Confluence of Disciplines in Health Informatics: an International Perspective

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Key Words

Biomedical informatics, health informatics, medical informatics, international perspectives, global health informatics

Summary

Objective: To discuss international aspects as they relate to the convergence of disciplines in health informatics.

Method: A group of international experts was invited at a symposium to present and discuss their perspectives on this topic. These have been collated in a single manuscript.

Results and Conclusions: Significant challenges, as well as opportunities, appear when cumulating the intrinsic multidisciplinary nature of health informatics interventions with the diversity of contexts at the global level, in particular when considered in the perspective of a confluence, i.e., the mixing of different waters and their merging into a new, stronger entity. Health informatics experts reflect on key issues such as collaborative software development and distributed knowledge sourcing, social media and mobile technologies, the evolutions of the discipline from an historical perspective, as well as examples of challenges for implementing ubiquitous healthcare or for supporting disaster situations when infrastructures get disrupted.

1. Introduction

Inhabited by powerful geniuses of the water, the city of Mopti, in Mali, is the spectacular site of the confluence of the Bani and Niger rivers. Green and red waters mingle before they irrigate the fertile Inner Niger Delta. More than a mere confluence, this union of two rivers symbolizes the sacred alliance of the salt and of the cola nut. The mineral principles of the rock salt from the Taoudenni mines in the heart of the Sahara, transported by camel caravans to Timbuktu and then by pirogues to Mopti, and the vegetal and powerful nature of cola nuts from the tropical forests where the Bani River originates. Many ethnic groups live in the area, the Bozo fishermen, the Fula shepherds, the Bamana and Dogon farmers, organized in a complex social network of relationships and reciprocal duties that has enabled not only co-existence, but also collaboration and synergies.

Many challenges appear when addressing health informatics issues outside of the relative comfort zone of affluent countries. The ones listed in the introductory chapter are largely based on the experiences in developing a South-South medical capacity building and tele-expertise program in French-speaking Africa, the RAFT network [1, 2] which was initiated in 2001 in Mali, in the Mopti area.

1.1 Technology and People

The field of biomedical informatics has always evolved at the crossroad of many disciplines. It is now part of an even larger scheme, the nano-bio-info-cogno convergence [3, 4], where technologies are expected to re-engineer and perfect nature, including what would become partially-cybernetic human bodies. In parallel, and more concretely, as the healthcare sector is finally entering the Information Age at the global level, human and social sciences contribute ever more to the research activities and the developments of the field of biomedical informatics. This is the new alliance of the rock salt of technology and the cola nuts of peopleware.

1.2 Information Technology and Informatics

Over the last decade, information technology has been recognized as a significant contributor to help fix the deficiencies of health systems, first in the developed world and then globally. This trend culminated in the WHO eHealth Resolution, passed in 2005 [5, 6], and recently reaffirmed by African Ministers of Health [7]. Efforts to understand the role of biomedical informatics for development have led to the specific sub-domain of “global health informatics”.

Visionaries of the 1980s predicted that it would be possible to skip the industrial age and evolve directly from agricultural societies to the information-based economies. Even though these visions have not been realized, there is a large consensus that resource-constrained, disease-burdened, infrastructure-poor, and human resources-
deprived developing countries will benefit, probably more than others, from the advantages of dematerialization. These include improved access to remote expertise, large-scale capacity building and life-long learning, information-driven coordination and management of health systems and their scarce resources, and, ultimately, patient empowerment through affordable, mobile and connected devices.

Although evidence of impact and return on investment is still scarce, the IT-enabled tools of healthcare are now being prefixed with all possible letters of the alphabet, e-Health for electronic, m-Health for mobile, p-Health for personal, u-Health for ubiquitous, etc. Even if technology can certainly bring important advances, these will only bring significant benefits if they are coupled with similar progress in informatics, i.e., the ability to manage and process information meaningfully, rather than just transporting it.

1.3 Glocalization and Reverse Innovation

“Glocalization”, or the ability to localize products designed, in general in the North, for global markets, has been the main drive of the industrial growth over the last decades. With the increasing importance and strength of emerging markets, new approaches are considered by some industry leaders to maintain innovation and growth. One of them is the “reverse innovation”[8], where products, originally developed for less affluent markets, are finding new usages in the richer countries. Examples include low-cost ECG and ultrasound devices.

The fundamental differences between glocalization and reverse innovation have important implications for the development of the field of global health informatics. For example, there is a tension between the proponents of highly integrated systems and those of interoperable, replaceable components. Glocalized products, such as the major hospital information systems, have successfully been deployed in the homogeneous markets of North America, but have faced significant challenges to adapt to the different realities in Europe and Asia, let alone in developing countries. If open-source solutions have facilitated the localization process, they still mostly rely on integrated models.

