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# Routinely-collected general practice data are complex, but with systematic processing can be used for quality improvement and research

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## ABSTRACT

**Background** UK general practice is computerised, and quality targets based on computer data provide a further incentive to improve data quality. A National Programme for Information Technology is standardising the technical infrastructure and removing some of the barriers to data aggregation. Routinely collected data is an underused resource, yet little has been written about the wide range of factors that need to be taken into account if we are to infer meaning from general practice data.

**Objective** To report the complexity of general practice computer data and factors that need to be taken into account in its processing and interpretation.

**Method** We run clinically focused programmes that provide clinically relevant feedback to clinicians, and overview statistics to localities and researchers. However, to take account of the complexity of these data we have carefully devised a system of process stages and process controls to maintain referential integrity, and improve data quality and error reduction. These are integrated into our design and processing stages. Our systems document the query, reference code set and create unique patient ID. The design stage is followed by appraisal of: data entry issues, how concepts might be represented in clinical systems, coding ambiguities, using surrogates where needed, validation and piloting. The subsequent processing of data includes extraction, migration and integration of data from different sources, cleaning, processing and analysis.

**Results** Results are presented to illustrate issues with the population denominator, data entry problems, identification of people with unmet needs, and how routine data can be used for real-world testing of pharmaceuticals.

**Conclusions** Routinely collected primary care data could contribute more to the process of health improvement; however, those working with these data need to understand fully the complexity of the context within which data entry takes place.

**Keywords**: medical informatics, medical records systems computerised, primary care, quality indicators healthcare, terminology

## Introduction

General practice is highly computerised in the United Kingdom (UK), and the use of information technology in routine practice is set to increase. A National Programme for Information Technology (NPfIT) is standardising the infrastructure throughout the National Health Service (NHS).[1] This will facilitate data aggregation for two reasons. Firstly NPfIT will reduce the number of clinical systems; and secondly, making them all compatible with a national information Spine will facilitate information sharing. In addition, the move to a single comprehensive controlled vocabulary for structured data, SNOMED-CT (Systematized Nomenclature of Medicine – Clinical Terms), will make it easier to transfer data between different services, including the primary care computer record.[2] New contractual arrangements for general practitioners (GPs) will provide a further boost to record structured data, and build upon existing data quality initiatives.[3] The new GP contract includes financially incentivised, evidence-based quality targets, such as measuring and controlling cholesterol in patients with ischaemic heart disease.[4] A limited set of general practice computer codes is used to monitor progress towards achieving these targets.

Current experience would suggest that even where there is a single national coding and classification system, variation and complexity exist. In the UK, we currently have a single coding system, often referred to as the 'Read codes'. However, this has a number of versions, including the 4-byte and 5-byte variants of the earlier hierarchical system, as well as the more complex concept-based Clinical Terms Version 3.[5] This is further complicated by a number of other factors: one system does not use the Read drug dictionary, preferring a proprietary alternative; some general practice computer systems allow the user to create their own codes and add them to the classification or have them as free-standing unmapped items; the coding systems are dynamic: new codes are added all the time without old ones being removed. Generally the older codes from previous coding and classification systems, which are often more generic, cannot be mapped forward and therefore are left accessible via the coding look-up engine. There is an old adage in informatics: 'You can map many to few; but you can't map few to many'. Where a more general code exists it can be mapped to more specific ones; but more specific codes cannot be mapped to generic ones. For example, the ethnicity code 9S6.. for 'Indian' can't be readily mapped forward to the more detailed 9i... codes. For example, 9SA4. – North African Arab/Iranian has several alternative codes in the 9i... hierarchy as 9iF.. – Other, 9iFA. – North African or 9iFD. – Iranian. These newer codes allow a larger number of codes covering more specific ethnic backgrounds. Sometimes these older codes are selected because their less specific nature fits better with the more generic nature of primary care.

