work procedures in medical and non-medical areas of healthcare. Increasingly, e-Health is concerned with the attempt of key stakeholders to provide access to healthcare information and services using Internet to make patients actively involved in their treatment. Initial studies have shown that the use of such information sources has a positive effect on a patient's course of illness and can benefit involved stakeholders. Nevertheless, the risks for patients using Internet-based sources have also begun to emerge, such as the difficulty of guaranteeing authenticity of information. This article provides an overview of the state of research in the field of Internet-based health information.

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1 Introduction

Electronic Health (e-Health) denotes the improvement of healthcare through the use of information and communication technologies (ICT) (Bauer 2000; Della Mea 2001; Eysenbach 2001; Fitterer et al. 2009; WHO 2005). This includes both telemedicine applications (e.g., remote surgical procedures), applications which provide administrative support (e.g., hospital information systems) as well as the general ICT-driven development of network systems in the healthcare system. One example of this is the system of centralized electronic patient data (“integrated electronic health

records”) the aim of which is to enable the nationwide exchange of data across many different stakeholder groups through a lifelong integration of all patient-related data (Beyer et al. 2006; Gunter and Terry 2005; Haux 2006, 2010; Reichertz 2006). In this respect, e-Health is primarily understood as a means of optimizing working procedures in medical and non-medical areas (Brikner 2006, p. 15). One of its aims is to optimize the treatment process in order to achieve a high level of efficiency for frequently occurring cases (Anoraganingrum et al. 2009; Roeder and Küttner 2007, p. 8). However, the implementation of ICT does not per se and necessarily lead to greater efficiency in healthcare. This accounts for why many studies have found very little to suggest that the intensive use of information technology (IT) reduces administrative costs or improves procedures, quality and safety (Black et al. 2011; Himmelstein et al. 2010; Köbler et al. 2010; Romano and Stafford 2011; Spil et al. 2010). This immediately calls to mind the well-known IT productivity paradox (Brynjolfsson and Hitt 1998) which states that there appears to be no positive connection between investment in ICT and productivity, and that other factors such as a continuous interaction between ICT and other processes play an important role (Davenport 1993, 1994). The adoption rate of e-Health systems in the healthcare system has also shown itself to be marginal (Fitterer et al. 2011, 2010).

Increasingly, however, e-Health is also seen as the endeavor of those stakeholder groups involved in healthcare (e.g., insurance companies, physicians, hospital and patient associations, patient support groups) to make Health Information via the Internet accessible and to make patients become actively involved in their healthcare (Ferguson 2002). Included in this are, for example, information portals and web-based sources provided by insurance companies, supporting training or self-service applications, patient platforms such as PatientsLikeMe.com, Netdoktor.de and Imedo.de, or specialized groups on specific illnesses, treatment options and other medical issues on social network sites like Facebook, as well as personalized patient files like Microsoft HealthVault. Decentralized and patient-managed electronic health data (“personal health record”), in contrast to patient files managed by third parties (e.g., G.P. or hospital) or national, centralized solutions, are supposed on the one hand to improve data protection, thereby increasing acceptance amongst patients, and on the other to make patients actively involved in the management of their health records (Anhalt et al. 2004; Jaspers et al. 2006; Knaup et al. 2007; Sunyaev and Chorny 2012). Since information is so central to the healthcare system (Macintosh-Murray and Choo 2006), health information and information management are becoming a key factor across all areas (Winter et al. 2007). Initial studies have shown that the use of such information sources can have a positive effect on a patient’s course of illnesses and can benefit patients (Murray et al. 2005). Nevertheless, the risks for patients using Internet-based sources have also begun to emerge, such as the difficulty of guaranteeing the authenticity of the supplied information (Greene et al. 2010) or its legibility (Eysenbach and Kummervold 2005).

It is the aim of this article, using a comprehensive analysis of existing research in business informatics and domain-specific health publications as well as an investigation into related research conducted within transfer and translation projects, to provide an overview of the current state of research in the area of Internet-based health information, in order to identify possible starting points and interesting areas for future research. This article therefore fills a gap in a subject area which in praxis-centered material has already been comprehensively

examined in compilations such as the Telemedicine Guide (Jäckel 2009).

The article is structured as follows: Sect. 2 provides a thorough overview of the state of research related to health information in healthcare. In relation to this, the section will focus in particular on the themes of health information and patient-centeredness as well as the dissemination of health information over the Internet. Following this, Sect. 3 describes the methodology of the literature review and the set of criteria on which this is based as well as the analysis of transfer and translation projects. Section 4 goes on to present the results of research conducted in both scientific and applied research projects concerned with the topic of Internet-based health information, and in Sect. 5 this is discussed specifically in relation to future research areas.

2 Health Information in Healthcare

2.1 Health Information and Patient-Centeredness

The aging of Germany’s population presents a significant challenge for the country’s healthcare system, as chronic illnesses such as diabetes, osteoporosis, and dementia increase with age (Robert-Koch-Institut 2006, p. 19). Further, chronic illnesses are characterized most notably by their longevity (Corbin and Strauss 2004; Schaeffer and Moers 2008). Typically, this longevity goes hand in hand with a course of illness marked by stable and unstable phases, which in turn means that a patient’s need for support and information constantly fluctuates (Schaeffer 2004, 2009). This is also highlighted by studies which identify a connection between the management of chronic illnesses and a heightened need for information of those affected (Allen et al. 2004; Charmaz 2000; Coulter and Fitzpatrick 2000). For these reasons, experts from the disciplines of Health Care and Public Health in particular are insistent about the need for an accessible body of knowledge and information that is oriented towards the everyday life and living environment of those affected (Ewers and Schaeffer 2007; Schaeffer 2009; Schmidt-Kaehler 2006). Adequately meeting this need for information of chronically ill people is one of the great challenges of

the healthcare system (Geuter and Weber 2009). As demands for “participatory healthcare” become louder, patients are expected to become actively involved in the management of their illness as well as in the decisions relating to the treatment and care of that illness (Schaeffer 2004). This entails greater patient autonomy but equally it requires the supply of relevant information and support.

In this article, health information refers to all information which deals with questions about health-related issues (e.g., promotion of health, illnesses, examination or treatment options, facilities of the healthcare system, etc.) (Sänger et al. 2006, p. 12). On the one hand, this includes information for non-experts; patients concerned about health issues should be placed in the position of understanding an illness and identifying its symptoms (so-called evidence-based patient information, Sänger et al. 2006, p. 12). On the other hand, however, this also explicitly includes the support of service providers in the healthcare system, for example, health professionals, physicians, industry, medical councils, or insurance companies, through the provision of information (Joncheere et al. 2010).