The very successful mobile phone industry, the large deployment of tools from the social web, coupled with the increasing demand from individuals to participate in the management of their health and healthcare, provide useful lessons. They also highlight the limitations of the traditional ways of developing and deploying health information systems. In countries that have few legacy systems but an urgency to find solutions, it is likely that more agile, distributed, user-driven tools will become predominant. The challenge therefore, is to make sure that the fundamental “infrastructures” are in place to enable the meaningful use of these tools, not only for each individual, but also as a way to strengthen health systems, which are and will remain mostly pyramidal in nature.

The identification of individuals, care professionals and care facilities, standards for data and privacy protection, for interoperability, and for the aggregation of indicators for decision-makers are the top priority challenges to be addressed in these settings.

There are certainly lessons to be learnt from the mechanisms developed by the many ethnic groups who live together in the Inner Delta Niger, and are able to share natural resources and co-operate while still maintaining their own cultures and traditions.

1.4 Building Capacity and Sustainability

The confluence of waters leads to strong and powerful rivers, but these would be quite useless if there were no one to sail on them or to value the resources that they provide. Fishermen must not only learn how to use their nets, but also to make and fix them, and build ships that are adapted to their environment, their needs, and their means. Competent professionals in biomedical informatics have to be trained so that they not only master the technologies and tools, but also the concepts and methods, and can, in turn, develop their own tools, research, and training program, locally.

Sustainability is as essential for projects in resource-constraint settings as it is for the fragile ecosystems of the Sahel. Often overlooked in implementation projects, this dimension must be taken into account at all levels: in the formulation of the (national) strategic plan that makes sure that resources are not wasted by parallel vertical projects but foster synergies and reuse, in the technological choices adapted to the local infrastructures and capacities for operations and maintenance, and in the business plans that should demonstrate that the benefits of these projects, whether financial or others, will produce enough returns to justify the investments.

1.5 Learning from Diversity, Accepting Change

“Just because someone is easier to reach does not mean they are easier to understand. The opposite, in fact, is true. The more our differences are revealed, the more tension is created”[9]. If we can overcome our instinctive ethnocentrism, these tensions can actually lead to positive outcomes, as they can be oriented towards emulation and sharing. This requires that each partner has the possibility and means to fully contribute, in a multilateral and multidisciplinary manner, ready to challenge one’s own values and pre-conceived ideas, respectful of identities and cultures. Then, the confluence will lead to a new, stronger river, and alter its composition, course, and even its name. And it may well be that mechanisms such as the “cousinage” or “joking relationship” developed between different people of Mali [10] would enable the respectful challenges that our field needs in order to continue its progress.

This paper further details some of the significant global issues faced by our field, exploring the ability to deal collaboratively with the development of software and the formalization and sharing of knowledge, and the role and potential of social media and mobile technologies. National examples illustrate the opportunities of ubiquitous computing, and the role of health information technologies in the
context of major disasters. Finally, the role of an historical approach is discussed, as it applies to a better understanding of existing experiences and how these would influence or facilitate other projects in diverse regions of the world.

These contributions are derived from the presentations made in June 2011 during a symposium on “Biomedical Informatics: Confluence of Multiple Disciplines”, on the occasion of the 50th year of Methods of Information in Medicine, in Heidelberg, Germany.

2. Collaborative Software Development and Distributed Knowledge Sourcing for Global Health

The use of informatics tools to enhance care and prevent disease in developing countries has increased dramatically in the past decade, in part due to 1) the realization that bridging the information divide is critical to enhance health for all, which has been well documented in the pages of Methods [11–13] and 2) capacity building programs that emphasize informatics as a critical component of health systems. [14–17]. Health information systems are being developed and deployed in underserved settings at a rapid pace, and this allows the biomedical informatics community to leapfrog over some stages that were needed for system design and implementation in developed countries [18]. The recent literature contains several reports of health information systems that are currently being used in developing countries [19–21], as well as the steps necessary for their successful implementation [22].

Some health information systems that have been implemented in low-income countries may be relatively simple in design and functionality, but they present a major contribution by the biomedical informatics community to preventing and/or alleviating the burden of disease. These systems perform a variety of documentation and decision support functions, and evaluations have shown that they can help decrease the time until diagnosis or treatment [23], recommend appropriate treatment of complex conditions [24–26], optimize workflows and distribution of resources [27], as well as other functions that lead towards the ultimate goal of improving patient outcomes. Not surprisingly, m-health (mobile computing) applications [28] have enjoyed much success in regions of the southern hemisphere where a significant portion of care happens in households or in locations in which tethered computing is impractical due to unreliable, unaffordable, or unavailable electrical power. Such systems have been used to collect data [29], inform users about applicable clinical practice guidelines and provide other types of simple clinical decision support [18, 30]. The most recent applications rely on smart phones [31, 32]. Having these devices in the hands of caregivers (and in some instances in the hands of patients) is an important step towards providing accurate and actionable information at the point of care. Communication capabilities, combined with significant computing power, allow both passive and active consumption and production of information in ways there were not possible just a few years ago. However, the number and quality of applications that make full use of these capabilities is still somewhat limited and cross-cultural collaborative development is not yet in place.

