# Empowering Patients: Making Health Information and Systems Safer for Patients and the Public Contribution of the IMIA Health Informatics for Patient Safety Working Group

#### E. M. Borycki<sup>1</sup>, M. S. Househ<sup>2</sup>, A. W. Kushniruk<sup>1</sup>, C. Nohr<sup>3</sup>, H. Takeda<sup>4</sup>

<sup>1</sup> IMIA Patient Safety Working Group Co-Chair, University of Victoria, Victoria, British Columbia, Canada

<sup>2</sup> King Saud Bin Abdulaziz University for Health Science, College of Public Health and Health Informatics, Riyadh, Saudi Arabia

- <sup>3</sup> Aalborg University, Department of Development and Planning, Virtual Centre for Health Informatics, Aalborg, Denmark
- <sup>4</sup> IMIA Patient Safety Working Group Co-Chair, Jikei Institute, Osaka, Japan

#### Summary

**Objectives:** The objectives of this paper are to explore issues and perspectives from four regions of the world where health information systems are contributing to patient empowerment and influencing patient safety.

Methods: Members of the IMIA Working Group for Health Information Systems Safety came together to explore global issues at the intersection of health information systems safety, patient empowerment and patient safety. The group carried out a review and synthesis of the empirical and grey literature in four different regions/countries of the world that have differing health information system safety priorities.

**Results:** Regions/countries from differing parts of the world are developing: (1) high quality, safe information for individuals to use in their health related decision making, (2) patient portals and testing them for their safety, (3) methods for identifying unsafe health information system features and functions, and (4) ways of engaging citizens in identifying unsafe features and functions of health information systems.

**Conclusions:** Internationally, there has been a rise in the number of health information systems and technologies that are being developed to support patient care. The amount of health information available on the World Wide Web (WWW), and the use of mobile phone software to support consumer health behaviours and selfmanagement of chronic illnesses has also grown. The use of some of these health information systems and technologies has helped citizens to improve their health status (e.g. patient portals, mobile phones). However, the safety of these systems and technologies has come into question. As a result, there is a need to refine these systems and ensure their safety when they are used by patients and their families.

#### Keywords

Patient safety, health information systems safety, technology induced errors, international perspectives

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## Introduction

Globally, over the past several years we have seen the number of health information systems designed to support patient care rise exponentially. In conjunction with this phenomena, we have seen an extensive proliferation of health information over the world wide web (WWW) [1], the development of mobile software applications to support consumer health behaviours [2] and the development of systems that support consumer self-management of chronic diseases such a chronic obstructive pulmonary disease, diabetes, asthma, hypertension and depression [2, 3]. In addition to this phenomenon, we have seen the development of health information systems (e.g. electronic patient records and personal health records) accessible over the WWW [4] and webbased portals that allow both healthcare consumers and healthcare professionals to access and participate in the management of their own healthcare over the WWW (e.g. Sundhend.dk) [5].

With the proliferation of health information technologies and subsequent research and evaluation of these technological advances, we have seen considerable benefits accrued to the health of consumers and to national healthcare systems. Some of the more significant improvements to patient care and consumer health have arisen from improvements in patient safety as a result of the use of health information systems (e.g. physician order entry, decision support systems, PHR systems), information resources (e.g. web-based, disease specific guidelines) [2-5] and consumer/patient portals [5].

In recent years (i.e. since 2005) we have seen a significant shift in our perceptions surrounding health information systems and technologies and the information they provide. Questions have arisen about the safety of the systems used by health professionals (i.e. features and functions of these systems) and the quality of their content (e.g. quality of the information content) [1]. Researchers such as van der Sijs [6], Aarts [6], Ash [7], Koppel [8] and Kushniruk [9] documented the ability of health information systems to introduce new types of errors (i.e. technology-induced errors). Technology-induced errors refer to those errors that "arise from: (a) the design and development of technology, (b) the implementation and customization of a technology, and (c) the interactions between the operation of a technology and the new work processes that arise from a technology's use" [10, p.154]. In this research some health information system features, functions and emergent workflows were found to be able to lead to technology-induced errors [7-9]. Since these errors have emerged, re-

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searchers have identified a number of methods that can be used to identify these types of errors before, during and after health information systems implementation [11]. These methods include: use of patient safety heuristics [12], clinical simulations [13], usability testing [9], computer based simulations [14], ethnography [15] and the use of case study approaches (to understand an error after an error has occurred) [16]. Most of this work has focused on research examining health professionals' use of information technology. However, issues surrounding safe patient and citizen use of health information resources, systems and technologies are also emerging and coming to the fore.

### **Objectives**

There is international recognition that health information systems and technologies and their safety exists on a continuum, anchored on one end with systems that have a high degree of safety associated with their design (including features, functions, and workflows emerging from their use) and on the other end of this continuum unsafe health information systems and health information technologies (see Figure 1).