In Germany, health information is concerned with making information vetted by experts accessible to as many patients as possible and available through a number of institutions. The legislative basis for this is, for example, Articles 135 and 137, book 5, of the German Social Code (SGB V). In line with this, for example, the “German Agency for Quality in Medicine” maintains a patient information service (<http://www.patienten-information.de>) and the “Institute for Quality and Efficiency in Health Care” with its bilingual website (<http://www.gesundheitsinformation.de>) fulfills a part of its legal obligation to educate the public in health-related questions. In addition to these, independent patient centers which, for instance, inform service users about patient rights and offer guidance are of great importance (Robert-Koch-Institut 2006, p. 207). That said, existing sources of information are marked by considerable deficits (Schaeffer 2006, pp. 41–43). Despite the great number of informal and institutional sources of information it is almost impossible to access, for example, information comparing the quality of treatment in individual healthcare services (Robert-Koch-Institut 2006, p. 207). This goes hand

in hand with a very slow integration of the different stakeholders within the healthcare system (Gericke et al. 2006; Mettler et al. 2007). Although the past years have seen the creation of numerous sources of patient information and advice, the uncoordinated emergence of diverse advice services has led amongst other things to the fact that advice centers simply fail to reach large numbers of patients (Dierks and Seidel 2005; Müller-Mundt and Ose 2005; Ose and Schaeffer 2005; Zillien and Lenz 2008). Further, too little is known to date about the specific need for information of different patient groups (see, for example, Hsu et al. 2006; Johnson et al. 2004; Ngo-Metzger et al. 2003). In addition to this, many patients still feel insufficiently informed about healthcare (Dealey 2005; Eysenbach et al. 2002). At the same time, however, studies have shown that high quality information does indeed have an impact on the choice of sources which patients consult (Wübker et al. 2008).

2.2 Health Information on the Internet

In the United States, over 61 % of patients are already using the Internet to inform themselves about their illnesses and possible treatment options (Fox and Jones 2009). Amongst Internet users with disabilities or chronic illnesses the number is even higher: 75 % of those interviewed with chronic illnesses state that their last Internet search influenced a decision about the treatment of their illness (Fox 2008). In Germany, too, the Internet has become an integral part of everyday life; especially for young people up to the age of 29, it is already the most important medium of information – far ahead of radio, television, newspapers, and books (BITKOM 2010). Concurrently with this, Lausen et al. (2008) have identified a clear rise in the general as well as established (at least once a month) use of the Internet for health-related questions during the years 2005–2007 (from 44.4 % to 56.6 % or from 22.5 % to 32 %). Altogether, the perceived importance of the Internet as an information source on health issues has risen amongst all age groups in both men and women (Kummervold et al. 2008).

In addition, however, it has also become clear that the “second generation” of Internet users is not only using the Internet to read information, but also as a direct channel of communication with

health experts and other sufferers. Under the term “Web 2.0” these interactive and collaborative mechanisms and concepts have found their way into the discussion (Bächle 2008; Vossen and Hagemann 2007). Platforms such as “The Diabetes Blog” demonstrate that these concepts can also be applied to health information (Deshpande and Jadad 2006; Seeman 2008). The value of network effects for healthcare emerges, for example, in the form of electronic self-help groups (Leimeister et al. 2005; Leimeister and Krömar 2005). Through these virtual communities, patients are able to network with other sufferers and communicate with them. Further, participatory concepts such as “volunteer recruiting” (Seeman 2008, p. 108) or “self-empowerment” (Barr et al. 2003) are supported, or indeed made possible, through Web 2.0 applications and the Internet. Even if the advantages of virtual communities and electronic self-help groups are still not yet fully understood (Dannecker and Lechner 2007; Eysenbach 2003; Eysenbach et al. 2004; Griffiths et al. 2006), the number and longevity of the available sources alone already indicate that the majority of their members recognize the benefits in them (Jadad et al. 2006; Zrebiec 2005). This connection between e-Health and Web 2.0 is also conceptualized as “Health 2.0” (Eysenbach 2008a) or “Medicine 2.0” (Hughes et al. 2008).

Studies conducted to date in the field of health information on the Internet and Health 2.0 have failed to produce clear results regarding the technology’s positive and negative impact on health (amongst others Eysenbach et al. 2004; Parsell 2008; Schielein et al. 2008). Thus, for example, Hughes et al. (2008) have identified a lack of research in the area of “personalized health”. According to these authors, research is clearly lagging behind praxis in its understanding of the effects of Web 2.0 applications and Internet based health information. This is why Boulos and Wheeler (2007) insist upon the careful examination of “Best Practice” cases, in order to exhaust the potential of Health 2.0.

3 Approach and Set of Criteria

There are a number of independent variables which have an impact on the theme of health information on the Internet. Where these variables are known,

concrete conclusions regarding the design of an information source can be drawn. However, this level of knowledge has, to date, not been attained, neither on a theoretical nor an empirical level. With the aim of describing and evaluating the results of existing scholarly research in the field of business informatics and related disciplines, an analysis of the current state of pure research as well as of relevant applied research projects in the field of health information was carried out.

The analysis of existing research is based on a literature review which takes as its starting point the study by Webster and Watson (2002). This structured approach has ensured that a comprehensive number of relevant articles were taken into consideration. In addition, publicly funded transfer and translation projects conducted within the context of applied research were also examined. The purpose of the analysis was to identify gaps in research and starting points for future research, in particular for the field of business informatics. The chosen sources (international scholarly journals and conference proceedings as well as German-language book-length studies), the key words used, the databases of the individual funding agencies which were consulted as well as the method used in the selection and classification of the examined scholarly sources are presented in detail in the appendix (Table 1-A, available online at <http://link.springer.com>).

For the classification of the selected literature and the research results a research framework was defined. The complete research framework is presented in Fig. 1-A in the online appendix. Initially, two classic structural components (“research methods” and “research topics”) were adopted from similar studies (Alavi and Carlson 1992; Palvia et al. 2004), to which sub-categories relevant to the topic were added. This produced three categories (non-empirical, behavior-focused and design-centered) for the “research method” component. The categories of the “research topic” component include: (1) primary user groups of the application systems considered (patients, physicians, etc.) and (2) level of analysis (individual, organization, etc.). Five further components were added (“information flow”, “type of application”, “purpose of application”, “properties of information transmission”, and “TEMPEST Category”), each with their own additional sub-categories and which, in contrast to

the two structural components, are concerned with content-related aspects of the applications – or services – in the context of health information. They are explained further below.

Health information can involve a number of stakeholder groups in the healthcare system and their interaction and communication with one another, for example, patients, physicians, hospitals, or health insurance companies. There are information and communication flows between the different stakeholder groups. These have a direct impact on the development and implementation of information systems which are designed to facilitate information and communication in the most economically efficient way possible (Krcmar 2004, p. 25; WKWI 1994, p. 80). It is therefore part of the task of business informatics to evaluate the benefits of these information and communication flows and to influence their design and configuration. For this reason, these information and communication flows form the first content-related part of the analysis (“Which information and communication flows between which stakeholder groups are considered?”). The stakeholder groups can be arranged in accordance with the main players in the healthcare system (Table 1) who are often interconnected (Busse and Riesberg 2004, p. 31). (The stakeholder groups partially overlap with the constituents of the primary user group.)

