Milestones of the IMIA-NI History and Future Directions

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Abstract. IMIA-NI's past achievements are reflected upon in the context of its current strategic directions. Two key historical milestones are described in some detail, the ISO Reference terminology model for nursing and the International Nursing Minimum Data Set development project, as this work is continuing to influence future directions in health and nursing informatics. Current features of our health care environment are explored noting the current desire of most nations to implement electronic health records (EHRs) and its relationship with IMIA-NI's strategic directions. Nurses can play their part by working collaboratively, converting their knowledge into computer processable formats, establishing the necessary professional knowledge governance infrastructure and lobbying key decision makers to establish national infrastructures that will enable the adoption and optimum use of EHRs.

Keywords: History, Health Records, Knowledge, Standards, Terminology

1. Introduction

IMIA-NI's achievements to date demonstrate how via its global encouragement, the world's knowledge leaders have been able to come together to effectively and efficiently create, assemble, integrate, synthesize and assimilate intellectual knowledge required to advance nursing/health informatics in its role of improving health and healthcare. IMIA-NI has been recognised as the nursing informatics association that effectively and efficiently connects people and the nations of the world to be able to accomplish activities that realise its vision. IMIA-NI is about the provision of global leadership in the development, implementation, and evaluation of Nursing Informatics. IMIA-NI embraces and challenges the multidisciplinary health focused community and policy makers in order to enable the transformation of healthcare in accord with the world-wide vision of improvement to the health of the world population[1].

This paper summarises IMIA-NI's activities undertaken since its establishment and expands on two key historical milestones achieved by IMIA-NI as this work is continuing to influence future directions. Features of our current health care environment and e-health strategies are identified within the context of how these key IMIA-NI continuing activities and nurses generally may play a part in ensuring that such national strategies enable nations to have sustainable health systems. IMIA NI's strategic future challenges directly relating to this future vision include:

- Developing and/or adopting electronic health records that both use and inform nursing knowledge and that are integral to the professional practice of all nurses.
- Developing clinical data standards to enable the development and communication of nursing knowledge and allow the comparison of what nurses do and the results.
- Achieving access to reliable decision support and evidence based care options for clinical care in whatever location the patient receives care, treatment or advice.
- Promote linkages and collaborative activities with national and international nursing and healthcare informatics groups and nursing and health care organisations globally.

IMIA-NI promotes the adoption of a patient centred approach to nursing informatics that will support high quality and safe care in an ethical and innovative manner based on evidence.

2. An Historical Overview of IMIA-NI

An international focus for Nursing Informatics activities began in London in 1982 under the leadership of Maureen Scholes, then the Director of Nursing Service at the London Hospital in Whitechapel with an international open forum on 'the impact of computers on nursing'. This was the result of an unexpected large nursing section during the 1980 Medinfo conference held in Tokyo. The 1982 London event resulted in a report requesting the establishment of a Nursing Informatics working group within IMIA that was sent to the IMIA Board who were meeting in Melbourne later that month. This request was granted, its first meeting was held the following year in Amsterdam. At that time IMIA was a special interest group of the International Federation for Information Processing (IFIP), IMIA became an independent organisation in 1989[2].

The NI working group became an IMIA special interest group with new bylaws in 1995. Links were established with the International Council of Nurses (ICN), the European Federation of Medical Informatics (EFMI), other USA based nursing groups with an interest in Nursing Informatics and several IMIA working groups such as those focusing on hospital information systems and data protection and privacy. In addition the foundation members made contact with their own country's national professional body and their nation's IMIA representative.

IMIA-NI endorsed international conferences held once every three years as well as special topic working conferences from which publications continue to be produced. The latter were usually held as post conference events although one working conference on education held in Stockholm in 1987 was a separate event. In addition individual IMIA NI members made significant local contributions to the NI discipline, undertook research and shared their experiences at the IMIA-NI conferences.

