Risk to privacy versus benefit of quality care: what do patients with chronic medical conditions choose.

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Use of patient-held paper-based & electronic-based portable health files (PHFs) to facilitate reliable health knowledge transfer among direct health-care providers and their consumer- patients: a clinical trial.



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Real Case Study

- 18 August 2004: Dr Lassere's private rooms
- New patient Mrs RI, 68 yrs,
- GP referral letter: date 25 May 2004
- Problem: pain in hands, knees, neck
- Medical conditions: diabetes, arthritis, hypertension, osteoporosis, thyroid disease
- Meds: Diabex, Pravachol, Lipitor, Atacand, Karvezide, Lasix, Zantac, Oroxine, Diamicron, Ostelin, Caltrate, Brufen, Voltaren,

Dr Lassere: "so you are on Atacand, ... for"

Mrs RI: "no, the heart doctor or was it my GP ... changed my tablets ... I'm not taking Brufen. And I'm now on a little white tablet for my heart"

Dr L: when did this happen?

Mrs RI: 6 weeks ago.

Dr L. "Why did you see a heart doctor?"

Mrs RI: "Because I had pain in the chest"

Dr L. "who is your heart doctor?"

Mrs RI: "I think I have his card here No I don't. My daughter can tell you .. She's at work now .. You can give her a call"

Dr L Why were the tablets changed?

Mrs RI: I don't know

Dr L: Did he think the pain in the chest was your heart? Or did he think it was from your stomach?

Mrs RI: I don't know.

And so on

Exam: Synovitis wrists, MCPJs, knees

PDx: Inflammatory arthritis? RA

DDx: pseudogout, seronegative RA, CTD, maligancy, viral

Investigations:

Dr L: "...I would like you to get these blood tests done"
Mrs RI: "More blood tests! But I just had blood tests last
week."

Dr L: "what were they for ..? Where were they done ..? Mrs RI: "kidney I think ... down in the shopping centre ..."

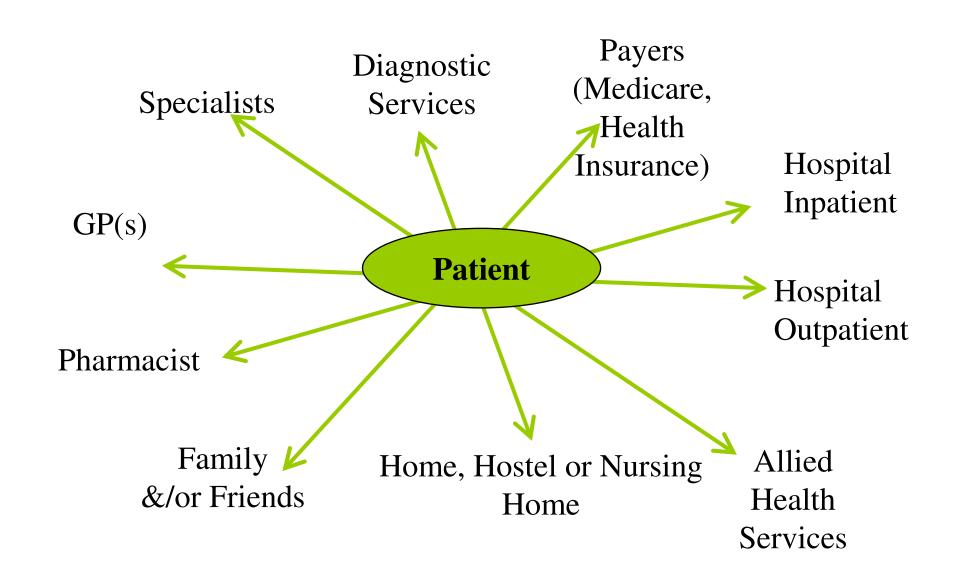
Dr L: (rings GP practice, phone engaged) "I will have to ask you to get these blood tests again ... they probably are different to the one's you had last week anyhow. You also need to have xrays of your hands and knees.

