Policies on Actions of the Japan Association for Medical Informatics (JAMI):

## Current Issues and the Role of JAMI

<div align="right">June 5, 2014</div>

The Japan Association for Medical Informatics (JAMI) was established in 1983 as a forum for scholarly exchanges between researchers and system implementers interested in medical and healthcare information. JAMI is Japan's sole academic society specializing in Medical Informatics. JAMI is a member of the International Medical Informatics Association (IMIA), and became a member of the Japanese Association of Medical Sciences in 1997. The term "Informatics" means "the science" of representing, collecting, categorizing, compiling, searching, selecting, and using information. Medical Informatics refers to the science of dealing with information in medical, healthcare, or health context. In other words, Medical Informatics is the science of dealing with Medical and Sociological information, such as information related to healthcare, systems of healthcare service delivery, healthcare provided by clinical facilities, provision of care, patient participation, patient's choice, and so on. JAMI promotes academic research and engages in activities that are directly linked to disseminating the results of research among the medical and healthcare community. JAMI contributes further to society through interdisciplinary developments in fields such as science and engineering, economics, legal study, and agriculture as well as humanities.

Research, Implementation, and Training of Personnel

Decision-making in diagnosis and treatment

Decision-making with regard to healthcare (support for decision-making) has been a research topic since the JAMI was initially founded. Medical Informatics lies at the heart of "a physician's diagnostic process, which is a process that involves processing information." Research on decision-making in diagnosis and treatment was actively conducted in the 1960s and

1970s and focused on statistical techniques such as multivariate analysis and mathematical techniques. In the 1980s, attention focused on expert systems using artificial intelligence and techniques such as genetic algorithms. Representing and processing knowledge subsequently became a central framework for Medical Informatics. Over the past decade, medical expertise has increased and ontological approaches to, for example, represent the meaning of concepts evident during care, have advanced. That research has made steady progress. A major role of the JAMI is to represent given knowledge (including a host of clinical medical knowledge) in a processable form and to use techniques such as data (text) mining and machine learning to derive new knowledge from large sets of data, including unstructured data and narratives. This new knowledge will be incorporated in clinical medicine to spur further advances.
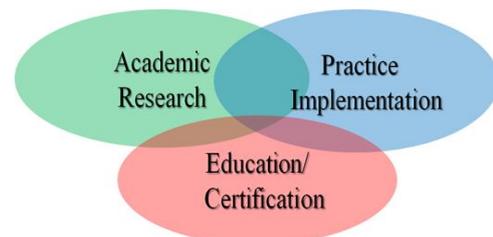
Research on and development of hospital information systems and health information systems

Information systems were first introduced in hospitals in Japan and abroad in the 1970s. Healthcare is considered exceedingly complex, and the introduction of information systems in healthcare proceeded primarily in front-line specialized care. The development of hospital information systems is a new approach in research and an extremely difficult approach that requires implementation in care settings. Exchanges between researchers and system implementers who are engaged in pioneering research on and development of those information systems have been at the heart of JAMI since its founding. Pioneering research and development originated with hospital information systems. A number of exceptional medical or health

information systems have been developed, and these systems help to improve the safety and quality of healthcare.   Moreover, JAMI has made great contributions to the security and privacy of health information, e.g. JAMI helped to devise the Ministry of Health, Labour and Welfare's Security Guidelines for Healthcare Information Systems; other countries have even recognized the caliber of these Guidelines.   Information systems have changed substantially with advances in information technology, changes in care settings, and changes in society's needs.   The topic of healthcare information systems lies at the crux of Medical Informatics, and this area is one in which JAMI should lead.

Standardizing medical information

The need to promptly standardize healthcare information was noted as hospital information systems and health information systems developed, and JAMI has worked to promote that standardization.   JAMI has a strong track record in terms devising various master indices, disseminating standards for the exchange of patient information, and formulating guidelines for the use of health information standards.   In cooperation with various organizations that formulate standards in Japan, JAMI helped to launch the Health Information and Communication Standards (HELICS) Board and directly helped to devise standards of the Ministry of Health, Labour and Welfare (the first of their type in Japan).