Until 1997 the IMIA-NI members were country representatives, then the bylaws were changed to enable the formation of focused working groups where the members are not restricted to only IMIA member countries. This enabled participation by a greater number of nurses and the promotion of nursing informatics relative to topics such as education, research, evidence based practice, management, standards & concept representation. The latter group has been most active. It established a steering group in 1999 to develop a reference terminology model for nursing in conjunction with the ICN requiring the identification of existing nursing terminologies, developers and contacts aiming to bring these together within a recommended framework. In 2000 a working project focusing on international nursing minimum data sets (iNMDS), co-sponsored by the ICN, was formally launched.

During the last 10 or so years future strategic and action plans have been developed and implemented by the various working groups as the means of serving the specific needs of nurses in the field on nursing informatics and to act as an international focus for NI activities by fostering collaboration amongst nurses and others.

3. Key Historical Milestones

3.1 Reference terminology model for nursing

Early 1999 I became aware of a number of new work items for the standards development organisation ISO TC215 that had implications for nursing. I advised IMIA-NI and the nursing and health policy consultant of the ICN suggesting that we work collaboratively and propose a new work item for a nursing terminology standard, I received a positive response. That same year Dr Judy Ozbolt [3] had hosted a Nursing Vocabulary Summit Group attended by 36 authors of nursing vocabularies, experts on language and standards, representatives of United States government agencies, professional associations and the health informatics industry. This group reached consensus on the need for a reference terminology model for nursing and other clinical disciplines and agreed collaborate in its creation. Via the IMIA-NI network other experts on nursing vocabularies such as those involved in the European based CEN standards work and the Association for Common Nursing Diagnoses, Interventions and Outcomes (ACENDIO) were also recruited to collaborate.

A new ISO TC215 work item titled 'Development of a Reference Terminology Model for Nursing' was drafted and submitted through the US TAG (Technical Advisory Committee), a national member body. Both the ICN and IMIA are external liaison organisations to ISO TC215 and not permitted to submit new work items. Following much debate at the ISO TC215 WG3 1999 Tokyo meeting it was accepted but with a title change to 'Integration of a Reference Terminology Model for Nursing'. It was subsequently accepted as a new work item for the WG3 programme of work by a majority (14) of national members and the real work began. A small steering committee representing the strategic partnership between IMIA-NI and the ICN, provided the necessary project oversight and Dr Suzanne Bakken accepted the position of Task Group Chair. Following numerous meetings, lots of communication and hard work the document produced became a Full Draft International Standard in 2003[4].

This achievement was viewed as 'an essential first step in creating comparable nursing data across settings and countries'[5]. Its purpose is to accommodate the various nursing terminologies and classifications in use incl. the International Classification of Nursing Practice ICNP). It facilitates the representation of nursing concepts and the mapping of nursing terms with other healthcare terminology for developers, coders, modellers and engineers to integrate into healthcare information systems. This standard is now being reviewed and updated in a manner that makes the diagnosis and intervention models more generic so that these may also be used as reference models for other health disciplines.

3.2 iNMDS

At NI2000 in Auckland, New Zealand another initiative co-sponsored by the ICN was launched. The International Nursing Minimum Data Set (iNMDS) project was Chaired by Connie Delaney and undertaken by key nursing leaders in numerous countries with established, emerging and future intent to establish a national nursing minimum data set. Its aim is to enable nursing care around the world to be described in a comparable manner. The iNMDS is to consist of 'a minimum data set of items of information with uniform definitions and categories concerning the specific dimension of nursing that meets the information needs of multiple data users in the health care system'[6].

Dr William Goossen coordinated an international pilot research project in 2001 to test the feasibility and usability of an iNMDS by collecting and analysing a limited set of variables with associated conceptual and operational definitions. The results of this pilot were presented and discussed at the Medinfo2004 conference[7] where a prospective international study was planned. An iNMDS Beta version was published in 2006[8]. This work was linked not only with the ICN's work but also with that of the World Health Organisation (WHO) Nursing and Midwifery. In 2007 the Centre for Nursing Minimum Data Set Knowledge Discovery was established at the University of Minnesota[9], this is an ICN accredited research and development centre. The iNMDS framework consists of three categories of data elements, setting, patient demographics and nursing care. The ICNP concepts can be used to represent the nursing care data elements. The latest developments about this work item were presented at the preconference ACENDIO meeting.

