Senate Enquiry submission from A/Prof. Terry Hannan.

Dr Terry J. Hannan MBBS;FRACP;FACHI;FACMI
Consultant Physician
Clinical Associate Professor School of Human Health Sciences, University of Tasmania
Department of Medicine, Launceston General Hospital

President Australasian College of Health Informatics(2007-9)
Visiting Professor, Universita di Modena, e reggio emelia, Italy (Sept-Nov 2010)

Biosketch:

- Consultant Physician and Health Informatician.
- Fellow Australian College of Health Informatics (2002-)
- Fellow American College of Health Informatics (2004-)
- President of the Australian College of Health Informatics (2007-2009).
- Member AMIA International Affairs Committee
- Medical Director of the transfer of the Johns Hopkins Oncology Clinical Information System from Johns Hopkins to an Australian tertiary hospital.(1984-1992)
- Co-Founder of the Mosoriot Medical Record System an Electronic Medical Record (EMR) project in Kenya that preceded the AMPATH and OpenMRS e-record systems. This is currently the largest open-source web based EMR for developing nations. Main focus has been on end-user acceptability of eHealth technologies.
    - Member of the OpenMRS (www.openmrs.org)Implementers / Users Listserver committees.
- Clinical Associate Professor, School of Human Health Sciences, University of Tasmania, Launceston Campus.
- Invited Visiting (Sabbatical) Professor (Sep-Nov 2010) Modena University, Italy.
- Multiple peer-reviewed publications on health informatics in journals.
- Health Informatics Consultant and commentator on e-health in Australia via a non profit website www.austemrs.com.au
- Moderator GHDonline www.ghdonline.org –January 2012 to July 2012.

This is my submission the Senate enquiry; ***Personally Controlled Electronic Health Records (PCEHR) Bill 2011 and one related bill,***

http://www.aph.gov.au/Senate/committee/clac_ctte/pers_cont_elect_health_rec_11/index.htm ,

I am making this submission based on my extensive experiences in e-health projects both in Australia and internationally.
My Australian experiences in e-health implementations relate to my role as the Medical Director of the first successful international translocation and implementation of a complex electronic medical record system. This was the partial implementation of the Johns Hopkins Oncology Centre Information System (OCIS) from 1984 to 1992 in the Prince of Wales Oncology Centre.

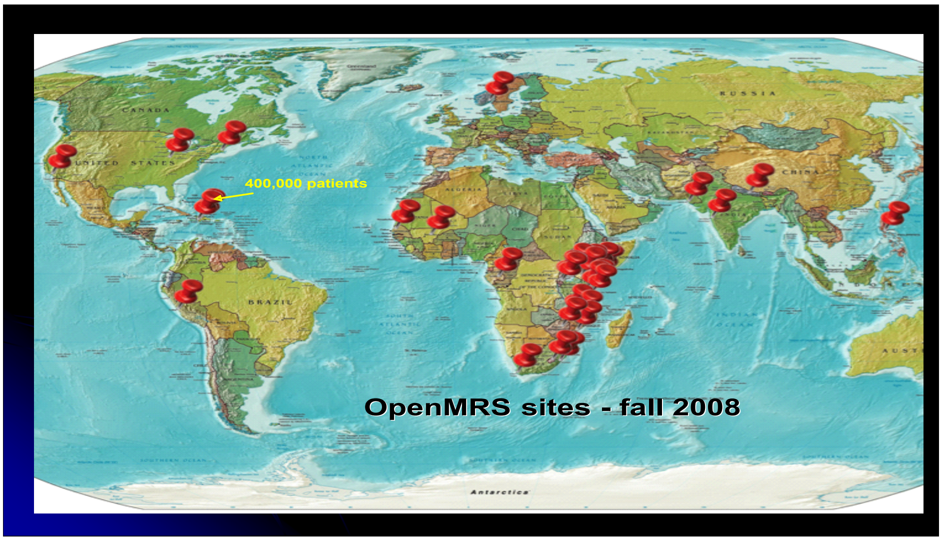
My experiences with the OCIS project were significant in the invitation to cofound the now largest Electronic Medical (Health) Record (EHR) system in developing nations in the world (www.openmrs.org).