2.1 Collaborative Communities for Software Development

Current trends, inspired by Web2.0, may influence those who are currently initiating the design of new systems into thinking about collaborative development that may accelerate launching and continuous improvement of their applications, as well as help populate the knowledge base required for some of these applications. Important considerations relate to coordination of effort and quality assurance [33]: there is high variability in quality and quantity of software developers in developing countries, making it imperative that these collaborative initiatives rely on capacity building initiatives to achieve a minimum level of expertise among all developers. Successful examples of collaborative software development abound outside the healthcare domain (e.g., the development of the Linux operating system and the R system for statistical analysis). For healthcare systems, however, these examples are relatively rare, especially for software systems that are designed to operate in underserved settings. A notable exception is OpenMRS [34, 35]. In that project, developers from institutions around the world collaborate in the development of an electronic health record system. Some key challenges for the long-term sustainability of this remarkable initiative are funding, governance, coordination, and developer turnover. Furthermore, just as in many developed countries, sharing of clinical data beyond a single institution, even in de-identified form, is still not commonly observed in practice due to privacy and other concerns, hindering efforts towards health information exchange and regional public health surveillance, which become particularly challenging across country boundaries [36]. Therefore, although wiki-style communication within the environment of electronic health records has been proposed as an effective way to handle complex patients [37], there are still very few examples of systems that offer that level of interactivity for a complex case outside a single institution or consortium.

2.2 Collaborative Communities for Content Development and Review

On the knowledge base front, examples of collaborative content creation and knowledge management abound [38], including sharing of biomedical knowledge [39, 40], sometimes with funding support for developing countries [41]. Furthermore, data repositories allow researchers to share experimental data and protocols. Nevertheless, some key challenges remain the same: many initiatives exist only while the research grants that fund them are active, rigorous evaluations are often not performed due to scarcity of resources, quality and coverage are varied, and the trade-offs between producing general-purpose materials and case-specific ones go understudied.

Social media may have an important role to play in this scenario, given that coordinated networks of people have the potential to be powerful agents to combat
disease and promote health [42–44]. Access to clinical knowledge through the scientific literature and postings on the Internet helps caregivers stay informed of best practices, whereas access to experienced peers through professional networks helps finding custom solutions that apply to particular settings [45]. Developing systems that take advantage of interconnectivity and enhanced access to peers, while at the same time exercising quality control through a reliable and practical mechanism constitutes a real challenge that, once resolved, may help both healthcare providers and consumers. Individuals are evoking from passive absorbers of online materials to become also their creators, challenging the status quo of traditional peer-review models from scientific journals. Although this model of distributed knowledge works well in the software development community (e.g., programmers seeking solutions to particular problems who “follow” postings of highly-rated peers), understanding whether such model can really help caregivers who seek solutions to their specific questions requires further investigation.

There is a wealth of useful information that clinicians who are practicing at a particular setting can offer to their peers, but whether they have the time to do so, and whether their peers can find them and sort what is reliable from what is wrong or not applicable (intentionally or not) is a big challenge that our community is beginning to address in clinical social networks developed around global health themes (e.g., www.docratic.com). Peer voting for answers provided by crowd sourcing constitutes a partial solution that is widely used in such networks, but in this case the system applies equal weighting to the voters. Traditional peer-review is at the other extreme, where only a handful of experts decide whether a proposed solution is both accurate and adequate to the proposed environment. The ideal process probably lies somewhere between these extremes, and helping organize and monitor these collaborative knowledge environments is an important way for biomedical informaticians to make a lasting contribution to global health.

New approaches to instrument global health initiatives with informatics have never been so needed. The current alignment of researchers, clinicians, educators, developers, and policy makers in the creation of global health informatics solutions has been facilitated by funding from foreign government initiatives such as the Medical Education Partnership Program by the NIH (www.fic.nih.gov/Programs/MedicalEducation/) in the U.S.A., private foundations such as those founded by Gates and Rockefeller, support from local governments, as well as the increased visibility of global health informatics research groups and training programs. Global health informatics has evolved from scattered efforts from pioneering individuals to organized international collaborations involving many disciplines. Together these groups are forging new ways to advance care and change the health status of millions of individuals in developed and developing countries.

3. Will Social Media and Mobile Technologies Support a Confluence of International Connectivities?

We are moving, barring unexpected catastrophes, into an era when many people around the world, both those directly involved in our health and biomedical informatics disciplines, and those touched by them through the influences we have on health maintenance and healthcare delivery, are increasingly electronically connected. This raises many challenges and opportunities for the ways in which people interact, exchange information, and develop scientific disciplines, both technologically and socially. Many patients and their families and informal carers increasingly expect health services and health professionals to use the same kind of technologies for health care delivery as they use within their everyday lives; and are frequently frustrated when this is not possible. It will be important in coming years for health and biomedical professionals and organisations to address this mismatch between patients’ expectations and organisational practice, to provide an evidence base for the benefits of new technologies, as opposed to the current rhetoric that still prevails in many areas, and to address the socio-technical implications of increasing connectivity and changing realities of online privacy.