In between these two points on this continuum of health information systems and technologies there are both safe and unsafe features, functions and work-flows that emerge during health information systems use in differing healthcare contexts. There is a need for coordination and knowledge exchange at an international level to identify those aspects of health information systems that lead to greater safety and those that detract from patient safety.

This is particularly important when considering patient and citizen access to health data and systems. Such knowledge is key to making health information systems safe and eliminating those aspects of these technologies that make

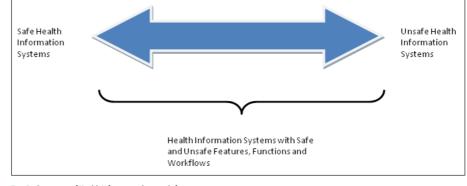
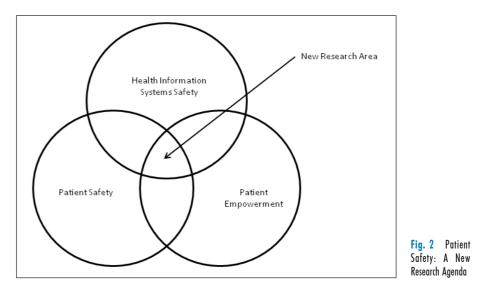


Fig. 1 Continuum of Health Information Systems Safety



them unsafe over time (much as has been done in the aviation industry). The objective of this paper is to explore and examine issues and perspectives from four regions from around the world where health information systems are contributing to patient empowerment and influencing patient safety. In this paper we also present a research agenda at the intersection of patient empowerment, health information systems safety and patient safety (see Figure 2).

### Methods

Members from several international regions from around the world who are part of the International Medical Informatics Association Working Group for Health Information Systems Safety came together to explore and examine global issues at the intersection of health information systems safety, patient empowerment and patient safety as well as to identify a research agenda that needs to be undertaken at a global level to advance work in this area. The International Medical Informatics Association Health Information Systems Safety Working Group was formed in response to an increasing recognition that health information systems can improve patient safety. The group carried out a review and synthesis of the empirical and grey literature (including published reports and government documents) in four different regions at the intersection of these three areas and identified that countries around the world have differing health informa-

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tion system safety priorities that involve promoting patient safety. Many of these issues are ongoing such as those involving the development of high quality safe information for individuals to use in their health related decision making, developing patient portals that are safe to use and also giving patients an opportunity to identify unsafe features and functions of these portals.

### Results

In our review and synthesis of these literatures we identified several important areas of research internationally. The results will be considered in terms of several areas of the world: Denmark, Middle East, North America and Japan.

## Initiatives in the Arabic World Focusing on Patient Safety and the Quality of Health Information on the World Wide Web

With the growing number of Internet subscribers in the Arab world and the lack of trustworthy Arabic health information content online, patient safety initiatives are needed to help the Arab health consumer navigate the complex environment of the WWW. For years, healthcare organizations in the Arab world have been successful in implementing patient safety initiatives to improve the quality of care within hospitals [23]. Many of these initiatives have occurred within the context of the healthcare organization and have neglected the Arab health consumer [23-25]. Today, with the increase in Internet usage in the Arab world, the Arab consumer is searching for health information online relating to illness, medical treatment, and drug therapy. Much of the work thus far has focused on developing online Arab health content [26]

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with a lag in the development of PHRs and with even less discussion around the issue of patient safety.

For years, the development of trustworthy health information online within the Arab world has been neglected. Much of the Arabic health information content has focused on providing information about a healthcare organization's goals, services, and policies [4]. A study conducted by Al-Tuwaijri, found that out of the 122 Arab health websites evaluated for providing high quality health information only five met the criteria of providing trustworthy health information to the Arab consumer [4]. As a result of this research, healthcare organizations within Saudi Arabia began to invest in the development of Internet based health information content. The largest of these initiatives, which is currently under development, is the King Abdullah Bin Abdulaziz Arabic Health Encyclopedia (KAAHE) on the Web. The initiative is being lead by the Saudi National Guard Health Affairs with the goal of providing credible and reliable health information to the Arab world [4], which is different than more local initiatives that have focused on a certain population or disease groups. KAAHE has made it a goal to reach the entire Arab speaking world that consists of 22 countries and with a population of nearly 300 million people. With regards to patient safety, the KAAHE project is expected to be a credible source of health information that is sensitive to Arab and Muslim culture within the region. By providing a credible and trusted source of health information, KAAHE is expected to improve health literacy and indirectly improve patient safety.