The second content-related component of the analysis considers which type of IT application is used to communicate information (“What type of application supports the information and communication flows of the individual stakeholder groups?”). The analysis of the selected literature in relation to the “type of application” was carried out on the basis of the stage model for e-Government applications developed by Siau and Long (2005). The fundamental approaches in the context of e-Government can successfully be applied in the context of healthcare (Ballardini et al. 2004; Reinermann 2002), since the structure and the participating institutions are comparable. For this reason, the different variations of the stage model were adapted for the present study. The resulting differentiation between the levels of interaction in terms of the intensity of that interaction between the different parties highlights the very different demands that each stage places on the technical and organization design

Table 1 Players in the healthcare system

Level	Player
Individual	Patient/insured individual, relatives
	Physicians
	Hospital
	Health professionals/carers
	Pharmacists
	Medical researchers
	Statutory health insurance or private health insurance company
Organizational	Medical associations
	Hospital associations
	Patient associations
	(Umbrella) associations of statutory health insurance and private health insurance companies
	Associations of healthcare professionals
	Pharmacy associations
Others	Medical technology industry
	Pharmaceutical industry
	State-run organizations and institutes

Table 2 Type of application used for the support of information and communication flow

Category	Content
Information	Supply of information for e.g., patients and physicians via information portals
Communication	Exchange of information between two parties (e.g., patient-physician, physician-physician) without direct and immediate response from the communication partner
Interaction	Exchange of information or data between two parties with immediate response from the communication partner
Transaction	Targeted exchange of data between different parties with the aim of being able to completely reproduce and perform medical services in electronic form
Integration	Lifelong recording of all data relating to a patient’s state of health. Consolidation of all data from medical and paramedical sectors and completion of information in the form of entries and information from the patient him/herself

(Reinermann 2002). Table 2 summarizes the categories used in the section “type of application”.

Further, health information-related applications and services can be initially classified according to their “intended use” (Tulu et al. 2005) into medical (e.g., treatment advice or care support) and non-medical aims (e.g., patient education) (“What intended use does the provided information serve?”). Further, the different ICT implemented in the health sector can also be differentiated according to their potential transmission properties or media options (Tulu et al.

2005) (e.g., audio, visual or data, synchronous/asynchronous; “What properties characterize the implemented media/ICT?”).

Additionally, research on the use of ICT in the healthcare system can be classified into four main disciplinary fields (Currie 2009, p. 5): clinical studies, studies on the use of information systems (IS) and ICT, medicine or health informatics and management or organization studies. In order to structure this knowledge, the TEMPEST model was developed with the aim of evaluating and comparing e-Health approaches (Currie and

Table 3 TEMPEST categories

Category	Themes and sub-categories
Technological	(a) Emerging technologies, applications and standards for health service providers, (b) interoperability and integration of technologies and applications as well as (c) data protection, safety and storage.
Economic	(a) Funding and health expenditure, (b) ICT penetration, and (c) general infrastructure of the healthcare system.
Market	(a) Market-driven healthcare, (b) consumer-driven healthcare, and (c) capability and skills of the IT market.
Political	(a) Principles and guidelines, (b) education training, and (c) institutional infrastructure.
Evaluation	(a) Governance, regulation and compliance, (b) e-Health adoption, and (c) performance measurement.
Social	(a) Social inclusion and access to ICT, (b) patient-centered healthcare, and (c) patient access and choice options.
Transformational	(a) Integrated healthcare, (b) Reform agendas, and (c) e-Health strategies and implementation.

Finnegan 2010). It includes medical, ethical, social and economic factors as well as aspects of ICT in the healthcare system. The model consists of indicators which enable a comparison of actual and future technologies in healthcare. These can be divided into seven main categories (Table 3). Each of these seven categories is made up in turn of three thematic sub-categories each with four (qualitative or quantitative) indicators. The total of 84 indicators are seen as relevant for the implementation and use of e-Health technologies (Currie and Finnegan 2010, pp. 13–15). The seven main categories make up the third content-related part of the analysis as they enable the categorization of literature based on the independent variables considered (“Which factors are considered?”).

4 Study and Analysis

4.1 Overall Analysis of Sources

In total, 352 articles published in German and English language journals, the proceedings of national and international conferences as well as German language book-length studies were identified as relevant. The 352 articles were published in the years 1995–2010 (Fig. 1). Overall, an increase in the number of publications across this time period can be observed, a trend which runs parallel with the increasing significance of the Internet and its greater availability. The number of articles increases steadily and in 1999 reaches its first peak with 34 publications. The reason for this high number is the inaugural edition of the “Journal of Medical Internet Research”, which includes a total of 24 relevant articles. The all-time peak occurs in 2009 with 40 publications.

As far as the applications focused on in the articles are concerned, 29.26 % of the articles consider “transaction-based applications” in the healthcare system. These are applications which enable the specific exchange of information between different parties with the aim of fully reproducing and performing medical services in electronic form. In this context, for example, there are numerous studies on the implementation (amongst others Frießem et al. 2005; Hampton 2008; Shachak and Jadad 2010), adoption (amongst others Angst and Agarwal 2009; Kim et al. 2009; Simon et al. 2009; Weitzman et al. 2009), security (Wiljer et al. 2008) or advantageousness (amongst others Horan et al. 2010; Powell and Buchan 2005; Rey 2008; Tsai and Starren 2001) of decentralized and personally managed electronic patient records (“personal health record”) as well as descriptions of different portal structures aimed at the exchange of information between different parties involved in healthcare (amongst others Dyson et al. 2001; Puschmann 2000; Yücel 2009). 21.31 % of all relevant articles consider “information-based applications” for patients (amongst others Honekamp 2009; Stroth et al. 2007), physicians (amongst others Boulos et al. 2001; Koch 2010; Peiris et al. 2009) or other parties in the healthcare system (amongst others Nagel and Jähn 2004; Sass 2006; Sellerberg 2010). These include all applications which provide information for patients, physicians, etc. via information portals. 20.17 % of all articles deal with the subject of “interaction-based applications”, which are concerned with the exchange of information or data between parties with a direct response from the communication partner (e.g., Home

