



Revera i3
Visiting Fellow
on Patient Engagement
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After-visit report & plan

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THE REVERA i3 VISITING FELLOWSHIP ON PATIENT ENGAGEMENT WAS A JOINTLY SPONSORED OPPORTUNITY TO RAISE REVERA'S PROFILE AND COMMITMENT TO "DIGITAL HEALTH TO UNLEASH THE POTENTIAL FOR ALL NEW ZEALANDERS," IN PARTNERSHIP WITH HIGH-PROFILE ALLIES FROM WAITEMATA DHB AND THE HINZ TECHNICAL SOCIETY.

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Opportunity, purpose & activities

New Zealand is uniquely positioned to benefit from, and participate in developing, the potential value of combining e-health innovations with patient engagement. The country's evolving demographics, expanding infrastructure and widely dispersed population combine to set the stage for relevant innovations.

Aptly, this fellowship was a partnership between private sector infrastructure / innovation (Revera), government (Waitemata DHB and i3), and

technical workforce (HINZ). Revera's infrastructure is enhanced by its cloud platform for integration of data from diverse sources. Waitemata DHB is at the forefront of Digital Health and patient engagement in NZ, and HINZ is New Zealand's meeting place for digital health, providing a neutral and constructive environment for information sharing. Never in my travels have I encountered such a relevant partnership.

Empowerment, paradigm change & engagement



In considering this report I found it important to set the context by explaining clearly what I've seen in my travels about the emerging world of patient empowerment and engagement. Much has been said about these concepts but little has been formally developed into anything methodical, on which programs can be built. This section will explain some of this context.

One key definition is important at the start: 'e-patient' is a term created by 'Doc Tom' Ferguson, founder of the e-patient movement. In the 1990s he used it to describe patients who were online – 'e-patient' is to 'patient' as 'e-mail' is to 'mail.' Later, as nearly everyone got online, he came to say that the 'e' meant empowered, engaged, equipped, enabled, educated, etc. After his death, in 2009 his followers created

the Society for Participatory Medicine, whose site says Tom "envisioned health care as an equal partnership between e-patients and health professionals and systems that support them." This is precisely aligned with our vision for New Zealand's health system.

In short, e-patients are proactively involved in their health, understanding as much as they can, thinking for themselves, setting their own goals, and taking informed action, all in partnership with their clinicians. At his death Ferguson was working on a manifesto, funded by Robert Wood Johnson Foundation, which his colleagues finished after his death. In its closing chapter, *The Autonomous Patient and the Reconfiguration of Medical Knowledge*, he quotes Angela Coulter's book 'The Autonomous Patient':

We must redefine the patient's role to emphasize autonomy, emancipation and self-reliance instead of passivity and dependence.

THESE KEY TERMS 'EMPOWERMENT', 'PARADIGM CHANGE', AND 'ENGAGEMENT' REQUIRE CLARITY.

EMPOWERMENT

After years of seeking a good working definition of empowerment, I found one at a 2013 conference. Tellingly, it was presented by a chronic disease patient!:

Empowerment is increasing the capacity of [people] to make choices and to transform those choices into effective actions and outcomes.

It's the definition the World Bank has used since 2002 when they go into a developing nation where the citizens have no capacity to take effective action. This nicely models what we hope to achieve with New Zealand citizens: increase their capacity to take effective action.



A 1991 precursor paper recently came to light, from the discipline of Performance Improvement:² ‘Empowerment: In Search of a Viable Paradigm’.³ The paper speaks of “the totality of behaviors that are actually available to a given person” and says “An individual is empowered to the extent that he or she possesses a rich repertoire of behaviors and is expected and permitted to make full use of this repertoire.” Note the emphasis on society wanting and welcoming the behavior. If the behavior is discouraged, the individual is disempowered, just as the World Bank’s definition suggests.

The most touching and humbling moment of the fellowship week came when a member of the Head and Neck Cancer patient community at North Shore Hospital said, after an informal discussion with them, “Thank you. I never knew

I could have any power.” She had clearly just experienced her personal awakening into a new, empowered persona, willing to think for herself, make choices, and strive to take effective action.

