

REPORT OF THE NHSCR REVIEW GROUP

FINAL VERSION

26 FEBRUARY 2004

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1. FOREWORD

This NHS Central Register (NHSCR) review was conducted at the request of the Minister for Health and Deputy Minister for Justice, recognising that major developments on patient confidentiality had taken place since the NHSCR had last been subject to review. Its aim was to identify the future role and function of NHSCR and to make recommendations on its role, functions and relationships. It also considered the Register's future options in the light of developments in information technology, legislation in relevant areas and changes in the needs of NHSScotland and other users of its data.

The review was carried out over four meetings in the latter half of 2003. The membership of the Review Group is listed at Annex A.

The review established that the NHSCR is a vital component that ensures the smooth running of NHSScotland. It has adapted well to new requirements of law and best practice in the use of personal information. The review group supported the way in which the NHSCR functions and processes to ensure privacy, security and the public interest. It meets the requirements and expectations of key users of the service, primarily NHSScotland and the Registrar General's office. The review group encourages the NHSCR to explain its work to more of its key users and the interested public, develop modern governance arrangements and exploit its resource to support integrated care and to increase knowledge through research. Given medium-term uncertainty over strategic developments of a new and regularly updated population register for wider civic purposes, the Group recommends no change to the NHSCR's management arrangements. The Group commends the current management for its work and its stewardship of the NHSCR.

I wish to thank the Review Group for their work in producing this report.

A handwritten signature in black ink, appearing to read 'Andrew Fraser'. The signature is written in a cursive style with a large initial 'A' and a distinct 'K' in the middle.

DR ANDREW FRASER

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Former Deputy Chief Medical Officer

2. BACKGROUND

2.1 Introduction to NHSCR

The function of the NHSCR is to maintain (on a repayment basis) for the Scottish Executive a register of all NHS patients who are on the lists of general medical practitioners in Scotland, and to supply to NHS Boards, and to approved medical researchers, information held on this register about individuals. The NHSCR has no separate statutory existence. Organisationally, it is part of the General Register Office for Scotland (GROS), a devolved government department headed by the Registrar General.

The currently stated aims of the NHSCR are:

- To record accurately on a database, comprehensively covering Scottish NHS patients, new information about individuals supplied by GROS Vital Events section (about recent births and deaths), by NHS Boards (about movements and changes-of-name), by the Information & Statistics (ISD) and Practitioner Services (PSD) divisions of the Common Services Agency for NHSScotland, by the England & Wales NHSCR at Southport and by other sources.
- To supply information about individuals to NHS Boards, to the Information and Statistics (ISD) and Practitioner Services (PSD) divisions of the Common Services Agency for NHSScotland, to NHSCR Southport (for England and Wales), and to approved medical researchers, timeously and at a reasonable price.
- To maintain by agreement between GROS and the Health Department a repayment arrangement for the NHSCR service.

2.2 History of NHSCR

The registers, which subsequently became the NHSCR, were originally set up in September 1939 very swiftly after the outbreak of World War II with a view to administering (a) the call-up of personnel for military service and (b) food rationing. With the creation of the National Health Service in 1948, and the end of National Registration in 1952, the registers assumed their present role in the administration of the healthcare system. With its current funding and management arrangements, the data may now be regarded as healthcare data in the stewardship of the Scottish Ministers, although a prime input is the register of births and deaths.

2.3 Scope and location of records

The NHSCR holds a record for:

- every patient registered, now or in the past, with a Scottish general medical practitioner (GP);
- everyone born in Scotland since 1985 (and some earlier), who have not been registered with a Scottish GP;
- patients formerly registered with a Scottish GP, who died after 31 December 1992.

A corresponding NHSCR based in Southport deals with all patients registered with a general medical practitioner in England & Wales, and an NHSCR in Belfast with all patients registered with a general medical practitioner in Northern Ireland. The NHSCR Scotland has 18 GROS staff located in Ladywell House, Edinburgh.

2.4 Dataset held

A 'thin' set of data is held about each patient:

- a unique ‘NHS’ number (which, for anyone born in Scotland since 1939, is normally the number of their entry in the register of births and is therefore a ‘birth registration number’);
- a unique Community Health Index number (which is the standard number now used to identify patients for an increasing number of NHSScotland administrative purposes in primary, secondary and tertiary healthcare);
- forenames; surname; former names or other names under which the patient has presented for treatment;
- date of birth;
- current and previous areas of registration with a UK health authority, (with dates) and
- flag(s) indicating membership of particular medical research survey(s), including patients recorded in the Cancer Registry.

NHSCR has no access to General Practitioner information, patients’ addresses, telephone numbers or general clinical data. Some of these data are held on the Community Health Index (CHI). The NHSCR system is matched against the CHI on a weekly basis to ensure that common data items such as name and date of birth are kept synchronised. The only clinical data held by NHSCR– as a flag on the patient’s record- is where there has been a notification of the diagnosis of cancer.

At the beginning of September 2003, the NHSCR held 6.5 million records, of which 6.3 million were allocated to a specific Scottish Health Board and 0.9 million were for deceased patients. Since Census records show that the total population of Scotland in 2001 was just over 5 million, the NHSCR contains a substantial number of additional records. These additional records can be accounted for in the following ways: some patients are now resident

in England or Wales; some patients use multiple names; and some patients have moved away from Scotland without that fact having been recorded.

2.5 Operational Management

The NHSCR is managed as part of GROS. The NHSCR computer system is operated and maintained within the NHS Scotland contract for national IT services.

2.6 The Law, Policy and Service User Expectations

The Data Protection Act 1998, which came into force in March 2000, sets out a framework for the protection of individuals' rights in relation to how information about them is used. This framework is buttressed by the Human Rights Act 1998, which incorporates into UK law the Article 8 of the European Convention on Human Rights guarantee for respect for a person's private and family life. This legislation, as well as the common law duty of confidentiality, and professional and organisational standards in relation to confidentiality and privacy, all have a bearing on the operation of the NHSCR.

Significant policy developments have accompanied these changes in the regulatory environment in relation to privacy. Public services are working ever closer together to help ensure the effective and efficient delivery of services to the population, in order to help safeguard their health and well-being. This move to the more seamless delivery of services can only succeed if relevant and accurate personal information is shared between public authorities, with appropriate safeguards for individuals' privacy in place.

