

BUILDING AN ELECTRONIC DISEASE REGISTER

getting the computers to work for you

Alan Gillies, Bev Ellis and Nick Lowe

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to work for you

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What this book is about

This book has two aims. The first is to demonstrate that computers can work for you and not the other way around. No, please don't laugh ... it really is possible. Computers can play a major role in improving patient health and patient care.

However, in order to achieve this, it is necessary to do a number of things:

- computerise patient records
- implement systems to process those records in accordance with best known practice and available evidence
- change working practices and procedures
- train staff to give them new skills
- manage the process of change.

Thus the second aim of the book is to show how to do these things in practice. We shall use the example of an electronic coronary heart disease register (CHD) to show how this may be achieved.

We shall draw upon a case study from a local primary care group (PCG) where we shall consider the implementation in two practices, with different proprietary general practice systems. We shall consider the example from the perspective of a GP and a practice manager.

How the book is organised

The first section of the book provides an overview of the process of implementing an electronic disease register and the issues involved.

The second part of the book shows how Fylde PCG have implemented their coronary heart disease register.

The third part of the book considers future developments, including the impact of the NSF CHD.

The Appendices include more information about products and services that may be helpful.

The clinical computer system suppliers inevitably modify and reconfigure their systems to meet the changing needs of the NHS. This means that practices may have slightly different versions or configurations from one another. This book uses specific examples from general practice in the UK (in 2001) and is intended to increase awareness of how the systems can be used to benefit PCG/Ts, practices and, not least, patients. Earlier versions of clinical software may not include all the features described – latest versions may offer enhanced features. Most of the features described are available on the majority of current systems from the main suppliers – if the descriptions do not exactly match your system, please refer to your current system manuals and training support teams.

About the authors

The book is the result of a collaboration between three authors each bringing their own perspective:

Professor Alan Gillies is Professor of Information Management at the University of Central Lancashire. He is an academic with 12 years experience of working with the NHS on information issues.

Beverley Ellis is Practice Manager with the Ash Tree House Surgery in Kirkham, Lancashire. The practice is an NHS Beacon site for informatics, and was one of the first users of the VISION system in the UK.

Dr Nick Lowe is a GP in Lytham, at the Holland House Surgery. He is an active member of the EMIS User Group and was responsible for the practice's award winning web site: www.lythamsurgery.co.uk.

The purpose of telling you this is not to blow our own trumpets, but rather to indicate the perspectives from which the authors come.

Acknowledgements

At the risk of sounding like an Oscar ceremony, this book has been made possible by the collaboration and co-operation of a wide range of people including, but not exclusively:

- Fylde PCG for giving permission to use them as a case study.
- The staff of Holland House Surgery and Ash Tree House Surgery.
- In Practice Systems and EMIS for their help in relation to the implementation sections.
- John Howard, Health Informatics Unit, UCLAN for the screen shots from the GPIMM and TNAMM tools.
- Magnus Hird at Blackpool PCG and Dr Hilary Devitt from Leeds NE PCG for contributing the CHD code matrix and content in Chapter 9. This is work still in progress (December 2000).

The authors wish to express their grateful thanks to all who have helped.

Part One

The process of implementing an EDR



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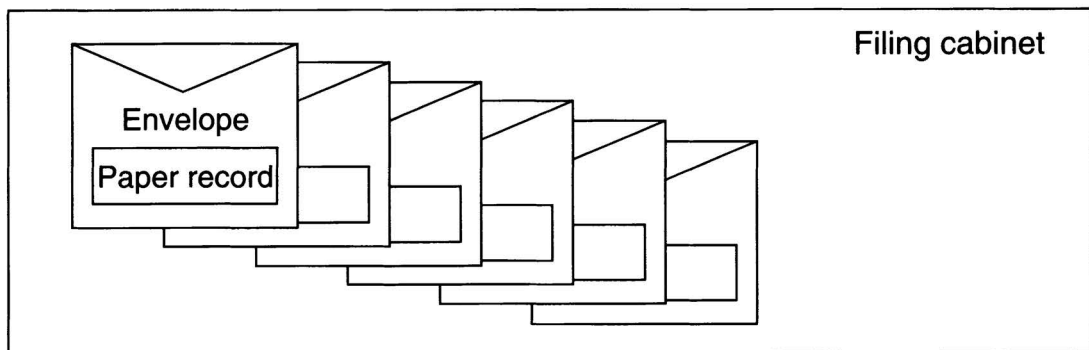
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Chapter 1