If we want to increase competence of all citizens in managing their health, these definitions spell out that we want to increase the range of behaviors available to them, to achieve the health outcomes they want, and develop their ability to do them, in partnership with their clinicians.

1. Fulvio Capitano, a Parkinson’s patient, at the World Parkinson Congress, Montreal, 2013
2. Performance improvement, e.g. International Society for Performance Improvement, is “a systematic approach to:
1) Assess a need or opportunity; 2) Identify causes or factors that limit performance; 3) Design solutions; 4) Develop solutions; 5) Implement the solutions; 6) Evaluate the results”
3. Putman, A.O., Performance Improvement Quarterly



Note something distinctive about these

sources: neither comes from within medicine.

That reflects part of a dominant paradigm, which has limited patient contributions.

It's worth examining what a paradigm is.

PARADIGM CHANGE

The definitive book on paradigms is Thomas Kuhn's 1962 classic *The Structure of Scientific Revolutions*, which Ferguson also cited. Kuhn analyzed how paradigms evolved through history in numerous sciences: physics, chemistry, astronomy, electricity, etc. Kuhn said a paradigm

is an agreement by practitioners of a field about the important concepts in the field, which in turn leads to agreement on what questions are worth asking. A simple example is $F = ma$, in which the key concepts are mass, acceleration, and force, with a well defined relationship.

A PARADIGM PROVIDES THE AGREED MODEL FOR EXPLAINING ANY OBSERVATION, AND FOR PREDICTING WHAT TO EXPECT FROM A PROPOSED INTERVENTION.

It's easy to see that if a paradigm is out of date, our eyes will be closed to new possibilities. This is, for instance, why an outdated paradigm of woman led earnest thinkers to believe women could not hold positions in professions or government.

Medicine's history reflects several implied paradigms. Long ago diseases were thought to be a function of the "four humours," then autopsy revealed the relationship between organs and disease, then germs were discovered, then DNA, etc. Importantly, when a paradigm is missing an important factor, all attempts to design solutions will be to some extent grasping in the dark. This was the case with addressing disease or preventing infection before germs were understood, or treating cancer before it was known to be DNA damage.

Similarly, to re-engineer the relationship between patient and clinician, we need to re-examine our paradigm of how value is created in the

clinical relationship. The old paradigm says value derives from clinician contributions, sometimes involving compliant patients. This paradigm could be summarized thus:

The traditional model of medicine is that doctors, with their valuable education and clinical experience, know everything that's worth knowing in healthcare, and citizen-patients, lacking that training and experience, do not and cannot.

Today we know that this is not the only path to value, and we seek to improve healthcare by adding the contribution of the stakeholder who's been missing from the model: the patient. When patients are informed and empowered as defined above, they can act in new ways, resulting in openings for patient engagement.

But this term, too, is subject to mixed interpretation and paradigm errors, so let's examine it.

ENGAGEMENT

In paradigms, definitions are important. The term patient engagement is potent but loaded with peril, because it's used loosely without careful definitions, so varying statements cannot be evaluated and compared in a consistent framework.

Indeed, when the policy journal *Health Affairs* ran a special issue in February 2013 titled 'New Era of Patient Engagement', at least three definitions were implied by different articles, and even the editors didn't notice or comment on it. One article spoke of patients engaging at all levels of the health system, from visit to governance (the fullest model), but the pharma article only spoke of engagement as getting patients to take their pills as directed and buy more. (At the press briefing about the special issue, that author said he'd given up on patient engagement!)

To get anywhere in designing solutions that can succeed, health system designers must settle on a model that suits the task.

More on this above right.

'The blockbuster drug of the century': The most quoted statement about patient engagement is that it's 'the blockbuster drug of the 21st century.' (Kish, 2011) Subsequent analysis, though, suggests that as with an actual drug, designing for best potential requires understanding the application, the mechanism of action, and the specific benefits achieved. Early work is just beginning and not yet well organized, but it's possible to point to early learnings. The most important is this: properly understanding engagement's potential requires a paradigm change.