Changes in patients' and service users' perceptions and expectations about how healthcare and other services are provided to them are also a salient feature. Patients not only expect

that they receive appropriate care and support for their well-being as and when required, but also that there are improved outcomes for them as a result of that care and support. Such improvements are only brought about by audit and research. Audit and research activities not only serve the public interest, but also help improve the outcomes and health and well-being of individuals. Together with professional good practice guidance, the report prepared in April 2002 for Scottish ministers by the Confidentiality and Security Advisory Group for Scotland (CSAGS) on protecting patient confidentiality, with the Scottish Executive Health Department's response in August 2003, forms a substantial part of the policy framework in NHSScotland on safeguarding patient privacy.

The task, then, is to strike a careful balance of interests between, on the one hand, adequately protecting patient privacy, and on the other, ensuring that the public interest is served through judicious and responsible use of health data.

3. THE FUNCTIONS OF NHSCR

3.1 Health Purposes

3.1.1 Data Accuracy

A key role for the NHSCR is to improve the quality and accuracy of the information about patients, which is held within NHSScotland. This helps to link the records for patients who have changed name or moved to, or within, Scotland. The NHSCR performs this function by linking closely to the civil registration system and with the corresponding registers covering the other parts of the UK. To understand this role better, it is necessary to set out some background about patient information held within the NHSScotland.

Prior to January 1997, all patients registered with a General Practitioner (GP) in Scotland, or those who have had other contacts with NHSScotland, such as the Child Health programmes, or Tayside Hospitals, have been allocated a CHI number on one or more of 8 local independently operating CHI databases. Under this old system, each time a patient moved from one geographic area covered by one CHI database to another e.g. from Glasgow to Edinburgh, then another CHI record (and therefore additional CHI number) was generated for that patient on the receiving Lothian database. In January 1997 the 8 regional CHI databases were brought together with the creation of a search index. This process ensured that each record was allocated one CHI number that would uniquely identify that record for future. All current authorised users (e.g. Practitioner Services Division (PSD) of the Common Services Agency for NHSScotland) are able to access their local CHI database as before. However, the Search Index gives users access, under strict control, to the other (non-local) CHI databases that cover the rest of the population of Scotland.

There are nightly computer updates from the CHI to the NHSCR database. These are for patients who have registered with a General Practitioner out-with their previous Health Board area, or to reflect a change to any part of the demographic information NHSCR holds. There are weekly electronic updates of death notifications from the NHSCR to the CHI System.

NHSCR interactions with the CHI help to ensure that the record created when an individual makes a new contact with the system has the correct relationship with existing records in the system. Nightly matching and counter matching processing between NHSCR and the CHI enables the control and linkage of potential duplicate records, and ensures that in at least 98% of cases the correct match is made. The remaining cases are returned to the originator of the data with a request for more detailed information. This resolves about half of the problematic cases. The remainder are allocated a new NHSCR number (in a special series prefixed by code 9, to denote the possibility that it may be a duplicate record). The true identity of the duplicate record can often be identified by the NHSCR with the passage of time and, in such cases, the two records are linked.

These processing arrangements are vital to NHSScotland meeting the statutory requirement to maintain accurate personal data, set out in the Data Protection Act 1998.

3.1.2 Medical Records Transfers and Data Updates

A key function of NHSCR is to help Scottish Healthcare providers move patients' medical records across UK borders. Each year, about 250,000 patients move across Health Board boundaries within Scotland and 50,000 patients move in each direction, to or from England/Wales and Northern Ireland. In each case, the NHSCR provides information to "importing" and "exporting" health authority. In a further 600,000 cases per year, changes of name or other data (not involving a change of location) are registered.

3.1.3 Medical Research

NHSCR assists with certain kinds of research projects, and approximately 75,000 disclosures to medical researchers are made annually. Examples are given in Annex D.

NHSCR is particularly useful for forward-looking studies in which the subjects of a study population (e.g. persons employed in a particular industry, resident in a certain area, or who have received certain forms of treatment) are mainly identified by the researcher. Their

records are specially marked on the Register with a code representing the study so that when deaths notified to NHSCR are found to relate to such entries, researchers can be informed of the death and supplied with copies of the death draft entries. Researchers can also be informed of other events that may occur before or after a record has been marked e.g. cancer registrations or for other reasons e.g. name change, area moves, other surveys or leaving the country.

NHSCR also helps with the use of Vital Events data (births, marriages and deaths) for straightforward verification of the status of persons not found when following up research studies. For those found to have died, copies of the forms of particulars are supplied, giving details of the date and certified causes of death. When the death of a specially marked patient occurs in Scotland, (or anywhere in the United Kingdom) NHSCR can, if requested, supply the researcher with a death certificate, bearing the cause of death coded to the World Health Organisation's International Classification of Diseases (currently version ICD10). For approved medical research projects with the appropriate informed consent, NHSCR can also supply cancer registration information, name of the health area in the UK in which the patient is currently registered, notification of change of name, or the fact a person is no longer registered with a UK NHS doctor.

All requests to use the NHSCR database for medical research purposes are submitted to the Privacy Advisory Committee (PAC), details of which are given in Annex B. The principal function of this committee is to protect the privacy of patients while at the same time recognising the need for legitimate access to records by researchers and those involved in health administration for well-defined and bona fide purposes, subject to appropriate

safeguards to maintain confidentiality. Wherever practical, access is only granted to anonymised data.

3.1.4 Tracing

As well as the 6 million plus records on the NHSCR database, a link to Central Register Southport (the English and Welsh Register), which enables only the reading of information by NHSCR staff, is in place. NHSCR also has online access to the indexes of the 36 million births, deaths and marriages registered in Scotland since 1855. This theoretically allows quick access to tracing 'lost patients' for health care providers and approved medical researchers. A 'Traceline' service is in place in England and Wales, on a cost recovery basis, to perform this service. Since March 2000, this service has not been available in Scotland. This is because in March 2000, the Directors of Public Health at the NHS Boards, responsible for safeguarding the patient confidentiality of some of the NHSCR data that had originated from CHI, adopted a cautious approach to such uses of patient data, in the light of the changing legal framework at that time. Some 400 tracing requests were received by NHSCR in 2002-03 for which NHSCR data could not be used. Of these, all but 82 could be assisted using GROS's registration database. The Review Group was made aware that a UN agreement, to which the UK is a signatory, was in existence to allow the kind of tracing which had continued in England and Wales.