With regards to the development of PHRs, the efforts on this front continue to lag with less than 12% of healthcare organizations in the Arab world providing their patients access to their PHR online [4]. There are several reasons for the delay in PHR implementation. Currently, within the Arab world, many countries do not have the basic infra-

structure or funds for the implementation of the electronic medical record (EMR), which is a precursor to the development of the PHR. Those with the infrastructure and financial resources for EMR implementation are introducing it to improve healthcare delivery, quality of care and patient safety. The link between EMR use and its potential to harm patients has yet to take shape. Furthermore, a high level of Internet penetration is needed in order for patients to use the PHR. Regrettably, Internet usage rates are very low in the Arab world with highest level of Internet penetration in the United Arab Emirates, at approximately 70%, and with the lowest Internet penetration in Iraq at 4% [26]. Also, with the development of the PHR, various privacy and confidentiality laws are needed to ensure the safe transfer and use of health information by the patient. Currently, in the Arab world there are no comprehensive health privacy laws to protect the Arab health consumer, which represents another challenge to the implementation of the PHR and especially around issues of patient safety.

Overall, the potential negative impacts of untrustworthy health information on patient safety are beginning to emerge within the Arab world especially after the recent Institute of Medicine report on health IT and patient safety. The Arab world is currently focused on developing credible health information through projects such as KAAHE, which indirectly will promote health literacy and improve patient safety. As for PHR implementation, it will take time for the implementation of the PHR in order to begin to assess its impacts on patient safety within the Arab world. There are several challenges that need to be addressed prior to the development of PHRs such as the low EMR implementation within Arab hospitals, the need to improve IT infrastructure to promote Internet use, and the introduction of privacy and confidentiality laws. Once such challenges are overcome, policy makers and healthcare organizations will become more aware

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of the need to address patient safety concerns from a health information technology perspective. However, for now, the topic of Health IT and patient safety will be of concern, but little action will be taken to address it until the various challenges noted above are addressed.

## Initiatives Focusing on Patient Safety and the Electronic Health Record in North America

Significant progress has been made in North America over the past several years in implementing electronic patient and medical records. Investments by organizations such as Canada Health Infoway and the Office of the National Coordinator in the United States as well as the National Library of Medicine (NLM) have increased the rate of adoption of electronic medical records and EPRs as well as improved the quality of health information on the WWW. This has spurred on improvements in the types of tools used to evaluate the quality of health information on the web and health technology development targeted at healthcare consumers. Much of this work has also spurred on developments at the intersection of patient safety, patient empowerment and health information systems research.

For example, in North America we have seen the introduction of: (a) patient education portals that provide trustworthy health information [18], (b) patient portals that provide patient specific views and access to PHRs [19, 20], and (c) patient and family access to their own health information or view only access to healthcare institutional EPRs used by healthcare providers in their local healthcare facility [21]. Much of the focus of this work has included providing patients and their families with access to their health information and studying the impact of this access upon patient-healthcare provider interactions and patient health outcomes including safety [19-21].

Early work in this area was funded by the NLM. These projects (i.e. PatCIS and PICASSO) identified how patients could be empowered to take greater ownership of their healthcare simply though access to the information located in their EPR [21,22]. PI-CASSO researchers were able to provide patients with access to their EPR over the WWW [22]. In a related project, PATCIS researchers were able to give patients and their families access to their EPR over the WWW [21]. Those patients and families, who accessed their EPR, identified they felt more empowered in managing their chronic illnesses and in their discussions with healthcare providers about self-management strategies. Physicians identified the quality of the physicianpatient visit discussions improved with a greater focus on patient specific issues. No adverse events occurred during the course of the study. These studies found that there could be positive outcomes arising from patient and family access to their EPRs. Although this work is significant, the researchers on the project felt that the patients and families who participated in this project represented a limited group of educated individuals. Therefore, the patient and family participants in these studies may not have been representative of all patients and families who require healthcare [21].

Since the 1990's there have been other projects that have attempted to evaluate the impact of patient and family access to their health information upon patient safety where PHRs and patient portals that provide access to electronic records are concerned. Some researchers have extended this work in terms of investigating specific PHR and patient portal features and functions that could contribute to improving patient safety [e.g. 17]. For example, Schnipper and colleagues [17] designed and implemented a web-based patient portal that links to an electronic health

record. The aim of the design was to improve medication reconciliation via a Patient Gateway medication module. The module allowed patients to both view and modify their allergies, medication list, report on medication related problems and side effects, and non-adherence. The module also enabled communication between healthcare providers and patients. Other publications have found that patient access to such portals and their alert and reminder functions can improve preventative behaviours and reduce the number of errors in the patient's record. This work is significant as it explores the effects of physician-patient communication via an EPR over the WWW on one aspect of safety: medication reconciliation [17, 50]. More work is needed to identify other types of decision support that can be used by patients, families, physicians and healthcare providers and combinations thereof.