Mrs RI: "but I had xrays last year ..."

Poor Information Communication

- The patient-consumer is the link among providers the patient is the physical person in the centre.
- The patient provides a history, but their medical knowledge and understanding is limited and they can't provide details of previous examinations, findings, investigations etc
- Poor medical information flow
- Compromised medical decisions
- Adverse events, hospitalizations and death
- Duplication of services
- Frustrated and helpless providers and patients

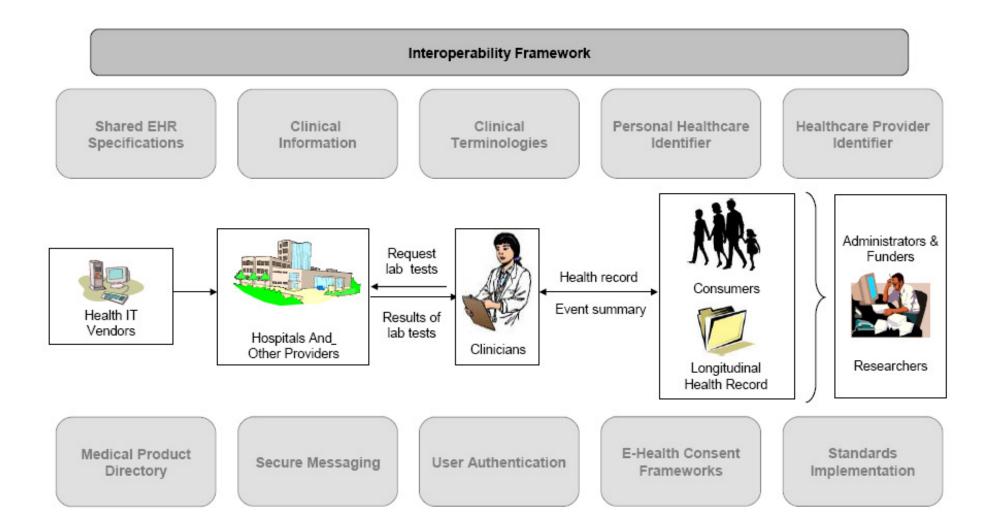
Patient is the 'Glue' Information Communication carried by the Patient



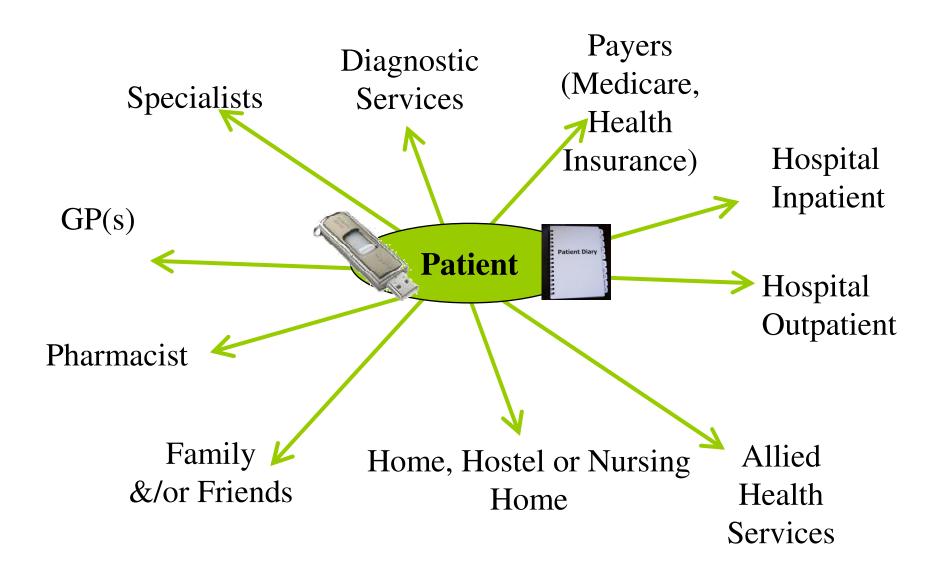
E-HealthTop-Down Approach

Providing a roadmap to achieve system interoperability

nehta



Project: Alternative solution while we wait for Top-Down Shared EMR to be rolled out



