

# Medical and Care Compunetics

## The Future of Patient-Related ICT

Drs Lodewijk Bos<sup>1</sup>  
*President ICMCC*

**Abstract:** This article deals with the role of compunetics in the future of patient-related ICT. Information supply, knowledge centers, gathering of personal and secondary data, the role of patient and professional networks, e-learning are the topics covered here.

### Introduction

Compunetics deals with ICT, Information, Communication and Technology. The word Compunetics is derived from the combination of Computing and Networking [1] but the new term allowed including social aspects, becoming “computing and social and technical networking”. [2]. Now, three years after the introduction of the word, it can be defined as the field concerned with the social, societal and ethical implications of computing and networking (**COMPU**ting & **Netwo**rking, its **ETH**ICs and **Social**/societal implications). The concept of compunetics was first applied in the area of medicine and care by ICMCC (the International Council on Medical & Care Compunetics) and is quickly gaining ground. [47][17] A logical consequence of this concept is the now emerging field of behavioral compunetics.

### 1. Information

Information is the core of our modern society, as it is the basic ingredient of the knowledge society. It can be defined as: “data that have been organized and communicated” (Quote from Marc Porat). [3] “In the early nineties, under the aegis of the United States National Information Infrastructure, the Internet facilitated the creation of an “information-for-all” environment. Despite the unstructured nature of its existence, the Internet has seen an unprecedented global growth in its role as a promoter of information solutions to the citizens of the world” wrote one of the ICMCC founder fathers Swamy Laxminarayan [4]. Information should be made available in as broad a way as possible to the citizen as well as the professional. In health, for both target groups the largest network in the world, the World Wide Web, will be the source of information in the future. However, there is a problem with the web.

---

<sup>1</sup> ICMCC, Stationsstraat 38, 3511 EG Utrecht  
[www.icmcc.org](http://www.icmcc.org), [lobos@icmcc.org](mailto:lobos@icmcc.org)

- In the day of books and classical libraries, you knew where to find your information, in what specific book, on what specific shelf.
- There were, and are, ways – standards – how to find information in libraries even if you didn't know in advance what you were looking for. If you had trouble finding it, there was always someone who could point out a starting point or who would mention a recent addition to the material of your subject. And afterwards you would remember where that information was physically stored.
- If you had doubts about the reliability of the information that same person, the librarian, could help you, from his experience and knowledge.

We all have had numerous moments of frustration when discovering that you could not repeat the steps you took on the internet that caused you to stumble upon certain information and therefore the information was lost to you. Since a while, we see all kinds of web facilities coming up to bookmark that information and annotate it. We have to learn to create our own librarian.

In our days, information is available in abundance. Through publications, research communities, international projects, more and more people have access to information. Especially in the health area there is a need for it. "The number of U.S. adults who have ever gone online to look for health or medical information has increased to approximately 117 million, up from about 111 million last year (2004) [...] Almost six in 10 (58%) say that they have looked for information about health topics often (25%) or sometimes (33%), an increase of eight percentage points from 2004 (50%)." [5]

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

Research has taught us that information on the internet is often biased or plain simply wrong. [7] Most people have no way to recognize this. In a qualitative study, using focus groups, the researchers concluded: "The results showed that there was a range of search and appraisal skills among participants, with many reporting a limited awareness of how they found and evaluated Internet-based information on medicines. Poor interpretation of written information on medicines has been shown to lead to anxiety and poor compliance to therapy. This issue is more important for Internet-based information since it is not subject to quality control and standardization as is written information on medicines. Therefore, there is a need for promoting consumer search and appraisal skills when using this information. Educating consumers in how to find and interpret Internet-based information on medicines may help them use their medicines in a safer and more-effective way." [8] As all the information is freely available, the internet information supply might be seen as one of the leading problems in patient safety in the coming decade. It is relatively easy to find agreements or standards on any other aspect of patient safety; it will be hard, maybe even impossible

to do so for the web, although there are a number of initiatives for quality labelling. [9][10][11] “Regulation does not seem like the right strategy for improving the quality of health information on the internet. Other approaches, such as educating the producers of this content, look like a better long term bet. However, such initiatives should not hinder the evolution of communities, resources, and processes that are improving healthcare outcomes.” [12]

## **2. Knowledge centre**

With the right of the individual to be informed a whole new problem emerges related to those who are involved in decision making processes concerning the individual. For with the empowerment of the individual, the classical way of decision making will disappear and the individual, the citizen, the consumer, the patient will either want to know on which information decisions are based and might want to verify that information, or will possess knowledge exceeding that of the decision maker, in casu the caregiver (a growing phenomenon in the medical world called “expert patient”). This is a double edged sword, for it means that the information and knowledge accessible to the decision maker should be made available to the individual and the decision maker should be able to quickly acquire the information and knowledge that he seems to lack. However, “[i]f we assume that about 1% of the new literature added every year is of relevance to a healthcare stakeholder, then it would still take a stakeholder 10 years (reading an average of one article a day) to be updated with the healthcare advances of 1 year.” [13]

On the other side, “[b]roadly speaking, the patient’s perspective of healthcare knowledge sharing aims to educate and empower patients [...] to understand their health condition and to self-manage their healthcare process. This aim is pursued by facilitating the provision of online patient-specific healthcare knowledge [...] in a proactive and timely manner through patient education and support programs.” [14]

And that is where knowledge centres based on the principle of compunetics will play an essential role.

