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Foreword

The invitational workshop entitled *Personal Health Information Management: Tools and Strategies for Citizens' Engagement*, held in Vanajalinna, Finland July 1-4, was the tenth in a row of post-congress workshops arranged in connection with an IMIA-NI sponsored Nursing Informatics congress. Each time a different theme has been selected, profoundly discussed and analyzed and thereafter disseminated to a larger audience. From the beginning, one of the aims for IMIA-NI has been to develop recommendations and guidelines related to nursing informatics (Tallberg, 2008).

The first workshop with invited experts followed our first congress in London 1982. A wish to get many countries represented at the workshop was linked to a compulsory paper by each participant. The post-congress papers and discussions were then edited and published together with the congress papers, a glossary and a bibliography, both these last items being much needed at that time. In his conclusions to the proceedings Barry Barber made a statement we should never forget: “The human needs of individuals must not get lost in the elegance of systems...nurses must control nursing and computing systems must not lure them into making decisions incompatible with good nursing practice.”

The 1985 Calgary post-congress slogan, *Challenges for the Future*, mirrored many challenges that are still with us today, for example, the integrated patient record and nursing language. Three years later in Killarney, Ireland, we discussed decision support systems in nursing from the perspectives of nursing practice, education, management and administration and research.

In summarizing the *Healthcare information technology: implications for care* at the Melbourne 1991 post-congress workshop, Kathleen McCormick made an early prediction of the demand on nurses today: “...smarter nurses will use technology to practice nursing more efficiently and may reduce costs, or at best balance the high costs of rising salaries and technology costs”. *Informatics: The Infrastructure for Quality Assessment and Improvement in Nursing* was the theme for the fifth workshop held in Texas in 1994. In Lidingö, Sweden in 1997, there was lively discussion among participants debating ethical views related to patient’s preferences versus clinical guidelines. Recommendations from that post-congress workshop were sent to the International Council of Nurses.

Evidence was the overall theme of the event in the year 2000, held in Auckland, New Zealand - how to build evidence, how to access it and how to apply it. Group work was also completed on applying clinical pathways and outcomes; implementing evidence-based practice in acute care as well as in primary care, community care and home health care.
The goal of the Rio de Janeiro workshop in 2003 was to recommend an agenda for patient safety in the field of health informatics. Sixteen papers were presented as a start for the group work, the results of which are presented in the proceedings: *Improving Patient Safety with Technology*. In the proceedings of the workshop after the Seoul congress in 2006 Peter Murray wrote: “The purpose of the NI2006 Post Congress Conference was to explore a range of possibilities...all of which need to be considered in order to move towards a future we do seek to envisage or influence”.

With this historical overview my intention has been to show how large the field of nursing informatics is in reality, and perhaps also to awake a desire in many nurses to acquaint themselves with some of the publications. I hope there will also be a wide distribution for this new IMIA-NI publication. I will take the opportunity of writing this foreword to thank the Finnish Nurses Association for all their efforts to make the Tenth International Congress on Nursing Informatics and its post-congress workshop so successful.

Marianne Tallberg  
*Honorary member of the International Medical Informatics Association  
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**Reference**

Preface

The 10th International Nursing Informatics Congress (NI2009) sponsored by the International Medical Informatics Association Nursing Informatics Special Interest Group (IMIA-SIG NI), was held in Helsinki, Finland at the Helsinki Fair Centre June 26th to July 1st, 2009. The Finnish Nurses Association co-sponsored the Congress together with IMIA-NI and supported the organisation of the conference. In the tradition of IMIA-SIG NI a post-congress workshop was held and this took place from July 1st to July 4th in Vanajanlinna.

This year the post-congress workshop theme was Personal Health Information Management: Tools and Strategies for Citizens' Engagement. All together, 31 experts representing 18 countries worked intensively for almost three days both in groups and joint sessions. These proceedings present the key outcomes of the workshop with content organized in six sections. A summary of the main NI2009 Congress main conference is provided followed by several papers introducing and describing personal health information management systems (PHIMS). Reports from the post-congress event demonstrate the intensive and innovative work of the groups and country reports give an overview of the international state of art in PHIMS. The purpose of the workshop and the publication of the proceedings is to enhance the our understanding of the citizen’s role in health information management.

As the chairmen of the workshop we want to thank the enthusiastic participants for all their knowledge, skills and efforts and their sharing of time in such a generous way. It was very rewarding to experience the commitment of the working groups, the friendship among participants and the shared enjoyment of moments of the Finnish culture, especially when visiting the sauna and swimming in the lake.

We hope this book will give as much inspiration to our readers in their work as the workshop gave us.

Patricia Flatley Brennan  Kaija Saranto
Chair for the workshop  Co-chair for the workshop
Introduction

The workshop which is the subject of this book of proceedings was planned to follow the 10th International Nursing Informatics Congress (NI2009), an event sponsored by the International Medical Informatics Association Nursing Informatics Special Interest Group (IMIA-NI - www.imiani.org). In this opening chapter we set the scene for the chapters to follow by providing and overview of the themes and key messages from the main Congress (Saranto, Brennan, Park, Tallberg and Ensio, 2009).

NI2009 was held in Helsinki, Finland at the Helsinki Fair Centre June 26th to July 1st, 2009. The Finnish Nurses Association co-sponsored the Congress together with IMIA-NI, and provided support for its organization. The Nursing Informatics Congresses have been a major activity of IMIA-NI. They are held every third year, with the venue changing from one continent to another so that nurses and others can participate more easily. The scope of the Congress programmes is drawn from the definition of nursing informatics used by IMIA-NI. This definition was updated at the meeting held during NI2009 in Helsinki, Finland, the first update since 1998. IMIA-NI states that: “Nursing Informatics science and practice integrates nursing, its information and knowledge and their management with information and communication technologies to promote the health of people, families and communities world wide.” All members of the special interest group are encouraged to use this definition in preference to others, especially in anything they are writing about nursing informatics.

Each country responsible for organizing the international NI congress has been able to give it their own touch, sharing the global view of nursing and health informatics. The theme for the conference in Helsinki: Nursing Informatics - Connecting Health and Humans was chosen in part because of the focus of current eHealth initiatives in the European Union but also because there are many global activities to strengthen the role of consumers in health information management. Keynote speakers were invited for their expertise in relation to the conference theme but also for their ability to present developments in the wider field of nursing informatics.

Messages from International Keynote Speakers

Since the Congress was being held in Europe, it was opportune that the present president of IMIA, Reinhold Haux, is from Germany. This made it easy for him to change smoothly his welcome address to introduce the first keynote presentation: Sensor-Enhanced Health Information Systems for Ambient Assisted living: New Opportunities for Nursing Informatics. The presentation was by Michael Marscholleck,
who demonstrated how sensors can transmit timely data from home to caregivers and enhance safety. The next speaker also focused on patient safety, a very acute international theme at the moment. David Bates from the USA shared with the audience some astonishing research results and statistics that demonstrate just how patient safety can be improved with IT. Professor Bates also described contributing factors to adverse events and medication errors and emphasized the importance of safety risk management in health care.

Charles Friedman, also from the USA, shared his vast experiences and described major initiatives in eHealth. This topic has been of high priority in the member states of the European Union and a special session was organized during the conference to disseminate experiences in different EU countries. Helena Leino-Kilpi from Finland inspired the audience by focusing on confidentiality and privacy questions in nursing care. As a newcomer to the specialty she had searched the literature to see whether and how ethical issues were addressed by nurse informaticians. Her conclusion was that there is plenty of material on ‘how to act right / well’ but almost none on ‘what is right / good’. She concluded that the concept of ethical competence in health technology was not evident, indicating there needs to be more of a focus on the theme of ethics in future scientific papers.

All previous NI congresses have provided a good introduction to newcomers in the field of nursing informatics and this was no exception. The keynote presentation given by Evelyn Hovenga, a pioneer in the field, described the major milestones in IMIA-NI’s history. Being an active member in the work of the International Standards Organization she also highlighted the importance of future activities for nurses, especially increased participation in health Information technology (HIT) development at national and international levels. Evelyn is also a pioneer in educational initiatives and has influenced recommendations for health informatics education developed by IMIA.

The importance of resources and finances was the essence of the keynote presentation in the closing ceremony of the Congress. Jacob Hofdijk, special advisor and president of the European Federation of Medical Informatics gave examples of contributing factors that affect nursing costs. He also shared ideas on how to develop casemix information when defining healthcare costs. The title of his paper was provocative: The Health Care Delivery Revolution is about to Start – Take your Chances! Perhaps due to the global economic situation, the audience totally agreed with his statements.

Congress Themes

During the three days of the Congress, the programme followed 10 themes: Clinical Workflow and Practice Applications; Patient Safety; Consumer Health Informatics and Personal Health Records; Education for Consumers and Professionals; Evidence Based Practice and Decision Support; Health Information Technology; National eHealth Initiatives across the Globe; Patient Preferences and Quality of Care; Strategies and Methods for Training; and Terminology, Standards and NMDSs. Out of more than 400 submissions, 132 oral presentations were made and 105 scientific posters presented, including 11 student posters. There were 11 panel discussions, eight workshops and seven scientific demonstrations. The presenters represented more than 35 countries.

The three days programme was organized according to the Congress themes so that the different presentations complemented each other. As in previous congresses, among the
most popular sessions were within the theme Clinical Workflow and Practice Applications. The solution to almost eternal question of how nurses will benefit from information technology in nursing practice and management has only slightly changed over the years. This time the focus was on nursing sensitive outcomes and how HIT can facilitate assessment of the effects of nursing care. The development and implementation of information systems, electronic records and terminologies were described from various perspectives. In many papers there was also a relation to patient participation, evidence-based practice or patient safety. It was clear that there is still a debate about how best to integrate nursing informatics into nursing curricula and on how to structure NI education in order to support development of health informatics competencies in all nurses.

Outcomes and Lessons for Future Events

Feedback based on the conference evaluation forms was very positive. Presenters were assessed as experts in the field; the chairs of the sessions were felt to have guided the presenters well and given the audience time for discussions. The posters were well prepared and there were active discussions but also lively debates on the material presented. All comments and questions were highly valued by the authors. The poster Peer Support from Online Community on the Internet among Patients with Breast Cancer in Japan by doctoral student Yoko Setoyama received the first NI poster award donated by the Caring society.

Recent advances under the concept of Social Media were also presented and used during the conference. Social media is an umbrella term for Internet sites that are set up for users participate and generate content. It includes social networking through sites such as Facebook and group working sites such as Google groups (http://groups.google.com/). Khanna (2008) referred to social media as the new resource for healthcare information. Experiences in using Second life in education and new web tools were topics that greatly interested the audience. The Congress was also accessible through twitter - you could receive brief summaries of presentations each day, even if you were miles away from Helsinki. Obviously, the event stays alive in many Facebook pages where participants have stored their memories of NI2009.

It was clear that one of the sessions most highly values by the participants was the panel on Nursing Informatics History; it was so popular that all attendees could not be seated in the room! With hindsight, this special event should also have been recorded using new technology. However, some of the fine content can be accessible through the nursing informatics history project pages (https://www.amia.org/niwg-history-page) However, in the panel the spontaneous comments and questions made by our distinguished pioneers will always remain unique memories.

References


**Personal Health Records: Infrastructure and Standards**

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**Introduction**

In the last few years, personal health records (PHRs) have been developed as an addition to the computerized medical record or electronic health record. There are many definitions and conceptualizations of these records and there is overlap among them. However, it is clear that the core of the PHR is that the person is in control. He or she decides what goes in the PHR, what goes out, how it is managed and who gets access. There are enablers and barriers that influence the uptake of PHRs. Increasingly patients fulfill a double role of both subject of care and member of the multidisciplinary team of health care professionals. In some instances, the person even coordinates the professional team. In the context of this new emerging role mix, the PHR is moving from the simple storage system of free text facts to a full health informatics system. Thus, the PHR itself is professionalizing and it requires different standards and infrastructural requirements. This paper defines the PHR and reviews barriers and enablers. It sets some baseline infrastructural options, and illustrates those standards in health care systems that are common, with proposals for the level to which the PHR should address such standards.

Personal health records have gained more interest in the last decade. Individuals use these applications to store data and manage a health / illness history. Tang, Ash, Bates, Overhage and Sands (2006) envision the PHR as an addition to professionally managed electronic health records (EHRs). Legal requirements will usually enforce health professionals to manage patient records and document their assessments, diagnoses, treatment and care. However, it is largely acknowledged that during a patient's lifetime the number of discontinuities is uncountable, errors can be attributed to lack of continuity and information technology can contribute to health improvements if used wisely (IOM, 1999).

**Defining the PHR**

There are several definitions available, but since the topic of this chapter is standards for the PHR, the proposed definition from the International Standards Organization is presented here: *The Personal Health Record of an individual is a repository of information considered by that individual to be relevant to his or her health, wellness, development and welfare, and for which that individual has primary control over the record’s content.* (ISO, 2009).

The core here is that the record is about an individual and that the individual has control over the record content (Tang et al., 2006). ISO (2009) argues that: "The key distinction between the Personal Health Record and the Electronic Health Record is..."
that the individual who is the subject of the record is the key stake-holder determining its content and with rights over that content”. This can be handled by individuals for themselves, and or for family members, for example, a child caring for an elder, or alternatively a parent for a child and so on. How all that can be done using different infrastructures will be explained first, after which existing standards are discussed, followed by the impact these might have on the PHR.

Enabling or Blocking?

Miller, Yasnoff and Burde (2009) identify key barriers and enablers for the PHR. Barriers include costs, lack of incentives, lack of integration and data exchange, among others. Enablers include incentives, collaboration and integration. Incentives and reimbursement can help PHR emerge, such as payments for e-Visits and/or monitoring. Miller et al. (2009) suggest looking at a prevention oriented payment scheme. Collaboration models stimulate patients to use PHRs, for instance where patients can self manage chronic diseases, are encouraged to comply with treatment plans, practice efficiency, or complete pre visit questionnaires Integration of PHRs into existing EHRs or other Health care IT are helpful. This would improve the ease of use and limit problems due to absence of data communication.

Consumer barriers include privacy concerns, data entry and lack of integration (Miller et al., 2009). For example, only tethered PHRs are covered under US Health Information Portability and Accountability Act (HIPPA) (Miller et all, 2009). Consumer enablers include trust in safety of system, ease of use, feeling empowered and control and incentives. According to Miller et al. (2009), the single group that is most active is individuals with highest number of different medical diagnoses in PHR.

Infrastructural Considerations for the PHR

There are different options available to put a PHR in place. The baseline is that there are three main approaches to the PHR (Tang et al., 2006, Miller et al., 2009). The first option is that an individual uses a free available software package on a stand alone machine. That requires manual maintenance, data entry and data management. Miller et al. (2009) argue that stand alone versions can have consumer data entry, physician of staff separate log in, and are not integrated or only partial integrated with an EHR. The stand-alone model is mostly used by practices that have no EHR, or no PHR integrated in EHR.

Another evolving approach is the always and everywhere accessible dedicated web based health records like Google Health or Microsoft Health vault among others. Here the individual does have to do their own data management, but is independent of location. The big advantage is that if in hospital, the record still can be accessed. Of course, it still is necessary to manage the data separately from an EHR and to sort out access by health professionals. Both of these approaches are more or less independent of the professional health records, requiring duplication of effort and granting another opportunity for errors caused by that.
The best option seems to be that the PHR functionality is provided by allowing individuals to view the health information that is stored about them in their health care provider’s EHR. A key question here is whether such an integrated PHR, or its source HER, allows further data communication and if the content of record is transportable from one system to the other. For instance, use of the HL7 v3 Care Record message would allow the data to become more independent from one particular system, and allow exchange of data.

Example PHR systems that are integrated with provider EHRs include that of Kaiser Permanente in the US (for all patients generically) and Portavita in the Netherlands and Germany (for cardiology and diabetes patients specifically). Such so-called 'tethered' systems have the advantage that the quality of data and continuity of care can be achieved. One legal requirement will be that the data entered by the individual can be distinguished from the data entered by the health professional.

There are different examples of means to allowing individuals to access to the PHR. For instance: by allowing the individual personally entering the content; by the individual authorising one or more parties or systems to contribute to the PHR; or by the individual authorising the creation of a PHR on his or her behalf by an organisation or person whose anticipated purpose is considered relevant and trustworthy by the subject (ISO, 2009). Each form will require setting up an access system and security measures.

Classifying PHR Functionality

In the ISO new standard development, the following five axes for classification of PHR are defined (ISO, 2009). This is likely to change during development, but gives a good starting point to discuss some issues in relationship to infrastructure and standards.

Axis 1: Scope of the information: to what extend and what kind of information is stored and managed in the PHR. But also, what use can be made of the data in the PHR, e.g. summarizing data in reverse order, for instance via date/time stamp or source, setting trends etc. Also think about the quality and validity of (true) data, using data standards in order to obtain and use discrete data for analysis.

Axis 2: Access control; how is that arranged and who is granting access to whom.

Axis 3: Data custodianship; who is responsible for the quality and content, and what legal requirements are relevant.

Axis 4: Repository auditability; is it possible, and if so how, to control who is getting access to data and how the data are managed.

Axis 5: Interoperability and communication; is it possible for the PHR to automatically send and receive data to and from EHR or other electronic systems.
Miller et al., 2009 identify legal issues, like data ownership, consumer id verification, malpractice (large volume, quality, accuracy and completeness, change in defining standard of care). Also, opt in/out regulations are important for individuals and are best profile based.

**Standards Typology**

One of the challenges of the application of modern health care information and communication technology (HIT) is the integration of clinical materials with technology that traditionally have been developed in different areas of research and development. A core issue in the EHR is that of semantic interoperability, best in such an intelligent format that the receiver knows what to do and can do it correctly. Goossen (2006a) defines it as follows: "Intelligent semantic interoperability between EHR systems in health care is defined as ‘the electronic exchange of clinical patient information in such a format that the intended meaning of the information from the sender can be interpreted by the receiver without changes or loss’. The addition of ‘intelligence’ implies that clinically relevant knowledge is applied to the content, structuring and processing of the electronic documentation and of the information exchange. It can be argued that the same holds for PHR, but with one caveat: the carefully defined concepts in the professional EHR, are not necessarily well understood by a lay person deploying a PHR.

Goossen (2006b) has developed a typology of five different standards domains that need to be applied in order to achieve intelligent semantic interoperability. These are briefly discussed here as a step up for the consequences of each for PHR development. The first domain is knowledge, in the format of clinical standards to achieve quality care for patients, based on evidence. Examples include reliable and valid assessments, scales, evidence on treatments, medication effectiveness and so on. The second concerns the terminology used to document the care for purposes of continuity and semantics. Examples include standard terminology as ICNP and SNOMED CT, classifications such as ICD 10, but also the exact wording of, for instance, a Braden Scale.

The third category concerns workflow for workflow. Care processes, including the cooperation between professionals, and decisions made and leading to the selection of the best course of action are modelled to allow support of the dynamic nature of health care in electronic systems. In particular clinical pathways and decision support systems can help health care delivery and need standardisation. The fourth area is the information modelling area in which in particular the objects in the real world are represented in information classes, the objects’ characteristics are defined in attributes, and relationships between classes are expressed. Information modelling serves as method to develop systems that facilitate semantic interoperability via exchanging information between different electronic systems. The fifth area covers the technical standards, those necessary to let ICT operate, and in particular the technical measures that guarantee the privacy and protect data, among others.
Implications for PHRs

If we look at the impact from infrastructural and standards deployment perspective we can identify several areas of work related to PHRs. These will be discussed below using the typology of standards, where most areas from the classification fit in well. Firstly, clinical content quality would include making medical knowledge and data understandable by lay people. This handles the scope of information and implies that the individual can manage the information in a meaningful and sensible way. It is consistent with axis 1 of the proposed ISO standard for PHRs. If data quality is good, then options become available that can contribute to better health, lesser complications and longer life. Miller et al. (2009) suggest for instance predictive modelling becoming possible after years of data collection on populations levels from PHR. This does require research and ethical committee standards for research policies. It is mainly secondary data use and data analyses. Would it allow behavioural changes into desired healthy directions?

Related to the content of data, that is, their meaning, which is often represented by using standard terminologies, the use of lay terms and mapping from lay terms to professional terms might be important. But how and to what extend? This would also cover ISO axis 1. Workflow and care processes need to be defined around the patient, the individual as an actor deploying a kind of self management in the context of complementary professional care. How can we design self care pathways? What is the role of the PRH in the overall care management?

Information modelling is important as it is a core requirement for PHRs, in order to access data from EHR and other health IT systems, or to submit such data. It covers axis 5 from the ISO proposal. If patients are using devices more frequently, for example, blood glucose meters, blood pressure meters, and so on, how can such devices interact with the PHR? And how are data send from PHR to EHR? Devices can feed data automatically to the EHR, so why not to the PHR? But then, what standards ensure the semantic interoperability in an intelligent way? Are we also going to integrate the PHR with decision support systems, if only for self medication interactions with prescribed medications, or for advice on healthy behaviours? Would a decision support system, based on standards be able to tackle adverse medication interactions in the PHR? If that is going to happen, then the PHR must adhere to a wealth of standards and regulations.

Finally, a fifth impact concerns technical standards, in particular the infrastructural issues that need to be addressed (stand alone, world wide web, or safe integrated with EHR systems). This is consistent with the axes 2, 3 and 4 from the ISO proposal. In particular, questions include how to arrange access control and the question who should be in charge? Also there is the responsibility for governance of data. Can we allow the individual to erase inconvenient data from the EHR, where the professional is legally responsible for? Finally, it is common practice to never erase information from EHR, just define it irrelevant from a point in time onward. How can we manage this so that audits can take place? This concerns both the individual, but also, who is protecting the professional in such circumstances?
If integration of data sources is missing to a large extent on the professional level (Miller et al., 2009), how can it be expected to be integrated with the PHR? Money can be an enabling factor, but will we pay for the right functions here? One development is of interest here: Detailed Clinical Models are a new concept for technical content standards that specify small amounts of clinical data with respect to guidelines / evidence base, terminology, data modeling, workflow along with technical specifications where relevant (Goossen, 2008).

Summary and conclusions

By discussing the PHR from the perspective of infrastructure and standards it becomes clear that a PHR fully integrated with the EHR offers both patients and health professionals the best opportunities for effective and efficient health care, in particular through management of health care information. Different infrastructures such as stand-alone systems, fully internet based but not integrated portals, and so called tethered systems that are fully integrated are evolving but it is these latter that offer the best value, according to the literature (Tang et al., 2006; Miller et al., 2009). In relation to standards, it is clear that all types of standards apply in a similar manner to the PHR, although another dimension is created due to the need to address the individuals themselves. This does require similar standards applied to PHR compared to the EHR, but each time with the extra dimension of making it understandable and controllable by the individual lay person. Information analysis then can be seen as a core enabler. That work should be linked to business needs, data specifications and workflow. Many questions still need to be answered, and we can contribute to that right now.

References


Aims, Settings, Stages and Strategy for the Post-Congress Workshop

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Introduction

The purpose of the IMIA NI post-congress workshop is to bring together, immediately after the triennial international nursing informatics Congress, an invited international group of health care and informatics professionals with wide expertise in nursing and health informatics to draw up a synthesis of a special topic. The 2009 theme was \textit{Personal Health Information Management: Tools and Strategies for Citizens' Engagement} reflecting the importance consumer involvement in health care. In many countries, eHealth strategies strongly emphasise the development of means to engage citizens more thoroughly in managing their own health related information.

Personal health information management systems (PHIMS) encompass a broad range of information processing tools and strategies, computerised or not, that assist individuals in managing their engagement in health care and in carrying out healthcare actions. These systems include but are not limited to personal health records and web-based portals to clinical information systems. These tools hold great promise for engaging citizens in their health and health care. Nurses will play key roles in the design and deployment of these innovations.

Aim and Themes

The NI2009 post-congress workshop took on the challenge of providing guidelines for creating and using information technologies in support of an informed, engaged population. The aim of the workshop was to produce recommendations for PHIMS adoption world-wide. To achieve our aim, invited experts worked in seven groups chaired by leading nurse informaticians, addressing the following content areas:

- \textit{Personal Health Information Management Systems (PHIMS): What are they? Who's using them? What should nurses know about them?}
  - Chair: Patricia Brennan

- \textit{Usability questions: Specifying user requirements for PHIMS}
  - Chair: Suzanne Bakken

- \textit{Technology: Technical and infrastructure requirements for PHIMS}
  - Chair: William Goossen
• **Practice**: Integrating PHIMS into clinical practice: guidance for nurses  
  o *Chair*: Patricia Dykes

• **Consumers**: PHIMS - Confidentiality and Safety  
  o *Chair*: Peter Murray

• **Governance**: PHIMS - Policies that foster adoption and use  
  o *Chair*: Heather Strachan

• **Education**: PHIMS & Education: Preparing nurses to practice in a wired world  
  o *Chair*: Diane Skiba.

**Process for the Workshop**

The 2009 workshop proceeded in four stages: preparation for the discussion; on-site engagement and discussion; web-engagement; final report.

**Preparation for the Discussion**

Thirty-one experts and students in the field of nursing informatics from 18 countries were invited in the spring of 2009 to participate in the post-congress workshop. They were asked to provide, by June, a short paper describing the state of PHIMS deployment in their country, summarising the key nursing issues related to the design and use of PHIMS and proposing agendas for action. It was very rewarding to notice how engaged each authors were. Their prompt responses made it possible to review the reports from various countries prior to the main NI2009 Congress. The country reports served as an introduction to the workshop and enabled a broad, multi-national perspective on the themes and questions that were developed to guide the workshop content and activities.

**On-Site Engagement**

The workshop took place between July 1st and 4th, 2009, north of Helsinki. The venue, approximately 100km from the city centre, afforded easy access yet provided the inspiring atmosphere of an old mansion called Vanajanlinna. The event began with introductory remarks by all of the participants. Next, the 31 experts were reviewed and affirmed the aims and objectives of the workshop.

Seven invitees accepted invitations sent prior to the NI Congress to serve as group leaders. The groups each addressed one of the seven themes listed above. Each group leader (chair) started with a framing talk that outlined and focused the work of her/his group. Small group work sessions allowed in depth discussions; large group meetings permitted cross-group exchange. The outcomes of the discussions during the working hours were shared with other attendees in joint sessions. Feedback of the overlapping issues was argued during the joint discussions and guidelines for further development for the reports and recommendations were stated.
**Web engagement**

During the workshop, a shared work space was set up by one participant in the Google Groups environment (http://groups.google.com/). By supporting joint-work on documents and helping to maintain version control, this technical innovation helped accelerate the work of all of the groups. Resource materials could be posted and accessed by members throughout the workshop itself and members could also keep track of the work of all other work groups. After the workshop, the web environment supported international collaborations and ensured that members of each group, regardless of location, could engage in the development of the final report.

**Final Report**

This volume serves as the official repository and final documentation of the work of the Post-Congress workshop of the NI2009 Congress. The definitions, statements and recommendations related to personal health information management systems are presented in this volume as the key output of the workshop, contributed to by experts from across the globe. The country reports provided by the attendees and others provide examples of how the tools and strategies considered in the workshop are being deployed in the different regions of the world with their very different healthcare models and cultures.

**Conclusion**

We hope that readers will find this volume a starting point for accelerating adoption of personal health information management technologies in their home countries. The papers that follow contain both conceptual considerations and practical strategies that can support the development and deployment of information technologies in support of health and everyday living!
Personal Health Information Management Systems

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Introduction

Personal Health Information Management Systems (PHIMS) encompass a broad range of information processing tools and strategies, computerized or not, that assist individuals in managing their engagement with health care services and in executing healthy action. PHIMS include but are not limited to personal health records, web-based portals to clinical information systems, and special-purpose use of emerging social network tools like Facebook and Twitter. PHIMS represent one type of health information technology, that, in conjunction with electronic health records and health information exchange initiatives, usher in the era of technology enhanced health care.

The idea of applying information technology solutions to the challenges of personal health information management enjoys wide acceptance by the medical informatics research community (Tang, Ash, Bates, Overhabe & Sands, 2006), health care providers and payers (e.g. Aetna, 2009), and the lay public world wide (Cronin, 2006). In the United States, these innovations are frequently referred to as personal health records. In Australia, innovations like “Health Book” serve the purpose of supporting personal health information. “Wise Health Cards” are found in Slovenia, and in the United Kingdom, a Web application called “Health Space” is found.

PHIMS support personal health information management. Examples of personal health information management challenges include tracking the results of laboratory tests, recalling instructions from a physician office visit, or monitoring one’s own health or the health of family member (Moen & Brennan, 2005). Lay people develop robust, rich strategies for managing health information in the home. They use familiar objects like file folders and calendars to keep track of information deemed important or to remind them of appointments and significant events. Work by Brennan and colleagues (Moen & Brennan, 2005) explored the personal health information management challenges faced by 49 community-dwelling adults. They documented that most households handle 8-10 different types of health information, including treatment advice and instructions, insurance claim forms, appointments and clinical contact data, and general health resources and health promotion information. Although physicians and clinics were the most common sources of information, lay people also valued health information they received from family and friends, local news reports, and the public library. The family calendar served as a common health information management tool, as did binders, file drawers, and, occasionally, computerized files. Importantly, in more than two-thirds of the households, a single member, usually a woman, served as the primary health information manager.
This is an auspicious time for nurses around the world to systematically consider how PHIMS could assist lay people in accomplishing health goals. The so-called “first generation” PHIMS, which focused largely on acquiring and storing health data, is rapidly being replaced by “next generation” solutions that effectively use data to help guide lay people in taking health actions. The remainder of this chapter will serve to advance a definition of PHIMS, speculate on their value to nursing, examining some of challenges that must be faced when advocating for wide-spread adoption of PHIMS, and illustrate how some next generation PHIMS addressed some of those challenges.

PHIMS – What are they?

Personal health information management systems (PHIMS) are best defined as:

...an electronic application through which individuals can access, manage, and share their (health) information, and that of others for whom they are authorized, in a private, secure, and confidential environment (Connecting for Health, 2003).

While this definition was originally advanced as referring to personal health records, one type PHIMS, it includes all of the key components found in any PHIMS component:

...an electronic application – PHIMS are consumer-facing computer tools that could be accessed intentionally by lay people, through a web-browser or some other computer system, but also available on cell phone platforms, embedded within devices, or integrated with other emerging technologies. Ideally, PHIMS reside in a networked environment affording access to and sharing of data and related applications in a technologically-integrated manner.

...through which individuals – PHIMS are designed for use by lay people, not health professionals, and therefore may share features with other consumer electronics, such as simple interfaces, ubiquity (accessible everywhere), and durability;

...access, manage and share their health information – PHIMS enable individuals to acquire, read, or send health data. PHIMS have a wide range of information management services, including mechanisms to acquire health information from clinical records, databases for storage of health data on a local computer or in some public repository such as Microsoft’s HealthVault© or GoogleHealth©, and electronically send health information to other parties such as family caregivers or clinicians. Next-generation PHIMS, such as those described below in the Project HealthDesign initiative, not only display relevant data but use innovative data integration and visualization approaches to provide meaningful, interpretation of the data, launch clinical alerts or make health behavior recommendations. A significant challenge in personal health information management at the present time arises from the lack of common data and terminology standards that preclude integrating data from may sources into a single display.

...and that of others for whom they are authorized – a notable aspect of PHIMS is that they reflect and support personal health information management behaviors. In many households and family situations, one member handles the health
information for another, such as an adult daughter for a parent. Such informal sharing of health data has long been an informal practice in many families, however, introducing an electronic tool to support such common family behaviors makes more formal these informal arrangements;

...in a private, secure, and confidential environment – PHIMS must provide a level of privacy and security that matches that desired by the individual about whom the information refers to at a level desired by that individual. Some individuals may prefer to keep all information strictly private; others may wish to share information with family caregivers, health professionals, or emergency response workers. A hallmark of PHIMS is that the privacy management is under the user’s control, and needs to be technically implemented in a way that is easily managed by lay people (Simons, Mandl & Kohane, 2005).

These characteristics of PHIMS, although expressed in idealized fashion and not yet fully implemented in PHIMS in most countries, describe essential features and functions of personal health information management tools. PHIMS complement and extend information gathered at the point of care by providing a focal point of health information integration around the patient, not the clinical care provider or institution. The data embedded in PHIMS are envisioned to include genetic information, results of clinical encounters, and observations generated directly by the patient (Adida & Kohane, 2006). Currently, the perceived primary value, and consequently the informatics development efforts, favor PHIMS that support institution-generated data and needs over those which may best serve the patient. Next generation solutions are envisioned to be more consumer-facing, using the data gleaned from various sources into decision support and guides for action that improve the health of lay people.

PHIMS developments over the last 15 years emerged first in specific clinical populations and later extended to generalized applications supporting access to clinical records for all persons receiving care from a facility. Some approaches to patient-contributed health records are found among pediatric care settings (O’Flaghery, Jandra, Llewellyn & Wall, 1987) and in behavioral health interventions (Giglio, Spears, Rumpf & Eddy, 1978). The wide-spread adoption of WWW tools contributed to the development of web-based access to clinical information systems (e.g. PatCIS (Cimino, Patel & Kushniruk, 2002), PatientSite (Weingart, Rind, Tofias & Sands, 2006).

Health information technology vendors are rapidly developing patient access tools among their suite of electronic medical records (e.g. Epic MyChart, www.epicsystems.com). However, most of these approaches are “tethered” to a given institution or care situation, and largely focus on insuring patient access to data collected in the course of clinical care. “Untethered” personal health records are free-standing repositories into which an individual can record various observations, such as dietary plans or exercise monitoring information. An example of an untethered PHR is that provide by WebMD™ (www.webmd.com).

Tang and colleagues recently provided a state-of-knowledge assessment of the prototype PHIMS, personal health records, with an emphasis on computer-based implementations (Tang et al., 2006). Personal health records serve as repositories of
clinical and self-monitoring information, and hold greatest value when the personal health record is closely integrated with the records created in the course of clinical care. Tang and colleagues acknowledge the need for augmenting access to clinically-generated data with the ability to record personal observations and gain access to helpful resources such as decision support and care management guidelines.

The very idea of using clinical records to engage lay people in personal health information management is not new. Indeed, in 1975, Ruth Lubic, a nurse midwife, created a then-revolutionary clinical information management system at the Maternity Center in New York (Lubic, 1975). In the Maternity Center, patient charts were kept in front of, not behind, a reception station, and on arrival, the patient recorded observations such as weight, urine protein, etc. Lubic’s records presaged a fundamental concept found in today’s personal health records agenda: patients and clinicians serve as co-authors of the clinical record (Fischbach, Sionelo-Bayog, Needle & Delbanco, 1980), and the record itself as an information link between the clinician and the patient. However, Lubic’s records remained stored on-site at the clinic, and did not offer any support for health information management in the home.

PHIMS are growing in sophistication and acceptance, and could provide significant value to nurses as they help lay people manage chronic conditions and ascribe to health-promoting behaviors. It is timely for nurses around the world to consider how PHIMS may be useful in their practice and what clinical, technical and ethical considerations must be addressed to insure full value.

**PHIMS – Considerations for Nurses**

In this section clinical, technical, and ethical, legal and social issues related to PHIMS and nursing are explored. This is not intended to be an exhaustive treatment of these issues, but rather an introduction to some important considerations related to nurses’ uses of these innovations. Detailed exploration of these themes is provided in the chapters that follow reporting the work of experts at the post-congress workshop.

**Clinical Issues**

PHIMS have great potential to assist nurses in their work with patients both in institutions and in the community. Institution-based nursing practice can be enhanced by the understanding of the every-day health experiences of the individual that can be afforded though PHIMS, and PHIMS may provide the pathway for institution-based nurses to extend discharge teaching instructions into the everyday lives of patients. Community-based nurses can use PHIMS to help people better track health concerns, observe and interpret patterns that provide insights into the relationship between every-day living events and health indicators, and foster independence and self-management among patients.

PHIMS provide technological adjuncts to clinical nursing practice, complementing and extending nurses’ abilities to shape people’s lives and promote their independence and well-being. Perhaps the most valuable contribution of PHIMS lies in their potential to help lay people understand their health and take action based on meaningful interpretation of data.
It is useful to think of PHIMS suite of applications that draw from a range of health data, from excerpts of clinical records, to journal entries recording mood changes over time, to recordings of daily exercise activity. Visualization tools applied to these various types of data could reveal patterns relating health events and life activities. Decision support tools could integrate laboratory values, daily nutrition choices and insulin regimes, helping people with metabolic syndrome maintain optimal blood glucose control.

**Technical Issues**

Unlike their institutional counterparts which rely on relatively standard computer terminals and data models PHIMS are characterized by a wide-range of technologies. PHIMS may be embedded in standard computer systems, but increasingly may rest on cell-phone platforms, “smart” clothing and devices in the home that are integrated into the health and every-day living of the people who use them, and Web 2.0 tools. Thus, the technological environment of PHIMS is characterized by great diversity. This diversity is good, in that it is likely to spawn really useful tools that easily fit into people’s lives; however, hallmarks of quality and trustable information systems need to be augmented with those better fitting the highly varied technological environment.

PHIMS are part of the larger health information technology infrastructure, and are subject to some of the same technology development challenges found in the development and deployment of clinical records systems and computerized provider-order entry systems. Currently, the approach to PHIMS development and deployment can be characterized as fragmented and non-scalable. The absence of data standards, shared terminologies, and common architectures plague PHIMS as much as their absence continues to challenge the development of electronic health records.

Current conceptualisations of the PHIMS rest on implicit expectation that a person (clinician, patient, parent) must literally read, then process the specified content of the record. Indeed many discussions of personal health records emphasize screen design, layout, and the availability of on-screen navigation and interpretation assistance as critical success factors. However, the benefits of PHIMS could be greater if new models of human computer interaction, such as those arising from agent-based models, were incorporated in their design. PHIMS might be designed to support dynamic capture of data gleaned in day-to-day living situations; and integrated those observations with advice, recommendations or engaging displays; and guided action, not simply data collection. For example, a camera-equipped cell phone could be used to capture a picture of a meal, send the image through an analysis program, query a nutritional database, and make a recommendation about modifications or warnings for food allergies.

Sophisticated processes, such as medication reconciliation now recommended for every clinical encounter could be accomplished by automatic, agent-directed review of electronic documents, rather than having the nurse and patient together review a screen-summary or a printout of recent prescriptions. Additionally, configuring patient preferences for care activities (e.g. life support, advanced directives) as a type of guideline implementation and inserting that guideline into an electronic record system could form the foundation of rules to govern subsequent care decisions.
Thus the technological challenges arise from an unusual co-occurrence of events - a plethora of technology platforms whose application and use is restricted by a vision of health information technology anchored in a view of human computer interaction in which all computer output must be filtered through the eyes and cognition of a person. Accelerating innovation and adoption of PHIMS must be tempered be consideration of the ethical, legal and social issues related to their use.

**Ethical, Legal and Social Issues**

PHIMS raise unique ethical, legal and social issues not found in other applications of information technology in health care. These issues include privacy and security, the benefits and risks of a unique health identifier, and economic considerations including who will pay for PHIMS and how to stimulate wide-spread use of PHIMS while not exacerbating the digital divide, and managing consumer expectations of clinicians' willingness to use PHIMS in the care process. It is worth paying particular attention to the issue of privacy and security.

PHIMS present an interesting and somewhat paradoxical set of issue around privacy and security of health data. If one considers privacy as the individual’s discretionary right to disclose personal information, then PHIMS afford a unique opportunity to provide a technological mechanism to implement that perspective. The largely distributed structure of PHIMS, where data may reside in several institutions and public repositories, demands a mechanism to safely integrate data about an individual person.

This need suggests that a unique person identifier could be of significant value; indeed, several countries, including Australia, New Zealand, the UK and Norway have embraced this identifier. Other countries, including the United States, perceive that a unique person identifier creates security risks disproportionate to the benefit. Complete resolution of these paradoxes is unlikely yet need not hamper adoption of PHIMS. New models of data security will emerge, ones driven more by the protection of data elements rather than the institutions where data are stored or used. Furthermore, given the involvement of other family members in each other’s care, privacy and security models must be robust enough to support the realities of how people experience health in their lives.

PHIMS raise one consideration related to privacy and security not found in any other health information technology application – the challenge of managing privacy in informal settings. The very presence of a health-focused technology in the home raises awareness on the part of other family members of health concerns that an individual might prefer to keep private. PHIMS raise the challenge of expanding the privacy model beyond focusing solely on the data alone but also on the manner in which devices could inadvertently disclose private information.

This section identified and reviewed clinical, technical and ethical, legal and social issues related to PHIMS. The next and final section includes a description of an initiative designed to illustrate a new vision of PHIMS.
Next-Generation PHIMS

The Project HealthDesign program is presented here in some detail to illustrate progress towards achieving the vision of robust PHIMS. Project HealthDesign, an initiative sponsored by the Robert Wood Johnson Foundation with the support of the California HealthCare Foundation, sought to expand the idea of PHIMS, specifically personal health records, from data collection and storage tools to vibrant, powerful tools that assist lay persons to take action that promotes accomplishment of health goals and management of complex health problems. Nine teams participated in a 6-month intensive design experience, set up to insure that their approach to PHIMS design engaged and responded to the needs of their self-identified populations of interest. Creating a new vision of PHIMS, one that encompassed the idea that PHIMS should guide action for health, required exciting the medical informatics community, health information technology (HIT) vendors, behavioral health specialists, and clinicians engaged in the use of HIT to improve health.

One way to stimulate innovation in personal health records is to encourage designers to think about separating the unique aspects of an application from the infrastructure needed to support the application. Unique aspects of an application include the specific components, such as blood glucose level capture and presentation or nutritional advice based on food preferences. The infrastructure dimension includes general health information and technical functions that undergird the application. These might include core data elements, such as medications, laboratory results, allergies, diagnoses and family history, and technical services, such as message handling and access controls that can be shared by multiple applications. For example, two personal health applications could include a medication management tool that would alert someone when it was time to take one of his or her medications and a tool that could help someone minimize medication expenses by searching the Internet to offer generic substitutions or discover the lowest available prices.

