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Women in Health Informatics

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Contents

To the memory of Professor Jana Zvárová

This Special Issue on Women in Health Informatics was initiated and planned with Professor Jana Zvárová. We three, Jana, Pirkko, and Diane, worked together in planning the issue, in inviting people to contribute, and in reviewing their submissions.

In July 2017, however, Pirkko and Diane received the sad announcement that Jana had passed away. This was very unexpected as Jana was working on this special issue until her very last days. After her death, it was very clear to the two of us remaining that we would finalise this special issue, and do it in such a way that it would pay tribute to Jana's memory.

Professor Jana Zvárová was really one of the pioneers and leading ladies in health informatics. She was a very respected, qualified, and experienced researcher and one of most influential health informatics scientists in Europe and in the world.

Professor Zvárová had a wide area of expertise: she was a scientist and teacher in medical statistics, biostatistics, medical informatics, biomedical informatics, and epidemiology. She was nominated as a full professor to Charles University, Prague in 1999, and she was a very active Czech representative in the European Federation for Medical Informatics (EFMI) and in the International Medical Informatics Association (IMIA). She was also a driving force in the Czech Republic in initiating medical informatics and bioinformatics education programs and research activities. She founded the EUROMISE Mentor Association (www.euromise.net) in 2014. Its main focus is to deliver high-level courses and mentoring activities in the field of biomedical informatics, in close cooperation with the Czech Society of Biomedical Engineering and Medical Informatics. These activities have offered Czech PhD students and researchers a platform to communicate and collaborate with international colleagues. As a result, many international students have participated in the courses.

Professor Zvárová delivered presentations and published widely internationally on medical informatics and biostatistics. She was a person with an extraordinary

working capacity. She also sought, in her own research, to apply new theoretical knowledge in biomedicine, particularly in relation to epidemiology and public health. Her publications include 10 monographs, and more than 300 articles in peer-reviewed journals. The total number of citations of her work is more than 600. She was also the main author of three patents focused on biomedicine. She organised several IMIA and EFMI international conferences and workshops in Prague. In 2015, Jana Zvárová was nominated as an Honorary Fellow of European Federation of Medical Informatics (FEFMI), and in 2017 she was elected as a Member of the International Academy of Health Sciences Informatics (MIAHSI).

All the women who have provided their personal health informatics story to this special issue have had the privilege to know Professor Zvárová, and to learn and to work with her. With these stories, each of us wants to pay tribute to, and remember, the achievements of Jana, as a professor, as a colleague and as a friend. These stories by qualified health informatics women also highlight Jana's influence on the health and bioinformatics field and on the careers of all of us.

We all remember Jana as a very friendly, cordial, and supportive mentor, and as an excellent academic scientist. As a wide-area expert, Jana was always willing to help, support, mentor and participate, with energy and knowledge, in new ideas and initiatives, and she had time for everyone on all occasions.

We are all very grateful to Jana, and we will always remember her. With this issue, we show our willingness to continue her work and to express our gratefulness and admiration for her activities, achievements and collegiality.

The EUROMISE Mentor Association (EMA) (www.euromise.net), established by Professor Zvárová, will continue its activities by organising mentoring courses and conferences and by publishing scientific articles. The first big future event planned by EMA will be the Jana Zvárová Memorial Conference in Prague in 2018. This conference will be a continuation of a series of EMA conferences organised by Jana Zvárová, where many of the authors in this special issue have actively participated over the years. Information on this Jana Zvárová Memorial Conference will be available at the EUROMISE Web pages in the near future. Several other future activities are also being planned.

As a result, and as a final word, this volume contains not only this special editorial tribute to Professor Zvárová and her EUROMISE work, but also the stories of the careers – all written in their own voices – of more than a dozen exceptional women from around the globe who have worked over the years in bio-informatics, health informatics and digital health. Each paper also provides a view of the health informatics work that has been undertaken in their own country, and insights into where health informatics may be seen to be heading in the future.

Pirkko Nykänen and Diane Whitehouse

An Austrian perspective on medical informatics

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Abstract

After 20 years of working in the field of medical informatics, this paper summarizes career highlights, the state of education and research on health informatics in Austria as well as future prospects of the field. In 1981, the Austrian Working Group Medical Informatics was founded that now represents Austria within IMIA and EFMI. Austria has a good maturation of clinical IT and is now on the way to establish a comprehensive national eHealth infrastructure and a lifelong electronic health record (ELGA – Elektronische Krankenakte) to exchange patient-related data between health care institutions. Future prospects of health IT in Austria include patient-centred care across health care institutions, an increasing demand for health informatics experts with various backgrounds, secondary use of clinical data and health IT to support patient empowerment.

Keywords

Medical informatics, evaluation studies, telemedicine, patient participation

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1 Entering the field of medical informatics

Already during my school time, I got interested in computer science, due to the structure and predictability of computers, as well as in medicine, as I came from a family of doctors. I was unsure which of the two fields I should pursue. Fortunately, a school advisor knew about a programme in medical informatics at the University of Heidelberg in cooperation with the University of Applied Sciences Heilbronn. So, he told me: "If you are interested in both fields, why not study medical informatics?" It was the first time that I had heard of medical informatics (it was around 1988), but I was immediately intrigued by the opportunity to combine both fields. I thus started my studies in medical informatics in 1991. In 1997, I graduated.

At that time, I was offered a position as research assistant at the Institute of Medical Biometry and Informatics at the University of Heidelberg that was directed by Prof. Dr. Reinhold Haux. I got the chance to participate in several research projects and quickly was able to initiate my own projects. I very much enjoyed the open and supportive atmosphere at that Institute and I am very thankful for the trustful relationship with and strong support from my mentor, Prof. Reinhold Haux, throughout my career.

In 2001, I completed my PhD. At that time, I was unsure whether to continue a scientific career or to go into the health IT industry. At that time, Reinhold Haux was asked to take over the first rectorate of the newly founded Tyrolean University UMIT – University for Health Sci-

ences, Medical Informatics and Technology. He asked me to join him at UMIT and to take over the position of research group leader. I happily agreed and started to work at UMIT in September 2002. At that time, UMIT only comprised around five staff members and ten students! Now, in 2017, after 15 years, UMIT has grown to a prosperous Health & Life Sciences University with around 160 staff members and 1,800 students! I completed my habilitation in 2004 and was appointed full professor for medical informatics in 2005. In various roles, I contributed to the development of UMIT: at present, I am head of the programme in health information management, head of the PhD programme at UMIT, head of the committee for quality assurance in teaching, and member of the senate of UMIT.

2 The state of health informatics in Austria

Three aspects of health informatics in Austria are explored here: its foundation, current developments, and the educational field.

2.1 Working Group Medical Informatics in Austria since 1981

This section is an update of a contribution written together with Günther Gell for the History Project of the International Medical Informatics Association IMIA.

In 1981, the Austrian Working Group Medical Informatics named AGMI – Arbeitsgruppe für Medizinische Informatik (later renamed to AKMI – Arbeitskreis Medizinische Informatik) was established as a joint working group between the Austrian Computer Society (OCG) and the Austrian Society for Biomedical Engineering (ÖGBMT). The first chair was Günther Gell from the University of Graz (Chair, 1981-2003). At the start of AK-MI, most of the members came from universities doing research in or connected to medical informatics.

The purpose of AK-MI was to enhance communication of medical informatics professionals within Austria and also to establish links to the international community and to the international organizations in medical informatics. Consequently, AK-MI became a member in the European Federation of Medical Informatics (EFMI) and in the International Medical Informatics Association (IMIA). One highlight was the hosting of MIE 1991 (Medical Informatics Europe) in Austria.

AK-MI organized yearly meetings where participants, mostly from university settings, presented ongoing research projects, experiences from clinical applications and other advances in the field of health informatics. These meetings were also a forum to discuss other questions such as the professional organization of medical informatics in the universities, in hospitals and other clinical settings; data protection and data security; and ethical questions. Attendance rates were typically in the range of up to 50 people.

In 2005 Günter Schreier (AIT Austrian Institute of Technology) and Elske Ammenwerth (UMIT) were appointed chairs of AK-MI and Elske Ammenwerth became the representative to IMIA and EFMI.

In 2006, the newly appointed chairs of AK-MI contacted all AK-MI members to ask for their expectations concerning the future work of AK-MI. The results showed that many members appreciated these yearly meetings and even wished to intensify this form of direct interaction. At this time, the name of the AK-MI working group was enlarged to Working Group for Medical Informatics and eHealth.

The AK-MI chairs decided to expand the annual workshop into a fully-fledged conference. The resulting conference series was called "Health informatics meets eHealth" and started in 2007 with 160 participants. During the subsequent years, the number of attendees increased steadily and reached 330 participants by 2017.

Since 2010, the eHealth conference has chosen to focus on a specific annual topic: after "Patient-Centred Systems" in 2010, the following annual topics were "Critical Care", "mHealth", "Big Data", "Outcome Research", "Personalised Health", "Predictive Modelling" and finally "Digital Insight – Information-driven Health & Care" in 2017: these topics reflected developments in the field.

In 2013, the AK-MI joined forces with the Health Information Management and Systems Society (HIMSS) to organize the conference under the name of "eHealth Summit Austria" (www.ehealthsummit.at). HIMSS added application-oriented programme elements, which helped to attract more participants from health care organizations and the health IT industry.

Until 2013, all full papers of the eHealth conference were published in a national book series of OCG. Since 2014, all full papers have been published as open-access in the book series, "Studies in Health Technology and Informatics", published by IOS Press. Selected papers are also published in the "Applied Clinical Informatics" journal. Since 2015, the scientific sessions are held in English, to encourage participation by attendees from non-German speaking countries.

Overall, AK-MI is a working group of people interested in promoting research and practice of medical informatics. The annual eHealth conference in Vienna has become the central conference of the medical informatics community in Austria.

2.2 Medical Informatics in Austria

As in other European countries, health care in Austria is not possible without the use of information and communication technologies. The application of information technology (IT) in health care has increased in the last decade due to demographic change, cost pressure, medical progress and technical progress. The large majority of both private and public hospitals use electronic health

records, nursing documentation systems, order entry systems, patient data management systems, or picture and archiving systems (PACS) [1]. Also, a majority of hospitals use mobile tools (such as tablets or laptops) to support information access and clinical documentation at the patients' bedside.

However, there are some areas where IT support is still limited and is only available in a minority of hospitals. These areas include documentation of medication, documentation of vital signs at the patients' bedside as well as the use of decision support systems, for example for medication-related alerts.

A special strength of health IT in Austria, compared to neighbouring countries, is eHealth. The Elektronische Gesundheitsakte (ELGA), Austria's national architecture and infrastructure for exchanging clinical data, connects hospitals and physicians in private practice as well as other health care providers. ELGA, as a lifelong electronic health record, was established by the Healthcare Reform Act in 2005 [2] and by the ELGA Act in 2012 [3]. ELGA is based on international standards such as Clinical Document Architecture (CDA®) and Integrating the Healthcare Enterprise (IHE).

At the moment, ELGA allows access to laboratory results, radiology findings, and discharge summaries. In the next years, also medication information [4] as well as other types of patient-related information will be made available via ELGA. Evaluation shows that especially e-medication holds great potential to reduce medication errors and related adverse events by making the full medication history of a patient available to all treating health care providers [5]. A patient portal within ELGA will also be established.

Another strength of health IT in Austria is the number of telemedical and telemonitoring projects that allow to exchange patient-related data for certain groups of patients. Several pilot projects have been conducted in the last years, such as a telemonitoring system for patients after acute myocardial infarction [6], for patients with diabetes, or for patients with heart failure [7, 8]. As the first telemonitoring system in Austria, the HerzMobile Tirol project, that is based on an integrated treatment of patients with heart failure, will be introduced in routine patient care and funded by insurance companies in 2018, after promising evaluation results provided by my group [9].

As a conclusion, the health IT and eHealth landscape in Austria has developed over the last decade, with a strong focus on clinical IT, eHealth, and telemedical and telemonitoring applications. Future developments will comprise the further roll-out of ELGA, IT support for medication, and stronger integration of patients and citizens in the national eHealth architectures.

2.3 Education in medical informatics in Austria

Several universities and universities of applied sciences offer programmes in medical informatics in Austria.

The Health & Life Sciences University (UMIT) has offered a full-time bachelor's and a master's programme in biomedical informatics since 2001 [10]. A graduate survey showed good job perspectives, with around three-quarters of all graduates working in the field of medical informatics [11]. In 2017, an online-based master's programme in Health Information Management started at UMIT to allow part-time study by students with various technical or clinical backgrounds (www.umit.at/him).

Programmes in medical informatics or related fields are also available at the Technical University Vienna (bachelor's and master's in Medical Informatics), at the Medical University Vienna (master's in Medical Informatics), at the Carinthia University of Applied Sciences (master's in Health Care IT), at Danube University Krems (master's in IT in Health Care) and at University of Applied Science Sankt Pölten (master's in Digital Healthcare). A PhD in medical informatics can, among others, be obtained from UMIT, the Technical University Vienna or the Medical University Vienna.

3 My research results and achievements

During my doctoral work in Heidelberg, my research focus was on nursing informatics (especially the implementation and evaluation of nursing information systems) as well as in requirements engineering for hospital information systems. During this time, I got to understand medical informatics not as a technical discipline, but as a socio-technical field that affects the way clinicians deliver health care. I found it very motivating for my work to see that medical informatics can directly contribute to the quality and efficiency of health care by developing, introducing and evaluating tools that change health care processes and outcomes.

After moving to UMIT, I decided to focus on health IT evaluation that I found to be of tremendous importance for the future of health informatics. Evaluation was a topic not yet broadly covered by other research groups at that time. To learn more about health IT evaluation, I organized an European Science Foundation (ESF) funded workshop "Assessment of Health Information Systems" at UMIT in 2004 [12]. I was surprised and happy that so many renowned colleagues agreed to participate in this workshop. We had wonderful and intensive three working days that lead to a strong international network of experts and to a Declaration on Health IT Evaluation [13]. Based on this positive experience (and because Peter McNair said: "Just do it!"), I applied for a new working group on Assessment of Health Information Systems to the EFMI Council, and the Council agreed. Thus, since

2005, I am chair of this working group. We closely cooperate with the IMIA working group on Technology Assessment and Quality Development. In this core group of around 10 people, we were able to develop some widely recognized papers, such as the GEP-HI guidelines for conducting health IT evaluation studies [14] and the STARE-HI guidelines for publishing health IT evaluation studies [15, 16] (for a full list of the publications of the working group, see https://iig.umit.at/efmi/index.htm). In 2016, together with Michael Rigby and supported by the whole working group, I edited a book on Evidence-Based Health Informatics that provides a summary and a vision for Evidence-Based Health Informatics [17] as a logical consequence of our work on health IT evaluation.

Another line of research for me was health IT and patient safety. My group participated in the EU project PSIP – Patient Safety and Intelligent Procedure in Medication – where we worked on contextualizing decision support in medication systems [18]. I also coordinated a review on this topic [19]. To continue the work, I founded a German-Austrian-Swiss working group that met regularly to exchange new ideas and research results in the area of medication safety. Several publications emerged from this group, among others a memorandum on the use of health IT for medication safety [20].

With both lines of research – health IT evaluation and health IT for patient safety – I want to contribute to high-quality health information systems that support health care. For me, this is the core purpose of medical informatics.

In the now nearly 20 years of working in the field of medical informatics, I found that the international medical informatics community is open, supportive and constructive in jointly conceptualizing and testing new solutions to improve quality and efficiency of health care. International collaboration in projects, working groups or medical informatics societies was mostly uncomplicated, open-minded and very fruitful. I am very happy to be able to contribute to medical informatics in such a stimulating environment and to work with so many exceptional colleagues. I feel especially proud to have been elected Fellow of the American Medical Informatics Association (AMIA) in 2011 and founding Member of the International Academy for Health Science Informatics (IAHSI) in 2017, thanks to the strong international networks from which I was able to benefit.

4 Future and prospects of health informatics

There are several fields of health informatics where I expect large progress in the next decade.

First, patient-centred health care is a process that crosses institutional and professional boundaries. Thus, cross-institutional eHealth architectures and infrastructures will continue to grow and to support real patient-centred care.

Second, due to the multi-professional perspective of medical informatics, more experts from non-technical backgrounds, such as a medical or nursing background, or with a background in quality management, risk management or process management, will enter the field of medical informatics. New educational programmes will support this, e.g. by offering part-time studies or online-based studies (such as the online-based, part-time master's programme in health information management at UMIT).

Third, large progress will be seen in the secondary use of clinical data to support research and health care practice. There is so much patient data available now in an electronic format that offer tremendous opportunities for precision medicine, decision support, or new scientific insights.

A fourth focus of medical informatics is patient empowerment. Medical informatics has focused on how to support doctors, nurses and other health care professionals in their work. But ultimately, it is the patient who has to decide what to do next. Patient portals are one way to provide patients with information about their health and disease [21]. Patient portals can empower patients to take over responsibility for their own health. I expect that, in the future, medical informatics will further increase its attention to the needs of patients regarding health IT.

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A Personal Journey into the field of Healthcare Informatics:

Looking back and considering the future

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Abstract

The first section of this paper gives an overview of how the author got into the field of healthcare informatics as a profession, and reviews the state of healthcare informatics as it was, in the United States, at the beginning of her professional career. The second section of the paper focuses on the present state of healthcare informatics in the United States. The paper concludes with the author's vision of new technologies, new opportunities, and new challenges for this field.

Keywords

Healthcare Informatics, Patient centered care, Point of care, Nursing Informatics, history of Medical Informatics, Healthcare education, Healthcare information systems, Human factors, Mentoring

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1 How I Got into the Profession

As I look at my career over many years, I was fortunate to have some outstanding mentors who have guided me throughout my career and made possible many of my contributions to the field of health informatics. I would like to acknowledge the following individuals at this point as I share my career achievements with the reader. First, my father and mother, Dr. Ernst Jokl and Erica Jokl, and my husband Dr. John C. Ball. Secondly, Dr. Wellington P. Steward, Dr. Morris F. Collen, and Dr. Donald A.B. Lindberg. Internationally, my career was strongly influenced by Dr. Hans Peterson and Dr. Jan van Bemmel.

At the beginning of my career I was fortunate to be introduced to the field of medical informatics by working at the University of Kentucky for a pathologist by the name of Dr. Wellington P. Steward (Pete). He was a brilliant laboratory scientist. As Director of the pathology clinical laboratory at the University of Kentucky, he implemented one of the first computerized clinical laboratory systems in the nation. This was an IBM 1800 data acquisition and control system and at that time this was an innovative pioneering effort on the part of Dr. Steward. This involvement "hooked" me into the use of computers in healthcare. Consequently, one of my first books in the field was entitled "Selecting a Computer System for the Clinical Laboratory" published by Charles C. Thomas.

Shortly after, I accepted a position at Temple University where I became the Director of Computing for the Health Sciences Center, propelling me into the use of

computers in hospitals. During my tenure at Temple we installed a financial system developed by Lockheed Corporation, and selected and implemented a clinical laboratory system. During my 18 years at Temple University I completed my doctorate and became the author of several children's books and published a book entitled "How to Select a Hospital Information System."

In 1985, my husband and I became professors at the University of Maryland in Baltimore, where I became the Director of Computing for the Health Sciences Center. In 1996, I left the University of Maryland and worked as a consultant, ending my academic career as a Professor in the School of Nursing at Johns Hopkins University. In 2005, I accepted a position with IBM Research where I am currently employed.

