The HEARTS collaboration – delivering improved secondary prevention of CHD for patients with heart disease

The HEARTS collaboration in Tayside has successfully set up an integrated electronic database to help fully implement measures for the secondary prevention of heart disease in the region.

Abstract

Full implementation of the available evidence on secondary prevention should ensure that all patients after myocardial infarction should be offered both effective treatment and be maintained on treatment. This article describes the Heart disease Evidence-based Audit and Research in Tayside Scotland (HEARTS) collaboration which has been set up to try and achieve this. HEARTS can collect electronic data from many sources; prioritise data from multiple sources, such as hospital and general practice; process and link patient records; and, allow manual validation of electronic data. It can also facilitate clinical governance issues in general practice and hospital plus disseminate information to patients. It is hoped that, in addition to secondary prevention, it will be able to extend its focus to other aspects of cardiovascular disease in the future as well as being used for epidemiological and qualitative projects. The system maintains the security and rights of patients at all times.

Key words: record linkage, electronic patient record, chronic disease management, National Service Framework, managed clinical network.

Br J Cardiol 2002;**9**:634-8

Introduction

Implementing the evidence on secondary prevention is as challenging as discovering which interventions are effective.[1,2] The HEARTS collaboration (Heart disease Evidence-based Audit and Research in Tayside Scotland) is achieving that goal by extending the already successful DARTS model (Diabetes Audit and Research Tayside Scotland) to the secondary prevention of coronary heart disease.[3] This paper describes some of the key features of a process that started during 2000 in the Tayside region of Scotland with a regional consensus conference to consider a response to the 41st guideline from the SIGN (Scottish Intercollegiate Guidelines Network).[4,5]

Table 1. Contribution of modern cardiovascular treatment and risk factor changes to the decline in CHD mortality in scotland between 1975 and 1994

Hypertension treatment		9%
Secondary prevention treatments		8%
Heart failure treatments		8%
Aspirin for angina		2%
Measurable risk factor reductions		
	Smoking	36%
	Cholesterol	6%
	Secular fall in blood pressure	6%
	Changes in deprivation	3%

From *Heart* 1999;**81**:380-6.

The evidence base

It has been estimated that 4,000 lives could be saved every year in Scotland if the available evidence on secondary prevention was fully implemented[6] (see table 1). Although decisions about any particular intervention will depend upon individual decisions taken by patients and their clinicians, there can be little doubt that some patients are not being offered some effective treatments and that others are not maintained on treatment.[7]