There are ways to organise knowledge in a central semi-controlled, nevertheless open way, a knowledge centre. Avoiding the reinvention of the wheel as well as redundancy of science, research and experience, is a key argument in favour of those centres. We should develop the wheel, not reinvent it time and again due to the fact that we don’t know what knowledge and information is available. An inventory, a knowledge centre, could not only help to save billions of dollars a year by avoiding redundancy, could not only be an important source of knowledge to professionals, caregivers and policy makers, it could also be the basic information needed to assist in building new infrastructures.

Davenport et al. define knowledge as “a fluid mix of framed experience, values, contextual information, and expert insight that provides a framework for evaluating and incorporating new experiences and information. It originates and is applied in the minds of knowers. In organizations, it often becomes embedded not only in documents or repositories but also in organizational routines, process, practices, and norms” [15]. In this paper a shorter definition is used: Knowledge is information combined with experience. That is why best practices (evidence-based medicine) have become such an important concept in the informational health society. And we have to bring those

together. “At an individual level [evidence-based medicine] is a way of helping health practitioners who are overwhelmed with the information explosion.” [16] But not only best practices; failures and disappointments are often more important in the learning process. They should be included as well, if only to avoid that others have to go through the same experience.

Knowledge centres should be about knowledge sharing, between individuals, providers, professionals and projects. Therefore, it will be necessary to start knowledge centres that will focus on the inventory of a particular field and that will help to identify gaps in research and development and will stimulate or even initiate work to fill those gaps. As described above, especially in medicine and care such centres will be of extreme importance. These will be centres of sustainable knowledge of benefit on strategy and policy level as well as on the personal level of the individual. Knowledge centres will also be able to stimulate research in areas that lack sufficient attention, at the same time, as an independent institute, bringing global coordination in ongoing work like (bio)medical technology, disease surveillance and bioterrorism.

In the near future, many facets of (bio)medical technology and their products will get closer to the citizen, causing his interest in the matter to grow. A knowledge centre will also be a citizen portal of access to global knowledge, thus helping him to make informed decisions about his health and well-being. This possibility to control decisions that impact an individual’s life is called empowerment.

“Applied compunetics to support the public health mission of disease mitigation offers system users an opportunity to have the right tools at the right time in which to make the right decisions. Preparedness for disease outbreaks will, in part, be a function of rapid detection and action. Rapid detection equates to identifying indicators that an outbreak is likely. Build the right public health electronic environment and the technologist will be as valuable as the first responder to mitigating disease impacts.” [17]

“Computing and high speed communications are not only enabling governmental and secular institutions around the world at an unprecedented rate; the combination of these two synergistic technologies is even transforming the way we think of humanity and human potential. They are unveiling deep structure in the behavioral and social sciences that may forever alter the way we look at our selves and interact with others. These new technologies and methodologies are fundamentally changing the way we are approaching the prevention and management of large-scale social crisis.” [18]

A small example of such a knowledge center is the portal on Record Access created on the ICMCC website. This portal is the first in its kind, where most of the (scientific) information on the access of patients to their electronic health records is gathered [19]. Discussion platforms are being created to enable exchange of ideas and experiences, also between the professionals and the consumers. Other examples could be the areas of assistive technology and digital homecare.

### **3. Networks**

The internet is not only the leading source of information, it is also becoming one of the leading communication tools, especially in its capacity as facilitator of networks. In the concept of compunetics social, societal and ethical implications play a key role. Networks are a major example of the social and societal aspects. “The extraordinary value of [ICTs] lies not only in the information that can now be exchanged but also in

their ability to bring people together to build and shape partnerships and a joint programme of action, enabling more informed decision-making and more cost-effective use of resources.” [20]

Communication (and therefore networking) is an essential element in the knowledge society. In medicine and care this means communication between researchers and their tools, between caregivers and their tools, between all those tools, but above all between any of the aforementioned and the patient and between patients.

Of growing importance on the internet are networks of patients, often called support groups.

“Rather than worrying about "the quality of medical content" on the Internet, as many medical professionals do, patients figured out that the most effective strategy was to organize social networks focusing on specific healthcare issues. The power of these healthcare-oriented social networks can be quite phenomenal. Having good "medical content" may well be useful, but being able to tap into the expertise of hundreds or thousands of e-patients around the globe is considerably more powerful. The amazing thing is that patients figured this out a long time ago, while most healthcare professionals still don't really get it.” [21]