This system was originally a focal EHR record development in Kenya to manage the HIV/AIDS epidemic that involved ~ 40 million persons living with AIDS on the sub-Saharan African continent. The initial success of the project (MMRS/AMPATH) in the clinical information management of this epidemic led to the development of a collaborative project that now sees this open source EHR used for all disease states in the treatment, prevention, education and research.

The significance of the e-Health project was summarised in a 2009 publication in the journal JAIDS where the authors were able to state, "*Now HIV/AIDS programs are not only in place but some of them, including the partnership between the United States Agency for International Development (USAID) and the Academic Model Providing Access to Healthcare (AMPATH)1 are openly speaking of bringing the pandemic to its knees over the next 5 years through widespread screening and effective treatment and prevention of HIV.*"
[Braitstein P, Einterz RM, Sidle JE, Kimaiyo S, Tierney W., "Talkin' about a revolution": How electronic health records can facilitate the scale-up of HIV care and treatment and catalyze primary care in resource-constrained settings. J Acquir Immune Defic Syndr. 2009 Nov;52 Suppl 1:S54-7.]

The expansion and documentation of the success of this project can be seen in the next four slides. The original project was a single MSAccess^{R} database in Eldoret, Kenya.

They also demonstrate the expansion of the project into developed economies with all installations being documented in peer-reviewed publications.



OpenMRS sites - fall 2008

WHAT OTHERS SAY ABOUT THE INDIANA-KENYA PARTNERSHIP

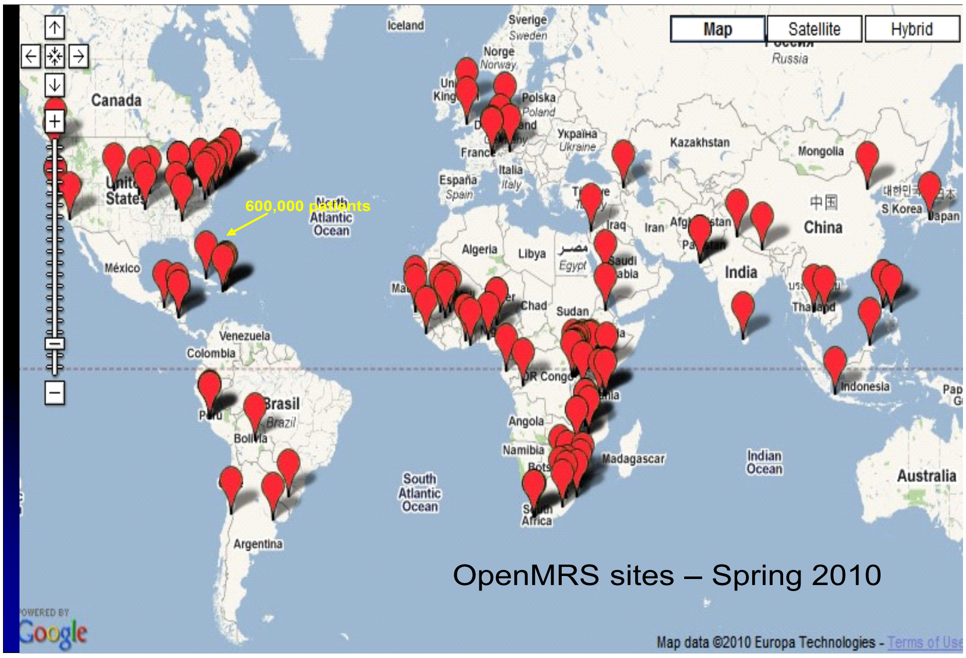
Nominated for the 2007 Nobel Peace Prize; featured in The Wall Street Journal

"The people working on this program are public health heroes. They are doing things that many people thought could never be done, and it is going to have a huge multiplier effect."
--Dr. Tim Evans, former director of health equity for the Rockefeler Foundation

