STUDIES IN HEALTH TECHNOLOGY AND INFORMATICS 300

Achievements, Milestones and Challenges in Biomedical and Health Informatics

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IOS Press

The technological advances in Biomedical and Health Informatics (BMHI) in the last 4 decades could barely have been imagined when the field was in its infancy. At the time, computers were large and unwieldy, memory was measured in kilobytes, and the Internet was accessible only to people in the technology professions. How the world has changed. The skills of BMHI are now essential for everyone who participates in healthcare, from practitioners and researchers to administrators and patients.

This book presents the 17 accepted papers of the International Symposium on Achievements, Milestones, and Challenges in Biomedical and Health Informatics (BMHI), held in Athens, Greece, on 29 October 2022. This event marks the retirement of Professor John Mantas, whose career in BMHI spans over 40 years, and a number of eminent colleagues from around the world were invited to present original review papers in their respective domains, not only to celebrate the work of Professor Mantas, but to review the achievements, milestones, and challenges of BMHI. Most of those presenting papers have worked in the field for decades, and their collective experience and wisdom highlights the accomplishments and limitations of the field. Each paper was peer reviewed by 3 independent reviewers before being thoroughly revised ensuring the high quality of the accepted papers.

The book is dedicated to the entire BMHI community. It covers the achievements attained, the milestones reached, and the challenges which have been overcome or which have not been conquered, and provides knowledge and perspective for both learners and practitioners in the field.

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ACHIEVEMENTS, MILESTONES AND CHALLENGES IN BIOMEDICAL AND HEALTH INFORMATICS

Studies in Health Technology and Informatics

Internationally, health informatics is driven by developments in biomedical technologies and medical informatics research that are advancing in parallel and form one integrated world of information and communication media and result in massive amounts of health data. These components include genomics and precision medicine, machine learning, translational informatics, intelligent systems for clinicians and patients, mobile health applications, data-driven telecommunication and rehabilitative technology, sensors, intelligent home technology, EHR and patient-controlled data, and Internet of Things.

The series Studies in Health Technology and Informatics (HTI) series was started in 1990 in collaboration with EU programmes that preceded the Horizon 2020 to promote biomedical and health informatics research. It has developed into a highly visible global platform for the dissemination of original research in this field, containing more than 250 volumes of high-quality works from all over the world.

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Preface

This volume contains the accepted papers of the International Symposium on Achievements, Milestones, and Challenges in Biomedical and Health Informatics (BMHI) to be held in Athens on October 29, 2022. This is an International Summit event, organised by invitation and attended by the most distinguished colleagues in the field, presenting original review papers in their respective domains with an in-depth, bird's eye, critical view which also looks in breadth across the timeline of an entire career. It spans an almost forty or even fifty year period that stretches back to the beginnings of the application of computers in health and healthcare, but from a more humble perspective, it can also be seen as just a droplet in the ocean of the scientific history of humanity.

We know that scientific progress is not always linear, and we also understand that, in a similar way, the progress of BMHI may have encountered a few mishaps, delays, failures and enthusiastic expectations, as well as some successes. Each distinguished author in this volume has, from his or her perspective, expertise, region, and background and with humility, attempted to describe the achievements attained, the milestones reached, and the challenges which have been overcome or which we failed to conquer. The Scientific Programme Committee followed all the accepted standards of organising such a Summit event, and each submitted paper was peer reviewed by 3 independent reviewers before being thoroughly revised and submitted to editing and proofreading procedures to maximise the scientific effort of the authors, but also to ensure the high quality of the accepted papers.

I would like to thank my fellow co-editors, Professor Emeritus Arie Hasman and Professor Emeritus Reinhold Haux, for their support during the entire process of organising this Summit event. Without them this event may never have come about. I would also like to thank all reviewers for their challenging work in improving the quality of the papers of the distinguished authors. Finally, I thank Dr. Emmanouil Zoulias for his support in the demanding process of editing the files of the proceedings preparatory to their acceptance by IOS Press.

It should be noted that these Proceedings are published as Open Access, with e-access for ease of use and browsing without the loss of any of the advantages of indexing and citation in the biggest Scientific Literature Databases, such as Medline and Scopus, which the series of Studies in Health Technology and Informatics (HTI) of IOS Press provides. This volume contains 17 high-impact papers in the field of Biomedical and Health Informatics and is dedicated to the entire community of our domain, as well as to the current and the forthcoming students of the discipline wishing to fathom the depth and the timeline of the evolution of BMHI.

The Editor would like to thank the Members of the Scientific Programme Committee, the Organising Committee, and all reviewers, who have performed a very professional, thorough and objective refereeing of the scientific work in order to achieve a high-quality publishing achievement for a remarkable and unique scientific event.

Athens, 18.09.2022

John Mantas, Editor

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Prologue

This book contains the contributions presented at the international *Symposion* on "Achievements, Milestones, and Challenges in Biomedical and Health Informatics" held in Athens, Greece, on the 29th of October 2022. This symposium marks the occasion of the retirement of our esteemed colleague Professor John (Ioannis) Mantas. A select number of senior informaticians from around the world participated in this by-invitation symposium and were each asked to present their personal view of the achievements, milestones, and challenges in biomedical and health informatics (BMHI) that they had experienced or envisioned during their career.

John Mantas asked the authors of this prologue to support him in the organisation of this *Symposion* and the publishing of this book, and we accepted and have served as his co-organisers with great pleasure; we have both known John for a long time. John Mantas can be characterised as a teacher, scientist, manager, and leader, and last but not least as a very good friend. He has accomplished many feats in BMHI, both nationally and internationally. In keeping with the theme of the symposium, we want to bring a few of John's achievements to your attention in the remaining part of this prologue, but let us first and very briefly summarise some of the steps in John's career.

John Mantas graduated from the Department of Electrical and Electronic Engineering at the University of Manchester in 1979, and completed his Master's degree with specialisation in Information Technology and Telecommunications the following year, receiving his Ph.D. in Computer Science from the University of Manchester in 1983. John began his academic career at the University of Manchester, then continued it from 1986 at the School of Health Sciences of the University of Athens, where from 1998 until his recent retirement, he was a full Professor of Health Informatics and Director of the Laboratory of Health Informatics, serving as a Dean of this School among others posts. He was also Vice-Rector of the Board of Trustees of the Cyprus University of Technology, and his still increasing record of publications, projects and supervisions of master and doctoral theses is impressive.

Here are some of his achievements in more detail. In the 1980s, John Mantas was responsible for starting health informatics courses for nurses in Greece at the University of Athens. He also played a leading role in obtaining funding from the European Commission for the setting up of a master of science programme in health informatics at the University of Athens. The programme was truly international, with both lecturers and students coming from quite a number of European universities to teach in or follow the master course. In addition, John was heavily involved in two European projects with a focus on education: NIGHTINGALE (as coordinator) and IT-EDUCTRA, both approved in 1995. The NIGHTINGALE (Nursing Informatics Generic High-level Training in Informatics for Learning & Education) project was focused on the educational needs of nurses in the field of nursing informatics. The goal of the project was to develop multi-media CD-ROMs emphasising the need for information technology and developing educational material in nursing informatics, developing a nursing informatics curriculum for undergraduate and postgraduate nursing schools, and publishing a textbook in health informatics with an emphasis on nursing applications. IT-EDUCTRA had as its goal the development of educational material in information technologies which would introduce physicians, nurses and hospital administrators to the advantages of the health informatics discipline. The material was distributed on a CD-ROM.

John was involved in the working groups (WGs) on education of both the European Federation for Medical Informatics (EFMI) and the International Medical Informatics Association (IMIA). He was co-chairman, and later chairman, of the EFMI WG and member and later chair of the IMIA WG. He led the task force to revise the original IMIA recommendations on education in biomedical and health informatics. Recently he has also been very much involved in the second revision of the IMIA recommendations.

John was not only involved in providing education, he was also interested in the quality of educational programmes. He participated in several site visits to BMHI programmes in the trial period of IMIA accreditation and now chairs the Accreditation and Certification Committee (AC2) of EFMI. As well as serving the EFMI as co-chair and chair of the WG on education, he was also President of EFMI from 2010 to 2012 and thereafter represented EFMI to IMIA as Vice-President of IMIA.

Figure 1. Professor Emeritus John Mantas and Professor Emeritus Marianna Diomidous at Acropolis in Athens during ICIMTH 2022 on July 1, 2022.

Last, and by no means least, we want to mention that he organised a series of annual ICIMTH (International Conference on Informatics, Management and Technology in Healthcare) conferences, first in Samos and later in Athens. This year, the 20th edition of ICIMTH took place in Athens. Now a professor emeritus, John has decided to continue this important activity for the international BMHI community. In his attendance at these conferences in particular, it has become clear how much John loves Athens, the city where he was born and where he has now lived for so many years with his wife Marianna. The picture (Figure 1) shows them both, Professor John Mantas and Professor Marianna Diomidous, during ICIMTH 2022, with the famous Acropolis in the background. Many of the ICIMTH participants were impressed by the comprehensive and detailed knowledge of Greek history that John shared with us during the social events of the conferences, in particular during his legendary walking tours through Old Athens, events which also demonstrated his impressive hospitality and that of the ICIMTH organising team.

From the above, it will be clear that Professor John Mantas has devoted his working life to the promotion of biomedical and health informatics, and that he can be justly proud of what he has accomplished. Therefore, and on behalf of all participants of the *Symposion,* we dedicate this book to him.

Arie Hasman and Reinhold Haux
Co-Organizers of the *Symposion*

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Prolegomenon

"Achievements, Milestones, and Challenges in Biomedical and Health Informatics"

On the occasion of the retirement of Professor John (Ioannis) Mantas, a number of senior leaders in the field from around the world have been invited to celebrate not only the work of Professor Mantas, but also the achievements, milestones, and challenges of the field of biomedical and health informatics (BMHI). Most of us presenting papers and speaking at this symposium have been working in the field for decades, and the collective experience and wisdom of this group highlights the accomplishments and limitations of the field.

BMHI has ridden a wave of technological advances in the 4-5 decades that could never have been imagined when most of us started working in the field. Many of us presenting at this symposium started our careers when computer processors and memory were measured in kilohertz and kilobytes. The Internet was in its infancy, and accessible only to people in the technology professions. We can now consider how the world has changed, with essentially all citizens of the planet having access to the Internet, with its wealth of biomedical and health knowledge, often via devices they can carry in their hands. In recent years, especially in the era of the COVID-19 pandemic, we have also seen how this technology can be used to undermine personal and public health. Nonetheless, it is clear that the skills of BMHI are essentially for everyone who participates in healthcare, from physicians, nurses, and other clinicians to researchers, administrators and patients, and to information technology professionals and vendors.

The papers and presentations of this symposium celebrate the accomplishments of BMHI, but also highlight the challenges still to be solved by those who work in the field. Several of the papers describe personal journeys that have paralleled the major advances in the field in practice, research, and the education of future professionals and leaders. Other papers describe challenges in specific application areas, including imaging, nursing, and consumer health informatics. Some of the papers also provide context for the linkage of BMHI to larger societal challenges beyond healthcare.

Some papers describe challenges critical for the field to achieve its promise. How can we integrate the various disciplines that comprise our interdisciplinary field? How do we ensure that the benefits of the field accrue to those who are historically underrepresented and potentially further marginalised by biased data and algorithms? How should we harness the value of artificial intelligence and implement it in fair and equitable ways? How are we to keep data and information systems secure?

The papers in these proceedings provide a rich foundation for discussion and debate on the road ahead for BMHI. The path first followed by Professor Mantas and other presenters at this symposium will guide the rest of the field in continuing the vision and actions set forth in their distinguished careers. This volume will add knowledge and perspective for both learners and practitioners in the field.

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Symposium
on
"Achievements, Milestones, and Challenges in Biomedical and Health Informatics"

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Contents

Achievements, Milestones and Challenges in Biomedical and Health Informatics
J. Mantas et al. (Eds.)

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50 Years of Achievements and Persistent Challenges for Biomedical and Health Informatics and John Mantas' Educational and Nursing Informatics Contributions

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Abstract. Biomedical and Health Informatics (BMHI) have been essential catalysts for achievements in medical research and healthcare applications over the past 50 years. These include increasingly sophisticated information systems and data bases for documentation and processing, standardization of biomedical data, nomenclatures, and vocabularies to assist with large scale literature indexing and text analysis for information retrieval, and methods for computationally modeling and analyzing research and clinical data. Statistical and AI techniques for decision support, instrumentation integration, and workflow aids with improved data/information management tools are critical for scientific discoveries in the -omics revolutions with their related drug and vaccine breakthroughs and their translation to clinical and preventive healthcare. Early work on biomedical image and pattern recognition, knowledge-based expert systems, innovative database, software and simulation techniques, natural language processing and computational ontologies have all been invaluable for basic research and education. However, these methods are still in their infancy and many fundamental open scientific problems abound. Scientifically this is due to persistent limitations in understanding biological processes within complex living environments and ecologies. In clinical practice the modeling of fluid practitioner roles and methods as they adjust to novel cybernetic technologies present great opportunities but also the potential of unintended e-iatrogenic harms which must be constrained in order to adhere to ethical Hippocratic norms of responsible behavior. Balancing the art, science, and technologies of BMHI has been a hallmark of debates about the field's historical evolution. The present article reviews selected milestones, achievements, and challenges in BMHI education mainly, from a historical perspective, including some commentaries from leaders and pioneers in the field, a selection of which have been published online recently by the International Medical Informatics Association (IMIA) as the first volume of an IMIA History WG eBook. The focus of this chapter is primarily on the development of BMHI in terms of those of its educational activities which have been most significant during the first half century of IMIA, and it concentrates mainly on the leadership and contributions of John Mantas who is being honored on his retirement by the Symposia in Athens for which this chapter has been written.

Keywords. Biomedical Health Informatics, Scientific-Technological Evolution, Historical Achievements, Open Persistent Informatics Challenges

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1. Introductory Overview: Biomedical and Health Informatics as Evolving Art, Science, and Technology for Inclusive, Equitable Digital Healthcare

On the occasion of honoring John Mantas in Athens for his contributions to Biomedical and Health Informatics (BMHI), it seems appropriate to start by quoting, in Chaucerian English translation, an original Greek aphorism ascribed to Hippocrates, the father of humanistic healthcare practices: “The life so short, the craft so long to learn.” [1, p 251]. BMHI has evolved over the past 50 years into an interdisciplinary endeavor that has radically transformed healthcare and its underlying biomedical research leading to life-saving scientific, clinical and public health advances [1,2,3,4,5,6,7]. Yet, this modern cybernetic, digital health craft is indeed very long to learn. Being an exceptionally broad umbrella discipline that draws on the diversity of scientific, technological, and humanistic approaches to health, BMHI is necessarily guided by an equally broad set of goals and expectations that push the boundaries of what is scientifically and practically achievable through art and science [8]. And, when technologies are prematurely or poorly implemented they can lead to harm [9], referred to as e-iatrogenesis as an unintended consequence [10].

From its inception, BMHI has sought, through its interdisciplinary education professional initiatives [11,12], to synthesize the many informatics insights in order to improve scientific understanding of the wide range of connected ecologies of life from molecules to populations [13,14], and serve as a bridge that translates these understandings into best practices based on evidence from “bench to bedside” [15]. In so doing, a great challenge for system designers and users alike is to adhere to the Hippocratic ethical dictum usually summarized as “First, do no harm” in helping care for individual patients [16] while also developing general methods for biomedical and health informatics, clinical and management advances and preventive healthcare policies around the world [17,18]. Problems of diversity, equity, and inclusion have become more recognized over the past decade [19,20], and calls to action have become more urgent as disparities in care for underserved and vulnerable populations have become more obvious than ever as result of the COVID -19 pandemic [21,22].

Technological and scientific achievements in BMHI have been many and largely reliant on human ingenuity and creativity in exploiting a happy juncture of practical and theoretical informatics insights derived from the underlying mathematical, basic sciences, and engineering source disciplines. In contrast, the persistent and often frustrating informatics challenges - which also provide many exciting and provocative opportunities - have arisen largely from scientific limitations on matters of research and education, as well as the complexities of fraught human social and psychological constraints for matters of clinical care, management and preventive digital health. The intersections of practical clinical arts with the sciences and technologies of information, therefore present a uniquely rich and fruitful source of problems for scientific inquiry in the biosciences with its information sciences. However, these complex intersections can also prove to be frustratingly and ethically difficult sources of problems for the cognitive and social sciences. These are needed to deepen our understanding with humanistic insights of what can be developed as “best” healthcare practices for patients and consumers in rapidly evolving techno-societies where surveillance is ubiquitous [23] and cybersecurity dangers are pervasive [24,25].

2. History of some of BMHI's Early Milestone Achievements and their Evolution

The main precursor achievements and milestones leading up to the founding discipline of Medical Informatics that preceded the more general BMHI we know today, can be traced to several major workshops, conferences and proceedings volumes and a key scientific journal paper starting over 60 years ago in the late 1950's. All involved the then emerging applications of computers, communications, and control (to which the name Cybernetics coined by Norbert Weiner was frequently applied based on his 1948 book of that title [26]) in medicine using computer programs implementing statistical and mathematical simulation methods to analyze data for various types of biomedical problems. The leading US computer company at the time, IBM, had its scientists and engineers collaborating with physicians at the Cornell Medical School in New York, investigating the feasibility of using computers for clinical data analysis. In 1959 they begun an annual series of IBM Medical Symposia [27], demonstrating, among other biomedical data analysis applications, the potential of using computers to implement medical diagnostic logic. This can be taken as a precursor to the more recent applications of computers with machine learning for the analysis of big data in biomedicine [28].

It was in the same year of 1959, however, that a widely known scientific publication event occurred that can be considered as the first major milestone for BMHI advances, setting the field on a path of investigating how to model medical reasoning and provide clinical decision support for practitioners using general, well recognized, though often controversially interpreted statistical methods for handling uncertainty and risk in decision-making. The publication involved was an article by Ledley and Lusted which appeared in the prestigious US journal Science entitled Reasoning Foundations of Medical Diagnosis [29], and introduced for the first time, a formal logical probabilistic framework- that of rational utility theory - for representing clinical reasoning with a mathematical model. The Bayesian statistical methods they proposed had the virtue of being able to update subjective prior probability estimates that a physician might have about a sick patient's disease using the probabilities of observed clinical evidence derived from previous studies of similar patients. These methods still remain the most frequently used formal methods for computationally modeling of inferencing for clinical diagnostic reasoning and many epidemiological applications today [30] within the commonly used hypothetico-deductive frameworks for decision-making.

However, many fundamental open scientific questions around scientific statistical inferencing methods in biomedicine still persist today and are related to some of the difficulties being encountered in applications using Artificial Intelligence and machine learning algorithms and data-driven inferencing especially [31]. These include problems of coming up with subjective probability estimates which are clearly agent-and-context specific in medicine, healthcare, and most other psychological/cognitive science and social science problems, together with the frequent misuse of probabilistic independence assumptions for complex evidence and hypothesis definitions and relationships. Underlying ontological assumptions about illness and disease, their etiologies and processes are complicated in populations with high degrees of diversity arising from environmental, genetic, cultural and other factors and for all species. Modern insights into the complicated but still poorly understood interactions with microbiomes and other ecological factors at all scales adds to the open scientific problems at both the ontological and epistemological levels. As result, practical methodological disagreements and debates about the applicability of statistical models for arriving at inferences about specific individuals is extremely fraught since ethical issues about responsibility of both patient and practitioner are involved. Scientific epidemiological inferences about groups or populations, involving very different levels of abstraction for decisions in biomedicine are likewise the subject of much debate. Consequently, alternative statistical analytical approaches based on hypothesis testing using either the Fisher, Neyman-Pearson or other paradigms for null hypothesis significance testing (NHST) are still major competitive inference reasoning candidates across BMHI applications today [32,33].

Historically these likelihood-based methods for probabilistically modeling medical diagnostic and automated multiphasic screening were the preferred statistical inference approach [34] of another key founding member of medical informatics in the USA, Dr. Morris Collen. His contributions to, and leadership roles in BMHI internationally have led to him being called the “father of medical informatics” [35]. After taking leadership of many international and educational initiatives in medical informatics, and sponsoring an award for research excellence through the Academy for Medical Informatics (ACMI), he wrote a very detailed history of the field in the USA with quite a few references to worldwide activities in healthcare informatics. An updated version, co-edited with Marion Ball, was published in 2014 after Collen’s death at the age of 100 [36].

Yet, during the first full decade of early or precursor work on the fundamentals of computer information processing it was the more general encyclopedic textbook by Robert Ledley from 1965 entitled Use of Computers in Biology and Medicine that became the first comprehensive book encompassing the main informatics subjects of the time – the logical, statistical, and other algorithmic methods for problem-solving in the biomedical sciences and medical care more generally [37].

A different, yet even more significant early achievement for the field of BMHI was the founding of the first scientific journal covering medical documentation and statistical methods - Methods of Information in Medicine by Gustav Wagner published in German in 1962 [38,39]. This journal switched to being published in English and became the official journal of IMIA when the international association was founded in 1979.

In the 1960’s another precursor milestone achievement for BMHI was the publication by Donald Lindberg of the book The Computer and Medical Care in 1968 [40] which for the first time covered most of the principal applications of computers in healthcare from clinical rather than formal mathematical or technological and computational perspectives. Lindberg was a pioneer in computer methods for laboratory medicine who rapidly became a leader of medical informatics in the US, envisioning early the future of the field as revolutionizing library operations through computerization of information retrieval and informatics methods. As Director of the USA’s National Library of Medicine (NLM) from 1984 until his retirement in 2015, he turned the NLM into the main sponsor of BMHI research and development both in-house in the National Institutes of Health, by funding academic and professional educational programs across the US, and internationally by his close connection and active participation in IMIA activities. It would be hard to overstate Lindberg’s and the NLM’s contributions to the dramatic worldwide expansion of BMHI and the catalytic role they have played in biomedical research discoveries, and their impact on the practices of medicine and healthcare [41]. This is most especially true for the emerging translational medicine achievements, which NLM’s informatics infrastructure is critical in supporting, just as it did the Human Genome Project, which led to the genomic and other -omic biomedical advances. The NLM produced powerful indexing and literature search capabilities open to all without cost long before online commercial search engines and software like Google were envisioned. The development of a Unified Medical Language System and support for Natural Language Processing, together with biomedical research databases and knowledge bases of all kinds, expert systems and the Visible Human Project were all major achievements for BMHI which have transformed the life sciences, biomedicine and healthcare over the past 50 years. The educational impact of NLM's informatics breakthroughs in biomedicine and informatics has been likewise incomparable to that produced by any other institution. A contributed volume describing Lindberg's major contributions to BMHI written by his colleagues and collaborators entitled Transforming Biomedical Informatics and Health Information Access: Don Lindberg and the U.S. National Library of Medicine has been recently published by IOS Press [42].

Returning to the first decade of BMHI achievements, Lawrence Weed proposed a ground-braking change in how medical records could be organized – and oriented towards patients' medical problems, in order to guide and teach practitioners and patients alike, rather than just following traditional difficult-to-understand practitioners' notes of clinical encounters [43]. His articles and book on the Problem Oriented Medical Record had great influence on how researchers and practitioners looked at the structures for recording information about patients [44] and continues to be relevant today [45].

During the first decade of BMHI in the 1960's researchers in what was to become medical informatics were active in Europe as well as the USA and Canada. In France, the physician and biophysicist Francois Grémy taught university and medical school courses on the subject, and he took the initiative of founding the first international professional organization for medical informatics under the aegis of the International Federation of Information Processing (IFIP) Societies [46]. The success of the IFIP-Technical Committee 4 for Medical Informatics described next in this article contrasted with the relative ineffectiveness of an earlier and excessively theoretically-oriented international organization for Cybernetic Medicine [47], and followed soon after a most productive first international meeting in Ellsinore, Denmark, under the shadow of Hamlet's castle [48]. This meeting brought together many of the early leaders in what was to become medical informatics, and effectively demonstrated that practical computer information systems for hospitals and other clinical and biomedical research and educational purposes would be a more promising future direction for the field – which proved true historically [49].

As one can see from the above, the groundwork for educational directions in BMHI was being laid even before the word informatics (derived from the French "informatique" thanks to Grémy's role in the formation of IFIP–TC4) came to denote the disciplines involved, which did not start to happen until the 1970's and even the 1980's when it gradually started to replace the earlier strictly computational, statistical, or documentation emphases used to characterize the emerging medical informatics field.

3. Early Historical Milestones in the emergence of Medical Informatics professional organizations

The major accomplishment and milestone in the history of Medical Informatics as a discipline was its establishment with its own professional organization. As mentioned above, the Technical Committee 4 (TC-4) of the International Federation of Information Processing Societies (IFIP) was organized by Francois Grémy in 1968. That same year he also established the French Association for the Applications of Informatics in Medicine (AIM). In the following years he became the promoter and organizer of a number of workshop conferences on different medical informatics topics such as information processing for medical records in Lyon in 1970, the analysis of biomedical signals for ECG and VCG in Hanover in 1972, and health informatics education in Lyon in 1974 under the aegis of TC-4 [50,51,52,53]. A number of European countries led in the early organization of national medical informatics societies. In Denmark, a society for medical informatics associated with the Danish medical societies was established as early as 1966, while the Swedish Society for Medical Information Processing was founded the next year. In the Netherlands, the VMBI was founded in 1970, and the Norwegian and Belgian (MIM) society were both established in 1974. Other major European countries such as Germany and the UK, had scientific or technological professional societies like the GMDS (covering informatics, biometrics, and epidemiology) and the British Computer Society's Health Informatics Specialist Groups, taking responsibility for the professional organization of informatics in their countries [54].

BMHI can be said to have reached a milestone of international recognition as a distinct discipline in its own right after the success of the first World Congress or MEDINFO held in Stockholm in 1974. This was the first official milestone for BMHI using the word informatics in a major conference that coalesced people with their ideas about how medical information was being processed by computers and shared widely in an interdisciplinary manner. This first MEDINFO generated enthusiasm among the participants who became aware that the time was ripe to carry out the organizing and planning for not only national, but also regional and international societies for medical and health informatics. These included COACH (Canadian Health Informatics organization) in 1975, the European Federation of Medical Informatics (EFMI) in 1976, and the International Medical Informatics Association (IMIA) in 1979 when it became independent from IFIP, though still in association with it.

In the USA, the earliest professional society precursor to informatics was an offshoot of the American Hospital Association (AHA), which evolved into the Health Information and Management Systems Society in 1966. More technically oriented was the Society for Advanced Medical Systems (SAMS) formed in 1967, while the more clinically oriented Society for Computer Medicine (SCM) was organized in 1971. These were to merge in 1982 to form the American Association for Medical Systems and Informatics (AAMSI). It took until 1989 for AAMSI to merge with the Symposium on Computer Applications in Medical Care (SCAMC), founded in 1976, and the American College of Medical Informatics (ACMI), the honor society founded in 1984 for them to all join, and establish the integrated focus for academic healthcare informatics in the US - the American Medical Informatics Association (AMIA) [36]. Internationally, most countries, like the US, did not develop scientific and academically oriented informatics societies until the decades of the 1980's or beyond, encouraged by IMIA's activities to spread worldwide through the regional associations that followed EFMI: IMIA-LAC for Latin America and the Caribbean, APAMI for the Asia-Pacific, HELINA for Africa, and MEAHI for the Middle East.

Nursing Informatics (NI) has had a very different beginnings and evolutions than medical informatics, with their organizations founded by members of the nursing profession who were interested in tackling the challenges and dealing with the opportunities of information processing and computer systems, as they started to be introduced clinically by hospitals and clinical institutions beginning in the decade of the 1970's [55]. This circumstance in great contrast to medical informatics, where most practicing physicians were able to largely ignore information technology (IT) developments until the late 1980's, leaving the early evolution of medical informatics to just a few visionaries and enthusiasts among practitioners usually collaborating with interested scientists, mathematicians, computer scientist/informaticians or engineering technologists. Nurses became very aware early that the "lack of standards for clinical language and data limited the functionality and usefulness of early applications"[55]. It is not surprising then, that for its first decades, most nursing informatics activities were devoted to education and connected to medical and health informatics organizations as special interest groups or working groups. Later, practitioner oriented professional organizations have arisen as computer and information systems became more prevalent, and the TIGER initiative was developed to promote nursing informatics educational reform through technologies [56]. A very comprehensive overview of nursing informatics today can be found in [57].

4. Overview of Educational and Nursing Informatics and the Contributions of John Mantas.

The world-wide impact of research and practices in BMHI has been highlighted by the recent publication of an eBook by the International Medical Informatics Association (IMIA) [58], which in its first volume online details the personal stories of a number of pioneers and leaders in the field, including John Mantas.

Since the present book and this chapter is designed for the Symposia held in Athens on October 29, 2022 to honor John Mantas on the occasion of his retirement, it is appropriate to highlight his contributions to the discipline of BMHI, especially in the fields of education and nursing, where his teaching, insights and collaborations have developed the educational practices and perspectives that have significantly advanced the field [7,11,17]. In [58] Mantas says: "What we are, what defines us, is mostly the accumulation of the efforts of others who influence us", reflecting for nursing education, the epitome of caring approaches that support the health and lives of others. This in many ways explains Mantas' choice of nursing informatics and his focus on educational activities of BMHI as an academic specialization. He describes his professional journey and the influence that Arie Hasman and Rolf Engelbrecht had on him to join the EFMI Working Group on Education, and his appreciation for Reinhold Haux who introduced him to the broader international informatics community of IMIA, where he led the Task Force on Educational Recommendations [11] which were subsequently updated and led to an IMIA Accreditation Program [59]. Mantas goes on to describe his efforts to introduce health informatics into the curriculum of medical and nursing schools in Greece, which resulted in the "first time in the literature that we encounter an official use of the term for a course, which was accepted very late in the 1990's and beginning of the 2000's as the appropriate generic term reflecting our field" [58, p. 142]. Mantas also recounts how a serendipitous invitation to represent Greece to the European Commission in Brussels for the announcement of the new program of Advanced Informatics in Medicine (AIM) led to his collaboration with many European colleagues such as Engelbrecht, Stefanelli, De Moor, and Rector. Shortly afterwards Mantas also joined another EC program on education in Health Informatics at the M.Sc. level – the Erasmus Inter-University Cooperation Programme, which drew 35 lecturers from across Europe from 1990 to 1997. During this time, Mantas was the principal investigator and coordinator of the NIGHTINGALE (Nursing Informatics Generic High-level Training in Informatics for Learning and Education) project, also funded by the EC from 1995, which convened workshops across the continent and developed a nursing informatics curriculum and the compilation of a textbook [7].

Mantas is a Full Professor at the National and Kaspodistrian University of Athens, where he is Director of the Health Informatics Laboratory. He has presented talks, and written and edited a number of very comprehensive articles about the history of educational efforts in BMHI – with the most detailed one being a 2016 article in the IMIA Yearbook of Medical Informatics [60] entitled Biomedical and Health Informatics – the IMIA Years. This provides a systematic overview arrived at from a literature search of title and abstracts of papers written in English beginning with the founding of IMIA. The results were an analysis of the educational topics covered by a wide range of curricular developments and course offerings, with their sources and durations of educational activities, and special attention paid to the international dimensions and impacts of the work. The IMIA Yearbook review was based on an earlier paper, which proposed a five-stage evolutionary framework for describing the history of BMHI education [61].

Most recently John Mantas has contributed to the ongoing inquiry by international experts in BMHI into research strategies that can lead to thought-provoking critical proposals that will encourage scientific debate on the nature of good research in medical informatics [62]. It is fitting to end this section on the accomplishments of John Mantas with such a forward-looking and constructive prospect – which bodes well for a productive retirement.

5. Conclusion: Historical Greek origins of rational, altruistic healthcare - inspired by Mantas' speech to the General Assembly of EFMI on his election as President

Upon his election as President of EFMI in 2010, Mantas made an acceptance speech to the General Assembly and Council of the Federation at their meeting held in Athens, which is both unique, and most elegant. It uses Greek-derived English words exclusively (except for articles and pronouns) to thank the "Panethnic Synod" or General Assembly of EFMI for his election! Mantas in this way reminds his audience – and us - of just how much medicine and healthcare owes to its mythical founder Asclepius, in Ancient Greece, whose daughters Hygieia (Healthiness), Iaso (Healing), Aegle (Good Health goddess), and Panacea (goddess of universal remedy) continue to join with him in inspiring the healing practices today, with Asclepius' staff or rod enduring as the main symbol of medicine [63]. Empirical clinical observation and rationality in searching for the etiology or causes of illnesses in the practice of healing was introduced about a century later by Hippocrates of Ionia, whose book Of The Epidemics [64] is especially relevant in the present age of emerging pandemic infectious disease [65], and whose Oath still guides the ethics of medicine [66]. Five hundred years after Hippocrates, Galen of Pergamon, another Greek healer from Ionia, became the personal physician of the Roman philosopher-emperor Marcus Aurelius, and compiled the most extensive and influential medical and pharmacological texts which were translated first into Arabic and later into many European languages, preserving and transmitting the healthcare lessons from antiquity to the Islamic and Western civilizations [67]. Another key contribution to modern healthcare - the organization of hospitals - can trace its origins to the later Greek cultural sphere of the Byzantine Empire, where hospital institutions arose to charitably and altruistically help alleviate the suffering of patients during the many epidemics that had become a documented recurring and almost global scourge during medieval times [68] – still relevant as the COVID-19 pandemic continues to evolve today. As suggested by the title of a 2016 article [69] by distinguished colleagues who were the founding editors of the IMIA Yearbook of Medical Informatics - that John Mantas has contributed to so often and well - a renewed promise of medical informatics would be to mitigate such tragic threats to human life and health.

The contributions of Greek science, medicine and healthcare across the centuries emphasizes the distinguished practical cultural heritage that John Mantas has brought to his professional career in Biomedical and Health Informatics. His academic and professional leadership are reflected in John's many accomplishments and the responsible positions of societies and institutions that he has been entrusted with – as President of EFMI, Dean of the School of Health Sciences at the University of Athens, and Vice-Rector of the Cyprus University of Technology.

May he enjoy a healthy, relaxingly productive, and well-earned retirement!

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Achievements, Milestones and Challenges in Biomedical and Health Informatics
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Capacity Development to Leverage Advances in Health Informatics for All

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Abstract: In this essay we will discuss capacity development in health informatics research and application, which to us is among the major contributions of Professor John Mantas scholarship. Specifically, driven by the inspiration of his scholarship we will elaborate on advancing new applications areas, additional actors and geographical uptake of health informatics and eHealth solutions over time. We will illustrate capacity development in health informatics and address challenges that systematically foster digital health literacy, engagement and empowerment, and building health informatics capacities regionally, in Europe and globally.

Keywords: Capacity building; curriculum; accreditation; nursing informatics

1. Introduction

Using opportunities to commemorate contributions that matters to over time shape the field of Biomedical and Health Informatics is important to learn, celebrate and point out important priority areas going forward. The opportunity to give a tribute to Professor John Mantas and his scholarship under the heading "Achievements, Milestones, and Challenges in Biomedical and Health Informatics" is an excellent and much welcomed opportunity for us to do so.

Over time, as we have become active researchers ourselves in the field of health informatics, we greatly appreciate insights, projects and outcomes of activities under the leadership by Professor John Mantas and his extensive network. We see an unfolding trajectory of activities, always seeking to systematically grow capacity that ensure meaningful use health informatics research and development outputs, in particular to expand and develop educational offerings and health services. In this essay we will select examples that we find important to exemplify capacity development that address challenges and contribute solutions that leverage the achievements in health informatics for all. We draw from selected, significant examples of capacity development activities that matter for many constituencies, and these are initiatives which Professor John Mantas has initiated, contributed to shaping or inspired. It is not an exhaustive or comprehensive account but reflects our observations and reflections on the impact to grow the field over time. We seek to give special emphasis on importance of Professor

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Mantas initiatives that has developed and matured nursing informatics within the larger picture of Biomedical and Health informatics. These initiatives have indeed contributed to strengthen nurses' capacities to leverage eHealth solutions in ongoing health care transformations. These efforts are now inspiring inclusion of all actors, and we are especially excited about the recent efforts to support additional, traditionally underserved constituencies, in particular patients and their support network.

2. A trajectory of activities leading to capacity development for all

2.1. Capacity Building: planting the seeds

At the center of all capacity building is the people, creating opportunities for people to learn and comprehend is important for appraisal and uptake of any idea. For Biomedical and Health informatics, peoples' opportunities to develop competencies to explore, exploit, critically appraise and go forward with new insights are key drivers for responsible innovations and digital transformation. In Europe, led by Professor John Mantas and his team, Greece has paved the way, being early to provide undergraduate informatics courses to nursing students (since early 1980's) and advanced education in Health Informatics for health professionals, (since 1989) at the Faculty of Nursing of the National and Kapodistrian University of Athens (NKUA) [1]. These educational activities have started in nursing with a clear interdisciplinary perspective and outreach. It was therefore the term "Health Informatics" was used in the official name of the courses, for the first time in the 1990s (2). This change reflects developments that are significant for signaling that design and development of digital tools and services to be used in health care are not only to support medical doctors and their clinical information management, but usable eHealth tools are required by all health professionals. Another important fact is that the MSc program was also an Erasmus Inter-University Cooperation Program funded by the European Commission for 10 years. The program was coordinated by Professor Mantas and the NKUA [2], and enabled exchange of professors and students from more than 20 European Universities during the operative period. This MS Program developed to a national inter-university program that inherited the quality and expanded the strong interdisciplinary character of the study program, for the teaching faculty, the students, and graduates. The undergraduate courses and master program in health informatics at the NKUA are still offered after more than 30 years. Over those years, nurses joined the labor market well-equipped with the necessary health informatics skills and competencies. Furthermore, graduates from the master program in health informatics are prepared to take on and fulfill leading roles in the field.

The Faculty of Nursing of the NKUA has been the first to provide nursing education at university level in Greece since 1980. After that, other universities created nursing schools, and recent mergers in higher education led to even more nursing programs at university levels. Informatics topics and health informatics courses are now well incorporated in the curriculum of the nursing programs in Greece. Professor Mantas initiatives to introduce health informatics in nursing education already in the 1980´s might have played an important role. Furthermore, he played an important role in restructuring nursing higher education in Cyprus. Health Informatics and Nursing Informatics are taught in the undergraduate and postgraduate programs of Cyprian universities. This is in clear contrast to other countries that were late to introduce informatics in undergraduate nursing education, for example in Norway digital skills and health informatics is included in the national curriculum guidelines in 2019 [3].

Capacity development is not only formal requirements to curriculum and structure of education programs. With new tools, offering hands-on experience is important, and this is another important aspect of Professor Mantas contribution to capacity development. With a wide variety of teaching, research and networking activities organized by the Health Informatics Laboratory that he established at the NKUA, there have been plenty of opportunities for hands-on experiences and skills acquisition. Several EU-funded projects, in which the laboratory was a partner, gave the opportunity to many students to harness skills and for young researchers to gain valuable experience from working in EU projects, collaborating with partners all over Europe. With his collaborators came the opportunity to participate in many international events, thanks to his wide network and his involvement in the European Federation of Medical Informatics (EFMI). EFMI is the leading federation for health informatics professionals in Europe (www.efmi.org). All these experiences are highly valued by and in the international job market, as many NKUA graduates and his collaborators have had the opportunity to continue their career inside Greece, in Europe and internationally.

More recently, the PH-ELIM Erasmus+ project, lead from Montenegro is an example of further regional uptake of capacity building efforts, where focus on health informatics seeking to support public health with educational activities and services for health information management, sharing well-known EU best practices to ensure progress and sustainable development [4]. PH-ELIM has contributed tangible results that will help foster a sustainable public health community at national level in Montenegro, with necessary capacity to embrace the digital transformation in health care and civil society at large [5]. Working with faculty and giving them and their higher education institutions visibility, will create awareness and make efforts to meet the highest global standards, as a key prerequisite for building cooperation within the public health community and incorporate health informatics topics in all healthcare education.

To overview and drive for harmony of the Biomedical and Health informatics offerings, the AC^2 (Accreditation, Certification Committee) has been set up by EFMI under leadership of Professor Mantas. AC^2 collected and systematized information about health informatics educational offerings across Europe, and more than 500 universities and colleges in Europe were checked for educational programs in health informatics at all academic levels. The outcome of the research includes review of 316 study programs at undergraduate and postgraduate level including a variety of specializations [6]. To prepare health professionals the higher education programs in biomedical informatics and health informatics are continuously developing, and accreditation can help ensure quality, harmonize programs and support mobility. Therefore, AC^2 oversees a system with updated guidelines, and process for voluntarily accreditation of the educational offerings [6]. This will help the community of health professionals to become well prepared to respond successfully to the challenges in design, deployment and use of the digital solutions driving the transformation of the healthcare systems and their jobs.

2.2. Broadening user-constituencies in Biomedical and Health Informatics

Bringing digital opportunities to develop literacy, build proficiency and broadening capabilities in professional constituencies makes health care a complex, interdisciplinary activity is necessary for progress. Ensuring eHealth solutions that support decision – making, coordination of care and information to monitor treatment processes to support all members of the interdisciplinary team is important for success. Professor Mantas have led important efforts to prepare the community with knowledge to take advantage of digital tools and services leading to transformation of health care services. This is contributions that over time have paved the way for us.

Early on, NIGHTINGALE [7] was a pioneer project in its goal to boost training in health informatics and digital health for nursing in Europe. The project set out to specifically educate and train nurses in a harmonious way across Europe, to be prepared for issues of concern in the upcoming field of nursing informatics and build capacity to use information systems in coordination with other health sector training initiatives [8]. Supported by the expertise of professional nursing users' group the project developed a curriculum and accompanying courseware material using multimedia technologies, appropriate software packages, books, and traditional teaching material as common training resources basis for the corresponding courses.

TELENURSE [9] is another early project, that set out to promote formalizing data entry and systematizing health information recorded by nurses. The project sought to drive the development and use of an International Classification for Nursing Practice (ICNP) and a clinical nursing minimum data set (NMDS) in Electronic Health Records (EHR). One of the discussions and concerns in TELENURSE was availability of and access to health information from different professional perspectives and future opportunities to combine such information in the care processes, and report on quality and patient's health outcomes [10]. Grappling with increasing requirements for formalization and standardization, outputs of efforts as initiated in the TELENURSE project, could counter the lack of uniform and comparative descriptive data about hospital nursing, their contributions to patient outcomes and its cost-effectiveness in Europe. Sharing information is important, and suitability of standardized terminologies, like ICNP that was the focus of this project, are still being investigated and evolving. Progress is underway, demonstrating the need for co-creation and collaboration. Insights into the representation of clinical processes and capacities of actors to present cross-disciplinary perspectives, continues as an important discussion to ensure continuity of care processes, including the nursing care contribution across health system levels to ensure safe quality care and cost effectiveness.

The H2020 funded project CrowdHealth**;** "Collective wisdom driving public health policies" is an example of evolving efforts to build momentum and bring out the full potential of health informatics and the ongoing digital transformation of health care [11]. Working with partners around the Mediterranean, CrowdHealth sought introducing the paradigm of Holistic Health Records (HHRs) that include all health determinants, demographics, diseases, lifestyle choices, nutrition, activity etc., in health systems in South Europe and North Africa. The novelty of HHR would contribute to stimulating robust communities where the clinical, social and human perspectives would constitute collective knowledge for these different factors pertaining to a population segment. Here is another contribution that demonstrates how to engage, create co-creation opportunities and make progress towards a "health in all policies" approach.

As demonstrated by Professor Mantas scholarship, necessary multi-disciplinary health informatics competencies are vital capacity for continuity, collaboration and information sharing between healthcare providers and their patients. As the ultimate beneficiary of health services, citizens; as patients and/or family caregivers, are the least supported and systematically "utilized" resource in contemporary health care. The challenges for timely information access, and active use of accumulated personal health information from multiple sources requires digital health literacy capacity to comprehend and use the information [12]. Similar to early efforts to support all health professionals, as initiated by Professor Mantas, offering new, novel functionality, access to information and knowledge and digital health literacy comes with tremendous potential to empower citizens in everyday health choices that accelerate health transformation and personalize care across Europe and internationally.

2.3. The multiplier effect

The impact of Professor Mantas work goes beyond the activities that he participated personally. Through his role as a teacher and supervisor for students and PhD candidates and as mentor for colleagues he has actively passed on his knowledge and ideas to others. This continue his mission in Greece but also in several other countries, and here is a clear multiplier effect of his scholarship. Health informatics, as taught and debated at the Faculty of Nursing of the National and Kapodistrian University of Athens, have been successful in preparing health informatics professionals to understand these sensitive and complex topics. Those benefiting from and inspired by Professor Mantas can continue to make a difference for their students and colleagues, creating a multiplier or snowball effect that has the potential to develop health informatics and transform health care. In this section we mention some of these activities, and although Professor Mantas has not been directly involved, they are certainly in line with his teachings and builds from his initiatives.

The potential of eHealth to empower citizens as taught and advocated by Professor Mantas, has been explored by several research projects. The eRehab project in Northern Norway (2010-2014, funded by Northern Norway Regional Health Authority) aimed in supporting the self-management of cardiovascular disease patients after cardiac rehabilitation [13]. The eRehab intervention had the ambition to be a tool for citizens for assisting them to maintain their level of physical activity after a cardiac rehabilitation stay. The project addressed the dilemma of who knows best what the citizens need from eHealth: the citizens, health professionals or technologists [14]. eHealth solution for this project was not implemented as a tool, not even for other health professionals.

The EU-funded project BETTEReHEALTH (Horizon 2020) aims to increase international cooperation in eHealth, strengthen end-user communities and policy makers in making decisions for the successful implementation of eHealth and digital solutions in Africa [15]. As it has been crucial for health professionals in Greece and Europe to be educated in Health Informatics, the project is also promoting the capacity building initiatives targeting health professionals and IT developers in Health Informatics, to give them the tools, but also the empowerment they need to lead the development of effective eHealth solutions. Professor Mantas career is also legacy for international cooperation and networking. In a similar manner, BETTEReHEALTH has strengthen the cooperation between several African and European countries and has established four Regional Hubs in the respective regions of Africa to disseminate eHealth knowledge in host country and countries around. Finally, the BETTEReHEALTH project, following the example of earlier successful EU projects, is collaborating with policy-makers in the participating African countries to promote eHealth at policy level. Involving policy-makers has the potential to improve uptake of eHealth at large scale, as effective eHealth policies and transformation strategies can unlock the unharnessed potential of eHealth both in developing and developed countries.

Gravitate-Health Public-Private Partnership is another on-going project that seek to bring innovative digital health information tools for person-centred healthcare, in efforts to engage and empower users with digital information tools, specifically safer use of medicines for better health outcomes and quality of life [16]. Gravitate-Health's digital tools with focusing mechanisms offer easy access to health information from trusted sources and ensure good understanding of this information mindful of context, user capabilities and therapy. This is important for everyday health related self-management and open opportunities for active use of personal health information [17].

3. Significance of contributions

Professor Mantas has been teaching Health Informatics at a Nursing department, educating nurses and other health informatics professionals. We envision that this environment, in the spirit of the ancient academic tradition of Athens, inspired the dialectics between nursing theories and theories of informatics that led to the flourishing of the field of health informatics. Interprofessional capacity building, as demonstrated over the trajectory of Professor John Mantas' scholarship, particularly efforts to develop programs and prepare all health professionals for the opportunities to prepare for and influence the health informatics driving health systems evolution and digital transformation. Curriculum development and accreditation of programs as well as post-graduate education and professional development has over time built digital literacy and digital health literacy. Investing in the people and seeking to strengthen capacity is at the core for advancement in eHealth and sustainable health care transformation [12]. Over time, health professionals, patients and their support network can now take advantage of eHealth regionally, in Europe and globally.

Capacity development following the initiatives by Professor Mantas work goes beyond the careers of his collaborators and students. By passing the torch of his engagement and dedication to his field on his collaborators and students, they are in position to develop capacity among their collaborators and students. This snowball effect has the potential to continue for generations, and lead to further advancements in health informatics and as a result in health care in general.

4. Conclusions and congratulations

Our view, as presented here, is that initiatives which Professor Mantas spearheaded and led has been very important to successfully prepare generation of nurses, other health professionals and health informaticians for collaboration to develop the dynamically evolving field of Biomedical and Health Informatics. Furthermore, Professor Mantas has been working from within at a Nursing Faculty, many initiated activities stemmed from needs and opportunities observed there. This has been an important multiplier for the role of nurses in health informatics. We believe this as a driver for interdisciplinary approaches, making sure there is support for the full health care team including patients and their support network, emphasizing coordination and collaboration in addition to health care decision making. Continuing to expand the application areas and introducing knowledge and new services to professionals, patients and their support network will be important to continue to build capacity in Biomedical and health informatics and to reap benefit of ongoing health care transformations for all.

Congratulations to Professor Mantas and your team and thank you for the important imprint your scholarship has made for biomedical and health informatics to ensure capacity development for all.

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Informatics Opportunities and Challenges in Medical Imaging: A Journey

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Abstract. The role of the field of informatics in medical imaging is vital; novel or adapted informatics' core methods can be employed to realise innovative information processing and engineering of medical images. As such, imaging informatics can assist in the interpretation of image-based, clinically recorded evidence. This, in turn, leads to the generation of associated actionable knowledge to achieve precision medicine practice. The discipline of informatics has the power to transform data to useful clinical information patterns of observable evidence and, subsequently to generate actionable knowledge in terms of diagnosis, prognosis, and disease management. This paper presents the author's personal viewpoint and distinct contributions to innovations in the acquisition and collection of imaging data; storage, retrieval, and management of imaging information objects; quantitative analysis, classification, and dissemination of imaging observable evidence.

Keywords. Medical imaging, quantitative imaging informatics, image quality assurance, image exchange and interoperability

1. Introduction

Medical Imaging is a key and invaluable component of modern clinical medicine in the study of human health and disease. Imaging procedures, often being non-invasive and with limited side effects, generate rich data in terms of structural, compositional, and functional information of the human body [1], thus supporting the characterization and management of disease for an individual patient. The role of the field of informatics in medical imaging is pivotal; novel or adapted informatics' core methods can be employed to realise innovative information processing and engineering of medical images. As such, imaging informatics can assist in the interpretation of image-based, clinically recorded evidence and, consequently, generate associated actionable knowledge to achieve precision medicine practice [2].

The sub-discipline of medical imaging informatics presents, over the past three decades, a rapidly growing scientific endeavour within the field of biomedical and imaging informatics [3, 4], with many achievements and innovations. This paper discusses some of the important opportunities and challenges for the application of informatics in medical imaging, during this period. The author is presenting his personal

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viewpoint and distinct contributions to innovations, achieved throughout this journey of progress in the medical imaging informatics field.

2. From Data to Actionable Knowledge - the role of medical imaging informatics

As early as the 1960s, the concept of automating the analysis of medical images, with the use of computers, was identified as a potential innovation to be explored by the community of clinical radiologists and associated scientists [5]. In 1959, during the Memorial Fund lecture of the forty-fifth annual meeting of the Radiological Society of North America, Lee B. Lusted (a radiologist and associate professor at the University of Rochester, at the time) elaborated on the potential of "electronic computers" in the analysis of radiographic images, by using "an electronic 'scanner-computer' to look at chest photofluorograms and to separate the clearly normal chest films from the abnormal chest films" [6]. This pioneering proposition recognizes that, bringing together medical imaging and informatics has been key, in the early reasoning of scientists and clinicians, on how to harness imaging information and use of computers into achieving medical diagnosis, and in extent making clinical decisions [7].

Modern imaging modalities can generate substantial amounts of data, rich on clinical information. The discipline of informatics has the power to transform data to useful clinical information patterns of observable evidence (imaging phenotypes) and, subsequently, to generate actionable knowledge in terms of diagnosis, prognosis, and disease management, thus achieving the current precision medicine goals [8, 9]. In this journey, from data to actionable knowledge, the discipline of informatics plays a vital role in the acquisition and collection of imaging data; storage, retrieval, and management of imaging information objects; quantitative analysis, classification, and dissemination of imaging observable evidence. In the following sections of this paper, we will discuss these topics in terms of challenges and opportunities from the author's personal perspective, as these themes developed over the past 30 years.

3. Capturing Imaging Observable Evidence

An information representation of the structure, composition and functioning of the human body, through imaging, requires the use of appropriate medical imaging modalities and associated protocols for the acquisition and collection of relevant data. To achieve this, the role of informatics has been complementary to that of medical imaging science. To harness the full utility of imaging data, imaging informatics provided, over the years, core quantitative and information management tools to capture, extract, organise and curate effective information from such data [10].

3.1. Imaging Protocols: capturing imaging information

At an early stage, the community has recognised that, the standardisation of imaging protocols is an essential component of digitally based image data collection during routine clinical patient assessment and of imaging-based clinical research [1]. Imaging protocols need to consider the subsequent analysis requirements of image data points, through informatics tools, and aim to normalise varying imaging capabilities without compromising image quality. Protocol standardisation includes acquisition parameters (e.g., MR-pulse sequences, patient positioning, image reconstruction algorithm used, etc.) and quality assurance & control procedures (e.g., signal-to-noise acceptable levels, scanner calibration approaches, artifact reduction, etc. – discussed in the next subsection).

The author has contributed to the challenge of protocol standardisation, as part of his long-standing research programme on functional imaging-based characterisation of childhood brain tumours [11], together with his national and international collaborators. Standardisation of MR imaging acquisition is critical in enabling multicentre clinical research studies, related to childhood central nervous system tumours. Ensuring the adoption of a common imaging protocol facilitates the harmonisation of useful data collection (while preserving image quality). The availability of quality image data, collected by multiple clinical centres with varying imaging capabilities, is critical in clinical trial analysis work for CNS tumours. The European Society for Paediatric Oncology (SIOPE) Brain Tumour Imaging Working Group (in which the author has been a member of) has established such an imaging protocol. The Working Group has derived this protocol as a consensus, based on past clinical research experience/practice and research evidence (some of which will be discussed in the subsequent sections of this paper) from earlier clinical research studies [12, 13]. The protocol has provided recommendations to advanced imaging methods, including functional imaging approaches of MR spectroscopy (MRS), diffusion tensor imaging (DTI) and perfusion imaging. Various elements of the author's and his collaborators' work on MRS [14-19], DTI [20] and perfusion imaging [21], and the value of these approaches on childhood brain tumour imaging, has been instrumental in the accumulation of this evidence. Protocol consensus brings the opportunity of its application to specific clinical trials and studies; in the case of the aforementioned protocol, this includes the SIOPE Ependymoma II clinical study [22] and the SIOPE PNET V Medulloblastoma clinical programme [23].

3.2. Image quality assurance: the role of informatics

Dealing with imaging artifacts and applying imaging quality assurance & control, to ensure appropriate and acceptable image quality for reproducible imaging data, has also been an important challenge over the years (e.g., [24-26]). Informatics and analysis methods play a significant role in the management of this challenge. The author's beginnings, in the field of medical imaging and informatics, included his PhD work. In the early 1990's, the author's research focused on the understanding of the challenge of imaging artefacts in Magnetic Resonance Imaging and Spectroscopy. The author's thesis focused on the study of a particular example of motion related MR artifacts, the respiratory motion artifacts. With the aid of theoretical and simulation work, the source and appearance of these artifacts were carefully studied. This knowledge was used for the application of an informatics-based time-series analysis method (Lomb-Scargle periodogram), as an approach in the study of MR artifactual imaging data; thus, contributing to further opportunities for research in this area [27].

3.3. Curating Data and Imaging Evidence

The curation and management of the vast amounts of imaging data are essential functions, provided by medical informatics solutions. In clinical practice, the development of commercial Picture Archiving and Communication Systems (PACS) focused on providing "economical storage, rapid retrieval of images, access to images acquired with multiple modalities, and simultaneous access at multiple [imaging] sites" [28]. PACS have brought opportunities for efficient management and exchange of digital imaging information as part of the clinical workflow. In section 6, a more detailed account of the informatics' challenges for PACS and associate standards, in terms of interoperability and image presentation, is given. Here, we address the challenge of developing curated data repositories, which can support the research imaging informatics community, in the development of innovations that relate to methodologies, models and tools.

Indeed, incorporating novel imaging techniques into clinical research studies and trials presents specific challenges due to the lack of standardisation in data collection, quality control and analysis. In addition, there is an ever-increasing need for expert analysis of novel imaging data, which may only be available at a remote location. The establishment of secure, internet-accessible research data repositories can provide a solution to the above-mentioned needs. The author and his national collaborators, as part of a Cancer Research UK – Engineering and Physical Sciences Research Council (CRUK-EPSRC) funded programme grant (2008-2013), and as part of the Children's Cancer and Leukaemia Group Functional Imaging Group in the UK, have developed an e-Repository of functional imaging data, to be used in clinical trials for children with brain tumours [29]. The e-Repository, which consists of a remote data entry system and associated database, seamlessly incorporates both clinical and functional imaging datasets in the context of multi-centre studies for childhood brain tumours. The data entry system (available at https://rde.cclgfig.bham.ac.uk/) is accessible through a secure shell connection on a web browser, allowing role-based access control for the addition, editing, and reviewing of data by principal investigators, study coordinators, data managers, and researchers, through remote access. Clinical and laboratory data, as well as conventional and functional imaging data are contained within the database. The current number of cases amount to more than 1500 cases from around 10 clinical centres, covering about three quarters of the UK population. Furthermore, all data are made available for both central and remote processing. The e-Repository also provides integrated automated data processing software tools. The overall design of the e-Repository has been made to be modular and expandable, to accommodate opportunity for future growth of imaging-based research in childhood brain tumours and other types of image-based clinical trial work [30].

