

1970 British Cohort Study

Linked health administrative datasets – Scottish Medical Records (SMR)

User guide

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Contact

Questions and feedback about this user guide should be sent to

clsfeedback@ucl.ac.uk.

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UCL Social Research Institute

University College London

20 Bedford Way

London WC1H 0AL

www.cls.ucl.ac.uk

The UCL Centre for Longitudinal Studies (CLS) is an Economic and Social Research Council (ESRC) Resource Centre based at the UCL Social Research Institute, University College London. It manages four internationally renowned cohort studies: the 1958 National Child Development Study, the 1970 British Cohort Study, Next Steps, and the Millennium Cohort Study. For more information, visit www.cls.ucl.ac.uk.

This document is available in alternative formats. Please contact the Centre for Longitudinal Studies.

tel: +44 (0)20 7612 6875

email: clsfeedback@ucl.ac.uk

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About the 1970 British Cohort Study

The 1970 British Cohort Study (BCS70) is a longitudinal birth cohort study, following a nationally representative sample of over 16,000 people born in Britain in a single week in April 1970.

We have surveyed cohort members throughout their childhood and adult lives, mapping their individual trajectories and creating a unique resource for researchers. It is one of very few longitudinal studies following people of this generation anywhere in the world.

Featuring a range of objective measures and rich self-reported data, BCS70 covers an incredible amount of ground and can be used in research on many topics.

Evidence from BCS70 has illuminated important issues for our society across five decades. Key findings include how reading for pleasure matters for children's cognitive development, why grammar schools have not reduced social inequalities, and how childhood experiences can impact on mental health in mid-life.

Every day researchers from across the scientific community are using this important study to make new connections and discoveries.

1. Introduction

This user guide describes the linkage of medical records and prescription records in Scotland (henceforth “Scottish Medical Records”, or SMR) to cohort members’ data in the 1970 British Cohort Study (BCS70). These medical records have been made available to CLS on the basis of informed consent by the Information Services Division (ISD) part of NHS National Services Scotland. The records were linked to cohort members from the British Cohort Study who had given their consent for linkage to administrative health record data. The main aim of this data linkage is to enhance the research potential of the information we collect in the surveys, making it an even richer resource for the research community.

BCS70 originally aimed to examine the social and biological characteristics of the mother in relation to neonatal morbidity, and to compare the results with those of the 1958 National Child Development Study.

There have been a further 9 surveys which have sought to gather information from respondents living in England, Scotland and Wales, in order to monitor their health, education, social and economic circumstances.

2. Consent to health data linkage

In the 2012 data collection sweep (Age 42), which was a face-to-face interview, cohort members were asked for consent to link NHS records, DWP records and HMRC records. Cohort members could agree to one or more of these.

Consent forms were double printed on carbon backed paper. All participants were given a carbon copy of their consent form to keep, with the other going to the operations department of the fieldwork agency, TNS BMRB. An information leaflet was provided explaining why CLS wanted to link the records and what records would be sought. Consent from the partners of cohort members was also sought.

Detailed information on the fieldwork and consent collection can be found in the BCS70 Age 42 Technical report and BCS70 Age 42 User Guide. All documents can

be found under 'documentation' at <https://cls.ucl.ac.uk/cls-studies/1970-british-cohort-study/bcs70-age-42-sweep/>

3. Health data linkage

3.1 SMR datasets

The Scottish Medical Records (SMRs) are held by the Information Services Division (ISD) part of NHS National Services Scotland. Together, they contain information about all hospital admissions in Scotland. It is comprised of six data collections: Outpatient attendance (SMR00), Inpatient and day care attendance (SMR01), Maternity records (SMR02), Scottish cancer registry (SMR06), and Prescribing Information System (PIS). The ISD website contains detailed information about each dataset, including background information, data dictionaries and definitions.¹

Table 1: List of datasets provided

Dataset	Contents
SMR00	Outpatient attendance, years 1996-2016
SMR01	Inpatient and day care attendance, years 1981-2016
SMR02	Scottish maternity records, years 1984-2016
SMR04	Scottish mental health records (linked but not shared due to sparse data)
SMR06	Scottish cancer registry (linked but not shared due to sparse data)
PIS	Prescribing Information System, years 2009-2016

The linked Scottish health data cover diverse topics including: diagnosis, maternity, mortality, types of therapies, treatment length, Scottish Index of Multiple Deprivation (SIMD), Carstairs deprivation index, developmental milestones and anthropometry.

