# Using 1° & 2° care EHRs for primary & integrated care research:

## *continuity, safety & quality*

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*underpinning the PHC Informatics Stream*

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# Good governance is the key

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1. Data/information governance
2. Clinical / professional governance
3. Organisation / corporate governance
4. *Joint venture (LHD-ML-Uni)*

# Governance must be informed

**Data**

- Data quality management (DQM)
- Information governance

**Clinical**

- Quality: cost-effectiveness
- Safety: patients and clinicians

**Corporate**

- Enterprise wide risk management
- Accountable learning organisations

# Governance integrated across data cycle

| | |
|---|---|
| Collection & creation | • Integrity & fidelity; controlled vocabularies |
| Extraction | • Precision, accuracy (sensitivity / specificity) |
| Storage | • Integrity & security of data; architecture |
| Linkage | • Precision, accuracy (sensitivity / specificity) |
| Cleansing & analysis | • SQL and statistical tools |
| Curation & use | • Display to user / pass on to applications |

# Fundamental question

EMA Emergency Medicine Australasia

doi: 10.1111/j.1742-6723.2011.01486.x

*Emergency Medicine Australasia* (2011) ••, ••–••

EMA

ORIGINAL RESEARCH

## Health reform: Is routinely collected electronic information fit for purpose?

Siaw-Teng Liaw,[1,2,3] Huei-Yang Chen,[2] Della Maneze,[2] Jane Taggart,[2] Sarah Dennis,[1,2] Sanjyot Vagholkar[1,3] and Jeremy Bunker[1,3]

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# Others asking similar questions

**Big Bad Data:** Law, Public Health, and Biomedical Databases

*Sharona Hoffman and Andy Podgurski*

*J Law, Medicine & Ethics 2013*

# The obligatory literature review....

ELSEVIER

journal homepage: www.ijmijournal.com

Review

## Towards an ontology for data quality in integrated chronic disease management: A realist review of the literature

S.T. Liaw[a,b,c,*], A. Rahimi[a,d,e], P. Ray[a,d], J. Taggart[b], S. Dennis[b], S. de Lusignan[f], B. Jalaludin[a,g], A.E.T. Yeo[h], A. Talaei-Khoei[d]

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# Deciding if EHR data is fit for purpose....

## Key Concepts to Assess the Readiness of Data for International Research: Data Quality, Lineage and Provenance, Extraction and Processing Errors, Traceability, and Curation

S. de Lusignan[1], S.-T. Liaw[2], P. Krause[3], V. Curcin[4], M. Tristan Vicente[5], G. Michalakidis[6], L. Agreus[7], P. Leysen[8], N. Shaw[9], K. Mendis[10]

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Int Med Informatics Assoc Yearbook 2010

# Are hospital EHRs fit for purpose?

eJHI electronic Journal of Health Informatics
www.eJHI.net
201x; Vol x(x):eX

## The Quality of Routinely Collected Data: Using the "Principal Diagnosis" in Emergency Department Databases as an Example

*Siaw-Teng Liaw[1,2,3], Huei-Yang Chen[1], Della Maneze[1], Jane Taggart[1], Sarah Dennis[1], Sanjyot Vagholkar[2,3], and Jeremy Bunker[2,3]*

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# Are general practice EHRs fit for purpose?

AMIA Annual Symposium Proceedings Archive

AMIA INFORMATICS PROFESSIONALS. LEADING THE WAY.

Performing your original search, ***Liaw ST and data quality***, in PMC will retrieve 4 records.

AMIA Annu Symp Proc. 2011; 2011: 785–794.
Published online 2011 October 22.

PMCID: PMC3243124

## Data quality and fitness for purpose of routinely collected data – a general practice case study from an electronic Practice-Based Research Network (ePBRN)

Siaw-Teng Liaw, PhD, FRACGP, FACHI,[1,2] Jane Taggart, MPH,[1] Sarah Dennis, MSc, PhD,[1] and Anthony Yeo, MBBS, PhD[3]

# Are data extraction tools fit for purpose?

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## From small practice based data to big data – data extraction errors

ePBRN electronic Practice Based Research Network

Siaw-Teng Liaw, PhD, FRACGP, FACMI[1], Jane Taggart, MPH[1], Simon de Lusignan, MD(Res), FRCGP[2]
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### Introduction and background

Small practice-based clinical datasets are increasingly being extracted into big clinical data repositories to be mined for business analytics and secondary purposes, such as research and quality improvement audits. Many commercial data extraction tools (DET) exist, but they are largely "black-box" solutions with intellectual property protection preventing adequate assessment of their fitness for purpose and assessment of whether there are design or execution errors.