4. Image Segmentation: an informatics challenge

A long-standing challenge of imaging informatics has been the accurate delineation of an imaging region of interest (ROI), as part of the process of characterizing health status and disease [1]. ROIs enable imaging specialists to focus on the extraction of relevant image features (qualitative and quantitative) that outline structural and functional human body components, to be used as part to the analysis that supports our understanding towards diagnosis, prognosis, and response to treatment for an individual patient. Image segmentation methods (semi-automatic or automatics), and their associated challenges, have been studied extensively over the past 30 years [31].

The author and his co-workers, as part of their work on brain tumours [11], have contributed to advance the community's understanding for this challenge. Image segmentation is a critical step in the analysis and subsequent diagnostic/prognostic characterisation of brain tumours, using MR-based functional imaging approaches. The team has conducted a systematic review of 572 brain tumour segmentation studies, as reported during the period 2015–2020 [32]. The review assessed "physics or mathematics-based methods, deep learning methods, and software-based or semi-automatic methods, as applied to magnetic resonance imaging techniques" [32], including T1-weighted, T2-weighted, gadolinium-enhanced T1-weighted, fluid-attenuated inversion recovery, diffusion-weighted and perfusion-weighted MR imaging. The performance of each segmentation method was assessed through its median Dice score (initially proposed as image segmentation performance metric by Zijdenbos et al. [33]). The work found that the U-Net deep learning segmentation approach was cited the most and has reported high accuracy (Dice score 0.9), making U-Net a promising brain tumour segmentation on magnetic resonance images. Though substantial progress has been made for this challenge by the imaging informatics community, there remains an opportunity, in the future, to expand our knowledge in this area. The author and his team are currently continuing in the pursue of this quest.

5. Informatics Methods and Quantitative Imaging

As it was already argued, state-of-the-art imaging technology processes and the large-scale, novel, computational analysis of data sets, including the use of machine learning and artificial intelligence, are improving our understanding of human health function and disease. This, in turn, is creating a powerful driver to achieve precision medicine through quantitative imaging informatics. Computational quantitative analysis provides opportunities in aiding diagnosis, deriving diagnostic imaging biomarkers, providing prognostic biomarkers, aiding surgical decision-making and therapy planning, while offering clinicians with early indications of response to therapy [2, 34]. Although, many researchers and imaging specialists have worked, over the years, with different imaging technologies and have, most recently, successfully applied quantitative imaging informatics for different areas of disease, in this section, the author presents his own journey with quantitative imaging informatics.

The high-throughput identification, extraction, and analysis of quantitative functional imaging features, as well as the use of radiomics for the diagnostic and prognostic characterization of paediatric brain tumours, have been the main emphasis of the research work of the author and his co-workers. Clinical improvements have been made in diagnosis, management and predicting survivability, which deliver benefits directly to patients, healthcare providers, and the health service [16, 35].

While survival rates have steadily improved for childhood brain tumours, with approximately 75% of patients now living beyond five years [36], accurately predicting how the disease will progress in individual patients has remained a challenge. Over the past 15 years, the author's research attention has centred into developing quantitative imaging informatics methods in childhood brain tumours. This approach allows the investigation of tissue properties and the tumour's microenvironment, in a non-invasive manner, with the aim of answering clinical questions more directly, than can be achieved using conventional structural imaging. Noteworthy progress has been made in developing, implementing, and evaluating advanced MR-based functional imaging and associated computational quantitative analysis, leading to major advances in the field of quantitative imaging informatics. These include:

- Automated quantitation of metabolites [37, 38]; and discovering novel biomarkers [39, 40];
- Informatics-driven, quantitative textural analysis and radiomics [41-44];
- Advanced machine learning in multi-parametric functional imaging [45-48];
- Clinical verification and experimental validation of novel biomarkers [49];
- Development of imaging-based, clinical decision support tools [50, 51].

In particular, the emerging sub-field of radiomics, where the personal contributions of the author are recent, provides a solution for non-invasive tumour characterization, by converting medical images into mineable data, through the extraction of quantitative imaging features. When developing quantitative medical image analysis techniques, it is usual to consider attributes (e.g., intensity, morphology and texture) that radiologists explicitly or implicitly use in their assessment of a specified tissue appearance. Image texture can be defined as the spatial variation of pixel intensities within an image and is sensitive for the assessment of pathology. Visual assessment of texture is, however, particularly subjective. Additionally, it is known that human observers possess limited sensitivity to textural patterns, whereas computational texture analysis (TA) techniques can be significantly more sensitive to changes. Therefore, the radiomics area presents a new and exciting opportunity for the field of medical imaging informatics, with a lot of promise for achieving the objectives of precision medicine [52].

6. Image Interoperability and Presentation

The use of standards for image information exchange and interoperability has been central to the increased use of information systems for medical imaging. In particular, the increased use of Picture Archiving and Communication Systems (PACS), one of the most important informatics innovations in medical imaging, has been vital in the management and exchange of digital image information for clinical purposes. As early as 1981, during the first international meeting on PACS, it was recognized that internationally agreed digital image exchange standards would be essential for the successful development and deployment of imaging information systems [53]. In 1982, the American College of Radiology (ACR) and the National Electrical Manufacturers Association (NEMA) initiated a standardization effort on digital image exchange and communication, resulting in DICOM (Digital Imaging and Communications in Medicine) standard [54]. DICOM has enabled ubiquitous interoperability and connectivity of imaging equipment and PACS, over standard communication networks.

To develop such efficient, standardized PACS, it is important to appreciate the challenge of understanding the intricacies of clinically feasible network topologies and associated information system architectures. This challenge has been studied by many in the 1990s and beyond [55-58]. In the context of this challenge, and within the perspective of DICOM interoperability in PACS, the author and his team have investigated modelling and realistic simulation methodologies, to model a range of scenarios of DICOM session and application layer implementations over various network communication protocols [59, 60]. The work has demonstrated the importance in recognizing both the relevant clinical and technology requirements for a cost-effective the planning and deployment of PACS and associated imaging information systems.

In addition to the standardization of effective communication of raw imaging data over networks, DICOM has also evolved to facilitate appropriate image display/presentation for interpretation and reporting, within the context of distributed radiological/clinical work. Appropriate presentation of image and related data can support clinicians to consistently visualize imaging findings and effectively communicate, between themselves, any manipulation and analysis of imaging data for clinical purposes. The DICOM Structured Reporting (SR) has provided a robust clinical documentation methodology to capture and display specific image and associated clinical data elements, in an interoperable format [61]. The DICOM SR can, therefore, relate imaging information to other clinical information, such as data from Electronic Healthcare Records and/or specialist Clinical Information Systems. The harmonization efforts [62] with other health informatics standards (e.g., HL7, FIHR) makes DICOM structured reporting a powerful informatics tool that provides consistency, scalable data capture, semantic interoperability, and robust information sharing between healthcare professionals [63].

The informatics community efforts to achieve such a ubiquitous information sharing of imaging data, included early challenges on display and presentation standardisation. In this journey, research has been focusing into developing uniform ways to specify the layout and image presentation parameters for imaging informatics. The author and his collaborators have originally looked at the development of a meta language, called Interscreen, to allow the recording of all information needed to reproduce a previously captured image representation/display on any PACS and associated device, while retaining the user's freedom to interact with the imaging data [64]. Inspired by the early DICOM SR work, and as part of the European Committee of Standardization (CEN/TC251 "Health Informatics" Technical Committee - Project Team 34), they have worked on the design and specification of Health Care Multimedia Reports [65] and have provided early implementation options for supporting the specification of presentation of electronic patient record content, including imaging data [66]. This work has offered opportunities for further developments of the DICOM SR standardisation effort.

Furthermore, the challenge of "economical" digital storage of images has also been an area of research and technology advancement for the imaging informatics community. Over the years, low-cost and high-capacity storage has been available to imaging facilities. However, image compression has been identified as a necessary technology for imaging, due to imaging data requiring substantial amounts of storage [67]. This, in addition to challenge of efficient transmission of large imaging datasets, has brought forward the necessity for investigating robust medical image compression algorithms (including both lossy and lossless image compression approaches) and their comprehensive evaluation [68]. The author's early work, in this area, has investigated different thresholding and quantization strategies for digital angiography image compression and, with co-workers, have developed a perceptual quality assessment method to assess any visible/invisible differences between original and compressed digital angiogram images. In particular, the work derived a multistage perceptual quality assessment (MPQA) model for compressed digital angiography images [68]. The research concluded that this model had better agreement on what is deemed to be a diagnostically acceptable lossy image reconstruction (by human experts) compared to objective error measurement methods; thus, contributing a useful addition to evaluation methods for assessing image quality reconstructed by different compression technologies, and opening new opportunities for further research on this challenge.

7. Concluding Remarks

In early 2015, the author was interviewed by the BQ Magazine (the UK's West Midlands leading business to business publication), reaching almost 24 000 readers [70]. He highlighted the power of imaging informatics and, more specifically, how informatics accurately diagnose and support the treatment of childhood brain tumours. The core innovation of the author's past and current work, in the field of imaging informatics, effectively supports the conversion of images from standard medical scans into data that can be mined and processed to identify useful characteristics, patterns, and disease markers, including for example MRI image texture. Gathering this data into one place (curated data repositories) and running it through complex software, incorporating computational and machine learning techniques, is aiding disease diagnosis (e.g., childhood brain tumours), and is providing more accurate prediction of disease progression, responsivity to treatments, patients' survival, and quality of life. This not only greatly improves the potential to advance clinical management of patients for successful therapy and cure, but supports more informed discussions between medical staff, patients, and their family on how to manage the challenges of the disease. Consequently, "imaging informatics" is emerging as a powerful 'weapon' in the arsenal of biomedical and health informatics technologies, for us to win the battle against disease.

This has been an amazing journey…and it continues, into the future!

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Indigenous Scientist: Digital & Health Science Transformation

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Abstract. As an indigenous scientist, I have dedicated all my professional life to protecting people using informatics for public policy to the privacy of users, patients, clients, and citizens as a human right and obligation as part of the United Nations international development goals. I am reflecting on my earliest knowledge of the impact of data and information privacy on my journey as scientist. I was just a number out of many other numbers as a indigenous child. The aim of this paper is to share my own personal experience together with one of my students. Now working with data as a scientific task within the data modeling to measure poverty. As a datum with human value, I was a 1) Female child with young parents,2) Low socioeconomic status & 3) Identified as an indigenous person within a minor language group. These three data descriptions described me as a person who needed protection of my human dignity and identity as a child, based on all the protocols of social services for providing help. In conclusion, as scientists, we need to remember when using client data in vulnerable contexts and protection of their privacy, due to the potential risk of active discrimination. Thanks to my extensive education in Australia, I became an outlying datum that deviated from the data modeling applied to me. Today, I work for Privacy digital standards to impact real life with respect to human dignity and obtain accurate scientific interpretations of human beings' realities.

Keywords. data, science, digital interpretation, life & impact

1. Introduction

I'm a grown woman dedicated to researching the power of data for healthcare improvement within the justice system in Australia and around the world. Nowadays, I am writing these lines while sitting peacefully in my beautiful regional home in Geelong. While I reflect on my current reality and all the blessings I am living with my current professional life as a leader in legal services using data governance principles for protecting human dignity, I cannot believe all the growth I reached by educating myself at every chance I had in Chile, Latin America and Australia.

Some key data from my education journey include i) during my infancy I traveled through several public schools while moving homes several times with my family, with poor academic performance, ii) during my teenage years, I was bullied for being different and dressed poorly with the expectation of the educational uniforms, iii) I performed the

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entry national exam for entering to the local university at my eighteen years, obtaining an extremely low mark, from the 850 I got below the average mark, only reaching 381 marks.

In contrast, the data from my educational journey at the international level is very different, especially considering how I arrived in this world: a girl with indigenous blood. My origin is very extraordinary and particular; I was born as a human being with three very marked social characteristics: i) born a girl, ii) poor and iii) indigenous far south of the world, in an underdeveloped country called Chile [1],[2].

Data for my adult life was very amazing when I arrived in Australia in 1991, a migrant who could not speak English and had poor management skills for embracing new paradigms for an indigenous woman without an identifiable local community. Just remembering my own parents who were teenagers who formed a family without any social or community support: gives me the strength to try my best in this new educational adventure in a land far away called folklore Down Under.

Let's share my own journey of witnessing real-life impact using my own data for my own human awareness and development. This area of interest is well researched for decades within health informatics as a discipline for the implications of using data, information, knowledge, decision, and actions in real life. Firstly, the implication of being a girl in Science is explored in the section on the science of living. Secondly, daydreaming as a way to understand the world is shared with possible wishes as a teenager. Thirdly, the science of pain in life explores the challenges where my life was hard without proper healthcare services within a vulnerable community as indigenous woman. Finally, I reflect on the transformation based on Digital and Healthcare Informatics and share thoughts for future generations.

2. The science of living

There is not a book to teach us how to protect our lives in this digital world, however, despite all the hard experiences in life during my time as a future scientist: education is the power that has transformed my own destiny in health informatics. With each concept, research project, new investigation, and several digital innovations for human dignity I embrace them in my own life for the last 30 years. My learning process started with the wisdom of extreme challenges in the family I was born in. For my first two decades of life, I was hugely a datum for society in general, then when I arrived in Australia as a migrant in 1991, I discovered the possibility to enter university as a new mother and wife. As a mature aged student, I embraced my first bachelor of Nursing with an emphasis in psychiatry, to then being selected to do an Honours degree to conduct research in Quality and Safety for healthcare management. I always worked in clinical services at public hospitals in Melbourne and regional services, since I lived on a farm with my young family. Once I completed my first research project in the local innovation centre for a new hospital, I started to enjoy the science of caring for healthcare delivery using the electronic health record at the time. I was invited to join three research teams to do my Ph.D. with a full scholarship. I truly embrace research and teaching at University part-time since I was committed to providing patient care by doing night shifts. Reflecting back, I did shift work for twenty years in order to gain a good education, while completing my doctorate program and then my post-doctoral for patient safety using artificial intelligence.

In my personal memories, during my early days as a future scientist, I do not clearly remember having close friends from my birthplace, where I lived with my parents. I also don't remember very well the physical place where I was born, since we moved many times with my family throughout the metropolitan region of my country of origin, Chile seeking a safe and healthy life. However, now I can see data describing the place where I came to this world with interactive maps online, and this region is still a place highly stigmatized by most of my compatriots and strangers to this part of the world [3].

This town is called “La Legua”. Its name comes from the old measurement of distance similar to what can be covered in a day, either on foot or on horseback. However, “La Legua”, my place of origin, is a poor neighborhood, with very challenging social issues, located almost exactly 5 kilometers from the center of Santiago, within the area of San Miguel. This is a very symbolic geographical place from a political perspective since vulnerable communities were established with a collective commitment to reach housing for their families. It emerged in the 1930s, with the arrival of dozens of working families of saltpeter miners in northern Chile and peasants from the south. My grandparents came from the north, and they came with their indigenous heritage to the capital, to this poor neighborhood, with our Aymara blood.

It is fair to remember Chilean history, during the 1970s, the capital of the metropolitan region used to have one million inhabitants, with a life expectancy at birth of 62 years, and a national poverty headcount ratio was over 70% (4). Nowadays, 50 years later, the population stands at nearly 10 million with some of the best income and life expectancy indicators in Latin America. In contrast, during my infancy, my family reality had all key social determinants shaping the impact of our growth as children: including being the middle daughter of teenage parents who unexpectedly became a family of 5. I can't even imagine how difficult it must have been to take care of us, in an underdeveloped country of the last century.

2.1. Girl in Science

The precision of living as a girl in science is very challenging within the developing environment in South America. Access to mathematical exercises, science and technology is rare for children within that given social context. Only 16% of my generation have university studies, indigenous women in Chile are historically underrepresented in the academic context without access to science or technology studies [5], to be honest, no one in my family ever talked about university. The urgency of our needs and narrow circumstances did not allow us the privilege of reflecting. My own dad reached third grade and my mum completed a certificate for sewing. Consequently, I knew when I had my two girls that they deserve to have access to the right education, and all the research I have done while I was pregnant with my first child, made me recognize the importance of data and quality information for human development [2]. More than twenty years ago, while doing my Ph.D. in health informatics at the number one university in Melbourne, Australia, my first daughter as a baby provided me with the commitment and passion to work toward mobile computing for patient safety [6]. Respecting the accessibility to healthcare was a real necessity for me since at the time, the father of my gorgeous baby was a patient that had the fortune of having a kidney transplant and provided us the opportunity to have our own family. Then I was awarded a scholarship to do my doctorate at the faculty of medicine and nursing as part of the collaboration between clinical placement at one of the largest public hospitals in the state of Victoria. Having access to science and knowledge allowed me not to take 180 years to get out of the material poverty in which I was born [7]. Today more efforts and opportunities must be generated so that every indigenous or non-indigenous girl and woman has the option of taking the path of science and technology with equity, non-discrimination, and self-determination.

3. The science of daydreaming

The next chapter of my life includes the power of daydreaming as a teenager and not much data available for the opportunities for my adult life within my original territory. Opportunities to engage with science or technology at school were totally absent at the time of entering my youth [8]. I used to be very proactive in my community. I learned to measure the kilometers to exercise. Despite all the hard work for my physical training at the local gym, I dedicated myself to being a missionary of the local church. At home, I always dreamed of having a celebration on my own terms with my friends from school: but that never happened. When I started to mature, I thought that just being alive was an existential blessing for every human being thanks to my instinct to help others. I have always considered myself a contemplative, of deep reflections, but I also, always as a woman felt in the wrong place at the wrong time. I couldn't share these ideas with others at that time, because of my surroundings. I did not know that these ideas were part of my passion and vision of life as an indigenous scientist.

There is only an opportunity to recognise the good times with my family. When I turned 14, my mum told me that I had the wonderful opportunity to finally have my own birthday celebration, with all my family and my friends: a dream comes true finally.

The occasion was made on the entrance patio of my humble home. This was built with recycled wood collected by my own parents. At that moment in my own history, I felt important and valued, maybe for the first time, it was when we sang the happy birthday song, but this time was dedicated to me. I couldn't help but feel the joy in my sore stomach, I was, for the first time, the center of attention for my loved ones. I was wearing a dress made just for me; its colors were soft and highlighted my brown skin (just like my grandfather: truly Aymara). I also remember how well dressed everyone was that day. My family even invited some of our friends, neighbors, and clients. I felt alive and loved by my family. I felt beautiful, like a rough diamond looking for an opportunity. I was a diamond in the rough waiting for the chance to show how beautiful I was. I can say this now, understanding that every girl or boy is a blessing, like what happened that day. I can't help but evoke my feelings at that time even now, as a mother. That amazing day was very special and full of hope for my life. Until now, I keep photos of that birthday that I currently share with my daughters and students seeking projects of digital innovation to help vulnerable communities.

The festive feeling from my family was lived with the most delicious cake I've ever tasted, and even one of my best friends was dressed up as Michael Jackson, to brighten up the evening. He was clean-shaven and ready to show off his best dance steps. It was a lot of fun and made me feel part of that community as I feel right now with my colleagues from the large academy of Health informaticians around the world. That day I felt for the first time that I was already a full-fledged woman. That local community also expected me to marry soon and have children as a social norm. I realized then, at that party, that my destiny was not there for me. That proposal looked like a shortsighted horizon for me for what, intimately, I believed could become my own possibility: felt a different instinct at the time.

This transformative birthday was an invitation to be me and to see my own values clearly. I started reading actively for the first time in my daily life. The only book I had within my reach was the Bible, thanks to a local church activity. It was a social worker and nun who played with the children in town and invited me to help others. We used to run around the soccer field that was near my house.

I recall this stage of my life as Courage. All social data about me and all the adverse events, and complex family challenges make me stronger. It is difficult to understand social circumstances that are not lived. My parents were beautiful teenagers who were good parents as they could, in a complex and dangerous place, I learned to be resilient and to understand love as the force that It allows us to believe and not let ourselves be destroyed by the environment. Especially now, I work with this type of young families in Australia, especially the priority groups for protecting their dignity using data governance principles, including indigenous data, family violence victims, child protection data, and criminal reinsertion into the community.

4. The science of pain

Several initiatives around the world show key data elements for the first thousand days of child development with the intention to predict the kind of human being that person becomes [9]. Reflection on my own infancy: poverty was part of this stage of life with several pain in the process. Firstly, I hate to wash dishes right now and I believe this is the trigger for the type of living conditions I had [10]. Doing the dishes is a constant trauma for me, peeling potatoes is another one, and having a bathroom inside my home.

Multiple influences of social data are based on the difficulties of our family living in areas without electricity and water. When I was a child, I was assigned to do the dishes at the local restaurant that my parents owned, and I was in charge of making sure the business kitchen was available for the clients [11]. You may be wondering why.

I grew up with a strong entrepreneurial family. My parents, who were teenagers, found themselves without a proper home and we as a family needed to survive anywhere with a roof over our heads. Washing the dishes was always a challenge for everyone and for some reason I always finished doing them in order to help.

Since I was a baby, I lived and was raised in a home without a toilet. I was 14 years old, the family was able to access a social housing place, where my parents decided to open a neighborhood bar. Therefore, I did not live with the expectation that my parents would go to work and eat dinner as is expected of a family.

The task that I had to perform every day as a teenager was to wash the dishes not only for my family but also for everything that was busy in the bar. Sometimes, I found myself washing dishes for hours on end. Many times I felt like a slave, so I was constantly looking for reasons to leave the house. I used to like to sell food on the street to have the opportunity to experience my own freedom. Until now, having my hands with liquid soap makes me cringe from the lack of control of my life: until now that scares me a lot.

To any girl or boy who goes through similar situations, who understands that he was born out of love. That it will not be easy, that you will have good and bad experiences, but that you can learn from each one of them. You will have scars, but those scars will also be a push to find your being and find what you are called to be, your destiny, your life [10] [12].

5. The transformation based on Digital & Healthcare informatics

The journey I am living as an indigenous scientist, allows me to work with millions of patients, users, and clients' data within vulnerable contexts. The process of making informed decisions allow me to delivery projects of big data for complex public services for vulnerable populations.

When I turned 35 years old, I was invited to be part of the United Nations team at the knowledge network at the World Bank. I truly never thought of working at a financial institution with over 188 members states, since all my professional life I have practiced health informatics principles within the health sector and academic environments. I was a clinical teacher while doing research at health smart initiatives in Victoria, Australia. Once, I collaborated to open the only center of clinical informatics in Australia at the time, I was approached to be an eHealth adviser for the implementation of an electronic health record for the whole state.

Entering the public arena opened many opportunities to achieve digital transformation with clinical data for quality services. Together with my local team, we embrace new informatics structures for the diversity of software for more than 150 healthcare centers.

Reflecting on this professional journey as a national leader and then global indigenous scientist into digital health for quality and safety using member state investment portfolios, allows me to humbly suggest the following:

- In any type of digital transformation, we must as scientists respect the human dignity and see any type of data with a human face [13].
- Digital transformation is about helping people within health informatics parameters for respecting human dignity, especially minorities groups such as indigenous communities [14].
- Healthcare informatics involved not only the person who requires the service, in addition to the rights as a human being within an ecosystem for human development in their own family and community [15].

6. Impact for new generations

The following lines are from one of my research students, as evidence of the current role I dedicated myself for the last two decades. Mario Donoso Fredes said:

I write these lines as a co-author, student and young researcher. I have had the opportunity and the privilege of making learning and knowledge my path, a path that for various reasons has been digital. These contexts have given me the opportunity to connect with an infinite and diverse set of sources; people, communities, literature, data, but also expose me to risks of being inconsistent, superficial, fragmented and liquid.

I remember the interview I had with Carol for my first research internship at CIDLA, it was honestly not what I expected for an academic interaction based on my own prejudices and Chilean culture. This meeting allowed us to know each other not only as student and teacher, but also as persons; our histories, families, interests, motivations, and hobbies were central themes of an extensive talk.

Our first interactions planted two crucial milestones in my learning and research journey. First, **the reflection of being**. Before I joined the research team, I received two uncomfortable questions during my interview. They asked me, Who are you? Why do you want to be a researcher? Those questions made me blush because I did not expect a question of this nature in a highly technical context. With the courage that only ingenuity can give us, I asked why is it important for you to philosophize in digital innovation, software development and applied research? The answer was, of course, much more sophisticated than my question: "We live in an ocean of data and information, an infinity of sources, qualities, quantities, therefore, we will always have the risk of getting lost. How lost we are will depend on our ability to reflect, be faithful to our being and our compromise for the truth at the service of others". As you can expect, my first assignment was not a literature review or data analysis. I spent at least three weeks studying and reflecting with the team about teaching and learning, leadership, and the role of being in research, a human integration of knowing, doing and being.

Second, **the community of practice**. My first days at CIDLA were marked by a great diversity of people, disciplines and areas of knowledge. For the first time I experienced that learning and knowledge rests in a diversity of opinions and that the ability to see connections between fields, ideas, and concepts is a core skill in research. Those of us who dedicate ourselves to research understand that this is not about a particular task or a job, it is a lifestyle in which, moved by curiosity and self-awareness, we offer intangible and personal resources to contribute to the generation and interpretation of knowledge. Fortunately, we share this beautiful and frustrating lifestyle with many people, diverse disciplines, our main opportunity. Collaboration! is the mantra and principle that I hear every day at CIDLA. It refers to the ability to engage and connect effectively, while preserving autonomy and control over the resources provided in a common project. Collaboration is about will, passion and self-determination not regulated by a contract, is related to the principle of good faith. This new way of learning, connectivism, gave me a new perspective as student and researcher, an invitation to practice with pluralism and based on trust"

7. Final thoughts

The impact of using data, information, and knowledge is powerful for helping others and for our own self-evaluation for inner awareness of our own actions. I learned 8 years ago of the impact of justice in our lives by completing a Master of Law, with an emphasis on constitutional rights. I remember after visiting around sixty countries as part of my work as a consultant for the World Bank, the necessity of health informatics in the ***legal and ethical*** framework for digital education & health. I called this my magic triangle for human rights within digital transformation: health, education & justice.

Therefore, I decided to study law, conducting applied research at the faculty of law number one in Latin America. It was difficult to study for a couple of years with lawyers and several experts in constitutional law in Spanish. My emphasis is to invite all the future generations innovating in digital transformation to seek the ethical and legal implications of their creation in hardware, and software and most importantly educate the new digital skills, knowledge, and attitudes toward cybersecurity.

Right now, I am a happy indigenous scientist that works for the Australian government as a data governance manager for vulnerable communities seeking access to justice. In addition, I am the co-founder of CIDLA.ORG with an amazing scientific team from all over the world, including a 1) registered research center, 2) ONG for digital innovation with social impact and 3) my own company that works with indigenous communities to create prototypes using artificial intelligence by using mobile technologies. My commitment to vulnerability is real eveyday by using the principles of health informatics science in indigenous communities, and poor contexts for protecting the privacy of vulnerable people and communities in order to prevent intentional discrimination.

After all, I had become an outlying datum that deviated from the data modeling applied to me since I was a poor child and migrant to Australia 32 years ago. Today, I dedicated all my research to Privacy digital standards, as a manner to impact real life with respect to human dignity and obtain accurate scientific interpretations of human beings' realities. We, as research community, must ensure human dignity for all when doing our investigation with digital data and that requires us to protect our user, patients, help seeker or client's data within their social, economic and political environments.

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My Journey Through the Field of Medical Informatics

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Abstract. In this contribution some achievements and milestones in the field of medical informatics, especially concerning decision support, as perceived by the author, are presented. The author focuses on those topics with respect to decision support that during his career in medical informatics impressed him and triggered him to convince his PhD students to start research on related topics. Both some of these achievements and the related research of some of his PhD students will be presented. The contribution starts with signal classification. Both ECG classification and sleep EEG classification are discussed. Then the use of Bayes' theorem for diagnostic purposes is discussed and some early applications pass review, among which the AAPHelp system developed by de Dombal and colleagues. Attention is subsequently paid to the advent of expert systems and other knowledge-based systems such as MYCIN and INTERNIST and to guideline-based decision support systems. Finally, the author presents his ideas about challenges for the field.

Keywords. milestones, medical informatics, computer-aided diagnosis, history

1. Introduction

This contribution is about achievements, milestones and challenges in medical informatics. I still use the term medical informatics and not biomedical and health informatics in this contribution because I grew up with this term.

In this contribution I want to discuss a number of what I regard achievements and milestones in the area of computer-aided diagnosis. Of course, this does not mean that these are the only achievements and milestones in this area, but I mention some of those that during my career in medical informatics impressed me and triggered me to convince my PhD students to start research on related topics. Therefore, I will not only refer to articles describing these achievements but also to articles describing the results of related research of some of my PhD students.

After obtaining my PhD I got a job as radiation physicist in the department of Radiotherapy and Nuclear Medicine of the Radboud Hospital of the Catholic University in Nijmegen, the Netherlands. During that period, I became interested in how physicians diagnosed patients. When does a physician, for example order an X-ray or a scan? If he does not have a clue of what the patient suffers from or when he is almost certain that something will be detected? How does the physician arrive at a diagnosis? If the patient is diagnosed, is the treatment then obvious or can different physicians prescribe various

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therapies? At that time, I had the idea that interpreting images was rather straightforward and error-free. I was totally surprised when I read an article of Yerushalmy [1] about the reliability of chest radiography in the diagnosis of pulmonary lesions. He stated for example that in judging a pair of serial roentgenograms for evidence of progression, regression or stability of disease, two competent and experienced physicians are likely to disagree with each other in nearly one-third of the cases, and a single reader is likely to disagree with himself in about one-fifth of the pairs. So, I asked myself whether such a variability also occurs for other types of diagnoses and if so, whether the situation can be improved by better training of the physicians.

After three years I moved to Amsterdam where Jan van Bemmel had just started the department of Medical Informatics. In his former job he was involved in ECG and VCG analysis. I learnt that also the interpretation of ECGs showed interrater variability. So if physicians use different criteria in deciding whether an abnormality is present or not, how can you improve the situation? Appropriate training could be a solution, but how to reduce the variability that trainers will also show? Protocols for managing several situations were developed for nurses and ancillary personnel. The protocols were usually based on consensus. Does consensus lead to the truth, given the inter-rater variability? Could guidelines for physicians reduce variability? The various criteria used by expert physicians should be discussed and unified. I learnt about the Delphi technique with which variability in criteria can be reduced by involving a panel of experts, asking each one individually about their judgements of for example certain problem solutions and feeding back the answers of each member anonymously to all other members. On the basis of this feedback each member can adapt his answers in the next round, etc. It is expected that this procedure will converge and lead to consensus. So, the Delphi technique could be used for reaching consensus. But again, is the consensus indeed the truth? Probably the best approach is to use biomedical literature as a gold standard.

In this contribution I will tell about my journey in medical informatics. What did I learn and what do I expect for the future?

2. Analysis of Electrocardiograms and Electroencephalograms

When in 1974 I entered the Medical Informatics field by joining Jan van Bemmel's department at the Free University in Amsterdam, I soon became acquainted with the research leading to the modular TNO EGG/VCG interpretation system, carried out by his group in Utrecht [2]. Interpretation of an ECG is a complex task that requires knowledge in a number of fields like anatomy, electrophysiology, and pathophysiology.

An advantage for ECG and VCG interpretation is the availability of a (patho) physiological model. No such physiological model is available to support the analysis of EEGs. So compared to ECGs EEGs need a different approach to analyze them. The diagnostic value of EEG abnormalities is limited: different pathologies may produce similar abnormalities. However, the ease with which continuous monitoring can be achieved and the very fact that the EEG is unspecific makes it a valuable tool for the monitoring of many physiological variables, because changes in these variables may lead to changes in the EEG. For example, the EEG can be a valuable tool during open heart surgery, for sleep staging and for assessing the adequacy of dialysis programs.

2.1. ECG Analysis

The use of computers for ECG interpretation was first applied to the orthogonal 3-lead VCG and later the 12 lead ECG. Hubert Pipberger started in 1957 investigating the prospects of computer analysis using three simultaneously recorded orthogonal leads [3]. In 1959 Cesar Caceres and colleagues in the National Institute of Health in Washington started analyzing the 12 lead ECG, initially by processing one lead at a time [4].

Computer analysis of ECGs (VCGs) consists of two parts: a measurement and a classification part [5]. In the measurement part features relevant for diagnosis are measured (time intervals, wave durations and amplitudes of the various deflections, etc.) and in the classification part these features are used for classifying the ECG (VCG) into one or more diagnostic categories.

Since I was familiar with signal and image analysis, I was especially interested in how ECGs were classified. I learned that predominantly two different approaches were used by existing ECG analysis computer programs: a heuristic and a statistical one. In the heuristic approach the reasoning of the cardiologist is simulated (the earlier mentioned NIH program [4] for example used conventional clinical ECG criteria). For simulating the cardiologist's reasoning decision trees and fuzzy classifiers are among others used. When a database with labeled ECGs is available, decision trees can be automatically constructed [6]. A disadvantage of the use of decision trees is that a small change in a feature value can lead to a different path through the decision tree, possibly leading to a different diagnosis if the feature value is close to a threshold value. Fuzzy set classifiers can be applied to prevent this or to cope with imprecise descriptions, like 'a large Q-wave'.

In the statistical approach multivariate statistical techniques are applied to ECG features. The VCG interpretation program AVA (Automatic Vectorcardiogram Analysis), developed by the group of Pipberger, used the Bayesian approach [3]. The probability density functions of the relevant features needed for disease classification were obtained from a database of VCGs. The Bayesian classification procedure computed the patient's posterior probabilities of various disease categories like normal, various types of hypertrophy and myocardial infarction, etc. The results were promising, suggesting that diagnostic ECG classification can be significantly enhanced through the use of multivariate analysis.

Comparing several computer programs analyzing identical ECGs showed large differences in measurement results. Such large differences limit the possibility of exchanging diagnostic criteria between programs. To overcome some of these problems a concerted action, CSE (Common Standards for Quantitative Electrocardiography), a large international co-operative project, sponsored by the European Commission, was launched in 1980. The project led to standardization of ECG measurement procedures, standardization of diagnostic criteria and to the establishment of an ECG reference library with well annotated wave reference points. A board of cardiologists visually determined the onsets and offsets of the P, QRS, and T waves on highly amplified parts of ECG tracings and by using a modified Delphi approach, individual outlying point estimates were eliminated in four successive rounds [7,8].

The library proved to be a useful instrument. Using a set of ECGs and VCGs from the reference library it was shown that combined cardiologist and program results demonstrated the highest accuracy, higher than the result of any individual reader or program [9]. Another study compared the performance of nine electrocardiographic computer programs with that of eight cardiologists using 1220 ECGs from the library.

The median total accuracy level was 6.6% lower for the computer programs (69.7 percent) than for the cardiologists (76.3 percent). However, the performance of the best computer programs nearly matched that of the most accurate cardiologist [10]. The results of the concerted action have become internationally recognized milestones for the standardization of quantitative electrocardiography.

I was involved in the comparison of serial ECGs of patients, who suffered a myocardial infarction [11]. The two most recent ECGs were compared, and a trend analysis based on all ECG recordings of the patient was performed. It could be concluded that serial ECG comparisons are useful in acute myocardial infarction management.

2.2. Monitoring the EEG

As mentioned earlier the EEG can be a valuable tool for monitoring purposes. Therefore, a method to detect changes in the EEG whenever they occur is valuable. I became involved in research concerning this topic when supervising PhD candidate Ben Jansen [12]. The main goal of his study was to design an objective method that could quantify changes in the EEG and that could be applied in such diverse areas as monitoring the level of anesthesia, the efficacy of perfusion during open heart surgery or automatic sleep staging.

According to Elul [13] short EEG segments (one to five seconds long) can be regarded as stationary. Each short segment represents a specific state of the EEG. Most likely only a limited number of states (and thus differing segments, called elementary patterns) will be encountered in one recording. Stationary intervals can be lumped together into clusters, where each cluster presents a state of the EEG. This results in a description of the EEG (a profile) in terms of the percentage of time the EEG remains in each state.

Several researchers syntactically modeled the EEG as the output of an auto-regressive filter of an appropriate order with random noise as input. Fernando Lopes da Silva used the model for detecting spikes in the EEG [14]. He adapted the model to the first few seconds of a recording and then the remaining part of the tracing was used as input to the inverse model, thus generating random noise as long as no transients occurred. Spikes were detected when the output of this model exceeded some pre-set threshold. Jansen also used an autoregressive filter of order five to simulate a given measured EEG and applied a Kalman filter to compare the output of the auto-regressive filter with the measured EEG. The updated filter coefficients minimized the difference between the measured and the simulated EEG. Because of the earlier mentioned stationarity considerations, the EEG was segmented into 1.28 second intervals. Each interval was represented by a vector, consisting of the five (averaged) filter coefficients and the range of the EEG amplitude in that interval. The vectors representing the EEG intervals of a training set were used in an unsupervised cluster analysis. From this analysis emerged different clusters, representing different states of the EEG. The interval in the center of each cluster was regarded as the elementary pattern representing that cluster. These elementary patterns were used to classify the vectors of the segments in a test set.

After clustering each EEG interval from the test set was assigned to the most similar elementary pattern from the training set. For sleep staging profiles indicating the number of intervals assigned to each elementary pattern in an EEG recording (in sleep staging 30 second epochs were used) obtained from a test set were classified according to their similarity with the average profiles of the various sleep stages determined in a training phase. Using the profiles (per sleep stage) of one subject as a reference, about 80%

correct classifications of the sleep stages were obtained with the profiles of two other subjects. Between 60% and 90% agreement between judges was reported for sleep staging. Automatic sleep staging could reliably be done by means of profile classification. Frequency changes, induced by the starting and stopping of the pump and by the cooling and rewarming cycles during open heart surgery could reliably be detected.

3. Bayes Theorem

At the end of the 1950s Ledley and Lusted wrote several articles about medical diagnosis and decision making (among others [15]). They indicated that a physician in the processes of determining the diagnosis and formulating the treatment plan for a patient is frequently faced with a sequence of complex decisions. For the most part these decisions are made by means of heuristic procedures, on a largely intuitive basis. They suggested that logical analysis for determining a differential diagnosis, probabilistic analysis (Bayes' theorem) for determining the probabilities of the diseases contained in the differential diagnosis and value theory (decision analysis) to assist in the choice of the treatment plan if more options were available, could be successfully applied. Moreover, they advocated the use of computers for supporting physicians.

I wondered whether knowledge about how physicians diagnose a disease could be used to attack diagnostic problems with the help of computers. I learned from Elstein et al. [16] that physicians generate specific hypotheses very early in their encounter with the patient. These provisional hypotheses are generated out of the physician's background knowledge of medicine, including his range of specific experiences, in conjunction with problematic elements which he recognized in the early stages of the encounter with the patient. After hypotheses have been generated and roughly rank-ordered, they are systematically tested in the familiar medical work-up. This strategy, used by physicians, is called the hypothetico-deductive approach and was for example also used in INTERNIST (see further). But eliciting the knowledge and procedures used by expert physicians during diagnosis does not reduce interrater variability given the fact that even experts make diagnostic errors or do not agree between themselves. Randy Miller and colleagues, involved in the design of INTERNIST and QMR (see further) indeed remarked that the standard model for building expert systems (eliciting knowledge through the collaboration of domain expert and knowledge engineer) was not sustainable. They came to the following recommendation: use the biomedical literature as a gold standard for setting up a clinical knowledge base.

The idea of using Bayes' theorem for diagnosis was attractive because it allowed taking into account the uncertainties the diagnostic process has to deal with. Soon after Ledley's and Lusted's publications, articles dealing with the computer-assisted diagnosis of for example congenital heart disease, thyroid function and bone tumors [17-19] appeared. As we saw, also the AVA VCG interpretation program used Bayes' theorem for classification. From the literature [20-22] it is clear that Bayes' theorem was often used in the 1970s for computer-aided diagnosis. The performance of some of these programs was almost as good as those of experts in the respective fields. However, the output of programs using Bayes' theorem were difficult to value by physicians. The physician should know how the program arrives at its results and he should be aware of the quality of the statements made by the computer program. Only then can he take responsibility for his actions that are based upon results of computer programs. Use of weights of evidence makes the output of programs based on Bayes' theorem easier to interpret [23].

In the beginning of the 1970s Tim de Dombal from Leeds University presented a system for diagnosing acute abdominal pain (AAPHELP) [24]. Their choice of the "acute abdomen" was a deliberate one: it is a common clinical dilemma, the number of possible diagnoses is relatively small, the clinical diagnosis is usually made on the basis of a patient's symptoms and physical signs rather than on biochemical tests and the final diagnosis is usually made at surgery. The program was based on an independence model of Bayes' theorem as were most of the programs using Bayes' theorem. The prior probabilities of the diseases and the conditional probabilities of the symptoms and signs given the diseases were determined from a database of 600 patients. A structured form was developed on which the data needed by the system were documented by the clinician. The performance of the clinician increased during the trial, probably due to the discipline of data collection (the structured form) and feedback about their performance. However, after the trial the performance of the clinicians decreased to the 'normal' level.

The system was validated in a controlled prospective trial in which the diagnostic performance of the unaided clinician was compared with that of the system. It appeared that the system performed better than the clinicians, even the most senior ones. The abdominal pain program could not always be used successfully: sometimes problems were encountered when the system was transferred to another location. The quality of the advice of the system is, among others, dependent on the referral policy in that new location. Different referral strategies may result in different prior probabilities of the diseases. Also, geographical variations in disease probabilities may occur. Although the abdominal pain system performed well, it was not used on a large scale. The problem probably was too specific, given the amount of time it took physicians to obtain a diagnostic prediction. The desktop computer version took the clinician five minutes, which is far too long when 15 to 20 patients are seen daily. So, even though de Dombal et al. could prove that the system performed at expert level, it was not used regularly.

Spiegelhalter and Knill-Jones [23] presented a statistical application for the diagnosis of dyspepsia, GLADYS (Glasgow Dyspepsia System), that made use of weights-of-evidence, being the logarithm of the likelihood ratio of a finding for a given disease. According to independence Bayes these weights, when added, are equal to the logarithm of the likelihood ratio of the posterior probability of the considered disease. The physician can now better interpret the size of the posterior probabilities: the higher the weight the more important the finding influenced the result.

According to Gorry and Barnett [25] calculating the posterior probability distribution for the diseases in question is one aspect of diagnosis but another important aspect is the determination of an appropriate sequence of questions and tests: determining which question should be asked or test be ordered next should be based on the information available after the previous question is answered or test result obtained. A sequential approach leads to a minimum number of questions and/or tests and saves discomfort to the patient, time and money. Bayes' theorem can also be used in this case. Gorry and Barnett describe the procedure for determining the appropriate sequence of questions and tests. For each ordered pair of diseases, the cost of misdiagnosing one disease for the other was specified. The cost of misdiagnosis given the current differential diagnosis can now be determined (when for example the diagnosis with the highest probability is selected as the definitive one) using the provided costs of misdiagnosis. This cost can be compared with the cost that results from asking a new question or requesting a new test. That question is asked or that test ordered for which the cost, averaged over the differential diagnoses obtained for each possible outcome, is lowest and also lower than the cost of the differential diagnosis before this question is asked or test ordered. Then the posterior probabilities of the diagnoses in the differential diagnosis are updated. The procedure is repeated until no test or question will have a lower average cost than that of the current differential diagnosis. Also, other strategies for sequential diagnosis were introduced. Gleser and Collen [26] calculated the entropy of the distribution of the prior or posterior probabilities of the diseases and selected the test or question that gave rise to the largest reduction in entropy whereas Rector et al. [27] selected the test or question that maximized the weighted difference of the new and current posterior probabilities. For a detailed description the reader is referred to their papers.

The above publications were an incentive to dedicate part of a block course given at the Free University in Amsterdam [28] to the use of computers as an aid to diagnosis [29, 30]. The student was given an overview of what had been done in this field and the benefits and limitations of the approach were explained. As mentioned earlier Bayes' theorem was often used. This was the reason for demonstrating this statistical rule in the block course. Also, attention was paid to objections raised against using this theorem [31].

A database of 277 patients (including 63 normal patients), all referred to the hospital suspected of having congenital heart disease, was established. In total, seventeen questions could be asked about the status of the patient. The questions concerned age, sex, EKG data, radiologic data, presence of heart murmurs, cyanosis, femoral pulsations, and hepatomegaly. For each heart disease and the 'normal' population and for each answer subjective probabilities were available.

One of the tasks the students had to carry out is presented here. A clinician has to determine an optimal sequence of diagnostic tests for a particular patient and computers can be used to obtain such an optimal strategy. In the program this problem was translated into the problem of asking questions efficiently. The student could direct questions at a patient randomly selected from the database. The aim was to arrive at the correct diagnosis by asking a minimal number of questions. After the student had obtained the correct diagnosis (s)he could compare her/his strategy with the outcome of the computer that applied the sequential strategy explained in [27]. In this way (s)he could learn which questions were relevant and which were irrelevant in the present situation. But (s)he would also notice that the sequence of questions asked by the computer looks more erratic than the sequence of questions asked by physicians.

Not only Bayes' theorem was used to support decision making. Several statistical techniques like linear discriminant analysis or logistic regression were also applied. It was shown that these statistical techniques produced similar diagnostic results and had similar performances. The statistical approach to medical decision making was popular until in the early 1970s AI was introduced. Spiegelhalter and Knill-Jones [23] discussed various criticisms the AI community had towards statistical systems like the frequent assumption of conditional independence, the restriction to mutually exclusive and exhaustive diseases, the ignorance of the rich physiological knowledge and judgmental experience of clinicians, the need for large amounts of data, the placement of all shades of inexactness within a single probabilistic framework and an unavoidable loss of comprehensibility to the physician. They conclude that a synthesis between AI and statistical approaches is possible with the logical medical knowledge organized using an AI representation and any inexactness modelled using weights of evidence.

4. Knowledge-based Systems

The advantage of knowledge-based systems is that the knowledge for solving a problem is stored separately from the part that reasons with this knowledge. In order to be useful for physicians a knowledge-based system should be able to explain its knowledge of the domain and the reasoning processes it employs. Because the knowledge base is separate from the rest of the program the knowledge can more easily be updated than in algorithms, where the knowledge is interspersed with the code. There are various ways to represent knowledge, like IF-THEN rules, frames, ontologies, etc. Rules were considered as a model for human cognition and were therefore used for the representation of knowledge in expert systems. However, experts often appeared to have problems in formulating their medical judgements in the form of rules and to keep the rule base consistent. Also, the necessity to specify the context in which the rule is eligible may cause problems.

When I read about MYCIN, an early expert system developed by Ted Shortliffe and colleagues [32], used to identify bacteria causing severe infections and to determine an appropriate therapy, I was impressed. By backward chaining through applicable rules and asking the user medical information about the patient where necessary, the system could determine a diagnosis and suggest a medication. In addition, the system worked with certainty factors that indicated how certain either the antecedents of the rules or the certainty of the conclusions were. So, reasoning under uncertainty was possible in MYCIN.

Expert systems based on IF-THEN rules could explain to a certain extent how they arrived at a conclusion by showing the chain of rules that was followed. For example, when MYCIN asked a question, the user could ask why that question was posed. The system then presented to the user the higher-level goal it was attempting to satisfy. The user also could ask how the system arrived at certain conclusions. MYCIN was an example for many expert systems to come. Several of my PhD candidates developed decision support systems using a rule-based approach. Here I present one example.

To manage test consumption in the region of Maastricht in the Netherlands GPs got bi-yearly written feedback by human experts about their test requesting behavior. The feedback on GPs ordering behavior was highly effective and appreciated by the GPs, but such a form of feedback was laborious. Therefore, the aim of the research of Rianne Bindels [33] was to develop and evaluate an accurate and reliable reminder system that would give GPs immediate feedback about diagnostic test ordering that was not in line with national or regional guidelines and to provide the opportunity, when the GP agreed with the feedback, to change a request immediately after a reminder was shown. The reminder system, GRIF, consisted of a knowledge base, an order entry system and modules to provide passive support when the GP asked for background information and active support in the form of reminders when a test request was not according to the guidelines.

Knowledge was represented in the form of rules. With the help of a GP and an experienced internist the relevant parts of the guidelines were formalized. Not all guidelines could be formalized because of the lack of well-defined conditions like ‘the elderly’, ‘atypical complaints’, etc. These guidelines would be formalized later. The knowledge base used for testing consisted of 149 reminders concerning various medical problems.

The output of the system was validated using 253 randomly selected request forms from GPs with together 1217 test requests, also containing medical information about why the test was requested. Three expert physicians independently indicated whether the tests were appropriately requested, based on their knowledge of the guidelines. In a first validation round the intra-rater and inter-rater agreement were determined. The intra-rater agreement varied between 72% and 85%, the inter-rater agreement between two raters varied from 67% and 74%. Also, the kappa values were relatively low (around 0.6 for each individual rater validating a number of forms twice and around 0,4 for couples of raters). Therefore, the majority agreement of the three experts was taken as the gold standard and the results again analyzed. In 13% of the requests the system did not react correctly. However, 4.5% of the accepted test requests, where the system accepted these requests using the majority judgement, appeared to be inadequate.

Also, the potential effect of the system on the test ordering behavior of 24 GPs was assessed. The GPs reviewed a random sample of 30 request forms they filled in earlier that year. If deemed necessary, they could make changes in the tests requested. Next, the system displayed critical comments about their non-adherence to the guidelines as apparent from the (updated) request forms. Both the number of requested diagnostic tests and the fraction of tests ordered that were not in accordance with the practice guidelines decreased due to the comments of the automated feedback system. The GPs accepted 50% of the reminders.

I was also very much interested in the program INTERNIST [34] that could diagnose complex cases and covered some 600 diagnoses in internal medicine. The technique used was similar to the hypothetico-deductive approach used by physicians.

The program was developed by Jack Myers, Harry Pople and Randy Miller and coworkers at the University of Pittsburgh in the beginning of the 1970s. In the knowledge base of INTERNIST the disease profiles of more than 600 diseases from internal medicine were stored. Contrary to expert systems philosophy prevalent at that time, where a "knowledge engineer" debriefed a "domain expert" to subjectively construct a knowledge base it was decided to use the peer-reviewed published literature as the independent gold standard source of knowledge on which to build the knowledge base.

A disease profile consists of all manifestations (patient's history, physical exam, and laboratory data) that are associated with that disease. From the disease profiles a differential diagnosis list for each manifestation can be determined. Each manifestation in the disease profile was characterized by the values of two parameters: evoking strength, a kind of positive predictive value (how probable is the diagnosis when the manifestation is present), and frequency, a kind of sensitivity (the probability that patients with this diagnosis have the manifestation). The clinical importance of the manifestation, independent of the disease, is described by the value of a third parameter, import. The parameter values were – as a result of medical judgement - divided into classes and each class had a certain weight.

For each of the patient's manifestations for each item present in the manifestation's differential diagnosis list a disease hypothesis is created. The disease hypotheses of all manifestations are stored in a master list. For each disease hypothesis from the master list the weights of the evoking strength parameter of all manifestations present in the patient that also appear in the profile of that disease hypothesis were added. From this total score the sum of the weights of the frequency parameter of those manifestations that appeared in this disease profile but are not present in the patient was subtracted (because it reduces the probability of the disease to be present). Also the sum of the weights of the import parameter of manifestations that do appear in the patient but not in the disease profile was subtracted from the total score. For each diagnosis hypothesis the resulting score is an indication of the probability that it is present. The hypotheses are now ranked according to their total score and the disease hypotheses whose scores are more than a specified amount less than the highest score are temporarily discarded. The diagnosis with the highest score qualifies as a definitive candidate for the diagnosis of the patient. But there may be competitors of which the set of manifestations is a subset of the set of manifestations of the diagnosis with the highest score. Of this group of competitors only one can be the definitive diagnosis and therefore these competitors form the differential diagnosis. Different strategies were used to determine the definitive diagnosis, depending on the difference between the score of the diagnosis with the highest score and that of the competitors. When the system cannot determine further questions or tests and the differential diagnosis contains more than one disease, the program displays these diagnoses together with their scores as tentative diagnoses. When the remaining manifestations have an import of 2 or less, the program ends. As soon as a definitive diagnosis is established all manifestations explained by the definitive diagnosis are removed and a new differential diagnosis is determined in the same way as explained above for the remaining disease hypotheses, including the ones that were temporarily discarded.

The program was evaluated on 19 clinicopathological complex cases published in the New England Journal of Medicine. A comparison was made with human experts. There were 43 possible correct diagnoses for the 19 cases. INTERNIST made 17 correct definitive diagnoses and 8 correct tentative diagnoses (when INTERNIST presented a differential diagnosis instead of a definitive diagnosis and the tentative diagnosis with the highest score was the correct diagnosis), whereas the clinicians made 23 correct definitive diagnoses and five correct tentative diagnoses (if the physicians presented a differential diagnosis with the correct diagnosis on top). In addition to demonstrating the impressive capabilities of the system, the evaluation identified several shortcomings of its approach. First, the knowledge base and diagnostic algorithms did not adequately represent disease and finding severity. Second, the temporal course of a patient's illness could not be fully described. Also, the program could not "reason" anatomically regarding aspects of the patient's presentation [35].

The role of the physician, when using INTERNIST, was limited to the entry of data, the system did the diagnostics part. Later it was realized that this approach was wrong: the approach was called the Greek oracle approach, clearly indicating the role of the system. In the 1980s QMR (Quick Medical Reference) was developed. The system functioned as an information tool, providing users with multiple ways of reviewing and manipulating the diagnostic information in the program's knowledge base [36].

5. Computer-interpretable Guidelines

Not only reminder systems were developed, but also interest also existed in the formalization of clinical practice guidelines, that describe how to diagnose or treat a patient. Protocols were already in use for a long time to support nurses and ancillary personnel. Protocols can be seen as directives of how the user should approach a problem and were usually displayed as flowcharts or decision tables. Guidelines are less restrictive than protocols and serve as recommendations that may be rejected by the physician as long as the physician documents the reasons why he did not follow the guideline. From the early 1970s several studies demonstrated wide variations in medical practice among physicians, hospitals and different geographical areas. Gradually physicians started to use paper-based guidelines to ensure consistent high-quality care. However, these guidelines were written down in large documents in a textual format, were often cumbersome to read and difficult to integrate in the patient care process. Updating paper-based guidelines in addition required the production of new documents. Grimshaw and Russell reviewed published evaluations of the application of clinical guidelines [37]. All but 4 out of 59 guidelines resulted in improvements in the process of medical care and all but 2 out of 11 evaluations that also measured the outcome of care reported improvements in outcome. Their conclusion was that guidelines can change clinical practice if they are appropriately developed, disseminated, and implemented.

To improve access to the paper-based guidelines they were entered into the computer. But most of the guidelines were still presented as large documents in a textual format. Marieke Vissers started a research project with the goal to develop and implement a prototype information system that would present guidelines in a well-organized and user-friendly way. Users should be able to familiarize themselves with the system in a short time and limited data input by keyboard and an easy to control user interface should enhance the acceptability of the system. The system, ProtoVIEW, had the characteristics of a reference system, provided solicited advice and guided the user through the protocol [38]. Among others the value of the system for assisting inexperienced residents in the management of common medical problems in the A&E department was evaluated [39]. The residents stated that they found ProtoVIEW easy to use. However, although consultation of ProtoVIEW under routine circumstances took only one and a half minute, residents doubted whether the use of ProtoVIEW would be faster than consultation of other information sources, like colleagues. Later a Web-based version of ProtoVIEW was developed that contained all its functionalities plus several new ones. The web version contained an X-ray viewer and provided a great deal of interactivity such as validation of electronic patient data forms. The most important additional function was the context sensitive protocol support that may lead to improved protocol adherence. Finally, the web-based version could be accessed from any working place since patient data and protocols were stored centrally [40].

Implementing executable guidelines in a computer-based decision support system could improve the application of guidelines still more because the actions and observations of care providers can be monitored, and advice related to the individual patient is generated when needed. Many parties developed decision support systems that incorporated guidelines, covering a wide range of clinical settings and tasks [41]. However, only a few systems progressed beyond the prototype stage. Building systems that were both effective in supporting clinicians and accepted by them proved to be a difficult task. Yet, of the few systems that were evaluated by a controlled trial, the majority showed impact [42]. To make the advice patient specific the system must be able to access clinical data. The guideline system therefore should be interfaced with the EPR system, otherwise the physician has to enter data twice.