4. Features of our health care environment

The adoption of health informatics or e-health is simply a requirement of doing business in 21st century healthcare[10]. The Health problem space is complex. For example, sharing electronic health records is a more complex task than sharing financial information or travel bookings. Close to 40 years ago Martin and Norman[11] predicted that in medicine the computer promised revolutionary changes. Today the same may be said about communications and knowledge management technologies. In 2005 the World Health Organisation's (WHO) world assembly adopted a resolution on e-health[12] recognising that eHealth is about the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research. All member states were urged to develop and implement an e-health strategy. The European Commission reported that "without significant reforms, including the better use of eHealth, health expenditure is expected to increase from 9% of GDP at present to around 16% by 2020 in response to an 'ageing' Europe" [13]. According to the World Business Council for Sustainable Development (WBCSD) 'nearly everyone agrees that the way we manage health today is unsustainable - it costs more than we can afford, and delivers less than we expect'[14].

Any health system has many and varied stakeholders who need to work collaboratively. Health systems are complex highly connected social constructs that control: funding, access to services, workforce supply and demand, availability and cost of drugs, supplies, equipment, physical facilities and technologies, research opportunities and adoption of research results. This shapes consumer expectations and ultimately clinical outcomes. All these processes and outputs are constrained by a nation's political, legal, workplace, cultural, financial and business systems [15]. A national e-health framework needs to focus on the best possible use of information and communication technologies to support the business of health care in accordance with national health policy directions.

There is a strong need for all health care providers to analyse, create, share and use the most up-to-date and available knowledge to support the delivery of health care services to improve outcomes of care. Knowledge is information in context so that it may be applied to guide actions. The knowledge used as a basis for clinical, management and

policy decision making to support health care, varies in terms of quality, accuracy and soundness. It is often clouded by values, opinions and other people's views, and consists of or comes from a number of possible sources. Ultimately we need to be able to present this knowledge in a computer processable format to enable the best possible use of this knowledge.

5. Ensuring that national e-health strategies create sustainable health systems

Technology may be defined as any new way of doing something. New technologies impact the way health care providers can or should be providing health services. Many of the crucial data feeds needed to monitor health system behaviour come from patient records, wherever they are held, or in whatever structure or format, hence the focus on patient-centred health care and record management. Making the best possible use of available technologies to safely deliver quality health services requires every nation to establish some electronic means for storing these patient data. The electronic health record thus becomes the foundation for our sustainability infrastructure.

All health information needs are best met via the establishment of a framework that enables health professionals and health information systems to communicate with each other in a timely and reliable manner. Such a framework consists primarily of the adoption of any number of agreed health informatics standards but also on agreed policies and methods of operation. Many now argue that optimum efficiencies can only be achieved with the widespread adoption of *semantically* interoperable information systems i.e. systems capable of transferring, sharing, exchanging and meaningfully using information and knowledge, in a machine processable format, for decision support, regulatory reporting, population surveillance, clinical practice evaluation, outcome analysis and more[16]. The implementation of national e-health strategies is well advanced in a number of nations but this remains a work in progress for everyone.

5.1 Electronic health records (EHRs)

Now that we have entered the electronic era we expect our health records to be maintained in an electronic form. Achieving this in a manner that truly is worth the investment and that provides a real benefit to us requires a paradigm shift in thinking. The "Integrated Care Electronic Health Record" (EHR) is defined by the International Organization for Standardization[17] as:

"...a repository of information regarding the health of a subject of care in computer processable form, stored and transmitted securely, and accessible by multiple authorised users. It has a commonly agreed logical information model which is independent of EHR systems. Its primary purpose is the support of continuing, efficient and quality integrated health care and it contains information which is retrospective, concurrent and prospective."

Optimising the use of information and communication technologies to support the management of health and the delivery of health care services requires the engagement of visionaries, computing experts, innovators, risk takers, movers and shakers and a change of thinking by managers, purchasing decision makers, legislators, policy developers and implementers. Health and nursing information and knowledge needs to be patient centred, recorded and managed in a manner that enables ease of

documentation (data/information collection), storage, access, retrieval, timely and multi-purpose use.