The model 'only physicians can know anything worth knowing' puts all the burden on the clinician, and robs patients of both responsibility and opportunity for self-determination – autonomy. That paradigm has never been formally declared, but signs of it are everywhere, anytime a patient or clinician assumes patients can't offer anything useful.

To be fair, the disempowering model has a historical basis: before the internet, it was indeed hard for patients to know anything useful. But those days are gone, and what we lack is the knowledge and tools that can produce realistic engagement today.

'Knowledge is power' makes that paradigm obsolete.

Three profound shifts in the genesis and flow of knowledge have occurred in the past generation have render the paradigm obsolete.

- First, the internet (particularly the Web) vastly amplifies the liquidity of medical information: knowledge can now flow to a point of need thousands of times more easily than in the past.
 - Since knowledge is power, it's now possible for patients to have more power than in the past. It doesn't make them doctors; it does make it possible for them to bring valuable knowledge to the conduct of their case – if they know it's possible and if they know how.
 - This is where additional work can be done to turn the potential into reality.
- Second, the genesis of apps and sensors means today it's possible for patients to have information their doctors don't have (yet). When used properly, this can enable patients to take important action without necessarily waiting for a physician.
 - Ideally, a new infrastructure will mean clinicians do have real-time access, which will further amplify the partnership's potential.
- Third, the internet has enabled patient networks to arise, in which patients with a condition can connect with each other, letting patients share both clinical information and emotional support, peer to peer, outside the clinical relationship. This puts an end to exclusive dependence on the clinician and lets patient peers choose their own priorities and values a step toward full autonomy, sometimes declaring new priorities or sources of value that researchers have never discovered.





IT'S NOT JUST THE TECHNOLOGY: ROLES MUST SHIFT.

It's easy to see, then, why the old paradigm would not think in the concepts used by the World Bank ("making choices") or Performance Improvement ("expected and permitted to make use" of a "rich repertoire of behaviours.") Why would such behaviour make sense, if clinicians are the source of all wisdom? In the new paradigm, clinicians are still the experts on the craft of medicine, but the paradigm of patient shifts radically: the patient is capable of knowing useful things, thinking autonomously, and taking effective, self-directed action.

The new infrastructure, and its impact, are summarized in the one minute animation in my 2015 BMJ essay 'From Patient Centred to People Powered: Autonomy on the Rise.'

Such change doesn't happen just by giving people tools, nor even telling them they have choices. Patient engagement is a cultural change, which must be activated and must grow into new patterns of practice, enabled by technological change.

The technological change spans low-level infrastructure (the internet) and higher

layers that touch on workforce and data flow. Change is already starting in small ways locally, as we saw during our site visits. Achieving the ultimate potential will require replicating these local successes at scale. To do that will require teaching and encouraging new behaviors among all stakeholders: patients, clinicians, vendors and government. That will, optimally, be accompanied by technical evolution, re-tuning the data flows and use of apps to collect and distribute the information that lets citizens achieve their potential, and lets clinician expertise be distributed to the point of need, serving dispersed populations across wide geography.

LAST-MINUTE UPDATE: While this was being written, a new column appeared in the New England Journal of Medicine: 'What Gives Us the Right to Empower Patients?' A key passage: "instead of 'empowering' users for a preset goal, we should let them determine their role in this program." That's self-direction.

These definitions set the context for my observations from this week-long fellowship.



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Observations & recommendations

CULTURE

New Zealand's culture is well suited to encourage a shift toward participatory thinking. While local newspapers and blog comments show no shortage of disagreement, people in general seem more aligned than some countries to move forward together. I was also struck by the conspicuous sense of mutual respect between the European culture and the Maori, and the obvious 'stew' of mingled races and origins.

TECHNOLOGY

The new e-health infrastructure and app environment sets the stage for all kinds of new opportunities for citizens to collect or generate valuable information. We have much to explore in this area.

In particular, telemedicine: The dispersed population, and openness to innovation, create a fertile opening for telemedicine. The July article about Maori physician Lance O'Sullivan's virtual

clinic in Patea is an excellent example. Tellingly, while some comments on the article criticized the lack of an in-person physician, people who actually live there expressed relief about the innovation. Note, too, that this intervention is wisely limited to simpler cases, correctly illustrating that telemedicine provides a certain tier of care, dispatching some cases without the burden of face to face visits, while leaving the more demanding cases for traditional visits.