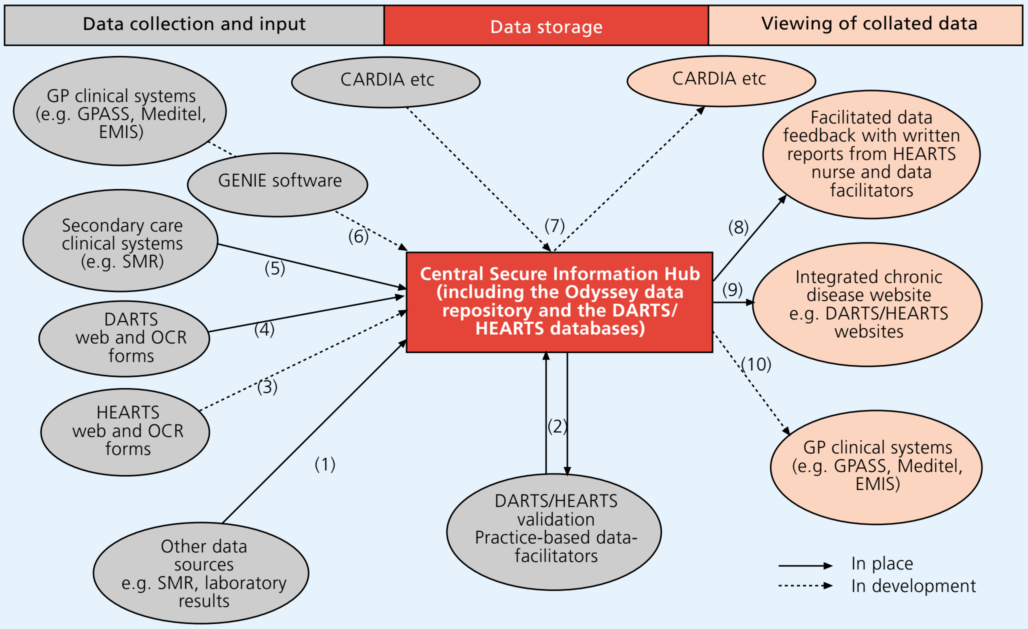
Glossary of terms used in the article

ACHI	Area Community Health Index
CARDIA	Clinical decision support software for ischaemic heart disease
EMIS	Egton Medical Information Systems
GENIE	Generic importer/exporter
GPASS	General Practice Administration System Scotland
OCR	Optical character recognition
SMR	Scottish Morbidity Register
TECCI	Tayside Electronic Clinical Computing Implementation

Key elements of the HEARTS collaboration

The key feature of the HEARTS

Figure 1. HEARTS IT data flow



approach is integration. Following the example set by DARTS, we consulted widely before embarking on this development.[8] The consultation process involved all professions and disciplines in the community and hospital services as well as patients. The principles agreed by our regional consensus were:

- Effective management options for chronic disease should be applied in an equitable manner.
- A regional framework to support and facilitate best clinical practice was needed.
- The framework needs to support a co-operative, integrated, multidisciplinary approach across primary and secondary care.

Key mechanisms proposed were:

- Collaboration and agreement between the NHS and the local universities on the development of a generic managed clinical network facility in the region.
- Establishment of multidisciplinary groups of health care professionals in primary and secondary care committed to a regional approach to improved patient care.
- An agreed organisational structure that emphasises the importance of patient involvement, multi-specialty collaboration, education and training, and clinical governance.

Information sharing

When patients register with a general practitioner (GP) in Scotland they are allocated a unique 10-digit identifier, known as the Community Health Index (CHI) number which incorporates date of birth and sex.[9] Incorporation of the CHI number within routinely collected primary and secondary care data is already almost 100% in Tayside. Access to the Community Health Master Patient Index enables patients to be tracked as they move between areas within Scotland. Because the CHI number is unique, it facilitates direct matching of index cases to subsequent events.[10] Within Tayside, a number of local and national computer systems have already been linked providing direct access to comprehensive patient-level data including information on drug prescribing, hospital admissions, laboratory and other investigations. It is the intention of the NHS in Scotland to create regional repositories of data that enable integrated care.[11]

> ***‘4,000 lives could be saved every year in Scotland if the available evidence on secondary prevention was fully implemented’***