Routinely collected data from general practice is an underused resource. It has the potential to be harnessed to provide information about the quality of care, data for health service planning, and can also be used for research.[6] This paper describes the method which we have developed for working with primary care data for over ten years and provides examples of the clinical analyses that are underpinned by this approach. We describe the systematic approach we use to take account of the complexities of primary care data.

## Method

### Introduction:

Our method has three elements:

1 a system for ensuring traceability of any data processed, which is applied across all projects undertaken
2 a design method which ensures proper planning and piloting of data extraction
3 a processing system with quality controls at each stage.

### System for ensuring traceability

It is important that data used for analysis is traceable, that is, any data item can be checked back to its source data. To achieve this we have identified a number of components which must be labelled in every project. These are:

- a query library – which holds the queries used to extract the data for the project
- listing and storage of a copy of the look-up tables used to code and decode data. Generally this will consist of a Read look-up engine, either a defined version of CLUE (Clinical Information Consultancy Look Up Engine)[7] or Triset browser.[8] We usually also need to specify additional look-up tables where a clinical system does not use Read codes for drugs or uses system-specific codes
- unique identifiers for each practice, primary care organisation (PCO) and patient. The unique identifiers for each practice and PCO are arbitrary numbers which are only linked to their originating IDs on a separate secure server. We compound these

numbers with unique arbitrary references extracted from practice systems, which we convert into case-insensitive, numeric-encoded ASCII (American Standard Code of Information Interchange) format so they can be used in a range of database tools

- finally, a system of metadata headers ensures that those cleaning, processing and analysing these data know what is original and what is derived data, and the queries from which the data were derived.[9]

## Design

All data projects require careful planning. Design processes need to meet the objectives of any given project but need to be flexible and evolve. As our projects are usually clinically focused we need to define: (1) the dataset we plan to extract, (2) audit criteria, and (3) an analysis plan before data collection commences.

As the capacity and capability of computer systems have increased, so we have been able to extract and aggregate more data and perform more complex analyses. We judge whether output is up to standard by using the definition of data quality used in total data quality management (TDQM) as data fit for purpose by its consumers:[10] that is, in our case, data useable to improve chronic disease management, to improve the health of populations and for research.

The design process also includes the production of project documentation, and ensuring the process meets the standards set out in information governance and research ethics guidelines. We conclude the design stage by piloting the data extraction and processing. Important lessons learned from this are fed back into the design process.

## Process stages

Our method of processing data has seven further distinct steps after the design phase.[11] The phases are an adaptation of taxonomy for error classification published by Berndt *et al*,[12] developed in the context of quality assurance of the healthcare data warehouse.

These are:

1 appraising data entry issues
2 data extraction
3 migration of the data into the data repository
4 integration of the data with other data sources
5 data cleaning
6 data processing
7 data analysis.

Appraisal of data entry is important as many things can influence what is recorded in computerised records. These range from bias associated with particular picking lists to the potentially distorting effects of targets. Previously, data extraction was exclusively carried out using Morbidity Information Query and Export Syntax (MIQUEST), a Department of Health-sponsored data extraction software. More recently a broader range of tools have started to become available (such as the Apollo SQL Interface[13] and the proprietary extraction of the entire practice dataset from back-up tapes); as computer systems become compatible with the national Spine, so the scope to extract data will increase further.

Migration and integration of data require careful control. We have developed a system of metadata that allows consistent titles to be applied to data from the point of extraction to that of analysis. We use a variable name (effectively a column header) compounded from a number of sources. The first part of the variable name is a bi-gram which describes the type of data; next comes a repeat number to say whether this is the first time the data item has been collected; and, finally, the Read version 2 code for the data item being collected.[9]

Data cleaning involves removing out-of-range values and converting values where there is clearly a mixture of units (for example, heights in metres and in centimetres are all converted into metres). Data processing involves looking at the frequency of all the codes within each variable; converting them into plain English; and then grouping them into useful categories to meet the audit criteria or analysis plan defined at the design stage. Data analysis is done in a standard statistical analysis package; we generally use SPSS (Statistical Package for Social Sciences).