3.2 Non-health Purposes

The NHSCR continues in a limited way to perform its original function as a population register for purposes not linked to the health service. The key uses to which the NHSCR is put for these purposes are listed below.

3.2.1 Person Level Data

NHSCR participates in a range of activities for non-health purposes that involve disclosures from individual person records. These include the following:

- Assistance with the prevention and investigation of the most serious criminal offences, after all other avenues have been explored, including war crimes investigations associated with World War 2 and social security fraud. In addition, the NHSCR can offer limited assistance to the Department of Work and Pensions, and their Child Support Agency, in tracing maintenance defaulters. This information only confirms the identity of the individuals, mainly by the use of the GROS registration data.
- Assistance with civil judicial investigations, for such matters as missing persons, wills and estates, in particular those conducted under section 9(1) of the Presumption of Death (Scotland) Act 1977.
- Responding to requests by individuals under the Data Protection Act to view the personal information stored about them on the NHSCR.
- Disclosures of date of birth information to the Department of Work and Pensions where eligibility for a pension or age-related benefit is in question.

3.2.2 Aggregate demographic data

The Registrar General uses NHSCR information on the numbers of patients moving between Health Board areas of Scotland and between Scotland and other parts of the UK, which provide the single most important statistical source for internal migration data. More recently, anonymised information from CHI has also been made available to the Registrar General to provide data for patient movements within Health Board areas, to assist him with the production of Council area and small area population estimates between Censuses.

Whilst not an authoritative count of migrants, these sources are an important input to the production of accurate population estimates between Census years.

4. THE NHSCR IN THE WIDER ENVIRONMENT

4.1 Introduction

It is clear from earlier sections that the NHSCR provides a service to NHSScotland, the Registrar General for Scotland, the health research community and other central registers in the UK countries. It holds a limited data set that interacts with other information held by these organisations, thereby making their operations effective and efficient. This set of relationships, and changes in the role, function and information systems of each organisation, influences the work of NHSCR.

Decisions for changes in NHSCR's function will be influenced by its commitment to efficient operation, developments in information management and best practice that determines the storage, retrieval and linkage of information. But many of the likely influences to affect NHSCR will come from outside.

This section offers a brief description of the key activities and developments of each organisation with which the NHSCR interacts, identifying potential effects on its role and operation. A diagram outlining NHSCR's key external interactions and relationships is at Annex G.

4.2 NHSScotland

NHSScotland commissions and provides health services for all registered patients in Scotland and, on an emergency/humanitarian basis, all visitors to the country. While NHSScotland provides most services, it does so in collaboration with a range of other statutory and voluntary organisations. NHSScotland has entered a period of further organisational change to unify local health services into NHS Board systems. Boards become responsible for public health, strategic management, and integrating acute, primary and community care delivery. Each is developing Community Health Partnerships (CHPs) as a local service delivery organisation with close ties to social care, voluntary organisations and a range of local agencies which impact on health, particularly with the Local Authorities. Patient Focus and Public Involvement are also prominent themes of health policy, in order to shape a modern and responsive public service. Workforce developments and higher investment in information systems are key NHSScotland commitments.

Information systems seek to deliver sound management information towards clear public accountability. Information is vital to assure clinical governance and measure health improvement. These requirements reinforce and clarify the NHSCR's role in assuring accurate patient listings and supporting more intensive use of the Community Health Index (CHI). Reliable and consistent authentication of patient information is vital when assembling different fragments of patient information into the same electronic record. The keystone of NHSScotland's strategy for health records management is to use the CHI number with the associated patient demographic data held on the CHI. The importance of this aspect of NHSScotland's eHealth strategy cannot be underestimated. Further plans are being made to enhance the current CHI system with the creation of an index to be known as the SCI Index (Scottish Care Information Index) set on a more modern computer platform and available to a wider range of health service staff round the clock. These developments will help create a full person demographic service for NHSScotland. NHSCR will play a pivotal role in assuring data accuracy and completeness helping NHSScotland safely to create, maintain and make available Integrated Care Records and meet its statutory requirement for accurate personal data, set out in the Data Protection Act 1998. These developments within NHSScotland provide the opportunity to clarify and improve the quality control function of the NHSCR. Indeed, its quality control role could be enhanced if resource was available to carry out regular SCI Index and NHSCR record matches, with any discrepancies pursued and explained. Thus, the future prime role of the NHSCR will continue to be one of quality control to NHSScotland. Its potential for use as a population register, as an alternative future function, may be explored at a later date (section 4.3).

4.3 Other Care Services

The nature of care is becoming steadily more complex. A large number of voluntary organisations provide health care, and NHS organisations commission care jointly with Local Authorities and other interests to offer integrated support. One example is the development of child protection teams that share information between health and other agencies as necessary to support the most vulnerable groups of young people. Whilst matters of confidentiality are of great importance, accurate person-level health records are essential to offer quality information that enables planning and delivery of services, which, in turn, protect and improve the well being of individuals, whatever the original source of care.

Whilst the NHSCR is primarily a resource for health care, the inevitable consequences of developments in care are its use in supporting integrated care delivery between health and other care providers.

4.4 21st Century Government

The Scottish Executive is committed to improving public service delivery in Scotland. The need for better use of data to ensure that service delivery is co-ordinated in ways which minimise duplication and maximise effectiveness to promote the well-being of citizens is core to the Executive's 21st Century Government vision of improving public service delivery. Citizen focused delivery of services is characterised by choice of means of access; by convenience; by effectiveness; and by continuous improvement.

As part of its work, the Scottish Executive's 21st Century Government Unit and GROS are liaising closely with the Office for National Statistics which, with the close involvement of HM Treasury, is examining the feasibility of developing a high-quality common population register. The Citizen Information Project study team has concluded that benefits could be realised by holding in one place a tightly-defined and appropriately verified selection of basic identity information about people that could be widely used across the public sector. There are also plans for a Personal Public Service Number, expected to be based on the NI Number which could pave the way for members of the public to have one truly unique number linking them to all public sector services. This **population register** would be at the heart of an effective and secure system for sharing citizen data. In particular there is scope for:

- citizens only needing to update details with government once, either directly through the registration authority or via a government department with which they have dealings;
- improving efficiency of the public sector by reducing duplication of effort in different departments and agencies;
- raising the quality of basic identity data accessible to all public services and improving the statistical basis for policy-making;

- providing a strong legal basis for personal data holdings and exchange;

eventually allowing government to personalise and target communications and services more easily and accurately.

