

The Two Weeds. Understanding the concept of Denial in the world of medicine and its relevance to the PCEHR.

In this edition we are going to investigate historical issues that are critical to any success of an e-Health system in Australia and provide warnings that there is an enormous potential to get it wrong by not observing or learning from "history".

In a historical context, within the world of health informatics, it would be impossible to ignore the vision, research and discoveries of a colleague of mine, Lawrence Weed whom the *InformaticsInsider* first met in Canada, 1989.

Dr Weed is a pioneering figure when it comes to breaking new ground and having the genius of vision in health informatics and e-Health long before anybody had any idea of what it was.

The health informatics views expressed by Dr Weed over 40 years ago highlight both how far we have come in e-Health, however these views also crucially highlight what we seem to have forgotten to learn from health informatics and e-health history.

Historically Dr Weed and others worked from 1969 to 1982 at the University of Vermont to computerise the problem-oriented medical record (POMR).

As the *InformaticsInsider* has stated repeatedly in previous issues of the *InformaticsInsider*, this research has recognised that the mind of the physician, just like any human being, cannot effectively process the large amount of information received and knowledge to be accessed for effective clinical decision making. This has significant and often adverse effects on patient care.

The core component of Weed's work is to organise and pair the clinical data in a temporal fashion to make it more available to the physician. This led to the development of a commercial product called the Problem

Oriented Medical Information System (PROMIS) which was one of the first electronic medical records to implement support from other parts of the medical care delivery systems such as pharmacy and nursing.

Within the PROMIS system a patient's profile can be accessed at any terminal with little delay in the transfer of the information, making healthcare more efficient. This access to critical information and knowledge was facilitated through the use of the systems Problem - Knowledge Couplers (PKC) that linked medical knowledge to patient care. This knowledge coupling supports the clinicians' inability to manage the incapacities of the human mind to learn and know all that is required for appropriate care.

Another recurring theme from the *InformaticsInsider* is that technology is not the problem in health care delivery it is the information management. So using the technology with its limitations of that era, the PROMIS system used touch screen interfaces, real-time data and information displays, flow charts and the facility for clinician entered medical notes. These are some of the essential tools that have been previously described as being essential for effective Clinical Decision Support (CDS).

In Australia we are on the cusp of implementing a significant step in e-Health reform with the proposed national PCEHR so the *InformaticsInsider* felt it was timely and appropriate to record some of the historical and recent views by Dr Weed on health informatics and e-Health in 2011.

In January 2011, Dr. Weed and his son Lincoln published "*Medicine in Denial*" from which the *InformaticsInsider* has permission to quote.

For the *InformaticsInsider* "*Medicine In Denial*" documents what Leape revealed in his report five years after "*To Err Is Human*" that change is slow and the causes of this are multi factorial and span all levels of care delivery and are associated with burgeoning health costs and continued poor outcomes of care.

Dr Weed defines a number of core principles when dealing with health informatics that is focused on clinician behaviour and the patient;

- Teaching a core of behaviour instead of a core of knowledge. The latter being the core of most 'credentialling' programs in health education.
- 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.

In 1981 Weed also defined eight major points to be considered in addressing information management and knowledge access in health care.

The health care of an individual is the product of the efforts of many providers over a lifetime-care should be cumulative and maximally coordinated.

The patient's role on his own behalf should be central to the overall health care effort. The individual must work with a copy of their own health record and modern communication tools to make the right choices. *"The provider must only intervene when it is not possible for*

the patient to take care of themselves reliably."

Medical practice should NOT rely too heavily on human memory and analytical capacities and use e-Health tools for communication and knowledge coupling.

The e-Health tools should be reliable and capable of being kept up to date.

The uniqueness of the patient must be recognised and respected. Conclusions based on statistical analysis should NOT be allowed to override patterns of individuals regardless of how unusual these patterns (variations) are.

It does not make sense to license practitioners based on their undergoing didactic education and passing board examinations on the limited knowledge they temporarily learn. Students and practitioners need to access and apply knowledge, not to learn it.

Standards for medical practice should be regarded as accurate, up-to-date maps for all travellers through the health care landscape and should not impose a fixed sequence of action on a patient. Good standards will be met when each action can be defended within the context of a patient's life and with the best choices known to medical science at the time.

Corrective feedback loops in medical practice are essential and are not possible with tools that do not couple knowledge to clinical decision making.

Now let us look at the word denial and how it is relevant here. Dr Weed looks at denial within a medical perspective;

"A culture of denial subverts the health care system from its foundation. The foundation-the basis for deciding what care each patient individually needs-is connecting patient data to medical knowledge. That foundation, and the processes of care resting upon it, is built on the fallible minds of physicians. A new, secure foundation requires two elements external to the mind: electronic information tools and standards of care for managing clinical information."