“The patients who produce these sites certainly don't know everything a physician might know, but they don't need to. Good clinicians must have an in-depth working knowledge of the ills they see frequently and must know at least a little about hundreds of conditions they rarely or never see. Online self-helpers, on the other hand will typically know only about their own disease, but some will have an impressive and up-to-date knowledge of the best sources, centers, treatments, research, and specialists for this condition. A smart, motivated, and experienced self-helper with hemophilia, narcolepsy, hemochromatosis or any number of rare genetic conditions may well know more about current research and treatments for their disease than their own primary practitioner. And when it comes to aspects illness that some clinicians may consider secondary-e.g., practical coping tips and the psychological and social aspects of living with the condition-some experienced self-helpers can provide other patients with particularly helpful advice. The things clinicians know and the things self-helpers know can complement each other in some interesting and useful ways.” [22]

Also the caregiver might benefit from social networks. “Knowledge sharing through discussion forums has both a problem-solving aspect and learning aspect to it, because observing practitioners not only learn about a potential solution to a atypical clinical problem, but, as the discussion unfolds, they also observe the tacit problem-solving strategy and reasoning methods employed by specialist practitioners. [...] Sharing the tacit knowledge of healthcare experts, via socialization, can assist fellow practitioners in terms of providing them practical insights into what solution will work, why it will work, and how to make it work.” [14] A very recent example is the Ask Dr Wiki site opened in March 2007. [23]

The interaction between the networks of these two groups, patients and caregivers is becoming more important.

“These online community networks do not replace traditional research channels or the healthcare process, including doctors visits, but they do augment it and improve it by leveraging the organizational, analytic, and communicative ability of a few to inform, support, and guide many. Although online patient networks are run by patients

for patients, we think that if providers are integrated into these networks, quality can be improved and errors reduced. Healthcare professionals can seed the communities with quality scientific information, which will augment the experiences being shared.” [24]

Not only do these groups provide exchange of information between participants, they can also be assistant in research. “The prospect of research-oriented online support groups offers a number of appealing scenarios. Patient groups could design and conduct their own studies, collecting their own data, analyzing their results, and publishing their results. They could provide researchers with access to perfectly targeted study populations at little or no cost. But whatever role they play, once they become active players in medical research, patient groups will demand a voice in deciding what should be studied and how that research will be conducted. And while such e-patient initiatives may encounter some resistance, in the end it seems likely that the financially-strapped medical research establishment will come to consider such e-patient research an offer it can't afford to refuse.” [25] A recent example is a project from the Kennedy Krieger Institute, started in April 2007. “IAN, the Interactive Autism Network, is an innovative online project designed to accelerate the pace of autism research by linking researchers and families.” [26]

The exchange of experience will not only play an essential role in decision making, it will also help to overcome health inequalities.

#### **4. Data**

The term “data” is commonly used to indicate the basic elements for scientific research. In the context of this paper on medical and care compunetics we look at two different sets of data: personal and secondary.

##### *4.1. Personal data*

For the patient to have access to the appropriate information to make informed decisions, access to his personal health information is elementary. Record Access (RA) is an essential part of patient empowerment also because it enables the patient to have control over his treatments. The Electronic Health Record (EHR) will be the central container of data about a specific patient. A number of different names are circulating to indicate the various elements of the EHR, namely the EMR (Electronic Medical Record), PHR (Personal Health Record), CCR (Continuity of Care Record) [27]. Discussions are ongoing about the differences between these terminologies and how the various elements can or should be combined. [28]

In this paper the EHR is seen as the final storage of all information concerning the patient:

- medical and care information;
- monitoring data from external sources;
- personal input from the patient.

In my view, all medical and care data concerning a person should be gathered in one “document” that should be, in principle, fully accessible to the individual (examples of exceptions are young children and mentally incapacitated persons). Caregivers and other persons of his choice should also have access; whether third party

access should be full depends on the indication of the owner of the record and the role of the caregiver.

“The benefits of RA appear to be substantial. Patients describe improved trust in their doctors, improved confidence in their clinicians, and they feel more informed and in control of their condition and its management. There is some evidence for improved health practices by patients – for example, improved compliance in heart failure. In general, patients are keen on RA in principle and in practice. Additional advantages of RA include that it can be used to reduce recording errors and thus increase patient safety, and that patients looking up information in their records can save time for practices.” [29]

#### *4.1.1. Medical and care information*

All information concerning the individual’s health, condition and treatment should be included in the EHR. This will help to build an overview of on-going treatments and exams, avoid duplication of exams – because they are requested by a different doctor or institution – and will also be a tool in helping to avoid medication errors/interactions. It will also create a personal health history from which both patient and caregiver can benefit. Care related information (e.g. information from nurses, physiotherapists) should be included in the EHR as well to complete the patient’s medical picture.

“Over time these may join up to provide a “clinical pathway” highlighting the journey a patient makes as they move from one stage of management to another.” [30]

Communication between doctors and patient as well as between doctors should also be part of the EHR. “Many physicians who began exchanging email with their patients because of repeated requests from patients have become active promoters of doctor-patient email because of its benefits for physicians and provider organizations.” [31]

#### *4.1.2. Monitoring data from external sources*

With the growing development of digital homecare and other ways of monitoring and tele-medicine, the data gathered by these procedures will also have to be included in the EHR. It can be discussed in which form this should be done, like weekly summaries or development curves.

