

Using linked administrative data: Hospital Episode Statistics linked with the CLS cohorts

6 December 2022

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Economic and Social Research Council

Housekeeping

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- Technical issues please email us: <u>ioe.clsevents@ucl.ac.uk.</u>
- We would be grateful for your feedback. Please follow the link in the chat at the end of the event for the short survey.
- Slides and recording will be made available after the session.
- Thank you for joining us today.

Today's schedule

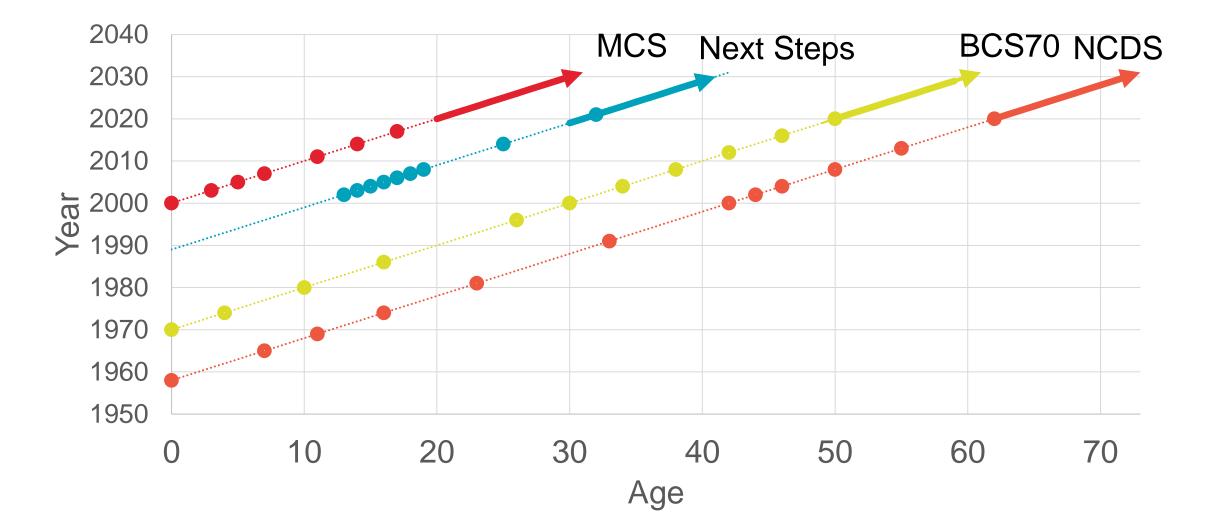


Time	Topics covered	Speaker
1.00 – 1.15pm	Brief introduction to the cohorts	Richard Silverwood
1.00 – 1.13pm		Associate Professor of Statistics
1.15 – 1.30pm	HES data and linkage overview	Sarah Kerry-Barnard
1.15 – 1.50pm	TILS Uata and inikaye overview	Research Data Manager
1.30 – 1.45pm	Accessing linked HES datasets	Danielle Gomes and Karen Dennison
1.50 – 1.45pm	Accessing inked hes datasets	Record Linkage Managers
1 15 2 15pm	Analysing linked LICC data	Richard Silverwood
1.45 – 2.15pm	Analysing linked HES data	Associate Professor of Statistics
2.15 – 2.30 pm	Q&A	All

CLS stu	CLS studies follow people across life								
National Child De	evelopment Stud	y 1958							
1970 British Coh	ort Study								
Next Steps (form	erly LSYPE)								
Millennium Coho	rt Study								
1920	1940	1960	1980	2000	2020				

Study timelines





Typical information covered



Views and expectations

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Forthcoming training events



Introduction to NCDS 25 January 2023, 1.00–2.30pm

Introduction CLS cohorts to biomedical researchers (CLOSER) 9 February 2023, 1.00pm–2.00pm

Handling missing data in the CLS cohorts 28 February 2023, 1.00–4.30pm

Introduction to BCS70, Next Steps and MCS Later in 2023

https://cls.ucl.ac.uk/events/

Call for papers - Children of the noughties: a conference to celebrate 21 years of the Millennium Cohort Study



- A scientific conference in London, 13-14 June 2023
- Papers may include substantive research topics and research methods. Studies involving cross-study or intergenerational comparisons, or analyses of linked data, are all welcome. It must include MCS data or another millennial longitudinal study. Deadline: Wednesday 18 January 2022





NHS England – Hospital Episode Statistics (HES)

Linked Health Administrative Data

- NHS England Hospital Episode Statistics (HES)
 - NCDS
 - BCS70
 - Next Steps
 - MCS*
- NHS Scotland Scottish Medical Records (SMR)
 - NCDS
 - BCS70
 - MCS

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*available Wed 7th December 2022

Hospital Episodes Statistics User Guide(s)

- Covers everything in this webinar and more
- Available publicly from UK Data Service (UKDS) and CLS websites for NCDS, BCS70 and Next Steps

1. Introduction

2. Consent to health data linkage

3. Health data linkage

3.1 HES datasets

3.2 Matching strategy

3.3 Matching rates

4. The research datasets

4.1 Licensing

- 4.2 Data documentation provided
- 4.3 Identifiers

4.4 Data processing

4.5 Data de-identification

- 4.6 The Accident and Emergency (A&E) data
- 4.7 The Admitted Patient Care (APC) data
- 4.8 The Critical Care (CC) data
- 4.9 The Outpatient Care (OP) data

5. Disclosure control: requirements for data users

- 5.1. UKDS requirements
- 5.2. NHS Digital requirements

6. Data access and variable selection

- 6.1 UKDS Secure Access application
- 6.2 Selection of variables
- 6.3 CLS Licence Agreement

Appendices

Modifications to the Accident and Emergency Data

Modifications to the Admitted Patient Care Data

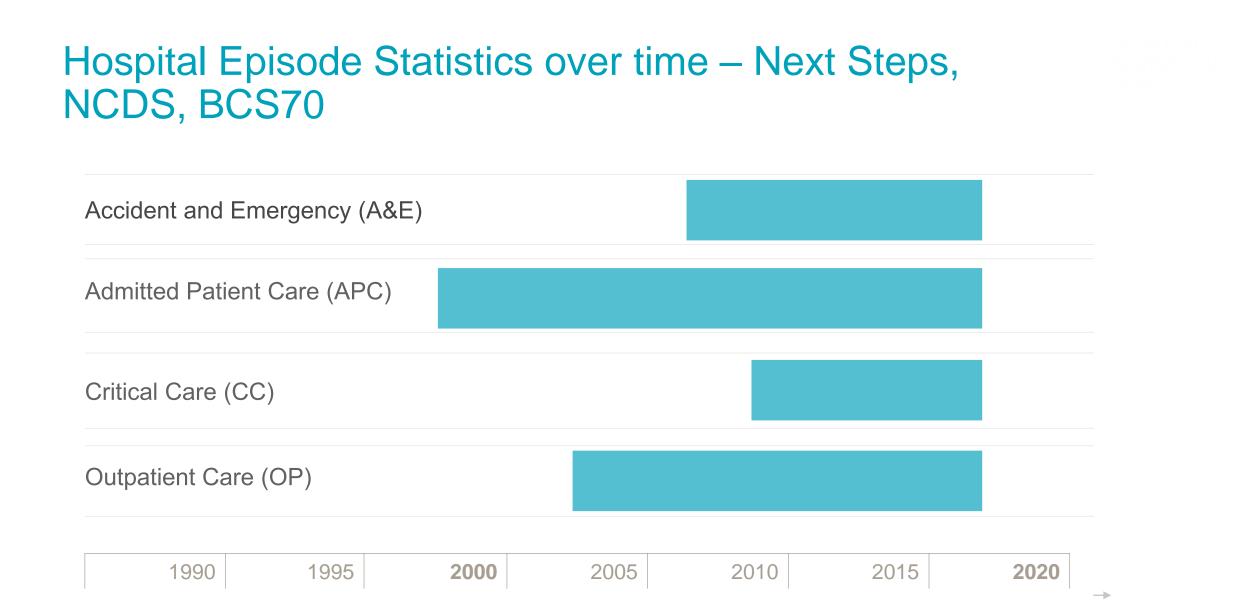
Modifications to the Outpatient Care Data