The concept of a PHR emerged strongly in North America and can be defined as "An electronic application through which individuals can access, manage and share their own health information, and that of others for whom they are authorized in a private, secure and confidential manner" [27]. PHRs developed to date and deployed in North America range from stand-alone PHRs which do not integrate with other systems to tethered PHRs where patients get to see some limited amount of their data, to highly interconnected PHRs that would allow for patient access to a variety of information about themselves obtained from a range of information systems and databases [17,44]. In describing the evolution of PHRs in North America, Halamka, Madl and Tang [28] describe three early integrated PHR implementations. As an example of a vendor created, clinic hosted application, they note that Epic Systems decided to develop a patient portal to their EHR product called MyChart in 1999. An example of a self built hospital hosted system was an early system called PatientSite, which allowed patients access to a problem list,

medication, allergy and other types of information maintained at Beth Israel Deaconess Medical Center. Also, early on in the late 1990s researchers at Children's Hospital in Boston began work on Indivo, an open source system allowing for personal control of health records.

Since then, progress in this area has been rapid, with millions of people in the US having access to some form of PHR [29]. Examples include development of personal interfaces within commercial products such as the MyChart extension of the widely used EPIC system and the US Veteran's Affairs MyHealthyVet, which allows US veterans to access a range of personal information and resources. As well, health plans and employers are increasingly offering members access to healthcare data (e.g. Blue Cross and Blue Shield). In addition, in 2006 a number of large employers, including Intel, Wal-Mart, and others have worked to provide access through the Dossia project. In Canada, Microsoft Health Vault is being integrated with access for patients to regional health information systems (i.e. the Telus project) [34].

This work has begun to stimulate discussion about how PHR designs and patient portal designs can impact upon patient safety from both usability (including interface design) and workflow perspectives (i.e. patient and health providers). More importantly, this research is now indicating the design, development, implementation and maintenance of such health information systems for patients should be better understood in terms of their contributions to patient safety and outcomes as well as how these technologies detract from patient safety. With the addition of new system features and functions where portals allow physicians and patients (along with their families to communicate, exchange and verify their health related information) as well as review alerts and reminders there is a need to obtain a better understanding of the effects of these features and functions on patients, their families and healthcare providers.

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More importantly, there is a need to understand how we can help patients to use these technologies to improve health and wellness as some research suggests there is a electronic record literacy gap.

Such work will need to receive greater attention. There is a need to study the effects of health, digital and electronic record literacy upon patient safety. Initial work has already been conducted in the area of health and digital literacy. Research will be needed to understand the interactions between health, digital and electronic record literacy where patient empowerment, patient outcomes and patient safety are concerned. Conducting this work will be essential in the upcoming years as PHRs and patient portals will need to be effectively designed.

## Initiatives in Japan Focusing on Patient Safety and the Electronic Health Record

In Japan, patient safety has been a significant focus for those working in healthcare [44-49]. In 1999, two serious medical accidents occurred at about the same time that the Institute of Medicine (IOM) report "To Err is Human" was published in the United States. One medical accident occurred at Yokoham City University Hospital (YUCH) [35] in January of 1999 while the other occurred at Hiroo General Hospital (HGH) in February of 1999 [36]. At YUCH two patients were mixed-up: a patient who needed a heart operation was mistaken for another patient who required a lung operation. Both the patients (i.e. the heart operation patient and the lung operation patient) underwent the wrong operations. Both patients died within a year of the patient mix-up. At HGH the medical accident involved a nurse administering an antiseptic intravenously. The nurse mistook the antiseptic for heparin sodium (after another nurse had left the medication on a cart). The patient died immediately. A series of serious accidents at reputable hospitals in Japan received much domestic media attention [37]. The government response has been to adopt a policy of intervention when such events occur (as a precautionary measure). After these accidents occurred new regulations were introduced in quick succession by the Japanese Ministry of Health, Labour and Welfare (MHLW). In 2001, a Patient Safety Action plan was issued and the Patient Safety Council was established for the first time. Effective in October 2002, the Medical Service Act was revised to require that all hospitals and clinics with inpatient beds take necessary measures (including following an institution-specific guideline for patient safety, instituting an internal reporting system, introducing training and monitoring for patient safety issues). Some of this work involved the implementation of health information technology to improve patient safety. This was especially the case for teaching hospitals, which are under the jurisdiction of the Ministry of Education, Culture, Sports, Science and Technology (MEXT). Teaching hospitals were obliged to appoint a full-time "risk manager" to prevent accidents and they were asked to take appropriate action in cases where patient safety claims arose.

