

# Optimising the use of observational electronic health record data: Current issues, evolving opportunities, strategies and scope for collaboration

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## Background

With increasing computerisation in general practice, national primary care networks are mooted as sources of data for health services and population health research and planning. Existing data collection programs – MedicinesInsight, Improvement Foundation, Bettering the Evaluation and Care of Health (BEACH) – vary in purpose, governance, methodologies and tools. General practitioners (GPs) have significant roles as collectors, managers and users of electronic health record (EHR) data. They need to understand the challenges to their clinical and managerial roles and responsibilities.

## Objective

The aim of this article is to examine the primary and secondary use of EHR data, identify challenges, discuss solutions and explore directions.

## Discussion

Representatives from existing programs, Medicare Locals, Local Health Districts and research networks held workshops on the scope, challenges and approaches to the quality and use of EHR data. Challenges included data quality, interoperability, fragmented governance, proprietary software, transparency, sustainability, competing ethical and privacy perspectives, and cognitive load on patients and clinicians. Proposed solutions included effective change management; transparent governance and management of intellectual property, data quality, security, ethical access, and privacy; common data models, metadata and tools; and patient/community engagement. Collaboration and common approaches to tools, platforms and governance are needed. Processes and structures must be transparent and acceptable to GPs.

General practice is the cornerstone of primary care in Australia. The computerisation of general practice has placed general practitioners (GPs) at the forefront of moves to use the pooled data they hold to improve the care of populations<sup>1,2</sup> as well as individual patients through the development of a national shared record.<sup>3</sup> The many, often competing, data collection programs that operate at national, regional and local levels can be confusing to GPs and their patients. This detracts from a core issue that arises from the fact that electronic data derived from patients now have use beyond the GP's clinical record. The bottom line is that GPs require an understanding of data quality and governance and the implications for the GP as a clinician and manager.

Optimising patient-care processes and outcomes requires effective communication, coordination, teamwork and judicious use of information and communication technology:

- within a medical home<sup>4</sup>
- across the health 'neighbourhood' comprising other primary and secondary care services and providers.<sup>5,6</sup>

Governments<sup>7,8</sup> and health professional organisations<sup>9,10</sup> have recommended the effective use of electronic health records (EHRs), personal health records (PHRs) and electronic decision-support tools to collect, share and use good-quality information. This information should support the provision of safe, effective and coordinated care across 'patient journeys' and 'care pathways' in the health system.<sup>11-13</sup> Routinely collected observational EHR data, aggregated in data repositories, are increasingly mined, linked and used for audit, continuous quality improvement in care, health service planning, epidemiological study and evaluation research, and for measuring and monitoring the quality of coordinated care of patients with chronic diseases.

Despite increasing research and development (R&D) in health informatics, and improved informatics capabilities supporting the extraction, linkage and use of EHR data in a number of

countries,<sup>14–19</sup> data quality metrics in primary care<sup>2</sup> and hospital systems<sup>20</sup> are not optimal. There is also a lack of mutual trust and respect among primary and secondary care clinicians, researchers and managers, which hinders optimal information sharing.<sup>21</sup> Many existing tools that collect/extract data, and assess and manage data quality, are inconsistent. These tools are also not validated in a transparent manner within a robust data and clinical governance framework.<sup>20,22</sup> Data management methods using ontologies to define properties and relationships among the concepts within the dataset can automate and improve data quality management and fitness for purpose.<sup>23,24</sup>

## Objectives

We aimed to facilitate a discourse, including a series of workshops, to scan existing R&D programs in this domain, identify potential issues and implications, discuss potential solutions, and explore future directions. While the focus was primary care, the discussions also included secondary care in the context of integration and coordinated care.

## Participants

Participants included representatives from existing primary care data collection programs in Australia: Electronic Practice-Based Research Network (ePBRN), Melbourne East MonAsh GeNeral PracticE DaTabase (MAGNET), MedicineInsight, Improvement Foundation, Bettering the Evaluation and Care of Health (BEACH) and the Australian Institute of Health and Welfare (AIHW); and international participants (UK, Europe, Canada and US) at the 2014 North American Primary Care Research Group (NAPCRG) meeting.