I am also currently Professor Emerita at Johns Hopkins University in the School of Nursing and an affiliate Professor in the Division of Health Sciences Informatics in the School of Medicine at Johns Hopkins University. I also hold an affiliate Professor in the Department of Information Systems at the University of Maryland Baltimore County as well as holding an appointment at the Uniformed Services University of the Health Sciences in the Department of Biomedical Informatics. I am currently employed as a Senior Advisor, Healthcare Informatics in the Center for Computational Health at IBM Research, as well as an IBM Industry Academy Member.

1.1 State of Health Informatics in the United States

Most recently, the emphasis in our field is concentrating on the use of enabling technologies in patient safety, process engineering, change management, human factors, stress management, simulation, security, privacy, and confidentiality as well as user-friendly clinical point of care initiatives.

We are also seeing a very specific emphasis on chronic disease management with an emphasis on adherence to medications and care plans, with patient involving a primary concern, which is often referred to as participatory medicine in the era of patient-centric care. Probably one of the most difficult areas currently being addressed is interoperability from a technical point of view as well as the need for the patient having access to a personalized healthcare system through electronic health record banks and patient portals, with the objective of providing patient access to their own total health status, with primary goals that could lead to prevention and well-being. What we have presently is a disjointed collection of databases that do not communicate with each other, making it very difficult for a patient/citizen to have a clear picture of their health status. Many of these issues could be solved if indeed we had a unified patient identifier in the United States, which at present does not exist. Furthermore, we have in the current environment a sick care system rather than a health care system.

1.2 My Research Results, Achievements, and Awards

In the 1970s, there was very little available for informatics in the nursing profession. The Allied Health professions had not yet entered the Information Age. To address this void, my esteemed colleague, Dr. Kathryn Hannah, a Canadian nurse, and I wrote the first book in this field entitled "Using Computers in Nursing" which launched us eventually into establishing the Springer Series in Healthcare Informatics.

At present, there are 85 volumes in the Springer health informatics series, of which approximately 27 volumes are authored, edited or co-edited by me with my colleagues. The latest books in the series, published just within the last 18 months, include the "History of Medical informatics in the United States" Second Edition, Senior Editor, Dr. Morris Collen. A second book "Health Information Management Systems: Cases, Strategies and Solutions," Fourth Edition, coedited by Charlotte Weaver, George Kim, and Joan Kiel, culminated my particular interests in inter-professional informatics. In addition, in the nursing arena, we have published the Fourth Editions of "Introduction to Nursing Informatics" as well as "Nursing Informatics, Where Technology and Caring Meet."

In addition to my various books, I have also published over 250 journal publications in the field of health informatics, education, electronic health records, consumer informatics, health record banking, and most recently in the field of point of care issues.

In my career, I have served on a multitude of boards and have become a fellow in a variety of healthcare related organizations. I am a member of the Institute of Medicine (IOM) now known as the National Academy of Medicine (NAM) and served until recently on the National Library of Medicine's Board of Regents. I am a founding board member of the Health on the Net (HON) Foundation. I have served on the American Medical Informatics Association (AMIA) Board, and was President of the International Medical Informatics Association (IMIA).

I have twice been a Board member of the College of Health Information Management Executives (CHIME). I was elected to the Health Information Management Systems Society (HIMSS) Board, where I served for three years. In addition, I have been a member of the American Health Information Management Association/ Foundation of Record Education (AHIMA/FORE) Board, and have also served on the Advisory Council for the Department of Biomedical Informatics at the University of Pittsburgh. Most recently I have been asked to serve on the Health Record Banking Alliance Board as an advisor.

I have been fortunate and honored to have received numerous academic, national, and international awards for my contributions to the field of health informatics. I am the recipient of the Morris F. Collen Lifetime Achievement Award from ACMI/AMIA, the Award of Excellence—a lifetime achievement award from International Medical In-

formatics Association (IMIA), and the Distinguished Service Award from AHIMA.

I was selected as one of the 50 most influential IT professionals over the last 50 years by HIMSS, called the HIMSS 50 in 50 awards. I am an honorary member of Sigma Theta Tau International and an honorary Fellow of the American Academy of Nursing (AAN). Most recently I was honored with the HIMSS Most Influential Women in Health IT Award in February 2017.

1.3 Future Focus of Health Informatics

The use of analytics in exploring big data availability will be transformational in the fields of research as well as applied informatics. Analytic tools, in addition to data mining and machine learning tools and the power of Watson-like initiatives, are entering the clinical settings just as they have demonstrated their successes in the financial arenas and other industries besides healthcare.

We will see much more involvement in wearable technologies, addressing the patient-centric movement of making the patient part of healthcare diagnosis and treatment. The expansion of telemedicine, robotics and simulations have proved to be a great asset to the current state of state of education, research, training, and treatment.

We are also starting to see the benefits of bringing the social sciences into the field of healthcare informatics. This became clear as the emphasis of human factors and user-friendly methods, to more effectively use the technologies at the point of care, in the field of education and consumer satisfaction.

More effective use of the technology, such as re-examining the current electronic health record systems, is where we are currently putting our efforts in the field of health informatics. The current hype cycle well known in technology adoption starts with an innovation, a high point of adoption, and then when reality sets in we hit a trough of disillusionment and re-examination, with a hope of building on the systems in place and adjusting their usefulness to the healthcare professional. A good example is the current status of electronic health records (EHR) in the United States.

Specifically, in my area of interest, I have dedicated much of my career to the field of Nursing Informatics and I am a founding member of the TIGER (Technology Informatics Guiding Education Reform) Foundation initiative. This effort addresses the importance of integrating the most current enabling technologies into the nursing profession from bedside practitioners to researchers. TIGER has now moved into the international arena and is embracing the inter-professional disciplines as well as nursing. Currently my interests lie in research of point of care initiatives towards adherence issues, stress management and using enabling technologies towards compliance issues.

With the current enabling technologies and more recent analytic tools such as telemedicine, visualization, robotics, and machine learning as well as other technologies mentioned above, the field of health informatics can expect exponential growth in the use of technology to transform our sick care system into a true health care system for the citizens of the United States and the world.

2 Past and Future Focus of Health Informatics in the USA

The next section of this article addresses the history of my field in the USA much of which has taken place during my lifetime.

At the end of 2015 Dr. Morris F. Collen and our US informatics colleagues compiled *The History of Medical Informatics in the United States* [1]. In addition, over the last 25+ years, a book series named Health Informatics, published by Springer, has documented the history and details of innovations and technical developments in this field, in the US and beyond [2].

The progression of US health information technology use can be characterized by several emergent themes:

- *Exploration and innovation of electronic tools and standards to support healthcare information management.*
  Pioneering efforts by investigators within university settings and larger healthcare organizations explored the possibilities of computers to measure and improve healthcare. Federal agencies funded many projects: The National Library of Medicine, the National Science Foundation and military and public health agencies.

- *Steady but slow adoption and diffusion of computers to improve healthcare processes.*
  As systems became progressively distributed, their uses evolved from billing and business functions (on mainframe systems) to data sharing among hospital service departments (via mini/microcomputers and networks) to direct access by clinicians for patient care, communication, and education (using personal computers, workstations, and the Internet). Progress again was led by visionaries within larger institutions with resources, with lack thereof hindering adoption and diffusion.

- *Progressive impetus from diverse stakeholders to use IT to improve healthcare outcomes.*
  Pressure from public and private sectors to improve healthcare quality, safety, and outcomes, and to reduce errors and costs led to federal leadership to align incentives to increase HIT adoption. Electronic health record technology provides a platform on which to collect data and measure performance and health outcomes.

- *Ongoing challenges and opportunities for healthcare IT.*
  Increased US adoption of health IT has given rise to a new generation of tools, challenges, and opportunities for informatics innovation to help realize a

vision of a data-driven national learning healthcare system.

Themes in the progression of US healthcare informatics development have included:

Terminologies and Standards Development

The US has many stakeholders and organizations involved in the creation, development, maintenance and use of terminologies and standards. Examples include:

- The US Centers for Medicare and Medicaid Services (CMS) has extended the World Health Organization's International Classification of Disease (ICD) for use in coding diagnoses and inpatient medical procedures in US health care encounters. The current version (ICD-10-CM [3]) is used by CMS and by insurers for documentation, tracking and billing.
- The American Medical Association (AMA) owns and has developed the Current Procedural Terminology (CPT [4]) for coding of US ambulatory therapies and procedures for documentation and billing.
- The US National Library of Medicine (NLM [5]) has been instrumental in developing terminologies for health IT. Beginning with the development of the Medical Subject Headings (MeSH [6]), used to index databases of current clinical publications [7], genomic data [8], cancer information [9], consumer health [10], pharmacology [11] and clinical trials [12], NLM has facilitated access to terminology tools for health IT development through its Unified Medical Language System (UMLS [13, 14, 15]).

Many international healthcare standards development organizations (SDOs) began in the US as collaborations among stakeholders to develop and connect systems. Examples include:

- The American National Standards Institute (ANSI [16]) and Health Level Seven (HL7 [17]) which promote collaboration among clinicians and IT professionals to create standards for electronic health data exchange and management for integration and interoperability of systems.
- Digital Imaging and Communications in Medicine (DICOM [18]), managed by the National Electrical Manufacturers' Association (NEMA), which is the standard for medical imaging.
- Integrating the Healthcare Enterprise (IHE [19]) promotes collaboration to achieve coordinated use of established standards in health information and other technologies to optimize clinical care.

Education, Workforce Training and Professional Certification

Funding for informatics training has come from several sources in response to the need to train the healthcare workforce in the use of and leadership in guiding the development of information technology in healthcare:

- The National Library of Medicine. NLM has provided funding for various forms of medical informatics training: short courses [20], onsite training programs for medical trainees and postdoctoral students [21] and university-based informatics programs [22]. This source of funding has helped establish many academic training programs in various areas of health informatics [23].
- The American Medical Informatics Association (AMIA [24]) and the American Nursing Informatics Association (ANIA [25]) have been instrumental in helping to develop clinical board certification for their member practitioners. AMIA also provides short ("10x10") courses [26]. AMIA, ANIA and HIMSS (as part of the Alliance for Nursing Informatics [27]) have developed the Technology Informatics Guiding Educational Reform (TIGER) program (now transitioned to HIMSS) [28] to define the informatics core competency for healthcare professionals in the 21st century. Work in US informatics and information management certification is also provided by the American Health Information Management Association (AHIMA [29]).
- The Healthcare Information Management Systems Society (HIMSS) North America [30] is a non-profit membership organization of individuals, corporations, and non-profit organizations to foster and shape professional development, leadership and public policy to improve the quality, cost-effectiveness, access, and value of healthcare through IT.
- Professional medical associations have member-driven interest groups that participate in education, development, and advocacy of health IT within other specific domains [31]. AMIA has also led efforts to define informatics certification in other professions [32].

The Role of Federal Advocacy for Health IT Adoption and Regulation

The US Department of Health and Human Services (DHHS) has been central in coordinating efforts in leveraging health IT as part of its overall oversight of US healthcare [33]. In addition to NLM and CMS, DHHS provides advocacy and oversight for health IT through its agencies:

- The Office of the National Coordinator for Health Information Technology (ONC [34]) has become cen-

tral in defining standards, with professional medical and standards development organizations, for US clinical health IT including EHR data and use, certified health information technology (HIT), privacy/security and interoperability [35] for implementation by health IT vendors.

- The Office of Civil Rights (OCR [36]) is charged with enforcement of health information privacy regulations as defined, initially by the Health Information Portability and Accountability Act (HIPAA) in 1996 and extended under the Health Information Technology for Economic and Clinical Health (HITECH) in 2009.
- The Food and Drug Administration (FDA) and Federal Communications Commission (FCC), in conjunction with the ONC, have worked to create a regulatory framework for the safety in innovation of HIT [37], including mobile medical applications in response to a 2012 law passed by Congress.
- The maturing health IT infrastructure has enabled development and implementation of electronic quality measures as a part of overall healthcare delivery and payment reform [38] for value-based care programs [39] under the Medicare Program

Patient Safety, Quality Improvement and Security

The landmark Institute of Medicine reports *To Err is Human: Building a Safer Health System* [40] and *Crossing the Quality Chasm* [41] pointed out the dangers of the healthcare environment to patient safety with recommendations that included the role of health information technology to streamline care and reduce errors. In addition to these functions, well-designed health IT can provide practice-based data and evidence on which to base patient and population-wide clinical decisions for care.

As health IT has gained prevalence, experience has shown that poor design and implementation and misuse (intentional or otherwise) can create errors and harms. Increasing organizational and clinical dependence on electronic information systems has led to the discovery of vulnerabilities to new types of unforeseen failures [42, 43] , which now include system-wide cyber-attacks and security breaches that require multi-level approaches to mitigation and prevention [44].

New Technologies, New Opportunities, New Challenges

The evolution of electronic health records and connectivity has led to increased efforts to realize a vision of a data-driven national learning healthcare system to improve clinical knowledge and practice in areas such as cancer research [45] and cardiovascular care [46, 47] . New technologies such as predictive analytics and cognitive computing are being explored for their potential roles in improving and informing decisions and care for healthcare providers and for patients.

Most recently, the emphasis in our field is concentrating on the use of enabling technologies in patient safety, process engineering, change management, human factors, stress management, and clinical point of care initiatives such as adherence and emphasis on patient-centric care.

With the current enabling technologies and more recent analytic tools such as telemedicine, visualization, robotics, and machine learning that have become available, the field of health informatics can expect exponential growth in the use of technology to transform healthcare for the citizens of the world.

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e-Health in Switzerland:

developments and challenges

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Abstract

This article presents the situation of eHealth in Switzerland and its evolution since 1996 with a focus on an initiative to improve the quality of online health information on the Internet. With the ever-increasing amount of online health content, the HONcode attempts to standardize and improve online health information quality.

Keywords

Internet, eHealth, trust, quality standard, search engine

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1 My e-Health journey

In 1995, the terms e-Health, eHealth or eHealth informatics had not been heard. Geneva, Switzerland was put on the map in the virtual world thanks to Sir Tim Berners Lee, who was working at CERN at the time he discovered and invented the World Wide Web. It was a revolutionary find and now, more than 20 years later, almost everything in our lives has been taken over by the Internet.

But at that time, when the Internet was still brand spanking new, health was one of the first domains to start using the Internet for its own advancement. At that time, it was very difficult to anticipate the outcome of this particular technology. However, a few visionaries, such as Prof. Jean-Raoul Scherrer, Prof. Donald Lindberg MD, Prof. Marion Ball, Prof. Jan van Bemmel, Prof. Denis Hoschtrasser, and Prof. Ron Appel, foresaw that the World Wide Web would become a major asset and change the way the world works, especially in the health [1]. And just as predicted, indeed it has.

eHealth is now a well recognized area of healthcare, with its own experts, articles and book chapters, university programs and hospital departments. Indeed, eHealth is the future.

1.1 How did I enter the field of eHealth informatics?

The early 1990s was the early stage of Internet use, accessible to computer scientists or researchers, and only though universities or major administrations. As a computer engineering student, I was at the forefront of the latest technologies and had access to the networks that the Internet brought. I was amazed by the power of the Internet as a major international communication network – it was as if computers were communicating among themselves. Indeed, at that era communication would not be impacted simply by the failure of one connected computer. In terms of robustness and efficacy, this fact was quite amazing. It also meant that the information transmitted

by the network could not be controlled or regulated. However, also at that time, access to a network was available, for example, via Gopher, which was mainly adapted to the needs of scientist and students and not really to the general public.

My interest in medicine made me realize the potential of computers and the Internet in the health domain. My computer engineering allowed me to contribute to finding a pragmatic solution to the ever increasing presence of health information available on the Internet to the patient.

2 The state of health informatics in Switzerland

Switzerland, in particular the city of Geneva, has played a very specific role in the development and spread of the Internet. Until 1993, the Internet was accessible only to a limited group of researchers, scientists and major industries because to gain access to the technology was not intuitive enough to enable a wider diffusion. At that time, the Internet had already existed for a number of years; however, it was the World Wide Web that brought the Internet to the mass of people by making it more accessible to a wider community. Indeed, before April 1993, it was almost necessary to know programming in order to be able to use the Internet. The http technology of the World Wide Web (Web) did not exist at the time. In April 1993, CERN (Centre Européen de REcherche Nucléaire), based in Geneva agreed to make technologies such as the underlying code of the HTML (HyperText Markup Language.), URL (Uniform Resource Identifier) and HTTP (Hypertext Transfer Protocol.) free for use so that it could "be a universal space" [2]. These three technologies, which allowed Web pages to be linked to each other and communicate among each other, were developed by Sir Tim Berners Lee under the direction of Mike Sendall.

So, it is only fitting that it would also be in Geneva, under the aegis of the World Health Organization (WHO) and the United Nations, that the first international body to guide Internet users to quality information on the Internet would be created. This organization was named the Health On the Net (HON) Foundation. HON came about as a way to address the vast amounts of health information of varying quality and to help guide users to make the right choice of information. To do this, criteria were drawn up. It was determined that these criteria should be fulfilled by all websites if they were to be approved for use, thereby enabling a standardized pool of uniformly, high quality health information. After over 20 years of existence, HON and its code of conduct, the HONcode [3], currently now covers 102 countries in 35 languages.

Figure 1: HONcode seal displayed on certified websites once the HONcode experts manually check the site for compliance with all HON principles.

The Internet penetration in Switzerland in 2017 is estimated to be at 89.4% [4]. Coverage has always been important, and it is this good coverage that enabled the development of the first electronic patient files at the Cantonal Hospital of Geneva with Diogene [5] in the 1990s. Nowadays, health and media literacy is a challenge in Switzerland: patient information is well documented in electronic medical records (EMRs), understandable and accessible to the whole Swiss population, which is typified by it social diversity, multi-culturism, and an increasingly elderly population. The electronic health record (EMR) has the aim to take into account all the different demographics of a patient. It allows the healthcare team to provide better health options, complemented by all the other relevant or available technologies and objects.

The use of mobile applications and social networks is also growing in Switzerland [6, 7].

More and more data is now being integrated together to create 'Big Data', which has immense uses in various sectors - one of which is healthcare. Big data makes even more information accessible such as researchers, allowing them to use big data to complement their clinical studies and thus, further advance medical knowledge.

However, big data is not without its challenges. To create big data, various data sets have to be amalgamated and, with unclear political boundaries and different framework conditions, this can get tricky. Additionally, current networks lack the capacity to handle the sheer size of big data to enable proper analysis.

Personalized health aims to use personal data - genomics and other data, such as clinical data from hospitals and primary care, data from biobanks, or health data collected by individuals themselves (self-tracking) - in order to achieve added value for the population at large [8, 9].

In order to bring Switzerland to the forefront of research in personalized health, the Swiss State Secretariat for Education, Research and Innovation (SERI https://www.sbfi.admin.ch/sbfi/en/home.html) has launched a national research initiative entitled Swiss Personalized Health Network (SPHN) [10]. SPHN establishes nationwide interoperability of clinical, "omics" and other health-related data, allowing researchers in Switzerland to share information and collaborate efficiently. Since January 2017, SPHN brings together university hospitals, schools of higher education, research institutes, and or-

Table 1: The eight HON Code of Conduct (HONcode) criteria for medical and health websites – `www.hon.ch/Conduct.html`

Principle	Detail
HC1-Authority	Indicates the qualifications of the authors
HC2-Complementarity	Information supports, does not replace, the doctor-patient relationship
HC3-Privacy policy	Respects the privacy and confidentiality of personal data submitted to the site by the visitor
HC4-Attribution of	Cites the source(s) of published information
– reference criteria	
– date	Dates medical and health pages
HC5-Justifiability	Backs up claims relating to benefits and performance
HC6-Transparency	Presentation is accessible; contact information is present
HC7-Financial disclosure	Identifies funding sources
HC8-Advertising policy	Clearly distinguishes advertising from editorial content

ganizations working in the area of personalized health, as well as other health-related research activities across Switzerland. To achieve its goals, information generated by the various organisations involved, and personalized health platforms, have to become mutually compatible ("semantically interoperable").

