



Today, Tomorrow and Beyond

Michael Whitt

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Perspective:

I am a lawyer, patent and trade-mark agent, and have practiced law since before the personal computer. I have had decades of experience dealing with health informatics and the law, and have also developed expertise in the area of personal information privacy regulation. I am on the board of directors of both COACH and CHITTA. I practice law in Calgary, Alberta. This means I bring a “perverse” perspective to current issues in health informatics.

I recently had the rare privilege of co-chairing a conference on Electronic Health Records in Calgary, and the honour of delivering some closing remarks, and I thought I’d share some of my thoughts. Please don’t take any solace or meaning out of the presentation order, but the following ideas capture my attention when I think about healthcare informatics in Canada in 2008.

Complex Legal Environment:

From a lawyer’s perspective, healthcare information systems contracts involve multiple parties, complex systems, partially formed specifications, unclear implementation plans, unknown training requirements, very little experience in the community, fuzzy deliverables, immature regulatory regimes providing little guidance (privacy, interoperability, etc); and the legal team is usually brought in late. These deals are more “constitutional” in nature than “transactional” – they deal with ongoing and developing and changing relationships between many parties over extended periods of time, and with systems which go from embryonic through mature to end-of-life transitions, all of which must be captured in contractual terms.

A proliferation of information-sharing agreements is occurring, in an environment where one-to-one agreements are not well co-ordinated or tracked or managed, and in a setting where information-sharing has not previously been formalized due to an immature and inexperienced culture in the contractual management of data relationships. There are IT challenges, data challenges (structure, metadata, data synchronization and access, etc), accountability issues, and conflicting professional obligations and ethics. This is an interesting area for IT and IP lawyers as both.

Patient-centricity:

I’ve noticed a shift in the attention of health Informaticians from a focus on IT solutions providers to a focus on Healthcare services providers (e.g. institutional) to a focus on Healthcare primary care providers (e.g. physicians), and now it seems, to a focus on serving Patients. There is a tension around the locus of control of the process of automation of the delivery of health services. We are seeing Google and MicroSoft and others entering the Patient Portal business, and I think this follows the social movement known as “prosumerism”; although I’m not sure that the service offerings are quite ready for prime-time. This “prosumer” movement changes a lot of things, based on the end-user (beneficiary) “expectation set” about access, privacy, control, involvement, trust and choice - among other things.

Some examples: the Spanish province of Andalusia started by understanding and then modifying and working with citizen expectations of healthcare, and then designing its systems to meet those “end-user” expectations. The Calgary Health Region, under Bill Trafford’s coaching, started with a definition of goals and principles based upon rational citizen expectations of a 24/7/365 “healthcare utility system”, and is working from there toward satisfying those expectations.

Patient rights with regard to patient records, lock-boxes, control, ownership, access, all devolve to a discussion of trust - trusted advisors and advocates, and trust in systems.

Network Effects:

Over the past decades, we’ve moved from large IT infrastructure systems, e.g. “mainframe”, “time-share computing” etc., through an era of “personal computing”; now we are moving in a converged world to “cloud computing” where the Network IS the Computer, to coin a phrase. There is a tension between the fierce independence of individual stakeholders in these systems and the massive interdependence demanded for “cloud” computing.

At once stage, our goal was “the chartless office”. We now speak about “automated decision support systems” and “patient portals”. This speaks volumes

about the maturation of our conception of health informatics.

Data warehousing:

I see the de-silo-ization of data stores, large databanks with access to analytics tools, targeting utility of data-mining for chronic care, epidemiology, public safety, health policy, system efficiency, fraud detection, citizen monitoring, drug-test efficiency, private gain for stakeholders, private gain for third parties. There is a tension between data repurposing and social values. At a deeper level of analysis, these things will inevitably have some effects on things such as “trust” by consumers and operators of the systems, of each other, of the record, and so on.

Attempts to manage these large data stores are beginning to devolve to independent data governance structures and bodies, begging the question “independent of whom”? Governments are payors in this system, and physicians are ‘interested’ in a professional and a financial sense. This should be a hot and interesting debate, but it hasn’t been had in the open just yet.