Among the many factors that presently influence the nature of health care, and will continue to do so into the future are: the changing locus of healthcare delivery, with increasing community-based and patient-centred delivery and models of care; the changing expectations of patients and the public on how and where health care will be delivered; the potential of the “Internet of things” [46], where ‘smart’ physical objects are integrated into the information network, and services, and people, interact with them over the Internet; the increasingly mobile nature of access to information, through smartphones, mobile Internet, and cloud computing; and increasing connectivity between people through the interaction of these technologies and applications such as social media. As technologies develop, and as the infrastructures grow to support increasing interaction between people in all parts of the world, it is likely that new forms of interaction will emerge from growing use of what the technologies make possible. As more connections are possible between people, the questions will inevitably arise within the academic and scientific communities as to the ways in which they influence how people work together, exchange information, and develop knowledge.

3.1 Social Media Use: Rhetoric Versus Reality

The new social media (a term that is increasingly used in preference to “Web 2.0”) tools that many people are increasingly using offer potential for exploring new and interesting ways for health professionals, including those working in health and biomedical informatics, to interact, to share experience, and to compare and contrast lessons from their work experiences, whether they work in clinical areas, in education, in research, or any other area of nursing or health care. Whether the nature of the interactions facilitated by these new tools are qualitatively or quantitatively different from those facilitated by longer-
established mechanisms, such as through email discussions, is an area that needs further research in the coming years.

There has long been considerable speculation on the potential that social media or Web 2.0 technologies might provide, and the impacts of healthcare delivery, interactions between patients and health professionals, and education and research [47–49]. It has been suggested that, through increased access to the Internet and mobile communications, combined with appropriate uses of social media, public health information, for example, might be made available to more people, more quickly and more directly than previously possible [50]. The question arises as to whether this access to information will actually lead to improvements in health.

Until recently, there has been a lack of evidence of benefits and scientific support for the claims made about the impact of social media on health and, to date, little research into their use. Studies, still often somewhat small scale, are now emerging to demonstrate the ways in which, for example, health care organisations use social media [51], patients are using platforms such as Facebook [52], or social media applications are being used in the context of major public health issues [53]. Case studies exist to demonstrate some of what has been achieved in developing professional learning communities, providing information to health professionals, using mobile technologies to support access to educational materials, and to reinvent access to and interaction with scientific meetings [54, 55].

3.2 Developing a Research Agenda

The growing use of social media by health informatics organisations such as the International Medical Informatics Association (IMIA), American Medical Informatics Association (AMIA) and others demonstrates ongoing interest in exploring the potential benefits of social media and other new technologies. These applications themselves might provide new methods for providing and improving connectivity to develop the scientific basis and practical application of our discipline, and to disseminate that best practice more widely and more quickly. There is a need to develop a research agenda or roadmap to explore these issues, and also to determine what might be the appropriate research methods, or develop new ones. More needs to be known and shared about how best to use social media, and many advocate the use of action research and similar methodologies as most appropriate [50]. IMIA, through its Social Media Working Group (SMWG) is undertaking a series of activities to begin this exploratory work [56, 57].

We also need to explore and research the potential of many of the new online and social media tools for actually conducting research [58]. These new tools offer, potentially, the opportunity to reach wider cohorts of participants in our research, more quickly than previously possible; but again, we need to explore whether this potential is being translated into reality. In addition, we will need to investigate the emergence of possible new techniques that using these tools, in real-time, online collaborative ways, may offer; and reflexively use the tools themselves to research that potential.

3.3 Conclusion

The hardware (which is increasingly mobile) and software (though increasingly social applications) exist, and will develop further, that will facilitate increasing connectivity between people and professionals in all parts of the world. We are increasingly able to collaborate, to share experiences, and to develop scientific knowledge, and possibly develop new methods of collaboration. Whether these opportunities will be used to simply reinvent current ways of working, or to develop beneficial new ways of connecting with colleagues, and improving the health of the world population remains to be determined. Only by actively engaging in these activities, including proactively contributing to the underpinning research, can we hope to shape the future as we would like to see it.

4. Telemedicine and Ubiquitous Healthcare in Korea

Use of biomedical informatics by healthcare professionals will increase as information and communication technology advances. Emerging technologies such as wireless monitoring, environmental sensing, personal area networks, body area networks, ubiquitous access to computer networks, lifelong electronic health records, wearable monitoring and treatment devices, and treatment-based genetics medicine have already made telemedicine and ubiquitous healthcare possible, and they will continue to influence health care significantly.

Telemedicine continues to grow in Korea with the increasing number of elderly patients, patients with chronic diseases, and patients who are discharged early. Many telemedicine systems have been developed and tested over the past 10 years in Korea [59], one of which is the teleconsultation system initiated by the Korean government. Such systems allow, for example, a primary care physician at a health center in a remote area to have a telepathology or a teleradiology consultation with the specialists of a tertiary hospital. Another example of telemedicine is the telecare of patients at home. Practitioners at a hospital take care of their remote clients using virtual reality technology via the Internet.