Both of these applications would rely on access to an accurate, up-to-date medication list, which could be provided as part of a common platform. Having a standards-based common platform with open application programming interfaces (APIs) and a highly flexible architecture could stimulate greater competition and innovation in the development and marketing of PHR applications, which could lead to a greater diversity of products and services.

Encouraging designers to develop PHR applications that can easily enter the public domain represents a second approach to stimulating innovation. The contemporary proprietary approach to software development contributes to a legacy of non-interoperable applications. Lay people face many health problems concurrently, and a proprietary approach to PHR development necessitates that the individual cope with multiple stand-alone, potentially incompatible tools to manage their health information and health practices. Project HealthDesign promoted a new vision of development, one in which a range of applications rest on a common data exchange platform, all developed within a public-domain approach to software development.
Nine innovative demonstration projects emerged under the Project HealthDesign initiative. Video stories, software products, and documentation can be viewed at www.projecthealthdesign.org. Two projects addressed medication management. The Vanderbilt team built “My medi-health” – a cell-phone enabled medication alerting, dispensing, and recording system for use by children who need to take medication throughout the day. A bar-code scanner and hand-held computer display was built by the University of Colorado team to assist elders returning home from hospital care with reconciling new medications with existing medications. The way adolescents integrate technology, friendships and health prompted a team from the Art Center College of Design and Stanford University to devise a health/time line to improve adolescents’ coping independently with complex health problems.

The University of California-San Francisco team created a public-domain integrated calendaring system that helped women facing breast cancer treatment to incorporate their treatment schedule with important family and work events, thus supporting optimal function during a crisis period. Using a hand-held device the University of Massachusetts team built a tool to help patients with non-cancerous pain better understand what aggravates their pain and what responses are most effective.

Three teams dealt with patients with metabolic syndrome: the RTI project implemented a proven behavioral-change strategy in a web environment; the University of Washington team developed a cell-phone/glucometer linkage to support insulin management between office visits and the Joslin/TRUE team created iGoogle gadgets to provide throughout-the-day decision support to patients with unstable diabetes. At the University of Rochester, a computer science team investigated natural language tools to guide patients in a self-assessment. These tools demonstrated two important advances in PHIMS design: patient-centered design leads to devices that fit into everyday living and public-domain approaches lead to significant sharing and innovation.

Technical challenges

Two major classes of technical challenges must be addressed to make the applications envisioned in these projects fully functional. The first set includes a range of tools needed to capture and display data in real time. For example, some of the proposed PHR applications required a way to capture and record the food consumed or the activities undertaken in the course of day to day activity. Applicants envisioned using videophones, diaries contained on personal digital assistants or web sites, and audio recordings to capture these data. The second technical challenge focused on the need to extract data from electronic clinical records or personal health records. Many challenges exist in this arena: identity, authorization and authentication management, efficient tools for locating and extracting information from clinical records, language and message standardization to insur that information drawn from disparate sources can be integrated into a single view.

The potential of creating useful personal health applications can be defeated by the technical challenges that underlie effective electronic information capture, transfer, and integration. These challenges are not unique to the personal health records arena; indeed, devising effective strategies to integrate data from different electronic health records would benefit the entire health IT industry and health care as a whole.
Nonetheless, it is through envisioning the potential of personal health records that it will be possible to enumerate the challenges common across various applications and begin to set priorities for solving them. By envisioning the technical challenges that are common across multiple personal health applications we hope to stimulate development in this area. Rather than having each PHR and personal health application solve the same technical challenge repeatedly and potentially in a suboptimal manner, identifying the common shared challenges will allow creating common, shared solutions.

**Conclusion**

The future for PHIMS that can support health promotion actions is bright and vibrant! PHIMS may provide the technological support to patients that enable them to better engage in health care services and health promoting behaviors. PHIMS can extend nurses abilities’ to support patients’ toward self management. Technical challenges and ethical, legal and social issues, while daunting, may be best addressed through new approaches that address the context where personal health information management occurs. PHIMS hold great promise to engage lay people worldwide in health promoting behaviors and full realization of the benefits of contemporary health care.

**Acknowledgement**

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Usability Considerations for Personal Health Information Management Systems

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Introduction

There has been minimal emphasis on usability considerations for personal health information management systems (PHIMS) despite decades of research and theoretical model development that have linked usability with acceptance and use of technology, in general, and in health care (Davis, 1989; DeLone & McLean, 2003; Venkatesh, Morris, Davis, & Davis, 2003). Only few studies have applied usability testing methods in consumer-oriented application domains such as a text summarization system (Kushniruk et al., 2002), online health information searching and appraisal (Eysenbach & Kohnler, 2002), telemedicine for case management of elderly patients with diabetes (Kaufman et al., 2009), smartphone for diabetes self-help (Arsand, Olsen, Varmedal, Mortensen, & Hartvigsen, 2008), and smart home features for older adults (Demiris et al., 2006). Several authors (Arsand & Demiris, 2008; Kushniruk & Patel, 2004) have emphasized the need for application of user-centered usability approaches to systems designed for direct use by consumers or patients.

The overarching premise of this paper is that there is a critical need for usable tools that support high-priority tasks for personal health information management. In this paper, we present a model for framing usability for PHIMS, identify key issues related to usability of PHIMS, describe two scenarios of PHIMS use, propose a set of foundational principles for usable PHIMS, and provide a brief overview of methods for assessing and enhancing usability for PHIMS.

Framing Usability for Personal Health Information Management

Usability has been defined by multiple authors; some definitions focus primarily on the ease of use of a particular product or system while others also take effectiveness or usefulness into account. For this paper, we use the International Standards Organization (ISO) definition which states that "Usability is the effectiveness, efficiency and satisfaction with which specific users can achieve a specific set of tasks in a particular environment" (Schoeffel, 2003) (p. 6)." This definition is consistent with an earlier model by Bennett (Figure 1) which illustrates the relationship between user, task, and tool in an environment (Bennett, 1984). The ISO definition and Bennett’s model highlight the fact that usability of a particular tool may vary across users, tasks, and environments.
During our brainstorming sessions, we created a framework to help us organize our thinking regarding usability in the context of PHIMS (Figure 2) and guide our development of foundation principles for usability. The core of the model is a set of user goals that generate associated tasks in order to achieve particular health outcomes. Task completion is facilitated by various data sources, a common technical architecture, and tools with specific features and functions in the context of an environment.

**ENVIRONMENT**

*Figure 2 - Framing Usability for Personal Health Information Management*
Key Issues Related to Usability of PHIMS

Key issues related to usability of PHIMS can be considered according to the four components in Bennett’s model: user, task, tool, and environment.

User

A number of user characteristics influence usability. These include having the mental and physical abilities to use a particular tool or system. Levels of health literacy, functional literacy, numeracy, and competency with information technology also influence the extent to which a tool is considerable usable for a particular task and user (Ancker & Kaufman, 2007; Chang et al., 2004; Gerber et al., 2005). Age (Czaja & Lee, 2003) and culture (Moen, Gregory, & Brennan, 2007) also affect usability and must be considered in design decisions. A key issue that must be addressed is identification of the perceived value and benefit to the multiple users who may have different tasks to achieve. For instance, the PHIMS may be perceived as directly beneficial for managing one’s own care or supporting care done on the user’s behalf (e.g., clinician use). On the other hand, patients or consumers and their families may not perceive as valuable secondary uses of PHIMS data for quality assurance, clinical research, and comparative effectiveness research since no direct benefit is apparent.

In a recent systematic review that focused on patient acceptance of consumer health information technology (CHIT), Or and Karsh (2009) found that only seven of 52 studies addressed usability factors in spite of strong evidence showing that perceived ease of use and usefulness predict acceptance of CHIT. They concluded that future research is needed to address human-technology interaction variables in this application area.

Task

Despite strong theoretical and empirical linkages regarding the importance of technology-task fit (Goodhue & Thompson, 1995), there has been little research about personal health information management tasks. One notable exception is a study by Moen and Brennan that examined the manner in which health information management occurred in the household (Moen & Brennan, 2005). A clear understanding of the tasks of personal health information management is a necessary prerequisite for usable PHIMS thus it is important to apply task analysis techniques to inform user-centered design.

Tool

Conceptualization and design of PHIMS must evolve beyond existing tools such as personal health records (PHRs) and patient portals which are frequently based upon electronic health record data and models. While such models meet many needs (Tang & Lee, 2009), they are likely insufficient for self-management tasks across health promotion, disease prevention, and illness care. Moreover, they may not meet the needs of adolescents and young adults who are more accustomed to social networking approaches and platforms (i.e., Web 2.0) than more traditional web-based platforms.
There are relatively few reports of user-centered design in proportion to the rapidly increasing number of PHIMS. User-centered design is critical to the achievement of usable PHIMS (Arsand & Demiris, 2008; Kushniruk & Patel, 2004). Consequently, it is important to incorporate methods such as those specified in Table 1 as part of the iterative system development life cycle.

Table 1 - Methods for Assessing and Enhancing Usability

<table>
<thead>
<tr>
<th>Primary Purpose</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>User Analysis – characterize intended users in terms of demographic characteristics, computer literacy, familiarity with domain</td>
<td>Survey, interview, observation, personas</td>
</tr>
<tr>
<td>Environmental Analysis – specify physical and sociocultural environments in which system use is to occur</td>
<td>Observation, interview, focus group</td>
</tr>
<tr>
<td>Task Analysis – identify user goals and how system should support achievement of goals</td>
<td>Survey, interview, laboratory study, field study</td>
</tr>
<tr>
<td>Representational Analysis – identify external representation that best supports user tasks</td>
<td>Low-fidelity prototyping, user sketching exercise</td>
</tr>
<tr>
<td>Heuristic Evaluation – identify heuristic violations in prototype user interface through expert inspection</td>
<td>Survey, think aloud protocol</td>
</tr>
<tr>
<td>Comparison of Designer and User Mental Models – discover mismatches between mental models of designer and users</td>
<td>Comparison of designer and user times for completing scenario-based tasks such as keystrokes, clicking, thinking; cognitive walkthrough by analyst (including identification of goals, sub-goals, system responses, and potential problems) and comparison of user behavior with analyst behavior</td>
</tr>
<tr>
<td>Small-scale Laboratory Study – determine if system performs as desired in controlled environment</td>
<td>Think aloud protocol, survey (may include behavioral intent to use), interview</td>
</tr>
<tr>
<td>Pilot Study – determine if system performs as desired in realistic environment</td>
<td>Observation, log file analysis</td>
</tr>
<tr>
<td>Satisfaction – assess user perceptions of system ease of use and usefulness</td>
<td>Survey, interview, focus group</td>
</tr>
</tbody>
</table>

Environment

Physical environmental factors (e.g., noise, light) can positively or negatively influence individuals’ abilities to use technologies such as PHIMS effectively and efficiently (Or & Karsh, 2009). Other environmental factors such beliefs and values of a community or group may also affect the extent to which PHIMS are considered usable. For instance, in a culture in which the clinician is expected to take all responsibility for an individual’s health, patients may not perceive PHIMS as useful tools. Other environmental challenges are those related to a lack of clear governance structure, support for sustainability, and confidence in the security of the information contained in PHIMS.
User Scenarios

Two user scenarios (below) illustrate a future vision of PHIMS functionality and motivate the foundational principles for usable PHIMS described in the next section.

1. Sandwiched Mom

Katharine is a 50 year old single working mother of two children (Andrew and Sarah). Her mother, Margaret, lives nearby. Other family details include:

- Son Andrew is 18, and is going off to college in distant state
  - Has asthma which has been typically well-controlled
  - Albuterol inhaler as needed and rescue medications prn
- Daughter Sarah is 15 years old, beginning high school
  - Going to sport camp
  - History of right knee injury related to playing soccer
- Mother Margaret is 80; lives alone in two-story large old house with large yard
  - Enjoys gardening
  - History of hypertension – Norvasc & Hydrodiuril twice daily
  - Recent fall on ice this past winter but no fracture
  - Recent death of spouse with subsequent depression, sleeplessness, loss of appetite and weight loss
  - Nurse practitioner (NP) recently recommended the installation of sensor devices to monitor activity and assess potential for falls.

Katharine has full access to her 15-year old daughter’s PHIMS, has been granted full access to her mother’s PHIMS, and has partial access to son’s PHIMS. This morning she received a text message from the nurse practitioner indicating that she would like to have a chat about sensor alerts received regarding mother’s movement around her home.

Three (non-disruptive) reminders have been posted at Katharine’s health dashboard: 1) schedule immunizations for daughter, 2) authorize release of son’s immunization records, and 3) schedule colonoscopy per guidelines as warranted by a positive family health history. In this scenario, the key users are the individual (i.e., Katharine), family members, and clinicians. Possible health-related tasks for Katharine and her family are listed below.

Possible Tasks for Katharine

- Arrange videochat with NP regarding sensor alerts via secure messaging
- Check Margaret’s medication monitoring box remotely to see if medications removed as expected
- Authorize general practitioner (GP) to grant access to son’s health history, including recent pulmonary function tests, to new GP, pending son’s agreement.
- Order a refill of Andrew’s asthma control medications.
- Review prescription refill records for Andrew’s rescue medications (notes that these are being refilled with increasing frequency); send secure message to GP.
- Search for free immunization clinic being held in the area.
- Search and compare clinician ratings/prices for colonoscopies or schedules with hospital per clinician recommendation.

**Possible Tasks for Andrew**
- Andrew has already negotiated with his mother the areas of the PHIMS that will have shared access (e.g. ability to see medications used and order refills). Today he authorizes the future release of information from GP
- Link the GPS application on cell phone to pollen count in order to graph the time of day he should schedule his run
- Synchronize his rescue inhaler to software application that records amount of medication, time and ambient pollen count
- Send a text message to “The Vault”, a private area to record personal reflection, experiences, and stories.

**Possible Tasks for Sarah**
- Upload the data from the pedometer on her shoe and graph her progress with an application that links her data with her friends’ in friendly competition for a “walk around the world”
- Respond to a text message from “The Vault” asking for a short reflection on “My Proudest Moment” by creating a photo collage and adding a short narrative.

**Possible tasks for Margaret**
- Play a few rounds of sudoku on the computer (for mental stimulation and maintenance of function)
- Record personal reflections in electronic diary
- Participate in a discussion board for those who have recently lost a spouse.

This user scenario illustrates the seamless integration of multiple data sources, formats, and technologies including sensor devices (pedometer, smart home devices), GPS, text messages, gaming data, existing electronic health record, community service kiosk, pharmacy refill records, medication vehicle (inhaler), and personal reflection narratives.

2. **Data Mining Nurse**

In 2009, national statistics demonstrated a significant escalation in the incidence of Type II diabetes. One culturally-diverse region had a particularly high rate which was continuing to increase annually within a population of 1.5 million citizens. The Ministry of Health provided funding to five nurse practitioner-led primary care clinics to implement an electronic solution to address this situation. The research team representing each of the clinics identified five PHIMS modules that could be used to monitor and understand the self-management and the experience of Type II diabetes patients with in the region:

- Culturally-appropriate, age-sensitive educational modules (system log files automatically capture use of the modules in order to calculate an educational intervention “dose”)
Dietary intake monitoring
Weight and BP monitoring
Continuous blood glucose and HbA1c monitoring
Experiential narratives.

Every diabetic patient within each of the clinics was asked to incorporate these modules into their PHIMS and consent to participation in the research. The study was designed to monitor all participating patients for a one year period. Regardless of data source or structure, all data are stored in a common clinical data warehouse.

In this scenario, the tasks are described from the perspective of the nurse researcher thus illustrating secondary rather than primary use of PHIMS data. Researcher tasks include extraction and linkage of data from various sources (e.g., electronic health record, scheduling system, laboratory system, medical devices [weight, BP, blood glucose], and patient narratives) that populate the data warehouse and subsequently anonymisation prior to data analysis. The researcher may wish to apply a natural language processing tool to extract and encode data from the patient experiential narratives. Other researcher tasks include calculations (e.g., dietary intake, education “dose”) and application of a variety of data mining algorithms.

**Foundational Principles for Usable PHIMS**

We generated twelve foundational principles for usable PHIMS (Box 1, below) based upon our knowledge of the literature, personal expertise, brainstorming sessions, and the model and user scenarios that we developed. The principles address breadth of content and users as well as features and functions.

**Methods for Assessing and Enhancing Usability**

A number of authors have highlighted the importance of assessing usability throughout the system development life cycle and proposed triangulation of methods to maximize what is learned (Arsand & Demiris, 2008; Jaspers, 2009; Johnson, Johnson, & Zhang, 2005; Kushniruk & Patel, 2004; Wilson, 2006). Kushniruk and Patel (2004) note that cognitive and usability engineering approaches typically encompass four aspects: 1) characterizing the ease with which a user carries out a task using the system; 2) assessing how users attain mastery in using the system; 3) assessing system effects on work flow; and 4) identifying user-system interaction problems. Table 1 above provides a brief overview of the major approaches for assessing and enhancing usability. A more detailed review of methodological approaches is given by several authors including Kushniruk and Patel (2004), Johnson et al. (2005), and Jaspers (2009). Not all methods have been specifically reported in regards to PHIMS. However, several authors have demonstrated methodological triangulation across the system life cycle for consumer-oriented systems that may serve as examples for others. Three illustrations follow.

Ruland et al. (2007) and Ruland, Starren, & Vatne (2008) engaged healthy and ill children at different stages in the development of SISOM, a support system for children with cancer that elicits symptoms/problems in a child-friendly, age-adjusted manner. Children without cancer contributed to: the graphical design of the system's interface;
selection of understandable, child-friendly terms used in the system; and iconic and graphical representations through the use of scenarios and role playing. Children with cancer performed usability tests of SISOM using a think aloud protocol in the hospital setting.

Lai and colleagues published a series of studies about the development of a web-based system for management of depressive symptoms in persons living with HIV/AIDS (PLWH) that included: 1) focus group with caseworkers (Lai & Bakken, 2006a) to discuss mental health needs and physical and sociocultural environment of potential system use by PLWH; 2) heuristic evaluation (survey and think aloud protocol) with usability experts to detect usability principle violations in prototype user interface (Lai & Bakken, 2006b); and 3) laboratory study with PLWH (think aloud protocol and survey) (Lai, Larson, Rockoff, & Bakken, 2008). Arsand and Demiris ((2008) and Arsand et al., (2008) described a longitudinal process in which persons with and without diabetes participated in the design of a mobile tool for supporting lifestyle changes (e.g., physical activity, nutrition) among people with Type 2 diabetes. Methods included focus groups, paper prototyping and sketching, questionnaires, and participant homework between the focus group sessions.

**Box 1 - Foundational Principles for Usable PHIMS**

1. Intentionally target content, features, and functions to health goals and outcomes
2. Encompass disease prevention, health promotion, and illness care across the life span
3. Support primary (individual, family, clinicians) and secondary users (payors, system planners, public health, quality management, researchers, social services)
4. Accessible by users with of different ages with varying levels of health and computer literacy, cognitive and physical ability, and different cultural backgrounds
5. Visualize and integrate data and information (user configurability) according to user needs (e.g., age, physical ability, cognitive ability, literacy level) and preferences (e.g., push vs. pull) in a manner that provides cognitive support
6. Support user learnability and memorability
7. Include user involvement from requirements specification to evaluation in a manner consistent with user-centered design
8. Integrate data information, and knowledge sources and data types (e.g., coded, unstructured text, voice, video, sensor, environmental data) including those reflective of the patient’s interpretation of their experience
9. Represent data, information, and knowledge in a manner that is executable and actionable where appropriate
10. Display multiple data sources and types on a variety of information and communication technologies
11. Integrate current and evolving healthcare standards
12. Assure private and secure communication, including management of identities, roles, and permissions, and support for audit trails
Conclusions

With notable exceptions, there has been little attention in the published literature to usability considerations of PHIMS. The twelve foundational principles that we generated provide guidance for developing usable PHIMS and can form the basis of an assessment of PHIMS. Application of user-centered design principles and triangulation of usability assessments across types of users, methods, settings, and phases of the system development life cycle will enhance the usability of PHIMS.

References


Technical and Infrastructure Requirements for Personal Health Information Management Systems

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Introduction

Technical infrastructure, tools and standards for personal health information management systems (PHIMS) are essential for achieving their use by persons so that they can achieve their health goals. This chapter discusses how the requirements for PHIMS determine the infrastructure, tools and standards that are necessary, and vice versa: how the existing infrastructure, tools and standards will influence PHIMS. The goals of the chapter are to:

- identify high level consumer requirements of PHIMS to facilitate understanding of the technical issues
- discuss how the technology, infrastructure and tools can assist consumers in meeting health goals, making informed decisions and influencing the decisions of others
- identify infrastructure, tools and standards that meet consumer requirements and that can handle information access, recording, managing, viewing, communication, controlling, reminding, prompting, alerting and more
- identify responsibilities and consequences as a method for development and use of PHIMS
- suggest different assessments of PHIMS technology.

The starting point for discussion of technical aspects of PHIMS is to relate them to consumer health goals and then to identify consumer requirements from such systems. The different infrastructural components and tools are then described, with an overview of the types of PHIMS systems, infrastructural demands and solutions. Standards that are required to achieve appropriate use of these systems are discussed and a framework provided for PHIMS assessment on three levels: individual, population and technology. The chapter ends with recommendations for practice and research.

People’s Requirements from PHIMS

Each person, group or community will have different requirements from PHIMS, depending on their health goals and context. These goals and requirements would often be identified by the person, group or community person as they consider how they will interact with health systems, providers and others in pursuit of their goals.
If the professional and cultural context supports the person/group/community to be a partner in the healthcare process, these requirements may be identified as part of nursing assessment, as the participants together identify whether and how to integrate PHIMS into the plan of care. In other cases, the idea of PHIMS may be introduced by the nurse so that people can consider whether and how they prefer to interact with information and communication technologies.

Categorisation of general requirements for PHIMS is useful as a starting point for understanding the domain and developing practice. This categorisation can be done from a number of perspectives such as functional or usability requirements. Here we consider general, person centred PHIMS requirements to underpin the discussion of infrastructure and standards. These reflect the current state of knowledge about the use of Information and Communication Technology (ICT) by healthcare consumers from sources such as Fox and Jones (2009); many of these requirements would also apply to a group or community.

The list of requirements for PHIMS is based on an assumption of personal health goals that include:

- being able to understand a health issue and the way it is managed
- being able to make informed healthcare decisions
- self management of health, well being or illness (often in partnership with health professionals)
- obtaining advice and support from others in similar situations;
- being supported to remain at home / independent.

Person-centred PHIMS requirements to meet these general healthcare goals include being able to:

1. access and download health information from trusted sources
2. access and download my health information that is held by providers and others
3. organise and manage my health information so it supports me to be proactive in managing my health / illness
4. manage a health related diary / schedule;
5. maintain a personal health record;
6. control access to and use of my health information (based on secure ID management);
7. gather, view and make sense of data about my health status;
8. send data to provider or other about my health status, treatment variance etc;
9. communicate with providers and others, for example, to ask questions or request appointments;
10. receive reminders, prompts, alerts and advice – including personalised health decision support.

Specific health goals and related requirements are the starting points for integration of information and communications technologies into health management plans, for the person, the group or the community. Once these are identified and agreed, the appropriate infrastructure and tools can be identified.
**PHIMS as a Subsystem of the Care Relationship**

System analysis is the separation of systems into components for further study, which usually consists of examining the influence of one or more components on system performance (Roemer, 1991). With respect to PHIMS, we see many interacting components, each of which is a large system by itself. To fully understand the technical and infrastructure requirements for PHIMS we need to be able to see what system components are present and interact with each other. The Soft System Methodology (SSM) is used as a guideline for this purpose (Checkland, 1984; Checkland and Scholes, 1990).

**Soft Systems Methodology**

Checkland (1984) delineates human activity systems, of which PHIMS are one example, as processes in which an ever-changing social world is continuously re-created by its members for some meaningful purposes. According to Checkland (1984), perceived problems in human activity systems are usually ‘soft’, ill-structured problems of the real world. He developed the SSM to be able to manage unstructured problems. This methodology consists of a logical stream of seven stages. In a later publication Checkland and Scholes (1990) argue that the logical stream is too often seen as a linear process, which it definitely is not. It is possible to start the SSM in any of the stages and to apply it in a cyclical and recurrent process. Further, additional approaches in SSM concern problem solving, the social system, and the political system. The cultural stream deals with the intervention, the social changes and the power based aspects of human affairs (Checkland and Scholes, 1990). Here, we use the logical stream as a guide for describing the relevance of PHIMS to individuals and for the relationship of PHIMS to the infrastructural components required for their use.

**Seven Stages of the SSM Logical Stream**

The first stage of the SSM consists of different descriptions of the system, including problematic areas. Since technology itself has no value but will permeate value laden systems, introduction of new technology itself is problematic (Kunneman, 1986). In stage two, a viewpoint or, better still, several viewpoints are selected from which to further study the problem situation. Here the structure, the process and their relationships are displayed so that a range of possible and relevant choices can be revealed.

Stage three consists of a ‘root’ definition: a concise description of a human activity system. Root definitions can be considered as hypotheses concerning the eventual improvement of the problem situation by means of implemented changes. The core of a root definition is a *transformation* process, the means by which defined inputs are transformed into defined outputs. We can relate that to PHIMS when we discuss the need for PHIMS that meet consumer requirements (inputs), and determine an implementation strategy to achieve this (outputs). Further components of root definitions are: the owner of a problem; actors that carry out the system’s activities; customers or stakeholders affected by the system; in the PHIMS context, the infrastructural constraints; and finally, a series of ‘Weltanschaungen’: outlooks, frameworks or images which make this particular root definition meaningful.
Stage four answers the following question: What activities, in what sequence, must be done to do the transfer i.e. to achieve the required technical infrastructure? The system is seen as an entity, which receives some inputs and produces some outputs; the system itself transforms the inputs into the outputs. This stage is usually represented in conceptual models.

In stage five the problem situations, as expressed in stage two, are examined alongside the conceptual models to generate debate about possible changes to improve the problem situation: desirability and feasibility are the core issues here. During stage six, after several iterations and improvement of inadequacies in the initial analysis or root definitions, the discussion moves to possible changes. Three kinds of changes are possible: in structures, in processes and in attitudes. Also, the proposed changes must be desirable with respect to solving the problem situation, and feasible with respect to its acceptance in the culture of the system. Finally, in the seventh stage the proposed and accepted changes are implemented and evaluated.

**Subsystems that serve systems**

According to Checkland (1984), it is possible to identify subsystems in a particular system that are systems in their own right. These subsystems may again have sub-subsystems. However, if system B serves the purpose of system A, then it is not possible to form a root definition and conceptual model of B without first doing so for A. In the context of PHIMS, the relationship between the person and/or family and health care providers are considered to make up the root system. Human beings have needs with respect to their health, and there are professionals who can help them improve their health status.

Thus, this person-to-person relationship serves as system A according to Checkland’s methodology. Then, the health system at large is a system that serves the purpose of health care delivery to individuals (system B). Since we are not looking at health care itself, but at PHIMS, these technologies must be defined as subsystems of A and of B. Further, we need to make a distinction in the kind of technology a consumer wishes to use to achieve his or her personal health goals (system C), and the information for personal health that is available and used in health care at large (system D). Note that system D here refers to PHIMS for particular patient populations.

We now have four interrelated systems: health goals and actions taken to achieve them defined as a human activity at individual level; support for achieving goals with PHIMS in whatever fashion for that person; the health care delivery system addressing the individuals goals and actions; and the PHIMS infrastructure supporting both the individuals PHIMS and health care delivery models.

This is illustrated in Table 1 below, and should be read to mean that subsystems B, C and D all serve (the many million instances of) system A.
Table 1 - Four identified human activity systems in health care that are relevant to this discussion with respect to PHIMS.

<table>
<thead>
<tr>
<th>Health care</th>
<th>Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual level</td>
<td>A</td>
</tr>
<tr>
<td>Group or Aggregate level</td>
<td>B</td>
</tr>
</tbody>
</table>

**Discussion**

Viewing PHIMS as a subsystem of individual health care helps to place it in the right perspective. At present, this subsystem is not a very controlled environment and an individual might choose to use a practical, but perhaps less safe system. Once the PHIMS begin to interact with the electronic health record (EHR) held by the health care provider organisation and with other health care systems, additional regulations and methods come into place making the environment more controlled. A comprehensive PHIMS infrastructure and technology needs to become available in order to have secure and interoperable systems that meet requirements and adhere to established standards.

**Infrastructure and Tools**

There are three main approaches to PHIMS (Tang et al, 2006; Miller et al, 2009). The first approach is a freely available software package on a stand alone machine. This requires manual maintenance, manual data entry and manual data management. Miller et al (2009) argue that stand alone versions can support data entry by the consumer, have separate log in for staff, and are not integrated or only partial integrated with an EHR.

The second approach is dedicated web-based health records like Google Health or Microsoft Health Vault among others. An individual has to do his own data management, and the personal record is not connected to the provider EHR. This kind of system is independent of location and machine, and is accessible where there is an internet connection. The third option is that the PHIMS functionality is provided by allowing individuals to view their own health data in the EHR managed by the health professionals. There are multiple technical options for this approach but all are under control of the professional.

**Infrastructure Requirements for PHIMS**

The International Standards Organisation (ISO) is working on a standard for the personal health record (PHR), a major aspect of PHIMS. Five axes for classification of PHRs are currently proposed as listed below.
Five axes for classification of personal health records are:

1. the scope of the information in the PHR
2. access control,
3. custodianship of data,
4. audit of the repository and access, and
5. interoperability with provider EHRs (ISO, 2009).

The work on this international standard was commenced at the end of 2009 so cannot be presented here. However, we can give an overview of functions or areas of concern to PHIMS and how they serve the needs of individuals, based on an understanding of the technology in current use. An example is the conceptual model of technical requirements has been developed by the Healthcare Information and Management Systems Society (HIMSS) personal health records (PHR) technical work group (2009). This model is comprised of: security and privacy, standards, interoperability, data integration, system architecture, reporting, and technical support. Recognising that PHIMS is a concept in development, we provide here an initial set of 11 draft requirements for the technological infrastructure that is needed to realise people’s health goals.

A first requirement for the infrastructure is a means for managing a person’s health related data. This can be any data, for example, about vaccinations, medications, diseases and treatments in the past, test results and so on. Beside this traditional disease related information, more health oriented data can also be managed. For example, about self management of conditions including weight control, blood sugar levels and so on. We are beginning to see individuals managing more health related information, for example, keeping exercise diaries and using images, graphs, tables and other formats to identify progress and manage their personal goals. Even in these early days of PHIMS, we do not see any restrictions on the information that can or could be handled in PHRs, particularly when free text fields are available. So the first requirement is that PHIMS can support management of any kind and any amount of information.

A second core requirement for the infrastructure is the management of identities. The person needs to be securely identified as the right individual about whom data are entered and managed in a PHIMS. A simple username and password protection system might not be sufficient. Some countries have experimented with health cards that allow greater levels of security. Authentication measures may also be needed so that the professional can be certain that a person is indeed who he or she says he or she is before setting up access. In the same area of concern is access control of others. This third requirement relates to PHIMS by significant others such as parents for their young children, or the child or spouse of an older person. It includes access by professionals and other caregivers: can their identity be authenticated, and can their authorization and credentials be checked? Both organisational and technical measures are required, including recording of professionals and their credentials in national professional registries and licence systems. Technical measures include setting up of authorisation profiles, the use of access cards with encrypted information, and password / pin code protection.
A fourth area of concern is the custodianship of data. Depending on whether the system is stand alone, internet based or EHR linked, the custodian might be different. The person will have ownership of his or her stand alone system. Those offering internet based PHIMS need to take care of the data and allow access to the individual but what happens in case of the system going down, or discontinuation of such a system? A specific requirement here is for measures that allow downloading of the information in a structured format in case of discontinuation. Further, timely informing clients of such events should be part of the legal infrastructure guiding PHIMS.

A fifth requirement is for an audit trail of the data repository, in particular the logging of access and the entry, use, deletion and communication of data. Such audit trails help detect any unwanted activity so that appropriate action can be taken. Next, is the use of data standards and terminologies which are required to support interoperability and communication between PHIMS and other systems, particularly data exchange with EHRs. Electronic communication between the individual and the health provider will depend on the type of systems used. There are a number of data exchange standards available such as those published by the Health Level 7 (HL7) standards organisation (www.hl7.org). Additional communications can be developed with medical devices. For example, the automatic retrieval of a blood glucose value from a blood glucose meter into the PHIMS (and EHR) and downloading of blood pressure recordings from a blood pressure meter are currently possible provided both systems adhere to the same standard. This issue of interoperability is further discussed in the section on standards below.

Area 7 is about the architecture of health care ICT into which PHIMS must fit. A multi-modal approach seems required to allow for a diversity of developments. In addition, a multiple platform infrastructure seems necessary, in particular if the PHIMS and EHR are not internet based. The whole architecture for PHIMS depends on linkages of many tools, gadgets and systems – it is only by applying the appropriate standards that integration of data from different sources can be achieved. Area 8 concerns the use of data by the individual for monitoring, assessing and perhaps even controlling health. When different data are combined, the PHIMS can support decisions from reminding about appointments or prompting to take a pill, to alerting about a too high or too low value of blood glucose. Such functionality requires careful testing and risk management as it could introduce new safety risks or potential for error. The PHIMS should help the person to manage his or her health information in order to support proactive self management (in time, fitted to the person’s behavior and habits). A question that is yet to be addressed in relation to the use of data from PHIMS is whether health care and other organisations should be allowed to obtain data from PHIMS for aggregate purposes such as quality assurance and health statistics.

Area 9 deals with the communication infrastructure, particularly the spread of broadband, cellular access, or other upcoming technologies. Does the individual who wants to use a PHIMS have sufficient access to such an infrastructure? Is it available and is it affordable? Choosing a PHIMS supplier is part of this requirement area. Allowing individuals to choose their own, versus have them use a required infrastructure will have impact on vendors that have to conform to communication and safety and risk standards.
Area 10 relates to the financing and/or costs for PHIMS. Is PHIMS functionality something a professional should request from the vendor to be included in the EHR? Does an individual have to pay for it, or is the health insurance paying because it saves in the long run? Due to cost factors, individuals, consumer groups or professional groups may decide to create their own PHIMS, use a commercial supplier or a PHIMS offered by a healthcare provider, insurer, or employer. Each of these options can include a free versus a paid system with varying risks including the availability of long term support, disengagements, moving between jobs, vendor going out of business, and so on. Finally, area 11 is the requirement for a social-legal-ethical infrastructure to be in place in order to ensure a safe and interoperable infrastructure and measures in case of violations.

It is apparent from this draft set of requirements that the infrastructure must accommodate the wishes of clients for PHIMS use. Depending on the type of system they choose, different areas of concern and both organisational and technical infrastructures come into the picture and require different operationalisation.

Standards to Support PHIMS

The standards required to support safe, effective use of PHIMS are the same regardless of the PHR or EHR model: stand-alone, web-based, provider-based, payor-based or employer-based models. They include:

- PHIMS functionality
- behavioural (Practice) standard & Process (work flow) standard
- information modelling and data standards
- terminology standard including consumer terminology
- technological standards including infrastructure, identity, confidentiality, security and privacy oriented technologies
- access control standards.

Even though there is increasing interest in PHIMS among governments, healthcare insurance plans, vendors and providers, consumers, and other organisations, there is no consistency in capabilities or approaches. Thus, it is important to align with standards to achieve interoperability between approaches and various components or elements of the PHIMS, to reduce risks of inappropriate or unlawful access or threats to data security, to increase adoption and decrease associated cost. In this section, we introduce examples of standards that are required with rationale and resources for each standard.

Examples of Standards

A standard for PHIMS functionality defines the set of functions that may be present in PHIMS to create and manage an effective PHR. It also offers guidelines that facilitate health information exchange among different PHIMS and between PHR and EHR systems according to other standards. Examples of standards for the PHIMS functionally include the HL7 Personal Health Record System Functional Model (PHR-SFM) and the ISO standard for PHR in development mentioned above. Practice standards are important to guide normal practice in a particular situation and to help clinicians to integrate PHIMS into clinical practice.
They provide guidance for nurses with a framework for practice. Practice standards for PHIMS could include guidelines for the complete personal health record in the PHIMS environment, implementing electronic signatures, consumer-provider e-mail communications, electronic data management, core data sets and use of voice recognition technology. Such standards also provide the industry with practical guidelines for areas that play an integral role in development of PHIMS.

To achieve interoperability of the data that is captured, represented and communicated in the PHIMS, we need to represent meaning through different approaches such as reference models, clinical data structures and clinical terminologies. Generic reference models such as ISO 13606 Part 1, HL7 Clinical Document Architecture, HL7 Care Record, and the openEHR Reference Model can be used to represent clinical data. Clinical data structure definitions such as openEHR archetypes, ISO 13606 Part 2, and HL7 Templates can be used to represent clinical information consistently. In particular, the approaches for Detailed Clinical Models hold promise for PHIMS interoperability, since they are more or less technology independent. All of these data standards depend on the proper data format or type, which is available in the ISO 21090 data types standard.

Clinical terminology such as SNOMED-Clinical Terms, LOINC and the International Classification for Nursing Practice can be used as clinical coding schemes. Health information in PHIMS needs to be understood by the people using the systems so should be presented without technical jargon. Databases of health information should include multiple descriptions of the same health items to accommodate users' differing levels of comfort with medical terminology. Unfortunately, no standard on consumer terminology is available.

Data exchange standards are needed to link and transfer between PHIMS and EHR systems. ISO 27931: 2009 is one of ISO/HL7 standards establishing an application protocol for electronic exchange of data in healthcare environments. Also, uniform data standards with definitions and formats for the PHIMS are necessary to allow the free exchange of such data between information systems.

A core requirement for PHIMS is that information is accessed by the appropriate persons for authorized use only. To help accomplish this, standards for authentication, authorization, audit trail, violation log management and review are necessary. ISO standards on Information Security (ISO IEC 27001: 2005) deals with access control in general and ISO/TS 22600-2:2006 specifies privilege management and access control in the health care environment. RFID (radio-frequency identification) and biometric technologies such as fingerprint, iris, and voice recognition can be used for identity management and tracking of consumers and healthcare professionals. However, unique identifiers often carry additional information on consumers and professionals colliding with privacy aspects. Thus it is very important to guarantee the required level of privacy at the same time. ISO TS 22220: 2009 deals with identification of subjects of health care; ISO TS 17090-1, 17090-2, and 17090-3 address the business requirements of identification as well as the data needs in order to improve the confidence of health service providers and subjects of care identification.
To preserve the security and privacy of personal healthcare information in the PHIMS environment, information security management standards providing process and controls for managing information are necessary. ISO 27001 and 27002 are among the most specifically defined standards defining an information security management. ISO 27001 and 27002 could provide the formal approach needed for security management in PHIMS environment. Another example of Security and Privacy standards are the HIPAA security and privacy regulations in the USA (www.hhs.gov/ocr/hipaa/).

**Discussion**

In order to achieve interoperability between various components of the PHIMS, it is important to align with standards. However, to develop a PHIMS based on standards is not an easy task because there is no agreement yet on what a PHIMS must contain. Also, since the available standards were not developed specifically for the PHIMS, we can expect some issues and problems when we try to implement them into a PHIMS. For example, the above mentioned standards might not be practical enough to use in the PHIMS because they are too general or too broad.

We need specific standards related to functionality, behaviour, work flow, information modelling, terminology, data, access control, identity, security and privacy for an interoperable PHIMS. It will be important to identify which of the existing standards can be used for the PHIMS and make sure these are properly implemented. In this context, the ISO work to work related to PHRs is an important development.
Realizing the Infrastructure and the Tools for PHIMS

This section focuses on realising the appropriate infrastructure and tools that are essential in deploying a PHMIS that supports desired health goals and individual / population requirements. Careful planning and evaluation helps to implement a PHIMS effectively. The ADPIE (Assess, Diagnose, Plan, Implement and Evaluate) approach is familiar in clinical patient care and can be utilised as a strategic planning tool for a PHIMS.

In the *Assessment* phase, the goals of implementing a PHIMS are defined, including desired health goals and individual or population requirements. What purposes is the PHIMS going to serve? What are the purposes for the individual, population, organisation or general health policy? Will the focus be on specific population (e.g. the elderly), disease (e.g. diabetes), care processes (e.g. reminders, alerts), health information (e.g. portals), exchange of health data or something else? Is there external pressure such as global trends that support the implementation of a specific PHIMS?

In the *Diagnosing* phase, the existing supportive or limiting forces are identified. Does the organisational / regional / national IT-strategy support new innovations and implementation of PHIMSS? What is the stage of organisational / regional / national readiness, both technical and managerial? A business case approach is recommended to prioritise, evaluate and balance between the population needs and requirements, and effectiveness and affordability of the PHIMS. The business case includes also expected benefits and risk assessment of the PHIMS. What are the perceived benefits and how can they be identified and measured? What potential human, quality, technical or time schedule related obstacles and barriers will be faced, what are their likelihood and impacts and how can they be realised? By what means can the potential risks be avoided?

In the *Planning* phase, the appropriate infrastructure with suitable tools will be designed, developed and built up. Building up the infrastructure may include basic issues like power supply, providing the broadband, designing websites etc. In this phase, means like community relations and strategic networking may be useful.