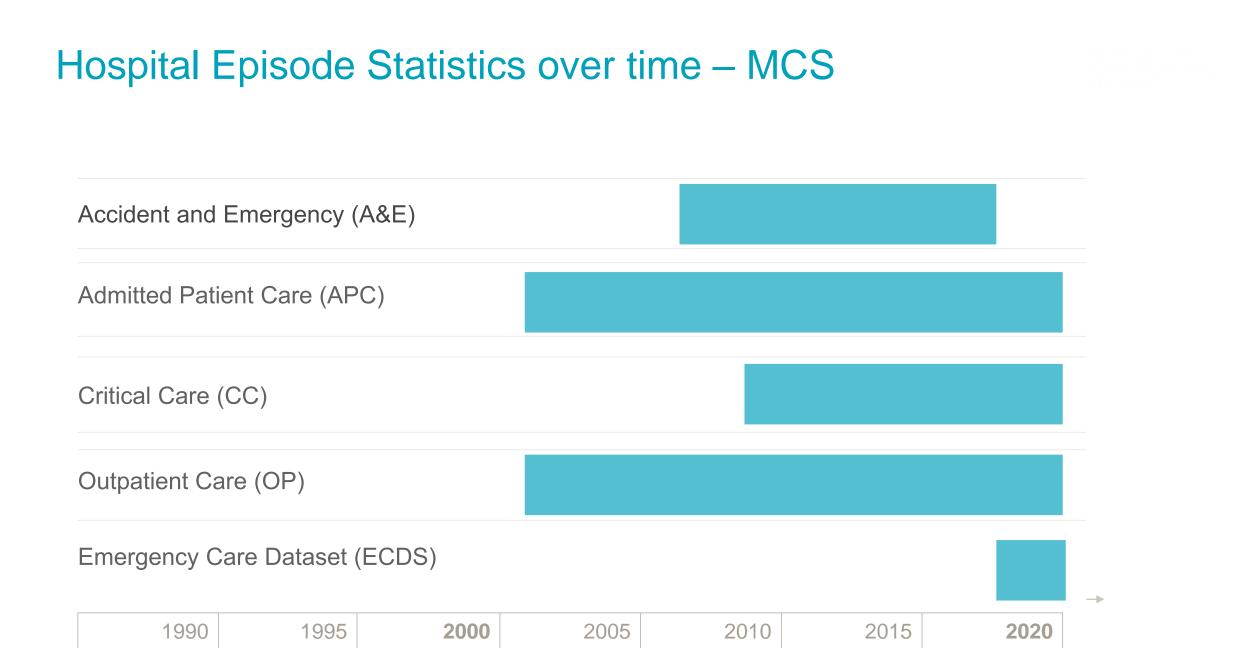
NHS England – Hospital Episode Statistics (HES)

Datasets available:

- Admitted Patient Care (APC)
- Critical Care (CC) linked to APC records
- Accident and Emergency (A&E)
- Outpatient Care (OP)
- Emergency Care Dataset (ECDS MCS only)

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	Number in sweep*	Gave consent (% of in sweep)	Has matched data (% of consented)
Next Steps	7,707	4,895 (63.5)	4,579 (93.5)
BCS70	9,841	7,048 (71.6)	5,488 (77.9)
NCDS	9,790	7,065 (72.2)	6,188 (87.6)
MCS	10.757	9.214 (86.7)	7,396 (81.5)

* Sweep in which consent was sought for linkage:

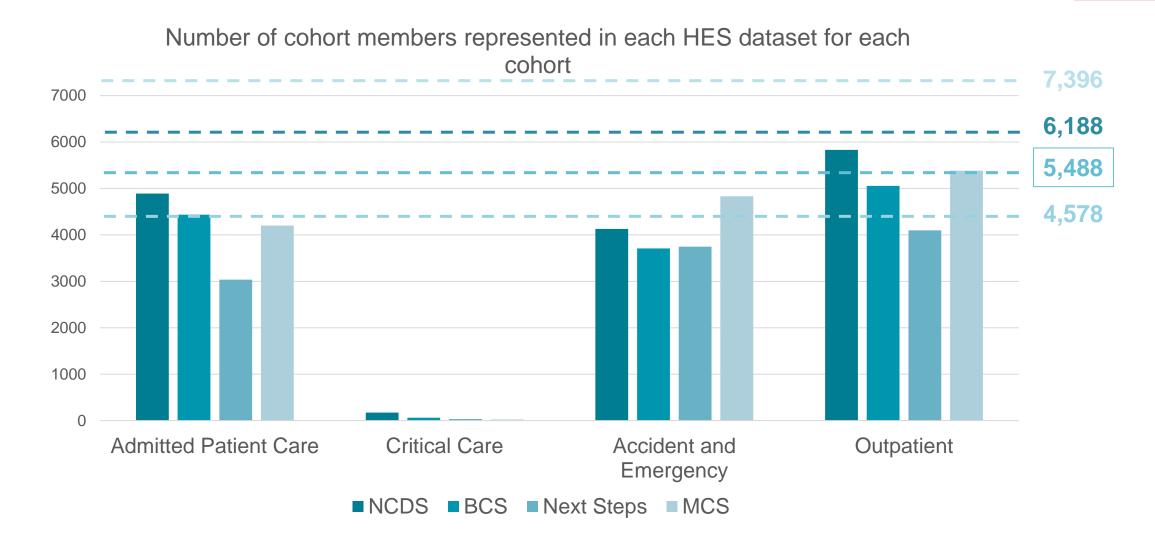
• NCDS: Age 50 Survey

- Next Steps: Age 25 Survey
- BCS70: Age 42 Survey

• MCS: Age 17 Survey

HES – Linkage





HES – Structure of the data

The NHS organizes the data into episodes

- Episode
 - A continuous period of patient care administered under one consultant within health care providers.
 - Each episode is a row in each dataset.
- Hospital Spell
 - Total time spent by a patient in the same care provided by a hospital, from date of admission to date of discharge.
 - Spells cover one or more episodes.
 - To avoid double counting, use the last episode in a spell (spelend = Y).



HES - What data are available?

Admitted Patient Care 1997-2017

- Diagnostic codes (ICD-10)
- Operation Chapter (OPCS-4)
- Maternity data
- Indices of Multiple Deprivation
- Administrative data e.g. Health Authority
- Dates of admission, discharge etc

Critical Care 2009-2017

- Types of specialist support i.e. Renal
- Number of days spent with assistance for specialist care.
- Every critical care episode links with an APC code (D_SUSID)



HES - What data are available?

Outpatient Care 2003-2017

- Diagnostic codes (ICD-10) (poorly completed)
- Operation Chapter (OPCS-4)
- Indices of Multiple Deprivation
- Administrative data
- Dates (DD/MM/YYY) seen

Accident and Emergency 2007-2017

- Diagnostic codes (A&E)
- Treatment codes
- Administrative data
- Dates (DD/MM/YYYY) time admission and discharge

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HES – what data are available?

Emergency Care Dataset

- SNOMED-CT
- Diagnostic codes
- Causes of injury & drug information
- Treatment
- Dates of arrival/being seen

HES - Dictionaries & Supplementary Documentation

- <u>CLS User Guide</u>
- NHS Data Dictionaries
- HES Analysis Guide
- International Classification of Diseases ICD-10 (Diagnoses, Symptoms, Causes)
- Operational codes OPCS-4
- A&E Diagnosis and Treatment codes