## Methods

The methods for this program included:

- a scanning and scoping workshop at the Primary Health Care Research and Information Service (PHCRIS) conference in Canberra in August 2014<sup>25</sup>

- an issues, methods, quality and 'potential for a national approach' workshop at the University of New South Wales (UNSW) in Sydney in October 2014
- contextualisation of the Australian findings and perspectives at an international workshop held at the 2014 NAPCRG meeting in New York in November 2014.<sup>26</sup>

The workshops were facilitated, questions clarified and answers discussed prior to being recorded in the notes. The presentations and notes from the Australian workshops were reviewed and themes identified. Participants in the UNSW workshop also voted on a number of priorities discussed. Following the NAPCRG workshop, the outcomes and suggestions from both Australian workshops were further clarified and contextualised internationally with groups such as the International Medical Informatics Association's (IMIA's) Primary Care Informatics Working Group. Key themes were identified.

## Outcomes of the workshops

Scanning of projects and issues from all three workshops highlighted much commonality and some differences in the approaches taken by the main EHR-based programs (Table 1).

## Challenges

Participants at all three workshops highlighted the common challenges as:

- data quality, interoperability, fitness for use
- fragmented data and information governance
- proprietary models and transparency
- business model and sustainability of data linkage
- differing ethical perspectives to processes along the data production cycle
- cognitive load on patients and clinicians.

## Solutions

Proposed solutions to the above issues were discussed and categorised as the need for:

- building on Australian standards-based data and information models (eg National Health Information Model) and metadata (eg National Health Data Dictionary) and existing EHR-based programs, in an integrated 'top-down' and 'bottom-up' approach, to underpin the development of tools and applications
- standards-based tools and methods for data extraction, linkage, quality assessment and management that are amenable to critical appraisal prior to adoption and sharing
- engagement of user (clinician and manager) to maximise the workflow-friendliness of EHR implementations and promote a culture of good data quality and documentation
- integrated data and knowledge management, and intellectual property governance across the healthcare enterprise, promoting it as a core element of the organisational culture
- transparency at all levels and phases of the data production cycle, including the interactions with, and contributions of, consumer and clinician data creators and collectors
- strategies to address the proprietary model that inhibits sharing and rigorous evaluation of the quality and robustness of EHRs and data tools
- inclusive national and international partnerships, including professional bodies, consumer bodies, non-governmental organisations (NGOs), commercial groups and governments, to achieve consensus rules and governance for sharing of resources, tools and metadata (note: Metadata Online Registry [METeOR] defines metadata as 'data about data' [eg source, time of collection or documentation and other characteristics about data]; see <http://meteor.aihw.gov.au/content/index.phtml/itemId/268284> for more information)
- open engagement of the vendor community in quality assessment of systems, tools and data
- engagement of the patient and community to promote quality of data and care.

## Next steps

There was agreement by workshop participants to use a common methodology to report on the quality of studies using routinely collected data. The Reporting of Studies Conducted using Observational Routinely Collected Data (RECORD) template<sup>18</sup> was suggested as a starting point. Coding of data, using a standard or reference terminology, is to be encouraged. A coordinated approach and common metadata are essential to interpret loose terms entered into EHRs.

There was agreement on the need for a national consensus on basic principles, scope and organisational levels of governance, with the aim of engendering trust with primary care practitioners to facilitate their participation in EHR-based projects. This includes a recognition that data, information, clinical and managerial

governance must be integrated across the health enterprise in order to address different clinical and managerial uses for, and stewardship of, data.<sup>27</sup> Should the governance structure, data stewards and data quality management protocols be established at micro-, meso- or macro-organisational levels to optimise the engagement with clinical, managerial, informatics and technology stakeholders and the patient? There is a role for local Human Research Ethics Committees (HRECs) or similar institutional agencies in any local, regional, jurisdictional or national governance arrangements.