In 1999, the MEXT required the Japanese Council of National University Hospital Directors (CUHD) [38] to take necessary actions to prevent medical malpractice and to undertake medical risk management activities. The CUHD decided to establish an organization for medical safety - the CMSNH in the national university hospitals in 2002, and this secretariat has been in the Osaka University hospitals (placed in the central department of medical quality management) [39]. One of the authors of this article was the first president of the CMSNH for six years (i.e. Dr. Hiroshi Takeda). A third party council that focuses upon quality of healthcare was also set up (i.e. the Japan Council for Quality Health Care - JCQHC) [40]. The Empowering Patients: Making Health Information and Systems Safer for Patients and the Public

JCQHC, which was set up and co-financed by the Japanese Medical Association (JMA), and the MHLW, which was set up in 1995 to focus upon new hospital accreditation schemes, started developing a patient safety incident reporting system for large hospitals in Japan in 2004. In April of 2005, the JCQHC reported its first statistics on medical errors rates in large hospitals (276 hospitals as of March 2005). In 2005 the Japanese Society for Quality and Safety in Healthcare (JSOSH) [41] was established to develop and promote scientific approaches to patient safety. Today, the JSQSH holds annual meetings and the number of its members has grown to about 1500 members (as of 2012). The society has also led the Japanese version of the "1 Million Lives" campaign (along with other healthcare societies in Japan from 2008 onwards) [42]. In 2010, the MECS approved the opening of the first graduate school in Japan, specializing in the science of patient safety: The Graduate School of Health Care Sciences at the Jikei Institute in Osaka, Japan [43].

It is a widely accepted that the Internet and ubiquitous computing environments will lead to greater participation by patients in their healthcare. The CUHD report suggested that there is a gap between hospital attitudes and patient needs. Currently, three university hospitals in Japan allow patients to access their own data archived in the EPR. Only one university hospital provides patients with a card that tells them about medication contraindications and allergies. In Japan many trials are about to start that support patient empowerment using the EHR. There has been a clear shift to a "patient -centric" paradigm. The development of a national level electronic health record (EHR) is being discussed in Japan. The government has proposed the "My charts anywhere" project [48] as a strategy for healthcare reform. Some pilot EHR models have been developed for regional EHRs. These EHRs will exist. For example, a regional EHR project was developed for the Kamaishi area,

Iwate Prefecture. The Kamaishi area was affected by the severe earthquake and tsunami that occurred on March 11, 2011. This earthquake and tsunami led to the loss of many citizens and healthcare resources (i.e. healthcare providers, medical instruments, medical records and so on). The community is now rebuilding citizen homes and healthcare facilities. However, the network infrastructure in the area remains poor. A document-centric EHR (DEHR) has been proposed to avoid the development of a "digital divide". The architecture of the DEHR is one of a central repository of the electronic healthcare records in PDF format with meta-data, terminal devices at healthcare facilities, and a secure virtual private network. The characteristics of the DHER include: 1) independence from any specific software application, 2) updates and displays at anytime and anywhere by those who are allowed to access patient personal data, 3) access to a terminal device that functions as fax, a scanner, a personal computer and a tablet, 4) effective linkages with the EHR in the health information system by interfacing with the document archiving and communication system (DACS) [49], 5) a common patient id generated logically with the citizens name and birth date, 6) data sharing among care providers (i.e. medical, nursing and home care as well as the patient and their family, 7) a life-long PHR for back-up of records in each facility, and 8) utility for disaster recovery and business continuity planning of healthcare services (if necessary). In summary, Japan has made significant strides in advancing patient safety efforts as well as EHR record implementations. The current use of EHRs and EPRs in Japan is a significant step towards patient empowerment (as empowering a patient with access to their health information promises to improve patient safety). More importantly, work involving EHRs has benefited healthcare providers, patients and citizens and those affected by the earthquake and tsunami that occurred in March of 2011. One regional EHR is being used to empower patients' and their families while at the same time providing the necessary patient information to support healthcare provider decision making (therefore improving the quality and safety of healthcare).

### Initiatives in Denmark Focused on Patients and Citizens

In Denmark there have been several health information technology (IT) patient (i.e. health consumer or citizen) health initiatives that have been documented in the literature. These initiatives provide health professionals and patients (or citizens of Denmark) with access to their health information (e.g. Sundhed.dk portal). On the strategic level, national health information technology (IT) initiatives in Denmark are represented by the National Board of E-health (NSI). In their strategy document specific health IT functionalities are not connected to patient safety issues. On the regional level the Regional Health IT (RSI) was established in 2010. This organization issued a strategic statement entitled: "Milestones for Health IT" [5]. In this document four strategic milestones were identified by this national organization: establishment of clinicians workplace, optimization of hospital operations, coherence and cooperation, and patient empowerment.

There are several health IT initiatives that have empowered the citizens of Denmark, among them Sundhed.dk, the official portal for the public Danish Healthcare Services, which enables patients and healthcare professionals to find general and personalized health information. The portal also allows patients and providers to communicate through secure connections, book appointments etc. through the Sundhed.dk portal. Such access to high quality health information and health professionals via a portal provides citizens

with on-line access to essential personal health data such as current medications, and enables earlier diagnosis and treatments, empowering patients to actively manage their healthcare while at the same time providing them with access to high quality general and specific health information – such access may improve patient safety as health professionals and citizens have high quality, timely health information on which to base their healthcare decisions.