Fig. 1 Distribution of publications within the investigation period

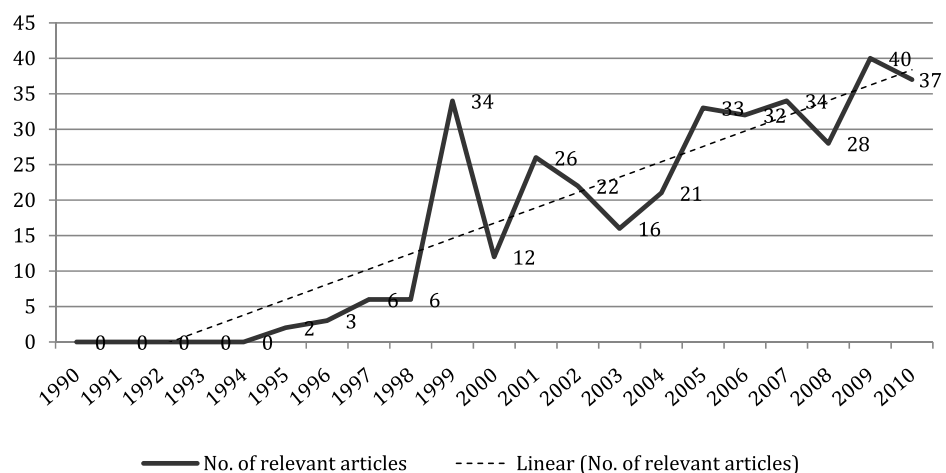


Table 4 Distribution of publications based on intended use of health information

		Medical						Total
		Professional development	Patient education	Research support	Public healthcare	Administration	No information/ not applicable	
Non-medical	Triage	0	1	0	0	0	1	2
	Diagnosis	0	2	0	0	0	2	4
	Non-surgical treatment	0	8	0	2	0	0	10
	Surgical treatment	0	0	0	0	0	0	0
	Consultation	3	23	0	2	7	10	45
	Monitoring	0	5	0	1	1	8	15
	Special treatment	0	0	0	0	0	0	0
	Supervision of primary care	0	0	0	0	1	1	2
	No information / not applicable	24	44	9	61	78	58	274
	Total	27	83	9	66	87	80	352

Monitoring), or the design, the implementation and the evaluation of virtual communities (amongst others Leimeister et al. 2005; Spallek et al. 2008; Wicks et al. 2010) or other health information media (u. a. Paul 2006; Zahedi and Song 2008). 13.07 % of articles consider “communication-based applications”, and the majority of these are studies concerned with the exchange of information of individual parties without a direct and immediate response from the communication partner through media such as e-mail (amongst others Brooks and Menachemi 2006; Franklin et al. 2006; Patterson et al. 2007; Singh et al. 2009), blogs (Kovic et al. 2008), or mobile applications (amongst others Königsmann et al. 2006; Meer and Simonin 2005). The smallest portion with 9.66 % is made up of articles on “integration-based applications”, which in the context of health are concerned with the life-long recording of all patient data relating to his/her state of health and the consolidation and completion of these data. A significant number of these publications undertake studies on the introduction, structure and adoption of the electronic health card or other similar applications (amongst others Hornung et al. 2005; Loos 2005; Schwarze et al. 2005) as well as considerations of the structure and design of regional, national or

international health networks (Schicker et al. 2007). Included in this are articles which consider personal or centrally managed electronic patient files from the perspective of integration between several stakeholder groups (“integrated electronic health record”) (amongst others Katehakis et al. 2001; Miller and Tucker 2009). In 6.53 % of all articles considered, the type of application could not be identified.

In relation to the intended purpose of health information, **Table 4** shows that 78 articles (sum of articles listed vertically in the table) consider health information in the context of medical aims. (Note: an article can be classified in such a way that it considers both medical as well as non-medical intended use.) In this context, patient advice is predominant (e.g., electronic physician consultations via Chat). Nevertheless, the majority of the studies (272) deal with non-medical intended use (sum of these articles listed horizontally in the table). Of these, 27 articles address the issue of professional medical development and 83 articles are concerned with patient education (e.g., websites with information on illnesses or medical technology). The largest portion of articles (87 out of 272) analyzes applications and services aimed at supporting administrative tasks.

43.18 % of all articles focus on the patient or insured individual or his/her relatives as the primary user group within the framework of Internet-based health information. Roughly one quarter of the articles examines more than one medical stakeholder group (patient and physician, physicians and the entire medical administrative apparatus, etc.). In 7.95 % of the articles analyzed, physicians are focused on as the primary user group. In 3.98 % of the articles medical or other researchers are considered as a user group. In 2.27 % of the articles, several medical administrative bodies are regarded as the primary user group and in 0.85 % healthcare professionals form the focus. In 16.19 % of cases, the articles are not concerned with any of the user groups in the framework, or the primary user groups cannot be identified. In a further stage of the analysis, the flows of information between the individual user groups and parties are of interest. **Table 5** summarizes these according to source and destination (sender/receiver).

In 164 articles the flow of information proceeds from the patient, for example in studies looking at virtual communities aiming at the exchange between patients themselves (Leimeister and Krcmar 2006; Leimeister et al. 2006) or between patients and physicians or healthcare professionals (van den Berg et al. 2007). In precisely one quarter of all articles the flow of information is instigated by several medical parties. This applies primarily to those studies dealing with electronic health (Loos 2005; Schwarze et al. 2005) and other data transfer methods from medical practitioners to other players in the healthcare system (Kassner 2006). In 24 of the publications analyzed, physicians constitute the source of the information flow. This is the case, for example, in studies of networking between physicians themselves (Heintze et al. 2004, 2006) or analyses concerned with physicians searching for information (Butzlaff et al. 2002; Reng et al. 2003). In total there are very few articles (approx. 6 %), in which only hospitals, insurance companies, state institutions, or other stakeholder groups are the starting or end point of the information flow. Nevertheless, a significant number of articles look at applications which support the flow of information between several medical parties or administrative bodies. On the receiving end of the information flow, several medical stakeholder groups make up about half of the addressees. This

Table 5 Distribution of publications based on information flows

		Receiver																				
		Patient	Physicians	Hospitals	Healthcare professionals	Pharmacists	Medical or business informatics researchers	Statutory or private health insurance co.	Medical councils	Hospital associations	Patient associations	(Umbrella) unions of insurance co.	Healthcare professional unions	Pharmacist Unions	Medical technology industry	Pharmaceutical industry	State organizations and institutes	Several medical parties	Several administrative bodies	None included or non-identifiable	Total	
Sender	Patient	8	17	4	4	0	2	3	0	0	0	0	0	0	1	0	4	11	7	2	2	16
	Physicians	3	5	0	0	0	2	0	0	0	0	0	0	0	0	0	2	11	0	1	4	24
	Hospitals	1	0	1	0	0	0	0	0	0	0	0	0	0	1	0	0	4	0	0	0	7
	Healthcare professionals	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
	Pharmacists	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Medical or business informatics researchers	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Statutory or private health insurance companies	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Medical councils	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Hospital associations	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Patient associations	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	(Umbrella) unions of insurance co.	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Healthcare professional unions	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Pharmacist unions	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Medical technology industry	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1
	Pharmaceutical industry	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	2
	State organizations and institutes	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	3	0	0	5
	Several medical parties	11	2	0	0	0	1	0	0	0	0	0	0	0	0	0	2	32	40	0	0	88
	Several administrative bodies	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	1	0	4
	None included or non-identifiable ^a	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	55	55
	Total	25	24	5	5	0	5	3	0	0	0	0	0	0	2	0	9	16	9	46	59	35
																					2	

Notes: ^a Either the article makes no mention of the stakeholder group in either a sender or receiver role in the information flow, or a sender or receiver cannot be clearly identified.

includes, for instance, telemedicine systems (Paul 2006) or personalized health records (Puschmann 2000), where often multiple receivers such as physicians, healthcare professionals, or administra-

tors can be addressed. In just 7.10 % of the articles, patients, insured individuals, or relatives are focused on as the receivers. Only 8 articles are dedicated explicitly to the information flow “Patient-

Patient” (Leimeister et al. 2005; Miller and Pole 2010; Zahedi and Song 2008).

