

The journey of patient portals in New Zealand general practice: early learnings and key challenges

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Since first proposed by the National Health Information Technology (IT) Plan in 2010, New Zealand has embarked on a patient portal journey. The Plan was a roadmap towards an integrated healthcare system enabled by health IT and included a goal that all New Zealanders would have electronic (e) access to a core set of personal health data.¹ This core set is mainly held by general practices that are highly computerised, receive e-laboratory and hospital discharge data and use e-referral and web-based decision support functions. In the ensuing years, several software companies developed patient portals as an additional function within existing patient management systems.² These applications integrated with health provider electronic health records, allowing patients a secure internet entry point to view their health information, facilitate patient-provider messaging and provide other functions such as requests for repeat prescriptions and booking appointments. Through portals, patients could also potentially access information on their current diagnoses, medications, test results, immunization history, alerts and allergies and past events such as hospital discharge summaries, specialist letters and consultation notes.

Portals have been adopted in many countries including the United States (US), United Kingdom (UK), The Netherlands and Scandinavian countries although impetus for implementation has varied. In the US portal implementation has been largely driven by a competitive health market and health IT incentives via 'Meaningful Use' of health IT policies.³ The NHS England had a different approach with a 2016 mandate that their GPs register for portal use 10% of the patients by March 2017 and 20% by March 2018.⁴ As of July 2017, 78% of English practices had 10% or more patients enabled for online access (R Sullivan,

personal communication, Patient Online UK 2017).

So where are we up to?

New Zealand did not incentivise or mandate the implementation of patient portals. Instead in 2014, \$3 million was set aside for Primary Health Organisations (PHOs) to develop portal implementation plans for their member practices and seven early adopters (six of whom were GPs) were appointed by the Minister of Health as e-health ambassadors to support uptake in general practice.⁵ In the three years since, portal uptake has been remarkably rapid; 47% of New Zealand general practices have now implemented a portal with 407,049 patients registered (representing ~10% of the New Zealand population over 18 years).⁵ Portal adoption as a contributory measure to some of the regional health alliances' system level measures will support further uptake.⁶

However, all new technologies and interventions can increase population health disparities due to differential uptake. Monitoring the registration and use of portals by age, gender, ethnicity, deprivation and geography will be important. At present these data are not routinely collected and available at practice, PHO or regional level.

What are the lessons so far?

Portals represent a new partnership between patients and providers and this change is developing and maturing. In an era of Facebook, TradeMe, internet banking and booking travel on-line, there have been few reports of difficulties for patients using the portals. While patient experience so far is limited, a qualitative study focusing on rural New Zealanders in this issue⁷ concluded that while patients were variably engaged with different portal functionalities,

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they readily accepted the technology and were enthusiastic adopters. Benefits described were improving access and understanding of laboratory results, knowing the availability of appointments with their preferred doctor, the ability to obtain an appointment in the middle of the night when sick and being able to get a repeat prescription rather than have to make an appointment.⁷

Providers have overcome many challenges of portal implementation including the development of new policies and governance, satisfying privacy and security concerns and working through the need to develop parallel work processes within practices for online versus traditional practice interactions such as booking appointments, prescription refills, and the ability for patients to view their laboratory results and securely message the practice. Applying the 80:20 rule, portal implementation is at least 80% a socio-cultural, role and work flow adjustment and 20% a technical intervention.⁸

New Zealand reports of consumer and practice issues with portal functions have been rare; ~2 patient in 1000 patients get alarmed by results that are essentially 'normal' or expected but outside of laboratory ranges (personal communication R Medlicott, 2017); 1 patient in over 125,000 may inappropriately book multiple daily or weekly appointments (personal communication C Driven, 2017). Acknowledging the considerable upfront costs of change (eg person-time needed to register patients), for the most part the benefits have outweighed concerns in terms of patient satisfaction and convenience, safer results handling and time saving (e-health ambassadors have reported that for every 30 portal appointments booked, this saves an hour of front desk time).

What are the next key challenges?

The next key challenges in the portal journey are opening up consultation notes to patients and tackling the complexity around access for youth.

While a patient has a fundamental right to see all their medical records, the prospect of opening up the electronic patient record, especially the consultation or visit notes, is a major patient-provider relationship change that has many GPs

alarmed and apprehensive. If the functionality is turned on, the portal facilitates electronic patient notes to be shared anytime, anywhere with registered patients outside of the practice and without face-to-face conversations with their doctor or nurse. Doctors have been concerned that access to visit notes may cause patients to be unduly alarmed, confused or anxious.^{9,10} The notes serve (among other functions) to remind doctors of their patient's unique characteristics, and medical history, outline possible differential diagnoses (including worse case scenarios) and possible strategies for action.¹¹ There are concerns about the security of patient on-line records especially for sensitive health issues.¹² The visit notes have traditionally been written for an internal practice audience and would require doctors and nurses to write their notes differently (and potentially take more time) if the audience widened to patients.¹¹ Doctors' notes tend to be highly idiosyncratic and may contain cryptic abbreviations and incomprehensible jargon. The fear is that this may lead to patient complaints or require increased time as patients raise concerns or seek clarification or potential liability issues.¹¹

The good news is that Open Notes project in US (a highly litigious health market) has found that these fears have largely not eventuated.¹³ This project and other studies have cited major benefits of open notes for patient-provider relationships, trust, improved patient-provider communication, greater engagement of patients in their own care, improved adherence to medications, self-management of chronic conditions, improved recording of drug interactions and allergies and follow-up of referrals and test results.^{9,12-18} Indeed, if patients are the most under-utilised resource in the health system, portals are a catalyst to a new shared working model. As e-patient David deBronkart said at the 2017 Health Informatics New Zealand conference, *'Let patients help. If one party has access to data and the other hasn't there can be no teamwork.'* Rather than passive recipients of care, access to their own health information allows patients to be engaged, empowered and equipped to deal with their health problems.

In New Zealand, an estimated 20% of practices with portals have opened up their patient notes often prospectively from a set time forward to

allow for a change in the documentation mindset. There have been no reports of issues with open notes access so far but this requires further evaluation.

The second challenge is youth access. Up to this point, portal registration has largely occurred for adults over 18 years. Assuming it is in the child's best interests, providing proxy access for parents or caregivers to access their children's health information on their behalf (and to look after elderly members of the family) is a logical next step. However, at some point this arrangement may not be appropriate. For example, when a five year old grows to be 15 and needs to confidentially discuss sexual health issues with their doctor. Therefore on-line record access will need to shift from parental access or shared parent-child access to independent portal access by a competent young person who may be less than 16 years old. While health information privacy and informed consent are not new, patient portals are a new medium for information disclosure and need to be considered within the same legal and ethical framework. In this issue of the *Journal of Primary Health Care*, Wong and Morgan-Lynch provide us with an approach to address portal access to health information for young people and point us to a resource to assist general practices.¹⁹

The New Zealand patient portal journey in general practice is in its early stages and holds much promise for new models of care. However we require more studies evaluating uptake, indicating how to use this technology more effectively and identifying applications that are especially beneficial to support health literacy, teamwork and long-term condition self-management.

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