A further example of a Danish initiative that has focused upon citizens or healthcare consumers in Denmark is the shared medication record. The shared medical record is currently being implemented in Denmark (i.e. the initiative began in 2011). The implementation is to be completed by the end of 2012. It is a solution that gives all citizens an electronic medication record in a central database. The medication record provides an overview of a citizen's current medication, and is available to patients and every healthcare provider (e.g. physicians) in Denmark. The system is intended to assist in the process of Medication Reconciliation, when patients are admitted to hospital from the community. This shared medical record is expected to prevent medication errors once fully implemented.

Another important initiative in Denmark is the Danish Patient Safety Database. The database is important as it allows for reporting of safety issues [31]. The reporting system allows for safety related reporting including safety issues involving medical devices "including the software necessary for its proper application intended by the manufacturer to be used for human beings for the purpose of: diagnosis, prevention, monitoring, treatment or alleviation of disease" [32]. The system allows health professionals and patients to report patient safety issues.

Health professionals can report patient safety incidents and in September of 2011 patients and their families could also report such incidents. For example, Figure 3 shows the distribution of the six most common incidents reported by patients and staff from September to December 2011. Patients and their families focus less on medication error incidents in their reports than health professionals. Alternatively, patients and their families identify infections and incidents involving communication with health professionals as patient safety issues in the reports.

Although there is no direct connection between specific health IT functions and patient safety in the Danish national health IT strategy nor is there mention of patient safety specifically in this document, the strategy does mention that IT systems will provide "feedback (that) will give Health Care Professionals a knowledge that can be used to improve patient care and increase patient safety" [33]. More research will be needed to systematically document the impact of health IT initiatives upon patient safety. Initiatives aimed at collecting data that document the impacts of these systems upon safety are areas for where more work is needed. As well, future initiatives may involve developing a coding system for automatic identification of specific patient safety events involving health information technology related incidents. This may also involve developing methodologies to identify patient safety issues as well as automatic data extraction of patient safety events. Progress is being made in these areas and reports on patient safety events are being collected in the Danish Patient Safety Database since 2004 [31].

### Conclusions

Internationally, health information available on the WWW and in health information systems has empowered patients and improved patient safety. Credible and trustworthy health information on the WWW has raised patient awareness of the signs and symptoms of health conditions (so that patients have sought out medical attention early in their disease process) [1, 18]. Patient portals, PHRs and patient access to EPRs has also enhanced patient empowerment [17]. Patient portal systems that are well designed and implemented

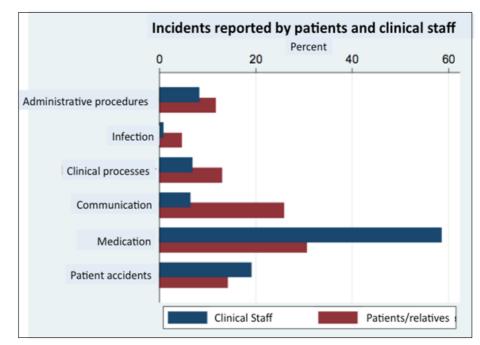


Fig. 3 Incidents reported by patients and clinical staff in Denmark from September to December 2011. [5]

have lead to some patients taking a more active role in their healthcare (e.g. obtaining vaccinations, mammograms etc) [17, 50], engaging in discussions with the healthcare providers about how they can best self-manage their diseases, helping patients and families to correct incorrect information in their electronic records [17], and acting as vital sources of health information following a disaster [49]. In general health information on the Internet, EPRs, PHRs and patient portals can improve patient safety.

Yet, even as these technologies have empowered patients to become more involved in the management of their health and transferred significant health and patient safety benefits, there are opportunities for new types of patient safety issues to be introduced while other patient safety issues remain. There is an ongoing need to certify websites and to provide consumers with good quality health information so they do not experience any undue harms [1,4]. In the last few years we have also seen the introduction of a new type of error - technology-induced errors. Technology-induced errors arise from healthcare providers interactions with health information technologies during the process of care [9, 10]. The experiences of differing regions around the world suggest that technology-induced errors may also arise from healthcare consumer, patient or family member interactions with health information systems used in the process of self-care [31]. In some countries (e.g. Demark, United States) technology developers and implementers have already recognized the issue that health information found in an electronic record or patient portal as well as electronic record or patient portal features and functions may lead to such errors [17, 31]. These health informatics researchers and practitioners are studying the technology to refine its design [17]. They are providing opportunities for patients who use the technology to correct the errors found in the electronic record or to submit descriptions of the errors and the

circumstances when they occur so that the error can be addressed and the safety of the system can be improved.

Internationally, there is recognition that health information technologies can improve patient safety and an understanding of how these technologies introduce technology-induced errors is essential to future refinement of existing systems and to the development of safer systems into the future [11, 31]. A new area of focus these researchers have identified is at the intersection of patient empowerment, health information systems and patient safety. Essentially, this area of research involves identifying those health information technologies, including health information technology features, functions, and workflows that improve patient safety and those aspects of these technologies that reduce patient safety (to eliminate them).

