

PRIVACY, AND OTHER E-HEALTH LEGAL ISSUES, FROM A CONSUMER PERSPECTIVE

Medical Law Conference

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MAKING COMPLEX ISSUES SIMPLE

AGENDA

SCENE SETTING

- Health challenges – the big picture
- Communications Technology – its role in the solution

PERSONAL ELECTRONIC HEALTH RECORDS

- Overview
- Privacy issues

TELEHEALTH

- Background
- Legal issues

SECTOR TRANSFORMATION

A BIT ABOUT ME

- Background as a business lobbyist, most recently 1999-2010: TUANZ (Telecommunications Users Assn)
- 2010-present: consultant in Digital Economy
- Relevant work has included:
 - Chaired NHITB Consumer Panel 2010-12
 - Led the Telehealth Demonstration Project in Tairāwhiti and BoP 2013-15
 - Continuing to work actively in telehealth field

HEALTH CHALLENGES – THE BIG PICTURE

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- Aging population
- Aging health workforce
- Exponential advances in medical science
- Ever-increasing expectations by health consumers – sometimes unrealistic
- Health budgets everywhere groaning under the strain
- Add these together and we have an unsustainable system in its current form

COMMUNICATIONS TECHNOLOGY – ITS ROLE IN THE SOLUTION

The face of health service delivery is starting to be revolutionised by the combination of:

- Telehealth (video, remote monitoring)
- Consolidated personal health records on line and accessible to the patient
- Greater health literacy

COMMUNICATIONS TECHNOLOGY'S ROLE IN THE SOLUTION

- Globally, health is still a decade behind other sectors in embracing the capability of the information age
- However, it has started to catch up rapidly in the past 5 years.
- Overall NZ is doing as well, or better than, most
- But we are doing two things badly:
 - working in silos, and
 - Insufficient attention to the crucially important element of privacy

PERSONAL ELECTRONIC HEALTH RECORDS

PERSONAL ELECTRONIC HEALTH RECORDS

- A massive task, impressive progress made
- Extremely positive for the system & consumers
- The PEHR is dependent on coordinating numerous sub-systems; this has been a giant task technically and politically, and in general is being done very well
- Patient portals are the icing on the consumer cake



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Patient portals

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Patient Portals

Patient portals are secure online sites, provided by GPs, where patients can access their health information and interact with their general practice.

Benefits

Patient portals give people convenient and secure electronic access to their health information, increasing their ability to manage their own health care

Portals can allow patients to:

- request repeat prescriptions
- book appointments

Related

[Ministry
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Portals can allow patients to:

- request repeat prescriptions
- book appointments
- see their lab results
- see GP's clinical notes
- see their current diagnosis
- see a list of their medical conditions
- see a list of the medications they are on
- see their immunisation and vaccination history
- receive reminders and recalls from the practice team
- send and receive secure messages to and from their GP or nurse.

Implementation

PEERSONAL ELECTRONIC HEALTH RECORDS

- The scope of data contained in personal records will inevitably increase over time – everything written into a record today must be assumed to survive or outlive the patient and to be accessible to a wide range of people

PERSONAL ELECTRONIC HEALTH RECORDS

- Who might see a person's electronic record?
 - The patient's GP, and their practice nurses
 - Specialists who see the patient during their life
 - Pharmacists
 - Medical receptionists
 - Allied health services – physio, testing labs, etc
 - Health researchers, and people they employ
 - Pharmacy staff
 - Health system auditors/administrators
 - Social workers (e.g. Vulnerable Kids programme)

PERSONAL ELECTRONIC HEALTH RECORDS

- This level and range of access is vastly wider than in the past
- This requires privacy protocols, training, and enforcement to protect consumers

PRIVACY: BACK TO FIRST PRINCIPLES

The concept of doctor-patient confidentiality:

- derives from English common law
- is codified in many states' statutes
- is based on ethics, not law
- goes at least as far back as the Roman Hippocratic Oath taken by physicians
- is different from “doctor-patient privilege,” which is a legal concept.
- is fundamental to patients' expectations

Consolidation into a single electronic file is game-changing

WHAT IS THIS DOING TO PRIVACY:

- Hypocrates failed to factor in the Internet
- Personal Electronic Health Records interfere with the expectation of confidentiality by requiring clinicians to record sensitive data in a common database without knowing who might access it now or in the future
- That **IS NOT** an argument against such records
- But it **IS** a reason for implementing robust protections for consumers from the outset
- This has not been done

WHO WORRIES ABOUT PRIVACY OF PERSONAL HEALTH RECORDS?:

- People who have been treated for sensitive issues – eg mental health, sexual health, domestic violence
- People who require complete anonymity
- People who feel that some detail of their health history, if revealed, could result in financial, social, or relationship harm
- “Private people”

PRIVACY – WHAT DO CONSUMERS EXPECT?