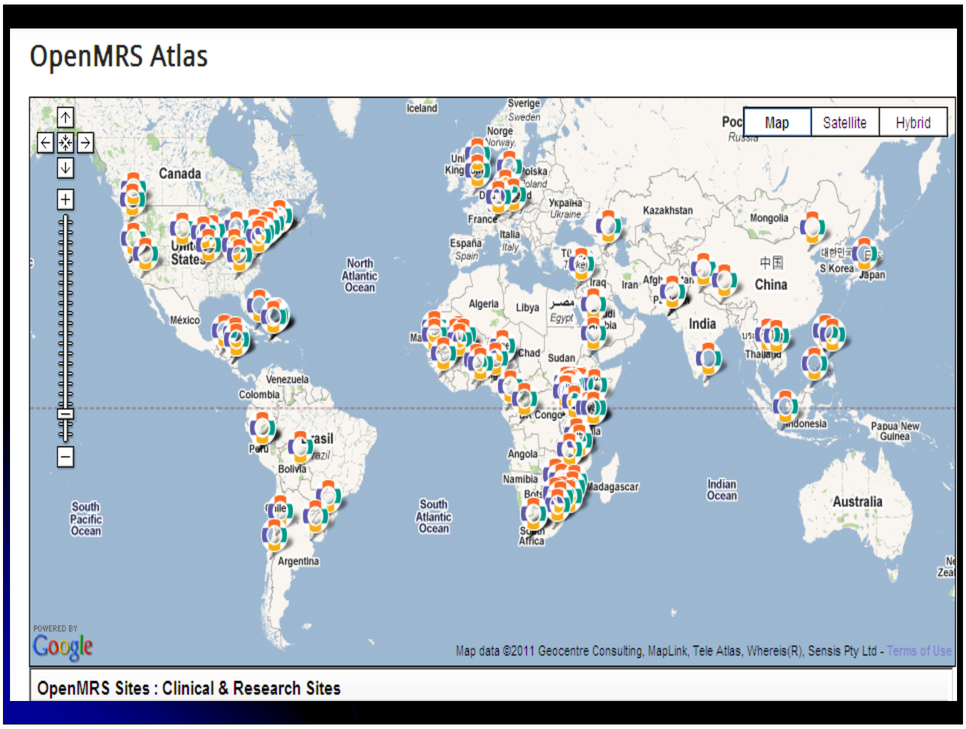
"Much more accurately described as an Academic MIRACLE in response to AIDS."
--Michael E. Ranneberger, U.S. Ambassador to Kenya

"The most important and comprehensive HIV/AIDS effort in all of Africa."
--James Morris, former executive director, United Nations World Food Programme

3 January 2012



OpenMRS sites – Spring 2010



OpenMRS Atlas

OpenMRS Sites : Clinical & Research Sites

The core components to the success of this e-health project have been defined by Biondich and Mamlin and are shown in the next slide.