>Available on the Secure Access server at the UK Data archive

➤Can be viewed alongside the data

➤Links can also be found in the CLS user guide

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ICD-10	Search	? [Advanc	ed Search]	ICD-10	Versions - Languages	Info //	
	 ICD-10 Version:2010 	🖻 In	iternationa	l Statistica	al Classification of D	iseases and Related Health	
	I Certain infectious and parasitic diseases	Pr	oblems 10	th Revisio	n (ICD-10) Version	for 2010	
	II Neoplasms						
	III Diseases of the blood and blood-forming organs and	C1	Chapter I				
	certain disorders involving the immune mechanism		-	ious and n	arasitic diseases		
	IV Endocrine, nutritional and metabolic diseases		(00-B99)	ious and p	arasitic diseases		
	V Mental and behavioural disorders		(00-855)				
	VI Diseases of the nervous system	In	cl.: diseases g	enerally recogn	nized as communicable or tra	insmissible	
	VII Diseases of the eye and adnexa						
	VIII Diseases of the ear and mastoid process	Us	e additional code	e (U80-U89), if	desired, to identify the antib	piotic to which a bacterial agent is resistant.	
	IX Diseases of the circulatory system	Ex	cl.: carrier or	suspected carri	ier of infectious disease (Z22)	
	X Diseases of the respiratory system			•	is - see body system-related		
	XI Diseases of the digestive system		infectious	and parasitic d	iseases complicating pregnar	ncy, childbirth and the puerperium [except	
	 XII Diseases of the skin and subcutaneous tissue XIII Diseases of the musculoskeletal system and connective 			tetanus] (<u>098</u>			
	tissue					tal period [except tetanus neonatorum, perinatal human immunodeficiency virus [HI]	
	 XIV Diseases of the genitourinary system 		disease] (permatar namar initial odenciency viras [ni	
	XV Pregnancy, childbirth and the puerperium		influenza a	and other acute	e respiratory infections (<u>100-</u>	<u>122</u>)	
	XVI Certain conditions originating in the perinatal period						
	XVII Congenital malformations, deformations and		is chapter con		-		
	chromosomal abnormalities		0-A09 Intestin		seases		
	XVIII Symptoms, signs and abnormal clinical and laboratory		<u>5-A19</u> Tubercu 0-A28 Certain		rial diseases		
	findings, not elsewhere classified		0-A20 Other b				
	XIX Injury, poisoning and certain other consequences of external causes				ominantly sexual mode of tra	nsmission	
	 XX External causes of morbidity and mortality 	<u>A6</u>	5-A69 Other sp	oirochaetal dise	eases		
	 XXI Factors influencing health status and contact with health 	<u>A7</u>	<u>0-A74</u> Other d	iseases caused	by chlamydiae		
	services	<u>A7</u>	<u>5-A79</u> Ricketts				
	XXII Codes for special purposes				central nervous system	- 6	
					fevers and viral haemorrhagi erized by skin and mucous m		
			<u>5-B19</u> Viral he		Shee by skin and macous n		
					ncy virus [HIV] disease		
GITUDINAL			<u>5-B34</u> Other vi		-		
IES		<u>B3</u>	<u>5-B49</u> Mycoses	5			
		B5	0-B64 Protozoa	al disaasas			

ICD-10	Search	? [Advanced Search	ן י	ICD-10	Versions - Languages	Info	
	 ICD-10 Version:2010 I Certain infectious and parasitic diseases A00-A09 Intestinal infectious diseases A15-A19 Tuberculosis 	~	hı pı se		odeficieny s associate perculosis ([HIV] disease resulting in tub ed with tuberculosis (<u>J65</u>)	erculosis (<u>E</u>	3 <u>20.0</u>)
	 A20-A28 Certain zoonotic bacterial diseases A30-A49 Other bacterial diseases A50-A64 Infections with a predominantly sexual mode transmission A65-A69 Other spirochaetal diseases A70-A74 Other diseases caused by chlamydiae A75-A79 Rickettsioses 	node of A15 Respiratory tuberculosis, bacteriologically and histolo A15.0 Tuberculosis of lung, confirmed by sputum microscopy Tuberculous: • bronchiectasis • fibrosis of lung • pneumonia • pneumothorax				oscopy wi	ith or without culture	
	 A80-A89 Viral infections of the central nervous system A90-A99 Arthropod-borne viral fevers and viral haemorrhagic fevers 		A15.1		-	confirmed by culture only 5.0, confirmed by culture only		
	B00-B09 Viral infections characterized by skin and mucous membrane lesions		A15.2			confirmed histologically 5.0, confirmed histologically		
	 B15-B19 Viral hepatitis B20-B24 Human immunodeficiency virus [HIV] disease 		A15.3		-	confirmed by unspecified 5.0, confirmed but unspecified		acteriologically or histologically
	 B25-B34 Other viral diseases B35-B49 Mycoses B50-B64 Protozoal diseases B65-B83 Helminthiases B85-B89 Pediculosis, acariasis and other infestations 		A15.4	Tuberculosis Tuberculosis • hilar • mediast • tracheo	of lymph i inal	1		teriologically and histologic
	 B90-B94 Sequelae of infectious and parasitic diseases B95-B98 Bacterial, viral and other infectious agents B99-B99 Other infectious diseases 		A15.5		s of laryn	imary (<u>A15.7</u>) x, trachea and bronchus, c	onfirmed	bacteriologically and
	 II Neoplasms III Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism IV Endocrine, nutritional and metabolic diseases 			Tuberculosis • bronchu • glottis • larynx • trachea	IS	rmed bacteriologically and his	tologically	
NTRE FOR NGITUDINAL JDIES	 V Mental and behavioural disorders VI Diseases of the nervous system VII Diseases of the eye and adnexa VIII Diseases of the ear and mastoid process 	~	A15.6		of pleura	confirmed bacteriological	-	



NHS Scotland – Scottish Medical Records (SMR)

NHS Scotland – Scottish Medical Data (SMR)

Dataset	NCDS	BCS70	MCS
Prescribing Information System (PIS)	\checkmark	\checkmark	\checkmark
Outpatient Records (SMR00)	\checkmark	\checkmark	\checkmark
Inpatient Records (SMR01)	\checkmark	\checkmark	\checkmark
Maternity Records (SMR02)	\checkmark	\checkmark	
Birth and Neonatal Records (SMR11)			\checkmark
Scottish Immunisation & Recall System (SIRS)			\checkmark
Child Health Reviews (CHR)			\checkmark
1 st visit / 6-8 week visit / 8-9 month visit / 22-24 month visit /			
37-42 month visit / Preschool visit /School reviews			

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Accessing Health Data

UK Data Service (UKDS) UK Longitudinal Linkage Collaboration (UKLLC)

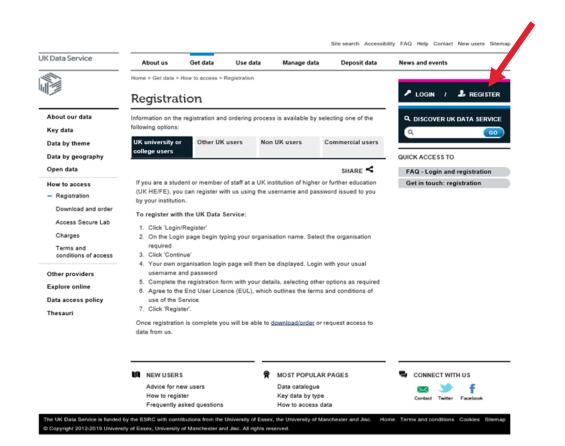
Accessing the data

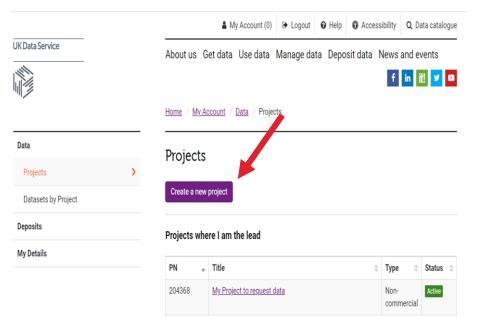
- Due to the potential disclosivity and sensitivity of HES and SMR data, these datasets are only accessible under Secure Access conditions through the UK Data Service Secure Lab.
- In order to have access to the data and as part of the application process:
 - you must be based in a UK organisation, and be affiliated with a UK HE or FE institution.
 - you must be an accredited researcher to use ONS data or apply to be one as part of the project application or you must fill in the accredited researcher form each time you apply to access ESRC data
 - your User Agreement must be authorised and signed by someone who can take legal responsibility on behalf of your institution
 - you must have attended and passed a Safe Researcher training course (a place on this course can be offered as part of the application process)
 - you must be able to access the data from a suitable safe environment that meets the UK Data Service's security requirements

