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What the hell is a PCEHR and what does it have to do with me anyway?

As part of their 2010/11 federal budget, our decision makers in the Federal government announced a $466.7 million-odd investment over two years for a national Personally Controlled Electronic Health Record (PCEHR) system as described in its Concept of Operations document released recently.

The *InformaticsInsider* felt it was appropriate to describe to the layperson what this PCEHR is, where it fits in the Australian health system and what is the reality of achieving its stated implementation objectives by the allotted time frame of July 2012.

Why is this important to the lay person? Because it is "personally controlled" meaning that each Australian individual has control over their own health record. An extremely ambitious concept if even if we knew all clearly knew what we are doing!

The publicised vision of our Australian Federal bureaucrats for this personally controlled electronic health record is;

Placing the person at the centre of their own healthcare by enabling access to the right health information, for the right person, at the right time and place.

The concept of each individual having their own "personal electronic health record" is a complex idea and thus it is absolutely necessary that some simplified explanation be given to facilitate a lay person's understanding of the project.

The *InformaticsInsider* will attempt to provided a layperson/end user understanding of the PCEHR and will be be covered in two issues of the *InformaticsInsider* newsletter.

Part 1 - What is a personally controlled electronic health record (PCEHR)?

Part 2 – What are the advantages, disadvantages and impediments associated with the implementation of this ambitious PCEHR project?

Part 1

For anyone within Australia not intimately involved in the clinical environment, the definition of a personally controlled electronic health record may well be a foreign concept. To assist in this understanding lets look at a number of definitions of what an "electronic health care record" is at national and international levels .

Defined by our the current federal bureaucrats in NEHTA and the DoHA, an Australian PCEHR is;

"a secure, private electronic record of an individual's key health history and care information. The record would provide a consolidated and summarised record of an individual's health information for consumers to access and for use as a mechanism for improving care coordination between care provider teams."

However, when we looked at from an international perspective, there are well over twenty different definitions of what constitutes an electronic health record, be it personal or not. Let's look at a couple;

"The medical record is pre-birth to post-death electronic record which meets the record keeping requirements for any setting, whether intensive care or primary care, whether obstetrics or gynecology." (Ed Hammond et al 1993)

"The computer-based patient record. An essential technology for health care." (R Dick et al 1991 Institute of Health report into the computer-based health record)

With so many definitions of this e-record system it indicates that the whole concept of the electronic health record is difficult to compartmentalise and understand. It may even indicate we still do not know what it actually is!

This is confusion is understandable as the functionality of any such e-record system is '*evolutionary*' and it will over time impinge on the economic, political, social and human interactions and adaptations wherever electronic health record is utilised. This process is often called "change-management" and reflects the human adaptations required to mange the introduction of new technologies e.g. iPhones.

Specific aspects of these human (patient) interactions have been documented extensively, and a recent review by Calvin and others in 2011 in the Journal of the American Medical Informatics Association (JAMIA) provides an excellent summary of the relevant factors involved in patient acceptance of web-based interactive self-management technology.

Having said all that, one must answer a critical question that a lay person may well ask;

- What is the medical record, how is it built and how does it function?
- We know that the medical record, in ANY format, is described as;
- the primary communication tool for health care management,
- it is the essential device to provide Clinical Decision Support (CDS),
- it is the primary data capture tool used by clinicians in day to day care of the patient
- it is the essential "information management" tool for health care,
- it is (should be) used by all those involved in the delivery of health care.
- the medical record is not fixed and expands with the iterative interactions of a patient or patients with the health care system.

Therefore, based on the above, the medical record must be adaptable, timely, reliable, accurate and contain the complete data and information necessary to deliver quality care.

Having stated this, another question becomes readily apparent.

How is my personal medical record created and constructed?

To assist in answering this question lets consider the organisational processes in Figure 1 below that clinician's use to capture and utilise medical information in the creation and management of the medical record and see where the patient fits into these.

Figure 1 – The medical record creation and utilisation process.

Although health care is considered to be a service-based profession, it does not ignore the salient fact that most clinicians, including patients to a limited extent, manage information relating to the care of the patient. One must also be aware that this is exclusively about the clinical process and is independent of any form of media, technology or system that people involved in this process may utilise.

Looking at Figure 1 we can see that the basic processes, not necessarily in this order, utilised by the clinician dealing with the patient are;

- **Collect:** Collection of data provided by the patient or carers, which involves activities such as the taking a history, performing a physical examination, reading reports, look up laboratory data, reading x-rays.

- **Process:** Processing of information to arrive at a likely diagnosis or a hierarchy of possible diagnoses.
- **Record/ Transmit:** Recording data involving activities such as writing visit notes, preparing operative reports, prescriptions, and diagnostic test result. This will also involve the transmission of data through mediums such as the telephone, paper or electronic charts, and email.
- **Diagnose:** Diagnosis of issues through processing of information.
- **Treat:** Initiation of treatment which in most situations occurs outside acute care and must be managed by the patient and / or carers.

All of this leads to the creation of what we call the medical record, a repository of patient related information.

This therefore forms the basis of explaining the concept behind the personally controlled electronic health record (PCEHR).