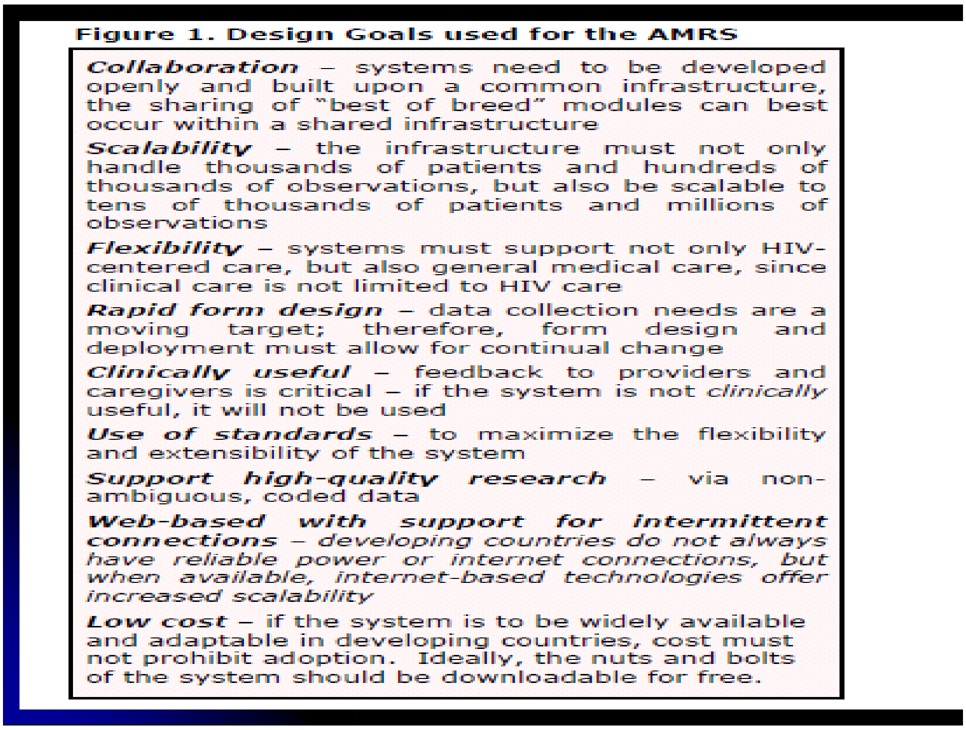


Figure 1. Design Goals used for the AMRS

Collaboration – systems need to be developed openly and built upon a common infrastructure, the sharing of "best of breed" modules can best occur within a shared infrastructure

Scalability – the infrastructure must not only handle thousands of patients and hundreds of thousands of observations, but also be scalable to tens of thousands of patients and millions of observations

Flexibility – systems must support not only HIV-centered care, but also general medical care, since clinical care is not limited to HIV care

Rapid form design – data collection needs are a moving target; therefore, form design and deployment must allow for continual change

Clinically useful – feedback to providers and caregivers is critical – if the system is not *clinically* useful, it will not be used

Use of standards – to maximize the flexibility and extensibility of the system

Support high-quality research – via non-ambiguous, coded data

Web-based with support for intermittent connections – *developing countries do not always have reliable power or internet connections, but when available, internet-based technologies offer increased scalability*

Low cost – if the system is to be widely available and adaptable in developing countries, cost must not prohibit adoption. Ideally, the nuts and bolts of the system should be downloadable for free.

My most current appointment relating to Health Information Technology (HIT) projects has been to the position of an online Moderator the Health IT component of GHDOnline (www.ghdonline.org) for the period January 2012 to July 2012.

With this background experience I believe I am able to make a significant contribution to the Senate Enquiry into the PCEHR in Australia and in the rest of this submission I resource my comments from my own publications on the PCEHR and taken from my personal, non profit website www.austemrs.com.au (http://www.austemrs.com.au/page/informatics_insider.html .

The submission is structured into Parts 1 and 2. Part 1 is an attempt to define what a PCEHRS is and Part 2 focuses on what are the possible advantages, disadvantages, issues and impediments associated with the implementation of the national PCEHR project.

Part 1. What is a PCEHR and what is its relevance to me as an idividual?

As part of their 2010/11 federal budget the Federal government announced a $466.7 million-odd investment over two years for a national Personally Controlled Electronic Health Record (PCEHR) system and was defined in NEHTAs (National E-Health Health Transition Authority) Concept of Operations document released.

As an informed health informatician I 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. This is an extremely ambitious concept if even if we knew all clearly knew what we are doing.

The publicised vision from NHETA and the Federal government is the 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.
This 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.
I have attempted to do this in a two part publication that were published on a non profit personal website. www.austemrs.com.au

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

For anyone within Australia not intimately involved in the clinical environment, the definition of a PCEHR 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. Definitions provided by 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.

Here are two.
1. "The medical record is pre-birth to post-death electronic record which meets the recordkeeping requirements for any setting, whether rintensive care or primary care, whether obstetrics or gynaecology." (Ed Hammond et al 1993)
2. "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 1991).