Various difficulties were encountered with respect to the guideline development process ranging from the development of a guideline representation model to the implementation of actual decision support systems that operate in daily practice. Existing paper-based guidelines had to be formalized and expressed in a common representation language, using a common terminology for expressing clinical data. The interpretation of the content of guidelines and therefore their formalization could be difficult: the exact meaning of terms was not always defined; recommendations were not always clearly articulated, and sometimes vague wording was used. In the Netherlands new cardiac rehabilitation guidelines were being drafted during the time Rick Goud started developing the decision support system CARDSS (cardiac rehabilitation decision support system) to support the entire process of rehabilitation, with a focus on needs assessment [43]. Goud could participate in all the meetings of the cardiac rehabilitation guidelines development committee and co-authored the flowchart summarizing the needs assessment procedure. The concurrent development and formalization of the guideline helped to identify in the narrative guidelines both vague, inconsistent as well as difficult to apply recommendations [44]. CARDSS was adopted in practice and was used in over 30 Dutch outpatient clinics.

A number of research projects started developing generic methodologies that could solve many of the problems related to the guideline development process. We mention some important approaches: GLIF [45], PROforma [46], Asbru [47] and EON [48]. Also PhD candidate Paul de Clercq developed and evaluated a generic approach that addressed questions such as how to represent, acquire and implement computer-based guidelines. The approach led to the development of the Gaston framework [49]. The project started in 1996. A number of systems were developed using the Gaston approach: the earlier introduced GRIF reminder system [33], that provided feedback on test ordering in general practice; CritiCIS, a real-time critiquing system used in critical care environments such as intensive care units [50], M-PADS, a psychopharmacological advisory system that supports the process of selecting the most suited psycho-active drug [51], a consumer health record system for managing chronic diseases [52], GASTINE [53] for intention-based decision support (see below) and CARDSS [43] for cardiac rehabilitation guidelines, presented above.

Decision support systems can issue reminders or alarms when the EPR shows that physicians are not working according to the guideline. But the physician may have executed an action that was in the spirit of the guideline and still get a warning. Such warnings of the system will annoy the user. If next to the suggested actions the guideline also contains information about why these actions are carried out (the intention behind the action) and which actions are in line with the intentions, the physician will not receive such warnings. Moreover, the intentions can be used to explain to the interested physician why a certain recommendation was given. Agnes Latoszek-Berendsen started research on intention-based decision support. The representation formalism for intentions and their implementation in guidelines was called GASTINE (Gaston intentional expressions) [53]. The formalism was used to formalize and implement the Dutch heart failure guideline. She demonstrated that the use of intentions offers the flexibility needed to avoid unnecessary error messages and warnings. When the system was used in the pro-active mode it provided the user with actions mentioned in the guideline. Only when the system was reacting to information entered by the physician in the EPR it would check whether the action that was different from the action in the guideline was in the spirit of the guideline and if so it would not present a warning.

6. Conclusions

During my journey I learnt a lot. For example, I came gradually to the conclusion that we have to live with uncertainties in medicine. Inter-rater and intra-rater variability for example will not disappear and therefore basing the gold standard on raters will not be error-free. Use of consensus between experts as a gold standard may help, but we saw above that 4.5% of the test requests were incorrectly accepted because the system agreed with the majority judgement of experts. Evidence-based knowledge used in decision support systems should come from validated studies reported in scientific literature.

Many studies have shown the human judgement to be unreliable. Moreover, the capacity of man as an effective problem-solver is very limited. Man tends to gather information indiscriminately, although he is only capable of combining a limited number of facts simultaneously. Furthermore, men are conservative information processors, who do not extract all the material inherent in the information. Therefore, systems that provide pro-active reminders (before actions are taken) or reactive warnings (when actions have been taken) are necessary tools. In my opinion we should not try to design systems that can solve everything as long as the user provides the relevant data. The INTERNIST project showed that such a Greek oracle approach is unwanted. The physician should get support in a way that interferes with his work as little as possible. Decision support systems with executable guidelines that can follow the physicians' actions via the EPR and that provide warnings when the physician does not work according to the guideline or give reminders so that a physician does not forget to take certain actions are in my view most wanted. They will reduce errors.

Computer systems combine observed facts and interpret them, based upon the existing scientific knowledge available in the programs. We have to remind ourselves that this knowledge is generalized knowledge in the sense that it is pertinent to 'the patient' and that it only describes quantifiable aspects of real patients. The physician is responsible for the management of an individual patient: he has to combine the information delivered by the computer program with other available information about this patient, e.g., non-quantifiable data. Only the doctor as a human being can make decisions about the management of the disease of another human being. The role of the computer is to remind the doctor of possibilities overlooked by him and to furnish him with scientific knowledge pertinent to the patient under consideration. A computer can never be responsible, the physician is. Therefore, the computer can be a useful tool, but can never replace the doctor.

Our goal should be to make tools that can support physicians and do not replace them, as we saw with INTERNIST. We have to admit that the physician is the pilot of the system. Therefore, we should build tools that can be used by the physicians almost in the same way as they use the results from laboratory tests or ECGs. They can use the information of the tools to make up their minds. Also, patients can use the information and be involved in deciding what to do. As a last remark: I did not go into detail about the prospects of NLP and machine learning. I think that they will get an important role in the future. But again, 5we should be modest and not try to build artificial physicians.

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Personal Health Informatics: New Tools and Roles for Health Care

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Abstract. Technological advancements have introduced wearable and passive monitoring tools that can capture aspects of daily living, health and well-being in homes and communities. Personal Health Informatics is the study of any information system, tool or platform designed for individuals and their families/ communities with the goal to facilitate decision making, access to information, education, managing health, prevent disease, and improve communication whereby the individual patient or consumer is the end user whose needs and preferences inform the design and implementation of the system. Examples of such tools include digital phenotyping, consumer genomics and smart homes. Such platforms capture patient generated health data and allow for proactive models of care, whereby patterns or trends are analyzed to identify opportunities for tailored interventions. Future research needs to address the impact of personal health informatics systems on health outcomes, shared decision making and patient empowerment. We discuss new roles and opportunities that arise with the growth of this field, including the role of the personal health data navigator who can guide and assist patients and families in navigating the complex digital landscape in order to most effectively utilize inclusive personal health informatics tools.

Keywords. Personal health informatics, digital phenotyping, smart homes, genetic testing, patient generated health data

1. Introduction

Pervasive computing solutions have enabled individuals to monitor their own health and well-being, the environment they live in and work, and track and share health and wellness related parameters through wearable sensors, mobile health apps and even home-based passive sensing solutions. Precision medicine, namely “prevention and treatment strategies that take individual variability into account [1]” has been an emerging paradigm shift in biomedical research that calls for collecting and analyzing large data collected on the unique individual’s behavior, lifestyle, genetics and environmental context. Such data include large scale biologic databases, and the use of proteomics, metabolomics, and genomics to better understand individual patients and populations but also the use of emerging technologies such as passive sensing and wearables to capture physiological, behavioral and environmental data for individuals and communities. This calls for advance computational tools to mine and analyze such large data sets.

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Behavioral sensing, that includes passive monitoring and wearable technologies, aims to objectively, remotely and continuously measure aspects of patient physiology, behavior and symptoms. Consumer technologies such as wearables and other sensors provide the ability to capture behavior and activities of daily living, replace the need for human observers, eliminate reliance on self-report shifting from episodic to continuous monitoring and furthermore facilitate assessment of daily living in the real world and not a laboratory setting. These tools also offer the ability to an individual to gather data about their health and well-being outside of clinical settings and be in charge as to if and how their data are shared with others. The recognition of the role of technology in allowing patients to be actively involved in their own health care delivery and disease prevention has led to the growth of the sub-discipline of biomedical informatics, called personal health informatics (PHI). PHI is emerging as an evolution of consumer health informatics. Gibbons et al defined consumer health informatics as "any electronic tool, technology, or electronic application that is designed to interact directly with consumers, with or without the presence of a health care professional that provides or uses individualized (personal) information and provides the consumer with individualized assistance, to help the patient better manage their health or health care" [2]. Along these lines, Personal Health Informatics is defined even more broadly as the study of any information system, tool or platform designed for individuals and their families/ communities with the goal to facilitate decision making, access to information, education, managing health, prevent disease, and improve communication whereby the individual patient or consumer is the end user whose needs and preferences inform the design and implementation of the system.

The growth of various digital tools in health has led to continuous growth of patient generated health data (PGHD). The Office of the National Coordinator for Health Information Technology (ONC) in the US defines PGHD as "health-related data including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information-created, recorded, gathered or inferred by or from patients or their designees" [3]. This definition highlights the unique role of patients as the responsible entity for the capture and oversight of the collected data and introduces a paradigm shift from the more paternalistic model of medicine whereby the patient is the passive recipient of services to one where the patient is actively involved and at the center of information gathering. Tools that capture PGHD have the potential to "amplify" the patient voice and increase patient safety [4].

There is a broad range of platforms that can facilitate the capture of PGHD including paper-based tools such as diaries or forms to wearable or even implantable devices. Electronic tools may offer not only the ability to capture and store data but also provide alerts for individual data points, or even embed more sophisticated informatics approaches such as predictive analytics, natural language processing or machine learning, to identify patterns and trends and ultimately facilitate a proactive approach to symptom management and health. Data can be communicated and shared with various stakeholders including family members and clinicians in various ways, including visual summaries, online dashboards or even integration of PGHD into the patient's electronic health record.

2. Personal Health Informatics Applications

The following section discusses some examples of current and emerging trends in personal health informatics that facilitate a paradigm shift, promoting new systems for data collection and knowledge generation that take place outside of formal clinical settings of care and introducing numerous opportunities and challenges that call for technical, clinical, ethical and policy considerations.

2.1. Digital phenotyping

The use of smart phones has introduced the ability to track movement, time spent online, and even engagement in social interactions. The use of digital tools to capture real time behavioral patterns has introduced the concept of digital phenotyping, defined as the "moment-by-moment quantification of the individual-level human phenotype *in situ* using data from personal digital devices [15]" This approach is informed by traditional Ecological Momentary Assessment (EMA) that aims to assess behaviors and experiences in one's own natural environment and in real time. Data collection for digital phenotyping can be passive without user involvement (for example, capturing one's movement in space using the GPS sensor of one's smart phone) or active with user input (for example, being prompted to enter a rating or provide other information in real time). Similarly, the approach of digital phenotyping systems can be further categorized into content free patterns (e.g., capturing reaction time for tapping, scrolling, typing) or "content rich" (e.g., analyzing social media postings, voice recordings, or one's search history). In addition to smart phone data, wearable biosensors are often integrated in digital phenotyping platforms to capture physical or emotional state, for example to assess physiological change during opioid use (based on a decrease in locomotion and increase in skin temperature continuously captured [16]); to monitor real-time drug use [17] or alcohol consumption [18], or to capture and analyze autonomic nervous system activity via electrodermal activity, 3-axis acceleration, ECG and temperature, in order to detect arousal events and automatically send therapeutic and empathetic messages to the patient using cognitive behavioral therapy (CBT) [19]. Social media data are also used in digital phenotyping studies to study autism spectrum disorder (ASD); for example, Hswen et al [20] conducted a textual analysis of tweets about repetitive and obsessive-compulsive behavioral characteristics typically associated with ASD.

There is a broad range of other application domains for digital phenotyping highlighting its potential for mental health. For example, studies have collected sensor, keyboard, voice and speech data from smartphones to measure behavior, cognition, and mood or sleep quality. Such tools also provide the ability to deliver context-sensitive intervention as in situ support to people experiencing depressive symptoms or severe anxiety (including through personalized text messages and videos). As Dagum points out [21], digital phenotyping introduces many opportunities to enhance our current models of care in psychiatry. Capturing digital biomarkers has the potential to predict relapse for addictive behaviors, cognitive decline or mood disorders. Such tools are also increasingly used in child and adolescent psychiatry and for suicide prevention. The emergence of digital phenotyping has the potential to facilitate the ubiquitous identification and prediction of health-related behavioral trends within the context of individuals' social, physical and mental state in their own natural environments. At the same time, this concept introduces ethical challenges that include considerations pertaining to privacy, consent, and potential third-party access to collected digital biomarkers. These challenges need to be addressed in the broader context of use and protection of patient generated health data (PGHD) also discussed later.

2.2. Consumer Genomics

Direct to consumer (DTC) genetic testing has been available for the past twenty years, allowing consumers to obtain information about genetic predisposition to diseases and traits on their own [22]. This aspect of personal health informatics highlights the opportunity for consumers to find causal mutations of genetic diseases before experiencing any symptoms, and when possible, take action, recognizing, however, the significant challenge of false alarms of pathogenic alleles [23]. DTC genomics enables consumers to access genetic testing outside of formal clinical systems of care which introduces a challenge for clinicians and health systems to support patients who are exploring these options, including emotional support for those who experience distress after receiving test results [24]. Genetic counselors who are tasked to help patients understand the information generated by genetic tests as well as the limitations of these tests and potential actionable recommendations, are asked to play an increased role in this growing DTC genomics era.

Advances in testing technologies and consumer expectations have accelerated consumer targeted solutions with some ambiguity as to what constitutes a medical test or device and what the consequences of DTC targeting are. Legislature is trying to catch up with this evolving reality [22]. In the United States, the Food and Drug Administration (FDA) ordered the DTC genetic testing company 23andMe in 2013 to stop offering health-related genetic risk information to new customers [25]. The company complied with this ruling by agreeing to disclose to new customers only information on genetic ancestry (which does not fall under the purview the FDA). In the European Union, while the safety of DTC genetic tests entering the EU market is covered by a Directive, a review by Kalokairinou et al [26] highlighted that there is large heterogeneity in the way EU countries have chosen to regulate aspects of genetic testing (including the need for medical supervision, genetic counseling and informed consent). A further challenge is introduced by the rise of nutrigenetics testing, which assesses how the body responds to nutrients based on one's genetics. This type of testing is introduced as a lifestyle product and an alternative to medical genetic testing as companies offer advice on lifestyle changes [27]. As Saukko et al [27] argue, the label of 'lifestyle products' recognizes the severity of a genetic test but negotiates for a "hybrid or compromise category" standing "between medicine and consumer culture". DTC genomics calls for adequate and ongoing education for health consumers but also for health care providers who are called to help patients navigate and interpret this landscape. As is the case with other personal health informatics tools, we need to carefully examine issues of informed consent, protection of personal and sensitive health information, accuracy and validity of testing modalities, and weigh the risks and benefits of accessible personal genetic information.

2.3. Smart Homes

Sensor technologies have been used to transform residential settings into "smart homes" for health and well-being. A smart home is broadly defined as a residential setting with embedded technologies that promote passive monitoring of residents with the goal to support their health, safety and well-being. While the emergence of Internet of Things (IoT) devices, namely interconnected devices that can be controlled remote, has led to a significant growth in smart home applications, the concept is not new. In the late 1990s sensor technologies were explored to facilitate passive monitoring in the home mostly for older adults and persons with disabilities. The Aware Home at the Georgia Institute of Technology, for example, explored ubiquitous computing technologies that detected potential crises, assisted an older adult's memory and tracked behavioral trends [8]. The ENABLE project was a joint research effort from five countries (the UK, Ireland, Finland, Lithuania and Norway) to explore the potential of smart home features in order to support people with early dementia [9]. The smart home prototype included various features such as a locator for lost objects, and automatic light control. Similarly, the PROSAFE project [10] explored the use of infrared motion sensors for automatic recognition of residents' activity and detection of possible falls. More recently, Chung et al [11] tested the feasibility of a home-based sensor system designed to assess mobility and daily activity patterns among Korean American older adults and Gaugler et al [12] explored a smart home system using motion sensors to facilitate remote activity monitoring for persons living with Alzheimer's disease. In both of these studies, while initial issues around system modification and calibration were identified, ultimately the smart home features were found to be useful in preventing adverse events and supporting family caregivers. Another intervention called Sense4Safety [13] uses smart home tools to provide a nursing intervention for socially vulnerable older adults with mild cognitive impairment. In this system, depth sensors are used to calculate a fall risk score for people living alone based on continuous gait assessment in their own residence. A nurse coach accesses information about fall risk scores, gait characteristics and consults with individuals regularly about appropriate exercise or environmental modification interventions. Additionally, the system generates alerts when a fall has been detected allowing the nurse coach to review a sequence of a silhouette extraction for the last few minutes prior to the fall to confirm that the alert is a true positive one.

Many of the smart home initiatives and commercially available products target older adults and their family caregivers in order to support aging in place. In a scoping review [14] the adoption of smart health systems for people with dementia and their family caregivers was examined. This review highlighted challenges in the adoption of the technology including the lack of tools to help match the appropriate technology to each individual and their family based on their unique needs and preferences, and lack of clarity as to when the right time is to introduce the technology.

Smart home systems have the potential to facilitate a shift from a reactive to a proactive models of care. Currently, our systems of care respond to an adverse event (such as a fall or a hospitalization) trying to reduce the consequences after it occurs. Smart home technologies may promote a proactive response (for example, detecting patterns of decline that can lead to a prevention of the adverse event). A typical example that has been well documented is the early detection of a urinary tract infection that is more rapidly identified based on the use of bed sensors that capture a significant increase in bathroom visits at night; an early detection can prevent unnecessary hospitalization. The challenge is to create effective linkages between the smart home technology itself and timely, effective and personalized interventions when alerts or notifications are generated. Additionally, ethical implications including privacy and autonomy, data sharing and accountability have to be further examined.

3. Personal Health Informatics: Future Research Directions

Further research is needed to evaluate how PGHD can be used to support clinical decision making and their impact on health outcomes and cost of care. Additionally, studies are needed to address quality, accuracy, and reliability of the data produced in various settings and case scenarios. The accuracy and reliability of data capturing platforms will have to be examined as more individuals decide to generate and share data with their clinicians. Many premises of personal health informatics still remain unanswered: Does the use of personal health informatics tools lead to more patient engagement and ultimately patient empowerment? How does it affect an individual to be continuously aware of a potential health decline? What may be other unintended consequences of personal health informatics tools as we introduce ongoing monitoring of one's daily living?

The design of personal health informatics tools calls for usability studies that will capture the patient voice and address needs and preferences of patient groups, and explore how to most effectively visualize data to provide actionable and meaningful feedback to various stakeholders (including patients themselves, family caregivers, clinicians and others). In this context, emphasis needs to be placed on inclusive design that allows individuals with varying degrees of cognitive and functional abilities as well as experience with other technologies to fully benefit from personal health informatics tools.

3.1. Policy Implications

Policy considerations for the field of personal health informatics include the challenge of interoperability of devices and systems, the use of standards for various tracking modalities, issues of reimbursement and frameworks that introduce safeguards for liability and privacy. Determining the frequency or intervals of tracking and analysis, techniques of measurement, and how providers should manage the data are a few examples of tracking modality challenges. A mismatch between system development and readiness to successfully integrate and use the data can emerge when technological advancements happen too quickly for current healthcare practices to catch up [5]. Identifying the entity accountable for the analysis of the data—the provider or health system, the vendor of the digital tool, or a third party is critical to addressing liability. Additionally, creating policies and processes for dealing with PGHD and upholding transparency on the use of the patient's information is an important step in documenting liability. The present payment structures do not currently cover many of the personal health informatics platforms to care management or delivery, which may currently restrict the integration of PGHD in practice. New digital tools must align with institutional goals, and organizations need to develop business cases that include payment methods and value-based reimbursements.

The integration of PGHD into Electronic Health Record systems has not been completely investigated, and current initiatives have shown the necessity for widespread industry acceptance of interoperability standards [6]. There are challenges in regulating PGHD-related hardware and software. Since they are marketed as "lifestyle devices," many mobile apps and sensors do not require FDA approval.

A further challenge with the emergence of PHI technologies is the potential to exacerbate existing inequalities. We must rethink health innovation through a lens of equity and the needs of patients, families, and communities to engage in improving health, wellness and safety. The COVID pandemic as well as recognized societal crises such as climate change and structural racism have highlighted how technological innovation may exacerbate inequality by ignoring or sustaining marginalization and injustice. We can design technological solutions with active engagement of marginalized communities with the explicit goal to challenge rather than reproduce structural inequalities. Person centered innovations in health care need to center on the needs of individuals, families and communities including and potentially prioritizing low resource high need populations and marginalized groups. Innovations can provide solutions if focused on the right needs and the right problems and we can only get the right problem by working directly with the individuals, families and communities of interest as co-creators and co-designers of solutions. Furthermore, we need to re-define the design process for PHI tools whereby individuals and families are co-creators with active engagement in all design phases, rather than passive recipients of new processes, hardware and software tools. Patient empowerment and shared decision-making are emerging as key principles in health care systems; however, current information technology applications fail to reflect the input from individuals, families and communities in their design. The design of health innovations requires a careful examination of values that are encoded and reproduced in the created systems, as well as the impact any new technology or device has on communities, particularly marginalized ones.

3.2. The Clinical Workflow

In addition to integrating data into EHRs, the clinical workforce must be trained in the use and interpretation of PGHD. This requires the establishment of best practices and procedures for integration of PGHD into the clinical workflow. For example, real-time alert systems that align with the health systems' workflow may help clinicians effectively process a large quantity of data to identify when follow-up action is needed. Such an approach would require careful consideration of rules and thresholds in order to minimize alert fatigue. While opportunities emerge when integrating PGHD into the clinical workflow, there are also identified challenges. Health care providers have expressed concerns over the potential added burden of reviewing PGHD outweighing any potential for added efficiencies [3]. In a simulation study to understand changes to a health system when PGHD are added into the clinical workflow, researchers identified indirect consequences of additional time and cognitive demand, increase in labor cost with additional time required to assimilate PGHD [7]. Workdays and patient visits were extended and became less predictable, with nurse utilization rates increasing while physicians' remained relatively unchanged. The authors concluded that the impact of PGHD is nontrivial and would cause longer workdays or mandate sacrifice of other activities. They warned that using PGHD without adequate preparation could have serious consequences, and that realistic responses to the impact of PGHD are required.

4. The Personal Health Data Scientist: Implications for the Clinical Workforce

The technological advances that have introduced novel personal health informatics (PHI) tools have created a new landscape whereby consumers are faced with many choices but also little to no guidance as to how to navigate this reality, select the appropriate tools, identify the reliable ones, and integrate them effectively into their own health care. This calls for a new role for clinicians and/or other staff within health care systems, that of the "personal health data scientist."

Responsibilities within this role include

- Assisting patients and families in the selection of appropriate and tailored tools (including hardware and software)
- Maximizing effectiveness of use based on individual information needs and preferences
- Explaining risks and benefits, including terms of use for various commercial platforms and an education in how data are collected, stored and potentially shared in the future
- Helping in the curation of personal health data
- Overseeing the integration of patient generated health data, when appropriate, to support clinical decision making and determining whether or how such data may be relevant to processes of care
- Facilitating the interpretation of data recognizing that patients and family members may have varying degrees not only of literacy and health literacy but also data literacy (the ability to interpret data points and processes of data collection and storage) and graph literacy (the ability to meaningfully extract knowledge from various graphs and visualizations).

PHI tools are often designed without active involvement of the end user target group in the design phases, and as a result, they fail to become accessible and meaningful to many end users. Furthermore, many of these tools may require infrastructure thatnis not readily available. Indeed, many commercially available PHI tools may be inaccessible to patients who lack required infrastructure such as broadband Internet. In the US specifically, according to the American Community Survey (ACS), 18.1 million Americans (15% of all households) in 2018 did not subscribe to any form of "broadband" Internet service (which the Census Bureau defines as anything faster than dial-up access) [28] and it is hard to estimate how many of the remaining households have continuous, fast and reliable access. Of those households with a broadband subscription, 14 million only have a cellular data plan, and 12.3 million only have a wireline subscription. Broadband gaps exist throughout the country. While adoption rate is lower in rural areas compared to urban ones, the majority of digitally disconnected households lives in urban areas. Additionally, personal health informatics systems may be inaccessible to patients who experience functional or cognitive limitations, visual or hearing impairments, lack experience using technology, have limited English proficiency or lack a personal support network to help them access these systems.

There are existing solutions to some of these challenges that have been emerging. New videoconferencing solutions, for example, introduce features such as closed-captioning, screen readers, web templates that meet accessibility standards for users with functional, visual or hearing limitations and peripheral monitoring devices with accessible design that can be used by these patients. Medically qualified interpreters can participate in telehealth encounters and on-demand video interpreting services can be integrated into the scheduling and delivery of telehealth services. Finally, personal health informatics tools can adapt to limited connectivity (e.g., by offering services that use cellular networks or text messaging services to reach patients when appropriate). Partnerships are being built to implement long-term solutions to connectivity in rural communities.

Inclusivity needs to be a mandate for personal health informatics systems. To this end, five strategies can be pursued to create a more inclusive and accessible PHI ecosystem:

1) Given the significant reliance of health care, education and tele-work on digital platforms it is important to consider what Zuckermam [29] calls a "digital public infrastructure" that will recognize the Internet and online platforms as public utilities accessible to all (and regulated as such). Coordinated efforts at the federal, state and local levels need to aim for universal accessibility of broadband Internet and necessary hardware.
2) The inclusivity mandate needs to be reflected in product design for new PHI hardware and software and in reimbursement requirements.
3) Health systems and industry partners must build partnerships with patient advocacy groups to ensure their engagement and representation in the design, implementation and evaluation of PHI systems.
4) The medical and nursing curricula need to provide future health care providers with tools to advocate for accessibility of digital platforms for patients and families and strategies to improve the patient experience in a digital world.
5) This is a unique opportunity to rethink the role of patient navigators as those not only assisting with the navigation of the medical system and coordination of services and scheduling, but also assisting with the navigation of the digital health landscape for patients and families with varying degrees of digital literacy. This could be in partnership with the "personal health data scientist" function described earlier.

5. Conclusions

Personal health informatics continues to grow and evolve as a domain. Consumer expectations and technological advances are generating new approaches to one's monitoring of their own health and well-being. Advanced computational approaches including predictive analytics, machine learning and natural language processing are explored to unleash the potential of big data created by a plethora of wearable, passive sensing and other consumer-oriented systems. This field is a truly interdisciplinary one, as it calls for a comprehensive assessment of clinical, socio-technical, ethical and legal implications of the design and evaluation of PHI tools. We need to ensure that these tools are accessible and do not exacerbate existing inequities, as health technologies often do. This requires that we recognize inclusivity as a mandate for the design of PHI tools and explore the opportunities to promote consumer education and help patients navigate the digital landscape. Many ethical issues including informed consent, autonomy and right to privacy as well as policy considerations regarding interoperability, reimbursement and accountability still need to be further explored. Furthermore, PHI introduces an opportunity to co-design solutions with end users as experts of their own lived experience and health needs and preferences actively involved in the conceptualization of these systems.

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Organisational Change: Using Health Informatics Education as a Change Agent

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Abstract. This paper highlights some of the challenges, achievements and collaborations using health informatics education and research as a change agent in which I have been involved over the last 40 years. The Open Software Library (OSL) was a specialist publisher of Computer-Based Training materials (CBT) mainly authored by nurses and medics. The "Rainbow" series of distance learning materials, "Using Information in Managing the Nursing Resource" sold over 55,000 copies. It was utilized as the basis for seven Universities' Certificate and Diploma programmes and in-house training by the NHS to encourage organisational change. Workshops at Manchester University's HSMU focusing on evaluation studies highlighted that most NHS IT projects failed because of human and organisational issues rather than IT. This led to the development of a master's degree in Health Informatics shared between four European Universities. IMIA conferences, Working Groups and the development of the IMIA approved Education Recommendations and the IMIA Knowledge Base are effectively used worldwide.

Keywords. Strategy, Change Management, Evaluation, Education, Health Informatics

1. Introduction

Mine has not been a solo journey; it was only possible because of the involvement of many collaborators who supported my journey.

My employment since 1980 has been in management and organisational change within the UK National Health Service (NHS), Consultancies, and Universities. In parallel, I have had an academic interest and voluntary involvement in Health Informatics through the Centre for Health Informatics Research and Development (CHIRAD) and the British Computer Society (BCS). Much of my consultancy work has been "Business in Confidence" and thus cannot be published, in particular, my MBA thesis "A Review of the NHS IT Strategy". However, in this paper, I will attempt to give a flavour of the impact of some of the other projects with which I have been involved.

2. The Open Software Library and Computer Based Training

I started my Certificate in Education (Cert. Ed.) in 1980 at Huddersfield Polytechnic and had the opportunity to take an advanced computer programming course. The assessment

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of which was to produce a teaching program and a paper explaining the overall functions and purpose. On my return to Warrington General Hospital, I was asked to provide some sessions about computers, which were enthusiastically received, and inaugurated the Warrington Hospitals Computer Club and the Open Software Library (OSL) with David McKendrick [1].

The obstacles we faced included over 20 models of computers with incompatible operating systems and a lack of understanding of the uses and limitations of Computer Based Training (CBT) by healthcare teachers. Some of the solutions we tried to overcome these hurdles are listed below:

1. Using authoring tools. Microtext was available for several operating systems and soon enabled a catalogue of software to be created; the authors received 70% of the sale price.
2. Partnering with the Nation Health Service Training Authority (NHSTA) to undertake several functions including assessing, cataloguing, and publishing their materials via OSL including a simulation of a major disaster in Microtext and using a Laser Disk Drive.
3. OSL ran workshops and demonstrations at IT conferences including the BCS annual Health Informatics Conference, which had over 4000 daily attendees.
4. Publishing papers at conferences including Medical Informatics Europe (MIE) 1985 and the 1st International Conference on Human Resources in Health Care [2] and in journals [3].
5. The journal Nurse Education Today commissioned OSL to write a series of six articles explaining computers and their potential use in nurse education.
6. In partnership with NHSTA, OSL organised two Computer Based Training Conferences at Keele University in 1986 [4] and 1988 [5].
7. In 1985 the first International Conference paper about OSL was presented at MIE 85 in Helsinki [6] to a "who's who" of the BCS and EFMI and AMIA nursing informatics colleagues.

The first national conference on the "Use of Computers in Health Care and Training" was organized in partnership with the NHSTA and is widely believed to have been the first UK Conference to have its proceedings edited, published and printed before the start of the conference, so participants were presented with a printed copy of all the papers on arrival. In 1988 a second conference was organised at Keele University and featured many leading edge developments including CBT packages linked to the Phillips Laser disc and a demonstration and paper about the Fidonet emailing system [7].

In 1986 OSL set up a free-to-access Bulletin Board System (BBS) [8] on Fidonet that ran continually for 21 years on the same computer until 2007. Fidonet is still in existence https://www.fidonet.org. Tim Berners-Lee who ran an English Fidonet node just a few nodes down the chain was always complaining about the inefficiency of the system and how perhaps we could use the Post Code or letterbox numbers style number to represent an individual BBS. He went to CERN to develop their communication and developed the World Wide Web (WWW) in 1989. Berners-Lee persuaded CERN to give the copyright to a foundation later named the World Wide Web Consortium (W3C) https://webfoundation.org/about/boards/tim-berners-lee/. He is also a Fellow of the British Computer Society (FBCS). The activities of OSL and its membership had a significant impact on the adoption of Computer Based Training in the UK.

3. Free and Libre Open Source Software (FLOSS) and Value Systems

Several thoughts occur in mankind's behaviour that puzzle, particularly regarding the value of software and services. OSL was asked to submit a proposal for an online database to house the NHS Surplus Equipment database. We had access to the SQL database used by the NHS and so installed it on the Fidonet BBS and gave a demonstration of it completely operational online. As we had done the work to put it online the only real cost was the expense of continuing to run a BBS. We saw the news sometime later that a national telecom company had been given a three-year contract to develop it, but nothing more was heard of it. It seems that mankind is wary of FLOSS software solutions but happy to pay large amounts of money to a large nationally known company. There is no doubt that this risk avoidance behaviour is present in many government departments and national corporations. Bill Gates showed that putting a new frontend on MSDOS to make it easier for ordinary people to use and look good could be the basis of charging for software. He persuaded the manufacturers of micro-computers of its added value and so many machines came complete with Windows.

Peter Murray and I had these and similar conversations when we were helping to facilitate members of the European Commission Expert panel. He helped with the English grammar, and I gave financial input regarding what was permitted and what wouldn't be funded. We aimed to help projects find the right balance to achieve acceptance for funding. We established that some Health Informatics organisations needed help to understand the notion of FLOSS and put together a structure to support open source via the IMIA working group systems, the IMIA OS WG was formed in October 2002 https://imia-medinfo.org/wp/open-source-health-informatics , followed by the European Federation of Medical Informatics (EFMI) Libra and Free Open Source Software (LIFOSS) in 2006. In 2003 people in Washington smiled at us as we pinned up information about a meeting to start a FLOSS group, saying we wouldn't get the required 50 AMIA members. They were right we had over 200 people in the room and so the AMIA Open Source Working Group was formed.

An EMFI Special Topic Conference at the BCS HQ in London [9] was organised by CHIRAD, EFMI OSWG, and the BCS chairman. Thomas Karopka later said "The ideas and theses in this paper were stimulated by discussions with various participants at the EFMI special topic conference "Open Source in European Health Care" which took place in September 2008 in London. My special thanks go to all participants of this conference" [10]. Thomas became Chair of the IMIA group when I emigrated to South Africa. He was foremost in the development of the online repository of FLOSS in Health and the results of the IMIA OSWG thinking [11].

During Covid-19 the world moved to online seminars and I was invited as Chair of the HELINA and SAHIA Education Groups, to facilitate several seminars including a series of eight sessions by the open source GNU Health team which are available on the GNU site. So my passion for FLOSS continues.

4. System Failures

Victor Peel opened the Centre for Health Informatics in the Health Service Management Unit (HSMU), Manchester University and invited a number of us to be Honorary Fellows, Sir Duncan Nichol, Denis Protti, David Colin-Tome and myself in 1989. We organised several three-day courses on nursing information and had an unexpectedly high number of applications, so the course was repeated quarterly. The team undertook multiple reviews of hospital systems, and I took the lead on the nursing systems. Thus, we had people attending the courses and people from the reviews talking about the current situation, but we needed to look to the future and try to change the number of failures.

In the majority of sites under review, technology usually did what it was supposed to do. Then the opportunity came to look at an implementation in Winchester and Eindhoven both using the same system. The Royal Hampshire County Hospital had a "full-blown" Electronic Health Record (EHR) that eventually ran for 25 years, while the same system in Eindhoven never became operational before it was decommissioned. Jos Aarts, Victor Peel, and I, together with input from Denis Protti discussed all the causation issues for these failures. We developed a model to address them and in 1997 presented our initial thoughts at a conference (12) and the paper was published in the conference proceedings "Health Telematics Education" edited by John Mantas. Whilst sitting in a Copenhagen café the three of us worked most of the day drafting the full model paper as evidenced by our reviews of implementation failures, which are shown below.

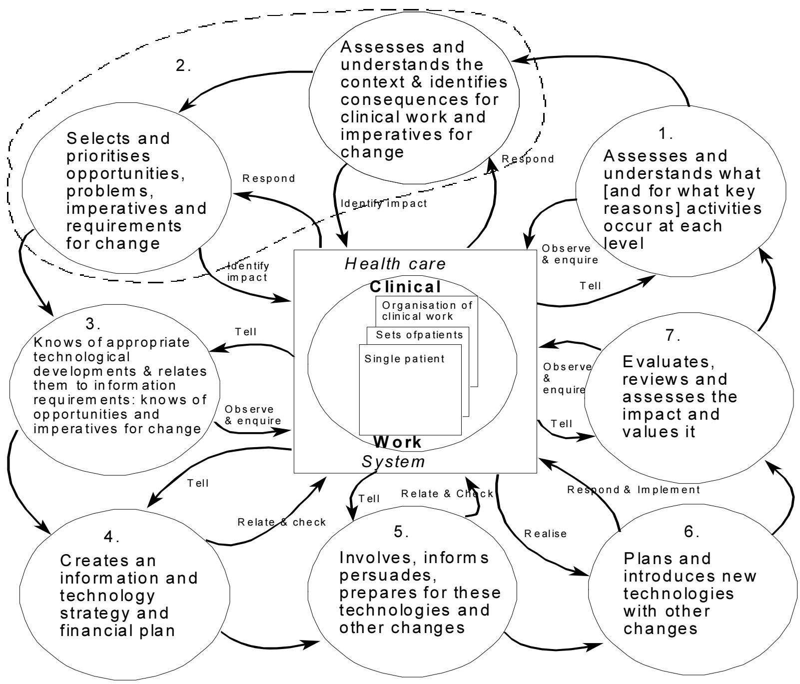

Figure 1. Showing the Aarts, Peel and Wright model [13]

Using the issues identified during reviews and looking at the areas absent from the many health informatics programmes we designed a master's degree. Looking at the expertise required to provide the different modules it was decided that we should offer the MSc Health Informatics programme at Surrey University's European Institute of Health and Medical Sciences (EIHMS), where I was Director of Education. Manchester University and Erasmus University would be partners. I recruited John Bryant (BCS Treasurer, IMIA and EFMI board member) to manage the programme at Surrey University. The first cohort was oversubscribed and most of the group were known practitioners in Health Informatics, who wanted to have a post-graduate qualification.

The full paper describing to degree design was published in the "International Journal of Medical Informatics" as "Organisational issues in health informatics: a model approach" in 1998 [13]. It is the highest cited of my papers after the IMIA Education Recommendations article [14]. Human and Organisation modules then started to appear in other HI master programmes.

5. How do you Train a Total Population of a Nation's Nursing Staff to Understand the Use of Information when Managing Resources?

Christine Greenhalgh, Director of Greenhalgh and Company Limited (GCL) had answers to the question. One was having the staff who could work together with the talent of being able to deliver the vision. In 1990 she persuaded NHS senior nurses that the model of large population training needed to be based on the experience of senior nurses working in learning sets to produce the training needs and then write learning material that could be used as in-service training supervised by a trainer, self-learning or as part of a formal education programme. The overall programme decided by the Chief Nurses would be called "Using Information to Manage the Nursing Resource", having five main headings, Quality, Workload, Skill Mix Management, Financial Management and Human Resource Management and two modules developed by GCL Consultants, Setting the Context and Analysis and Presentation [15].

Each of the five main module workshops was hosted by the Chief Nurse of the region together with a GCL consultant who produced a draft outline following all the day-long meetings. Hence feedback to the teams producing the materials for each chapter and the Steering Committee of Regional Nurses allowed rapid development. When the final collection of books was ready for testing and production, the following points were noted:

- Each book contained a standalone learning module
- Topics could be studied in any order according to the needs of the individual or organisation
- Two modules Setting the Context and Analysis and Presentation could be used as reference texts
- The Health Service Management Unit and GCL would produce a formal Certificate and Diploma programme using the materials
- The initial press run would be 35,000 sets, 27,000 of which went to the NHS training schools. A second run of 17,000 was produced and sold for 70 pounds a set

During cover design, it was agreed not to show a reading order and so it was printed in the seven colours of the Rainbow to the delight of Jean Roberts who was responsible for marketing. From that day on the materials were known as the Rainbow course [16]. It was the first of a series of training materials (Rainbow Series) produced for and used by the NHS that was accompanied by supportive training from GCL. A report from the NHS in England identified it as "an excellent development programme for nurses, which was relevant in the NHS agenda, providing a flexible approach to learning" [17]. The following year an evaluation of Rainbow in Scotland found that over half of their colleges used the material and that there were demonstrable changes as a result of this training [18].

"Using Information" was the resource used in formal programmes at Manchester University; a Certificate level for users and a Diploma level for future facilitators that also included marking and setting credit-rated assignments, and facilitation skills so the diploma graduates could run the program in their health workplace or in conjunction with a university. Manchester University subsequently franchised to all six institutions in the University of Wales.

6. Cognitive Mapping and the IMIA Knowledge Base

One of the BSC and CHIRAD's joint projects was a cognitive mapping exercise called "Open Steps" using several interesting methods to identify concepts employing Bloom's Taxonomy as the indicative level of intellectual thinking to undertake health informatics activities at certificate, diploma, graduate, or postgraduate level. BCS funded a 24-hour workshop at an Otley conference venue near Harrogate, England so attendees could also attend HC2005. A grid was used to map the range of experiences and functions that would identify potential attendees, and an outline paper regarding the workshop and reading materials were sent to them. There was an excellent response rate and individuals invited replied positively, including overseas participants from South Africa, the USA, and Europe. Presentations of the exercises and a timetable of activities were followed by group exercises to identify the main headings of Health Informatics. Small groups, led by a researcher had a rapporteur to record the discussions. Each group developed learning objectives on Post-it notes which were then photographed so they could be projected.

Figure 2. One of the brainstorming outputs, each group had a different colour Post-it notes: this is one of the group's outputs, projected for all to see and vote on.

Overnight the next exercise was prepared using the identified 13 headings, each one on a separate large sheet of paper prepared with Bloom's six levels of Taxonomy. A grand dinner including the after-dinner speaker, the BCS Health Chair Glyn Hayes relaxed the participants who continued to discuss the next stage of the exercise. In brainstorming sessions participants produced learning outcomes on Post-it notes that were placed in the appropriate space on the Bloom's taxonomy grid.

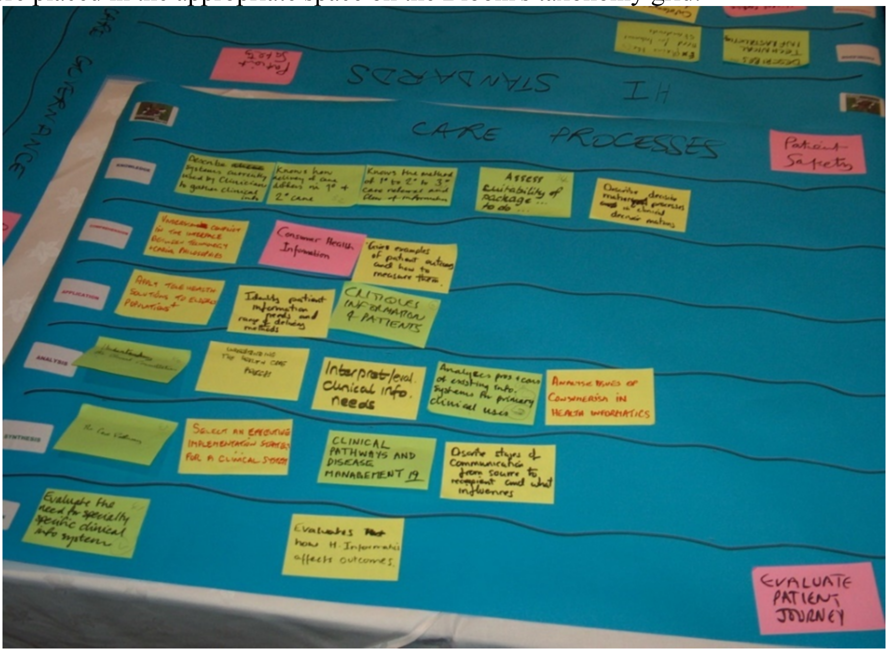

Figure 3. One of the paper sheets indicating Bloom’s Taxonomy levels

Participants had to place one of the 13 subject tables at the level of Bloom’s Taxonomy. Where people thought they could exist underneath different subjects then duplicates were allowed and if somebody disagreed, they could put an X on the statement.

Figure 4. showing multicoloured Post-it notes being placed on the Hierarchy of Bloom’s Taxonomy by participants.

The resulting Bloom's Taxonomy mapping was describing learning outcomes in health informatics use at the time and place as perceived by the participants. It was tested out by the team using an electronic voting system during presentations and workshops at several IMIA, EFMI and BCS events [19].

7. The IMIA Knowledge Base

Nancy Lorenzi, President of IMIA recruited a task force [20] that included some of the team involved in the BCS Cognitive Mapping project to update the IMIA strategy. It was agreed to use the cognitive mapping outcomes to develop a Knowledge Base using the keywords in published papers. Reference Manager could generate keywords for documents than had not listed them as such. Some 10,000 different words were produced. These were given to teams of informatics experts at a workshop in London in January 2007 who reduced this list to 444 words, by voting out spurious words to remove firstly common language words. The next stage had "voting in" the remaining words that were applicable to the informatics labels. This was undertaken by emailing all members of all the IMIA working groups and countries to use a spreadsheet to vote for sections of the spreadsheet which had all the letters of the alphabet as column headers. They were asked to focus only on the columns that used the first letter of their surname. XYZ was combined with W to even out the occurrence of surnames.

The results were collated by teams of experts over several weeks and placed under the Cogitative map 14 final headings [21] and the report was submitted to the IMIA General Assembly [22].

Computer Science for Health	Health & Social Care processes	Health (care) records	Health and Social care Industry	Health informatics standards
1	2	3	4	5
Biomedical equipment interfaces	Advantages and disadvantages of existing systems for primary clinical uses	Audit trails	Assess Health Informatics readiness of an organisation	Clinical coding systems
Collaborative Internet architectures	Application of telehealth solutions to the elderly population	Case note tracking	Financial management	Clinical interface protocol

Figure 5. an extract from the 245 units The IMIA Knowledge Base

8. Using the IMIA Knowledge Base and the Education Recommendations to Create an MSc Content

I have perceived the IMIA Education Recommendations as the overarching curriculum structure and the IMIA Knowledge Base as the detailed content. The former was overtly so with its relationship to degree structures and implied weighting. The Knowledge-Base started as learning outcomes using Bloom's Taxonomy's six stages but emerged as content heading within the format of the Knowledge Base. Thus they could describe the content within each of the Recommendations [23].

The review at The University of Rwanda, College of Medicine and Health Sciences (CMHS) firstly identified the skills required by Master's graduates in Rwanda and then undertook a gap analysis with the existing programme. An SQL 3D database was built by Frank Verbeke having the IMIA Recommendations and IMIA Knowledge Base within its database. A full explanation can be found in several publications [24] and a new edition of Nursing and Informatics for the 21st Century – Embracing a Digital World, 3rd Edition, Book 2 [25].

The following example is taken from the curriculum document and shows part of one of the modules that was developed using this database to ensure a spread of concepts and equity of module values.

Table 1. Extract of Module from REHCE Curriculum Review

Brief description of aims and content
This module is an introduction to the discipline of Health Informatics and the scope of the program. It covers several basic concepts in Health Informatics and ensures that the students from different backgrounds have the opportunity to share perceptions of Health and Medical Informatics.
Learning outcomes (IMIA competencies)
1.1 Evolution of informatics as a discipline and as a profession
1.4 Use of personal application software for documentation, personal communication including Internet access, for publication and basic statistics
3.1 Basic informatics terminology like data, information, knowledge, hardware, software, computer, networks, information systems, information systems management
3.2 Ability to use personal computers, text processing and spreadsheet software, easy-to-use database management systems
3.3 Ability to communicate electronically, including electronic data exchange, with other health care professionals, internet/intranet use
3.4 Methods of practical informatics/computer science, especially in programming languages, software engineering, data structures, database management systems, information and system modelling tools, information systems theory and practice, knowledge engineering, (concept) representation and acquisition, software architectures
3.5 Methods of technical informatics/computer science, e.g. network architectures and topologies, telecommunications, wireless technology, virtual reality, multimedia
IMIA KB Indicative content (units)
Access to information
Computer literacy (ECDL)
Computer systems
Computing methodologies
Data management and storage
Databases
Demystify IT for users
Explains health informatics
History of methods of gathering information in the clinical workplace
Human-Computer Interaction (HCI) principles Information sources
Information Storage and Retrieval
Internet, intranets, and associative technologies

The learning outcomes are from the IMIA Education Recommendations and the indicative content from the IMIA Knowledge Base. The programme was successfully validated in 2014 with all the modules generated using the same process [24].

9. Reflections: Work that Disappeared or had a Different Impact than Envisaged!

Following the 1986 First National Conference on the Use of Computers in Health Care Education and Training at Keele University, David McKendrick and I received an invitation to present at a 3-day conference in Kielce, Poland for the Deans of Polish Medical Schools, as a result of the attendance at Keele University by a Senior Polish Professor. On arrival at the airport, I was greeted by a senior academic and three UK speakers sponsored by the British Council, including Dr David Ingram who had presented at the Keele conference [26]. I was asked to Chair the day with the UK speakers as they said, "They could understand my English"! Extremely strange as all three had Oxford English accents. The first problem was a lack of computers and no projector, so we spent a day writing acetate folios using coloured pens as they had an Over Head Projector (OHP). We had applause after applause, as they had never seen a coloured acetate pen. We left lots of presents and I secretly carried home a bundle of Scientific papers that eventually were all published under pseudonyms. They had seen lots of OSL logos on the teaching materials that their delegate had taken home and assumed that I was the director of the NHSTA and could donate millions of pounds in funding. They were however extremely happy to receive all the OSL Software Library CDs and a collection of Public Domain software. Whilst I was playing the guitar with a local Polish rock band, David Ingram asked our translator to dance. After a long courtship when Poland became liberated, they married.

An early attempt at populating the BCS/CHIRAD cogitative map with published work was started by assembling as many papers as possible that were available electronically mostly from CD publications. Several online search engines became available for desktops, including Google Desktop, Copernic and ASK. Fourteen months into the analysis of the massive collection housed on two Lacie250 hard drives the results showed no consistency between the search engines. The results were meaningless between the group of search engines and an SQL database search. A rethink and conversation looked with interest at the use of keywords used in many papers. Interestingly Reference Manager would compile keywords from a paper where they were missing. Fortunately, the "Open Steps" workshop produced the 14 key headings and so the process described earlier was followed.

The Learning Set "Caring for the Community" explored the information models required to underpin a strategic funding model. It lasted two years coordinated by me as a member of staff of both organisations, the HSMU, Manchester University and GCL. It had an invited membership of experts from Health and Social Care and was facilitated by Christine Greenhalgh and Victor Peel. When the report was ready for publishing a section of the group requested not to be named as participants. The resulting document seemed to be the health service telling the social service how it should change its strategy. Northern Ireland had an integrated model of Social and Healthcare at the national level at the time. The Prime Minister was questioned about it in Parliament resulting in the opposition party requesting multiple copies from the Manchester University Library [27]. I never expected either of those incidents nor did Christine and Victor, but we suspect our social care colleagues might have done.

Greenhalgh and Company (GCL) were a partner in the follow-on to the successful EU Commission funded Eductra project to be called IT Eductra [28]. With Jean Roberts and I providing input, organising Authors and content. Later I was asked to organise the distribution of the CDs in the UK as we had experience with learning material distribution of 60,000 copies of Rainbow 1. The main outcome was a CD-ROM containing the teaching materials and tools in 8 European languages. The HELINA Education WG loaded many of the still relevant materials onto the HELINA website in 2020.

The IMIA Knowledge Base was approved together with the IMIA strategy. It is an IMIA approved document, but unlike its fellow IMIA approved "Education Recommendations" document has only a handful of citations. Perhaps I should have published a "How to use" with the IMIA Knowledge Base with the IMIA Education Competencies paper earlier than 2014.

Methods of Information in Medicine publication of "Biomedical informatics: We are what we publish" was completely unexpected in the form it was to emerge in print [29] as part of a "For-Discussion-Section of Methods of Information in Medicine on Biomedical Informatics: We are what we publish". It consisted of an editorial, a paper by P Elkin, S Brown and G Wright followed by a commentary paper with 12 invited experts (30), Hammond, W E, Hasman, A Hussein, R, Koppel, R, Kulikowski, C A, Maojo, V, Martin-Sanchez, F, Moorman, P W, Moura, L A, de Quirós, F G B, Schuemie, M J, Smith, B, Talmon, J. On the day I presented the report on the IMIA Knowledge Base to the IMIA GA, Peter Elkin and I had a long discussion and he spoke about the intended use of SNOMED as a higher archival framework. Three years later he asked me to be a part of this somewhat out of the blue, even though we had met on numerous occasions. If you believe in coincidences or degrees of connectivity; SNOMED CT used Read Codes in its structure which were developed by Dr James Read a GP in England and as a Junior Doctor on the medical team where I was a Charge Nurse in the Intensive Care Unit (ITU). Some years later he was the Head of the NHS Coding Centre and I was Chair of the BCS Nursing Group which had some of his staff as prominent members. He said that I was responsible for him taking the path away from clinical medicine in front of me and most of the eminent Health Informaticians attending the National BCS HC Conference in Harrogate.

Discussion or Closing Remarks

In 1997, Professor Jim Bridges at the European Institute for Health and Medical Sciences, University of Surrey asked me whether I wished to be remembered as a facilitator or a researcher and stated that I needed to choose at this point in my career. I have thought about this in the 24 years since and realise that I am a Facilitator or Change Agent who helps others to rethink their current paradigm. Sometimes I engage them in activities to allow them to rethink and produce different scenarios. In other situations I get them to undertake simple analysis, for example in 1989 I took charge of the Mersey Region amalgamated Mental Health Nurse Training School to prepare the move into higher education at Liverpool Polytechnic. I had all the teaching staff keep a diary and record their main activity in hourly slots during the day for two weeks. At a two-day workshop, they were asked to look at their employment as a Mental Health Tutor and the functions as described by several General Nursing Council and English National Board documents. After agreeing to the list of contracted duties and another list of recorded activities they had made, 93% of the second list was missing from the job specification/role list. In other words, they worked very hard but not for their employer. Unfortunately, although they agreed they were happy doing activities they liked doing for the Hospital like running committees and sitting on interview panels, I failed as a change agent as they all were unemployed a year later because they failed to change. To be a facilitator one has to be able to undertake research which is used and makes a difference. My reply to Jim was "both".

The jobs titles that I have held include ITU Charge Nurse, Clinical Teacher, Senior Nursing Officer Teaching (SNOT), Senior Managing Consultant, Director of Education and Professional Training, GP Clinical Tutor, Company Director, GP Strategic Manager, Research Professor, Research Champion, Chair of Health Sciences Research, Adjunct Professor, and currently Visiting Professor (Rhodes University) and Professor Extraordinarius (UNISA). As you can see a bit of a Jack of All Trades.

Acknowledgements

My significant collaborators include Peter Murray, Jean Roberts, Christine Greenhalgh, Victor Peel, Dennis Protti, Sir Duncan Nichol, Jos Aarts, David McKendrick, John Bryant, and Glyn Hayes.

I published a paper by Helen Betts in 1988 and she has been my partner ever since in most of my academic work and several companies. She is my life and my wife, Dr. Helen Wright.

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Milestones and Outcomes in Health and Human Services Informatics Education Programmes

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Abstract. This chapter describes the milestones and outcomes of Health and Human Services Informatics (HHSI) education programmes at master and doctoral degree level. In Finland, since the year 2000 the programmes have been based on the International Medical Informatics Association (IMIA) recommendations on biomedical and health informatics and the master's degree programme has been twice accredited by the IMIA Accreditation Committee. The paradigm created to advance and support both education and research in the health and human services fields is used to analyse and synthesize the research focuses of students' theses and evaluate milestones. The outcomes of HHSI programmes are described using quantitative and qualitative data from a student administrative database and student theses. The research focuses and research methods were coded for master's and doctoral theses based on the HHSI paradigm. Experiences from the accreditations and feedback are summarized to provide insights for future development. Based on the results, recommendations for further development of the programmes are provided.

Keywords: accreditation, education, paradigm, informatics, curriculum, thesis

1. Introduction to Health and Human Services Informatics education

In Finland, as in many countries, health and biomedical informatics education has expanded along with the development of the information management systems and electronic health records (EHRs) used in health care since the 1990s [1-2]. Digitalization continues to play an important role in the current health and social services reform [3]. Information and communication technology (ICT) solutions and digital services are tools for improving healthcare and social welfare services and creating better opportunities to maintain and improve citizens' health and functional capacity. Digital services can also help people to follow their health and functional capacity themselves [4]. Information system services have been adopted in healthcare and social welfare across the country and the coverage for EHR usage in hospitals is 100% [2, 5]. The national Kanta services are designed to serve both citizens and professionals in healthcare and social welfare. At present, the Kanta services include electronic prescriptions, a Patient Data Repository, and the opportunity for everyone to view their health information online (My Kanta) [6]. The content of Kanta services is expanding and will in time include social welfare

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services, oral health services, and the Personal Health Record designed for citizens' use [7]. All of these developments and changes in service systems clearly require advanced knowledge and skills among all experts working in the health and social welfare services.

The University of Eastern Finland (UEF, previously University of Kuopio) established the very first programme 'Information Management in Health and Social Care' in 2000, which was regarded as the first step towards expansion of health and biomedical informatics education. Initially, the programme was partly financed by the EU (European Social Fund). In 2005, a permanent degree programme was established and funded by the Ministry of Education. The programme currently operates under the title Health and Human Services Informatics (HHSI), which reflects its present focus. A clear objective from the outset has been to combine the perspectives of two key service sectors – health and social care – within the education programme based on the developments in Finnish society [8].