In the *Implementation* phase the plan will be put into action by methodically developing resources to accomplish the objectives identified in the plan. The implementation of PHIMS needs not only human and financial resources, but also educational and advisory support for the end-users. This support requirement needs to be supplemented by the infrastructure itself, and the tools required to deploy it. Finally, in the *Evaluation* phase, the outcomes of PHIMS need to be evaluated. Have the expected benefits been achieved; i.e. have the health goals or individual / population requirements been fulfilled and on what cost? Have the funds and other resources been used efficiently? Has the infrastructure ensured the optimal use of PHIMS? Evaluation may include a variety of measurements depending on the type of PHIMS in question.

Realising the appropriate infrastructure and tools that are essential in deploying a PHMIS that supports desired health goals and individual / population requirements does require a careful process of planning and evaluation. The five phases described above are one approach that can be used for that.
A framework for Assessment of PHIMS

Four kinds of assessments are required to support decision making about the use of PHIMS, two that focus on the potential users of technology and two on the technology itself. These are:

- person PHIMS assessment
- society / population PHIMS assessment
- health technology assessment
- nursing technology evaluation.

With the exception of health technology assessment, there is limited literature on these topics and there are few tools to support assessment and evaluation in practice. The scope of available evidence related to person and population assessment is illustrated by, for example, Hebert et al (2002) who investigated stakeholder readiness for home telecare diabetic support using a quality-of-care framework that addressed structure, process and outcome. Bertera et al’s (2007) studied the readiness of an elderly minority population to use various technologies for telecare. They found that the top five situations in which respondents would be receptive to new technology were all related to improving communications with a doctor or a nurse, especially when a medical emergency occurred. In Australia, Cummings and Turner (2009) investigated the influence of ICT on the health outcomes and experiences of patients with chronic obstructive pulmonary disease (COPD) some of whom were supported by an ICT symptom monitoring tool. Their findings highlighted the need to use of a variety of methodological approaches in designing and evaluating e-health projects.

A recent systematic review of patient acceptance of health information technology identified 94 different variables that were tested for association with acceptance (Or and Karsh 2009). Most of the variables were related to patients themselves, for example, their socio-demographic characteristics and previous exposure to health technology. They found no studies that examined the impact of social and task factors on acceptance and few that considered organisational or environmental factors.

In the Chapter on Integrating PHIMS into Clinical Practice the topic of person PHIMS assessment is addressed; here we introduce some principles related to population PHIMS assessment, provide a brief overview of health technology assessment and give an example of two approaches to nursing technology evaluation.

Society / Population PHIMS assessment

A wide range of assessment activities are needed to understand how PHIMS can contribute to sustainable support for populations’ and individuals’ health goals and their shift toward knowledge-based decision-making on health related issues. Even before health ICT is considered, there needs to be an understanding of the ‘e-readiness’ of the population. E-readiness is defined by the Center for International Development (2000) as ‘the degree to which a community is prepared to participate in the networked world’. It is measured by assessing ‘the community’s relative advancement in the areas that are most critical for ICT adoption’. A comparison of e-readiness assessment models and tools is available at: www.bridges.org/publication/128.
One example of the ways in which general e-readiness can be assessed is the Global e-Health Research and Training Program project in Pakistan (Khoja et al, 2008). Five readiness components are used in the readiness assessment for that project:

1. core readiness – including identification of need, dissatisfaction with the status quo, awareness, comfort with language, and comfort with technology
2. cultural readiness (Access) – including speed and quality of internet, hardware and software, internet availability and affordability, regular usage of computer and internet
3. learning – measurement of the minimum required knowledge and training in the community to use ICT
4. society - measurement of Internet use and interaction
5. policy - including ICT regulations, ethics, mandatory courses and increasing availability (Khoja et al, 2008).

Evaluation of technical infrastructure needs to include issues such as penetration of ICT including communication networks and devices (e.g. broadband, mobile telephones), power supply and (global) trends. There are many sources of data for this aspect of assessment, for example, the Organisation for Economic Cooperation and Development (OECD). In 2007, OECD reported that average in households with access to the Internet at home was 58 percent. The figure was highest in Korea (94 percent) and lowest in Turkey (8 percent). Internet access is most frequent at place of work or education in the Baltic countries whereas but in Latin America and China it is highest in Internet Cafes. Furthermore, 45 percent or more of adults in Luxemburg, Finland, the Netherlands, Iceland and Germany sought health information on the web. (OECD, 2008). It is clear that cultural factors are critically important in the assessment of populations for personal health information management.

The aims of population assessment in relation to PHIMS are to:

- understand the population readiness on a community or wider level in order to influence infrastructural developments
- support planning and implementation of PHIMS-related health/nursing interventions for the community (or wider level)
- support outcome measurement of PHIMS-related health/nursing interventions
- support health monitoring and delivery of public health services to the population
- relate the wider PHIMS context to assessment and care provision for the individual person
- evaluate the progress of developments and their impact/outcomes.

Decision making in the region or country related to PHIMS will depend on resources as well as the overall health strategy and the health IT strategy as the country reports in this book demonstrate. Consideration of any PHIM system needs prioritizing, evaluation and balancing between the population needs, and effectiveness and affordability of the PHIMS. These are the elements that need to be included into a business-case to justify the required expenditure of any PHIMS (see Figure 1 below).
Health Technology Assessment

Health technology assessment is carried out for many new technologies in healthcare. In particular the efficacy and efficiency of new medications, treatment methods and other technologies is investigated. Brender (2006) summarises a set of evaluation methods that would be applicable in health informatics in general. A selection from her methods overview would be useful in assessment of PHIMS. In particular, the assessment is a process of performing evaluation, verification and/or validation.

Verification is the act of checking well-defined properties against its specification, which can be done by stakeholders in PHIMS developments. Evaluation is the act of measuring quality characteristics of a technology. For PHIMS, that would imply evaluation of the content, technical bits and pieces and security measures, for example. Validation is the act of comparing properties of an object with the stated goal as a frame of reference, i.e. set of requirements. For PHIMS, that implies requirements must be set carefully against the goals and validated in a practice situation.

Nursing technology evaluation

The purpose of nursing technology evaluation is to support decisions about whether to integrate, or recommend integration, of a particular technology into the care of an individual, a group or a population. In the absence of literature on this topic we have used a framework from the Royal College of Nursing (RCN) in the UK as an example of the type of issues that need to be addressed in this type of evaluation. The RCN’s SAFE framework (see Box 1 below) and accompanying guidance was developed to help nurses assess the safety and effectiveness of systems that have been or will be introduced into a specific area of clinical practice (RCN, 2008).
Box 1 - Framework for nursing evaluation of health ICT systems (from RCN, 2008).

Systems and the way they are used must:

S  conform to STANDARDS
A  be ACCEPTABLE to persons using them
F  be FIT for purpose and practice
E  be supported by EVIDENCE
R  be RISK MANAGED throughout the system lifecycle

The most important component of this assessment framework is evidence. As would happen with any other innovation in health care, the nursing team make a judgement based on the evidence that is available about: fitness for purpose, acceptability, the success of risk mitigation actions and whether the technology conforms to standards (particularly safety standards). A balance must be found between, for example, customisation for usability and standards that must be followed for electronic communication, for safety or for legal reasons. The RCN framework is published as guidance only; it has not been validated in practice. Nurses are accountable for the techniques and tools they use in support of patient care and those they recommend for people to use for self care. There is a clear need to develop, test and disseminate practical tools to assist nurses in making decisions regarding the use of specific technologies and in supporting people in their own decision making. Perhaps the most important part of evaluation is risk management which begins with risk assessment.

Discussion

Nursing competence in PHIMS assessment needs to cover: person and population level assessment as well as health and nursing technology assessment. Decision making based on these assessments must be based on evidence of effectiveness. However, more research is needed to validate specific assessment and outcome measures for different clinical and cultural situations. A decision framework for integrating home telehealth into chronic illness care published by Hebert et al in 2006 is a useful starting point for moving from assessment data to plan and deliver interventions that will support the person in achieving health goals.

Conclusions and Recommendations

This chapter related PHIMS to consumer health goals and identified the systems and consumer requirements at a high abstraction level. Different infrastructural components have been discussed, presenting overviews of types of PHIMS systems, infrastructural demands and solutions. It is obvious that many standards are required to achieve safe and appropriate use of PHIMS. A project phasing is required to actually develop and implement PHIMS. The chapter finishes with an overview of assessment of health technology on different levels: person, population, health technology assessment and nursing technology evaluation.
Based on current understanding of the issues addressed in this chapter, the following recommendations for practice and research are made:

1. Detailed identification of health goals for the person, the group or the community is a precondition for decisions about PHIMS tools and infrastructure
2. Those at all levels making decisions in relation to PHIMS must identify the values that inform the decisions and the implications of their decisions related to the rights and responsibilities of stakeholders. The analysis of PHIMS with respect to systems and subsystems allows handling issues at the right level
3. Infrastructure requirements for PHIMS need to be further explored and defined; the 11 areas considered in this chapter provide a framework for this work as does the ISO standard for PHRs that is currently under development. Alongside technical areas, societal infrastructure needs to be addressed, for example, legal arrangements, payment structures and responsibilities for PHIMS
4. The realisation of a PHIMS requires a thorough ADPIE (Assess, Diagnose, Plan, Implement and Evaluate) approach in order to ensure optimal outcomes
5. PHIMS must in principle adhere to appropriate standards: clinical practice, workflow, data content, terminologies, and technological. In particular, measures for identity management are required and the application of the whole set of security and privacy protection standards.
6. Use of PHIMS implies consent and active engagement of the person. Where PHIMS is part of a health delivery strategy, there must be an assessment of the implications for those who choose not to engage or are unable to. Alternative strategies may need to be put in place to ensure that these people are not disadvantaged.
7. Research is needed to develop and validate assessment tools and outcomes measures for person and population PHIMS assessment tools for different clinical context and for nursing assessment and evaluation of PHIMS technology for practice.

References


Integrating Personal Health Information Management Systems into Clinical Practice

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Introduction

While many challenges await nurses as they assimilate technology into practice, the potential benefits of doing so include sustainable models of care delivery that extend limited resources and support consumers and patients globally in actively achieving positive health outcomes. Thirty years ago, Virginia Henderson described the nursing practice challenges associated with “preserving the essence of nursing in a technological age” (Henderson, 1979). Henderson defined the essence of nursing as: helping “persons, sick or well, from birth to death, with those activities of daily living that they would perform unaided if they had the strength, the will and the knowledge” to do so (Henderson, 1979, p. 246). The challenges that Henderson described relate to the conflict between the humane (the art of nursing) and the technological aspects of nursing practice (the science). Henderson’s goal was to preserve the unique function of basic nursing care which she believed is essential to human welfare, while achieving technological competence to enhance clinical practice.

Significant advancements in technology have occurred over the past thirty years. In addition to the life sustaining equipment found in intensive care units that inspired Henderson’s writing, technology is now pervasive across care settings and communities around the world. Personal Health Information Management Systems (PHIMs) are but one example of the ubiquitous nature of technology in the twenty-first century. This chapter explores the challenges of integrating PHIMS into clinical practice, recognising that, as societal demands for technological competence intensify, the challenges associated with preserving the essence of nursing practice become more acute. For example, the patient safety benefits related to use of electronic patient record systems have led to demand for uptake of these systems. However, nurses may fear a potentially dehumanizing effect of these systems on the nurse-patient relationship (Dillon, Blankenship & Crews, 2005). This factor may be a barrier to adoption and use. Despite such risks, technological innovation provides an opportunity to advance sustainable models of care that promote self-management and family and community help, rather than institutionalization and dependency.
Nursing care in the technological age can continue to be both an art and a science: getting to know the patient is fundamental to understanding the degree to which technology can be used so that its use is consistent with goals that are mutually acceptable to those who give and receive care. Knowing the patient is also important in terms of understanding a patient’s willingness to allow others to use PHIMS on their behalf.

Widespread uptake of PHIMS is dependent upon integration of appropriate applications and tools into the clinical practice of nurses across care settings and levels of care. Perhaps even more important is the acceptance and use of PHIMS by consumers and patients. Two major processes influence both integration and acceptance: advocacy and workflow. These processes are closely linked to nursing practice when managing patient health information and when using PHIMS in the context of patient care. The significance of the nurse as patient advocate in achieving integration of PHIMS into clinical practice through cultural transformation, the building of mutual trust, securing data completeness, and access to PHIMS are explored in the sections below. Following the discussion of advocacy, an analysis of nurse, consumer and patient workflow processes are considered as a means to support adoption and use of PHIMS along the continuum of care. The conceptual framework for integrating PHIMS into practice is displayed in Figure 1 and elaborated in the discussion below.

*Figure 1 - Conceptual Model for Integrating PHIMS in Practice*
Advocacy

Advocacy is a key component of nursing practice across cultures and is integral to promotion of a patient’s well being (Vaartio & Leino-Kilpi, 2005). It is a central element of the nurse’s efforts to promote and safeguard the well-being and interests of patients. Advocacy involves ensuring that patients are aware of their rights and have access to information needed to support informed decision-making (McFerran, 1998). The integration of PHIMS into nursing practice presents new challenges to the nurse particularly as it relates to the advocacy role. New challenges include protecting the patient’s right to make informed decisions regardless of whether or not that decision includes uptake and use of PHIMS applications and tools. As the penetration of PHIMS becomes more widespread, one key challenge is familiar to those who have cared for patients in intensive care settings (Benner, Tanner & Chesla, 1992; Cooper, 1993): nurses have long advocated for critically ill patients by helping them to achieve a proper balance between quality of life with or without supportive technology. While many of the new technologies enable self management and illness prevention, rather than life support, the role of the nurse continues to include advocating for a sense of balance in accordance with quality of life from the patient’s perspective.

For the patient who wishes to use technology, the nurse advocates by promoting access and by providing the education and training needed to attain competence. For patients who choose not to use technology, the nurse may advocate by involving others (if sanctioned by the patient) to use technology on the patient’s behalf and by tempering the potentially dehumanizing impact of technology on patient care and dignity (Cooper, 1993). Table 1 provides examples of the role of the nurse as patient advocate relative to PHIMS using the three core attributes of patient advocacy described by Bu and Jezewski (2007): safeguarding patients’ autonomy; acting on behalf of patients; and championing social justice.

Table 1 - Core Attributes of Patient Advocacy

<table>
<thead>
<tr>
<th>Core Attributes of Patient Advocacy</th>
<th>Examples</th>
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<tr>
<td>Safeguarding autonomy</td>
<td>Nurse assesses patient’s readiness for adoption and use of PHIMS and supports informed decision-making relative to patient preferences.</td>
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<tr>
<td>Acting on behalf of patients</td>
<td>Homebound patient chooses not to use PHIMS, but requests that the nurse ensures that his daughter is given access to his PHR.</td>
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<tr>
<td>Championing social justice</td>
<td>Nurse informatician lobbies for improved access to PHIMS and for upholding consumer/patient-centered solutions that promote informed decision-making and involvement in achieving positive health outcomes.</td>
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The concept of nurse as patient advocate cuts across practice settings and defines the roles and responsibilities of the nurse relative to the outcomes of cultural transformation, the building of mutual trust, securing data completeness, and access to PHIMS, further explored below.

**Cultural Transformation**

Practicing nurses are in a key position to support and drive the cultural transformation needed to advance the diffusion and uptake of PHIS and to build mutual trust between consumers/patients, nurses and other healthcare providers. In many countries, consumers and patients are largely passive recipients of health care. Cultural transformation is needed before consumers will be willing to fully participate in health care and wellness processes and accept responsibility for healthcare outcomes. Moreover, the issues of technology adoption and diffusion of innovation must be addressed before new technologies will be incorporated into the person’s day to day healthcare management routines. Some of the key cultural barriers to integrating PHIMS into clinical practice are included in Box 1.

**Box 1 - Cultural barriers to integrating PHIMS into practice**

- Lack of patient/consumer ownership and responsibility for an individuals health status and health care solutions
- Sense of discomfort nurses and other providers may feel related to changes in the traditional provider–patient roles brought about by integrating PHIMS into practice
- Unwillingness of nurses and other providers to accept individuals (the person) as “full fledged” member of healthcare team
- Varying levels of trust in patient/consumer ability to accurately enter information into PHIMS
- Lack of appreciation for the patient perspective and the role of patient entered information with PHIMS
- Varying support within society for diffusion of innovations such as PHIMS and the rate of adoption of technology within the society

To overcome such barriers and incorporate PHIMS into general societal behaviour requires a change for both patients, consumers and for nurses. Actively managing this transformation will ensure that technical innovations deliver the desired benefits while minimizing the risks that new technologies can bring. This transformation requires active support for the changing role of the person in managing their healthcare outcomes. The degree of cultural transformation required is a factor of both the relative change required in the person role in the health context and the extent to which that society generally incorporates new technologies to support consumer/patient participation in managing healthcare outcomes. Proposed actions to support the cultural transformation in the context of nursing practice are addressed below based on a combination of change management, innovation diffusion, and technology adoption theories. Procsi’s (2009) change management model provides a framework for planning change.
Prosci’s model encompasses:

- awareness of requirement to change
- desire to participate in the change; knowledge on how to change; ability to implement required skills and behaviours, and
- reinforcement to sustain the change.

‘Diffusion of innovation’ theories such as that of Rogers (2003), provide a framework for developing specific innovation diffusion initiatives. These theories address all aspects of the innovation decision process theory where individuals:

- require knowledge of the innovation to be convinced of the value of the innovation
- participate in activities that assist with deciding to adopt the innovation
- integrate the innovation into practice, and finally
- confirm the benefits of using the new innovation or technologies as a means to reinforce adoption (Rogers, 2003).

In addition, developing initiatives that support technology adoption within the society are required. Staub (2009) proposes an approach that acknowledges and then manages the complexity of the technology adoption process. Therefore, initiatives are needed to simultaneously address the social developmental processes and the individual’s perceptions that may influence adoption and facilitate change from cognitive, emotional and contextual perspectives.

One of the central tenets of PHIMS is that the patient/consumer is as the owner of the health information and in that role actively contributes, analyses and acts on the information. In this context, there is a significant shift to empower the person. This is a major change for patients, consumers and the health professionals. Increasing empowerment of the person, has been described by Jones and Meleis (cited by Lau, 2002, p. 372) as a “social process of recognizing, promoting and enhancing people’s ability to meet their own needs, solve their own problems, and mobilize the necessary resources to take care of their own lives”. While PHIMS have the potential to support individuals in taking a more active role in health related problem-solving, to date the patient/consumer has played a more passive role in this process. The notion of the individual using PHIMS to mobilize resources to meet personal health and wellness needs represents a significant shift in current thinking and practice. PHIMS is an enabler of empowerment and can be effectively supported through the nurse advocacy role. By utilising PHIMS, a person has control of their health information, can utilise the information to maintain their healthcare status and outcomes.

Ultimately, PHIMS provides the tools needed to transform patient/consumer relationships with nurses and other providers to one where the focus is the person interacting with the health care professionals as needed to support their health and wellness. In this context, the patient/consumer assumes a central role within the healthcare team.
However, cultural transformation is a process. People may exist at any point along the continuum of this transformation and, based on their position along the continuum, they may require varying levels of support from nurses and other providers.

**Change Models and Initiatives.**

Utilising the Prosci change model and aspects of Rogers’ Diffusion of Innovation theory as a conceptual framework, potential change initiatives to support cultural transformation for patients/consumers can be identified (Table 2, over). The second perspective of the cultural transformation relates to the nurse. This transformation involves incorporating PHIMS perspectives into nursing practice. Such a change will challenge nurses to increase their understanding of PHIMS (including ongoing advancements) and their understanding of how new technologies are accepted and taken up in society. Samples of the change initiatives listed in table 2 highlight a number of areas for the change in nursing practice. These initiatives require integration into the process of life long learning for the nurse.

**Nurse Informatician Role**

Nurse informaticians are well placed to support cultural transformation through change initiatives such as disseminating information on PHIMS, including the benefits and risks of using PHIMS. Nurse informaticians can also identify the knowledge and skills required to effectively utilize PHIMS, develop strategies for knowledge and skill development and methods for applying PHIMS to practice. Nurse Informaticians should look to the research on technology adoption and innovation diffusion to guide the development of cultural transformation programs. There are a number of factors such as patient/consumer educational level, gender, computer self efficacy, prior experience and the degree of voluntariness of use that will impact technology adoption.(Wu & Lederer, 2009). A working knowledge of these factors may assist in developing effective PHIMS adoption strategies that support cultural transformation. Top priorities for nurse informaticians related to cultural change include the following:

- developing and maintaining effective communication strategies related to PHIMS, its benefits, risks and implications for use in both personal health management and nursing practice
- applying the concepts of empowerment to the nurse advocacy role in the context of PHIMS
- developing validated PHIMS readiness assessment tools for implementation and use in nursing practice
- leveraging the knowledge from countries implementing PHIMS to support emerging countries in their efforts to establish a successful PHIMS adoption framework.
- analysing new knowledge and skill sets required to effectively utilise PHIMS specifically through analysing the impact on existing and emerging workflows.
- developing programs to increase knowledge and skills related to the use of PHIMS.
• defining evaluation frameworks to demonstrate the value of PHIMS to reinforce the benefits of PHIMS adoption.

Table 2 - Change Initiatives Related to PHIMS to Support Cultural Transformation

<table>
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<th>PERSON NURSE INFORMATICIAN</th>
<th>NURSE</th>
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<tr>
<td>Overall understanding of PHIMS including what it is, the value and benefits of using PHIMS, the key risks that need to be managed and the knowledge and skills required to support use of PHIMS</td>
<td>Assist the patient/consumer to increase awareness of PHIMS through provision of facilitated discussions and education on PHIMS, its benefits, key risks and identification of knowledge and skills required to utilise PHIMS</td>
<td>Analyses PHIMS solutions to develop education packages and programs on PHIMS, including benefits, risks, risk management strategies and knowledge and skills development required to utilise PHIMS. Provides education to nurses</td>
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<tr>
<td><strong>Increased Desire to utilise PHIMS</strong></td>
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<tr>
<td>Investigate PHIMS options and personal requirements to utilise PHIMS</td>
<td>Supports the patient/consumer to evaluate PHIMS options, assesses level of readiness to adopt the PHIMS and identify the additional skills and behaviours required to utilise PHIMS</td>
<td>Provides tools to assist with PHIMS Readiness Assessment</td>
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<td><strong>Increased knowledge on how to change</strong></td>
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<td>Explores, investigates and utilises aspects of PHIMS and addresses personal requirements e.g., additional skills development such as. internet skills</td>
<td>Supports the patient/consumer to utilise the PHIMS through demonstration, education and identification of options to address skills deficits</td>
<td>Develops range of educational materials and information on options for skills development</td>
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<td></td>
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<tr>
<td><strong>Increased ability to implement required skills and behaviours</strong></td>
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<tr>
<td>Determines the level of utilisation of the PHIMS and commences use. Develops an increased knowledge of PHIMS and skills increase in use of PHIMS</td>
<td>Supports the patient/consumer to utilise the PHIMS including discussing their use of PHIMS. The nurse utilises PHIMS information in nursing assessments, defining nursing interventions and assessing outcomes.</td>
<td>Provides scenarios on the effective use of PHIMS; Monitors the environment for changes in practice and skills for continued effective and safe use of PHIMS</td>
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<tr>
<td><strong>Reinforcement to sustain the change</strong></td>
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<tr>
<td>Improvements in health care status, knowledge and outcomes provides effective feedback on the benefits of PHIMS</td>
<td>Supports the person to review the changes in health status, knowledge and improvements in outcomes to demonstrate the benefits of PHIMS</td>
<td>Develops and implements research programs to demonstrate the value of PHIMS</td>
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Whilst there are significant benefits to be gained from taking a global perspective on these initiatives, it is also important from a cultural transformation perspective that the initiatives are sufficiently tailored to reflect local customs, practices and norms to ensure cross cultural adoption.

**Securing Mutual Trust**

Trust has been defined as “the optimistic acceptance of a vulnerable situation, following careful assessment, in which the truster believes that the trustee has his best interests as paramount” (Bell & Duffy, 2009, p. 50). The role of the nurse in securing mutual trust is essential to integrating PHIMS into nursing practice.
Trust between the nurse and the patient contributes to the shared understanding that PHIMS applications and tools and associated health information will be used responsibly to support mutually agreed upon goals. Bell and Duffy (2009) identify four attributes of trust: expectation of competence; goodwill of others; fragility/vulnerability; and element of risk. In Table 3, these attributes of trust provide a framework for understanding the process for development of mutual trust as it relates to integrating PHIMS into practice.

Table 3 - Change Initiatives Related to PHIMS to Support Cultural Transformation

| Expectation of competence: | • Patient has an expectation that the nurse will use PHIMS in a way that is in their best interest and consistent with mutually agreed upon goals.  
• Patient has an expectation that PHIMS will meet their identified health/wellness need. |
| Goodwill of others: | • Patient has faith in the goodwill of the nurse. Once trust is established, the patient hands over an element of control to the nurse.  
• The nurse provides education and mentoring to assist patient with learning effective use of PHIMS to maximize wellness and to minimize power differential. |
| Fragility/vulnerability: | • Patient need for trust speaks to the essential vulnerability of the nurse patient relationship.  
• The nurse reduces patient vulnerability by providing them with support to use PHIMS to take responsibility for own healthcare outcomes. |
| Element of risk: | • Trust always involves risk and the possibility that the person being trusted may not act appropriately.  
• Getting to know the patient, demonstrating competence, goodwill and effective use of PHIMS to meet mutually agreed upon goals decrease the element of risk for the patient. |

True integration of PHIMS into nursing practice requires that both patients and nurses use PHIMS. Therefore patient trust in nurses that they will use personal health information in a way that is safe, secure and to their benefit is essential, but nurses must develop trust in patients as well. They must appreciate and value the patient perspective and trust that patient-entered information is a valid source of data. In addition, nurses must advocate for inclusion of patient-centric information in PHIMS. While technology has been used in nursing practice for several decades, many of the applications and tools currently available are relatively new and continuously evolving. Educational scripts and competencies for nurses are needed to inform nurses about how PHIMS are used including features to safeguard safety and privacy, and the risk and benefits of use (or choosing not to use).

Data Completeness

Complete data and information are prerequisites to integration of PHIMS into practice. Unless patients, consumers, nurses and other users believe that data are accurate and complete, PHIMS will not be used. Nurses and other providers may have concerns related to the consistency with which consumers and patients maintain information in their record. Nurses are in a key position to advocate for a complete record.
This may be accomplished by educating consumers and patients on the importance of accurate and complete data. Currently a minority of people maintain a complete record of their health care practices or record complete health-related data. Due to their proximity to the patient, nurses can play a crucial role in educating them about the benefits of keeping a formal health record with or without PHIMS. Data should be reviewed at the start of each visit to involve patients in updating the record and to model the process. Nurses may also need to educate each other about patients’ ability to accurately enter information into PHIMS and the benefits of encouraging them to do so. Published research indicates that the validity of consumer entered information related to their medical history is comparable or more complete than similar data charted by providers (Porter & Mandl, 1999).

In addition to a more complete record, there is potential for improved efficiency associated with engaging the patient in entering information into PHIMS. While nurses must advocate for data completeness, they are also obliged to make people aware of the potential risks associated with full disclosure. Policies are needed to protect consumers’ and patients’ ability to enter complete health information into PHIMS without fear of discrimination or loss of benefits.

Besides education, standards are needed to facilitate data completeness. For example, standards are needed to establish data types that will feed the PHIMS including which data will be available for viewing and editing versus data required for re-use for decision support and reporting purposes. Nurses may advocate for the inclusion of consumer and patient-centric data for use in PHIMS. Nurse informaticians are needed to define the data structures and meta data required to assure that the context related to entered data is preserved.

Access

Nurses at the point of care are in a key position to facilitate the public’s access to PHIMS. The International Telecommunication Union (ITU), a United Nations agency for information and communication technologies issues, suggests that access involves providing a method for equitable communication via the following:

- accessible design: accessibility has to be built into products and services from the very beginning
- availability: accessible products and services must be on hand to users, and
- affordability: access to products and services must be reasonable (ITU, n. d.).

The World Health Organization has produced a draft recommendation on record access stating that any user of a health service should have power to access all of their personal health information (Fisher, Fitton & Bos, 2007). Citizens should have access to their records to increase transparency of healthcare activities which may improve health, to empower patients, to improve record keeping, and to benefit provision of health services by reducing unnecessary appointments (Fisher, Fitton & Bos, 2007). These tenets are in alignment with the 2003 declaration of World Summit on the Information Society (WSIS) that put forth a world vision for “a people-centred, inclusive and development oriented Information Society, where everyone can create,
access, utilise and share information and knowledge, enabling individuals, communities and peoples to achieve their full potential in promoting their sustainable development and improving their quality of life” (Jørgensen, 2005, p. 91).

One of the barriers to access is the digital divide in which there is a gap between those who have access and those who do not have access to technologies. (Warschauer, 2003). Several factors have been implicated in the digital divide including geography, socio-economic status, education, disability, literacy, race and language (Warschauer, 2003). It is well documented that populations with higher socioeconomic status have better access to the Internet and to broadband services and that minorities often do not have access to culturally relevant information (Jørgensen, 2005).

According to 2008 data from the ITU, there are on average 23 Internet users per 100 people internationally, however only 6 people per 100 are broadband users. More importantly, the 2008 data indicate that there was very low Internet usage for countries such as Myanmar (0.08 per 100 inhabitants), Sierra Leone (0.25 per 100 inhabitants) and Bangladesh (0.32 per 100 inhabitants) as compared to Norway, Sweden and the Netherlands with 84 to 86 Internet users per 100 inhabitants (ITU Statistics, 2008). Even within developed economies such as the European Union (EU) disparities still exist, with Bulgaria (25 per 100 inhabitants), Romania (30 per 100 inhabitants) and Greece (31 per 100 inhabitants) having the lowest levels of usage in the EU.

Early evaluations of the digital divide focused on Internet penetration, however due to the ease of use and general low cost of cellular telephone technologies some countries have a very high technological penetration of cell phones compared to the Internet. For example, in Guatemala 10 people per 100 inhabitants use the Internet, but 100 per 100 inhabitants use a cell phone (ITU statistics, 2008). Knowledge of technology usage is important, as nurses must assess which method of communication people might use.

Disability is another important issue related to access. Several assistive technologies can be used to support disabled persons who are much less likely to use the Internet than their non-disabled counterparts. However, when disabled persons use the Internet, they are more likely to seek out health information (Dobransky & Hargittai, 2006). Dobransky and Hargittai reported that persons who were hearing or mobility disabled were equally as likely to use the Internet as their non-disabled counterparts, but persons with visual disabilities or disabilities that precluded typing were much less likely to use the Internet. The Internet Global Foundation (IGF), the arm of the United Nations that carries out the mandate of the WSIS, has recently made the following recommendations to governments: the IGF “Strongly urge that basic building blocks of assistive technologies, such as Text to Speech and Speech to Text software, Interactive Voice Command, Real time text solutions, Optical Character Recognition software and language rule tables for Braille transcription, are developed with high priority for all languages of all countries and licensed under an open source license, and open standards for structured access to oral and visual knowledge to enable development of various assistive technologies, such as screen reading software, text reading systems, talking mobile phones, talking ATMs, and real time text alternative communications that depend on these basic building blocks” (Dynamic Coalition on Accessibility and Disability, 2008).
From a nursing practice perspective, factors related to access include the availability of technology for the person, the person’s ability to use such systems, and the person’s preferred mode of communication. Nurses must remain aware that it cannot be presumed that people will receive their health education via the Internet or other technologies. Given this, the nurse will need to examine the person’s level of readiness to use technologies as well as the availability of technologies (if any) in the person’s community/home. In addition, the person may have a preferred mode for receiving communication or information. For example, in a region where there is limited Internet access but widespread cell phone coverage, a patient may prefer to use text messaging as the mode of communication.

As care coordinators, nurses can examine an individual’s ability to use technology, their ability to understand health information, and their ability to implement health recommendations and thus can ensure equitable access to all people.

**Workflow**

Workflow is defined as a system of transferring tangible and intangible items from one agent to another for a purpose (Ozkaynak & Brennan, 2008). As it applies to integration of PHIMS into clinical practice, workflow includes the context into which the technology is introduced. Therefore, consumer, patient and nursing practice related workflows are relevant. Research is needed to better understand consumer, patient and nurse current and future state workflow processes and existing gaps to support integrating PHIMS into clinical practice along the continuum of care. For example, there is a dearth of published research to provide guidance on how these tools might be used in the context of an acute care hospitalization to support the nursing process of assessment, diagnosis, planning, intervention, and evaluation of care or how PHIMS will support discharge teaching processes. Questions remain regarding how PHIMS will be incorporated into the processes of care to support consumer and patient education and informed decision-making.

Additional areas for research include the use of PHIMS to support patient self-management of chronic illness and preventative health outside the walls of formal care provision. As PHIMS applications and tools become more widely available, workflow and care processes must be defined around the individual as an actor deploying a new kind of self-management in the context of complementary professional care. Changes in communication flows resulting from shared decision making should be examined when introducing PHIMS. Work is needed to explore ways to make the use of PHIMS a value added activity, rather than simply adding additional processes into already complex workflows.

A conceptual model for integration of PHIMS into practice is displayed in Figure 1 above. The target areas for PHIMS include all sites and levels of care across the health and wellness continuum. Integration of PHIMS into patient/consumer and clinician workflow processes leads to continuous generation and use of personal health information (PHI) by both persons and clinicians. Systematic review of data completeness by nurses contributes to data integrity in repositories.
Ongoing review and redesign of workflows are needed to identify barriers and to strengthen facilitators to integration and use of PHIMS by persons and clinicians. To achieve the ideals represented in the PHIMS conceptual model, a method for analyzing PHIMS workflow processes is needed. Complete understandings of person and clinician workflow processes are prerequisite to efficient and effective use of PHIMS in practice.

Applying methods from process engineering and quality improvement may provide a useful framework for a more complete understanding of the workflow process components associated with the use of PHIMS by both persons and clinicians, including the following strategies:

1. developing a more complete understanding of the workflow processes associated with the use of PHIMS by interviewing and observing stakeholders

2. breaking workflow processes down into components or “unit processes”

3. reducing “unit processes” into process, resource and management subcomponents. The process subcomponents include actual workflow including input, output and functions of the workflow. The resources subcomponent includes resources needed to perform the functions and the management subcomponent includes indicators of success and supplementary methods to be followed when issues arise

4. mapping out the relationships between processes, subcomponents of persons and consumers on a unit process flow chart (UPFC). The UPFC is a standardized module that serves as a visual display of PHIMS workflow processes that allow for in-depth analysis of barriers and facilitators to integration of PHIMS into practice. (Shimono, Tsuru, Iizuka, Kato, Munechika & Kaneko, 2009).

Understanding both person and clinician workflows at a micro level facilitates modifying workflow units to improve efficiency, limit barriers and strengthen facilitators to integration of PHIMS into practice. In Figure 2, workflow components are analyzed at the subcomponent level. Proposed improvements are made and efficient and effective person and clinician workflows are linked. Improved workflow processes are diagramed using a UPFC and then tested using clinical scenarios from across PHIMS target areas.
Future research should include analysis of the nature of PHIMS related work from multiple perspectives including those of consumers, patients, nurses and other care providers. Workflows designed to support use of PHIMS in the context of multidimensional organizational characteristics can bring value to consumers, patients, nurses, providers and organizations. However, integrating PHIMS into clinical practice will require workflow changes. Iterative design of workflows that support the generation and use of personal health information in practice will drive adoption and use of these systems as the benefits accrue. In this regard, research is needed to clarify the change over time in the elements of PHIMS related work (job elements) and their features, as well as the relationship between PHIMS elements and the type of user, user class, and the role of the organization or site where PHIMS are used (e.g. hospital, home, senior center) (Numasaki et al., 2008).

Time-motion studies are needed to analyze the use of PHIMS by user type, and organization or site where PHIMS is used. This process will support workflow redesign using component based architecture and ensure that emerging workflows are developed and tested using an iterative process. Iteration in workflow redesign allows for swapping out or exchanging workflow components associated with inefficient or ineffective processes and developing and testing more effective processes with minimal disruption to users and surrounding systems.
Conclusion

This chapter explores emerging issues related to integrating PHIMS into clinical practice. Recommendations are made for addressing and overcoming challenges to technology access and adoption in ways that preserves the unique function of basic nursing care while working with consumers, patients and other providers to build more sustainable models of care delivery. In their role as patient advocate, nurses are in a key position to assure that PHIMS applications and tools are available and used across settings. A commitment to knowing the patient and keeping consumers and patients at the center will ensure that PHIMS applications and tools support informed decision-making and are mutually acceptable to consumers, patients and other providers. Using a systematic, patient/consumer-centric approach, PHIMS will be integrated into practice in ways that preserve the essence of nursing in a technological age.

References


Confidentiality and Safety: the Personal Perspective

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Introduction

This chapter addresses the interrelated issues of confidentiality, privacy, safety and security in the use of Personal Health Information Management Systems (PHIMS). In particular, we consider emerging forms of electronic, often Internet-based or Internet-accessible personal health records (PHRs). The perspectives of the end-user or 'owner' of the PHIMS or PHRs, i.e. the individual person or citizen, and those of the health professional are addressed. These two perspectives are linked in many ways, not least because most health professionals expect PHIMS or PHRs to interact in various ways with other forms of healthcare provider-based electronic records. In addition, the provision of health care or health maintenance and promotion around the world requires that the individual interacts with a variety of healthcare providers.

The recommendations at the end of the chapter address both health professional and individual end-user perspectives. The chapter tries to take an international perspective, while recognising that much of the current drive for the development of PHRs, and the majority of the current literature, derives from the USA. However, differing legislative frameworks in different countries, and the increasing need to consider the effects of mobile citizens and distributed computing, mean that challenging international socio-technical perspectives will arise.

There are no definitive answers provided here to any of the issues raised, but rather an exploration of a number of questions that will need to be addressed by all stakeholders, i.e. by individual citizens, health professionals, informal family carers, and providers of PHIMS and PHRs.

The concluding recommendations are framed mainly around the need for educational and other actions to address these questions, in particular the development of guidelines for best practice in the areas of confidentiality, privacy, safety and security by all stakeholders involved in the use of PHIMS. Definitions and descriptions of PHRs and the four main themes introduce the chapter. The need for confidentiality, privacy, safety and security is taken as a 'given' in all forms of health records, including PHRs and in PHIMS.
What is open to discussion are the implications for these four interrelated issues in a world where:

- records will be increasingly held and accessed electronically
- the locus of control on making decisions on access to and use of the records is, in many countries, shifting away from the health professional and towards the empowered individual citizen or person, and
- different people or groups may have differing views on the relative importance they attach to the issues of confidentiality, privacy, safety and security.

We make the assumption that, to the greatest extent possible, there is a wish to foster equity of access to and use of PHIMS and PHRs by any individual person in any society or situation, and using any health care system, anywhere in the world. Such equity of access may be limited by many factors, not least the various forms of the digital divide, or restrictions on access and use through any one of the many forms of disadvantage that may be present.

**Exploring definitions**

**EHR, EMR, PHIMS and PHR**

The descriptions of PHIMS and PHRs used here are congruent with those used elsewhere within this text, although we recognise that these concepts are still evolving. PHIMS are described as “a suite of tools and sources of data that support health for individuals” and PHRs as “an electronic, universally available, lifelong resource of health information maintained and owned by an individual”. It is important to note that there are differences between the electronic health record or electronic medical record (EHR or EMR) and the PHR. Although the legal situation varies between countries, the EHR and EMR are either viewed as being owned by the healthcare provider, with information entered into the record(s) by a range of health professionals or as being jointly owned between provider and the individual. Distinctions are made in some countries between ownership of the record itself and of the information held within the record.

The emerging models of the PHR increasingly view them as owned, or controlled, by the individual person: the record may stay with them, and so be available wherever they are. Online PHRs are seen as offering portability, interoperability and security; they are close to the top of the healthcare technology agendas in many countries. They are viewed by many as helping to meet the expressed aims of many governments aims of personalising care, and of increasing the participation or people and patients in the ways in which decisions about their care are made (OpenClinical, 2007). The Connecting for Health Markle Foundation (2003) report on PHRs has influenced discussion of models of PHRs, describing them as “an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.”
This view challenges the traditional model of provider-held and professional-controlled health records. It requires a shift in thinking by health professionals and healthcare providers about the locus of control on access, definitions of confidentiality, privacy, and other issues. The Healthcare Information Management and Systems Society (HIMSS) described the electronic Personal Health Record (ePHR) as being “owned, managed, and shared by the individual or his or her legal proxy(s)” and stated that it “must be secure to protect the privacy and confidentiality of the health information it contains” (HIMSS, 2007).

The dominant model that is emerging in many countries is that the individual person is the primary user and controller of the PHIMS/PHR. He or she may allow access to all or part of the records to a legitimate stakeholder, for example, a nurse, doctor, family member, employer, insurance company. This shift in the locus of control, along with the need for new forms of “anytime, anywhere” access to the systems, have implications for the features of, and approaches to confidentiality, privacy, security and safety.

Confidentiality, privacy, safety, security

Harman (2002) acknowledges that confidentiality, privacy and security are often used interchangeably, but that there are important distinctions; privacy relates to a person's right to be free from intrusion into or observation of their private affairs, and to maintain control over personal information. Confidentiality is seen as relating to responsibilities for limiting disclosure of information shared in confidence, and to it being disclosed only with the consent of the individual. Security relates to access control and protection of information, through physical and/or electronic protection of the availability and integrity of information, and of resources used to store, process and communicate information. Safety is generally viewed as relative freedom from danger, risk, or threat of harm, injury, or loss to personnel and/or property, whether caused deliberately or by accident.