JAMI inaugurated a project in 2011 to develop two sets of standardized data items that allow reuse of data and facilitate consolidation of data from sources with differing purposes. One is the Minimum Data Item Set (MDIS) and the other is the Standard Data Item Set for Self-Management (SDISM) for Diabetes Mellitus. In 2012, Japanese Society of Hypertension, Japan Atherosclerosis Society, and Japanese Society of Nephrology joined the project, and MDIS and SDISM were developed for Hypertension, Dyslipidemia, and CKD. The MDISs and SDISMs were developed in coordination to ensure data consistency including data items name, granularity, and unit (expression of result). The MDISs and SDISMs were endorsed by the respective society's board and published on the web.

As part of an organizational effort spearheaded by JAMI's Group to devise and maintain informatics standards, JAMI is working to establish key standards for Japan and to devise and maintain information standards such as SS-MIX2.   JAMI will focus on shifting from health information systems with mere interoperability to those with semantic interoperability, being able to exchange information and also being able to exchange clinically significant findings.   JAMI focuses more on studying and implementing those systems.

Certification for Healthcare Information Technologists

Information technologists who "understand the nature of healthcare" and "who view their work as their calling" are essential to efforts by hospitals and companies to computerize healthcare information.   Thus, JAMI began certification for Healthcare Information Technologists in 2002, and the 1st exam took place in 2003.   As of November 2014, in all 13,934 individuals had been certified as Healthcare Information Technologists.   JAMI began the exam for Senior Healthcare Information Technologists in 2007.   As of June 2014, 309 individuals had been certified as Senior Healthcare Information Technologists.   This is a unique qualification that involves the healthcare profession as well as the profession of system engineer.   When seeking to use an electronic medical record system to improve the quality of care and improve population health (a concept indicating health-related outcomes for a population and the determinants of and interventions responsible for those outcomes), various constraints arise in terms of system development and care settings. Approaches that seek to unite personnel in different professions and occupations are essential.   Linked by a view of their work as a calling, Healthcare Information Technologists are expected to play a vital role in improving the systems for quality care.   JAMI will spur society to offer (Senior) Healthcare Information Technologists a commensurate social status and treatment so that they can consistently operate as professionals.

Issues for JAMI to address and JAMI's action plan

JAMI has a very broad range of research topics and issues in Medical Informatics that it should address. Among them, below are the issues that warrant concentrated effort by JAMI as an organization, particularly in terms of creating an infrastructure for healthcare society, and JAMI has elaborated upon these issues in its action plan.

1. The scope of Medical Informatics, expertise in Medical Informatics, and future informatics professionals

Topic 1 Biomedical Informatics and Medical Informatics

Internationally, analysis of genomic information and clinical use of the results of those analyses is increasing, and lifestyle and health data are increasingly being used in care to improve individual health and prevent disease. Accordingly, efforts are underway to broaden or expand the scope of Medical Informatics. The result is a field known as Biomedical Informatics. Biomedical Informatics is presumed to be a field primarily engaged in by research facilities, but healthcare related to genetics is already becoming a reality in Japan. This leads to the social issue of the handling of genomic information in a hospital information system. Biomedical data or information is added to healthcare information, basic research and clinical research are conducted, the results of that research are incorporated into clinical practice, and then healthcare is provided. In times like these, JAMI is working to identify and resolve issues with the discipline of biomedical informatics in terms of sociology, ethics, health information systems, and clinical databases.