With so many definitions of an 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). Tis publication 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. This is, *" 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 statements the medical record must be adaptable, timely, reliable, accurate and contain the complete data and information necessary to deliver quality care as well as timely access to knowledge resources. (See *Medicine In Denial*. L. Weed. 2010.ISBN 14566417061]

Having stated the above another question becomes readily apparent. That is, how is my personal medical record created and constructed?
To assist in answering this question let us consider the organisational processes in Figure 1, 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. (Copyright Martin Hannan www.austemrs.com.au)

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, used 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 these patient care interactions 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.

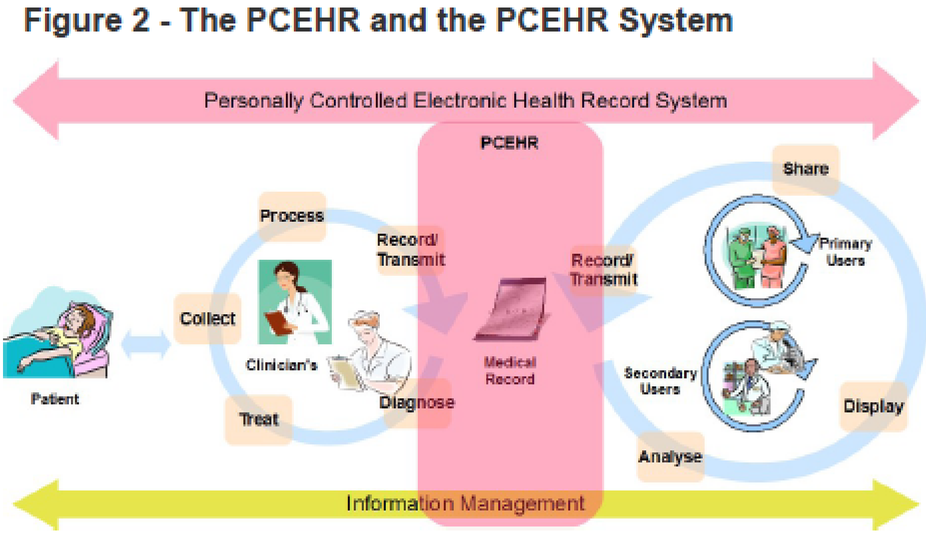
We can see that the basic processes in Figure 1, not necessarily in this order, utilised by these primary and secondary users are;

- **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 patientmanagement requires effective management of patients' clinical information.(WHO-Gonzalo Vecina Neto, head of the Brazilian National Health Regulatory Agency].
This descriptive model is critical to understanding where the PCEHR fits into the Australian health care system, as is represented in Figure 2 below.

The PCEHR itself is akin to the medical record as described in Figure 1.

Figure 2 – The PCEHR and the PCEHR System. (Copyright Martin Hannan www.austemrs.com.au)



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 their project has elements that point to it becoming a costly administrative failure. Also making the patient a significant player in the e-health system is critical.

This relevance of the patient was 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 plans relates to the mechanics of the implementation of the PCEHR within Australia.

NEHTA has stated; *"...that all individuals seeking care in theAustralian healthcare system, who choose todo so, will be able to register online for a PCEHR from July 2012"*.

The implications of this statement are that within thirteen months of this declaration 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 am 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 I am qualified to make such a statement. I have more than 25 years experience in e-Health implementations internationally dating from the mid-1980s. Previous e-Health programmes and projects I have worked on and still remain functional on complex evolutionary paths thirty years after initiation.
Also having been a cofounder of a de novo EHR project treating an epidemic of 40 million people I know it has takes more than a decade to achieve measurable goals and change health care delivery. (www.openmrs.org).

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 of the clinical decision making processes 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 data 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.

My discussions in 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.

Part 2

The If's, the But's, the Hope and the Hype... Is the PCEHR implementation practical, ambitious or unrealistic?

In Part 1 I hope I have established what a medical record is, how it is created and managed within a holistic clinical process and how it pertains to the PCEHR and the PCEHR system that the Federal government is intending to implement around July 2012.