The TEMPEST categories are also used in different ways in the analysis (Fig. 2).

The most frequently published stud-

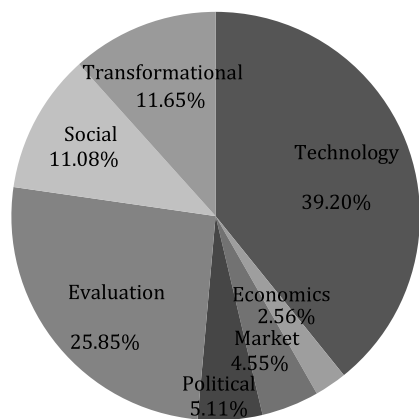


Fig. 2 Distribution of publications based on TEMPEST categories

ies in the research field to date are those which can be assigned to the “technology” category (39.20 %). This includes, for example, design-focused articles concerned with developing new technologies or standards (amongst others Braa et al. 2007; Leimeister and Krcmar 2005; Ure et al. 2009). The second largest category is “evaluation”, into which fall around 25.85 % of all publications analyzed. Articles in this category review the effectiveness of the implementation or use of Internet-based technologies as well as behavioral models (amongst others Angst and Agarwal 2009; Eminovic et al. 2004). This is followed by 11.65 % of articles which belong to the “transformational” category. These are mostly essays or commentaries (Della Mea 2001; Eysenbach 2001; Simborg 2010) which are concerned with reform agendas, e-Health strategies and their implementation. The smallest number of articles can be assigned to the categories of “market” (4.55 %) and “economic” (2.56 %).

In connection with the media used, **Table 6** shows transmission options and their division into asynchronous and synchronous communication. (Note: an article can be classified in such a way that it covers both synchronous as well as asynchronous transmission options.)

68 articles deal with technologies which support synchronous communication of data between stakeholder groups in the healthcare system (e.g., chats). Technologies which provide a combination of multiple media for synchronous communication (e.g., chat and video conference) could be identified in 48 articles. A considerably greater portion of the articles deals with technologies which enable asynchronous communication. In a

Table 6 Transmission properties of the ICT-media in the articles

		Asynchronous					Total
		Audio	Visual	Data	Combination (audio, video, and data)	No details given / not applicable	
Synchronous	Audio	0	0	0	0	0	0
	Visual	0	0	1	0	1	2
	Data	0	0	61	7	0	68
	Combination (audio, visual, and data)	0	0	2	45	1	48
	No details given / not applicable	0	0	170	8	56	234
	Total	0	0	234	60	58	352

total of 234 articles, the technologies considered are those aimed at supporting data communication (e.g., via direct exchange of data, telefax, email, websites, or Wikis), whilst in 60 articles multiple combinations of asynchronous modes of communication are considered (e.g., voicemail and video or audio streaming). In the analysis of the operating location (e.g., mobile, at home, in the hospital, etc., Tulu et al. 2005) the problem emerged that the majority of articles provided no or unclear details of the context in which the use of ICT occurs. As a result, only 15 articles, for example, could be placed clearly in the “mobile” category, whilst over 300 articles provided no or unspecific information and thus made any clear classification impossible.

4.2 Segment Specific Analysis of Literature with Regard to Research Approach and Method

As part of a segment specific analysis, this section investigates which research approach and methodology are used in those articles described in Sect. 4.1 in terms of their frequency. To this end, the following presents articles identified in the literature review based on the categories “type of application” and “TEMPEST category” described in Sect. 3, as well as looking at the research approaches on which they are based (theoretical, behavior-focused, design-focused) and their methodology (**Fig. 3**).

In total, 137 of the 352 articles adopt a behavior-centered approach whilst 74 design-focused articles carry out an empirical evaluation and 141 articles are purely theoretical or cannot be clearly categorized into a particular research approach. A nuanced consideration of the articles regarding their behavior-focused and design-centered research methods shows that 32.61 % of the behavior-focused articles are based on data collected from a survey. In 21.01 % of the behavior-focused articles the authors chose a multimethod approach comprising several methods (such as experiments and surveys or case studies or interviews and surveys). The majority of the design-focused articles (36.11 %) take a multimethod approach in their evaluation of a product. In 13.89 % of the identified articles it is the design-focused rather than the behavior-focused approaches – in the context of Internet-based health information – that draw on experiment results. Survey and interview results as well as the conclusions from one or more case studies are only used for the purposes of evaluation in 8.33 % of the articles.

As **Fig. 4** highlights, 30.43 % of the articles which consider “information-based applications” adopt a behavior-centered approach.

Following the articles on “integration-based applications”, articles on “communication-based applications” constitute the second smallest group within the analysis. Of those publications which ad-

Fig. 3 Percentages of individual research methods within behavioral and design-focused approaches

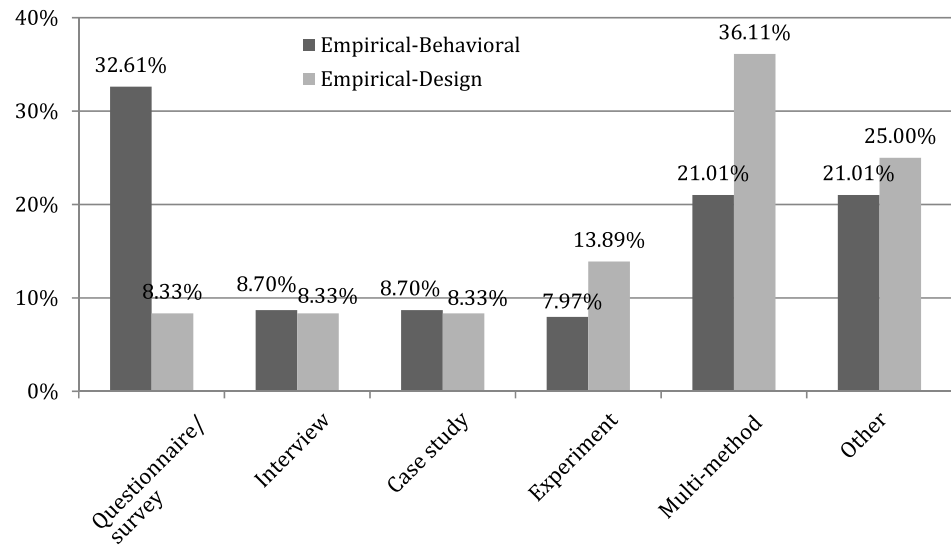
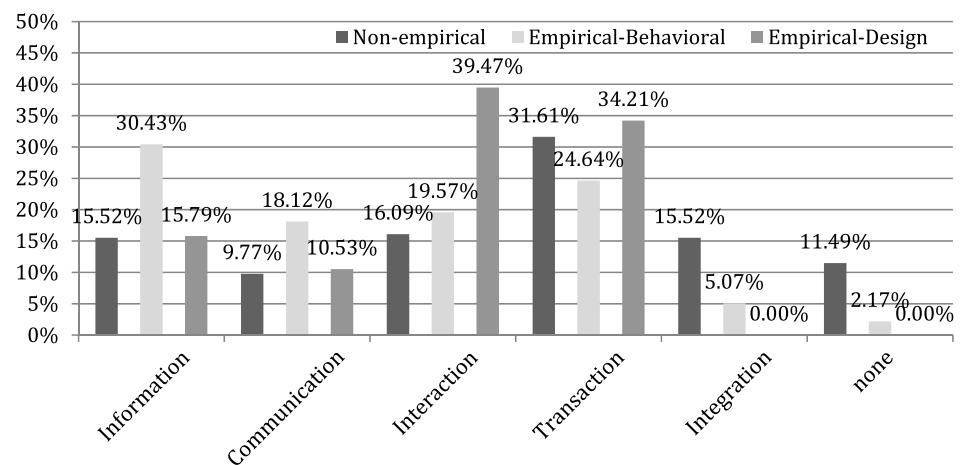