- Health IT Board Consumer Panel developed a list of requirements after extensive public consultation in 2011/12. Key elements:
 - Goal – nobody ever avoids treatment because of confidentiality fears
 - A single national authority responsible
 - A national consumer charter
 - Consumers can access an audit trail
 - Comprehensive and open review of research and non-clinical uses before electronic records launched
 - Common nationwide rules on when any person can/cannot access a file including close associates
 - Common penalties consistent with IRD data
 - A common training regime and signed undertaking

PRIVACY – WHAT DO CONSUMERS EXPECT?

- That initial paper has bounced among the Consumer Panel, various health sector groups, and Ministry staff for the past 3 years
- It has expanded from 2 pages to 9
- There is an expectation it will go out for consultation at some stage (noting that it was founded on the extensive consultation in 2011/12)
- But since 2012, aside from talking and wordsmithing papers, none of these safeguards have been implemented to adapt the health privacy regime to reflect the new ways personal health information is shared. We are no further ahead than 3 years ago.

TELEHEALTH

- What is telehealth? Many definitions – not always helpful ones! Examples:
 - 1 Any usage of any element of telecommunications as an enabler of clinical or managerial communication involving health services
 - 2 Video consultations in which there is a patient present, and remote monitoring of patients' conditions
 - 3 Anything in between the above
- “Telehealth” is understood in the sector, but for public understanding we are learning to talk about “Video Doctor Services” or “Remote Monitoring” or “Video Outreach Clinics.”