Our first step in analysis is ensuring that we have an accurate population denominator; without this much of the analysis would be meaningless. Although UK general practice has a system of registration that should only allow individual patients to register with one GP at a time, GP lists are known to be inflated above the population numbers shown in the census data.[14] Practice list turnover also appears to influence recorded prevalence of disease: the higher the turnover the lower the apparent disease prevalence. Data loss occurs as only paper records are transferred between practices, and structured, coded data has to be manually re-entered.

We next examine the prevalence of the disease or problem being investigated. Local variation in age–sex profile influences disease prevalence, as inevitably most chronic disease increases in prevalence with advancing age. For single practices, providing age–sex profiles compared with the national average is usually sufficient to convey an understanding of why prevalence might be different – we do this using bar charts or population pyramids.

The rest of the analysis generally follows the pattern of investigating key risk factors, co-morbidities and use of therapy, as defined in our audit criteria and analysis plan.[15]

## Orientation of programme

Our method always involves feedback of clinically relevant evidence-based comparative data to the end-user of systems who have provided the data. This is summarised both at the practice and locality level, and in our view is best done in a non-judgemental educational context.[3]

# Results

## Design

Defining the dataset to be extracted, developing robust audit criteria and devising an analysis plan are critical parts of managing a research study. Box 1 shows the dataset used and audit criteria from an atrial fibrillation (AF) study, designed to investigate whether there was scope to further improve the quality of care of patients with AF.[16]

## Overcoming the barriers to data entry

Problems can arise because of confusion about the classification system. Bronchitis provides examples of this. In patients with bronchitis it is not obvious from the coding screen (see Figure 1) that the H06 code should be used for acute disease, and that any of the codes that belong to the H3 hierarchy imply the patient has chronic obstructive pulmonary disease (COPD). This picking list is taken from one particular general practice computer system; other systems offer different lists which could bias code selection in a different way.[17]

## Example output from routinely collected general practice data

Examples are provided of output from: (a) a large cross-sectional study; (b) data used to identify at-risk groups; and (c) early results from the use of a new therapy. In a study based on a population of 2.4 million patients we were able to demonstrate, based on general practice data collected in 2002, that half of patients with coronary heart disease had their cholesterol raised above the target level of 5 mmol/l, and of these only half were prescribed a statin (see Figure 2).[18]

We have processed data to identify groups of patients at risk. We have calculated the glomerular filtration rate (GFR) in patients with creatinine recorded to assess whether they have chronic kidney disease (CKD). We have also assessed stroke risk in patients with AF. In both cases patients at risk were identified who could benefit from readily available, low-cost, evidence-based interventions.[19] Table 1 shows the proportion of people with stage 3 to 5 CKD who have cardiovascular disease, hypertension and diabetes.

Table 2 demonstrates there are considerable numbers of people with atrial fibrillation suboptimally managed (only the data for male patients is shown, but the same phenomena were seen for females).

We have also used this method of data collection to monitor the efficacy of the cholesterol-lowering drug ezetimibe. Early data from 12 practices suggest that it achieved similar lowering results to that reported in clinical trials.[20]

## Where data are difficult

Although we can graph the age–sex profile of the practice, ethnicity data important in many disease areas (including CKD) are usually recorded in *less than 0.5%* of cases.[19] We were also not certain whether undiagnosed CKD in computer records was due to poor computer data quality or true failure to record this diagnosis in GP records. Only a manual search of 500 paper records confirmed that the computer data were reliable.[21] Data quality is also variable between different clinical areas. The input problems associated with the diagnosis of bronchitis make it hard to extract meaningful data about COPD from general practice computer records. The situation is even more difficult in osteoporosis. We have collected data from 78 practices and found that practices use different codes to label the same group of patients. Many more patients are on anti-osteoporosis therapy than have the diagnosis.[22] However, feedback of the inter-practice variation in data recording does seem to improve data quality.[23]

