Conference paper

Secondary uses of clinical data in primary care

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ABSTRACT
This paper, presented as a panel at the American Medical Informatics Association (AMIA) Fall Symposium 2006, explores a number of secondary uses of primary care clinical data derived from point-of-care systems, and the issues arising from those uses. The authors (from the USA and the UK) describe, compare and contrast some secondary uses: pay-for-performance, public disclosure, clinical audit, health resource planning, and clinical system usage; in various environments: national health system, network of small family practice offices, and university teaching centres. In the UK, such data are now being used in pay-for-performance for GPs, and approximately 35% of their salary has been put at risk, which has resulted in close scrutiny. In the USA, pay-for-performance is at an earlier stage but is increasingly prevalent and continues to be hotly debated. Some of the issues that arise from these uses of clinical data – data quality including accuracy, comparability, perverse incentives, effect of secondary uses on care provision, and security and confidentiality among others – were discussed. Finally, options and opportunities for improving secondary uses of data in the light of the issues covered earlier were considered.

Keywords: data quality, primary care, secondary uses of data

Secondary uses of clinical data in primary care in the UK

Background
In primary care in the UK, there are 10 000 family practices, and 30 000 family physicians (GPs), independent contractors who provide 80–90% of care to registered patients. Almost every practice uses a clinical computer system, and around half are now ‘paperlight’, and use the system during the patient consultation.

The main driver for this ubiquitous primary care uptake of clinical computer systems is that they support both the clinical and business processes of general practice. Alongside this are the various government initiatives over the last 20 years, from the accreditation of systems, through data-driven contracts from 1990 to the present, to the major information strategies in the NHS.
The system market has changed considerably in the last 20 years, from 120 suppliers in 1985 to seven now; one of those supplies three different systems and covers 55% of the market.

In UK primary care, the functions of clinical computer systems are shown in Box 1.

### Box 1 Characteristics of GP clinical computer systems

- Used with patient at office visit – clinically-focused
- Structured and coded records
- Electronic prescribing
- Some decision support (warnings, reminders, contraindications)
- Electronic lab results
- Half practices are paperlight
- National registration system linked with PAP smear and mammography screening systems, and childhood vaccination system
- Sophisticated reporting tools
- No billing

### Uses of primary care clinical data

Primary care clinical data contained in or derived from those systems are used for a variety of purposes. Their primary use is to support direct clinical care, and most practitioners now use electronic patient records during the consultation, both to guide and record clinical care. In addition, there is a broad range of secondary uses of the data: support of preventive care and health promotion; clinical audit and clinical governance; national screening and preventive campaigns; audits against national standards; payment; national statistics; planning future services; and resource allocation. Examples of some of these uses are given below.

#### National audit

The National Diabetes Audit standards are built from the Diabetes National Service Framework; the audit combines anonymised patient-level data from general practice and hospitals. The second annual audit report (September 2006) includes data from 500,000 patient records covering 43% of practices. It estimates that 20% of diabetes patients remain undiagnosed, particularly women; it also calculates the increased risk of specific complications of diabetes, for example, a five-fold increase in risk of angina. The process of care for patients with diabetes shows 80% of patients having most routine checks. Intermediate outcome measures showed 58% with good blood glucose control; 88% with BP lower than 160/100 mmHg; 24% with BP lower than 135/75 mmHg; 68% with an acceptable cholesterol level; it also replicated the heart disease finding of undertreatment with statins of women.

#### Monitoring of preventive care

National preventive campaigns using data direct from primary care clinical systems include the influenza and pneumococcal vaccine uptake surveys; in 2005–2006 75.3% of patients aged 65 and over were vaccinated against influenza, and 48% of those under 65 classified as ‘at risk’ were vaccinated. Pneumococcal vaccination showed similarly good results, with 64.4% of patients aged 65 and over having been vaccinated.

These results were obtained not least because tools were provided to allow practices easily to identify and vaccinate those patients who were eligible because of age or pre-existing conditions.

#### Monitoring of health status

The Department of Health requires quarterly monitoring and reporting of smoking and obesity rates; in 2005 data were reported on 39 million patients aged between 15 and 75. Smoking status (recorded in the last 15 months) was available for 58% of those patients; 25% of those with status recorded were smokers (14% of the population between 15 and 75). BMI was recorded (in the last 15 months) for only 30% of the 15–75 population; of those 28% were recorded as obese (i.e. 8% of the population aged 15–75; Dr Michael Soljak, personal communication). These results suggest preferential recording of those who smoke and those who are obese. From a clinical perspective these findings are easily explicable: if a patient has never smoked, it is unlikely that they will start the habit, so GPs do not ask them every year and record their response; likewise, if a patient does not look obese, the GP will not weigh them and the system will therefore not calculate and record their BMI. These measures have been refined (at least for smoking status) for the 2007 data collection.