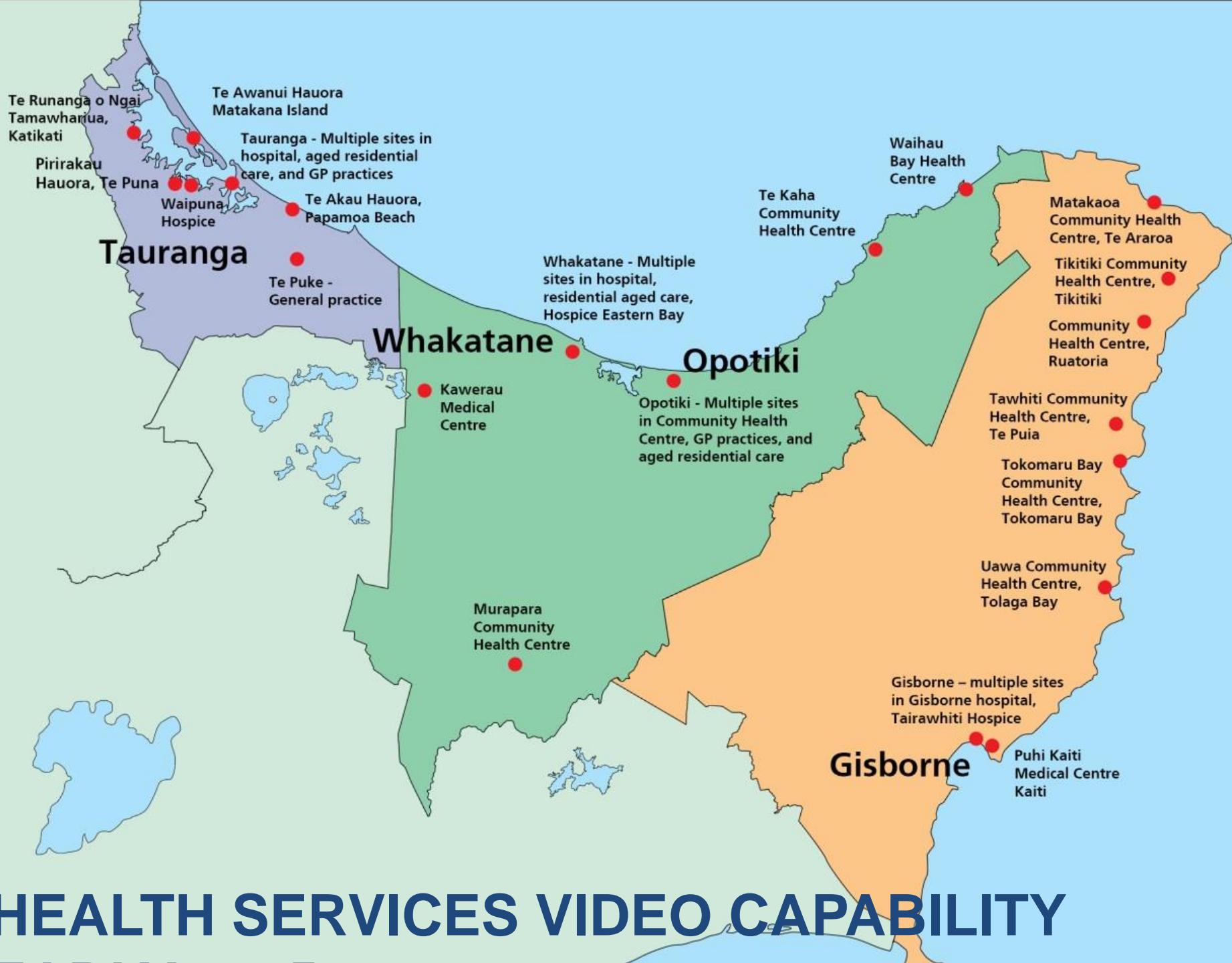
SIMPLY PUT: JUST ANOTHER COMMUNICATION TOOL

- Telehealth is just the incorporation of video communication into day-to-day workflows and practices – just as phones, faxes and mobiles have found their place over time.



THE TELEHEALTH DEMONSTRATION PROJECT:

- Idea spawned in MBIE – Ministry of Business, Innovation and Employment – responsible for government broadband investment and wanted to understand how health delivery will benefit
- Supported by National Health IT Board – part of Health IT Plan
- BoPDHB selected as partner due to demographics, innovation culture, and existing telehealth footprint
- Tairāwhiti District Health joined early 2014
- Focused on the use of video communication for clinical consultations between health professionals and patients, outside the DHB.



HEALTH SERVICES VIDEO CAPABILITY

KINDS OF TELEHEALTH SERVICE

- **Video Outreach Clinics**
- **Video Doctor Services**
- **Emergency Support**

EXAMPLES:



A healthcare professional with glasses and a dark t-shirt is seated at a desk, smiling while looking at a computer monitor. The monitor displays a video call with an elderly woman with blonde hair. On the desk, there is a black keyboard, a black mouse, a black telephone, and a black webcam mounted on top of the monitor. To the left of the monitor, there is a stack of books including 'GRAY'S ANATOMY' and 'MIMS', a small white stuffed animal, and a black device. The background wall is covered with various posters, including one titled 'HEALTHY SKIN' and another titled 'Protect YOUR CHILD'. The text 'VIDEO OUTREACH CLINIC' and 'Church Street Surgery, Opotiki' is overlaid at the bottom of the image.

VIDEO OUTREACH CLINIC

Church Street Surgery, Opotiki

VIDEO OUTREACH CLINICS

- Hospital-based services being delivered to patients in outlying communities
- Examples:
 - Diabetes, Tauranga hospital to Opotiki practice
 - Diabetes, Gisborne Hospital to Te Puia and Tokomaru Bay Hauora
 - Mental Health - Christchurch specialist with Tauranga patients, and Gisborne hospital with Ngati Porou clinics
 - Renal, Hamilton Hospital to Whakatane Hospital – now contemplating similar service to Fiji
 - Pacer clinics Tauranga Hospital-Whakatane Hospital ready to begin July 2015

VIDEO DOCTOR SERVICE:

- GPs consulting patients in hard-to-reach communities by video
- Examples:
 - Te Awanui Hauora on Matakana Island, with Te Akau Hauora at Papamoa Beach – later joined by Katikati and Te Puna
 - Ngato Porou sites – patient at one clinic with GP at another