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Step 1: Register

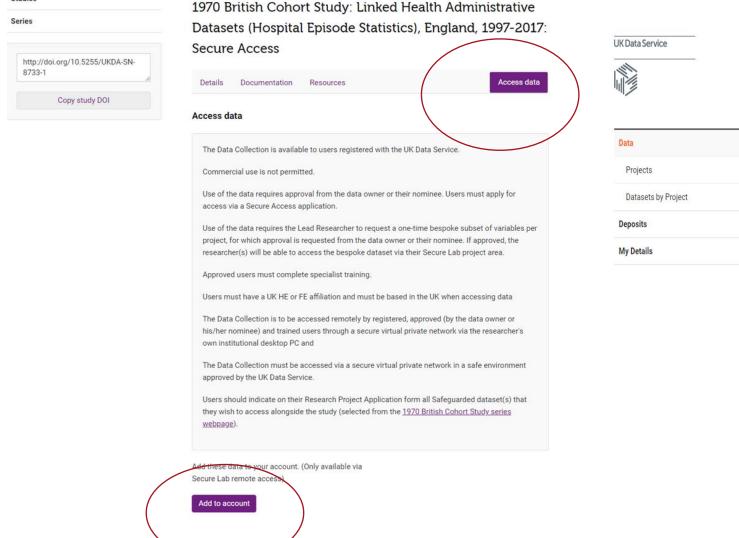
Step 2: Create a project



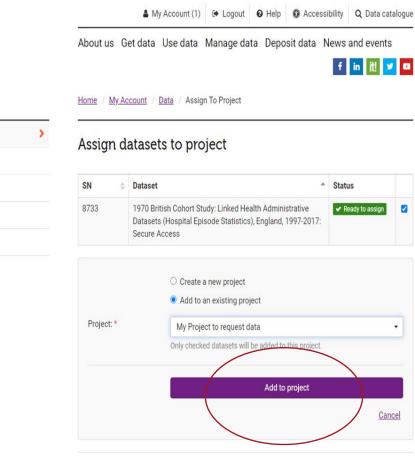


Step 3: Select your data

Studies



Step 4: Assign dataset to a project



Existing datasets in project

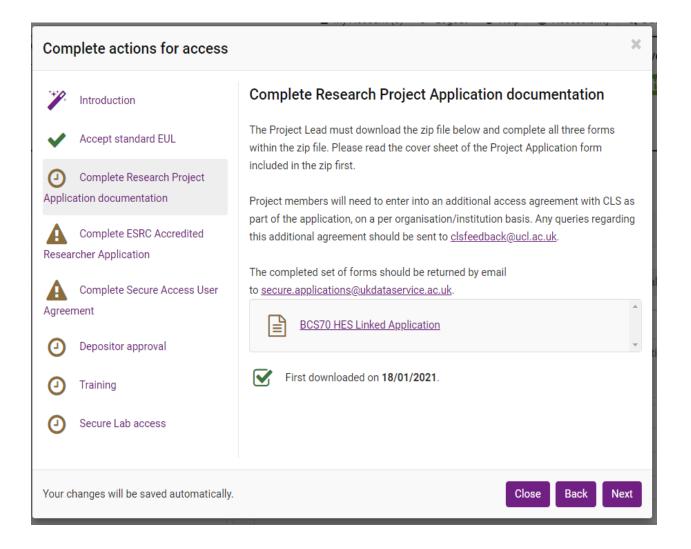
Step 5: Access the appropriate forms

My Project to request data

Proj		Datasets	Members	Notes	Log					
ata	sets ir	n project						Se	lect all datas	ets
SN	\$	Dataset				-	Status			
8733	}	Administra	h Cohort Study tive Datasets (England, 1997	(Hospital Ep	oisode		A Request acc	cess	Actions -	
~	Accep	t standard El	JL							
A	Comp	lete Research	n Project Appli	cation docu	mentation					
A	Comp	lete ESRC Ac	credited Resea	archer Appli	cation					
A	Comp	lete Secure A	.ccess User Ag	reement						
0	Depos	itor approval								
0	Trainir	ng								
0	Secure	e Lab access								$\overline{\}$
								Со	mplete actior	าร

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To apply to use the data Step 5: Download Application forms





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Step 5: Application forms (HES and SMR data)



• Completed by : Project Lead

Completed by: the Principal Investigator/Project Lead



- Any project member who requires access to statistical analysis before release from the UK Data Service
- PhD supervisors and co-authors (even if they will not be analysing the data)

Step 5: Application forms- Agreements (HES and SMR data)

UK Data Service



Secure Access User Agreement

External 13 October 2016 Version: 09.00

T +44 (0)1206 873546 E collections@ukdataservice.ac.uk ukdataservice.ac.uk Project lead and their organisation signatory need to read and agree to terms.

Signed by :

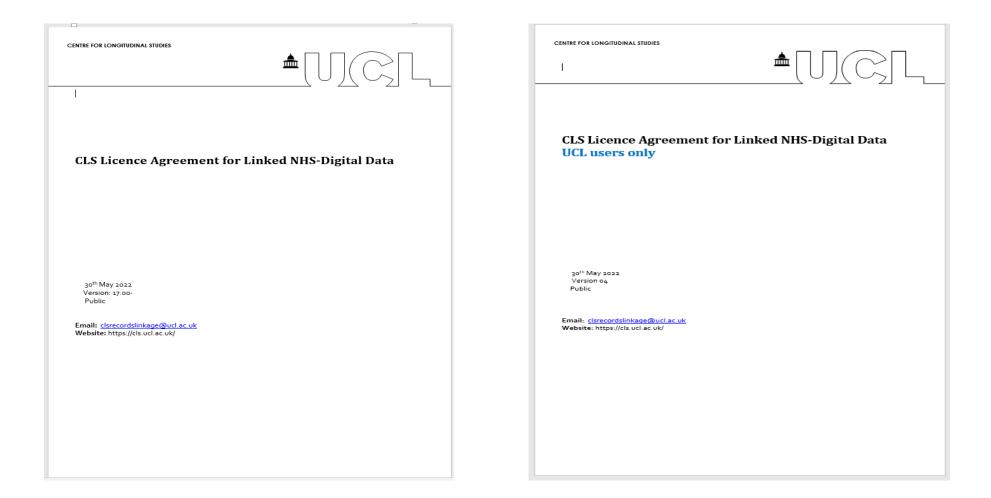
- Project Lead &
- Institution Contracts Office or person authorised to sign on behalf of the organisation.



Step 5: Application – HES Variable selection (e.g. NCDS_HES_variables_List_1.xlsx)