There is recognition that some of the most complex interactions in healthcare involve patients, their families and healthcare providers (e.g. physicians, nurses) and as a result there is a need to better understand how these healthcare stakeholders interact. More importantly, there is recognition that health technologies such as the EPR, PHR and patient portals are key to patient empowerment and health management. There is also a need to understand how these technologies can influence patient outcomes and error rates, and to learn and disseminate these researcher and health informatics practitioner findings and experiences globally so that we can learn from each other to advance the fields of health and biomedical informatics.

#### References

- Eysenbach G, Powell J, Kuss O, Eun-Ryoung S. Empirical studies assessing the quality of health information for consumers on the World Wide Web. JAMA 2002;20(287):2691-700.
- Borycki, E. M-Health: Can chronic obstructive pulmonary disease patient use mobile phones and associated software to self-manage their disease. Cure for Kids Summit, June 9-11,2011.
- 3. Demiris G, Afrin LB, Speedie S, Courtney KL,

Sondi M, Vimarlund V, et al. Patient-centred applications: Use of information technology to promote disease management and wellness: A white paper by the AMIA knowledge in motion working group. J Am Med Inform Assoc 2008;15(1),8-13.

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- Altuwaijri MM. Empowering patients and health professionals in the Arab World. The King Abdullah bin Abdulaziz Arabic Health Encyclopedia on the Web. Yearb Med Inform. 2011;125-30.
- 5. Sammenhængende Digital Sundhed i Danmark: National strategi for digitalisering af sundhedsvæsenet 2008 – 2012. [Connected digital health in Denmark: National strategy for digitalizing public health 2008-2012] Available at: http://nsi.dk/ M a a l - o g - M i l e p a e l e / ~/m e d i a / o m N S I / SDSD\_Strategi\_2008\_12.ashx
- van der Sijs H, Aarts J, van Gelder T, Berg M, Vulto A. Turning off frequently overridden drug alerts: Limited opportunities for doing it safely. JAMIA, 2008: 15(4), 439-448.
- Ash JS, Sittig DF, Dykstra RH, Guappone K, Carpenter JD, Seshadri V. Categorizing the unintended sociotechnical consequences of computerized provider order entry. Int J Med Inform 2007: 76S: S21-S27.
- Koppel R, Metlay JP, Cohen A et al. Role of computerized physician order entry systems in facilitating medication errors. JAMA 2005;293:1197-203.
- Kushniruk AW, Triola MM, Stein B, Borycki EM, Kannry JL. Technology induced error and usability: The relationship between usability problems and prescription errors when using a handheld application. Int J Med Inform 2005:74(7-8):519-26.
- Borycki EM, Kushniruk AW. Where do technologyinduced errors come from? Towards a model for conceptualizing and diagnosing errors caused by technology. In: Kushniruk AW, Borycki EM, editors. Human, Social and Organizational Aspects of Health Information Systems. Hershey, Pennsylvania: IGI global, 2008. p. 146-66.
- 11. Borycki EM, Keay, L. Methods to assess the safety of health information systems. Healthc Q 2010;13, 49-54.
- Carvalho CJ, Borycki EM, Kushniruk AW. Ensuring the safety of health information systems: Using heuristics for patient safety. Healthc Q 2009;12,49-54.
- Kushniruk, AW, Borycki EM, Kuwata S, Kannry J. Predicting changes in workflow resulting from healthcare information systems: Ensuring the safety of healthcare. Healthc Q 2006; 9,78-82.
- 14. Borycki EM, Kushniruk A, Keay E, Nicoll J, Anderson J, Anderson M. Towards an integrated simulation approach for predicting and preventing technology-induced errors in healthcare: Implications for healthcare decision-makers. Healthc Q 2009, 12:90-6.
- 15. Ash JS, Sitting DF, Poon EG, Guappone K, Campbell E, Dykstra RH. The extent and importance of unintended consequences related to computerized provider order entry. JAm Med Inform Assoc 2007;14(4):415-23.
- Horsky J, Kuperman GL, Patel VL. Case Report: Comprehensive Analysis of a Medication Dosing

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Error Related to CPOE. J Am Med Inform Assoc 2005;12(4):377-82.