Confidentiality, privacy, safety and security related to paper records have been well addressed in the literature, and in legislation in many countries. As we move into a future where health data and information will be held, managed and accessed electronically, there is discussion about whether current approaches to managing these issues still apply, or whether they need to adapt to changing expectations and practices. Healthcare has been described as lagging behind other sectors (in particular the aviation and financial sectors) in its adoption of computing and of information and communications technologies. Other sectors have already addressed the implications of the changing use of technology for issues such as confidentiality and privacy of data (e.g. banking and financial data), individuals' attitudes, and safe and secure electronic storage, transmission and use of data. There may be lessons from these other sectors that can be adopted or adapted by health care sector.

The commercial bank model for health records, and in particular PHRs, is seen by several authors, who see it as having advantages, and practical examples of the model are being explored (Dimick, 2009). The concept of a "health information bank" was suggested in the late 1990s by Bill Dodd, a Scottish GP, as a model wherein
information would be shared through a variety of ‘transactions’ based on the person’s or patient’s explicit consent (Dodd, 1997). The "bank" would store extracts or summaries of health records, with the individual granting access to other on the basis of professional need; it would also serve as the summary lifetime health record (as per many PHR models today), which would contain links to locations holding more detailed information about care episodes (Dodd, 1997; Protti, undated). Gold and Ball (2007) and Ball, Costin and Lehmann (2008) also discuss the possibility of emulating the commercial banking model for collection and storage of health information in 'health record banks', with data collected from a variety of sources, and models for data sharing.

Confidentiality, in relation to any health-related information about an individual, is generally viewed as legally and ethically required principles and practices that compel professionals to not disclose information without legal authority and the consent of the involved parties. It is the right of an individual to have personal, identifiable health information kept private. In England, the National Health Service’s (NHS) Confidentiality Code of Practice (Department of Health, undated), describes a “duty of confidence” for all NHS staff “when one person discloses information to another (e.g. patient to clinician) in circumstances where it is reasonable to expect that the information will be held in confidence”. It further notes that this duty of confidence is a legal obligation, a requirement established within professional codes of conduct, and must be included within NHS employment contracts as a specific requirement linked to disciplinary procedures. Similar regulations and sanctions apply in other countries.

Amatayakul (2002) notes that confidentiality is implicit in the sharing of information, stating that when information is shared with someone else in confidence, then a condition is established that is termed ‘confidentiality’. Security in this context relates to the measures to ensure that this confidential information can only be accessed by those to whom the individual has granted permission. Similarly, the American Health Information Management Association (AHIMA, 2007; 2008) believes that confidentiality, privacy, and security are “essential components of a viable health record”, and that they are necessary to support both trust and the reliable exchange of health information between individuals and their healthcare providers. They recognise that there are “no infallible means to ensure absolute respect and protection for the confidentiality and integrity of a patient’s personal health information”, and propose that trust can only be maintained by the use of laws and regulations to mandate adherence to standards, and through the prosecution of those who breach the trust. AHIMA’s (2007) recommendations for achieving confidentiality, privacy, and security of health information are predicated on the need for:

- all health information, wherever it may be gathered or stored, to be collected and used legitimately
- uniform standards to be applied to protect individuals from harm as a result of intentional misuse
- the development and application of high standards and uniform practices that respect the rights of the individual and the public and that apply in whichever medium the health information is gathered, stored, or used, and
- the rights of individuals to access their health information in any setting.
They also support the need for individuals to understand their privacy right and options, and to have the right to appropriately challenge the accuracy of any information held.

Privacy is an issue that is often treated in combination with confidentiality. For example, the UK's Human Rights Act 1998 discusses the "duty to protect the privacy of individuals and preserve the confidentiality of their health records" (Department of Health, undated). In the context of this discussion, information or data privacy refers to the relationship between collection and dissemination of data, the technology used, the public expectation of privacy, and the legal and political issues surrounding them. Privacy concerns are related to personally identifiable information that is collected and stored, increasingly in digital form, and the improper disclosure of or access to the information.

Security of electronic PHRs/PHIMS terms can be maximised by using suitably secure, encrypted online communications and interactions. In the past, this has meant encrypted websites are viewed as having good security, while e-mail and SMS are not secure unless using encrypted systems. Of equal importance in the security equation is preventing the wrong people from accessing records, ensuring that the right people can access health information and records (Patientsknowbest wiki, 2008).

The health and medical literature, as well as the popular media and opinion polls, show that in many countries, the public, patients and health professionals are skeptical about the privacy, security, and safety of health information systems, and this has been suggested as one major reason why adoption has been slower than the related literature and polls on perceived benefits would suggest should be the case (Connecting for Health, Markle Foundation, 2008a; Terry & Francis, 2007). In practical terms, there has to be a balance between confidentiality and security on the one hand, and convenience and cost. A totally safe, secure and confidential system for using and accessing PHIMS/PHRs would be one that, in practical terms, no-one else would be able to access. In the context of multidisciplinary health maintenance or healthcare, this would be impractical. Individuals increasingly access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location.

The need for robust security will have to be balanced with the need for PHIMS/PHRs to be easily accessible; perfect security is incompatible with perfect utility. For security, systems will be needed to authenticate users. Such systems may include technology such as smart cards, hardware tokens or independent agencies that provide digital signatures or certificates to confirm the identity of PHR users. To maintain privacy, people need mechanisms that will allow them to specify what parts of their PHIMS/PHR will be shared with specific providers and institutions (Connecting for Health, Markle Foundation, 2003).

**Attributes of Personal Health Records**

Consideration of some of the distinct attributes in the Connecting for Health, Markle Foundation (2003) description of PHRs, identifies some of the issues that arise:
• Each person controls his or her own PHR, deciding which parts of their PHR can be accessed, by whom, and for how long. This means that systems have to be developed to support such individual control, including for how long permissions for access may last (e.g., on an episodic basis, or for a longer period of care). Access control to the PHIMS/PHRs needs to be sufficiently secure to meet both the requirements of the individual and the practicalities of providing support or care.

• PHRs contain information from one’s entire lifetime. If a PHIMS/PHR is to be truly a lifelong record, the system design and technical standard must support current information exchange and portability (Tang & Lansky, 2005), as well as being interoperable with other systems, and being future-proof, which probably means the use of open as opposed to proprietary standards to avoid vendor-specific problems of future use and data migration.

• PHRs are “transparent”; PHRs permit easy exchange of information. If individuals are to exercise full control over their records and information, they need to be able to see who entered each piece of data, where, when and how it was transferred to and from if shared with other records or people, and who has viewed it. Confidential systems need to support legitimate use and sharing, but security controls need to not only track usage, but deter unauthorised use, and be such that the individual is comfortable with the degrees of security.

Practical challenges

This exploration of some aspects of the issues raised above is framed around a series of higher level questions and issues, and for each one, some of the emerging practice is introduced, and a number of other questions generated. The section begins by exploring issues around the ownership of the data, information and records, from which arise issues of who controls access and how it is controlled.

The section concludes with exploring whether the issues for electronic systems and records are the same as, or different from those of traditional paper records, and how attitudes to the issues might be changing, and so might impact the future development of systems and of education and awareness raising of all stakeholders in using emerging forms of PHIMS/PHRs. As indicated earlier, questions are raised within the discussion that still await answers; it may be some years before consensus is reached on solutions.

Ownership of the information and the record

One of the fundamental issues underpinning all discussions in the areas of confidentiality, privacy, security and safety for PHIMS/PHRs is that of ownership of the data that are put into, and stored, manipulated, or accessed. The basic questions are: whose data is it? who owns the data? Are the data owned by the individual generating the data, i.e., the person whose blood pressure or blood sugar, or weight is measured, and then somehow stored?
Are there circumstances in which they might not own the data? If the data are stored in a PHIMS or PHR, are the data then owned by a third party, such as the system/record provider, by the hospital or health professional to whom the data are given or with whom they are shared? We can ask the questions in a number of different forms, such as whose health record is it? who determines what can be in it? who determines what can be done with the data or the record?

As health information becomes increasingly networked and technology permits health information to be transferred more easily, the lines demarcating ownership of health information become further blurred (Coffield, 2009). Whatever answer is reached on the issues of ownership, much health data is stored because someone thinks that it will be useful to share it with other people or organisations in certain contexts, often in healthcare encounters. There are, therefore, a number of legitimate users and stakeholders, as summarised in Table 1 (over). Users are those people or organisations that have authority to use an application, equipment, process, or system, or who consume or employ a good or service to obtain a benefit or to solve a problem, and who may or may not be the actual purchaser of the item. In the context of PHIMS/PHRs, they include nurses, GPs, allied health professionals, and family members. Stakeholders are people or organisations with a direct interest, involvement, or investment in something; in this context, they will include governments, Ministries of Health and/or Social Welfare, WHO, and other organisations.

Controlling access or sharing of the data and record

Under traditional models of health records, usually paper-based, healthcare providers are viewed as ‘owning’ the health/medical records they maintain, with individuals (in this context, usually patients), having rights of access to the information in the record. In many countries, individuals have always had, but perhaps not understood or realised, or have gained, rights to request corrections to their medical information and the assurance that such records are maintained confidentially.

In emerging PHR models, which are underpinned by the rhetoric, if not necessarily the practice, of ‘person/patient-centric records’, this provider-based ownership model is changed. Instead of provider-based control, where the healthcare institution or professional provides access to and/or copies of the record, the PHR model puts the individual person, or patient, in control of his or her medical and health information (Coffield, 2009). In a US survey, more than 90 percent of people said their express agreement should be required for each use of their online health information (Connecting for Health, Markle Foundation, 2008a).

Related to the ownership of any health-related data are issues of who has access to the data, and who is able to determine or delegate whether others access. In patient-centric PHR models, or PHIMS where the individual is at the centre of the model, there is an assumption or implication that the person themselves decides who they will allow to access, or share the data/information. In most encounters with other health professionals, whereby a multi-professional or multi-agency team of people is involved in healthcare, health promotion or health maintenance, there will be a need for some sharing of information. In considering who determines access, there are the related issues of who is responsible for ensuring confidentiality and safety around such access?


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Halamka, Mandl and Tang (2008) are among many who have recently explored the implications of patient-centred PHIMS/PHRs, and the issues arising. They note that there will be many new policy and technical challenges for healthcare institutions, but that this may also provide opportunities. Through placing the person or patient at the centre of healthcare data exchange, and empowering them to become the steward of their own data, the responsibility for protecting confidentiality is also shifted and becomes the personal responsibility of every participating individual or patient. This is seen as a way of ‘solving’ many of the privacy and consent issues faced by organizations desiring to exchange data today by simplifying consent models among producers and consumers of healthcare data.

The issue also arises of whether there might be circumstances when, in the interests of the larger public good, the wishes of the individual will need to be over-ruled. If an individual has, for example, a communicable disease, and is behaving in what society would deem an irresponsible manner in relation to putting others at risk of contracting the disease, does society have rights to access the person’s information, even if they have to over-rule the person’s wishes to obtain it? How do we accommodate balance between privacy needs/desires of individuals and the need to access/share information so as to provide healthcare? when does the public good prevail? Other issues also arise in relation to control of access to PHIMS/PHRs. Bourgeois, Taylor, Emans, Nigrin, and Mandl (2008) note that access control policies need to take account of developmental and age-defined rights of users to preserve privacy, confidentiality, and best interests.
They suggest the development of access and security policies, tailored such that the PHR is not only under patient control, but one that may also be accessed by parents, guardians, and third parties. For increasing mobile populations, there is a need to take account of differing national and regional legislations relating to confidentiality and safety of PHIMS/PHRs, and to data that may be stored in different jurisdictions from that where it is generated and/or used, and that is accessed from multiple locations by individuals and health professionals.

Pagliari, Detmer and Singleton (2007) suggest that a 'one size fits all' model for different types of ePHRs would be inappropriate, and that different models confer different rights for access, privacy and control, with the resultant need for appropriate standards to ensure transparency of contributorship and access, as well as interoperability and valid data integration. The Connecting for Health, Markle Foundation (2008a) report found that around 90 percent of people surveyed identified one or several privacy practices as factors that would affect their use of an online PHR, including an individual being able to review who has had access to their personal health information, there being clear processes to request corrections or dispute the way their information is handled, and individuals having control over what information from their records was made available to others (eg, decide not to include information about treatment for a sensitive medical condition).

A UK study of patients’ views on the information held in their paper GP records that could be included in a national EHR system illustrates some of the practical issues that might also arise within PHR systems (Powell, Fitton and Fitton, 2006). Concerns were raised about issues of data accuracy, security and confidentiality.

Study participants were asked to highlight information which they would not want to be shared on the national electronic database of records, and information which they considered to be incorrect. While less than one in six patients identified information that they would not want to be shared, relating almost entirely to sexual health and mental health, one in three identified incorrect information in their records. The findings in relation to data sharing fit with the commonly held assumption that matters related to sensitive or embarrassing issues, which may affect how the patient will be treated by other individuals or institutions, are most likely to be censored by patients.

Are the issues related to PHIMS the same as in manual/paper systems?

As PHIMS and PHRs increasingly imply electronic storage of health information, all stakeholders need to consider whether the approaches, attitudes, laws and regulations and sanctions against misuses that have applied, or evolved, over many years to paper-held records can still apply to electronic records.

If the answer is 'no', even 'not necessarily', then consideration needs to be given as to what new approaches are needed, and to what effects the use of current and future technologies might have. Among the questions to be considered are:

- do issues of confidentiality and safety apply the same across all of these types of storage and use?
- do they vary depending on the nature of the technology etc?
- are there some common issues and some variable ones?
- are existing legislations, approaches and attitudes adequate?

The predominant model for the PHR is a repository of all clinically relevant health information kept securely and viewed privately by patients and their health care providers. While this type of record does seem to have beneficial effects for the patient-physician relationship, the complexity and novelty of these data coupled with the lack of research in this area means the utility of personal health information for the primary stakeholders - the patients - is not well documented or understood. Kaelber, Jha, Johnston, Middleton and Bates (2008) found that, although there are potential technological privacy and security advantages for PHRs, the general public appears more concerned about these issues for electronic records then for paper-based records.

Important issues that will need to be addressed in terms of both technological and social solutions, as well as education and awareness raising, emerge where many organisations and individuals may be sharing the data within the PHIMS/PHR. People may wish to share their PHIMS/PHR information with others not involved in healthcare (and in some countries the distinction between health care and social care or social welfare is becoming increasingly blurred). Practical issues of people being able to remember passwords may diminish use, while easy or shared passwords and security controls increase the likelihood of security breaches.

**Who uses PHIMS/PHR? - are attitudes changing?**

The Connecting for Health, Markle Foundation (2008a) survey of American adults found that, while almost half of those surveyed would be interested in an online PHR, and 80 percent believed that they would be beneficial in managing their health and healthcare, over 55 percent of those who were not interested cited concerns of privacy and security as part of their reluctance. In addition, despite the anecdotal evidence cited by many proponents of PHRs that they would be a natural progression of the personal and family records that many people purportedly maintain, the study found that 60 percent did not keep any form of health personal health records, and less than three percent had an electronic PHR. Despite this, Schorsch (2008), commenting on the launch of Google Health and Microsoft Healthvault, suggests that "PHRs and electronic medical records remain an industry-driven vision, not a consumer-driven one - focused on efficiency and reducing costs. ... we’ve lost sight of whether the consumer really desires and is willing to participate in these services."

A more recent (2009) survey (Deloitte Center for Health Solutions, 2009; McCabe, 2009) found that among the US population, only nine percent report having an electronic PHR, although over 40 percent said they would want one; this is higher than the two percent of hospitals that have 'comprehensive' EHRs. On specific issues of privacy and security of personal health information, 38 percent were "very concerned", while 24 percent "had no reservations about it". Interestingly, and perhaps in part contrary to the conventional wisdom, women over 65 years of age and men aged 18-24 were least risk averse to sharing personal health information online.
Are views of confidentiality changing (especially among the younger generation)? Are people’s views changing on what they share (and so on confidentiality and privacy)? A study by the Robert Wood Johnson Foundation (Robert Wood Johnson Foundation, 2009) explored African Americans’ and Latinos’ attitudes towards confidentiality of personal health records, wherein the individual’s health information is controlled by the individual, rather than by any segment of the health care system. Using focus groups, whose members were generally unfamiliar with the concept of the PHR, but who recognized its potential for improving health care, the study found that most participants distrusted the security of electronic records systems and preferred a record kept on a portable "smart card.” Participants wanted control over who has access to their personal information, and what information they could see. Most existing personal health records lack many of the features, such as smart cards, that would appeal to the populations represented in the focus groups.

In many surveys (for example, California Healthcare Foundation, 2005; Ball, Smith and Bakalar, 2007), concerns are expressed about the privacy of personal health information held in various forms of health record, and in particular about the confidentiality of the information, and their ability to control access, such that other people who they might not wish are not able to access that information (often employers or insurers).

Privacy and confidentiality concerns will affect consumers’ choice of media for a PHR, although there may be variations between sectors of populations with different expectations or experiences of a range of technologies; younger people might prefer to keep their PHR online, while others might be concerned about identity theft or hacking and will carry their data on a universal serial bus (USB) key in their pocket (Ball, Smith and Bakalar, 2007).

While there is a growth in health care providers (e.g. hospitals) and third parties (e.g. Google) providing forms of PHR, there is also the emergence of online communities of people and patients, either with health and disease issues, or wishing to maintain and promote healthy living, who are using new Web 2.0 technologies to share information among themselves. Questions are emerging as to the nature of these types of PHIMS, which may have no involvement of, or interaction with, health care professionals or healthcare providers. This indicates the emergence of new attitudes to the maintenance and sharing of information online with other people. One study (Pratt, Unruh, Civan and Skeels, 2006), of breast cancer patients, found that they expressed a need for additional information management, and to share aspects of their personal (as well as health) information with other people. They routinely made trade-offs between the efficacy of immediate communication about private health information in a public setting and their desire to maintain their personal privacy.

There is some evidence that attitudes to privacy and confidentiality may be changing. We therefore have to consider whose definition of confidentiality will be applied in relation to any health data. Will it be the definition of the hospital record provider, for example, who may take a narrower, more traditional view of the issues? Or will it be the definition, for example, of the teenager who is happy to share all of his or her personal information on their Facebook profile, or via other social networking media, with their friends, and who may be much more open about sharing information – or
who may be insufficiently aware of the implications of that sharing. It will be important to consider such changing attitudes in the future, and for health professionals, including nurses, to work with individuals, groups and communities, to address new 'cultures' and forms of interaction and of searching for, evaluating and sharing health information. Research into these areas, and education to address the issues will be important areas to address.

Few studies examine the use of personal health information by patients themselves. A study of PatientsLikeMe (Frost, Massagli, 2008), an online community built to support information exchange between patients with tools to help patients understand and share information about their condition and reference personal health information within patient-to-patient dialogues, found new attitudes emerging. Data on their current treatments, symptoms, and outcomes are displayed graphically within personal health profiles and are reflected in composite community-level symptom and treatment reports. Users review and discuss these data with a variety of commenting and questioning behaviours by patient members.

Members referenced data to locate others with particular experiences to answer specific health-related questions, to proffer personally acquired disease-management knowledge to those most likely to benefit from it, and to foster and solidify relationships based on shared concerns. This project suggests how patients who choose to explicitly share health data within a community may benefit from the process, helping them engage in dialogues that may inform disease self-management. Future designs will need to address each individual's health information as clear as possible, automate matching of people with similar conditions and using similar treatments, and integrate data into online platforms for health conversations.

PatientsKnowBest (2008) also propose the development of an 'openness philosophy', as opposed to the common 'privacy policy'. They describe the approach as counter-intuitive, but believe it may help to address many of the issues raised over privacy as a result of person-centred PHRs/PHIMS. The philosophy is based in the view of sharing healthcare experiences and outcomes being a good thing for people to do. They propose that when people share data, and collaborate on a global scale, new treatments and changes in healthcare and healthcare systems may become possible. They also suggest that opening up access to people's healthcare information, as opposed to the current systems wherein most healthcare data is inaccessible due to privacy regulations or proprietary systems and approaches, patients are not always able to get the information they need to make treatment decisions, and research is additionally slowed. In a manner akin to the Web 2.0 concept of the 'wisdom of the crowd', they suggest that if the data belongs to the person or patient, to share with other patients, caregivers, physicians, researchers, pharmaceutical and medical device companies, then through sharing and adding to collective knowledge, everyone's health will benefit.

Promoting equity, avoiding digital divides

It has been suggested that, while paper records have many drawbacks in terms of access and sharing, they have benefits in that anyone can use them, while electronic, online and networked PHIMS/PHRs potentially risk creating, or encouraging, digital divides. There are many complex issues involved in promoting equity and it is not
possible to explore them in detail here. However, these issues need to be considered in
the development of PHIMS/PHRs as do the education and awareness raising that is
required among individuals, patients, and health professionals and healthcare providers.
Among the sectors of the population who might be disadvantaged are the elderly,
disabled, dependent people, technology non-users, migrants and the homeless.

Challenges in promoting equity and avoiding digital divides include:

- ensuring that the individual has access to personal health information when
  needed
- addressing the current lack of technical standards for interoperability
- exploring the provision of PHIMS/PHR services through a wide range of
  personal, portable devices, and access through public service kiosks, or similar
  for those unable to access or use other methods
- promoting health literacy
- ensuring that access is not restricted through language issues.

Examples of tools and approaches

Several organisations have sought to provide education or have developed frameworks
aimed at individuals and/or health professionals, to foster 'best practice' in the issues
explored. The examples provided below are not an exhaustive list but they illustrate the
kinds of approaches that have been or are being tried, many of which have common
features, and that might provide guidance in the development of international or
regional guidelines on the ways in which people interact with PHIMS/PHR.

Canada – Ombudsman Manitoba, Privacy Compliance Tool The purpose of the
checklist in this tool is to provide a diagnostic process for privacy compliance that
covers the basic requirements of sound information privacy practices. It is designed to
assist organizations evaluate the privacy compliance of a program, a specific initiative,
a policy or an information system. (Ombudsman Manitoba, 2003).

Together” was published by the Ministry of Social Affairs and Health in January 2009.
(http://www.stm.fi/c/document_library/get_file?folderId=39503&name=DLFE-
7801.pdf). Its vision is that, by the year 2013, patient safety will be embedded all
structures and methods of operation to ensure that care and treatment are effective and
safe. It includes addressing data management and issues related to data/knowledge
transfer. By addressing a combination of culture, management, legislation, and
personal responsibility the Ministry seeks to engage patients and individuals through
education, systematic promotion of safe practices, and safety. These are also being
embedded in health research and teaching.
USA - AHIMA The American Health Information Management Association (AHIMA) has developed a website aimed at a range of types of individual (including patients, parents, family caregivers, and those seeking to maintain health) with a section titled “Your Privacy Rights” that provides basic, simple information on privacy issues, and on the question of ‘who owns your health information’. This resource can be accessed at http://www.myphr.com/index.php/privacy_and_phrs/your_privacy_rights/

England - NHS Care Record Guarantee The NHS Care Record Guarantee is a document explaining to patients how their records will be kept secure and confidential under the new systems being developed. It covers systems of access control to the records, for example through smartcards used by NHS staff, with additional password-controlled security, which aim to ensure that health professionals are only able to access the information they need for the patient's care and treatment, based on the professional's job role. Audit trails that log every time someone accesses a record are kept, providing additional security to ensure confidentiality of the records. http://www.nigb.nhs.uk/guarantee/crs_guarantee.pdf

USA - Medicare PHR Choice A website that provides information on a range of types of PHR, a comparison chart, and information on security and privacy policies for this organisation. http://www.medicare.gov/PHR/PHRChoice.asp

USA - Markle Foundation, Common Framework for Networked Personal Health Information Policy Brief A document that provides summaries of a number of issues to be addressed as PHRs are developed, or other networked PHIMS. http://connectingforhealth.org/resources/CCPolicyBrief.pdf

The above examples are primarily approaches developed by healthcare providers. Others have proposed alternative approaches, such as the development of a “Cyber-Patient’s Bill of Rights” (Abril & Cava, 2008) that outlines the rights and responsibilities of patients (and by extension people who might wish to use PHIMS/PHRs to maintain or promote healthy living) in the areas of confidentiality, privacy, etc. The document begins from the premise that we should “Start with what is right rather than what is acceptable”, and seeks to “systematically anticipate, address, and organize a set of norms and rules for the online health networking environment.”

The proposed “Bill of Rights and Responsibilities” is based on principles that include educating and engaging people through developing trust in the systems, technologies, and in the communities of people and stakeholders they might interact with, and fosters a duty to respect for other users. Among the articles of the Bill are that the ‘cyber-patient’ has rights, including:

1. **Right to an Effective Architecture of Privacy** – this is based on the providers of PHIMS/PHR systems ensuring that they make use of the latest technological advances and resources to protect information from being used or accessed inappropriately, so as to protect the integrity, security, and confidentiality a person's health information.
2. *Right to Informed Consent* - the right of the person to know, or be educated, before disclosing personal information online, how the provider will safeguard any information the person provides and/or shares. This means that they must have understandable information about the technological system and its capabilities, privacy policies, and who has access to any records, postings, or other online activities.

3. *Right to Control Disclosure of Information* – if the premise underlying many PHRs/PHIMS is that they are truly person-centric, individuals are in the best position to decide what information to disclose and to whom. Users must, therefore, have the right to control their information, and the ability to grant or deny access to their information on a context-by-context basis. This includes allowing them to set the specific levels of confidentiality expected of each piece of information they add to the PHIMS/PHR.

4. *Right to Accessibility and Portability* - the person has the right to access, alter, and delete any information pertaining to them, and to easily transfer their profiles, information or records to other online health record systems (Abril & Cava, 2008)

With rights also come responsibilities or duties, and the Bill proposes that the individual be charged with responsibilities over their online privacy as follows, including:

1. *Duty to Understand* – a duty to ensure that they understand the nature of the online environment they are using, and adjust expectations of privacy accordingly
2. *Duty to Maintain the Confidentiality of Fellow Users’ Information*

To some, especially to some health professionals, the proposals in such a Bill of Rights may seem to tip the balance too far away from the traditional model of sharing and control over records, but it is a logical extension of the move to true person-centred records.

**Looking to the future**

While many people may struggle with the challenges of PHIMS and PHRs, it is important to consider that many of the solutions we adopt will need to be future-proof, to take account of new and emerging technologies and new forms of health information that the technologies will provide and support. Perhaps one of the most important of these new areas is the vast amount of genetic information that will be available about individuals, and that will become part of, or interact with, their health records.

McGuire et al (2008) acknowledge that, as we move towards more personalised health care, which they also imply will be more effective, the amount of complex genetic and genomic information contained within electronic health records will increase. In the same way as AHIMA recommend for records, they see a need for appropriate
protection of this information, but also question whether genetic/genomic test information should be treated differently from other health information for purposes of data access and permissible use, and whether special protections should be created for genetic/genomic information that is held in the EHR. We are seeing the emergence of PHRs being provided not only by ‘traditional’ healthcare provider organisations, who recognise the importance of emerging new models of care and relationships between people and their care providers – and who, in countries where competition exists, presumably wish to maintain their market share – but also by ‘non-traditional’ providers of PHRs. The most well known examples of the latter are Google Health and Microsoft Healthvault. A recent study of users’ experiences (Peters, Niebling, Green, Slimmer & Schumacher, 2009) found that participants preferred Google Health, mainly due to its greater ease of use, although features such as security, privacy and trust did influence participants’ overall evaluations. It is critical to note that their major difficulties with both applications - and their strongest criticisms - were related to the user experience. As Perry (2009) notes, both companies have a lot to lose if their records are not secure.

If there is to be widespread adoption and acceptance of PHRs and PHIMS, there will need to be further research into, and education and guidance on, a wide range of issues, not least “clarification of boundaries and responsibility for ensuring accuracy and integrity of health information across distributed data systems; and understanding confidentiality and privacy risks” (Weitzman, Kaci & Mandl, 2009).

**Recommendations**

The recommendations arising out the preceding discussion of the issues aim to provide direction in the areas of confidentiality and safety, and form the basis of an action plan, including the development of resources aimed at individual people, health professionals and care providers. We recommend that:

1. Education and awareness raising, for all concerned, is probably the best way of fostering best practice in ensuring the confidentiality, safety and security of people's health information in PHIMS. For health professionals, this will usually be supported by some kind of legal or professional sanctions to deal with breaches of confidentiality, safety best practice, etc. The former will be both country-specific and require international guidelines; the latter will most likely be country-specific

2. The Special Interest Group on Nursing Informatics of the International Medical Informatics Association (IMIA-NI) should establish a Working Group on Confidentiality and Security to further address the issues raised and develop specific actions, working with the IMIA-NI Standards and Education working groups.

3. An online resource (website, wiki, or similar) should be developed that brings together a suite of tools and sources of data to support health through confidentiality and safety (multi-lingual; multiple media).

4. Clarification of the ethical principles that are going to inform the PIHMS (person autonomy, ownership information, professional secret, etc.) needs to be undertaken and consensus gained about the concept “owner of information” in order to know if there is any information belonging to the PHIMS that the holder (the citizen) cannot access (or directly access).
5. Nurses who are engaged in the care process of an individual, group or community must have the legal and professional right to access to all the information that belongs to the PHIMS, if the owner (citizen) give the necessary permission;

6. There needs to be deeper participation of nurses, and national and international nursing organisations and other professional regulators in the debate with statements positions prepared about the issues related to nursing practice, ethics and deontological codes;

7. There needs to be harmonisation (worldwide or at least within the European Union) of the legislation about nursing and the others health professionals’ and citizens’ rights to access to PHIMS information.

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Introduction

This chapter explores governance and policy issues that influence the uptake and use of Personal Health Information Management Systems (PHIMS). The authors identified six key areas for governance: health policy; finance and incentives; people engagement; legalization; professional practice; and evaluation. These key areas are not intended to be the complete list but were considered by the authors to be the most significant areas for governance. A goal that would influence the adoption and use of PHIMS is identified for each of the six areas, together with a rationale and key stakeholders that we suggest influence each issue or upon whom the issue will primarily impact. Further detail about the area is then provided; it should be noted that the two chapters in this text related to professional practice and confidentiality and security provide a further level of detail and understanding in those two key areas of governance. Also explored here is the overarching influence of culture on governance and policy. Finally, overall recommendations are made regarding governance issues that are essential to the future design, development and implementation and use of PHIMS.

Before proceeding to highlight the key governance issues it is necessary to define PHIMS. The literature often references electronic personal health records and while there is no universally agreed definition of the ePHR, it has been described as “an electronic application through which individuals can access, manage and share their health information…in a private, secure and confidential environment” (Pagliari et al, 2007b p330). Models of the ePHR vary in the extent to which the content and control is with the patient or the healthcare provider, although there has been a gradual convergence towards electronic health record systems that combine both patient and provider contributed content (Gaunt 2009).

From examples of ePHRs in use, additional functionality means that they have the potential to support the management of health as well as management of health information. We provide a definition that is deliberately broad, in recognition that this field of health informatics is still developing. For the purposes of this chapter, a Personal Health Information Management System is defined as “a toolkit of information and information communication technology resources that enables personal health management.”
Functionality may include: supporting access to information: supporting access to services; and providing alternative methods of communication with health professionals, healthcare providers and sources of support. The main goal is not simply improving access to information or services but also supporting empowerment, engagement of people in their healthcare and shared decision making between the professional and the person (Bradwell & Farook, 2009).

Access to information may include:

- Information about illness, treatment or care plans for self management
- Providers’ clinical records e.g. medical history or results reporting
- Personal health information e.g. personal preference.

Access to services may include:

- Personal health organiser (e.g. appointments diary or contact lists)
- Health promotion tools (e.g. health or lifestyle questionnaires)
- Ordering drugs, supplies or equipment.

Communication mechanisms may include:

- Appointment alerts from the healthcare provider (e.g. reminders, clinical appointments)
- Tools to capture symptom or health behaviour data to share with health providers.
- Seeking advice from a clinician (e.g. patient-nurse email)
- Links to sources of support (e.g. virtual peer networks) (Pagliari et al, 2007a; Guant 2009).

Governance may also mean different things to different people. The group therefore defined governance as "the policies and processes that drive the use and benefits realization of PHIMS”.

**PHIMS and Organisational Culture**

‘Culture’ is an umbrella word that encompasses a whole set of implicit, widely shared beliefs, traditions, values and expectations that characterise a particular group of people. Issues that may influence the adoption and use of PHIMS include the culture of the country, the organisation, the profession and even the individual person. To an organization, culture is what personality and character are to the individual. It identifies the uniqueness of the organisation, its values and beliefs. Just like an individual's values and beliefs influence behaviour, so, too, does an organisation's culture influence the behaviour of its members (Leavitt & Bahrami, 1988b).

The implementation of any information and communication technology (ICT) requires change. Such change impacts people within the organisation, their roles and working practice, communication flows, information and control. Leavitt and Bahrami (1988a) suggest that managing organisational change should start with the organisation’s
mission, philosophy and vision of what kind of an organisation to create, and that these are reflected by the organisational culture. It is therefore useful to examine what sort of culture would be required to influence adoption and use of PHIMS. This understanding of culture could potentially be used to assess an organisation's readiness or extent of change in culture required to adopt PHIMS.

Culture Dimensions

One of the landmark studies which attempted to establish the impact of culture differences on governance was conducted by Geert Hofstede in the late 1960s (Hofstede 1991). The original study was based on a survey involving 116,000 IBM employees in 40 different countries, asking for their preferences in terms of management style and work environment. Hofstede identified four “value” dimensions on which countries differed: power distance; uncertainty avoidance; individualism/collectivism; and masculinity/femininity. Later he added a fifth dimension which he called long term orientation, based on differences in countries (Asian, African countries) that were not involved in the original IBM study.

The conceptual framework that we developed to support this exploration of governance issues, asserts that the achievement of the goals identified in each area of governance is dependent on the level of balance for the relevant cultural dimensions at either the country, organisation or individual level. It was assumed that emphasis towards one side of a dimension means less emphasis of the other side. It is also assumed that for each dimension, the culture can influence the choices being made. For example the organisation may need to respond to different patient cultures and some patients may not wish to use a PHIMS. If the culture of nursing is a person-centered model of care, then the nurse needs to respect the person's choice. Assumptions made in relation to the conceptual framework require validating. We have attempted to apply these concepts in some of the governance areas that we identified and we offer you the opportunity to validate them as well.

*Power distance* indicates the extent to which a society accepts the unequal distribution of power in institutions and organisations. This may apply to the relationships between the supervisor and the employees, but also to teachers and students, to health professionals and patients. Hofstede (1988) argued that organisations in countries with a high power distance would tend to have more levels of hierarchy (vertical differentiation), a higher proportion of supervision, and a more centralised decision-making. Status and power would serve as motivators. Leaders would be seen as authorities. Introducing PHIMS, which challenges the power balance between health professionals and patients, will probably be easier in countries or organisations with a smaller power distance. PHIMS puts the person more in control of his or her own health (record) rather than it being controlled by the professional.

*Uncertainty avoidance* refers to a society’s discomfort with uncertainty, with most preferring predictability and stability. In countries with a high uncertainty avoidance, organisations would tend to have more formalisation by rules and procedures. There is greater specialisation related to technical competence in defining jobs and functions. The role of leadership would be one of planning, organising, coordinating, and controlling. In relation to PHIMS, we expect that in these high uncertainty avoidance
Individualism/collectivism reflects the extent to which people prefer to take care of themselves and their immediate families, remaining emotionally independent from groups and organisations. In countries with a high collectivist orientation, there would be a preference for group as opposed to individual decision making. Consensus and cooperation would be more highly valued than individual initiative and effort. Motivation derives from a sense of belonging. In countries with a high individualist orientation, emphasis is put on personal achievements and individual rights. Everyone has a right to his own opinion and is expected to reflect those opinions. The concept of PHIMS is clearly developed in an individual culture putting high emphasis on “personal” health. In these countries, focus will be placed on access rights to the person’s health record (who has access to what data). In a collective culture, more emphasis might be placed on a “family” or “group” health record in which the health of a family or a group is managed. More emphasis might be placed on public health issues, discussing life style issues (eating, drinking, and health prevention) for the group rather than individuals.

The masculinity/femininity dimension reveals the bias towards either “masculine” values of assertiveness, competitiveness and materialism towards “feminine” values of nurturing, and the quality of life and relationships. (It should be noted that the research from which these concepts were developed was undertaken in the 1960’s and cultural shift in this area could mean the use of the terms masculine and feminine and their associated values could be challenged today. However, we believe that the opposing sides of the dimension are still useful). In countries ranked high on masculinity, the management style is likely to be more concerned with task accomplishment than nurturing social relationships. In more feminine cultures, the focus would be to safeguard employee well-being, and concerns about social responsibility. In relation to PHIMS this dimension is strongly related to what people value. In some cultures, the length of life (quantity) is valued. It might be that PHIMS in these countries are focused on life style (to prevent), medication (to cure), exercises and rehabilitation (to recover). In countries with feminine characteristics, quality of life is more highly valued. The focus will be more on living with disease, giving meaning to illness, how illness and disease bring people together, the work-life balance, etc.

Long term orientation is the fifth of Hofstede’s dimensions and was added later to distinguish the difference in thinking between the East and the West. It originated from a Chinese value survey across 23 countries and was built on an understanding of the influence of Confucius. An example is the meaning of “old age.” In the West it is mainly seen as something to postpone as it is linked with disability and discomfort and should begin as late as possible. In the East it is something to strive for as it is linked with status and wisdom.
Long-term-oriented countries put more value on learning, accountability, and self-discipline than on truth; short term orientation focuses on the values of freedom, rights, and success. An example of the impact of this dimension on PHIMS is the role of evidence-based healthcare that is highly valued in the Western world. Incorporating information about the evidence of interventions would be highly valued in these countries. In long term focused countries, evidence-based healthcare is less valued (there can be many truths at the same time); greater value is given to relationships, self-discipline and long term health promotion.

**Health Policy**

The health policies of governments and healthcare delivery organisations will shape the way healthcare is delivered. This will be directed by their vision for healthcare, based on the country's and organisation's culture and is achieved through the adoption of various strategies, policies and governance arrangements, supported by financial incentives and monitored via standards and performance targets. To foster the adoption and use of PHIMS, their introduction must be explicitly linked to these health policies.

**Goal:** PHIMS should facilitate the delivery of health policies that emphasise health promotion, disease management and the quality of healthcare to support person-centered healthcare, improve people’s healthcare experience and health outcomes.

**Rationale:** The drivers for PHIMS should be to support the goals of the healthcare delivery system and people’s health needs, rather than be driven by the opportunities enabled by the technology itself.

**Stakeholders:** Patients, the public and their representatives; nurses and managers; professional regulators and societies; healthcare provider and purchaser organisations; academic organizations; voluntary agencies and charities; ICT industry; and government.

It is recognised that ICT is likely to be both a driver for change as well as enable the changes needed to address future challenges and improve healthcare services. While key stakeholders including governments and organisations should consider how ICT might assist in delivering better healthcare, the implementation should be driven by healthcare needs and policies rather than the technology itself. This will support funding decisions and business cases necessary for adoption and use. ICT that is introduced as a business change rather than an ICT project is more likely to be adopted by clinicians who will need to adopt new roles and working practices as a result of the new technology such as PHIMS.

Currently, the health of populations is affected by a number of drivers, the main ones being an increasing elderly population, an increase in chronic diseases, new disease patterns caused by changing lifestyles, and health inequalities. Correlate this with advances in technology itself and the opportunities this brings to improved access and sharing of information, the ability to provide services in different ways, and the resulting change in culture of information use means our future healthcare delivery systems have the potential to look very different than the current state.
Together with tension brought about by increasing demand for healthcare and decreasing resources, in terms of both manpower and funding, brings further drivers for change that are both challenges and opportunities. Most countries in the world are facing these challenges and their responses are reflected in health policies which will require changes to the structure and provision of healthcare service. These are likely to focus in three areas:

1. patient-centered healthcare - healthcare that is centered around the values, preferences and expressed need of the patient rather than the need of service providers
2. shift from a hospital care setting into primary and community care
3. increasing number of service providers - both public and private, including partner agencies such as social care.

Increasingly, the response to these challenges also includes a policy for patients and their caregivers to take more responsibility for their health management and be more involved in self management of long term conditions (The Royal Society, 2006). Patient-led healthcare is not a new concept; patients, often with the support of their families, already manage much of their own care. When they do interact with health professionals, many decisions ultimately remain with the person, as do the consequences. Information can help people improve the control they have over their health and lifestyle and is critical to how people provide their own care in the form of self-management or in making decisions or choices about their care. However, simply providing information is not enough.

People require health literacy, which means they need to possess a wide range of skills and competencies to enable them to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase the quality of life (Waterton, 2009). This will require people and health professionals to develop different relationships and places an increased emphasis on the role of the nurse as a knowledge worker (Institute of Medicine, 2004). PHIMS has the potential, along with cultural changes, to support both patient-centered healthcare and nurses in their knowledge-worker role.

A number of the cultural dimensions described above link to the health policy drivers and may be useful to identify the balance required for the introduction of PHIMS. Health improvement, for example, may be dependent on the dimension of individualism / collectivism. PHIMS can support people with individual health screen programmes but may be of less value in a public health approach to health promotion. If health policies support this approach to health promotion, then PHIMS will be an essential tool to deliver this policy.

It has been recognised that increasing standardisation of care through professional guidelines can conflict with the exercise of choice at the stage of the patient involvement process (UK Department of Health, 2004). The uncertainty avoidance dimension can support disease management approaches such as case management (i.e. delivering care according to pre defined care pathways) on the one end of the dimension, but must be balanced against the need to incorporate individualised care, taking into account personal preferences which are less controllable at the other end of
the dimension. PHIMS have the potential to enable patients to record their personal preferences and for health professionals to deliver personalised health messages to support self-care.

The masculine/feminine values dimension may underpin patient-centered care policy. The need to balance care that is organised for the efficiency or convenience of the health professional and service providers may benefit high performance (masculine values), but it needs to be balanced against the delivery of person-centered care which recognises the relationship issues identified in the feminine values. It is not intended to assume that high performance and person-centered care cannot co-exist but suggests that a balance is required in this dimension.