Health and Human Services Informatics is understood as the management of the information resources of an entity, e.g., an organization, covering the activities, actors, and methods involved in the production of health and welfare services for public and private sector organizations. Information resources are understood as systems, applications, devices, communications tools, data repositories and, most importantly, people as sources and utilizers of information. Management of information resources is crucial when changes in practice are planned [9-10]. The HHSI master's programme is the first of its kind in Finland and aims to produce professionals, developers and researchers in informatics and information management for the needs of society [11]. From its outset, the programme has been based on the Recommendations on Education in Health and Medical Informatics of the International Medical Informatics Association (IMIA) [12-13].

The HHSI programme is offered at UEF's Department of Health and Social Management, which aims to conduct interdisciplinary research and offer high quality postgraduate study programmes. The department is considered a pioneer in its field regionally and nationally. The Department of Health and Social Management provides education in three disciplines: 1. Health and Social Management (MSc, PhD, since 2017; previously Health Management Sciences, since 1979); 2. Social and Health Economics (MSc, PhD, since 2017; previously Health Economics, since 1997); and 3. Health and Human Services Informatics (MSc, PhD, since 2000). All of the disciplines belong to the joint doctoral programme Welma (Welfare, Health, and Management) at the Faculty of Social Sciences and Business Studies, launched in 2016 [14]. The department employs approximately 35 professional staff. As a nationally unique interdisciplinary community, the department's researchers and teachers participate as experts in developing services in the health and social care sector and their management, as well on a regional, national, and international level.

The aim of this chapter is to describe the milestones and outcomes of Health and Human Services Informatics (HHSI) education programmes at master's and doctoral degree level in Finland since the year 2000. The HHSI paradigm created to support education and research is first described and then used to elaborate the outcomes of the programme. The experiences of the IMIA accreditation process are also described, and the outcomes and future direction of the programme are then presented in the discussion and conclusion section.

2. The Health and Human Services Informatics Paradigm

The education and research of the Health and Human Services programmes at master's and doctoral level follow the paradigm [15] created by the core education team based on previous studies and theoretical assumptions in Biomedical and Health Informatics (BMHI) development over the years [12-13, 16-19]. A paradigm can be generally defined as a pattern or model, an exemplar, or a typical instance of something [20]. Scientifically, the most often used citation refers to Thomas Kuhn [21], who defines a scientific paradigm as 'universally recognized scientific achievements that, for a time, provide model problems and solutions for a community of practitioners. Kuhn also highlights the development of science-like policy through revolutionary discourse leading to changes in paradigms or totally new paradigms [21]. Paradigm shift in BMHI may refer to the historical development from computers as tools to computational ubiquity, the shift to digitalization and social networking, or the shift from discipline-specific standards and systems to global and universal concepts and structures. Paradigm shift has also been of interest among BMHI researchers [13, 22-27].

Referring to Kuhn, Boon presented an expanded vision of science, an engineering paradigm of science, highlighting the interdisciplinary nature in 'real-world' problem-solving contexts of research. Essentially, the discrepancy between 'real' and 'proposed' suggests gaps regarding issues such as value, ontology, or interoperability requiring attention, development, and ultimately adoption, demanding a universal standards framework [28]. It is also highlighted that knowledge generation and usage for solving complex real-world problems require higher-order cognitive skills, because rules or algorithms for how to use a concept, theory, model, or data in this respect are usually seen as interdisciplinary. Thus, teaching higher-order cognitive skills is a crucial part of evolving expertise [28-29].

The importance of graphically representing the fields of science attached to BMHI or describing past and current trends in ICT development has been especially valued by educators [16, 17-18, 30-31]. Following Kuhn's theory [21], a paradigm indicates: What should be studied and investigated; What kind of research questions should be presented and studied; How are these questions proposed; and How are the results interpreted? These questions have guided the education and research development of the HHSI programme.

Emphasizing the interdisciplinary nature of the HHSI programme, the core concepts of the paradigm: data, action, technology, and actors, should be identified based on the literature as the body of knowledge in HHSI. The core concepts are defined as follows:

- Data: meaning a hierarchical continuum from data, information, knowledge to wisdom (DIKW) [18, 23, 32-33]
- Action: meaning planning, implementation, use, and evaluation in a service system [19, 34-37]
- Technology: meaning social and technical procedures used in gathering, processing, analyzing, storing, and retrieving data related to actions [38-42]
- Actors: meaning users, producers, and developers in the health and social service system [8, 12-13, 31, 43-49].

The core concepts with their multiple interpretations have strong connections with the context health and social care. Further, to guide research in the informatics field, the core concepts' entities were connected to each other to constitute four research areas:

- Steering and organizing of information management in work processes,
- Use of information and communication technologies (ICT),
- Knowledge management and informatics competencies, and
- Data models and structures (Figure 1.)

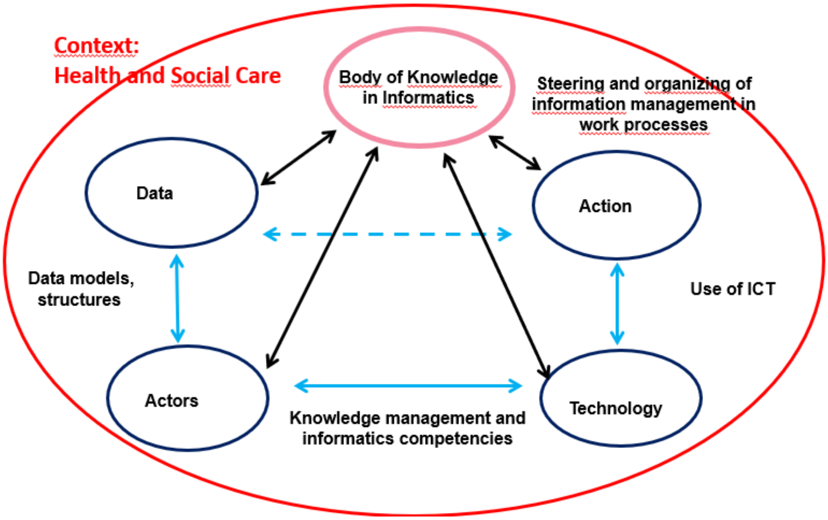


Figure 1. The health and human services informatics paradigm: core concepts and research areas.

The research area *Steering and organizing of information management in work processes* focuses on business processes and modelling, especially using data for analyses and assessing information needs and flow in practice. *Use of ICT* focuses on information system implementation and evaluation, interoperability, usability, and security concerns as well as digital services. The *Knowledge management and informatics competencies* research area focuses on data and information management, governance, decision making and leadership questions as well as education and training in developing these competencies. The *Data models and structures* research area focuses on data structures, terminologies, standards, data repositories and documentation. The paradigm has been implemented in the curricula since 2008 and is used especially in acquiring theoretical and methodological competencies for compiling theses at both master's and doctoral degree level [15,50].

3. IMIA Recommendations as the Basis of the Curricula

The Health and Human Services master's degree programme unifies in practice health care, social care and information and communication technology in a unique combination. Representing an interdisciplinary major, HHSI especially adopts management, computer and information sciences as well as health sciences (e.g., medicine, nursing, pharmacy) and social sciences (e.g., sociology) [12-13,17-18]. The aim of the programme is to build a bridge between ICT and service systems. The strategic goal is to produce generalists with competencies to elicit user needs, advise software developers, implement guidelines, and manage information resources, who have a good understanding of the field of health care and human services as a whole and of the area's special features and needs with respect to emerging technologies in digital health and social services. The need for this kind of education and research for generalists in organizations as well as for having the competencies necessary for training future professionals is indisputable [43, 51].

In Europe, higher education studies are measured in credits based on the Bologna Agreement [52]. The structure of the two-year curriculum (120 credits in the European Credit Transfer and Accumulation System (ECTS, one credit corresponds to 27 hours of work) has been compiled and applied and updated on the basis of the IMIA recommendations' six knowledge and skills areas: BMHI core principles, Health sciences and services, Computer, data, and information science, Social and behavioural sciences, Management science, and BMHI Specialization. [12-13, 51].

Study courses are quantified according to the workload required. One year of studies is equivalent to 1,600 hours of student work on average and is defined as 60 credits. The Bologna agreement was adopted implemented by the University of Eastern Finland in 2006. In accordance with the Finnish higher education system and the Finnish way of providing health and social services, the structure of the knowledge and skill areas for the master´s degree level programme has been modified, as shown in Table 1.

Table 1. Suggested share (%) of the six BMHI domains within BMHI master's programmes compared to the HHSI programme [51]

Master's programmes		Medical informatics, bio-medical informatics, health informatics	Health and Human Services Informatics
Programme type		Postgraduate	Postgraduate
Programme length		Either 1-year OR 2-years full-time study	2-years full-time study
Knowledge/Skill Area		%	%
1	BMHI core principles	40	30
2	Health sciences and services	15	10
3	Computer, data, and information science	15	20
4	Social and behavioural sciences	5	5
5	Management science	5	5
6	BMHI Specialization	20	30
Σ		100	100

A prerequisite for the master's degree programme is a bachelor's degree (first-cycle degree). Since there is no bachelor's degree programme available in HHSI, students enter the programme with various backgrounds, e.g., first-cycle degree at a university of applied sciences or a university degree, e.g., in health sciences, computer science or social sciences. The heterogeneous first-cycle degree background has proved to be an advantage, as at the beginning of the programme the core principles are jointly discussed with the students. As a result, the new terminology gained through the concept definitions and aims of HHSI enhance the students' study process. Further, at the beginning of the first academic year each student is required to draw up a personal study plan (PSP) with the guidance of the programme tutor, who also approves the PSP. The plan is updated during the programme.

The master's degree thesis is a compulsory part of the curriculum and accounts for 30 ECTS. The methodological component of the curriculum includes the following courses: Advanced Course in Qualitative or Quantitative Research, Concept Formation and Data Modelling, Evaluation Research in Social and Health Services, Evidence-Based Health and Social Care, and HHSI Research and Methodology (Figure 2). In addition to 120 ECTS, a student entering the HHSI programme must have demonstrated competencies in research methods. Depending on the student's previous education, some students are required to complete courses on complementary basic qualitative or quantitative methods, as well as courses on information retrieval, and health and social care legislation. The latter is required for students without a background in health or social care.

Master's in Health and Human Services Informatics, 120 ECTS

1st year

- Developing Health and Human Services Informatics Expertise, Introduction to HHSI studies and research, 2 ECTS
- Basics of Health and Human Services Informatics, 5 ECTS
- Information security and ethics, 5 ECTS
- Theory Building in Health and Human Services Informatics, 5 ECTS
- Evidence Based Social and Health Care, 5 ECTS
- Advanced Course in Qualitative or Quantitative Research, 5 ECTS
- Effectiveness in Social and Health Services, 5 ECTS
- Comparison of International Health and Welfare Systems, 5 ECTS

2nd year

- Health and Human Services Informatics Research and Methodology, 5 ECTS
- Knowledge Management in Health and Human Services Informatics, 5 ECTS
- Practical Training in Health and Human Services Informatics, 5 ECTS
- Developing Health and Human Services Informatics Expertise, Research Seminar, 3 ECTS
- Master's Thesis (Health and Human Services Informatics), 30 ECTS
- Maturity test, master's thesis, 0 ECTS
- Evaluation Research in Social and Health Services, 5 ECTS
- Concept formation and data modelling, 5 ECTS

Compulsory minor: Basics of Computer Science, 25 ECTS

Figure 2. Curriculum of HHSI 2021-2025.

From the beginning of 2000 the programme has been carried out using multifaceted teaching including web-based studies, which has facilitated the transition to online teaching during the Covid-19 pandemic. Each study course is assessed by the students via an electronic feedback system and jointly discussed at the end of each term for development purposes.

Doctoral education in HHSI is part of the Welma (Welfare, Health and Management) doctoral programme at UEF. The curricula are joint for students studying in various fields in the Faculty of Social Sciences and Business Studies. The HHSI specialist role [51] is achieved through the personal study plan (50 cr.) and doctoral thesis. Students have joint courses in Welma, e.g., philosophy, ethics and statistics, as well as courses related to their research topic. The average length of the doctoral studies is five years but varies depending on whether studying full or part time.

4. Educational Outcomes of the Master's and Doctoral Programmes

The goal of the Health and Human Services master's degree programme is to give students an in-depth understanding of service systems and to develop informatics competencies from the needs and viewpoint of the special characteristics of the health and human services sectors.

The focus is especially on strengthening students' abilities in planning, implementation, management, and evaluation of information resources in health and social care. In addition to the legal requirements for degree qualifications, education and research follow the above-mentioned paradigm created by the core educational team [15].

The research method chosen for the master's thesis depends on the research topic and the individual interests and skills of the student. The most used method in HHSI theses (N=197) during 2002-2021 was a survey, performed using quantitative or qualitative methods or both. Complementary research strategies are usually applied, in which other methods, such as literature review, register-based research, or observational study, are utilized in conjunction. The quantitative method alone has been used in 64 theses, and its role has increased in recent years. A qualitative method alone has been used in 39 theses. In total, 26 literature reviews have been carried out. Register-based research has been used in 24 theses. Registers utilized have most often consisted of electronic nursing records and hospital incident reports. Figure 3 presents the research methods applied in the master's degree theses during 2002-2021.

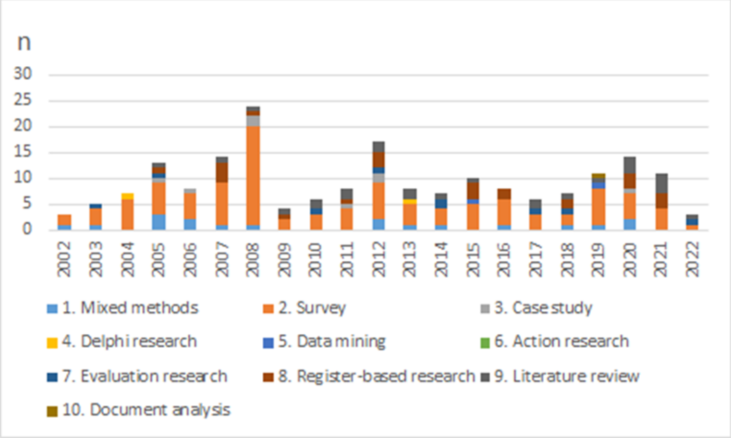


Figure 3. Research methods used in HHSI master's degree theses 2002-2022 (N=197).

The HHSI paradigm is based on previous studies and theoretical assumptions in HI development over the years. The usefulness and validity of the paradigm are accomplished with the master's theses and doctoral dissertations. To guide students in thesis planning, we have summarized the key ideas of the paradigm research areas and their connection to the research foci and applicable theories (Table 2).

During 2002-2021, 79 master's theses have focused on steering and organizing information management in work processes and, especially in the years 2008 and 2012, the research interest has mostly been in this area. The focus on data models and structures has been almost the same during the last ten years.

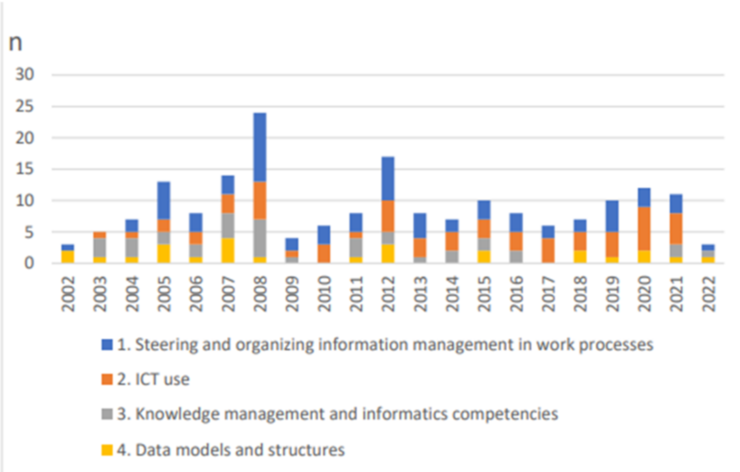
In doctoral dissertations (N = 19) the research has focused on all four research areas in the paradigm. Over the years, six topics have focused on the area of steering and organizing information management in work processes and on data models and structures. Figure 4 summarizes the research areas investigated in master's theses (a) and dissertations (b).

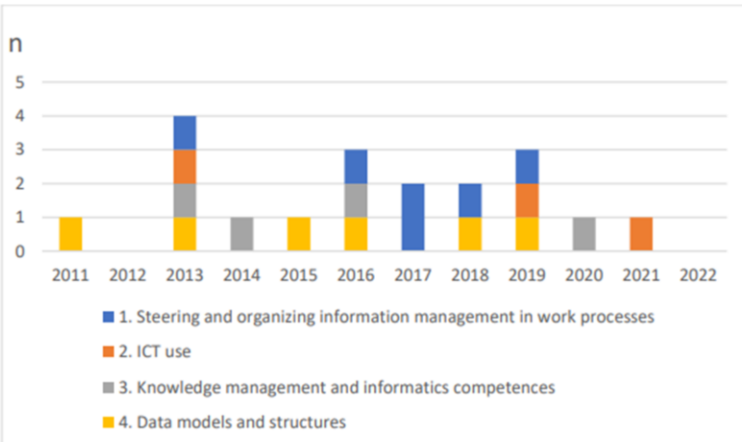
Table 2. Paradigm research areas connected with research foci and theories

Research areas	Research focus	Theoretical background*
Steering and organizing of information management in work processes	1.1 Operational process modelling 1.2 Operational process evaluation and analysis 1.3 Information needs in operational processes 1.4 Safety	Information process model (Choo) Innovation theory (Rogers) System theory (Bertalanffy) Organizational theory (Hatch) Theory of planned behaviour (Ajzen)
ICT use	2.1 Information system development 2.2 Evaluation of information system implementation 2.3 eBusiness and eServices 2.4 Usability 2.5 Interoperability 2.6 Enterprise architectures 2.7 Data security and protection	Innovation theory (Rogers) Implementation theory (Myers) Organizational theory (Hatch) Change theory (Lewin) Socio-technical approach (Avgerou) Nielsen's heuristics EUCS model TAM model (Davis) Success model (Delone & McLean)
Knowledge management and informatics competencies	3.1 Educational planning 3.2 Evaluation of education 3.3 Competency development 3.4 Personnel's skills and competencies 3.5 Data re-use 3.6 Management and leadership 3.7 Decision making 3.8. Governance	Stagger's levels of informatics knowledge and skills IMIA recommendations TIGER initiative (HIMSS) Various tools for ICT literacy assessment Knowledge management (Nonaka) Evaluation models, Activity theory, theory of expansive learning (Engeström) Management theories (Mintzberg)
Data models, structures	4.1 Data repositories, data sets 4.2 Terminologies, classifications, codes; use and re-use 4.3 Mapping (e.g., terminologies) 4.4 Standards	Data mining methods Information reference model (Goossen) Terminology models, structures (Cimino) Information process model (Choo) Sociology of information Standards (e.g., ISO, FAIR)

*Possible bibliography

At the beginning of the doctoral programme, it was evident that not all students will have a master's degree in HHSI. The first doctoral students with varying backgrounds started in a joint group of health economics, management, and informatics students in the Department of Health and Social Management of UEF. This was a practical but also inspiring solution to teach students in a cross-disciplinary group. As the number of students increased, a HHSI doctoral student group was established leading to a more coherent and goal-directed group of students. The intended learning outcomes are connected to the substance of the paradigm entities and their implications for both research and practice.





Figures 4 a and b. Research areas used in master's and doctoral theses/dissertation, 2002-2021.

The alumni work in various positions in the public, private and third sectors. They have positions at ministry level, in national operational units such as the Finnish Institute of Health and Welfare and the National Supervisory Authority for Welfare and Health, in ICT enterprises, and in various managerial and expert levels in the health and social care sector, as well as in education and research institutes. In recent years, surveys of alumni have not been conducted due to the Covid-19 pandemic; however, based on the contacts no cases of unemployment after HHSI education have been reported to the programme leaders. On the contrary, some alumni hold leading positions in development and digitalization of health services.

5. Experiences from IMIA Accreditation

The World Health Organization has launched a strategy to guide countries to establish bodies for accreditation to guarantee high quality education for health care workers [53]. Accreditation can be defined as the process or actions of officially recognizing someone as having a particular status or being qualified to perform a particular activity or an official certification that a university or course has met standards set by external regulators [20]. All in all, accreditation relates to quality assurance and improvements. Accreditation can be defined as an independent, third-party evaluation of a conformity assessment body (such as a certification body, inspection body or laboratory) against pre-existing standards, and conveying formal demonstration of its impartiality and competence to carry out specific conformity assessment tasks (such as certification, inspection, and testing) [54-55].

Along with frameworks for teaching BMHI, accreditation of educational programmes was seen of importance [12-13, 16, 56-57]. Based on the survey by the European Federation of Medical Informatics (EFMI), the AC2 Committee mapped all of the academic programmes related to the field of Biomedical and Health Informatics (BMHI) across Europe [58]. A draft online catalogue was created and validated by EFMI national societies to describe the state of the art in various European countries. Cooperation with national societies was essential to have a valid catalogue of programmes. In autumn 2022, BMHI education programmes number 1,000 in 13 thematic areas across 30 EFMI countries [59]. The unique work of the AC2 Committee is supported by the EFMI Education Working Group (EDU WG) especially in promoting and fostering the accreditation process of BMHI programmes in Europe and assisting the AC2 certification process of the knowledge and skills of users in BMHI [60-62]. The AC2 accreditation follows the accreditation model launched by the IMIA in 2010 [63-64] and strengthens the accreditation process from European perspective. A programme accredited by a national accreditation committee does not necessarily follow a European quality level in BMHI [13, 51]. Thus, international accreditation provides a competitive advantage to the programme and gives learners and collaborators of the institution insight into the programme's quality [51].

In the United States, a corresponding accreditation system was originally launched by the American Health Information Management Association (AHIMA), which was established to mandate curricula in Health Information Management (HIM) at multiple educational levels. AHIMA has been collaborating with the American Medical Informatics Association (AMIA) on developing accreditation standards for both HIM and informatics. At present, the Commission on Accreditation for HI and Information Management Education (CAHIM) is responsible for quality monitoring and programme accreditation processes [11, 65].

The IMIA accreditation process [62-63] starts with agreement between IMIA and the applying institute for accreditation and then follows the following three phases: 1) Internal assessment of the educational programme by the institution is carried out and a written self-assessment report is drawn up in accordance with the IMIA accreditation framework. The report, containing narrative descriptions and tables, is structured to provide basic data on the educational programme, a description of the institute, the goals of the programme, the programme staff and facilities, and internal quality assurance. The report is submitted to the Accreditation Committee. 2) The IMIA Accreditation Committee convenes an external Assessment Panel (usually consisting of three experts) that is responsible for the external assessment of the educational programme on location. The Assessment Panel assesses the potential quality of the programme and whether the programme fulfils the criteria set out in the IMIA accreditation framework. The Assessment Panel creates an Assessment Report that contains objective findings, subjective considerations, and conclusions. The report contains an explicit proposal to the IMIA Accreditation Committee to take either a positive or a negative accreditation decision. 3) Evaluation of the assessment report and the overall conclusions expressed in it by the IMIA Accreditation Committee. This committee verifies whether the programme meets the standards that are defined in the IMIA accreditation framework. The IMIA Accreditation Committee takes a final accreditation decision and lays down its findings in a final accreditation report [56, 63, 66-67].

The master's degree programme in HHSI was accredited in February 2012 and again in January 2018. Based on the IMIA instructions to draw up a 'Self-Assessment Report for the site visit of the Accreditation Committee of IMIA', statistical data and information on the programme was gathered by the staff in charge of the programme for both accreditations. The reports were sent before the site visits to the experts invited by the IMIA Accreditation Committee to carry out both the accreditation and the re-accreditation procedure. The three-day site visits included discussions from several points of view of the self-assessment report. Professors, senior lecturers, the academic rector and the library director of the university, representatives of the faculty and department, alumni, master's and doctoral students, representatives of working life, and cooperation partners were included in the site visit programme.

The main actions carried out in the HHSI programme after the first accreditation were the IMIA Accreditation Committee's recommendations focused on the number of personnel, quite high study load, more possibilities for supplementary studies, corporation collaboration, and teaching collaboration with the Department of Computer Science. These notifications were discussed with educators, students and the department's leadership team, and improvements were made to the curricula, teaching methods and collaboration with partners [15]. Re-accreditation again followed the IMIA guidelines and the improvements made after the first accreditation were approved according to the IMIA guidelines [67]. The site visit was valued not only by educators but also students and partners, e.g., the Finnish Institute for Health and Welfare, for offering opportunities to reflect on the programme's development and outcomes.

The accreditation processes have influenced the education and research development of the HHSI programme. The accreditation committee guidance on improving the structure and content of the curricula was especially rewarding for educators. The committee's suggestion to focus on student lead-times and to improve procedures in organizing teaching and research more intensively together improved both students' and educators' motivation to develop courses together. The balance between quantitative and qualitative research methods was discussed with a view to facilitating focusing on more thoroughly on the outcomes of the education, especially on the significance of students' thesis work.

International accreditation also helped to value educational accomplishments at national level and to affirm that the programme is an established national brand. Cooperation with alumni has been intensified and some are regular speakers on special course topics. Cooperation with research units with convergent research interests has increased and joint proposals have been made easier to submit.

6. Discussion and Conclusions

The establishment of a new major at a university is always challenging and raises considerable debate as to whether the discipline in question is sufficiently scientific to be included in a faculty. The establishment of the Health and Human Services Informatics degree programme was no exception in this respect. However, the strategic plans and national developments in electronic records and information systems in the health and social sector highlighted the need for experts and the importance of education in this area. Thus, the national ICT strategy was brought under discussion several times already in 1995 [68] before the HHSI programme started.

In 2022, there is still a clear need for users, generalists, and specialists in BMHI and for effective guidelines and procedures to help educators establish and launch new programmes and renew existing programmes in BMHI [51]. Thus, the support of the IMIA recommendations on teaching Biomedical and Health Informatics since 2000 [12-13] has been highly valued in academic settings. The international group of experts behind the recommendations harmonize the establishment of BMHI programmes globally. The IMIA, with its established services and recommendations for the accreditation of high-quality educational programmes in the field of BMHI worldwide, acts as an international benchmark for programme accreditation [62].

By investing in the establishment of new, strategically significant areas of expertise in education and research, the role of the UEF has been strengthened in the national and international innovation system. The university's education and research meet the needs of society and respect academic freedom. Besides education and research, the aim of third-sector activity is to be actively engaged in cooperation with various organizations, stakeholders and society. Such cooperation is highly rewarding in terms of feedback and benchmarking for a newly established education programme such as HHSI. It opens up opportunities to update teaching and create new research initiatives. It has also proven very beneficial for student internships, providing new placements for training, areas of research for master's theses, and even permanent positions after graduation.

International cooperation with other higher education institutes has provided possibilities not only to work together but also given insights to benchmark curricula and education in practice. The joint Erasmus project eHealth4all@eu is an example of how teaching and learning can be implemented and reach outcomes that are not possible with only a local group of students and educators [69]. Collegial feedback and discussion during the IMIA accreditation process has also been highly rewarding. The evaluation process itself was already familiar due to various evaluations previously carried out at the UEF, but the focus on health informatics was particularly valued. Instructions for completing the self-assessment report were clear and guided the analysis of the programme in a comprehensive way [66]. The timeframe of the process was optimal for HHSI as the programme had already existed for several years. However, the data collection proved challenging due to fragmented databases at the university administration. The administrative information system has however since been modified, which should facilitate more fluent data gathering for progress reports. The level of expertise of the panel members was high, and the site visit was highly valued by the university staff and partners.

The HHSI curriculum has been updated based on the re-accreditation feedback since 2019, but also due to changes in legislation, harmonization of curricula at the university level, and advances in the field. Additionally, the UEF aims to standardize the qualification structures of its master's programmes. This will enable students to choose courses not only from their own programme, but also from other programmes. The recently updated IMIA guidelines for teaching BMHI will guide the future development of the HHSI programme at both master's and doctoral level [51]. The guidelines will also support harmonization of teaching and learning BMHI globally. This will be reflected in the quality of the workforce with respect to competencies in BMHI corresponding to their roles as a user, generalist, or specialist.

The accreditation process, i.e. third-party evaluation, was a demanding but well-planned process and the guidelines provided to support the process mitigated the excitement of the expected outcomes and the final report. An outsider can identify aspects and solutions that may be too close to daily practice to be noticed by insiders, including critical questions and arguments that may be disruptive and unexpected. The experiences of the HHSI programme accreditation positively influenced not only the education itself, but also cooperation with partners and, most importantly, students' motivation to study in the accredited programme.

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Competencies and Curricula Across the Spectrum of Learners for Biomedical and Health Informatics

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Abstract. The field of biomedical and health informatics has taken its rightful place in the development and evaluation of methods and systems that aim to help those working in health, healthcare, public health, and biomedical research fields to optimally use data, information, and knowledge to improve human health. In the current century, competencies and curricula have been developed and have matured not only for informaticians but also clinicians, researchers, and patients/consumers. This paper provides an overview of the history and evolution of efforts around the world, interspersing history from the field with the author's own personal journey.

Keywords. Biomedical and health informatics, competencies, curricula, online learning

1. Introduction

Biomedical and health informatics (BMHI) is the field to devoted to the use of data and information, usually aided by technology, aiming to improve health, healthcare, public health, or research.[1] BMHI is an interdisciplinary field, requiring practitioners and researchers to have some level of knowledge and skills in biomedicine, healthcare, computer science (CS), mathematics, data science, and machine learning (ML). Many note that BMHI also requires the ability to navigate people and organizational issues.

BMHI is not, however, just the sum of math, CS, biomedicine, healthcare, and other disciplines. Despite the interdisciplinary nature of BMHI, there are unique aspects at the intersection of these disciplines. Greenes and Shortliffe highlighted some of them, noting, for example, that a PhD student's dissertation was not novel enough for all of the interdisciplinary fields making up BMHI yet quite so for BMHI.[2] Friedman coined his "Fundamental Theorem" that noted the goal of BMHI is to augment human capabilities with computing technology and not replace them.[3] He also contrasted what informatics "is and isn't," noting that aiding people and biomedical processes was informatics while "tinkering" with computers or large data sets was not.[4] Payne et al. compared BMHI

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with data science, noting that the former included not only the methods of data science, but also their implementation and evaluation in real-world healthcare settings.[5]

I have also written about aspects of BMHI, including early overviews[6] and discussions of progress and barriers.[7] Further analysis described what we knew about those work professionally in informatics.[8] Additional focus on the workforce assessed the need for further estimates of its size and demands of who work in it.[9] I also led an elucidation of competencies for medical (or actually all health professionals) education.[10] I summarized my longer path more recently.[11]

2. Educational Perspective of Biomedical and Health Informatics

One lens through which BMHI can be understood is from the educational needs of those who work within it. This perspective has guided how we think about the required competencies for the profession and the curricula required to impart those competencies. At one level are the practitioners and professionals who work in different areas of BMHI. This includes a wide spectrum of informaticians, from researchers to developers to implementers. There are also so-called "users" of BMHI, including clinicians, researchers, administrators, policy-makers, and consumers/patients/citizens. This results in many different types of learners, with diverse needs and educational requirements.

Many sets of competencies for BMHI have been developed over the years, mostly focused on informatics professionals. One early set of competencies for BMHI learners were the educational recommendations of the International Medical Informatics Association (IMIA).[12] Other sets came from the American Medical Informatics Association (AMIA), elucidating the core content of the clinical informatics (CI) subspecialty for physicians,[13] core competencies for graduate education in biomedical informatics,[14] and foundational domains of applied health informatics.[15] More recently, AMIA published the domains, tasks, and knowledge for clinical informatics subspecialty practice[16] and for health informatics practice.[17] Efforts to develop competency frameworks and professional development from countries besides the US include the United Kingdom Clinical Informatics Core Competency Framework,[18] the Australasian Institute of Digital Health,[2] and Digital Health Canada.[3]

There have also been delineations of informatics competencies for health professionals. One early analysis from the Association of American Medical Colleges (AAMC) focused on medical education, noting the different roles of physicians as clinicians, educators, researchers, and leaders.[19] A more recent analysis elucidated the competencies in CI for 21st century physicians.[10] The TIGER initiative started with a focus on nursing and has expanded to other health professions.[20]

One challenge for BMHI education is the varied roles and skill sets required for those who work in the field. However, I would argue there is some common fundamental knowledge and skills that provide informaticians with a core vocabulary and a basic knowledge across all informatics domains. Another key is an understanding of the environment in which informaticians function, whether individual health, healthcare, public health, or any type of research.

Another aspect of BMHI learning and practice is the growing role of individual certification. In the US, this process has been led by AMIA. It started with the

[2] https://digitalhealth.org.au/

[3] https://digitalhealthcanada.com/

designation of CI as a subspecialty of all specialties for physicians.[21] This has been followed by certification for the rest of the field through the AMIA Advanced Health Informatics Certification (AHIC).[22] As with all health professional certification, its goal is to ensure fitness and safety for practice. The ultimate value will be determined by its requirement for hiring. At this point, it is clear that board certification of physicians is a consideration of hiring physicians for operational CI roles in healthcare delivery organizations. It is probably more important for those who work in operational than academic or research settings. Nonetheless, CI certification is a recognition of the field, and is probably more important for younger entrants into the field. The role and value of the AHIC certification is still to be determined by the employment marketplace.

3. Personal Journey in Informatics Education

The remainder of this paper shares my journey in developing educational programs, courses, and other activities to meet some of the above needs. These include a graduate program that I was instrumental in developing and leading, a highly-subscribed online introductory course, a more recent course in applied machine learning for clinical informatics students, and development of curricula for "users" of informatics, including medical students and graduate students.

3.1. OHSU Biomedical Informatics Graduate Program

Biomedical informatics began at Oregon Health & Science University (OHSU) in the late 1980s, with the awarding of a National Library of Medicine (NLM) Integrated Advanced Information Management Systems (IAIMS) grant.[23] The original Director of the program was J. Robert Beck, MD, and among his earliest faculty recruits was myself in 1990. OHSU joined the NLM T15 Training Grant Program in 1992, with Dr. Beck as PI. We also developed our first graduate course around that time, an introductory overview of the field, led initially by Kent Spackman, MD, PhD and then transitioning to my leadership. The course was initially an elective in the OHSU Master of Public Health (MPH) program.

I was always interested in more than a single course, so led the effort to establish OHSU's initial degree program, a Master of Science (MS) of Medical Informatics. After approval by the state of Oregon, the first students matriculated in 1996 and graduated in 1998. One interesting early lesson was that despite our anticipation of training future researchers and academics in the field, many of the students aspired to work in more operational settings. This led us to make course content practical as well as theoretical.

The introductory course that began as an MPH elective became the entry course for the graduate program when it was launched, taking on the course number MINF 510. When the name of the program changed to Biomedical Informatics in 2003, the course was renumbered to BMI 510, which it still carries as present.

The structure of the MS curriculum borrowed from existing programs of the time, namely University of Utah and Stanford University. We adopted the notion of domains, with each domain having required courses, individual competency courses (selecting from a menu), and electives. The initial domains were Medical Informatics, Health Care, Computer Science, Evaluative Sciences, and Organizational Behavior and Management.

We always anticipated that the second major development of the graduate program would be a PhD program. However, in 1999, I developed an interest in online teaching.

This was in part due to receiving queries as to whether our courses could be taken online, along with my own growing interest in educational technology. In 1999, I developed an online version of MINF 510, with the main teaching modality consisting of lectures of narrated slides that were delivered by the leading media platform of the time, RealMedia.[24] We also stood up an instance of the Blackboard learning management system (LMS), which at that time could be downloaded and used for free.

The transition to online teaching led to a number of changes in my approach to teaching. As the LMS could deliver multiple-choice questions (MCQs), I changed my homework assignments from short answers to MCQs. (Even though I loathed such questions in my medical education, I came to find them as an effective means to assess knowledge and interpretation.) Eventually I reached the point where it no longer made sense to stand in front of students and lecture, even in on-campus classes. As such, I adopted a flipped-classroom approach for all of my classes. Even among "local" students, the flexibility of listening to lectures online was appealing, and eventually I abandoned regularly scheduled class times even for on-campus courses.

The success of the introductory course led the program to adapt a number of courses to the online format. We did not believe that students would want a full MS degree online, so our first credential to be offered was a Graduate Certificate (which is comparable to a postgraduate diploma in other countries). However, there was interest in having the entire MS program online, so within a few years, we launched an online version of the MS program. As we did believe that students obtaining an MS online via OHSU should set foot on our campus at least once, we redeployed some of our courses as 3-5 day short courses. (We later called them "hybrid" courses since they usually included an online component before and after the visit to campus.)

Despite the detour into distance learning, we did establish a PhD program that launched with the renewal of our NLM training grant in the 2002-2007 cycle. In 2003, we accepted our first PhD students, funded by the NLM grant. The first graduate of the PhD program was Adam Wright, PhD, now a Professor in the Department of Biomedical Informatics at Vanderbilt University.

In keeping with the desire of many students to obtain practical education with less emphasis on research, we joined the tide of many graduate programs in the early 2000s in developing a "professional" master's program. We opted to name this degree the Master of Biomedical Informatics (MBI). The different degree names introduced an element of confusion about our programs, and we ultimately changed to using the monikers of MS with thesis and MS without thesis to designate the research and professional degrees respectively.

Another development of the program was its bifurcation into two "tracks." The original program maintained its biomedical, clinical, and health focus, while a new track developed with a focus on bioinformatics and computational biology (BCB). The newer track used the same curricular structure of domains and courses categorized within them, but with different names for the domains. Over time, the two tracks became two different programs, with BCB adopting a much deeper dive into data science. It was eventually decided to call these two disparate programs "majors," of which there are now two: Health & Clinical Informatics (HCIN) and Bioinformatics & Computational Biomedicine (still BCB). Table 1 shows the domains of each major mapped to a high-level competency.

One feature of the degrees and certificates in the OHSU program is its "building block" approach. As seen in Figure 1, the MS program is the "knowledge base" of the program, with the Graduate Certificate being a subset of that and the PhD adding specialized courses of research methods, a cognate area, and dissertation.

Table 1. OHSU biomedical informatics core curriculum domains.

High-Level Competency	Domain Names for Health & Clinical Informatics (HCIN)	Domain Names for Bioinformatics & Computational Medicine (BCB)
Apply core concepts of using data, information, and knowledge to advance health and biomedicine	Health & Clinical Informatics	Bioinformatics & Computational Biomedicine
Apply knowledge of appropriate area(s) of health and biomedicine to informatics practice and research	Health Care	Biomedical Science
Apply computing skills to biomedical informatics	Computer Science	Computer Science
Apply quantitative methods to biomedical informatics	Evaluative Sciences	Biostatistics
Apply people and organizational knowledge to informatics	Organizational Behavior and Management	N/A
Apply advanced scholarship to biomedical and health informatics	Thesis/Capstone/Dissertatio n Requirements	Thesis/Capstone/Dissertation Requirements

A more recent expansion of the program has been as the educational component of our CI Subspecialty Fellowship for physicians. A requirement of the fellowship is completion of the Graduate Certificate, with pursuance of the MS optional. About a half-dozen other CI fellowship programs, mostly without a local graduate program from which to draw courses, have enrolled their CI fellows in our online program. The mostly asynchronous nature of the program is highly compatible the practice-oriented fellowship. Also of note related to the CI subspecialty is that physicians who are pursuing board certification through the Practice Pathway ("grandfathering") are able to become eligible to sit for the board exam by completing the MS degree. This option will end after 2025.

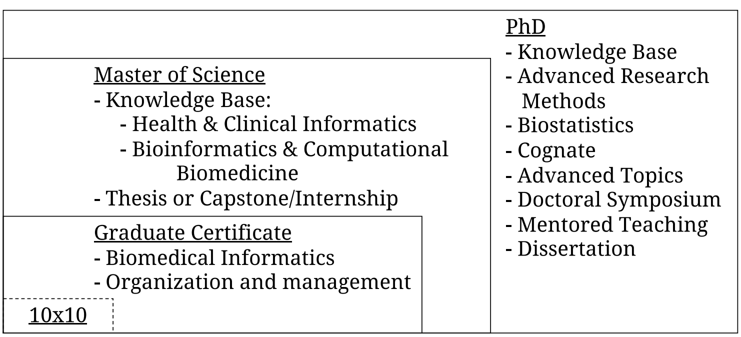

Figure 1. OHSU building-block approach to degrees and certificates.

Table 2 shows the total number of degrees and certificates awarded for both majors in the program since its inception in 1996 and first graduates in 1998.

Table 2. OHSU degrees and certificates awarded.

Degree or Certificate	Total	HCIN	BCB
Doctor of Philosophy (PhD)	38	23	15
Master of Science	422	351	71
Graduate Certificate	483	483	-
Total	943	857	86

3.2. 10x10

Certainly, a passion of mine has been teaching OHSU's introductory BMHI course. I enjoy introducing learners to the informatics field. In 2005, a series of events transpired that would probably end up defining one of my major contributions to BMHI. About that time, Charles Safran, MD, who was Chair of the AMIA Board of Directors, stated that there should be at least one physician and one nurse in each of America's 6000 hospitals having some formal training in BMHI. He asked various educational program directors how much capacity they could increase in their programs. He chuckled when my reply was that I could train "all of them." I felt this way because I knew how scalable online learning was, and already had a half-decade of experience doing it. AMIA had been looking for help in developing online teaching materials, but it was prohibitively expensive. I, on the other hand, already had an online course that could easy be adapted.

I proposed the name 10x10 ('ten by ten") for the program, where we would aim to train 10,000 individuals in informatics by the year 2010 [25]. The numerical goal emanated from Dr. Safran's call for one physician and one nurse in each US hospital to have some formal training in informatics. The 10x10 program was launched based on a mutually non-exclusive relationship between OHSU and AMIA, with OHSU retaining the ability to offer courses based on its materials elsewhere (including within our own graduate program) and AMIA being able to offer 10x10 courses from other universities. One addition to the 10x10 course was an optional in-person session at the end of the course, typically taking place at an AMIA meeting, bringing together students and the instructor.

Although 10,000 people did not come forward by 2010, about 1000 people did. Shortly thereafter, with the establishment of the HITECH Act in 2009, there was increasing interest in the program. OHSU was and still is the largest and most successful offering of the 10x10 program, with over 3000 completing the course by mid-2022.[4] While most offerings of the 10x10 course have been directly with AMIA, the two organizations partnered with other organizations to offer courses with the in-person session at their meetings or facilities. Table 3 shows the various organizations, number of course offerings, and individuals completing them through mid-2022. Figure 2 shows the enrollment by year, peaking in the HITECH years but remaining strong since then.

Since the OHSU 10x10 course was based on the introductory course in our graduate program, we were able to allow students to take an optional final exam, from which a sufficient grade would give them academic credit for BMI 510 at OHSU. This would also allow those who were interested to enroll in the OHSU graduate program. Due to the building block structure of the program, students could progress from 10x10 all the way to a PhD, and two have done so. About 10-15% of those completing the 10x10 course have pursued graduate study, mostly at OHSU.[25]

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[4] https://dmice.ohsu.edu/hersh/10x10.html

Table 3. Collaborating organizations, number of 10x10 course offerings, and people completing them.

Organization	Offerings	Completed
American Medical Informatics Association (AMIA)	48	1953
American College of Emergency Physicians (ACEP)	14	221
American College of Physicians (ACP)	1	25
Association of Nutrition and Dietetics (AND)	7	126
Centers for Disease Control (CDC)	1	18
California Healthcare Foundation (CHCF)	1	16
Gateway Consulting, Singapore	26	377
Israel Ministry of Health	1	11
King Saud University (KSU), Saudi Arabia	4	83
Mayo Clinic	2	87
New York State Academy of Family Physicians	3	22
Abu Dhabi Health Services (SEHA)	1	54
Scottsdale Institute (SI)	1	15
Society for Technology in Anesthesiology (STA)	1	5
Total	111	3013

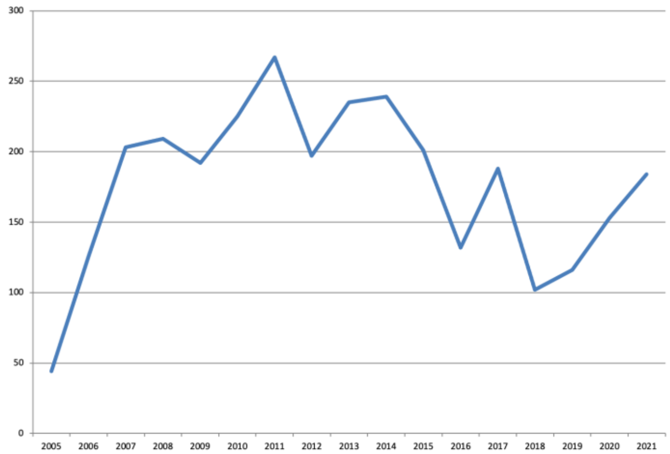

Figure 2. Enrollment by year in OHSU 10x10 course through 2021.

The current curricular outline for the 10x10 course includes units covering the following topics:

- Overview of Field and Problems Motivating It
- Computing Concepts for Biomedical and Health Informatics
- Electronic and Personal Health Records (EHR, PHR)
- Standards and Interoperability
- Data Science and Artificial Intelligence
- Advanced Use of the EHR
- EHR Implementation, Security, and Evaluation
- Information Retrieval (Search)
- Research Informatics
- Other Areas of Informatics – Public Health, Nursing, Consumer

The BMI 510 course at OHSU has also had substantial enrollment, with 1598 completing the course between 1996 and mid-2022. As seen in Figure 3, the course or portions of it have been adapted for a number of other courses. The 10x10 course was translated into Spanish and is still delivered in Latin America.[26] There has been a number of customized offerings of the course with various healthcare and other organizations, including Providence Health and Services, Kaiser Permanente, Bangkok Hospital, and the Health and Human Heredity in Africa Bioinformatics Network (H3ABionet).[5] The virtual course proved highly valuable in medical education in the early days of the COVID-19 pandemic, when medical students were not able to attend in-person activities in classrooms and on hospital wards. In early to mid 2020, the course was delivered to 222 students from 17 US medical schools. It is still available to OHSU medical students as an elective.

Materials from the course have also been used in other courses, such as an undergraduate course in the public health program at Portland State University (PHE 427) and a course for clinical and translational science researchers in the OHSU Human Investigations Program (HIP 520). Portions of course material have also been adapted for curriculum development projects, such as the Office of the National Coordinator for Health IT (ONC) Curriculum,[6] the National Institutes of Health (NIH) Big Data to Knowledge (BD2K) Program,[7] and the new NIH Bridge2AI Program.[8]

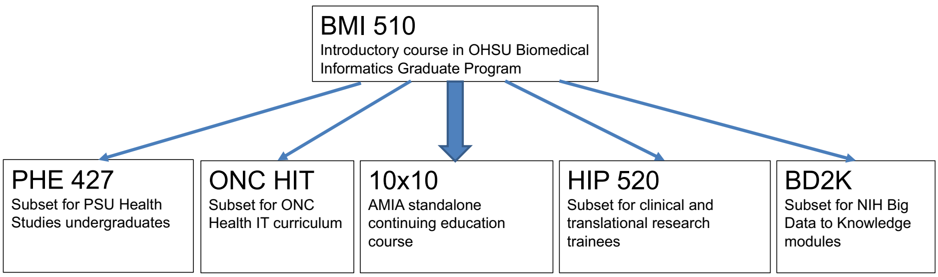

Figure 3. Lineage of materials from OHSU introductory course.

3.3. Approaches and Lessons Learned from Online Teaching

Although I ventured into online teaching with little formal training, I learned over time what works well for the kinds of teaching I prefer. When I started down this path, the technology was primitive. In 1999, many people were still accessing the Internet via telephone modem. The quality of microphones and speakers was much lower than today.

Although lectures sometimes get a bad rap, I find that an engaging speaker can provide a highly effective learning experience, especially if he or she explains the big picture and fills in the necessary details. I know that Powerpoint also gets a bad rap, yet it too can be highly effective, and perhaps more so in an asynchronous setting where lectures can be paused or reviewed. As such, my main teaching modality has always been voice over Powerpoint slides. I have used many different tools for preparing narrated lectures over the years, starting with RealMedia in its heyday and for a number of years using tools that output the now-defunct Adobe Flash. At present I record lectures in Powerpoint and export them to MP4 video, which allows their viewing on any type of device from smartphone to computer. One common recommendation for online lectures is that they should be delivered in segments of 20-30 minutes duration. A typical three

[5] https://www.h3abionet.org/

[6] https://www.healthit.gov/topic/health-it-resources/health-it-curriculum-resources-educators

[7] https://dmice.ohsu.edu/bd2k/

[8] https://commonfund.nih.gov/bridge2ai

hours' worth of lecture is segmented into 6-9 lectures. I also provide students with PDF handouts of the slides and a complete list of references cited in the slides. The "homework" of the course consists of ten MCQs per unit. In the questions, I aim for students to have to apply the material. The course does not have a required textbook, although I do note to students that it follows the content of a textbook of which I am Editor.[27]

One criticism of online learning has been a perception of lack of interaction. However, I have always taught from an LMS that features discussion forums. I advise students to think of such discussion forums as the online equivalent of a classroom. Students are encouraged to speak up, not feel intimidated, and remember that everyone has something valuable to say. In the introductory course, I seed the discussion with 1-2 questions but encourage students to also post their own questions, including asking about things they do not understand (rather than sending them to me via email, for which I usually reply asking to post their question in the discussion forum).

I have also learned, and advise students at the outset, to follow some simple etiquette for the discussion forums. Messages should be neither too short, i.e., just an affirmation, nor too long, such that few will read it. Everyone should be constructive and respectful. Students should reply to messages in their respective threads so everyone can see the evolving discussion. Students should not copy and paste from Web sites, but rather use own words and provide a link if appropriate. They should also not discuss homework questions until after due date.

At the beginning of a course, I lay out what I consider to be my expectations of students. They should complete the lectures and participate in the discussion. They should observe proper etiquette in the discussion forums and not be afraid to speak up. They should ask questions about anything that is unclear in lectures or others materials. Most of all, they should feel free to challenge the instructor, as I am hardly the expert on every topic in the course. Students should complete all assignments by the due dates. I do allow them to occasionally complete assignments late, but warn them not to fall too far behind, as they will have difficulty getting caught up.

By the same token, I tell students they should have expectations for me. They should expect me to create an environment of learning and objective inquiry. I should maintain high availability, replying by email as quickly as I can. They should expect that I am there to serve them, as students are not wasting my time. The best method of initial contact is email, and we can talk further via videoconferencing or phone as needed.

For my lectures, students should expect the quality to be very good although not perfect. I am not a talking head, and try to convey my view of informatics, getting into the details but never losing the big picture. One of my best compliments ever came in a course evaluation from a student who said, "I like that Dr. Hersh pauses and makes mistakes and corrects himself … It shows he is thinking about what he is saying instead of reading off a paper." (Even though I do maintain a script to make sure I cover all the topics.) Students should also expect that in the discussion forums, I will read all postings, even if I cannot reply to each individual one. I usually try to reply in threads where dialogue has developed and also reply to different students and not the same ones each time.

3.4. Course in Applied Data Science and Machine Learning for Clinical Informatics Students

A more recent destination in my journey has been figuring out what and how to teach in data science, especially to those who are not "wranglers and modelers," but instead are the clinicians and informaticians who will be implementing and evaluating data science, machine learning (ML), and artificial intelligence (AI). This includes individuals who do not have the math and programming background for traditional ML courses, such as advanced calculus and linear algebra. (Or, are like me in having had courses so long ago that most has been forgotten.)

The prominent role that data now plays in health care (not to mention larger society), its use in machine learning, and the growing understanding of biases in data and algorithms, make it imperative that all who work in informatics implementing and evaluating systems have enough understanding. Clinicians whose work is or will be impacted by them also need some basic understanding. Even patients and consumers, especially those impacted by biased data and algorithms.

The big challenge for informatics education is what is the right education for those who will not be developing ML applications and who have modest math and programming backgrounds? There are some parallels from statistics. In modern times, one need not understand all the math underlying statistical tests. However, the modern user of statistics must understand the proper use of each test and have some concept of its limitations. Modern statistical packages allow anyone who can manage a spreadsheet to enter data and generate results. In some ways, ML is taking the same path. There is emergence of visual programming packages that let one load data and build ML models, such as RapidMiner[9] or Orange.[10] Or for those who are programmers, there are libraries in languages such as Python and R. But to use these tools requires an understand of what these tools do and what are their limitations.

Most students in our HCIN major have modest math and programming backgrounds. But many are very interested in applications of data science. The courses in the BCB major require too much math background, and also have more of a focus on omics than clinical data. The primary developer of this course was Steven Chamberlin, ND, a postdoc in our department. Dr. Chamberlin and I developed this course for HCIN students with hands-on use of data and modeling tools, with the goal of understanding how they work and not to teach them to become developers in them. (I also quip to our students who are physicians that they are too expensive to be data science programmers.)

The course outline includes:

- Overview of biomedical data science
- Overview of biostatistics, ML, and AI
- Critical assessment of machine learning literature – both development and implementation
- Introduction to data sources and programming languages
- Data preparation
- Data exploration

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[9] https://rapidminer.com/

[10] https://orangedatamining.com/

- Using code libraries or visual programming tools for ML algorithms, including k-nearest neighbor (kNN), logistic regression, decision trees, random forest, support vector machines and neural networks
- Model implementation
- Ethical considerations

Like almost all HCIN courses in our graduate program, this course is mostly asynchronous and makes use of narrated Powerpoint lectures, readings from a clinically-oriented data science textbook[28] and selected articles. Students are also provided programming and modeling skills development, with weekly assignments in Python or a visual programming tool aiming to impart necessary skill development for application to each phase of the course project. The hands-on portion of the course includes the course project, which is a longitudinal project starting early in the course.

One challenge for the course project is which dataset students choose to use for their project. There are some large clinically-oriented datasets that are highly used in biomedical data science education, including Synthea,[29] NHANES,[11] and MIMIC.[30] Students are also allowed to use their own data sets, with caveats that the data cannot contain protected health information (PHI) or otherwise be proprietary to their employer organizations. Over the weeks of the course they incrementally explore, develop model, and evaluate performance.

In its initial two offerings, the course has been well-received for HCIN students who wish to learn to apply data science. As these are early days for this course, there are some larger questions for its future. Should it be a required course in informatics education? Is this the right amount to learn, or should the course be lengthened?

3.5. Learning for Others Who "Do" Informatics

Another important aspect of education has been teaching beyond those who aspire to work in BMHI. With the maturation of search systems, electronic health records, and other technologies, it is critically important for health professionals, researchers, and others to gain practical skills in BMHI used for their work. Thus, there are many groups of users of BMHI who need basic knowledge and skills in informatics, including:

- Physicians and medical students – first addressed by AAMC Medical School Objectives Project[19]
- Nurses[31]
- Patients – 58% of US adults look online for health information and 35% attempt to diagnose illness in that manner[32]
- Clinical and translational scientists[33]
- Next-generation research scientists[34]

Informatics is an important subject for modern health professions education. Glasziou et al. noted that the "search engine is as essential as stethoscope" for modern clinical practice.[35] Saran stated that "informatics training for clinicians is more important than hardware and software."[36]. Fridsma declared informatics a "required skill for 21st century clinicians."[37]

Ironically, for all my successes in developing educational programs to train informaticians, breaking into the medical school curriculum took a considerably longer

[11] https://www.cdc.gov/nchs/index.htm

time. I began advocating for informatics training for medical students in the 1990s, and was even appointed to the medical school curriculum committee by one Dean to facilitate it, but little headway was made until the arrival of a new Senior Associate Dean for Medical Education around 2012. This Senior Associate Dean was supportive of innovation and change, and funding by an Accelerating Change in Education (ACE) grant from the American Medical Association (AMA) opened the door to add informatics. (New medical school curricular leaders tend to blow up existing curricula when they come make way for change, and this helped as well.) Once the door was opened, a half-dozen informatics faculty came together and developed a set of competencies for medical education,[10,38] the curriculum teaching them,[39] and noting the challenges.[40]

The current set of competencies in CI for medical students (or really all health professions students) include:

- Find, search, and apply knowledge-based information to patient care and other clinical tasks
- Effectively read from, and write to, the electronic health record for patient care and other clinical activities
- Use and guide implementation of clinical decision support (CDS)
- Provide care using population health management approaches
- Protect patient privacy and security
- Use information technology to improve patient safety
- Engage in quality measurement selection and improvement
- Use health information exchange (HIE) to identify and access patient information across clinical settings
- Engage patients to improve their health and care delivery though personal health records and patient portals
- Maintain professionalism through use of information technology tools
- Provide clinical care via telemedicine and refer patients as indicated
- Apply personalized/precision medicine
- Participate in practice-based clinical and translational research
- Apply machine learning applications in clinical care

The OHSU MD program CI curriculum is one of the most comprehensive in the US. CI is infused as a thread throughout the four years of medical school. At the beginning of medical school, students are provided a login to the institution's electronic health record system, where cases in their case-based learning curriculum are accessed. In the first month of medical school, I provide an overview lecture, *Information is Different Now That You're a Doctor*, which introduces the important aspects of information as they assume their new professional role and also introduces CI. Throughout the curriculum, various skills labs and other activities are provided.