3 My research results and achievements

Almost all my entire career has been dedicated to the pursuit of improving access to quality online health information for the general public. As such, much of my work centres around this topic. Quality of health content is the complex challenge [11]; therefore, complementary approaches were required. With the HONcode certification, the manual evaluation approach by expert is conducted. This approach needed to be optimized with automated detection of HONcode criteria, and my PhD research work focused on this and is presented below. . I also examine some of the other projects for which I am responsible.

My PhD research work was on an automated tool to evaluate pre-selected criteria of quality health information [12]. The HONcode criteria were used and the review results of the automated tool were compared with the results of human expert reviewers. My thesis explores the automated detection of the HONcode principles for health Web sites. A crowd intelligence arm was also added to offer a global approach to the quality of health online that would cover both Web sites and health mobile apps (also called mHealth).

Firstly, specifically, my thesis considers the feasibility of such automated detection, the benchmarking and assessing of natural language processing methods, the multilingual automated detection of the HONcode principles, the identification of documents in the English and French languages according to their complexity level, and how to help refine search results.

Secondly, it studies the use of HONcode principle classifiers that can be applied to health Web pages. It also investigates the development of an automated system to detect the reliability level of a document and to classify health documents online.

Thirdly, it examines directions for the integration of the tools into a user-centred health domain search engine dedicated to trustworthy information and the testing of the feasibility of integrating the automated detection system into a dedicated search engine. This includes the development of a generic solution to enable integration in different contexts, such as through a Web browser extension.

Fourthly and lastly, the thesis explores the results of usability testing of the integration of the tools into a health search engine, by evaluating the benefits of a search engine that provides access to trustworthy websites and the implementation of the filtering capability of trusted sources via the automated tool developed within the research activities.

There are other projects under my responsibility and of value. These include:

- Provisu.ch – a site which provides free access to its database of information about eye diseases and conditions in the English, French, German and Spanish languages. The site is mainly targeted towards persons experiencing various eye diseases, their relatives and any other interested party.

- Health Curator (healthcurator.org) is a crowd sourcing website which has only very recently been launched. It enables the general Internet user to actively participate in the evaluation of online health information and mobile health applications. Internet users who have been invited by other Health Curator users can sign up to create a profile; they then have the ability to provide a review of any health website. This review is available for public access.

- KConnect (search.kconnect.eu) provides healthcare professionals, researchers in the bio-medical industry, and the public with the very latest and most relevant medical information through medical text analysis, semantic annotation and semantic search services.

As a result of my research activities for the past 20 years, there are many domains which have come to the fore: they include health literacy, and the quality of health information which with new devices need to be adapted and integrated in the delivery of a solution. eHealth has still many large opportunities and challenges, since its benefits will be more and more visible from being identifiable and measurable. A lot of domains of investigation are still in working progress, such as access to the patient electronic record and mHealth; others are emerging, such as health serious gaming, personalized health, and the connectivity of smart devices.

4 Future focus of health informatics

Just as the landscape of the Internet has drastically changed over the past two decades, so it will continue to develop in the years to come. Health informatics and eHealth will also see major changes in the future.

Patients are better informed than ever before, and they are now recognized as being active participants in their own healthcare, rather than the passive observers they once used to be. As such, the demand for online health information will only increase and, accordingly, the need for a quality standardisation tool like the HONcode. I am, as a result, excited about what the future holds for us, and am geared to change and innovate in tune with the dynamic nature of the World Wide Web.

The whole computing domain is innovating at great speed, which allows access to increasingly better technology. However, as Prof. Antoine Geissbuhler, head of the eHealth and Telemedicine department of the Geneva University Hospital states, this could be a problem, as currently we are quite overwhelmed at the legislative level [13]. Prof. Geissbuhler goes on to say that it seems important to be more proactive and to integrate human issues, first of all to ensure that the developing technology reflects our ethics and our values.

Conflicts of interest

No conflict of interest.

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An Irish engineer's perspective on Health Informatics

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Abstract

This paper presents a personal perspective on Health Informatics from the point of view of an Irish engineer. It describes how the author initially became involved in the field and the contribution she has made. A brief overview of the state of Health Informatics in Ireland is given together with some thoughts on the future of the field.

Keywords

Health Informatics, policy, standards

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1 Becoming a health informatician

I graduated in Engineering from the University of Dublin, Trinity College in 1970 following which I obtained my masters and doctorate in Computer Science from the Universities of Toronto and Edinburgh, respectively. I returned to Trinity as a lecturer in 1980. Prior to my retirement in 2014, I was seconded as Director of Health Information and then as Acting Chief Executive of the Health Information and Quality Authority, the newly established Irish health and social care regulator established in 2007 [1].

I first became interested in Health Informatics, or Computers in Medicine as it was called then, in the early 1970s while studying for my Masters in Computer Science at the University of Toronto. I was asked to write a program to analyse the workload in his Laboratory by a relative, a haematologist in Toronto General Hospital who wanted evidence to support a reduction in unnecessary typing and cross-matching of blood in advance of surgical procedures. It was this relatively simple piece of work which gave me a first, albeit small, glimpse into the potential of ICT in healthcare.

Health Informatics is an interdisciplinary field in which health, computer and management sciences, statistics and engineering are all represented. Apart from the direct contribution which engineering knowledge and expertise makes to the development of Health Informatics, Engineering is a good preparation for entering the field as we are trained to solve problems whose solutions matter to people and society. And furthermore, the solutions have to be practical and implementable and are subject to many different types of constraints – financial, environmental, safety, etc. So while I had a lot to learn about the healthcare field itself when I started working in Health Informatics, my background in Engineering gave me a firm foundation on which to build. I found it particularly beneficial to spend time in the hospital observing work practices and in particular the management and use of information. It therefore became standard practice in my research group for new postgraduate students who came from a technical background to do the same. This helped to ensure that our research was practical and grounded in reality.

2 The state of health informatics in Ireland

The "founding father" of health informatics in Ireland is Professor Rory O'Moore [2], who also served as President of the European Federation for Medical Informatics from 1987-1990 [3]. The Health Informatics community in Ireland grew rapidly during the 1990s and 2000s with a succession of mainly European projects, the establishment of the Healthcare Informatics Society of Ireland in 1996 [4], and of the first interdisciplinary Masters in Health Informatics at Trinity College Dublin in 1997 [5]. I was particularly proud to be awarded the O'Moore medal in 2007 in recognition of my contribution to Health Informatics in Ireland.

Prof. O'Moore led the clinical aspects of the research at St James's Hospital while the technical aspects were led by me at Trinity College Dublin, and my husband, Bill Grimson at the Dublin Institute of Technology. Together we were involved in one of the pioneering EU projects in Health Informatics, namely OpenLabs [6] led by Professor O'Moore. A number of successor projects followed including Synapses [7] and SynEx [8]. This was undoubtedly a period of optimism and collegiality among a vibrant and pioneering European Health Informatics community.

However, in spite of a dynamic and successful research group in Dublin, the uptake of Health Informatics in Ireland was and continues to be very low within the public healthcare system. The annual budget for ICT was a mere 1.2% of the total in 2013 compared to an EU average of approximately 3% and the verbal commitment by politicians to the importance of ICT has not translated into implementation. Successive Ministers of Health have focused on dealing with crises of spiralling budgets, long waiting times, and failures in care. A National Health Information Strategy was published in 2004 [9] but virtually none of its actions was implemented. It was not until the collapse of the Irish economy in 2008 following which the country was bailed out by the "troika" of the World Bank, the International Monetary Fund and the European Central Bank, that there was any evidence of change [10]. Under the bailout programme (2010-2013), the Government was required to introduce a number of reforms which interestingly included the requirement to develop an eHealth Strategy. This was published in 2013 [11] and initially there was momentum behind its implementation. A Chief Information Officer, Richard Corbridge, was appointed in 2014 [12]. He has succeeded in energising those throughout the healthcare sector with an interest and commitment to eHealth and has started to implement the eHealth strategy with national projects including ePharmacy, eReferral, and the introduction of a national health identifier [13], which finally went live in June 2017. However, so far this has not translated into a significant increase of expenditure on ICT by the Government. We are yet to see whether there is the political willingness to commit to the major long-term investment required of up to $e1$ billion to implement a national EHR.

3 My contribution to health informatics

My contribution to Health Informatics lies in 3 main areas: education, research, and policy. Under the education heading, Prof. O'Moore and I established an interdisciplinary Masters programme in Health Informatics at Trinity College Dublin in 1997 [5]. This programme was unusual in that students came from both ICT and health backgrounds and worked together in teams. Several hundred students have graduated from the programme over the last 20 years. Students from an ICT background take an introductory module in health sciences which provides an introduction to human biology and disease, so that students can appreciate the basis for scientific/technical procedures in the diagnosis, treatment and basic research associated with human disease. Students from a health background take an introductory module in programming (through Java), the objective of which is to provide an understanding of the process and challenges of software development.

Under the research heading, I have published many papers in the field and also been Principal Investigator on a number of nationally and internationally funded grants. In particular, I would single out the Synapses project funded under the Health Telematics Programme of the EU. Synapses, focused on the development of a Federated Health Records Server. A key underlying principle of the Synapses approach was to facilitate the exchange of electronic health records (EHR) and extracts of records in such a way as to ensure that both the structure and meaning (syntax and semantics) of the information being exchanged were preserved. Synapses built on my previous research in the field of distributed and federated database systems and made an important contribution to the development of CEN standards for the exchange of electronic healthcare records [7].

Finally, in relation to policy, I was seconded to the newly established Health Information and Quality Authority [1], established in 2007. In addition to regulation of health and social care, HIQA unusually also had responsibility for setting standards for all aspects of health information – from data definitions, to national health data collections, to technical standards. As Director of Health Information, I was responsible for establishing a programme of national eHealth standards as well as making important contributions to policy including, for example, the introduction of a unique health identifier in Ireland [14]. Under my leadership, it was agreed that all the technical standards to support eHealth should be based on proven international standards, which are already available in software products and with minimal local customisations. Ireland with a population of only 4.5 million is a small country and therefore developing

bespoke standards would be prohibitively expensive. I also realised that Ireland could take advantage of being a late adopter of eHealth by learning from others – both what had worked well elsewhere and what had not. Therefore, before selecting any standard, my team would conduct extensive international research and consult widely producing a comprehensive review report of the area for publication. This would then provide the basis for the development of consensus among the key stakeholders on an advisory committee. While the ultimate goal might be a national EHR, a number of key building blocks needed to be put in place first, including for example unique health identifiers and an agreement to adopt SNOMED-CT as the clinical terminology standard. Furthermore, there was already a service, HealthLink [15], in place based on HL7 v2 to facilitate communication between General Practitioners (GPs) and hospitals which is used by the vast majority of GPs and hospitals throughout the country. Initially it provided only for the reporting of Laboratory test results to GPs but now includes referrals and a growing number of additional services. In other words, the approach I promoted was an incremental one building on what is already working well. Given the financial situation in Ireland at the time, there was no possibility of a strategy based on "rip-and-replace". It was particularly encouraging to see that many of the policies which my team and I at HIQA had been promoting were reflected in the national eHealth strategy and have ultimately become government policy.

4 Future focus of Health Informatics

One of the key approaches to managing the spiralling costs of healthcare and of improving outcomes is to empower citizens, who after all represent the greatest single under-utilised resource, and encourage them to take responsibility for managing their own healthcare. This involves moving away from healthcare systems which are focused primarily on treating illness – the so-called "sickness systems" – to ones which are focused on promoting health and well-being. ICT is central to achieving this vision and at the heart of the ICT strategy should be an electronic record which is truly person-centred. Traditionally, the development of Electronic Patient Records (EPRs) and Electronic Healthcare Records (EHRs) have focused on the development of systems to support the healthcare professionals in decision-making and patient management and this still remains important. However, as we seek to empower patients they need to be centre stage and to take ownership of their own records providing access by healthcare professionals as and when required with specific provisions for emergency access (break-glass). Instead we continue to develop EPRs and even national EHRs with patient access at worst added as an afterthought and at best coming later on in the roll-out. There are important lessons – both good and bad to be learned from the public engagement with social media and the wider digital economy.

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The Health Informatics research of a Dutch female scientist

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Abstract

This paper describes how I, as a female scientist, entered the field of Health Informatics; how health informatics evolved in the Netherlands; my own research and educational activities, and my focus on the future focus of Health Informatics research.

Keywords

Health informatics career; female scientist

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Nicolette de Keizer

1 How I entered the field of health informatics

Since I was a little girl I wanted to become a physician. At the time I finished high school the Dutch universities used a selection process based on drawing of lots. Unfortunately I was not one of the lucky ones that 'won' access to the Medicine program but found an, in 1990 new to start, Medical Informatics program at the University of Amsterdam. At that time my experiences with and interest in computers was limited but I always liked mathematics and data analyses so a study in which you can learn how to obtain new knowledge from medical data and how to implement new knowledge into medical care sounded very attractive. Although I started with the idea to change to Medicine in the next year, I never draw a new lot as I felt I already won the lottery with the discovery of this new field.

2 Health Informatics in the Netherlands

Founding fathers of Medical Informatics in the Netherlands are among others prof. dr. Jan van Bemmel, prof. dr. Arie Hasman and Dr Jan Talmon. Coming from physics they started to develop the field with research on signal processing. As they were based in a university hospital that was involved in the development of a national hospital information system, the field evolved into the direction of among others hospital and GP information systems, structured data entry and standards.

In 1990 the Academic Medical Center and University of Amsterdam started a Master program in Medical Informatics. No other Dutch university offers a program in Medical Informatics although some related Master programs exist such as technical medicine, mostly offered at technical universities.

In 1994 when I finished my Master in Medical Informatics there were five universities in the Netherlands with a department of Medical Informatics. Although the University of Amsterdam was and still is unique in offering a Master program in Medical Informatics, all others offered PhD programs. Unfortunately during the first decade of the 21st century, due to budgetary cuts, all universities except those of Amsterdam and Rotterdam closed their departments of Medical Informatics. Nowadays, the research focus in Rotterdam is on medical imaging, (semi)automatic extraction of knowledge (from documented databases) and structured medical data to record data in the context of clinical care with sufficient detail so that the data can also be used for secondary purposes [1]. The research in Amsterdam focuses on the following themes [2]: Decision support (especially how to facilitate physicians to do the "right thing"), Modelling (mainly prognostic and etiological), Terminology systems and information models to support unambiguous data collection and reuse of medical data, and Evaluation of IT systems and of quality of health care. The department maintains and contributes to the development of (inter)national quality registries in intensive care, renal replacement therapy and cardiac surgery. Since 2015 the department also offers an online post-doctoral Master program Health Informatics for care professionals. All three Bachelor and Master programs are based on IMIA's recommendations on on Education in Biomedical and Health Informatics [3]. Outside academia, The Netherlands also has a national center for standardization and eHealth, called Nictiz [4]. This organization is among others the national release center for SNOMED CT and performs an annual monitoring of eHealth implementations in the Netherlands. Although there exist just two specific departments of medical informatics, research on eHealth, especially self-management apps and telemedicine, is more and more embedded in regular medical research and public health /epidemiological research institutes all over the country.

3 My activities in Health Informatics

Within the research group I am directing three research lines can be distinguished:

1. Evaluation of quality of health care: as the managing director of the National Intensive Care Evaluation (NICE) registry I focus on how to assess and improve the quality of Dutch ICUs [5]. Institutional comparison based on case-mix adjusted outcome is central and therefore my research group investigate the mechanisms behind Audit&Feedback systems, case-mix correction by prognostic models, methods to develop quality indicators, and data quality.

2. Evaluation of health care information systems: as a member of the EFMI and IMIA working group on Evaluation (IMIA WG chair from 2009-2015) I was involved in the development of guidelines for performing and reporting evaluation studies in health informatics: GEP-HI [6] and STARE-HI [7]. These guidelines supported several evaluation studies on decision support e.g. [8, 9, 10] and EHR in the Netherlands as well as in developing countries [11].

3. Sematic interoperability: during the founding years of the IHTSDO I was involved in standing committees to evolve SNOMED CT and contribute to its implementation in the Netherlands. Structured and standardized data recording is essential to reuse this data for secondary purposes such as automatic calculation of quality indicators [12].

Research experiences are fed back to our Bachelor and Master program Medical Informatics and the online Master Health Informatics. I am the director and a lecturer of this online Master program.

4 Future focus of Health Informatics

The main goal of health informatics is to improve the health of people and the health care system by optimally use data, information and knowledge often by means of healthIT systems. Theory-based development and evaluation of interventions, such as Audit&Feedback systems, are needed to understand the mechanisms behind these systems and contribute to identifying the active ingredients of successful interventions. Furthermore, reuse of routinely collected data, e.g. for calculating quality indicator presented within Audit&Feedback systems, is needed to obtain and provide new knowledge without additional registration burden. Therefore research on natural language processing, terminological systems and information model are essential to standardize and structure routinely collected data. Research on current hot topics in medical informatics such as big data, eHealth and self-management, personalized medicine are not restricted to departments of Medical Informatics. This type of research will be further integrated with clinical research and large collaborative research projects together with medical departments and computer science departments.

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Health or Medical Informatics in Education, Healthcare, and Research: The Croatian Perspective

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Abstract

This paper starts by outlining the author's early career in health (or medical) informatics in Croatia. It offers a dedicated overview of the Croatian field as it developed, particularly from the educational viewpoint. There are special insights into the curriculum at the School of Medicine at the University of Zagreb. How to improve electronic healthcare applications, and a focus on data analysis, have been focii of the author's later career development. The paper ends by exploring five key elements at the intersection of (future) information technology and medicine/health care.

Keywords

Medical informatics profession, Medical informatics education, Medical informatics research

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1 How I got into the profession

After graduating from the University of Zagreb, Faculty of Science in 1972, I got a job as a statistician in the epidemiological project at the Andrija Štampar School of Public Health. Programming statistical routines was one of my duties. Data processing and interpretation of results were the others. At that time, the curriculum of School of Medicine already contained the subject on computers in medicine and health care. It was introduced by Professor Deželić several years ago. However, it was only rough information on the topic.

My first steps in health (or medical) informatics started with education of medical students. It was a demonstration of how to prepare the medical data and how to process them. In the early-1980s design of integrated health information system for Croatian health care system was initiated, and, especially, for health center (in much more details). I was involved in both of these projects. Work on the project required knowledge of the health care system:

information the medical professions need, data collected in the system, and their flows.

2 The state of health (or medical) informatics in Croatia

Health informatics and medical informatics will be used in this text interchangeable, and could be considered as synonyms.

2.1 History

Croatia started with education and practice of health informatics in the late-1960s. A health center in the city of Zagreb was a model of computer data processing for out-patients institutions, and the "Sveti Duh" General Hospital, a model for computer data processing in hospitals. Chronic disease registries were created for cancer, psychosis, and alcoholism along with registries for patients suffering from tuberculosis, and diabetics.

At the same time Andrija Stampar School of Public Health at the University of Zagreb started to provide education in IT possibilities for health professionals at the postgraduate level. In the early-1970s health informatics education was introduced at the University of Zagreb, School of Medicine. Universities in other three Croatian cities having the schools of medicine were following the Zagreb practice several years after.

More historical details can be found in publications of Kern [1] and Dezelic et al [2].