Fig. 4 Distribution of publications based on type of application and chosen research methodology



dress a communication-based application, the majority of these – 18.12 % – take a behavior-focused approach. This is not the case with “interaction-based applications” where most of the articles (39.47 %) are concerned with the design of an IT product and its evaluation. In “transaction-based applications”, proportionally the largest group of articles, the identified articles primarily take a design-centered approach (34.21 %). The smallest group of the overall investigation is made up by analyses of “integration-based applications” of which most – 15.52 % – are purely theoretical. Interestingly, in the 20 years covered the articles considered, none of the studies of integration-based applications have adopted a design-centered approach.

When the identified articles are considered in relation to a category within the TEMPEST model as well as the selected research approach, a very one-sided picture emerges as a result of the predominance of articles from the technology and

evaluation-based categories of the TEMPEST model (Fig. 5). Thus, 68.42 % of all articles which take a design-centered approach come from the technology category of the TEMPEST model. More than half of all theoretical articles – 51.72 % – can also be assigned to this category. Finally, 14.49 % of articles with a behavioral science background also fall into the technology category of the TEMPEST model. The second dominant group is made up of articles which fall into the “evaluation” category of the TEMPEST model. Thus, almost half of the studies with a behavior-focused approach – 49.28 % – belong to this category. Likewise, over a quarter of all design-centered studies – 28.95 % – also fall into this category. Again, of the articles which can be assigned to the social or transformational categories of the TEMPEST model, none take a design-centered approach. 16.67 % (social) or 2.90 % (transformational) of the articles from these categories are behavior-focused. Purely theo-

retical studies were identified in 9.20 % or 21.26 % of the identified articles belonging to the “social” or “transformational” categories, respectively. The “economic”, “market”, and “political” TEMPEST categories only play a minor role.

Finally, Fig. 6 demonstrates that an overwhelming majority of the articles on Internet-based health information considered so far can be seen assigned to an individual perspective. 86.23 % of all behavior-focused approaches in this field consider the role, actions, perception or significance of an individual player in the healthcare system (e.g., patient or physician). Similarly, 73.68 % of the design-centered studies also carry out their analysis at the individual level. Studies on an organizational level (e.g., within a hospital) are carried out in 21.05 % of the design-centered articles, in 10.92 % of the theoretical articles and in 7.25 % of those articles with a behavioral focus. Those studies which approach their analysis on the level of “industry” were conducted

Fig. 5 Distribution of publications based on TEMPEST category and chosen research method

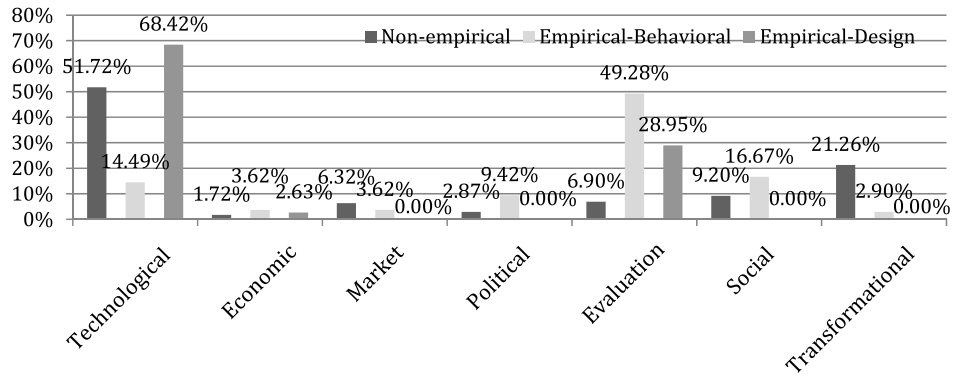
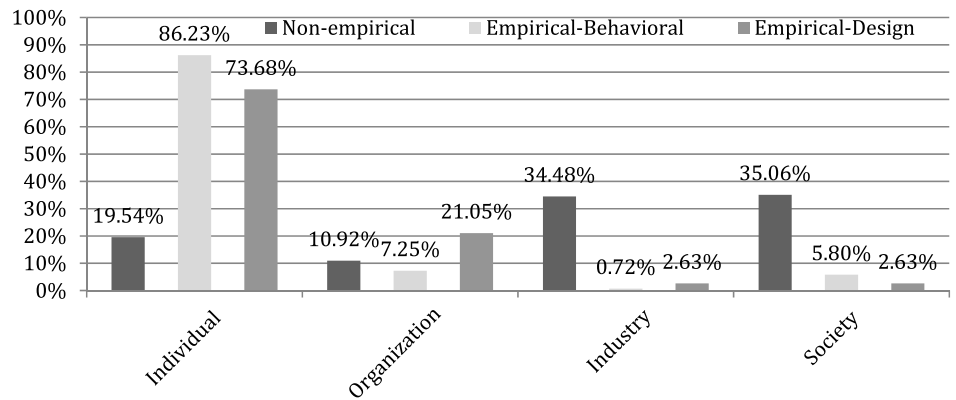


Fig. 6 Distribution of publications based on level of analysis and chosen research method



within a specific context, for example in the pharmaceutical or medicine technology industry. Over a third – 34.48 % – of the theoretical studies can be seen as dealing with this level of analysis. In design-centered studies and behavior-focused articles this analytical level plays almost no role. A similar picture also emerges in those studies looking at the social level; 35.06 % of the theoretical studies consider a topic from this level of analysis (e.g., essays).