“Today, with the huge amounts of medical data and information and the growing number of medical information systems, there is an increasing need for medical information that is complete, homogeneous, precise, updated, reliable and accessible at the point of care. Information based on the historical medical data of the patient collected in real time from all relevant internal and external sources can be the basis for an optimal decision-making process. This information is essential to insure the quality of the medical care process and healthcare service and it needs to be provided effectively and efficiently utilizing all the sophisticated techniques for collecting, browsing and presenting data that today’s information technology has to offer.” [32]

Integration and interoperability are key issues to achieve the gathering and storage of these data. “Interoperability implies a number of different concepts, e.g. functional interoperability and internetworking, semantic interoperability and application gateways. Health information integration (eHealth) established a demand for interoperability between clinical and healthcare-related stakeholders, systems and processes or workflows. Domain-specific communication and interoperability standards are well established, but have to be supplemented for trans-domain use.” [33]

#### 4.1.3. *Personal input from the patient*

Patients should be encouraged to input their own health observations. Personal habits, use of over-the-counter drugs, sleeping problems, alcohol and recreational drug use but also work or relationship related stress are some examples of what could be included. “Illness narratives refer to the reflective and insightful autobiographical accounts of illness. They are not merely chronicles of events but can also provide valuable insights in how patienthood, brought upon by the assaults of illness, is experienced as a disruption of selfhood. [...] Stories have a recuperative role and can be used to recuperate persons, relationships, and communities. [...] Narratives shared over a prolonged time allow strong bonds to be formed, engendering trust and effective care.” [34]

“Accessing medical records has also shown improvements on patients’ education, a better knowledge of the disease and more participation in their health treatment. Improvements on adherence made patients more careful in following medical recommendations and provided for self-empowerment. It allowed them more autonomy and self-efficacy by increasing a sense of ownership to their medical records. [...] The access to medical records helps correcting errors and omissions but patients can also make unauthorized additions or deletions.” [35] Nevertheless, patients should be able to point out possible errors in the record and request for correction.

To be able to provide the patient with optimal information about his condition the data in the EHR should be linked to independent and accurate information on the internet. From there the patient should be able to make further searches to information. This is where knowledge centres can play a major role.

#### 4.2. *Secondary data*

Secondary data are data derived from other data sets.

Data gathered anonymously from the **EHRs**, medical, personal as well as from digital monitoring, can be used for research purposes e.g. for epidemic and pandemic surveillances. Other data to be used are:

- Pharmaceutical and Over-the-Counter Sales
- Hospital Emergency Department and Emergency Medical Services Encounter Data
- General Information “Hot Lines”
- School and Work Absenteeism
- Animal Disease Reporting
- Medical Examiner Reports
- Hospital Discharge Data [36]

“Healthcare at the moment is a reactive process; we should be turning it round to proactive productive testing to prevent people from being ill. We could get a much better profile for diseases and use predictive profiles to help or to warn people in advance. [...] People must realise we are what we eat and breathe.” (quote from Prof. Michel ThicK) [37]

Another aspect is that the use of these data “is expected to streamline patient check-in, provide up-to-date health information, support referrals among providers,

facilitate parent access to immunization and other records, automate patient appointment reminders and promote access to preventative health information.” [38] Use of these data can “enable health risk assessment, determine an individual’s baseline susceptibility to disease, their current health status and current risks for major, chronic or uniquely inherited diseases. [...] the individual and their provider should develop a strategic health plan to mitigate risk and track health status in order to determine if any particular diseases are developing.” [39]

“A major attraction of the [EHR] is the potential that it creates for conducting records-based clinical research, epidemiological studies and quality monitoring on very large data sets. However, it is in breach of European privacy standards to use data in this way originally collected for the purpose of providing healthcare to the individual. This could be achieved by incorporating into the information charter references to use personal health records without patient’s explicit consent for the purpose of clinical audit, performance review, research, epidemiology and other activities deemed necessary for provision of high quality healthcare. It will also be necessary to identify under what circumstances the patient’s consent would be sought.” [40]

“In today’s global community the ability to prepare for a disease outbreak in order to mitigate the public health, social, and economic impacts on a community depends upon data to support the decision and response process. Data can come from a variety of sources. These sources not only include the medical and health care community, but also geographic, demographic, and socio-economic data. The ability to capture and utilise the data effectively from these types of data sources can mean the difference between a manageable disease outbreak that represents little or no threat to a community and one that causes a significant social and economic impact.” [17]

“[I]n the case of the US population (compared to the rest of the world) this society is much more “transient” or mobile. As people move seeking better job-opportunities, the associated consequence is that the individuals will be seeking care in the new locations which generates having scattered medical records. Not having the complete picture is a problem that not only can generate “medical errors”, but does not allow those caring for the individual to have the information needed to do to risk assessment / management, prevention, and disease management. In the future as we evolve our system more into the phase of prevention, the “total picture” will be even more critical since genetic information could be associated with environmental data for example (i.e. quality of air, water, etc.)” [18]

Another aspect of gathering secondary data is **social networking analysis**. On the level of healthcare professionals knowledge flows and knowledge gaps in healthcare providers can be identified by social network analysis which can also examine different types of knowledge applies by healthcare professionals. [41] It would be interesting to see if these procedures could also be used for patient networks.