2.2 Electronic healthcare applications

In 2003 Croatia started to deploy integrated healthcare information system at the primary healthcare (PHC) level as the first step for connecting all other stakeholders and levels of health care (i.e. hospitals, pharmacies, laboratories) into a single enterprise healthcare network [3]. According to the National Health Care Strategy (NHCS) 2012-2020 published in 2012 "...at the moment, all general practice/family medicine offices (approximately 2350), all paediatric offices (approximately 270), all gynaecological offices (approximately 270), all dentist offices (more than 1900), all pharmacies (more than 1150), primary health care laboratories (approximately 120), all school medicine offices (153), out-of-hospital specialist-consultation health care (approximately 800) and information system of the Croatian Institute for Health Insurance are connected to the Central Health Care Information System in Croatia CEZIH."

In 2011 two key applications were introduced in CEZIH (e-prescription and e-referral to biochemical laboratories). Hospital information system (HIS) is present in approximately two third of public hospitals, while others have almost no central HIS. The project of computerization established two new applications, e-waiting list and e-appointment, and they are the first step in integration of the hospital system in CEZIH.

Telemedicine as the medical services provided from distance through information and communication technologies are currently provided at primary, secondary and tertiary level of health care.

All the eHealth applications were based on HL7 standard.

2.3 Funding and evaluation of electronic healthcare applications

The whole project CEZIH, development, maintenance, and upgrading, was funded by the Croatian state budget. A procedure of evaluation, i.e. certification of all the applications was documented at the CEZIH web (http://www.cezih.hr/). There could be found information for vendors (what to do to achieve certificate for their product), and for health professionals (what is new in CEZIH).

2.4 Education

The main problem of introducing health informatics education in medical curriculum was its position in the curriculum. Nowadays the position of Medical informatics course is not the same at all the schools of medicine in Croatia. University of Zagreb positioned the Medical Informatics course at 5th year, together with Medical Statistics and Introduction to Research. The other two, the University of Rijeka and University of Osijek, positioned the Medical informatics course at the 2nd year in their curriculum. University of Split also started with medical informatics in the medical curriculum, but recently it does not have this subject in the curriculum.

Nursing studies at the universities as well as nursing at the universities of applied health sciences in Croatia show a lot of varieties in education in the eHealth topic. Some of them incorporated serious course of this subject, but some of them use only the basic skills.

Several faculties of computer sciences or information sciences incorporated some eHealth topics in their curriculum, mostly as elective courses.

The textbook on medical informatics published in 2009 by Kern & Petrovečki as editors [4] has been the basis for medical informatics courses at all the institutions in Croatia giving education in this topic. The textbook was prepared according to IMIA recommendations on educational needs for health care professionals to acquire knowledge in information processing and information and communication technology with learning outcomes defined in terms of knowledge for health care professionals in their role as IT users.

To achieve the practical skills, the students at the School of Medicine (University of Zagreb), use the manual with problem solving tasks and instructions how to solve them (also prepared harmonized with IMIA recommenda-

tions for IT user). The manual is available at the LMS – system for eLearning at the Web of School of Medicine, University of Zagreb (https://lms.mef.hr/main/en/).

Medical informatics courses are also an integral part of several post-graduate specialist studies at the School of Medicine, University of Zagreb (e.g. public health or family medicine). PhD program (Biomedicine and Health) includes several elective courses dealing with medical informatics issues.

Based on our previous experience in post-graduate education in medical informatics, the idea of specialist postgraduate studies was born. It was agreed that this new training program should be realized as the cooperation between the two faculties of the University of Zagreb – Faculty of organization and informatics and School of Medicine. Following this idea, the project was finished and published under title Medical Informatics - Qualification and Profession. Subtitle "Qualification Standard University Specialist in Medical Informatics" gives the description of qualification standard in details [5].

2.5 Research and funding

Health or medical informatics has not been recognized as the scientific field in Croatia. Research, development and innovations in health or medical informatics have been considered as Biomedicine, Computer science, and Information sciences.

However, there are a number of research projects in the field related to medical informatics. Most of them are dealing with health information system or subsystems, and published as conference papers, publications in journals, or as PhD or MSc theses. Some of them are dealing with public health interventions, or with knowledge discovery and prediction.

Most of such projects were funded by the Croatian state budget, Ministry of Science, Education and Sport.

3 My research results and achievements

The area of my research can be divided into three parts: (1) problems of medical informatics education of health professionals, (2) how to improve eHealth and evaluate IT applications, and (3) methods of data analysis/data interpretation (as a team member in the medical/healthcare projects).

3.1 Problem of medical informatics education of health professionals

The main issues related to the education of future physicians in the field of medical informatics were: medical informatics subjects in the medical curriculum – when [6], and how to tailor the course to the given stage of student knowledge [7].

Namely, through the history of the School of Medicine (University of Zagreb), position of the Medical/Health Informatics course was changing - from the first to the sixth year of study. To find the optimal position, we asked our students what they think about it. Given the fact that the situation in the curriculum was changing, at a moment we had the same program in two years of study, in both, the second and the sixth year of study. Conclusion of investigation was: "the position of medical informatics should not be prior to completing the (at least one) clinical subjects".

3.2 How to improve eHealth and evaluate applications

Development and implementation of applications in healthcare does not go smoothly - a lack of understanding among the participants or lack of knowledge of the problem (resulting in dissatisfaction of end users) [8].

Therefore, The Committee of eHealth of the Croatian Academy of Medical Sciences has developed and published a Declaration on eHealth as a lighthouse in an ocean of information and communication technology in health [9]. As the outcome of the Declaration some of statements were directly copied in the Strategic Plan of eHealth Development in the Republic of Croatia [10]. Other actions dealing with problems of improvement of eHealth applications were investigations of end-users' satisfaction with applications [11] and development of methods for evaluation [12]. Several book chapters also reflect the issues and points to the challenges arising from eHealth [13, 14, 15, 16].

3.3 Methods of data analysis/data interpretation

As a member of various teams I participated in the development of methods of data analysis, evaluation of these methods, and the interpretation of results [17, 18, 19]. Also, as a team member I used to participate as the statistician in publications and projects in health.

4 Future focus of health informatics

According to van Bemmel, the "medical informatics is located at the intersection of information technology and the different disciplines of medicine and health care". It means that medical informatician should be educated in both, information technology and medicine/health care. So, the future focus of health informatics should be as follows:

1. The most important problem for educated medical informaticians is to find their place in the real world/system. It is obvious that he/she should be a bridge between the two sides, but a little bit closer to medical/health care side - at the source of health information, with health professionals, and to un-

derstand their information needs. The consequence of such a view is that health institutions should employ medical informaticians [9]. His/her obligations should be:

- To participate in development/improving the applications intended to health professions (and cooperate with other IT professionals),
- To participate in developing medical classifications, coding systems, standards and similar,
- To participate in research conducted by health professionals (as data designers, data analysts, and interpreters of results),
- To develop methods of data processing and making decisions,
- To create information security policy of the health institution,
- To assist in education in medical informatics for health professionals.

2. Medical informatics terminology should be standardized (Electronic Health Record - EHR, Electronic Medical Record - EMR, Electronic Personal Health Record - EpHR) at the international level,
3. Guidelines for development/improvement the EHR, EMR, EpHR, and relation among them, should be developed,
4. Medical informatics associations should insist on legal and ethical aspects of all activities dealing with information and communication technology in medicine and healthcare,
5. Medical informatics should be a part of education of all the health professionals as the end-users of information technology in healthcare, and it should be properly located in their curriculum.

If we want prosperity to medical informatics as a profession, professionalism and satisfaction of all participants in the health sector, it is necessary to consider all the five elements. The international level is necessary. The assumption is, of course, that there exist educational programs in medical informatics in accordance with the IMIA recommendations for education in medical informatics.

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The evolution of medical informatics in Germany:

From structured clinical documentation to decision support for individualized therapy

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Abstract

A major prospect of Medical Informatics are methods, tools and infrastructures to support data-driven medical care and biomedical research. We need new concepts for application systems that also care for transparency which data from which sources in which quality build the evidence base for individual decisions. These systems have to be able to take into account patient generated data, patient preferences, and environmental contexts for an individualized decision that really meets the patients' expectations, values and needs. Currently, these soft factors for medical decision support are not sufficiently understood and researched in all its dimensions.

Keywords

Medical informatics, health informatics education, data integration for biomedical research, systems medicine

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1 How I came to work in Health Informatics

The Medical Informatics program Heidelberg / Heilbronn was established in 1972 and successfully running for 14 years when I finished school in 1986. I looked intensively for a program which would combine my interests in mathematics and my fascination for medicine. There it was - the only one in Germany at that time. My internationally most recognized teachers were, in alphabetical order, Hartmut Dickhaus, Reinhold Haux and Franz-Josef Leven. Unfortunately, Jochen Möhr had just left when I started my studies. Although the Heidelberg / Heilbronn program proved also successful for working in fields outside medicine [1] – that was never an option for me. The fascination of medicine as area of application of informatics approaches is still alive and is continuously offering new exciting challenges.

2 The state of health informatics in Germany

In Germany, the emergence of medical informatics was strengthened by the awareness that structured medical

documentation is needed to advance clinical medicine. In 1926, the first epidemiologic tumor registry was set up with the aim to improve aftercare and monitoring. In the middle of the 20th century, 15 million patient histories were available in the central archive for military medicine [2]. Medical colleagues recognized electronic data processing especially useful in hospitals and worked on systematic approaches to store and retrieve diagnoses, clinical findings, therapy results and literature [2]. They explored different types of punchcards and elaborated different coding systems for diagnosis. In 1966, this resulted among others in the 'Klinischer Diagnosenschlüssel' as German version of ICD-8. To enable computer-based analysis of medical data a standardization of demographic data was developed and published for general use for patients of all medical domains [3]. Heidelberg University Hospital was the first one that stored these data on a single punching card. To identify patients unambiguously during their stay in hospital innovative methods for unique patient identifiers were developed.

Early topics of medical informatics in Germany were also laboratory automation, medical signal processing, clinical decision support, and intelligent support of medical report writing. Therefore, the awareness was rising that computer-based tools are helpful to improve processes, e.g. for patient administration, logistics and reimbursement. Processes in laboratories started to be supported by computer-based tools and the monitoring of patients in intensive care units by ECG-analyses [4]. That was the beginning of the evolution of computer-based hospital information systems in Germany. Clinical application systems, communication servers, and decision support, especially for computer-based diagnoses and artificial intelligence became an important topic of research and development in the last decades of the 20th century. Another important focus of medical informatics at that time was methodological research on biomedical data analyses and medical signal and image processing.

With the beginning of the 21st century more industrial solutions for computer-based components of hospital information systems were available. Hospitals introduce electronic patient records and digital archiving. The process is still ongoing, methods and tools become more and more widespread. General physicians have to use their electronic practice information systems and electronic data transmission to fulfil reimbursement purposes. Nevertheless, despite these advances, eHealth in the sense of electronic data exchange among care providers in different institutions and telemedicine approaches are not yet fully established. There exists a variety of pilot projects but transfer to routine use is still a challenge. The German electronic health card is on its way, first applications of administrative patient data management and electronic medication plan have just started.

Medical Informatics research in Germany currently offers a broad variety of topics, e.g.: Methods and tools in the fields of information and process management are optimized, computer-based surgical planning and computer-guided surgery are advanced, and the use of sensor-based technologies in patient care is explored.

With the increasing availability of –omics data it became relevant to provide information technology (IT) solutions to integrate biomedical data from heterogeneous sources and to correlate genotype and phenotype data. Therefore, IT infrastructures for biomedical research and the secondary use of clinical data for research purposes is an ongoing scientific topic. New methodological approaches and algorithms are under research since there is an expansion from hypotheses-based research in medicine to data-driven research. Additionally, patient-generated sensor-based data might contribute to future patient care. In this context, in 2016, the German Ministry of Education and Research (BMBF) has established an extensive funding scheme of 100 million Euro on top of other funding schemes to support German university hospitals in building effective IT- and information management infrastructures for exchanging patient data for care and research.

With regard to education the Heidelberg / Heilbronn medical informatics program is of course no longer the only one in Germany. In the last decades, several medical informatics programs and courses were established at German universities e.g. Göttingen, Braunschweig, and Lübeck and there is currently a multitude of programs at universities of applied sciences.

3 My research results and achievements

After finishing my studies of medical informatics, I started with a PhD-project where we successfully implemented and published a German text book for internal medicine as a hypertext on electronic media – long before Internet technologies were in widespread use. Nevertheless, my major interest was to directly improve patient care by medical informatics methods and tools. Thus, I continued after PhD with a cooperative nationwide project on Documentation and Therapy Planning in Pediatric Oncology (DOSPO). The major aim was a multiple use of data that was recorded and calculated for patient care and to transfer it into multicentre, nationwide clinical trials [5]. A variety of innovative tools e.g. for terminology management system and database generation were developed [6, 7] and in 2000 we received the international telematics award from the German Ministry of Health for the most successful application in telemedicine. About that time, I became managing editor of the IMIA yearbook for six years together with other young colleagues and together with Reinhold Haux and Casimir Kulikowski as chief editors - which was definitely a highlight in my career [8]). It continued my impressing international experiences I could gain in early years as scientific secretary of the IMIA WG1 'Working Group on Medical Informatics Education' [9] and by contributing to the first version of the IMIA recommendations on education in health and medical informatics [10]. In 2002, also in an international team, we

published a paper on 'healthcare in the information society – a prognosis for the year 2013'[11] and in 2014 the systematic comparison whether the prognosis had become true [12, 13].

Despite industrial solutions for hospital information systems advanced considerably with the beginning of the 21st century, two major challenges still remain: i) knowledge-based decision support in patient care and (ii) multiple use of data for care and research. In the last years my research group could successfully explore the potential of openEHR [14, 15] and we could implement a variety of data integration projects and generic tools for biomedical research [16, 17, 18]. Nevertheless, there is still a barrier to automatically transfer data for research purposes and to translate research results for individual patient care decisions. A new concept to achieve this is 'systems medicine'. To implement systems medicine, new medical informatics solutions are necessary to enable medical decisions based on heterogeneous data at the point of care. Systems medicine [19] is currently advanced in Germany by the German Ministry of Education and Research in the research program e:Med and we participate in the project CLIOMMICS [20] with the aim to establish a multi-level data management and IT infrastructure to integrate data heterogeneous sources, to map them to up-to-date knowledge and to support care decisions. New medical informatics tools are needed to process the variety of data and knowledge and to make transparent the evidence at the point of care. Thus, my major research interest for future medical informatics is to contribute by this research to truly individualized care which not only takes into account genomic data but also individual preferences, circumstances and values.

Education in Medical Informatics is continuously an important aspect of my work. I am responsible for the Heidelberg part of the Medical Informatics bachelor and master program. We participate in the Erasmus+ project PH-ELIM on 'Capacity Building in Higher Education in Public Health in Montenegro'. In recent years we build up a Biomedical Center of Excellence in Jordan and a master program in Biomedical Informatics at the university of Santiago de Chile.

4 Future and prospects of health informatics

In Germany, a major prospect of Medical Informatics are methods, tools and infrastructures to support data-driven medical care and biomedical research. The exciting, above mentioned, initiative funded by the BMBF will also advance solutions for the challenging issues of data protection and security. It will be interesting to observe if the results can also be used to strengthen international cooperation for patient care and medical research. The technical infrastructure and processes to provide interinstitutional medical data seem to be available in a few years. To my expectation, the time to be able to use this data directly for an individual clinical decision at the point care will be much longer. We will need new concepts for application systems for clinical decision support that also care for transparency which data from which sources in which quality build the evidence base for individual decisions. These systems will have to be able to take not only the biomedical and clinical data of a patient into account but also patient generated data on daily activities, patient preferences, and environmental context for an individualized decision that really meets the patients' expectations, values and needs. Currently, these 'soft' factors for medical decision support are not sufficiently understood and researched in all its dimensions. Therefore, the major challenge of medical informatics in the future will not only be to provide new methods for data analytics but to provide solutions that medical research results are available for use in patient care and for the patient itself.

Young physicians in Germany are more and more used to work with computer-based application systems and mobile tools right from the beginning of their professional career. They have to be educated to be the clinical partners in the processes of requirement engineering, information modelling and user interface design. They have to be increasingly aware about the relevance of data quality and availability for high quality patient care and biomedical research.

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Health informatics in Sweden – a personal view

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Abstract

This paper summarizes my health informatics journey starting as an undergraduate student in medical informatics in 1988 until my current position at Karolinska Institutet in Stockholm where I was appointed as the first full professor in health informatics in 2008. Besides my own and my group's work in the fields of dental informatics, collaborative home care, clinical informatics and consumer informatics, this paper further gives an overview of health informatics research, education and implementation in Sweden. My personal view on the future of this exciting cross-disciplinary field concludes this paper.

Keywords

Clinical informatics, consumer informatics, dental informatics, ehealth, home care, Sweden

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1 How I entered into the field of health informatics

After finishing high school, I did an apprenticeship in information technology and economics. I then wanted to get more education in the field of informatics in combination with an application area. Economics would have been a choice, but I chose medical informatics because I saw a lot of potential in this field and I liked the combination of structure and humanity. I studied medical informatics at Heilbronn Technical University and Ruprecht-Karls University in Heidelberg, Germany and received my MSc degree in 1993. The Heilbronn/Heidelberg programme was one of the first in the world of its kind and although collaborations with other universities existed, there was no established exchange for doing a master thesis abroad when I decided to do so by the end of 1992. Communication was cumbersome. The World Wide Web had been released but Internet was not really accessible to undergraduate students at that time. We did for example not have access to email at our university. I am thus forever grateful to the research assistant whose email account I could "borrow". Thereby I got into contact with Professor Werner Schneider, head of the Center for Human-Computer Interaction at Uppsala University, Sweden who also was the head of UDAC (an University owned IT&T service organisation). This turned out to be my start into an academic career in this exciting field. I continued to live in Sweden after finishing my master thesis and Sweden became the country that I know best regarding its state of health informatics. My experiences of health informatics will thus describe the Swedish context.

2 The state of health informatics in Sweden

The Swedish context covers health informatics applications, research and education which are described here in different sub-sections.

2.1 eHealth – an integrated part of Swedish healthcare

Use of information and communication technology (ICT) is a natural component of everyday life in Sweden, where 90 percent of residents (aged 12+) have broadband access to the Internet from their homes and 93 percent have Internet access in general. In 2015, on average 80% of the population used Internet from home daily [1]. Also, health care in Sweden is highly computerized, with electronic patient records (EPRs) being implemented in all primary care , psychiatry, and hospitals, owing partly to the fact that each Swedish resident is equipped with a unique identification number that is used for any public service nationwide. Whereas EPRs were introduced into primary care in the early 1990s, often supported enthusiastically by primary care physicians, the introduction of EPRs into hospitals was lagging and occurred mainly during 2002 - 2010. Today, four different vendors of EPRs cover 86 percent of the Swedish market [2]. Sweden is leading the world with regard to e-prescription, and today 99 percent of all prescriptions are made electronically. Further, all laboratories are fully computerized, and digital picture archiving and communication systems (PACS) are standard in all radiology departments.

Computerized provider order entry for various laboratory tests, radiology, and pathology are provided to varying degrees (50-100%) within single county councils. Electronic referrals between providers in different county councils have previously not been possible due to the lack of interoperability standards. A national solution, that currently started to be introduced in almost half of the county councils, is expected to change this situation [2]. Collaboration between county councils and municipalities within the same region is important from a patient's perspective, however, and almost all county councils provide systems for electronic exchange of hospital discharge summaries.

To communicate with patients, a number of e-services, such as appointment booking and renewal of prescriptions, are provided through a national portal. To date, 33% of all residents have set up an account for this portal. Further, 19 out of 21 Swedish county councils and regions offer their residents online access to the patient record – a function that was used by more than 10% of the population by the end of 2016 [3]. Technically this access is granted through a national health information exchange platform that also enables access to a summary care record for care providers.

