

In this issue

Computerised routinely collected primary care data: essential for patient access to records, quality improvement and research

Simon de Lusignan BSc MBBS MSc MD(Res) FBCS CIPT FRCGP
Reader in General Practice and Informatics, St George's – University of London, UK and Editor,
Informatics in Primary Care

Introduction

Computerised primary care data are essential for patient access to records, quality improvement and research. Whilst patients can request paper copies of their records and audit of quality is possible on paper – providing larger numbers of people convenient access to their records and monitoring quality on a national scale requires computerisation of routinely collected primary care data. So much of what we know, and what defines our discipline of, comes from the study of routinely collected clinical data;¹ enabling patient access and systematic monitoring of quality should further improve record quality.

However, there is controversy about how these data should be accessed for research – especially whether we need to get permission from individual patients to access records to see if they are eligible for a particular study. The potential need to request permission to look at records to assess suitability for recruitment into a study has come to be called 'consent for consent'; an issue much debated within the pages of this journal.^{2–8} Records can clearly be accessed with consent; but when consent is not available methods are needed to search and flag people who are eligible for a particular research study without anyone outside their practice knowing the patient's identity.

Identifying people for research studies without revealing their identity: theory and practice

The Editorial in this issue describe a theoretical framework⁹ and the paper by Treweek *et al*, a practical

example¹⁰ of how we can identify people for research studies without revealing any of their personal details to researchers. The Editorial suggest that it should be possible to migrate from copying anonymised primary care data to a secure data 'vault' to using 'agents' or 'cloud' technologies to identify individuals eligible for research studies. Treweek's paper shows that it is feasible to use these technologies to recruit into a diabetes trial – they have done just this.

IT to support self-management

Two papers in this issue set out how technology can enhance care; and a third cautions as to how internet use in healthcare may help perpetuate the 'Inverse Care Law'. Nagykaldis *et al*, describe how influenza information – personalised on practice websites – is used and is acceptable to patients.¹¹ Perhaps a more integrated approach to providing information about influenza than the centralised approach used in the UK in the recent pandemic? Hannan's paper describes formally, his pilot of providing patients online access to their medical records.¹² This case study sets out the rationale, process and uptake of access to records. This landmark pilot was rightly awarded the John Perry Prize – the annual excellence award of the Primary Health Care Specialist Group of the British Computer Society (www.phcsg.org). It goes beyond shared access to medication lists, described previously by Schnipper *et al*, in this journal.¹³

A third paper adds a note of warning – the 'Inverse Care Law'¹⁴ may well apply to those who access health information online. Research by McInnes *et al*, suggests

that many characteristics associated with better health: younger age, better income, more education were associated with greater internet use.¹⁵ However, reassuringly so was 'worse health'.

Implementing electronic patient record systems in practice. Are we nearer to a generalisable approach?

Gagnon *et al*, refine the themes associated with successful implementation of an electronic patient record system – identifying three key themes:¹⁶

- 1 a project leader who combined the roles of clinical, technology, and knowledge champion
- 2 an organisation that was open and supportive to change
- 3 an 'evidence-based' implementation strategy tailored to the local context and adoption pace.

These findings resonate a previous paper in *Informatics in Primary Care*: Carr-Bains described a 'Champion' as a critical success factor and the importance of an implementation plan.¹⁷ However, others have focused on the business aspects of implementation: Stream concluded practice size and finance were important issues;¹⁸ Yoon-Flannery *et al*, also felt that the management and business elements of IT implementations were critical. They identified six factors: (1) effective communication; (2) successful system migration; (3) sufficient hardware, technical equipment, support and training; (4) safeguards for patient privacy; (5) improved efficiency; and (6) a sustainable business plan.¹⁹ Earlier papers from both Croatia²⁰ and Cyprus²¹ focused on the barriers and pitfalls in implementation. Adopting Gagnon *et al*'s framework may help earlier recognition of barriers to implementation.

The advantages of the poly-hierarchical structure of SNOMED CT

Vikstrom *et al*, highlight the potential advantages that can be gained from the poly-hierarchical structure of SNOMED CT.²² They compare SNOMED CT (Systematic Nomenclature of Medicine – Clinical Terms) with a more traditional hierarchical structured hierarchy – ICD10 (International Classification of Disease – Version 10) Swedish primary care version. The use of

the more structured alternative hierarchical relationships of the data enabled them to look at their data from more than one perspective. Food for thought as the UK and other countries move towards SNOMED CT.

