Considering governance for patient access to e-medical records

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Open Sesame Study
Background

“Our eHealth vision is for New Zealanders and the health professionals caring for them to have electronic access to a core set of personal health information.”
PHR/portal definition

“... electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.”

Method

Aim: To examine concerns and attitudes towards giving people access to and use of their medical records

- 30 interviews
- Survey
  - 421 patients
  - 83 GPs

Interview topics
- Accessing the record
- PHR content, design, functions
- Organisational implications
### Who we interviewed

<table>
<thead>
<tr>
<th>Role/Constituency</th>
<th>Number of interviewees with role/constituency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient advocacy or consumer representative role for Health IT</td>
<td>5</td>
</tr>
<tr>
<td>GP clinical practice</td>
<td>7 (2 early adopters of portals)</td>
</tr>
<tr>
<td>DHB clinical practice</td>
<td>2</td>
</tr>
<tr>
<td>PHO, DHB, or professional Collegial role</td>
<td>12</td>
</tr>
<tr>
<td>Development of Advisory for Health IT policy</td>
<td>7</td>
</tr>
<tr>
<td>Evaluation of Health IT policy</td>
<td>5</td>
</tr>
<tr>
<td>Implementation of clinical data sharing Health IT projects</td>
<td>6</td>
</tr>
</tbody>
</table>
Uncertainty about nature and design of portal

- Continuum
- Extension of right to view
- Unknown territory

“...we’re changing the way in which we share the information, not what we’re sharing or the safeguards we put around it necessarily”.
Identity authentication, privacy and proxy

- Guiding principles and protocols
- Extension of Health Information Privacy Code
- Virtual profile
- Proxy

“As individual clinicians we don’t have the networks or the time or the skill to develop that well and we want to be developing consistency so we need those professional groups to really guide us in that area.”
New take on governance

• Existing scope, future extension
• National light touch vs collaboration
• Vendors and implementers
• NHITB to ‘at least come up with the bones of a standard patient portal.’
Discussion

Assumptions

- Primary care
- Invitation policy
- Role of registration councils

“Our eHealth vision …”
New developments

Health Information Governance Expert Advisory Group (HIGEAG)

The Health Information Governance Expert Advisory Group (HIGEAG) has been established to develop a health information governance framework for the New Zealand health sector. HIGEAG reports to, and advises, the National Health IT Board (NHTB).

The framework will help the Ministry of Health, district health boards, primary health organisations and service providers to manage the sharing of health information across the sector consistently and safely.
Patient access to general practice electronic health information and interaction with their health care team via patient portals

Guidance for PHOs and general practices
Governance input

Top down, bottom up, middle out

• Clinical input vs population/patient input
• Role of National Clinical Leadership Group and Consumer Panel
• Regulatory Councils
• National, regional, local
Next steps

**Further reports:**
“Impacts and design of patients’ access to their records: The consumer voice.”
“Methodological transitions in health informatics research: From in-person, pen and paper to online presence.”

Survey results
Organisational readiness and impact

**Next research step:** Ask the patients