Sweden also has a long record of developing national quality registries (NQRs). From 15 NQRs in the early 1990s, Sweden now has more than 100 NQRs that contain individual-level data on problems or diagnoses, treatment interventions, and outcomes and are organized by condition [4]. The successful development of the Swedish NQRs is explained largely by their decentralized nature. Caregivers that have the greatest use for the data also have the main responsibility for developing the system and its contents, and the databases are spread out among different clinical departments throughout Sweden. Registry content is continually validated in different ways by registry managers and units that use the registers. This is complemented by annual quality control, represented by the annual reports and grant applications submitted for central funding. Data quality in the NQRs is sufficient for use in clinical research. However, the quality and usage of the registries varies and the sheer number of different registries that are also partly overlapping and incompatible shows a lack of a thorough informatics infrastructure to build upon. Another problem to date is also the insufficient integration between NQRs and EPRs. Today, data is registered separately because of the lack of interoperability, although there exist local implementations where data can be transferred from specific EPRs to a specific NQR. Nevertheless, NQRs have certainly fuelled structured documentation in Swedish healthcare.

Albeit a high level of IT in healthcare practice and a high level of IT literacy in the Swedish population, also among the elderly population, Sweden is challenged by IT applications that are incompatible, not always meet end user needs, and lack semantic and organisational interoperability. Also, from a practical point of view, we see that the data quality of clinical documentation does not satisfy the needs for automated clinical decision support [5, 6].

Further challenges result from inconsistencies between development that takes place at a national level and decisions that are made at the regional/county council level. The goal of the most recent Swedish eHealth policy is to be best in the world in eHealth in 2025. To achieve this goal, Sweden has to benchmark against other countries, not least other Nordic countries. Within the Nordic eHealth Research Network, we have been monitoring eHealth implementation in the Nordic countries since 2011 and at present, despite the fact that some common indicators for eHealth measurement do exist, a sustainable model for governance of eHealth monitoring in the Nordic countries is still lacking [7].

2.2 Health informatics research in Sweden

Health informatics research in Sweden started in the late 1950's, early 1960's through Paul Hall and Hans Peterson in Stockholm and Werner Schneider in Uppsala as well as Ove Wigertz in Linköping. Leading research in nursing informatics was performed by Margareta Ehnfors and Anna Ehrenberg in Örebro who developed the VIPS model. Also Ulla Gerdin was engaged in nursing informatics early on. The field matured in the 1990ies with health informatics research groups at mainly Linköping University, Uppsala University, Karolinska Institutet, Umeå University, Örebro University, Gothenburg University and Lund University. Today, some health informatics research (in the broadest sense) is performed at most universities and researchers rooted in computer science, clinical medicine or nursing, social sciences as well as other research fields show an increased interest in entering into the field.

2.3 Health informatics education in Sweden

Although Sweden is known as an early adopter of technology with a high level of IT literacy amongst its residents, health informatics programmes came in very late into the undergraduate curricula of Swedish Universities. The first four year degree programme in medical informatics (in Swedish) started in 2002 at Karolinska Institutet. Otherwise undergraduate education was and still is often restricted to single courses offered by different universities. Between 2006 and 2008 six Swedish Universities reviewed the state of health informatics education at that time and collaborated on a distance education course in health informatics [8]. There were attempts to start programmes at bachelor or master level but most of them closed down again due to low numbers of enrolled students. Today, only two master's programmes exist: The two year global master's programme (in English) [9] which started in 2010 and is a collaboration between Karolinska Institutet and Stockholm University leading to a joint degree, and the master's programme in eHealth (in Swedish) at Linnaeus University in Kalmar which starts autumn 2017. Health informatics courses within the medical curricula are almost non-existent in Sweden and a clinical informatics sub-specialty as in the U.S. does not exist. However, medical students start requesting subjects such as health informatics and digital health within their curricula and at some universities discussions have started to integrate health informatics into the medical curriculum.

3 My achievements in research, education and transfer of research results

Coming to Sweden, I combined my education in medical informatics with the field of human-computer interaction when joining the Center of Human-Computer Interaction at Uppsala University. My early research (1993-1999) was in dental informatics especially dental imaging and IT supported integrated care concepts for dental offices [10]. In the late eighties and early nineties dental informatics was an upcoming area with few research groups worldwide. Together with Werner Schneider and Ina-Veronika Wagner I contributed to this field by researching concepts for integrated chairside support. The work was done within the framework of several European projects such as ORATEL, ORQUEST, VIP and VIP+. My personal contributions were novel methods for automatic quality assessment and controlled diagnosis-oriented enhancement of digital (or digitized) intraoral radiographs and orthopantomographs. Results from this research were sold to industry and implemented in clinical practice.

Since 2000, I subsequently widened the application domain of my research from dentistry to medicine and healthcare, especially home care. As principal investigator of one of the first home care projects in Sweden, named Old@Home, I introduced mobile informatics solutions for collaboration between health care professionals, elderly patients and their next-of-kin. We explored new methods for user needs and requirements elicitation in collaborative care settings [11], provided solutions in form of a virtual health record accessible through mobile devices [12] and evaluated them from different perspectives. The successor – Old@Home2 - was funded by the European Union. I also set the work of my group in the broader context of ambient-assistive and health-enabling technologies [13] and provided a number of highly cited review articles in the area of elderly home care [14, 15]. My work in this area also led to co-authoring a white paper about integrating health and social care for the European Science Foundation.

In 2005, I built up the first Centre for eHealth in Sweden which was set up as an interdisciplinary research centre across the faculties of medicine, technology and social sciences of Uppsala University. Researchers involved had different scientific backgrounds and apart from health informatics included information science, information technology, human-computer interaction, medical law and ethics, economics as well as medicine and nursing.

In 2008, I received the Strategic Professorship in health informatics at Karolinska Insitutet in Stockholm where my group studies similar methods for collaboration and decision making in several areas such as stroke care [16, 17], intensive care and acute care and with increased focus on the patient's role [18] and shared decision making.

At Karolinska Institutet we also ran one of the first eHealth Massive Open Online Courses (MOOCs) with more than 8 000 participants (clinicians, informaticians and patients) from 165 countries [19].

4 The future of health informatics

The future of biomedical and health informatics (BMHI) has been recently discussed by informatics scientists in three panel sessions at leading international conferences (MIE 2015, Medinfo 2015, HEC 2016). The panellists discussed research topics and methodological approaches in informatics that they perceived being insufficiently addressed. Conclusions of these discussions highlighted that BMHI is still maturing as an academic discipline at the same time as vendor-supplied applications are often uncritically accepted. Also there existed diverse opinions amongst panellists on whether the field is grounded in theoretical foundations or not [20].

In my opinion, multi-disciplinarity is both the challenge and the opportunity of our field. We borrow methods and theories from many different fields and the definition of genuine BMHI methods and theories is difficult. Whereas we can find medical informatics methods such as e.g. signal processing or knowledge representation, the theoretical and conceptual base of our field is rather

blurry. Another characteristic of our field is the ambition to contribute to informatics science and at the same time to improve healthcare. As a researcher it is often frustrating to see that our research developments have low uptake in clinical practice. Many IT applications are not adapted to the users' needs and thus not used or not used as intended, which prevents the expected benefits from being achieved. On the other hand, many IT applications are not built on rigorous information models and thus not scalable. We do not systematically build on each other's research results to progress science and our research results are not systematically applied and implemented in practice.

With the advent of new sources of health data we can observe some current trends:

- Clinical research is going towards personalised and precision medicine;
- Health care providers are eager to measure the effect of their actions and to build a learning health care system;
- Data science is the new buzzword in computer science albeit not clearly distinguishable from conventional statistical methods for data mining; and
- Patients start measuring themselves and analyse their own data to personalize their treatment.

Consequently, the health informatics community needs to find ways to build data models to systematically extract and link data along the continuum of care including their contexts and deliver the results according to research agendas that are driven by patient needs.

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Personal successes in working life are always dependent on the context and environment you find yourself in. I have had inspiring mentors, female role models, extraordinary PhD students, colleagues and collaborators and fantastic students. There were of course also people giving me a hard time and working against me. Thank you all for supporting and/or challenging me!

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Diversity in Health Informatics

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Abstract

Diversity is a goal, concern and challenge in health informatics. My story started as engagement as domain expert and lead to life long curiosity. Further achievements will require re-engaging end users; citizens and health providers. Digital health literacy and systematics professional recognition will be important to make the next stride.

Keywords

Diversity, nursing, health informatics, citizen services, digital health literacy

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Anne Moen

1 How I came to Health Informatics

My engagement and experiences in Health Informatics over time, ties to curiosity about new technology in health care and nursing, opportunities to participate, and others' trust in my abilities. Engaging with domain experts follows the Scandinavian approach to software development [1]. Acknowledging diversity, working with nurses, medical doctors and other health professionals to ensure informatics support for clinical practice was core premises for the development work in health informatics at that time. Therefore, I was recruited as a nurse domain expert, charged to work with transition of nursing documentation to digital form, and prepare for development and adoption of electronic health records (EHR). For me this also lead to graduate studies, and I defended my PhD in 2002 [2]. Today I teach graduate and postgraduate students, undertake research with patient facing apps and health informatics for self-management, and I am active in the health informatics community in Norway, Europe and internationally.

2 Health informatics in Norway

The health informatics activities in Norway can be grouped into 3 areas:

- Design and deployment of comprehensive electronic health records (EHR)
- Digital resources for collaboration, quality care and patient safety, as well as coordination of care within or across levels of care
- Informatics support for citizens

These areas of activity are similar to accomplishments within other European countries. Our most important

policy papers sum up the goals and direction for digitalizing our health care system [3, 4]. Collecting information from all health encounters in a comprehensive electronic health record for every citizen and provision of quality care over time at various sites capture the essence of these goals. Today most clinical work in Norway is supported by organization specific electronic health record systems; in fact these systems were well diffused 15 years ago. Collaboration between health professionals in hospitals, General Practitioners and community nurses, are supported by implementation of specific messages. This information exchange has fostered collaboration and coordination of care [5]. Interoperability, collection of the appropriate data and exchange of health information are major concerns, specifically for development in primary care [6] for further advancement of quality care, supported by development of health informatics [3].

These achievements will be completed and even strengthened by digital tools for citizen engagement and independent living [7], enabling personal contributions to maintain personal health, and prevent/postpone common public health concerns [8]. Such concerns relate to physical activity, nutrition, compensate sensory loss and maintain preferred social participation. Today, more services are available at the national, citizen centered health platform www.helsenorge.no. Using data, knowledge and information at the point of care [9], taking advantage of distributed data collection, and developing robust and trusted analytic strategies to personalize care and treatment will be in more demand.

3 My research results and achievements

In addition to the my early focus on nursing leadership and diversity by presence and participation in design and deployment of EHRs, participation in the Health@Home project (PF Brennan, PI) significantly shaped my focus of research, discovery and application in health informatics. Understanding citizens' health information management work, and detect more of their robust health information management and storage strategies [10] opened a new field of inquiry for me. Therefore, digital services to support self-management and prevention to avoid illness, control a condition or postpone requirements for resource intensive health services is a keen interest. As examples and proof of concept, we created the prototype REPARERE (learning REsources for PAtients and RElatives in REcovery) in 2004 to demonstrate presentation of information relevant to common challenges in a recovery period, mindful of temporal development in a trajectory of recovery [11].

Currently, I research thrive as a perspective for health management, improvement and activation by individual, and required service innovation in our communities when health care activities migrate to new arenas, outside organized care facilities. Informatics support and patient facing apps for social participation [12], and interventions to stimulate healthy eating among elderly people [13] are first steps. We have tried to understand how to leverage ease of use coming with tablets, and suggest strategies to take advantage of digital opportunities for participation and eating among elderly people. We recently released the app "APPETITus" as a project result.

4 Future prospects of health informatics

Appreciating diversity in health informatics, actively recruiting and engaging multiple users will better acknowledge the interdisciplinary aspects of our discipline that I find especially important, rewarding and challenging. I am excited about the evolving nature of our discipline, and thankful for the opportunities to contribute to health service and community development.

Moving forward, re-engagement of end users, that is citizens' as well as health professionals, in active, collective involvement to develop best possible tools and services, relevant for the clinician or patient and their family or the public at large, will be important. Active citizens, collecting relevant Observations in Daily Living (ODL) and tools for sharing information will foster collaborative relationships. I believe advancement and uptake of innovations will call for Digital Health literacy. Educational offerings at all levels and programs in clinical informatics, including data science, will be in great demand world wide. Accessing and critically appraise available information from multiple sources will be competencies necessary to navigate in the emerging terrains of digital health. Our proposal for a digital health compass [14] to benefit from more personalized care and treatment, maintain trust and integrity, and safeguarded privacy and confidentiality will depend on acquired digital health literacy. Furthermore, assessment strategies and evaluation approaches starting from well established methodologies to provide best evidence for innovations in care and treatment will be important to transcend the prevailing "innovation by expectations". Then health informatics will evolve to a more mature field where diverse approaches to recognize the inherent complexities in clinically oriented information work in inspire to design of systems that embrace and support diversities in patient-provider encounters and citizens' contribution to personal health and information management activities.

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Health informatics – my way from medical technology to health informatics in Finland

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Abstract

This paper describes briefly my long journey with medical and health informatics research and development. I started as an information systems designer and analyst with medical technology projects in 1975 and finally became a university professor in health informatics. My activities have focused on the core topics around health information systems and their evaluation. I also have tried to synchronise my research activities with the national situation and research needs. I conclude this article with my personal thoughts on the future challenges of health informatics with the need to integrate health informatics with biomedical informatics, big data and precision medicine.

Keywords

Medical technology, health informatics, health IT infrastructure, health information systems, national research

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1 Introduction – The early years

I started my research and development work with medical technology in 1975 in the Technical Research Centre of Finland (VTT) Medical Engineering Laboratory as a senior systems designer. I had studied computer science, information systems science, statistics, mathematics and economics in the University of Tampere.

The early years (1975-1985) were medical technology-oriented, focused on health information systems design and programming, e.g. laboratory information system for virology, dose planning systems for computer-based radiotherapy, a Bayesian application for acute appendicitis, and simulation models of hospital information systems. With the growth of artificial intelligence in medicine (from 1985 onwards) we started many projects focused on expert systems and knowledge engineering with the purpose of improving health professionals' clinical work through the use of knowledge-based tools and decision support. We developed embedded expert systems for intensive care, clinical chemistry, and clinical microbiology. These knowledge engineering activities were shared in Nordic collaboration, and they also led us to EU research with European colleagues in projects where many very challenging and interesting research activities were carried out (1989-2003).

Biomedical technology-oriented research was widened with artificial intelligence towards medical or health informatics, to the emerging areas of telematics and advanced informatics in medicine. We focused our research especially on knowledge acquisition, integrated health system architectures, federated health care record architectures, evaluation and validation of health IT applications, medical expert systems, and the application of advanced information technology for optimization of clinical laboratory services [1, 2, 3, 4, 5]. I was very enthusiastic on decision support and expert systems and finalised my PhD-thesis on conceptualisation of medical decision support systems in 2000. After my PhD I worked for one year in the USA

at PennState University to familiarize myself with health informatics research in USA and to continue research in health informatics.

All these experiences, and the EU research activities, supported also our growing national research which was then focused on e.g. the development and evaluation of regional health information systems, and interoperability of health information systems. My personal interests were extended to evaluation methodologies and issues of functionality, usability and impact evaluation of health information systems, and development of guidelines for good evaluation practice of health information systems and technology [6, 7]. In these activities I have had a privilege to work with my international colleagues in the Working Group for Assessment of Health Information Systems of the European Federation for Medical Informatics (EFMI) and the Working Group Technology Assessment and Quality Development in Health Care of the International Medical Informatics Association (IMIA).

These experiences helped me to focus my research on three research problems throughout my later research activities:

1. Study of processes, functions, data and information in medicine and health care,

2. design and development of information systems and tools that support medical and health professionals in their clinical practice, and

3. study of effects and impacts caused by information systems and solutions on medicine and health care.

2 Career highlights

An important step in my career and research with health informatics was the position I have held as a university professor from 2003 onwards in the University of Tampere, School of Information Sciences. This position enabled broadening of the scope of my activities to teaching and supervision of students, and extension of research in the inspiring university environment including international collaboration. I also had a possibility to support with my research team our national progress with many research projects, e.g. the national health IT infrastructure development and assessment of the national electronic health record system.

In the university our research was very much focused on those issues which were seen as problematic in Finland, e.g. semantic interoperability of electronic health record systems, terminologies and classification used in electronic health records, usability of health information systems, privacy and security issues, and the Finnish national eHealth infrastructure which was under development (from 2007) [8, 9, 10, 11, 12]. We also paid a lot of attention to disseminate the lessons learned in Finland with the national development through international collaboration [13, 14, 15].

The recent focus of my research has been on evaluation issues, effects of integration of social and healthcare information systems, and development of an ecosystem for procurement of social and health care services information system [16, 17, 18]. International collaboration and longer research visits abroad (France, USA, PR China) have been good learning experiences and have supported my research and opened wider perspectives.

Now when I am retired, as an emerita professor, I am still doing research and trying to share all the lessons learned during my active working decades with developing countries in Africa in voluntary work on health information systems, their development, evaluation and purchase.

3 State of health informatics research in Finland

The activities described briefly above and their progression during my working life reflect the changes in the focus of research in the Finnish health informatics domain over several decades.

First the focus was on research and development of specialized medical systems and individual, stand-alone decision support systems. Then it was on the issues of interoperability and on integration of stand-alone systems with the health IT infrastructure. The development of regional and national health information networks and national services started in early 2000. In this situation, we wanted to include the citizens into the health care process, and we were studying citizen-based services and the personalization of health care services.

Today, health informatics research is active and wide in scope in Finland and there are many universities and other health institutions participating in research and delivering health informatics courses and education programs. During the recent years he importance of evaluation has been better understood and there is a growing need to find out the effects and impacts achieved through health IT systems in use. It is extremely important now to focus on health informatics research as we have a comprehensive health care reform under design and it is planned to be implemented soon. We need evidence-based information on the solutions and systems, how they work, are they usable and effective, what are the effects and impacts etc.

The EFMI WG Assessment of Health Information Systems has provided excellent support to this trend and, since the 2003 has offered me an inspiring environment and active collaboration with development of health informatics evaluation guidelines and approaches [6, 7, 13, 15]. Altogether, the EFMI and the IMIA societies have been an inspiring discussion arena for scientific and practical health information issues, which I consider to have had very important effects on my personal research activities.

I have also had the opportunity to work closely with professor Jana Zvarova from Prague, first on many international activities and in the later years in the Euromise

Mentor Association (www.euromise.net) where we were involved in organizing workshops and mentoring courses for international PhD-students. These activities have offered excellent opportunities for international collaboration and sharing of knowledge between Finnish and other European students and researchers, and I myself has had the privilege to enjoy Jana Zvarova's mentorship and collegiality.

4 Thoughts on the future of health informatics

Since the 1970s the health informatics domain has made much progress, however, we still face many problems before we can speak about evidence-based health informatics. To obtain explicit evidence we need to perform more scientifically rigorous evaluation studies that show that the systems developed and used are acceptable, safe and effective and support health professionals in their clinical tasks as well as patients and citizens in managing their health and wellness. We also need to pay more attention to the design and implementation methods of health information systems in order to have predictably acceptable, safe and effective systems for user environments.

The technological development has been very rapid and, in many cases, we have paid more attention to the technologies applied than to the health care user contexts and health care service processes. Today, the challenge is to manage health information entities at all levels, at the personalized level of the patient or the citizen, and at the societal level taking into account the varying health care cultures and use contexts.