А	В	С	D	E
Vext St	eps - Accident & Emerge	ncy - Data Dictionary	Please select the variables you need in the 'Requested' drop down cells	
var_orde	variable_name	variable_label	value_labels	Requested ? (YES/blank
1	NSID	NSID - cohort member identifier		Yes
2	AEARRIVALMODE	Arrival mode	(-1) "Missing: not applicable/not available/not given" (1) " Brought in by ambulance (including helicopter)" (2) "Other"	
3	AEATTEND_EXC_PLANNED	Attendances excluding planned	(0.0) "Planned AE Attendance " (1.0) "Unplanned AE Attendance"	
4	AEATTENDCAT	Attendance category	(-1) "Missing: not applicable/not available/not given" (1) "First Accident and Emergency attendance" (2) "Follow-up Accident and Emergency attendance - uplanned" (3) "Follow-up Accident and Emergency attendance - uplanned" (9) "Not known".	
5	AEATTENDDISP	Attendance disposal	(1)"Admitted to hospital bed at same HCP" (2)"Discharged follow-up treatment to be provided by GP" (3)"Discharged did not require any follow-up treatment" (4)"Referred to A&E clinic" (5)"Referred to fracture clinic" (6)"Referred to other outpatient clinic" (7)"Transferred to other healthcare provider" (10)"Died in department" (11)"Referred to other healthcare professional" (12)"Left department before being treated" (13)"Left department having refused treatment" (14)"Other" (99)"Not known"	
б	AEDEPTTYPE	Department type	 (-1) "Missing: not applicable/not available/not given" (1) "Emergency departments" (2) "Consultant-led mono specialty accident and emergency service" (3) "Other type of A&E/ minor injury activity with designated accommodation for reception of patients" (4) "NHS walk-in centres" (99) "Not known" 	
7	AEINCLOCTYPE	Incident location type	(-1) "Missing: not applicable/not available/not given" (10) "Home" (40) "Work" (50) "Educational establishment" (60) "Public Place" (91) "Other" (99) "Not known"	
8	AEPATGROUP	Patient group	(-1) "Missing: not applicable/not available/not given" (10) "Road traffic accident" (20) "Assault" (30) "Deliberate self-harm" (40) "Sports injury" (50) "Firework injury" (60) "Other accident" (70) "Brought in dead" (80) "Other than above" (99) "Not known"	
9	AEREFSOURCE	Source of referral for A&E	(-1) "Missing: not applicable/not available/not given" (0) "General medical practitioner" (1) "Self referral" (2) "Local authority social services" (3) "Emergency services" (4) "Work" (5.0) "Educational establishment" (6) "Police " (7.0) "Health care provider: same or other" (8.0) "Other " (92.0) "General dental practitioner" (93.0) "Community dental service"	
10	ARRIVALDATE	Arrival start date		
11	ARRIVALTIME	Arrival Time HH:MM (00:00 to 25:59)		
12	CARERSI	Carer support indicator	(-1) "Missing: not applicable/not available/not given" (1) "Yes" (2) "No"	
13	CONCLDUR	Duration to conclusion (in minutes)	(-1) "Missing: not applicable/not available/not given"	
14	CONCLTIME	Conclusion time HH:MM (00:00 to 25:59)		
15	DEPDUR	Duration to departure (in minutes)	(-1) "Missing: not applicable/not available/not given"	
16	DEPTIME	Departure time HH:MM (00:00 to 25:59)		
17	DIAG_01	A&E diagnosis (1)	he A&E diagnosis is a six character code made up of, diagnosis condition (n2), sub-analysis (n1), anatomical area (n2) and anatomical side (an1). (-1) "Missing: not applicable/not available/not given"	
18	DIAG_02	A&E diagnosis (2)	he A&E diagnosis is a six character code made up of, diagnosis condition (n2), sub-analysis (n1), anatomical area (n2) and anatomical side (an1). (-1) "Missing: not applicable/not available/not given"	
19	DIAG_03	A&E diagnosis (3)	he A&E diagnosis is a six character code made up of, diagnosis condition (n2), sub-analysis (n1), anatomical area (n2) and anatomical side (an1). (-1) "Missing: not applicable/not available/not given"	

Step 5: Application forms- Additional agreement required (HES data only)



Step 5: Application forms- Additional agreement required (HES data only)

Important sections in the document: These are NHS Digital requirements.

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- ✓ Legal basis
- ✓ Organisational Security
- ✓ Project proposal
- \checkmark Provide project's expected measurable benefits to Health and/or Social Care
- ✓ Select variables (this is different to Scottish health data where only datasets are specified)
- \checkmark Completed by Project Lead and each member applying to use the data.
- ✓ Signed by Institution Contracts Offices or authorised signatory.

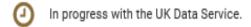
Access to secure data

Step 6: Depositor approval

- The application will be presented to the CLS Data Access Committee (DAC) for approval.
- For applications requesting access to HES data, DAC will assess whether the researcher has provided satisfactory information to the NHS Digital requirements sections highlighted previously.

Depositor approval required

This dataset requires approval from the depositor before it can be accessed. Please wait while we service this request. You will be notified by email when approval has been granted.



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Access to secure data

Training required

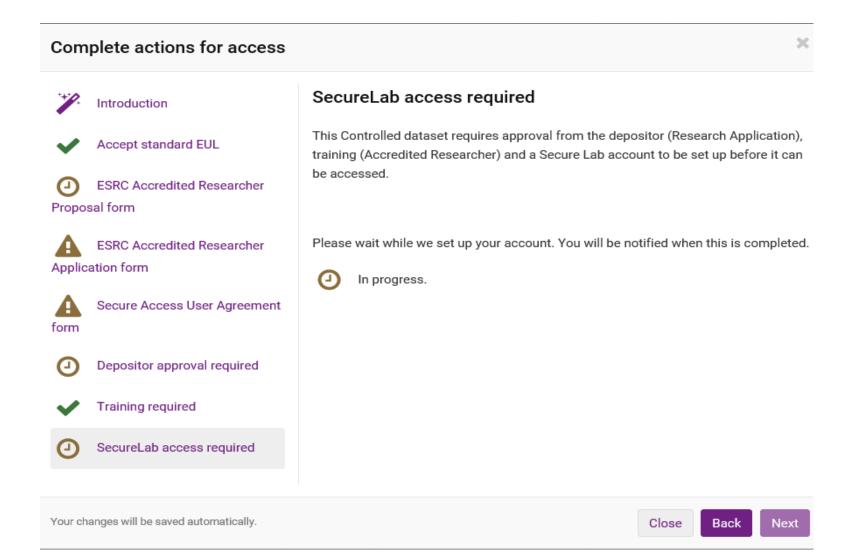
This Controlled dataset requires approval from the depositor (Research Application), training (Accredited Researcher) and a Secure Lab account to be set up before it can be accessed.

Step 7: Training

- New Secure Lab researchers who haven't previously completed the Safe User of Research Environment (SURE) or Safe Researcher Training will be invited by the UKDS to attend training.
- Researchers who completed training since January 2016 will be required to complete a short online training that covers the specifics of the Secure Lab,
- Current Secure Lab researchers who have not accessed the Secure lab for 30 months will be asked to complete a short online refresher course.

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Access to secure data: Secure Lab Access



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Accessing the data

- For more information on how to apply for access, please visit <u>https://www.ukdataservice.ac.uk/get-data/how-to-access/accesssecurelab</u>
- If you have any enquiries regarding the application process, please contact the UK Data Service via their 'Accessing data' web form: <u>https://beta.ukdataservice.ac.uk/help?id=accessingData</u>
- Alternatively, the UK Data Service can be contacted via email at <u>help@ukdataservice.ac.uk</u>, or by telephone on 01206 872143.

Timescales

CENTRE FOR LONGITUDINAL STUDIES All applications must be validated and processed by the UK Data Service and then approved by the data owners. The UK Data Service works through a high volume of applications throughout the year. The UK Data Service endeavour to process applications as soon as possible but each application may take a number of months from start to finish.

Welsh health data in the MCS via the SAIL Data Bank

Datasets available:

- Emergency Department Dataset
- Primary Care GP dataset
- Outpatient Dataset
- Patient Episode Database (episodes of inpatient and day case care)
 - MCS1-6 currently available
 - Data for CM's (up to age 14) and parents

Access

Secure Anonymised Information Linkage (SAIL) Databank – a Wales-wide research resource offering a range of health related datasets.

- Can apply for any health data in the SAIL Databank via <u>https://data.ukserp.ac.uk/Organisation/Category?</u> <u>nodeld=1&orgld=0</u>
- Application process can be found at <u>https://saildatabank.com/application-</u> process/two-stage-process/
- There is a charge determined on a case by case basis

Linked health administrative data available at the UKDS in the near future

- HES refresh for Next Steps, BCS70 and NCDS.
- CLS will refresh the Welsh health dataset linked to MCS (2001-2012) currently available at the <u>UKDS</u>.

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Thank you Any questions?

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LEUK a research resource for the longitudinal research commun

UK LLC led by the Universities of Bristol & Edinburgh







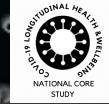
STUDY

Funded by In collaboration with UK Research and Innovation UK Research and Innovation In collaboration with

A work package in the COVID-19 Longitudinal Health & Wellbeing National Core Study



Slides provided by UK LLC and adapted/presented by CLS



ILCUK

A globally unique cross-cutting resource

20+ Longitudinal Population Studies

- COVID-19 collections (Questionnaires, Serology)
- SES & demographic
- Baseline physical & mental health
- Baseline family, SES and life-course indicators

NHS COVID-19 datasets

- •GP Data
- Vaccinations
- COVID-19 test data (Pillar 1-3)
- Accident & Emergency
- CHESS

Wider NHS datasets

- Hospital Inpatient data
- Cancer & mortality registers
- Community Mental Health (MHSDS, IAPT)
- Prescribing data

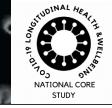


Administrative records

- HMRC • DWP • DfE
- Approvals in place

Environmental & neighbourhood

- Air pollution
- Noise
- Greenspace
- SES & demographic indicators
- Service provision
- Property data