# Discussion

Improvements in data quality, and the capacity and capability of information and communications technologies, mean that progressively more use can be made of routinely collected general practice computer data. However, the interpretation and processing of primary care data is a complex task. Informaticians need to develop systems for processing that take into account the complexity of these data. Their methods need to be shared in an open way so that it is transparent to the users of their output how they have derived meaning from the structured data they have extracted. The clinical consultation is a complex narrative between clinician (often a GP) and patient. This

**Box 1** Example of dataset and audit criteria taken from a study to examine whether there was scope to improve the management of atrial fibrillation (a heart rhythm disorder with an increased risk of stroke)

**DATASET**

| | |
|---|---|
| *Demographic details* | *MIQUEST unique ID, age and sex* |
| Diagnostic data | Atrial fibrillation, hypertension, diabetes, coronary heart disease, TIA (transient ischaemic attack) or stroke, heart failure, mitral valve disease |
| Cardiovascular risk factors | Blood pressure, BMI (body mass index), smoking status, cholesterol level, electrolytes, ECG (electrocardiogram) recording, echocardiogram results, INR (international normalised ratio) |
| Drug treatment | Warfarin, aspirin, clopidogrel, dipyridamole, digoxin, ACE inhibitors |

**AUDIT CRITERIA**

1 Co-morbidity
- The percentage of people with AF who have cardiovascular co-morbidities recorded, including previous stroke or TIA, diabetes and heart failure
- The number of people with mitral valve disease or a history of rheumatic fever

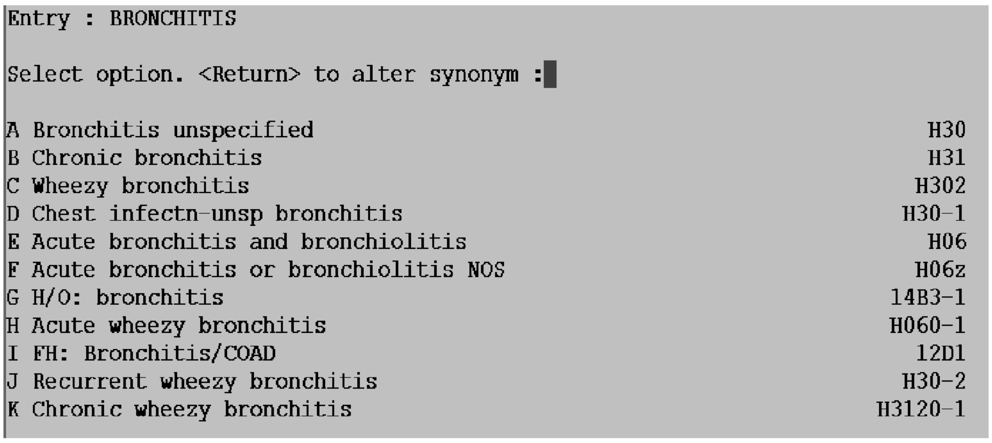
2 Blood pressure management in AF
- The percentage of people with a blood pressure recorded
- The percentage of people with a blood pressure above the 140/85 mmHg and 150/90 mmHg thresholds

3 Left ventricular hypertrophy
- The percentage of people with an ECG or echocardiogram result
- The proportion of these that indicate left ventricular hypertrophy

4 Lifestyle in people with AF
- The percentage of people with a smoking habit and BMI recorded
- The proportion of smokers and those with a raised BMI

5 Lipids and monitoring of electrolytes
- The percentage of people who have had their cholesterol measured
- The achievement of national targets (<5 mmol/l for total cholesterol)
- The percentage with electrolytes recorded, and number with hypo- or hyperkalaemia or impaired renal function