The future will very probably emphasize biomedical aspects, big data, personalized precision medicine – moving from the collection of huge amounts of data to the utilization of all available data to develop better treatments, better tailored and individualized care, and to integrate the health subfields and medical specialties into holistic, integrated care [19, 20].

The impressive rate of generation of human biological data during the last decades has contributed to the development of numerous statistical, computational and mathematical methods to extract, analyze and exploit this information. The emerging big data research has great potential to contribute to the development of standards for consolidating, characterizing, validating and processing of data and to the ontologies for knowledge and to the definition of relationships between knowledge entities such as genes, drugs, diseases, symptoms, patients and treatments. In big data analytics we need solutions how to integrate various data sources and information systems and environmental data with individual genomic measurements.

In the future we might need to broaden the scope of health informatics to cover also in-silico medicine, a scientific and technological domain which is based on clinically-driven and clinically- oriented multiscale biomodelling, and which translates the mathematical and computational biological sciences to clinical practices through exploitation of information technologies.

The emerging new approaches offer possibilities to connect molecular and cellular biology to the clinical world, and allows us to consider individual variations and not simply population averages, and to improve health both at a public health level and at personalized medicine level. However, still many questions need to be solved with these new approaches. The most important ones are the security and privacy aspects of personal health and wellness data – this will be a challenge as, in the ubiquitous world, we are dealing in the future with both regulated and non-regulated healthcare environments and with reuse of data and secondary use of health data.

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Health Informatics in Israel: a focus on clinical decision support

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Abstract

The article summarizes the career highlights of Prof. Mor Peleg from Israel, whose research focuses on knowledge representation and decision support systems, and in particular on computer-interpretable clinical guidelines. In addition, it reviews the state of art in medical informatics in Israel and emerging future directions in the medical informatics field.

Keywords

Clinical decision support systems, computer- interpretable guidelines, Israel

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1 Introduction – How I came to work in health informatics and how the atmosphere was like

In the early 1990's, the human genome project started and I was swept with enthusiasm. Having been trained in biology and having worked as a programmer, I wanted to focus my studies and career on the use of information systems that would find order in the vast amounts of data that were coming out of this project, and translate it into knowledge that would impact human health. Back in Israel of 1994, as I was looking for a topic and advisor for my PhD dissertation, I couldn't quite find what I was looking for and decided to focus on real-time process analysis and design instead. Towards the end of my dissertation, I heard a fascinating talk by Yuval Shahar, who completed his dissertation at Stanford's Medical Informatics program. I decided that I wanted to be trained there as a post-doctoral student. With the help of Yuval and Mark Musen, I came to work with Ted Shortliffe, Samson Tu, Bob Greenes, Vimla Patel, and others on the InterMed project. Our goal was to develop in a consensus-based process that leverages methods and results that have already been achieved by the community, a computer-interpretable formalism for clinical guidelines. This formalism, called GLIF3, would enable us to specify any clinical guideline as a care process with formal semantics of decision criteria that would allow matching the formalized guideline knowledge with patient data to output patient-specific guideline-based recommendations. In this way, the computer-interpretable guidelines (CIGs) would serve as a decision-support system (DSS) for clinicians during patient encounters, at the point of care.

The decision to go to Stanford has shaped my life and career. I have worked with the best researchers and leaders in the field of biomedical informatics and they have shared with me their vision, their philosophies about science and communities. By setting an example and by explaining their strategies, they have taught me how to collaborate and work in teams and how to create communities of people, where everybody is invited to share and contribute, and where every person's opinion counts, whether he is a student, just starting his career, or an established professor.

2 Career Highlights

After spending four years as a post-doctoral student at Stanford's center for Medical Informatics, which had transformed into the Center for Biomedical informatics research, I wanted to go back to my home country and to continue my career there, in the field of biomedical informatics. In October 2003, I accepted a tenure-track position at the newly-formed department of Information Systems at the University of Haifa, Israel. Six year later, I became department head (2009-12). Together with Prof. Yuval Shahar who had been at a similar department at the Ben-Gurion University of the Negev, Israel, we were at that time the only two health informatics people in academia.

But I had been lucky to be able to travel with my family and spend time working with my mentors and collaborators each summer. These opportunities, in addition to conferences, inspire me with new ideas and emerging methods and allows me to collaborate face to face with wonderful researchers in health informatics. Thanks to Mark Musen and Samson Tu, I spend most of my summers at Stanford University, and I had also spent two periods of Sabbatical there (2007-9, 2016-7). In addition, I had the pleasure of spending periods of time working with Vimla Patel and Dongwen Wang at Columbia University, with Wil van der Aalst at the Technical University of Eindhoven, with Silvana Quaglini at the University of Pavia, Italy, and with Vojtek Michalowski at the University of Ottawa, Canada.

While I continue to have many collaborations and activities within the American Medical Informatics Association, I also have many collaborations within Europe. I have been co-organizing workshops related to computer-interpretable guidelines within the Artificial Intelligence in Medicine and the Business Process Management community. In an effort to converge these communities, I led a successful effort to unify (in 2011) the Knowledge Representation for Healthcare Workshop (KR4HC) and the Process Support for Healthcare (ProHealth) workshops. I was also the scientific program chair of the 2011 Artificial Intelligence in Medicine Conference in Bled, Slovenia.

My most major career highlight was the European FP7 large-scale project MobiGuide: guiding patients any time, everywhere (`www.mobiguide-project.eu/`). I was the coordinator (head principal investigator and scientific project manager) of this project which involved over 60 researchers, engineers and practitioners, from five European countries, spanning academia, industry, hospitals and a patient organization. Together we developed and evaluation over a period of four years (2011-15) a personalized and distributed guideline-based decision-support system for patients and their care providers, using mobile sensors and Smart phones.

I had been honored with recognition and opportunities for being involved in the health informatics community. In 2005 I received the New Investigator Award from the American Medical Informatics Association (AMIA), recognizing my role in developing the GLIF3 language. In 2013, I was elected International Fellow of the American College of Medical Informatics (ACMI). In 2014, I became Associate Editor of the Journal of Biomedical Informatics. The AMIA and ACMI community have invited me and offered me opportunities to act in leadership roles, such as chairing AMIA's Best Paper competition and being a member of ACMI's Executive Committee.

3 The state of health informatics in Israel

The health informatics community in Israel includes people from academia, industry, HMOs, academic hospitals and government. They all meet together to exchange ideas and present their work, in the annual conference of the Israeli Association for Medical Informatics, which is part of European Federation for Medical Informatics. Funding for research comes from national resources such as Israel Science Foundation, The Israel National Institute for Health Policy Research, the Ministry of Health. Israeli researchers may lead and participate in projects funded by the European Commission, and may participate in USA projects funded by the National Institute of Health or the National Library of Medicine. Several bi-national grants are available for research cooperation between Israel and Germany, USA, Italy, Canada, and China.

The majority of the community comes from the major HMOs, government, and from high-tech companies. The HMOs and academic hospitals have been developing EHR systems, (rule-based) decision-support systems for management, billing, and clinical decision support, and patient portals. More recently, the main HMOs have been working on business intelligence and data analytics for patient safety, and on coaching applications, for increasing patients' compliance.

High-tech companies, include international companies such as IBM, Microsoft, Phillips, Hewlett Packard Labs and national companies and national companies such as NESS, or DBMotion (which has been acquired by Allscripts Healthcare Solutions) focus on data management, integration, and analytics. Many Israeli companies focus on medical imaging and image recognition for diagnosis (companies like Elscint and newer companies like Zebra medical vision). Emerging companies (e.g., Vaica, Medisafe) focus on medication adherence solutions.

The academia-based community has grown from consisting only of Prof. Yuval Shahar and myself, but it is still rather small and includes a dozen faculty members from six higher education institutes, focusing on clinical decision-support applications and medical decision making, knowledge representation, text mining, temporal reasoning and planning, health systems management, and health economics.

4 My research focus and achievements

My field of research focuses on knowledge representation and decision-support systems, applied to the biomedical domain. In particular, I am interested in two domains: clinical-guideline based decision support and systems biology. My work combines knowledge representation (ontologies) with computational methods for reasoning, knowledge discovery, and data analysis.

Since my post-doctoral work that started at Stanford in 1999, I have been internationally-known in the area of clinical-guideline-based decision-support systems (CDSS) [1, 2]. I was the lead developer for GLIF3 [3], which is notable for its object-oriented layered approach to modeling and enactment of the knowledge encoded in clinical guidelines.

I have continued to expand my work in this area to include patterns for exception handling, understanding the lifecycle stages of guideline development, methods for identifying implementation barriers of clinical algorithms, ontology-mapping and data integration that facilitates knowledge sharing via guidelines, and user-centered design of CDSSs that use computer-interpretable guidelines. I have over 70 publications on this topic alone, with an h-index of 33.

In 2011-2015, I have led the FP7 ICT MobiGuide project [4, 5] (www.mobiguide-project.eu/), with over 60 researchers, clinicians and engineers, from 13 different organizations in five countries, in the area of guideline-based personalized medicine. MobiGuide is a scalable, secure, ubiquitously accessible, and user-friendly mobile solution for designing, deploying, and maintaining a DSS for patients and their care providers. The novelty of the approach is in patient-centrality, personalization, and distribution of decision-support for patients who use a mobile CDSS that includes a Smartphone and wearable biosensors that interacts with the main web-based CDSS of the physicians. The CDSS is based on clinical guidelines and personal health records, provides personalized evidence-based clinical recommendations, and has demonstrated in our proof of concept implementation (by gestational diabetes patients in a hospital in Spain and atrial fibrillation patients in Italy who were using the system for several months) an increase in patients' satisfaction and compliance to evidence-based clinical guidelines.

My systems biology work focuses on process modeling for understanding and simulating cellular processes (including metabolic and regulatory processes). It combines Process Management- formalisms, including workflows and Petri Nets, with ontologies. I have applied it in diverse areas such as Malaria parasites life cycle, protein translation, and recently, to explore complex disease comorbidities applied to autism spectrum disorder and inflammatory bowel disease and predict new roles for mutations in comorbid conditions, based on comparative simulations of Petr-net based models [6].

I am also interested in leveraging ontologies to improve machine learning and vice versa. I have used machine-learning methods to learn knowledge about comorbidities from patient phenotypic data and integrated this data-based knowledge with literature-based knowledge into an ontology [7]. Additionally, I have applied natural language processing algorithms that parse textual clinical trial eligibility criteria according to an ontology that we have developed. In this way, study authors could potentially compare criteria across different studies and investigators could screen electronic health records for eligible patients.

5 The future and prospects of the health informatics field

In the early 2000's, as the field of bioinformatics was growing and receiving recognition, Ted Shortliffe and others have recognized the similarity of research methods between bioinformatics and health informatics. To foster a community that leverages new and existing research methods, the field of biomedical informatics was established, which includes both disciplines. While the focus of health informatics had been on how to represent expert knowledge, the focus has shifted to data and how knowledge could be automatically learned from it. Programs that focus on "data sciences" and "big data" and methods that use "deep learning" are very popular. Projects such as IBM's Watson are receiving public attention and becoming very popular.

In addition, advances in ICT, such as mobile technology, drive opportunities to develop mobile health applications that can be used by patients.

These two advances are leading to an emerging focus on patient-centrality and a learning health system, where patients are involved in their health, are coached and motivated by CDSS, report outcome data, receive ubiquitous decision support, make shared decisions with their providers, and contribute to the body of evidence about treatment effectiveness, which could be mined by machine learning methods.

Patient-centrality and the advance of new computational methods will also lead to development of complex health management systems that include decision-support and management of patients with multi morbidities and which support coordination of care across different healthcare institutions.

Technology has also been an enabler in communication between people, which has enabled remote cooperation and collaboration in research and education. Much of the research done today already involves world-wide collaboration of virtual research teams. On the other hand, sharing data and knowledge electronically is done not only in a peer to peer manner, but through databases that allow researchers who don't necessarily work with each other to mine data and reason with knowledge that had been shared by others. This will speed the pace of new discover-

ies, such as molecular-level disease mechanisms of action, which could translate to personalized precision medicine.

In terms of education, web-based courses that are emerging will allow a larger body of new students and researchers to be trained in the methodologies of our field from the best instructors, using hands-on customized tutorials.

These advances will lead to more connected and involved health.

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A long and varied career in international Health Informatics

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Abstract

This paper outlines a personally rewarding career of over 45 years in various local and global health informatics initiatives. It tracks activity selectively within the context of policies and personal interests. Many developments across the domain have originated through operational requirements and some through scientific research and clinical progress, capitalising on wide-ranging technologies. The health informatics community has benefited greatly from international collaboration and cooperation addressing a wide range of applications which are only outlined here.

Keywords

Health informatics, global development, e-learning

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1 My Beginning and Career in Health Informatics

Little did I know that my degree course industrial placement (1969/1970) was a precursor for a lifelong career in health informatics. In year 3 of a 4-year first degree I took up an appointment with a local authority in Middlesbrough, Teesside. Then non-hospital community functions were coordinated by local government. After discussions of the processes involved, I wrote an operational childhood immunisation and vaccination appointment system. Challenges arose when monitoring the various pathways for rubella, mumps and pertussis protection. Some general practices did not appear to have improved their performance in vaccinations. On investigation, it was found that a well-meaning community nurse was routinely throwing away the computer-printed invitations for injections to children of a certain age because 'Doctor X does not believe in the schedule, so I did not want to bother him with the cards'. Lesson one in beta-testing, always cross-check functionality with all end-users!

After graduation and 2 years in industry, in 1972 I was in a university team helping the local hospital, using American university computer power on an overnight basis, deploying an early version of Statistical Processing for Social Sciences to analyse its Accident and Emergency Department activity profiles. For the far-sighted clinical leaders in the Royal Lancaster Infirmary I developed diverse applications such as hospital ward cross-infection monitoring, electromyography signal processing, intravenous feeding calculations and a wide-ranging on-site pathology system that produced a broad spectrum of tests including radiation lead analysis on blood samples from local power station staff and various tests on specimens for veterinary practices in the area. I have them to thank for encouraging me to write up these systems scientifically and get support to present them formally at International Medical Informatics Association (IMIA), European Federation of Medical Informatics (EFMI) and British Computer Society (Health) congresses from 1977 [1].

Over those first few years, I had the honour of becoming the first locally-funded Health District Computer Services Officer in England (the second one was also a

woman too!). After working in a local health authority, it was somewhat logical to move (1985) to the wider Regional Health Authority and get involved in establishing a programme that ultimately put Patient Administration Systems in 19 Health Districts and Manpower Management Systems across the same area. My next step was in a vendor company (1987-90) as Product Planner and later Health Marketing Manager; thereafter for 10 years in niche management consultancy, where the notable deliverables included input to and teaching from the 'RAINBOW' series [2] of e-learning materials (so-called because of the colours of the boxed set of materials, each of which addressed an aspect or staff group of health practitioners).

The health sector continues to merge and re-structure - health delivery organisations, vendors and consultancy service providers. I have kept a consultancy track to my career for the past 37 years. I also had academic responsibilities in various universities from 2002 (external tutor and examiner) through to Senior Lecturer and Course Lead (from 2004 onwards). I continue to research, write and comment when appropriate. Mine has been a varied, but rewarding, pathway through an ever-changing health informatics landscape.

2 The State of Health Informatics in the UK

Domain developments since the 1960s have included many initiatives: stand-alone, complex, interrelated, subjects of numerous strategic documents and expert commentary that have referenced England alone or covered the UK as a whole. It is not possible to exhaustively cover the full transition of 'Health informatics in the United Kingdom' (see [3] for more) so here I highlight selections of impact in my own areas of interest.

2.1 Strategic Directions

Strategic reviews and plans for health informatics for the National Health Service (NHS) in England are numerous over the last 40 years. For instance, the 'Körner Committee' (1980-1984) reports on health computing were legendary, producing six major sets of recommendations (JR contributed to [4]), all of which were adopted and put into action by the government, thus paving the way for a full-scale computerisation of the health service for the next 20 years. Statistical monitoring information was known colloquially as "Körner Data", defined as 'that without which it was not possible to operate the health service effectively'. Much is still identifiable today, albeit modified due to sectoral convergence (what data should be shareable between organisations and for research purposes) and technologies (data anonymisation and in what circumstances patients have the right to opt out of such sharing).

The subject of considerable critical evaluation, the National Programme for Information Technology (IT) (NPfIT, 2002-2013) was intended to migrate the NHS in England towards a 'single, centrally-mandated electronic care record for patients' and to connect primary care to hospitals via a technological 'Spine' network [5]. Elements of its challenges/successes still exist, including an alleged cost of £12 billion, a well-adopted x-ray management/picture archiving system, a later reversion (2017) to developing solutions on a more localised basis via professional working together, and technological interoperability of 'best of breed' systems connected nowadays through standard interfaces.

Sir Derek Wanless led pertinent reports for the government [**?**]. The reviews identified better use of information and communication technology (ICT) as key to potential productivity improvements and health gains and recommended a doubling of the ICT spend by 2003/4, to peak at around £2.7 billion in 2007/8 in the solid progress and fully engaged scenarios. In view of the overall constraints on NHS funding, these levels were not achieved. A third Wanless report [7] in 2007 reflected on those recommendations - noting 'NPfIT in the NHS is responsible for implementing an integrated care records service, an electronic prescribing system, an electronic appointment booking system, and underpinning IT infrastructure by 2014. Given the well-documented delays that beset the programme, it is not surprising that actual spending on ICT in England has followed neither the solid progress nor the fully engaged spending trajectories [projected]'. For example, actual spending fell short of these projections in 2003/4, increased significantly in 2005/6, and in 2006/7 overshot spending trajectories; it seriously undermined the productivity gains envisaged by the original 2002 review.

After NPfIT was closed down in 2011 after an estimated expenditure of £6.4 billion, 'reorientation' exercises, included organisational rebranding from Connecting for Health to the Health and Social Care Information Centre (HSCIC) which indicated the proposed convergence of health and social care. The organisation changed its name again in 2016 to NHS Digital to 'help to build public recognition, confidence and trust committed to produce high quality information, IT systems and services for health and social care, as well as showing how technological development and effective use of information can transform the quality of care a patient receives'.

Personalised Health and Care 2020 [8] promises 'using data and technology to transform outcomes for patients and citizens'. This proposed central body will run national systems, promote standards to facilitate interoperability, set up innovation test beds and encouraging local trusts to collaborate in collective purchasing. Withdrawing the central procurement of solutions to 'let a thousand flowers bloom' became the mantra. Subsequently 'Making IT Work: Harnessing the Power of Health Information Technology (HIT) to improve care' [9] 2016 indicated pragmatic support to digitisation of the NHS, demonstrated cross-overs with the 'Five Year Forward View' of NHS strategic policy [10] and recognised Treasury support of £4.2 billion. Key themes include: greater interoper-

ability, a balance between privacy and data sharing, the importance of user-centred design and a requirement for workforce development in informatics.

2.2 Research funding for projects relating to or involving health informatics

The UK has made a significant contribution to various European Union (EU)-funded research programmes in addition to national activities. As an example, the first Advanced Informatics in Medicine (AIM) initiative (1990-1994) included funding for a multinational taskforce that scoped informatics topics for education for health practitioners across Europe. It was followed in 1994-1998 by the European Telematics for Healthcare Fourth Framework (FP4) IT EDUCTRA which produced guidelines for curricula and example learning materials in multiple languages. Zvarova (co-editor of this journal issue) and Roberts both worked on IT EDUCTRA. After FP7, the Horizon 2020 (2014-2020) Framework for Research and Innovation [11] will have dispensed 80 billion euros between 2014-2020). Other related health informatics themes are being funding under other EU programmes such as the Innovative Medicines Initiative (IMI, 3.3.billion euros) and the Active and Assistive Learning Joint Programme (AAL, 700 million euros).