A third aspect would be the analysis of the way health information sites are being used, e.g. using **click-through analysis**. It could be a tool to provide information to the patient in a more efficient and consistent way as it would give indications of the information needs of the patient. A study analyzing how users interact with the list of ranked results (i.e. the “results page” for short) from the Google search engine and how their behaviour can be interpreted as relevance judgments shows “that users make informed decisions among the abstracts they observe and that clicks reflect relevance judgments. However, we show that clicking decisions are biased in at least two ways.

First, we show that there is a “trust bias” which leads to more clicks on links ranked highly by Google, even if those abstracts are less relevant than other abstracts the user viewed. Second, there is a “quality bias”: the users’ clicking decision is not only influenced by the relevance of the clicked link, but also by the overall quality of the other abstracts in the ranking. This shows that clicks have to be interpreted relative to the order of presentation and relative to the other abstracts.” [42]

Data sets should be linked to provide a maximum effect. This is where interoperability plays a key role.

“Surveillance systems reduce the risk to public health from dangers such as communicable diseases, hazardous or unsafe foods, terrorism and other catastrophes. In such emergencies it is absolutely necessary to alert both clinicians and consumers quickly. By knitting together a unified network of surveillance systems from hospital organisations, physician practices, public health agencies and other sources of incoming data on medical threats, public health professionals will have the relevant information they need to react early or issue preventive measures. The only way to create such a network is to make all the data-collection systems interoperable.” [43]

As Allwes and Popovich argue in their article about orphan diseases “ACC, in and of itself, doesn’t have the large numbers of affected individuals to be sway policy and industry to stop and take notice. However, if taken in whole with the rest of the orphan diseases, there is a strength that all orphan diseases can draw from. Disease processes can be explored for generalization, drug development can be based on the uniqueness of orphan diseases, and patient participation can be capitalised through a common area of shared knowledge.” [44]

## **5. e-Learning**

As knowledge should be used to create knowledge, knowledge centres should become the basis for the development of e-learning programs, on different levels and not only for professionals. “One of the essences of the knowledge society is the ability to learn [...] based on the concept that we learn how to learn. Education must no longer be seen as a period of learning limited in time but as a process to be pursued throughout one’s existence.” [3] “Knowledge sharing [...] is not just an activity, but in itself is a knowledge resource.” [14]

For the professional the classical master/apprentice relationship has modified and partially disappeared, as information as well as knowledge has become more openly available. In earlier days, the master taught his apprentice his skills, according to prescribed procedures, and within the confines of his trade or trade group. Building knowledge societies should involve not only promoting, wherever appropriate, distance education but also developing the capacity for learning and continuous discovery. [3]

Education is one of the most important tools for empowerment. With the internet and its accessibility, the concept of education has changed. Having a basic education means that you have the means and know-how to satisfy your curiosity and know how to get answers to questions. The internet enables people to find answers, often in abundance and mostly in an unstructured way. In principle, we have learned how to learn.

Basic in the educational discussion, also because of the important role of it in the UN Millennium goals, should be the issue of the responsibility of the “user” (i.e. the

one who is learning). The need of people to be informed can not be structured in the way we used to do it in previous times. The acquirement of knowledge will become more and more personalised. Therefore education, beyond the classical schooling (up to the level of universities), will lose its directional structure, i.e. from a certain point onwards it will be a person's private decision to continue his education, either through specified programs or by just looking for answers to specific questions, always assisted through networks of discussion and exchange. E-Learning could be an important tool in achieving this new education paradigm. Projects like the UNESCO Avicenna Virtual Campus [45] have shown that students do benefit immensely from this form of education. For the individual consumer, knowledge centres can be the point of reference for (exchange of) information and experience.

To promote e-learning we will also have to use economical arguments, like the fact that people can study when and where they wish, so there are less costs involved locating and transporting people to fixed locations. The overhead costs for e-learning will be considerably lower. The downside is, that you will have to trust the user's sense of responsibility because you lack the possibility to control it the way it was done at any educational institution. Another negative aspect might be the, lack of, social interaction (see also [46]); however, the growth of networks and communities on the internet seems to offer a strong counter balance. This is one of the key elements of the compunetics concept.

The third aspect in the definition of compunetics is the ethical implications of ICT. E-learning, as well as patient networks can be important tools in tackling the problems of health inequality. "[E]ffectively addressing inequalities will require innovative collaborative approaches that address patient factors, provider factors, healthcare system factors and relevant environmental factors. While the magnitude of quality and inequality problems combined with the relative failure of past efforts to improve these inequalities represent daunting challenges, recent and impending advances in information technology and compunetics offer significant opportunities for improvement the provision of high quality medical care and the reduction in inequalities. If governments and healthcare systems are to reap the maximum potential the field of compunetics has to offer, more work will need to be done in several key areas." [47]

