Time for research networks to be trained in informatics and based within informatics centres

Simon de Lusignan MSc MD(Res) FHEA FBCS CITP FRCGP
Professor of Primary Care and Clinical Informatics, University of Surrey, Guildford, UK

Introduction

Public investment in research is thought to underpin a lot of UK business success and there has been considerable investment to make greater use of healthcare data for research. UK Universities, recognised to be an international success, provide much of our research infrastructure. Approximately 10 years ago it started to be recognised that the potential to carry out research within the NHS was not being realised. In recent years there has been a growing realisation that the UK has not been exploiting the enormous research potential offered by the NHS.

Since then we have seen the creation of a much more efficient and effective research network focused on supporting applied clinical research. In January 2005 a new national health research strategy was produced, with the mission:

...to create a health research system in which the NHS supports outstanding individuals, working in world-class facilities, conducting leading-edge research, focused on the needs of patients and the public.

This strategy has led to the creation of a National Institute for Health Research (NIHR); with a national portfolio of trials, clinical research networks and topic specific networks in national priority areas including a Primary Care Research Network (PCRN). They are all focused on supporting applied clinical research and facilitating access to patients.

The English NHS is has well established, stable and comprehensive computerised medical data; albeit that hospital data are largely highly structured and complete datasets about episodes of care, whilst primary care records much less well structured data with each encounter with a patient. The national hospital dataset is known as Hospital Episode Statistics (HES) while primary care data are coded using the Read terminology.

In such an environment it is likely that computerised data will be ever more important in helping researchers identify eligible cases for studies. This editorial reports the current state-of-the-art in using computerised records for case finding and suggests what more might be done.

Finding people to participate in trials

Many research studies start with a ‘database search’ – a search of computerised medical record (CMR) systems to identify cases eligible for studies. However, these searches often fail to recognise the complexity of primary care data. The protocols for such studies are usually written in isolation from the constraints of the coding systems used to record data, and rarely written taking into account what data are actually recorded in primary care. There may need to be mapping of the concept used in the study protocol to the best available term within the clinical coding system (e.g. can ‘Coronary artery disease’ be mapped to ‘Ischaemic Heart Disease’?).

Understanding the context of data recording is critical for interpreting data

Much coding in primary care and record keeping has evolved to support direct patient care with little
thought that these data may also be used in research. Using data recorded for one purpose, for another has problems. Chronic obstructive pulmonary disease (COPD) and diabetes provide examples of diseases which should have a clear-cut diagnosis but finding cases from routine data are fraught with difficulty.\textsuperscript{8,9}

The context of data recording is further complicated by both doctors and patients adopting behaviours to support their preferred outcome. We have recently interpreted discrepancy in doctor and patient reported symptoms as reflecting patients wanting to achieve their desired outcome (an antibiotic) while doctors record sufficient information to justify their action (prescribing or not).\textsuperscript{10} There may also be a gap between clinicians and managers perceptions of what the coding process represents; clinicians seeing coding as part of a sociotechnical interaction with the patient.\textsuperscript{11}

The First Law of Informatics states that data can only be used for the purpose for which they are recorded;\textsuperscript{12} though the Second Law states you can ignore the First Law if you fully understand the context of the data recording.\textsuperscript{13}

Analysing study recruitment requirements

Conceptually the requirements for recruiting into a study can be divided into: (1) demographics of the patients required, or who should be excluded. Generally this relates to age, gender and ethnicity; (2) case finding – what defines a case or subject for your trial. For each case or subject there can be comorbidities, risk factors, and therapy which make up inclusion or exclusion criteria; and (3) depending on the study design it may be necessary to recruit or identify control groups.

Do research networks have the required informatics skills?

Data extraction is a complex business.\textsuperscript{14,15} If research networks run searches of low sensitivity and specificity it will mean that cases needed for trials will be missed and that people will be called in unnecessarily who were actually not eligible for a trial. This all adds overheads and inefficiency as well as risking alienating members of the public who unnecessarily have their time wasted.

Linking research networks to informatics centres?

Informatics should not be seen as peripheral to or a bolt on extra to research networks. It should be seen as integral, like statistics. Whilst it would be inconceivable to develop a trial protocol without statistical input, studies which involve case finding from routine data will usually not include an informatician.

Those engaged in facilitating research should be trained in clinical informatics and have an in depth knowledge and understanding of the architecture and structure of clinical records as well as to how to case find in routine data.

It is time for research networks to be trained in clinical informatics and be based within clinical informatics centres.

REFERENCES

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