In view of the UK declaration in 2017 to leave the EU (termed Brexit), the status of many areas of informatics in health research involving UK partners and also of UK-based international researchers is sadly as yet unclear.

2.3 Education in health informatics: the UK

UK universities have run academic courses in health informatics-related subjects, ranging from 2-year Foundation degrees to Masters and Doctorates for many years, both full-time and in parallel to work commitments for continuing professional development purposes. The list of courses increasingly includes specialist opportunities such as the training for health senior scientists in clinical bioinformatics/health informatics [12], targeted at the emerging role of Chief Clinical Informatics Officer. Other vocational initiatives that are offered by third party training providers may be used to demonstrate fitness to practice when recognised by professional bodies.

The Wachter Review [13] outlined 10 recommendations to inform the English health and care systems approach to the further implementation of health informatics, especially the use of electronic health records and other digital tools to achieve paper-free systems.

A research commission [14] from NHS Digital, on behalf of the Paperless 2020 'Building a Digital Ready Workforce' (BDRW) programme, specifically recognised that both informatics specialists and the wider workforce need consistent competences in health and care informatics, albeit at differing depths. The delivery of training, education and knowledge to the whole workforce will need to be a creative process, for a number of reasons identified in the literature review: pressures on staff time, the speed of technological change and the fluidity of organisational changes in health and social care. Evidence suggests that learning that can be made available by electronic means is useful and desirable. This material can then be used on an ad hoc basis as required, for example, on the career pathway; as a requirement in an organisational change situation; or for personal development.

3 Research results and achievements

My involvement in the field of health informatics has been varied in both range and depth and has spanned the major part of my career since 1974. In parallel to operational duties 'in and for' NHS England, I take all opportunities to 'spread the word' about health informatics (I have over 120 publications). I have published project notes, research findings, implementation guidance and evaluation, in addition to passing on experiences through e-learning and student support, consultancy assignments, conference presentations and proceedings. My 'hard copy' contributions are both formal scientific and have also been produced in 'grey' informal publications such as trade papers, magasines and as student information. Reflecting on the outcome of my health informatics doctorate, gained through previous publications [3], confirms the range of dissemination routes by which information and experience can be shared in practice.

Involvement in IMIA, EFMI and multi-national projects gave me a wide platform to work from, which was recognised in 2011 by HIMSS Europe awarding me the HIMSS Europe Award for eHealth Leadership, the first woman to receive it. Dr Petra Wilson, HIMSS Europe Government Council Member, introducing the award, kindly drew attention to my "work in driving professionalisation; leadership in helping to grow the next generation of eHealth professionals; and research work on operational deployment of healthcare informatics into everyday healthcare services provision". In 2017 I was elected by my peers as a Founding Member of the IMIA International Academy of Health Sciences Informatics.

I was a member of teams which launched the inaugural UK Current Perspectives in Health Computing conference and exhibition (now running as UK eHealth Week) and the initial EFMI Medical Informatics Europe congress (1974), as well as having the honour to chair the London Organising Committee of IMIA's MEDINFO2001. Involvement in the establishment of the professional registration body, the UK Council for Health Informatics Professions (UKCHIP), in 2002 culminated in 2017 when the organisation is transitioning to a wider health and social care scope. My work as the Director of Standards (UKCHIP) was informed by experience, previous curricular development, work with a range of new and established academic / vocational courses, contributions to NHS Na-

tional Occupational Standards development and work on the IMIA Knowledge Base. This was a great example of how knowledge silos can really become synergistic!

Deliverables that (mostly) stand the test of time and to which I gave input include the RAINBOW series of learning materials mentioned earlier, editorial/review contributions to books [15, 16, 17] and the Radical Steps think tank outputs [18] which were coordinated under the aegis of the BCS Health Groups (the messages from 2002 contain thoughts which are still reflected in current strategic directions). In revisiting my doctoral thesis [3] for this paper I was pleased to see that many current initiatives were signposted in my 2005 observations about the future.

4 My Predictions for the Future of Health Informatics

Many of the initiatives that I envision for the future are 'people-oriented'. Enhanced roles for the whole health and social care professional workforce will emerge, containing skillsets of informatics competences appropriate to the role of the individual. Health informatics experts additionally will be challenged to design, develop and capitalise on new technologies, where and when they empower care delivery, research and management. Increasingly multi-disciplinary informatics should be explicitly recognised in development plans for the whole workforce (and also for third parties working 'for' the services through out-sourcing). Technology will also have an effect on 'back office' and indirect care situations, which could bring about better cost-management in health and care delivery.

Robust e-learning tools will be used in both ad hoc and formal modes when previous practice or changes in circumstances and responsibilities indicate a requirement. International mobility will be stimulated by recognition and cross-mapping such tools and the competence standards that they demonstrate [19].

Many more artificial intelligence, assistive and ambient learning concepts will be developed and operationalised to support independent living, smart homes, clinical monitoring, disaster / pandemic monitoring and management. UK occurrences of doctors informing colleagues of major accidents and medical incidents via their own WhatsApp-type groups could be more formally replicated elsewhere. Gaming theory may well be utilised to contribute to staff training, assist citizens with health challenges and promote fitness and wellbeing.

New deployments will see a greater emergence of collaboration between professionals and citizens, with demands for digital empowerment often being driven by younger citizens, to whom technology is a 'given' rather than a challenge! The involvement of citizens in the ongoing management of their own care and their need for lifestyle, general clinical and social issue knowledge will increase exponentially. Contributions personal to each citizen will play an increasingly integral part in maintaining healthy status overall – adding 'life to years' in parallel to 'years to life'. Digitally-enabled apps for self-management and clinical monitoring will not happen at the same pace in every country.

Technology-enabled health and social care will continue to develop multi-nationally across a range of themes. For example, under test now are 3-dimensional printed bones/organs, but their routine use is still in the future. An independent certification and standards body has produced a Code of Practice for Planning Services and Providing Technology-enabled Care Services (CECOPS) (cecops.org.uk). International research repositories contribute to patient safety, ensuring up-to-date relevant evidence and practices, and provide comprehensive access to holistic patient record histories on a need-to-know basis for all authorised users. Shared information about personal care histories, special cohort datasets about rare clinical conditions, and population profiles will need to be sensitively handled. Research data must be operationally advised by evidence-based systems, so that innovative therapies can be validated and introduced as soon as feasible. Data access, availability and shareable use should not be seen as a threat to professional practice or data-subject preferences, but should be handled sensitively and openly. Informed use will ultimately be beneficial. Holistic records, right-sourced and evidence-based, will support population well-being.

Population health monitoring in conjunction with health and social care being delivered together will have a major impact on overall wellness and a person's own lifestyle/fitness. Quality of life will continue to improve with non-invasive support from robots which will also contribute to patient safety. There will be linkage to emerging patient-controlled health care records systems that enhance the historic documentation of patient / client status.

For example, deploying drones to deliver services/drugs between hospitals will, with appropriate safeguards, be operational by 2018 [20]. This telehealth concept of the future could release more professional time to deliver direct patient care.

International dissemination of operational solutions, research findings, situation monitoring and opportunities to improve wellbeing are crucial. Sharing developments and experiences will create 'better together' opportunities – through explicit projects and web-based knowledge-sharing. Increasing the knowledge base globally will improve effectiveness, efficiency and efficacy of care delivery and outcomes.

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From Probability-Based Systems to Expert Systems and Guideline-Based Clinical Decision Support Systems:

Using Health Information Technology to Improve the Quality of Care

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Abstract

I entered the medical informatics domain through the door of decision support (DS). My aim was to contribute to the improvement of healthcare quality. With OncoDoc, I developed a document-based approach for the management of breast cancer. More recently, I proposed to use an ontological reasoning for the reconciliation of single-diseased clinical practice guidelines for the management of multimorbid patients. The next step of DS will undoubtedly be data-based.

Keywords

France, Decision support, Clinical practice guidelines, OncoDoc, Ontology

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1 Introduction

I was born in Tunis, Tunisia, and nothing predisposed me to research activities in health informatics. However, about fifty years later, thanks to a great dose of passion, some persistence, a lot of energy, and an unshakable motivation, I did it. As a woman in the health informatics domain, it was not easy every day to discuss, argue, negotiate, and even fight, but I am happy I won some important points in the game.

2 Entering the Field of Health Informatics

When my parents emigrated to France, I went to the French Public School, made very good studies, and was accepted in the very selective "Ecole Centrale Paris", an institute of research and higher education in engineering and science (top three of French "Grandes Ecoles"). Later, I got a Master in Computer Science at the University Paris 6 (with a major in Artificial Intelligence) and a PhD in Biomathematics at the University Paris 7.

Since my young age, I have always been attracted by life sciences. Thus, in parallel to my studies in biomedical informatics, I studied medicine at the University Paris 5 and graduated in General Practice. In this way, I was a precursor in the adoption of a mixed curriculum combining computer sciences, mathematical modeling, and medicine. Thanks to my double education, I could work with the rigor of logics and formal analysis, and be comfortable with the fuzzy, uncertainty, and incompleteness, specific to medical practice. I combine these two antagonist paradigms in my research work to model, develop, and implement clinical decision support systems (CDSSs). Another dimension of my work is to assess the impact of CDSSs on clinicians' behavior, including the understanding of why these tools sometimes fail to reaching their goals beyond usability issues [1].

As a health practitioner in the Public Health Department of the Tenon Hospital (Paris, France), at the Assistance Publique – Hôpitaux de Paris (http://www.aphp.fr), the largest university hospital of Europe, I used to chair the assembly of physicians in charge of care quality and patient safety within the cluster of the five hospitals of the eastern Paris (Tenon, Saint-Antoine, Trousseau, Rothschild and Laroche-Guyon hospitals). More recently, I have been in charge of the clinical evaluation of the tools that support care continuity and help the coordination of practitioners involved in the management of patients engaged in complex clinical pathways. Since 2012, I work part-time at the French Ministry of Health, in the Delegation in charge of building the Strategy for Health Information Systems at the national level. Since the same date, I am one of the editors of the International Medical Informatics Association (IMIA) Yearbook. I became part of the IMIA board as the Vice President for Services in 2016. I am also the representative of France at the EFMI (European Federation for Medical Informatics) Council since 2011.

3 Biomedical Informatics Research and Education in France

During my medical studies, I had the opportunity to have training periods at the laboratory of Biophysics headed by François Grémy at the Pitié-Salpêtrière hospital (Paris, France), and I had the chance to be close to him at the moment he played a major role in the birth of IMIA and made some great contributions to the development of medical informatics worldwide. François Grémy was an admirable humanist strongly engaged in social equity and solidarity, and against any clinical form of discrimination and racism [2]. I really enjoyed working with him at this time and after. When François Grémy moved to Montpellier and decided to engage more deeply in Public Health, his disciples took over and nationally disseminated the methods, tools, and principles of medical informatics: Pierre Lebeux at Rennes, Roger Salamon in Bordeaux, Marius Fieschi in Marseille, Régis Beuscart in Lille, and Patrice Degoulet and Marcel Goldberg (more involved in epidemiology) in Paris. Today, I consider that the second generation of François Grémy's pupils continues to produce a very high quality research in biomedical informatics. They also work to train the future medical informaticians in a few university laboratories and hospital departments distributed across the whole national territory (Paris, Lille, Nancy, Grenoble, Marseille, Bordeaux, Rennes, Rouen). Great achievements have been obtained in research works carried on in knowledge engineering, especially in ontologies [3] and pharmacovigilance [4], natural language processing [5, 6], and clinical decision support [7]. The work of Darmoni et al. to offer the catalogue and index of French-speaking health resources CISMef to the French-speaking health community is especially noticeable [8].

However, while biomedical informatics is now recognized as a medical subspecialty in the US, biomedical informatics is hardly considered as a scientific discipline in France although it was born in France. Neither informatics nor medicine, biomedical informatics is attached to biostatistics and public health domains under the label "New Information Technology". As far as I am concerned, biomedical informatics is absorbed by these two disciplines and actually loses its specificity. As a consequence, it is not easy to involve the deans of medical faculties and have them accept to provide biomedical informatics courses within medical curricula. In addition, opportunities for professor and assisting professor positions in biomedical informatics are scarce.

Recently, we benefited from an evolution of the French regulation, and the publication of a law that proclaims education in informatics and internet (C2i) is mandatory for students of different curricula including medical studies. A practical course of 10 hours has been collectively developed by biomedical informatics professors and assistant professors from the universities Paris 5, Paris 6, Paris 7 and Paris 13. It was accepted by the deans of the corresponding medical faculties and provided as a mandatory course to fourth-year medical students (in France, the core medical education is six-year long, then four to six years, depending on the medical specialty, should be added to complete the curriculum). This is a start and the aim is to take advantage of the digitization of the healthcare industry that the French government is announcing to go further and implement a "real" biomedical informatics course in medical faculties.

Indeed, the digital transformation of the healthcare profession is something that is now happening in France. In 2016, we observe a 100% adoption rate of electronic health records in 60% of medical institutions, a full implementation of electronic drug and complementary exam prescriptions in 65%, resp. 50% of hospitals, and biology reports are computerized in 90% of laboratories [9]. As it is often the case, France started to digitalize administrative activities (salaries, billings, and accounting) between the 1960's and the 1990's, followed by the computerization of technical platforms between the 1990's and the

2000's. More recently, digitalization has been focused on the delivery of care. But, since only 2% of medical institution spending were devoted to health information systems in 2013, this transformation is carried out at a very slow pace. However, I believe that the need for biomedical informaticians is already a reality to help leverage the adoption of health information technology and make practitioners aware of what health information technology can bring them and the benefits in terms of care quality and patient safety it could provide.

4 My research work in clinical decision support systems

My research work is focused on the development, implementation, and assessment of clinical decision support systems. I started to work on medical decision-making at the end of the 1980s, using numerical (probabilistic) methods for the diagnosis of acute abdominal pain (Bayesian approach under the assumption of independent clinical signs, in a way similar to de Dombal's work [10], but with the application of the Lancaster model to account for order-2 interactions between signs [11]). With the advent of Artificial Intelligence in the medical arena, my work evolved towards the development of so-called "knowledge-based" systems. These systems, supposed to be able to simulate the reasoning process of experts, have as their main characteristics the use of domain knowledge to infer certain conclusions or actions from data or facts. I used this approach for the system SEPIA [12] applied to the monitoring of patients hospitalized in hemato-oncology departments to manage the critical episodes of acute illness that frequently occur due to the high toxicity of the antimitotics used in chemotherapy protocols. The originality of this approach had been to model the knowledge base according to the principles of the control theory of dynamic systems and to represent the patient condition with state variables continuously updated as new monitored data were recorded.

In the late 1990s, I coordinated the European project DOME (♯ MLAP-63221) which aim was to study whether natural language processing tools and documentary systems could help in the development and processing of medical reports. This project allowed to test how structuring a computerized care record with hypertextual links between relevant reports and notes could help a physician assess a patient condition in an efficient way. Indeed, we organized focus groups during the project that emphasized that physicians were attached to their work habits and were willing to continue to benefit of the expressiveness of natural language and textual reports. However, they were also very much interested by the benefits of digitalization to improve the structuring of medical reports and, consequently, information retrieval in a patient care record.

At a time where all existing electronic medical records were data-based, the DOME project made me understand that a patient is more than the sum of his/her data, and that textual observations are far richer than a set of parameters. This analysis underlines that the formalization of medical knowledge is limited and that the operationalization of formalized medical knowledge is by construction biased: the lost of context when cutting a patient condition in a set of data is indeed prejudicial to the understanding of the complete picture of the problem to be solved. On the basis of this observation, and in collaboration with Jacques Bouaud (researcher at the Medical Informatics Department of the Assistance Publique – Hôpitaux de Paris), we proposed a documentary approach to medical decision-making that we applied to improve the implementation of clinical practice guidelines (CPGs).

In order to preserve the flexibility in interpreting CPGs, we proposed to delegate the knowledge interpretation task to the physician at the moment of the decision, when the context of the patient is available. Our proposal relies on both formal and informal principles and is halfway between knowledge representation and text reading. On the formal side, the clinician is proposed a structured knowledge base (KB) encoded as a decision tree which formal properties (exhaustivity and mutual exclusivity of decision variable modalities) guarantee the completeness in guideline coverage and the uniqueness of solutions. The KB is not expected to be automatically run on data, but read by the clinician who has the opportunity of interpreting the guideline knowledge for a given patient when navigating through the decision tree. At each depth level of the decision tree, the clinician is asked about a clinical parameter and has to answer taking into account the clinico-psycho-sociological reality of the patient. The clinician is then involved in the categorization process of his/her patient, which he keeps control over and he is responsible for. At the leaf level, he may choose among the proposed therapeutic recommendations. The approach has been initially developed with the CDSS OncoDoc applied to the management of breast cancer patients [13, 14]. The system has been used routinely in multidisciplinary tumor boards (MTBs) and showed a positive impact on clinical practice (increase of the compliance rate with CPGs of MTB decisions) [7]. This approach has also been applied to the management of hypertension, type 2 diabetes, and dyslipidemia within the different ASTI projects [15, 16].

However, if the implementation of CPGs in CDSSs may be useful to provide clinicians best patient-centered recommendations to manage a given pathology (e.g. hypertension, type 2 diabetes, or dyslipidemia), it is not sufficient to improve care quality and overall public health since multimorbidity is common. Thus, some research teams have proposed to work on the a posteriori reconciliation of multiple single-disease CPGs. Wilk et al. [17] have proposed a framework based on first order logic to represent CPGs and to mitigate possible adverse interactions (drug-drug or drug-disease) when concurrently applying multiple CPGs to a multimorbid patient. Other authors have proposed semantic web ontology-based approaches [18] for the integration of multiple single disease

clinical pathways in a unified disease-specific clinical pathway. We have developed GO-DSS, a CDSS that relies on an ontological reasoning to manage patients with multiple pathologies from single-disease guidelines [19].

5 Perspectives and conclusions

Given the growing adoption of health information technology tools (electronic health records, computerized physician order entry systems, and decision support systems), given the increasing use of social media, given also the starting wave of the internet of things (wearables and quantified self), we are in the era of Big Data. Based on this data, machine learning (especially deep learning) is providing daily new astounding results. The future is thus in the data. Of course guideline-based decision support systems would keep their role to help physicians improve their decisions, but what would be the meaning of guidelines, evidence-based medicine, and clinical research when the doubling time of medical knowledge is 73 days as it is projected to be the case by 2020? I think that we are entering in the era of data, and all health systems, including decision support systems, will be data-based according to the learning health systems paradigm [20]. To manage a patient characterized by some clinical parameters, the process will be to search for similar patients in big data warehouses, to assess the treatments and the clinical outcomes of these treatments they have received, and to propose the different scenario to the patient. Medicine will definitively be the 4P medicine: preventive, predictive, participative, and personalized.

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Healthcare Informatics – a Wonderland

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Abstract

The paper presents career highlights, my research focus and several achievements in relation with digital healthcare education and practice, ending with opinions for further development of the health informatics field. It is a sort of paper that brings one face to face with oneself, looking in the mirror and slide into the creative reality of healthcare informatics.

Keywords

Healthcare informatics, education, communication, national status

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1 Down the rabbit hole or how I joined the healthcare informatics community

It was 1980 and I had to choose a faculty domain – not from many alternatives at that time in Romania – law, medicine or computers! Law and medicine had too much material to store, Big Data and Cloud Computing were not in cards at the time. Medicine was great in healing people, but there was too much blood, dead bodies and again too much to memorise. So computers had it all, a lot of storage and processing possibilities, decisions, mathematics and English language, as an irresistible combination.