In 2015, CLS obtained consent from ISD for linkage of SMR records for consented cohort members.

¹ <https://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets/>;
<https://www.isdscotland.org/Health-Topics/Prescribing-and-Medicines/>;

3.2 Matching strategy

Those BCS70 cohort members who resided in Scotland at any of the first five sweeps (“ever-Scottish”) and who gave consent to linkage of administrative medical records at the age 42 sweep were selected for linkage - 693 of a total of 994 cohort members, representing 70% of the Scottish sample.

In order to conduct the linkage, identifying information (surname and first initial, full date of birth, sex, address including postcode, and hospital reference number), was sent securely to the ISD with a CLS proxy ID. At the ISD, these identifiers were used to match to Community Health Index (CHI) number, which was in turn used to match to the health records.

The CHI is a population register used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index. The health records were then returned securely by ISD to the CLS data management team, and contained the CLS proxy ID but without the identifying information and the CHI. The health records could then be linked to the BCS70 data.

3.3 Matching rates

Tables 2 and 3 show the number of successful matches of SMR records following data linkage. Altogether, 785 cohort members had at least one linked SMR.

Table 2. Consent and linkage

Number of ever-Scottish cohort members age 42 sweep	994
Number with valid consent	693
Total number with matched SMR data	542
Linkage rate, as proportion of consented	78%

Table 3. Number of matched cases per dataset

Dataset	Number of research participants
SMR00	495
SMR01	441
SMR02	203

4. The research datasets

The administrative data includes:

SMR00 – Outpatient attendance

SMR01 – Inpatient and day care attendance

SMR02 – Maternity records

SMR04 – Mental health records (linked but not shared due to sparse data)

SMR06 – Scottish cancer registry (linked but not shared due to sparse data)

PIS – Prescribing Information System

Each data collection needs to be applied for individually.

4.1 Licensing

The linked SMR data have been processed by CLS and supplied to the UK Data Service (UKDS) under Secure Access licence. Applicants wishing to access this data need to establish the necessary agreement with the UKDS and abide by the terms and conditions of the UKDS Secure Access licence.

An additional condition of the licensing is that it is not permitted to link SMR data to BCS70 data that include any Scottish geographies lower than 'Scotland'.

Access to the SMR linked data will only be provided via the UKDS. The data may only be accessed through a secure private network (Secure Lab), via the researcher's own institutional desktop PC or at the Safe Room at the UK Data Archive. Applicants wishing to access this data, need to establish agreement with the UKDS and abide by the terms and conditions of the UKDS Secure Access licence. Before gaining access, researchers must make an application detailing the intended analysis and provide a justification as to why this data is requested.

To apply to access this data please visit the UKDS website here-

<http://ukdataservice.ac.uk/use-data/secure-lab/about.aspx>.

4.2 Data documentation provided

Users are advised to use the SMR datasets in conjunction with the data dictionaries and documents provided by CLS available via UKDS, as follows:

Documentation file	File name
User guide	BCS70_ScottishHealth_UserGuide_v1.pdf
ISD Guides	PHS-Deprivation-Guidance-version-3-4.pdf
SMR Crib Sheets	SMR00_CRIB_080518.pdf SMR01_CRIB_080518.pdf SMR01Long_stay_Geriatric_CRIB_2014_April.pdf SMR02_CRIB_080518.pdf PIS_fields_for_researcher_v5_eDRIS Guidance PRISMS-data-manual-2.4.pdf
British National Formulary	BNF chapters and subchapters.pdf
ICD-9 codes	Complete_ICD-9_manual.txt
ICD-10 codes	ICD-10: International statistical classification of diseases and related health problems-V1-eng.pdf ICD-10: International statistical classification of diseases and related health problems-V2-eng.pdf ICD-10: International statistical classification of diseases and related health problems-V3-eng.pdf
OCPCS-4 codes	OPCS48 Metadata File Description V1.0.pdf OPCS48 ToCE Analysis Nov 2016 V1.0.xlsx OPCS48 ToCE Specification V0.1.pdf

Acronyms

Users may find useful to become familiar with the following list of acronyms used in the data dictionary and data labels.