These proposals would require legislation and would be implemented within a legal framework that helps to protect privacy (further detail in section 4.5). The proposals might be implemented progressively from 2007, and have important implications for the NHSCR. It is not proposed that the NHSCR should be the starting-point for the proposed register (which would be derived principally from passport, driver's licence and employment/pension data). However, the NHSCR is currently the most comprehensive source of change-of-area data and might therefore play an important role in updating the register. More fundamentally, the new register might provide NHSScotland with an alternative source for the quality control/accuracy function at present performed by the NHSCR.

4.5 Other Legislative Matters

The past five years have seen important developments in legislation relating to information, including the European Convention on Human Rights and its adoption into Scottish legislative policy, the Data Protection Act 1998, and the Freedom of Information (Scotland) Act 2002. This raft of legislation aims to protect the rights of individuals, in balance with the public interest, ensuring the involvement of people in decisions about the use of their information. Legislation also facilitates access to official information held about individuals and the ability to share personal information between public services (provided stated conditions are met and with appropriate safeguards). These powers are accompanied by the individual's ability to withhold permission to share personal information between public services, where this is an informed decision not covered by statutory exemptions.

Within this legislative framework, there now exist increasingly complex and careful controls. The NHS Caldicott Guardian network, comprising senior clinicians tasked with safeguarding patient confidentiality in their organisations; and the supporting Data Protection Forum of NHSScotland Data Protection Officers, ensure good health information practice and the sharing of best practice. There are protocols for handling data in a number of situations and

for restrictions on access. Protocols have also been devised under the National Statistics Code of Practice in relation to the statistical and research uses of personal information.

Health information systems, of which NHSCR is a part, are in place to serve the public as patients and citizens. There is much common purpose between effective operation of the NHSCR as a resource that holds patient interests central, and the effective management of NHSScotland. The NHSCR also supports knowledge about health and healthcare, through its routine and research activities, and contributes significantly to population statistics, which in turn play an important role in planning and managing health services. It plays a key role in assuring data accuracy, a requirement of the Data Protection Act 1998.

The NHSCR continues to operate in a dynamic legal framework, shaped by case law on privacy and confidentiality and interpretation of existing statutes, together with codes of best practice. Patient confidence depends on continued attention and investment to help guarantee the proper use of data, the maximum use of information and the upholding of rights to privacy. These factors are likely to influence policy that, in turn, impacts on the NHSCR and ways in which it uses and shares data.

4.6 Other Countries

Similar central registers exist for England/Wales and for Northern Ireland. Staff at these Registers are keen to establish consistent data standards, data sets and procedures with the Scottish Register, to facilitate effective flow of patient information as individuals move across country borders.

The Review Group were informed by the results of an extensive review carried out in England of their NHSCR function. This review, carried out by the Department of Health in England through the NHS Information Authority, concluded that the quality functions carried out by NHSCR are critical to the effective management and maintenance of patient demographic services. Previously, England and Wales briefly set aside their data quality function, but realisation of its utility prompted its re-establishment. In its present form, it takes a different approach to management of the database and there is a well-advanced plan for a more holistic approach and integration of their equivalent of CHI and NHSCR.

Brief study of arrangements in other countries yields limited comparison. Developments in the rest of the EU may offer the prospect of better tracking and support of patients across the EU zone, as patients register for treatment in other member states. However, as no other countries have comparable single public health services, use of Health Service derived data has few parallels with the UK and Scotland. Benchmarks of best practice are therefore limited. Other countries tend to hold NHSScotland information systems in high regard, not least in that Scotland is able to produce health information and facilitate health research in larger measure which are amongst the best assets in the world, backed by high accuracy, reliable population information, and good research collaborations.

5. QUESTIONS ADDRESSED BY REVIEW GROUP

5.1 Do we need NHSCR?

Although NHSScotland holds very comprehensive patient databases separate from NHSCR, the Review Group was clear that an additional quality checking system is vital to enhance accuracy; in particular, to minimise double counting and to act as an enabler for the transfer of appropriate records to and from the rest of the UK. As a strategic resource in supporting large-scale research, the NHSCR is useful and efficient, although similar processes elsewhere could perform a similar function. While important research relies on civil registration—particularly the fact of and cause of death- it may be possible to meet this need by using other NHSScotland systems fed by GROS data. The NHSCR has other functions based on its high quality “population register” work, namely providing migration data for the Registrar General, and tracing and verification of identification for other purposes. In time these functions performed by the NHSCR may become obsolete, but only when a good-quality population register replaces the quality functions currently performed by a separate NHSCR.

Other ways of delivering a similar function to NHSCR would entail a checking system for the CHI locally or nationally, and a pooled arrangement for NHS Boards to relate to other Central Registers in other UK countries, possibly further afield. The Community Health Index (CHI) might in future fulfil the NHSCR’s role as a resource for research. The Registrar General would not be able to provide such accurate inter-censal population estimates if there was no alternative source of migration data. We therefore judge that the population register/quality control function provided by the existing NHSCR should continue at least until a viable alternative is in place. It is, however, important that contact is maintained with those working on alternative population registers and that the potential for synergy is not lost.

We considered the full range of activities undertaken at NHSCR, from its assistance with valuable medical research; to its assistance with the investigation of crime and some types of fraud; to its potential for providing a tracing service equivalent to the ‘Traceline’ service in England and Wales. We judge that these are useful purposes for the NHSCR to serve, and that they should continue, or be reinstated (as in the case of tracing), so long as appropriate safeguards are in place.

5.2 Does NHSCR provide value for money?

The Registrar General manages the NHSCR on behalf of the Scottish Executive Health Department. The agreed charge for 2003-04 is £950,000. A copy of the Service Level Agreement and the Memorandum Trading Account is at Annex E. In terms of value for money, we have relied on accounts from NHSCR representatives and GROS managers of past efficiency and improvement schemes, computerisation and means of allotting public money to investments toward improvement. The Review Group noted that efficiency improvements have allowed GROS to reduce the charge for the service from £1.2 million in 2000-01 to its current level.