4. Conclusions

When I first decided to pursue BMHI training in a postdoctoral fellowship, I assumed my career would focus on research. However, I have always enjoyed teaching, and was able to develop educational programs from early in my career at OHSU. I quickly came to realize I had a passion for it, perhaps in part because you get to learn the material that you teach. As Aristotle has been quoted, "Those that know, do. Those that understand, teach."[12]

I have certainly learned many lessons along the way. One has been no matter how focused your work in informatics (e.g., machine learning, implementation specialist, or interoperability researcher), it is important to have big picture, e.g.,

- Operations of the healthcare system – the good and the bad
- Downsides to the EHR – alert fatigue, burnout, etc.
- Clinical decision support – benefits and shortcomings
- Data standards and interoperability
- Data and algorithm bias

No matter to whom we are teaching informatics, we must provide the right knowledge and skills to the appropriate audience. We "own" the downsides to the EHR, biased data and algorithms, etc., so we must teach about the good and bad. But that said, teaching is still fun and rewarding. It provides a way to not only pass on the knowledge and skills of our field, but also the passion we have for the use of informatics to better human health.

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Health Information Systems: Past, Present, Future – Revisited

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Abstract. *Background:* Health information systems (HIS) represent an essential part of the infrastructure for the delivery of good health care. *Objectives:* To present the author's personal views on HIS developments over the last decades and on the opportunities and priorities for future HIS developments. *Methods:* Reflecting on his views, the author identified relevant semantic dimensions, which are denoted as development paths, and searched for appropriate periods to characterize HIS development leaps. *Results:* HIS developments were divided into the periods past (1961-2016), present (2017-2022), and future (the next decades). Eight development paths for HIS were considered as being relevant to presenting the author's views: life situations related to health care, entities for health care, health care facilities, settings of health care, data to be processed, features for functions, architectures of HIS, and management of HIS. For each of these paths, the past and present states as well as challenges and opportunities for future HIS developments were outlined. Discussion and Conclusions: The presented views on HIS developments and the selected development paths and periods are by nature subjective 'avant la lettre'. The views were, however, formed over almost half a century during which the author has been engaged with HIS developments, and thus may be worth reporting and discussion. If past is prologue, the tremendous HIS developments in the past and in the present may predict a similar development intensity in the future. Present HIS are significantly better than HIS of the past, however they leave room for continued improvement with an end of HIS developments far from sight.

Keywords. Health information systems, hospital information systems, medical informatics, health informatics, biomedical informatics

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[2] This is a written version of a talk, given on October 29, 2022, in Athens, Greece, at the Symposion on Achievements, Milestones, and Challenges in Biomedical and Health Informatics. The Symposion was held in honor of Professor Ioannis (John) Mantas on the occasion of his retirement. Before, a talk on this topic had been given by the author on June 24, 2021, at the Joint Session of the 2021 Frank-van-Swieten-Lectures on Strategic Information Management of Health Information Systems. The title of this talk was: "Now here I am, a fool for sure! No wiser than I was before"? HIS Developments 1961-2021: On Lessons for the Future". The topic was also discussed with the author on June 30, 2022, in a panel at the 2022 Frank-van-Swieten-Lectures and on July 3, 2022, in a workshop at ICIMTH 2022.

1. Introduction

1.1. Background and Significance

Health information systems (HIS) represent an essential part of the infrastructure for the delivery of good health care [1] (section 1.1). Table 1 reflects the increasing interest in HIS and HIS research. In response, the International Partnership in Health Informatics Education (IΦE) [2]-[8] implemented an international course on HIS, the so-called Frank-van-Swieten-Lectures on Strategic Information Management of Health Information Systems [9]-[11]. The Frank-van-Swieten-Lectures commenced in 2001 and the author was one of the founders.

Table 1. Number of publications and citations on health information systems and on hospital information systems from 1961 to 2020. Search in the Web of Science Core Collection. Search terms: "health information systems" (first publications in 1971) [12], [13], [14], "hospital information systems" (first publication in 1966) [15]. Search date: July 16, 2021. Please note that, whereas publications on "hospital information systems" mainly focus on institution-centred information systems of hospitals and complex health care facilities, publications on health information systems usually comprise reports on information systems in various health care settings as well as on trans institutional information systems

year	health information systems		hospital information systems	
	publications	citations	publications	citations
1961-1970			6	
1971-1980	29	11	5	11
1981-1990	14	14	34	34
1991-2000	112	420	159	562
2001-2010	428	4.909	259	3.182
2011-2020	1.184	25.233	378	8.762

1.2. Occasions

On the occasion of his last 'active' [3] participation as a teacher with a history of shaping parts of HIS developments himself [4], the author was asked by Professor Alfred Winter, another teacher in the lecture series, to share his impressions of HIS developments with the students and teachers at the joint virtual meeting of the 2021 Frank-van-Swieten-Lectures. The joint days, where students and teachers of all participating universities meet, traditionally include lectures of this type. Dr. Winter requested of the author an understanding of his own personal views. In particular he was interested in views on:

- When can HIS be determined to be "good" HIS? And, in this context:
- Why do we often regard current HIS as "bad", or at least as not good enough?
- What improvements on HIS have been achieved during the last decades?
- When can we expect to have "good" HIS?
- What contributions can today's informatics graduates make to achieve "good" HIS in the future? What can motivate them to work on this problem?

[16], (questions translated into English with some rewording by the author).

[3] The author is retired since October 1st, 2021. He is still engaged in medical informatics, but now as professor emeritus.

[4] In 1973, almost 50 years ago, the author studied medical informatics and in 1978, more than four decades ago, he started to work in this profession. HIS were part of his field of study as well as of his professional work.

The author agreed to elaborate on this subject at the joint virtual day concluding the 2021 Frank-van-Swieten-Lectures. This manuscript is a considerably updated and revised version of the 2021 presentation, which the author could present in October 2022 in Athens at the Symposion on Achievements, Milestones, and Challenges in Biomedical and Health Informatics.

1.3. Questions

While focusing on Alfred Winter's questions, the author decided to rephrase them into more general ones:

What are the author's personal views of HIS developments during the last decades?

What are the author's personal views on opportunities and priorities for future HIS developments?

Regarding the definition of the "the last decades", the author elected to start in 1961 covering six decades.

1.4. Outline and Reminiscences

The author's answers to the refined two questions will be discussed in the result sections 3 and 4 entitled *HIS Developments: Revisiting Past, Present and Future* and *Views on HIS Development Paths*. The methods section 2 entitled *Terms, Methods, Notes, and Quotes* precedes the results. The manuscript will close with discussion and conclusion sections 5 and 6. The heading of the conclusion section 6 is a quote from Johann Wolfgang von Goethe's Faust [17] (p.19). Shall or shall we not say with respect to HIS developments "*Now here I am, a fool for sure! No wiser than I was before*"?

This manuscript recalls as reminiscences and homages two landmark events: An international seminar on medical documentation and statistics, taking place in 1961 in Berlin, Germany [18]. During this seminar, final decisions were made to launch the first international journal in 1962, devoted solely to information in biomedicine and health care and focusing on a new emerging discipline: medical informatics [19]. Also, during this seminar, a new information processing tool was presented: With punch card sorting machines, biomedical and health data could be analyzed much faster than it had been possible before. A quote from the seminar's report stated: "Prof. G. Wagner (Kiel) dealt with the various types and uses of machine punch cards, which are likely to become very important for future clinical documentation tasks. For practical demonstration, IBM had set up a complete set of machines in the conference building, so that Prof. Wagner was able to demonstrate the usefulness of machine punch cards with vivid examples from his field of work. His introductory overviews were therefore particularly valuable to the seminar participants because they were necessary as a prerequisite for understanding most of the lectures given by the American speakers." [18] (p. 27, translated into English). The report also contained a picture of Dr. Wagner's demonstration, which is presented here as Figure 1. Professor Gustav Wagner (1918-2006) was crucial for successfully launching research on information in biomedicine and health care as recognized research field of medical faculties in Germany and beyond ([20], [21].

A keynote lecture on "hospital information systems - past, present, future", given by Peter L. Reichertz during MIE 1984 in Brussels, Belgium (manuscript first in [22], later also in [23]). Professor Reichertz (1930-1987) was one of the international pioneers in the field of medical informatics [25]. He was visionary enough to recognize very early the potential of informatics for biomedicine and health care, including diagnosis, therapy, and HIS. In the 1960s, health information systems were considered an unusual research field in medical faculties. Peter Reichertz's work in research and clinical practice strongly supported the development of HIS as a major research topic in medical informatics, with hospital information systems as an important instance [24]. His probably most comprehensive and visionary paper on health information systems was the one focused on the past, present and future of hospital information systems that he presented as his MIE keynote in 1984.

The title of this manuscript refers to a talk on "Health Information Systems: Past, Present, Future" that the author gave in 2004 at the Plenary Session of the Conference EuroMISE 2004 in Prague, Czech Republic ([26], subsequently denoted as 2004 Lecture). The title of this 2004 Lecture was deliberately chosen as hommage to the mentioned landmark paper by Peter Reichertz two decades earlier.

Prof. WAGNER (Kiel) bei der Demonstration im Maschinensaal

Figure 1. Dr. Gustav Wagner, 3rd from left, demonstrating in 1961 punch card machines as powerful new tools for clinical documentation and biomedical data analysis ([18], p.28).

2. Terms, Methods, Notes, and Quotes

2.1. Terms

First, the author will define the term HIS as used in the Frank-van-Swieten-Lectures. *Health information systems are socio-technical subsystems of health care settings, comprising all data, information and knowledge processing* [1] (section 2.6). Based on this definition, HIS usually are comprised of computer-based tools as well as non-computer-based tools. If we refer to HIS of specific health care facilities, we may use more specific terms like, e.g., *hospital information systems* for the information systems of hospitals. When health care is delivered to patients by more than one health care facility (e.g. when care is jointly provided by medical offices and by outpatient nursing organizations) such information systems are called here *transinstitutional HIS*. More detailed definitions and further explanations can be found in chapter 2 of [1]. Please note that the terms health care institution and health care facility are used similarly here. For example, hospitals may be referred to as health care institutions or health care facilities. The term health care setting will be used more broadly. Patients' homes may also be settings of health care, although they are not facilities or, respectively, institutions dedicated to this purpose. Also, for the sake of ease, the term *data* will be used here instead of *data, information and knowledge*, assuming that data will, hopefully, contain information or even knowledge.

2.2. Methods

As the author was asked to share his personal views, the methods to be used for preparing this manuscript were obvious and straightforward:

Firstly, the author reflected on his views.

Secondly, the author tried to arrange these views in a manner that supported communication. As in [26] the author searched for relevant semantic dimensions and referred to them as development paths.

Finally, the author searched for appropriate periods with respective thresholds to characterizing HIS developments.

2.3. Notes

The author's personal views of HIS developments, selected development paths, and selected periods by nature are subjective 'avant la lettre' [27]. While admittedly subjective, they were formed over almost half a century during which the author was an active observer and, also, participant of HIS developments. The expressed views have also been influenced by collaborations and many valuable discussions with other persons (colleagues, decision makers, users, etc). Important persons, who strongly influenced the author when he was first engaged with this topic in the 1970s and 1980s included Marion Ball [28], Carl-Theodor Ehlers [29], [30], Gerd Griesser [31], [32], Klaus Köhler [33], Peter Reichertz [34], [35], [22], and Alfred Winter [36], later leading to [37], [38], and [1] and many others. Of course, ultimately the presented views are the author's, who claims responsibility for this manuscript. However, if credits are due, they must be shared with many others as well.

The development paths selected in the author's 2004 Lecture (there called lines of development) – amount of data, range, users, functionality, complexities, data types, technologies of / in HIS [26] (Figures 5, p. 276, and 6, p. 277) – did only partially match with the semantic dimensions that the author wanted to communicate here. Therefore another set of development paths was selected. The thresholds of the selected periods are fuzzy. There are no exact limits. Finally, others may have different opinions and might have selected different development paths and other periods.

The references were not collected systematically, as it would be usual in reviews. The references reflect the work of colleagues, who influenced the author's work and with whom the author had discussions or collaborations on HIS developments. Therefore reference selection by nature may be biased.

2.4. Quotes

Engaging with HIS developments requires dealing with HIS architectures [38]. Being aware of the relationship of HIS with architecture - the discipline dealing with the architecture of buildings as well as of cities or landscapes – may help to better understand HIS architectures. In this context, the following quote offers a remarkable statement on the architecture of buildings: “We ‘re architects. We have designed numerous buildings, used by many people. We know about users. We know well their complaints: buildings that get in the way of the things they want to do. We also know well users’ joy of relaxing, working, learning, buying, manufacturing, and worshipping in buildings which were designed with love and tender care as well as function in mind. We’re committed to the belief that buildings help people to do their jobs or impede them and those good buildings bring joy as well as efficiency.” [39] (p. 6).

HIS also have a relationship with the discipline of medical informatics, where HIS form an important aspect of this discipline, as can be seen in investigations on the discipline’s content [40]-[45] as well as in its international recommendations on education [46], [47]. The second and final quote in this section is a maybe unusual description of the medical informatics discipline:

“Medical informatics is a wonderful discipline. It deals with organizing, representing, and analyzing data, information, and knowledge in biomedicine and health care. This is done in one of the most important areas for the life of all people in our world. It is engaged in an exhausting, but exhilarating struggle with one of the biggest challenges that science is facing: How do we translate data into information and how do we turn information into knowledge? Working in this field is demanding, it needs clear thinking, good judgement, and flair.

Medical informatics has many facets, all of them are both, challenging and fantastic. Medical informatics.

(1) is a *modelling discipline*. It forces us to view and understand medicine and health care better in a very broad and comprehensive manner. This may comprise pathophysiological processes, diseases, decisions, and health information systems see [48], [49] for more details.
(2) is an *empirical discipline*. In the "micro-macro spectrum of medical informatics" [50], (it demands both (i) nature (e.g. cells, human beings, populations) and (ii) institutions, devoted to health care and good and healthy living, to provide answers.
(3) is an *engineering discipline*. In medical informatics we are able to do both: In "preparing for change" [51] we may passively observe and comment, but we also can actively change our world by building tools to support diagnosis, therapy, and/or the many other facets in organizing care and healthy living.
(4) is an *organizational discipline*. It helps to change processes and organisations in order to make our world better prepared for providing good and affordable care as well as contented, joyful living in dignity and safety.
(5) aims to contribute to high-quality, efficient health care and to quality of life on the one hand and to progress in science on the other. What could, as its quintessence, be better and more stimulating as *objectives* than these, for all of us working either in practice or in research or in education?”

[52] (p. 25). Please note that the original numbering of references had to changed). The manuscript will refer to both quotes later.

3. HIS Developments: Revisiting Past, Present, and Future

3.1. Periods and Thresholds

As for the 2004 Lecture, it made sense to divide HIS developments again into the periods past, present, and future, with respective thresholds.

For the present, roughly, the last five years were selected – from about 2016 to about 2021 (when this talk was presented), or 2022 (when the manuscript was finalized).

For the past we included several decades, but no further back than 1961, the year of one of the mentioned landmark events.

To discuss opportunities and priorities on future HIS developments, the next or perhaps the next few decades should be considered.

As mentioned, these periods are imprecise, with no exact boarders. And others may choose different periods.

3.2. Development Paths

The eight development paths for HIS, which according to the author's views are critical to suggest answers to the questions raised, are presented in Table 2. These developments are abbreviated with Δ_x, x Δ {1, …, 8}. In addition, another line of development, Δ_0, will be mentioned, mainly to permit a link to the 2004 Lecture.

The symbol Δ was chosen as it is often used to represent change. It is also the initial letter of the Greek word Διαδρομή, pathway (Δια: through, Δρομή: road, path), and thus fitting to symbolize development paths.

3.3. Δ_0: Access to Increasing Data volumes

In the 2004 Lecture [26] (Figure 5, p. 276), increasing amounts of health-related data was the first development path discussed. In Figure 2, Δ_0 is visualized across the past, present, and future. The increase of health-related data is linked to emerging opportunities in computer-based data analysis, storage, and communication. The data increase is in part due to the increase of diagnostic and therapeutic procedures [53], [54]. New information and communication technologies, allowing the capture and processing of more data, constitute another important factor e.g. [55], [56].

Table 2. Development paths relevant to HIS developments

HIS development paths	
Δ_0	access to increasing data volumes
Δ_1	life situations related to health care
Δ_2	entities for health care
Δ_3	health care facilities
Δ_4	settings of health care
Δ_5	data to be processed
Δ_6	features for functions
Δ_7	architectures of HIS
Δ_8	management of HIS

In the past, opportunities to use computers with software products, installed there, increased continuously. The challenge of shifting data from paper-based and film-based storage to computer- based storage played a major role. This shift was combined with significantly changing processes for functions, due to the continuously increasing features of the mentioned software products. Having such data primarily on paper was related to much slower access compared to accessing data, stored on computers. This held true for patient data as well as biomedical and health knowledge data.

To date, this shift seems to have been completed for most of the developed countries. For patient information as well as biomedical and health knowledge, computer-based access to data through respective features has clearly improved the speed of access and reduced the associated effort. Finally, continuously increasing data volumes will probably lead to new ways for living and practicing health care ([57]-[60]).

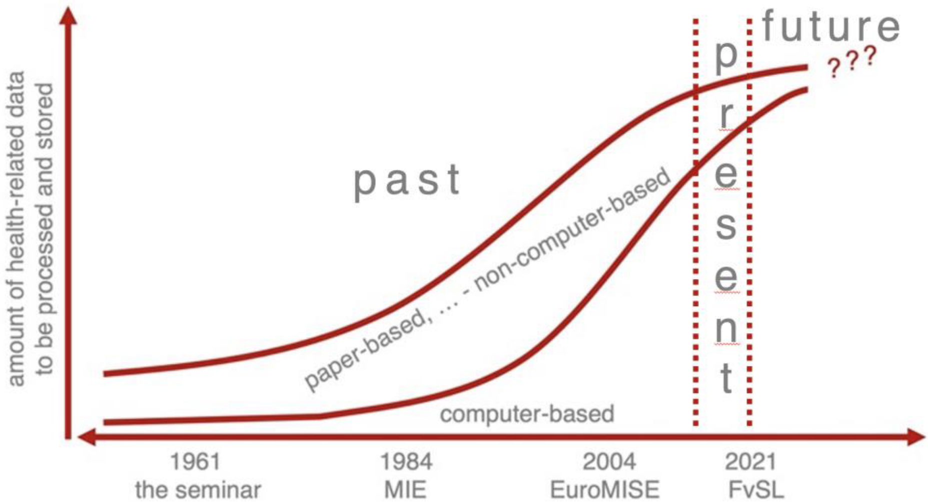

Figure 2. Roughly visualizing the increasing amounts of health-related data and their access as HIS development past across the selected periods for past, present and future. The years and events selected were discussed in sections 1,2 and 1.4.

As this shift from data stored on paper to data stored on computers seems to have been completed, we will omit Δ_0 as HIS development path. In addition, from the author's point of view, the following eight paths Δ_1 to Δ_8 can now better describe HIS developments, including the aspect of increasing data volumes.

3.4. Δ_1: Life Situations Related to Health Care

To better understand Δ_1 on life situations, related to health care, and their relevance to HIS developments, we should reflect on the fact that health care is an integral part of our lives. Health care starts when people are born (even earlier) and ends when people pass away. During some periods of our lives, the relative share of health care appears negligible, e.g., when we are in good health, living our 'normal daily lives'. Sometimes the relative share of health care is intensive, e.g., for persons, suffering from severe acute diseases and being inpatients in hospitals. Sometimes it is in between, e.g. for persons with chronic diseases who need medication or other therapeutic measures on a regular basis. Major life situations with respect to health care are prevention, wellness, emergencies, acute diseases, chronic diseases, care, and rehabilitation. In all these life situations health care is provided through appropriate services, e.g. for diagnosis, therapy, or care (from [1], chapter 1, where more details can be found). The main objective for HIS and so also the focus of HIS developments, is to support appropriately and sometimes even to enable provision of good health care for people in their various life situations (more details can be found in [1], chapter 2). In recalling what has been mentioned in the quint-essence of the second quote, good health care supports high-quality and efficient health care and improves the quality of life. Affordability and availability are other important facets of good health care.

In the past, Δ_1 HIS developments centred primarily on the episodic treatment of diseases, e.g. on diagnosis and therapy of inpatients in hospitals. HIS were designed to support health care services, where the relative share of health care was intensive. HIS developments were mainly institution-cantered with single health care facilities in focus. Although primarily episode-based, there was an expressed desire to overcome this limitation and to support patient-centred care as well, at least within single health care facilities.

To date, health care services, supported by HIS, still remain primarily focused on treating diseases, with the relative share of health care being intense. Even though still mostly only within single facilities, they now better focus on patients, not on single disease episodes of patients.

In the future, HIS should develop with respect to Δ_1 to support the full spectrum of health care services including in life situations, where the share of health care is negligible or in between. This extension would lead to a shift from patient-centred health care services – for persons with diseases – to person-centred health care services – for persons with diseases as well as for healthy persons.

By extending care in this fashion, health care becomes more rigorously integrated in life. In addition, other services, not considered traditionally part of health care, may become more integrated with processes of obtaining care including banking, shopping, learning, teaching or participating in cultural events. So, e.g., shopping may be combined with purchasing medication in a pharmacy or with visiting a medical office. Banking services may be obtained in a bank, located close to this office. In both cases, travel plans must take all of these services into account. HIS developments should consider that health care related services may have to be orchestrated jointly with other services, which is certainly a challenge [61], [62], [63] (pp. e27-e28).

3.5. Δ_2: Entities for Health Care

After in Δ_1 life situations related to health care have been discussed, we now will put the focus in Δ_2 on the various entities, who are giving this health care, again with respect to HIS developments.

In the past, HIS developments focused on supporting health care professionals. Initially, the support was limited primarily on physicians and later and with less intensity on nurses. With methodological and technical progress, the range of health care professionals supported through HIS grew more complete over the years.

To date, health care professionals remain the focus of HIS developments, which, for obvious reasons, makes sense. In addition, HIS developments now also take place to better support informal caregivers, i.e. persons informally taking care of patients such as family members, as well as to support the persons concerned, may they be sick and so patients or may they be healthy (see e.g. [64] with Finland as example). Enabling informal caregivers as well as patients / persons concerned to participate in health care will allow them to contribute more. With this, HIS would also support subsidiarity, an important principle, not only in health care (e.g. [65]) by distributing required work including less but still qualified individuals.

In the future, HIS developments probably will and also should continue to address these priorities including better collaboration among health care professionals and between professionals and informal caregivers and most importantly between professionals and the patients.

A two-decade-old statement "Any technology sets a relationship between human beings and their environment, both physical and human. No technology can be seen as merely instrumental. This is especially relevant when dealing with large automatic information systems, developed to contribute to the management and integration of large organizations, such as hospitals." [66] in the author's opinion still addresses this situation of collaboration very well.

To illustrate the future Δ_2 HIS development path, additional entities for health care must be introduced in addition to the previously introduced players like health care professionals, informal caregivers, patients / persons concerned, all human beings. In the future, functionally comprehensive, 'intelligent' machines as well as other living entities (in addition to humans) such as animals and plants or a combination thereof will play an increasing role. Collaboration of intelligent machines with humans, which may be described as the collaboration of natural and artificial intelligence, will play an increasing role in good health care and should also be considered for HIS developments [67]-[69].

Further discussions on intelligent machines can be found in [70]-[76]. Of importance is that such intelligent machines differ from other machines through their autonomic decision-making capabilities (e.g. on diagnosis and therapy) or by offering shared decision making between humans and machines [77]-[79]. The author's viewpoint on such intelligent machines is explained in [68]. His suggestion that such entities should become users of HIS, with respective rights and duties, is described in [79], pp. e18-e19. With regards to HIS developments, it is important to note that HIS users are no longer exclusively humans (in their various roles: health care professionals, informal caregivers, patients / persons concerned), but machines have become actors as well. Instances of such intelligent machine entities are robots in operating rooms contributing to surgical therapies [79] and intelligent homes that support vulnerable persons as servants [68].

3.6. *Δ_3: Health Care Facilities*

For Δ_3, we focus on the HIS development effect by facilities that are used to provide health care services. Examples for health care facilities include hospitals, medical offices, nursing homes, nursing centres (day care, outpatient services, etc.), pharmacies as well as rehabilitation centres (inpatient, outpatient, etc.). These facilities all provide health care services, frequently in collaboration. The above list is by no means complete.

In the past, HIS developments concerning Δ_3 focused on major health care facilities such as hospitals (initially primarily university medical centres) and later and with less intensity on medical offices (e.g., [15], [22], [23], [28]-[36] as well as [80]-[83] for some early references on hospital information systems and [84]-[86] for references on information systems in medical offices). Based on these findings, development of health care services were focused primarily on those services with an intensive relative share of health care as described in Δ_1 for the past.

To date, more or less all health care facilities are considered in HIS developments, maybe in different intensities. As far as the author can see the focus is still mainly on those services, where the relative share of health care is intense, as described before in Δ_1 for the present.

Also, in future health care facilities remain of particular importance with respect to HIS developments. However, in addition, another 'facility' has to be taken into account, which is not actually a facility at all, strictly speaking. In this facility the author wants to include informal caregivers and the patients / persons concerned. As mentioned in Δ_2 they may also participate in providing health care. For also supporting this facet of health care, this 'facility of enabled informal caregivers and patients / persons concerned' has to be included into HIS developments.

3.7. Δ_4: Settings of Health Care

Concerning settings of health care let us keep in mind that the term health care facility is used here for institutions dedicated to deliver health care services, whereas the term health care setting is used more broadly. In Δ_2 and Δ_3 HIS developments were discussed, with the focus on *who* (Δ_2: entities, Δ_3: facilities) is providing health care for the life situations in Δ_1. In Δ_4 the question will focus on *where*, in which settings, health care will take place. These settings can for obvious reasons be the facilities themselves, and so hospitals, medical offices, nursing homes and centres, pharmacies, and rehabilitation centres. In addition, other settings of health care, being located outside the walls of these facilities, have to be taken into account with respect to HIS developments. These are settings, where our 'normal' living takes place.

In the past HIS developments were concentrated on supporting physicians and nurses and had to be centred on selected health care facilities such as hospitals and medical offices (recall Δ_2 and Δ_3) and there, because of technical limitations, within the walls of these facilities.

To date, as in Δ_3, more or less all health care facilities are considered in HIS developments, again mainly within their walls. However, due to much better connectivity and a broad availability of mobile devices, present HIS developments also try to overcome such walls when appropriate for good health care services, e.g. for virtual consultations between patients, being at home, and their physicians, being in their medical office.

Due to the methodological and technical progress achieved in recent decades, for future HIS developments, technology is no more a major limitation for even globally reaching settings, where health care might be provided through entities and facilities of health care. Settings within the walls of health care facilities may still remain in the centre of HIS developments, but these walls are no more borders for HIS. Other settings can now also be taken into account, may it be locally, e.g. within a community, and even worldwide. Among these additional settings of health care are homes, workplaces, and even transport media such as cars. With this progress in future services for life situations, where the share of health care in our lives seems to be negligible or in between, can better be considered. And so the full spectrum health care services (recall Δ_1) can now be better taken into account for HIS developments. Some references, reporting on these developments, are [87]-[101].

Examples for health care, which could now better be supported by HIS, are prevention, wellness, functional deficits (frailty, …), 'mild' chronic situations, and palliative care.

3.8. Δ_5: Data to be Processed

This line of development discusses questions on data to be processed or provided in HIS (see [1], section 3.2 for details regarding current HIS). To discuss this line of HIS developments let us at first have a look at Figure 3. In the Figure's centre are 'classical' methods for diagnosis and therapy. These methods are, e.g., conversation with and direct physical examinations of patients, lab tests or signal and imaging procedures in diagnostics, or talk, medication, and surgical, internistic or radiological interventions in therapy. In addition to these classical methods, molecular methods and environment-based methods have meanwhile been added, for both diagnosis and for therapy. In [102] this is described as spectrum of methods for diagnosis and therapy first primarily investigating the patients 'phenome' and then having been extended to also include investigating their 'genome' and their 'exposome'. All these methods produce data.

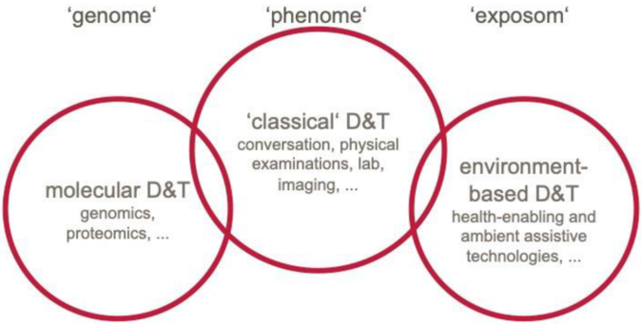

Figure 3. Methods for diagnosis and therapy (D&T).

In the past HIS developments had to consider a huge variability of data from classical methods, which in themselves were tremendously improved and extended during this time. Discussion on interoperability standards for representing and communicating data were at the beginning not a priority. With increasing amounts of data on computers (recall Δ_0) this changed, and interoperability standards came up. Also, molecular data have been successively added.

To date, HIS developments are considering phenome and genome data. Also, data from the environment of patients / persons concerned started to be used. Progress on health-enabling and ambient assistive technologies played an important role, with improved sensor and communication technologies on or at their bodies or in their rooms and with extensive use of smart mobile tools (recall [87]-[101] from Δ_4 as well as [103], [104]). Interoperability standards for representing and communicating data are now a priority.

For future HIS developments all types of data, mentioned here – phenome, genome and exposome data – will have to be extensively considered for providing good health care. The still ongoing discussions on interoperability standards will hopefully lead to opportunities for globally sharing and communicating data, when needed.

3.9. Δ_6: Features for Functions

Closely related to Δ_5, this line of development discusses questions on functions to be supported by features of HIS (see [1], section 2.9, on the meaning of the term features, as used here, and [1], section 3.3, for details regarding on functions to be supported by features in current HIS).

In the past HIS developments on Δ_6 centred on developing software products in order to provide features for basic health care functions, so that the increasing amount of data to be processed could be handled (recall Δ_0). The entities, for whom these features have been provided, were health care professionals. Features on these software products were mostly for functions on patient care (less for research) and, at least at the beginning, closely related to administrative and documentation matters as well as to meeting legal requirements. Features for functions on decision support started (see e.g. [81]). During the years, such features were continuously extended for further functions.

In to date HIS developments, features are now significantly extended for a broad spectrum of patient care functions. They also include analytics functions beyond direct patient care. Users of these basic and advanced features are still primarily health care professionals. There are extended opportunities for decision support in patient care, often discussed and implemented under the term artificial intelligence (recall [67]-[76] from Δ_2).

In future these HIS developments on basic and advanced features for functions will continue. And, as the spectrum of functions will continue to be modified (recall the increase of diagnostic and therapeutic procedures, mentioned in section 3.3), they are in some respect developments on a moving target. In future such HIS developments should be provided for supporting all entities of care (recall Δ_3 and see e.g. [105]), although, with good reasons, features to support health care professionals remain in the centre of this development path. Also, such features will have to be provided in all health care facilities and in all settings of health care, as discussed before.

3.10. Δ_7: Architectures of HIS

Let us now discuss the last two paths of HIS developments, which are actually the central ones for those, being involved in such developments. The first of these paths is on HIS architectures and their infrastructures and so with a focus on technology and functionality.

In the past, from 1961 to present, there were tremendous HIS developments, mostly related to an increasing use of computers with their steadily expanding software products, better communication networks, and better and more kinds of devices for entities of care as users, leading to better access (recall Δ_0 and Δ_5) and better features for functions (recall Δ_6) in HIS. HIS developments concentrated on health care facilities and health care professionals. Approaches for modelling and analysing HIS architectures were developed (e.g. [37], [106]-[108]). Knowledge on HIS architectures is now content in educational programs in biomedical and health informatics and in health information management (e.g. [46], [47], [111]-[117]). Textbooks on HIS or with HIS as chapters became available (e.g. [31]-[33], [38], [116]-[120]).

To date, this development path continues still intensively, now on the institutional as well as, and with greater emphasis as in the past, on the trans institutional level (recall Δ_1). Architectural styles are on debate. As institutional architectures might not be able to be easily and straightforwardly extended to trans institutional ones, paradigm shifts might be needed.

Future architectures of HIS should take into account what has been mentioned in paths Δ_1 to Δ_6. This will clearly be challenging for the practice of and for research on HIS. And this will have consequences for teaching about HIS.

3.11. Δ_8: Management of HIS

The second path of HIS developments, which is central for those, being involved in such developments, is on management of HIS and so with a focus on organizational and governance aspects.

Compared to developments on architectures of HIS (Δ_7), reflections on appropriate approaches on how to manage HIS started later, as issues of technology and functionality were paramount. Like in Δ_7 they concentrated on health care facilities and health care professionals (e.g. [121]-[123]), of course, as in all paths, with exceptions (e.g. [124]). Many of the textbooks, mentioned in Δ_7 also considered this management aspect, some even put the focus on this topic (e.g. [125]-[127]). In particular in larger health care facilities, such as hospitals, organizational units on information management and information technology with chief information officers (CIOs) as chairpersons had partially been established in the long run.

To date, like in Δ_7, this development path continues on the institutional and also, and here as well with greater emphasis as in the past, on the transinstitutional level. It became apparent that transinstitutional HIS management differs from institutional HIS management. Also, it became clear that transinstitutional HIS management is of considerable importance for patient-centred care as well as for biomedical and public health research. CIOs and respective units are now the rule, no more the exception, at least in larger health care facilities.

Future management of HIS should take into account what has been mentioned in paths Δ_1 to Δ_7. Like in Δ_7 this is as well challenging for the practice of and for research on HIS. And this will have consequences for teaching about HIS. Like in enterprises outside health care and due to the increased relevance of information for providing good health care – and so also due to the increased relevance of HIS – consideration should be given to CIOs becoming members of the boards of directors in health care facilities.

4. Views on HIS Development Paths

4.1. The Development Paths in Summary

The main impressions on the development paths Δ_1 to Δ_8, described before, are summarized in Table 3.

For the sake of ease, let us also recall the instances, which have been mentioned for the topics in the development paths Δ_1 to Δ_6. These were

for life situations related to health care (Δ1): prevention, wellness, emergencies, acute diseases, chronic diseases, care, and rehabilitation as major life situations;

for entities for health care (Δ2): the patients / persons concerned, health care professionals (physicians, nurses, …), informal caregivers, and 'intelligent' machines;

for health care facilities (Δ3): hospitals, medical offices, nursing homes, nursing centers (day care, outpatient services, …), pharmacies as well as rehabilitation centers (inpatient, outpatient, …) and the 'facility provided by informal caregivers and the patients / persons concerned';

for settings of health care (Δ4): the health care facilities, mentioned before, as well as homes, workplaces, and even transport media such as cars;

for data to be processed (Δ5): phenome, genome and exposome data;

and for features for functions (Δ6): basic and advanced features to support functions.

Table 3. Summarizing major impressions on past, present and future HIS developments, as described before, for all development paths. While entries in past and present intend to characterize existing developments, entries in future mention opportunities and priorities. In order to point out major trends the impressions are strongly simplified, both in content and time. In addition, they are personal views of the author, with the risk of being subjectively biased.

		HIS developments		
	development paths	**past main focus**	**present main focus**	**future opportunities**
Δ_0	access to increasing amounts of data	paper-based, shifting to computer-based	computer-based	(see Δ_1 - Δ_8)
Δ_1	life situations related to health care	disease episodes; institution-centred	diseases; patient-centred	health care as part of the whole life; person-centred
Δ_2	entities for health care	health care professionals	health care professionals, caregivers, persons	these humans plus ‘intelligent‘ machines
Δ_3	health care facilities	selected health care facilities	health care facilities	health care facilities plus enabled caregivers, persons
Δ_4	settings of health care	selected health care facilities	health care facilities	health care and other settings, global reach
Δ_5	data to be processed	phenome	phenome and genome	phenome, genome and exposome
Δ_6	features for functions	basic health care features	plus advanced features, for professionals	plus advanced features, for all entities of care
Δ_7	architectures of HIS	institutional, for health care facilities	also transinstitutional, for health care facilities	architectures also take paths Δ_1 to Δ_6 into account
Δ_8	management of HIS	institutional, for health care facilities	also transinstitutional, for health care facilities	management also takes paths Δ_1 to Δ_7 into account

4.2. HIS Developments Paths Grouped into Thematic Spaces

Table 4 is clustering the eight HIS developments paths into three thematic spaces. The questions, raised for each space, may be helpful in approaching on how HIS can be appropriately further developed.

Table 4. The HIS developments paths grouped into thematic spaces.

	Space	Major Question	Line
α	HIS health care space	- For which life situations related to health care, - by which entities for health care, - from which health care facilities and - in which settings of health care will health care be delivered?	Δ_1 Δ_2 Δ_3 Δ_4
β	HIS analytics space	Given α: - Which data can be processed - by which features?	 Δ_5 Δ_6
γ	HIS management space	- How can HIS be managed so that - HIS architectures and infrastructures are available, which appropriately support and sometimes even enable to deliver good health care for a given α and a given β?	Δ_8 Δ_7

4.3. Management of HIS as Mapping

For some readers it might be helpful to formulate management of HIS as mapping (recall the thematic spaces of Table 4).

Let LS be the set of all life situations related to health care and let $\wp(\text{LS}) := \{x \mid x \subseteq \text{LS}\}$ as powerset of LS comprise all combinations of such life situations. Let EHC be the set of all entities for health care, HCF the set of all health care facilities, SHC the set of all settings of health care, D the set of all data to be processed, F the set of all features for functions, and let $\wp$(EHC), $\wp$(HCF), $\wp$(SHC), $\wp$(D) and $\wp$(F) be the respective power sets, as defined before for LS. Let HIS-A be the set of all instances for architectures of HIS.

Management of HIS, viewed as mapping, here denoted as HIS-M, may then be defined as

$$\textbf{HIS-M}\text{: } \wp(\text{LS}) \times \wp(\text{EHC}) \times \wp(\text{HCF}) \times \wp(\text{SHC}) \times \wp(\text{D}) \times \wp(\text{F}) \rightarrow \text{HIS-A} \quad (1)$$

This mapping might be put into words as follows: Given combinations of certain life situations, certain entities for health care, certain health care facilities, certain settings of health care, certain data, and certain features available: HIS management has to make available HIS architectures and infrastructures, which appropriately support and sometimes even enable entities for health care to deliver good health care for people in their various life situations.

Please note that the parameters, mentioned in the HIS-M function, relate to instances of the development paths, which have been summarized before in section 4.2.

4.4. Management of HIS versus Health Care Planning and Organization

Management of HIS, at least as it is formulated here, does not reflect on why certain parameter values for the HIS-M-function were taken.

This may lead to the question, why one has to consider such values for the parameters of this mapping as taken. Shouldn‘t they be regarded as subjects for modification? And why not trying to identify ‘good parameter value constellations‘ to achieve ‘good HIS architectures’? Reflecting about good or even optimal parameter value constellations concerns parameters in the HIS health care space and in the HIS analytics space of Table 4.

Let us recall, what has been stated in section 3.4: “The main objective for HIS” … “is to support appropriately and sometimes even to enable provision of good health care for people in their various life situations” and that “good health care supports high-quality and efficient health care and improves the quality of life” as well as affordability and availability.

Reflecting about delivering good health care for the various life situations is primarily a matter of health care planning and organization and so for persons / institutions being responsible for making decisions here. This means that looking for good or even optimal parameter value constellations in the HIS health care space and in the HIS analytics space is in their responsibility. It is not primarily a task of HIS management. However, providing information for decision makers in health care planning and organization on how HIS can well support and enable to deliver good health care is in the scope of those persons / institutions involved in HIS management.

Are there clear borders between tasks of HIS management and tasks of health care planning and organization? As far as the author can see this is not the case. The main reason is probably that planning and organizing health care needs in-depth knowledge on opportunities for HIS and for HIS developments for doing their tasks well. And for managing HIS it can be helpful to be well-informed about potential alternative parameter value constellations in the HIS health care space and in the HIS analytics space for future health care services. Insofar HIS management and health care planning and organization seem to mutually influence each other.

5. Discussion

5.1. Limitations

As already mentioned in section 2.3, these are the author's personal views of HIS developments. Although there has been always an international exchange, this work has been done primarily in Germany and Austria and so in Europe, in two developed countries, having a certain organization and legislation of health care. The views as well as the selected development paths and periods must probably be subjective. Others may have taken other development paths and other thresholds for periods and even the content of past, present and future in the paths could have been different. The views were, however, formed over almost half a century, during which the author has been engaged with HIS developments, and thus may be worth reporting and discussion.

As also mentioned in section 2.3 the references are mainly addressing the work of colleagues, who influenced the author's work. Therefore, reference selection by nature may be biased.

The focus laid here is on HIS developments with respect to supporting health care, which might also be regarded as limitation. An additional focus could have been laid on HIS developments supporting research, in particular in biomedicine and health sciences, but also in computer science and engineering. In [1] this aspect has been e.g. addressed under an additional life situation called research for life and in sections like the one on information systems in medical research.

Last, but not least, the complexity and variability of HIS and HIS developments is huge and hard to grasp, which per se limits to deal with this topic. The level of discussion here could be compared to that of briefly characterizing the tip of an iceberg, where the iceberg would have to be discussed as a whole.

5.2. Balancing Issues

Opportunities can be associated with challenges. Such conflicts might lead to the necessity of carefully balancing the advantages of opportunities against the disadvantages of challenges. With respect to HIS developments the author wants to highlight some conflicts, where careful balancing is needed.

Increasing amounts of health-related data can be helpful for providing good health care to people. This increase may also lead to a higher risk of violating data protection and data security. However, safeguarding informational self-determination of individuals is an important asset.

Virtual communication, maybe in a global reach of care, and, maybe, given by 'intelligent' machines is mentioned as opportunity. This can also lead to disadvantages, as virtual communication should support, but by no means substitute personal relationships. Also, here appropriate balances have to be found, to avoid a loss of direct personal contact between humans through this development.

Health care services from informal caregivers and patients / persons concerned themselves is ambiguous, too. On the one side the wish to receive comprehensive services from health care professionals is obvious but increasing services through health care professionals will at some point come to limits in various ways. On the other side informal caregivers and patients / persons concerned may also want to be more responsible for oneself, in particular if they are enabled. But they will in many cases not be able to replace professional help. Also, here appropriate balancing is necessary, also in the context of achieving appropriate subsidiarity (recall Δ2). In addition, HIS may help to support this balancing through helping to enable good collaboration between all entities of health care.

5.3. Other Factors and Paths

When looking at the thematic spaces in Table 4 we can see that the mentioned development paths concentrate of being able to adequately deal with HIS management and HIS architectures. Aspects such as (maybe competing) interests of the various stake holders in health care and in IT industries, of how and which health care services are reimbursed, aspects of financing, of political priorities, of the intention to primarily generate profit, or of legal and governmental actions are not considered here. They might be of equal or of even more influence on HIS developments. Whereas in the past technology was often a major limiting factor, the mentioned future opportunities of HIS developments now often are limited by traditional health care planning and organization and respective legislation and reimbursement schemes, not considering the new opportunities of HIS developments.

Evaluating HIS has been and is an important additional factor for HIS developments, which could not be discussed here (e.g. [129], [130]). Systematically evaluating HIS and their benefits for entities for health care, for health care facilities, for public health, and for research in biomedicine and health sciences through well-designed studies (if possible, through randomized trials) remains a major issue.

The author also wants to refer to topics, mentioned in [53], pp. 605-607, for medical informatics research fields. Many of them correlate to HIS developments, such as “seamless interactivity with automated data capture and storage for patient care, and beyond”, “informatics diagnostics”, “informatics therapeutics”, “informatics capability-enhancing extensions, both mental and physical”, or “automated, individualized health advice and education”. Although they would have been worth to be discussed in more detail, they have been touched only marginally here in order to have the major HIS development paths in the focus.

Last, but not least, education has to be mentioned as important additional factor for HIS developments. Education here is twofold. One the one hand education concerns empowering HIS users, i.e. entities of care such as health care professionals, informal caregivers and patients / persons concerned. On the other hand it concerns adequately educating specialists in HIS architectures and HIS management. The latter has briefly been touched in paths Δ_7 and Δ_8.

5.4. Discussion Outcomes from Frank-van-Swieten-Lectures and ICIMTH

As mentioned at the beginning, before the Symposion on October 2022 in Athens these thoughts have been presented and discussed during the 2021 and 2022 Frank-van-Swieten-Lectures and during ICIMTH 2022.

In particular in the 2022 discussions it was raised that two additional development paths might have been worth to be mentioned in addition:
Interoperability standards, because of their importance as well as because of the progress achieved.
Devices, as in particular tremendous progress has been made through mobile devices with their ‘apps‘, and that this progress has significantly influenced and improved functions and features of HIS.

In the development paths, the author considered as relevant, standards were part of the Δ_5 path on data to be processed and devices were part of Δ_7 on architectures of HIS. The author agrees that it might be worth to consider standards and devices as separate paths, as well as some other paths, mentioned in section 5.3.

One colleague - well-known, high-qualified and well-respected, not only by the author - added that in his opinion the mentioned future developments in HIS are already a reality. Here the author did not share this opinion and suggested to run studies in order to see whose opinion is more in line with the reality of HIS.

5.5. Call for Research

The views of HIS developments, described here, reflect the author’s personal views of HIS developments. Others are kindly encouraged to do research on the statements made, e.g. on some of the development paths. Can it be shown that the author’s statements on paths are correct or wrong? And if they could be shown as being wrong, are there other development paths with better evidence? Is there any data to verify or falsify some of the statements? Or is there any data to specify development paths more precisely?

5.6. Call for Discussion

The author wants to put the presented views on past, present and future HIS developments up for discussion. Comment on these views, critically discussing the author’s statements in each of the paths and so participating in a debate on HIS developments, are very welcome.

Unfortunately, there was no immediate invited discussion of the paper, resulting of the 2004 Lecture ([26]). Such a discussion, however, took place on a related paper, forecasting related future developments in 2000 for the year 2013 [128]. It might be of interest looking at the invited comments there, with a very broad view on how HIS developments should support health care [131]-[143] and at the reflections made in 2013 [144]-[147].

6. “Now here I am, a fool for sure! No wiser than I was before”?

The conclusion section starts with recalling and commenting the two quotes of section 2.4:

With respect to the quote on architecture, we have to recognize that we are still on our way to reach the goal of building HIS, where users enjoy “relaxing, working, learning, buying, manufacturing, and worshipping” [39] (p. 6). Transposed for HIS this means: where entities for health care are appropriately supported and enabled through HIS in delivering good health care for people in their various life situations. And so, for HIS specialists, to having designed HIS “with love and tender care as well as function in mind”

[39] (p. 6). It has to be added that systematically dealing with the theory and practice of the architecture of buildings and with their engineering has a much longer tradition than dealing with HIS architecture and HIS management. Books on architecture of buildings have already been published two thousand years ago [148]. Another significant difference can be found in the materials to be used. For the engineering of buildings, they developed rather steadily, at least as far as the author can see. For information systems there was a huge change in the materials to be used, when computers with their software products became available during the last century.

With respect to the quote on medical informatics, we can see that also for HIS we are "engaged in an exhausting, but exhilarating struggle with one of the biggest challenge that science is facing" [52] (p. 25). Even more, HIS developments will remain a major topic for future medical informatics research, practice, and education.

This conclusions section closes by giving an answer to the question:

Shall or shall we not say with respect to HIS developments
"*Now here I am, a fool for sure! No wiser than I was before*"?

and so referring to Johann Wolfgang von Goethe‘s Faust [17] (p.19), as mentioned in section 1.4. After describing HIS developments in past and present the answer is evident, at least in the author's opinion. With respect to HIS developments Goethe‘s Faust statement can not be applied. We are wiser now! We learned many lessons! There were tremendous developments in the past and we can contribute to such developments in the future: For good health care for people in their various life situations. Present HIS are much better than HIS of the past and probably nobody would want to get back to a past state. We, however, also have to recognize that we are by no means at the end of HIS developments. It seems that we are still in the middle or even at the beginning. There is room for continued improvement with an end of HIS developments far from sight.

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this section and in section 2.3, as well as authors in the References section. Many others could be added.

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Surveys Aimed at General Citizens of the US and Japan About Their Attitudes Toward Electronic Medical Data Handling – 10 Years Change, Before and After Covid-19

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Abstract. *Objectives:* To clarify the views of the general population of two countries (US and Japan), concerning handling of their medical records electronically, disclosure of the name of disease, secondary usage of information, compiling their records into a lifelong medical record, access to their medical records on the internet, questionnaire filling for delicate history, comprehensive consent for laboratory results, chart and genome profile, and AI use in diagnosis and explanation. *Methods:* The authors contacted people nationwide in the United States at random via Random Digit Dialing (RDD) in 2008. Same questionnaire plus some new items were surveyed in 2022 by mail invited web entry. The authors had also surveyed people in Japan in 2007 and 2017 using same questionnaires sent by mail. *Results:* In US, accessing own chart by internet became accepted (positive 52% to 61%) and popular in these 14 years. Japan showed small change, as regional medical record sharing is yet to come. About medical records in un-identifiable manner to be used for the purpose of medical error precautions, infectious disease measures and device/drug developments, in US, positive answers are constantly low, even for infectious disease prevention like CoVID-19. About preference to compile medical record into one file as a lifelong medical record, sharp contrast was observed. US people became favor of lifelong record (46% to 71%), while Japanese people decreased (76% to 57%). As for comprehensive consent, Japan positive answers are more than US for all situations, except if genome profile is included. US answers are almost same, even genome profile is included. About AI (artificial intelligence) application to healthcare, both US and Japan survey showed best preferred is "Doctor may use AI and everything, and explains in person". Japanese people largely prefer explanation in person, while US showed small preference.

Keywords. Surveys, public opinion, electronic health records, privacy, AI use in medicine, comprehensive consent

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1. Introduction

The authors conducted questionnaire surveys in US and Japan to investigate the awareness of people regarding medical data handling. In these studies, it was hypothesized that the sharing medical data among different healthcare providers, compiling them into one lifelong record, secondary use of anonymous data, are not yet enough accepted in these countries.

The target population for this survey was not physicians or patients, but the general population. Similar surveys have been conducted with physicians [1,2,3,4,5] and patients [6,7,8,9,10,11], but few studies have targeted citizens [12,13,14,15,16]. As public funding allocated to healthcare services is expected to expand, taxpayers' views should be of significant concern as well as the opinions of patients and healthcare professionals. The general population includes healthy people, people that are, and had been in therapy.

The first survey was in Japan on 2007, then with same questionnaire translated, in US on 2008[17]. To see 10 years change, the author conducted again in Japan on 2017 with same questionnaire with some news topics added. They were; 1) questionnaires filling for treatment, health check-up and insurance contract 2) comprehensive consent for laboratory results, medical chart text, genomic profile, and all of them 3) AI use in medicine for diagnosis and explanation.

2018 US survey was postponed due to COViD-19 breakout, as a result, however, change before and after COViD-19 was observed.

The research questions are:

(1) What kinds of doctors, public organizations, private companies, people are allowed to access their medical data?
(2) Is a scheme allowing healthcare providers or private companies to access people's unidentifiable medical data for the purpose of healthcare cost savings accepted?
(3) Do people prefer to compile their medical records into one lifelong record?
(4) Is access to their medical data via the internet considered acceptable and safe?
(5) Do the results differ between these two countries, considering the differences in their healthcare policy?

Above items were for 2007/2008 survey. New items added to 2017/2022 are:

(6) Do people fill questionnaires even about their delicate history?
(7) Do people accept comprehensive consent?
(8) How should AI be used in diagnosis process and explanation to them?

2. Methods

2.1. Survey in the US

The target of this survey was ordinary citizens who live in the US. In 2022 US survey, the author used commercial survey company. On July 26 – Aug 3, 2022, 3296 requests were mailed to the registered respondents, and answers were collected until they got 200 valid answers. Registered members were of many groups of people, like airline members, net shopping users, etc., mixed in order to avoid vias. They were awarded small amounts, like 500 miles.

For the 2008 US survey, On 28 September 2008, people were contacted at random via US nationwide Random Digit Dialing (RDD) to obtain 200 eligible responders aged 19 years old and over who completed the telephone interview.

2.2. Survey in Japan

A survey using the same questions was conducted in Japan on 2007, a year before the 2008 U.S survey, and on 2017 with some new questions added. The methods were all the same with 2007 and 2017. The target was the general population including men and women aged 20 to 69 years old who live in Shizuoka Prefecture (population in 2019 was 3,638,000, about 1/35 of that of all Japan).

The questionnaire was sent to 2,000 households which were selected at random from the telephone directory. We asked that the responder should be a person whose birthday was nearest to the received date among the family members aged 20–69 so that we could obtain responses from different age groups. This was done because without this assignment, the elderly are more likely to become responders because they are likely to stay at home. The surveys offered 500 yen (4USD) stored value card for valid answers. The survey period was 16–31 October 2007, and 1-31 January 2018 (Survey planned and mailed in December 2017).

2.3. Limitation of Comparison

In 2008 in US survey, method was RDD, while 2022 survey was internet survey for pre-registered "general citizen", which makes the comparison only for observing trends and not for statistical validity.

Japan 2007 and 2017 methods were same, but different from both US survey.

2.4. Explained Definition of "Identifiable" and "Un-identifiable"

About the terms "identifiable" and "unidentifiable," we consciously use these terms with only some explanation in both surveys due to limited response time and not too long sentences. There are many methods and guidelines of making information de-identified [18,19,20,21,22,23]. The explained definition of "identifiable" was "with your name and address," and of "unidentifiable" was "without your name, address, your other access, and your profile and clinical history are made anonymous such that nobody can spot you."

3. Results

3.1. Responder Attributes

The cooperation rate was calculated based on the definition of the American Association for Public Opinion Research (AAPOR) [24]. Each case was coded according to one of the AAPOR categories. These categories were as follows:

US 2008 survey: I (Completed Interviews) = 200, P (Partial Interviews) = 28, R (Eligible, Non-interview, Refusal) = 443, NC (Eligible, Non-interview, No Contact) = 8,649, O (Eligible, Non-interview, Other) = 81, UH (Unknown Eligibility) = 10,141, and NE (Not Eligible) = 1,367. The Cooperation Rate (AAPOR CR4) was calculated by employing the formula: CR4 = (I + P)/(I + R + P). The cooperation rate of this survey was 34.0%.

The average session period, for the US 2008 survey, was 23 minutes 25 seconds.

US 2022 survey was conducted by mailing 3296 requests and answer period was cut off as soon as 200 valid answers were collected. Cut off was not by each category of age and gender, but just total numbers of 200. Rough response rate before cut off was 6.07%.

Japan 2007 survey: I = 457, P = 53, R (Refusal, no return) = 1,379. The valid response rate (AAPOR CR4) of this survey was 27.0%.

Japan 2017 survey: I = 225, P = 101, R = 873. The valid response rate of this survey was 27.2%.

The attributes of eligible respondents in the US and the Japan survey have been summarized in the following Figure 1.

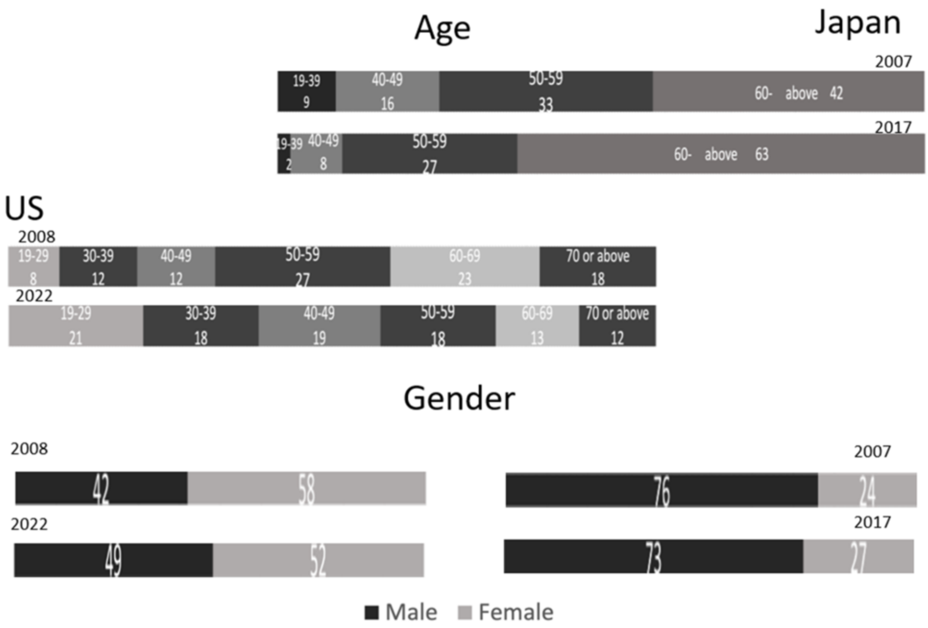

Figure 1 Respondent attributes

3.2. *Questionnaires and Results*

The questionnaires and results have been presented in the figures inserted in each discussion paragraph.