LCUK

UK Longitudinal Linkage Collaboration

20+ longitudinal studies with >280,000 participants A new Trusted Research Environment Novel NHS Digital data pipeline Approvals for hitherto inaccessible data Public contributors & application panel 23 approved research projects

AIRWAVE Health Monitoring Study Tissue Bank **ALSPAC**: Avon Longitudinal Study of Parents and Children **BCS70** British Cohort Study

Born in Bradford

ELSA: English Longitudinal Study of Ageing **EPIC-Norfolk**: The European Prospective Investigation into Cancer (EPIC) Norfolk Study

EXCEED: Extended Cohort for E-health, Environment & DNA **The Fenland Study**

Generation Scotland

GLAD: Genetic Links to Anxiety and Depression Study **MCS**: Millennium Cohort Study NCDS 58: 1958 National Child Development Study Next Steps

NICOLA: Northern Ireland Cohort for the Longitudinal Study of Ageing

NIHR BioResource_COPING: National Institute of Health Research BioResource, COVID-19 Psychiatry and Neurological Genetics Study NSHD46: MRC National Survey of Health and Development Cohort/1946 Birth Cohort SABRE: Southall & Brent Revisited TRACK-COVID Study TwinsUK Understanding Society - the UK Household Longitudinal Study





Submit expression of interest via Health Data Research UK gateway <u>https://www.healthdatagatewa</u> <u>y.org/</u> - search for UK LLC - in the UK LLC record, click on 'How to access'

- Free to ONS accredited UK Researchers
- Public benefit with public review
- Requirements for reproducible research
- UK LLC distributes applications to contributing studies
- UK LLC has delegated review authority from NHS Digital

NATIONAL COR

ILCUK

8 - week Service Level Agreement



Access to the data



All processing *within* the ISO 27001 accredited Trusted Research Environment

- Access via Windows 10 remote desktop environment using twofactor authentication
- Project-specific database views
- Access to code lists and code mappings
- Standard packages for analyses include Python, R(+RStudio), Stata and SPSS
- Outputs checked for statistical disclosure control before released from the Trusted Research Environment

Looking ahead

- Currently funded until May 2023 application for new 5-year funding submitted
- Q3 and Q4 2023
 - Opening up to research beyond Covid-19
 - Addition of Welsh NHS data
 - Addition of HMRC data
- Q1 and Q2 2024
 - Addition of Scottish NHS data
 - DWP then DfE to follow

Help/questions

access@ukllc.ac.uk







Analysing linked HES data

Richard Silverwood Associate Professor of Statistics & CLS Chief Statistician

CENTRE FOR LONGITUDINAL STUDIES

6 December 2022



Economic and Social Research Council

Outline

CENTRE FOR LONGITUDINAL STUDIES

- 1. HES data structure and variables
- 2. Defining your analysis sample
- 3. Recent analyses
- 4. Resources

HES data structure and variables

HES data structure: Episodes and spells



- Each record in HES is a hospital **episode**.
- Episodes relate to a period of care for a patient under a single consultant within one hospital provider.
- A stay in hospital from admission to discharge is called a **spell** and can be made up of one or more episodes of care.

HES data structure: Example (made up) data



ncdsid	provspnops	admidate	epiorder	epistart	epiend	disdate	spelend
N3674M	HS6Q9B4HU27D96MF61P5	16jan2010	1	16jan2010	18jan2010	18jan2010	Y
N8429G	JS8G36DJV8538JSBDNH8	07aug2003	1	07aug2003	07aug2003		Ν
N8429G	JS8G36DJV8538JSBDNH8	07aug2003	2	07aug2003	13aug2003	13aug2003	Y
N4275R	H836FTK2SN9JTEB533N2	21feb1999	1	21feb1999	22feb1999		Ν
N4275R	H836FTK2SN9JTEB533N2	21feb1999	2	22feb1999	22feb1999		Ν
N4275R	H836FTK2SN9JTEB533N2	21feb1999	3	22feb1999	25feb1999	25feb1999	Y
N4275R	64NQF48J6D2UH76WN382	09nov2015	1	09nov2015	09nov2015	•	N
N4275R	64NQF48J6D2UH76WN382	09nov2015	2	09nov2015	14nov2015	14nov2015	Y

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HES data structure: Example (made up) data



ncdsid	provspnops	Admidate	epiorder	epistart	epiend	disdate	spelend
N3674M	HS6Q9B4HU27D96MF61P5	16jan2010	1	16jan2010	18jan2010	18jan2010	Y
N8429G	JS8G36DJV8538JSBDNH8	07aug2003	1	07aug2003	07aug2003		Ν
N8429G	JS8G36DJV8538JSBDNH8	07aug2003	2	07aug2003	13aug2003	13aug2003	Y
N4275R	H836FTK2SN9JTEB533N2	21feb1999	1	21feb1999	22feb1999		N
N4275R	H836FTK2SN9JTEB533N2	21feb1999	2	22feb1999	22feb1999		N
N4275R	H836FTK2SN9JTEB533N2	21feb1999	3	22feb1999	25feb1999	25feb1999	Y
N4275R	64NQF48J6D2UH76WN382	09nov2015	1	09nov2015	09nov2015		N
N4275R	64NQF48J6D2UH76WN382	09nov2015	2	09nov2015	14nov2015	14nov2015	Y

Basic data checks

- Variable completeness and quality differs by variable and dataset.
- Important to conduct some basic data checks, e.g.:
 - Dates correctly recorded/formatted (e.g. within plausible range).
 - Ordering of dates is plausible (e.g. within spells).
 - Observed episodes within spell consistent with epiorder.

ICD-10 coding



- International Classification of Diseases version 10 (ICD-10).
- Codifies diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases.

ICD-10 Version:2010

https://icd.who.int/browse10/2010/en#/

Search hypertension	[Advanced Search] ICD-10 Versions - Languages Info						
 ICD-10 Version:2010 I Certain infectious and parasitic diseases II Neoplasms 	(I00-I99) Hypertensive diseases						
 III Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism IV Endocrine, nutritional and metabolic diseases V Mental and behavioural disorders VI Diseases of the nervous system VII Diseases of the eye and adnexa VIII Diseases of the arc and masterial process 	(IIO-II5) Excl.: complicating pregnancy, childbirth and the puerperium (010-011, 013-016) involving coronary vessels (I20-I25) neonatal hypertension (P29.2) pulmonary hypertension (I27.0)						
 VIII Diseases of the ear and mastoid process IX Diseases of the circulatory system 100-102 Acute rheumatic fever 105-109 Chronic rheumatic heart diseases I10-I15 Hypertensive diseases I20-I25 Ischaemic heart diseases I26-I28 Pulmonary heart disease and diseases of 	 Essential (primary) hypertension Incl.: High blood pressure Hypertension (arterial)(benign)(essential)(malignant)(primary)(systemic) Excl.: involving vessels of: brain (160-169) eye (H35.0) 						
 pulmonary circulation I30-I52 Other forms of heart disease I60-I69 Cerebrovascular diseases I70-I79 Diseases of arteries, arterioles and capillaries I80-I89 Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified I95-I99 Other and unspecified disorders of the circulatory system 	 Hypertensive heart disease Incl.: any condition in I50, I51.4-I51.9 due to hypertension Hypertensive heart disease with (congestive) heart failure Hypertensive heart failure Hypertensive heart disease without (congestive) heart failure Hypertensive heart disease NOS 						
 X Diseases of the respiratory system XI Diseases of the digestive system XII Diseases of the skin and subcutaneous tissue XIII Diseases of the musculoskeletal system and connective tissue XIV Diseases of the genitourinery system 	I12 Hypertensive renal disease Incl.: any condition in N00-N07, N18, N19 or N26 due to hypertension arteriosclerosis of kidney arteriosclerotic nephritis (chronic)(interstitial) hypertensive nephropathy nephrosclerosis						

ICD-10 coding: Chapters



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Chapter	Block	Title
I	A00–B99	Certain infectious and parasitic diseases
II	C00–D48	Neoplasms
ш	D50–D89	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
IV	E00–E90	Endocrine, nutritional and metabolic diseases
V	F00–F99	Mental and behavioural disorders
VI	G00–G99	Diseases of the nervous system
XXII	U00–U99	Codes for special purposes