#### Quality and Outcomes Framework

The new GMS Contract includes a pay-for-performance scheme known as the Quality and Outcomes Framework; 30–40% of practice income depends on achievement against 136 quality indicators, including 76 clinical indicators covering the most frequently-encountered chronic conditions. The indicators were developed by an expert group of ‘quality gurus’. Such indicators are not always computable, however: what started out as ‘The percentage of patients receiving treatment for hypertension whose blood pressure is 150/90’ became ‘The percentage of patients with [a
recorded diagnosis of hypertension in whom the last blood pressure (measured in the last 9 months) is 150/90 or less. Each indicator is fully defined by ‘business rules’ which are used by clinical system suppliers to create validated search routines to provide the data for the measurement of achievement.\(^13\)

It is possible to ‘exception report’ patients for the following reasons: patient refusal; not clinically appropriate; newly-diagnosed or recently registered; already on maximum dose of medication. Clearly, there is potential for gaming. For most of the indicators the measurement period is 15 months, so January–March clinical activity can be counted in two years; batch data entry can be used for all patients with a condition; minimising prevalence could appear to maximise process and outcome achievement (however, this last is adjusted using ‘national prevalence’); and over-use of exception reporting codes (though practices who use such codes frequently are required to justify their usage).

Practices have performed well on these measures: in 2004–2005, 50% of practices achieved maximum points; in 2005–2006, 97.1% of practices achieved maximum points.\(^14\)

**Secondary uses of clinical data at Partners Healthcare**

Partners Healthcare is a large integrated healthcare delivery system in northeastern USA. It includes Brigham and Women’s Hospital, the Massachusetts General Hospital, several smaller hospitals, and a large number of physicians from the greater community. Partners has long prided itself on delivering high-quality care and doing outstanding research, but until recently the organisation had relatively limited resources for actually measuring quality, although that has begun to change. Under the leadership of Chief Executive Officer Dr James Mongan, Partners has recently implemented the ‘High-Performing Healthcare System Initiatives’, which are intended to substantially improve the safety, quality and efficiency of the care delivered throughout the system. A cornerstone of this effort has been developing the ability to use clinical data in a variety of ways. Some of the main ways that data have been used for secondary uses to date are for clinical audit, pay-for-performance and clinical research.

The key secondary use stores to date are the Partners Quality Data Warehouse, led by Dr Jonathan Einbinder, which includes Partners-wide data about key clinical issues such as diabetes and facilitates clinical audit;\(^15\) the Research Patient Data Repository, led by Dr Shawn Murphy, which includes a wide array of data allowing identification of patients for research;\(^16\) and health insurance claims databases, which allow assessment of performance on pay-for-performance contracts.

The Quality Data Warehouse supports ad hoc queries, includes many reports and a summary of performance or ‘quality dashboard’, and facilitates population management broadly. Some of the types of reports (see Figure 1) include reports for asthma, diabetes, medications prescribed, and the description of a provider’s panel. The specific reports for conditions like diabetes (see Figure 2) let a provider rapidly assess their performance, and drill down to identify specific patients if necessary.

The Research Patient Data Repository allows a provider to identify the number of patients with specific combinations of findings, for example myocardial infarction within a specific timeframe (see Figure 3). Then, with the appropriate institutional review board clearance, the researcher can obtain patient-level data if necessary.

Not surprisingly, a number of issues have arisen in each area. For clinical audit, it continues to be challenging to determine the right denominators. In particular, some of our systems do not clearly identify the primary care provider, so that defining a provider’s panel is challenging. The situation is even worse in specialty care, as one individual may be seen by multiple specialists (e.g. cardiologists), and good mechanisms for identifying who is responsible have not been defined. Another issue is that when errors are identified by providers, we do not have good mechanisms in place for repairing them. Getting reports to individual clinicians has also been challenging. Often reports are only made available to quality leaders or department heads, and they may or may not filter down to individual providers. Finally, getting providers to use clinical audit results remains a challenge. Building trust with providers takes time, and one observation is that obtaining buy-in requires that providers be able to drill down to the patient level for any measure, so that they can for example see which individual patients are out of compliance.