Data warehousing also probably requires better data constructs or structures in order to be truly useful, and those may not have been invented yet. There will be a

layer, somewhere, of data interoperability translation/transformation, which may be an opportunity in IT-land. Data warehouse analytics (mining) will be nearly irresistible to marketers, systems efficiency, public health and other interests. It may give rise to a “tyranny of best practices”, and constrain caregiver behaviours and choice. It also may provide secondary revenue sources, the ownership or beneficiaries of which revenue may not yet be ascertainable.

We don’t have the principles we need in place to deal with some of the questions that this may raise, although we’re learning.

Physicians:

Tyranny of “best practices” – outcomes-based medicine sounds good, but...A common complaint amongst physicians within “managed care” systems has to do with constraints by payors on physician discretion with respect to tests, procedures, protocols, drugs, referrals, etc. Does this signal a loss of professional autonomy?

Physician adoption seems slow. There are tensions within billing structures and desired or required behaviours in a modern delivery system, issues with IT costs, controls and standards for systems, and no clear compelling choice of system or system type. There are

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matters of trust, control, compensation, subsidization, information sharing, ethics, and patient demands.

Ethical concerns at the College level may produce tension between the Colleges, the Medical Associations and the payors and acute-care institutional communities, with respect to ownership, access, subsidization control, and operation of large-scale EHR implementations.

Information Literacy – is there a need for physicians to obtain training, sort of a “health information system drivers’ license”? Is it malpractice to operate as a physician without having training in how health IT systems work, are limited, and fail, how to perform research, and information availability over networks? Should physicians be trained to operate, read, write to, and deal with automated systems, how to deal with UI (user interface) and Database flaws/shortcomings and search-engine styles and data trust issues which may cloud judgement or introduce cognitive errors?
- All interesting questions, entering the mainstream of Physician discussions.

Cognitive errors introduced by IT systems’ design:

There is a lack of good usability testing, a lack of statistical rigour in post-implementation review. There is discussion of “IT as medical device” for certification and licensing issues. There is a lack of training and awareness within the user community of the many ways that large systems and automated interfaces/displays can introduce cognitive errors, and how to deal with those environments to avoid errors during use as well as during design. We need to learn from the avionics, aviation, and automotive control people about how to optimize UI design and provide failure tolerant systems.

Effectiveness, Adoption, Accountability:

Canada is, surprisingly to me, a laggard in implementation. A recent EU study ranked Canada 30th out of 29 EU countries in terms of patient-centric measures such as service, wait times, convenience, and results versus dollars spent in the system.

There do not seem to be many good, peer-reviewed studies or reports with clear evidence of successful EHR or EMR implementations; nor does there appear to be much consensus on how to measure success of large-scale health informatics systems. We can start to be encouraged, though, as more informatics professionals begin to focus on IT systems as mere tools, useful in some aspects of delivery of healthcare services to populations of patients. I’m encouraged by adoption of models for healthcare IT systems more along the lines of always-on utilities rather than bank teller automation networks.

We are quite likely entering the beginning stages of payors requiring evidence of some improvement in population health and delivery of healthcare - beyond reductions of wait-times. How these questions will be

answered is as yet not clear; that is, there are currently only limited conceptions of how to measure success.

Demographics:

The maturation of the Health Information Technology (HIT) industry has resulted in an impossible-to-fix HR shortage (by the demographics) of HIT workers and health workers generally. There are unsettled training requirements, and a known but underestimated need for project management and business process analyst skills. These important issues now seem intractable, but are being dealt with through, amongst other things, increased post-secondary curricula and course availability, and things like the COACH HIP definitions and HITS programme.

Hope:

On a bright note, there are new tools which provide some assistance as we move forward:

- strong and reliable encryption technologies, large scale “automated trust” authentication systems and role-based security systems are growing up;
- IT security folks are developing into a professional group of trained specialists with doctrine and protocol, thought constructs, and improving theoretical approaches to risk management and mitigation;
- statistically provable anonymization engines are available, which makes some types of privacy-respecting data sharing feasible;
- new models of conceiving of system design,
- the increased involvement of trained project management specialists, and (not least important)
- the continued predictive effectiveness of Moore’s Law.

There are also new ways of thinking about these issues, as we begin to understand more about network effects on data, data security in the “cloud” environment, personal data privacy as a “built-in” item, and the expansion of the “circle of care” to include more parties, not just front-line caregivers, but a broad constellation of assistive technologists in healthcare, information and communication roles. ●