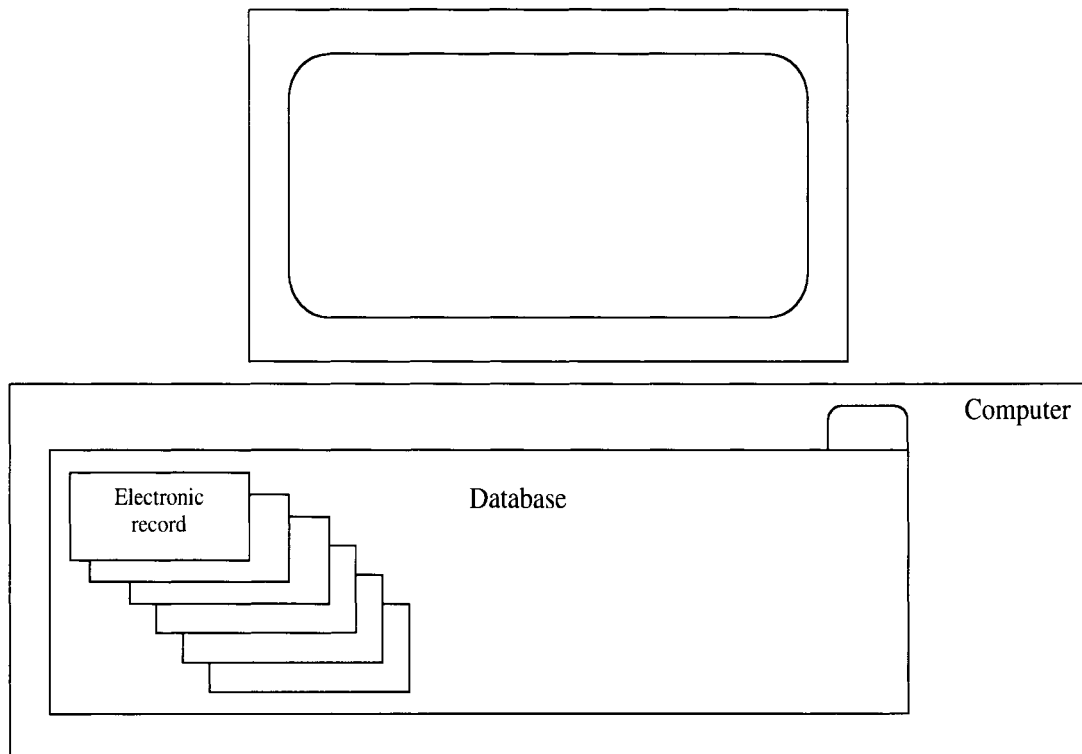
What is an electronic disease register?

The foundation for any patient records system are the records themselves. Traditionally, they have been held on paper, kept in brown envelopes and filed into a crude system by arranging them into alphabetical order within a filing cabinet:



Schematic representation of a paper-based clinical records system.

A computerised record system may be viewed in a similar way:



Schematic representation of an electronic patient records system.

However, the superficial similarity can be misleading. The paper-based system exists within a passive container. The database holding the electronic records is active, bringing with it the possibility of automating many information management functions.

At its simplest, the database management system allows us to sort the records in a wide range of ways:

- by surname
- by date of birth
- by home postcode etc.

The next function is the ability to filter records, i.e. to pull out a sample of the population with specific characteristics, e.g.

Women patients between the ages of 18 and 65

or

male patients in the age range 35–50 who are overweight, smoke and with a family history of CHD.

Whilst this can be done by manual inspection of paper records, for any significant population, the task is laborious and unreliable.

A traditional disease register is a collection of patients with specific characteristics. At its simplest, it might be regarded as a list of patients with a specific diagnosis. However, as healthcare moves towards prevention and health promotion, so disease registers are becoming prospective in identifying groups of patients considered 'at risk'.

Thus for CHD, factors identifying patients 'at risk' would include:

- adverse Body Mass Index (BMI)
- smoking
- heavy drinking
- diabetes
- family history of CHD, and so on.

As disease registers become more and more prospective in nature, the need to make them electronic in order to keep them reliable and manageable becomes greater and greater.

A further dimension is provided by clinical governance. This places a clear requirement to demonstrate in a verifiable way that practice conforms to best evidence. The electronic system has the potential to both guide the clinician in accordance with protocols and guidelines and to audit practice.