4. Discussions

4.1. RDD vs mail-evoked web survey

Kwak, et al. reported difference between web-based and RDD[25], Pierannunzi et al pointed out issues of mail-, telephone- based surveys transfer to web-based [26] because of cost benefit and quickness of web-based survey. Schonlau et al. reported RDD vs propensity-weighed web survey[27]. All pointed out that web survey is quicker and less response rate. Schonlou resulted that propensity weighing makes response rate improved. Therefore, the authors' surveys are for limited to reference, except for Japan 2007/2017 survey.

4.2. Respondent attributes (Figure 1)

About age distribution, Japan results became old age dominant even more. The mailed survey requested to answer by "a person in your family whose birthday comes first." Generation became even older, family size became smaller, are the reasons. In US, 2008 survey was RDD, while 2022 survey was mail invited web based. US 2022 survey showed very equal respondents among age categories. This is because of pre-balanced population of survey company registrants. Although the authors did not set limit of respondent to each category, over limit category respondents can be refused at the entrance of the survey.

The questionnaire was sent to 2,000 households which were selected at random from the telephone directory. We asked that the responder should be a person whose birthday was nearest to the received date among the family members aged 20–69 so that we could obtain responses from different age groups. This was done because without this assignment, the elderly are more likely to become responders because they are likely to stay at home. The surveys offered 500 yen (4USD) stored value card for valid answers. The survey period was 16–31 October 2007, and 1-31 January 2018 (Survey planned and mailed in December 2017).

4.3. Q1. How would you feel if only you could view your medical records on the internet?

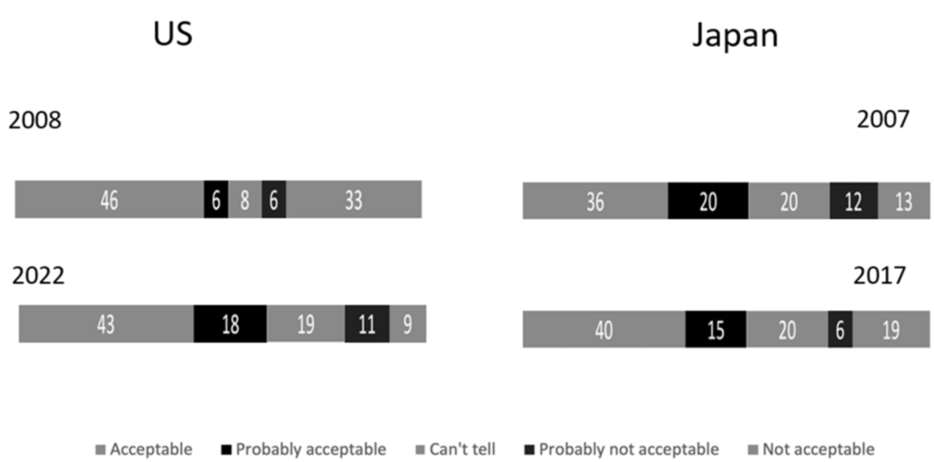

Figure 2 Medical record on internet

In US, sum of "acceptable" and "probably acceptable" (positive answers, hereafter) became significantly large (p=0.034), as well as negative answers ("probably not accepted" and "not accepted") became smaller. Accessing by internet became accepted and popular in these 14 years. In Japan, both positive and negative are unchanged, though definite answers increased at both sides. In Japan, still regional patient record sharing is minor practice, while CD/DVD and envelop based sharing is mainly taking place. In 2020, Japan Ministry of Health Labour and Welfare reported the status of regional patient record sharing[28]. It reported that though 218 regional sharing were subsided and surviving, 59 of them have only one provider presenting patient record. Participating providers are total of 15,492, among all providers in Japan are more than 80,000.

In a questionnaire survey conducted in five clinics in Australia and New Zealand [7], patients' attitudes toward sharing their electronic health records (EHR) were found to be influenced by three factors which were identity of recipient: level of anonymity: and type of information: In this survey, the authors obtained similar results.

4.4. Q2. Assuming that you are needed to visit the hospital or physician's office, please rate how you'd feel if, without your consent, but for the purpose of treating your illness, your medical records were disclosed in an identifiable manner to the following recipients?

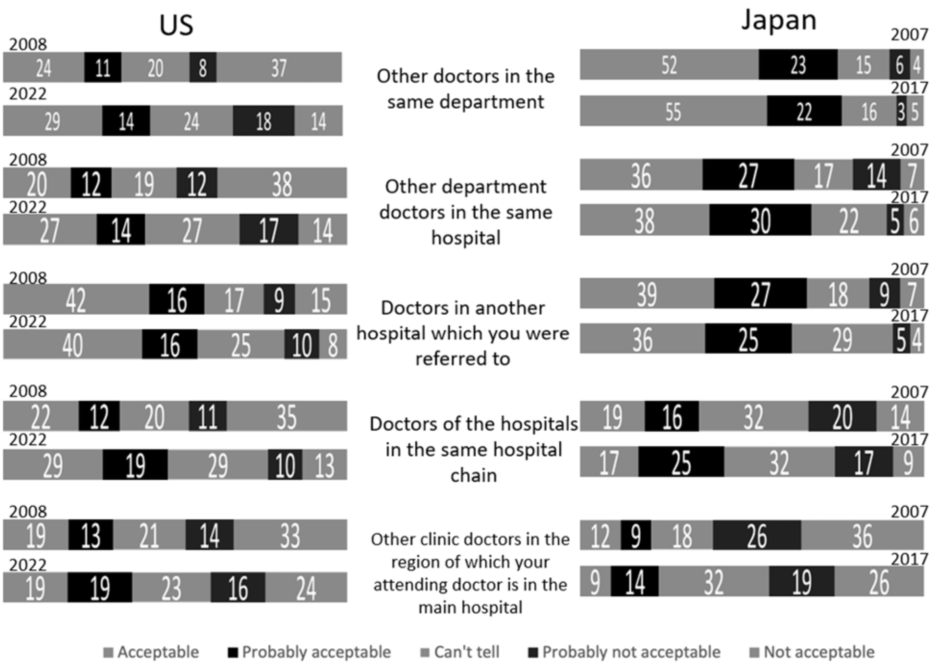

Figure 3 Medical record seen by other doctors

Except for "referred doctor", positive answers in US survey show small numbers and minimal difference among remaining four, while Japan survey show apparent decrease from high at the top of the column to low at bottom column. Same as in 2007/2008 report [17], still in US 2022, patients are cared by "the attending doctor", while in Japan 2017, by "the hospital or clinic".

In US, positive answers increased in all four through 14 years, which again the authors conclude that regional sharing became popular in US.

4.5. Q3. Your medical records are disclosed in un-identifiable manner to pharmaceutical companies and DHHS/MHLW for the purpose of error precautions, infectious disease measures and device-drug developments

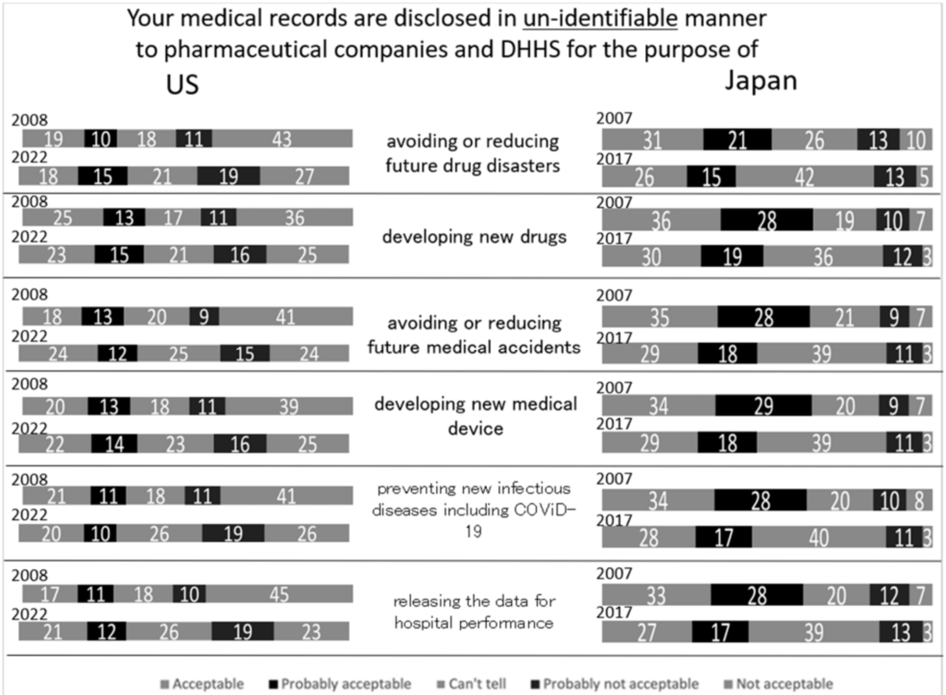

Figure 4 Use for health policies

In US, positive answers are constantly low, even for infectious disease prevention. In Japan, positive answers are larger compared to US, but decreased in all purposes. It should be noted that both in US and Japan, both in 2000's and recent, skeptical answers (Can't tell) became larger.

Willison's survey [14] of the Canadian public, concerning consent of secondary use of unidentified data in 2007 showed that 11% felt no need for notification or consent, 24% supported notification and opt-out, while 32% needed consent for each use. 22% favorable attitude of our study is considered almost similar to sum of 11 and 24 of the Canadian survey.

4.6. Q4 Do you want your medical records to be compiled into one database as a lifelong medical record? How about 5% discount on healthcare cost, insurance payment. How about IC-chip card security?

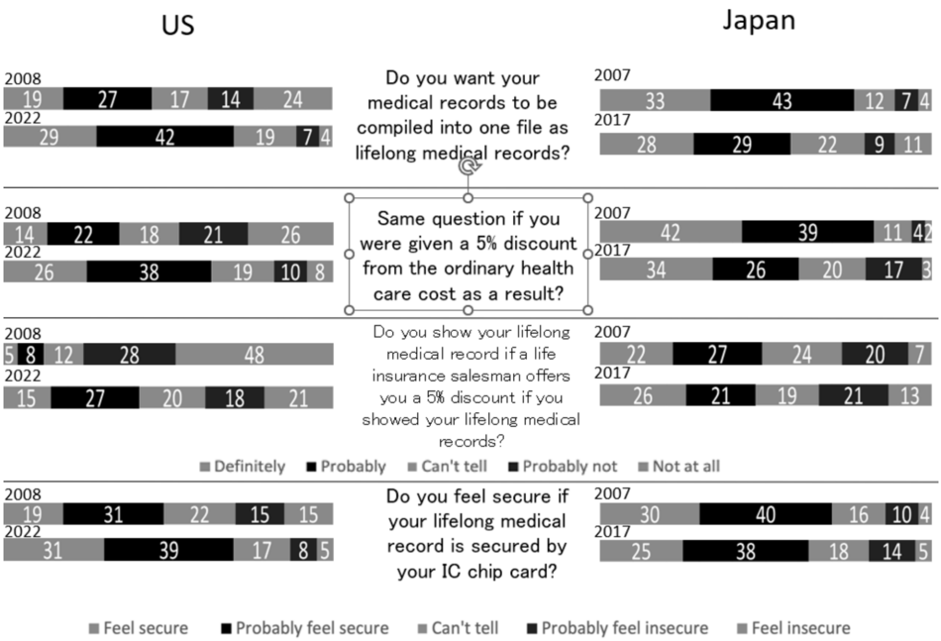

Figure 5 Compiling into one lifelong record

Sharp contrast was observed. US people became favor of lifelong record (46% to 71%), while Japanese people decreased (76% to 57%). US people said yes to both 5% discount, while refusing Japanese people increased. Reason of US increase lifelong medical record is some providers are already offering the service, and people saw advantages. Japan's insurance allow patients free access to any provider nationwide, which makes compiling into one record difficult, therefore Japanese people have not seen one (except for drug dispense record in paper book, which is very popular). Hoerbst's survey for EHR among Austrian and German citizens [15] showed that between 80% and 90% were supportive of the idea of exchanging health related data between health care providers. Also, Perera's survey citizens of Ontario, Canada [16] showed that most (>90%) supported the computerized sharing of the patient's health record among their health care providers. Thinking that our questionnaire is clearly stating "compiling as one database", these Austrian/German and Ontario answers are nearer to 2007 Japanese 74.6% positive answers.

The result, however, indicates that people in both countries may fear the possibilities of cherry picking by insurance companies (trying to contract only with low risk people). In the US, people can choose insurance, and at the same time, insurance companies can choose the people to whom they offer the policy. This discount is thought to be an invitation for people with lower health risks, while those with high risk may lose a chance to avail a moderate price. In Japan however, healthcare insurance coverage is universal. This resulted in lesser change in the unfavorable response of the participants.

The 2012 Commonwealth Fund survey [29] revealed that the percentage of doctors who used electronic patient medical records in their practice varied among countries. In this context, more than 90% of the doctors in the Netherlands, UK, Norway, New Zealand, and Australia used such electronic records, while the same was found to be 69% in the US. Japan has not joined this survey; however, a Japan Association of Healthcare Information System Industry survey in 2012 shows this figure to be 18.7% [30]. The surveyed countries were found to exhibit a low use of EMR as compared to other countries of Commonwealth survey. As a result, doctors are less accustomed to using digital medical records and the internet for healthcare.

This is in contrast to the fact that that Taiwan started IC chip card identification for healthcare professionals since 2007 [32].

It is important to note the difference between the healthcare systems of the two countries surveyed in the present study. A universal coverage policy is maintained in Japan, while citizens have the choices to select their insurance provider (including none) in the US. Further, the consumption tax is rather low in these two countries (US less than 10%, Japan 10%), which is generally high, especially in the northern European countries, which cover healthcare mainly by tax budget.

IC chip card acceptance rise in US, sink in Japan is of the same reason. US people are starting to see this security measure, which caused less trouble than predicted.

4.7. Q5. When filling questionnaire, are you going to fill delicate history?

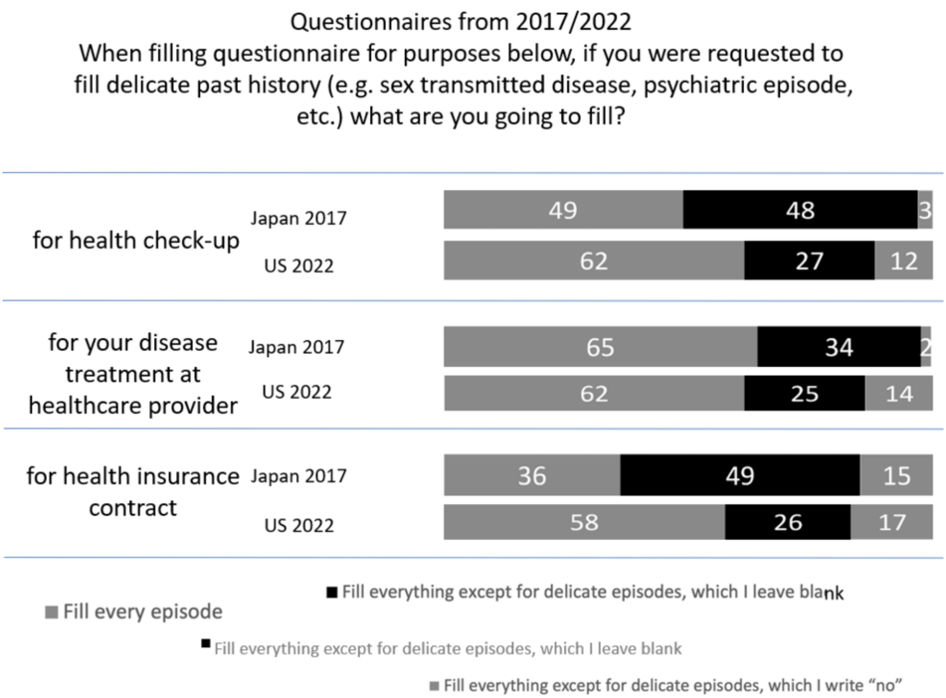

Figure 6 Filling delicate history in questionnaire

The results show that Japanese people say everything to attending doctor, but not for check up and insurance. US answers are almost same among three. Sharp contrast is shown at insurance questionnaire. It seems like failure of notification may cause failure of insurance coverage and consequently, payment.

4.8. Q6. "Comprehensive consent" is a consent which you allow your blood sample, medical chart text, genome profile to be used in future research (medical research purpose only) in unidentifiable manner. Do you accept?

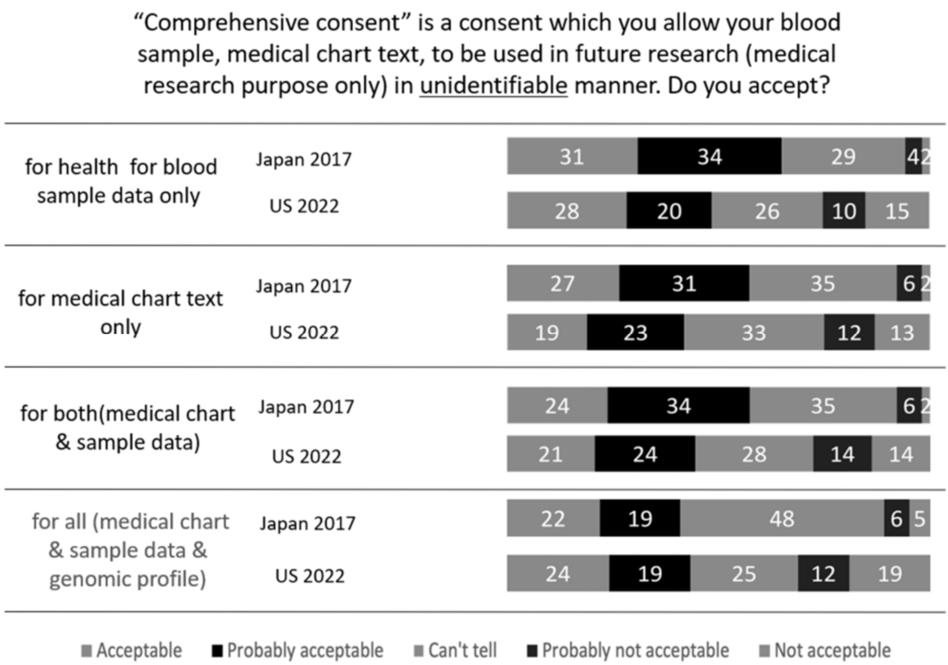

Figure 7 Comprehensive consent

Japan positive answers are more than US for all, except if genome profile is included. US answers are almost same, even genome profile is included.

As long as there is such a substantial negative attitude in both countries, an opt-out consent approach is not considered to be acceptable, not only in the US. In other words, an opt-in approach should be required when considering the possibility of commercial secondary usage. As indicated in a study about possible forms of consent in an electronic environment [4], comprehensive consent cannot always serve the needs of each subject and the content should be designed on a case-by-case basis, although this could be time consuming.

It is a surprise that US answers are not affected even if genomic profile was included. As genomic profile itself is an "identifier", there are two ways to protect privacy; limitation of collection, and limitation of spotting. The latter should be also considered to protect people's privacy.

4.9. Q7. About AI (artificial intelligence) application to healthcare

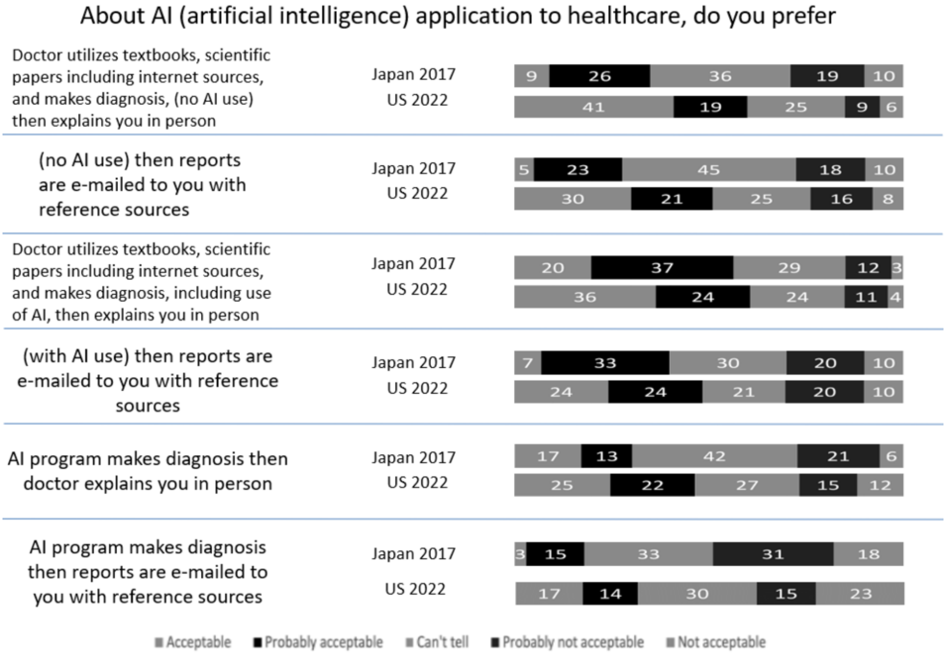

Figure 8 AI use in diagnosis and explanation

Both US and Japan survey showed best preferred is “Doctor using AI and everything, and explains in person”. Japan results shows sharp drop at all three diagnosis process, if explanation is not in person, while US showed small changes.

It seems like both in US and Japan, advantage of AI use in diagnosis has not yet to be seen by the survey of this time.

4.10. Limitations of This Survey

The sample size (200 for both US and 457, 225 for Japan, respectively) was not very large to exhibit the phenomenon tested by the hypotheses sufficiently. Further, different methods were applied in the two surveys (RDD and by mail). In addition, RDD is known to involve a significant level of bias [25].

Respondents of these surveys were living in their house, either contacted through the RDD in the US, or mail in Japan. Consequently, patients suffering from severe diseases may have been eliminated from this survey. Such patients may have a higher motivation to compile their medical records into one.

5. Conclusions

In US, accessing chart of their own by internet became accepted (positive 52% to 61%) and popular in these 14 years. Japan showed small change, as regional medical record sharing is yet to come.

Same as in 2007/2008 report, in US, patients are cared by "the attending doctor" while in Japan, by "the hospital or clinic", judging from answers about chart seen by other doctors.

Even for infectious disease prevention like CoVID-19, in US, positive answers are constantly low for medical records in un-identifiable manner to be used by pharmaceutical companies and DHHS/NHLW for the purpose of error precautions, infectious disease measures and device/drug developments. In Japan, positive answers are larger compared to US, but decreased in all purposes. It should be noted that both in US and Japan, both in 2000's and recent, skeptical answers (Can't tell) became larger.

Preference to compile medical record into one database as a lifelong medical record, showed sharp contrast was observed. US people became favor of lifelong record (46% to 71%), while Japanese people decreased (76% to 57%). US people said yes to both 5% discount, while refusing Japanese people increased. Reason of US increase lifelong medical record is some providers are already offering the service, and people saw advantages. Japan's insurance allows patients free access to any provider nationwide, which makes compiling into one record difficult, therefore Japanese people have not seen advantages.

As for comprehensive consent, Japan positive answers are more than US for all, except if genome profile is included. US answers are almost same, even genome profile is included. Not only collection, but also spotting procedure should be limited to protect privacy.

About AI (artificial intelligence) application to healthcare, both US and Japan survey showed best preferred is "Doctor using AI and everything, and explains in person". Japanese people largely prefer explanation in person, while US showed small change, both regardless of diagnosis process, which people think "Use whatever good and available."

Acknowledgments

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Achievements, Milestones and Challenges in Biomedical and Health Informatics
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Nursing Informatics Integration into Mainstream Health Informatics

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Abstract. Nursing Informatics emerged in Australia during the early 1980s and drove the Professional development and acceptance of Health Informatics. Milestones achieved include the development of a national journal, the establishment of the Health Informatics Society of Australia and the Australasian College of Health Informatics (now collectively the Australasian Institute of Digital Health), nursing participation in Health Informatics standards development activities, adoption of the HL7 messaging standard, the delivery of numerous workshops, an annual national health informatics conference since 1993, hosting international conferences, the development and delivery of Health Informatics post graduate programs and establishing a research centre where the first prototype for an archetype repository was developed. This became the openEHR Clinical Knowledge Manager. The most recent milestone was the establishment of a private company that became a Registered Training Organisation. Continuing challenges include workforce capacity building to address the poor understanding of the need for improved data and IT governance at every level, the need to comply with proven scientific and technical principles and a need to transform national and international traditional infrastructures no longer fit for purpose to enable adequately support for global sustainable digital health ecosystems. Desired personal and aggregate data supply chains must be taken seriously and be supported by the best available technologies. Our collective biggest challenge is to improve multidisciplinary and intersectoral collaboration, semantic interoperability and optimum digital support to maintain global public health.

Keywords. semantic interoperability, digital health ecosystem, professionalization, workforce planning, standards

1. Biomedical and Health Informatics (BMHI) Challenges Experienced

My nursing career commenced in 1963. An interest in computing began around 1978 when I decided to take the computing course offered by the local high school. My career in biomedical and health informatics essentially began in the early 1980s. Over the last 40 or so years I have been working towards addressing national challenges such as the adoption and governance of data and health informatics standards, building health workforce capacity in BMHI whilst experiencing numerous challenges and witnessing their subsequent impacts.

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My biggest challenge throughout was to maintain a life/work balance and obtain the funds required to meet my career objectives. Table 1 lists a summary of the challenges and obstacles encountered within the work environments encountered that have shaped my life experiences.

Table 1. Personal View of Challenges Encountered and their Impacts

Challenges	Impacts
Poor understanding of the need for improved data and IT governance at every level.	A continuing fragmented health system unable to consistently support continuous person-centred care.
Lack of understanding by the nursing profession as a whole of the importance of BMHI.	• As a policy officer for the Royal College of Nursing I was made redundant for having an information bias. • BMHI integration into a Nursing curriculum was undermined.
Lack of buy-in by Professional/Clinical Colleges.	• Enabled vendor/ICT dominance • An absence of strong clinical drivers to shape the BMHI strategic directions
Vendor/ICT community dominance influencing procurement practices, Government policies and BMHI strategic directions.	Government funding benefiting the vendor community more than 'point of care' clinicians, patients and the health system as a whole.
Poor appreciation of the need for clinical, including nursing, data, workflows, regulatory and ethical requirements by vendors, the ICT profession and decision makers.	Implemented systems unable to adequately meet clinical workplace needs resulting in numerous shadow systems.
Poor planning, coordination and continuity of BMHI related policy initiatives by Governments.	Stop, start initiatives, ad hoc funding strategies never able to make the desired or intended impacts.
Organisational restructuring, government and public service changes.	Changes in leadership and non-continuity of programs
Research infrastructure not fit to support multi-disciplinary collaborative research.	Impossible to attract external research funding to support BMHI research.
Disciplinary and gender discrimination	Limited opportunities for career advancement, not being take seriously.
Autocratic/hierarchical health service management structures and cultures.	Non-recognition of a considerable workforce talent at middle management and point of care levels which has impeded innovation.
Ego driven/narcissistic power driven people, mostly males, in leadership positions.	Stifled progress, prevented effective collaboration.
Fear of change, ignorance of what is best for the greater good	Inaction, inability to move forward, change agent ostracization.
Leaving school at 14yrs of age, being educated while working full time and supporting a family as a single parent.	• Completing my PhD at 50yrs of age. • Two very independent capable daughters. • Great life experiences informing my leadership style, professional and academic contributions.

This paper explores my research, education, international connections, professional activities and standards development key career adventures, within the context of available technologies and events at the time, that led to the revelations listed in the table above.

2. Early Achievements and Milestones

In 1979 I passed an entrance exam and was accepted as one of the first group of Registered Nurses able to undertake post registration tertiary studies in Australia. One of its lecturers had decided that nurses needed to learn computing, this became part of the curriculum. That computing subject consisted of learning how to program in BASIC, making use of a main frame at the RMIT University, and how to make use of their computer based statistical analysis system (SAS). In 1982 I was asked to deliver my first lecture in computing to the Victorian Nursing Research Group.

A career change in 1980 occurred when I applied and was accepted to a new position as a work study consultant for the Health Management Services Division of the Health Commission Victoria (HCV). This progressive Division's activities centered around the development of work standards and automation. I participated in examining the feasibility of a day to day nursing dependency tool which was to contribute to a hospitals' output value for a system known as HOSPOWER [1]. This research focused activity resulted in the development of the Patient Assessment and Information System (PAIS) that later formed the foundation for my PhD.

I had access to a personal computer (TRS80) which required programming in BASIC to manage my work sampling data analysis. The 'Systems' section within this Division had introduced a State-wide computer-based staff establishment system, implemented a computer-based personnel/payroll system and provided these resources to the Hospitals Computer Service, Victoria for operational management and system development. More than 180 health care organisations were making use of eighteen computer systems managed by this service, including the Medical Information Direct Access System (MIDAS) and a system used for the collection and analysis of morbidity statistics on a State-wide basis. Reported data from these systems were pivotal to my subsequent research activities.

3. Nursing Informatics: Early Challenges and Milestones

The 38 hour week had been introduced for all hospitals during 1983, and this had resulted in a need to employ an additional 2000 nursing staff. The Health Minister, Tom Roper, established a Committee of Enquiry into Nursing in Victoria in August 1983. This Committee was requested to examine and review existing establishment numbers, roster patterns, turnover, supervision, and the effects of new technology and to develop guidelines on which basic staff requirements could be based. Its brief was extended in April 1984 to include a review of the District Nursing Service [2].

I was seconded to the Nursing section within the Hospitals Division as a senior nursing advisor in 1984, to manage the research undertaken to inform this Enquiry. I arranged the purchase of the first IBM (XT) personal computer within the nursing section. This PC used the DOS operating system and I installed Lotus 1,2,3, the new spreadsheet application which was used for all my data analysis. I was also able to use the printouts produced by the Hospitals Computer Service which provided nurse staffing data for every publicly funded hospital by staff category, budget and actual costs. A Statewide consolidated report was used to calculate cost implications of options considered and negotiated to resolve a number of nursing industrial disputes.

The enquiry's final report identified a number of specific issues including workload management, a clinical career structure, shift work problems, child care facilities, nursing education, industrial democracy and technological change [3]. This resulted in having a first ever government budget allocation to support nursing service delivery, including an increase in the number of district nurses enabling them to provide 24/7 palliative care at home, refresher courses for non-practicing nurses, the establishment of a Critical Care Course and funding to support the transfer of nursing education from hospital based programs to Universities which required the appointment of around 2000 additional RNs to replace the student workforce.

A 'non-nursing duties' dispute in 1984 was resolved via an agreement that registered nurses and students of nursing should not be required to perform a list of 22 specified non-nursing duties. I had been a member of the Government's negotiating team. Additional resources provided by the Government allowed 900 extra staff to be allocated to public hospitals to carry out tasks delineated as comprising non-nursing duties [3]. This number of additional non nursing support staff was insufficient and not able to meet the demand, this plus continuing low wages and a desire for a nursing career structure, led to another major dispute in October 1985. This culminated into a 50 day State-wide strike in 1986, only a skeleton staff remained [4].

The Australian Nurses and Midwives Federation (ANMF) aimed to receive appropriate financial recognition of clinical contributions made by highly experienced nursing staff. It was later argued that these events were the result of nurses seeking professionalization of their discipline, which in turn resulted in their politicization during this period [5]. The ANMF also noted the potential need for nurses to undertake data entry once computers were introduced. I received approval from the State's Premier's Department to travel around the globe to assess the impact of computing on nurses. The ANMF produced a position paper in 1986 on 'Computerised Patient Data and Nursing Information Systems' based on an earlier discussion paper.

Despite my work on developing and costing a new nursing career structure and associated disruptive events, I presented at the Seventh National Conference of the College of Nursing, Australia (now Royal College of Nursing Australia) held in Melbourne in May 1985. It had as its theme 'information processing - challenges and choices for nurses'. This conference inspired a small group of midwives, including Robyn Harvey and Joan Edgecumbe who established a group to promote improvement in nursing care through the use of information technology and to provide a forum for sharing knowledge and experiences. I attended its first meeting and became a committee member of the Nursing Computer Group (Victoria) (NCGV) in 1985 [6]. This group's textbook on Nurses Using Computers- Australian Experiences, was published in 1989 [7].

4. International Connections

Maureen Scholes, Director of Nursing Service, The London Hospital (Whitechapel) invited me in 1984 to represent Australian nurses at the newly established Nursing Informatics working group within the International Medical Informatics Association (IMIA)'s framework. This was the result of a very successful conference held in 1982 London and Harrogate, UK, on "The Impact of Computers on Nursing. Its aim was to promote Nursing Informatics as a discipline [8].

This connection assisted me to make arrangements for my 1986 around the world trip to assess the impact of hospital computerization on nurses. I met with Dr Ralph Korpman, President and Chairman of Health Data Sciences Corporation in Los Angeles, who presented me with a copy of his book [9, 10] and alerted me to the need to transform from departmental focused information systems which were prevalent at that time, to person centred electronic medical records. I later met with senior nurses from hospitals in San Francisco, Edmonton, Canada, Cleveland, New York, Washington DC and met with Dr Virginia Saba, Dr Kathleen McCormick and Dr Marion Ball over lunch in

Baltimore. I then visited places in Stoke on Trent and London in the UK, Leiden in the Netherlands and Geneva in Switzerland. I learned that we needed to plan for bedside terminals. Great conversations with many impressive nursing informatics leaders and researchers were inspiring.

Later that year I attended my first ever Medinfo (SCAMC) in Washington DC where I first learned about interoperability and the difference between 'interfacing' and 'integration' from Jack Harrington who was leading an IEEE MEDIX project at that time. An invitation pinned to the notice Board by Dr Branko Cesnik enabled me to connect with 20 other Australians who shared my interest in informatics. This became the network of founders who subsequently collaborated to establish the Health Informatics Society of Australia.

My first attendance at an IMIA WG8 invitational workshop was in Stockholm in 1987 where I was a member of a taskforce on education to define broad competency statements about nursing informatics [11]. At home I had convinced the NCVG's committee to prepare a proposal to host the 1991 IMIA WG8 international conference in Melbourne. This was presented to and accepted by the IMIA WG8 executive at that time. Preparing for this conference was an enormous challenge as the NCVG consisted of around 200 members and had around $700 in the bank. In preparation for chairing NI'91, I was invited to attend the 1988 post conference workshop on Decision Support Systems in Dublin where I was a scribe which led to me becoming the first author for a chapter in the book subsequently published [12] which won the American Nurses Association's 'Book of the Year prize [8].

During the late 1980's I undertook further study in information systems at RMIT University where I learned about database structures, entity relationship diagrams and the need for data dictionaries. I made use of this new knowledge to design the database I used to manage all speaker submissions and their reviews for the NI'91 conference. Furthermore, at the Medinfo'92 conference in Geneva I presented a paper promoting the need for a Nursing Data Dictionary and to make use of this as a reference model to assist with accurate data exchange [13].

Following the successful 1991 Melbourne conference, I became the fifth Chair of IMIA WG8 in 1997. A strategic plan was developed for the first time. The resulting new organizational structure enabled a greater number of nurses to contribute. I later chaired the IMIA Education Working Group when we explored options for sharing the delivery of specialist courses across Universities. IMIA institutional academic membership was heavily promoted with very positive results. These activities resulted in the Global Health Informatics Education text and a number of other publications [14-16].

Collectively these events were great learning opportunities for me, they provided a very significant foundation for my subsequent career in Health Informatics.

5. Political Turbulence and Its Impact on my Career

Victoria was experiencing major industrial unrest amongst its nursing staff. The Health Commission of Victoria (HCV) had assumed authority for all State Government health services in 1978 following legislative changes. HCV became a Government Department which was regionalized. This change resulted in the establishment of the Health Department in 1985 consisting of Corporate and Regional Services divisions thus changing the governance dynamics. Regional Directors, one for each of the eight regions, were appointed early 1985 but Industrial negotiations undertaken to resolve the nursing disputes continued to be undertaken centrally by the Corporate division. It was transformational!

My nursing workload management system PAIS had been used as an aid to resolve workload disputes since 1984, it was fully supported by the HCV Chair and the Health Minister who had instructed Hospital Boards to make use of this methodology to improve their nursing resource management processes.

"Patient Assessment Information Systems (PAIS) are now operating in a number of public hospitals and the program of PAIS evaluation was continued with the aim of developing a more objective approach to nursing staff requirements, patient dependency assessment and quality assurance programs" [2]

This system provided nurses with information they were able to use to control their workloads. Many hospitals had appointed nursing project officers to manage the information generated by PAIS. These project officers became members of the admission team to ensure sufficient nurses were available to service all occupied beds.

In March 1985 a new health Minister, David White, was appointed following an election which resulted in further organizational leadership changes. I was caught in the middle of these transitional governance arrangements and was essentially demoted. The new Minister decided that the use of PAIS was contrary to his policy aimed at reducing surgical waiting lists. I was prevented from providing any further educational support for PAIS users who were actively discouraged from using this nursing workload management methodology. This Minister managed to eventually remove all nursing project officer positions and I became a political liability.

The Public Service had a non-redundancy policy so they couldn't sack me. I was 'put out to pasture' and asked to work as a research officer for a Clinical Costing project in preparation for the implementation of Diagnosis Related Groups (DRGs). This required me to undertake a major literature review on nursing workloads from which to calculate nursing service weights.

I made use of this 'persona non grata' opportunity to undertake my doctoral studies and establish a private consulting business. This enabled me to continue my research activities, manage the delivery of the 1991 international conference and prepare the proceedings (17) while continuing to be paid by the Victorian Government for most of that period. I had also secured a major consulting project with the Private Hospitals Association Victoria to undertake research to develop a nursing career structure. This resulted in the Nursing Career Evaluation System (UNCES) which was incorporated in the Queensland Private Hospitals Association's industrial award [18, 19].

Meanwhile PAIS was taken up by more than 100 other hospitals in New South Wales and Queensland. The original research was validated in Queensland in 1996 [20]. The data collected from these hospitals were later used to establish nursing service weights for major national clinical costing studies that ultimately resulted in the adoption of DRG based funding in hospitals [21].

6. Professional Activities Post NI'91

The success of NI'91 resulted in a substantial financial profit which was used to collaborate with other State based Nursing Informatics groups with the objective of formalizing a new National body. One representative from each State based group was appointed to form the Australian Nursing Informatics Council in 1992 to facilitate networking and ongoing discussions to unite the groups into one national organisation.

This proved to be problematic due to differences between the State based groups regarding affiliations with other professional nursing organisations. Subsequently the Nursing Computer Group Victoria changed its name to Nursing Informatics Australia (NIA), launched a new look magazine and established a secretariat with the Symposium proceeds.

In addition, a number of other State based groups, with a medical informatics focus, had emerged with particularly strong ones in South Australia and New South Wales (NSW). The Australian Computer Society was the official IMIA representative at that time. It had supported the emergence of a special interest group managed by a GP in Western Australia who established the Australian Medical Informatics Association focused solely on doctors, more or less in competition with informatics activities being undertaken by the Royal Australasian College of General Practice since 1978.

In 1992, an interim “Council” of 22 different informatics groups came together to resolve the fractured nature of informatics in Australia. After much debating and negotiating this ‘Council’ led to the establishment of the Health Informatics Society of Australia (HISA) and HISA became the official IMIA representative.

I was instrumental in initiating and chairing the first national health informatics conference (HIC) in 1993 with seed funding provided by the Victorian NIA group with the agreement that the profits would be used to establish HISA. NIA then transformed into the Victorian State branch of HISA. As a consequence of these events, Nursing Informatics had become subsumed within HISA. The NIA journal became the Health Informatics Journal.

Whilst Australia had a thriving health informatics community, there was still no professional recognition of informatics, no training pathway, workforce development strategy, or mechanism to accredit individuals. In 2001, Dr Enrico Coiera proposed the creation of an Australian College of Health Informatics (ACHI), to fill these gaps. He had support from the Federal Government who had provided seed funding to make that happen. HISA’s secretariat provided the necessary administrative support. A list of 50 individuals working in health informatics was created by a small group of senior academics, I was one of those. These 50 people were contacted and invited to nominate others, and then asked to vote for their top 20 from the total list. These 20, including me, became ACHI’s Foundation Fellows, with Coiera its first President, in 2002.

By then I had been recognized as a Fellow of the Australian Computer Society (ACS) and chaired its Health Informatics Committee. I made use of the ACS Fellowship documentation, with their permission, and established such a process for ACHI to enable it to grow over time.

7. National Workforce Capacity Building Activities

In 2003 I was invited to attend the Australian Government’s Health Information Workforce Capacity Think Tank held in Canberra. Its overall vision was to develop the workforce to ‘enable effective use of health information and information technologies in the health sector nationally’. One of its agreed reported activities was to ‘discuss with ACHI its potential interest in taking up leadership regarding the development of accreditation/credentialling guidelines’. Its report remained on the shelf due to a change of Government in 2004.

Early 2006, while preparing to host Medinfo2007 in Brisbane, I prepared a fully budgeted proposal, at the request of Joan Edgecumbe, manager of the HISA secretariat, for the HISA Board to consider:

1. Providing a webspace for a Health e-Community Centre for HISA members for the management of their lifelong learning activities
2. Establish a comprehensive Continuing Development Program (CPD) title Health Informatics Lifelong Learning (HILL learning) using ‘Moodle’ , open source learning management software.

This was followed with a full business plan detailing a program consisting of ‘just in time’ learning modules, to be developed by a consortium of world leaders in health IT from HISA members, CQU (Central Queensland University), ACHI and HL7 Australia. Perhaps we were ahead of our time as the HISA Board refused to adopt this initiative at that time.

I became ACHI’s President in 2008. ACHI hosted an inaugural stakeholder workforce capacity building meeting in Sydney early 2009. Stakeholders represented were health and IT professional organisations, the medical software industry, Universities and the Australian Government who supported this initiative financially. There was a common recognition that the Health Informatics (HI) discipline was not well understood by government, industry, and academia and that the ICT industry did not understand healthcare. It was agreed that there was a need for a recognised HI career structure and pathways with generic sets of competencies for the many different roles and functions within the health industry as a whole, an agreed HI body of knowledge and education framework, a critical mass of Health Informaticians to assist in lobbying for health informatics as a discipline. There needed to be an entity to address the issues identified and assist government, academia, and industry to implement a national program to produce enough people able to do the eHealth jobs.

This initiative resulted in a signed contract between the Australian Government’s Department of Health and Ageing and the Australian College of Health Informatics to undertake this challenging project which I chaired. This entity became known as the Australian Health Informatics Educational Council (AHIEC). Later that year a draft strategic workplan consisting of 12 projects was circulated to all stakeholders for comment. A budget had been prepared to formerly enable the establishment of this entity. Despite a considerable amount of discussion, there was no consensus regarding the adoption of a governance structure required to move forward despite a unanimous, in principle agreement with the ultimate goal.

A fair amount of research was undertaken resulting in a number of publications made freely available via its newly established website. One of these titled, ‘AHIEC_HI_Scope_Careers_and_Competencies’, has since been cited by a number of others working in this space. This initiative stalled as a result of the key HISA representative not wanting to accept that ACHI was driving this professional initiative. HISA wished to manage its continuing governance as in the HISA Chair’s view that should be HISA’s role as they were in a better financial position. This HISA Chair was an ACHI Fellow but failed to recognize a difference between an industry based organisation where anyone could be a member, and a Professional College providing disciplinary leadership.

As a consequence of an inability to reach consensus regarding governance, ACHI’s vision of providing leadership towards workforce digital health capacity building in a collaborative professionally and educationally sound manner, with full support of the

Australian Government, was lost. A further dilution occurred in 2018 when ACHI and HISA amalgamated to become the Australasian Institute of Digital Health.

A couple of years following the demise of the AHIEC Australian Government supported initiative, HISA established a new education committee that made use of AHIEC's original materials as a foundation from which to develop a set of competencies. The Certified Health Informatician Australasia (CHIA) credential, administered by HISA, supported by ACHI and Health Information Management Association of Australia (HIMAA) was launched in 2013. David Rowlands [22], a management consultant specializing in health and health informatics and past HISA Chair, established the Digital Health Workforce Academy, a private company. David collaborates with HISA to develop and deliver online training courses in health informatics leading to the Certified Health Informatician Australasia (CHIA) post nominals to represent a 'credentialled digital health workforce'. CHIA is not compliant with the Australian Qualifications Framework (AQF) [23] nor does it leverage our educational regulatory requirements [24, 25]. The CHIA competency framework was evaluated and updated in 2022 [26]. No assessment guidelines are provided.

8. Contributing to National eHealth Initiatives

Australia's government established a National Health Information Management Advisory Council (NHIMAC) in 1999 to address barriers to e-health and Health Online was launched [27]. A number of sub-committees were established to advise on:

- Development of a national framework for electronic health record systems
- Health Supply Chain reform
- Development and implementation of national policies and standards aligned with clinical practice and business objectives linked to telehealth
- Provide advice on health informatics standards that should be adopted. I was a member of this group that developed a national health information standards plan for Australia.

In 2004 the Australian government was advised that the implementation of a comprehensive e health program was problematic due to the implementation of too many small, loosely coordinated e health initiatives underway across the States and territories. These were considered to be neither interoperable nor scalable [28]. An evaluation in 2005 of the subsequent HealthConnect implementations concluded that the lack of infrastructure and connectivity had limited its success. A change of Government in 2007 resulted in the adoption of new strategic directions. Late 2008 the National Health and Hospitals Reform Commission (NHHRC) reported that.

'Health care professionals were forced to practice with incomplete or incorrect patient information and up to 18 per cent of medical errors resulted from the lack of availability of adequate patient information' [29].

8.1. My Standards Development Contributions

While being employed part time as a policy officer for the Royal College of Nursing Australia I was made aware that Standards Australia was about to establish a Health Informatics Standards Development Committee (IT/14) in 1991. The College was invited to send a representative to its inaugural meeting, and I volunteered. I continued this involvement as an academic representative following my change in employment to Central Queensland University. I also became a member of two technical committees, one for Electronic Health Records (EHR Interoperability) and the other for Health Concept Representation. I held these positions till 2007.

HL7 Australia was established in 2002 to support its user community. I accepted the invitation to take on the responsibility for education and contribute to many HL7 conferences and workshops promoting all the latest development that occurred between 2002 and 2005. These collective standards development work activities complemented and informed my academic work.

I became aware that I was usually the only nurse making a contribution. These standards development experiences alerted me to the likelihood that standards being developed for EHRs would not support nursing practice. Around 2000 I had been invited by Professor Judy Ozbolt to attend their annual Nursing Terminology Summit Conferences [These later became known as the HL7 Terminfo meetings]. These meeting attendees agreed with my risk assessment, and it was agreed that we would need to take action.

As the IMIA Chair I was able to gain support not only from all key nursing terminology developers but also from the President of the International Council of Nursing for the need to develop a Health Informatics standard on the integration of a reference terminology model for nursing [30]. Further support was gained from Professor Chris Chute who was able to get this proposal accepted by the American National Standards Institute (ANSI) who then submitted this proposal to the ISO TC215 committee, and it was approved as a work item. The resultant ISO standard was first published in 2003, reviewed and updated to represent ‘categorial structures for representation of nursing diagnoses and nursing actions in terminological systems’ in 2014 [31]. Its latest review has just been completed by me to represent the ‘categorical structures for representation of nursing practice’. This change of title is the result of the nursing profession’s desire to enable data analytics to be undertaken to document nursing contributions to patient care and outcomes, and for supporting quality improvement, research, management, reimbursement, policy and other use cases.

9. Australia’s Health Informatics Research & Education Evolution

The first research and education unit for medical informatics in Australia began under the leadership of Dr Branko Cesnik in 1988 at Monash University, he represented the first IMIA Institutional academic member. This was followed by Hovenga’s group at Central Queensland University (CQU) in 1992. Dr Coiera was appointed as the first Chair in Medical Informatics in Australia, in the Medical Faculty of the University of New South Wales (UNSW) and co-founded the Centre for Health Informatics in 1999, the same year Dr Yellowlees established the Centre for Online Health at the University of Queensland. Bernie Crowe and Peter Yellowlees were early pioneers of Telemedicine following the Australian Government’s Health Online initiative [32]. Celler, co-founder of the UNSW Research Centre, pioneered the use of telehealth for the management of chronic disease in the home. The UNSW Centre transferred to Macquarie University some years later.

9.1. My Academic Career

One of the attendees at the NI'91 conference I hosted was Dr Amy Zelmer who had been appointed as the Dean of Health Science at Central Queensland University (CQU), to establish a new nursing degree program designed to facilitate the transfer of nurse education from hospital based programs in that State to this University. Dr Zelmer invited me to work with the newly appointed Associate Professor of Information Systems from the Business Faculty, Dr Greg Whymark, to develop their first Graduate Diploma of Health Administration and Information Systems. My academic career began by working from home, remotely (2000km + distance) from CQU, using my 96kb modem and IBM XT computer for the first 12 months.

The new course we developed became a success and was later expanded to become a Master's program. My academic career progressed to being appointed as the first Professor of Health Informatics in Australia [33,34]. Whilst working from the Health Science Faculty I was also given the responsibility of overseeing the management of this Faculty's local area network, and the research underway into the development of multimedia prior to the availability of web technologies [35]. This position resulted in me being a member of the University IT committee.

CQU had evolved with a strong focus on distance education, it had multiple campuses hundreds of kilometers apart. As a result of a desire to link communications between campuses the University had received a grant to establish its own microwave network. [This was in the days when the only alternative was to make use of the ISDN telecommunications network which was expensive]. We designed a technical infrastructure able to facilitate students in one campus to activate a microphone and camera to ask questions of the lecturer based in another campus via a video conference arrangement. Lecturers were also able to show their slide presentations at multiple campuses simultaneously [35].

A change of Dean following Dr Zelmer's retirement, a lack of support for my health informatics curriculum integration agenda from my nursing colleagues and a University wide restructure, provided me with the opportunity to be employed within the newly established Informatics Faculty. This Faculty's funding and research agenda was a big improvement; it enabled me to establish a Health Informatics Research Centre, a free access peer reviewed online journal [eJHI], accept exchange students, employ some research staff, two post-doctoral positions and several adjunct Professors.

My international connections and my participation in standards development provided additional opportunities. Our team was appointed to provide workshops and deliver a series of lectures for the Ministry of Health in Chile. Professor John Mantas invited me, along with Dr Virginia Saba, as an international advisor to the EU funded NIGHTINGALE project (36). During those years we were also able to contribute to the EU funded TeleNurse project [37] and the development of the International Classification of Nursing Practice terminology [38].

Participating in the Standards Australia IT/14 EHR technical committee had introduced me to the openEHR specifications. My post-doc fellow Dr Sebastian Garde and I pondered how to teach archetype development which led to the realization that once archetypes were developed, we would need a repository. We developed the first ontology based prototype in 2004 [39] for what has since become the international openEHR Clinical Knowledge Manager [40] supported by an extensive multidisciplinary community of 2885 users from over 100 countries [41]. I later worked with the HISA secretariat to develop the successful proposal to host Medinfo2007 in Brisbane and I chaired that conference.

9.2. Retirement?

Central Queensland University decided to close its Health Informatics program and research centre at the end of 2007. I was of retirement age so accepted a redundancy. Following Medinfo2007, the HISA Board asked Joan Edgecumbe to retire. Joan was angry for the Board's failure to support our proposed HILL project and convinced me to establish a private company to effectively implement this project; Heather Grain agreed to join us and eHealth Education Pty Ltd (eHE) [www.ehe.edu.au] was born.

Since 2008 we've become a Registered Training Organisation specializing in enabling the delivery of a variety of digital health courses, including clinical coding, ICD-10-AM, and SNOMED CT. The Moodle LMS turned out to be cumbersome to use for that purpose. We established a not-for-profit company, Global eHealth Collaborative (GeHCo) [https://gehco.org/], which enabled us to work with Governments. The Victorian Government funded us to collaboratively with one other vocational educational organization and a health facility, develop a simulation system designed to improve the quality of clinical coding education. Its design was based on our prior experience with using a Moodle, Canvas and Blackboard LMS. The result was a system now known as eHRoL [Electronic Health Record Online Learning - https://gehco.org/ehrol/], which now contains thousands of real de-identified medical records. eHRoL is available to others via licensing arrangements and is now being extended to include a full EHR functionality based on the openEHR platform and CKM simulation for educational use. Our business continues to grow with an increasing number of digital health related courses on offer.

The Australian Catholic University invited me to work with them to integrate digital health informatics into their programs in 2020. GeHCo/eHe and ACU now have a formal arrangement to continue our joint digital health education initiatives collaboratively.

9.3. My career drivers

An early understanding of the importance of health data exchange and database structures have driven my research interests over the years. This has resulted in a better understanding of the key factors necessary to achieve semantic interoperability.

My learnings over the last 40 years made it apparent that a failure by decision makers and many others to understand foundational scientific and technical key concepts, has resulted in numerous failures to meet desired strategic outcome objectives [42-44]. We must ensure that this foundational knowledge is adequately covered in curricula designed to upskill the existing workforce and to prepare future generations. Agreed BMHI competencies need to be de-composed to identify their key knowledge and skills.

My final career outcomes were recognized by being awarded one of twenty-five Brilliant Women in Digital Health by Telstra Health in 2021 [45] plus the publication of two recent textbooks [46, 47]. Transformations are urgently needed at every level to ensure we all have access to well-connected digital health ecosystems. Now it's over to the next generation.

10. Conclusions

Australia has played a significant role in the development of informatics standards internationally. Peter Schloeffel, and Sam Heard were instrumental in shaping several ISO standards for EHRs, as well as OpenEHR. Tom Beale is the originator of the two level modelling approach that is central to the openEHR specifications. Heather Leslie, contributed to the openEHR Foundation's further development of the Clinical Knowledge Manager, Grahame Grieve was the instigator of what is now known as HL7 FHIR, (Fast Health Interoperability Resources). Heather Grain contributed to many standards adopted by the ISO TC215 technical committee and continues to Chair Working Group (WG)3 Semantic Content [https://www.iso.org/committee/54960.html].

My career path started in nursing, but over the years the division between nursing and health care generally became somewhat blurred. Nursing Informatics in Australia was very strong in Victoria in the early days, but this group surrendered to the governance power of others and lost its influence. Being a woman and a nurse has often resulted in double jeopardy. Some of my past work environments have exhibited covert, insidious discrimination and bias, positive contributions made were not always rewarded. When working for Governments, I found that expert advice and committee reports were frequently ignored or severely modified or recommendations made were not implemented by a leader with the right talent, resulting in less than optimum results. Despite the many obstacles I am proud of the achievements and contributions made.

On a positive note, I am indebted to many national and international colleagues for believing in me, supporting me and for inviting me to work with them and for providing career advancing opportunities. It is with this gratitude that I list the following key career milestones:

- National and International nursing and health informatics leadership activities
    - The development of the PAIS and UNCES methodologies.
    - Chairing NI'91, Medinfo2007, IMIA NI, IMIA Education.
    - Enabling the establishment of a growing national digital health organization, now known as the Australasian Institute of Digital Health (AIDH).
    - Contributing to the European NIGHTINGALE, Telenurse and ICNP projects.
    - Addressing large nursing and health professional audiences as an invited keynote speaker in many countries.
    - The many publications, journal articles, book chapters and books.
    - Health and Nursing Informatics education and research.
- Contributions to National and International Governmental digital health initiatives and Health Informatics Standards developments especially:
    - The ISO Nursing Practice standard [31].

I have found that effective collaboration across disciplines, sectors and cultures, when working towards achieving a common goal, is extremely valuable and rewarding. Integrity, transparency, and ethical behaviour are paramount to success. I overcame the many and varied obstacles along my life journey by identifying and embracing new opportunities, accepting what I could not control and forging new pathways with persistence and passion.