Over recent years NHSCR and GROS have reviewed working practices and introduced new ways of working that have generated significant efficiency savings, by reducing the number of staff and carrying out work analysis to streamline previously manual functions. Much of this work has been in partnership with NHSScotland and continued savings are expected through closer working e.g. the NHSCR computer system is operated and maintained within the NHS Scotland contract for national IT services. This arrangement adds little to the costs of the NHS contract, and is much less expensive than maintaining a separate arrangement for NHSCR.

It is difficult to make comparison between England and Scotland for the provision of an NHSCR service due to the different tracing methods used in each country. It is not possible to carry out an exact comparison in overall terms of the budgets between Scotland and England because of the difference in storage of civil registration records for tracing purposes. There are economies of scale for the Southport operation, which deals with about 10 times as many records, and differences in outputs (e.g. more resource in Scotland is devoted to tracing duplicate records, resulting in less inflation in the register). It has therefore not been possible to reach precise comparisons with other countries. We therefore judge that value for money estimates may be reasonable, but could be made clearer by improved governance and accountability (see later).

5.3 How do service users view NHSCR?

Discussion with users of the NHSCR's business has given a generally good account of relationships and the value placed by its key users. NHSCR has over the last decade developed a close and effective working relationship with NHSScotland. This is particularly evident in the participation of NHSCR management in key NHS project groups such as the CHI Project Board and CHI Data Quality Group. Day to day working practices require mutual understanding and co-operation at all levels and this is demonstrated by the reliance and confidence that each organisation places on the other. Nonetheless, there is scope for improvement: there is not, for example, a complete match between records on the CHI database and NHSCR. Also the current computer system does not allow straightforward production of statistics and tables, which would allow service users to improve their understanding of the quality of the database.

NHSCR is a low-key operation performing so-called "back office" functions and many areas of the health service do not generally know about its contribution. It is important for service users, opinion formers and senior managers to be aware of its existence, value and relationship to their work. It was judged to be unnecessary to identify NHSCR functions separately from other data, statistical and checking functions and to make these specific functions more public. However, for the purposes of law and best practice, it would be better in general terms for the NHSCR to be known to groups discussed above, and to be mentioned

in some general information materials connected with the use of information within the NHS and GROS.

5.4 Can we be sure about NHSCR's business processes?

NHSCR business planning and other corporate matters are included in the GROS's annual departmental planning and accounting process. A service level agreement for the NHSCR function is in place between the Scottish Executive Health Department and the GROS. The Review Group heard accounts of reasonable, some exemplary, business processes and assurances of good practice during the review, including standard operating procedures governing the disclosure of personal information, and the inclusion of confidentiality clauses in staff contracts. 'Investors in People' status had been awarded to the organisation recently. We therefore judge that internal quality assurance of the NHSCR's work is sound. Notwithstanding, given the clear and higher expectations of public bodies to assure external service users of the soundness of their management and business processes, we judge that governance arrangements should be formed, that are proportionate to the scale of the business, and reflect the key nature of its function and complexity of its relationships.

The Review Group was assured of the NHSCR's arrangements for business continuity in the event of catastrophic loss of its IT systems, as electronic backup systems are in place should such a disaster occur. However, paper records are not available in copy form, and the Review Group was concerned that a vital resource and archive material would be lost if there was a catastrophic failure in protection of the building which houses the NHSCR. The Review Group noted the need to review the current arrangements in relation to paper records.

5.5 Where should the NHSCR be located, organisationally and geographically?

The Review Group considered who should run the NHSCR in the future. Factors considered in answering this question included the need for clear lines of accountability and the need for a close association between NHSCR's key service users and suppliers of data. Three obvious candidates were considered: the Office for National Statistics (which run the NHSCR in England & Wales); GROS (the status quo) and NHSScotland.

There is merit in maintaining a separate identity from the systems in the rest of the UK, given the devolved responsibility for the function, present good relations and the ability to compare systems as a means of continuous improvement. Nor does there appear to be a significant financial advantage of merger. Of the two remaining options, the balance of advantage appears to be the retention of GROS management. This has worked well in the past, without impeding the close relationship with NHSScotland. It links the NHSCR with the civil registration system, a prime source of data. Furthermore, if plans for a new population register are implemented under the responsibility of the Registrar General, it would be easier to organise the substitution of that population register for the NHSCR as the prime quality control for the CHI, if that was deemed to be the best solution. From the perspective of NHSScotland, there were no contrary views that presented a compelling case for a switch of management.

The Review Group considered whether the current name for NHSCR was appropriate, and whether it would continue to be so in the future. It was agreed that with its current close links with the NHS, and its 'national', as opposed to 'regional' role, its current name remains valid. Should the role of the NHSCR change in the future, in particular in relation to the proposals on a population register, its name should be reviewed at that time.

The NHSCR database is currently located in Dundee. NHSCR staff are located in Edinburgh, which is particularly satisfactory because it permits NHSCR staff close communication with the civil registration system, the GROS staff who work on vital events and the Information Services Division of the Common Services Agency for the Scottish health service. There is a

strong argument for retaining the present location until the way forward on the population register is clear – because the register may subsume the NHSCR work and require its closure.

6. CONCLUSIONS AND RECOMMENDATIONS

The key roles of the NHSCR in Scotland were set out in the introduction. The NHSCR's main interfaces are with the Common Services Agency for the NHSScotland; the Registrar General in updating population statistics; the Central Registries of England, Wales and Northern Ireland, and the research community for an agreed range of studies. It provides miscellaneous other functions set out in section 3.2.1.

The NHSCR's purpose, even its existence, is comparatively little known compared to other information elements and more conspicuous parts of NHSScotland. Nevertheless, it is a vital component that ensures the smooth operation of the NHS.

1. The NHSCR should establish, maintain and project, a clear purpose, role and function with respect to key service users, and governance of its operations.

We judge that NHSCR is an integral source of support to NHSScotland, GROS, other interested parties and public interests. As such the NHSCR does not require to justify further its separate existence but should seek appropriate opportunities to explain its work and its role. Whilst a projection of the role and identity of NHSCR is required, it should be proportionate to its scale and public profile. The NHSCR communications approach should be web based, and consistent with the relevant requirements on accessibility to all sectors of the population. The approach should also dovetail with the national awareness programme for staff, patients and the public that the Scottish Executive intend to carry out in response to the recommendations of the April 2002 report of the Confidentiality and Security Advisory Group for Scotland.