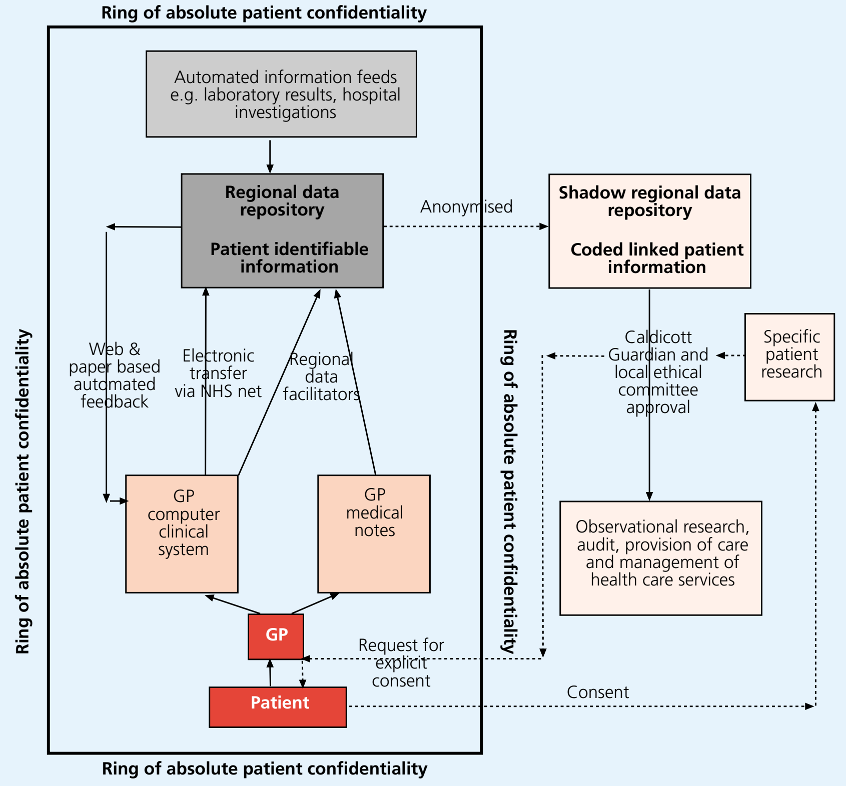
HEARTS collects the majority of its data electronically and four properties are crucial to its success:

- The ability to automatically collect electronic data from many sources.
- Prioritisation of data derived from multiple sources.
- The ability to operate and link patient records regardless of the unique patient identifier (UPI) scheme(s) in place.
- Manual validation of electronic data.

Automatic data collection

Automating the collection of information from different health computer systems in the NHS and elsewhere remains

Figure 2. The HEARTS collaboration – how it all fits together



difficult.[12] HEARTS addresses this problem through the use of a tool, known as GENIE, developed with DARTS, which greatly simplifies the task.[13] GENIE manages the overnight transfer of new or modified data from the practice to a regional computer, where the files are uncompressed and unencrypted. HEARTS takes this data and merges it with patient information already held on the database (see figure 1).

Prioritisation of data from multiple sources

Through a process of consultation between the professions in primary and secondary care, the quality of each data source is determined and a hierarchy established. Each data source is then allocated values indicating its various abilities to provide information on different aspects of disease. When displaying or summarising data, HEARTS uses the best and most relevant source of information at all times. For example, the cardiology clinic is more likely to generate accurate information regarding risk stratification than a general practice. Conversely, a practice is more likely to be accurate regarding the current treatment regime. Cardiology clinic records then take precedence where there is any ambiguity regarding the state of a patient's risk status and a general practice record would take precedence when describing a patient's current treatment regime.

> ***'Ultimately we intend to deliver an integrated approach to the management of chronic disease in the community'***

Patient identifier linkage

To operate across health authority boundaries, a system must be capable of dealing with multiple patient identification schemes and to deal with patients who have more than one number even within a consistent numbering scheme. The system we use supports any number of patient identification schemes and there is no limit on the number of identifiers any one patient can possess (see figure 2).

Manual data collection and validation

Since comprehensive electronic records are rare and we want to provide a high quality of information to support equitable care, some data have to be collected manually. HEARTS minimises this task by identifying data collection holes for a facilitator to target. The five regional data facilitators have several roles including responsibility for the dissemination of patient, clinic and practice

Key messages

- Integrated cardiology services produce improved outcomes for patients
- The key to integration is improved communication: amongst all clinicians involved with cardiac patients; amongst clinicians and patients
- Modern information tools make effective communication easier
- Tayside has implemented a strategy which is being evaluated rigorously

information, providing a human interface to the project, identifying training needs and general help and facilitation. They work with three nurse facilitators whose role is to work with practices to improve care of cardiovascular disease in practice. After a practice validation process has been completed, a meeting is held among the facilitators and the practice team to discuss the meaning and implications of their results.