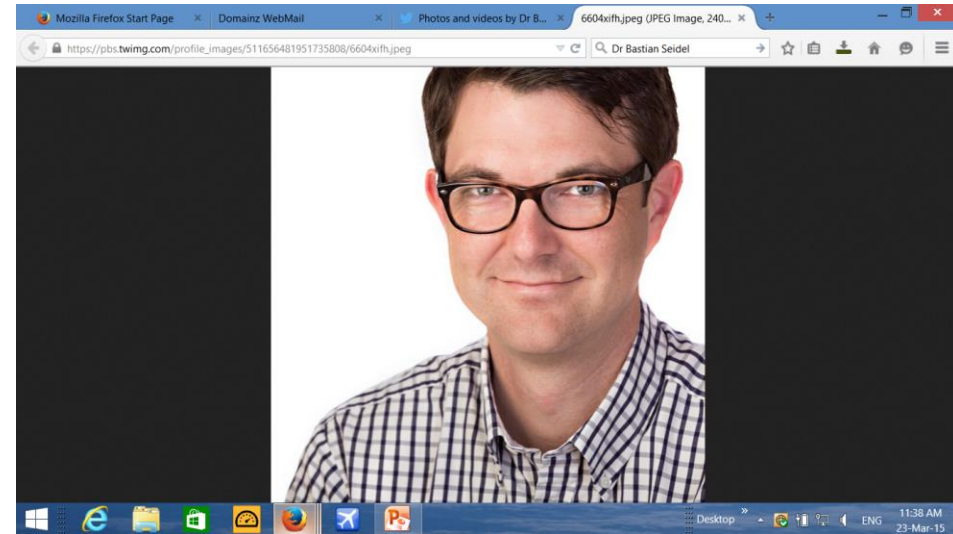
Emergency support

TELEHEALTH ELSEWHERE

- NZ: Lots of isolated pockets; for example:
 - Northland – Kaitaia Hospital support from Whangarei
 - Pediatrics based in Starship
 - Dermatology – Dr Amanda Oakley, Waikato
 - Multi Disciplinary Meetings in several regions
 - Canterbury support for West Coast
- Global: Some international exemplars:
 - Veterans Affairs USA
 - Flying Doctor Service, Queensland
 - Alaska – support for isolated areas
- Huge Potential to Explore
- Innovation can come from many sources

- “By 2020 the majority of GP consultations will be by telehealth”

Dr Bastian Seidel, GP, Huon Valley, Tasmania, speaking at the Australian Telehealth Conference in Melbourne, March 2014.



OTHER LEGAL ISSUES ARISING FROM TELEHEALTH

- Need to ensure legal protection for a clinician who places reliance on another clinician in a telehealth setting
- Need to review the Mental Health Act which in some circumstances unnecessarily requires that a face-to-face presence is required for certification
- Need to clarify and authenticate the use of video as a legitimate and effective clinical communication tool within its obvious limitations – Medical Council statement is a good start
- **OVERALL:** Legislators in the health and related sectors need to lift their pace to match or beat that of the new technologies coming on stream

SECTOR TRANSFORMATION:
How can we move ahead faster?

SECTOR TRANSFORMATION

- We are in exciting space with massive scope to modernise health service delivery to meet the daunting challenges we face
BUT:
 - This is the hardest sector in which to achieve change
 - We need an ongoing top level conversation bringing together all the opportunities – technology, workforce, medical science – to replace the current silos
 - Clinicians must be fully engaged but are not the only party with a stake
 - Privacy changes must precede new initiatives, not vice versa
 - Telehealth must be driven by the designers of the system and the big spenders – not left to IT departments

IN CONCLUSION – A CHECKLIST:

IN SUMMARY

- Communications technology is on the cusp of revolutionising health services as it has done for financial services and others
- NZ is a global leader in this movement
- Privacy must be designed into the system, not added later
- The legislative process has to start moving at Internet speeds
- Fences at clifftops are a one-off cost; ambulances at the bottom cost money forever
- The direction of telehealth needs to be progressed as part of a holistic suite of opportunities for service modernisation and not in isolation.
- Lets get aboard this movement and give it more sunlight!

Thank you

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