To improve the clarity of purpose of the NHSCR, its functions and aims should be re-stated as follows:

- To record accurately on a database, information about all individuals registered with GPs in Scotland – including information supplied by GROS (about recent births and deaths), by NHS Boards (about movements, changes-of-name etc), by the Common Services Agency for NHSScotland, by the NHSCRs for England & Wales and Northern Ireland and by other sources;

- To supply information from that database:
 - To NHS Boards, to facilitate the transfer of patients' medical records between health authorities, and to improve the quality and accuracy of information about patients;
 - To the Registrar General, to derive statistical information relevant to the measurement of migration within, and to and from, Scotland and jointly with the NHS to facilitate research studies;
 - To share information with other parts of the public sector, where appropriate, for the wellbeing of the citizen or the state, subject to data protection and other laws that protect privacy interests.

2. The NHSCR should maintain robust internal quality assurance procedures consistent with the law and best practice, and develop a strategy for external quality assurance.

We noted that the NHSCR has and maintains a high reputation for its relationship with its service users, albeit restricted to those aware of its existence and those who interact with it. This reputation is underpinned by robust internal quality assurance, and success in demonstrating its quality through external scrutiny whenever this has occurred. External quality assurance has usually resulted from specific review exercises. This good practice should be formalised into a coherent strategy of internal and external quality assurance checking.

3. The NHSCR, with its host organisation, should establish governance arrangements that will include representation from key service users and offer strategic advice on its external relations, governance and effective policy developments.

There is a steady stream of policy developments that require analysis and resolution by NHSCR staff, often in association with their key service users. Implications for the NHSCR are resolved through effective internal management and in association with the Registrar General, as steward of the resource. Taken together with the need for clear governance arrangements, the capacity for adjustment to a range of external influences on the NHSCR and the complexity of influences on the Register's functioning, the Review Group judges that a modern set of arrangements to guide and direct the NHSCR would be appropriate.

The Review Group received assurances about levers to improve management efficiency, and heard accounts of substantial IT investment and change management in the past. The NHSCR looks forward to further IT developments in association with the NHS mainframe computer system, which will hold out the potential for further improvement. While the financial and personnel arrangements were deemed satisfactory, further clarity would ensure public accountability in setting out the arrangements and incentives for continuing improvement.

4. The NHSCR should continue to explore opportunities with its key service users to maximise its use for health, population and research purposes while upholding its reputation and avoiding any diversion from its prime purpose.

The NHSCR works within a complex legal framework and underpins the public accountability of the NHS. Modern healthcare does not restrict itself to pure healthcare interventions from the NHS. Such care is only a component of support and protection for vulnerable or sick individuals and populations. Use of the NHSCR for non-health purposes is already happening on a carefully controlled basis. Reflecting the joint NHS and civil registration sourcing of the NHSCR's data, its principles of use must encompass the interest of patients as citizens, upholding their rights to benefits and other entitlements, as well as those to privacy and security.

There is scope for continuing improvement in the NHSCR's role as a quality control for the CHI. Efforts should be devoted to identifying cases on CHI that do not have a one-to-one relationship with NHSCR and vice-versa, and pursuing the scope for resolving the reasons for these cases. Such efforts need to be made not only on the part of the NHSCR, but also on the part of users of the CHI. Further joint work with those in NHSScotland who manage the CHI

should, between them, establish where cancer registry and other tracing markers are best placed. Efforts should also go toward improving the analytical capabilities of the database.

The potential for the NHSCR database to support more medium to large sized medical research studies should also be explored and, where practicable, exploited. The Review Group was concerned about the risks associated with the current fragmented status of disease registries (excluding cancer). These registries support clinicians in their day-to-day care of patients, and also in their audit of practice and research into improving that practice. Corresponding attention should be paid to ensuring the adequacy of privacy protection measures in all instances of data use.

5. The NHSCR, with the GROS, should track closely the proposals for changes in residency and population registration, and plan to enhance the NHSCR's ability to support population enumeration and NHS entitlement for those residents in Scotland who were not born in the UK.

Whilst the NHSCR provides an excellent link between NHS registration and vital events such as birth and death, there are limits to its ability to ensure the accuracy of registration relating to people who are not born in the UK. Since there is no requirement to de-register with the GP on leaving the country, the NHSCR can include people who are no longer UK resident. This is a matter with broader implications than its relation to healthcare entitlement, given its linkage and association with the Registrar General's population indices. Wider policy developments relating to UK residency may help to clarify entitlement and, in turn, improve the NHSCR's accuracy still further.

Proposed developments of a UK population register might provide NHSScotland with all the information currently supplied by the NHSCR; or the NHSCR might, subject to any necessary legislation, act as a source of information for the proposed new register.

The NHSCR should keep track of wider developments and ensure that core functions of the NHSCR are integral to any future developments.

6. The NHSCR should examine the cost effectiveness of creating a backup to its paper resources, proportionate to the risk of destruction of vital archive material and irreplaceable information.

Although the risk of loss of the paper records is low (they are stored in metal cabinets with high degree of security and fire prevention), advances in digitising techniques may now make it cost effective to create a digital version of the irreplaceable records. Approximate costs made available to the Review Group indicate a range up to £1 million to capture the images and allow tracing access.

7. The NHSCR should remain part of GROS and a decision on its future location should be deferred until there is a clear view on the impact that the population register proposals would have on the future work of the NHSCR. The GROS would therefore ensure the stewardship of the NHSCR and the implications of the recommendations of this report.

While the data presently provided by the NHSCR will remain essential both for NHSScotland and for the Registrar General for the foreseeable future, the proposed national population register may, in time, be a more cost effective source of that information, making the NHSCR surplus to requirements. Continued oversight by the Registrar General who, it is proposed, should operate the population register, maximises the scope for finding a cost effective solution and underlines the fact that the NHSCR has already effectively become a population register, containing little (and potentially no) clinical data.