Project

Using **rapid prototyping** and the expertise of the team, two patient-held portable health files

Pilot Trial to evaluate the PHFs

- Study population: 76 patients with rheumatoid arthritis requiring specialist care, 4 specialists and 61 GPs
- PHFs 'Interventions' for evaluation:
- 1. My Health Record 2. p-PHF(patient diary), 3. e-PHF







My Health Record

NSW Health initiative introduction of the "red book" My

Health Record

Version 1 released in December 2002

Evaluation 2004

Revision released in September 2005

- Rationale: simple practical method to encourage people to record and track all information concerning their medical condition and have it easily accessible (similar to the baby "blue book")
- Ensure continuity of care and reduce pressures on the health system by avoiding unnecessary hospital admissions.
- NSW Privacy Commission and NSW Health Legal Branch were represented on the NSW Personal Health Record Steering Committee and oversaw the development of My Health Record





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My Health Record

People with chronic illness such as cancer, diabetes, stroke, heart disease, asthma and chronic obstructive pulmonary disease may need to see many health services providers. For example are doctors, general practitioners, specialists, pharmacists, physiotherapist, nurses, optometrists, dieticians, podiatrists, psychologists, dentists...

In some cases, you may find it difficult to keep important health information altogether in one place. This can include keeping track of prescription, referrals, emergency details, medical history and diagnoses, test results, treatments, assessments, care plans and many other things.

To address this problem, you, your carers and health services providers require a tool to keep all of this information in one place. My Health Record was developed to address the problem.

My Health Record is to assist you, your carers and health service providers to have ready access to relevant accurate and timely information. My Health Record is also to help you by reducing the need to repeat the same information or medical history every time you see health service providers. Therefore, duplication is avoided and continuity is enhanced.

What is My Health Record?

It is a sturdy booklet that holds information about your health in one place. It contains details
about your medical condition and the treatment recommended by doctors and other health
services providers.

It Failed

- It was a bright red (that's OK), large (10 x 6 inch), heavy plastic book (not OK).
- It was primarily meant for patients to add information and it was difficult for doctors to work out where they could add the information they thought important.
- The feedback from GPs was particularly damning and the evaluation is now not available.

Objectives of our project

Overall aim of the project was to develop and evaluate methods of improving health information exchange among health-care providers. Project had 6 objectives.

Objective 4: Using qualitative research methods, investigate the attitudes, perceptions and opinions influencing the effective use of a patient-held portable health file by patient-consumers, with a particular focus on issues of privacy, health information security and confidentiality.

Project

- Project Team: Specialists, GPs, allied health professional, nurses, patients, clinical informatics experts, software programmers, social scientists, health policy experts, consumer organisations
- Funded by Commonwealth Department of Health and Ageing
- Human Research Ethics Committee Approval
- All subjects were required to give informed consent.

Methods: Patient focus groups

- 2 semi-structured focus-groups were conducted prior to project start
- 2 semi-structured focus-groups conducted after the PHFs were rolled-out
- 22 patients
- All had at least one chronic medical condition and more than half were retired and/or older than 65 years.
- Gender ratio was 1:1 for this part of the project.
- 1st focus group was led by a social scientist with particular expertise in focus group methodology, two focus groups were led by two research nurses and one focus group by a research nurse and medical practitioner.
- All focus group sessions were transcribed.