Illiteracy is an important aspect of the health inequality. "Language barriers and illiteracy have been identified as common obstacles to ICT access. The convergence of voice, video and images, and the increasing variety of languages available on the Internet means that the importance of this obstacle may be diminishing. However, text-based rather than voice protocols still remain the most widely-used Internet applications, so basic literacy is still considered an important determinant of access." [20] Part of this can be corrected due to the recent technological developments which enable sites like YouTube. Here you can provide people with information by image and speech, not requiring trained reading abilities. An example is the collection of small EHR information clips put on YouTube by Dr. Hannan Amir. [48] Another example are the patient information videos produced by Nobel Films in The Netherlands. [49]

Especially in health and care illiteracy is a serious problem, influencing aspects like dosing levels of prescribed medications; immunization requirements and schedules; disease symptoms or warning signs; treatment or therapy instructions. [50]

“[H]ealthcare organizations can take a number of steps to enhance patients' understanding of health information. These steps include replacing complicated medical words with plain language and writing information at an appropriate reading level. In addition, more and more organizations are turning toward resources that support visual learning, including diagrams, illustrations, videos, and animations that deliver important information in formats most patients can comprehend.” [51]

One of the first and essential steps in the development and acceptance of patient e-learning in health has been the development of information on prescription as introduced by Healthwise. [52] In a recent white paper Don Kemper pointed out the “three rules for a consumer-based health care transformation”: the rules of

- self-care – help people do as much for themselves as they can;
- guidelines – help people ask for the care they need. Give them tools to understand the evidence-based guidelines;
- veto – help people say “no” to care they don’t need. Give them a sense of their autonomy. [53]

As stated before, finding the correct information is a problem on the internet. “While we are beginning to expect that the information we need will be instantly available, we want individual specific information to only be available to those that have a right to see that data.” [54] Information on prescription is part of the solution. We should be looking at developing ways to use the data in the EHR to function as the basis for a personalized search engine.

Prescribed information can and should be extended by visual tools. “Eventually, as patients begin to have online access to their electronic health records, the doctor could even “prescribe” visual health information for the patient to review, which would be waiting when the patient logged on. This would not only provide a documented record that information was recommended to the patient, but would also capture data regarding which information was actually viewed by the patient.” [51]

“People with low health literacy will have difficulty learning information from many written patient education materials because these tend to require higher reading proficiency than many patients possess. They may have difficulty reading medical forms and medication labels, and difficulty with taking their medications correctly. Although health literacy can affect all social classes, it more commonly affects elderly, low income, and minority patients. Low literate patients with chronic physical and mental diseases have been found to be less likely to improve their health.” [55] Unfortunately almost all research done into the use of pictograms in patient information has been in relation to medication information. A good example of a more general site working with pictograms, although still in its construction stage, is Foldercare. [56]



Figure 1 Page from Foldercare website.

Another step should be the standardization of terminology. “Language is not used uniformly in medicine. Clinicians often use different phrases to mean the same thing or the same phrase to mean different things. Standardisation, using a concept-based clinical terminology, largely resolves this situation by creating a common platform for practitioners to deliver enhanced patient care while allowing a basis for comparison and communication. Relevant clinical information concerning a citizen will need to be consolidated from many different clinicians and from different care settings to ensure that the citizen’s care is coordinated and continuous. The variety and diversity of health information technology currently employed within and across care settings presents an added problem which is overcome by using a standardized clinical terminology to enable system interoperability, i.e. the ability for unambiguous data to be exchanged between systems, regardless of the technology used. Without such standardisation, specially built interfaces and other workarounds become necessary, creating the potential for errors, costly additional administration and compromising the care of citizens.” [57] With a global terminology standard it will be much easier to implement the use of plain, national, languages for the benefit of the individual.

Health inequalities are especially obvious in the fields of urban and rural health. In these areas compunetics, both medical and care and behavioural, should and could play an important role.

## Conclusion

Through compunetics, the gathering of knowledge, information and (social) data will be the basis to making health and care delivery more efficient for the professionals, to help build new infrastructures, even to confront the consequences of a disaster, be it man made or natural. It will also help patients to make better informed decisions.

Knowledge centres can function as information containers providing better overview of and access to knowledge, causing a positive economic benefit, and bringing awareness about the necessary changes in infrastructure and education. Organizations like ICMCC can build the bridge between patients and professionals by creating these knowledge centres and stimulate the use of compunetics.