Telemedicine concept is extended to ubiquitous healthcare in Korea. Ubiquitous healthcare denotes healthcare that is provided – through ubiquitous computing technology – to everyone and everywhere without any dependence on time or location. It is considered an alternative to traditional face-to-face healthcare services in Korea. Since the 2002 revision of medical laws to include e-prescriptions and telehealth, the Korean government has initiated several projects to utilize ubiquitous computing in healthcare; such as the Smart Digital Home project that uses ubiquitous IT for underprivileged populations, the Ubiquitous Home Healthcare project for the elderly, and the u-City project [60]. The local governments have followed suit with health-center-based home health care, tele-
The proposed ubiquitous healthcare system consists of the consumers, the ubiquitous healthcare center, and clinical care facilities. A person can live in a ubiquitous healthcare environment at home, at school, in the community, or at work, according to where sensors monitor health-related data. Personal health information variables and data are transmitted to the ubiquitous healthcare center via the wired or wireless network infrastructure. The data are analyzed, processed, compared with the optimal profile of the individual, and stored at the ubiquitous healthcare center, which provides feedback to the individual based on the monitored data. If adverse events occur or symptoms of illness are detected, the consumer is contacted by employees of the ubiquitous healthcare center and assisted in correcting any problems. These employees are healthcare professionals (e.g., nurses) who are trained to assess and develop clinical pathways and individual care plans for consumers. If a consumer turns out to be unable to comply with correctional activities related to symptoms of illness, the ubiquitous healthcare center refers them to a healthcare facility, which can be a hospital, clinic, or any other healthcare environment. When the healthcare facility discharges the person to their home setting, the individual’s data can be monitored by the ubiquitous healthcare center until the condition has stabilized. The ubiquitous healthcare system thereby provides a closed loop of surveillance, supervision, and treatment, covering consumer needs related to the maintenance of wellness and health.

The private sector has also made various attempts to utilize ubiquitous computing in healthcare. One example is the business-to-consumer (B2C) ubiquitous healthcare model, which was developed to help manage chronic diseases (e.g., diabetes and hypertension), promote health in the general population (e.g., exercise, diet, and lifestyle management), and support disease prevention in the private sector. Another example is the B2B model, in which medical information solutions companies collaborate with healthcare organizations and insurance companies to provide ubiquitous healthcare services.

Recently, major healthcare organizations, leading telecommunication companies, universities and government research institutions, medical device and sensor companies, medical information solutions companies, and the safety and security industries are beginning to collaborate in ubiquitous healthcare in Korea. For example, a consortium led by private telecommunication companies is developing ubiquitous healthcare models for private clinics and major healthcare organizations. About 8,000 patients with diseases such as diabetes, hypertension, cancer, chronic respiratory diseases, and metabolic syndrome will participate in this pilot project.

Ubiquitous computing is being used in nursing as well. Home care nurses send data measurements of their clients to doctors at health centers. Doctors monitor data sent by the home care nurses and send them recommendations in return. Nurses then deliver nursing care to home care clients using short message service (SMS) systems or phones. Another example is the use of ubiquitous computing by community health practitioners. Community health practitioners share with doctors the bioinformation collected from clients with hypertensive and diabetic medications. Nurses prescribe and dispense medications for the patients based on doctors’ orders delivered to them via wireless networks. Ubiquitous computing is also used in nursing homes; nurses working in nursing homes can consult with doctors at a remotely located hospital via teleconferencing technology. Nurses working in community settings and for vendors are actively involved in different types of ubiquitous healthcare activities as healthcare providers, business model planners, and developers.

Healthcare in the ubiquitous computing environment introduces major changes to the traditional roles of healthcare professionals, patients, and health services, and to the place of technology within the healthcare system. The healthcare professionals of the future will play a key role as an information mediator to facilitate the use of technology by consumers. Current education will not adequately prepare healthcare professionals for the envisioned ubiquitous healthcare environment. Patients will be redefined as consumers, users, and partners. Consumers of the future will be older and more likely to have chronic diseases, and will require more health services than before. However, an additional important focus will be on health promotion and maintenance to reduce the burden on the health services. Thus, healthcare services in the ubiquitous healthcare environment will occur within an environment of new consumers, new services, new technologies, and a new understanding of healthcare.

### 4.1 Challenges and Lessons Learned

Even though it remains to be seen whether ubiquitous healthcare in Korea can deliver alternative healthcare services to traditional face-to-face healthcare services and realize promises to reduce healthcare costs, there are a few lessons we learned from our efforts to introduce the ubiquitous healthcare in Korea. First, it is important to have advanced key technological capability and information sharing capabilities readily available. Second, it is necessary to have strong commitment of the central government and inter-government collaboration especially in funding, and laws and policy making. Third, all the stakeholders such as government, industry, healthcare professionals and consumers need to work together. Fourth, it is important to have the support and confidence of healthcare professionals and the public for measures designed to protect patient privacy, confidentiality, and processing of sensitive information electronically.

