In this issue

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

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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; 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. 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 framework and the paper by Treweek et al, a practical example 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’. Nagykaldi et al, describe how influenza information – personalised on practice websites – is used and is acceptable to patients. 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. 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.

A third paper adds a note of warning – the ‘Inverse Care Law’ 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. 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. However, others have focused on the business aspects of implementation: Stream concluded practice size and finance were important issues; 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. Earlier papers from both Croatia and Cyprus 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. 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.

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