The focus of Part 2 will be what are the advantages, disadvantages, issues and impediments associated with the implementation of this ambitious PCEHR project?

This will also relate to the reader issues that are very likely to have a significant impact on whether this PCEHR implementation will be successful or not and whether in the government time frame for implementation it will become an effective patient care entity.

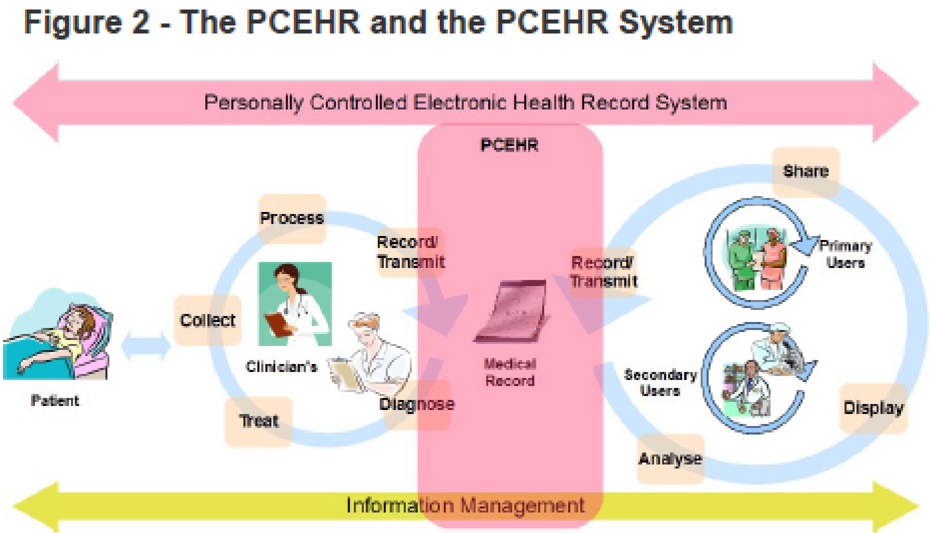
I believe that there will be the good the bad and the ugly interactions as the PCEHR project moves forward with a strong potential for cross party political animosities that are very likely to set back e-Health developments in Australia for decades.

From a political will perspective the existing attitudes are reflected in the statement, this is apparent through the comments of a Federal politician; *"What we are trying to do (in health) has nothing to do with patient care. It is all about the money and getting re-elected."*
This statement made by an eminent opposition parliamentarian should make all politicians consider what will become of the billions of dollars already invested in e-Health with no significant measurable outcomes?

What we need to do is clearly define-legislate- the advantages of the current e-Health plan so that they are unable to be dismantled by political whims.
So the ground work needs to be laid now.
What is not in dispute is that the PCEHR project as a concept can be considered an "ideal" to be achieved for the betterment of patient care in Australia, but can it realistically be done by July 2012? Or is it just false hope, the big hype or the road to hell as discussed in the publication *InformaticsInsider* May 2010, No.1 (http://austemrs.com.au/files/informaticsinsider_may_2010_no_1.pdf). This publication is a reiteration of the principles for successful e-Health implementations by Dr. Mark Smith of the non profit Californian Health care Foundation in 2009. (http://www.chcf.org/).

A further review of Figure 2 in Part 1 leads me to provide discussions on the critical aspects of "*information management*" in the use of the PCEHR in the current Australian health scene that demonstrates how difficult a process this is.

Figure 2 – The PCEHR and the PCEHR System. (Copyright Martin Hannan www.austemrs.com.au)



To have effective "*information management that supports clinical decision making*" individuals need the accurate and adequate data collection in standardised formats that can be distributed across the health system(s) in a timely manner and can be understood by those who use it. These are clinicians such as nurses, doctors, pharmacists, allied health, emergency services and patients.

What is needed within this PCEHR project are individuals who know how to effectively interact with and integrate the relevant health integration technologies that allow for necessary decision support tools to be delivered in real time to the clinical decision makers.