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The Essence and Role of Nurses in the Future of Biomedical and Health Informatics

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Abstract. The whole healthcare system is evolving fast due to environmental pressure related to pandemics, climate change, personnel shortages, and financial limitations, to name but a few. Nurses are central actors in the sustainability of healthcare systems. Rapid technological development can support innovative means for holistic and applied critical thinking to improve healthcare delivery based on the uniqueness of nursing. Nurses need to develop adaptive and scientific skills regarding technologies and develop and apply these for better use of "smart" systems in care delivery. The paradigm shift in nursing roles will impact all levels of care, from primary to specialized care, all age groups, from newborn to elderly care, as well as all domains, such as preventive, reparative, rehabilitation, and palliative care. The impact of technologies on human behavior addresses human-factors interaction, computer interaction, and other effects of technologies on wellbeing, including but not limited to robots and artificial intelligence -based assisting nursing deliveries. Nursing competencies need to be developed at all levels of education to prepare a mindset and culture of the healthcare workforce in a digital health system. Gamification and simulation as educational tools help prepare educators to educate healthcare clinicians and researchers who become key mediators between technologies and practice.

Keywords. Digitalization, Healthcare, Nursing, Education, Skills, Artificial Intelligence, Robots, Information Technology

1. Introduction

The health and care needs of populations are evolving. The increase of noncommunicable diseases in aging populations, as well as communicable diseases in general, and a lack of universal health coverage is a major global concern for healthcare systems [1]. The nurses are the closest health professionals to the population and the patients. Hence, their work is not only crucial to all health systems but also provides an opportunity for effective interventions on a large scale. The Covid-19 pandemic has shown the fragility of health systems and amplified the need for nursing. However, new means are needed to help nurses suffice and extend the impact of nursing. Digitalization provides an opportunity to harness data to better support care delivery across settings. The precision

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of data used is crucial in providing more accurate care for each health condition. Nurses contribute to generating precise and reusable data. But they need the competence to produce, validate and retrieve the data and aggregate it for relevant and interpretable meaning, allowing the best care for each health problem and bundles of health problems for patients individually. Augmented technology is needed with the increasing shortage of health professionals and the care environment, which is becoming increasingly complex. The term augmented technology refers to getting the right health-related information at the right time with the help of information technology (IT) in general.

2. Nursing Reengineering

The information society and digitalization have enabled increased access to knowledge on health-related issues and care. Concurrently, the possibilities to improve population health literacy are growing and seen as an essential factor in empowering people [2]. Health literacy may be defined as "the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions." [3]. It has been interpreted as "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions [4]. This definition may also be extended to the context of technology through digital health literacy [5].

Recently, a distinction between personal and organizational health literacy has been made, where the organizational health literacy focuses on how organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and activities [6]. Increasing professionals' and individuals' health literacy and implementing advanced technologies in healthcare to better support individuals, professionals, and organizations transform the field of healthcare and nursing. Individuals become better empowered to monitor, sustain, and improve their own and their families' health [7], while nursing will respond to more complicated and demanding needs. This transformation of nursing practice will better respond to the increasing needs of aging populations with challenges to recruiting and sustaining a sufficient and competent workforce on a global scale.

Adopting any technology in the health sector can only be done in collaboration with numerous specialists from the fields of health and technologies [8]. The level of collaboration may, however, differ. It may be described as multi-, inter-, or transdisciplinary collaboration. These three levels concern the varying degree of participation of specialists from different disciplines. "Multidisciplinarity draws on knowledge from different disciplines but stays within their boundaries. Interdisciplinarity analyzes, synthesizes, and harmonizes links between disciplines into a coordinated and coherent whole. Transdisciplinarity integrates the natural, social, and health sciences in a humanities context and transcends their traditional boundaries." [9]. Learning to collaborate between disciplines is challenging, and it takes years to understand each other's fields, terminology, and ways of working. These all are prerequisites for smooth and efficient collaboration. Although a transdisciplinary approach may not be needed in all technological adoptions in healthcare, a multidisciplinary approach may often not suffice [10].

Guidance on the appropriateness and relevance of technologies in health and healthcare is needed on content, use, and functionality aspects [11]. Nurses have an important role in this work for improving health outcomes and reducing disparities [12]. Appropriate technological health development will require nurses' active involvement, as understanding the end user perspective is key in succeeding with developing and implementing technologies that support individuals' health, care processes, and service outcomes. On the organizational level, essential elements for successful technology adoption include an evidence-based approach, where competencies, infrastructure, and leadership meet to support the technology implementation needs. This can be boosted by designated roles placed on all hierarchical levels with responsibilities and authority to develop strategic goals and action plans for execution [13]. Developing practical implementation processes and attitudes to support the vision are also needed [14]. Leaders will benefit from easily available validated tools that help assess organizational readiness and attitudes towards technology. Research has shown that nurses' involvement in technological development and adoption is still scarce [15][16]. Hence, new means for enabling nurses to be better involved in these processes are needed. But also, interventions to support the development of an organizational culture of positive attitudes towards biomedical science and informatics as well as systematic development of sufficient competence to adopt new related technologies for different actors.

3. Biomedical Science and Health Informatics

3.1. Nursing meets biomedical science and informatics

In a moving environment (migration, climate change) with biomedical science reaching a level of complexity never reached before, nursing is also facing a worldwide shortage of personnel stapled by leakage of personnel with a consequent risk, the loss of expertise. Nursing encounters with information technology represents both an opportunity and a risk. To overcome the risk, integrating new information technologies into practice must be considered a support for practice improvements, not as a replacement for professionals. The goal should not be to save money but to support the scope of practice and to improve quality (security, efficiency, equity) [17][18]. It would be tempting in a period of global shortage of healthcare personnel to act this way.

In the World Health Organization (WHO) report; *State of the world's nursing 2020*[19], the chronic shortage[2] [20] of nurses is described as a worldwide problem of a global shortage of health workers. We can hypothesize that the impact of shortage will be exacerbated by the loss of professional expertise due to the premature departure of nurses because of the exhaustion of professionals due to the increasing caregiver burden [21], worsened by absenteeism and the retirement of the baby boomer. This health policy problem might become a vicious circle for employers. Many solutions are already proposed by most of the national nursing associations. By WHO's *Global strategic directions for nursing and midwifery 2021-2025,* researchers [22][23][24] reduce the burden on the nurses. Education, leadership, organization, etc., are the most common topics. The use of technology is rarely proposed as a means of improvement.

Aware of the complexity of the problem, especially after a health crisis like COVID-19, information technology is a new block that could be explored. To solve complex situations, the first step is to model reality [25][26]. In this paragraph, we shall conceptualize nursing in its complexity; this step is unavoidable before meeting

[2] https://www.who.int/news-room/fact-sheets/detail/nursing-and-midwifery

biomedical sciences and informatics. To simplify the demonstration, let's describe the essence of nursing as a professional activity through three dimensions:

1. Caring, the core of nursing [27], it contains all the activities directly dedicated to the patient, family, or close helper. This means, for example, evaluation, surveillance, diagnosing, treating, teaching, supporting, etc., independently from any nursing theory.
2. In any type of setting, in particular hospitals, time is risk management, quality of life, and money. To reach the organizational goals, nurses play a central role in making things happen in time with the right patient and professional at the right place. This dimension has a practical application, multiple flow management.
3. Coordinating in an inter-professional environment, physicians, physiotherapists, occupational therapists, radiologists, etc., bring a specific point of view. With their presence 24/7, nurses are responsible for facilitating communication between professionals and patients.

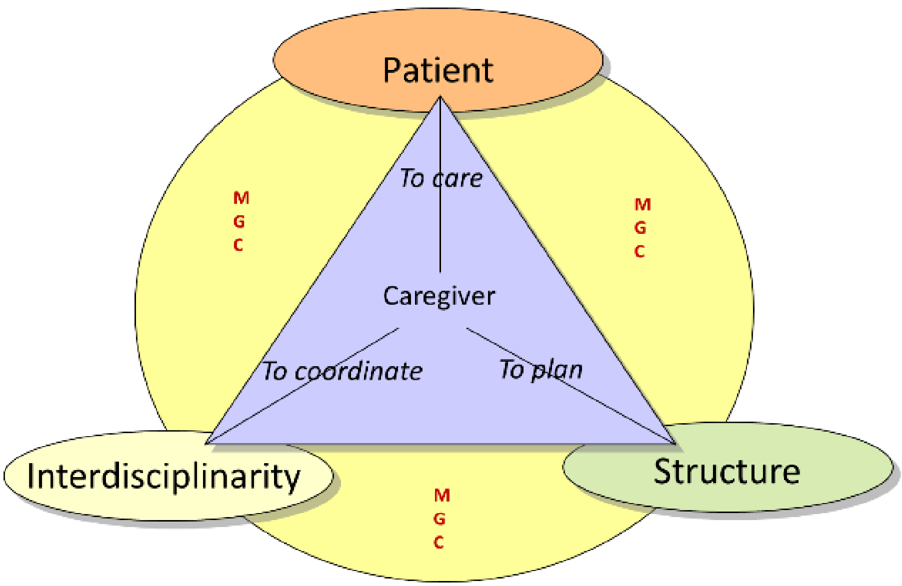

Figure 1: Model of care Alain Junger 2010 (Management Governance Communication - MGC)

This model was built empirically before introducing an electronic health record (EHR) in the University hospital in Lausanne and was confirmed by a study on how nurses spend their time at work [28]. We must consider the meeting between nursing, biomedicine, and information sciences broader than this title. To reinforce nursing as a production of care, we need to take into account the two other dimensions. The use of information technologies as solutions should:

- Free the nurses from most time-consuming activities that are not clinical focused.
- Eliminate the mental burden of administrative, coding, organizational activities, and rules.
- Improved patient flow management, the logistic flows, and the communication as information flow of data.

- To care, coordinate and plan other dimensions of nursing play a central role.
- Safety as the goal of risk management. Prevention is multidimensional because every activity in the health care environment generates risks.
- Simultaneity, nurses face simultaneity of events constantly. When a nurse achieves care, she is also watching the patient, his monitor, answering questions, etc. When a particular activity is organized, it simultaneously requests the right patient, equipment, etc. Another example is taken from clinical practice. During a stay, a care project can combine different objectives, solve a problem, prevent risks, reinforce rehabilitation resources, and maybe accompany the patient with a chronic deficit.
- The simultaneity is also at the organization level. Many healthcare professionals are supposed to pay attention to the same patient.
- Continuity, during the hospital stay, any transfer, all along the clinical pathway, between shifts.
- Predictive and prospective are concepts thus far underestimated in nursing. The likelihood of clinical response after care or treatment is never 100%.
- The nurses themselves mostly provide interoperability. Manual entries are necessary for the use of medical equipment or the recording of results. Fortunately, the first solutions are available to connect tools to EHRs, this is far from a general reality and requires local adaptations to overcome the lack of standardization.
- Interdisciplinary / inter-professional / patient partnership. The multiplicity of actors all along a clinical pathway requires communication and coordination. This supposes standardized languages and procedures.
- The progress of biomedical sciences and technologies is changing the needs. The improvements create new opportunities, risk and benefits. Hospital accommodation becomes secondary to outpatient medicine. Genomics is changing the relationship to disease. The place of health promotion and patient involvement in managing their health is becoming more prominent.

3.2. Biomedical science and informatics meet nursing

Biomedical science can be applied to the nursing process, including assessment, nursing diagnosis, planning, intervention, and evaluation. It supports evaluating a person's health status and allows the development of knowledge, interventions, and technology in healthcare and public health [29]. Using informatics allows nurses to access all available data to support the process. The physio-pathological aspects resulting in the data analyses drive part of the nursing process to help the patient manage or recover. The sociocultural aspects and the environment are also to be considered in the nursing process.

Genomics, the analysis of an individual's gene, is participating in precision health, helping nursing sustain and enhance evidence-based practice. When nurses implement precision health, it provides holistic and systemic care, including relatives and communities [30]. Biomedical science opens the analyses of the biomarkers to be explored with informatics tools. Biomarkers exploit the omics data issued from genes, proteins, and metabolism. The informatics tools should present the data in an understandable display giving a decision tool to the nurses where the nurses' expertise and judgment will finalize the analyses for a decision. Precision nursing based on selected biomarkers helps educate the patient and the families in how they take care of their health and, for example, on the modern medication aspects.[31].

With the aging population, multidimensional disabilities and diseases are increasing. Home care is becoming more expanded and complex. With the help of well-defined biomarkers, biomedical science will help prevent illness and treat individuals at home. Systematic evaluation of the living and environmental conditions determines what type of care should be provided by whom.[32].

Biosensors are part of the exponential development of data storage, microchips, and wireless capacities. Many different biological variables can be registered and transmitted instantly. The condition of having appropriate well-designed software in collecting and aggregating data biosensors will improve efficiency and effectiveness to secure patient health and reduce costs. Patients will take advantage of empowerment for self-care and health prevention. The living environment is changing with the adoption of multiple sensors in daily life. An intelligent home uses many sensors and facilitates life, especially for older people. It increases the safety and security of monitoring the activity of the elderly. Patients with chronic conditions, such as those suffering from diabetes, benefit from the sensor developments.[33]. However, up to now, the data collected with sensors are not consistent with the Findable Accessible Interoperable Reusable principles (FAIR) [34]. To be FAIR the data stored must comply with common international standards.

Covid-19 boosted the development of distance consulting and tools for detection of the infections. One example is a Covid-19 detection system developed to analyze exhaled breath. Artificial intelligence and biomarkers facilitate the creation of this electronic nose in the analysis of the breath. The result is a low-cost, non-invasive, and portable system.[35].

Biosensors and online consultation reduce the cost of care, not only in rich regions but also in the middle- and low-income regions. The use of teleconsultation, together with online sensors is a key element for prevention and cost contained healthcare [36].

Nanotechnology allows many targeted body parts or cells to be reached, evaluated, and treated. Nurses have a role to play in knowing how it works and how the effects should be measured. Nurses' observations are important to be reported and used to ameliorate nanotechnology development.[37].

In the future, with the help of technology, part of the prevention should be driven through the Internet of Things (IoT), specialized applications on computers or smartphones, or implanted chips or other formats not yet known. The part of implanted chips is now just experimental, but this will surely be a major provider of health information in the future. The challenges are to collect the data inside the body and share the data outside of the body. Antennas of implantable devices are a key element for sharing data outside the body. Many obstacles should be solved [38]. The other main difficulty is the duration of the battery. Currently, research on how to charge the battery with body activities is done. New implantable devices are battery-free. There is functioning based on electricity produced by the body itself.[39]. As such, wearable devices are becoming more performant, collecting many health-related data and new technologies facilitate rapid access to data collected.[38].

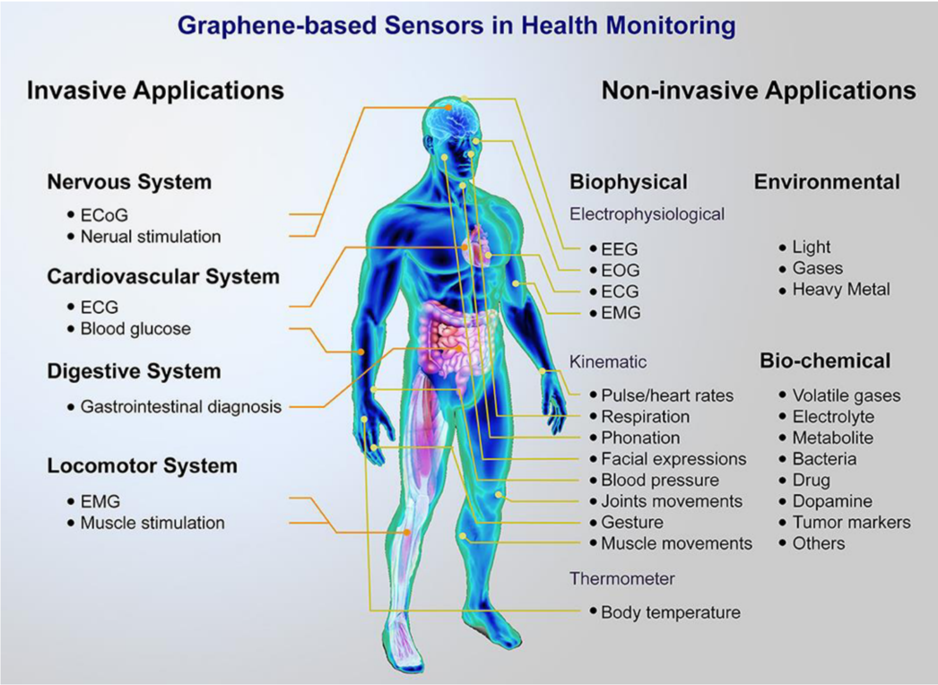

Figure 2. Brief of graphene-based sensor platform for health monitoring. A major distinction can be made between non-invasive and invasive applications, including wearable sensors for monitoring biophysical, biochemical, environment signals, and implantable devices for nervous, cardiovascular, digestive, locomotor system [38].

4. Virtuous circle of evidence-based nursing: from knowledge to practice

From a front bedside perspective [40], the development of the information sciences [41] combined with the progress of biomedical science are challenges for the future of nursing. Both will change the content of nursing and reinforce this role. Uncertainty is a growing characteristic in nursing practice as a cause of chaos and complexity. This is due as much to the evolution of the patient's multi-morbidity, the shortening of hospital stays, and the continuous evolution of technology as the multiplicity of human factors (culture, generation, poor health literacy, anthropology, etc.).

The early years of nursing informatics were influenced by medical informatics in a vision that was very much focused on the digitalization of paper documentation. The next step must answer the needs of the nursing professionals described in the previous paragraphs are very diverse to meet the functions of caring (evaluation, diagnosing, education, risk, crisis management, treating, prevention, etc.), coordination in a multi-professional environment, and planning.

Lifelong, each person will have episodes [42] in different structures. Each person will follow a clinical trajectory paced by episodes of care. These are determined by health problems, medical and surgical treatments, but also disabilities and dependencies from birth to death, and organized long clinical pathways.

To conceptualize a nursing information model as a part of a clinical information model, its essential to apply the concepts and models of information science to nursing science [43][44]. To remodel the nursing concepts [45][9], it becomes necessary to consider them as information or a set of data. From such a perspective, the paradigm is shifting. It is inevitable that a care model, in the data age, allows an integration of continuity, simultaneity, and interoperability centered on the patient. It becomes necessary to have an epistemological thought that describes how nursing science proposes an ontology that:

- Integrates sciences such as social science, biomedical science, management science, etc.
- Considers concepts, and their semantics through reference terminologies (ICNP, SNOMED, NANDA, LOINC, ICD, ICF, etc.)[3] and standards (ISO).
- Integrates the other professionals in a patient-centered multi-professional collaboration [46] also at a data and language level.

On such base, it is possible to imagine the development of artificial intelligence applied to nursing as their clinical dimension. Artificial intelligence or decision support tools must be expanded for all organizational, administrative, and planning activities. Most of these algorithms exist in other industrial fields but must be adapted. Even if this need is not a clinical priority, it becomes a priority to free nurses from many non-value-added, time-consuming activities that contribute to the loss of meaning in work.

5. Healthy populations with a focus on prevention

The key element of maintaining a healthy population is the collaborative activity of working on prevention instead of waiting for a disease declaration. Population health may be seen as a consequence of the health of a group of people, including patterns of health factors and outcomes, as well as policies and actions done to support a healthy population. The approach applies to individual, practice, organizational, and community levels [47]. Around the world and the communities' access to preventive action are very different, from no preventive action to high engagement in the prevention. Caring models also differ when including prevention in their concepts. Unfortunately, the quality of the prevention action is related to financing. The value of prevention could be statistically evaluated but seldom acknowledged in healthcare budgets. When a society bases the budget on the cost of treatment, including many actors for the payment, prevention is not put in place because the benefits will probably not be of value to the payer. Only a closed group of the population, healthcare professionals, and infrastructures can base caring on prevention and measure the health and financial benefits [48].

In prevention, the concept of early detection of a complication is crucial and could save lives [49]. Nursing narrative and nursing documentation could be used to predict adverse events in hospitalization and care. With the help of machine learning system analyzing structured nursing documentation together with non-structured documents analyzed with natural language processing systems and multimodal methods, researchers and technology developers are building alerts for better identification of adverse event

[3] ICNP International Classification of Nursing Practice, SNOMED Systematized Nomenclature in Medicine, NANDA North American Nursing Diagnosis Association, LOINC Logical Observation Identifiers Names & Codes; ICD International Classification of Diseases, ICF International Classification of Functioning, ISO International Organization for Standardization.

risks [50]. In nursing documentation, if the structured data is well defined (description and scope) and used properly, it shows an efficient and holistic picture of the patient's situation and measures risks for impairment. The human-computer trust and nursing care expertise facilitate the acceptance of systems capable of analyzing data for patient evaluation.

Recently sustainability perspectives have gained more and more recognition within the healthcare sector, targeting different approaches from effectiveness, efficiency, economic and environmental perspectives [51]. In line with this the WHO is pushing for universal health coverage, which is built on strong, individual-centered primary health care where everyone has access to all necessary health [52]. However, discussions and action regarding the role and responsibility of the healthcare sector in environmental pollution and sustainability have thus far been insufficient, and these issues need now to be better acknowledged [39]. Environmental sustainability may be defined as ”meeting the resource and services needs of current and future generations without compromising the health of the ecosystems that provide them and more specifically, as a condition of balance, resilience, and interconnectedness that allows human society to satisfy its needs while neither exceeding the capacity of its supporting ecosystems to continue to regenerate the services necessary to meet those needs nor by our actions diminishing biological diversity” [53]. When developing and adopting technologies into the healthcare setting, minimizing environmental harm needs to become a priority. Environmental sustainability thinking needs to be embedded in organizational education and practice throughout systems. However, environmental sustainability aspects become complicated to evaluate due to system effects. Regulatory authorities' actions to steer the development of a sustainable healthcare system is necessary for effective and sufficient outcomes.

6. Discussion

6.1. Biomedical and health informatics applications to respond to nurses' shortages

Nurses' shortage is a reality today and will increase in the future. According to WHO key facts 15.03.2022, “there is a global shortage of health workers, particularly nurses and midwives, who represent more than 50% of the current shortage in health workers”. “Nurses play a critical role in health promotion, disease prevention and delivering primary and community care. They provide care in emergency settings and will be key to the achievement of universal health coverage” [54]. Countries are promoting health-related professions to attract more people to embrace this profession. To reach the WHO universal health coverage, the need for nursing services will increase. To respond to the increasing needs and consider the workforce shortages, new nursing care approaches should be adopted.

The collection of nursing activities data allows allocating the best person with the best competence to fulfill the patient's needs. Analyzing the data gives the opportunity to select what skills are needed to respond to the patient's needs. Once the skills are evaluated, the best professional to respond to the patient needs is called grade mix. Therefore, skill and grade mix is a way to dedicate the best competence to respond to patient needs based on the data collected. Competencies are not always fulfilled by a healthcare professional. A machine could also fulfill it. Robots, chatbots, or intelligent object of things can cover competencies to inform and or collect data from the patient.

Collection of basic patient assessment could be done by a robot or a chatbot. The health professional will, with her his expertise, analyze the data and finish the anamneses with the contact of the patient and or the family. The Internet of Things is the development of tools to help follow patients' health situations. IoT could fulfill all actions, not needing interpretation.

Artificial Intelligence will be used in many computer applications. The capacity of the AI to retrieve the most accurate information for the patient will play a key role in helping the nurses to respond to patient needs in terms of quality of care, safety, and ethical considerations. Nurses will play an active role in developing AI applications [55].

Hospital-at-home model developed in South Africa increases the access of care for poor people in rural once and for elderly persons. “Recent research shows that the hospital-at-home model is an effective strategy and can reduce costs on average by 42%, mortality by 20%, and re-admission rates by 6%, while improving outcomes and the patient experience” [36].

6.2. Informatics competence necessary in future nursing environments

Ample research and different frameworks on informatics competencies for health professionals and leaders exist [56][57][58][59]. In nursing, these have mainly focused on knowledge, skills, and attitudes targeted at nursing students, entry-level nurses, general nurses, nurses in a specific role, and core competencies from an international perspective [60]. Recommendations for informatics teaching in nursing benefit curriculum development [61], and international networks aid in knowledge dissemination globally [13]. However, keeping up-to-date with the rapid development of technologies and the constantly changing healthcare environment is challenging. Hence, competence requirements regarding biomedical and health informatics from a nursing perspective will continue to evolve as nursing and healthcare transform, and digital health literacy becomes one key issue in service delivery.

Prior forecasts have, for example, highlighted future needs regarding informatics competence that targets omics [62], big data, and analytics [63]. However, as nursing is an action of collaborative care that involves individuals, families, and communities in all settings, more efforts are needed to clarify future competency needs regarding technological development and implementation of different actors, including the patients, their families, and professionals on different levels, in different settings and in different roles, as well as to find methods to develop the collaboration between these actors. Tailored instruments for measuring the development of competencies help guide continuous curriculum development for up-to-date education on undergraduate, graduate, and postgraduate levels as well as professional development are also needed.

7. Conclusions

Healthcare professionals will benefit from the development and application of information technologies. Future tools will support the capture of essential objective health data from the population. The practice of nursing will change. It implies collaboration between nursing schools, employers, payers, and politics. Technology will never replace nursing expertise. Nurses' expertise guarantees delivering the best care to face a health problem in due time and financially adequate [64].

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Temporal Phenomics – A Powerful Approach Using AI to Achieve "Earlier Medicine"

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Abstract. The resurgence of machine learning AI has triggered the importance of collecting "personal big data" over a long period of time from wearable devices and EHRs. Collecting data from this large number of variables over a significant period of time has further induced the study on "Temporal Phenomics", which can be a powerful approach to achieve pre-emptive and "earlier medicine". The paper presents a methodology to make studying "Temporal Phenomics" more feasible and convenient without limitations on the number of variables and the length of time periods.

Keywords. Decision making, temporal phenomics, artificial intelligence

1. Background

Machine learning (ML) has been a very hot topic in all research fields equipped with large amounts of data. ML-based Artificial Intelligence (AI) resurged as the most promising approach to solve difficult problems after the rise of Internet in the 21st century which, in turn, accumulated immense amounts of user data (and hence, Big Data). In order to store and process big data, cloud, high-speed network and high-density computing units like GPU (Graphic Processing Unit) followed suit and evolved with the speed of "Moore's law" [1]. All these technology advancements led us into an age of democratized "deep learning", where everyone can harness extremely complex and powerful ML tools and use them to process, analyze and "learn" from very large data sets with billions of tuples and hundreds/thousands of dimensions without having to worry about the intricate and expensive infrastructure. We are in a brave new world that almost anything is possible as long as you know a little about ML and have access to enough data.

Like every new and exciting technology, people want to use it to solve the eternal problems of human health. Many of the medical problems are high-value and also highly complicated since we do not fully understand how the human body actually works. Furthermore, we do not know how to properly manage the individual differences of metabolism and patho-physiology and why everyone is distinctively different on things

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like drug-response and disease risk. The conception of "precision medicine" intends to mitigate the individuality problem in medical practices [2]. However, in order to really address the problem, we will need a way to capture all the personal health data elements (including genome, microbiome, environmental factors and those from the EHRs and wearable devices) over a sufficient period of time and an algorithm that can process such a "personal big data (PBD)". In the PBD, genomic data do not change over time, while microbiome and environmental factors could change slowly. Only the data in the EHRs and the vital signs/activity data from the wearable devices would change dynamically across the whole lifetime with a granularity from seconds to years.

As we know, the current healthcare system spends a great deal of resources on the later stage of diseases. Up to 10 percent of the healthcare spending went to the end-of-life care [3]. This trend is increasing the rocketing healthcare costs even more and contributes little to the quality of life. That is the reason why a promising branch of the "precision medicine" called "precision health" would, instead, focus on preventing the diseases from happening or worsening by properly managing each individual's health risk factors before the health- threatening events. The traditional approach to identifying risk factors typically involves an experts' nomination of candidate variables (factors) followed by a statistical selection and often dichotomization of these final variables to enter a fitting model such as logistic regression. Two major problems plaguing this approach are:

(1) we often have to eliminate a lot of variables so that the final fitted model can be explainable with a "manageable" number of variables (usually less than twenty), and
(2) we often have to ignore the ups and downs of disease progression and dichotomize a patient as just having a disease or not.

For example, a patient who had been through a difficult-to-treat twenty-year history of diabetes would be labelled as "positive" for diabetes, exactly like another patient who was recently diagnosed as diabetic but can be well controlled by merely a low-dose metformin. It is not hard to imagine how much of the "individualities" over the time dimension was actually thrown away by this process and how this overly simplified model can have inaccurate and even misleading conclusions.

2. The temporal phenomic map model

To amend these problems, we proposed a "Temporal Phenomic Map (TPM)" model that will inclusively take into consideration all the possible variables and their change over time [4,5,6]. Using data elements from the EHRs as examples, we can model all the diagnoses and medications that happened in a specific period of time before the initial diagnostic date of the target health threat into a two-dimensional map for each patient. For this map, all the disease and medication variables will be listed on the Y-axis and the time as the X-axis with months or weeks as the basic unit. Each patient will then be represented as a 2-D map with either 1 or 0 in each cell, where 1 can be disease or medication present on that specific time unit and 0 as the absence. Now we have numerous TPMs representing our sample patients and then we label each map as having the target health threat (positive) or not (negative) according to the EHRs. Using a widely-deployed ML algorithm specific for recognizing images called CNN (Convolutional Neural Networks), we can easily train a ML model to recognize a positive

TPM from the sample. Now the trained CNN can be readily used to spot the target health threat out of any patient. We have used the TPM to accurately predict the risk of several major cancers including non-melanoma skin cancer, lung cancer and liver cancer using 36 months of EHRs data [4,5,6].

3. Discussion and conclusions

As described above, current healthcare systems invest heavily on the later stage of care and tend to under-invest the early stage of diseases. Driven by the ever-evolving AI technology, further study into Temporal Phenomics may lead to a future where we can always spot a major health threat for each individual earlier than we possibly can now. Through achieving this "Earlier Medicine" vision, we may one day catch most of the cancer patients at stage zero and cure them, spot a heart failure at stage A or predict a stroke and avoid long-term disabilities, etc. [7]. The possibilities are endless. Is this not a future worth investing into? Is this not a future we all want to live in? I believe that the answer is crystal clear.

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Health, Digital Health and Decision Support: Sisyphus and Pandora

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Abstract. The history of medicine is punctuated by conquests, discoveries and revolutions. It is also marked by questioning. It is made of doubts and certainties. In this thousand years old history, certain recent battles bear witness to these questionings, such as quality, refocusing on the patient, medical errors, antibiotic resistance and the importance of gender, which has been neglected for so long in medicine. Digitalization is one of these many revolutions, and it is not immune to questioning. Building evidence and trust, equity of access for neglected populations, and training are among these issues. More specifically, in the field of decision support, the first enthusiastic hours of computing were followed by unexpected observations, such as the identification of human factors, such as alert fatigue. Today, immense hopes rest on the development of deep learning, and it is up to us to accelerate its development by investing energy, time and resources to build on evidence, trust, and a strong integration of health professionals and patients.

Keywords. Decision support, artificial intelligence, medicine, medical informatics

1. It all started because there are humans and there are Ancient Gods

Asclepius is supposed to be son of God Apollo and Coronis, a mortal woman from Trikala, Thessaly. There has been numerous children of Greek Gods and mortals, and there was more that made the birth of Asclepius so extraordinary. Coronis fell in love with Ischys, a mortal man, during her pregnancy, which made Apollo furious, and the God sent his sister Artemis to kill Coronis. Artemis burned Coronis on a funeral pyre. Apollo rescued the unborn baby by cutting open the womb of the burning mother. This is thought to have been the first Cesarean section in human history. Apollo entrusted the baby to wise centaur Chiron, famous for his skills in medicine, who became his mentor, making Asclepius becoming a famous and highly-regarded healer [1].

The history of mankind and the history of medicine are paved with complex relationships between beliefs and science, between human aspirations that draw their essence from the world of the Gods, and the reality of life that plunges its challenges into our human condition.

The Iliad of Homer describes the great plague which decimates the Greek army as a consequence of a human's unjust actions offended the gods [2]. The disease kills and

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mutilates. On the other hand, for some like Fritz Zorn, in Mars, disease mutilates, strikes, irreparable and inescapable, and it is also, paradoxically, liberating: " wherever it hurts, it is me " [3], illustrating how disease can be perceived as redemption.

The concept of normality is an important driver in medical science, and medicine driven at understanding what causes deviations, how to detect them, to prevent them, and to correct them.

As a result, there is a scientific translation of this dichotomic, Manichean vision of the world, diseases are measured as deviations from the “normal”. Cure consists in reducing, or cancelling, this deviation.

The disease and its therapies, as well as the bearers of this knowledge, have always been confronted with a double component, science and pragmatism on the one hand, but also, on the other hand, beliefs and divinatory practices. The diagnosis and actions belonged to the diviners, the shamans, and the priests; the decisions and prognosis belonged to the Gods. With Hippocrates, the conception of medicine entered a more structured and rational approach. It took a long journey through time in the West to arrive at Harvey's demonstration of the circulation of blood, thus introducing mechanics into medicine; or Morgagni and the anatomical method, to name only two of a long and prestigious list of scientists (Vesalius, Sydenham, Auenbrugger, Corvisart, Laennec, Louis, Mueller, Osler, …) who have allowed the development of today’s medical science. Medical science isn’t just about scientific knowledge. It is also a lot about a singular relationship. Already with the school of Hippocrates, the importance of questioning the patient, his medical history, the specific history of a specific disease, the physical examination, where it was considered as cardinal aspects of medicine. Building an *understanding* of the case, which than was improved with increased knowledge on disease nosology (Sydenham), and the use of various tools such as percussion (Auenbrugger), stethoscope (Laennec), ophthalmoscope (Helmoltz), which started a long list still growing today. All of it leads to careful, meticulous, and precise description of the knowledge about a context, embedded in a larger knowledge, the images, the anatomy, bio pathways, physiology, and of course patients, differential diagnosis, therapies, evolutions. The science of medicine is now in the era of personalized medicine, and is increasingly seen as a deterministic cascade of events, starting with the DNA and ending in a complex network of causal elements up to environment and lifestyle building arrays of risk factors, evolution, prognosis [4,5].

2. And computers joined humans and Ancient Gods

In 1982, Peter Szolovits edited an AAAS symposium on “Artificial Intelligence in Medicine” held at the 1979 AAAS National Annual Meeting in Houston (TX), which he generously reconstructed in HTML and made available in Internet [6]. This collection illustrates the “Greek Oracle” vision of electronic decision support in medicine, combining sophisticated approaches and computing techniques to properly represent expert physicians, so that it becomes possible to produce tools for improving health care. Several pioneer systems are presented by their authors, such as *INTERNIST*, a diagnostic aid using on a large database of disease/conditions and manifestation associations building partionning functions; *EXPERT* and the Glaucoma Program based on physiological models for diseases; *MYCIN*, a rule-based program for infectious diseases; the *Digitalis Therapy Advisor*, an interpretable order entry support for prescription of digitalis; and *ABEL*, using pathophysiologic models for decision support of acido-basic and electrolyte abnormalities. These early pioneering systems triggered a wave of developments and new approaches. For example, QMR, successor of INTERNIST-1, used a homology function, a numeric score assessing how "alike" any two diseases are [7]. So much so that in 1992, 10 clinical experts created a test set of 105 diagnoses and compared the 4 best decision support systems available at the time (Iliad, Meditel based on Bayesian logic; Dxplain, QMR using semi-quantitative probabilistic associations of findings). The results found that the proportion of correct diagnoses was 0.52-0.71 and the mean proportion of relevant diagnoses was 0.19-0.37, so that less than half of the diagnosis suggested by experts was proposed by any of the 4 systems [8].

In 2011, it was estimated that the doubling time of medical knowledge in 1950 was 50 years; in 1980, 7 years; in 2010, 3.5 years and in 2020 projected to be 0.2 years—just 73 days [9,10]. The explosive growth of knowledge in medicine and life sciences is way beyond human's brain capacities.

The second part of the 20th century was fed by an extraordinarily enthusiastic wave of hopes that computers would support a new revolution in medicine, that of the computerization of medical records, of the simplification of medical data acquisition and processing, and of course of the support of medical decision making and patient care.

3. Errare humanum est, perseverare diabolicum

Patient safety concerns in the healthcare system has been a key element to boost digitalization and electronic decision support systems. Between 1990 and 2000, several alarming reports raised the awareness on care safety in healthcare systems [11–13]. At the turn of the Millennium, reports of the Institute of Medicine estimate that preventable fatal medical errors of all types cause between 44'000 and 98'000 deaths per year in the USA, among them about 7'000 due to medication-related errors [14]. In the same report, it is estimated that patients in hospitals could face more than one drug related error per day. In 1995, the pioneer work of Bates et al. and the associated editorial of Kahn in JAMA demonstrate and underline the preventable nature of drug prescription errors [15,16]. Of all adverse events, 1% were fatal and not preventable in this work, 12% life-threatening, 30% serious, and among them, 42% were preventable. This work demonstrated that adverse drug events were common and often preventable [15] and, in 2003, Bates et al. published a list of recommendations to achieve best decision support systems in clinical environments [17].

The following ten years have been remarkable at developing and deploying digital solutions in hospitals, and especially computerized providers order entry (CPOE) with all sorts of computerized decision support systems, alert modalities, user interfaces, and numerous studies evaluating and assessing the impact of these systems, reported in numerous peer-reviewed publications. For example, a positive effects on patient outcomes such as fewer duplicates, dosage errors, drug-drug interactions [18–21], improving cost-efficiency of care, either directly, as enumerated above, or indirectly, for example in reducing lengths of stay or rehospitalizations [22–24].

As these systems were increasingly and massively deployed, however, some concerns started to raise about their effectiveness or unintended effects [25]. In 2013, Jung et all. published a large international study analyzing the attitude of physicians towards alerting in CPOE systems which concluded that while most physicians found alerting system useful, half of them found alert overload as a major problem [26], and started constructive discussions on how to address these concerns extremely well summarized in a comment to this work by Bates et al. [27]. The critical importance of predictive values and false positive rate have been well summarized in a systematic review published by Carli et all. in 2018 which reports PPVs ranging from 8% to 83% with most results between 20% and 40% [28].

Altogether, the learnings of that period can be summarized in few key points:

- User interface, human-machine interactions and processes are key.
- Positive (PPV) and negative predictive values (NPV) are major determinants.
- Which requires accurate and timely knowledge and clinical data.
- Which requires a highly connected and interoperable clinical information system.

One of the key challenges is missing interoperability. To quote the literature review of Ahmadian : "*Lack of semantic interoperability is the most important obstacle in clinical decision support system implementation*" [29].

4. The Pandora dilemma

Decisions are influenced by numerous determinants, such as deep knowledge about the patient (clinical data, genomics, …) and his living context, knowledge (the global science of medicine and biology), and local information such as a-priori probabilities for Bayesian evaluations. They are also influenced by the effect of decisions, such as their impacts, but also the resources required, the time, the cost, etc.

Digitalization provides increasingly access to more data which opens the hope to improve massively decision support. Among the numerous sources more and more available, the clinical data originating in health electronic records (EHR) have massively increased. There are many reasons behind this, one of them being the need to improve efficiency of care processes, resource management and billing processes. These forces have led to unintended effects, mostly at increasing burden on health care providers, leading to a high workload interacting with EHR at the cost of patients time [30–35]. This effects is more important for US physicians than non US-physicians [36]. Additionally, digitalization has facilitated the development of tools to improve, increase and fasten data acquisition by care providers. For example, the work of Holmgren at al. has observed that up to 77.5 US physicians composed automatic notes, leading to information duplication. CPOE has been shown to decrease errors and is widely adopted, however has also been shown to potentially produce errors, such as wrong routing, wrong dose, and duplicates [37–39].

More data of better quality is made available thanks to digitalization, which itself increases data acquisition burden for care providers and potentially leads to data quality challenges, such as duplicates. EHR's have become the source of data for many different usages. Patient care is the primary reason, but there are countless other needs, such as planning resources, regulatory documentation, quality measurements, certification and accreditation, billing, clinical research, public health, etc. All of these have contributed to increase and diversify the data acquisition processes.

In 2018, Stanford Medicine mandate Harris Poll to do a national survey of over 500 primary-care physicians (PCPs) on EHRs and reported the following key points [40]:

- *PCP see value in EHRs but want substantial improvements.*
    - o 63% of PCPs think EHRs have generally led to improved care (63%)

  - 40% believe there are more challenges with EHRs than benefits
  - 62% of time devoted to each patient is being spent in the EHR
  - 49% of office-based PCPs think using an EHR detracts from their clinical effectiveness
  - 71% physicians (71%) agree that EHRs greatly contribute to physician burnout
  - 59% think EHRs need a complete overhaul
- *EHRs are not seen as powerful clinical tools but rather storage systems*
  - 44% of PCP think EHR is essential for storage.
  - 8% say the primary value of their EHR is clinically related
- *Physicians agree on what needs to be fixed and when*
  - 72% think that improving EHRs' user interfaces could best address EHR challenges in the immediate future
  - 67%) consider interoperability deficiencies should be the top priority for EHRs in the next decade
  - 43% want improved predictive analytics to support disease diagnosis, prevention, and population health management

Altogether, it seems that decision support in EHRs has brought a lot, but at a high cost and without achieving yet its full potentials. The wave of *massive data* is now moving to the era of *actionable data*, which is the rise of semantics.

Science has been driven by understandability and the hypothetico-deductive approach proposed by Karl Popper in his cornerstone work on building a rational approach of science [41,42]. This work has considerably influenced science based on experimentation, reproducibility, and refutability. It thus comforted the development of decision support systems based on formal and verifiable knowledge. In medicine, it had several consequences. One of them was the idea that any complex system can be decomposed in small verifiable and simple components. In this movement, decision support systems have built increasingly large set of rules, originating from experts, from knowledge database, observations, understanding of physiology, metabolism. It has soon become impossible to keep the pace of such systems with the parallel massive increase of knowledge in all fields of medicine. In addition, the compositionality of decisions-based processes, that is that complex decisions can be made from numerous simple and verifiable smaller elements, has been increasingly questioned. All of it has open the door to the Pandora "black box" reasoning, which is one of the challenges of deep learning. Building post hoc interpretability and explainability [43–45].

5. Sysiphus and the new Eldorado

Interoperability has been shown to be at cornerstone of decision support. Interoperability means being able to put together many different data sources, modalities, and types considered a complex temporal framework. However, addressing interoperability is a complex question, as it requires to take into account the meanings of things being handled, their definitions and interpretations in various contexts. Decision taking processes are usually based on meaningful determinants interpreted with various instruments.

At the beginning of the second book of his "Posterior Analytics", Aristotle claims that there are four questions for investigating the nature of things and their properties, whose answers lead to demonstrable knowledge, or knowledge of a "scientific" nature.

- That it is (*to hoti*): Is it a fact that a thing has a property?
- Why it is (*to dioti*): Why does a thing have a property?
- Whether it is (*ei esti*): Does a thing or property exist?
- What it is (*ti esti*): What is the nature and meaning of a thing or property?

Building decision support systems is thus also facing the question of the nature of decision processes. For example, which decision processes do require intelligence, and which type of intelligence. One of the learning of the evolution of decision support systems in CPOE is that despite the fact that every rule is excellent with a low false positive rate, with the typical complex cases taken care off and the huge size of knowledge base, systems will fire thousands of rules for each case, thus with a high probability of having a few false positive. And, consequently, the system has a low predictive positive value. A comparison of two commercial products recently published by Shah et al. has reported that the one system triggering 94% fewer alerts for inpatients and 93% fewer for outpatient setting also had much higher sensitivity and specificity, with PPV of 83.81% versus 3.55% (p< 0.0001%) for inpatients and PPV 82.54% versus 4.84% (< 0.0001) [46]. Or the unexpected application of the *Less is More Medicine* [47].

Artificial intelligence, as a field of computer science, was born in the aftermath of the Second World War. History says that the term Artificial Intelligence was coined by McCarthy, during the Dartmouth Summer Research Project on Artificial Intelligence, a scientific workshop organized in the summer of 1956 by Marvin Misky and John McCarthy, in which about twenty researchers from many disciplines participated, and who have left their mark on history (Claude Shannon, Ray Solomonoff, Olive Selfridge, Herbert Simon, Alan Newell, etc.) [48].

In truth, the very definition of intelligence is subject to debate, and the same is true for artificial intelligence. These questions were already raised more than 50 years ago, leading Alain Turing to propose his famous Turing Test, which consists in having a blind observer examine a conversation between a human and a machine. If the observer is not able to identify the human and the machine in the conversation, then the test is passed[49]. In recent years, with the development of huge linguistic models such as GPT-3 from Google's subsidiary OpenAI [50,51], the performance of neural networks has required much more refined tests to evaluate whether these models are "intelligent" or simply gigantically probabilistic [52].

Data driven science and its corollaries in machine learning and the wider field of artificial intelligence (AI) have the potential to drive important changes in medicine. By nature, AI is a large field of research and development that requires multi-disciplinary approaches to address many aspects of it, from tools and methods used up to application fields. Since a few years, AI is mostly seen as the field focusing on autonomous learning, especially using methods regrouped under “Deep learning”. However, the landscape of AI research is much richer, and traditionally include knowledge representation and engineering; rule-based and symbolic reasoning; temporal reasoning and planning; sensing and perception; learning; evolutionary, emerging, social behaviors; and the ability to move and manipulate objects, to name the most important [53]. In one form or another, AI is already broadly used today in medicine. Decision support based on knowledge engineering and rule-based systems are implemented widely in CPOE worldwide. Advanced signal processing is implemented in pacemakers, implemented defibrillators to take decisions, in imaging to improve images, decrease irradiation, support diagnosis, in oncology to find the best matches between patients and existing literature, to quote a few examples. Consequently, the field draws at large through philosophy, mathematics, information sciences, computer science, psychology, anthropology, social sciences, linguistics, and many other.

This richness is also building silos between fields and generations of researchers, building waves of research and discoveries that repeat themselves across domains, and time. It is certainly an important hope of AI that it will help avoiding researchers to research and find what has already been researched and found.

6. Conclusions

The future of decision support in medicine is built around the evolution from complication to complexity. There is no one-fits-all solution to the wide area of decision support in medicine. Each problem will have to get the best answer, a sort of *problem-centric personalized decision support*. For this aspect, a rule-based approach will work best. For another, it will be about Bayesian networks.

Most of all, it is critical to enforce health technologies assessment towards digital health and artificial intelligence [54–56]. As written in a 2018 editorial of the Lancet :"*Continuing to argue for digital exceptionalism and failing to robustly evaluate digital health interventions presents the greatest risk for patients and health systems*" [57]. And also, make sure that no one is left behind [58], patients and care professionals.

Abbreviations

AAAS	American Association for the Advancement of Science
AI	Artificial intelligence
CPOE	computerized providers order entry
DL	Deep learning
EHR	Electronic health record
HTML	HyperText Markup Language
JAMA	Journal of the American Medical Association
NPV	Negative predictive value
PCP	Primary care physician
PPV	Positive predictive value
QMR	Quick Medical Reference

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Cybersecurity Challenges in Healthcare

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Abstract. Cyber security attacks evidence has shown that many sectors and industries are still at an insufficient level of readiness to counter these threats, including healthcare organizations and the entire healthcare industry. The COVID-19 pandemic has additionally launched the issue of cyber protection of healthcare systems and connected medical and other devices as well as modern IT components, which are often the entry point for attackers against healthcare organizations. With the aim of a systematic approach to cyber security in healthcare organizations, this article comprehensively presents cyber risks and possible consequences of attacks in the context of healthcare organization services, as well as identifies the five most important cyber security challenges and provides recommendations for establishing protection mechanisms in line with best practices.

Keywords. Cyber security, cyber-attack, cyber risk management, cyber challenges, health organization

1. Introduction

Digital technologies have transformed the healthcare industry, and through the development of modern information systems and the integration of smart devices, it has facilitated communication with patients as well as patient access to treatments. Some of the components of modern information systems that had a significant impact on increasing the quality and availability of health services are: (i) electronic health records (EHR) that replaced paper records and increased the efficiency of health services; (ii) telecommunication networks and services to support communication and cooperation between patients and health workers; (iii) mHealth, telehealth and telemedicine have improved the process of patient management as well as improving the quality of services. However, the application of modern technologies in healthcare has supported the collection of patient data with simultaneous contribution to an increase in the quality of services. On the other side, all actions that include activities over personal data represent a potential vulnerability of the system that can arise either from software vulnerabilities, human error, or security flaws [1].

The Covid-19 pandemic has contributed to the rapid development and general use of digital services in healthcare [1], general remote functioning of the societies, and thus users' efforts on integration of various online components mainly with a deficiency or a low level of cyber protection [4]. Consequently, the growth and diversity of cyber security threats have been followed with significantly increased level of vulnerabilities and cyber risks for health organizations.

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Violations of sensitive health data can occur because of both internal and external threats, and the most common among them are hacker attacks, unauthorized access and disclosure of data, theft, and loss of data, etc. The trend shows a rapid increase in the frequency of attacks, which have increased by 162% in the last three years, which represents over 700 attacks and illegal disclosure of health data in 2021 [2]. When talking about the consequences of such attacks, cyber security violations might have immediate consequences that arise as a direct response to the attack, as well as long-term consequences and intangible costs for the entire business that spread over a longer period of several years.

Cyber security is an obligation and imperative for all actors in the health care, including health service providers, insurance institutions, pharmaceuticals, and biotechnology institutions, as well as companies for medical devices and the production of software and other hardware components [3]. In this context, the basic tasks of cyber protection of health organizations can be defined as: (i) ensuring the availability of health services, (ii) ensuring the proper operation of medical systems and devices, (iii) preserving the confidentiality and integrity of data on patients and services, as well as (iv) ensuring timely response and prevention from external and internal cyber-attacks [4].

2. Current statistics and trends

The current cyber-attacks diversity, their scope and impact on healthcare organizations can be described with statistical indicators over cyber incidents that have occurred in the US healthcare system.

Data collected from the period 2016-2022 [2][6], shows that almost 30% of all major cyber incidents aimed on data abuse were targeting healthcare organizations, which undoubtedly lead to the conclusion that healthcare institutions are a very desirable target for cyber-attacks.

Even though healthcare institutions have invested over $65 billion in cyber protection [7], they still face a high volume of cyber-attacks. The number of cyber-attacks is continually increasing and since only those cyber incidents that affect at least 500 people are reported, it can be concluded that the number of cyber-attacks is significantly higher than reported. Table 1 shows the annual numbers of Data Breach Events and Data Records Breached for the period 2016-2022 [2] [6] [7].

Table 1. Healthcare Data Records Breached and Healthcare Data Breaches 2016–2022 [2] [6] [7]

Year	No. of Data Breach Event	No, of Data Breached Records
2016	115	13.429.721
2017	148	3.513.380
2018	164	9.992.440
2019	312	38.429.532
2020	416	26.424.309
2021	521	43.096.956
6 months of 2022	347	20.214.270

Cyber-attacks differ in their scope, techniques used by attackers and location of breached data. By extracting the cyber-attacks with the highest number of data records breaches, it can be concluded that 2% of cyber-attacks (10 of 521) in 2021 caused almost 44% (18,993,908 of the 43,096,956) of data records breach. Therefore, even large health organizations as carriers of critical IT infrastructure are the primary target of cyber-attackers, they have a great success in countering the attacks. However, the consequences of inadequate cyber protection of larger health institutions might have a huge impact on the health system functionality collapse.

Sensitive patient data is usually key resource targeted by cyber attackers, and they are very often stored in different locations in the file system, databases distributed through the computer network, while being copied in certain reports, tables and other files that are attached to emails and other communication messages.

Table 2 shows the number of cyber-attacks related to different locations of compromised patient health data. It is evident that the highest percentage of Breached Data occurred on Network Servers (66.79%) and Email service (27.06%), while a smaller number of cyber-attacks were aimed at Electronic Medical Record and Endpoint devices. A similar trend continued in 2022 [2] [6] [7].

Table 2. The Top Healthcare Data Breaches of 2021 by Location of Breached Data [2] [6] [7]

Location of Breached Data	Network Server	Email	Electronic Medical Record	PC/Laptop	Other
2021	348	141	12	13	7
6 months of 2022	185	90	37	16	15

Table 3 shows that the largest number of cyber-attacks were caused by "Hacking/IT incident" and "Unauthorized Access/Disclosure", compared to those caused by loss, theft, and improper disposal. The similar trend is relevant for 6 months of 2022 [2] [6] [7].

Table 3. The Top Healthcare Data Breaches of 2021 by Location of Breached Data [2] [6] [7]

Causes of Cyber Attack	Hacking/IT incident	Unauthorized Access/Disclosure	Loss	Theft	Improper disposal
2021	340	142	10	24	5
6 months of 2022	277	52	4	11	3

3. Why healthcare organizations are the biggest target for cybersecurity attacks

The exposure to potential cyber-attacks can be explained by identification of key actors with different motivations for carrying out cyber-attacks, and further understanding of the key malicious drivers for the execution of the attacks. The main motives for carrying out a cyber-attack on the healthcare system/organization are [7]:

- *Wide range of attacks* - due to the connection of medical information systems with medical devices (Internet of Medical Things, IoMT) and other hardware and software components that may have a weak level of cyber protection, as well as connection with external components that have access to sensitive patient data (e.g., telemedicine, mHealth components, etc.), with significantly expanded mass use due to the recent COVID-19 pandemic.
- *High value of personal health data on the black market*- due to the wealth of information about patients stored in patient health records, there are potentially diversified ways for data abuse such as identity theft, illegal actions with insurance companies, etc.
- *High willingness of victims (especially healthcare institutions) to pay large amounts to attackers* in order to release inaccessible data about patients and ensure the smooth functioning of the health services. The unavailability of certain services and/or inaccurate patient data can result in fatal outcomes, so

some of the privacy regulations (e.g., HIPAA[2]) foresee large fines for institutions that violate "privacy, security, breach notification and electronic health transactions" or do not cooperate with the GDPR. Therefore, actors in the healthcare system are obliged to take appropriate measures to prevent leakage of patient data and/or permanent disabling of services.

The reasons why healthcare organizations are targeted by cyber attackers could be found in proper understanding of their specificities and resource characteristics, which can lead to the identification of key system vulnerabilities. The following key reasons can be considered [8]:

1. *High value of sensitive patient data* - patient data has an extremely high value on the black market, making the entire healthcare industry as a high-demanding target for attackers.
2. *Vulnerability of medical devices to cyber-attacks*- Medical devices have a specific medical purpose (e.g., heart monitoring, insulin pumps, x-ray imaging, etc.) and are not primarily designed to meet cyber security requirements. In addition, even medical devices do not contain patient information, attackers can use them as an entry point to the system (on the server) and further malicious use (which does not have to be based only on data theft, but the attacker can in the worst case take control of medical devices and endanger the lives of patients).
3. *Necessity of remote access to confidential data* - medical staff, due to the necessity of teamwork, often have the need for remote access to the patient data and the use of personal devices (smartphones, etc.). This is the reason why only highly secured systems can identify and block access to compromised devices, fully supported by highly trained personnel related to cyber prevention mechanisms, which is often not the case in healthcare.
4. *Unwillingness of staff members to accept modern technologies* – medical staff in health organizations is usually occupied with very specific interventions and other tasks related to health care provision, thus being in lack of time for continuous training in the field of IT. This is the reason why even some more modern IT solutions in everyday business (e.g., Office 365) cannot be used in healthcare institutions, even though being characterised with a significantly higher degree of built-in cyber protection compared to all other solutions. The only way for establishing proper protection mechanisms is to align security measures with existing software which usage is highly experienced by staff members.
5. *Inadequate level of cyber security knowledge by staff members* - medical staff are not educated to recognize potential attacks through the computer network and they are not skilled in how to apply best practices for proper use of IT services. Nevertheless, medical personnel cannot be expected to use cyber security tools, and the only action which can contribute to cyber security of the health organization is in setting up highly secured computer network that is used in an easy and simple way.
6. *Connection of many devices and hardware components to the health organization network* - modern healthcare organizations have a need to connect

[2] The Health Insurance Portability and Accountability Act of 1996 is a United States Act of Congress enacted by the 104th United States Congress and signed into law by President Bill Clinton on August 21, 1996

many medical devices that collect and/or transmit a large amount of confidential patient data, as well as providing external data access to their staff. External access is often made through personal devices, which further undermines the cyber security of the system as a whole.

7. *Health information sharing as a permanent task* – the emergency medical services have clear requirement of making patient data immediately available and assessable by any device and from any distance location. This means that any security procedures and checks must not cause any waste of time and waiting procedures that could have fatal implications for the patient.
8. *Smaller budgets for security mechanisms in smaller organizations* - large organizations usually have enough resources to provide effective cyber solutions from the market, but they are enriched with a huge amount of patient data and thus being a much bigger target for attackers. On the other hand, smaller organizations are a potential target for attacks due to use of digital technologies, but usually they do not have enough budgets to invest in cyber security.
9. *Outdated technologies from the aspect of unsatisfied modern security standards* – the need for making money savings in operations, health organizations often decide to stop ordering modern updates for implemented technologies. This means that even though the technologies were up to date at the time of ordering, the vendor may cancel services due to untimely upgrades. On the other hand, upgrades are the only way manufacturers improve their products. Also, creating additional layers of security at the network level can be helpful in blocking further access if an attacker gets into a compromised device, thereby denying access to patient data. It is the responsibility of the healthcare organization to protect its computer network.