Finance and Incentives

**Goal:** PHIMS support decisions that are affordable, implementable, usable and acceptable to key stakeholders to ensure investment

**Rationale:** To enable governments and healthcare providers to fund PHIMS, and encourage clinical staff and people to use PHIMS to improve healthcare processes and health outcomes

**Secondary Goals:**
- Fund essential infrastructure and standardisation that fosters adoption of PHIMS.
- Introduce financial and non-financial incentives that encourage delivery of PHIMS by healthcare providers and use by people to improve health outcomes.

**Stakeholders:** Patients, the public and their representatives; professional regulators and societies; healthcare provider and purchaser organizations; voluntary agencies and charities; ICT industry; and government.

Whether they are publicly or privately funded, healthcare systems have finite resources to deal with potentially unlimited problems, resulting in cost constraints. Any new technology has to bring clear improvement to the delivery of healthcare to justify its introduction. Therefore, financial issues and incentives must be addressed to enable governments and healthcare providers to adopt and implement PHIMS, and encourage clinical staff and people to use PHIMS to improve health literacy and resulting health outcomes. PHIMS can provide a mechanism to improve access to services and to improve the quality of healthcare, while lowering costs, empowering consumers in their healthcare decisions, and ensuring the privacy and security of personal health information. Investment decisions should ensure that PHIMS are affordable, implementable, usable and acceptable to key stakeholders.

To ensure success in enabling the adoption, use and benefits realization of PHIMS, policymakers should recognise the need for continued financial support that is reflective of the current economic landscape and the needs of citizens and the healthcare community.
Policymakers should consider that financial support or incentives to encourage the adoption of PHIMS do not assure that investments can and will be balanced; competition for capital may erode an organisation’s commitment in light of other pressing needs.

In its analysis of National Health Service Funding in the U.K., the Wanless Report recommends the level of spending on eHealth should be greater than three percent of an organisation’s budget (Wanless et al 2007). Funding can be provided as a mixture of national and local investments and incentives – supported by business plans and focused on the underlying infrastructure and change management. Whatever the funding model, individuals should be able to access their health and medical data conveniently and affordably (Markle Foundation, 2005). Several key issues should be considered and addressed in order to enable widespread adoption of PHIMS to positively impact health outcomes.

Affordability - considers who will bear the cost and determine if the benefits will provide the desired value. Systems must be both affordable and cost effective and benefit the key stakeholders who will ultimately bear the cost.

Individuals will gain by being able to access and update their health information, and easily communicate with their care providers (Lang, 2009). This may ultimately save them time and reduce travel costs, in addition to improving the quality of their care experience, encouraging use of PHIMS to meet personal health needs. Authorised care providers will have access to more accurate, timely information for improved decision making and improved quality of the interactions between the person and clinicians. This has the potential to save the clinician time searching or communicating information as well as improving the quality of care, encouraging use as part of the care process. Organisations can provide new ways of delivering services, improving the patient experience and interactions with the organisation, ultimately improving health outcomes by enabling people’s involvement in their healthcare and decision making. Meaningful use of ICT has, for example, been adopted as a means of U.S. government investment in health IT investment under the 2009 American Recovery and Reinvestment Act.

Implementability - will require investment in PHIMS that must be both ambitious and achievable. As PHIMS is a relatively new area, incentives for adoption will require investment in significant change management that is necessary for implementation. This principle is recognised by the Royal Society (2006) in their recommendations regarding successful adoption of ICT. Health managers should “ensure that sufficient time is made available for healthcare professionals to contribute effectively at all stages of design, implementation and evaluation of healthcare ICT” (The Royal Society, 2006, p. 3). In addition, “Local and national health authorities should ensure that sufficient funding and time are allocated to provide initial training and ongoing support for healthcare professionals” (The Royal Society, 2006, p. 4).

Usability - requires standardisation and convergence of technologies to ensure the vision of PHIMS is realised and supports the goals of integrated and co-ordinated healthcare across the range of providers. PHIMS should allow innovation and encourage good practice to enable widespread benefits to be realized for all users and
improve quality of care. The need for convergence between national and international standards is also recognised by the Royal Society (2006) and others.

Acceptability - supports the principles of transparency and fairness. Transparency allows the identification of what is spent and by whom, which can open up the debate on the priorities for spending decisions. Where government or public funding is provided, it should be distributed to ensure equality, supporting a basic level of provision and infrastructure cost, keeping in mind economies of scale. Where there is a finite amount of funding, this must be linked with cost effectiveness.

To realise the adoption of PHIMS, the following financial strategies should be addressed:

- Investment in health IT should support better quality and improved productivity if it is to be cost effective and funded
- All stakeholders that are impacted by PHIMS should be assessed in terms of cost benefits including patients, clinicians and the organization.

The functionality on which these benefits depend should support a win – win – win situation. Ultimately, PHIMS should benefit governments and organisations who invest funds, clinicians who encourage PHIMS to be used to support the care process, and individuals who will benefit from quality healthcare.

Engagement of individuals

Goal: People are informed, involved and consulted as partners in the design and delivery of PHIMS to enable appropriate and competent use.

Rationale: Engagement will ensure that PHIMS are designed to support peoples' needs and reduce the risks of unintended and undesirable consequences.

Stakeholders: Patients, the public and their representatives; nurses and managers; professional regulators and societies; healthcare provider and purchaser organizations; voluntary agencies and charities; ICT industry; and government.

"The single most important factor in realising the potential of healthcare information and communication technology is the people who use them. The end user of a new technology must be involved at all stages of the design, development and implementation, taking into account how people work together and how patients, care giver and healthcare professionals interact" (The Royal Society, 2006, p 1). In this case, the people who use PHIMS will be patients and the public, with support from their families, caregivers and health professionals.

Why people should be engaged - The transition from provider-driven to a more patient-driven information management trend demands a shift in the power balance related to development, involvement and engagement. This shift in power balance challenges people at the individual level, at the group level and the providers themselves.
It is important to be aware of the asymmetry between professional knowledge and lay people's experience, and information need and management. In addition, engaged and well-informed people challenge providers in their encounters with patients and the public. (Barnoy, Volfin-Pruss, Ehrenfeld & Kushnir, 2009)

The goal of engagement is that people are informed, involved and consulted as partners in the design and delivery of PHIMS to enable appropriately designed systems and competent use. This approach accounts for cultural considerations as, for example, the collective versus individualism. However, people who belong to a culture which expects to have access to general health information, do not always currently have this possibility (Wang, Lau, Matsen & Kim, 2004). The rationale for engaging people is to ensure that PHIMS support users’ expectations in their healthcare efforts and take into account their own preferences and values. Expectations of empowerment and peoples’ competence to take control of their health situation, forces different approaches and differentiation in involvement with development of PHIMS.

In addition to cultural aspects, personal characteristic will influence involvement. For example, we need to take into account the aging population and ensure that their engagement is adjusted to their competency, health status, possibility and wishes (Hellesø, Eines, Sorensen & Fagervik, 2009).

A key point related to engagement and participation in development is to ensure user-friendly PHIMS and to prevent unintended results. An overall issue to take into account is confidentiality and security. Furthermore, PHIMS do not represent a single and/or uniform system, which may create problems with interoperability between different devices and systems. The system must be regarded as feasible and useful for those who the system is aimed to serve. To what extent this means structured and coded content or use of free-text or a combination of these approaches will depend on the need of the individual and the purpose of the PHIMS.

Free-text and narratives can provide in-depth information and understanding of the persons health trajectory and the characteristics of the healthcare system (Hellesø, Sorensen & Slaughter, 2009), as well as being therapeutic because it allows a personal style for interpreting an individual's health and illness (Johnson & Brennan, 2009). Therefore it is extremely important to involve and consult persons who have the knowledge and capacity to participate and advise.

Who should be involved and when - Engagement, involvement, and participation can be of individuals, groups of individuals, or organisations. Stakeholders need to be identified and their opinion and views must be shared and used. Engagement can last for longer or shorter time periods. Long term engagement can be on a political and strategic level. For example, persons representing a patient association provide one avenue for engagement of groups with specific interest. To develop robust and user-friendly PHIMS requires discussions and awareness of what it means to represent an association and who has the competency and qualification to be a representative. Short-term participation can enable development of a specific tool/device for fulfilling a defined purpose. Use of a participatory approach has been shown to be useful for developing web-based individual care plans for the persons and their families (Bjerkan, 2009).
Implications of engagement - Peoples’ engagement challenges the traditional professional's role. Concerns about the impact of a patient’s ability to read their health record or their competency and capability with regard to information literacy are examples of factors that cause barriers to engagement and deployment of PHIMS. Peoples’ engagement must therefore build on trust. Involvement is expected to evolve and take new forms in the future as a result of cultural changes, knowledge and experience within the field.

Legislation

Goal: PHIMS should enable the sharing of health information in a safe and secure manner with the person as the gatekeeper to ensure accuracy of information and optimal decision making.

Rationale: People will be confident that the right information is available to them and the nurse who has a legitimate relationship with the person in a timely manner to support shared decision making and person centered healthcare.

Stakeholders: Patients, the public and their representatives; nurses and managers; professional regulators and societies; healthcare provider and purchaser organizations; academic organizations; voluntary agencies and charities; ICT industry; and government.

In the UK, the term "information governance" refers to the policies and practices in place to ensure the confidentiality and security of the records of patients and service users to help deliver the best possible care. It enables healthcare organisations to comply with laws related to personal data. While different countries have different laws governing data collection, storage, access and use, most laws will provide a framework to protect the person to whom the data relates. If PHIMS are to meet necessary legal requirements and the expectations of professionals and people, many questions and practical considerations need to be addressed to ensure that any personal data is treated with as much respect as the person themselves should be. Successful adoption and utilisation of PHIMS will ultimately be influenced by how well the application of these laws protects personal data while at the same time making the right information available, at the right time and right place, to those who need to know. Apart from the person themselves, those who “need to know” could include their family, care givers and clinicians from a range of healthcare organisations, social care staff and voluntary agencies.

The questions and practical considerations relate to confidentiality, privacy and security of personal data. Each of these concepts means slightly different things, however ways of managing them often overlap. Confidentiality means limited disclosure or relevant sharing; privacy means the right of control over personal data, while security relates to access control. Ownership and control are often considered the most important issues with PHIMS and electronic records in general; this appears to be governed by the model of PHIMS and whether it is provider-controlled or person-controlled. While the person or their organisation might “own” what they enter, the law often allows the person to whom the data relates the right to access and alter any inaccuracies.
Addressing confidentiality concerns requires consent models governing how data is collected and shared. In relation to security, it is necessary that only authorised people can access PHIMS, which requires identity and access management systems to be in place - in other words, defining who has access, how they are identified and authenticated. Even those with access will not need to see all of the information held within PHIMS. To ensure appropriate privacy, role-based access protocols need to be explicit about the role of the person and what information they can view, add or alter. In the UK, the Information Commissioner recommends Privacy Impact Assessments are undertaken on all projects that could present a significant risk to an individual’s privacy (Information Commissioners Office, n.d.).

Not all systems can be totally confidential, secure and private. They would probably be unusable and of limited benefit. Recognising that risks are always present means that there needs to be systems to monitor access and, where there is inappropriate disclosure or access to information or poor quality data, some form of penalty must be available. Risks and unintended consequences should always be assessed. This could include assessing any negative impact on specific groups such as disabled or elderly people. Failure to address these impacts could go against discrimination laws in some countries.

The move to person-centered healthcare models that aim to empower people will ultimately challenge the provider controlled model of PHIMS. However, rather than think about PHIMS in terms of control and ownership, it might be more helpful to think about how information can be shared safely with those who need access to it to support both the person and the clinician in making optimal decisions. Where appropriate, this may include a caregiver or family member or another agency. Ultimately, person-centered healthcare is about organisational, professional and societal culture. Two cultural dimensions have the most influence in relation to information governance: power distance and individualism/collectivism. Person-centered healthcare promotes a partnership between the clinician as a provider of care and the person as recipient. This partnership is based on trust, with explicit rights and responsibilities for both patient and clinicians, underpinned by professional standards and education. Trust is potentially the most important factor in adoption and use of PHIMS.

Professional Practice

Goal: It is a requirement of professional nursing practice to be able to foster a person’s adoption and use of PHIMS as a ubiquitous tool to support their health management.

Rationale: Adoption and benefits of PHIMS are more likely to be realised when PHIMS is used as a part of the care process and in accordance with the cultural and personal preference of the person. This will impact on the role of the nurse as knowledge worker.

Stakeholders: Patients, the public and their representatives; nurses and managers; professional regulators and societies; healthcare provider and purchaser organizations; academic organizations; and government.
PHIMS has the potential to support health literacy through the provision of information and, if provided as part of the care process, the potential to assist the individual to understand and act on that information. The latter approach is essential to prevent the creation of additional inequalities for those people who may be disadvantaged through lack of skills, knowledge, ability or access to technology. It is also recognised that clinician prompting is a significant factor to adoption of PHIMS by people. Therefore, using PHIMS as part of the care process and integrated into clinical workflow could support adoption and use and ultimately contribute to improved health literacy. PHIMS is not only a tool for the person to manage their health, but also a new tool for the nurse to enhance professional practice. It can support the nurse in her/his role as patient advocate and knowledge worker. Hofstede’s (1988) cultural dimensions can influence the nurse’s professional practice. While person-centered health care has underpinned many nursing philosophies, there are still challenges to support nurses utilising these new tools. They require nurse leaders to:

- support nurses’ work in challenging environments where citizens and patients have a more active role in maintaining, completing and using their own health information
- work to enable nurses to develop the skills and knowledge to use PHIMS to support and guide citizens and patients to manage and use their health information
- promote new working procedures in healthcare services
- ensure nurses become familiar with and have the access to the latest information concerning PHIMS and all related matters
- recognise those patients who do not have the skills or opportunities to manage and use health information and need the extra help and guidance of nurses.

Evaluation

**Goal:** Evaluate and measure progress and impact of PHIMS to support benefits management, inform new policies and future eHealth developments.

**Rationale:** Evaluation justifies and gives direction for strategies, policies, plans, investment and governance arrangements associated with implementation of PHIMS.

**Stakeholders:** Patients, the public and their representatives; nurses and managers; professional regulators and societies; healthcare provider and purchaser organizations; academic organizations; voluntary agencies and charities; ICT industry; and government.

PHIMS are still relatively new and not yet integrated into healthcare systems and care processes in many countries. This means that experience and evidence from evaluation are limited. The importance of the evaluation of eHealth is noted in a recent review which concludes that “eHealth interventions have considerable potential to transform the health sector, hopefully for the better. As with any other intervention, however, the risk of harm exists, so policymakers, commissioners, clinicians, and patients alike need to remain aware of this possibility.
If we are to maximise the benefits associated with eHealth interventions whilst minimising risks, we must be able simultaneously to evaluate eHealth interventions while they are being designed, developed, and deployed” (Catwell et al., 2009, p8). This view is reinforced by the Royal Society (2006) which suggests that only by rigorous and thorough investigation will we learn how to enhance healthcare ICTs to determine which specific systems actually lead to improved healthcare process and outcomes. Evaluation needs to explore the sociological aspects of healthcare ICTs as well as economic analysis. Government health departments should adopt an iterative and incremental approach to the design, implementation and evaluation when introducing new healthcare ICT (Royal Society, 2006).

Evaluation must be conducted to ensure new and continued investment in current and future PHIMS development and implementation. Questions of concern include what needs to be evaluated, how it should be done and who should be involved. Formative and summative approaches are regarded as useful for evaluating PHIMS (Stoop, Heathfield, de Mul & Berg, 2004). Formative evaluation focuses on the continuous improvement of the system, while summative evaluation focuses on the effectiveness of the system. This suggests that both the process and outcome must be considered and the two approaches fit with the overall goal to evaluate and measure progress and impact to inform new policies. An example of bilateral evaluation is the European Union evaluation of economic impact at ten European sites (Stroetmann, Jones, Dobrev & Stroetmann, 2006).

Summative evaluation is traditionally externally oriented, that is, it is initiated and requested from those who have paid for the project or are responsible for it on a political level. To apply summative evaluation, it is important to have defined goals and expectations of the outcome. Two expectations are that eHealth investment should give better quality and improved capacity. This type of evaluation may be of interest at the governmental level or for healthcare organisations to be able to justify investments by demonstrating benefits realization.

Formative evaluation serves to get knowledge about the different opinions that individuals and groups hold on PHIMS; it addresses implications for the person(s), quality aspects, satisfaction, life-cycle of systems, focus on improvements, etc. We can learn about the processes and explore effects, for example, what does not work during different phases of a project and deployment of systems. Both quantitative and qualitative methods are recommended. A quantitative approach is seen as suitable for establishing the size, extent or duration of certain phenomena.

It could also establish that a specific cause or intervention results in an expected effect. Examples of different evaluation approaches are provided in the report of a study evaluating the impact of specific home care web resources (Casper, Brennan, Burke & Nicolalde, 2009), analyses of patients’ information exchange with their provider exploring post-hospital health problems for persons with cancer (Andersen & Ruland, 2009) or research into factors influencing personal health information patterns (Wibe & Slaughter, 2009). Supplemental to the evaluation approach may be use of scenarios (Meristö, Tuohimaa, Leppimäki & Laitinen, 2009).
A European study on the impact of eHealth (not PHIMS specifically, but including some PHIMS functionality) suggests that given the right approach to implementation, benefits from effective eHealth investment include better quality healthcare and improved productivity (Stroetmann, Jones, Dobrev & Stroetmann, 2006). It also suggests that on average 43% of the benefits are received by citizens and 52% by the organisation. Once deployment and implementation stages have been completed, the value of these benefits rises each year and exceeds the cost, usually very significantly.

Conclusions and Recommendations

A major European study identified key success factors for introducing ICT into health care, including:

- strong health policy and clinical leadership that guides a flexible and regularly reviewed eHealth Strategy
- commitment and involvement of all stakeholders
- regular assessment of costs, incentives and benefits for all stakeholders
- strong leadership and good organisational change management
- multidisciplinary teams well grounded in ICT and clear incentives
- organisational changes in clinical and work practices
- long term perspectives, endurance and patience (Stroetmann, Jones, Dobrev & Stroetmann, 2006, p.10).

Many of these success factors relate to the governance policies and organisational culture issues highlighted in this chapter. To ensure that the future design, development and implementation foster the adoption and use of PHIMS, we make the following recommendations:

Key stakeholders should:

1) advocate and promote these governance goals for adoption in countries and organisations
2) consider how policies and processes can shift the imbalance of the cultural dimensions to work towards implementation of each goal, and
3) raise awareness and create mechanisms and opportunities for people to understand and contribute to the design, implementation and evaluation of PHIMS to support adoption and use, and enable person-centered health care and health improvement.

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Introduction

Nursing education and the nursing profession face many challenges today. The global nursing shortage, the faculty shortage, the demand for different teaching strategies that include emerging technologies and most significantly, the impact of the changing healthcare environment, are all presenting challenges to nursing. One such challenge is the incorporation of Information and Communication Technologies (ICT) and informatics competencies at all levels of education, from undergraduate and graduate programs to professional development and lifelong learning. Various driving forces are encouraging the use of health information technologies (HITs), including personal health information management systems (PHIMS) to provide safe and quality care. As these technologies permeate the health care environment, it is essential that all nurses have the necessary knowledge and skills to practice in a wired world.

There are several driving forces that serve as catalysts for educational change. First, the health care environment is being influenced and impacted by the integration of health information technologies into health care practice. Current and emerging health information technologies are becoming commonplace in many health care institutions and for others it is a constant discussion and part of their future strategic directions. The movement to eliminate medical errors, improve patient safety and increase the quality of care provided is facilitating the adoption of HITs. National, countrywide initiatives, the growth of consumerism, increased access to the Internet and its impact on globalization all serve as additional drivers of change. Second, access to the Internet has given new life to people’s involvement in their health care. The democratization of health information to patients and their families is allowing them to be more active in their health decision-making. Web-based tools targeted to consumers are not only changing their access to health information but also changing the nature of the person/patient and health care provider relationship. A third driving force is the growth of and reliance on evidence based practice that is inextricably connected to informatics.

In this first section, national initiatives, consumer movement and global adoption of HITs are presented. Since 2000, numerous national initiatives across the countries are facilitating the promotion of electronic health care records and the use of PHMIS. For some countries, new opportunities related to integration of electronic health records are the priority.
For others, it is the adoption of both electronic health records (EHRs) and personal health records (PHRs). No matter which scenario, the integration of health information technology, especially personal health information management systems, are having an impact on the practice of health care. As practice changes, it is important for education to also change. Nursing education must examine how to prepare nurses to practice in these new environments.

**Global developments**

What follows is a brief snapshot of major initiatives across the globe related to health information technologies and in particular PHMIS. This is not a comprehensive examination of the adoption of health information technologies; for a more complete picture see the country reports in the following sections of this text. The snapshot provided here is useful to get an understanding that as more health care facilities adopt the use of Electronic Health Records (EHRs), the nature of health care practice will change. The ability to use health information technologies to guide practice will necessitate a change in how education prepares nurses or other health care professionals for practice. It is equally important to see that this movement towards the use of health information technologies is happening across the globe and not limited to only industrialized countries.

In Europe, the European Commission’s Directorate for Information Society and Media has launched two major e-health initiatives regarding the EHR (E-Health Europe Newsletter, 2008). The first addresses recommendations for developing interoperable cross border EHRs. The second initiative covers the launch of the project Smart Open Services (SOS). Project SOS involves 12 member states and aims to remove linguistic administrative, technical and other barriers to make it easier for people to receive treatment when traveling or living abroad. The SOS project includes participation from Austria, Czech Republic, Germany, Denmark, France, Greece, Italy, the Netherlands, Spain, Slovakia, Sweden and United Kingdom.

In Scotland, NHS National Services Scotland (2008) has developed a programme that enables clinicians to examine people’s health information 24 hours per day, with the person’s consent. In this way health professionals can make more accurate diagnosis and treatment and can quickly collect important medical information that can save lives. In addition, the National eHealth Programme has developed a Clinical eHealth Toolkit to facilitate nurses, midwives and other health care professionals to engage in eHealth initiatives (Clinical eHealth Toolkit, n.d.). The toolkit provides an opportunity to share best practices within the national health care system.

In the United States, the Institute of Medicine reports on medical errors and the quality chasm spearheaded efforts to examine the use of health information technologies to insure patient safety and quality care (Kohn, Corrigan, & Donaldson, 2000; Committee on Quality Health Care in America, 2001; Aspden, Corrigan, Wolcott, & Erickson 2004). There were also reports to examine how technology might be useful to improve nurses’ work and help mitigate the nursing shortage (Page, 2004). These reports and other factors precipitated the creation of the Office of the National Coordinator of Health Information Technology. Federal initiatives were proposed that emphasized the adoption of EHRs by all health care facilities by the year 2014 (Brailer, 2004).
The initiatives also supported the development of a health information network for sharing of data to support surveillance and faster transfer of research results. E-health opportunities and the use of personal health records are also encouraged through these initiatives. As summarized by Detmer, Bloomrosen, Raymond and Tang (2008), there are three PHR models in the US: stand-alone, tethered and integrated. Stand-alone examples include Microsoft’s Healthvault and GoogleHealth. The two US organizations with the largest penetration of PHRs are the Department of Veterans Affairs (http://www.myhealth.va.gov) and Kaiser Permanente. A recent review of PHRs by the Medical Library Association and National Library of Medicine Joint Electronic Personal Health Records Task Force (2008) identified 91 PHRs, most of which were stand-alone products.

In Spain, there is a citizen centered health solution that contains the equivalent to an EHR (Protti, 2007). This system is based on four underlying principles: a single health record for each person; unified access to all services; including structured data of all relevant information; and system development by health professionals and providers. A fifth principle of customer precedence in which people are not clients or customers but owners of the data is also evolving.

In Denmark, health care professionals have access to patient data with the EHR and laboratory data through a Health portal (eHealthNews.eu, 2007). This portal also enables patients to look up their personal health data, request doctor appointment and request the renewal of prescriptions. As reported by the Computerworld Honors Program (n.d.): “All Danish citizens have access to sundhed.dk, enabling patients to communicate and patients and their families to get an overview of correct and updated health care information, making the health care services appear close-by, open and familiar. Additionally, every citizen has his own personal page (available upon identification), which reflects the specific situation of this particular citizen”.

In Finland, there has been a long-standing commitment to e-health. The focus in the last decade has been the development of a directory of patient record location information. At the present time most municipalities and hospital districts are part of the directory and the focus is on linking local and regional EHRs into the national eArchive (EHealth Europe, 2009). In addition, there is a project that supports electronic self-care services for citizens, allowing them to communicate with their health care provider and also to schedule appointments.

In 2003, the Portuguese Parliament announced a National Action Plan for an Information Society with the following objectives: to collect health information data of patients; to increase the quality of health care services; to increase the efficiency of the health care system; and to reduce costs for health care. Portuguese e-health policy is divided into three action lines – health information networks, on-line health services and patient smartcards (EHealth Europe, n.d).

In Norway, there are a variety of projects related to EHRs and consumer access to health information. A web portal “MyRec” connects health care professionals to many hospitals and other health care institutions. As a part of this portal, there is “WebChoice” that provides access to cancer patients and their families to help them report and monitor their health symptoms and problems.
The system also offers relevant resources to the patient and their family about the disease and a forum where cancer patients can talk to other patients and discuss their illness. Another project, “Kjernejournal”, enables sharing of EHR data among health workers. “The Kjernejournal is created by copying the relevant part of the EHR to a separate server with high availability and which allows other actors to contribute and read data in an automated fashion. In this way the data is kept consistent and readily available” (Torstein, Larsen & Kofod-Petersen, 2006).

Sweden recently launched the first stage of the Swedish National Patient Summary project designed to facilitate the creation of an EHR (Reuters News, 2009). As a part of the national IT strategy, partners in the project are IT vendors, InterSystems and Tieto. This is the first EHR for Sweden and one of the first of its kind in the world. At the beginning the programme, health care providers will have access to critical patient information at any time and at any place. In this way clinicians will be better informed for making further decisions regarding diagnoses, treatment and follow-up.

East Asian countries (Japan, Singapore, Taiwan and Hong Kong) have taken different approaches to the implementation of EHR systems in their public health care systems (Ghani, Bali, Naguib, & Marshall, 2008). Some have implemented systems on either a local or national level. In Singapore, the use of ICT is widely accepted in the health system and in the seven main hospitals. The first EHR implementation in Japan was started by the Wakayama Medical Association, with the collaboration of Osaka University and Wakayama Medical College. In 1994, they launched another initiative within the Health Information Strategy 21 strategy to support quality and efficient health care services for citizens.

Hong Kong’s approach to the EHR is different from other countries (Ghani et al, 2008). They started with building a solid infrastructure as a foundation, including administrative and financial databases. Then, all hospitals and clinics were connected with each other through a wide area network. This integration provides seamless access to results in clinical areas.

In Taiwan, the goal of the National Information Infrastructure was to develop and implement telemedicine services across healthcare facilities and levels. The EHR strategy development started with bottom-up field projects followed by a realisation that a strategic EHR framework was needed to maximise benefits. One such approach was the National Health Insurance Smart Cards, known as NHI-IC cards. With the NHI-IC, the existing paper-based health insurance cards were replaced with a card capable of updating patient’s critical health records (Ghani et al, 2008).

It is apparent from this brief review that many countries concerned with providing safe and quality health care to their citizens are installing EHRs in their health care facilities. Several countries have national initiatives and have set target dates for the adoption of EHRs by all facilities and healthcare providers. There are also initiatives in the realm of PHIMS. Some countries have initiated research and development projects addressing personal health records. In the United States, multiple companies are now providing consumers with access to their own PHR. In some instances, insurance companies have partnered with these companies to connect the PHRs to the EHRs supported by health care facilities.
Consumerism

Another important factor to consider when planning future educational programmes for nurses is consumer access to health information. The Internet and mobile technologies are providing people with instant access to health information that was once only available to health care providers. In many parts of the world people have access to sources of knowledge over the Internet although internet use varies greatly between countries and regions. According to Internet World Stats (2009), about 75 percent of the population of North America accesses the Internet, 60 percent in Australia and New Zealand and 50 percent in European countries. Access is rapidly spreading over developing countries with the greatest increase in the Middle East and African countries - over 1,000 percent from 2000 to 2008.

The spread of Internet use means that patients may have more in-depth knowledge about health maintenance, their disease and treatment options than the health care professionals do. In addition, patients and their families have the possibility for interaction with others in the same situation. Health care professionals have a broader knowledge and have extensive clinical experience, but usually they do not have in-depth knowledge in specific fields. Patients and families can be a driving force in the transition to personal health information management systems as they are increasingly being more knowledgeable about their particular disease.

This transition of knowledge challenges the traditional power balance within health care, where health care professionals were in control of the knowledge and patients’ perceptions and preferences were less acknowledged. This shift may be seen as threatening to clinicians and requires them to reshape their thinking about who has the knowledge and who can make decisions.

The consumerism movement leads to professional demand for education and training to use these knowledge resources, in order for professionals to be able to interact and guide patients. A constraining factor in this development is that at the same time as consumers became more knowledgeable and demanding, there is a need to establish priorities in health care because of limited resources. Also, there is a potential for consumers to become overwhelmed with the available information and knowledge that may not always be helpful and lead to good decisions.

Nurses need to insure that all people have access to health information to aid in their decision-making about their health and well being. The International Council of Nurses (ICN) supports this notion of universal access to health information stating that: “everyone has the right to up-to-date information related to health promotion and maintenance of health and the prevention and treatment of illness. Such health information should be easily accessible, timely, accurate, clear, relevant, reliable and based on evidence or best practice” (ICN, 2008, p1).

The ICN statement also recommends that “Nurses and other health professionals should acknowledge individuals’ rights to make informed decisions and choices about how to manage their own health and to accept or reject health care or treatment” (ICN, 2008, p1).
As well as understanding and promoting access to information, nurses need to understand how people are using technology to manage their health and to make pertinent health care decisions. A recent study reported by Fox (2007) found that of those patients with chronic diseases, at least “75 percent reported that their last health search affected a decision about how to treat an illness or condition, compared to 66 percent of other e-patients” (Fox, 2007, p2). Engaged patients are also sharing their stories online, posting advice about managing their disease and how to communicate with their health care providers (Fox, 2007).

This study as well as others reported that engaged patients were also sharing their “observations of daily living” (ODLs) on various social networks as well as in their personal health records devices. According to a Health in Everyday Living E-Primer#3, the “collection and use of ODL information - which includes information on such activities and experiences as sleep, diet, exercise, mood and adherence to medication regimens - is one area that is genuinely user-directed, both in the kind of information that is contained in the record and the health-related activities that stem from it” (Robert Wood Johnson Foundation, n.d). Based on this evidence, two important questions can be posed: are nurses aware of engaged patients and their behaviors on the Internet? And are nurses preparing to be partners with people who are actively engaged and knowledgeable about their health or their chronic condition?

Evidence-based practice

There is a strong movement for evidence-based practice (EBP) within health care worldwide with the primary focus on evidence from research. But we also need to be cognizant of patient preferences as an important pre-requisite for EBP. There is a need to rethink what is considered as evidence. The knowledge that the patient contributes about how they experience their disease and their symptom management is a form of evidence that needs to be included in evidence-based decision making. Research-based knowledge from different sources, collective expertise and accumulated experiences from everyday living contribute equally and in new ways as evidence and content for PHIMS. Given this context (the growing adoption of EHRs and PHRs on a global level, increased access to health information and the growing engagement of people in their health care), there is no doubt that the way nurses provide care will change dramatically. The emergence of a more engaged population concerned about health care decisions will provide many opportunities for the development of new models of nursing care.

New models of nursing care

Technology is pervasive and present in all human activities; information is readily available. As a result, people with chronic diseases are often better informed about their everyday challenges and the last scientific developments related to their condition. The engaged patient knows where to acquire information and gain knowledge. Given this context for the future practice of nurses, person-centered partnerships capitalizing on PHIMS will require models and approaches suitable for increasingly networked, global and diverse care environments.
**Person as partner in trajectories of care**

Person-centered partnerships are characterized as trajectories with multiple forms of participation, often managed at the discretion of the citizen’s situated preferences for care and their desired (and changing) level of participation. As partners in care, persons/patients are more often in charge of their personal health information management. They can act upon and personalize choices reflecting value systems, preferences, cultural and religious beliefs, available care programs, and reimbursement opportunities. Emerging technologies enable changing structures of participation in multiple sites – spatial and temporal – for care activity. Trajectories, as described by Strauss (1975) and Strauss, Fagerhaugh, Suczek, and Weiner (1985) point to the evolving nature of a person’s health and illness experiences.

Patient-centeredness and partnership-based care models are supported in increasingly wired environments with informatics applications including PHIMS. In these partnerships, acquired information about issues such as provider quality, diagnoses, treatment alternatives, strategies to improve experienced quality of life, collect observations of daily living and/or benefit of passive information gathering, complement and augment provider perspectives on care.

The trajectories of illness and wellness intertwine with other aspects of life in “seamless care paths”. The trajectories of persons and providers will intersect and take new, unique paths (Ludvigsen, Rasmussen, Krange, Moen, & Middleton, 2007) and provide a basis for the emerging, new practice models of the technology-enhanced practice environments. With new roles and new responsibilities for personal health management, the actual ‘division of labor’ shifts. Preparation of nurses at all levels should expand and acknowledge the challenges of the new, symmetric relationships where contributions reflect different perspectives of equal value, and additional cues for new forms of decision-making.

**Preparing for new practice models**

In the area of changing, person-centered partnerships, some key elements in the emerging practice models will be particularly important. Being involved in person-centered partnerships where the person’s trajectory of health and illness is at the center, calls for care environments with multiple forms of participation. There will be expanded communities of practice. Innovative solutions must be projected to address complex problems such as: an aging population; increased prevalence of chronic diseases; high costs of care delivery; and economic constrains to assure continuity, quality, and cost benefits of treatments and care. In such practice models the participants’ roles and responsibilities must balance in activities by consumers and providers to appropriate and exploit PHIMS.

Future care and services require balancing ‘philosophy of care’ and ‘philosophy of cure’ in new ways (Kim, 2000). This will lead to new models taking the multiple players, their resources and contexts into active account. The new practice models depend on patient activation in new ways, and value comprehensive, correct information when needed, that is: “just in time” and at “point of need”.
This ties into cultural aspects of tradition, beliefs, and ethics. Participation in new, PHIMS opportunities will contribute to expanded communities where the processes of socialization and structures of participation change. Person-centered partnerships imply decentralizing care where commitment to team work, enhanced communication, collaboration and decision making to include situated preferences for participation, engagement and commitment to patient’s health goals.

In summary, a caring relationship where the available and emerging PHIMS positively influence partnerships rests on new care-relationships to enhance patient outcomes, and for nurses to emphasize skills that demonstrate organizational agility in resolving complex patient care and communication issues (Marin & Sasso, 2006). The partnerships and their nature are likely to change over time, and future practice models should demonstrate flexibility to balance symmetric-asymmetric relations, recognizing that, at times, equality and equity in the partnership may not be possible, feasible or appropriate.

Educational challenges in changing practice models – care environments

For nursing and nursing education at all levels, the new practice models represent a shift in paradigm, where nurses’ roles and responsibilities will evolve from that of patient advocate to contributor for patient learning and participant in the partnership. Educational opportunities for nurses must be aligned with, assist or even drive the process where consumers can evaluate and interpret good information, known for quality, appropriateness, reliability, validity, as well as consistent with their needs and value structures. In an increasingly wired world, person-centeredness needs to be tied to and emphasized in the different initiatives to improve informatics competence.

The emerging citizen-centered partner models require shifts in continuing education programs for clinicians, so that they are able to care for the patient/consumer in these emerging technology-enhanced practice environments. There are significant challenges for the education of nurses at all levels, not least of which is the readiness of nurses to serve as partners in care (Skiba, 2009a). Nurses in all roles and at all levels must incorporate informatics competencies, and act upon the new information management demands in their practice models.

From an educational perspective this creates a multi-faceted, hybrid picture of needs and requirements for knowledge, skills and attitudes. This implies expanding and re-focusing nursing curricula at undergraduate, postgraduate and doctorate levels. The content in the curriculum must contribute to shifting patterns of collaboration, with nurses being aware of the patient’s needs, situated preferences and desired level of participation. This requirement is in addition to the required competencies related to ICT and informatics. Developing such competencies at the post graduate level will require further enhancement of professional development programs including continuous education, learning-at-work, as well as clinical ladder programs for nurses and other healthcare team members.
Current challenges in nursing education

Nursing education is struggling to address the global nursing shortage (Oulton, 2006). Nursing schools are constantly transforming their curricula and using many teaching innovations to prepare more nurses while dealing with fewer nurse educators, fewer clinical placements and less time (Skiba, Connors & Jeffries, 2008). In Europe, the transformation of higher education is asking academic institutions to prepare students at a baccalaureate level in three years (Gaston, 2008). In many countries, nurse educators are using human performance simulators to provide students with more experiences with clinical scenarios. In several states in the United States, the regulatory nursing board (State Boards of Nursing) is allowing a certain percentage of clinical placements to be substituted with practice using human performance simulations.

Across the globe, educators are experimenting with a variety of technologies to encourage critical thinking and provide students with necessary skills to learn how to learn. Web-based coursework is becoming commonplace and many nursing programs are being offered in solely online environments. Several schools, such as the University of Wisconsin at Oshkosh and Tacoma Community College, are providing clinical experiences and coursework in the virtual world of SecondLife (Skiba, 2009b).

Despite the many accomplishments of faculty teaching with technology, there are relatively few countries that have fully integrated ICT, informatics and PHMIS into the nursing curriculum. There are several reasons for this lack of integration; one major factor is that educators lack the necessary awareness, knowledge and skills to practice in a wired health system (Murphy et al., 2004). Most were educated prior to the use of health information technologies in health care institutions and those who are not practising in an electronic health care environment are usually not aware of the changing consumer population and how HITs will impact the nature and delivery of nursing practice.

A second factor is the lack of access to health information technologies within the academic setting (Fetter, 2008). It is difficult to change the way one teaches and what one teaches when one does not have access to the appropriate tools. A third reason for the lack of integration is the confusion around the differences between computer literacy, information literacy and informatics. Many nurse educators equate health informatics with IT skills. For example, in a study for the US National Library of Medicine, most educators confused computer literacy (creating a slide presentation) with informatics competencies (Thompson & Skiba, 2008). They also confused information literacy (searching the web) with informatics competencies. Without a core set of competencies that are agreed upon by the nursing profession, it is difficult for educational institutions to determine what is or is not important to be integrated into the curriculum.

There have been major strides made in several countries to emphasize the incorporation of informatics knowledge and skills into the nursing curriculum. In Europe, several countries have initiated the European Computer Driving License (ECDL) and the Health Supplement module (Kouri, 2009; Moen & Bratlie, 2009; Proctor, 2009). Several other countries have initiated preparation of nurses in the areas of ICT competencies, information literacy and informatics Bond, Lewis & Joy, 2009; Clark,

In the United States, there have been several initiatives that have catalyzed efforts to require that all nurses have informatics competencies and that these are incorporated into both pre-licensure and graduate education. In response to these efforts, the Institute of Medicine (IOM) recommended that all health care professionals have five core competencies (Greiner & Knebel, 2003). One of these core competencies is the use of informatics to mitigate error, promote safe and quality care and to facilitate clinical decision-making. A second US response is the Technology Informatics Guiding Education Reform (TIGER) Initiative. This grassroots effort created a vision and three- and ten year strategic plan to better prepare nurses to practice in increasingly automated informatic-rich health care environments (Technology Informatics Guiding Education Reform, 2007).

As a consequence of these initiatives, several organizations responded to the call for preparation of nurses to practice. Among these, the Quality and Safety Education for Nurses (QSEN) Project (Cronenwett et al., 2007) has developed knowledge, skills and attitude competencies for pre-licensure nursing students related to the IOM five core competencies and to safety. The American Association of Colleges of Nursing has included information management requirements in their Essentials of Baccalaureate Education and in their Essentials of the Doctorate of Nursing Practice programs (see Box 1).

**Box 1 – Resources for integration of ICT and PHIMS competencies into nursing**

- American Association of Colleges of Nursing Essentials of Baccalaureate Education
  www.aacn.nche.edu/Education/bacessn.htm
- American Association of Colleges of Nursing Essentials of the Doctorate of Nursing Practice programs
  www.aacn.nche.edu/Education/essentials.htm
- National League for Nursing Position Statement, Preparing the Next Generation of Nurses to Practice in a Technology-Rich Environment: An Informatics Agenda
- Nursing Informatics Australia, Position Statement: Integration of Nursing Informatics into Nursing Education www.hisa.org.au/system/files/u1/cs_Australia__Position_Statement_-_Education.pdf
- Prescription for nursing informatics in pre-registration nurse education. (Bond & Proctor, 2009).

In Australia and the United States, professional nursing organizations have written position statements about the integration of informatics into the nursing curriculum (Box 1). Nursing Informatics Australia, a special interest group of the Health Informatics Society of Australia, published a position statement that calls for the following actions:

- integration of nursing informatics content and learning experiences within the nursing curriculum
- support for faculty development
- establish a standardized curriculum
ensure accreditation board includes as a core competency, and
develop more graduate programs with specialization in nursing informatics.

Bond and Proctor (2009) have published a prescription for nursing informatics in which they outline the four major competencies needed in all pre-registration nursing curricula:

1. basic skills for information management
2. information needs of professionals and patients
3. information governance framework, and
4. information quality (Bond & Proctor, 2009).