ICD-10 coding: Example (made up) data



Diagnosis Diagnosas ad i BigDrotsos al Diagnatisis 2007 for teated DCD0-10

ncdsid	provspnops	D_DIAG_01	D_DIAG_02	D_DIAG_03	D_DIAG_04	 D_DIAG_20
N3674M	HS6Q9B4HU27D96MF61P5	177				 -
N8429G	JS8G36DJV8538JSBDNH8	Z85	G35	Z51		 -
N8429G	JS8G36DJV8538JSBDNH8	Z85	G35	Z51	•	 -
N4275R	H836FTK2SN9JTEB533N2	l42	K29		•	 -
N4275R	H836FTK2SN9JTEB533N2	l42	K29		•	 -
N4275R	H836FTK2SN9JTEB533N2	l42	K29		•	 -
N4275R	64NQF48J6D2UH76WN382	R06	Z87	K12	N23	 -
N4275R	64NQF48J6D2UH76WN382	R06	Z87	K12	N23	 •

ICD-10 coding: Example (made up) data



Optensodiadoristeosyo6anbeilvilgetaiputeneedtetriensliensedical care

ncdsid	provspnops	D_DIAG_01	D_DIAG_02	D_DIAG_03	D_DIAG_04	 D_DIAG_20
N3674M	HS6Q9B4HU27D96MF61P5	177				 •
N8429G	JS8G36DJV8538JSBDNH8	Z85	G35	Z51		 -
N8429G	JS8G36DJV8538JSBDNH8	Z85	G35	Z51		
N4275R	H836FTK2SN9JTEB533N2	l42	K29	•		
N4275R	H836FTK2SN9JTEB533N2	l42	K29	•	•	 •
N4275R	H836FTK2SN9JTEB533N2	l42	K29	•		 •
N4275R	64NQF48J6D2UH76WN382	R06	Z87	K12	N23	 -
N4275R	64NQF48J6D2UH76WN382	R06	Z87	K12	N23	 •

ICD-10 coding: Example (made up) data



ncdsid	provspnops	D_DIAG_01	D_DIAG_02	D_DIAG_03	D_DIAG_04	 D_DIAG_20
N3674M	HS6Q9B4HU27D96MF61P5	177	•	•		 •
N8429G	JS8G36DJV8538JSBDNH8	Z85	G35	Z51		
N8429G	JS8G36DJV8538JSBDNH8	Z85	G35	Z51		
N4275R	H836FTK2SN9JTEB533N2	142	K29			
N4275R	H836FTK2SN9JTEB533N2	142	K29			
N4275R	H836FTK2SN9JTEB533N2	142	K29			
N4275R	64NQF48J6D2UH76WN382	R06	Z87	K12	N23	
N4275R	64NQF48J6D2UH76WN382	R06	Z87	K12	N23	

ICD-10 coding: Example code



May want to group codes, e.g. into chapters:

- . gen $D_DIAG_01_ch = .$
- . replace D_DIAG_01_ch = 1 if substr(D_DIAG_01, 1, 1) == "A" |
 substr(D_DIAG_01, 1, 1) == "B"
- . replace D_DIAG_01_ch = 2 if substr(D_DIAG_01, 1, 1)=="C" |
 substr(D_DIAG_01, 1, 2)=="D0" | substr(D_DIAG_01, 1, 2)
 =="D1" | substr(D_DIAG_01, 1, 2)=="D2" |
 substr(D_DIAG_01, 1, 2)=="D3" | substr(D_DIAG_01, 1,
 2)=="D4"

• • •

Expand to all diagnosis positions by looping over D_DIAG_01, ..., D_DIAG_20.

ICD-10 coding: Example code



Often interested in whether an individual has *ever* had a certain diagnosis. E.g. for Chapter I:

- $. gen D_DIAG_01_ch1 = (D_DIAG_01_ch==1)$
- . gen D_DIAG_01_ch1_ever = D_DIAG_01_ch1
- . bysort ncdsid (D_DIAG_01_ch1_ever): replace
 D_DIAG_01_ch_1_ever = D_DIAG_01_ch1_ever[_N]

Extend to all chapters by looping over Chapters 1-22

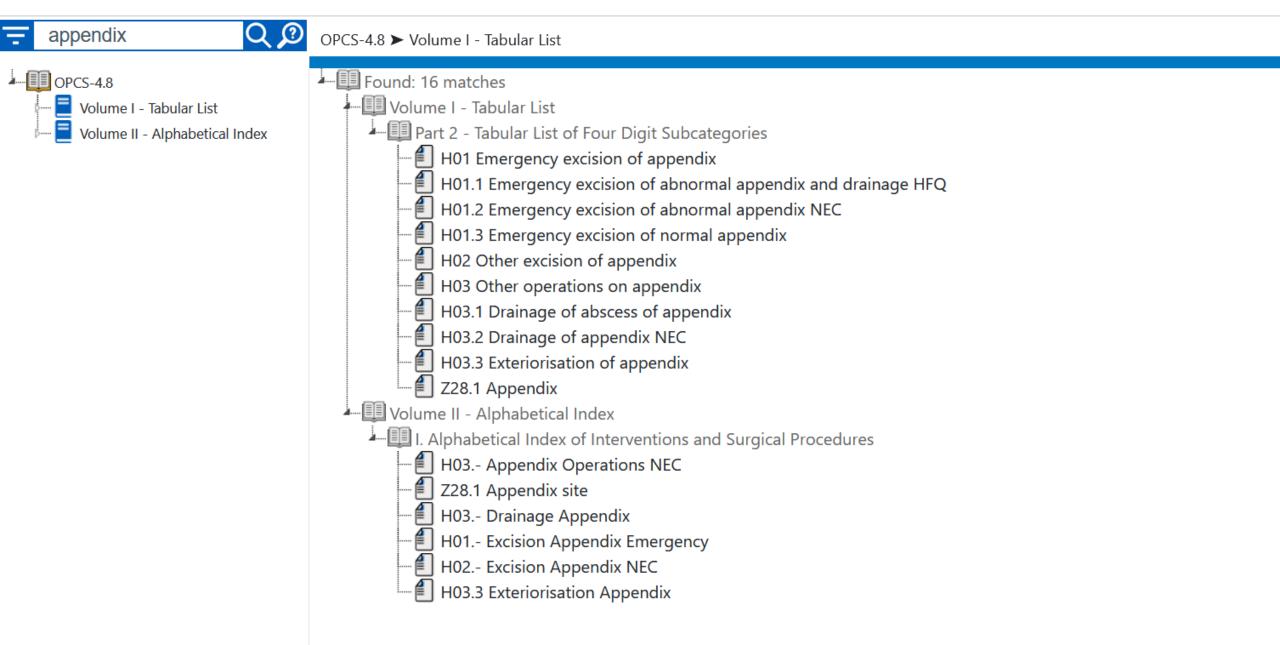
OPCS coding



- Office of Population Censuses and Surveys (OPCS) Classification of Interventions and Procedures.
- Codifies operations, procedures and interventions performed during in-patient stays, day case surgery and some out-patient treatments in NHS hospitals.



Classifications Browser OPCS-4.8



OPCS coding: Chapters



Chapter/first character*	Title
A	Nervous System
В	Endocrine System and Breast
С	Eye
D	Ear
E	Respiratory Tract
F	Mouth
Z	Subsidiary Classification of Sites of Operation

*Codes beginning with an "O" are overflow codes and should be handled differently.