4. The managing cybersecurity in healthcare organization

Cyber security information management includes three basic levels at the level of healthcare organizations that have a clear role in the implementation of cyber security and risk management, as presented in Figure 1 [9].

Executive level – responsible for providing information on available resources, as well as performing a periodical assessment of the tolerance level in accordance with cyber risks and defined priorities of cyber protection.

Level of business processes - a cyber risk management process is created in accordance with business processes and information received from the executive level, which is further forwarded to the level for implementation and operations. The basic result of this level is the Framework Profile, which is later supplemented with information from the implementation process.

Level for implementation/operations - oversees implementation of specific protection mechanisms based on the created Framework Profile, as well as generation of impact assessment results that are forwarded to higher levels. Also, implementation progress and observed changes in vulnerabilities and business risks are entered into Framework Profiles.

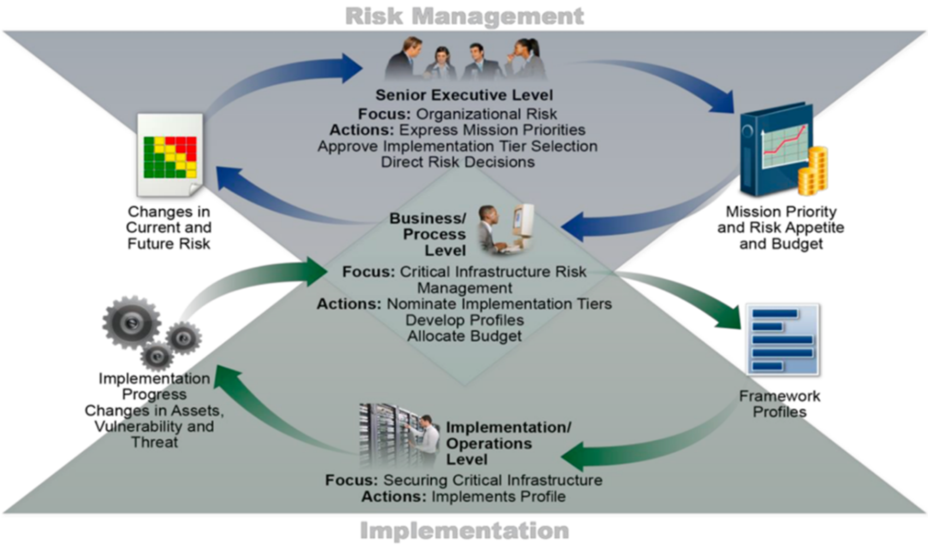

Figure 1. Information and Decision Flows within an Organization [9].

5. The five most important cybersecurity challenges for healthcare organization

For the adequate implementation of cyber security at the organizational level, it is not enough only to establish a department in charge of cyber security and provision of resources. The imperatives include close cross-sector cooperation in the cyber security industry and a proactive approach in terms of creating responses to increasingly sophisticated cyber-attacks, with rapidly growing varieties and improving approaches. Nevertheless, cyber-attacks on healthcare organizations can be categorized into five categories, which differ in terms of exploited system vulnerabilities, potential consequences of attacks, and protection mechanisms [10]. Recommendations are defined for each of the attack categories, in line with the recommendations in the HICP based on the National Institute of Standards and Technology (NIST) Cybersecurity Framework[3]—the gold standard of cost-effective cybersecurity best practices.

5.1. The email phishing attack

Email phishing is a common type of attack that is distributed in the form of an email with sending address that appears legitimate and known (usually a letter or two difference compared to the correct one) with a mandatory attachment in the form of a file or active link. After accessing an attached file or link, an automatic download of malicious software is made that further downloads files from the computer or a redirection is made to a website that may ask for sensitive information or proactively infect the computer [10].

Realistic scenario. Phishing e-mail can be sent to all employees who are in charge of patient billing in the form of a message by the IT department. The message can contain

[3] The National Institute of Standards and Technology (NIST) is a physical sciences laboratory and non-regulatory agency of the United States Department of Commerce.

a simple message about the necessity of changing the password for the payment system. If an employee from the billing department enters password data to access the billing system, an attacker will be able to damage the entire system and misuse financial data, as well as patient data [11].

Impact. Phishing attacks can serve as a way for attackers to obtain sensitive patient data (e.g., name, date of birth, insurance number, etc.) which can then be misused in terms of impersonation, selling on the black market, and harming healthcare institutions in the system. For example. one reported phishing attack from 2019 showed that by downloading credentials from healthcare workers (who were caught by phishing email), data for over 100,000 patients was downloaded [11].

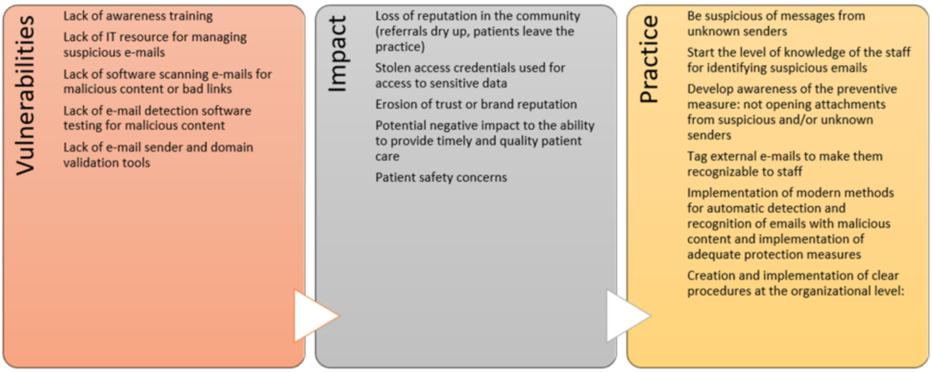

Figure 2. Suggested Practices to Combat E-mail Phishing Attacks **[11].**

5.2. The ransomware attack

Ransomware is a type of malicious software (malware) that involves encrypting data and blocking access to the device and/or all its systems, unless the "key" for decryption, known only to attackers, is possessed [12]. This is a method that attackers use to extort certain amounts of money from victims through various types of blackmail. Blackmail usually refers to the public endangerment of the victim's reputation, the complete destruction of information and the deletion of backup copies, and usually the complete inability to recover parts of the system and stored data [10].

Real Scenario. When trying to access patient data through the system, a family practice doctor in a small town noticed a complete inability to access the data, as well as other components of the system: scheduled examinations, billing data and other records. In the message, the attackers demanded an amount of 10,000.00e for the “key” needed for access, with no guarantee that it would be delivered. Furthermore, the attackers would not continue to ask for additional money after the first payment is made [11].

Impact. These attacks usually have serious monetary losses (especially for small healthcare organizations) because the loss of data causes damage that organizations cannot easily recover from. It is important to point out that although organizations agree to make payments to attackers, this is not a guarantee that the data will be returned. These types of attacks are becoming more and more sophisticated, and the attackers significantly increase the requested amounts mainly because of the value of health data and the imperative to protect the interests of patients [11].

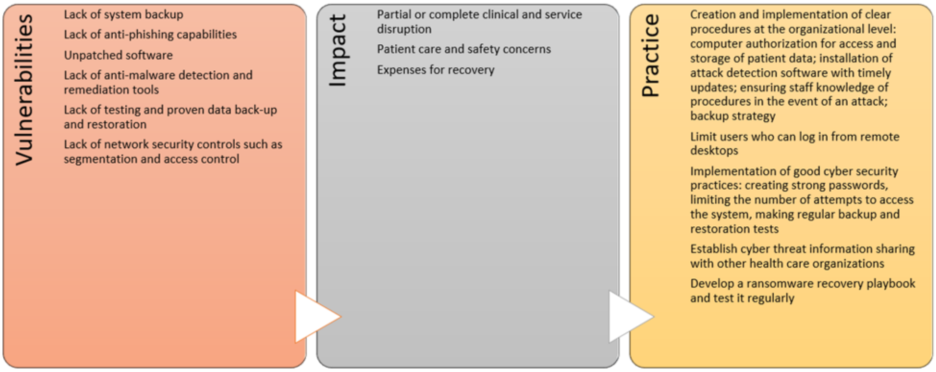

Figure 3. Suggested Practices to Combat Ransomware Attacks **[11].**

5.3. *The lost and theft of equipment or data*

Losing and stealing portable devices (e.g., laptop, tablet, smartwatch, etc.) are integral parts of everyday life that result in the hackers getting into their possession. Thus, device owners do not only have this loss, but hackers, if they manage to access the devices, can further use them to lock up systems and cause large-scale damage both for this individual (device owner) and for organizations and systems [10].

Real Scenario. The family practice doctor stopped in the cafeteria to order a coffee and during the break he checked the results of the patient radiology reports which did not arrive during the morning shift. A public Wi-Fi network is available in the cafeteria, through which the doctor used a Virtual Private Network (VPN) to review radiology reports. The Doctor got up to collect the coffee, but upon returning to the table he noticed that his laptop had been stolen [11].

Impact. The loss of sensitive patient data can lead to a large-scale loss that directly tarnishes the reputation of the organization and the doctor, and can lead to the identity theft of all patients (e.g., in 2019, 572 security incidents were reported and a total of 41.1 million patient records were stolen) [11].

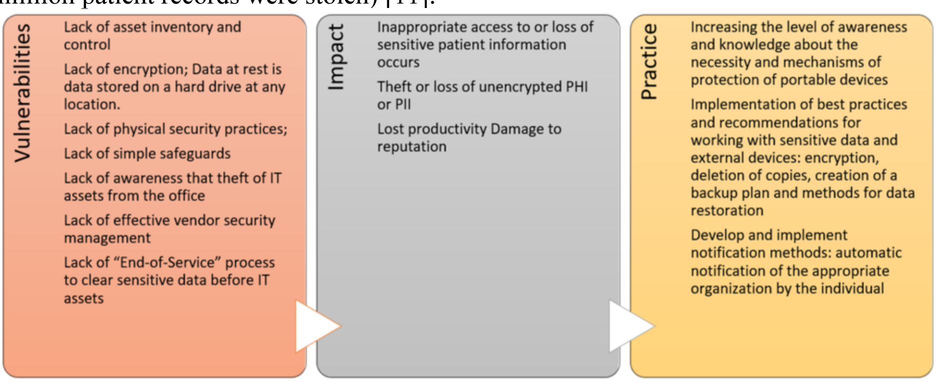

Figure 4. Suggested Practices to Combat Lost and Theft Equipment or Data **[11].**

5.4. The insider, accidental or intentional data loss

Insider threats exist in every organization where employees, associates and users have access to the IT system and/or its parts. Depending on the intent and awareness of the actor during the activity that causes the cyber-attack, malicious and accidental attacks are distinguished. Accidental attacks occur because of unintentional information sharing, procedural errors, or negligence. On the other hand, malicious insider attacks are the result of malicious intentions by an employee, associate, or user with the aim of personal gain or harm to the organization and/or other individuals/organizations [10].

Real Scenario. An employee with access rights to patient records makes random copies of patient data from the system. After enough copies, the employee tries to gain financial benefit by selling the data through the dark web [11].

Impact. Whether accidental or malicious, insider attacks can have serious consequences for patients, healthcare services and organizations. Also, this type of attack can be realized in a short period of time and immediately show consequences, while it can continue continuously for a long-time interval [11].

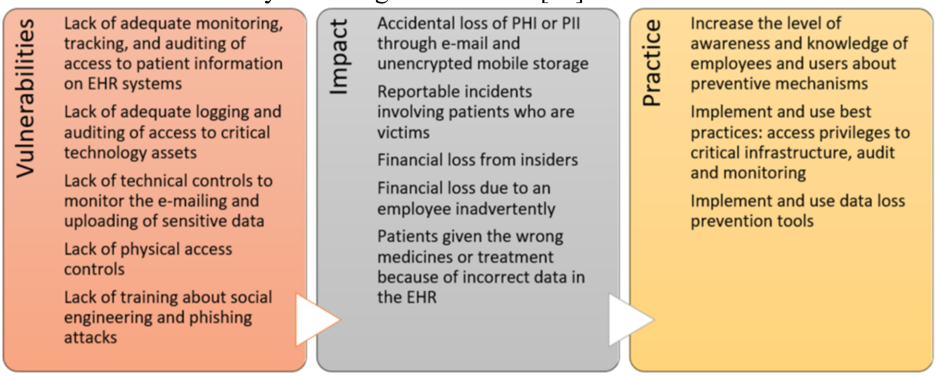

Figure 5. Suggested Practices to Combat Insider, Accidental or Intentional Data Loss [11].

5.5. The attack on connected medical devices that may affect patient safety

The Food and Drug Administration (FDA) defines a medical device as "an instrument, apparatus, implement, machine, contrivance, implant, in vitro reagent, or other similar or related article, including a component part or accessory which is recognized in the official National Formulary, or the United States Pharmacopeia, or any supplement to them; intended for use in the diagnosis of disease or other conditions, or in the cure, mitigation, treatment, or prevention of disease." If they are compromised, these devices can be used as an entry point into the computer network of a healthcare organization, which can further lead to misuse of data, malicious change of actions and results on the devices, which can even have fatal consequences for the patient [10].

Real Scenario. The attacker first carried out a phishing attack and entered the healthcare provider's system. In the system, a file with heart monitoring data was accessed, the control was taken over them (i.e., corrections over data are made) and incorrect heart data are displayed for all patients in the Intensive Care Unit (ICU), which potentially endangers the lives of most patients [11].

Impact. Medical devices are often of vital importance for patients, and the disruption of their operation can have direct consequences in the form of health impairment or even fatal consequences. Furthermore, this significantly undermines the health organization's reputation [11].

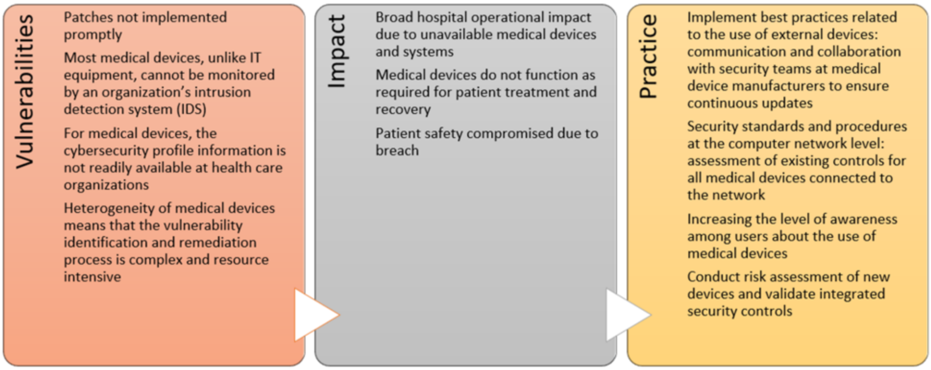

Figure 6. Suggested Practices to Combat Medical Devices that May Affect Patient Safety [11]

6. The best technical practice to mitigate cybersecurity threats in healthcare organizations

The presented practices for combating various types of cyber-attacks include the entire range of mechanisms, from the level of policies and procedures defined at the level of the organization, over the development of good cyber hygiene and ensuring an adequate reaction of the personnel of the health organization, to the implementation of technical practices and recommended protection mechanisms. It is important to emphasize that the implementation of technical practices alone is not enough, but continuous evaluation and assessment of risks in accordance with technical practices is crucial for the prompt improvements of an organization's cyber security posture.

Comprehensive instructions for the implementation of technical practices are provided in the HICP publication[4], which categorizes health organizations by size (small, medium, large), also corresponding to the level of critical functions for the health system performed by these organizations. Furthermore, depending on the size of the organization, it is possible to typically define subsystems that are interconnected to ensure the functioning of the system as a whole, as well as the amount of sensitive data that is stored [11].

Technical practices are defined comprehensibly for technically educated personnel in healthcare organizations and include the ten most effective groups of practices (defined in accordance with the CSA 405(d) Task Group): E-mail protection systems; Endpoint protection systems; Access management; Data protection and loss prevention; Asset management; Network management; Vulnerability management; incident response; Medical device security; Cybersecurity policies; which are further divided into corresponding Sub-Practices (a total of 88 sub-practices depending on the size of the organization and the application of the evaluation methodology) [11].

Figure 7 shows an example of the practices and sub-practices for medium healthcare organization, with further implementation recommendations available in the HICP publication [11].

[4] Health Industry Cybersecurity Practices: Managing Threats and Protecting Patient

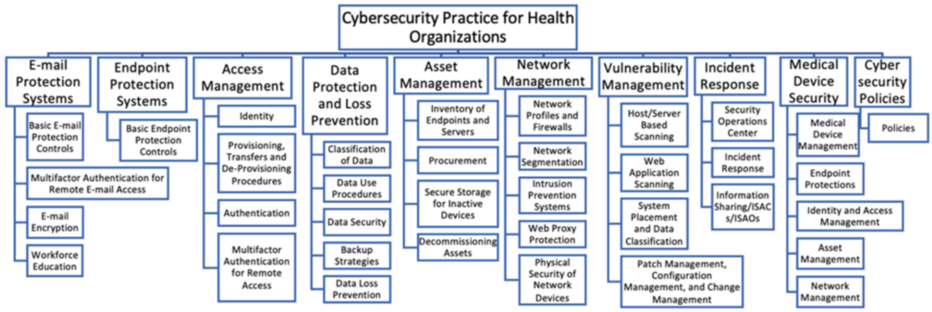

Figure 7. Cybersecurity Practices and Sub-Practices for Medium-Sized Organizations **[11].**

Conclusions

Cyber security threats are an integral part of everyday life and cannot be ignored even when it comes to healthcare organizations. Furthermore, healthcare organizations are a very popular target due to the wide range and potential value that attackers can achieve, from potential popularity and public visibility to financial gain. The size of the healthcare organization is not a key criterion, but any information system that is used in medical practice and performs activities over patient health records, integrates medical devices and other subsystems is the potential target of cyber-attackers. Data shows that cyber-attackers are very successful even with the most robust systems [12].

Cyber-attacks are rapidly improving and becoming more sophisticated day by day, and health institutions have the important task of putting as a priority of making investments in cyber protection, which undoubtedly contributes to the protection of their patients, in addition to their permanent role in the field of health provision. Available information about recorded cyber-attacks on healthcare organizations should serve as a basis for summarizing key lessons in the development of cyber security settings in healthcare organizations [10]. The key categories that are important and in which it is necessary to invest and build the capacities of the health organization are defined as [10]:

1. *Making employees ready to face a cyber-attack*: Employee Awareness and Cyber Hygiene
2. *Making the organization ready to face a cyber-attack*: Policies and Procedures
3. *Understanding Vulnerabilities*: Risk Assessments, Continuous Monitoring
4. *Having a Response Strategy*: Training/ Preparedness, Communication/ Information Sharing
5. *Hardening Cyber Infrastructures*: Access Controls, Redundancy, Patching, Encryption

Additionally, best practices that represent promising approaches to combating cyberattacks include the following [11]:

- *Understanding the health organization's assets and assessing the consequences of a cyber-attack*. Cyber protection measures must be developed based on the principle of "when" an attack occurs, not "if". This implies that all resources and assets are categorized according to the principle of critical infrastructure and that the consequences for the entire system are determined in the case of disabling the work of a specific component and loss/destruction/change of data.

Based on the above assessment, backup copies of the data are created, and the system back-up strategy is developed.

- *Expert assessment of the cyber-security risks and continuous monitoring*. The basic elements of cyber protection must be implemented at the level of the health organization's computer network (e.g., marking external e-mails, firewalls), with continuous training of employees (e.g., training on "phishing attacks"). Additionally, highly qualified technical teams should carefully and comprehensively look at system vulnerabilities and make a risk assessment. If the healthcare organization does not have adequate staff, it is often possible to use support services free of charge through regional/federal cyber security agencies, but this task should not be left unfulfilled. Regular vulnerability testing of the system is necessary with additional assurance that the management of health organization understands the risks and subsequent consequences, as well as the processes that must be undertaken to raise the higher level of cyber security prevention and protection.
- *Continuous strengthening of knowledge and skills of employees*. The organization of training, which will include theoretical knowledge, practical scenarios and exercises for prevention, recognition of cyber-attacks and reporting of incidents, are necessary for all personnel in the healthcare organization. It is important that trainings are continuously organized and that employees acquire the necessary skills in case of a cyber incident or a potentially consequential disaster for the health organization (e.g., a cyber incident in the middle of a public health emergency/patient surge).
- *Creating and establishing downtime procedures and required resources*. The cyber-attacks can lead to a longer stoppage in the functioning of the healthcare organization, so it is necessary to clearly define all the procedures that employees should follow and in order to ensure the fastest reaction of the organization to the resulting interruption. This includes the creation of adequate supplies necessary for work, as well as additional training of key personnel who will oversee managing the process and leading other personnel.
- *Creating key copies outside the computer network, including staff and patient schedules, key contact information and relationships with suppliers and other collaborators*. Coordination, communication and information exchange with partners, stakeholders, regional and federal institutions is crucial in the fight against cybercrime.
- *Understanding the vulnerabilities that exist in devices, technologies, tools, software and third-party technology deployed throughout the facility/enterprise*. Any device or component that connects to the system can be used as a potential entry point into the healthcare organization's system. Therefore, it is necessary to ensure that suppliers of external devices and system components have developed cyber security standards and are integrated with the devices/components they supply. Additionally, modern protocols for authentication and privilege verification are necessary to ensure continuous control of remote access and usage of personal portable devices (smartphones, tablets, laptops, etc.).
- *Establishing and continuously improving the "cyber security culture" within the healthcare organizati*on. The established protocols and standards must be adequately implemented by all employees in the healthcare organization.

Therefore, it is necessary to continuously check the implementation of cyber hygiene practices while simulating the real circumstances of cyber threats and cyber-attacks.

- *Establishing protocols and procedures for communication and information exchange with patients and staff members*. In case of identification of cyber-attempts or realization of cyber-attacks, it is necessary to send adequate information to patients and employees in an exactly appropriate manner. The key focus when selecting the information to be submitted should be on protecting the brand and mitigating further risks while considering the recommendations of law enforcement authorities.

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A Personal Odyssey in Health Informatics: The Journey to Ithaca

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Abstract. The aim of this paper is to share knowledge and experiences of a professional lifetime in the field of Biomedical and Health Informatics (BMHI), almost from the time of the initiation of the domain until today. The achievements and the milestones reached are not personal, but they just indicate the progress of the field as it was experienced by the observer. The challenges are still there waiting to be tackled for the benefit of healthcare. The paper is based on a systematic review of the author's published contributions across the professional timeline. For organizing the presentation of the results, the timeline is subdivided into five phases. In the discussion an aggregation of the achievements, milestones, and the challenges is presented.

Keywords. Biomedical and Health Informatics (BMHI), research methodology, scientific process, education, research projects

1. Introduction

Describing a personal voyage in time across the scientific progression of a discipline is mainly a subjective view based on personal experiences during the process of evolution of the field in the minimal time of a professional's lifetime. However, a few objective items are incorporated into the personal voyage in terms of publications, reports, and conference presentations. From past literature we know that the use of the term Odyssey is used in a metaphoric semantic way to indicate a journey that starts from an origin and has as target a destination where the in-between 'harbors' are planned but usually never accomplished due to unforeseen circumstances, challenges, discoveries, and opportunities. Sometimes, the destination, called 'Ithaca', is either reached or lost; even when it is reached, it may not be the one that the traveler was expecting, as the poet Constantinos Cavafy so eloquently described in his 'Ithaka' poem (see the Epilogue of this volume).

The personal voyage starts almost 68 years ago in Athens where the refugees' parents after the second world war and their aftermath life in camps managed to raise their children despite the immense the difficulties of those times. As matriculated primary and secondary students we had a very demanding and successful education giving us the background knowledge of humanities and scientific basis to pursue further

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our studies. However, as history is not linear, additional obstacles were raised due to the political situation at the time, requiring us to find a way out by leaving the country and continuing studies abroad at the University of Manchester in England. Thanks to the support received by tutors and supervisors, in terms of moral and financial assistance, the studies were continued at doctoral level in the field of image analysis and pattern recognition introducing us to the field of medical informatics from an imaging and artificial intelligence pathway [1],[2],[3].

The aim of this paper is to share knowledge and experiences of a professional lifetime in the field of Biomedical and Health Informatics (BMHI), almost from the time of the initiation of the domain until today. The achievements and the milestones reached are not only personal, but they just indicate the progress of the field as it was experienced by the observer. The challenges are still there waiting to be tackled for the benefit of healthcare.

2. Methods

Considering an earlier publication by the author regarding the evolution of education in Biomedical and Health Informatics [4], we are going to subdivide the timeline mentioned above into 5 phases: the commencement phase, the development phase, the expansion phase, the implementation phase, and the reflection phase. During each phase achievements, milestones and challenges are aggregated and will be mentioned at the discussion section supported by examples, reports, and literature, which will be detailed in the results section.

Therefore, the type of research methodology applied for this paper can be described as a literature review based on a subjective selection of topics.

3. Results

3.1 Commencement Phase

It is of particular importance how we define in European literature someone finishing their university studies and the corresponding ceremony which is named ‘graduation’. We give very much importance to finishing the studies. On the other hand, in the American literature the corresponding ceremony is called ‘commencement’, signifying that one chapter of one’s life is finished, and the next one, moving to the real life, is starting.

Hence, after receiving the doctoral degree, the commencement of the life started trying to find a way into the academia, which was the initial goal (‘Ithaka’). Then you realize how difficult it can be achieved in a rather small country with very few opportunities and a very intricate structure of the university hierarchy exists allowing only a few openings. An opportunity brought us close to the newly established department of Nursing at the University of Athens. Their need was to develop a computer science / informatics course within the Nursing curriculum. This challenge had to be tackled as soon as possible due to the specified deadlines. A literature review was conducted. These findings have some historical significance and are described in brief as follows.

Going through the medical informatics initiation literature and learning its history was an important milestone for us. We learned that Technical Committee Four (TC4) of IFIP became autonomous and established as IMIA by Francois Grémy [5]. Just 7 years before our commencement, for the first time in 1974, medical informatics education was discussed at a meeting in Lyon. During this meeting the competences required by health professionals were identified. They discussed roles and corresponding skills and knowledge. At that time there were already some educational curricula in medical informatics developed by Francois Grémy. A second meeting held in Chamonix followed in 1983. In the United Kingdom some universities provided education and training to medical students and/or physicians, for example at King's College John Anderson referred to his experience with research and education in medical informatics [6]. Entering data into the medical record part of the hospital information system was one of the topics. He developed also computer-aided learning programs [7].

Computer technology was changing very rapidly in those days. First only mainframes were available, restricting the introduction of computing considerably. Then relatively cheap mini-computers came on the market, resulting in systems that could be installed even in individual departments. This situation changed even more after the introduction of micro-computers in the eighties. Since computer technology was usually a subject in medical informatics courses, the courses had to be updated regularly. But it was increasingly realized that the principles of computer technology have to be taught only superficially to medical students. Instead, the methodology behind applications was important and the benefits but also the limitations of the use of computers should be explained [8].

Our experience at that time at the Nursing Department was a ZX Spectrum microcomputer connected to a TV set teaching to the amazed nursing students what a computer is and how we can work with it. Later on, we used a BBC micro as our next microcomputer which we brought to the eyes of the students. However, for serious research work we were relying on the mainframe computers CDC Cyber 6600, 7600 and later 172. To gain access to the mainframe computer, a terminal was required to be installed at the Nursing Department. That was only possible after six months' interventions with the Dean and the IT department. The question that we had to answer was 'why does a nursing department require access to computing facility' [8].

Moving back to the parallel story of the informatics evolution elsewhere, we learned that in Belgium Roger France introduced a course for medical students in which medical information processing, using an informatics methodology was taught to facilitate decision making [9],[10]. In the Netherlands at the Free University in Amsterdam in 1973 the department of Medical Informatics started education in Medical Informatics both for medical and informatics students. Informatics students could also specialize in medical informatics. During their study they had to spend a year specializing in medical informatics. Students had to study basic physiology and anatomy, biostatistics, pattern recognition, signal analysis and image processing, networks and communication and the structure of healthcare. In addition, they were confronted with special medical informatics subjects. [11],[12],13].

In Germany a degree in medical informatics could be obtained in several ways: via an application subject Medicine in an informatics study or via a postgraduate course. Since 1974 several universities offered courses in informatics with application subject Medicine. In total 20-25% of the study was devoted to the application subject [14],[15]. A certificate in Medical Informatics (not issued by a university but by the German

Informatics Society and the Association for Medical Documentation, Informatics and Statistics (GMDS) could be obtained by graduates from different disciplines after 5 years of on-the-job training (comparable to the requirements for becoming a clinical chemist) [16],[17]. The requirements for the certificate were specified. [18]. Already in 1972, a medical informatics program was established. This program was a collaboration of the University of Heidelberg and the University of Applied Sciences Heilbronn. The names of Franz Leven, Jochen Möhr and, later, Reinhold Haux are associated with this program. Initially the idea was to create a curriculum at the polytechnical school level (equivalent to an undergraduate curriculum). But in order to guarantee that graduates from the program would be accepted in the medical professional world cooperation with the University of Heidelberg was sought and obtained and a university level program was made, leading to a university diploma, corresponding to an MSc degree [19].

In 1973 Peter Reichertz together with the Informatics Society and the GMDS organized a workshop to define a framework for education in medical informatics. This meeting was held at the Reisensburg in Ulm, Germany. Jochen Moehr reported about this meeting in the IMIA Yearbook of 2004 [20] and also discussed the effects of the Reisensburg meeting, especially for Germany [21].

In Greece in the late seventies only a few hospital-based seminars and courses on the principles of computer science were taught to a healthcare professionals' audience as part of their continuing education, preparing them for the acceptance of the political decision of the early hospital information systems implementations. At that time no formal academic courses existed. Related formal courses were those included in the traditional Medical Physics courses already implemented a decade ago before that time in most Medical and Nursing Schools.

3.2 The Development phase

In Greece during the early 1980's formal courses started to appear in curricula in the Nursing School of the University of Athens. The lack of computer skills made it appropriate to introduce Introduction to Informatics as a first officially taught course combined with a laboratory practicum. At a later stage a separate course was introduced: that of medical informatics. As there was a strong objection by most of the conservative faculty members to accept new subjects as courses within the official curriculum of a traditional Nursing academic programme, it was difficult to have both above mentioned courses accepted as obligatory within the curriculum, so one course was accepted as obligatory and the other as optional. Due to the lack of computer skills among the fresh students in the first years of this initiation, the obligatory course was the Introduction to Informatics and the optional one was the Medical Informatics course later renamed as Health Informatics. Exactly the opposite occurred in early 1990's when the computer skills of the incoming students were at an appropriate level. Both Medical Schools of the University of Athens and the Aristotle University of Thessaloniki introduced Informatics courses as optional modules for a rather selected but limited audience of undergraduates in the late 1980's. This tendency improved after the late 1990's [22],[23].

An Erasmus Inter-University Cooperation Programme (a programme funded by the European Commission) had as target education in Health Informatics at the MSc level. The programme was funded from 1987 for eight years by Erasmus in two phases. The first phase developed a curriculum in the field of Health Informatics at an MSc level after an international workshop organised in Athens, and the second phase was the implementation of the programme by exchanging both professors and students among six European Universities in the beginning of the implementation to 20 European Universities at the mature stage of the programme. The first six European Universities/Institutions were: University of Athens, Polytechnical University of Madrid, University of Gent, City University London, University of Pavia, and the University of Manchester.

Table 1. Research projects are important milestones in the research process in BMHI (https://cordis.europe.eu)

Research Projects	Source of Funding	Description
PRECISE Consulting Room Systems	European Commission (EC) funded project under the Advanced Informatics in Medicine (AIM) program	Development of primary health care Information Systems, workstations appropriately configured to support the work of family physicians, workstations appropriately configured to support the work of Nurses in Hospitals.
GAMES A General Architecture in Medical Expert Systems	EC funded project under the Advanced Informatics in Medicine (AIM) program	Development of expert systems for the diagnosis and treatment of patients suffering from anemia, especially Mediterranean anemia.
EUCLIDES A European Standard of Transmission of Clinical Laboratory Data between different Information Systems)	EC funded project under the Advanced Informatics in Medicine (AIM) program	Creation of a standard methodology for the tele-transmission of Laboratory Information which includes among others: coding of the information, development of a communication protocol, compilation of the information package and encryption of the message.
EURODIABETA Modelling and Implementation of Critical Health Care- Example Diabetes	European Commission funded project under the Advanced Informatics in Medicine (AIM) program	Development of Information Systems for monitoring patients with diabetes.
Development of courseware using imaging techniques in Medical Informatics	European Commission funded project under COMETT II programme	Developing courseware material in Medical Informatics with the use of multimedia technologies.
Master's Programme in Health Informatics	European Commission funded project under ERASMUS programme	Coordinator and organizer of the Master's level Graduate Program in Health Informatics, with the cooperation of 12 European Universities. Coordinator for the development of the Study Program of the Graduate Program in Health Informatics.

The programme, coordinated by the University of Athens, was given at the Nursing School, and the overall evaluation merited it as a very successful coordinated effort despite the huge logistical overload and the very little funding support by Erasmus for a programme with no registration fees for the students. The aim of this curriculum was to give those working or intending to work in the health service a broad advanced postgraduate education in health informatics in order to develop the ability to understand and evaluate in detail the theoretical and practical requirements of informatics in medicine, nursing and healthcare. The course enrolled students from different European countries and also had lecturers from several European countries [24]. It should also be mentioned that the official title of the Erasmus programme established in 1989 was MSc in Health Informatics. The term Health Informatics was for the first time used in an official academic programme and academic title to represent our field.

In the mid-80's the European Commission planned and launched a new research framework programme related to the advancement of informatics technology and opportunities for applications of IT into healthcare. The programme was named Advanced Informatics in Medicine (AIM). As one of the very first researchers with an academic position in the country, the ministry of research asked us to be part of the representation in Brussels and contribute in formulating the new programme. It was a great experience as we met colleagues from the countries of Western Europe having similar experiences and wishes to establish this very young discipline not only in terms of education but also in research. The approval by the European parliament for the very first time of the AIM programme initiated a cascade of events and follow up programmes of much bigger scale that made the discipline of Biomedical and Health Informatics visible, having a direction and a means to supporting research centers across the members states of EU.

In these very early stages of the AIM programme we were successful in participating in projects as mentioned in Table 1.

Regarding our Department of Nursing, it is worth mentioning for historical reasons that in 1988 the taught course within the undergraduate curriculum of the Nursing School of the University of Athens changed from Medical Informatics to Health Informatics. It is the first time in literature that we encounter this term as an official course. The term became very popular at the end of the 1990's across the world as the appropriate generic term reflecting our field.

In the international scenery we have to major events: In 1976 EFMI (European Federation for Medical Informatics) was established and in 1979 TC4 of IFIP became an independent organization named IMIA (International Medical Informatics Association). Both organizations are Swiss based.

3.3 Expansion Phase

Medical informatics education was covered in IMIA and EFMI meetings. The education working group organized a workshop at each MIE meeting. In 2005 an EFMI special topic conference on Education in Medical Informatics was held in Athens attracting more than 200 attendees. This conference was also an IMIA meeting as indicated above. These conferences showed the interest that existed in medical informatics education, both to educate specialized professionals but also to educate medical students in the field.

The importance of information systems for healthcare was recognized by the European Community. Large amounts of money were funded to develop information systems of various kinds that could support professionals in their work. The AIM (Advanced Informatics in Medicine) initiative was a research and development activity of the European Community managed through Directorate General XIII of the European Commission. The programme focused on the possibilities of information and telecommunication technologies in the healthcare sector. It was realized that the developed systems would only be accepted and used when physicians and nurses had enough knowledge about and skills in the use of these new tools (Table 2 and Table 3).

Table 2. National and European Research projects are important milestones in the research process in BMHI (https://cordis.europe.eu)

Research Projects	Source of Funding	Description
Differential Diagnosis of Hematopathy	National Health Council	Development of an algorithmic process to provide a computer application in research for differential diagnosis of certain types of hematopathies
Clinical Labs Information System	National Health Council	Early research in developing approaches for message exchanges of information between different health information systems and laboratory information systems
Decision Aids in Chronic Care	European Commission COMAC/BME under the Medical and Health Research Programme	Literature survey in the field of decision support methods and tools in chronic care. Feasibility study for developing appropriate decision support systems
TELENURSING	European Commission funded project under the Advanced Informatics in Medicine (AIM) program	Concerted Action of the AIM for the investigation of systems of Nursing Applications. In this Concerted Action I was appointed to lead the Working Group on Nursing Informatics Education.
IT-EDUCTRA	European Commission 4th Framework Programme	A research project with a budget of 1.7 MECUs. This project develops curriculum and educational materials in Health Informatics using multimedia. Most countries of the European Union participated.

The results of European funded projects like EDUCTRA, the ERASMUS MSc Programme, the EuroMISE, etc. were the starting point of the IT EDUCTRA (Information Technologies EDUCation and TRAining) project that was approved in the Fourth Framework programme of the EU in 1995.

The main goal of the IT EDUCTRA program [25] was to create a training program for healthcare professionals in the basics of information technology and IT medical applications. The final product was a CD-ROM containing the teaching materials and tools and used new information technologies for the dissemination of knowledge and skills required for new health care systems.

The NIGHTINGALE (Nursing Informatics Generic High-level Training in Informatics for Learning & Education) project [26], again an EU financed project, was also approved in 1995. The project was considered essential for planning and implementing a strategy to train the nursing profession in using and applying healthcare information systems. The project was based on previous experiences obtained in the Telenursing AIM project and on the EDUCTRA Concerted Action which partially touched on the subject of education and training of the nursing profession. The main goal of the project was to bring to the surface, by means of a series of workshops, the user needs of the nursing profession with respect to telematics, to develop a nursing informatics curriculum for European nurses, and to develop educational tools and software assisting the educational process in nursing informatics. A number of European Conferences on Health Telematics education were also organized [27],[28],[29] and a textbook in health informatics for nurses was compiled [30].

Table 3. Research projects are important milestones in the research process in BMHI (https://cordis.europe.eu)

NIGHTINGALE	EC 4th Framework Programme	Research project with a budget of 1.2 MECUs coordinated by the Department of Nursing with John Mandas as the Coordinator of the project. This project develops Nursing Informatics curriculum and educational materials using multimedia. All the countries of the European Union participate. In continuous evaluations made by the European Commission NIGHTINGALE emerged as one of the best research projects of DGXIII.
TELENURSE	EC 4th Framework Programme	This work forms the International Classification of Nursing Procedures (ICNP). All the countries of the European Union participate
TELENURSE ID	EC 4th Framework Programme	Telematics applications for nurses - integration dissemination European nursing terminology in information technology
COAST	EC 4th Framework Programme	Research project with a budget of 2 MECUs with the participation of the Department. This project develops simulation programs for the education of students in the Health Sciences.
COASTER	EC 4th Framework Programme	COAST is seeking an alternative cheaper system for offering science and technology students the all-important benefits of laboratory (lab) practicals. The project uses mathematical models and multimedia material in an authoring package for simulation-based practicals.
GALEN-in-USE	EC 4th Framework Programme	Research project with a budget of 2 MECUs coordinated by the University of Manchester with the participation of the Department of Nursing with the Scientific Leader of the project J. Mantas. This project investigates the possibility of creating medical coded medical records from raw handwritten information.
WISECARE	EC 4th Framework Programme	Research project with a budget of 1 MECU coordinated by the University of Leuven, Belgium with the participation of the Department of Nursing with PI professor J. Mantas. This project studies the flow of information related to clinical nursing work and compares nursing practices between 5 countries of the European Union.

3.4 Implementation Phase

Over the years the number of programs in Health Informatics increased steadily. Beginning in 1990 the University of Maryland at Baltimore began to enter information collected on health/medical informatics programs worldwide into a database.

Table 4. Research projects are important milestones in the research process in BMHI (https://cordis.europe.eu)

Research Projects	Source of Funding	Description
PEP ATTICA	Co-funded Programme on European Infrastructures (2nd and 3rd Programme) Attica Region	Infrastructure program for the procurement of IT equipment for the Department of Nursing.
EPEAEK	Co-funded Programme on European Infrastructures (2nd and 3rd Programme)	A. Inter-university postgraduate program in Health Services Organization – Health Informatics with J. Mantas in charge of the entire project B. Reformation Program of the Nursing Department Curriculum. C. Evaluation program of the study programs of the Department of Nursing.
FRR	EU 5th Framework Programme – Key action on Ageing	The FRR is a research program aimed at improving facilities for the elderly as well as people with special needs. It also requires research to determine parameters for design and development. Many items related to the FRR concern meeting the needs of people with disabilities and dysfunctions in general.
EIPEN	European Commission -Leonardi Da Vinci Programme	The main objective of the EIPEN project was to develop a European Union network to share evidence-based education and training practices for interprofessional collaboration, as well as methods and materials for improvements in collaborative practice in health and social care. work.
MEDSKILLS	Leonardo Da Vinci	During the three years that the specific project lasted, a database was developed with elements that are based on clinical procedures, with the aim of offering an open source software for the standardization of clinical practices applied throughout Europe.
EUNetPAS	EU 6th Framework Programme Action on Patient Safety	The EUNetPAS research project aims to develop an active network of all 27 EU Member States, with the central aim of encouraging and strengthening their cooperation in the field of patient safety. In particular, EUNetPaS seeks to promote a culture of patient safety, structure education and training in patient safety, proposing European Patient Safety curricula in higher education and as part of continuing education.

IMIA's Working Group 1 on Education and Training in Medical Informatics provided guidance on critical issues of policy and purpose. In 1993 the database was revised to improve the quality and quantity of information accessible by remote users.

Although there were different opportunities worldwide for obtaining education in health informatics many countries had not, or at least not sufficiently, established such opportunities. Therefore, IMIA felt the need to develop international recommendations for health informatics education. The IMIA recommendations were accepted and published in 2000.

Regarding the involvement of our Laboratory to the research projects funded by EU (see Table 4) we report the EIPEN project supporting the interprofessionalism within the healthcare institutions. It has been proved by the project that Biomedical and Health Informatics is a facilitator of interprofessionalism.

Another project of extreme importance is the EUnetPAS project that aims at improving the Patient Safety conditions in the healthcare institutions across Europe by minimizing medical errors. All Ministries of Health and our Laboratory were involved in pursuing the task of education in patient safety by utilizing the Informatics technologies.

Regarding the educational recommendations we may report that they were received positively as can be concluded from the many references to them. Because of the tremendous progress in and the evolution of our field of health informatics, the contents of those recommendations became gradually outdated. Therefore, a first revision of the Recommendations was published in 2010 [31]. The name of the first domain area was changed into Biomedical and Health Informatics Core Knowledge and Skills, doing much more justice to our field than the earlier name: Methodology and technology for the processing of data, information and knowledge in medicine and healthcare.

3.5 Reflection Phase

During this period a number of important projects contributed to the understanding of the overall contribution of technology and educated healthcare professionals concerning the improvement of the health care system. Such a project was the RN4CAST project (see Table 5). Based on similar research work in the USA, the project focuses on Europe and tries to understand how to improve critical indexes of quality of health by correlating the hospital death rates with the educational level of hospital nurses. The results are impressive proving without any doubt that with university-based education of nurses the death rates of hospitalized patients are dramatically reduced. Among the skills required by the nurses with the university level education is the use of informatics.

The IMIA recommendations define the knowledge and skills necessary for these different types of health informaticians but also the required knowledge and skills of healthcare professionals. However, we need to have a mechanism for evaluating the quality of the programs (the accreditation process) and the knowledge and skills of individuals in BMHI (through a certification procedure).

In many countries the quality of educational programs is monitored via an accreditation procedure. As a first step the program writes a self-assessment report that serves as a reference for a site visit committee.

In some countries there are no accreditation requirements for individual graduate programs, only for universities. In this case the university determines the quality of programs that it offers, once it is accredited.

Table 5. Research projects are important milestones in the research process in BMHI (https://cordis.europe.eu)

Research Projects	Source of Funding	Description
RN4CAST	EU 7th Framework Programme	Organizations participating in the RN4CAST research project collected data from nursing staff asking for various characteristics of the nursing profession. These data were explored in terms of health outcomes and patient satisfaction. The aim of this research project was to examine the profile of nursing as well as how nursing as a profession relates to health.
BIOMED	Marie Skłodowska-Curie Actions	Marie-Curie Project lasting three years, coordinating institution EKPA and participation of universities and academies from Spain, Egypt and Jordan. The purpose of the project is to create infrastructure and educational programs in Biomedical and Health Informatics. Educational materials, curricula and a series of seminars were created.
CrowdHEALTH	EC Horizon 2020 Programme	CrowdHEALTH is delivering a secure ICT platform to collect and aggregate high volumes health data from multiple information sources in Europe. CrowdHEALTH also proposes the evolution of patient health records (PHR) towards Holistic Health Records (HHRs) enriched to become "Social HHRs" to capture the clinical, social and human factors.
PHELIM	ERASMUS+	The main objectives of the project are to strengthen and modernize the education system according to best practices in the EU, thus providing training of all levels to health professionals, enabling them to support the development and progress of a sustainable and flexible health system and to promote public health, following a cost-effective and at the same time effective approach.
DIGINEST	ERASMUS+	The project is focused to support modernization of Higher Educational Institutions by enhancing their cooperation with wider businesses in order to maximize the benefits from digital technologies in priority areas of agriculture and health while ensuring that students graduates, future experts and the workforce are adapting to the digital area.
HOSMARTAI	EC Horizon 2020 Programme	The HosmartAI mission is to guarantee the integration of digital and robot technologies in new healthcare environments and the possibility to analyze their benefits by providing an environment where digital healthcare tool providers will be able to design and develop AI solutions as well as a space for the instantiation and deployment of AI solutions. HosmartAI works under the premise that co-construction with stakeholders and citizens is the only way to develop a viable healthcare system accepted by end-users.
BE@WELL	ERASMUS+	The BeWell@DIGITAL project is aimed at improving the status of mental health of youth by empowering young people to enhance skills in digital educational routine and career development.

4. Discussion

The evolution of Biomedical and Health Informatics during the last 70 years is an amazing story of many successes, a few failures, and some disappointments. Overall, we can say that the discipline of Biomedical and Health Informatics gained the acceptance of the most demanding of all health professionals: the clinicians. For a discipline to be successful we require the description of the field of study in terms of its theories, corollaries, scientific methodology, semantics, and terminology. During this very little time, BMHI has successfully managed to tackle all the requirements in a very democratic way, accepting in its field all those that were interested and wishing to contribute irrespective of their original background. We can observe from the very beginning professionals and scientists in medicine, nursing, biology, computer science, information science, computer engineering, and other allied sciences to research and work in the field, named later as Biomedical and Health Informatics. This multi-disciplinarity of many contributions allowed the new interdisciplinary domain of Biomedical and Health Informatics to flourish, expand, and to become on its own a recognizable and accepted discipline.

Being a simple observer and participant of this evolution from the personal voyage perspective, we can note the following:

4.1 Achievements

The establishment of a course in Informatics in the Department of Nursing at the early 1980's can be considered as an accomplishment for that time considering the early beginnings of Nursing at University level. The University of Athens Nursing Department is one of the earliest established University level Nursing Departments in Europe. Nursing was already established in the USA at university level, a long time ago, even before the second world war, but in Europe that came a long time later. Even now in a few European countries the upgrading of Nursing from polytechnic technological institutions to university level happened only because those technological institutions were upgraded in their entirety to universities.

Another accomplishment of a larger magnitude can be considered the establishment of a master's programme in Health Informatics under the Erasmus programme [32],[33]. At the time there was no law allowing the establishment of the second level of education, the master's level programmes. So, by utilizing the Erasmus programme as a platform of cooperation with European Universities, a new master's programme was established. Therefore, the new programme was created through European cooperation and not because of national policy. The theme of the programme was Health Informatics, introduced for the first time in 1987 in the application to the Erasmus office in Brussels. The thought came to us that instead of the already used term Medical Informatics, for a Department of Nursing introducing a master's programme, the term Health Informatics was more appropriate and acceptable to the faculty. So, the term Health Informatics was born and even endorsed by the European Commission by approving the application for the new master's programme.

One of the most important projects with respect to nursing was project named after Nightingale [34],[35]. It was the introduction of nursing informatics across Europe establishing curriculum and introducing it to nursing schools at the European level. A series of conferences and books were published facilitating the nursing colleagues to introduce informatics to their departments.

Participation in European funded projects was a huge accomplishment as it brought new knowledge to the newly established Health Informatics Laboratory and much needed resources to support staffing and infrastructure [36],[37],[38]. The networking with European colleagues was the best outcome in this participation [39].

Also being part of the birth of the CEN / TC251 was an accomplishment. Standards in terminology, semantics, exchange of information, medical records.

An additional accomplishment was the induction to EFMI WG on education. It was important to be part of the educational process in medical informatics across Europe thanks to professor Hasman the introduction came in early 1990s and from that time onwards we were introduced to the fascinating world of European medical informatics. Through the WG on education many achievements when I call this such as participation in guidelines for education at the international forum. Also, many initiatives in European projects in education were part of the activities of the WG on education. Later on, this participation facilitated the progress of being elected to the board of EFMI, therefore contributing to important events and milestones for European medical informatics [40],[41].

Being President of EFMI gave the opportunity to revise the statutes allowing EFMI to be part of European projects. The overall election process became really open and accessibility to Board positions was very transparent. Also, introducing the fellowship programme in a more open way.

An achievement was also the participation in the European project called EUnetpas focusing on patient safety and also introducing educational models for schools of health sciences related to patient safety.

Furthermore, projects like RN4CAST were milestone projects in Nursing and in the quality of healthcare [42],[43].

The introduction of activities related to education either from the perspective of IMIA or EFMI brought huge impact to the BMHI expansion in the academia. Among those were the educational recommendations and the accreditation processes. Related to those discussions were also the interprofessionalism in healthcare [44],[45], where BMHI can contribute at a large degree, and the contributions of BMHI in cooperating with Biomedical engineering discipline [46].

Recent EU projects related to Big Data were a huge accomplishment for our Laboratory to be part of the state-of the-art and innovative usage and applications in healthcare [47],[48].

4.2 Milestones

The milestones reached are the following according to chronological order:

1983 - Development of database for the Greek version of MeSH terminology.
1985 - Introduction of Informatics to Nursing Curriculum at University of Athens.
1988 - The term Health Informatics is introduced for the first time.
1988 - Participation in European Research Projects.
1989 - Establishment of Master's in Health Informatics.
1990 - Founding membership of CEN / TC251.
1990 - Induction to EFMI and IMIA.
1993 - Council of Europe mandate introducing Health Informatics courses in Europe.
1997 - Establishment of the annual Health Telematics Education Conference (1997-1999)
2002 - Establishing the annual ICIMTH Conference with international participation.
2005 - Introduction of Informatics course in Nursing curriculum in Cyprus.
2007 - Top up Nursing educational programme to University level. Course BMHI.

2008 - Leading partner in the EUNetPas – Patient Safety initiative for Europe.
2009 - Revising the educational Recommendations in BMHI by IMIA.
2009 - RN4CAST project –Importance of Nurses university education for healthcare.
2011 - Accreditation process in Biomedical and Health Informatics.
2012 - BIOMED Marie Curie programme introducing BMHI courses to Middle East
2017 - Support via Erasmus+ project to Balkan countries to introduce BMHI.
2022 - Certification process in BMHI.

4.3 Challenges

Most of the challenges faced in BMHI have to do with the introduction and implementation of changes in education and in the clinical domain. Early challenges were the lack of awareness of technology and computer skills not only among the healthcare professionals but also in society. The field of BMHI and the professionals related to it was considered as a technical application domain and not a scientific one. The consequence of that was that the BMHI professionals in the very early phases were considered as technicians fixing electric appliances. Introducing an obligatory BMHI course in medical degree program is a huge task and it remains till our days a difficult process. Designing and implementing health information systems for many years was a difficult task; developing and adopting international standards; implementation of electronic patient records; cross-border medical files; security and privacy issues [49],[50]. Ethical and legal issues of telemedicine applications. Introducing artificial intelligence black box approaches in clinical decision making is a big challenge along with the acceptance of it by clinicians. Acceptance of BMHI as a profession remains still a challenge in many countries.

The challenges may be summarized as scientific, educational, ethical, and professional [51],[52],[53]. Looking beyond our sometimes, narrow or tunnel vision and crossing other continents as well, we may encounter additional challenges which are related to implementations issues and are due to lack of funding, poverty, and cultural issues.

5. Conclusions

The personal journey in the field of Biomedical and Health Informatics across the timeline of the professional lifetime was indeed very fruitful for accumulating experiences and knowledge. During this course, the navigation was challenging and indeed the trip was not linear, requiring often the changing of the route to be able to continue the journey without sacrificing the planned aim of the journey and the ethics of it.

Working in the field of Biomedical and Health Informatics one feels blessed and privileged to have encountered brilliant colleagues, who have changed the entire spectrum of Health Sciences by introducing new ideas, concepts, theories, and applications of BMHI. The networking among the peers in the field is the most important of the benefits of this journey, having always in our mind that we are all serving a field that aims at improving the healthcare system for the benefit of the patients and of the humans. This is the Ithaca that I wish to reach!

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Achievements, Milestones and Challenges in Biomedical and Health Informatics
J. Mantas et al. (Eds.)

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Epilogue

It is not so often that an epilogue is prepared for a volume of a *Symposion*. However, the international *Symposion* on Achievements, Milestones, and Challenges in Biomedical and Health Informatics (BMHI) that was held in Athens on October 29, 2022, had a particular task and a request to each of the participants. The request was to provide an expert's insight of their entire scientific career into their domains and have a self-critique view on the achievements, milestones, and challenges.

Each participant provided an in-depth review of their domain by sharing experiences, knowledge, and insights. We have read papers with a *De Profundis* approach, soul searching, very emotional, revealing the challenges one may face to be able to reach the envisaged goal. We know from literature that the strongest messages are coming through poetry. The quest for knowledge and truth is a never-ending journey of humanity, and one of the best poems reflecting this search is "Ithaka" by the Greek poet Constantine P. Cavafy (1863-1933) as translated by Edmund Keeley:

ITHAKA

As you set out for Ithaka
hope the voyage is a long one,
full of adventure, full of discovery.
Laistrygonians and Cyclops,
angry Poseidon- don't be afraid of them:
you'll never find things like that on your way
as long as you keep your thoughts raised high,
as long as a rare excitement
stirs your spirit and your body.
Laistrygonians and Cyclops,
wild Poseidon- you won't encounter them
unless you bring them along inside your soul,
unless your soul sets them up in front of you.
May there be many a summer morning when,
with what pleasure, what joy,
you come into harbors seen for the first time;
may you stop at Phoenician trading stations
to buy fine things,
mother of pearl and coral, amber and ebony,
the sensual perfume of every kind-
as many sensual perfumes as you can;
and may you visit many Egyptian cities
to gather stores of knowledge from their scholars.
Keep Ithaka always in your mind.
Arriving there is what you are destined for.

But do not hurry the journey at all.
Better if it lasts for years,
so you are old by the time you reach the island,
wealthy with all you have gained on the way,
not expecting Ithaka to make you rich.
Ithaka gave you the marvelous journey.
Without her, you would not have set out.
She has nothing left to give you now.
And if you find her poor, Ithaka won't have fooled you.
Wise as you will have become, so full of experience,
you will have understood by then what these Ithakas mean.

Translated by Edmund Keeley/ Phillip Sherrard
The poem is from www.cavafy.com

For the search of scientific knowledge, we have now the tools and methodology of the scientific process and of evidence-based reasoning. As we were travelling into this linear evolving scientific process, we have recently encountered a new and very tiny agent, an unknown virus, causing a pandemic, which for the last three years has disrupted the human activities across the globe causing millions of deaths and financial losses. Due to the scientific process, epidemiology, informatics, data analytics, and biology, we were able to devise mechanisms of immunization in a remarkable fast way to defend ourselves. However, during this period we realized how much we do not know, how vulnerable we are, and how other beliefs may endanger the arrival on a safe port. It is evident that in the Health Sciences we do not have a kind of periodic table as in Chemistry, where all the elements (known and unknown) are mapped and what we need is just to research ways to find the unknown elements (of course, this is still an enormous scientific task). In the Health Sciences, we are out in the vast ocean having as tools the scientific process and evidence-based reasoning, which are now enhanced by Biomedical and Health Informatics, trying to learn and acquire knowledge in order to understand the principles of the entire domain. So, we need to pursue further this long scientific journey for the quest of scientific knowledge and truth. The journey to Ithaka needs many, many, many, indeed many more years, but it is a wonderful and challenging journey.

Athens, 29.10.2022
John Mantas, Editor

Achievements, Milestones and Challenges in Biomedical and Health Informatics
J. Mantas et al. (Eds.)

Subject Index

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Author Index

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