ANNEX A MEMBERSHIP OF REVIEW GROUP

Dr Andrew Fraser (Chair) (Scottish Executive Health Department)

Dr Fiona Bisset (Scottish Executive Health Department)

Dr Harry Campbell (University of Edinburgh)

Muriel Douglas (General Register Office for Scotland)

Richard Ives (NHS Information Authority)

David Knowles (Common Services Agency- Information and Statistics Division)

Charlie Knox (Scottish Executive Health Department)

Adam Krawczyk (Scottish Executive Health Department)

Dr Graeme Laurie (University of Edinburgh)

Dr Malcolm McWhirter (NHS Forth Valley)

Wendy Nganasurian (Lay Perspective)

David Orr (General Register Office for Scotland)

Craig Russell (21st Century Government Unit)

Susan Wong (Patient Representative)

ANNEX B PRIVACY ADVISORY COMMITTEE

The General Register Office for Scotland (GROS) and the Information and Statistics Division of the Common Services Agency for the Scottish health service (ISD), receive regular requests for both anonymised and identifiable data to fulfil various medical studies. Prior to the release of such data, these requests are subjected to scrutiny by i) a Consultant Adviser on Medical Statistics for GROS - Dr Rod Muir; ii) a Consultant in Public Health Medicine for ISD - Dr Rod Muir. Advice is taken from the Privacy Advisory Committee (PAC) as part of this scrutiny.

PAC was established in 1990 with the following terms of reference: "To advise [the Consultant Advisers] on the use and release of patient identifiable data by GROS and ISD." The principal function of the committee has been to protect the privacy of patient identifiable data while at the same time recognising the need for legitimate access to records by research workers, and those involved in health administration for well-defined and bona fide purposes, subject to appropriate safeguards to maintain confidentiality.

Prior to this, the Privacy Sub-committee of the Information and Computer Services Advisory Group had provided general advice on confidentiality, including the use and release of patient identifiable data. Following its disbandment in 1987, Dr Susan Cole had dealt with this aspect, in her capacity both as Medical Adviser to the Registrar General for Scotland and to the Director of the Information and Statistics Division of the then Common Services Agency. The need for external advice was recognised and a mixed lay and medical committee was established resulting in the formation of PAC.

The new committee first met on 27 June 1990, when members met the Chief Medical Officer and the Registrar General for Scotland. It consisted of five unsalaried members, three medical and two lay representatives. In 1997 the PAC membership was extended to six with the addition of a third lay representative drawn from the newly formed Multi-centre Research Ethics Committee (MREC). Currently, PAC has 4 lay and 2 medical members.

PAC's function is to provide advice to the Consultant advisers of both departments. It has no executive authority and no statutory basis nor other constitutional significance. In particular, PAC is not a Scottish equivalent of the Patient Information Advisory Group (PIAG) in

England and Wales. PIAG was set up in England and Wales by Section 60 of the Health and Social Care Act, which does not apply in Scotland.

Most of PAC business is conducted by post where requests for information are received on an application form, developed in consultation with the Office for National Statistics (ONS) - the English and Welsh counterpart of the GROS. Individual requests are circulated to committee members as soon as they are received by both GROS and ISD, accompanied by a proposal on how each department proposes to handle the request. Members are invited to comment directly to the departments on matters of concern, who relay these back to the researchers. The PAC members normally meet twice yearly (June & December) to review the requests they received over the previous six months. Exceptional ad-hoc meetings can be called to discuss particular business.

Data held by both the GROS and the Office for National Statistics (ONS) are used in a number of UK-wide studies. The Medical Adviser for GROS and the Committee have recognised the need for a consistency of approach in matters of access to confidential data held in both Scotland and England. The mechanisms adopted, however, differ with ONS being advised by the BMA Central Ethical Committee. On occasions, PAC has refused requests to Scottish data held by GROS that were approved in England and Wales.

Both the Medical Advisers for GROS and ISD believe that PAC fulfils a useful function, and that the frequency of its meetings and the methods it has adopted are satisfactory. Both Advisers have found the committee's comments, advice and suggestions to be of great value in assisting them in their work.

The Secretariat for PAC is shared between the GROS and ISD.

ANNEX C ACTIVITY DATA

Summary: GROS releases of information from NHS Central Register for Scotland in 2002-03

For healthcare purposes	1,252,500
To health boards	900,000
To NHSCR Southport	50,000
To NHSCR Belfast	2,500
For approved medical research	300,000

In addition there are a small number of disclosures for non health care purposes (see 3.2.1).

ANNEX D EXAMPLES OF MEDICAL RESEARCH

At present there are just over 100 medical research studies linked to NHSCR where the majority of patients are resident in Scotland. NHSCR offer a UK wide service by working closely with NHSCR in England and Wales. All studies have ethical and Privacy Advisory Committee approval. The following are examples of the type of research undertaken:

- A follow up to a survey of Glasgow University students 1948-1970

This study was carried out to determine whether childhood development, health status and health behaviour in young adults are associated with cardio-respiratory mortality risk in adulthood. The cohort was scattered widely and 26% of the members were found to be in England and Wales. Of 15,000 students followed up, NHSCR established that only 9,000 were still resident in Scotland. Data on deaths, name changes and those who had left the UK were provided and 1100 notifications of cancer identified.

- Cancer among workers at a UK Semi-Conductor Manufacturing Plant

Concerns had been voiced by local campaigners about the possibility of cancers in current and former employees at a Semi Conductor Plant in the west of Scotland. Although the Health and Safety Executive (HSE) had no evidence for the existence of an increased risk of cancer or deaths at this plant, these concerns prompted HSE to investigate the cancer incidence in the workforce. NHSCR specially marked a cohort of 4987 patient records at the HSE's request – and 125 notifications of cancers have been notified to the researchers. This was undertaken with the explicit consent of the workforce.

- The Million Women Study

The research study is designed to determine the risk of breast cancer associated with the use of Hormone Replacement Therapy (HRT). The study is administered by Central Register Southport. Ethical approval was sought separately for each centre in the National Health Service Breast Screening Programme (NHSBSP). In November 2001 NHSCR Edinburgh began receiving requests for women resident in Scotland to have their records specially marked on the NHSCR Scotland database. All participants have consented to having their records specially marked. There are now around 93,727 records marked in Scotland. Around

5400 cancers have been notified to the researchers. Although recruitment to the study is now complete, further data relating to Scottish participants are still expected.

ANNEX E NHSCR SERVICE LEVEL AGREEMENT AND THE MEMORANDUM TRADING ACCOUNT

SERVICE CONTRACT BETWEEN THE SCOTTISH EXECUTIVE HEALTH DEPARTMENT AND THE GENERAL REGISTER OFFICE FOR SCOTLAND

1. SUMMARY

This is the service contract between The Scottish Executive Health Department Management Executive, hereinafter referred to as SEHD, and the General Register for Scotland Vital Events and NHS Branch, hereinafter referred to as GROS. The contract is for the provision by GROS of services, associated with the maintenance of the National Health Service Central Register (NHSCR) and the supply of vital events data to NHSScotland, and for payment by SEHD of the appropriate charge, all as detailed in this document. The period covered by this agreement is **1 April 2003 to 31 March 2004** with revisions as necessary. This revision is effective from 1 April 2003.