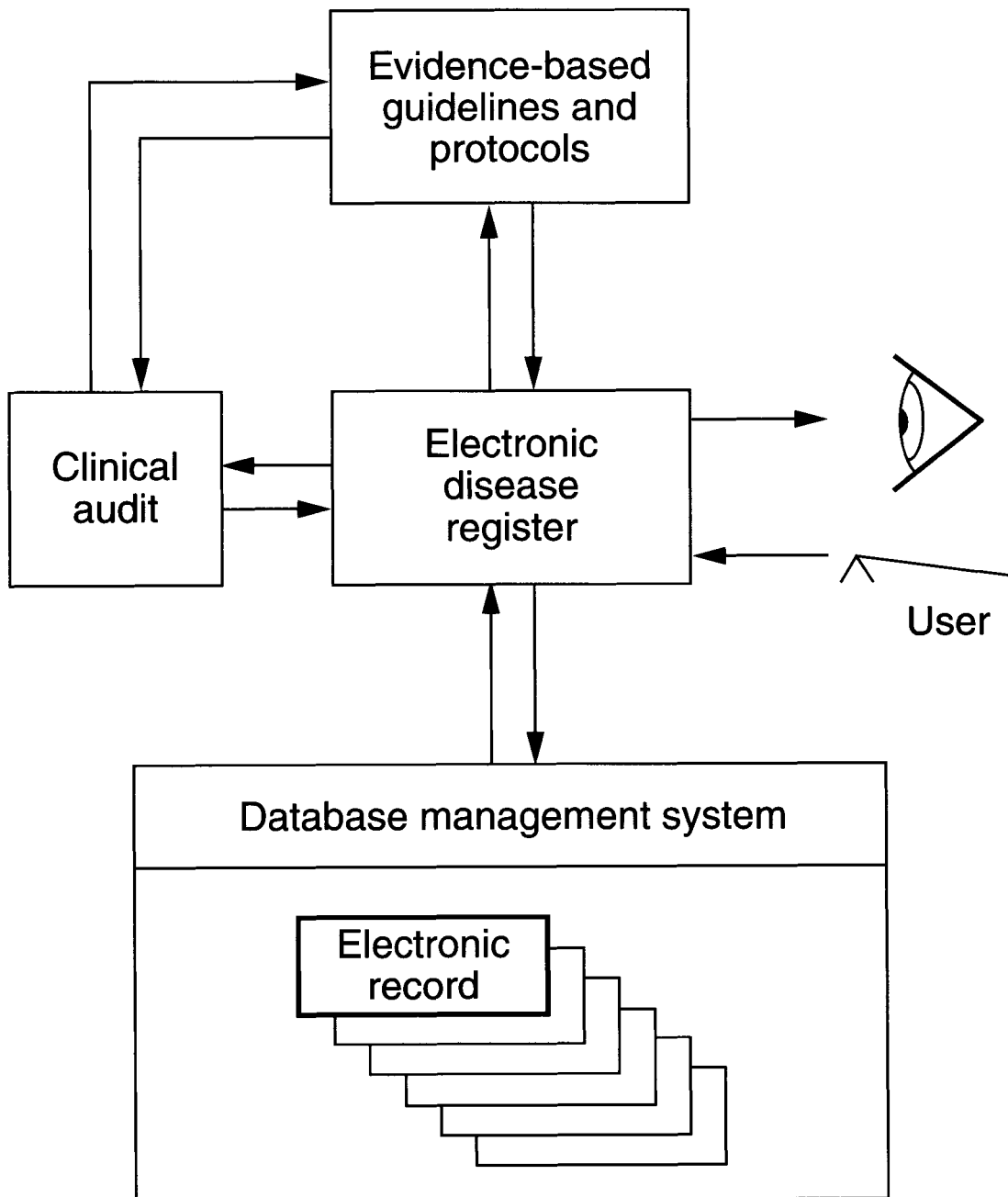
Thus our electronic disease register may be regarded schematically as shown overleaf.

The clinical benefits obtainable from such a system promise to be a reliable, comprehensive, accurate and workable disease register capable of identifying and helping to manage 'at risk' patients, with consequent reductions in adverse events. The management benefits promise efficient use of resources, auditable performance monitoring, and improved health outcome measures.

However, as most of us know from bitter experience, computers rarely deliver nice, neat, simple solutions, and the reality is often complex, difficult and frustrating. In the rest of this book, we shall seek to minimise those frustrations and barriers and facilitate delivery of some of these promised benefits.

In the next chapter we shall consider the fundamentals of establishing a computerised patient records system, on which an electronic disease register depends.

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Schematic representation of an electronic disease register.

Chapter 2

Computerising patient records

The problem with computers

In spite of the upbeat tone of the previous chapter, the reality of computing within the NHS is rather different. People's experiences are often negative. This has been due to a number of factors, including the following.



Seven reasons for the current state of information in primary care

- The focus has been on the computers and not on the information.
- Computers have traditionally been time consuming to use, and worse they have not given back commensurate benefits.
- Staff have traditionally received little formal training.
- The NHS has been subject to frequent policy changes meaning that system designers have been shooting at a moving target.
- In primary care, much of the initial development was focused upon management developments to support fund holding rather than clinical developments.

- The English NHS woke up rather late to the need to share clinical data between practices. As early as 1993, some authors (alright, it was me, but not just me!) pointed out that the development of incompatible proprietary systems would inhibit progress.
- There has never been a policy of investing in clinician time to extend consultations to allow them to enter data during already short consultations.

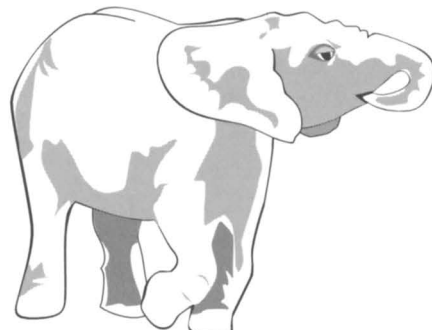
There have also been a number of myths that have contributed to the current, less than ideal, state.



Five myths about information management and technology for primary care

- IT is a magic bullet solution that will solve problems on its own.
- Computer systems are intuitive and do not need training for physicians.
- Data entered onto computers as freetext is useful.
- Medicine can be reduced to a series of prescriptive algorithms.
- There is good evidence available for much of primary care.

This has led to a common perception that computers are more trouble than they are worth, a view that the author has characterised as the elephant view of health information systems.



Spot the similarity?