Methods: other focus groups

Qualitative methods to probe issues Semi-structured focus-groups

- Allied health and consumers representatives focus group
- General practitioner: feedback meeting

Whether an electronic USB PHF be password protected:

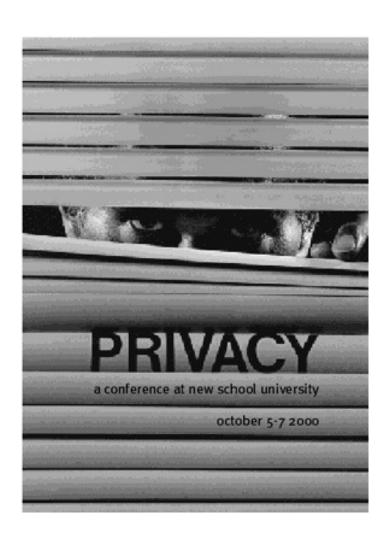
- "Well the use of information is useless to anybody – what could they do with it? You know it's not like your Visa card or anything. You know it's meaningless to anyone else, the only thing they could get out of it would be your name and address. That can under some conditions be a bit of a worry ..

Whether an electronic USB PHF be password protected:

 "It's no different – in fact it's less of a problem I think than writing it in a book. Because a book is plain for everybody to see, that little thing means nothing until you plug it in to a computer ... I would much rather medical people have access free access to my information I can't communicate myself. I'd much rather they had access to it easily than not at all ... one's life can depend on that and speed sometimes in this instance"

Whether an electronic USB PHF be password protected:

 "Probably somebody with say social diseases or something won't want everybody that will hear, you know a personal problem .."



 "It's boring for anybody to read."

 "What are they going to know – that you know – that you're ill, you take pills."



 "How boring – who wants to read it."





 "They're not going to blackmail you are they? I want your bottle of Prednisone."

 "I think confidentiality's gone too far."





 "If there was really personal stuff on there I wouldn't like it but you know – but if it's just in general like."

 One older female had no concerns regarding herself, but could see that it could be a concern for her son, who was in his twenties and employed.

If someone obtained their information and posting it on the Web.

- "I guess what are they going to find anyway, just what's in here."
- "The only person say if you were a famous personality."
- "But then you may not you'd be more careful with yours.."
- "That'd be different. But for all of us.."
- "It's so boring who'd want to look at that."
- "No pictures oh my God, we can't have that."
- "Perhaps we should say no X-rays."

Health Information Communication

 Many of the patients that took part in the focus groups had many health-care providers. One patient said:

- "I've got something like eight or nine specialists ... So you know, I mean it does get confused."

Health Information Communication

- Many of the patients believed that GPs and specialists had good lines of communication, although when asked not all could say why.
- Many knew that specialists wrote letters to their GPs after each visit.
- Many assumed that:
 - GPs also communicated with their specialists
 - specialists communicated with each other.
 - results of investigations, hospital admissions were also known by many of their doctors

Consumer Focus Group

- Thought it was a bad idea for patients to carry an e-PHF because of issues of privacy and confidentiality
- When told that in a patient focus group patients were not overly concerned, the consumer response was that the patients did not understand the issues.

GP focus group

 Twelve general practitioners attended a face-to-face feedback session.

 Although many did not see the need for their own personal PHF there was no hesitation recommending a PHF for their parents.

Discussion

 Any single approach advocated by stakeholders (health policy, information technology, legal profession, consumer organizations, medical profession) cannot reflect the diverse needs of the community.

Discussion

 Older patients with multiple chronic medical conditions that require the care of multiple health care providers, and that often need multiple hospital admissions, consume a greater proportion of health care resources, direct and indirect, than the young, the healthy and the employed.

Conclusions

- Older patients with chronic medical conditions that need care of multiple health care providers believe that improving quality of their health care outweighs the risk of losing privacy
- These views may not be held by young or healthy or employed or 'famous' people or people with conditions that they would not want disclosed.

Questions for the audience regarding next stage of project PHFs for older patients with multiple medical conditions

 Paper PHF – should there be identifying details (Name, address phone no. of patient, patients contacts etc)?

 Electronic PHF – it will be password protected but what to do in emergencies?

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