BNF: British National Formulary

Carstairs: Carstairs and Morris Index; a combined measurement of deprivation based on postcode sector. This does not include health as a contributing factor.

ISD: Information Services Division, part of NHS Scotland

ICD-10: International Classification of Disease; this is used to codify diagnostic data.

OPCS-4: Office of Population Censuses and Surveys Classification of Interventions and Procedures version 4; this codifies procedures, operations and interventions taking place in a clinical setting.

SIMD: Scottish Index of Multiple Deprivation

SMR: Scottish Medical Record

UKDS: UK Data Service

UKDS Data Dictionaries

The UKDS data dictionaries provide detailed information for each of the datasets. They include the variables names, format, labels or titles, positions in each dataset. They also provide information of the values included in each variable.

ISD Guides

Several datasets include deciles of deprivation related to the “data zone” – i.e. neighbourhood corresponding to a patient’s postcode of residence. Several values have been provided: Carstairs 2001 and 2011, and the Scottish Index of Multiple Deprivation (SIMD) 2004, 2006, 2009 and 2012. The order of deprivation changes in

scores from 2009 onwards, so care must be taken to ensure the most and least categories are not used the wrong way round. The PHS Deprivation Guidance should be referred to, in order to ensure proper use.

SMR Crib Sheets

The crib sheets from the ISD are available as supplementary documents. They contain the lookups for the codes used in most of the SMR datasets. These have been applied to the data, however some values did not correspond to any look-up.

British National Formulary

Section, chapter and subchapter names corresponding to the drugs groups in the prescribing data can be found here. These can be cross referenced with the variable BNF subchapter (D_PIBNFPPC) in the PIS dataset.

International Classification of Disease v9 (ICD-9) and v10 (ICD-10)

Both symptoms and diagnoses are recorded using ICD coding. Care should be taken to use the correct coding version.

These supplementary files originate from the WHO website² and will only be made available for approved projects:

- ICD-10: International statistical classification of diseases and related health problems-V1-eng.pdf
- ICD-10: International statistical classification of diseases and related health problems-V2-eng.pdf
- ICD-10: International statistical classification of diseases and related health problems-V3-eng.pdf

Researchers should refer to “ICD-10: International statistical classification of diseases and related health problems V1” to interpret the diagnostic codes in the

² International statistical classification of diseases and related health problems, 10th revision, Fifth edition, 2016 <https://apps.who.int/iris/handle/10665/246208>, Accessed 24th August 2020

APC and OP datasets, V2 and V3 may be of help in building lists of codes to search for by diagnosis.

Older records may use ICD-9. “Complete_ICD-9_manual.txt” comes from the Center for Disease Control³. As a general rule, the ICD-9 three character codes start with a number and the ICD-10 three character codes start with letters.

OPCS4 Interventions and Procedures Classification System

To interpret the OPCS data, researchers need to use the following supplementary files⁴:

- OPCS48 ToCE Analysis Nov 2016 V1.0
- OPCS48 ToCE Specification V0.1
- OPCS48 Metadata File Description V1.0

The version of OPCS-4 used over time does change, so codes for a procedure performed in 2007 are not necessarily the same as the same procedure performed in 2012, for example. The file “OPCS ToCE Analysis Nov 2016 V1.0” provides codes for each of the versions below.

