Of data, ehealth, interoperability and standards, of cabbages and kings | OJNI

http://ojni.org/issues?p=1676

July 1, 2012

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CITATION


COLUMN

“The time has come, “ the Walrus said, “To talk of many things: Of shoes–and ships–and sealing-wax– Of cabbages–and kings…” (Carroll, 1872)

In this series of columns, I think that those who have stuck with things from the start will agree that I have talked of many things. However, I have tried, and hopefully have generally succeeded, in linking them all together with at least a degree of coherence. The overall narrative throughout this series of columns has been one of exploring how I believe we can, and should, share our experiences of nursing, informatics and healthcare – wherever we live in the world. Linked to that has been discussion of how existing and new technologies might support and improve that exchange of information and experience, but in ways such that lessons can be adapted to local needs, rather than be imposed unchanged in some kind of imperialist manner.

To continue the nautical theme of this series, I want to steer a slightly different tack and look at the issues of sharing experiences and information from a different angle – but one that interrelates with the earlier columns. The areas I will touch on have emerged out of several events I have attended recently. They demonstrate either a degree of serendipity, or suggest that there are certain themes that are beginning to emerge strongly and be discussed with the degree they deserve, in the wider health and nursing informatics communities, rather than the niche specialist sub-domains of the standards world. I am not necessarily going to provide any answers on the issues, but ask that you think about the issues and how they relate to the work that you are involved with. So, to use a quote that I have included in several conference presentations in recent years, from the Spanish philosopher Miguel de Unamuno: “My aim is to agitate and disturb people. I’m not selling bread, I’m selling yeast” (Wikipedia, 2012). In fact, the regular readers should have realised by now that this has been a common theme through all of the columns; I am not claiming to have all the answers, or even many answers, but am asking you to explore around the ideas and questions that I am raising, and reach your own answers on the relevance to your particular needs and situations of the possible approaches and ideas introduced.

Sharing experiences of nursing and healthcare practice are important. However, equally important, and increasingly under discussion, are many other aspects of sharing, in particular of sharing patient information, often in the form of of electronic health records, or as components of personal health records, and the sharing for other purposes of aggregated and anonymised data extracted from such records. With the increasing development of ehealth and telehealth, and of mobile health (mhealth) applications, there is an increasing tendency and need for patient information to be shared across
borders, and between countries that may have different legal systems and approaches to a wide range of issues associated with such sharing. It is important that nurses are aware of, and involved in, the direction of such developments. Nurses have definitely been under-represented at many of the events that have discussed these issues.

At the time of writing this column I am in Brussels, Belgium – arguably the beer and chocolate capital of the world, depending on your particular tastes, because of the diversity, quality and quantity of what is produced. I am attending a conference that I have been involved for the past nine months in organising, and that the International Medical Informatics Association (IMIA) is hosting, together with a number of supporting and sponsoring organisations. The event, the “2012 European Summit on Trustworthy Reuse of Health Data” (http://euhealthdata2012.imia.info), is exploring a range of issues around how the vast and increasing amount of health data, in particular that within care records, that is collected about individuals either in particular episodes or over a lifetime can be reused for research, health service development, and other legitimate purposes – and what some of those legitimate purposes might be. Within a European Union of (currently) 27 individual Member States, and a wider European continent that has over 50 countries, depending on exactly where the boundaries are drawn, there are many issues that will affect sharing of information – the differing legal systems in different countries, the differing attitudes of health professionals, patients, researchers and healthcare administrators. While there are moves, at the European Union (EU) level, to develop regulations that might be adopted across the EU, much work remains to be done. While the outputs and recommendations from the Brussels Summit have yet to be written up, and so I cannot say too much about what the final recommendations might be, it is apparent from several of the presentations (available via http://euhealthdata2012.imia.info ) that issues of trust are important in any future directions. The need for all involved to be able to trust the quality of data, the purposes for which it is used, and the people who are using it, is a set of themes that arose many times during the two days of discussions. Antoine Geissbuhler, IMIA President, in his opening remarks noted the importance of using and sharing healthcare information and knowledge, in terms of sustaining health systems, promoting equitable access, and needing to increase the common good while respecting individual rights and values.

Antoine also noted that the issues discussed are global, but that the diversity within Europe makes it a good place to share and explore the issues. The Brussels Summit was based in format and purpose on a series of events hosted by AMIA in the USA several years ago. They resulted in discussion papers and recommendations on secondary use of health data (eg Safran et al, 2007). The Brussels Summit meeting and several other developments, such as the focus of this year’s conference of the Health Informatics Society of Australia (HISA) being on the theme of “Building a Healthcare Future Through Trusted Information” (http://www.hisa.org.au/page/hic2012 ) all contribute to reinforcement of the need for the issues to be addressed in many parts of the world.

Underlying the ability to exchange health data and information, even between healthcare providers in one country, let alone between countries, is the need for data standards and interoperability of systems. This is the focus of the second part of this column. A recent publication from the World Health Organization (WHO) and a recent event hosted by WHO and the International Telecommunications Union (ITU) together show the increasing importance of standards and interoperability, particularly in relation to ehealth, but implicitly in all healthcare delivery. The May 2012 issue of the Bulletin of the World Health Organization (WHO, 2012) provides a number of articles addressing diverse examples of the use and impact of ehealth and mhealth. These discussions are within the overall framework of providing “an authoritative, critical and independent overview of current knowledge about appropriate, trans-disciplinary methods and applications in e-health”, designed, in part, to “strengthen the commitment of high-level decision-makers to address e-health interoperability issues and seek to widened the application of e-health.” (Al-Shorbaji & Geissbuhler, 2012) The sharing of experiences derived from several of the developments discussed in this publication will, hopefully, go some way towards preventing continual reinvention of the wheel in the development and use of ehealth systems.
The Joint ITU-WHO Workshop on e-Health Standards and Interoperability, held in Geneva, Switzerland in April 2012 (http://www.itu.int/en/ITU-T/Workshops-and-Seminars/e-Health/201204/Pages/default.aspx) is the final item that I want to reference in this column; although many colleagues will recognise that there have been many other activities and events, and publications, devoted to the issues in recent years. However, the increasing recognition of governments, and international bodies, of the need for common approaches, represents perhaps a sea-change in thinking, and may lead to more rapid development of the adoption of the necessary standards and interoperability work. A report produced for discussion at the workshop (ITU, 2012) proposed five pre-requisites for transforming healthcare and improving access to healthcare globally, through efficiencies in information sharing and health information delivery contributing to lower healthcare costs. These five pre-requisites are greater interoperability through adherence to the same standards for electronic health records; increasing coordination of e-health standardization activity; ensuring a high degree of privacy protections, quality assurance, and security in the use of healthcare information; reducing equity gaps by addressing the many factors preventing developing countries from reaching advanced capability in standardization; and making better use of existing technologies and infrastructures that are already standardized. The report also suggests that social media and web 2.0 tools can be adapted to support access to health information, promote health initiatives, provide peer support networks, and create new communication alternatives, especially for those in lower and middle income countries (LMIC) seeking medical or healthcare advice (ITU, 2012).

Sharing information and experience are important; ensuring that the proper interoperable systems support such exchanges is also important. The imminent NI2012 nursing informatics congress in Montreal, Canada (June 23-27) will provide opportunities for many nursing and informatics colleagues to continue, and further develop, such exchanges and explore this range of issues. I look forward to the discussions there, and hope that many readers of OJNI will be actively involved in them, and in work to ensure that the nursing voice is heard as interoperable systems for ehealth, and healthcare supported by all forms of information and communications technologies, are developed.

References