## References

Last access to all internet links on April 10, 2007

- [1] Bos L. et al (eds), *Medical and Care Compunetics 1*, IOSPress, 2004
- [2] Chausalet T., Bos L., ICMCC special issue, *International Journal of Medical Informatics*, 75, 2006
- [3] *Building Knowledge societies*, Item 8.1 of the provisional agenda, UNESCO 164th Executive Board Meeting, 2002
- [4] Laxminarayan S., Foreword, in: *Clinical Knowledge Management, Opportunities and challenges*, R. Bali, 2005.
- [5] Krane D., Number of "Cyberchondriacs" – U.S. Adults Who Go Online for Health Information – Increases to Estimated 117 Million. *Harris Interactive, HealthCare News*, 2005, Vol. Issue 8, [http://www.harrisinteractive.com/news/newsletters/healthnews/HI\\_HealthCareNews2005Vol5\\_Iss08.pdf](http://www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews2005Vol5_Iss08.pdf)
- [6] 9th "Health on the Net Survey of Health and Medical Internet Use" - <http://www.hon.ch/Survey/Survey2005/res.html>
- [7] Ferguson T., From patients to end users, *BMJ* 2002;324:555-556, <http://bmj.bmjournals.com/cgi/content/full/324/7337/555>
- [8] Peterson G, Aslani P, Williams KA., How do Consumers Search for and Appraise Information on Medicines on the Internet? A Qualitative Study Using Focus Groups, *J Med Internet Res* 2003;5(4):e33, <http://www.jmir.org/2003/4/e33/>
- [9] Mayer M.A., Karkaletsis V., Stamatakis K., Leis A., Villarroel D., Thomeczek C., Labsky M., López-Ostenero F., Honkela, T., MedIEQ – Quality Labelling of Medical Content Using Multilingual Information Extraction, in: *Medical and Care Compunetics 3*, L.Bos et al (eds), 2006, pp. 183-190
- [10] Health on the Net Foundation, <http://www.hon.ch/>
- [11] QMIC, <http://www.qmic.nl/qmic/home.do>
- [12] Purcell G.P., Wilson P., Delamoth T., The quality of health information on the internet, *BMJ* 2002;324:557-558, <http://bmj.bmjournals.com/cgi/content/full/324/7337/557>
- [13] Dwivedi, A.N., Bali, R.K. Naguib R.N.G., Building New Healthcare Management Paradigms: A Case for Healthcare Knowledge Management, in: *Healthcare Knowledge Management*, Bali et al (eds), 2007; pp. 3-10
- [14] Abidi S.S.R., Healthcare Knowledge Sharing: Purpose, Practices, and Prospects, in: *Healthcare Knowledge Management*, Bali et al (eds), 2007; pp 67-86
- [15] Davenport T.H. and Prusak L., *Working Knowledge: How Organizations Manage What They Know*. Harvard Business School Press, Boston, MA, 1998
- [16] Fennessy G., Burstein, F., Role of Information professionals as Intermediaries for Knowledge Management in Evidence-Based Healthcare, *Healthcare Knowledge Management*, Bali et al (eds), 2007; pp 28-40
- [17] Popovich M.L. and Watkins T., Applied Medical & Care Compunetics to Public Health Disease Surveillance and Management: Leveraging External Data Sources - A Key to Public Health Preparedness, in: *Medical and Care Compunetics 3*, L. Bos et al (Eds), 2006 pp. 151-161
- [18] Kun L., The Use of Technology to Transform the Home into a Safe-Haven, in: L. Bos et al., *Medical and Care Compunetics 4*, 2007.
- [19] <http://recordaccess.icmcc.org>
- [20] Dzenowagis, J., Connecting for Health - Global Vision, Local Insight, *Report for the World Summit on the Information Society*, WHO 2005, [http://www.who.int/kms/resources/WSISReport\\_Connecting\\_for\\_Health.pdf](http://www.who.int/kms/resources/WSISReport_Connecting_for_Health.pdf)
- [21] Ferguson, T., Medical Knowledge as a Social Process: An Interview with John Lester, The Ferguson Report, Number 9, September 2002, <http://www.fergusonreport.com/articles/fr00902.htm>
- [22] Ferguson T., Can Useful and Reliable Online Health Resources be Produced by 'Medically Unqualified' Persons?, The Ferguson Report, Number 5, July 1999, <http://www.fergusonreport.com/articles/fr079902.htm>
- [23] [www.askdrwiki.com](http://www.askdrwiki.com)