Version	Time period
OPCS4.9	2020 until further notice
OPCS4.8	2017-20
OPCS4.7	2014-17
OPCS4.6	2011-14
OPCS4.5	2009-11
OPCS4.4	2007-09

³ CLASSIFICATION OF DISEASES AND INJURIES, Center for Disease Control, Atlanta https://simba.isr.umich.edu/restricted/docs/Mortality/icd_09_codes.pdf. Accessed 24th November 2020.

⁴ The OPCS Classification of Interventions and Procedures, codes, terms and text is Crown copyright (2019) published by Health and Social Care Information Centre, also known as NHS Digital and licenced under the Open Government Licence available at www.nationalarchives.gov.uk/doc/open-government-licence/open-government-licence.htm.

OPCS4.3	2006-07
OPCS4.2	Up to 31 March 2006

4.3 Identifiers

BCSID is anonymised unique cohort member identifier which is used to maintain the confidentiality of cohort members in the linked health records. The BCSID can also be used to merge this data and other deposited British Cohort Study datasets.

4.4 Data processing

Variable names

Variables that have been altered, either by truncation, top coding, recoding or creation of a pseudo-anonymised key are named with the prefix D. For example, the diagnosis variable diag_01 becomes D_diag_01 as it has been truncated to 3 characters.

Variable labels and value labels

Variable labels and value labels have been taken from the online Scottish Medical Records data dictionaries. Derived variables are labelled with “DV: [Variable name], [Truncated/Pseudonymised/Topcoded]”.

4.5. Data de-identification

CLS is committed to protect research participants’ rights and avoid data disclosure and re-identification of individuals using one or more variables in the dataset or in combination with other existing data.

Dates of birth, small geographical details and rare cases that could easily lead to data disclosure have been removed to comply with the NHS National Services Scotland Statistical Disclosure Control Protocol.

Similarly, some variables had categories grouped into wider categories to avoid the possibility of data disclosure. Geographical data for those living in sparsely populated areas have been grouped. ICD-10 codes have been truncated. These variables are prefixed with "D_". Cohort members from families with multiple births have not been included.

The SMR datasets include clinical information regarding diagnoses and procedures. Diagnoses are coded using the International Classification of Diseases version 10 (ICD-10). The codes have been truncated to the first three characters as a disclosure control measure. Operations and other procedures have been classified using the OPCS Classification of Operations and Procedures, version 4 (OPCS-4). This has been truncated to chapter as a disclosure risk control.

The Public Health and Intelligence Caldicott Guardian for National Services Scotland has given permission for the data as described to be deposited with the UK Data Service (UKDS) for access via its Secure Lab.

The UKDS perform a certain level of disclosure control on the outputs generated by researchers in the Secure Lab. This involves looking at outputs with cells <10 and the process is outlined in their SDC Handbook which can be downloaded from: <https://securedatagroup.org/sdc-handbook/>

Health Board variables, which are based on geographical area, have been replaced with a random key, this key is consistent across the datasets. Other changes to datasets SMR00, SMR01 and SMR11 have been outlined in the appendices.

4.6 SMR00 – Outpatient Attendance

This data includes records for appointments in medical consultant outpatient clinics, meeting a consultant or senior member of their team outside of an outpatient clinic session and attendances to see a nurse or allied health professional who has legal and clinical responsibility for the patient. Where there is more than one speciality of the clinic, multiple records will be made unless there is a single "main specialty" of that clinic. Care should be taken by researchers to avoid double counting these multiple records.

See also <http://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets//SMR00-Outpatient-Attendance/>

4.7 SMR01 – General/Acute Inpatient and Day Case

These data refer to patients receiving care in the general/acute specialties and who are inpatients/ day cases admitted to NHS hospitals from non-NHS locations or to NHS beds in non-NHS institutions.