6 Anti-thrombus and anti-coagulant treatment
- The percentage of people with concurrent cardiovascular disease who have been offered anti-platelet or anti-coagulant therapy; and the proportion where therapy is current (prescribed in the last three months)
- Recording of contraindications to aspirin and warfarin
- Proportion of those currently on warfarin with an ‘in range’ INR (2.0 to 3.0)



```
Entry : BRONCHITIS

Select option. <Return> to alter synonym :

A Bronchitis unspecified                                H30
B Chronic bronchitis                                    H31
C Wheezy bronchitis                                    H302
D Chest infectn-unsp bronchitis                       H30-1
E Acute bronchitis and bronchiolitis                    H06
F Acute bronchitis or bronchiolitis NOS                H06z
G H/O: bronchitis                                    14B3-1
H Acute wheezy bronchitis                            H060-1
I FH: Bronchitis/COAD                                  12D1
J Recurrent wheezy bronchitis                         H30-2
K Chronic wheezy bronchitis                         H3120-1
```

**Figure 1** Examples of where there is potential for confused data entry: it is not obvious that H06 should be used for acute bronchitis and H3 for COPD

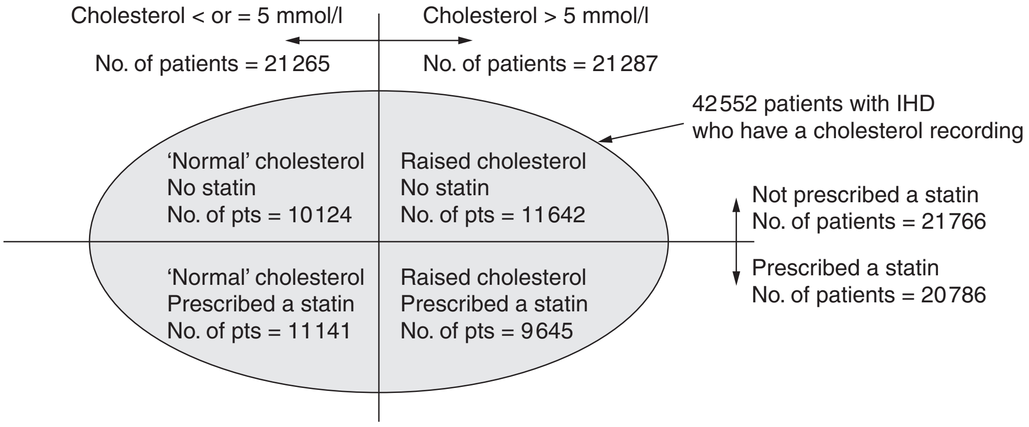


**Figure 2** Rule of halves for management of cholesterol in patients with heart disease

**Table 1** Proportion of patients with cardiovascular disease, hypertension and diabetes with normal or mildly reduced GFR compared with those with stage 3 to 5 chronic kidney disease

| Subgroup | Patients with GFR ≥60 ml/min/1.73 m$^2$ | | Patients with GFR <60 ml/min/1.73 m$^2$ | | | All | $\chi^2$ |
|---|---|---|---|---|---|---|---|
| Qualitative descriptions | Normal GFR (>90) | Mildly reduced GFR (60–89) | Moderately reduced GFR | Severely reduced GFR | Kidney failure | | |
| Stage of CKD | | | Stage 3 | Stage 4 | Stage 5 | | |
| Number | *n*=5791 | *n*=17 619 | *n*=5191 | *n*=211 | *n*=47 | *n*=28 859 | |
| All cardiovascular disease | 21.9% | 43.0% | 74.3% | 83.9% | 89.4% | 44.8% | *P*<0.001 |
| Diabetes | 7.7% | 9.6% | 14.9% | 25.6% | 19.1% | 10.3% | *P*<0.001 |
| IHD | 4.9% | 13.2% | 26.5% | 31.8% | 23.4% | 14.1% | *P*<0.001 |
| Heart failure | 0.4% | 1.3% | 8.5% | 17.5% | 8.5% | 2.6% | *P*<0.001 |
| Peripheral vascular disease | 0.6% | 1.1% | 2.8% | 6.2% | 2.1% | 1.4% | *P*<0.001 |
| Cerebrovascular disease | 1.9% | 4.5% | 11.9% | 14.7% | 14.9% | 5.4% | *P*<0.001 |
| Hypertension | 13.2% | 31.0% | 55.4% | 64.5% | 80.9% | 32.1% | *P*<0.001 |
| BMI recording | 67.1% | 75.9% | 77.2% | 73.5% | 70.2% | 74.3% | |
| BMI mean | 26.2 | 27.3 | 27.6 | 27.0 | 28.3 | 27.1 | *P*<0.001 |