Topic 2 Fostering researchers and fostering and certifying specialists

Professionals who can conduct academic research and who are equivalent to specialists in clinical and medical societies must be fostered so that Medical Informatics can make advances. In 2004, IMIA summarized its recommendations regarding a curriculum for education in medical and health informatics. In 2010, those recommendations were revised to broaden the scope to include biomedical informatics. In the US, the American Medical Informatics Association (AMIA) has been at the heart of efforts to develop Medical Informatics. AMIA created a system of specialists and certified over 400 specialists in Clinical Informatics in 2013. In South Korea, the Korean Society of Medical Informatics spearheaded the creation of a program for Certified Physicians in Biomedical Informatics (CPBMI) in 2012. Overseas, systems are presumably being established to certify specialists with the ability to utilize findings from Medical Informatics in clinical medicine. In order to foster future Medical Informatics professionals who are equivalent to specialists in medical societies, JAMI is working to define the core competencies of Medical Informatics Specialists and to create an educational curriculum for them.

Topic 3 Medical informatics for certain specialties

As the discipline of biomedical informatics has developed, specialties such as Clinical Informatics, Population Health Informatics, Nursing Informatics, and Dental Informatics have also developed overseas. JAMI is already actively engaged in Medical Informatics for certain specialties. Together, these fields should probably be labeled specialized Medical Informatics. JAMI is further encouraging researchers to participate in these fields and is spurring Medical Informatics to contribute to these specialties.

Topic 4 Chief Medical Information Officers

A Chief Information Officer (CIO) is the chief executive that is responsible for an organization's information and systems. In medicine, Chief Medical Information Officers, or CMIOs have been discussed in Japan and abroad. There are numerous accounts of such a position being established in organizations overseas. A curriculum for CMIOs has been devised as a pilot project of the Ministry of Economy, Trade and Industry in Japan, but certification for and the responsibilities of a CMIO have yet to be defined. Although certain

executives may serve in a role equivalent to a CMIO, determining the reality of that fact with statistics is difficult.　Electronic medical record systems and integrated community healthcare systems are expanding and the need for dealing with health, medical, and social welfare information is increasing.　Thus, the presence of a CMIO who is trained in operations, information strategies, and project management related to health and healthcare is essential.　JAMI will clarify the definition of a CMIO as an executive in charge of information and system integration and management and define the role and core competencies of a CMIO.　JAMI will also coordinate and cooperate with relevant organizations to encourage the designation of CMIOs.

2. Amassed healthcare information and clinical and epidemiological research

The primary goal of an electronic medical record system is to support care.　Moreover, interest in analyzing amassed and stored healthcare data to improve the quality of medical care and improve population health has heightened over the past decade.　Given its expertise in clinical medicine, epidemiology, electronic medical record systems, and clinical databases, JAMI has assumed responsibility for creating infrastructure on which to preserve interoperable, large-scale clinical databases for posterity.

Topic 5 Extractin registry and clinical data from electronic medical record systems

Clinical registries and databases have increased in number.　In current care settings, however, data are typically entered in registries by hand.　A hospital information system contains a number of data elements, but a feature needs to be added to select a given element, and developing a selection feature for a single purpose is not practical.　JAMI is examining ways to extract data from electronic medical record systems and ways to enter data in registries, and is working to implement those techniques.
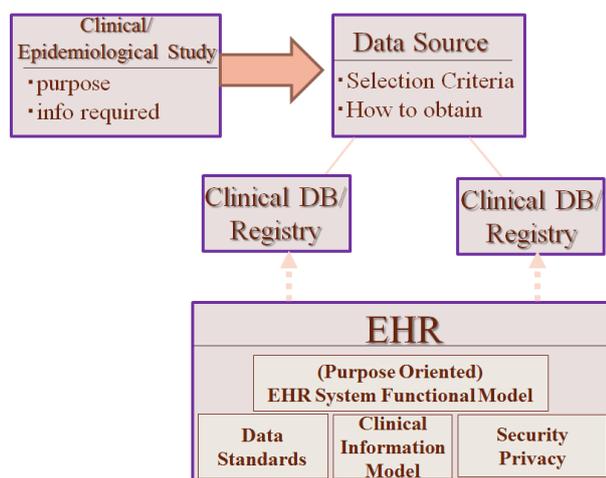
The concept of clinical data facilitating clinical research