4.2.1 Transfer and Translation Projects

A search of funding agencies’ databases produced a number of recent related research projects with a broad spectrum of aims in relation to the research field of Internet-based health information. A total of 51 projects were identified as relevant. Many of these research projects are presented extensively on the Internet (Table 7). Since however an evaluation of these projects using the selected criteria on the basis of their Internet presentation proved to be difficult, if not impossible, for a number of older projects (detailed information on some projects, for example, was no longer available), this idea was abandoned.

These projects conducted in the field of Internet-based health information span

from feasibility studies (e.g., the project “HEALTHSAT”, which analyses the feasibility of personalized satellite and Internet TVs) to the implementation of concrete, patented applications (e.g., the project “TexVital” in which sensors integrated into home textiles acquire and analyze vital data and transfer these over the Internet). Within the individual research projects, applications are already being developed which should make access to and the reception of Internet-based health information much easier for patients. For example, as part of the BMBF project “E-Health@Home” or the EU projects “OLDES” and “SAAPHO” applications have been developed which enable elderly people to live as long as possible in their own homes. In the framework of the EU project “E-REMEDY” applications supporting patients in their rehabilitation have been conceived and implemented. The provision of health information to decision makers is addressed in, for example, the EU project “Henvinet” which has implemented a network platform for the exchange of information. Equally, the support of terminally or chronically ill patients with the help of ICT is very often the focal point, for example in the BMBF projects “PAALiativ” and “INSPIRE” or the EU-/BMBF project “REMOTE”. In the field of

palliative care or palliative medicine using Ambient Assisted Living approaches, “PAALiativ” develops products for the technical support of people in their last years of life so that they can spend the time that they have left in familiar surroundings. A part of this is an Internet-based “home communications platform” which provides all interested parties with relevant information.

5 Discussion

The analysis of research conducted on the theme of Internet-based health information has shown that in relation to the type of application, one third of the studies look at classic e-health applications such as “transaction-based applications”. This is followed by “information-based applications” which can be counted as belonging to the core area of Internet-based health information. Around one third of the studies deal with “interaction-based applications” and “communication-based applications” without direct and immediate response from the communication partner through media such as email. Against this background of the increasing importance of Health 2.0 applications, it is to be expected that research projects in

Table 7 Selected research projects presented on the Internet

Project (URL)	Funding body	Duration	Brief description
3LGM ² (http://www.3lgm2.de)	DFG	2003–2008	Description, evaluation, and planning of information systems in the healthcare system
Agent system architects for active medical documents and information logistics in multi-contextual domains (http://mcceh.in.tum.de/projects_5)	DFG	2000–2007	Use of medical data by software agents
cloud4health (http://www.cloud4health.de)	BMW i	2011–2014	Provision of a Cloud infrastructure for e-health applications
COSMOS (http://mcceh.in.tum.de/projects_6)	BMBF	2001–2005	Community Engineering for Healthcare Communities
The influence of single case information from the Internet on the evaluation of vaccination risks – facilitators and processes	DFG	since 2009	Influence of Internet on the perception of the risks of vaccinating babies and infants
E-Health@Home (http://www.e-health-at-home.de)	BMBF	2008–2011	Support of elderly patients
E-REMEDY	EU	2001–2002	Rehabilitation support
Research map E-Health@Home (http://www.iat.eu/ehealth/index.php)	BMBF	–	Overview of projects from the field of telemedicine and Ambient Assisted Living
Health coach (http://www.connected-living.org/projekte/gesundheitscoach/)	BMW i	2011–2013	Support of preventive healthcare
HEALTHSAT (http://www.healthsat.org)	EU	2000–2003	Distribution of personalized health information via satellite and Internet
HENVINET (http://www.henvinet.eu)	EU	2006–2010	Support and knowledge transfer for decision makers in the healthcare system
HOMEY (http://www.openclinical.org/prj_homey.html)	EU	2001–2004	Internet-based dialogue system for home monitoring
INFOGENMED (http://www.infogenmed.net)	EU	2002–2004	Access to medical data
INSPIRE (http://www.inspire-healthcare.de)	BMBF	2010–2013	IT support for the care of stroke patients
IT EDUCTRA	EU	1996–1998	IT-professional development for healthcare professionals
Mobi-Dev (http://mobidev.informadoc.net)	EU	2001–20003	Mobile support in the healthcare system
NEUROWEB (http://nuke.neurowebkc.eu)	EU	2006–2008	Access to medical data
OLDES (http://www.oldes.eu/)	EU	2007–2009	Support of the elderly
PAALiativ (http://www.paaliativ.de)	BMBF	2009–2012	Support of terminally ill people
PeHeaMoN (http://www.phmon.de)	BMBF	2001–2005	Measurement of a patient's vital parameters
Public Health-Portal (http://www.ph-portal.info)	BMBF	2001–2003	Construction of an Internet portal on the theme of Public Health
REMOTE (http://www.remote-project.eu)	EU/BMBF	2009–2012	Support of older chronically ill patients
SAAPHO (http://www.saapho.eu)	EU	2011–2014	Support of the elderly
SPRINT (http://www.projekt-sprint.de)	BMBF	2007–2010	Development of a Personal Health Manager
TEDIANET (http://www.tedianet.org)	BMBF	2002–2006	Support for mobile patient-monitoring
TeleCARE (http://www.uninova.pt/~telecare/)	EU	2001–2004	Monitoring of elderly patients
TELEMEDICARE (http://www.telemedicare.net)	EU	2000–2002	Support of Home Monitoring
TESEMED	EU	1996–1998	Provision of information on medicines
TexVital (http://www.iaq-hd.de/index.php?id=44)	BMBF	2010–2013	Textile-integrated acquisition, analysis and transfer of data

the field of “interaction-based applications” will increase in the future. In particular, studies on the design of patient-centered Health 2.0 applications, their benefits and risks can also be expected to gain in importance. These also include mobile applications which provide both patients as well as other stakeholder groups in the healthcare system with in-

formation which is accessible from anywhere and at any time (Eymann et al. 2008; Sackmann et al. 2002). Yet the “classic” communication-based applications also leave room for further studies, investigating, for example, the design and effectiveness of e-mail consultations.

It is further to be expected that “integration-based applications”, which

are concerned with the life-long recording of a patient's data on his/her state of health and the consolidation and completion of these data, will also gain in significance as an area of research. In many countries such applications are already in the process of being set up (electronic health card in Germany (Dünnebeil et al. 2013; Frießem et al. 2005; Häber 2008;

Heinz 2009; Knipfl and Sunyaev 2011)) and in others these are already reality (e.g., the national health portal “sundhed.dk” in Denmark). There are also personalized patient records. In this context, there is a need for research into the effectiveness and efficiency of different approaches, how they compare with one another, their transferability as well as an analysis of their impact on the different stakeholder groups. This is particularly valid in the context of the access to and the provision of health information. Connected to this are legal questions about the management of personal data, their availability on the Internet, privacy and data protection (Blobel 2011; Schmücker 2006a, 2006b). Whilst great potential lies in Health 2.0’s ability to give other users controlled access to private and medical data (e.g., through personally managed patient records), this also gives rise to complicated data protection problems. Currently, little is known about users’ actual perception of data protection problems and privacy. Patients are in the position to demand more than a mere institutional “portal” which gives them access to health information and their data, but which does not give them full control over those data (Eysenbach 2008b).

