

Use of Patient-Held *paper* and *electronic* Portable Health Files (PHFs) to facilitate reliable health knowledge transfer among healthcare providers and patients

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Clinical and Epidemiological Research: Quality, Innovation, Technology

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Case Study

- **Dr Lassere's 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,

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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"

And so on

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Exam: Synovitis wrists, MCPJs, knees

PDx: Inflammatory arthritis ? RA

DDx: pseudogout, seronegative, CTD, malignancy, 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 ..."

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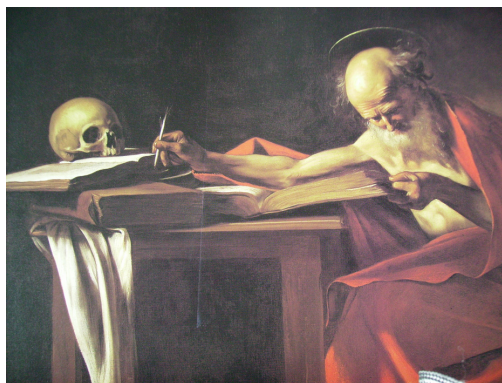
Rationale

- Patients with chronic medical conditions have multiple health care providers.
- Information exchange among these providers is limited, patient-consumer involvement is limited and reliable health knowledge is compromised.
- Suggested approach is a top-down, shared-electronic medical record: networked environment and unique patient and provider identifiers.
- However, complete (whatever that really means) information is not necessary, rather, **key** information is necessary
- Bottom-up solutions: 'the patient is the glue' patient held portable health file that empowers health care providers and patients

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The 'silo-based' medical record



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Australia's Web-based Top-Down Shared Electronic Record

- 1999 fanfare, hype, hope
- 2004 beaten, bankrupt, broke ...dropped

Medical use of the HealthConnect website is for archival reference only and will not be updated from the 27 June 2009. All current information can be viewed via the [Dashboard of HealthConnect website](#)

HealthConnect
What's happening

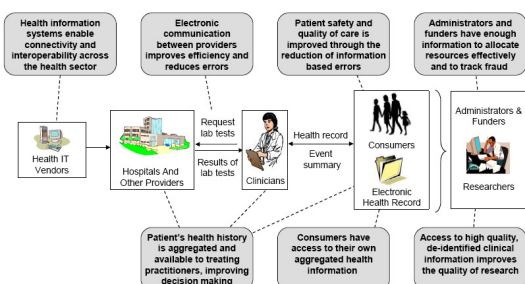
Archived document

Implementation of the healthConnect strategy requires a close working relationship between all the partners who are responsible for making healthConnect happen. Each partner has to confront different challenges that a health reform package of this magnitude brings. For example, no one state or territory is exactly the same. There are differences in geographic size, population density, investment capacity, information management infrastructure, staff and assets and resources. Consequently, each region will be at a different stage of implementation development.

Work is progressing in each Territory around Australia. For example, Tasmania is now moving to expand several projects. The Patient Discharge Warning System (PDWS) that sends comprehensive medication details to a patient's GP is rolling out state-wide, as is their Electronic Patient Discharge (EPDC) ambulance system. For further information please view each of the state pages.

Top-Down Approach

Where Australia Aims To Be In e-Health nehta

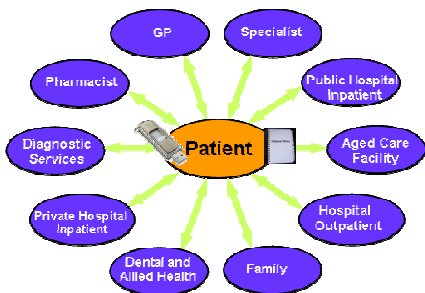


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Bottom-Up Approach - Patient is the 'Glue' Information Communication Travels With Patient




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Pilot Study Evaluate a Bottom-Up approach while we wait for Top-Down to be rolled out:

- **Develop** and **evaluate** a paper and an electronic hybrid EHR and PHR patient-held portable health file (**pPHF & ePHF**)
 - a **shared health record** used by patients and all the doctors and health-care providers they see.
- Explore issues regarding privacy, health information security and confidentiality

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Methods

- Over a 3 month using rapid prototyping and quality improvement methodology, two new patient-held 'shared-records' were developed:
 - a portable, USB-drive synchronized Java electronic PHF
 - a passport-sized, paper PHF.
- A quota-allocated trial evaluated the PHFs over a period of 4 months.
- Outcomes included feedback and change in practice.
- Two qualitative semi-structured focus-groups were conducted prior to project start and another two after the tools were rolled-out.
- All focus group sessions were transcribed.

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Methods

- Project Team: Specialists, GPs, allied health professional, nurses, patients, clinical informatics experts, software programmers, social scientists, health policy experts, consumer organisations
- Project funded for 9 months
- Funded by Australian Commonwealth Department of Health and Ageing
- Human Research Ethics Committee Approval

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Results

- Recruited 76 patients with rheumatoid arthritis, 62 GPs and 4 specialist rheumatologists.
- Paper and electronic-files contained a core-data set of information that functioned as a subset of a more comprehensive electronic or paper medical record held by the doctor
- Structured to be **doctor and patient friendly**
- PHF was updated by the doctor at each visit and could also be updated by patient between visits
- Java chosen for rapid development & supportable on most platforms
 - functions such as doctor authentication, audit trail, non-repudiation and saving of changes built-in and automated
 - file was read-only without USB drive
- many more interface and functionality features

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Results: Patients

- 80% of patients would recommend a PHF to others
- 95% of patients liked to idea of carrying their own health data using a PHF
- Men said they would not carry something that would not fit in their hip or shirt pocket.
- Only 13% of patients were often or sometimes concerned about privacy.
- 55% of patients added information to the PHF
- 70% said it was easy to ask their GP to fill in their PHF
- 90% said it was easy to ask their specialist
- 75% patients mostly perceived the PHF as a means of carrying information between health care providers.