### Methods

The UNSW electronic Practice Based Research Network (ePBRN) validated its extraction tool through a comparison with two commercial DETs in Australia. We compared identical extracts from patients with diabetes from 2 ePBRN practices (n=20,000+ patients) using the same clinical information

### Discussion

The significant variations due to differences in the data extraction tools and processes mandates a systematic and ecological approach to govern and manage the primary and secondary use of routinely collected electronic data to support health reform. Technical, personal, professional, organizational, ethical, social and legal factors determine

"Data extraction from electronic health records – existing tools may be unreliable and potentially unsafe" Australian Family Physician (in press)

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# Integrated Governance

Elsevier Editorial System(tm) for International Journal of Medical Informatics
Manuscript Draft

Manuscript Number:

Title: A sociotechnical framework to align data quality management and information governance with organisational objectives

Article Type: Review Article

Keywords: curation, information ecosystem, data quality management, data governance, information governance, data stewardship

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Currently under review and discussion with International J Medical Informatics

# Governance is only as good as system's weak points

HEALTH REFORM —LETTERS

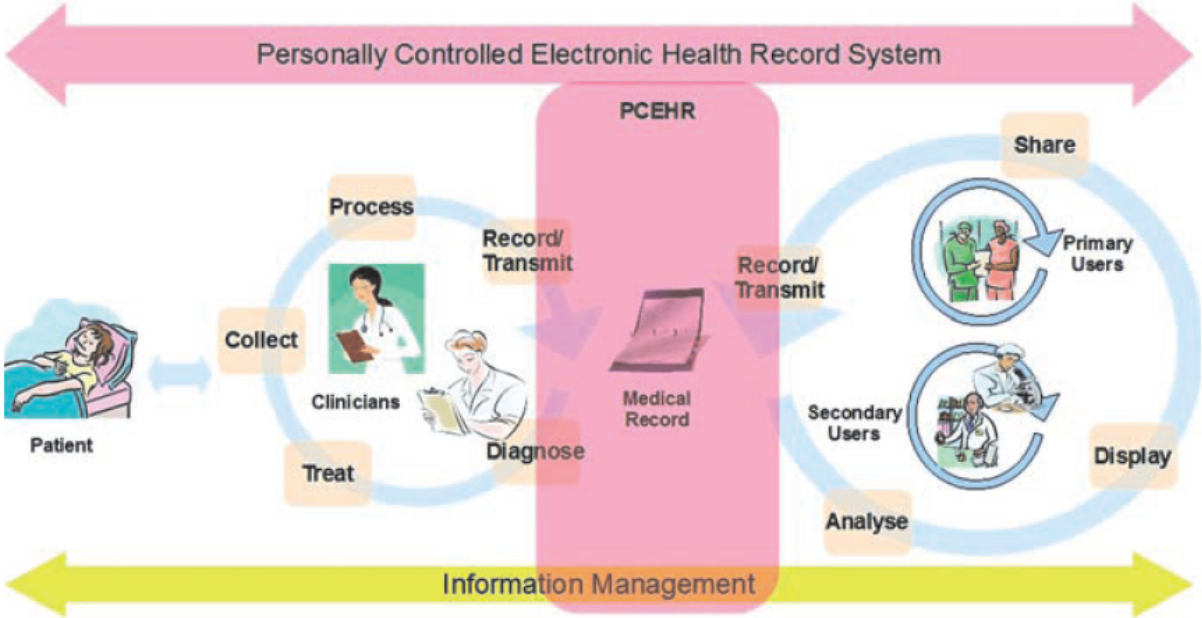
## Can we trust the PCEHR not to leak?