Topic 6 Linking electronic health records and epidemiology

In the past, the basic design of a study using clinical records was a case-control study which has limitative capability in deriving reliable evidence.　However, in recent years, new methods and analytics became available that allow studies to derive reliable evidence from amassed healthcare data.　The creation of national clinical databases, the National Clinical Database (NCD), clinical databases and registries of societies specializing in clinical areas, and cancer registries is being promoted in Japan.　Data are collected from these sources for different purposes and those data consist of different elements, so these data differ in terms of whether they are suitable for use in research.　The Pharmaceuticals and Medical Devices Agency (PMDA) has adopted a pioneering approach to explore the potential for data from multiple sources to be used in research on drug safety and to examine the limitations of using those data.　Studies have yielded few results indicative of "clinical data appropriate for use in reaching accurate conclusions."　Approaches that link electronic health records (EHRs) to evidence-based medicine through the coordination of Medical Informatics and epidemiological and medical statistics are essential.

Topic 7 Secure data links

In Japan, health and healthcare databases and clinical databases are being created one after another. If analysis is not possible with a single database, analysis may be possible if multiple databases are linked. Advances in technology have increased the potential to link data and they have increased the usefulness of existing databases, but there is a risk, i.e. links may allow an individual to be identified even if data are anonymized. JAMI is working to formulate guides on when to allow links, the techniques to establish links, establishing secure links, and what methods should be used to establish those links, from technical, sociological, and ethical perspectives.

Topic 8 Managing the quality of data

Even if facilities introduce a master index, the way in which each facility operates that index can differ, and data interoperability between facilities is not necessarily ensured. If individual facilities merely compile data they have amassed from electronic medical record systems, integrating those data to derive evidence can prove difficult. Data need to be standardized, but data also need to be integrated and managed and the quality of those data also needs to be managed. JAMI has deftly worked to research and develop hospital information systems and electronic medical record systems and must take the lead in managing data quality with a focus on integrated and managed "data."

Topic 9 Computer-enabled quality indicators

Improving the quality of care is the common goal of medical societies and professional organizations. A number of clinical facilities have now publish "quality indicators," and these indicators are used by the national government and local governments to formulate care plans. However, individual facilities use different indicators. Even if facilities use the same indicator, how those data are collected and calculated differs depending on the facility. Thus, the comparability of those indicators is not necessarily ensured. Moreover, data must typically be collected and calculated by hand even if an electronic medical record system has been introduced. JAMI is an academic society that links clinical medicine and health information systems. As such, JAMI is working with specialized organizations to devise standard specifications to measure, calculate, report, and transmit data via systems. Those specifications will allow a standard framework and they will feature detailed definitions so that data are interpreted in a consistent manner. These efforts will help to determine and assess the quality of care.

3. Legal and social issues and a health information infrastructure

Topic 10 Corroboratable electronic medical records

As clinical records and other medical records are dealt with electronically, the "corroboratability" of medical records has become an issue. Legal use is a secondary use of electronic medical records. Medical records are also used as the grounds for providing care. Over the past few years, there has been a heightened need for "corroboratable electronic medical records systems" so that healthcare data can be used for clinical research purposes. Whether electronic medical records facilitate care and whether they are a legally sound method of providing data for research are issues, i.e. societal demands, JAMI needs to address.

Topic 11 Sustainability of healthcare and welfare under the social insurance system

One issue in social informatics is the sustainability of healthcare and welfare under the current social insurance system. Directly speaking, this issue falls under medical economics. However, social insurance is highly individualized in different countries, and developing a general theory seems hardly feasible. A

sufficiently large sample is needed or extensive data must be analyzed to yield evidence.   JAMI must support to identify a sustainable social insurance system that provides healthcare and welfare.