2. BRIEF DESCRIPTION OF SERVICES PROVIDED

NHSCR

2.1 On behalf of SEHD, GROS maintains the NHSCR as a record of all NHS patients on General Medical Practitioners' lists in Scotland. The register also includes all persons whose births were registered in Scotland and who have not been recorded as having moved elsewhere. In carrying out this work GROS

- records patient moves between Health Boards in Scotland and between Scotland and Health Authorities in England and Wales;
- records events such as births, deaths and changes-of-name and accommodates a medical research flagging and tracing system; and
- supplies information from the register to Practitioner Services Divisions of Health Boards and to approved medical researchers.

2.2 SEHD provides the computer service which supports GROS work on the NHSCR and which holds the NHSCR database. SEHD has contracted out provision of this service as part of the Scottish healthcare computer package supplied by Schlumberger SEMA (SSEMA), mainly by SSEMA staff and equipment housed in Maryfield, Dundee. SSEMA supports 16 personal computers acting as on-line terminals at Ladywell House, Edinburgh and a further six (with 'read-only' access) at Smedly Hydro, Southport, where the Office for National Statistics run the NHSCR for England and Wales. Hours of service are from 08:00 to 18:00 from Monday to Friday each week. Security is provided by identifiers and passwords which enable authorised users to access the system. A manager of B1 or B3 grade allocates identifiers while passwords are controlled by authorised users. The responsible GROS managers are:

Muriel Douglas telephone 0131-314 4203 (GTN 7166 203); and

Carolyn Macpherson telephone 0131-314 4326 (GTN 7166 326);

7. Vital events data

2.3 Within GROS, Vital Events Section supply information about births and deaths to NHSCR Section on a weekly basis. Additionally, Vital Events Section supply weekly, quarterly and annual data files to Health Boards, Information and Statistics Division of the Common Services Agency, and other relevant parts of NHSScotland.

3. AGREEMENT

7.1 Maintenance of NHSCR

- 3.1 GROS will process up to 1,000,000 data changes and data quality verification annually.
- 3.2 GROS will flag up to 70,000 survey patients annually in response to requests from approved researchers.
- 3.3 GROS will notify survey sponsors about events relevant to medical research handling annually up to 20,000 such transactions on the Scottish Healthcare Database.
- 3.4 GROS will ensure continuity of care in the Health Service by maintaining on the Scottish Healthcare Index database at least 95% of the Community Health Index numbers notified by Scottish Healthcare sources.
- 3.5 GROS will continue the programme to repair damaged NHSCR volumes. This work will minimise long-term damage to these key historical volumes.
- 3.6 GROS will continue to improve procedures that allow updates to be handled electronically.

Provision of data on vital events#

- 3.7 GROS will supply provisional weekly data on births and deaths to relevant parts of NHSScotland within three weeks of registration.
- 3.8 GROS will supply provisional quarterly data on births and deaths to relevant parts of NHSScotland by the end of the following quarter.
- 3.9 GROS will supply final annual (calendar year) data on births and deaths to relevant parts of NHSScotland by the end of the following July.

8. Charges

- 3.7 For all the above work, SEHD will pay GROS the sum of £950,000 in one annual payment during the month of January 2004.**

4. FUTURE OPERATION OF NHSCR

- 4.1** GROS will liaise with the SEHD to ensure strict adherence to approved confidentiality guidelines.
- 4.2** GROS will contribute as necessary to the review of procedures governing the use of the NHSCR.

C B Knox
Director of Computing & IT Strategy
Management Executive for NHSScotland
Scottish Executive Health Department

G W L Jackson
Head of Vital Events & NHS Branch
General Register Office for Scotland

**GENERAL REGISTER OFFICE FOR SCOTLAND
VITAL EVENTS AND NHS BRANCH
MEMORANDUM TRADING ACCOUNT FOR 2001 AND 2002**

	2001 – 2002 8.1.1 VE & NHS BRANCH		2002 – 2003 VE & NHS BRANCH	
	Budget	Out-turn	Budget	Out-turn
1. Monthly pay including ERNIC/ASLC	£699,449	£658,891	£746,131	£678,188
2. Casual Staff	£0	£0	£0	£0
3. Overtime	£15,000	£8,727	£25,000	£17,198
4. Total	£714,499	£667,618	£771,131	£696,386
5. Consultancy	£0	£750	£0	£6,318
6. Travel and Subsistence	£10,000	£11,742	£10,000	£6,970
7. Subscriptions	£2,000	£713	£2,000	£970
8. Stationery – NHSCR	£0	£4137	£0	£0
9. Bureau Services	£30,000	£25,590	£30,000	£31,692
10. Hospitality	£1,000	£457	£1,000	£525
11. Non-pay running costs for relevant cost centres within GRO(S) vote	£43,000	£43,389	£43,000	£46,475
12. Non-pay running costs for CSB and HQ cost centres within GROS vote	£612,426	£645,493	£711,623	£685,449
13. Adjustment for closing and operating accruals	-	-	-	£3,362
TOTAL	£1,359,875	£1,356,500	£1,515,754	£1,431,672
14. Less net expenditure on production NOT directly relevant to NHSIS (marriages, divorces, adoptions etc)	(£417,963)	(£416,950)	(£454,726)	(£429,502)
15. TOTAL EXPENDITURE ON GROS VOTE FOR NHSS)	£951,913	£949,550	£106,1928	£100,2378
16. Sales income from medical researchers etc	(£50,000)	(£45,673)	(£80,000)	(£88,851)
17. Income from contract with Scottish Office	(£950,000)	(£950,000)	(£950,000)	(£950,000)
18. TOTAL INCOME ON GROS VOTE	(£1,000,000)	(£995,673)	(£1,030,000)	(£1,038,851)
19. NET OPERATING COSTS (SURPLUS)	(£48,088)	(£46,123)	£31,028	(£36,681)
As full cost is recovered from NHSiS add back capital x 70%	£43,294	£24,008	£72,398	£44,003
	(£4,794)	(£21,215)	£103,425	£7,322

ANNEX F NHSCR CONTEXT DIAGRAM