Information dissemination

HEARTS ensures that information is available to the appropriate users or healthcare professionals and performs extensive data collation in the generation of additional information. This greatly facilitates clinical governance issues in general practice and the hospital service. In addition to patient information, HEARTS provides comprehensive, regionally agreed treatment guidelines and patient leaflets in its attempt to give equal access to data/information for all users.

HEARTS generates information at three levels on a daily basis:

- Population statistics – prevalence, incidence, trends of disease, mortality of other adverse outcomes.
- Practice/clinic statistics – as above, but giving a practice/clinic the ability to view its own activity/performance and compare this to the region as a whole in comparison with the region.
- Patient statistics – data for all patients in a practice/clinic are reported using a variety of screens. These highlight patients lost to follow-up or who have indicators of high risk of adverse outcome.

Web-based guidelines and patient feedback

The increasing accessibility of the internet to patients makes this medium ideal for the dissemination of information.[14] In particular, the ability to cross-reference screens allows for the tight integration of patient data with guidelines, leaflets and service information. These sources are available on our website.

Data security and confidentiality

The UK Data Protection Act of 1998 has led to major difficulties for everyone engaged in record linkage of patient data.[15,16] HEARTS employs a variety of approved mechanisms to maintain security and the rights of patients.

- All communications involving confidential data are encrypted.
- Firewalls and subnet address restrictions help prevent inappropriate access via TCP/IP and the Internet.
- All attempts to log-on to HEARTS and every action subsequently taken are logged producing audit trails.
- Patients must be centrally registered as belonging to a practice before that practice can view that patient's data.

The patient should be ultimately in control of who can access their records. HEARTS supports informed consent though the use of consent granting and denial forms. Should consent be denied, all records pertaining to that patient with the exception of that patient's unique identifiers are deleted. Once consent has been denied, that individual's care is conducted using only their written records.

Research uses of the anonymised database

A regional database with validated numerators, denominators extending 10 years retrospectively and with contemporaneous data collection for prospective research is a potentially valuable research tool. We have already obtained ethical committee permission for several epidemiological and qualitative projects. If approved, we intend to evaluate a number of therapeutic and service reorganisation interventions prospectively.

In order to satisfy the Caldicott guardians we use a cleaning and anonymisation process (CLAM) to de-identify data items such as the CHI, references to a GP either by the NHS identifier or the General Medical Council registration, references to a GP practice, and references to a pharmacy. With these references anonymised, very nearly all the remaining data which can immediately identify individuals can simply be removed from the data sets. For example, all names and addresses and hospital or practice names can be removed without losing any information which might be of use to researchers.

Resources

The nurse facilitators have been funded by Tayside's Primary Care Trust and the NHS has made additional sums available to practices to increase practice nurse hours and meet greatly increased prescribing costs. The HEARTS collaboration received a significant boost by an unrestricted educational grant from Boehringer Ingelheim. The funding has been used to involve a wide range of professionals and to develop the information system described above. We hope that the value to the NHS in Tayside will be demonstrated sufficiently over the next year to ensure long-term funding.

Further development of a managed clinical network

HEARTS will soon move from its focus on secondary prevention following myocardial infarction to other aspects of cardiovascular disease. Ultimately, we intend to deliver an integrated approach to the management of chronic disease in the community.[17] Such a policy is soundly based on the research evidence of which methods effectively work to improve patient care: reminders, educational outreach, interactive educational workshops and multi-faceted interventions.[18] The importance of integration is also being emphasised by the requirements of clinical governance: quality improvement and accountability.[19] What appears to be required for effectively integrated management of coronary heart disease is provision of regular prompted recall and review of people with chronic disease by multidisciplinary teams collaborating across the increasingly artificial primary/secondary care interface.[20] We believe that the HEARTS collaboration, like its diabetic counterpart DARTS, will be shown to be ensuring implementation of 'best evidence' at least as well as our best European counterparts.

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