Conclusion

It is apparent that there is a growing use of health information technologies to support the delivery of health care and nursing practice. With the growing emphasis on EHRs and PHMIS, there will be the development of new models of nursing practice. The context of health and the changing health care systems are global in nature and will require transformation of care across the globe. Thus, it is important for nursing education to begin to prepare nurse that can use health information technologies that provides safe and quality care. There is a need to prepare nurse to deliver care in new and emerging models of care. Person-centered care that incorporates the person as partner will become the new care model. Although there is progress across several countries in the preparation of nurses to practice in the wired health care environment, it still remains an elusive goal across all levels of nursing education. The majority of the efforts focus on ICT skills with limited focus on informatics and PHMISs competencies. Given this context and these assumptions, it is important to set a bold goal for nursing education and to take action on the recommendations listed below.

Recommendations

To reach this goal, the following recommendations are set forth:

- Faculty and professional development programs that will provide the knowledge and experiences with informatics need to be developed and implemented.
- In each country, an appropriate strategy is needed to coalesce nursing leadership to develop a vision and plan for insuring all nurses have the necessary knowledge and skills to practice with engaged citizens in a technology rich environments.
Educators should work with their local health care institutions, in particular nursing practice, to incorporate the use of PHIMS into their mission and vision of health care.

Academia and clinical practice in collaboration must develop strategies to ensure that nurses have the opportunity to access and use PHIMS to engage citizens in their health care.

The Education Workgroup of the Special Interest Group on Nursing Informatics of the International Medical Informatics Association (IMIA-NI) should convene a panel to develop an educational initiative template to be shared with member countries and collaborating organizations that ultimately will accomplish the overall goal of curriculum integration of ICT, informatics and PHIMS.

References:


Australia

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Background

Australia has a population of approximately 21.5 million, spread across a land mass of 7.7 million square kilometres. The majority of the population resides along the eastern and southern coastlines with smaller rural communities inland. The centre of Australia is sparsely populated mainly with indigenous communities. Providing universal healthcare is a challenge in a large geographically dispersed country, with a small population. Australia is a federation of states (six states and two territories), where both Federal and State governments have shared responsibility for funding and delivering healthcare. Universal health care provision is through Medicare which is funded by a mix of taxation and government subsidy. Both Federal and state governments set healthcare policy and fund healthcare with based on respective responsibilities for health care provision. Healthcare is provided by both private and government organizations in a range of settings including hospitals (762 public hospital and 552 private hospitals), aged care, community health, general practice facilities and by individual healthcare providers.

Key health care issues include the increasing incidence of chronic disease and an ageing population. There is significant disparity in the health status of the indigenous aboriginal community to the general population with a 17 year age difference in life expectancy due to a range of health and socio-economic issues.

State of Deployment of Personal Health Information Management Systems

The landscape for the deployment of personal health records or personal health information systems (PHIMS) in Australia is not clear, however there is mounting support for such initiatives to improve and ensure the delivery of high quality, safe health care. This is reflected in one of the key visions from the National Health and Hospitals Reform Commission (2009) that in “2012 every Australian should be able to have a Personal Health Record that is owned and controlled by the individual, including designating Health Care Providers that can access the record and determining when and how the personal health record is stored, backed up and retrieved”.

According to the national e-health strategy (Commonwealth Government, 2008), achieving this aim will require continued significant investment in a range of foundation programs including:

- significant government funded e-health strategic investment for health care facility-based clinical information solutions that can provide relevant information that is securely transmitted to the personal health record
consistent legislation for information protection nationally and provision of the national broadband service (available all across the country) by the Federal Government (this will require bipartisan commitment to these initiatives)

funding the National eHealth Transition Authority’s Individual Personal Health Record Program. This program includes a number of initiatives providing the foundation for personal health records, some of which are listed below:
- privacy blueprint for unique health identifiers and individual health records.
- standards for secure messaging including Service Orientated Architecture, Web Services and XML standards.
- unique health identifier for all Australians and associated authentication regimes.
- unique health care provider identifiers and associated authentication regimes.
- completion of eHealth Solutions compliance framework for interoperability.
- national eHealth information standards including clinical data standards and terminologies, medicines terminology and technical to support interoperability and secure data transfer.

In addition, effective provision, uptake and utilization of personal health records requires:

- community awareness campaigns to increase community understanding of the benefits and operations of personal health records
- stakeholder reference groups to identify and address the range of stakeholders concerns with the implementation, delivery and maintenance of personal health records, not least the privacy, confidentiality and security of systems
- care provider financial incentives and accreditation to ensure that clinical information is available and can be securely transferred to and from the personal health record, and
- strengthening vocational and tertiary programs for health care providers to understand the benefits of personal health records, operational aspects of utilizing personal health records including legal frameworks and professional responsibilities including effective and consistent clinical documentation.

What is not clear is Australians’ individual uptake of currently available personal health records such as Google or platforms such as Microsoft Vault. Other smaller vendors are now offering personal health record solutions including Global Health Hot Health solution (www.hothhealth.com.au) and Medtech’s Manage My Health solution. Commercial developments demonstrate that there is a market for these products, however information on uptake is not readily accessible. One aspect worth noting is that many of these solutions are operating without adequate privacy and security frameworks, especially a legislative framework. This situation is placing a person’s health information at risk of disclosure or as a component of identity theft.
In the 2008, an Australian Government Summit 2020 identified a “Health Book” - a person’s individual longitudinal record - as a key initiative for Australia. However this has yet to be turned into a government policy initiative.

These examples are all evidence of strong strategic support for the provision of personal health records including PHIMS. The challenge is converting the vision to reality and the timely development and delivery of a coordinated approach that does not further fragment a person health information and communication across the health sectors.

Over the past five years there have been significant successful pilots of electronic health records solutions (summary longitudinal health records combining summaries from a range of providers) implemented by state or territory governments, including Northern Territory Aboriginal Health Record, New South Wales (NSW) Healthelink and the Queensland Electronic Health Record Pilot. The NSW Healthelink project is an electronic health record solution focused on chronic care and early childhood records.

The key aspect of all electronic health record initiatives is the collation of an individual health summary from a range of providers as well as the ability of the individual to record personal health information, including specific data recordings such as blood glucose levels, blood pressure etc for monitoring chronic disease conditions. Support from these types of records is also demonstrated by the success of paper based record systems such as NSW Health My Health Record, currently in use for mental health clients and early childhood services. This is a paper record that the person holds and includes summaries of visits to health professionals, care plans and personal health recordings according the areas under monitoring (NSW Government, 2008).

Key issues for nursing in design and use of personal health records

General challenges in designing and using personal health records that nurses can either lead or contribute begin with managing consumer expectation. Nursing is well placed to provide advice and support to consumers on the use of personal health records and key aspects to be aware of when participating in these initiatives. An important role of the nurse is to assist consumers to assess if the systems are safe and secure, and that privacy is addressed. Secondly, nurses, as the predominant health care providers in the community especially for people with chronic disease, can collaborate with the person to demonstrate the value of personal health records and assist with the effective use of systems. In this environment a considerable amount of data that the person is recording would be reviewed by the nurse as well as discussing with the person on managing health issues to the care plan.

Thirdly, nurses need to take a lead role in defining the type of health information that could be captured within personal health record. This includes defining common records structures and data standards for the information. This will ensure comparability of information as well as interoperability if any information is to be shared amongst systems. For nurses in Australia to participate requires representation at many of the initiatives of the National E Health Transition Authority (NEHTA), which is responsible for defining all the e-health standards for Australia.
A beneficial model of the personal health record is one where the information is a combination of personally entered health information as well as summary information from their range of health care providers. The fourth challenge is for nursing to ensure that discharge summaries or event summaries contain important nursing information. The key to this is to also ensuring nursing information is represented in the source systems e.g. electronic medical records solutions. Finally one of the key roles for nursing is to educate the community in the effective use of Personal Health Record and PHIMS.

Conclusion and agenda for action

Nursing needs to take a very active role in development and application of personal health information systems to ensure that the solutions benefit the consumer, support safe healthcare delivery and demonstrate the value that nursing brings to the community. For these goals to be achieved requires the following actions:

1. Nurses should actively engage in the debate and development of personal health records (and electronic health records) as a key initiative in improving the health of the community and delivery of safe effective health services. Key to this is promoting a wellness focus of health. Nurses need to ensure that the personal health records include all aspects of a person’s health including wellness assessments, wellness promoting activities such as diet, exercise and other lifestyle factors in conjunction with health interventions.

2. Nursing needs to be actively engaged with the not only with the information technology / solution providers, but also government and other providers who are responsible for providing these solutions to the community to ensure all health information is included in the solution (including nursing information).

3. To effectively be able to manage and share nursing information, nursing has to take a lead role in defining the nursing data definitions. Given that these initiatives are global and access to the personal health record may take place in a global context, it is preferable that this work be co-ordinated at a global level. This is one initiative that could be driven by the Nursing Specialist group of the International Medical Informatics Association (IMIA NI), in conjunction with other related organisations.

4. Nursing informaticians should contribute to activities that ensure interoperability , through contributing to data definitions of health concepts and the development of self care concepts.

5. From an Australian perspective, another key component of interoperability is the development and implementation of a range of national health identifiers, unique person identifiers (to consolidate all health information), unique health provider identifier (for secure access and authentication of contributions of information) and unique health organization identifiers (for secure transfer and authentication of information). In this arena, nursing informaticians should contribute the design and implementation of the national health identifiers.
6. There needs to be convergence of a personal health record and national / state electronic health records and electronic medical records. In the clinical setting it is critical to have access to all relevant information. Nurses need to be active participants in the debates and discussions on bringing together a total solution for personal health records to avoid disparate information sources which fragment care, impact on effective communication of health information and co-ordination of care.

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Brazil

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Brazil is the largest country of South America and the fifth largest one in the world, with its 8,514,876 sq km covering almost half (47.3%) of the South American continent. The population, around 200 million inhabitants, has an enormous cultural, social, economic, meteorological and geographical diversity. These characteristics stimulate development and utilization of the information and communication resources in the most diversified scenarios and contexts.

Related to the personal health information management systems (PHIMS), in summary, it can be said that there is no such resource available for most Brazilian citizens. There have been some initiatives; the first took place in 2007 when a German enterprise initiated a promotion to commercialize a product (Life Sensor) in the Brazilian market. Several other companies have since made similar resources available but there is no consensus on the systems and no political support from the Ministry of Health. Although the electronic health record is evolving and different versions are available in some parts of the country, there is no single policy for developing a national personal health information management system. According to the Brazilian laws, the patient record belongs to the person (he/she is the owner) and the hospital and/or clinicians have the right to keep it – the technical responsibility is given to the health organization.

Despite the lack of a national policy, resources are being deployed to promote interconnection among providers and clients/patients and several portals for consumer education are available. Since 2006, an important project has been underway in the country: the RUTE network (http://rute.rnp.br/). This infrastructure project was developed by the University Network of Telemedicine and Telehealth Care of the Science and Technology Ministry, which is coordinated by the National Network of Teaching and Research and the National Program of Telehealth Care for primary health care. The RUTE project integrates teaching hospitals and the basic health care networks.

Currently, the RUTE network integrates around 57 health care institutions throughout the country and hundreds of basic health care units in their respective states. It covers all Brazilian states and handles multi-professional integration in the health care of the community. Above all, the network has improved accessibility to care and health information for the populations of remote and difficult access regions. The RUTE project also opened an ongoing channel for the development of research, education and interchange of specialized health knowledge.
This has resulted in the growth of scientific collaboration, enlargement of health care training courses and continuing education, including the introduction of e-learning and m-learning, and the integrated evolution of telenursing procedures on a national scale (Dias et al., 2009). Another national initiative is DATASUS (the Department of Informatics of the National Health System – www.datasus.gov.br) developed the HOSPUB system, which is a hospital information system that is being distributed to the public hospitals in the country. Today, the system is implemented in 156 health facilities in 14 states.

Interoperability is a fundamental attribute to be considered by developers and in 2002, an important project to assure interoperability was initiated by the Brazilian Society of Health Informatics and the Brazilian Medical Council. The main objective of this project is to provide system certification through which any software in health care can be accredited according to defined requirements for national standardization (www.sbis.org.br).

Nursing professionals are taking advantage of the national political tendencies to develop telemedicine in the country in order to develop resources and use the available infrastructure to deliver nursing care to distant patients through the use of telecommunications technologies.

Reference

Canada

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Canada encompasses 3.9 million square miles and has approximately thirty-two million residents (Statistics Canada, 2006a). The population includes significantly diverse cultural communities within the large urban centers. There is also a significant First Nations, Inuit, and Aboriginal population within several of the provincial and territorial jurisdictions. Additionally, many Canadians reside in remote and rural communities with limited access to health services. The country is bilingual English/French, however large numbers of new immigrants from Asia, the Indian sub-continent and from Latin America have increased the need for healthcare provision in multiple languages. The number of Canadians whose mother tongue is not English or French neared 6.3 million in 2006, up 18 percent since 2001 (Statistics Canada, 2006b).

The national health insurance program is designed to ensure that all residents have reasonable access to medically necessary hospital and physician services. Instead of a single national plan, Canada has a national program that is composed of 13 interlocking provincial and territorial health insurance plans, all of which share common features and basic standards of coverage. Canadian health services are delivered by more than 400,000 health care professionals within more than 700 hospitals, primary and community care settings, and long-term care facilities (Canada Health Infoway, 2007a). While health service delivery is supported by a combination of public and private funding, the public-sector share of healthcare spending has remained relatively constant since 1997, at approximately 70 percent (Canadian Institute of Health Information, 2008). Nonetheless, as in other nations around the world, Canada’s health care spending continues to rise year on year.

There are an estimated 9 million Canadians living with a chronic illness such as diabetes, heart disease, and hypertension (Health Council of Canada, 2007). Furthermore, the management of chronic diseases accounts for between 40 and 70 percent of all health care expenditures thus warranting a particular emphasis on improving the management of same.

Although not widely documented, anecdotal evidence suggests that Canadians have an interest in having access to and managing their health information. A recent invitational symposium focused on “one patient – one record” captured the views of patients and health care personnel about patient access to electronic health information (Patient Destiny, 2009). More than 80 percent (n=31) of the patient participants expressed the opinion that they should be able to access their own health information without having to wait for their doctors’ approval and consent. Further, 97 percent (n=38), perceived value in accessing information such as lab results and consult notes to enhance their ability to manage their healthcare; however, underpinning this view was the need for support and education to help them to understand the content and information (Patient Destiny, 2009).
Canada Health Infoway – Building Canada’s Health Infostructure

Canada is in the midst of delivering the functional components of an interoperable Electronic Health Record (EHR) for all Canadians. Established in 2001, Canada Health Infoway is an independent, not-for-profit organization funded by the federal government. Infoway jointly invests with every province and territory to accelerate the development and adoption of electronic health record projects in Canada. Significant progress has been made in achieving this vision with federal investments of more than $2.1 billion to date (Canada Health Infoway, 2007a). Infoway believes that investments in key aspects of “infostructure” will have direct benefits to Canadians improving the quality, accessibility, portability, and efficiency of health services delivery across the continuum of care (Canada Health Infoway, 2008a). Infoway’s mandate includes:

1. strengthening and integrating health services through electronic health records
2. empowering the public by increasing health information access
3. addressing issues of privacy
4. developing and implementing standards, and
5. assuring the adoption of emerging technologies through private and public sector collaboration (Canada Health Infoway, 2008a).

Strategic investments have been directed to each of the provinces and territories in support of initiatives that provide the foundation for an interoperable pan-Canadian EHR. Most Canadian jurisdictions have the beginnings of the basic infrastructure in place to support an interoperable EHR including: client registries; provider registries; and drug, laboratory and diagnostic imaging information systems. In addition, national public health surveillance system has been adopted by every jurisdiction. Presently, there is substantial investment being directed to the deployment of primary care Electronic Medical Records (EMR) to support physician practice and a growing nurse practitioner practice across the country.

Infoway was also a charter member of the International Health Information Standards Development Organization (IHTSDO) in 2006. The development and deployment of health data and technical standards are germane to the evolution of an interoperable EHR and Infoway recognizes the centrality of this work in the achievement of its mission. To date, there has not been a national strategy developed for the advancement of personal health information management (PHIM). Nonetheless, recognizing the evolving emphasis on consumer empowerment, Canada Health Infoway has developed a pre-implementation certification process for consumer health platforms (Canada Health Infoway 2008b). The few efforts identified cross-country have been directed to providing limited patient access to health information through portals developed by individual health care organizations (Canada Health Infoway, 2007b).

Beyond these initiatives, a few pilot initiatives have focused on the development of health information management tools for patients such as kiosks for self-registration, ER triage (Canada Health Infoway, 2006), and self-care and personal health information management and monitoring tools such as My Chart™ (Sunnybrook Health Sciences Centre, 2008) and MedforYou (McGill University, 2009).
Infoway recognizes that PHIM tools are rapidly emerging and has begun to explore future linkages with the “pan-Canadian” health infrastructure access layer: “A number of technology vendors have expressed interest in creating solutions that will equip Canadians with the technology they need to view their medical data. Working with Infoway and its partners will help ensure the solutions available to Canadians will leverage the progress made in implementing electronic health record projects across Canada. Using technology solutions that are compatible with Infoway’s blueprint will ensure patient privacy and security provisions are adhered to” (Canada Health Infoway, 2008b).

Relative to PHIM tools, Infoway differentiates between consumer health platforms and consumer health applications, as follows:

**Consumer Health Platform** - An electronic system which provides a secure, interoperable environment and personal health information database. The platform enables a range of consumer health applications, most often from different vendors, to run and interoperate. These two elements together allow a consumer, as data custodian, to store and manage their personal health information and other health-related data. The Consumer Health Platform also facilitates the sharing of data by the consumer with clinicians, family members and other authorized individuals, as well as with other applications and health information systems (Electronic Health Records, Electronic Medical Records and Hospital Information Systems).

**Consumer Health Application** - An electronic solution that provides functionality for the consumer, including the collection, retrieval, management, use and storage of personal health information and other health-related data. This could include applications commonly known as personal health records and patient portals. If connected to a Consumer Health Platform, the consumer health application provides access to the services provided by the platform and the personal health information stored in the platform (Canada Health Infoway, 2008b).

Beyond the developments related to ehealth infrastructure foundations, in certain regions, Canada has also deployed extensive network infrastructure being utilized for the delivery of telemedicine services. One relatively unique initiative that has been highly successful is the development of a portal for the provision of informational support to family caregivers (Victorian Order of Nurses, 2008). Directed to supporting the more than 2,500,000 family caregivers across Canada, this portal affords them informational, emotional and material support from health professionals and other family caregivers.

In summary, the directions for PHIM have yet to be determined throughout Canada. Current initiatives are primarily organizational or clinical program or population-centric (e.g., My Chart in use with oncology patients in a single organization). Although there are many issues to be addressed, efforts need to be presently directed to the following:

- national and jurisdictional PHIM strategy development including the engagement of Canadian citizens
consideration of the extensive cultural/ethnic/language diversity
the unique needs of rural versus urban citizens – technical and practical
consideration of the current barriers to ICT access for all Canadians
development and adoption of PHIM data and technical standards
interoperability and leverage of existing health information and communication technologies
governance of PHIM related to funding and long-term sustainability.

Key Nursing Issues

Engagement - To date, nursing has had limited input to the national vision for the “pan-Canadian” electronic health record, but this must change. The Canadian Nurses Association (CNA) and the Canadian Nursing Informatics Association (CNIA) must continue to advocate for the engagement of nurses in the eHealth agenda across Canada. The CNA has published several position papers on issues of nursing practice related to nursing data standards, and information and communication strategies to support nursing practice. Canadian nurses also need to participate in the discussions regarding the evolution of PHIM initiatives in Canada. Perhaps the development of a position paper is warranted in the near term.

Education – The education issues are two-fold: 1) the education of consumers in PHIMS, and 2) the education of student nurses and practicing nurses in accommodating and incorporating PHIMS in their practice. This is but another dimension of the “informatics gap” which currently exists in a majority of nursing schools in Canada. Revamping curricula to address this gap should consider PHIMS as an important consideration. Consumers themselves will need guidance and support in the use of PHIMS; it will not supplant the need for nursing expertise.

Scope and Standards of Practice – The professional regulatory bodies will need to consider this emerging dimension of nursing practice and consider the implications for the scope and standards of practice. The profession will need to determine whether the evolution PHIM warrants an expansion or modification to the existing scope and standards. Additionally, the introduction of PHIM may necessitate the development of new health policy directives.

Agenda for Action in Canada

1. advance the engagement of nurses in PHIM developments – practice and policy
2. develop a national position paper focused on nursing and the implications of PHIM;
3. incorporate strategies to address the educational needs of consumers and nurses in the advancement of PHIM;
4. engage the regulatory bodies in discussions of the implications of PHIM on the scope and standards of nursing practice;
5. continue to network with international nurse colleagues through organizations like the IMIA-NI to exchange and derive learnings that may inform the Canadian landscape of PHIM.
Conclusion

Many technical and policy barriers will be overcome to accommodate consumer linkages to providers, hospitals, and pharmacies – not the least of which are issues related to privacy and security. PHIM tools have the potential to enable individuals and families to more effectively manage their well being by informing choices and interventions, monitoring outcomes, and facilitating improved chronic disease management. However, realizing the potential of PHIMs will also require that consideration be given to citizens’ needs for computer competency, internet access, and health literacy (Kahn, Aulakh, & Bosworth, 2009).

References


Widespread use of information and communication technologies (ICTs) is seen as the most important advance that the national health service (NHS) in the United Kingdom (UK) can make towards providing high quality, patient centred care. Personal health records, owned and managed by the health consumer are increasingly seen as part of that advance, as are other ICT resources that enable personal health management. The NHS in all four countries of the UK countries have published ehealth strategies (see box 1 below) that include central provision of personal health information tools and some level of access to central or provider held records. A growing number of primary care providers have the potential to provide or are already providing personal access to the primary care record. As in other countries, health advice and personal health records are also supported by a number of independent / commercial organisations.

Examples of PHIMs Deployment

The national ehealth programme in Wales started trials of My Health Online at a number of general practice surgeries in different parts of the country in October 2007. Patients at each of these surgeries are using the internet to book appointments and request repeat prescriptions. Selected groups of patients have the opportunity to access their own health records online. These pilots are the first stages of a plan to provide each person registered with the NHS in Wales an electronic individual health record.

Similar functions are provided at the national level in England. All residents who are aged 16 or over and have a valid email address can register for a HealthSpace account (www.healthspace.nhs.uk/). They can apply for an advanced account which will allow them to access the centrally held Summary Care record - an extract from the primary care record – although the spread of these summary care records is limited at present. HealthSpace has four main functional areas with plans to extend in near future including: being able to make hospital appointments; managing health and lifestyle by ‘keeping track of information like your weight, blood pressure, cholesterol levels and medications’; calendar and address book to ‘keep track of appointments and events, or the address book to store your NHS contacts like your GP, dentist or local pharmacy’; and links to NHS Choices, a knowledge store with information on health and general conditions such as asthma.

The next development is a ‘Communicator’ tool, which will enable patients to carry out e-mail consultations with GPs and other clinicians. So far, used by limited numbers of people but the plan is to sign up 4 million patients by 2014. The long term aim is to provide patients with a secure way of accessing their transactions with the NHS from anywhere in the world.
Security and authentication has been an ongoing issue and makes registration to use the service less attractive to potential users: the process for activating an advanced account involves patients presenting three forms of identification confirming their address, which must be the same as the address held by their GP. They are then issued with a log in card and receive an activation key by post.

Other national initiatives such as NHS Direct support personal health management with online and telephone health advice (www.nhsdirect.wales.nhs.uk/). Media groups have also addressed the personal health information management agenda, for example, the BBC provides advice on its website on ‘finding trustworthy health information and support online’ (www.bbc.co.uk/health/talking_to_your_doctor/home_internet.shtml).

Patients across the UK are beginning to access their primary care records, made possible because of full computerisation in this sector. A good example of how this is benefiting patients can be found at the Haughton Thornely Medical Centres (www.htmc.co.uk/) where patients can access all the information about them, make appointments, order repeat prescriptions, and access health information and decision support tools. According to general practitioner Amir Hannan, on-line access to GP-held health records for patients must be based on the 'partnership of trust'. He has reported that such access results in increased health literacy, better concordance, improved accuracy in the records, and a trusting adult to adult relationship that itself improves health. Despite the wide availability of information and tools to support personal health information management, most people in the UK do not yet have online access to their records and are confused about how to manage information about their health. According to Smith (2009), most people have not even considered online access to provider records. Until recently, the process of getting access was difficult but the main cultural barrier in the UK seems to be that public and professionals focus on negatives such as threats to security and confidentiality rather than on the benefits.

**Nursing Issues related to the design and use of PHIMs**

Person-centred care is the central philosophy that underpins the purpose and responsibilities of nursing (Royal College of Nursing, 2004a). According to the RCN, the nurse of the future will work ‘in partnership with patients and communities as an: information navigator; information interpreter; decision-making facilitator; patient empowerer’ (RCN, 2004b). Preparing nurses for these roles is the key challenge in relation to personal health information management. Other challenges include:

- **Working with multiple models.** Pagliari (2004) describes the current and possible future models such as: the patient viewing records in a clinical setting; personal web space with access to provider records and space for own information; an internet portal through which patient manages all health information online, communicates with providers, accesses decision support, networks with others etc.

- **Costs, access and choice.** The ‘digital divide’ and the potential to increase in health inequalities for those who are unable or choose not to engage in personal health information management.
• **Risks and risk management.** There are many hazards which must addressed with appropriate standards and safeguards including: access restrictions; identity management and authentication; protecting personal information from others including family members; semantic interoperability; the quality of knowledge and information resources supporting patient decision making.

• **Outcomes and benefits measurement.** Patient reported and other measurements need to be developed and validated so that practice can be evidence based.

• **Awareness, education and change management** for patients, public and professionals.

**Conclusions**

National policy agendas and ehealth strategies are driving the design and development of personal health information management systems across the UK. The two priority actions for the nursing profession are: practice standards for supporting personal health information management and education of nurses. Evidence based practice standards will help to address the challenges listed above. Changes to nurse education are required so that nurses of the future are competent to work with individuals, groups and communities to identify health goals, recognising where ICTs can help achieve those goals and then integrate the use of ICTs appropriately into the care process.

**References**


**Box 1 - Sources for information about UK national ehealth strategies and programmes**

- Scotland – see overview of PHIMS in Scotland in this text
**Finland**

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**Introduction**

The population of Finland is over 5.3 million. The Finnish national health care system represents the Nordic Welfare Model which is based on tax-financed public provision of a large number of social and health care services: child care, basic and advanced education, hospital care and health services, and care for the elderly. Characteristics of the model are that citizens have the access to basic welfare services independent of income and employment status. The Finnish system offers universal coverage for a comprehensive range of health care services delivered mainly by publicly owned and operated providers reimbursed through general taxation. All members of the care delivery team share respect for the knowledge and experience of patients and provide many-sided information for shared decision-making and control.

Finland has strong emphasis on ICT use in all administration branches. Simultaneously, as a member state of the European Union (EU), Finland follows EU development work. Five years ago the EU’s eHealth Action Plan called for the member states to draw up their national eHealth Roadmaps by the end of 2006 (EU, 2004). Finland’s eHealth Roadmap is a continuation of the work on national strategies that was started in 1996. It gathers together the main policy definitions and achievements of the Finnish development work from the last decade and outlines future challenges. It is also a continuation of the work which has been done during recent years to build up a nationwide operational network for health services emerged as a part of National Health Project 2003-2007 (Iivari & Ruotsalainen, 2007).

Our common objective is to secure access to information for those involved in care, regardless of time or place, in both public and private sector. This requires: a comprehensive digitalisation of patient data; development of the semantic and technical compatibility of the electronic health record systems in regard to the entire content of a record; development of the national health care infrastructure and information network solutions; identification and authentication solutions and electronic signature; and maintaining of information on the Internet that supports decision-making. According to the Finnish policy definitions, the storing and use of health information is based on networked corporate data with a high data security.

**General Targets for Health Information Management at National Level**

*KanTa – National Archive for Personal Health Data*

The Government has decided that the core of the national ICT infrastructure for social and health care will reside in a national digital archive for patient documents (eArchive) to ensure the availability of real-time patient information. KELA (The
Social Insurance Institution of Finland is responsible for KanTa – an archiving service system and associated services development. It will include a national public key infrastructure system for health care professionals. The legislation dealing with the creation of a nationwide level IT infrastructure for health was launched in year 2007 and is expected to be finished by the end of 2011. All the public care providers must join in. Private care providers can choose between the national archive and paper archiving.

KanTa services consist of a patient data archive and citizen online access to personal health information, and electronic prescriptions. With online access to personal health information, patients/clients have an enhanced ability to look up personal information and to supervise its use. Individuals over the age of 18 have online access to personal information stored in the Prescription Centre and the electronic archive of personal information. For example, everyone can use the system to check one’s vaccination status; or people can request a summary of their electronic prescriptions. Finally, people can request the pharmacy or their doctor to provide a summary of their electronic prescriptions. In future, an intelligent medical information system might be able to provide treatment recommendations and warnings about potentially harmful drug interactions.

**SAINI project**

The national SAINI-project (interactive electronic services for citizens) was coordinated by the Finnish Innovation Fund together with the Ministry of Social Affairs and Health, and other national organisations, operators, companies and financing institutions in health care and information and communications industries. The SAINI report creates a framework for supporting the public in their independent promotion of their own health as well as supporting flexible electronic transactions within the health care service system (Valkeakari, Forsström, Kilpikivi, Kuosmanen & Pirttivaara, 2008). The SAINI service concept is a combination of centralised and decentralised electronic services that are connected to data systems and registers in a customer-focused and functional manner. These include appointment services, transmission of laboratory results, prescription renewals, payment and compensation services and various types of information services. These services are used to support the citizen’s decision-making in health-related matters as well as interaction and information flow between professionals. The SAINI concept aims to fulfil the requirements set for user-friendly electronic services. The idea of a ‘one-stop-shop’ was a strong guiding principle: one place where all relevant services provided by the state and municipality, including healthcare, can be obtained. The services will enable self-service for citizens in those functions, where appropriate.

**Model of Finnish Nursing Documentation**

In Finland, eHealth developments have a strong nursing impact. There have been two major projects related to documentation model development: the HOIDOK/HOIDATA project and the eNNI project (http://www.enni.fi). The main development project is the Model of Finnish Nursing Documentation (http://www.vshsp.fi/fi/4519), based on standardized terminology and the nursing process. The nursing documentation model consists of four phases of the nursing process: needs assessment, determining of
nursing needs and nursing care aims, planning and delivering nursing interventions, and the evaluation of outcomes. Terminologies are used for nursing diagnosis and interventions to facilitate retrieval of data. The Finnish Care Classification (FinCC) is a validated translation of the Clinical Care Classification (CCC, formerly the Home Health Care Classification). FinCC consists of 19 Care Components describing the core of care, and these are divided into major categories and subcategories of nursing diagnosis and nursing interventions.

Different hierarchical levels of the classification can be used for documenting nursing care, together with narrative text when relevant. Each nursing diagnosis requires an expected outcome which is expressed using three qualifiers (improve, stabilize, and deteriorate). The outcomes of care are documented by using the same qualifiers. The model for the Finnish Nursing Documentation also includes the intensity of care, and the discharge summary which is assembled from essential data of the episode of care.

**Citizen Focused Health Care**

*Oulu SelfCare and Technology Healthcare Centre pilot project*

Along with development projects, such as Oulu SelfCare and Technology Healthcare Centre pilot project, nurses are learning new ways to cooperate with citizens. The ‘Technology oriented’ healthcare centre acts as a test-bed. The Oulu project activates the citizens’ role and responsibility in health care processes and offers alternative, reliable tools to get information and communicate with health care services. The objective is to form a new service concept, which offers the citizens a self controlled way to respond their own health and diseases, to get guidance and information and to communicate with their own health centre using a simple and reliable electronic service platform. The health centre has a user interface with rights to use patients’ health cards.

Service use is free for citizens but they need their own Internet and equipment. In addition, the citizen’s self care health card includes personal health information, electronic messaging and appointments, laboratory results for the 13 most common samples. Citizens can save measures such as PEF, blood pressure, blood sugar, weight, and record health diaries. They can search for locations of health care organizations and apply online. The card provides access to information about medication, health, disease and nutrition, with videos and simplified language to enhance health literacy. This new technology service will be tested and reported by the end of 2009. The desired outcome is a national service model, which could be adopted in other cities.

*Health library*

One important aim in Finnish health policy is to develop services for citizens and strengthen their empowerment. Practically, this means access to adequate information and counselling. The citizen should be given information about his or her illness and its treatment, particularly medicines, in an understandable way. There are two major national service providers for this information. Firstly, in 2006, to improve clinicians’ and patients’ access to health information, the Finnish Medical Society Duodecim built an internet portal - Terveyskirjasto (“Health Library”, www.terveyskirjasto.fi) - for the public. The portal contains thousands of patient-centric articles concerning diseases and
treatments, and many municipalities and hospital districts have linked this portal to their own websites. In 2007, the “Health Library” received about 20 million requests for articles, and the portal is becoming increasingly popular (Teperi, Porter, Vuorenkoski & Baron, 2009).

**HealthFinland**

In May 2009, the national citizen’s health information portal - HealthFinland Portal - was released. This portal is a national semantic publishing system and will provide Finnish citizens with reliable, up-to-date information about health. It will support people in making health decisions which are based on the evidence-based information. The content for the portal is produced by research institutions, expert bodies and the authorities, as well as the non-governmental organisations working in the field of health and health promotion. Finding the information is made easy by offering one address and one common user interface to the service. The portal supports the common objective of the EU to improve the citizens’ access to the high-quality health information (http://www.seco.tkk.fi/applications/tervesuomi/ui-presentation.html).

HealthFinland Portal utilizes semantic web technologies. Publications, guides and Internet services are produced with many different techniques and provided by different institutions and organizations. However, through semantic web technologies, it is possible to make these contents compatible and machine-readable. The semantic web technology enables a global view to distributed contents and it also enables concept-based information retrieval. The system consists of three parts: a centralized service of health ontologies with tools, a semantic content creation channel based on several distributed health organizations, and an intelligent semantic portal aggregating and presenting the contents from intuitive and health promoting end-user perspectives. The portal implementation is based on Semantic Web technologies developed by the National Semantic Web Ontology Project (FinnONTO - http://www.seco.tkk.fi/). The National Institute for Health and Welfare is responsible for operating of the portal with the financing of the Ministry of Social Affairs and Health in Finland.

**MyWellbeing**

MyWellbeing is based on the notion of a citizen as an empowered and fully informed partner in health and wellbeing services. The main goals of this project are to: identify the needs of citizens and how they can become the foundation for different health and wellbeing services; and identify how life changes, such as pregnancy or retirement, should be considered when different health and wellbeing service concepts are defined. As a result of the project, “the Coper”, a digital support tool for personal health and wellbeing management, was built. MyWellbeing aims to provide a solution by which citizens can better cope with life situations and concerns extending beyond health care and including such matters as insurance, taxation, and day care for children. The Coper is tested in different technologies, such as personal computers, mobile phones, and partner company solutions, to gain platform independence so the citizen can select the most suitable service options.

A sub-project of MyWellbeing, called “Family-Coper”, aims to study the Coper’s promotion of the wellbeing and health of one specific group: childbearing families and
families with a small baby, maximum two years of age. Family-Coper will offer families information related to health and welfare, and help them find information from both public/private health and wellness service providers and voluntary organizations. Family-Coper uses the social networking Ning-platform (http://about.ning.com/). Simultaneous individual empowerment and communality of families, such as forming and maintaining peer groups, are the goals of this project. With the help of Coper, researchers are studying how to personalize information to family needs, how peer groups will be composed and how they act, and how the digitalized service system works. New service models contributing to civic-oriented health and wellness services and greater interaction between families and health care professionals are anticipated. (http://www.it.abo.fi/cofi/omahyvinvointi/index.php?id=70)

**Future Developments**

In Finland, development of Personal Health Records is in the early stages. It has begun with the creation of various portals and other channels of information. Existing and future electronic tools for communication and data transition between health care workers and their patients/clients require new approaches also in nursing. Patients’ participation in decision-making concerning their health and care will emphasize further evidence-based practice, utilization of research, IT-related competences, and individual consideration of the patient’s abilities and preferences in receiving and accessing health information.

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In 2007, the population of Japan was 126,085,000 with 1,089,818 live births and 1,108,334 deaths. The natural increase of -18,516 for that year is indicative of the fact that the total population is decreasing. The leading cause of death is malignant neoplasm (343,000 per annum), second is heart disease (184,000) and third is cerebrovascular disease (126,000) (Ministry of Health, Labour and Welfare, 2009). There are 7,785 general hospitals across the country but many are small in size; only 428 have more than 500 beds and 721 have between 300 and 500 beds. The ratio of acute, short term admission to long term admission is 6:4, and government is promoting policies to change this ratio to 4:6. Length of stay is longer than in the USA and European countries, which is a major issue from the viewpoint of healthcare cost. The government is driving forward with measures to strictly reduce the length of patient stay.

There is a need to balance the problem of rising health care costs with the challenge of providing high quality care and treatment. It is necessary to prevent unnecessary or ineffective medical treatment and ensure the delivery of high-quality, evidence based medical treatment. Addressing these challenges can be assisted by accumulating and analyzing information on what care and treatment is delivered for individuals with particular health conditions. However, management systems supporting the generation and use of the personal health information are not yet well developed in Japan. A summary is provided here of the current situation in Japan. Issues of concerning personal health information management systems are presented and nurse's role described.

**Personal Health Information Management**

It seems that the Japanese people have not considered the idea of keeping their own personal health data somewhere and managing it themselves. However, in-patients and people with chronic diseases are often knowledgeable about their consultation history, their disease, laboratory results, treatment etc. and see this as important health information. In general, individuals keep any documents passed to them by the hospital but they simply file it somewhere.

They do not arrange the content or use the information to manage their health condition. Some health care professionals recognize the importance of the personal health information management systems but recognition that it is also the place where the diagnosis and treatment record and the nurse's record are managed is low. There are few discussions concerning the meaning and the value of the "Record" of healthcare services and although such discussions about the nursing are increasing, they are still only at a surface level. Personal health details are recorded in both preventive health care settings and in the medical treatment areas in Japan. The aim is to identify preventive needs at an early stage and to treat health conditions at the early stage.
However, the management system that links the personal health data of each area does not yet exist.

**Health Examination Result Information**

The computerization of health examination results is well advanced in Japan. All organizations are required to carry out annual checkups and provide health guidance and standardization of the checkup items is encouraged with the overall aim of reducing overall medical expenditure. The history of an individual’s health examination results can be referred to when the organization doing the checkup is the same. However, when the health examination organization changes, for example, if the person changes jobs, linking the individual’s data becomes difficult. In general, when a person consults a physician for a health examination, the previous year's data is referred to and printed. Health examination is often carried out by using the printed slip. It is difficult to obtain data that shows a mid/long-term healthy tendency when it is done in this way and the doctor’s judgment is not recorded. Important health problems may be missed.

There are two types are of systems evolving in Japan for storing personal health information. One is where data are accumulated in the electronic record medium that the individual owns. The other approach is where data are accumulated in a central server and accessed when necessary. The system searches for the personal health data that exists in different servers; batch referencing is done and linking becomes possible. However, challenges such as retrieval, delays for standard maintenance and security make this approach impractical at present: the project is only executed in a model area at present. It is legally possible for health examination results to be held in a small electronic storage medium, such as a USB storage device, and for the individual to carry their own health information. This approach has been tried in various places but the method of operation has not been well designed, for example, the recording procedure and the setting of the data input person.

**Hospital Information**

The consultation history, treatment, and outcomes of hospital care are important personal health data. The person producing this information may be a doctor or a nurse. It is important to recognize the following as personal health data: essential patient information; doctors’ and nurses’ orders; execution and results of orders. A comprehensive tool for recording and storage of personal health data would cover the following information:

- health insurance card data: essential information such as name, date of birth, address, occupation
- specific health information: various pocketbooks (maternal and children health handbook, diabetic pocketbook, infant heart failure pocketbook, and various disease pocketbooks)
- record of health examination: date, type of examination, results
- judgment of health examination (medical necessity)
- medical treatment consultation record: consultation date, disease name, content of treatment, and treatment result.
Challenges

The following inter-related challenges need to be addressed to progress with personal health records and systems in Japan:

- at present, much information is recorded on paper and there needs to be a person responsible for converting it into electronic data
- there is no standard terminology for managing coding of electronic data
- data is narrative rather than structured
- comparison is difficult because of the lack of standardization
- recorded information is not secure
- recorded information lacks accuracy
- it is not clear what should be recorded, when, by whom and who should confirm the content
- electronic data exists together with data on paper
- there is no standard for important management indicators for managing the state of the patient.
- nobody observes by using the value of the management indicator.

The quality of the recording of personal health data is negatively affected by a number of factors. Firstly, the record does not become the object of the medical treatment fee and the present EHRs contain limited data on the person’s health. Few doctors recognize the electronic record is for personal health data. Information on health examination is coded but observation information is free text. Finally, the difference in the quality of the record keeping depends on the person in charge.

Implications for Nursing Concerning Design and Use of PHIMS

Nurses are present wherever personal health data is produced and they are knowledgeable about the importance of timely recording. When the management item standard and the management algorithm are visible in the system, the nurse picks up the personal health data according to the standard, and can execute the input and review. It is preferable to design personal health information management systems and actual operation with the nurse taking the central role. It is essential to ensure that information is input accurately to produce each individual person’s health record.

To support the development of safe, effective PHIMS, the Nursing Special Interest Group of the International Medical Informatics Association (IMIA-NI) should undertake the following activities:
- ensure the development of educational courses concerning PHIMS
- develop teaching materials and the syllabus for national implementations
- coordinate feedback on the progress, evaluation, and outcomes of leadership training programs and educational activities related to nursing informatics
- develop and maintain the networks to support the above and so that experience and resources can be shared internationally.