It was recommended that primary and secondary care data linkage be promoted to enable studies into vertical integration to support coordinated care. This includes the use of Australian national individual health identifiers (IHI) and other methods

of patient identification, and working with both state/territory and Commonwealth government agencies.<sup>3</sup>

A communication and engagement plan and strategy are essential at this stage. It was proposed that electronic document sharing and communication platforms such as a 'list-serve' or 'wiki' be established to support this special interest group to engage with policymakers and tools developers. They will be able to discuss and guide the governance, development and implementation of robust and meaningful tools to optimise the use of observational EHR data.

## Conclusions

There is much overlap among the EHR-based and non-EHR-based data collection programs in terms of types of data, tools and platforms, suggesting a need

**Table 1. Summary of some existing Australian programs collecting and using primary care data**

Program	Objective	Denominator	Governance	Tools	Website
MedicineInsight	Collection of patient-level EHR data	National sample (target: 500 practices)	Data governance at program level; RACGP ethics	GRHANITE™ extraction tool	<a href="http://www.nps.org.au/about-us/what-we-do/medicineinsight">www.nps.org.au/about-us/what-we-do/medicineinsight</a>
MAGNET (Note: POLAR evolved from MAGNET to collect patient-level data)	ML-based collection of practice-level EHR data with links to other services	ML (Note: MLs now superseded by PHNs)	Data governance at program level; multiple ethics approvals	Was using PEN-CAT extraction tool, but now using GRHANITE™ as POLAR	<a href="http://www.med.monash.edu.au/general-practice/magnet">www.med.monash.edu.au/general-practice/magnet</a>
ePBRN	Collection and linkage of patient-level EHR data from primary and secondary care datasets in IHN	IHN = hospital, ambulatory care, community health and GP services	Data governance at program level; LHD and UNSW ethics committees; planned: ML/LHD joint governance	GRHANITE™ extraction and linkage tool; SQL/XML, SAS/SPSS, Semantic web tools	<a href="http://cphce.unsw.edu.au/research-streams/primary-health-care-informatics">http://cphce.unsw.edu.au/research-streams/primary-health-care-informatics</a>
Improvement Foundation	Collection of practice-level EHR data	National sample	Data governance at program level	PEN-CAT extraction tool	<a href="http://www.improve.org.au">www.improve.org.au</a>
BEACH	Specific, non-routinely collected patient-level data (not from EHR)	Rotating sample of 1000 GPs from a national sampling frame	Data governance at program level	BEACH in-house tools	<a href="http://sydney.edu.au/medicine/fmrc/about/index.php">http://sydney.edu.au/medicine/fmrc/about/index.php</a>
AIHW	Specific, non-routinely collected practice-level data (not from EHR)	National sample	Data governance at program level	AIHW in-house tools	<a href="http://www.aihw.gov.au/data">www.aihw.gov.au/data</a>

AIHW, Australian Institute of Health and Welfare; BEACH, Bettering the Evaluation and Care of Health; CAT, Clinical Audit Tool; EHR, electronic health record; ePBRN, Electronic Practice Based Research Network; IHN, Integrated Health Neighbourhood; LHD, Local Health District; MAGNET, Melbourne East MonAsh GeNeral PracticE DaTabase; ML, Medicare Local; PHN, Primary Health Network; POLAR, Population Level Analysis and Reporting; RACGP, The Royal Australian College of General Practitioners

for harmonisation to share tools and resources to meet common objectives. However, there are differences in scope, focus and context, leading to variations in whether patient-level or practice-level data are collected, data quality management, and approaches to data and information governance. GPs should recognise the inevitability that, as with hospital practice, the electronic data derived from their patients will be used beyond the GP–patient relationship and their EHRs. They need to understand the data quality management, provenance and governance of this secondary use of data in their EHRs, and the implications for them as clinicians and managers. The governance processes and structures must be transparent and acceptable to GPs, who have significant roles as collectors, managers and users of the data.

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