Summary

Another interesting issue of *Informatics in Primary Care* – with articles ranging from some potential advantages of poly-hierarchical coding; through emerging models of key factors in implementing electronic patient record systems; how we share health data and information with our patients – bearing in mind their variable access to and use of the internet; and how we might best utilise practice data for quality improvement and research.

REFERENCES

- 1 de Lusignan S and van Weel C. The use of routinely collected computer data for research in primary care: opportunities and challenges. *Family Practice* 2006; 23(2):253–63.
- 2 Gibson-White A and Majeed A. The Wellcome Trust Report: moving forward the use of general practice electronic patient records for research. *Informatics in Primary Care* 2009;17(3):141–2.
- 3 de Lusignan S. Using routinely collected patient data with and without consent: trust and professionalism. *Informatics in Primary Care* 2008;16(4):251–4.
- 4 Navarro R. People and technology must work together to solve the sharing problem. *Informatics in Primary Care* 2009;17(3):139.
- 5 Mathers N, Perrin N and Watt G. Using patient records from general practice for research. *Informatics in Primary Care* 2009;17(3):137–8.
- 6 Hinds A. Data confidentiality and data handling in research: a workshop report. *Informatics in Primary Care* 2008;16(4):271–5.
- 7 Neame R. Privacy and health information: health cards offer a workable solution. *Informatics in Primary Care* 2008;16(4):263–70.
- 8 Navarro R. An ethical framework for sharing patient data without consent. *Informatics in Primary Care* 2008; 16(4):257–62.
- 9 de Lusignan S, Sullivan F and Krause P. Vault, cloud and agent: choosing strategies for quality improvement and research based on routinely collected health data. *Informatics in Primary Care* 2010;18(1):1–4.
- 10 Treweek S, Pearson E, Smith N *et al*. Desktop software to identify patients eligible for recruitment into a clinical trial: using SARMA to recruit to the ROAD feasibility trial. *Informatics in Primary Care* 2010;18(1):51–8.
- 11 Nagykalai Z, Calmbach W, DeAlleaume L *et al*. Facilitating patient self-management through telephony and

- web technologies in seasonal influenza. *Informatics in Primary Care* 2010;18(1):9–16.
- 12 Hannan A. Providing patients online access to their primary care computerised medical records: a case study of sharing and caring. *Informatics in Primary Care* 2010;18(1):41–9.
 - 13 Schnipper JL, Gandhi TK, Wald JS *et al.* Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. *Informatics in Primary Care* 2008;16(2):147–55.
 - 14 Hart JT. The inverse care law. *Lancet* 1971;1(7696):405–12.
 - 15 McInnes DK, Gifford AL, Kazis LE and Wagner TH. Disparities in health-related internet use by US veterans: results from a national survey. *Informatics in Primary Care* 2010;18(1):59–68.
 - 16 Gagnon M-P, Desmartis M, Labrecque M *et al.* Implementation of an electronic medical record in family practice: a case study. *Informatics in Primary Care* 2010; 18(1):31–40.
 - 17 Carr-Bains S and de Lusignan S. Moving to paperlessness: a case study from a large general practice. *Informatics in Primary Care* 2003;11(3):157–63.
 - 18 Stream GR. Trends in adoption of electronic health records by family physicians in Washington State. *Informatics in Primary Care* 2009;17(3):145–52.
 - 19 Yoon-Flannery K, Zandieh SO, Kuperman GJ *et al.* A qualitative analysis of an electronic health record (EHR) implementation in an academic ambulatory setting. *Informatics in Primary Care* 2008;16(4):277–84.
 - 20 de Lusignan S. Relearning the lessons about the implementation of information systems in primary care: a report from the European Federation for Medical Informatics (EFMI) Special Topic Conference 2007 in Croatia. *Informatics in Primary Care* 2007;15(3):167–8.
 - 21 Samoutis G, Soteriades ES, Kounalakis DK *et al.* Implementation of an electronic medical record system in previously computer-naïve primary care centres: a pilot study from Cyprus. *Informatics in Primary Care* 2007; 15(4):207–16.
 - 22 Vikström A, Nyström M, Åhlfeldt H, Strender L-E and Nilsson GH. Views of diagnosis distribution in primary care in 2.5 million encounters in Stockholm: a comparison between ICD-10 and SNOMED CT. *Informatics in Primary Care* 2010; 18(1):17–29.