SMR01 records are generated when:

1. Inpatients and day cases are admitted to NHS hospitals from locations external to the NHS.
2. Inpatients and day cases are admitted to contracted NHS beds in non-NHS institutions.
3. Inpatients and day cases change specialty (with or without a change of consultant) when:
 - An Inpatient transfers to become an Inpatient in another specialty in the same hospital.
 - An inpatient becomes a Day Case in another specialty during the inpatient stay.
 - A day case transfers to become an Inpatient in another specialty (except when the day case episode is during an inpatient stay and the patient is transferring back to the original consultant).
 - A day case transfers back to resume an Inpatient stay but does NOT transfer back to the original consultant for medical reasons.
4. Inpatients and day cases transfer from another NHS hospital (including contracted NHS beds in non-NHS institutions).
5. Inpatients and day cases change consultant for medical reasons within the same specialty when:
 - An inpatient transfers as an Inpatient to the care of a different consultant for medical reasons in the same specialty in the same hospital.
 - An inpatient becomes a Day Case in the same specialty under a different consultant for medical reasons during the inpatient stay.

- A day case transfers to become an Inpatient under the care of a different consultant in the same specialty for medical reasons (except when the day case episode is during an inpatient stay and the patient is transferring back to the original consultant).
- A day case transfers back to resume an Inpatient stay in the same specialty but does NOT transfer back to the original consultant for medical reasons.

6. Inpatients move into and/or out of one of the valid significant facilities.

7. Inpatients return to hospital having been on pass for more than 5 days.

A new record is generated for a change of specialty or a hospital transfer or their inpatient/day case status is changed; this is indicated in the variable MANAGEMENT_OF_PATIENT. Therefore one stay may have more than one episode.

See also: <http://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets//SMR01-General-Acute-Inpatient-and-Day-Case/>

4.8 SMR02 – Maternity Inpatient and Day Case

These records are generated for patients receiving Obstetrics care from the NHS, including maternity appointments and abortions. Home birth records are also included.

The records have been collected over 18 years; during this time coding has changed and some variables (see table below) are sparsely populated as the variables were introduced after the maternity records were created. In addition, some value labels cannot be completely described as they have been retired (PREV_SMOKER, TYPE_OF_ABORTION, MANAGEMENT_OF_ABORTION).

Variables with limited data available
Sex (SEX)
Significant facility (SIGNIFICANT_FACILITY)
Admission reason (ADMISSION_REASON)
Admission/transfer from (ADMISSION_TRANSFER_FROM)

Admission type (ADMISSION_TYPE)
Discharge type (DISCHARGE_TYPE)
Total number of stillbirths prior to current pregnancy (N_PREV_STILLBIRTHS)
The total number of live babies born prior to the current pregnancy who died within 28 days N_PREV_NEONAT_DEATHS
Type of location the patient is booked to be delivered (DEL_PLAN_PLACE)
The pattern of obstetric care planned (DEL_PLAN_MANAGEMENT)
Patient type and/or pattern of care following change in management of delivery plan (BOOK_CHG_MANAGEMENT)
Type of location of delivery following change of location in delivery plan (BOOK_CHG_PLACE)
Smoking history recorded at booking clinic (BOOKING_SMOKING_HISTORY)
Episiotomy (EPISIOTOMY)
Tears (TEARS)
Indication for operative delivery (ICD10) (IND_OP_DEL)
Form of resuscitation used (baby 1) (RESUS_1)
Occipital frontal circumference in cm on 3rd day of life (baby 1) (OFC_BABY_1)
Length from crown to heel in cm (baby 1) (CROWN_HEEL_BABY_1)
Neonatal Indicator (baby 1) (NEONATAL_INDICATOR_BABY_1)

There are some derived variables with grouped data: Maternal height group (MOTHER_S_HEIGHT), birthweight groups (BIRWEIT_GP_[1|2]), duration of pregnancy (PREG_DUR_CENT_B[1|2]) and estimated gestation (EST_EST_CENT_B[1|2]). These groups are described with letters or numbers, but the labels were unavailable; researchers may have difficulty using these variables.

The data are routinely collected and therefore some errors are present; these have not been altered. The birthweight variables (BIRWEIT_1 and BIRWEIT_2) contain zeros.

See also: <https://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets/SMR02-Maternity-Inpatient-and-Day-Case/General-Definitions/>

4.9 PIS – Prescribing Information System

The PIS contains prescription and dispensary information linked to cohort member: including all prescriptions dispensed in Scotland outside of a hospital setting and those written in Scotland but dispensed elsewhere in the UK but excluding those dispensed in hospital but including those written in hospital but dispensed elsewhere. Each record reflects an individual dispensary episode.