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Results: Doctors

- 10% of patients forgot to bring the PHF to the visit
- Practitioners requested the patients PHF at the start of the consultation.
- GPs with older computers obtained a USB drive extension cord to facilitate ease of use.
- 15% of GPs were concerned about confidentiality and accuracy and 13% did not wish to participate, some dissuading their patients from continuing.
- Most common GP entry was BP, blood tests and medications
- At the GP workshop: many wanted their parents to have one.

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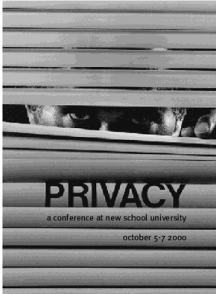
Risk to privacy versus benefit of quality care: what do patients with chronic medical conditions choose.

Results: Patient focus groups

- 22 patients
- Gender ratio 1:1
- All had at least one chronic medical condition and more than half were retired and/or older than 65 years.

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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”


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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.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”

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Regarding loss or theft of the USB drive whether confidentiality was a problem.



“It’s boring for anybody to read.”

“What are they going to know – that you know – that you’re ill, you take pills.”

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Regarding loss or theft of the USB drive whether confidentiality was a problem.

“They’re not going to blackmail you are they? I want your bottle of Prednisone.”

“I think confidentiality’s gone too far.”

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

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Professional 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 patients were not overly concerned, the consumer response was that the **patients did not understand the issues.**

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Conclusions

- Successful “**proof-of-concept**” study but limited by its size, duration and early prototype PHFs
- 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**
- Where **technology provides functionality that speeds the doctors’ workflow**, e.g. rapid generation of prescriptions, the adoption rate is high. Otherwise, clinical re-engineering needed

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Conclusions

- Although these are important outcomes, the fundamental question is whether use of PHF is acceptable enough short term to enable translation into long-term important clinical outcomes.

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Literature on EHRs & PHRs

- Different types of patient-held records have been considered: full copies of patient files, extracted summaries and censored summaries.
- Stand alone systems or systems integrated with health provider electronic medical records
- Can be carried on smart cards, CDs, USB memory drives, phones
- Promoted as a means of providing patients and providers with universal access to updated medical information
- Some systems are free or open source and claim to meet requirements of data encryption, secure access, authentication and authorization
- **None rigorously evaluated to quantify real risk/benefits using scientific methods**

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Randomized Controlled Trial

ARM 1	ARM 2	ARM 3
ELECTRONIC PORTABLE HEALTH FILE ON USB FLASH DRIVE	PAPER PORTABLE HEALTH FILE	CONTROL ‘ROUTINE CARE’

- **Enriched population:** ≥60 years; ≥ 2 different specialist visits in previous 12 months and ≥ 6 doctor visits a year, 50% with recent hospitalisation
- **Trial Size:** 600 patients, (50 GPs, 10-15 patients per GP, plus specialists and other health care providers)
- **Trial Duration:** 3 years
- **Primary endpoint:** powered to show a reduction in significant clinical outcomes – combined endpoint of reduction in **unplanned hospitalisations plus death**

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- **Other outcomes**
 - GP and specialist workflow, acceptability etc
 - Uptake of guidelines/quality indicators
 - Health service utilisation
 - Patient quality of life, co-morbidity
 - Impact on privacy and confidentiality
- **Trial Issues**
 - Smooth integration with clinician workflow
 - Security
 - Synchronicity and backup of data
 - Support
 - Computer viruses
 - Compatibility with future EHR directions

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Engaging the Clinician: The Value of Rapid Prototyping of ‘Lightweight’ Electronic Health Records

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Abstract
 Objective: To apply rapid prototyping of lightweight applications to clinical re-engineering.

Background: A 6 month program was funded to trial an electronic, patient-held portable health file (PHF) carried by the patient between different health-care providers.

Methods: Software, interface and functionality decisions required close co-operation between programmer and clinician. The process was iterative, simple and visible rather than total perfection. Three considerations drove technical specifications: What features were essential because they complicated the interface or were programmer’ functions rather than ‘doctor’ functions.

Results: The record was implemented as a file (stored PHF) in an accessible software to be read and modified using a custom program and carried on a USB drive. Java was chosen for rapid development to support on many platforms. The program used a ‘look and feel’ approach. The hardware ‘out of the box’ was ‘function ready’ for doctor substitution, with trial, user replication and testing of changes were built-in and automated. The PHF software was simple and generic rather than based on any existing medical records. The security, reliability, ease of migration by the program rather than driven by the data, features could be revised but not modified when USB drive was not present. The system was designed as ‘incidentally secure’ as loss of access to data was considered a minor problem. The data was stored locally. The system used a central authority to issue pre-configured USB drives to patients including the software and install software and substitution information on computers of participating health-care providers and patients.

Conclusions/Significance: Doctors and programmers’ think and work in different modes. The success of this program relied critically on the close co-operation of doctor and developer and keeping the road simple. Although the implementation of national e-health technology requires integrated complex systems, rapid prototyping to visibly solve niche problems may be an effective alternative.

Keywords: Clinical re-design, user-interface, lightweight vs. complex applications.

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Doctors, programmers and patient-consumers think (and work) in different modes

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