On the research front, one of the thorniest issues has been to determine how much de-identification to implement. De-identification is essential to meet privacy and security concerns, but it also presents technical challenges and can make it hard to answer certain research questions. Another issue is how secure to make access. Initially, this was set up so that only investigators could access certain things; later, the application was modified to allow investigators to delegate access for many activities, which was much more practical. Another ongoing issue is what fields to include in the database, as investigators are always requesting more data.

For pay-for-performance, one of the next steps will be to move from using claims data to extracting
information from electronic health records (EHRs) to assess pay-for-performance, which will allow a much more nuanced and accurate approach than is possible with claims. For that to be practical, it will also be essential to improve and refine measures, so that they can readily be extracted from EHRs.

In conclusion, we believe at Partners that many of the benefits from the conversion to the EHR will actually result from secondary uses of clinical data. Clearly, for this to be achieved, standardisation of data will be essential. In part as a result, the logistics of using secondary data today are still complex. In the USA, it
seems clear that pay-for-performance will represent a vital lever for moving forward in this area. Nevertheless, there are many societal issues around what will be permissible and what will not, and many of these issues still need case law.

**Secondary uses of primary care data: perspective from a US measure developer**

National and local efforts are underway in the USA to use primary care data to measure clinical quality at the individual physician level. The overarching goal for these national and local efforts is to have: timely, accurate data at the point of care to inform decision-making and facilitate patient-centred care; aggregate data for system-wide analysis; and de-identified data to be exported to multiple stakeholders. Significant time and effort are needed to meet this goal; however, the demand for data and public reporting of quality measures is immediate. Multiple stakeholders are calling for the following now:

- all physicians reporting on a common set of measures
- limited data collection burden
- confidence that data are accurate and reliable.

Several activities are underway to accomplish these requirements:

1. progress toward a core set of measures
2. integration of measures within EHR systems
3. exploration of alternative data collection methods.

**1. National measures: progress towards a core set**

The physician profession is at the forefront of evidence-based, physician-level measure development in the USA. Since 2000, the American Medical Association (AMA) has convened the Physician Consortium for Performance Improvement (Consortium). This is comprised of over 100 national medical specialty and state medical societies; the Council of Medical Specialty Societies; American Board of Medical Specialties and its member-boards; experts in methodology and data collection; the Agency for Healthcare Research and Quality; and the Centers for Medicare and Medicaid Services (CMS). To date, the Consortium has developed more than 174 individual measures in 28 clinical content areas, which address both primary and specialty care.

**Topic selection**

Consideration is given to what should be measured (for example, most frequent, costly conditions), and which types of measures to use in national programmes. In the UK, many types of measures (clinical processes, intermediate clinical outcomes, patient satisfaction, structural/organisational) are in use as part of the National Health Service Quality and Outcomes

![Figure 3 Research Patient Database query tool](image-url)
Framework for general practitioners. In the USA, many of the initial measures developed for individual physician use have addressed processes of care that are under the physician’s control; however, as the science of performance measurement evolves, measure developers are increasingly exploring physician-level measures in other areas of quality.

**National recognition**

The Consortium’s physician-level measures are gaining national recognition. Many have been endorsed by the National Quality Forum (NQF) and selected by the Ambulatory Care Quality Alliance (AQA). Endorsement by these national multi-stakeholder groups helps to move the USA toward a core set of performance measures.

2. Integration of performance measures into information technology

Information technology (IT) will play a key role in moving the United States toward national reporting and feedback on quality measures. However, currently only about 23.9% of physicians use EHRs in the ambulatory setting. Even among physicians who do have EHRs, many of the systems do not have the functionality to query and report on national performance measures, unless the physician practice devotes significant resources to build this functionality.

To facilitate the integration of measures into EHRs, the Consortium develops technical specifications by defining codes and algorithms for measure calculation. By way of example, to use one of the measures in the coronary artery disease (CAD) measurement set, 'Beta-Blocker Therapy for Patients with a Prior Myocardial Infarction' (see Box 2 for complete measure) in a physician practice with an EHR system, the following codes and definitions are needed:

**Patient selection criteria (denominator)**

- At least two face-to-face office visits (CPT® encounter codes)
- Age: 18 years or older (date of birth calculation)
- Documented diagnosis of CAD (ICD-9 codes or CPT® cardiac procedure codes) AND documented prior myocardial infarction [MI] (ICD-9 codes)
- Denominator exclusions: medical reason (such as contraindication to a medication); patient reason (such as patient refusal)

**Data elements required for numerator**

- Documentation of beta-blocker on the medication list or in physician notes of EHRs, OR searchable drug code (for example, NDC code).