OPCS coding: Example (made up) data



Intervention to roce to http://www.celector.cole

ncdsid	provspnops	opertn_01	opertn_02	opertn_03	opertn_04	 opertn_23
N3674M	HS6Q9B4HU27D96MF61P5	Z815				 -
N8429G	JS8G36DJV8538JSBDNH8	U212	W581			 •
N8429G	JS8G36DJV8538JSBDNH8				•	 •
N4275R	H836FTK2SN9JTEB533N2	•			•	 -
N4275R	H836FTK2SN9JTEB533N2	Y534	Z664	G451	•	 -
N4275R	H836FTK2SN9JTEB533N2	T202			•	 -
N4275R	64NQF48J6D2UH76WN382					
N4275R	64NQF48J6D2UH76WN382	•	•	•	•	 •

OPCS coding: Example (made up) data



Comprinted of joint

ncdsid	provspnops	opertn_01	opertn_02	opertn_03	opertn_04	 opertn_23
N3674M	HS6Q9B4HU27D96MF61P5	Z815				
N8429G	JS8G36DJV8538JSBDNH8	U212	W581			 •
N8429G	JS8G36DJV8538JSBDNH8		•	•	•	 •
N4275R	H836FTK2SN9JTEB533N2		•	•	•	 •
N4275R	H836FTK2SN9JTEB533N2	Y534	Z664	G451	•	 •
N4275R	H836FTK2SN9JTEB533N2	T202	•	•	•	 •
N4275R	64NQF48J6D2UH76WN382	•	-	-	•	 •
N4275R	64NQF48J6D2UH76WN382	-	-	-	•	 •

OPCS coding: Example (made up) data



ncdsid	provspnops	opertn_01	opertn_02	opertn_03	opertn_04	 opertn_23
N3674M	HS6Q9B4HU27D96MF61P5	Z815				 •
N8429G	JS8G36DJV8538JSBDNH8	U212	W581			
N8429G	JS8G36DJV8538JSBDNH8					
N4275R	H836FTK2SN9JTEB533N2					
N4275R	H836FTK2SN9JTEB533N2	Y534	Z664	G451		
N4275R	H836FTK2SN9JTEB533N2	T202				
N4275R	64NQF48J6D2UH76WN382					
N4275R	64NQF48J6D2UH76WN382			•		

Defining your analysis sample

Defining your analysis sample



- Cohort members may legitimately not have a HES record over the period of HES data availability, so don't usually want to analyses only those with linked HES records.
- If we believe that any cohort member with a HES record would have been successfully matched to it, we can conclude that any eligible cohort members without a matched HES record truly had no HES record.
- In order to do this, we need to consider who is eligible for linkage.
- Linkage consent certainly a condition for eligibility.

Defining your analysis sample



- HES data only relate to English (NHS) hospitals, so restrict eligibility to cohort members living in England over the relevant period?
- E.g. In analyses of linked NCDS-HES data we have considered cohort members to be eligible for linkage if they reported living in England at any one or more waves between waves 6 (2000, age 42) and 9 (2013, age 55).
- But eligibility definition may differ depending on context.

Silverwood RJ, et al. Examining the linkage quality and sample representativeness of linked National Child Development Study and Hospital Episode Statistics data. CLS Working Paper 2022/5. London: UCL Centre for Longitudinal Studies; 2022.

Recent analyses

Recent analyses: Mental health and hospital interactions in young people

- Nasir Rajah, Emla Fitzsimons.
- Aimed to investigate association between poor mental health in young people and subsequent hospital service use.
- Used linked Next Steps-HES data.
- Next Steps: self-reported mental health and self-harm.
- HES: any/number of A&E visits (A&E), diagnosis of mental or behavioural disorder (APC).

GITUDINAL

Recent analyses: Mental health and hospital interactions in young people



- Poor self-reported mental health at age 17 associated with:
 - i. 6 percentage point (95% CI 2, 10) greater probability of an A&E appointment in the following decade
 - ii. 6 percentage point (95% CI 2, 9) greater probability of a diagnosis of mental or behavioural disorder in hospital.
- Conclude that there may be associations between young people's poorer self-reported mental health and increased hospital interactions.
- Important implications for future research on demand and allocation of healthcare resources in England.

Recent analyses: Using linked HES data to aid the handling of cohort study non-response



- Nasir Rajah, Lisa Calderwood, Bianca L De Stavola, Katie Harron, George Ploubidis, Richard Silverwood.
- Growing interest in whether linked administrative data can aid analyses of cohort data subject to missingness.
- Used linked NCDS-HES data.
- Derived 58 variables from HES data (numbers of admissions and appointments, missed appointments, investigations undertaken, diagnoses and treatments received).
- Applied LASSO variable selection approach to identify HES variables predictive of non-response at age 55 sweep of NCDS.

Recent analyses: Using linked HES data to aid the handling of cohort study non-response



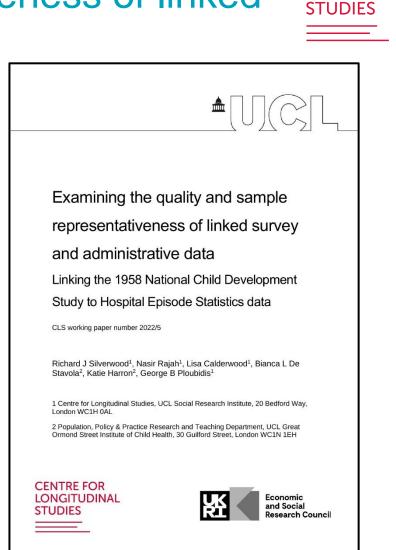
- Identified 10 such variables, e.g. cohort members treated for adult mental illness >70% more likely to be nonrespondents (risk ratio 1.73; 95% CI 1.17, 2.51).
- Included these variables as auxiliary variables in multiple imputation analyses to explore the extent to which they helped restore sample representativeness.
- However, only helped to a limited extent. Essentially no additional gain relative to using only previously identified survey predictors of non-response (i.e. NCDS rather than HES variables).



CENTRE FOR Resources: User Guides https://cls.ucl.ac.uk/data_documentation LONGITUDINAL **STUDIES ≜**|∪ ' Institute of Education National Child Development 1970 British Cohort Study Next Steps Study Linked health administrative Linked health administrative Linked health administrative datasets - Hospital Episode datasets - Hospital Episode datasets – Hospital Episode Statistics (HES) Statistics (HES) Statistics (HES) User Guide (Version 1) User guide User guide First edition First editio September 2020 ▲||| (C)CENTRE FOR CENTRE FOR **CENTRE FOR** LONGITUDINA LONGITUDINAL Economic and Social Research Council STUDIES STUDIES ____ ____ ____ National Child Development Study: Millennium Cohort Study Linked health administrative datasets 1970 British Cohort Study Linked health administrative - Scottish Medical Records (SMR) Linked health administrative datasets - Scottish Medical datasets - Scottish Medical Records Records (SMR) User guide (SMR) User guide First edition, December 2020 User guide First edition. October 2020 First edition, February 2021 **CENTRE FOR CENTRE FOR** CENTRE FOR LONGITUDINAL LONGITUDINAL LONGITUDINAL Economic and Social Economic and Social Economic and Social Bassarsh C STUDIES STUDIES STUDIES ____ ____ ____

Resources: Quality and representativeness of linked NCDS-HES data

- Examined associations between key cohort member sociodemographic characteristics and successful linkage.
- Compared the levels of successful linkage within strata of NCDS variables which may be expected to be associated with hospital attendance, and hence with successful HES linkage.

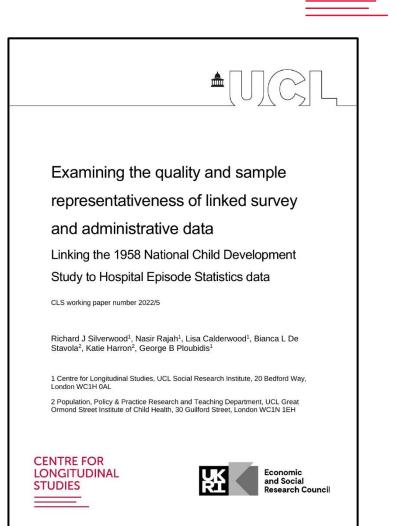


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Resources: Quality and representativeness of linked NCDS-HES data

- Evaluated the population representativeness of the linked sample using external data (hospital admission rates in the general population).
- Findings suggest that the linkage quality of the NCDS-HES data is high and that the linked sample maintains an excellent level of population representativeness.



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Other resources



- Boyd A, Cornish R, Johnson L, Simmonds S, Syddall H, Westbury L, et al. Understanding Hospital Episode Statistics (HES). London, UK: CLOSER; 2017.
- Herbert A, Wijlaars L, Zylbersztejn A, Cromwell D, Hardelid P. Data Resource Profile: Hospital Episode Statistics Admitted Patient Care (HES APC). International Journal of Epidemiology. 2017;46(4):1093-i.
- NHS Digital. Hospital Episode Statistics (HES). <u>https://digital.nhs.uk/data-and-information/data-tools-and-</u> <u>services/data-services/hospital-episode-statistics</u>.



Thank you.

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