The introduction of a new national EHR presents a chance to do things right from the beginning. Experience in the US has shown overwhelmingly that when patients have full access to their visit notes (so-called 'open notes', OpenNotes.org), many benefits accrue. Since knowledge is power, an essential part of empowering patients to act effectively is to offer access to their complete record.

I fervently hope the implementation of such a system will include an open API to receive

data streams from medical devices such as the Kardia AliveCor, wi-fi bathroom scales and home blood pressure devices, and data from fitness apps. We don't yet today have evidence of their benefits, but it's infinitely easier to leave the door open for such data when in the early stages of planning a system.

PRESENCE OF, AND READINESS FOR, E-PATIENT BEHAVIOR

An exemplary patient engagement case study presented itself during our trip to Rotorua, reinforcing that New Zealanders may be culturally ready. Rotoruans Ryan and Julia Portsmouth, innkeepers, contacted us about how their intervention on their newborn's case may have saved the child's life, as they spoke up in an empowered way and brought new information to the case. Importantly, after the immediate drama had finished and the Portsmouths wrote to Starship management, their argument was accepted, and Starship has changed its protocol for similar patients in the

future. This seems to be an exemplary response, again suggesting an amenable culture.⁴

The Head-Neck Cancer patient community at North Shore Hospital is a classic example of an e-patient community, the kind whose input helped save my life⁵. The development of additional communities of this sort can provide great peer support and knowledge sharing. As a teaching tool, an excellent new ten minute video on this, 'When it Comes to Health, Your Community May be Your Superpower', was published on Dec. 8 by my colleague Susannah Fox, the well known social observer, former Chief Technology Officer at the US Dept of HHS and former health researcher at Pew Research.

4. This is not to say that everything is perfect; there were indeed problems in the case, as there are everywhere in the world. The point is that in the end, the hospital open-mindedly examined the case and agreed that the family's observations added value – a truly participatory response.
5. I have become a member of their Facebook group, and had the chance to recommend them to a U.S. colleague whose husband has just had a throat cancer diagnosis.

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Impressions & next steps

I've not yet encountered a better country for implementation of the thoughts expressed in my book 'Let Patients Help', which I co-authored with my GP, Dr. Danny Sands.

The book lays out ten fundamental principles for understanding participatory medicine, ten areas of action, and numerous specific things doctors can do or not do to encourage or discourage engagement. It's intentionally a short book but it covers the landscape and earned a hearty endorsement from Dr. Eric Topol, who wrote its introduction.

On this trip our ability to survey the country was limited by available time and funding, but clearly we covered the ground well and gathered strong impressions, and it's exciting to think of further engagements for a methodical assessment of the country's status on these sociological factors, as the enablers of achieving the potential of New Zealand's growing digital infrastructure.

As one possibility, we could create a program for any or all of these over a period of years:

- Thoughtfully assess together (over several months) New Zealand's status on all of the factors spelled out in Let Patients Help.
- Select which of the factors would be most relevant and amenable to improvement by participatory medicine, to advance the country's status, via some intervention we believe is readily accessible.
- Design and prioritize a set of initiatives to produce measurable change in ways that clinicians, government, and patients would find most valuable and relevant.
- Brainstorm, perhaps with the other DHBs, additional interventions to improve citizen access to information.

- Collect patient stories from all over the country that illustrate the value of activated patients and the value achieved when doctors welcome them.
- Develop training for all affected stakeholders, including health IT workers, DHB staff, hospital and office staff, as well as patients, on the new world of patient power and participatory medicine, enabled by good use of technology.

Ideally this work would culminate in presentations at next year's HINZ; I can easily envision a patient engagement track (stream). How much of the above may have already been implemented in pilot projects would be a subject for stimulating discussion. Should we, or could we, offer to manage that track, organising speakers and designing a cohesive thread?

Thank you again for the opportunity to visit this fascinating country, meet so many residents, and learn so much. I look forward to more.

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