**Dual strategy to facilitate integration of performance measure**

Currently, the AMA Consortium is working toward national integration of performance measures using two approaches:

1. working directly with physician practice sites
2. working with EHR system vendors to create universal functionality.

These two approaches are described in more detail below.

- **Approach 1** (working directly with physician practice sites). In one of several physician-led projects, six practice sites with different EHR system vendor products and from different regions of the USA are working collaboratively to collect and report

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**Box 2 Performance measure for beta-blocker therapy**

<table>
<thead>
<tr>
<th>Clinical recommendation</th>
<th>Performance measure</th>
</tr>
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| Beta-blocker therapy is recommended for all patients with prior MI in the absence of contraindications (Class I Recommendation, Level A Evidence) | Percentage of patients with prior MI at any time who were prescribed beta-blocker therapy. **Numerator:** Patients who were prescribed beta-blocker therapy. **Denominator:** All patients with CAD who also have prior MI at any time >18 years of age. **Denominator inclusion:** Patients with CAD and prior MI. **Denominator exclusion:**
  - Documentation of medical reason(s) for not prescribing beta-blocker therapy.
  - Documentation of patient reason(s) for not prescribing beta-blocker therapy. |
performance measures for CAD and heart failure (the project is titled \textit{Cardio-HIT} and is funded by the Physician Foundation for Health Systems Excellence). The overarching goals for this project include: (1) to collect data for performance measures internally within practice sites for quality improvement; (2) to export de-identified data for the performance measures to a centralised data warehouse for benchmarking; (3) to assess the feasibility, validity, and reliability of national performance measures.\textsuperscript{19,20}

- **Approach 2** (working with EHR system vendors). The AMA, National Committee for Quality Assurance, and CMS are co-sponsoring an ongoing collaborative, which brings EHR system vendors, developers of clinical performance measures, and testers of these products to the table. The collaborative has two key working groups: one is addressing the technical issues and challenges of identifying key data elements for performance measures in EHR systems, and the other is defining how measure developers can best make their specifications available to EHR system vendors and how performance measure data can be exported from the EHR system.

3. Current alternative to EHR system-enabled environment

**National pay-for-reporting programme**

Given that the USA is far from universal adoption of EHRs, many initial efforts regarding national reporting on clinical performance measures operate within the current administrative claims system. In 2007, CMS has begun a programme called the Physician Quality Reporting Initiative (PQRI), in which physicians select up to three measures that are appropriate for the care they deliver, and report the measures using newly-developed administrative codes (CPT\textsuperscript{\textregistered} Category II codes) on claims forms. For example, the CPT category II code 4006F indicates that beta-blocker therapy was prescribed.

**Summary**

From the perspective of a developer of performance measures, efforts appear to be aligning toward the goal of having a common set of performance measures for physicians. Moreover, efforts are underway to achieve integration of performance measures within EHR systems. Given the pressures from multiple stakeholders to accelerate efforts, the federal government and private sector continue to evaluate alternative data sources (mostly administrative claims data) until such time as all physicians are using fully functional EHR systems or are participating in disease registries.

**Secondary uses of primary care data: chronic disease management**

The Association of American Medical Colleges (AAMC) sent out a request for collaboration among academic medical centres. The requests focused on chronic diseases such as diabetes, asthma and osteoarthritis. Our medical school, Southern Illinois University School of Medicine (SIU), was chosen to participate along with 32 other academic medical schools on care of patients with chronic disease. SIU chose to work on diabetes mellitus (DM) type 2. Southern Illinois University School of Medicine is a state-assisted school established in 1970 to help the people of central and southern Illinois in meeting their healthcare needs through education, research and service and develop new models for providing health care in rural areas. The school has 289 medical students (14\% minority/52\% women), 272 residents and 324 full-time, 23 part-time, and 904 volunteer physicians throughout central and southern Illinois. The main interest for entry into the collaboration, aside from the better health of our patients, was to provide an opportunity for the residents in family medicine to attain competency in practice-based learning and improvement. This competency is one of six competencies that residents must obtain prior to graduation through the Accreditation Council for Graduate Medical Education (ACGME). The other five competencies are as follows; patient care, medical knowledge, interpersonal and communication skills, professionalism, and systems-based practice. The practice-based learning and improvement competency states the residents must be able to investigate and evaluate their patient care practices, appraise and assimilate scientific evidence, and improve their patient care practices. The residents should be able to do the following:

- analyse practice experience and perform practice-based improvement activities using a systematic methodology
- locate, appraise, and assimilate evidence from scientific studies related to their patients’ health problems
- obtain and use information about their own population of patients and the larger population from which their patients are drawn
- apply knowledge of study designs and statistical methods to the appraisal of clinical studies and
other information on diagnostic and therapeutic effectiveness

- use information technology to manage information, access online medical information, and support their own education
- facilitate the learning of students and other healthcare professionals.