In Figure 2 I have intentionally made the clinical processes that create the medical record/ PCEHR look relatively simple, however this is not implying that these clinical processes are anything but simple. These clinical processes in real life are very complex, and the failure to adequately address the myriad of factors inherent in the complex processes of health care has lead to the wasting of billions of dollars around the world in implementing e-Health. These international failures create significant resistance in the introduction of health integration technologies in the clinical workplace from an end-user perspective, aka the clinician, therefore ultimately affecting the outcomes of patient care.

Hopefully this dissertation completes the full circle to the importance of understanding the implicit link between clinical decision making and information management within the clinical process.

Under the current e-Health implementation plans there is a realistic possibility based on local and international experiences that Australia is very likely to waste billions on health integration technology projects as the complexity of the clinical process, its information management needs and impact on the quality of patient care is being ignored or not being taken into account.

Having stated the point above there are other issues that are very likely to have a significant impact on whether this PCEHR implementation will be successful or not. If the PCEHR implementers want to have a set of successful clinical outcomes then they need to seriously consider the following historical issues.

- **Issue 1:** The patient is the “source” of the data and information necessary for their care.
- **Issue 2:** This data and information is “extracted” by the clinician in the direct patient encounter.
- **Issue 3:** The “integration” of all these data inputs is then attempted by the clinician in the Clinical Decision Making processes.

Looking at Issue 1 there is adequate evidence that the historical formats for history taking are unable to meet the needs of modern medical care and a major rethink of this essential activity needs to occur.

Looking at Issue 2, evidence confirms that clinicians can do this appropriately and inappropriately. Not extracting adequate data and information and extracting too much information to get the diagnosis. A phenomenon described in the New England Journal of Medicine as “*the diagnosis of uncertainty*”. In this scenario the more tests we order the further we get away from the diagnosis and accounts for one of the major dysfunctional processes in health care delivery called “*variation in care*”. This process has been well documented by Donald Berwick and Brent James.

Looking at Issue 3, the integration of patient care data requires systems that can communicate (interoperability) and share data that is decipherable and readable by all integrated systems (standardisation). Currently in Australia this level of uniformity does not exist and almost guarantees the failure the share data and information between the patient and their provider(s).

This discussion raises the importance of standardisation of patient data throughout the clinical process. This poses the question, what does standardisations have to do with patient care and the PCEHR?

Standardisation is necessary if patient data is to be exchanged between different health care professionals. It also allows patients to travel or move from one region or country with adequate record access and enables clinicians to adapt their e-health records for their own requirements. Therefore the aim of this standardisation effort is not to specify the e-health record systems as such but to bring structure to the data stored in such records that is relevant to the given health care location.
The most important message out of this is; "*if the clinicians cannot get it right then how do we expect the patients to get it right (in a PCEHR)*?"

In concluding this submission here are some other startling facts that are likely to be major impediments to the success of the Australian PCEHR system implementation.

- **Fact 1:** The use and adoption of e-Health systems by physicians in Australia is low as documented by Miles Osborne and others in 2009 and this reflects overseas experiences.
- **Fact 2:** With clinicians being the primary collectors and integrators of patient care information we have an enormous hurdle to jump to achieve any successful communication between patients and clinicians. Leape in 2005 noted that the '*culture of medicine*' amongst physicians is one of the greatest impediments to effective change that will reduce harm in health care.
- **Fact 3:** Knowing that clinicians have enormous troubles getting "*their act together*" how are patients responding?
- **Fact 4:** A recent report in the USA revealed that of USA citizens who have access to the Internet some 80% get their health information from the Internet and of these 60% share this information with another citizen who is not a doctor! At that time only 15% of USA-based doctors access their health information from the Internet.

Now we can see that there advantages, disadvantages and impediments associated with the implementation of this ambitious national PCEHR project. So one of the messages from this submission relating to the PCEHR in Australia is reflected the quotation by Dr. Mark Smith, CEO of the non-profit Californian Health Care Foundation (CHCF). *" Are we living in Hope, relying on the Hype or are we on another Road to Hell?"*