NATIONAL HEALTH SERVICE CENTRAL REGISTER

A General Introduction for Medical Researchers

Medical Research

Background

The Central Register maintains records of all NHS patients and birth records of those not registered with a general medical practitioner. In certain circumstances (e.g. immigration) NHS Numbers are issued (the basic identifier unique to a patient) and information is provided on patients who have died, left the country, joined the Armed Forces etc.
Each patient's register entry is marked with a cipher indicating the Health Board in which that person is currently registered with a doctor, or the reason for removal from their list (e.g. death or embarkation). Home addresses and the names of current GPs are not currently recorded.
The basic records were originally formed from the National Register, which was set up at the beginning of the Second World War in 1939 following an enumeration of the population. When it was decided that a National Health Service Central Register (NHSCR) was needed, it was a comparatively simple operation to adopt the National Register, with its coverage of the whole population, for that purpose. The register performed the dual function for a short time until National Registration was abolished in 1952.

What help can NHSCR offer?

Although the original purpose of NHSCR remains paramount, the potential for assisting certain kinds of research projects has been increasingly realised. NHSCR provides a variety of services.
Research projects can be helped in the following ways:

Flagging Study –this needs patient informed consent

NHSCR is particularly useful for prospective 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 can be identified on the Register. Their records are flagged with a cipher 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 flagging e.g cancer registrations or the fact that the individual is no longer currently registered with an NHS doctor and whether this is due to the fact that he or she has left the country, or for other reasons.

Tracing Study – this needs ethics approval only

An entry in the NHS Central Register will identify the Health Board area in which a patient is currently registered with a general practitioner.
Researchers can then write directly to the Practitioner Services Division (PSD) relating to the patient's health board area asking for a separate letter or questionnaire to be passed on to the person's doctor. The administrator at the PSD will at his or her discretion pass on such documents as requested and may be

prepared in special circumstances to give the doctor's name to researchers to allow a 'doctor to doctor' exchange of correspondence.
The register can also be used for straightforward verification of the vital status of persons lost to follow-up. For those found to have died, NHSCR will supply copies of the forms of particulars, giving details of the date and certified causes of death.

Co-operation with NHS Information Centre (NHSIC) and Medical Research Information Service (MRIS), Southport

It should be noted that NHSCR holds details of all those registered with a GP who live in Scotland and birth registration details for all people born in Scotland. NHSIC Southport maintains a Central Register covering patients registered with a GP in England and Wales. Constant touch is maintained with MRIS Southport concerning those based south of the border and the Registers co-operate fully to ensure that patients moving either way are not lost from sight and that customers see a 'seamless service'.

What are the current charges for these services?

NHSCR is a non-profit making Government organisation whose charges are designed solely to cover the running costs of medical research section.
Details of current charges can be found at Appendix C.

Points of Contact

For further informal enquiries, to obtain details of current costs, to arrange a visit to see the system or for queries on existing surveys.

Gail Turner

Cairnsmore House
The Crichton
Bankend Road
Dumfries
DG1 4GW

Tel: 01387 259823
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E mail: dumf-uhb.NHSCR-Scotland-Medical-Research@nhs.net

Sending Medical Research Data On Diskette or CD

Scotland Formatting Guidelines

Contents

Data Input Layout

Introduction

These instructions provide the information you need to be able to send data to National Records of Scotland (NRS) formerly General Register Office for Scotland (GROS) on diskette or CD; which type of diskettes to use, how they should be formatted and what format the data must be in.

Please follow the instructions carefully. If the data is not in the correct format our Computer supplier (ATOS Origin), might be unable to read it.

If you have any problems, please call 01387 259823.

The data can be held on as many disks as necessary, but each disk should contain just one file.

About the Diskettes or CD

The file should contain one header record and any number of data records between 1 and 5000 (attached layout – Appendix A).

N.B. If any patients are known to be resident in England or Wales, they need to be put on a separate disk. For formatting guidance please contact MRIS, Southport directly on 0300 365 3669.

On the following pages you will find detailed information about the layout of the data you may send us, whether it is for ‘flagging’ or ‘tracing’ studies

File Name

Each diskette or CD should contain one file and should be clearly labelled with the file name and place of origin.

Supporting Documentation

You should ensure that every diskette or CD is accompanied by a Diskette Description Form (Appendix B). Please take care to supply all the information requested.

NHSCR Survey Update File Format

File layout of FCS131SURVEYDATA is as follows:

Data for input to the NHSCR Survey Update program should be submitted as an **ASCII Test file** in **fixed length** format. Each line of text (or record) should have 348 characters, followed by CR and LF characters (Carriage Return and Line Feed). The first record in the file should contain a '1' followed by the Survey Code, followed by spaces, up to 348 characters. All other records in the file should start with a '2' followed by patient data (see below). There should be no more than 5000 records on the file.

Header Record:-

Record	Position			
From	To	Item	Size	Value
1	1	Record Identifier	1	1
2	7	Survey Code	6	
8	348	Filler	341	

Detail Record:- **ALL DATA SHOULD BE IN UPPER CASE**

Record	Position			
From	To	Item	Size	Value
1	1	Record Identifier	1	2
2	18	NHS Number	17	
19	38	Surname*	20	
39	53	Forename*	15	
54	68	Middle Name	15	
69	76	Date of Birth*	8	DDMMYYYY
77	77	Sex*	1	M, F, ?
78	157	Address	80	
158	161	Year Home Address Valid	4	YYYY
162	181	Former Surname	20	
182	201	Mothers Maiden Name	20	
202	213	Birthplace	12	
214	233	Occupation	20	
234	258	Patient Reference Number	25	
259	338	GP Name and Address	80	
339	348	CHI Number	10	

* Mandatory Fields

Any non-mandatory fields for which you do not hold information should be space filled.

Example

The start of a Survey Update file for survey code AB123 should look like this:-

(Note – only the first 74 characters of each record are shown).

```
1AB123
2          SMITH          JOHN        H          010119
2          BLOGGS          MARY                   010219
2          JONES           JACK                    311219
```

Appendix B

Data Submission Form

Please send this form with your diskette/s or CD/s to:

Medical Research Section
Cairnsmore House
The Crichton
Bankend Road
DUMFRIES
DG1 4GW

From:

……

……

……

……

……

Telephone number: ……..

SR/SMR/MR Study number: ……..

	Filename	No. of records
DISK 1		
DISK 2		
DISK 3		
DISK 4		
DISK 5		
DISK 6		

Appendix C

NHSCR-SCOTLAND SURVEY CHARGES - 2014/2015

Initial Set-up Fee	**£120.00**
Automatic matching/flagging	**£0.10 per record**
Hourly Rate	**£80.00**
Members and Postings Listing	**£40.00**
Cancer Copies	**£0.53**

NB: All charges are subject to VAT

Information found to be invaluable for quick, accurate identification of patients for flagging, therefore keeping your costs to a minimum:-

- NHS Number
- Community Health Index Number (the number held by Practitioner Services Divisions to register patients).
- Full forename(s) and surname. (**Full** first forename)*
- Date of Birth*
- Gender*
- Exact Place of Birth
- Present Home Address
- GP's name and address
- Whether patient is alive or dead (if dead give date and place of death)

* Mandatory