Reference

Healthcare information is scattered among health care facilities that patients have visited throughout their lives, and is often recorded in different media. Electronic medical record (EMR) systems are currently one of the prime transformers of health care information management in Korea. They have been shown to provide greater accuracy, efficiency, and significant cost benefits over paper-based systems. As the role of consumers increases in health management, personal health records (PHRs) that allow individuals to access and coordinate their lifelong health information are being introduced. The PHR systems offer an integrated and comprehensive view of the health information of an individual, including the information recorded at different health care facilities and information that consumers generate themselves. The PHR enables consumers to compile and maintain their own health records. These PHRs will continue to flourish as the related ubiquitous computing technologies evolve.

Access to information and communication technology

As a result of the rapid growth of its online and telecommunication sectors, Korea has developed into one of the most well-connected countries in the world. By the end of February 2009, there were 46 million mobile phone subscribers in Korea. According to statistics published by the Organization for Economic Co-operation and Development (OECD), there were more than 15 million broadband subscribers in Korea in June 2008, which translates to 31.2 subscribers per 100 inhabitants, ranking Korea 7th in the world. As at October 2007, 94.1 percent of all households in Korea had broadband access, ranking Korea first in the world for this measure.

In 2007, the Korean Ministry for Health, Welfare, and Family Affairs (MOHW) announced a national strategic plan for the implementation of National Health Information Infrastructure. One of the visions of this plan is to provide healthcare consumers with healthcare information anytime and anywhere through personal health management services connected to electronic health record system of healthcare facilities. Based on this vision, development of PHRs, self care services and evidence-based healthcare information services were proposed.

Personal Health Information Management

Personal Health Information Management Systems (PHIMS) in Korea are provided by different organizations such as the government sector, private business groups and health care facilities. Also, PHIMS in Korea comes in different formats such as web-based services (accessed through the Internet that store consumer’s information in a central place), hybrid services that allow consumers to store the information on their personal computer (with or without a thumb drive transfer of data to carry around), and transfer the information to a web-based account.
Most of systems run by government organizations and private business groups are web-based and most of systems run by the health care facilities are hybrid. Examples of PHIMS run by government organizations include HealthiN (http://hi.hnic.or.kr) maintained by the National Health Insurance Corporation, Health Guide (http://www.hp.go.kr) maintained by the MOHW, and Immunization Information Program maintained by the Korean Center for Disease Control. These web-based PHIMS provide consumers with health/disease information, health assessment, customized health management services such as hospital and pharmacist information, chronic disease management services, health care utilization history, and guides to physical examination.

Examples of PHIMS run by private business group are HealthKorea maintained by the UBcare, and 365Homecare (http://www.365homecare.com) maintained by the 365Homecare Company. Services provided by these web-based PHIMS include home visit, health assessment, healthcare provider information, consulting service via the Internet or phone, health and disease information, appointments with member health care facilities, and lifetime health management.

**Progress with hospital-based PHIMS**

There are several different types of hospital-based PHIMS in Korea. They are: hospital website-based PHIMS; home-based mobile PHIMS; USB memory-based PHIMS and web and mobile storage device-based PHIMS. Most of PHIMS run by the healthcare facilities are “tethered”, that is: linked to the hospital’s electronic medical record system. For example, Severance hospital offers a tethered PHIMS to its patients. Patients may view selected health information from the Severance hospital’s medical record system as well as enter their own information such as family history.

Hospital website-based PHIMS provide individuals with customized content based on patient interest and preference. They allow the person to perform self assessment, make and view an appointment, view lab results and prescription, issue a certificate, and pay medical bills. Seoul National University Hospital has a website-based PHIMS.

Home-based mobile PHIMS collect health related information and measure bio-information such as blood pressure, pulse, blood glucose level at home, provide remote health care services on exercise, diet and medication, and manage chronic conditions through mobile phone services. Health manager who are monitoring client health status 24 hours a day can dispatch home care nurse to the client or refer the client to doctor’s office when necessary. When the client visits doctor’s office or hospital, doctor can utilize accumulated health related information collected and managed by the mobile PHIMS. Bundang Seoul National University Hospital has home-based mobile PHIMS.

Kyung Buk National Hospital has developed a prototype PHIMS that has been implemented on a flash memory (USB drive) that is found to be compact, light weight, cost effective and sufficient enough to handle a large amount of clinical data. Care documents stored on a USB follow the Continuity of Care Document standard recommended by the international standards organization HL7 and provide a complete
and accurate summary of an individual health and medical history (Tran, Kim, & Cho, 2008). Care documents stored in USB can also support alerts, reminders, self-management, and stakeholder communication in a standardized manner. The proposed PHR system consists of modules that help collect distributed patient information from multiple sources to generate individual care documents as a personal health record. The preliminary experiment has demonstrated an acceptable performance. That is, the PHR was found to integrate and share various clinical data such as medications, procedures, patient demographics from admission system, test results from laboratory information systems, images from picture archiving systems (PACS), bio-signals from patient monitors. In particular, the system was tested by connecting it to a standardized monitoring device to collect ECG data. The PHR system was able to receive 3,410 HL7 messages for in an hour and then generate the CCD document.

Web and mobile storage device-based PHIMS can access servers of the health care facility and query information such as patient record, physical examination results, and medication prescriptions. Information viewed can be downloaded in USB and users can view it later using a mobile storage device-based PHR plug & play viewer when necessary. For example, clients can view information when they end up visiting a hospital during an overseas business trip or in an emergency situation. Health related information can be added via website.

Severance Hospital is currently developing a lifelong PHR, including medical records generated at hospitals and bio-information measured from various sensors while at home including measures of blood pressure, blood sugar, heartbeat, temperature, SPO2, ECG and body fat (Jeong, Kim & Bae, 2008). This system presupposes an information exchange network between hospitals’ servers and home sensors. For safe information exchange, users can query patient records from more than one hospital when they want. For this purpose, web servers were designed to only retain each hospital’s index, log and membership information. Users can also selectively save the queried information to their computer or mobile storage device. This system connects hospitals and home and mobile healthcare while minimizing the dangers of information leakage by not accumulating data. It supports sustained health management by loading a plug and play PHR viewer to a convenient mobile storage device. Development of a PHR system using USIM- and CDMA- based mobile phones is being planned by adjusting and supplementing current systems with feedback from demonstrative operations.

Consumer and provider views

To explore key issues related to PHIMS in Korea, a telephone survey to 715 consumers was conducted using a structured questionnaire (Kim, Kwak, Kim, Kwon & Kim, 2008). Almost 60 percent of healthcare consumers replied that they are willing to use PHR. In a related survey, around 84 percent of the health care providers indicated that they are willing to use PHRs for their services. Consumers replied that they would like to see patient problem list, history of medication, allergy information, history of operation and clinical laboratory. Perceived benefits and concerns, types of health information to be included, management types and security of information, and attitude toward PHIMS were surveyed.
Perceived benefits include more accurate diagnosis and treatment by healthcare providers, reduction in redundant tests and prescription, and acquiring more accurate information by consumers. Major concerns include leakage of consumer information, unwillingness of hospitals to provide the medical record or to use medical records from other hospitals, and initial cost for system development. Types of information consumers would like to have in the PHIMS include information related to medical diagnosis and health promotion and prevention. Regarding information related to health and disease, they would like to have information on specific symptoms or disease and results of clinical laboratory tests.

Information related to hospitals included quality indicators such as antibiotics use, information on facilities, location, available medical services and health care professionals. Survey participants ranked an integrated third party website as the best means to provide information on hospitals. They ranked the National Health Insurance Corporation as the most desirable management agency for consumer information. They ranked reinforcing liability of management agency, introducing state of the art security equipment, and reinforcing authentication of user’s agreement processes as ways to protect consumer information for PHIMS. They classified level of authorization into three groups: high, middle, and low. Resident registration number and name belong to the highest level; sex, age, and place of residence belong to the middle level; and other information belongs to the lowest level. They ranked pin number with magnetic card and seal or signature, pin number and certificate as a desirable method for personal authentication.

In this context, the key issues for Korean nurses related to the design and use of PHIMS include:

- difficulty of development and operation
- time required for information entry
- initial cost for system development
- information sharing between stakeholders
- how to persuade consumers and health care providers of the benefits of PHIMS
- safety and security of consumer information, and
- how to implement standards for document, data storage and communication.

References


New Zealand

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Introduction

With a population of over four million, New Zealand has traditionally embraced technology and is often at the forefront in the use of electronic systems. The use of technology has extended into the primary, secondary, and tertiary sectors of health. In line with many countries, New Zealand is aware that to improve the efficiency, safety and quality of care, information exchange between health service providers and patients must be improved. The personal health record (PHR) is viewed as an electronic, universally available, lifelong resource of health information maintained and owned by an individual. It is different from an electronic health record (EHR) system maintained by a healthcare provider organization. The PHR is maintained by each individual, who owns and manages the information in the PHR, which comes from both multiple healthcare providers and the individual themselves.

New Zealand Health Sector

New Zealand’s health and disability services are delivered by a complex network of people and organizations (see www.moh.govt.nz/healthsystem for more information). Over three quarters of all health care is publicly funded. Within the public sector, the health care purchaser and provider functions are combined and delivered by twenty-one district health boards (DHBs). DHBs plan, purchase, manage and provide services for the population of their district including primary, secondary and community care. Some DHBs also provide tertiary and quaternary services. This model has highlighted the need for information exchange and for a change to a sector-wide approach to the development and implementation of information systems. New Zealand does not currently have a Personal Health Information Management System (PHIMS). But there is a strong movement towards consumer involvement as shown by this year’s national Health Informatics New Zealand (HINZ) Conference themed Person-centred healthcare: eHealth as enabler.

There are also many consumer groups involved, including the recently establishment of a consumer forum by Health Information Strategy Advisory Committee (HISAC - www.hisac.govt.nz). New Zealand’s early recognition and implementation of a unique health identifier for patients, in the form of a National Health Index (NHI) number, was established in 1993 and has enabled health providers to manage health care safely from the width and breadth of the country. The NHI number is the link to the patient from birth to death for healthcare, each new born is allocated a NHI number which is linked to the EHR.
The New Zealand EHR now aims for a distributed model where information residing in many individual repositories, local, regional and national, can be linked to provide the appropriate information to support healthcare and achieve better health outcomes. The Health Information Strategy (HIS) New Zealand (Ministry of Health, 2000) focuses on communication and connectivity to share the distributed information. Focusing on practical solutions and achieving results in the 12 action zones listed in the HIS aims to deliver value for all stakeholders and move New Zealand closer to a distributed EHR.

Over the next 10 years, healthcare organizations, large and small, will complete their transition to the use of comprehensive health information systems that include EHR and PHR systems. During this time period, provider organizations will acquire and deploy EHR systems to better meet the clinical information needs of the healthcare providers in caring for their patients. At the same time many ordinary people, in addition to those with chronic and acute conditions that warrant close monitoring and support, will adopt the use of PHR systems.

**Stakeholders**

There are a number of parties participating in initiatives in New Zealand: the IT Health Cluster, which consists of health IT vendors and health informatics organizations such as Health Informatics New Zealand (HINZ) and Health Information Association of New Zealand (HIANZ); standards development group under Health Information Strategy Action Committee (HISAC); a range of professional organizations; and individual health care providers. The New Zealand government is taking a more active role in setting strategies for health information and is funding some initiatives that will support these initiatives. The approach focuses more on infrastructure and standards, leaving system implementations and change management to local or regional levels. HINZ, through its regular seminar programme in 2008-2009, has provided a forum for the many stakeholders to explore and debate EHRs in the New Zealand context.

One of the major stakeholders in PHRs and EHRs is the patient or consumer. There are few published New Zealand studies on this, one by Ryan and Boustead (2004) concluded that “there is a low level of awareness and many misconceptions amongst members of the lay public about e–health information and patient rights”. The same finding is reported five years later by Hunter, Whiddett, Norris, McDonald and Waldon (2009). National awareness campaigns are already underway to address this problem. As more clinical information is stored in wider health systems, rather than an individual patient record, debate continues on access to the information and who is to authorize access. Many stakeholders believe that the consumer should be the one to determine access and trials have been undertaken looking at “patient audit” regarding access to their records.

**Initiatives with PHRs and EHRs in New Zealand**

The EHR is still seen as the “Holy Grail,” but by using the philosophy of “not letting the perfect get in the way of the good,” New Zealand has decided that having some
components of an EHR is better than waiting for the ultimate solution, which may be financially out of reach.

New Zealand is fortunate to have a number of health IT vendors; health care is the largest software export category for New Zealand. Some of the health IT vendors have worked with the health sector to provide an integrated view of information. Patient information is often held in a number of disparate systems, including patient management systems (PMS) for registration; admission, discharge, and transfer (ADT); and outpatient scheduling, laboratory systems, radiology systems and clinical systems. For health professionals there is a need to see a patient-centric view of this information.

A Ministry of Health project is looking at Safe Sharing of Information and is in the early stages of drafting an engagement booklet, which they plan to circulate within the health sector and eventually the wider population. This booklet mostly outlines the current state of information sharing/use in New Zealand.

In the secondary sector companies such as Orion Systems International and IBA have products that allow a web-based view of information from different systems, providing seamless access to patient-related information. Orion’s Concerto product is a “Medical Applications Portal that is placed over multiple information systems to provide a single, seamless view of a patient’s information” such as ADT, laboratory, radiology, clinical documents etc. The Soprano product provides “solutions for clinical notes, discharge summaries and disease management. IBA’s Clinician View™ and HealthViews™ and the new Lorenzo product create a comprehensive view of patient information.

Creation of template-based clinical documents such as discharge summaries, referral letters and clinical letters are used by a number of secondary providers. These documents are often pre-populated with selected information from other systems, e.g., visit details, diagnosis, laboratory, and radiology results. On completion they can then be forwarded to other providers e.g. general practitioners, using secure networks offered by HealthLink and Telecom New Zealand. There are also initiatives underway in the areas of e-referrals, order entry and e-prescribing. Information from these clinical transactions will then form part of the EHR of the future.

Community-based caregivers are also using computerized systems that integrate patient administration and clinical data to provide an EHR. Because nurses deliver much of the community care they have significant input into information held in the EHR. The requirement for standardized terminology is urgent.

**Nursing Initiatives**

Chronic conditions pose increasing problems for quality of life with the burden of symptoms from these conditions internationally accounting for approximately 70 percent of all health expenditure. In New Zealand, the National Health Committee (2005) identified that chronic health conditions accounted for nearly 80 percent of all deaths, and 70-78 percent of healthcare expenditure. Consumers with chronic conditions mostly live their lives in their own communities and gain support from professionals and peers, therefore an increased focus on effective self management support is needed as this will aid consumers’ independence and confidence.
Effective self-management is underpinned by consumers having access to information that is appropriate and relevant for their situation. Reports from New Zealand indicate consumers want better explanations about their conditions. Health information can be provided in a variety of ways but little is known about how consumers prefer to receive such information. Nurses and midwives are traditionally patient-focused so see the benefits of developing multidisciplinary EHRs which are accessible from a range of places. Nurses and midwives are being utilized in the development of EHRs and through this are developing health informatics expertise. The initiatives in the EHR field involving nurses and midwives are the maternity sector, mental health sector, primary and community sectors. There is still a big gap in electronic systems designed to address the specific nursing requirements to aid assessment, planning, implementation, and evaluation of care.

Primary Care

The primary sector has had a high uptake of the use of electronic medical systems, initially stimulated in the 1990’s by the government requirement that all patients registers and claims for service provision be submitted electronically and contain NHI number. The NHI number is now used on almost all health records except some sexual records, although private providers may also retain their own local number for their own use.

The use of information systems and technology has now reached 100 percent in the primary sector and 75 percent use of full clinical functionality including clinical note taking during patient encounters, generation of prescriptions, laboratory and radiology request forms and well as electronic receiving of results. Nurses working as practitioners in these areas are also contributing to the patient record. There is now a high use of clinical messaging exchange in General Practices. New Zealand general practice has one of the highest electronic medical record adoption rates in the world. The use of HL7 as the standard for messaging exchange has been of great benefit as it is internationally recognized.

Mental Health

Mental Health is an area where progress in the use of an Electronic Health Record has also been made. The Auckland District Health Board has been utilizing a product called Health Care Community (HCC) from Intrahealth for a number of years. The original implementation in the community has now been extended into the secondary sector. This allows access to a single electronic health record across both community and secondary sectors. The three district health boards in the Auckland Region sponsored the Auckland Regional Mental Health Information Technology project to extend the use of the one instance of HCC to the three district health boards. This allows access to one regional mental health record for a client. Through the interfacing of systems, each of the DHBs can utilize the one record that is interfaced to their own patient management system.
Conclusion

New Zealand is beginning to capitalize on EHR and PHR initiatives. While effective use of information technology is likely to play a significant role in the country’s future success, the focus on building collaborative partnerships between government, clinicians, and patients is seen as the ultimate key to ensuring that the EHR and PHR becomes an integral part of improving patient care. New Zealand is working on sorting out the privacy issues and moving towards the concept of “safe sharing” of health information. We are not content to wait and see what happens but want to build this into its systems from the design stage.

References


Norway
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Norwegian Health Care System

Norway is a well-developed welfare state with a publicly financed and operated health care system. There are two levels of care: community health and specialist services, with different aims, roles and responsibilities, reimbursement structures and legislation. Community health is provided by municipalities and encompasses general practitioners, services for elderly and disabled, for example, home care, nursing homes, public health, occupational health and maternity care. Specialist services are managed by the Ministry of Health through four regional health enterprises, and encompass hospitals, rehabilitation centres and intermediate care centres of all sorts. Patients’ access to care and treatment at the two levels depend on severity judgments.

All Norwegians have a unique personal identifier. The Personal Health Act passed in 2001 state patients’ ownership and access to their health record(s). Patients are entitled to information and knowledge about their health conditions, available treatment choices, and potential risks and side effects, adapted to their capacities to ensure that content and significance of the information is understood (Sosial- og helsedepartementet, 2000). Since the first information and communication (ICT) strategy for health care in 1996, ICT infrastructures, interoperability, connectivity, security, electronic patient records (EPRs), standards, electronic messages, and access to professional support and knowledge are emphasised. In the recent strategies, Te@nwork 2007 and Teamwork2.0, services for participation and access to health information for patients, family members and the public at large is clearly accentuated (Helsedepartementet & Sosialdepartementet, 2006).

State of PHIMS Deployment

Persons engage in complex regimens of long-term care or acute illness in the context of their normal lives at work and at home. Being assigned or assuming new roles, deciding which information to attend to, knowing which prevention recommendations to follow, choosing among available self-assessments, or deciding health observations to perform and report are examples of responsibilities and challenges (Moen & Brennan, 2005). Support for personal health information management extends the widespread deployment of electronic patient records. There is close to 100% adoption of EPRs among GPs, and in hospitals digitalized information is mixed with paper forms scanned into the EPR system at patient’s discharge. Personal health information management systems (PHIMS) initiatives are mostly in an experimental and/or demonstration stage.
We will provide some examples of PIMHS initiatives in Norway, illustrating different roles of patients as follows: digitalised, digitally monitored and/or self-reporting, digitally participating or digitally producing patient (extended from Tjora, 2004).

**Digitalised patient**

The digitalised patient utilises access to information about their personal health, primarily accumulated by health providers in the EPR. The law grants patients access to his or her “patient record”, to obtain a copy, and upon request brief, simple explanations of medical terms, etc. Several hospitals in a regional health enterprise join efforts to develop a patient portal (www.minjournal.no) with a security infrastructure following requirements of the Norwegian Data Inspectorate. Through the portal patients can access parts of their EPR, report observations, accumulate their discharge letter(s), communicate with their providers and manage appointments with their provider.

Discharge summaries are exchanged across the two levels of care, and the document can also be handed to the patient at discharge. Although the EPR is considered an essential tool for information exchange between health care providers at different levels, gaps in this information exchange chain can lead patients themselves to handle such health information at home (Hellesø, Sorensen, & Slaughter, 2009). A consent-based patient summary is suggested as a tool to combat fragmentation and secure interoperability and security when sharing clinical information across levels of care, or in unexpected, emergency situations. It is planned that patients themselves also can record and store personal notes in this tool (Grimsmo, Remen, & Nystadnes, 2009). Persons who need coordinated and inter-disciplinary care have a legal right to an individual plan (IP). A well developed IP can be a valuable resource for the digital patient (Sosial- og helsedepartementet, 2001), and the patient’s active involvement, participation in and use of the IP is paramount for success (Vatne, 2008). Currently a web-based IP is being piloted to explore development of and use by consumers and providers alike (Bjerkan, 2009).

**Digitally monitored and/or self-reporting patient**

Strategies for self-monitoring and information storage can include caregivers’ to-do lists, diabetic patients’ diary of diet and blood glucose measures, or self-monitoring at home of continuous ambulatory peritoneal dialysis. Digitally monitored and/or self-reporting patients utilize special purpose devices, sensors, or telemedicine services for surveillance and reporting specific health concerns and symptoms. To ease transition from hospital to home or allow patients to stay at home, models of “hospital at home” are set up with monitoring technology and sensors to send information to the hospital unit. To complement monitoring, nurses and physicians visit the patient to provide specialist health care in their homes. This is offered to chronically ill children in transition from a pediatric ward (Ullevål Universitetssykehus, 2009), and for COPD adult patients (Brethauer, 2004). Other examples of monitoring include “Easy Health Diary” where blood glucose, diet and activities are reported from sensors (e.g., pedometer) via mobile phones from persons with obesity and type 2 diabetes to a repository (Årsand, Olsen, Varmedal, Mortensen, & Hartvigsen, 2008).
Eczema counseling using secure e-mail communication with digital pictures and parent descriptions of rash exemplifies services where parent caregivers for children with atopic eczema are reporting and are empowered to control the situation (Nyheim, Danielsen, Løvold, & Bergmo, 2001). Such technology-enabled data collection and reporting feeds into awareness and self-management by the patient, and enables more specific advice by the health providers.

**Digitally participating patient**

The digitally participating patient and their family members access and evaluate appropriateness, reliability and validity of health information they acquire from a variety of sources. This is a shift towards a reflective or conscious consumer of health care utilising information in processes of personal decisions relevant to their own health and well-being. The number of Norwegians who use the Internet as a source for health information increased from 31 percent in 2001 to 58 percent in 2007 (Andreassen, Wangberg, Wynn, Sørensen, & Hjortdal, 2006). The digitally participating patient and family members benefit from services offered by individual entrepreneurs, for example www.lommelegen.no with diagnostic information and health advice, or www.barnimagen.com offering information about issues during pregnancy, maternity care and care for newborn children.

Technology-mediated information and communication interventions support the digitally participating patient in their illness trajectories and in incorporating strategies for symptom management and self care. For example, cancer patients using WebChoice (Ruland & Andersen, 2004), or children using SiSom (Ruland, Slaughter, Starren, Vatne, & Moe, 2006), can report symptoms, access relevant best evidence, and quality information to handle significant symptoms, and communicate with their providers. The REPARERE prototype provides heart surgery convalescents and their families access to system tailored ‘just-in-time’ presentation; that is, filtering information according to “this is most likely relevant for you now”, and ‘just-in-case’ presentation, information that “is important about CABG-recovery” (Moen & Smørdal, 2006). Providing information according to common experiences, changing focus, and multiple perspectives (for example that of patient, family members, health care providers), gives the digitally participating patient a broader basis for engaging in symptom management, self-care and coping.

**Digitally producing patients**

The digitally producing patient and their family members use distributed solutions for virtual peer-work; collaboration, accumulation and systematization of knowledge and everyday experiences to produce health information for “living well”. Digitally producing patients explore synchronous and asynchronous means for ‘many to many’ interactions among peers, moving beyond traditional ‘one to one’ consultation, and ‘one to many’ interactions in patient portals. For example ACTION (Assisting Carers using Telematics Intervention) project report experiences of increased knowledge, social contacts and support by elderly caregivers using specially designed and set-up broad-linked PCs as gateway to information about topics like dementia, cerebral stroke, or nutrition, and oral discussion forums with other caregivers or health care providers.
(Torp, Hanson, Hauge, Ulstein, & Magnusson, 2008). *RareICT* provides a virtual environment for collective knowledge construction to support accumulation of everyday experiences, knowledge creation and peer-support within the secure environment users required. This initiative builds on social software and Web 2.0 platform in peer-activities for knowledge creation, and accumulation of self-care experiences and coping to “living well” with a rare condition (Moen, Smørdal, & Sem, forthcoming).

**Key Nursing Issues Related to PHIMS**

People in Norway are expected to take advantages of available PHIMS support, make deliberate, informed health decisions, and be an active participant in his/her health management. Unfamiliar or un-chosen situations coupled with limited capacity for information processing can lead to disappointment and ill-use of valuable energy in health and illness situations. Although 32 percent of consumers viewed Internet as a feasible and important resource for health information, still 72 percent preferred face-to-face communication with their provider (Andreassen et al., 2006). This indicates asymmetries operating in providers and patients/consumer relationships, and such interactions are likely to remain with increased use of PHIMS.

The Norwegian Ministry of Health and Care Service has launched a new health care reform this summer (2009) where the emphasis shifts from institutionalized and provider-centered care models to community health and patient-centered care approaches. The reform draws attention to patients’ and family members’ participation, provides incentives for more services at the community level, and resources for self-management, prevention, early detection and maintenance and learning. This calls for PHIMS, and challenges professionals, including nurses, to realign and consider carefully their new supporting roles and responsibilities.

Key nursing issues related to PHIMS sit along a provider-consulting-consumer continuum. Exploiting patient-centered practice models with informed, shared decision-making in patients’ and clinicians’ interactions expands on previous efforts in standardization, terminologies, EPRs, connectivity, interoperability and information exchange, information security, diagnostic technology, and resources for knowledge management. When sorting out the issues, it is important to refrain from reconstructing the institutionalized discourses and perspectives as health care moves out of the traditional patterns of interaction in hospitals.

**Agenda for Action**

The development and deployment of PHIMS challenge nurses in Norway to reformulate, rethink and reorganize their established working models as well as their approach to individual patient care and public health care. Exploiting patient-centered practice models along a provider-consulting-consumer continuum with informed, shared decision-making in patients’ and clinicians’ interactions requires new competencies, knowledge, skills and conceptualizations of new forms of interaction. Readiness for the electronic healthcare needs to be articulated and taken into account both for the clinical practice field and for the education system.
Conclusion

Experience in Norway illustrates how patient roles are expanding, from recipient of care to informed, active and deliberate participants in their health care. This has implications for PHIMS support, and knowledge development about information integrity, roles and responsibilities, accountability and trust, confidentiality and privacy. Increased access to and availability of health information changes expectations to patients’ and providers’ roles and relationship. Following improved access to and availability of informatics and PHIMS support, it is paramount to scrutinize patterns of utilization, and exploit conditions for feasible use of PHIMS.

References


Scotland’s vision for eHealth is to support the overall NHS Scotland goals, those of health improvement, reducing health inequalities, and improving the quality of healthcare (Scottish Government, 2008a). It will do this by exploiting the power of electronic information to help ensure that patients get the right care, involving the right clinicians, at the right time, to deliver the right outcomes. Scotland’s eHealth Strategy is working towards electronic patient records and electronic communication becoming the primary means to manage healthcare information within our healthcare system. Amongst the challenges identified in the strategy is the recognition that patients and carers need information. A specific strategic aim for eHealth is to contribute to health literacy and ensure that all citizens have the necessary skills, knowledge and confidence to manage their own health (Scottish Government, 2008b).

**NHS Scotland eHealth Strategy**

Scotland’s population of just over 5 million receives healthcare from 14 territorial Health Boards, who provide primary and community care, and acute services. There are a further 6 “special” Health Boards, which provide specialist services direct to the public or to other NHS Boards. Nationally and within each Health Board there has been investment in modern eHealth systems that have already delivered benefits to patients and staff. Building on this investment, the eHealth strategy makes a commitment to give NHS Scotland’s clinicians access to a clinical portal. Implementation of clinical portal and integration technology will allow data from existing and future systems to be shared more easily, thereby delivering a virtual electronic patient record. A clinical portal is an ‘electronic window’ that displays a range of information that is essential for clinicians to deliver patient care, even if the information is actually held in a number of different places.

The aim of the portal is to:

- display patient information from multiple applications and information repositories
- provide seamless access to these applications and repositories for viewing or data entry, as appropriate.

While the focus of the clinical portal is on allowing clinicians access to information about the patient and other clinical applications, the technology it uses could also support a “patient portal” and enable the people of Scotland to securely access health information, services and communication channels to help them manage their health. The literature tends to focus on provider controlled electronic health records or patient controlled health records rather than clinical or patient portals.
However in reality the capabilities may be similar and it is the model or delivery mechanisms that are different. Indeed whether it is an electronic health record controlled by either the provider or the person it is a somewhat misleading term as the technology usually supports wider capabilities than simply a record of an individual’s health and healthcare. A more appropriate term of Personal Health Information Management System (PHIMS) is growing in acceptance.

The capabilities of the patient portal are potentially wide ranging. In the future a patient portal could allow people access to their own health records as well as enabling them to record their own health data such as personal preference, health assessments or signs and symptoms. This could support better communication between the nurse and the patient, and therefore improved patient-centred care. It could provide easy access to trusted information sources on health and also support remote access to health services such as ordering medication or making appointments.

There is general enthusiasm from both patient and health care organisations for a patient portal which is seen as a potential enabler for improving health literacy in particular for health improvement and long term conditions management. The patient portal also has the potential to address a number of aspects of the Institute of Medicine's quality dimensions, which the eHealth Strategy aims to support, including patient safety, effectiveness, efficiency, equity, patient-centeredness and timely care. Evidence is emerging that it can improve shared decision making, self care and patient centered care by empowering patients to be more involved and active in their healthcare, improving access to services and supporting innovative new ways of delivering services. Recognising that for most countries using information and communication technology in this way to support healthcare is still a relatively new, the issues, challenges and benefits are currently being explored prior to agreeing an approach to a “patient portal” in Scotland.

**Current PHIMS in Scotland**

There is a plethora of websites delivered by local Health Boards, Managed Knowledge Networks, and Charities as well as national organisations. These provide general or specific information about services, conditions and treatment. Some of these websites link to patient portals which provide access to limited parts of a patient’s record. Some portals, particularly those focusing on primary care services, have interactive communication features that support, for example, booking of appointments, secure email and the ability to order repeat prescriptions. Of the examples listed in the appendix, numbers nine to 12 were demonstrator projects co-ordinated by NHS Knowledge Services as part of Scotland’s Knowledge Management Strategy.

These demonstrators utilise national information sharing tools to create a shared pool of national and local information. The demonstrators also focused on the role of the knowledge worker and on working with local partner organisations such as local councils, to support people to gain access, education and support to use these portals. Complementing this strategy will be the development of a new nationally co-ordinated resource called “NHS Inform” which will provide the public with access to trusted sources of health advice. It will be developed to complement the current national telephone helpline advice service.
The Scottish Government is currently funding one Health Board to undertake a Patient Portal Demonstrator Project and the learning from this project will be used to inform the future direction for further work. The project's will focus on supporting patients with chronic obstructive airway disease and diabetes but other client groups will not be excluded from using the patient portal. The project aims to develop a patient engagement model, provide a secure access model, identify benefits and share lessons learnt in relation to functional requirements that have been identified by patients to support them to manage their health. Early discussions with patients and NHS professionals have identified the main functionality and features, which includes a broad range encompassing access to information both from provider records and trusted sources on health, diseases and their treatment options, as well as the ability to access services and utilise electronic communication channels. The priority is for people to be able to personalise their own portal. Functionalities and feature include:

- make appointments with healthcare professionals in primary care
- order repeat medication prescriptions
- access to laboratory reports
- view immunisation status
- portal that can be personalised
- provide access to trusted sources of health information
- allow recording of self management goals and targets
- enable monitoring of own condition
- reminder about targets set and appointments due
- record and monitor home measurements
- information about local support groups
- peer to peer communications
- peer to professional communications
- use of telecare devices.

Nursing Issues

A patient portal or PHIMS has the potential to have a significant impact on how nurses, and other members of the multidisciplinary team, deliver care to patients in the future. Many of these issues should be explored further to ensure the delivery of real benefits for people’s health and minimise risk in areas such as confidentiality.

- Nurses will need to develop new skills and adopt new working processes to support changes in relationships with patients as PHIMS enables more active involvement of patients in their healthcare.
- Information governance policies need to consider the implications of the PHIMS on authentication, identity and access management, information sharing, data quality, audit and retention to ensure that nurses fulfil their professional accountability for maintaining confidentiality and security of personal information.
- Public engagement, equality impact assessment and privacy impact assessment can help to support the design of PHIMS to benefit patients and reduce risks and undesirable or unintended consequences that could result from introducing PHIMS.
• Patients should be able to choose whether they use PHIMS as part of their healthcare journey and may benefit from education, support and access to information technology, together with support to take action based on relevant information to improve their health.

• The implications of introducing PHIMS on communication flows and workload should be examined and any changes appropriately managed.

• Nurses should examine how they present information in the patient’s record to ensure it uses language that is understandable for patients. Patients will also require tools, processes and support to enable them to record their preferences in their health record.

Scotland’s eHealth Strategy is patient-focused, clinically led and benefits-driven and its vision to exploiting the power of electronic information is as relevant for patients as it is for nurses. Sharing the virtual patient record as a component of a patient portal has the potential to promote more involved, active patients and more proactive, prepared healthcare teams. This will contribute to the delivery of high quality patient care for the people of Scotland.

References


Further information

1. Primary Care – A Patient Online System. Patients in a GP practice can book appointments, access their own lab results, immunisation status and request repeat prescriptions http://www.townheadsurgery.com/online.htm

2. Children’s Services - Information for parents with a baby in the paediatric intensive care unit in Edinburgh Royal Infirmary, access to the child’s record with hyperlink to a glossary of terms, a static view of the child’s image on daily basis and diaries written with baby as first person to help bonding. www.babylinc.info/edinburgh/babyLink/intro_page.aspx

3. mihealth – A personal online healthcare organiser designed to provide patients with information support and tools to help them manage their practical needs. This has been implemented in oncology in Spire Murrayfield Hospital, Edinburgh and Royal Alexander Hospital in Paisley. www.mihealth.info

5. **Diabetes information** - My diabetes, my way, provides information about diabetes and how it affects people. It links with Scotland’s eLibrary information resource http://www.mydiabetesmyway.scot.nhs.uk/

6. **Renal Patient View** – Patient with kidney disease are able to access their record as seen by the clinician. In addition it gives access to information on kidney disease, treatment services. http://www.renalpatientview.org/

7. **NHS 24** provides health information and self care advice. www.nhs24.com/content/

8. **Clinical Decisions** - The NHS Scotland’s eLibrary provides a portal to support clinical decisions by both clinician and patients. http://clinicaldecisions.scot.nhs.uk

9. **Cancer Managed Knowledge Network Demonstrator**, collaboration between NES, Macmillan Cancer support, NHS Highland and Highland Council public libraries to create a cancer information online portal with patient and professional entry points and seamless links between the two. The portal brings together information from local and NHS, voluntary sector organisations and local authority sources. Information literacy training and support points complement this project www.cancerinfoplus.scot.nhs.uk (people) www.cancermkn.scot.nhs.uk (professionals)

10. **Borders Health in Hand** Virtual Patient Navigator, a partnership between NES, NHS Borders, Borders Council and local employers created a website for patients and carers, a network of facilitated access and support points in public libraries and employers premises and information literacy training of both patients and professionals. www.bordershealthinhand.scot.nhs.uk. The site provides support for long term conditions, lifestyle management and access to services.

11. **Developing a Knowledge Working Role to improve access to health information in the Gorbals in Glasgow**. The Gorbals health living network demonstrator showed how locally based knowledge workers can help people in disadvantaged areas take more control of their health and wellbeing. Community development staff in this project used health information literacy skills to share information with members of the public to help build peoples confidence in finding and using health information. www.healthinfoplus.scot.nhs.uk

12. **The Health Information Online demonstrator** show how the information sharing technology provided by NES creates a shared pool of national and local, patient and professional information. This can be used to widen access to resources and present information in tailored ways to meet the needs of different audiences. Partners in this demonstrator are NES, Scotland’s Health on the Web, Health Protection Scotland, NHS Western Isles and the Telephone Help Lines Association. www.healthinformationonline.scot.nhs.uk

Good health information systems are the key point to increasing the effectiveness of the health care system. The most significant element for management of the health system and for proper decisions at all levels and in all fields of health care is information. It would be very interesting to compare health systems between different countries because it is possible that the situation related to health information is similar in many other countries. In Slovenia, we are not satisfied with the health information that is currently available, but we also have to be aware of the huge burden for health workers who are expected to collect personal health data to the different central places, without any feedback of information (Eržen, 2004). At present, we have a difficult situation in relation to health information systems: we have legislation that allows health workers to collect different data, but we still do not have defined methods for collecting adequate health data.

**Historical context**

The situation was not always like this. In 1991, Slovenia was one of the very advanced countries in terms of information and communication technology and health informatics. The Health Insurance Institute of Slovenia had purchased 3,000 IBM computers which meant that 90 percent of all health institutions were equipped with personal computers. This was the starting point for implementing health information system in the hospitals, primary health care centres etc. in Slovenia (Iljaž, 2005). From then, experts started to build health information systems, but these systems enabled the collection of data instead of formation of electronic records. Data that were collected and reported are generally not the data that are needed for the realization of personal health goals. In addition, these data and systems do not adequately support management because of their incompleteness, incorrectness and inability to be adapted to the current needs. In Slovenia, we now have a lot of different health information systems, therefore we need standards to enable the proper transfer of data between different health institutions. Currently, in spite great efforts, we still are not able to ensure such standards.

One of the pioneers in development of health information systems in Slovenia was M. Premik who in 1960 created a “minimal data set” tool for health records. This is one example of how advanced Slovenia was in ICT and health information systems; it was the second country in the world to develop and implement electronic health record. This was called the “wise health card” and was the beginning of personal health record. Despite those very successful first steps, electronic personal records have not advanced far: the current health card does not include medical data, just the basic data about the health insurance of the person. During the last few years we have added some health data, but progress is restricted because the memory of the health card is only 8K.
Progress towards personal health records

A new identity personal card is being prepared that will also be the health card and will enable access to electronic health record (EHR). The construction of the architecture for electronic health records is not yet on the agenda at the Ministry of Health Republic. In addition, the project of the World Bank for standardization of management of health systems, including electronic health records, was not successful. The content of electronic health records for Slovenia is not yet defined, but according to the statements of some health insurance companies, these records are already in preparation and will be implemented in the next two years. One hospital is testing the proposed HER in a pilot project.

Nursing implications

The problem of current information systems is not only the lack of the standardization but also the narrow focus of development programmes; these are medically oriented and do not include the work of other health professionals such as nurses. In connection with those themes, there is concern about nursing and medical education in the field of information and communication technologies. In Slovenia, medical and nursing staff do not accept changes readily, which means that we will need a lot of time for the acceptance of new technologies and needs. Regarding this issue, in 2002, as part of the EU’s NICE project, we developed a post graduate specialist study programme for informatics in nursing care which we provided up until the study year 2007/2008 when we commenced Bologna masters degree programmes.

It is very important to build sufficient levels of ICT knowledge into all curricula of Bologna levels and not only into the post graduate programmes. The Faculty of Health Sciences at the University of Maribor educates professionals in nursing care, bioinformatics and management in health care and therefore responds in an adequate way to society needs and changes. We have developed the undergraduate nursing programme with the supporting subjects to the nursing field, including ICT, e-learning, simulations etc. but the programme was not supported by relevant official body in spite the fact that the potential employers of our graduates supported the programme and the ICT components. If we are able to teach students about the technologies they will be using in health institutions, then their adaptation time when starting to work would be shorter.

References


South Africa

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Background

South Africa has a population of just over 48 million in a country of 1,219,090 km\textsuperscript{2}. The country is divided into nine provinces, with a great diversity in size, flora, fauna, industry, natural resources, population and economic wealth. It is the overall responsibility of the national Department of Health to provide “access to health care for all …, and to focus on working in partnership with other stakeholders to improve the quality of care of all levels of the health system, especially preventive and promotive health, and to improve the overall efficiency of the health care delivery system”. However, this provision is co-ordinated through the Provincial Departments of Health. The funding for these structures is provided by the national fiscus.

Additionally, a vibrant and effective private sector also provides healthcare. There is an effective controlling system of Councils registering and authorising various health-care providers in addition to an effective Medicines Control Council charged with determining the “safety, quality and effectiveness of medicines”. Currently, there is much lively debate regarding the provision of a National Health Insurance system that is intended to provide universal access to all medical facilities throughout the country. See Bibliography and links end for links to further information about the health care system.

South Africa faces a number of significant challenges to the health care system. Perhaps the most commonly acknowledged challenge is the incidence of TB and XDR-TB amongst the population. Another challenge is the incidence of HIV/AIDS. According to the SA National HIV Survey in 2008, “among those between 15 and 49 years old, the estimated HIV prevalence was 16.9 percent in 2008”. A further significant challenge to the health sector in South Africa is the persistence of malaria. Although the percentages of people at risk of contracting malaria varies from province to province, the national risk percentage stands at 10 percent.

State of Deployment of personal health information management systems

In the 2005/2006 financial year, the South African government made available funding for the National Health Information Systems Project (www.hst.org.za/generic/91). This project was approved in cabinet and was driven by the National Treasury and Chief Directors in the National Department of Health (NDoH).
Its budget increased from R5.7 million in phase 1 (05/06) to R11 million in the 06/07 financial year (Phase II) whilst support days increased from 300 for the NDoH and 800 for provinces in Phase I to full-time support for both. The intention of the project was that health information data was to become available at optimal levels. There were to be improvements in both the quality of data available and the quantity of data. Shortcomings were to be identified and remedial steps taken. In 2005/2006, a project dealing with data from the Emergency Health Medical Information System was also set up. Again, the two major aims were to improve the quality and quantity of data available.