Siaw-Teng Liaw and Terry Hannan

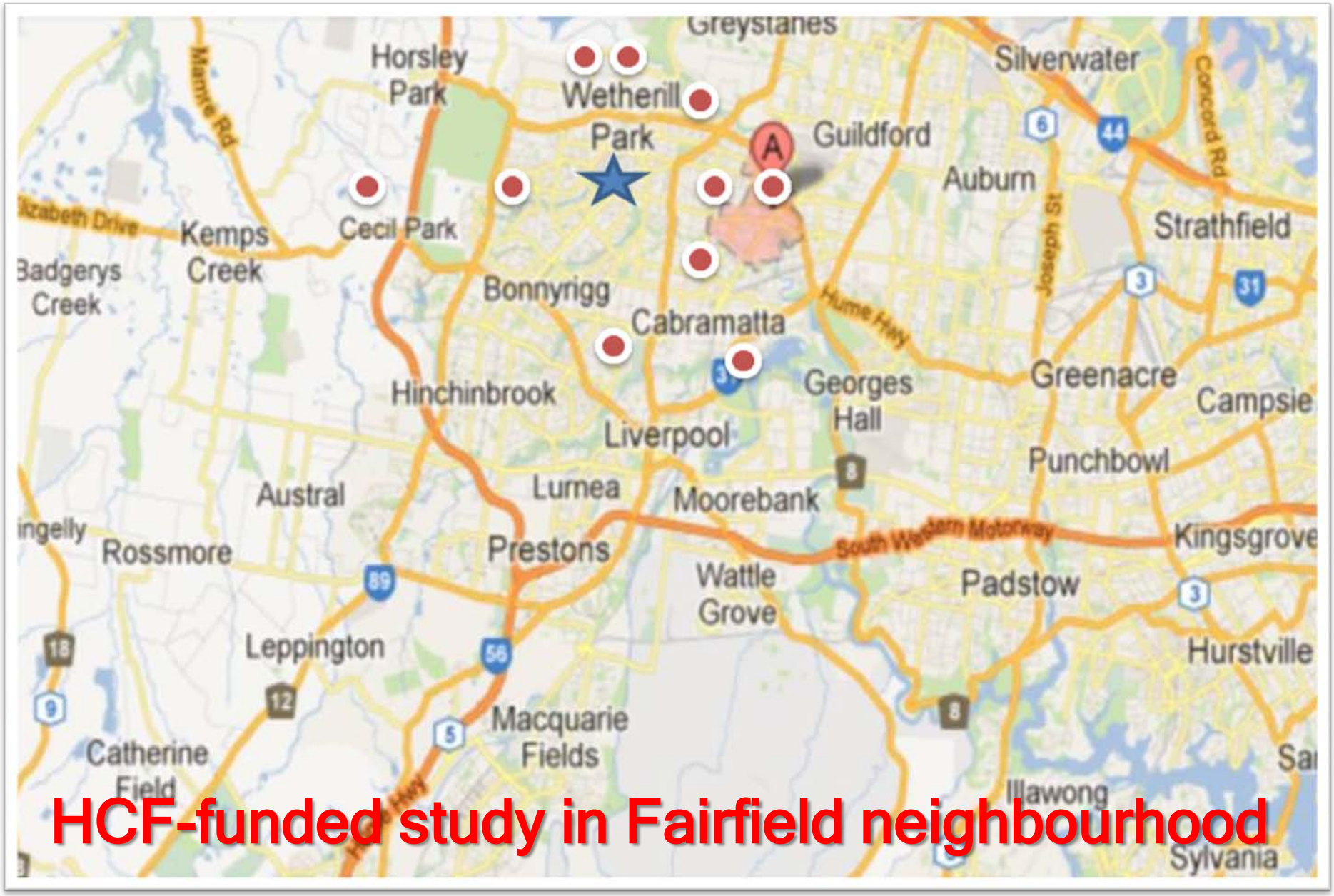
In April this year, the Federal Minister for Health and Ageing, Nicola Roxon, stated that by July 2012 all Australians will be able to "sign up for a personally controlled e-health record . . . [that] will enable better access to important health information currently held in dispersed records around the country".[1] Laudable aims, but can patients and clinicians trust the reliability and confidentiality of this personally controlled e-health record (PCEHR)?