- [24] Lester J., Prady S., Finegan Y., Hoch D., How Online Patient Networks Can Enhance Quality and Reduce Errors, *Patient Safety & Quality Healthcare*, 2004, <http://www.psqh.com/octdec04/lesterfineganhoch.html>
- [25] Ferguson, T., e-Patients as Medical Researchers, The Ferguson Report, Number 9, September 2002, <http://www.fergusonreport.com/articles/fr00903.htm>
- [26] <http://www.ianproject.org/>
- [27] See: <http://www.propractica.com/definitions.htm>
- [28] For an overview of the discussion see the EHR definitions page of the ICMCC RA portal <http://recordaccess.icmcc.org>
- [29] Fischer B., Fitton R., Poirier, C., Stables D., Patient Record Access – The Time Has Come, in: *Medical and Care Compunetics 3*, L. Bos et al (eds), 2006, pp. 162-167
- [30] Hannan A., Webber F., Towards a Partnership of Trust, in: *Medical and care Compunetics 4*, L. Bos et al (eds), 2007
- [31] Ferguson T., Online patient-helpers and physicians working together: a new partnership for high quality health care, *BMJ* 2000;321:1129-1132, <http://www.bmj.com/cgi/content/full/321/7269/1129>
- [32] Shabtai I., Leshno M., Blondheim O., Kornbluth J., The Value of Information for Decision-Making in the Healthcare Environment, in *Medical and Care Compunetics*, L. Bos et al (eds), 2007
- [33] Norgall T., Blobel B., Pharow P., Personal Health – the Future Care Paradigm, in: *Medical and Care Compunetics 3*, L. Bos et al. (eds), 2006, pp. 299-306
- [34] Lee C.K., Foo S., Narratives in Healthcare, in: *Healthcare Knowledge Management*, Bali et al (eds), 2007; pp 130-141
- [35] Ferreira A., Correia A., Silva A., Corte A., Pinto A., Saavedra A., Pereira A.L., Pereira A.F., Cruz-Correia R., Antunes L.F., Why facilitate patient access to medical records, in: *Medical and Care Compunetics 4*, L. Bos et al (eds), 2007
- [36] Popovich M.L., Daub E.M., White Paper: *Concept for an Integrated Bio-Intelligence Network by 2010*, Scientific Technologies Corporation, 2002
- [37] Data from half a million patients to aid research, *E-Health Insider*, March 29, 2007, <http://www.e-health-insider.com/news/item.cfm?ID=2578>
- [38] Western Governor's Report, WGA, 1999, <http://www.westgov.org/wga/publicat/newsltr/7-99web.htm>
- [39] Snyderman R., Yoediono Z., Prospective care: a personalized, preventative approach to medicine, in: *Pharmacogenomics* 2006, 7(1), 509, <http://faculty.fuqua.duke.edu/~mluce/hlthmgmt491/Snyderman%20Yoediono%20Pharmacogenomics%202006%20Jan.pdf>
- [40] Bassinder J., Bali R.K., Naguib R., Knowledge Management and Electronic Care Records: incorporating social, legal and ethical issues, in: *Medical and Care Compunetics 3*, L. Bos et al (eds), 2006, pp. 221-227
- [41] Liebowitz J., The Hidden Power of Social Networks and Knowledge Sharing in Healthcare, in: *Healthcare Knowledge Management*, Bali et al (eds), 2007; pp104-111
- [42] Joachims T., Granka L., Pan B., Hembrooke H., Gay, G., Accurately Interpreting Clickthrough Data as Implicit Feedback, *SIGIR'05*, August 15–19, 2005, [http://www.cs.cornell.edu/People/tj/publications/joachims\\_et\\_al\\_05a.pdf](http://www.cs.cornell.edu/People/tj/publications/joachims_et_al_05a.pdf)
- [43] Office of the National Coordinator for Health Information Technology (ONC), *Goals of Strategic Framework*, United States Department of Health & Human Services, <http://www.hhs.gov/healthit/goals.html>
- [44] Allwes D., Popovich, M.L., Empowering Patients and Researchers through a Common Health Information Registry: A Case Example of Adrenocortical Carcinoma Patients and Researchers, in: *Medical & Care Compunetics 4*, L. Bos et al (eds), 2007
- [45] <http://avicenna.unesco.org/>
- [46] Kay P., *Online Training and e-Learning*, March 8, 2007, [http://www.ukbusinessstraining.co.uk/articles/online\\_training.php](http://www.ukbusinessstraining.co.uk/articles/online_training.php)
- [47] Gibbons M.C., Health Inequalities and Emerging Themes in Compunetics, in: *Medical and Care Compunetics 3*, L. Bos et al (eds), IOSPress, 2006, pp. 62-69
- [48] <http://www.youtube.com/watch?v=LW4OcgVyB4w>
- [49] [http://www.depatientmaghetzegen.nl/dp\\_main.html](http://www.depatientmaghetzegen.nl/dp_main.html) (site in Dutch)
- [50] Taleff A.E., Sehgal V., Cook-Palmer A., Tackling Health Literacy, *Patient Safety & Quality Healthcare*, 2006, <http://www.psqh.com/julaug06/tackling.html>
- [51] Nienkamp M., Visual Learning Tools Overcome Health Illiteracy, *Patient Safety & Quality Healthcare*, 2006, <http://www.psqh.com/julaug06/visual.html>
- [52] Kemper D., Mettler M., *Information Therapy*, Healthwise, 2002
- [53] Kemper D., The Healthwise® Ix® Solution, 2007, [http://www.healthwise.org/f\\_white\\_papers.aspx](http://www.healthwise.org/f_white_papers.aspx)

- [54] Maloney D.L., *Card Technology in Healthcare*, CardTech/SecurTech 2001, [http://www1.va.gov/card/docs/CardCT2001c\\_DM.doc](http://www1.va.gov/card/docs/CardCT2001c_DM.doc)
- [55] Hill L.H., and Roslan M.M., Using Visual Concept Mapping to Communicate Medication Information to Chronic Disease Patients with Low Health Literacy, in: *Concept Maps: Theory, Methodology, Technology*, Proc. of the First Int. Conference on Concept Mapping, A. J. Cañas, J. D. Novak, F. M. González (Eds.), Pamplona, Spain 2004, <http://cmc.ihmc.us/papers/cmc2004-077.pdf>
- [56] [www.foldercare.co.uk](http://www.foldercare.co.uk)
- [57] Donnelly K., SNOMED-CT: *The Advanced Terminology and Coding System for eHealth*, in: *Medical and Care Computetics 3*, L. Bos et al (eds), 2006, pp. 279-290