Looking at Figure 1 again we can see that this medical record with its rich resources of clinical information can then be made available by those who need to manage an individual patient's journey through a complex health system by users such as primary care physicians, specialists and other health professionals such as researchers, public health officials and governments who fund health care. For larger groups and populations who have valid reasons for accessing the stored information and are called secondary users of the health information the e-Health record(s) these record(s) become an essential tool for their work.

We can see that the basic processes in Figure 1, not necessarily in this order, utilised by these primary and secondary users are;

- **Analyse:** with the accumulated confidential storage of record data and authorised access by relevant decision makers disease trends and incidences are more accurate and less costly to perform.
- **Display:** Displaying of relevant medical information in various formats, whether it be paper-based or electronically.
- **Share:** Sharing of medical information between individuals that contributes to the overall social structure and activities. Through the use of stored, secure and standardised e-health data major health benefits for the communities locally and more diverse populations can occur.
- **Record/ Transmit:** Recording data involving activities such as writing visit notes, preparing operative reports, prescriptions, and diagnostic test result. This will also involve the transmission of data through mediums such as the telephone, paper or electronic charts, and email (Internet).

This initial flow of information management in creating, managing and accessing the medical record is then followed by additional cycles of information collection, management, recording and processing to monitor and adjust care accordingly.

A critical overarching principle is that this information has to be communicated in standard, legible, reproducible and timely formats for all clinicians, primary and secondary users who use it including patients.

Thus, information is not a necessary adjunct to care, it is care, and effective patient management requires effective management of patients' clinical information.

This descriptive model is critical to understanding where the PCEHR fits into the Australian health care system as shown by Figure 2 below. The PCEHR itself is akin to the medical record as described in Figure 1.

The PCEHR must be an essential component of the Australian e-Health system however for NEHTA and DoHA to make this the initial focus for their $460million e-health project is fraught with danger and has elements that point to it becoming a costly administrative failure. Making the patient a significant player in the e-health system is critical.

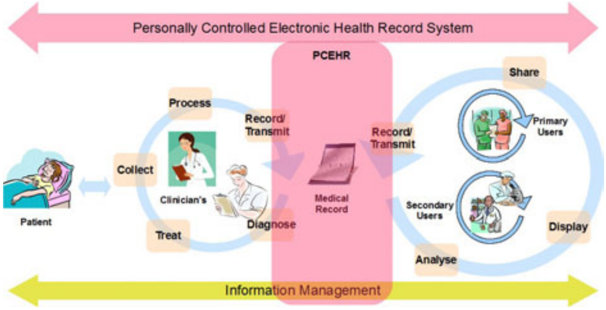

Figure 2 – The PCEHR and the PCEHR System

This point was very clearly stated by Professor Laurence Weed in 1989,

"We must think of the whole information system, and not just infinitely elaborate on the parts that interests us or fit into a given speciality. Patients do not specialise, and they or their families are in charge of all the relevant variables 24 hours a day, every day. They must be given the right tools to work with. They are the most neglected source of better quality and savings in the whole health care system. After all:

- *They are highly motivated, and if they are not, nothing works in the long run anyway*
- *They do not charge. They even pay to help.*
- *There is one for every member of the population."*

The next step to comprehend in the DoHA/NEHTA plan relates to the mechanics of the implementation of the PCEHR within Australia. The National e-Health Transition Authority (NEHTA) has stated;

"...that all individuals seeking care in the Australian healthcare system, who choose to do so, will be able to register online for a PCEHR from July 2012"

The implications of this statement are that in thirteen months time it is expected that (nearly) every Australian individual will have the chance to create a PCEHR.

As indicated above the PCEHR as a concept is very good from a theoretical standpoint, however, I, myself, the *InformaticsInsider* is able to state from first hand and extensive experience that this thirteen month implementation objective from a practical perspective is more like an impossible dream or a Lourdes-like miracle for the establishment of the PCEHR as a core component of the Australian e-Health system.

One may ask why the *InformaticsInsider* is qualified to make such a statement. The *InformaticsInsider* has extensive experience in e-Health implementations internationally dating from the mid-1980s. Previous e-Health programmes and projects the *InformaticsInsider* has worked on still remain on a complex evolutionary path thirty years after initiation and for a de novo EHR project treating an epidemic of 40 million people it has take more than a decade to achieve measurable goals and change health care delivery.

Health organisations that are implementing, or are intending to implement, e-Health or Health Integration Technologies (HIT), need to understand that technology is only an enabler within a clinical process and is not necessarily the problem.

The problem is that the clinical care processes that accompany the patient in the health care system must be fully understood from a people, information storage and capture viewpoint before addressing the information management needs that must be met to ensure successful health care outcomes. After all, the e-Health projects should be all about care and its successful outcomes.

Part 2 will advance the understanding of the electronic health record and its components within the PCEHR highlighting potential benefits and disadvantages as well as impediments to its successful implementation.

The *InformaticsInsider* is written by a well respected Clinical Associate Professor, Physician and past President of ACHI who has over 30 years international and national experience in Health Informatics

If you wish to provide commentary on the above article, drop an email to the *InformaticsInsider* at InformaticsInsider@austemrs.com.au

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