Graduating and becoming after several years assistant at the Faculty of Automation and Computers I started my PhD combining computers engineering and medicine, defending my thesis in 1999 with the title "Systemic aspects and integrated environments assisting cardiac diagnosis" and down the hole I went, in Healthcare Informatics wonderland, and still going.

I joined The Romanian Society of Medical Informatics in 1999, actively participating in all its conferences. Later, in 2003, all the roads leading to Rome, I joined the European Federation of Medical Informatics Council and family in Rome, Italy. Professionally and at human level EFMI was a special opportunity, meeting extraordinary people from all around the world, being part of a great community. My term as EFMI Vice-president ends in 2018.

Currently my activity is with the Department of Automation and Applied Informatics as university professor at the Faculty of Automation and Computers, University Politehnica Timisoara (UPT), in the beautiful student city of Timisoara situated in the western region of Romania.

2 The state of health informatics in Romania

Medical Informatics was fortunate in Romania to have visionaries and dedicated people supporting it from the

‘70s. The Romanian Society of Medical Informatics (RSMI) was officially born in1990 as the earliest organization in the field of Healthcare Informatics, but its first conference took place in 1974 in Satu Mare. In 1961 at the Politehnic Institute in Timisoara researchers built the first computer in a University in Romania, MECIPT-1, on which, starting 1964 neural networks and cellular division simulations were performed (Dan Farcas, Vasile Baltac, Zeno Simon).

Figure 1: Proud to meet one of the few ladies graduating Computer engineering in UPT 50 years ago (1966-2016).

There were bigger or smaller research centres with achievements in the field: Arad group building MODARD program (M. Angelescu, N. Mihalaș), Satu Mare with dr. Virgil Enatescu, aso.

Medinet [1] sentinel dispensaries network in Romania was a unique achievement as result of a project during 2000-2004. Medinet stations network consisted in 100 computerized GP practices nationwide, with doctors collecting primary care data and sent it to a central server through Internet. A team from University Politehnica Timisoara (Vasile Stoicu-Tivadar, Dorin Berian, myself) developed the GP software MedINS and trained the doctors, a landmark for this type of applications. The project manager was Marius Marginean, a dedicated and tough professional involved in many projects that modernized the GP clinical practice.

As education is concerned, all the big medical faculties in Romania have in their curricula lectures of Medical Informatics and statistic processing. Prof. George Mihalas, former EFMI president, was for a long time the chair of the Medical Informatics and Biostatistics department and coordinated many PhD thesis in the domain. Prof. Ioana Moisil is one of the important ladies in the medical informatics field in Romania, with data processing and analysis and main contributions to RSMI activity.

Most of the big technical faculties have in their curricula lectures or specialties related to the field of medicine. University Politehnica Timisoara has a long tradition using computers and electronics in medical domain (Dan Farcas, Vasile Baltac in the ‘60s, Anton Policec in the ‘80s). During the ‘90s the Faculty of Automation and Computers introduced in its curricula biomedical engineering packages including medical informatics, biomedical engineering, medical imaging, telemedicine, etc.

One of the great achievements of our Department from Politehnica University Timisoara is the Master degree in Healthcare Information Systems (MHcIS) started in 2009, a unique type of master bringing together engineers, informaticians, physicians, electronic engineers, economists, around the medical domain, creating a common platform of concepts and implementation. There were good times and hard times and we are proud that the team grows and the master is more and more attractive to students. I am coordinating the academic activities for MHcIS and keep the faith that is/will be a garden for the future solid trees that will populate a forest to modernise the medical system regionally and connected to field contributors in Europe.

Figure 2: Graduates and academic team - Master in Healthcare Information Systems.

The medical environment benefited by the results of diverse projects developed locally (lab test systems, pharmacy information systems, dentistry, etc).

At national level the EHR and the e-prescribing projects were the biggest endeavours started in 2014. The EHR is theoretically in practice, but the main part of the doctors and patients are not accessing it due to usability problems and no incentive for this kind of activities.

The e-prescription is a hybrid process. The prescription is performed electronically, the GP connecting to a server and selecting the medication for a certain patient based on the patient card. After that, a document is printed, and the patient is visiting the pharmacy where the pharmacists is connecting to the server using the patient card and confirms the transaction.

Introducing the e-prescription resulted in administrative benefits and avoiding hidden costs. The system should be developed further with benefits in clinical practice and public health. Unfortunately there is only a strong political angle related to these projects. We miss a stakeholders’ institution to moderate the interests and to evaluate the solutions.

The national emergency system is using telemedicine and information technology for improving time to inter-

vention and matching resources to the place of intervention (materials and human resources).

In relation to standards, DICOM is usual for image processing, and HL7 CDA is scarcely implemented in several hospital systems. HL7 Romania association is present in Romania from 2006, had a good start, and then after pause, since 2016 is active again. It presents the HL7 standards and from time to time organizes exams.

3 Summary of Research Accomplishments and Current Research Interests

Currently, I work with a team of young colleagues and PhD students mainly on three directions: Virtual Reality applications in medicine, ontologies supporting the diagnosis and treatment in obstetrics-neonatology-paediatrics, and IoT applied in medicine. Based on the up to date developments we intend to consolidate the results using Big Data benefits, smart analytics, and Cloud Computing for better doctor-patient team results. The developments in VR are focused for now mainly on education, and in the future we will extend it to clinical practice, if real use of these new tools will gain the acceptance of the medical domain. One of the reasons we started with the education domain is the need for the young generation of doctors to be familiar with IT tools that will support their work and make it easier in a rapid changing world, with results from medical research coming quickly and diverse from a multitude of sources. The main tools we use for new developments are Leap motion and Oculus, and interaction is done by gestures for medical and bioinformatics domains [2, 3]

Previous work, 2005-2015, was concerned with continuity of care, integration, and development of models and software systems that support these concepts, and tissue engineering. [4, 5] My belief consolidated by experience is that independent and isolate software in medicine does not return benefits. Stating this seems rather common, but looking into practice we still have to affirm it. The ICT benefits relate to communication and integration of data. During that time I entered also the field of Ambient Assisted Living as a domain full of possibilities and benefits for health challenged people and for seniors. The research was developed in 2 national important projects: SIMIMED – Integrated system for medical data management using HL7 standards – [6] and TELEASIS – Complex system on NGN support for seniors' homecare, 2007-2010. [7]

A great experience followed, as evaluator expert for the EHR project in Serbia in 2008 with Serbian colleagues working hard for an excellent project that unfortunately had dissemination issues after ending due to political reasons at the time. For the same domain I acted as expert in the EU project CASA (2014-2015) [8]. In 2016 I was invited in the Trillium Bridge EU USA standards levelling project and as reviewer for the eStandards EU Project [9].

Besides national and EU projects I worked also with industry, and had the privilege to be invited speaker for IBM Academic Days in Romania (Bucharest, 2008) and Europe (Milan, 2014) and to work in specific activities with company Syonic from Timisoara that has a national network of healthcare applications mainly in private hospitals and offices.

Currently, I act as Vice president of the European Federation of Medical Informatics in charge with Working Groups activity. EFMI WGs are a great opportunity to aggregate research from Europe on specific domains.

Currently, I chair the Romanian Society of Medical Informatics for the second term, until 2018. I am an IEEE Member. In HL7 Romania I act as Vicepresident in relations with academia. I chair the Ministry of Health commission on medical informatics.

In the future my goal is to develop more on Systems medicine, taking the opportunity of being a member in the EU COST project Action CA15120, Open Multiscale Systems Medicine (OpenMultiMed) [10] having as target to develop and evaluate a transdisciplinary framework for multiscale systems medicine, consisting of novel concepts, methodologies and technologies.

4 What does the future look for healthcare informatics

The important actors for the domain are the medical staff and the patient. If technology is suited to their needs it will be successful, otherwise it will be again loss of time, money and source of frustration for a lot of the stakeholders. Public health policies gain from digitizing the medical environment.

Internet and Artificial Intelligence are powerful tools for doctors. The IoT is snowballing and enters the medical domain. Apps are available to patients involving them in their healthcare and wellbeing.

Cloud computing is aggregating data and make it available ubiquitously and in an easy to reach manner. Lots of available data are using processing smart analytics tools for prevention and monitoring.

One very important aspect of medical informatics is the education of future doctors. Besides statistical processing useful for their future research and practice, they have to directly learn in an environment that is using the ICT tools, with technology as support for their work.

ICT has more to work in relation with data security, accuracy of sensors, reliability of apps, etc. These and more will be ready. The human factor and the management are still the ones where I see there is still much to do.

Change of management is a must. Managers have to learn how to implement digitization. Sharing data is important, aggregating it and supplying results measured in

a better public health, education and life is a desirable way for the future.

Finally, there are several words that will lead to my envisioned healthcare informatics forest: education, good politics, data aggregation and sharing, cooperation.

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[10] Open Multiscale Systems Medicine OpenMultiMed COST Action 15120, http://www.cost.eu/COST_Actions/ca/CA15120.

Digital health: Reflections on an organic career

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Abstract

Digital health has undergone a substantial journey over the past 40 years; my own experience of it has taken place only over a decade and a half. Of key importance during that time-period has been the shift towards putting the person at the centre. Despite this apparent commitment, it remains crucial to be alert to the challenges and threats implicit in approaches such as the quantified self and transhumanism.

Keywords

Digital health, digital society, eHealth, policy.

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1 Introduction

My career has been a journey through a landscape [1].[1] I have moved rather organically from topic to topic, subject to subject, and discipline to discipline. The benefit of a career grounded in the social sciences is that the field's disciplinary methods can be applied to many different domains – including those of health and the deployment of health-related services. Since the 1970s, my focus has always been on people's rights within a struggle for a good society: that is, not only a good information and communication technology (ICT) society [2], but overall a good and healthy society that benefits from the use of ICT [3].

I have spent only a relatively short period time in the field of digital health, and have worked largely on its policy-related elements over the past 16 years. Before that, for a decade, I concentrated on the uses of technologies to support people with impairments. Indeed, with today's societal focus often being on active health and ageing, these two fields – of health and ability – have moved much closer together. They share an interesting synergy – even though, nevertheless, it is absolutely necessary to remain aware that many barriers and difficulties remain societally and structurally created rather than being clinically or medically based.

Much of my background, whether academic or in applied research, prepared me for the digital society's contemporary orientation towards organisational change. This is a domain of activity that, in the past, I have lobbied to have included under the umbrella of digital health.

[1] I parallel a term used in the title of one of the first books on which I worked. This volume was the first, to my knowledge, to use the term 'landscape' as an analogy for developments in the information world. The original publisher resisted for some time the potential title out of a concern that the book might be housed in libraries under landscape gardening. The term, landscape, is today used commonly in its metaphoric sense.

So, I am currently thrilled about the policy recognition of the importance of these change management mechanisms.[2]

2 My own work

My career began in the early 1980s in London in the field of human rights and social responsibilities at the Institute for Social Research/Centre for Human Rights and Responsibilities, under the guidance of its director, Richard Hauser [4]. Around 1985, the centre was researching the employment opportunities and unemployment threats associated with changing technologies, particularly in the telecommunications and engineering fields. I was conscious that, as a social/political scientist, I was at that time ignorant of the functioning of many of the actual technologies. As a result, I undertook a master's degree in the field of the analysis, design, and management of information systems under the direction of Frank Land of the London School of Economics and Political Science. To paraphrase the terminology of Peter Checkland [5], colleagues said that I worked not simply on soft systems but "*soft, soft, very soft systems*". The two years of study, however, brought me to consider carefully and pragmatically what needs to be done to open up the minds of humanists and social scientists to the benefits of technology use [6].

Throughout the 1980s-90s, my focus was on the organisational, human, and ethical aspects of information and communication technology. This was manifest in my (incomplete) doctoral studies on the ways in which technology was introduced in universities throughout the United Kingdom (UK) [7]. It also showed in my involvement in the International Federation for Information Processing (IFIP), which I joined as a member in 1987.[3] I was privileged to work in the federation with Dick Sizer, Jacques Berleur, and Andrew Clement [1], and many other, highly inspirational, and thoughtful colleagues. Thanks to collaboration with Colin Beardon of Brighton University, we launched the first-ever IFIP summer school on the societal implications of information technology [8]. These involvements with conferences and summer schools continue even into the present, even though the schools themselves now focus much more closely on privacy and data protection issues [9].

In the late 1980s, when teaching organisational theory and behaviour at the London School of Economics and Political Science, I met by chance, Geoff Busby MBE, at a conference on education and training. The burgeoning friendship brought me to undertake voluntary activities for the British Computer Society Disability Group, and to assist with the monthly publication of its Ability magazine. My interest lay, not only in what could be done in the UK but also more internationally [10, 11].

It was my growing involvement with the use of ICT to support people with impairments that brought me to the European Commission as a project officer, and culminated in the publication of a ground-breaking Communication on Web accessibility. Three years later, Professor Jean-Claude Healy encouraged me to join the Commission's ICT and Health Unit: his influence was inspirational [12]. From 2001 onwards, there followed six years of very exciting work, seeing the establishment of the first eHealth action plan [13] and helping to establish the early, appropriate governance mechanisms.

I left the Commission a decade ago in 2007, and digital health has remained at the core of my contemporary activities. Although I now prefer to call the field digital health, I have seen its naming shift throughout the years from health informatics, to ICT for Health, to eHealth, and – indeed – was an instrumental part of the team that aimed for the field to be called eHealth.

In the decade since I left the European Commission, my work on digital health has continued principally through the European Health Telematics Association (EHTEL). Invited to join the Secretariat at the beginning of the decade, my main approach has been to work with stakeholders across the myriad fields of EHTEL's membership-related activities. The association has some 60 members that range across industry, insurers, payers, providers, and patients' organisations: the challenge faced by all these actors is to understand how to scale up digital health throughout Europe. The association brings together a wide range of people to listen to each other's voices and, ultimately, to set out a series of positive, constructive actions around digital health. The core threads of my work have been in policy development, organisational models, tools for scaling-up digital health, and patient engagement.

To further support this continued focus on the importance of digital health, I am a member of associations such as the Healthcare Information and Management Systems Society (HIMSS)[4]; attend a large number of digital health conferences each year; am involved with journals such as that of the European Association of Healthcare IT Managers (HITM);[5] and, in IFIP, co-lead the domain committee on health informatics.

3 Results and achievements

I consider that much of what I have done over the past 16 years relates far less to my personal achievements than to the opportunity to work with a phenomenal group of talented, dynamic, and committed people: all engaged in

[2] Change management is a topic at the core of one of the key four task forces that the Estonian Presidency of the European Union hopes to launch from winter 2017-2018 onwards.

[3] Interestingly, I was ignorant at the time of the previous existence of IFIP's technical committee on medical informatics, and its separation from IFIP – which led, in 1989, to the birth of the International Medical Informatics Association (IMIA).

[4] `http://www.himss.org`

[5] `https://healthmanagement.org/site/p/hitm`

the desire to improve the lives of others by building a society full of people who can age actively and healthily, supported by ICT. Nevertheless, it was with great honour and pleasure that I stepped up earlier this year to receive the 2017 HIMSS Europe eHealth Leadership Award that recognised my work over the years.[6]

I consider my top success, in policy terms, to have been to witness the launch of the first eHealth action plan [13], and to contribute towards building in the mid-2000s a regular series of eHealth weeks and conferences. Today, these activities are either in the hands of HIMSS and/or are supported by other stakeholder alliances, such as the European Connected Health Alliance (ECHAlliance). Latterly, a major accomplishment has been the small part that I have played in the spread of interest in digital health throughout a wide range of stakeholders, and the regular holding of the EHTEL symposia.[7] For this, I wish to pay tribute to the collaboration and cooperation that has resulted from my work with Marc Lange and Stephan Schug of the EHTEL Secretariat, and the support of the EHTEL presidents, such as – latterly – John Crawford of IBM, and the various board members who have been active over the past ten years.

In terms of introducing new readers and actors to the field, I am proud to have been involved in the publication of two innovative volumes [14, 15]. Still attracting readers, these two books focus on important societal, social and organisational challenges; the latter pays tribute to the one of the giants on whose shoulders I stand, Professor Jean-Claude Healy.

Work and activity is always fun when it is also a pleasure – this is very much true of the collegiality I experienced when working with several of my co-editors, Penny Duquenoy, Carlisle George, Magda Rosenmöller and her great team of colleagues at the IESE Business School[8] in Barcelona, Spain, and Petra Wilson. At Middlesex University in the United Kingdom (UK), with Carlisle George and Penny Duquenoy, I was pleased to help launch the ECELGHIT (eHealth) network,[9] which now runs a regular, bi-annual workshop. The next in this series will take place in March 2018, with a focus on emerging digital health technologies.

Having visited the Czech Republic several times, it was with especial honour that I was asked, in 2015, as the result of an amicable discussion with Professor Jana Zvárová, to join the EuroMISE Mentor Association.[10]

4 Health informatics in my own country

Although I am now resident in the UK, I admit to no particular familiarity with the country's health system or services.

In 2010, I reported, however, in general on eHealth strategies in a 2010 study undertaken by empirica, which is shortly going to be updating the current status of European Member States in terms of their policies and programmes. In the UK and in England specifically, digital health is a highly applied area (see the detailed piece by Jean Roberts in this journal issue). The latest in these kinds of developments are the transformation plans developed region-by-region under the umbrella of the English National Health Service (NHS England).

Instead, I prefer to focus on the European Union – and its mix of policy, research and development, and application/deployment, developed since the mid-1980s. In later years, Europe has focused on the way in which ICT can help older adults, and all those who wish to age actively and healthily. There are rapid developments, which continue to occur, in technologies in terms of a digital society and digital economy.

Perhaps more important, however, is the international scene [16]. Given the migration trends already identified by Organisation for Economic Co-operation and Development some 30+ years ago, it is crucial to build healthier and wealthier societies throughout the globe.

5 Digital health and its current directions

Over the past decade of policy directions – and especially in later years, it has been the financial aspects of health systems and services that have been predominant, with a focus on what new business models of health need to be developed.

Much exciting research continues, increasingly in the fields of organisational theory and behaviour. Labour is becoming more and more commoditised, as much in health and care services as in other professions and occupations. The 'person' or 'patient' is now being placed 'at the centre' of the system or service. This shift in preoccupation implies that much more work will be needed by all of us, as individuals, with regard to the meaning, and maintenance, of our own data and our own systems. Similarly, technologies are coming ever closer to us physically as human beings, including its insertion inside our bodies. There is increasing convergence in the computational world, and not only that foreseen by an IFIP conference on the brain, body, and being back in 2010.[11] It will be particularly important, and fascinating, to see how the General Data Protection Regulation (from 2016) plays out from 2018 onwards, and its specific implications for the health sector.

I sense a personal feeling of disquiet, however, with regard to many of the notions around 'the sharing of data'. As a result, I still stand by the words of Whitehouse &

[6] http://www.ehealthweek.org/ehome/198654/leadership-award/
[7] http://www.ehtel.eu
[8] http://www.iese.edu/en/index-default.html
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[10] http://www.euromise.net/en/
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Rosenmöller in 2012 [15], and by concerns relating to the 'quantification of the self' and transhumanism.

It remains fundamentally important to explore the societal and ethical implications, and the fundamentally human needs, in relation to technologies in general, and digital health specifically [17, 18]. As I wrote a decade ago [19]:

As we look towards the future, and particularly that peak in the West of baby-boom ageing around 2030, all citizens in our societies need to ask themselves certain basic questions. How [to find a balance] between those who need care and support and those few(er) who are economically active; between those regions and states which are blessed with abundant healthcare professionals and those which have insufficient; between those countries and institutions which extract the benefits of advanced telemedication and teleconsultation and those which remain as yet unconnected? How too can we move towards a more innovative and evolutionary view of thinking about and organising our healthcare systems and services?

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