To start the data collection and analysis process, an electronic management system or registry was required. Our residency did not have an electronic medical record system so we chose a registry system called Chronic Disease Electronic Management System (CDEMS). CDEMS is a software application developed by the Washington State Diabetes Prevention and Control Program in 2002. CDEMS is a Microsoft Access database application designed to assist medical providers and management in tracking the care of patients with chronic health conditions. CDEMS is pre-coded to track diabetes and adult preventive health but is customisable to change those tracking measures or define measures for monitoring other chronic conditions. Printed progress notes, patient lists, and summary reports generated from the registry database can alter the way services are delivered and measure quality improvement efforts.

The interdisciplinary team of faculty, residents, and nursing collaborated to support diabetes treatment for our patients. Components identified and tracked through the process included the following:

- community
- self-management
- delivery system design
- organisation of health care
- decision support
- clinical information systems.

Baseline goals for each measurement for the 18-month study were collected and run charts to display statistics were produced using data from CDEMS. Data were sent to the AAMC monthly to be correlated with the other medical schools’ data, since all participants use patient data registries and compare monthly performance on a number of measures (such as HbA1c, LDL cholesterol, tobacco use, and so on) against baseline. The data provided us with an opportunity to combine our Journal Club and chart audits along with the collaborative to enhance the teaching of practice-based learning. By integrating the Journal Club, chart audits and results from the collaborative, we were able to show quickly how we could put evidence-based medicine into practice and track to see how well we were doing for our patients.

We had a pilot population of approximately 182 that remained steady during the 18-month study. We looked at the following data points (see Table 1) and calculated our current baseline along with a goal for each measurement.

Some of the secondary outcomes of a quality improvement process during the collaborative period included an increased awareness of key clinical measures of DM care, reinforced interdisciplinary team approach to the care of patients, and a restructured Journal Club. The Journal Club articles and review of the evidence-based literature led us to do a focused chart audit on that topic in resident and faculty charts. Having the data available from CDEMS gave us quick feedback on how well we were doing for our patients and how close we were to using evidence-based medicine guidelines in the course of their treatment. The results of the chart reviews as well as the run charts from the collaborative provided the residents with a practical and clinical demonstration of the need to properly document in the chart what was being recommended for the patient. A common complaint from the residents regarding a poor performance in some of the measurements was that they knew they had spoken to the patient about a given topic but since it wasn’t written down in the chart, it was assumed that it hadn’t happened. This provided the residents with a clear example of how important proper documentation is in patient care. As a constant reminder we were also going to post statistics in the resident room for the residents, faculty, and nurses to see and track the progress throughout the collaborative.

SIU has since purchased an EHR system to better serve patients and enhance education. Chart audits were completed prior to our conference day and were very tedious and so it became quite apparent to the residents that a well-organised electronic record system would make manual chart audits more efficient and accurate.

**Issues arising from these initiatives**

Underlying the various secondary uses of primary care clinical data are a number of issues:

- Are the data being analysed and used of sufficiently high quality to allow decisions to be made based on them?
- If not, are there ways of improving the quality of data?
- Are there clinical effects if coding is standardised across the country?
- Are the data truly comparable across practices – are they extracted in a comparable way and are there demographic factors that confound the results?
Are there perverse incentives and if so what effect do they have on direct patient care?

How can these secondary uses/analyses be fed back to the providers of the data, and is such feedback likely to have a positive effect on quality of care?

Are there security and confidentiality risks once clinical data are extracted and analysed, and how can they be mitigated?

ACKNOWLEDGEMENT

This paper was presented by the authors as a Scientific Panel of the AMIA Primary Care Informatics Working Group at the American Medical Informatics Association Annual Symposium in Washington DC in November 2006.

REFERENCES

8 www.ic.services.nhs.uk/nca/sp/pages/audit_topics/diabetes
11 www.immunisation.nhs.uk/article.php?id=448
12 www.hpa.org.uk/infections/topics_az
13 www.primarycarecontracting.nhs.uk/145.php
14 www.ic.nhs.uk/psu/services/QOF/


22. www.cdehs.com/basics.html

CONFLICTS OF INTEREST
None.

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Accepted April 2007