- Schnipper JL, Gandhi TK, Wald JS, Grant RW, Poon EG, Volk LA, et al. Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: The Patient Gateway medications module. Inform Prim Care 2008;16:147-55.
- Medline Plus. Trusted information for you. http:// www.nlm.nih.gov/medlineplus/ [accessed on 13-03-2012]
- Hassol A, Walker JM, Kidder JM, Rokia K, Young D, Pierson S, et al. Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. J Am Med Inform Assoc 2004;11:505-13.
- 20. Hilton JF, Barkoff L, Chang O, Halperin L, Ratanwongsa N, Sarkar Uet al. A cross-sectional study of barriers to personal health record use among patients attending a safety-net clinic. PLoS One 2012;7(2):e31888.
- Cimino JJ, Patel VL, Kushniruk AW. The patient clinical information system (PatCIS): Technical solutions for and experience with giving patients access to their electronic medical records. Int J Med Inform 2002;68:113-27.
- Masys D, Baker D, Butros A, Cowels KE. Giving patients access to their medical record via the Internet: The PCASSO experience. J Am Med Inform Assoc 2002;9:181-91.
- 23. Alahmadi HA. Assessment of patient safety culture in Saudi Arabian hospitals. Qual Saf Health Care 2010 Oct;19(5):e17. Epub 2010 Apr 29.
- 24. Walston SL, Al-Omar BA, Al-Mutari FA. Factors affecting the climate of hospital patient safety: a study of hospitals in Saudi Arabia. Int J Health Care Qual Assur 2010; 23(1):35-50.
- Al-Ahmadi TA. Measuring Patient Safety Culture in Riyadh's Hospitals: A Comparison between Public and Private Hospitals. J Egypt Public Health Assoc 2009;84(5-6):479-500.
- 26. Internet World Stats. Web Access. http://

www.internetworldstats.com/middle.htm [accessed on 27-02-2012]

- 27. The Personal Health Working Group. Connecting for health: A public-private collaborative. The Markle Foundation: 2003.
- Halamka JD, Mandl K D, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc 2008;15,1-7.
- Kaelber DC, Ashish KJ, Johnston D, Middleton B, Bates DW. A research agenda for personal health records. J Am Med Inform Assoc 2008;15,729-36.
- Danske Regioner: Pejlemærker for sundheds-it 2010. Available at: http://e-pages.dk/regioner/31/ [accessed on 13-03-2012]
- 31. http://www.dpsd.dk/ [accessed on 13-03-2012]
- 32. European Commission DG Enterprise and Industry Directorate F-Consumer Good Unit F3- Cosmetic and Medical Devices: Guidelines on a medical device vigilance system. MEDDEV 2.12-1 rev 6, December 2009.
- The National Agency for Patients' Rights and Complaints. http://www.patientombuddet.dk/ [accessed on 13-03-2012]
- Telus Personal Health Record. http:// telushealthrecord.com/webconcepteur/web/TSS/en/ phr/nav/faq.html [accessed on 13-03-2012]
- 35. Hashimoto M. Safety management activities of Yokohama City University Hospital—safety management is the platform of quality improvement (in Japanese); abstract: http://www.ncbi. nlm.nih.gov/pubmed/12624976
- 36. Starkey LJ, Maeda S. Doctor as criminal; reporting of patients deaths to the police and criminal prosecution of healthcare providers in Japan. BMC Health Serv Res 2010;10:53-8.
- 37. Leflar R. The Regulation of Medical Malpractice in Japan. Clin Orthop Relat Res 2008;467(2):443-9.
- http://www.univ-hosp.net/ (in Japanese) [accessed on 13-03-2012]
- http://www.hosp.med.osaka-u.ac.jp/home/hp-cqm/ ingai/english/index.html [accessed on 13-03-2012]
- 40. http://jcqhc.or.jp/pdf/top/english.pdf [accessed on

13-03-2012]

- http://www.jstage.jst.go.jp/browse/jsqsh [accessed on 13-03-2012]
- 42. http://kyodokodo.jp/ (in Japanese) [accessed on 13-03-2012]
- 43. http://www.ghsj.ac.jp (in Japanese) [accessed on 13-03-2012]
- 44. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: Definitions, benefits and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2003;13(2),121-6.
- 45. Takeda H et al. Health care quality management by means of an incident report system and an electronic patient record system. Int J Med, 2003; 69(2); 285-293, 2003
- 46. Nakajima K, Takeda H. The use of e-learning in patient safety education. Qual Saf Health Cre 2008;17:e1.
- 47. http://www.jahis.jp/members/data\_list/data0204/ (in Japanese)
- http://www.kantei.go.jp/jp/singi/it2/iryoujyouhou/ dai1/siryou5\_1.pdf (in Japanese) [accessed on 13-03-2012]
- 49. Matsumura Y, Kurabayashi N, Iwasaki T, Sugaya S, Ueda K, Mineno T, et al. A scheme for assuring lifelong readability in computer based medical records. Stud Health Technol Inform 2010;160(Pt 1):91-5.
- 50. Wright A, Poon EG, Wald J, Feblowitz J, Pang JE, Schipper JL, et al. Randomized clinical control trial of health maintenance reminders provided directly to patients through an electronic PHR. J Gen Intern Med 2012 Jan;27(1):85-92.

#### Correspondence to:

Elizabeth Borycki University of Victoria Victoria, British Columbia Canada E-mail: emb@uvic.ca