Topic 12 Personal health records

Personal Health Records (PHRs) have been discussed in Medical Informatics over the past few years.   In Japan, health records start with the Maternal and Child Health Handbook and other records are created by educational facilities at different stages of development.   However, an individual is rarely aware of those records and individuals seldom maintain those records.   A PHR views important health information, such as vaccinations and allergy information, longitudinally starting at birth.   In a typical example, this health information would be controlled by the individual from birth until death and it would be referred to by healthcare workers and medical personnel.   In Japan, Electronic Medication Notebooks and Disease Management Notebooks are being developed and the concept of PHRs is spreading.   Sets of data items for different diseases were defined through the cooperation of the societies involved in clinical care.   These sets of data elements must be used in PHRs.   JAMI is concentrating on identifying and resolving social issues related to PHRs and encouraging the use of PHRs.

Topic 13 Facilitate at-home care, nursing care, and social welfare services

Japan is at the forefront of having an extremely aged population with a declining birthrate.   Domestic issues that must be addressed are issues in healthcare, medicine, and social welfare, such as at-home care, nursing care, and social welfare services.   Japan must overcome these issues in order to help other countries around the world with similar population problems.   Over the past few years, a major development has taken place with the shift from "medical information" to "healthcare, health, and social welfare information."   A framework must be presented to the healthcare community, and issues with a legal and social context must be identified.   A social system in which medical personnel, care providers, the patient, family members, and administrators participate must be created as an infrastructure for healthcare, health, and social welfare information.

Topic 14 The goals of EHRs

The term Electronic Health Records (EHRs) has spread around the world in recent years.   The discussion about EHRs is whether required healthcare information can be presented to an authorized party in a timely manner when needed (is the information available to that party).   As a given, EHRs should directly facilitate care.   Whether EHRs facilitate "improvement in the quality of care" or improvement in "population health" is a topic that has been extensively


Goal-oriented EHR functional model

discussed in terms of academic research, standardization, and actual practices.   Functional requirements for EHRs to facilitate improvement in the quality of care, improvement in population health, and sustained care should be defined.   JAMI should highly encourage the further standardization of EHRs.

４. Health information ethics

Topic 15 Ethical norms of the JAMI

In the book the Ethics of Electronic Patient Records, Eike-Henner W. Kluge explained how, in a sense, electronic medical records raise ethical issues akin to those involving actual people.   The clash between "the right to privacy" (the right to control one's personal information) with regard to one's healthcare information and "the use of [that information] in research" has been discussed for more than 10 years.   A determination regarding the use of that information has been made in ethical guidelines on epidemiological research (as one example).   However, ethics regarding healthcare information must constantly deal with new issues, e.g. discussions about "the sharing of healthcare information in a regional healthcare information system and the patient's right to control his or her personal information" and "integrating genomic information and healthcare information in a large-scale genomic cohort study."   Laws and regulations and practical rules on minimum requirements are needed, but not every ethical issue can be dealt with by laws and regulations and practical rules.   Genomic information is already part of hospital information systems and large-scale databases containing genomic information have been created.   Amidst these circumstances, JAMI's duty is to indicate applicable ethical norms.
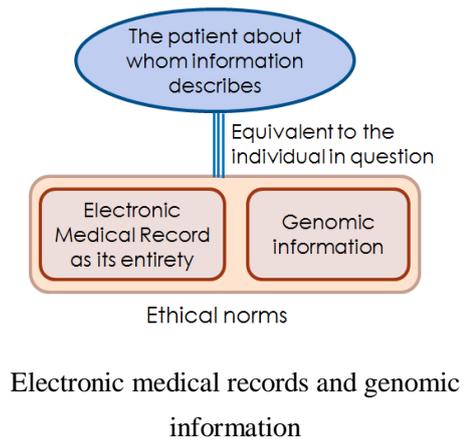
Electronic medical records and genomic information