is recorded as a mixture of narrative (free-text) and structured and/or coded data. The informatician usually only extracts the coded data, with associated dates and numerical values, and derives meaning from this.

Greater standardisation of data recording between practices also has a role to play in improving the information that can be derived from general practice computer system data. This can be achieved by taking part in data quality programmes like PRIMIS+,[24] reducing the number of different computer systems that practitioners use, and looking to achieve more standardisation in the approach to managing conditions. The 2004 new GP contract, with its associated financially incentivised quality targets, has also had an effect on clinical coding, by specifying particular codes upon which performance will be measured. Across

**Table 2** Management of male patients with AF by degree of risk

| Males | No. of cases (*n*) | % of people with AF | % prescribed warfarin | % prescribed aspirin | % hyper-tensive | % diabetic | % heart failure | Mean systolic BP (mmHg) | % smokers |
|---|---|---|---|---|---|---|---|---|---|
| Level of risk | | | | | | | | | |
| Very high: previous ischaemic stroke or TIA | 87 | 17.3 | 51.7 | 31.0 | 55.2 | 10.3 | 20.7 | 137.0 | 32.2 |
| High: age over 65 and one other risk factor, from: hypertension, diabetes, heart failure, left ventricular dysfunction | 202 | 40.2 | 43.1 | 30.2 | 75.2 | 26.7 | 34.2 | 137.5 | 30.7 |
| Moderate: age over 65, with no other risk factors, or age under 65, with other risk factors | 141 | 28.0 | 42.6 | 30.5 | 22.0 | 7.1 | 3.5 | 135.9 | 32.6 |
| Low: age under 65, with no other risk factors | 73 | 14.5 | 28.8 | 15.1 | 0.0 | 0.0 | 0.0 | 129.2 | 35.6 |
| Total/overall rates | 503 | 100 | 42.3 | 28.2 | 45.9 | 14.5 | 18.3 | | 32.2 |

much of the rest of Europe primary care uses the more limited International Classification of Primary Care (ICPC).[5]

General practice data has limitations. There are problems with the denominator, which is known to be inflated.[14] Data are inevitably incomplete for a variety of reasons, and missing data requires careful interpretation. The meaning of medical language and medical knowledge change with time, making it important to interpret data in the context of the time at which it was reported.

Rector has challenged the reuse of routinely collected data and stresses the difficulty of data collected in one context being used in another.[25] However, despite its limitations there has been a growth in the usage of general practice data, as reflected by the large numbers of databases that are listed in the Directory of Clinical Databases (DoCDat).[26]

Further research is needed to explore how to increase the low levels of ethnicity recording, and how to link more effectively to social class data than just using postal codes. Merging data with other sources from other agencies remains underdeveloped. Linkage to social services data may be problematic as social services use event- or problem-centred rather than person-centred records (for example, social services may have a case conference, the output of which contains important data about many individuals, whereas health records usually just relate to one individual).

## Conclusions

Improvements in technology and data quality have meant that larger datasets can be extracted from clinical systems and processed in more sophisticated ways. There is a growing evidence base that routinely collected general practice data is used in audit to improve the quality of chronic disease management, for health service planning and research. Informaticians and epidemiologists need to publish more details about their methodologies, so that the consumers of their outputs know they have taken into account the complexities of primary care data.

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## CONFLICTS OF INTEREST

None.

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