Using 1° & 2° care EHRs for primary & integrated care research: continuity, safety & quality

underpinning the PHC Informatics Stream
Good governance is the key

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
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 Vagholkar1,3 and Jeremy Bunker1,3

1School of Public Health and Community Medicine and 2Centre for Primary Health Care and Equity, University of New South Wales, and 3General Practice Unit, South West Sydney Local Health District, Sydney, New South Wales, Australia
Others asking similar questions

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

Sharona Hoffman and Andy Podgurski

J Law, Medicine & Ethics 2013
Review

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

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

\textsuperscript{a} University of NSW School of Public Health & Community Medicine, Sydney, Australia
\textsuperscript{b} University of NSW Centre for Primary Health Care & Equity, Sydney, Australia
\textsuperscript{c} General Practice Unit, South West Sydney Local Health District, Australia
\textsuperscript{d} Asia Pacific ubiquitous Healthcare research Centre (APuHC), University of NSW, Sydney, Australia
\textsuperscript{e} Isfahan University of Medical Sciences, Faculty of Management and Medical Information Sciences, Iran
\textsuperscript{f} Department of Health Care Management and Policy, University of Surrey, Guildford, UK
\textsuperscript{g} Population Health Unit, South West Sydney Local Health District, Australia
\textsuperscript{h} Ingham Institute of Applied Medical Research, Australia
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\(^10\)

\(^1\) Primary Care and Clinical Informatics, University of Surrey
\(^2\) General Practice, University of New South Wales, Australia
\(^3\) Software Engineering, University of Surrey
\(^4\) Imperial College London
\(^5\) St. George’s University of London
\(^6\) Computing department, University of Surrey
\(^7\) Center for Family and Community Medicine, Karolinska Institutet, Stockholm
\(^8\) Faculty of Medicine, Dept. of Primary and Interdisciplinary Care, University of Antwerp
\(^9\) ESRI Canada Health Informatics Research Chair / Scientific Director, Health Informatics Institute, Algoma University, Ontario, Canada
\(^10\) University of Sydney

Int Med Informatics Assoc Yearbook 2010
Are hospital EHRs fit for purpose?

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

Siaw-Teng Liaw\textsuperscript{1,2,3}, Huei-Yang Chen\textsuperscript{1}, Della Maneze\textsuperscript{1}, Jane Taggart\textsuperscript{1}, Sarah Dennis\textsuperscript{1}, Sanjyot Vagholkar\textsuperscript{2,3}, and Jeremy Bunker\textsuperscript{2,3}

\textsuperscript{1} UNSW Centre for Primary Health Care and Equity
\textsuperscript{2} Academic General Practice Unit, Fairfield Hospital
\textsuperscript{3} UNSW School of Public Health & Community Medicine
Are general practice EHRs fit for purpose?

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

Published online 2011 October 22.

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, PhD³
Are data extraction tools fit for purpose?

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

Siaw-Teng Liaw, PhD, FRACGP, FACMI, Jane Taggart, MPH, Si Tim de Lusignan, MD(Res), FRCP

1University of New South Wales Medicine, Australia 2University of Surrey, UK

Introduction and background
Small practice-based clinical datasets are increasingly being extracted into big clinical data repositories to be mined for business analyses 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 ePBRNs against the 30,000 patient claims from general practice 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 the reliability and potential utility of data extraction tools.
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

Corresponding Author: Prof. Siaw-Teng Liaw, MBBS, PhD, FRACGP

Corresponding Author’s Institution: University of New South Wales

First Author: Siaw-Teng Liaw, MBBS, PhD, FRACGP

Order of Authors: Siaw-Teng Liaw, MBBS, PhD, FRACGP; Christopher Pearce, MBBS, MFM, PhD, FRACGP, FACRRM, FAICD, FACHI; Harshana Liyanage, BSc, PhD student; Simon de Lusignan, MBBS, MD
Governance is only as good as system’s weak points

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

HCF-funded study in Fairfield neighbourhood
Linking 1° and 2° care records

Secure Data Repository

Doubly encrypted

Decrypted - hashed identifiers.

Records linked and processed

Push-pull model to predict admissions

Data modelling

Analyses

e.g. models of integrated care

Opt out consent

NSW Government

Health South Western Sydney Local Health District

ePBRN (Electronic Practice-based Research Network)

UNSW (The University of New South Wales)
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”?
Leading article

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

Harshana Liyanage BSc MBCS
Research Fellow, Department of Computing, University of Surrey, Guildford, UK

Siaw-Teng Liaw PhD FRACGP FACHI FACMI
Professor of General Practice, University of New South Wales, Randwick, NSW, Australia

Simon de Lusignan BSc MBBS MSc MD(Res) FHEA FBCS CITP FRCPGP
Professor of Primary Care & Clinical Informatics, Editor Informatics in Primary Care, Department of Clinical...
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

Simon de LUSIGNAN\textsuperscript{a,1}, Siaw-Teng LIAW\textsuperscript{b}, Ali Reza RAHIMI\textsuperscript{b}, Norman POH\textsuperscript{a}
Simon JONES\textsuperscript{a}, Members of Primary Health Care Informatics Working Group
\textsuperscript{a}University of Surrey, GUILDFORD, Surrey, UK
\textsuperscript{b}University of New South Wales, SYDNEY, Australia
Core Team: Liaw ST, Taggart J, Yu H, Dennis S, Rahimi A (PhD student);


Investigators (International): de Lusignan S (UK)