Both of these projects were successful to some extent, with the aims of the project initiators being met, in that:

- 3,928 provincial health staff were trained on the district health information system
- support for the implementation of the National Indicator Data Set (NIDS) in all provinces was achieved
- a health information systems audit was conducted in all provinces to determine the status of HIS staffing, equipment and infrastructure
- support was provided to strengthen the Provincial Quarterly Reporting System (PQRS) in terms of integration into the DHIS, improvement of data flow to meet National Treasury reporting requirements and improvement of data quality
- the District Quarterly Reporting System (DQRS) was developed and aligned with the PQRS
- inputs were provided for the development of the MESH tool and quantitative scoring of districts
- inputs were provided, from a health information management perspective, for standardized facility definitions and classification which has been approved by the Technical Committee for implementation nationally, and
- emergency Medical Services (EMS) and Environmental Health Service (EMS) information systems were developed, utilizing the DHIS. Training was conducted in all provinces and seven provinces (of nine nationally) started submitting EMS data to NDOH. (http://www.hst.org.za/generic/91)

However, despite the strides made as detailed above, in 2009 in South Africa, there is debate about the probability of the data collected becoming available in the public arena, and the constitutionality thereof. It is appears unknown to the majority of people that there already exists a large body of personal data available to public scrutiny. In terms of existing legislation, many of the dealings that individuals have with governmental agencies form a part of the public record. This is not generally realised. The thoughts of what has hitherto been regarded as “private and personal” forming part of a national database are leading to societal unease.

This unease, however unfounded, is magnified by the existing stigmatisation around HIV infection status. “In order to alleviate this unease, the Protection of Personal Information Bill … tabled in Parliament together with other recent developments in (South African) law such as the National Credit Act recognises and aims to strike a
balance between the right to privacy of the individual and the free flow of information in an open and democratic society” (Chetty, n.d.). It remains to be seen whether or not the mass of the public will be reassured by this measure and so will be amenable to having their personal particulars, their medical records, collected by public servants and, perhaps, losing a degree of confidentiality that they have regarded as a given.

This view is further compounded by the links of all Government departments through the forthcoming Home Affairs National Identification System (HANIS) using smartcard technology. According to one Australian commentator, ‘South Africa is intending to introduce a multi-purpose national ID smart card system, part of its HANIS system, which is plainly a Big Brother mass surveillance and information sharing system’. Nevertheless, it is a given that HANIS will be initiated in the near future. What is unclear is the amount of personal information that will be stored on the HANIS cards – and who may properly access that information?

Key Nursing Issues related to the Design and Use of PHIMs

South Africa will face many challenges with regard to designing and implanting PHIM systems. Much of the primary healthcare infrastructure is rural. There are many challenges to the provision of technology in the rural areas. In this respect, it is unfortunate that many of the primary care centres are without a reliable source of electrical power. Many of the Primary Health carers were educated some while prior to the general adoption of technology. There may be a level of apprehension regarding its use that could be regarded as technophobia.

Where technology is used to manage health information, there are expected to be challenges to the physical security of the equipment. Given that there are many of South Africa’s primary health care patients who live in rural areas, and who may be considered to be educationally-disadvantaged, there will be a degree of apprehension to be overcome. Nursing staff should be well-placed to overcome this apprehension and should be able to provide advice and support to the end-user consumer, in this case, the patients. One primary role of the nursing staff will be to reassure their patients of the security and confidentiality of their information. Nurses, as the primary care provider, must be educated themselves as to the kind and amount of data to be collected from the patient. They will also have to be taught to use appropriate technology. Another challenge to be overcome will be the pressing need to allow non-medical staff access to the technology used.

Agenda for Action

- The first item must surely be to have the nursing staff give informed input into the need and development of Health Information Systems. If these systems are to take their pivotal role in delivering safer, faster, more appropriate health services, the nursing staff must see themselves as providers of raw intelligence, rather than as mere care-givers.
The staff of the health resources need to be involved in the development of appropriate technology and systems. As the end-users of such systems, who better describe what the systems must achieve?

The staff that are likely to be using technology to collect data for the proposed Health Information Systems must be trained to use such technology. In some cases, this will mean formal training courses, in other cases, on-the-job training must be offered.

Infrastructure needs will have to be addressed. Where such facilities are already planned, their provision must be accelerated.

Conclusions

Nursing and Primary health care in South Africa needs to be very actively involved in the development and initiation of health informatics. If the primary aims of the governmental expenditure are to be achieved, the health care staff at the initial levels of contact with the patients must be assisted to make input into the requirements of the system.

Bibliography and Links


Information about health challenges:


This report will give a brief overview of the development of personal health information management systems in Swedish health care. Some examples of personal health information initiatives will be provided and concluding reflections from a nursing perspective presented. The intention is not to give a comprehensive overview of the situation in Sweden.

Patients' participation in Swedish health care

Patient participation in health care has been a cornerstone in Swedish health care legislation and regulation for many years (SFS, 1982). Patients are expected to be involved in decision making concerning their personal care and such involvement has proven to have an impact on the quality of care and patient outcomes (Ruland, 1999). In the last few years, the development of the “24 hour society” has been a strong movement in Swedish society, enabling citizens to be more autonomous and have access to information independent of time and place. Public demands for more transparency and access to health care information, both on a general and personal level, have challenged the professional power and control over health care knowledge.

Most Swedish citizens expect to have access to and be able to manage different aspects of their lives on the Internet. This engagement has yet not been fully acknowledged and used by the health care system. It is expected that this movement holds great potential to change health care behaviour and enhance public health. However, few initiatives have been taken to date to introduce information management systems that enable patients and citizens to be active partners in their personal health care. Research about the effects of such systems is also limited.

Personal health information management systems

The purpose of personal health information management systems is to support collaboration in the continuity of care between health care providers and between patients, their families and health care staff. A key tool for involving patients in decision making concerning their care is the personal health record (PHR). The International Standards Organisations (2009) has described the PHR as a repository of information considered by that individual to be relevant to his or her health, wellness, development and welfare, and for which that individual has primary control over the record’s content.

The patient is the owner of the data in the record with rights to decide what should be entered into the document and who should have access to the information. This means that the patient and family can enter data into the record or allow health care providers to contribute with data.
E-services in Swedish health care

In Sweden, the use of electronic services is widespread and the internet has been accessible since the mid 1990s. Sweden is one of the leading countries worldwide concerning broadband accessibility and Internet use. From a nursing perspective this development has had considerable impact in that many patients with chronic illnesses have access to more information and self care support on-line. People with health problems can be more independent from their care providers and can, to a greater extent, decide what information they want and where they want to obtain it. Some examples of frequently used repositories for health care information in Sweden are: http://www.netdoktor.se, http://www.vårdguiden.se and http://www.apoteket.se.

Electronic applications aiming to improve services for patients and citizens have emerged the last few years but are still not widely used in Swedish health care. Personal health management systems are not yet developed on a general level, although there is a long tradition of patient held paper-based records, for example, in antenatal care. Most common are e-services to facilitate patients’ access to health care, for example, systems for renewal of prescriptions and scheduling of health care visits. One widespread service is a “call back” function, which makes it possible for people to indicate when they want to be called by health care providers, instead of waiting on the phone. This service is commonly used within Swedish primary health care.

The lack of an infra-structure for IT-security and legal issues of integrity have hampered the development of e-services for patients, particularly patients’ access to their personal health records. A joint project of the Organisation for County Councils and Regions in charge of health care in Sweden is “Health Care on the Web”, which aims to develop more e-services for citizens.

Personal health records

A few projects have been initiated to make patient records accessible to patients and promote their participation in care. An example in one county is the “Sustain Care Account”, which made personal health care data accessible for the patients and enabled patients to communicate with their health care providers over the Internet. Another example of a PHR is a project within primary health care (Jerdén et al., 2004) and school health care (Jerdén et al., 2007). This work suggests that patient-held health records might be a useful tool for promoting lifestyle changes in primary health care.

Accessibility and security issues are crucial factors in the development of PHRs. However, there are conflicts between the need for security and easy access for professionals and patients. Swedish law allows the transfer of individual health data between caregivers only with the consent of the patient, which is now emphasized in the new Patient Data Act (SFS, 2008). This means that patients have the right to decide if data concerning their care should be available for other health care providers. Uncertainty among care providers about how to interpret this legislation has led to increased risks of omissions and errors, particularly in the care of elderly and cognitively impaired patients, when care providers have been reluctant to transfer health care data about the patient.
Conclusion

Patients are increasingly being seen as partners in care, which requires health care professionals to share their expertise and invite patients to participate in decision making concerning their personal health care. Knowledge is growing about the importance of patient participation and patient empowerment for more effective care and better patient outcomes. One means of making patients and their families more involved in care is to provide patient-held health records. Such initiatives are still scarce in Swedish health care and need to be further developed and tested.

In the development towards more patient centred care, including involvement of patients and families in decision making and more transparency in health care data, the abilities and preferences of the individual patient need to be taken into consideration by nurses. Based on research, both in Sweden and internationally, it should be recognised that all patients do not wish to be actively involved in decision making concerning their care, and that nurses and patients may disagree concerning patients preferences to be active partners in care (Florin et al., 2006). Also, Swedish research has uncovered resistance among professional carers towards the introduction of information and communication technology applications in elder care. Nurses in elder care perceived information and communication technology as a promoter of both inhumane and humane care, a duality that seemed to make them defensive and resistant to change (Sävenstedt et al., 2006). Although the development of personal health records holds great potential for positive patient outcomes, individual patient’s abilities and preferences for active participation in care need to be taken into account.

References


Switzerland

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In June 2007, Switzerland launched a federal eHealth strategy with ambitious objectives. Due to the political organisation of Switzerland, where healthcare is mostly managed at the Canton level, a coordination group has been organized in order to promote eHealth and insure interoperability between the Canton’s initiatives. This a challenging task: Switzerland has not one Minister of Health, but 26, that is, one for each Canton. Therefore this effort to coordinate the development at a national level is remarkable. More information can be found on the project’s website: http://www.e-health-suisse.ch

Benefits for citizens
Citizens will be the major beneficiaries of the national eHealth projects (eHealth Switzerland, n.d.). It is expected that better management of information, the use of a continuity of care record, smoother administrative processes and ePrescription will help in controlling costs, and thus have an effect on insurance taxes. Quality and safety of care will also be improved, with better availability of information and decision-support. Access to the record by the citizens will be possible and they will be able to grant accesses to care providers, thus empowering patients and reinforcing privacy. Finally, the Swiss Insurance card will hold an emergency dataset which should improve emergency care. Some of these aspects are detailed below.

Emergency data
Mobility is increasing, and a growing part of the population, due to aging, has diseases and is taking drugs. Therefore, it is crucial to access this information, reliably, in case of emergency, at any location: home, on the road, in ER’s. The Swiss Insurance Card supports the storage of a dataset of personal information that can be accessed in specific cases and can be updated by care providers. Though a small dataset, it holds major information, such as who to contact in case of emergency, drugs taken, allergies, for example.

Safer care
The US National Institutes for Health (Institute of Medicine, 1999) report “To err is human” indicated that medical errors kill more people in the US than car accidents. Providing access to the patient’s history, access to the right data at the right time, and being able to take well informed decisions and actions has been shown to be a major tool to improve care safety. In addition, these tools can provide decision-support during prescribing, such as interactions alerts.
Improved administrative processes
The Swiss insurance and billing system is very complicated, especially for inpatient care. It is a mix of fee-for-services, DRG-based reimbursements and per diem fees, amongst others. In addition, insurance coverage can be very complex, with numerous insurances involved for a single case. Comprehensive management of these administrative processes should lead to savings.

Patient empowerment
A comprehensive role-based access control system with strong identification, authentication and traceability in addition to the reinforcement of the law that states that the data belong to the patients will promote patient empowerment in Switzerland.

Useful and reliable online health information
As part of the Swiss eHealth strategy, useful and reliable online health information has to be made available for the citizens. This will be provided through a trusted and certification process of websites, such as the HON code (www.hon.ch).

The Current Situation
Despite a late start, international comparisons show that Switzerland is not so late in the development of the eHealth. This is due to the difficulties of introducing eHealth solutions and the need for maturation. Many countries started several years ago but have not shown substantial deployment. However, Switzerland is facing numerous challenges, including multilingual needs, 26 Cantons and little federal power in healthcare. Therefore, the strategy proposes an ambitious planning under the supervision of a Federal-Cantons coordination group.

Insurance card
Starting in 2010, a Euro-compatible Swiss Insurance Card (SIC) will be distributed to all citizens. The SIC will also have a chip that can hold emergency data. This card is intended firstly to simplify administrative processes, such as patient administrative data and insurance coverage. But the chip has also a crypto-processor and can convey several certificates in order to allow authenticated connections to access secured health data. On the care provider side, the Health Professional Card will be distributed probably in 2010 for physicians. This card will also allow identification and authentication of care providers, clarify roles and will support various levels of certified signatures.

Proposed architecture
Recommendations have been made for the principles of the architecture that is currently foreseen. The architecture supports strong decentralisation for patients and care providers indexes, and for content such as documents. It therefore supports the political organisation of Switzerland.
**Cantons’ projects**

Because of the Cantons’ predominance for health-related issues, the Swiss strategy does emphasize the role of Cantons for the implementation. For example, the Canton of Geneva has now an eHealth Law that clarifies rules and processes. A large implementation of eHealth is currently being prepared, the project ‘e-toile’, and pilots will start at the end of 2009.

**Personal health data**

Numerous systems are available for citizens to store their own personal health records, some of which are operated in Switzerland. There are no good figures to measure how these systems are currently being used. One Swiss consumer journal prepared a special issue about health documents on the Internet in which some voices objected that the use of some websites for storing health related data is not trustworthy and is limited, especially quoting GoogleHealth or MS HealthVault.

As shown by a survey of TA-Swiss (Technology-Assessment Switzerland), the electronic health record is viewed positively by the Swiss population. This survey shows that very few citizens are against the usage of an electronic patient record. Most of the citizens are in favour of having confidential data available for care providers with a specific protection. Citizens would like to determine which data should be stored and who can access it.

**Conclusion**

eHealth is becoming a priority in Switzerland and is considered as a major tool to improve care efficiency, safety and to empower patients. But introducing eHealth is a challenging task, addressing human, societal, political, ethical, legal, economical and technical issues. All aspects, effects and impacts of eHealth are not well understood and the future might hold some surprises. For example, there are some discussions about a new “disease” named *cyberchondria* - a disease suspected when a patient feels sicker than they should be, caused by an overflow of information.

**References**


Taiwan

Wen-Shan JIAN and Polun CHANG

Health Care in Taiwan

Taiwan is located in the western Pacific among Japan, the Philippines and mainland China. With a total area of about 36,179 square kilometers, Taiwan is 394 kilometers long and 144 kilometers wide at its widest point. Taiwan's population was estimated in August 2009 to be around 23 million. Life expectancy is 81 years for women and 75 years for men; the infant mortality rate is 6.29 per 1,000 live births. The ratio of physicians to patients and the number of specialists compare favorably with those in most developed countries.

In addition to private practice, Taiwan's 37,099 physicians, 11,093 dentists and 11,573 pharmacists pursue their professions as members of hospital staff and neighborhood clinics. About 20,364 nurses are registered nurses, and 82,403 are registered professional nurses. There are 515 hospitals and 17 medical centers in Taiwan. Most provide general medical care, but there are also psychiatric facilities, skilled facilities that provide geriatric care, and rehabilitation services. Average length of stay for inpatient admissions are 10 days for all acute care hospitals and 40 days for all hospitals combined.

Electronic Medical Records

The most significant movement promoting the electronic medical records (EMR) in Taiwan can be traced back to 1995 when the national health insurance program was put into practice. The main purpose of implementing EMR at that time was for reimbursement, and not for supporting caring, clinical decision making, or even patient wellbeing. Any need not related to reimbursement was not on the priority list of information system implementation for hospitals. As a consequence, nursing information systems were largely overlooked because nursing care was not a formal item in the long reimbursement list.

It was not until the last decade that the values of EMR were widely reexamined following the establishment of two formal medical/health informatics graduate programs in the Taipei Medical University and the National Yang-Ming University. The EMR movement has been on track with the active promotion from the Taiwan Medical Informatics Association and others like Health Level Seven Taiwan, the Taiwan Nursing Informatics Association, and many newly established informatics programs, such as the department of medical informatics, Tzu Chi University.

Of course, the Ministry of Health played the most significant role in terms of funding and policy making. In recent years, the Taiwan government has been actively promoting the EMR and electronic health records (EHRs). In addition to setting up...
relevant institutions, the government also promotes many policies, including:

- promotion of health care IT standards: HL7 (Health Level Seven), DICOM (Digital Imaging and Communications in Medicine), LOINC (Logical Observation Identifiers Names and Codes), etc.
- an EHR pilot project: TMT -Taiwan Electronic Medical Record Template (Jian, Hsu, Hao, Wen, Hsu, Li & Chang, 2007)
- making laws and regulations: Regulations Governing and Development and Management of Electronic Medical Records (Jian, Hsu, Wen & Yang, 2008)
- implementation of the NHI (National Health Insurance) IC Card. The medical system of Taiwan has ushered in a new era in January 2004 when almost all Taiwan people started using with the NHI IC Card. Citizens going for medical institutions only need to show the NHI IC card to receive all needed medical services. This was the foundation of identity development for personal health records (PHRs)
- establishing the Healthcare Certification Authority (HCA). The Department of Health established the HCA and conducted studies to initiate the IC card system for medical institutions and medical personnel for the EHR signature. The use of electronic signature encryption capability to ensure that sensitive information about people receiving health care and treatment will not be disclosed. The HCA provided API software to test and verify EHR signature.

The above achievements created a very rich and sufficient infrastructure for us to promote the personal health record and information management in Taiwan and many creative projects are underway based on these accomplishments. A representative project to promote the personal EHRs was built using the TMT templates (Jian et al., 2007) which will be introduced below.

The Portable Patient EHR (PHR) Approach

Based on the TMT templates and the Hospital Information System gateway, we are experimenting to build and extract patients’ EHRs in XML format from hospital information systems and to store those into a general file server as a PHR mini-server or the larger EHR paperless server for sharing and exchanging (Jian et al., 2007). With authorization by the patients, the document-based XML files in the PHR can then be exchanged among various institutes through the following four pathways, as follows:

1. via portable devices owned by the patient for private use. Devices such as USB flash memory, compact disks, PDA, cell phones, etc. are all good devices to store these XML files. Hospitals can also provide a PHR viewer for patients to see their EHR in private
2. the patient can personally transfer his/her EHR from one hospital to the next. In addition to providing medical references for medical professionals, patients can seek appropriate medical services on their own too
3. a network that can communicate between hospitals via the Internet. This needs the authorization of the patient, and
4. with a patient’s request and their authorization, the Internet can be used to
access medical records of patients stored in EHR banks, so that patients at any
place and time can directly access their medical record.

Some Representative PHR Projects

The development and application of PHRs in Taiwan has caught the attention of many
researchers and healthcare professionals. Many creative projects are underway but the
majority does not yet take account of the patients’ perspectives to realize the benefits of
PHRs. Most of published results are still from the clinical and technical perspective,
although it has been observed that some PHR projects have begun to put patients at the
center of implementing PHRs, for example, providing mothers with a first new born
baby a smartphone-based PHR for their babies after discharge from the hospital. More
results should be reported in the future but some examples of projects are summarised
below.

RFID (Radio Frequency Identification)

The Industrial Technology Research Institute of Taiwan developed a high-frequency
RFID chip and the "history of exposure to medical institutions RFID tracking control
system" in 2004. From then on, RFID has been used in the study of medical and PHR.
Recently, it was used to bind with medical records so the system can clearly track the
flow of medical records.

The IHE (Integrating the healthcare Enterprise) and the IHE-Based Personal Health
Record Management System

Since the implementation of National Health Insurance program in Taiwan, the quality
of healthcare has been increased remarkably. However, the public has also increased
the demands for better understanding and managing of their health related information.
In general, current personal health information is stored in healthcare institutions and
the accessibilities of that information are limited for public. This study developed a
Personal Health Record Management System (PHRMS) to combine the features from
various IHE integration profiles and use Web services technologies to build this
integrated system (Chen, Lin & Chang, 2009). The PHRMS can manage data from
different healthcare information systems and has friendly user interfaces that users can
integrate or exchange personal health information easily. It also put the privacy and
security into serious concern. This project has provided a representative model for the
exchange of PHRs in Taiwan.

Health2.0 Personal Healthcare Management System

This study utilized concept of Health2.0 to design a personally healthcare management
system (Huang, Chuang & Chiang, 2009). Using text-to-speech and web phone
techniques, it helped users to realize and manage personal health and effects of
medication and also assured patients’ compliance and medication safety.

A Patient-centric Real-time Two-way Referral System

The traditional referral process is a time consuming and inefficient procedure. Our
Ministry of Health started implementing a medical referral project in July, 2005. In this study, a web-based electronic referral system was implemented so any registered physician could refer the patients to any other medical organization registered in this system (Yu, Ho, Wang, Sung & Lin, 2009). Any medical images, such as the MRI, Xrays, and other pathologic examining results, could be sent to the referred hospital together with the EHR as a compressed file.

**Home-based Medical Information Integration System**

The Industrial Technology Research Institute proposed a home-based medical treatment information integration system which could detect medical devices and then collect data through wire or wireless network and send those data to remote nursing platforms with secure mechanism (Wu, 2009). Those data in the remote nursing platform were then used by doctors or nurse practitioner to diagnose patients’ health situations. Key components in this system are UPnP (Universal Plug and Play), Web Service, and SSL.

**References**


**Links for information about Taiwan**

Taiwan's Geography and Climate:
http://www.asianinfo.org/asianinfo/taiwan/pro-geography.htm

Health care information development in Taiwan:
http://203.65.42.165/e-learning/material/Exhibit_95/health_info.ppt
United States

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Current State of Deployment

The state of personal health information management systems (PHIMS) in the US is rapidly evolving from paper-based tools to online personal health records (PHRs). PHRs are best thought of as a suite of interoperable tools that help individuals track health status and meaningfully engage in health practices and health care. Anchored in data sources like electronic health records, PHRs may also include communication utilities, data interpretation and visualization routines, and access to knowledge resources such as evidence-based guidelines, quality ratings of clinicians and health care providers, and public health alerts. Individuals can use a variety of electronic devices, such as ‘smart’ cell phones, web browsers, and intelligent devices to interact with PHR tools; output may appear in the forms of reports printed on computer screens or papers, audible warnings, or electronic messages sent automatically to their care team. There is less work being done on other approaches for personal health information management such as the use of social network sites.

Three PHR models are dominant in the US: stand-alone, tethered and integrated. These three differ in respect to how content is created or populated, who controls or owns the record, and the degree of patient accessibility (Detmer, Bloomrosen, Raymond & Tang, 2008). Currently nine percent of consumers surveyed have a PHR; 42 percent are interested in establishing PHRs that are connected online to their physicians (Deloitte, 2009). PHRs are used more often when people have the opportunity to not only manage their own personal health data, but also given tools that help them manage their families’ health, as in the tethered PHR of Kaiser Permanente (Seidman, 2009).

The Medical Library Association (MLA)/ National Library of Medicine (NLM) Joint Electronic Personal Health Records Task Force enumerated a list PHRs that are electronic (web, CD, USB) and used beyond a single hospital or employer (Table 1). Many of these are stand-alone options. While not PHRs themselves, GoogleHealth and Microsoft HealthVault are providing the foundation for some PHIMS development in the US. Many institutions have moved or are moving toward tethered PHRs. Kaiser Permanente and the Department of Veterans Affairs (http://www.myhealth.va.gov/) are two large healthcare systems with a substantial PHR user base. Details are provided for two additional examples are Patient Gateway at Partners and MyHealthatVanderbilt.
Patient Gateway is a secure, web-based patient-portal developed by Partners HealthCare in Northeastern, MA, USA (Grant et al., 2006). Patient Gateway facilitates communication between patients and their providers over the internet and provides a means for patients to request prescription refills, schedule appointments and authorize insurance authorization electronically. Patients and authorized representatives use Patient Gateway to send secure messages to the practice and access understandable and valid health information online. Providers can save copies of Patient Gateway messages in the Longitudinal Medical Record (LMR) as a communication note. Recent enhancements to Patient Gateway include features to engage patients in the medication reconciliation process and to report medication side effects. In addition, Patient Gateway has tools to support patients in management of chronic illness, in entering personal health information, in updating family history and in promoting adherence to national health maintenance guidelines.

Table 1 - PHRs in the United States

<table>
<thead>
<tr>
<th>AHIP PHR Standards</th>
<th>KIS Medical Records</th>
<th>MyMedicalRecords.com</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allscripts Patient Portal</td>
<td>LAXOR</td>
<td>MyMedicare.gov</td>
</tr>
<tr>
<td>Band of Life</td>
<td>LifeLedger</td>
<td>myNDMA</td>
</tr>
<tr>
<td>Benefits Manager (American Airlines)</td>
<td>LifeSensor</td>
<td>myuhc.com</td>
</tr>
<tr>
<td>Care Memory Band</td>
<td>MedCard Online/Med-Id-Card</td>
<td>NoMoreClipboard.com</td>
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<tr>
<td>Chart Scout</td>
<td>MedCommons</td>
<td>PHR4me</td>
</tr>
<tr>
<td>CheckUp</td>
<td>MedDataNet</td>
<td>PatCIS</td>
</tr>
<tr>
<td>Dr. I-Net</td>
<td>MedFile</td>
<td>Pathway Technology</td>
</tr>
<tr>
<td>E-HealthKEY (MedicAlert)</td>
<td>MedTag</td>
<td>Patient Power</td>
</tr>
<tr>
<td>EMRy Stick</td>
<td>Medical Passport</td>
<td>Peoplechart</td>
</tr>
<tr>
<td>Enterprise Patient Portal</td>
<td>MedAlert</td>
<td>Personal Health Record (PepsiCo)</td>
</tr>
<tr>
<td>ePHR</td>
<td>MediCompass</td>
<td>Portable Health Profile</td>
</tr>
<tr>
<td>Evolution PHR</td>
<td>m3KEEPER</td>
<td>ProfileMD</td>
</tr>
<tr>
<td>FollowMe</td>
<td>MedStick</td>
<td>ReliefInsite.com (using Facebook)</td>
</tr>
<tr>
<td>FullCircle</td>
<td>MedInfoChip</td>
<td>Securamed</td>
</tr>
<tr>
<td>Global Patient Record</td>
<td>MedNOTICE</td>
<td>SGMSCorp</td>
</tr>
<tr>
<td>Google (still in development)</td>
<td>My Family Health Portrait</td>
<td>SynChart</td>
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<tr>
<td>Handymedical.com</td>
<td>My Health Connection</td>
<td>Telemedical.com</td>
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<tr>
<td>Health Account Basic</td>
<td>My Health Record</td>
<td>The Smart PHR</td>
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<tr>
<td>HealthFile</td>
<td>My HealthheVet</td>
<td>Touchnetworks H.U.B.</td>
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<tr>
<td>HealthFrame</td>
<td>My MediList</td>
<td>Vital Key</td>
</tr>
<tr>
<td>HealthVault (Microsoft)</td>
<td>My Medical CD</td>
<td>Vital Records</td>
</tr>
<tr>
<td>iHealthRecord</td>
<td>MyActiveHealth PHR</td>
<td>VitalChart</td>
</tr>
<tr>
<td>Indivo (Dossia)</td>
<td>MyChart (Epic)</td>
<td>Vividea (Lifetime Personal Health Software)</td>
</tr>
<tr>
<td>InfoVivo</td>
<td>myCIGNA</td>
<td>Waiting Room Solutions</td>
</tr>
<tr>
<td>iPHHR</td>
<td>MyFamilyMD</td>
<td>WebMD Health &amp; Benefit Manager</td>
</tr>
<tr>
<td>IQHealth</td>
<td>MyHealth123.net</td>
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MyHealthatVanderbilt (http://www.myhealthatVanderbilt.com) has approximately 24,000 users and includes the following features:

- Remote viewing of personal medical information, including laboratory test results, diagnostic imaging reports, medication lists, allergies, and vital signs.
- Laboratory results with normal ranges, patient historical values, trending graphs.
Interactive messaging to ask caregiver questions and request new appointments.

Single chart of all appointments with contact, location, and parking information

Ability to pay Vanderbilt bills online.

Topics on relevant medical information populated based on patient age and diagnosis (pulled from billing codes).

Ability to assign delegates to act on their behalf for these functions.

Links to Vanderbilt University Medical Center (VUMC) phone and other resource directories.

Internal organizational features include linking directly to StarPanel (VUMC’s internal electronic health record system).

The distinction between tethered and integrated PHRs is not totally clear in the literature in the US. In a recent New England Journal of Medicine perspective, Tang and Lee (2009) argued that an “integrated PHR that is an extension of physicians’ electronic health records (EHRs), will go further in facilitating the type of physician–patient relationship that will improve health and health care, at a lower cost.” They estimated that millions of patients are using such integrated PHRs and provide the example that 50% of patients at the Palo Alto Medical Foundation clinic use their online portal (http://www.pafmonline.org).

Detmer et al., (2008) consider the tethered PHR as a subset of integrated, interconnected or networked PHRs because the latter are populated with patient information from a variety of sources (e.g., EHRs, insurance claims, pharmacy data, home diagnostics) and allow patients to enter data into some portions of the PHR. A number of major US healthcare organizations have partnered with either Google or Microsoft to move toward this vision. For example, the Cleveland Clinic established a partnership with Google and Mayo Clinic has partnered with Microsoft HealthVault. A number of large organizations including Walmart, and Intel are providing or planning to provide access to PHRs for their employees. Walmart and Intel are members of a consortium of companies that have joined together to form the non-profit organization Dossia (www.dossia.org). In collaboration with Children’s Hospital of Boston and using the platform Indivo (http://indivohealth.org/), Dossia offers an employer-sponsored electronic personally-controlled health record (PCHR) that pulls data from multiple sources and functions as a repository for ‘lifelong health information.’ Data in the Dossia application are controlled by the patient and the application is integrated into WebMD. After a pilot phase, the retail chain Walmart deployed the Dossia application to its nearly 2 million employees as part of the employee benefit selection process for 2009. (Kolbasuk McGee, 2008). Progress to date has not been reported, but it will be interesting to follow the employer-sponsored activities as they move forward.

**Government and Foundation Initiatives**

A number of governmental agencies (including the previously described Veterans Affairs) and other organizations have initiatives related specifically to PHRs.
The Obama administration has earmarked 19 billion US dollars for health information technology (HIT), including the adoption of electronic health records. Nationwide, adoption of HIT among physicians is slowly rising – from 10 percent in 2005 to 14 percent in 2007 (US Department of Health and Human Services, n.d.). Receiving federal funds is tied to “meaningful use of EMRs”. This phrase has been predominantly interpreted as referring to what constitutes meaningful use by providers. However, Kibbe and Klepper (2009) suggest that patients need to be included in this discussion. These authors state that this money “could be re-imagined to take advantage of the new ways millions of consumers, patients, and care giving families are using information and communications technologies to solve problems, form online communities, and share information and knowledge.”

The Centers for Medicare and Medicaid Services (CMS) has been engaged in a number of pilot projects for PHR use among Medicare beneficiaries:

- Medicare PHR Choice - for people with original Medicare living in Arizona and Utah.
- MYPHRSC - for people with original Medicare living in South Carolina.
- Medicare Advantage/Part D Drug Plan PHRs.
- CMS has also launched a broad informational and educational campaign for their beneficiaries regarding PHRs.

In Project HealthDesign (www.projecthealthdesign.org), a US-based initiative funded by the Robert Wood Johnson Foundation, design teams work collaboratively with lay people and their clinicians and family caregivers to create new types of PHR tools. A core technical platform facilitates technical tasks common to most PHRs, such as identity authentication and authorization or medication list management.

Lay people think of PHRs as tools to help them better understand health in everyday living by monitoring highly individualized cues that give insight into the person’s health state and response to clinician-directed therapies. Labeled by the teams as “observations in daily living”, these cues include sensations and behaviors like mood, appetite, ability to walk a certain distance without pain, sexual satisfaction, and numbers of nights of un-interrupted sleep. The premise of Project HealthDesign is that PHRs may lead to better health and health care when they are designed to help people monitor health in everyday living, understand patterns that indicate improvement or disruption in progress towards health goals, and integrate these observations into clinical care conversations.

Connecting for Health, a public-private collaboration, has facilitated three phases of work related to PHRs and personal health technologies (http://www.connectingforhealth.org/workinggroups/personalhealthwg.html). In Phase one, The Personal Health Working Group identified consumer requirements, concerns, and values that must be addressed as PHR technology is refined and implemented. Products included: a baseline framework of the best available evidence regarding expected benefits of PHR as well as consumer and patient requirements. They also promoted the development and/or identification of data standards relevant to the PHR. Phase two focused on coordination between EHR and PHR.
The focus of the Phase 3 work of Connecting for Health is enabled through a Personal Health Technology Council that identifies and recommends solutions for policy challenges affecting the adoption of PHRs and related technologies with a sharp focus on the needs and concerns of consumers.

**Nursing Education Initiatives Related to Informatics and PHIMS**

Beyond the accomplishments of individual institutions in educational initiatives related to PHIMS, there are several important events that have occurred in the United States to prepare nurses to practice in technology rich environments. The first is the recent release of the TIGER Phase II Collaborative Report. This report highlights the work of the nine collaboratives and how each one has used the intellectual and social capital of the various nursing professional organizations to move TIGER’s agenda of preparing the next generation of nurses (www.tigersummit.com/).

Second, the National League for Nursing has been promoting their position statement, “Preparing the Next Generation of Nurses to Practice in a Technology-rich Environment: An Informatics Agenda.” Following up on the recommendations in this position statement, the NLN has a Task Group developing a Faculty Development Toolkit for Integrating Informatics into the curriculum. The Task Group is committed to continue its campaign to raise the awareness about the integration of informatics into the nursing curriculum and to provide necessary resources for faculty. (www.nln.org/aboutnln/PositionStatements/index.htm).

Third, the American Association of Colleges of Nursing has released its Essentials for Baccalaureate Education and has included an essential on information management. They also have informatics competencies as part of the Doctorate of Nursing Practice Essentials. The competency documents are available at: www.aacn.nche.edu/Education/bacessn.htm and www.aacn.nche.edu/DNP/pdf/Essentials.pdf

Lastly the Quality and Safety Education for Nurses (QSEN) Project focuses on the integration of five core competencies in pre-licensure programs. These five core competencies include informatics. Fifteen pilot schools have been implementing this curriculum and their work is available on the QSEN site: http://qsen.org

**Key Nursing Issues Related to the Design and Use of PHIMS**

Despite significant effort toward the design and use of PHIMS, several gaps exist. In terms of design, the consumer or patient voice has yet to be valued and captured in a meaningful way rather it has been recorded through someone else’s lens, or has been distilled to available words from a dropdown menu. Shared access to this narrative within a PHR may foster a richer dialogue between patient and provider, creating the opportunity for more thoughtful and congruent treatment approaches. Second, there has been little integration of decision support strategies into existing PHRs. Third, there is a need for PHR designs suitable for individuals with low levels of functional literacy and computer literacy.
Other design-related issues relate to the dearth of research regarding use of social network approaches as personal health information management strategies or integration of patients’ mental models or conceptions of phenomena such as wellness or healthy aging.

In terms of use of PHIMS, most nurses in clinical practice are unaware of PHIMS such as PHRs and have not directly integrated them into their nursing practice. These tools provide nurses a key opportunity to be consumer and patient advocates and educators in new ways. However, to take advantage of this opportunity, nurses must build upon their existing advocacy and education competencies. Nurse researchers also require new types of competencies to integrate PHIMS as intervention strategies and to mine PHIMS for research purposes. PHRs, in particular, are suitable for meeting some types information needs related to patient data or a particular institution (e.g., What is my laboratory test result? Who is my nurse case manager? What hours is the clinic open?). However, their use also results in additional information needs regarding the healthcare domain (What does this radiology finding mean?) Informatics strategies are needed to integrate answers to such questions as part of PHIMS in a manner that meets patients’ needs.

**Agenda for Action**

An agenda for action should include items related to design and use of PHIMS.

**Design:**
- Explore the potential for patient participation within a PHR in the form of a narrative.
- Build tools which capture patient conception and context within the PHR that are useful to all stakeholders: consumer/patient, provider and payer.
- Explore social network technologies as PHIMS
- Implement PHIMS technologies suitable for use by those with low functional, health, and computer literacy
- Integrate informatics strategies to answer patient-specific, institution-specific, and domain-specific information needs
- Build tools to manage, represent and mine the myriad of incoming data

**Use:**
- Educate consumers, patients, clinicians, educators, researchers, and policy makers regarding use of PHIMS and data generated from PHIMS
- Use PHIMS information to create care (including interventions) that is concordant with patient conceptual and contextual data.
- Advocate for funding to support use of PHIMS
References


NI Congress and Post-Congress Workshop Continuum

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Scientifically, NI congresses have always had an important part in knowledge generation for the field of health informatics. In 1993, Priorities for nursing informatics research were assessed by the National Institute of Nursing Research and were also reported in a Delphi study of nursing informatics research priorities in 1998 (Efken, 2003; Currie, 2005). According to Bakken, Stone and Larson (2008), many research priorities described in 1993 continue to be relevant even today, for example, user needs, informatics support for patients/families and consumers as well as nursing and health care practice. However, the authors emphasise that in the next decade (2008-2018) the research agenda must expand and highlight the importance of interdisciplinary and translational research. Further they state that "a nursing informatics research agenda must support integration and use of genomic data for nursing care and for nursing research" (Bakken et al., 2008).

Over 27 years, the congress programmes have reflected the state of the art of advances in nursing and health informatics education, management, research as well as in the clinical area. Based on the congress and post-congress workshop themes, nurses have been visionary innovators, leading the development and discussions of timely concerns. The congress themes (table 1) reflect futuristic, technical, social as well as interdisciplinary perspectives in the field of nursing informatics. As seen in the table, the idea of a post-congress workshop was already born together with the first conference in 1982 (Saranto, Tallberg & Ensio, 2009).

It seems almost unbelievable that as far back as 1988 the post-congress workshop in Dublin focused on decision support systems. However, the development path has not been smooth and many nurses still lack both evidence-based information and technical support in daily practice, management and education.
<table>
<thead>
<tr>
<th>Year and Place</th>
<th>Conference theme</th>
<th>Post-conference theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1982 London</td>
<td>The Impact of Computers on Nursing</td>
<td>The Impact of Computers on Nursing</td>
</tr>
<tr>
<td>1985 Calgary</td>
<td>Building Bridges to the Future</td>
<td>Challenges for the Future</td>
</tr>
<tr>
<td>1988 Dublin</td>
<td>Where Caring and Technology Meet</td>
<td>Decision Support Systems</td>
</tr>
<tr>
<td>1991 Melbourne</td>
<td>Nurses Managing Information in Health Care</td>
<td>Health Care Information Technology</td>
</tr>
<tr>
<td>1994 Austin</td>
<td>Nursing Informatics: An International Overview of Nursing in an Technological Era</td>
<td>Informatics the Infrastructure for Quality Assessment and Improvement in Nursing</td>
</tr>
<tr>
<td>1997 Stockholm</td>
<td>The Impact of Nursing Knowledge on Healthcare Informatics</td>
<td>Nursing Informatics: Combining Clinical Practice Guidelines and Patient Preferences Using Health Informatics</td>
</tr>
<tr>
<td>2000 Auckland</td>
<td>One Step Beyond: The Evolution of Technology and Nursing</td>
<td>An Informatics Basis of Evidence-Based Practice Through Clinical Pathways</td>
</tr>
<tr>
<td>2003 Rio de Janeiro</td>
<td>eHealth for all: designing nursing agenda for the future</td>
<td>Patient safety</td>
</tr>
<tr>
<td>2006 Seoul</td>
<td>Consumer-Centered, Computer-Supported Care for Healthy People</td>
<td>Nursing informatics 2020: towards defining our own future</td>
</tr>
<tr>
<td>2009 Helsinki</td>
<td>Nursing Informatics - Connecting Health and Humans</td>
<td>Personal Health Information Management: Tools and Strategies for Citizens' Engagement</td>
</tr>
<tr>
<td>2012 Montreal</td>
<td>To be announced in 2010</td>
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</table>

The aim of the post-congress workshops is to guide nurses in informatics during the next triennial with recommendations for practice, education, management and research published in the workshop proceedings. Each of the seven chapters reporting the themes addressed in the post-congress workshop advances specific recommendations in the substantive area. Below we summarise some over-arching principles to guide the responses to the recommendations related to personal health information management systems (PHIMS).
1. **Development of PHIMS is a country-specific issue**
   PHIMS need to complement and extend country-specific approaches to health care. Because of the very unique nature of health care in each country, and, by extension, the roles and responsibilities of people in their care, personal health information management needs and demands will vary.

2. **PHIMS are not just extensions of the Electronic Health Records**,

3. **As the targeted end users of PHIMS, people need to be involved in all stages of PHIMS development and evaluation.**

4. **PHIMS must be part of the national health IT initiatives**

5. **Privacy, security and confidentiality considerations related to PHIMS require both policy and technical innovations.**

**References**


Participants in the NI2009 Post-Congress Workshop

**Personal Health Information Management:**
**Tools and Strategies for Citizens' Engagement**

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAKKEN, Suzanne</td>
<td>School of Nursing and Department of Biomedical Informatics, Columbia University, New York, USA</td>
</tr>
<tr>
<td>BLAŽUN, Helena</td>
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