This denial goes further especially into the public domain as stated by Dr Weed;

“Contrary to what the public is asked to believe, physicians (clinicians) are not educated to connect patient data with medical knowledge safely and effectively.”

From the *InformaticsInsider's* viewpoint after reading some of the extensive documentation from NEHTA on the PCEHR it appears that this 'denial' by clinicians is not clearly addressed or the "knowledge" supporting any "coupling" it is not readily accessible.

A crucial point one wishes to make here is that this is not about the "blame game" on clinicians which was clearly explained by Dr Weed in the late 1980s;

“...the reader should understand that front-line physicians... are not to blame for the disorder in which they find themselves. On the contrary, physicians are waging a daily struggle to overcome that disorder (information overload). But all too often their efforts are unequal to the task, even in cases where favourable outcomes ultimately occur. Some favourable outcomes ... are achieved at an unacceptable risk, suffering and cost. Some favourable outcomes occur independently of medical intervention....”

Therefore, and the *InformaticsInsider* is in total agreement, that the traditional concept of the 'learned physician' is not workable and is very applicable to what is happening in Australia from an e-Health perspective. This is highlighted by Enrico Coiera in his commentary in the *British Medical Journal* in June 2011;

“One compelling explanation (for the inertia in health reform) is that clinicians are in fact making the best decisions they can, in the face of multiple competing demands. Not everything that should be done can be done in a single encounter. Clinical encounters are constrained by time and uncertain or absent data, and clinicians juggle multiple problems, prioritising some over others.”

The *InformaticsInsider* interprets this statement as being not only a challenge to how we traditionally care for patients using antiquated recording and interrogating techniques but also the credentialing methods / examinations for certification.

In this complex modern environment the significance of emerging digital information technologies has become a major turning point in medicine's history. When used and designed appropriately these technologies remove the unworkable traditional role of the clinician so that safer better standardised care can be delivered.

Because technology appears to be a major element of the PCEHR focussed on the patient it is worthwhile considering analogies with other complex information rich industries where technology has been enormously beneficial.

This was very well put by Dr Weed in an analogous perspective with the airline industry between specialised airline workers such as pilots and physicians.

Considering the functions of an airline pilot that exists in a system that;

“...carefully defines inputs by workers with specialised expertise, and they function within and integrated system, every component of which is subject to strict scrutiny and control....pilots do not have professional autonomy. They function within a protective system that is meticulously monitored.”

This goes to show that it is an industry with very high levels of safety, expected by the public, and this is supported by corrective technological feedback loops so that individual and collective actions remain compatible with the common general purpose.

So with the PCEHR focussed primarily on patients and their inputs this project has the high risk of not addressing *“the medical content built into the minds of physicians (clinicians) which is unstable, unreliable, unknown to others and not subject to organised feedback and improvement.”*

This raises a further question;

Is there a relationship between denial, technology and improvement of care?

Looking at the views of the health care quality expert Dr. Brent James of Utah. Any digital e-health information management system must reduce inappropriate variation and document continuous improvement. These tasks are not possible with paper-based record systems as has been shown in the airline industry and evaluations of our existing complex information predominantly paper based health care.

This brings us to a crux that is well pointed out by Dr Weed, who concludes that with individualised medical problem solving the issues of complex problem solving will never be trustworthy or affordable until its parts and their connections are reformed in three key respects which can be aligned to the PCEHR in Australia.

- Inputs by practitioner (clinicians) must be carefully defined and controlled. (does not appear to be clearly defined nor achievable in the existing PCEHR documentation)
- A trustworthy and transparent intellectual infrastructure for care must be established.(also not readily decipherable from the PCEHR documentation)
- The central role of the patient/consumer must be recognised.(the core focus of the PCEHR)

So in conclusion the *InformaticsInsider* states that we need to retain the focus that

“medicine is not a business, our business is clinical medicine”. Clinicians need to be involved.

Finally we must always be aware that the correct focus for improving care is the

comprehension of the coupling between information and knowledge management in a health care environment. Which is aptly covered in a previous *InformaticsInsider*.

http://austemrs.com.au/files/informaticsinsider_may_2010_no_1.pdf

This is well put by Brent James;

“To the extent that insurers and providers both see the problem of the uninsured as a revenue problem-which is to say, there are all these people out there who aren’t part of our system, we need to find a way to buy them into our system at more or less the systems price, at more or less our systems configuration, and more or less maintain the incomes of everybody in our system-that is a very different question from how can we make the underlying asset more affordable...”

The asset referred to here is *“the delivery of medical care.”*

In light of these historical issues espoused over the last 30 to 40 years we must be mindful to remember that they are critical to any success of an e-Health system in Australia and provide judicious warnings that there is an enormous potential to get it wrong by not observing or learning from “history”.

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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