This dataset uses the British National Formulary (BNF) code for each prescribed item that has been dispensed. The first two characters of the code refer to the chapter of the BNF, the second two characters refer to the section and the third two characters refer to the paragraph; the family of drugs. A copy of the section, chapter and subchapter names is available in the supplementary files.

See also: <http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=9>

5. Disclosure control: UKDS requirements for data users

As the SMR data linked to the longitudinal BCS70 data are only available via the UKDS Secure Lab, the UK Data Service will always perform a certain level of disclosure control on the outputs generated by researchers, as outlined in their SDC Handbook, which can be downloaded from <https://securedatagroup.org/sdc-handbook/>.

The two UK Data Service Secure Lab rules of thumb that will be applied to all outputs are:

- Threshold rule: No cells should contain less than 10 observations.
- Dominance rule: No observation should dominate the data to a huge extent.

Appendix 1. Modifications to the Inpatient data (SMR00)

Variable name	SMR original variable name	Variable description	Modification
D_PATIENT_CATEGORY	PATIENT_CATEGORY	Patient Category	Rare values recoded to missing
D_HBRES_CURRENTDATE	HBRES_CURRENTDATE	Health Board of residence	Pseudonymised with new key
D_HBTREAT_CURRENTDATE	HBTREAT_CURRENTDATE	Health Board of treatment	Pseudonymised with new key

Appendix 2. Modifications to the Inpatient data (SMR01)

Variable name	SMR original variable name	Variable description	Modification
D_CIS_MARKER	CIS_MARKER	Continuous Inpatient Stay Marker	Top coded at 15 days
D_PATIENT_CATEGORY	PATIENT_CATEGORY	Patient Category	Rare values recoded to missing
D_MAIN_CONDITION	MAIN_CONDITION	Main Condition	Truncated to 3 chars
D_OTHER_CONDITION_1	OTHER_CONDITION_1	Other Condition 1	Truncated to 3 chars
D_OTHER_CONDITION_2	OTHER_CONDITION_2	Other Condition 2	Truncated to 3 chars
D_OTHER_CONDITION_3	OTHER_CONDITION_3	Other Condition 3	Truncated to 3 chars
D_OTHER_CONDITION_4	OTHER_CONDITION_4	Other Condition 4	Truncated to 3 chars
D_OTHER_CONDITION_5	OTHER_CONDITION_5	Other Condition 5	Truncated to 3 chars
D_HBRES_CURRENTDATE	HBRES_CURRENTDATE	Health Board of residence	Pseudonymised with new key
D_HBTREAT_CURRENTDATE	HBTREAT_CURRENTDATE	Health Board of treatment	Pseudonymised with new key

Appendix 3. Modifications to the Births data (SMR02)

Variable name	SMR original variable name	Variable description	Modification
D_MAIN_CONDITION	MAIN_CONDITION	Main Condition	Truncated to 3 chars
D_OTHER_CONDITION_1	OTHER_CONDITION_1	Other Condition 1	Truncated to 3 chars
D_OTHER_CONDITION_2	OTHER_CONDITION_2	Other Condition 2	Truncated to 3 chars
D_OTHER_CONDITION_3	OTHER_CONDITION_3	Other Condition 3	Truncated to 3 chars
D_OTHER_CONDITION_4	OTHER_CONDITION_4	Other Condition 4	Truncated to 3 chars
D_OTHER_CONDITION_5	OTHER_CONDITION_5	Other Condition 5	Truncated to 3 chars
D_IND_OP_DEL	IND_OP_DEL	Indication for operational delivery	Truncated to 3 chars
D_HB_OF_RESIDENCE	HB_OF_RESIDENCE	Health Board of residence	Pseudonymised with new key
D_HB_OF_TREATMENT	HB_OF_TREATMENT	Health Board of treatment	Pseudonymised with new key