To realize the ubiquitous healthcare and gain greater acceptance and share of the ubiquitous healthcare market on the world stage, the Korean government faces following challenges. The Korean government needs to step up its engagement with international standards bodies and cooperate and collaborate with other countries in areas of convergent technologies such as RFID, ubiquitous sensor networks and context aware multi-model interfaces. The Korean government also need to address the soft issues of u-health such as devel-
5. Medical Records in Time of Disaster

On March 11, 2011, an earthquake of 9.0 magnitude hit the northeastern area of Japan. It is now known as the North-Eastern Pacific Coast (Tōhoku) earthquake, which is rated the seventh severest in history. The casualty count of this earthquake is more than 20,000, and, as of April 2011, more than 200,000 people live in refugee shelters. Healthcare must be continuously provided even in this situation.

The main obstacle concerning medical informatics was the discontinuation of personal medical records. Some hospitals and clinics were totally washed out by the earthquake or tsunami immediately following the earthquake. Even in the non-affected hospitals and clinics, inquiries of past medical records were impossible, because of electricity blackouts, and difficult telecommunications.

Japan has experienced many heavy earthquakes over ages. The oldest record is in the Nihon-Shoki (Imperial history of Japan) in 416AD. In 1995, Kobe city, in the west middle part of Japan, was hit by a magnitude 7.3 earthquake, the casualty count being 6,400 persons. Investigations into this earthquake left some lessons on how medical records should be prepared [61]. Some lessons were helpful, some were barely implemented.

5.1 Searching for Past Records in the Disaster Period

5.1.1 Problems

The primary purpose of a medical record is to provide a past healthcare history of the patient [62]. It is of course true even in disaster situations. The type of information needed, however, is different according to characteristics of the disaster.

In the Kobe earthquake in 1995, there was virtually no tsunami after the earthquake. The medical treatment needed was mainly for acute surgical care, caused by collapsed houses and furniture. Then, whatever surgical care was feasible, chronic disease patient care became mainstream. This situation is similar to the Haiti earthquake in 2010 and it is reported that simple PACS (medical imaging system) was useful [63]. In the 2011 Tōhoku earthquake, a record high (up to 15m) tsunami tidal wave hit the Pacific coast after the quake. Less collapsing of houses caused by the earthquake was observed, maybe because of the raised construction regulations after Kobe earthquake. But, a large number of houses were washed out by tsunami, causing many people to lose their homes. They rushed for shelters with little amount of necessities. Survivors were less injured but in this situation, health insurance ID numbers were difficult to be recalled, not to speak of personal medical records (paper or electronic). And mainly, chronic medical records were required to be maintained at refugee shelters.

5.1.2 Archives

Some healthcare providers’ paper medical records were washed out and providers’ electronic records (medical records, order entry records, and claim data) were also heavily affected. It is obvious that remote electronic archive of these records would provide a good solution. Ishinomaki municipal hospital, very near to the epicenter, had just started mutual online archive with Yamagata municipal hospital (86 km away) from February 2011 (one month before the disaster), and it was very easy to recover the whole electronic records [64]. Now in Japan, many IT solution providers are offering archive service. They offer many styles of archive frequency, media, and contents to be archived.

As for contents, it is reported that past prescription information is mostly needed for the continuity of healthcare, compared with other information [61]. In regular situations in most countries, it is kept with healthcare providers, and claims are reported to payment organizations mainly for reimbursement purposes [65]. In some countries and regions, not only prescription, also medical charts are centrally archived as electronic health records [66].

In Japan, each healthcare provider is mandated to keep a patient’s medical record for five years. Reimbursement claims, which include prescriptions, are sent to many kinds and scales of insurance organizations (from Ishinomaki Fishermen’s Mutual to Toyota Motor Health Organization). In the 1995 Kobe earthquake, submission and archives were paper based. In 2008, electronic reimburse claims were mandated. Moreover in 2010, a national project was launched to gather all reimbursement claims into one large database. It is to support healthcare policy making as well as other research. Each record of the national centralized database is anonymized in an unlinkable fashion, to protect privacy.

In times of disaster, medical records in most healthcare providers in the disaster area were inaccessible, because of the site being totally washed out or collapsed. Even in the less damaged providers, because of the electricity blackouts, the national centralized database was useless in pin-pointing healthcare for individual patients, because it is unlinkably anonymized. However, except for some local organization’s database, most healthcare organizations’ databases were safe.

A week after the Tōhoku earthquake, one physician member of JAMI (Japan Association for Medical Informatics) requested JAMI board to pressure the Ministry to make exception for regulations on enquires to each healthcare organization’s data. The regular procedure is as follows; only patients themselves can issue enquires of their reimbursement records. After their submission, the board is called to discuss whether the disclosure can cause harm to the patient’s medical care. In most cases except for psychiatric disease cases, they are approved. The member requested that doctors, with permission of their patient, could issue enquires, and the board need not be called. With the conditional clause limited to the disaster area, Ministry notified each healthcare insurance organization to honor this simpli-
fied procedure, 12 days after the earthquake.