In relation to user groups, the majority of the articles in the context of Internet-based health information so far focus on the patient or insured individual or his/her relatives as the primary user group. Equally, patients often play the role of sender in these information flows. Nevertheless, the information flow analyzed is often directed at several receivers; to date, there has been no detailed or extensive examination of the exchange between patients or between patient and physician. As far as Germany is concerned, what is most interesting is the fact that in the articles studied so far, insurance companies and patient associations feature neither as senders nor receivers. Their role is therefore unclear, or it remains to be looked at in detail. Equally, state institutions have played only a minor role in research conducted to date on Internet-based health research. Here, there is a need for more research on a national as well as international level.

With regard to the TEMPEST model, as is to be expected there are numerous studies which fit into the “technology” and “evaluation” categories. These align very easily with the core subject

area of business informatics. An interesting further area of research is provided in this context by virtual communities and social network sites as their influence on long-term user behavior, especially in connection with health issues, has hardly been looked at to date. It could, for example, be interesting to consider whether users change their behavior concerning health issues in the long term on the basis of health information which they have received from other members of the community. Social network sites can serve as the key application in, for example, motivating patients to manage their health records themselves, taking responsibility for their health and maintaining their long-term interest (Eysenbach 2008b).

In contrast, studies on other factors such as the economic categories “market” and “economy” are markedly underrepresented. In this context, there is room for further research on, for example, organizational issues such as participation, quality assurance and standardization or on business models relating to all aspects of Internet-based health information and Health 2.0. In this context, the so-called “long tail” effect of the Internet for patients with rare illnesses or in geographically isolated places has great potential (Eysenbach 2008b). The “long tail” includes the numerous individuals and groups who are normally not of interest for a particular focus because they do not represent the “average case” (Anderson 2004).

Amongst the research approaches and methods used to date, behavior-centered research projects and theoretical articles dominate (e.g., commentaries and essays). Nevertheless, amongst the applied research projects, a majority pursues design-centered research. Here, most of the projects have as their aim the manufacture of products in the form of applications designed to support patients or other target groups. At the same time, the increasing importance of integration efforts across the whole spectrum of the healthcare system on the one hand and patient-centered Health 2.0 applications on the other also presents numerous possibilities for manufacture and design-centered research, for example in the implementation and evaluation of conclusions from behavior-centered research conducted to date on the use of Internet-based health information in specific IT products. Further, regarding the concrete research methods used

in both behavior-centered and design-centered research there is great potential for a greater implementation of experimental approaches, for instance in interdisciplinary collaborations between medical or health researchers in the framework of randomized studies on the evidence-based evaluation of the usefulness of Internet-based health information or IT products for the improvement of an individual’s state of health (Prokosch and Ganslandt 2009). In this context the interdisciplinary set-up of infrastructure platforms takes on a greater significance (Prokosch et al. 2011).

In addition, research on Internet-based health insurance to date is dominated by studies of the individual as object of study. But it is precisely social network sites and virtual communities that present an opportunity for analyses of social networks and on a group level. Conversely, on the industrial or social level many questions are raised, for example regarding transnational integration, standardization and social ramifications.

The Internet is the first universal medium in the sense that it can serve as a medium for every kind of communication and interaction (Shirky 2008). In this, it overcomes the restrictions faced by traditional media (e.g., letters, newspapers, television, or radio) and supports every desired configuration of direction, number of participants and synchronization (Hagemann 2009, p. 20). The effects of this medium on the availability of health information still cannot be predicted. Existing patient-centered Health 2.0 applications are already making clear, however, that we have access to concepts and technologies which enable the transmission of knowledge, the answering of questions and the search for health information in a way that complements or bypasses traditional transmitters or “gatekeepers”, or indeed that can even surpass their capability (Eysenbach 2008a, 2008b). Nevertheless, the preference for the use of an intermediary (e.g., of a physician) can be heavily dependent on situation and context (Eysenbach 2008b). Possible key factors in the rejection of an intermediary are autonomy, confidence and domain-specific knowledge. Thus, whilst, for example, a patient might prefer an intermediary in the beginning, with increasing autonomy, confidence and knowledge the same patient might come to prefer Health 2.0 approaches. To date, no studies exist of

the effects of Internet-based health information on later behavior and it remains open whether and under which conditions Health 2.0 is better suited as an intermediation model. In any case, Internet-based, patient-centered Health 2.0 applications will not be able to solve the fundamental problems of healthcare. Nevertheless, in connection with other technologies such as personalized health portals, intelligent telemedicine or integrated infrastructure platforms they could play a critical role in healthcare (Jadad 2004).

6 Summary and Outlook

On the basis of a comprehensive literature analysis and an analysis of existing transfer and translation projects, this study has presented an overview of the current state of research in the field of Internet-based health information in order to highlight possible starting points and areas for future research. In the field of pure research, mainly aspects relating to health information and patient centeredness as well as the dissemination of health information via the Internet were considered. Within the area of applied research the focus lies predominantly on the development of products to support patients.

It is important to note, however, that the literature review is restricted in terms of its selection of sources. This article does not lay claim to completeness. A literature review cannot possibly collate all potentially relevant sources and it is inevitably subjective in its selection. For example, no databases from the medical context were used (e.g., the well-known Cochrane database). In order to classify the selected literature, an analytical framework was defined which incorporated both structural components as well as content-based components. On this basis, a total of 352 relevant articles were analyzed. The key conclusions of the review are:

- focus on transaction-based applications,
- patient-centered provision of information,
- focus of information flow: patient and multiple healthcare stakeholders,
- predominance of the “technology” TEMPEST category,
- predominantly theoretical and behavior-centered research approaches, and

- majority of research done at the individual level.

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Abstract

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Health Information on the Internet

State of the Art and Analysis

Electronic Health (e-Health) increasingly strives to provide health information and services to healthcare stakeholders via the Internet, and to actively involve patients in their care. One major chance for these participatory healthcare and patient-centered approaches that integrate patients in healthcare are the phenomena and ideas associated with providing information and healthcare on the Internet. This paper examines the existing body of knowledge on online health information and explores the current state of research through a review of literature as well as past and current research projects. The fundamental categories of the analysis represent the stakeholders in the healthcare sector, the connecting information flows, the information-transferring technological applications, as well as the categories of the TEMPEST model. Based on these findings, causes and future research fields are discussed. The technological category has the largest share of all categories. Based on these findings, causes and future research fields are discussed.

Keywords: Health information, Internet, Health 2.0, Literature review, TEMPEST-model

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