Knowledge transfer (semantic interoperability) is currently outside the scope of mainstream interoperability solutions but is an area of active research in health informatics [18]. We do know that this is a necessary pre-cursor to EHRs and that the key requirements to achieve semantic interoperability are: 1) a suitable reference model and data types, 2) clinical knowledge models (archetypes), 3) terminology and 4) unique identifiers. There are strong relationships between the first three characteristics[19]. There needs to be a standard EHR information (object) reference model as this forms the basis against which instances of clinical data in the real world can be modelled. Table 1 details the fundamental standards clinical systems need to comply with to ensure optimum usage of EHRs.

Table 1 Fundamental standards enabling the realisation of benefits via the use of ehealth records[20]

Standard Required	Explanation
e-Health record structure/architecture/information or object model	A structured record facilitates ease and accuracy of data extraction including data types suitable for holding clinical content
Set of clinical content models	To ensure that all clinical data stored within these records are structured and constrained in a standard manner.
Terminology	Standard terminology binding to all concepts within the model enables data/information comparison and aggregation without loss of meaning.
Unique patient identifier	To ensure that data from one provider record can be added to another provider's or patient held record that belongs to the same patient.

Beale[21] described four frameworks within a suggested standards typology where each framework essentially refers to the degree of interoperability that can be achieved following the set of standards within each framework. What needs to be understood is that there are qualitative differences between each standards framework adopted in terms of health budget impact, where each framework (set of standards adopted) brings significantly different advantages and cost characteristics. Achieving a high degree of semantic interoperability for clinical information exchange is the most challenging but necessary outcome of any e-health implementation strategy as this enables the successful adoption of birth to death electronic health records (EHRs). These in turn are essential building blocks to enable health professionals and consumers to make the best possible use of available information, knowledge and communication technologies at the point of care. A further flow on effect is attaining a sustainable health system.

Unfortunately we continue to purchase proprietary systems where each system has its own reference model and scope. As a consequence the much needed high level semantic interoperability cannot be achieved. Consequently we are failing to meet the information needs of clinicians[22]. Basic differences in the reference model and associated techniques, drive subsequent differences in clinical model design, modelling and implementation. Convergence is difficult if not impossible to achieve. Without major changes obsolete technologies will prevail. Such change requires active health policy initiatives as well as policy/regulatory incentives to interoperability[19].

5.2 Clinical nursing content models and terminology

Given IMIA-NI's key milestones to date, it makes sense that it continues this work and applies it to the development of standard sets of nursing clinical content models bound to nursing terminology that fit with a standard reference model and associated data types. All nursing clinical content models, also known as archetypes, are formal specifications of the clinical data structures used within EHRs and must reflect the most up to date evidence based nursing knowledge and need to be governed by the nursing profession. One way of capturing, presenting and storing such knowledge is via the openEHR Foundation's Clinical Knowledge Manager (CKM) web portal [23]. The openEHR CKM provides a tool to enable distributed communities to draft archetypes for new areas of clinical content and to peer review draft versions prior to final publication and use. This underlying model for archetypes has recently been standardized internationally by ISO [24].

6. Conclusion

The health industry's core business relies heavily on clinical data collected from patients and multiple health care providers, stored in a variety of systems and locations. Such information then needs to be electronically transferrable to be stored in consolidated individual electronic health or medical records. It isn't just about moving transactions electronically!

Generally speaking, Governments have no difficulty in describing their vision for a future sustainable health system. Increasingly there is a realisation that the only way to achieve this is via the adoption of EHRs. What is missing is a sound understanding and appreciation of a specific national infrastructure needed to support and enable such health reform, or how to realise the best possible use of available information, communication and knowledge management technologies. At the end of the day the adoption of semantically interoperable health information systems is dependent upon political decisions regarding standards adoption and e-health implementation strategies. This is where nurses can play their part by working collaboratively, converting their knowledge into computer processable formats, establishing the necessary professional knowledge governance infrastructure and lobbying key decision makers to establish national infrastructures that will enable the adoption and optimum use of EHRs. IMIA-NI has the necessary leaders, links and knowledge to guide this future direction.

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