5.1.3 Information Priority among Health Records

In 2007, the association for promotion of Public Local Information Communication reported “Healthcare, Welfare application working group proposal” [67]. In this, by means of interviewing to disaster teams, priority of healthcare information in disaster is listed as

- High: Severity of injury/disease, Prescription history, Type of injury/disease;
- Middle: Images of the patient (visible or X-ray), Past disease history (incl. examination results), Past progress notes;
- Low: Past health checkup record.

The above-mentioned report also says that a prescription history is of first priority rather than test results or medical record descriptions. In some countries, the history of prescriptions is recorded by e-prescription. The medical information format is standardized by HL7. If the problem of drug code is solved, then realization will be relatively easy.

5.1.4 Resident List

In Japan, a nationwide resident registration database and network system started operation since 2002. It includes name, birth date, sex, and address with past history. Only four days after the earthquake, the Ministry of Internal Affairs notified all cities and villages that the regulation, which requires database access procedure to be operated at the residents’ city/village ward office, was temporarily relaxed. Through this, the mayor of Futaba city of Fukushima Prefecture, where whole residents had to take refuge because of Fukushima nuclear power plant accident, could access the database to get his residents’ list at their shelter Saitama city’s ward office, 200km away from Futaba city.

5.1.4 Lessons Learned

Before electricity and network resume: health IT system is less helpful in this situation. Japan’s experience showed that cell-phone is less usable, but satellite phone is connectable with limitation of slow data transfer rate (128 kbps), and as long as user can get power for this. In other words, small healthcare contents sorted with patient unique ID can be useful even in this situation. Even in this period, at refugee stations, continuity of care should be noted. Dispatch doctor in refugee stations may change. The best way to keep the continuity of record is by patient’s hands. Duplication copy paper for doctors to write the prescription and intervention, one copy of which is handed to the patient may help.

Archive: there are two axes of archive: healthcare provider and patients. The case of Ishinomaki hospital’s remote archive in Yamagata hospital is exemplary. Centralized archives can be an alternative to medical record, if they are not anonymized, or, at most, linkably anonymized. As a patient oriented archive, the electronic health record (EHR) could be the best answer.

Contents of archive: interviews to dispatch team doctors shows that even if it is not the whole medical record, prescription history greatly helps. Because doctors can guess the patient’s healthcare history by looking at it. EHR may be good for other purposes, but for emergency use, at least prescription history should be included. This also means that reimbursement information can act as a medical record. In any case, record should be collected and sorted by patient’s ID.

Usability of the archive: to make this kind of remote archive useful, not only infrastructure robustness, also access procedure should be considered and drilled for both regular situations and disaster period. In other words, in extreme busy periods like disaster, nothing can be done additionally to regular accustomed procedures.

5.1.5 Final Remarks

There were many proposals and suggestions made by learning from past large disasters [61, 68, 69]. We observed “half decay time of interest on this issue” as three years, watching the numbers of symposia concerned in many academic conferences. Hospitals in Japan had priority phone line, which does not allow rejection of call request in congested period. Over the years, many hospitals switched their telephone line to Internet phone, which has no priorities.

Even so, these lessons should be reported again, with contemporary updates, in hope for catching the eye of current/future healthcare system designers and decision makers. Preparedness should be aimed not only for natural disaster, but also for more frequent man-made disaster, such as information system failure, network failure. This will be considered over the immediate interest on the issue.

6. Issues and Challenges for the History of Biomedical Informatics: Confluences and Divergences in the Evolution of an International Discipline

The 50th anniversary of Methods of Information in Medicine celebrated in Heidelberg in June 2011 was a unique opportunity to reflect on the methods of information (or informatics) that can be developed to describe the history of this international discipline. Not unlike medical informatics itself, which has a broad scope of covering from the micro (or nano) to the macro level of biology [70, 71] in its implications for human health and disease, the informatics of History needs to be developed to cover the equally broad scope of how we record, describe, and analyze the past [72], in order to fully measure our accomplishments in a scientific and technological field that has grown as rapidly in the past half century as have its anchoring disciplines of computer science and biomedicine [73–78]. Our biology results from an evolutionary process; that can both give us pause and inspire us to design and produce a historical informatics that mimics the ongoing evolutionary process that underlies science and technology themselves.
Medical informatics can serve to inspire a broad agenda to develop a new discipline of historical informatics. Such a new discipline would benefit from the experience and the international nature of biomedical informatics which has witnessed so many confluences of diverse ideas, technologies, and scientific accomplishments over the past 50 years, while also proliferating into so many divergent subspecialties [79–82] that it is sometimes hard to assess the degree of coherence in the discipline. By contrast, the discipline of History is highly subdivided in its choices of topic and method but it is unified by the common goal of creating analytical narratives of past events while also understanding that the way in which humans tell stories about their past serves to construct both past and present.