The National eHealth Transition Authority's draft concept of operations document proposes that individuals will be able to access a data repository ("My PCEHR") and tools ("My Access Controls") to make this dispersed information

Pathways for the collecting, sharing, and possible leakage of information in an individual personally controlled electronic health record

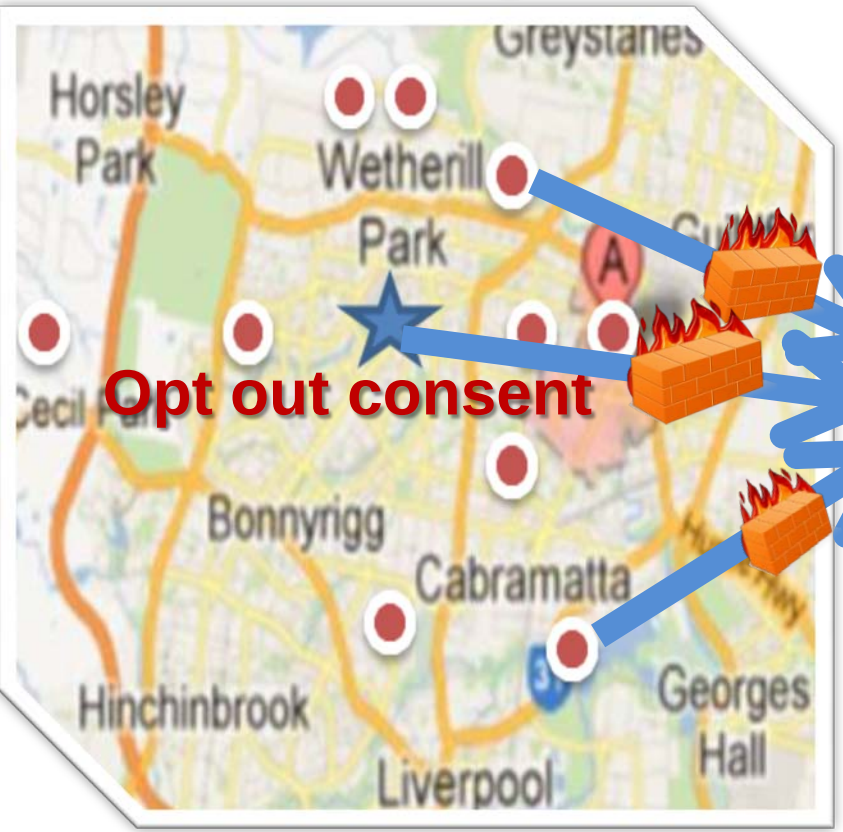



*Reproduced with permission from: Hannan T. What the hell is a PCEHR and what does it have to do with me anyway? The InformaticsInsider [internet] 2011; Jun (1). http://www.austemrs.com.au/page/informatics_insider.html*




# HCF-funded study in Fairfield neighbourhood

# Linking 1° and 2° care records




**Opt out consent**

**Secure Data Repository**

Doubly encrypted

Decrypted - **hashed** identifiers.

Records linked and processed

***Data modelling***

***Push-pull model to predict admissions***

***Analyses***

***e.g. models of integrated care***

# HCF-funded study: predictors of hospital admissions in the Fairfield neighbourhood

# Discussion and next steps

1. **Data Quality Management:**
   - ***Correctness and Consistency (intrinsic DQ)***
   - ***Completeness and Duplicates (extrinsic DQ)***
   - ***Patient/disease registers***
   - ***Denominators: RACGP / EHR active patients***
   - ***Context, process, and impact indicators***
2. **Data, information & knowledge governance**
3. **PCMH and the health neighbourhood:**
   - ***Access, equity, continuity, safety, quality***
4. **What is special about integrated care "big data"?**

*Informatics in Primary Care* 2012;20:81–6
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Leading article

# Accelerating the development of an information ecosystem in health care, by stimulating the growth of safe intermediate processing of health information (IPHI)

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*24th International Conference of the European Federation for Medical Informatics*
*Quality of Life through Quality of Information – J. Mantas et al. (Eds.)*
*MIE2012 / CD / Working Group Workshops*

**We conducted an international Delphi study to assess the desirability, validity and utility of this approach. The results are being presented at Medinfo 2013**

# Improving the Design of Research and Quality Improvement Using Routine Data in Chronic Disease: Ontology Driven Approach

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