A new discipline of historical informatics would share a sort of heterogeneity with biomedical informatics, because it will need to encompass not just the generation of specific narrative reconstructions, but also the production of information artefacts that will facilitate the systematic synthesis of multiple reconstructions, created by many protagonists and observers, into records that support historical reconstruction and narration. Such reconstructions, like those of nature itself, would form a "memetic web" [83] with which to understand the ecologies of human life as it is and has been recollected (that is, ecology in the sense of the totality of the constructed human past). Such a memetic web is very much like the "genetic web" of organismic evolution, which has allowed for the ongoing reconstruction of different ecologies of life-forms at every stage of biological evolution. Biomedical informatics, if analyzed for the confluences and divergences of its history by way of describing the thoughts and deeds of its protagonists, may be in a unique position to illustrate how groups of professional experts, sharing a common goal, have formed evolving "professional social networks" to generate the research, practice, and educational contributions that define their field. That such contributions have been heterogeneous and different for different groups around the globe illustrates the parallel between the memetic transmission, reproduction, and mutation of ideas and the genetic analogues to an evolutionary model of history.

At the same time, the confluences and convergences in intellectual and practical trends in informatics and biomedicine also illustrate the contrast of memetic to genetic evolution: people write history in conscious or deliberate attempts to simplify (or complicate, or obfuscate) their narratives of the past so as to make them more useful to, and consonant with, their present concerns, goals, and visions. This aspect of "conscious recursiveness" [84] is a unique phenomenon at the boundary of human perception and cognition, which, at its most inspired, has given rise to the scientific method and to the design of experiments that rest upon the deliberate simplification of observations of, and constraints on, natural phenomena, in order to produce the controllable and repeatable experiments that have made modern science possible. Biomedicine, however, has a seemingly infinite individualization of conditions, and that has made the traditional scientific reproducibility of experiments difficult or impossible, as seen in the difficulty of deciding which clinical trial results apply to which individuals in a changing landscape of genomic-phenomic diversity. Usefully, the immense individualization that we see in biomedicine might actually lead us to think differently about perceptions of past reality. It suggests a way of moving from conventional reconstructions of past realities by simple feature-matching from a space of descriptors, to a "narrative, image, and metaphor-matching" that introduces perceptual dimensions to amplify the purely cognitive ones upon which various logics operate. That is to say, an easy definition of historical informatics might be "the methods of information needed for archiving, analyzing, indexing, and retrieving source documents from a web-based digital-library." But the individualization of biomedicine, and the model of biomedical informatics, permits a more ambitious definition, along the lines of "the methods of information needed to generate alternative interpretive threads and visions reconstituting past events, their participants and environments." That more ambitious approach, inspired by biomedical informatics, would permit us to move towards an evolutionary model of historical ecology, or the ecological development of ideas ("memetic networks") and the people who produce them.

For our discipline, the ubiquity of the web and the consequent pervasive dissemination of biomedical knowledge has opened new opportunities for how biomedical informatics impacts not only the healthcare of patients, but also the conduct of research and educational practices. In the early days of the discipline, computational modeling of medical decision-making [85], together with educational activities [86] and hospital information systems [87] were unifying professional themes across medical informatics. Now the maturity of informatics methods, coupled with new technologies of mobile communications and cloud computing have extended the scope and reach of informatics methods to professionals and laypersons worldwide [88]. Despite this, cultural norms still dominate the practice of healthcare, so biomedical informatics is now faced with new sustainability challenges that go beyond just improving interoperability and access to information [89]. Chronicling the history of biomedical informatics can help us find out where, when and how local and regional standards of care mesh or are at odds with the most advanced international "best practices" and guidelines. This can come from critically documenting and assessing the maturity, robustness and reliability of different approaches to querying, information integration, decision-support, imaging, and other sophisticated informatics methods in biomedicine. Only by learning from our past will we be able to develop a semantic web—or Web 3.0—of biomedical information [90] that takes into account the diversity of health and biomedical practice across the world, which is so influenced by differences in human culture and language.

In short, the fifty-year history of biomedical informatics can inspire us to ask a simple, controllable question, with much wider ranging potential impact: can we develop the scientific methodology to underpin a history of biomedical informatics as a research field in its own right, one that looks at the past as the evolution of individuals and groups of individuals and how
they interact in their social-professional networks, and thereby helps us look to the future and the expected further evolution of these individuals and groups as they respond to new challenges and opportunities. Many of these will be technological, but most are human, where a central question rests on the roles or identities that we, as humans, consciously or unconsciously adopt as caregivers, scientists, technologists, informatics researchers, or humanists. The key challenge this perspective suggests is: how do we identify ourselves and our potential roles in improving human health individually and in groups (social-professional networks) in the context of healthcare. In facing that challenge, history helps us build shared memories, and thereby helps us learn from the past, and thus the development of a historical informatics directly addresses the needs of our field, and potentially of many others as well.

7. Conclusions

An international perspective on biomedical informatics is inevitably multi-faceted. If information technology is now mostly globalized, the main challenges we are currently facing relate to the intelligent management and sharing of knowledge and information for better health outcomes. This is the core business of our discipline; this is where the confluence happens. It requires a thorough understanding of the many streams of local realities and challenges, the ability to learn from successes and failure, and to disseminate new knowledge and make it usable and useful, wherever appropriate.

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