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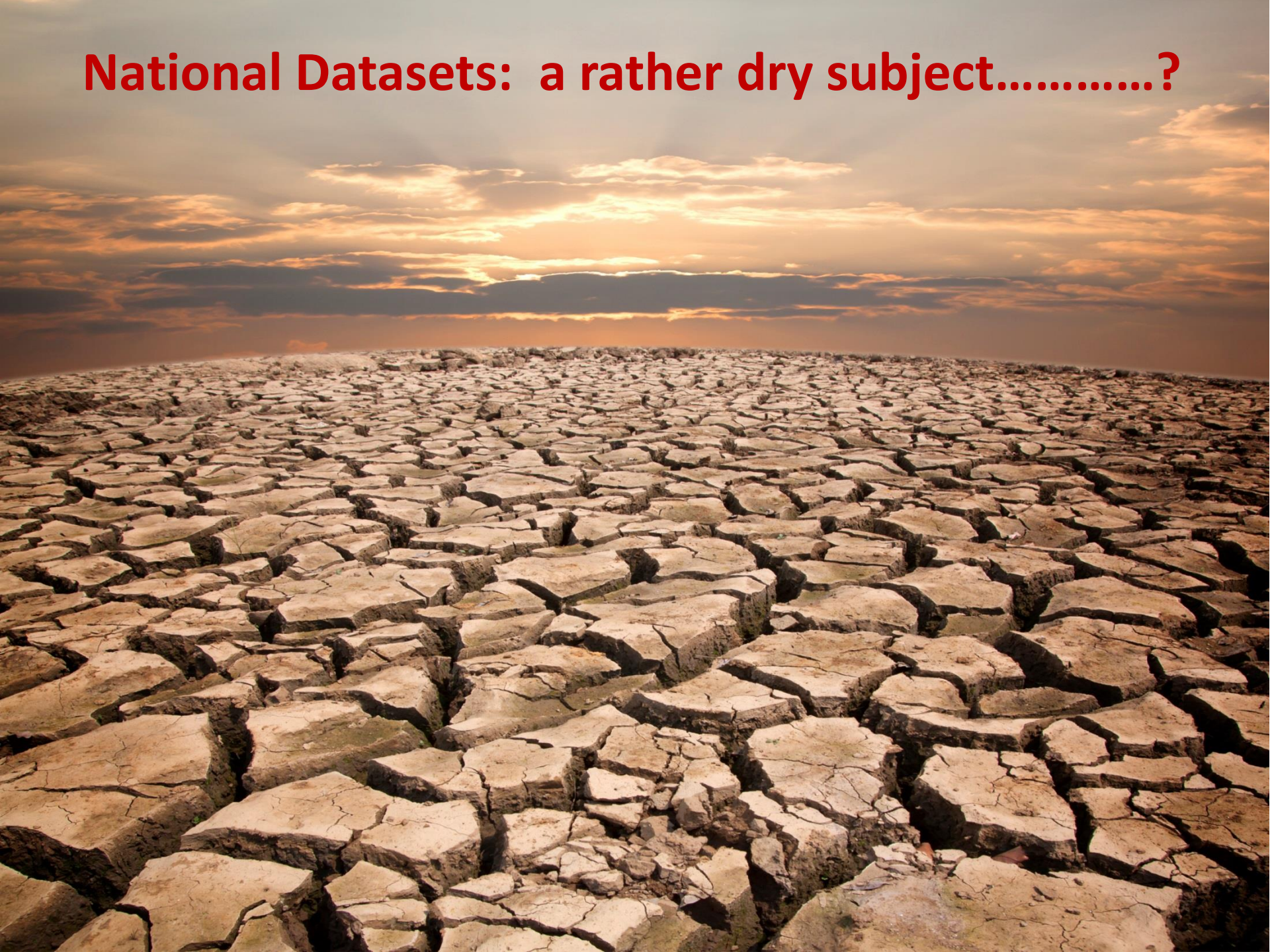
National datasets: a rich (and under-used) seam of information

Roger Parslow, Senior Lecturer in
Epidemiology.
School of Medicine

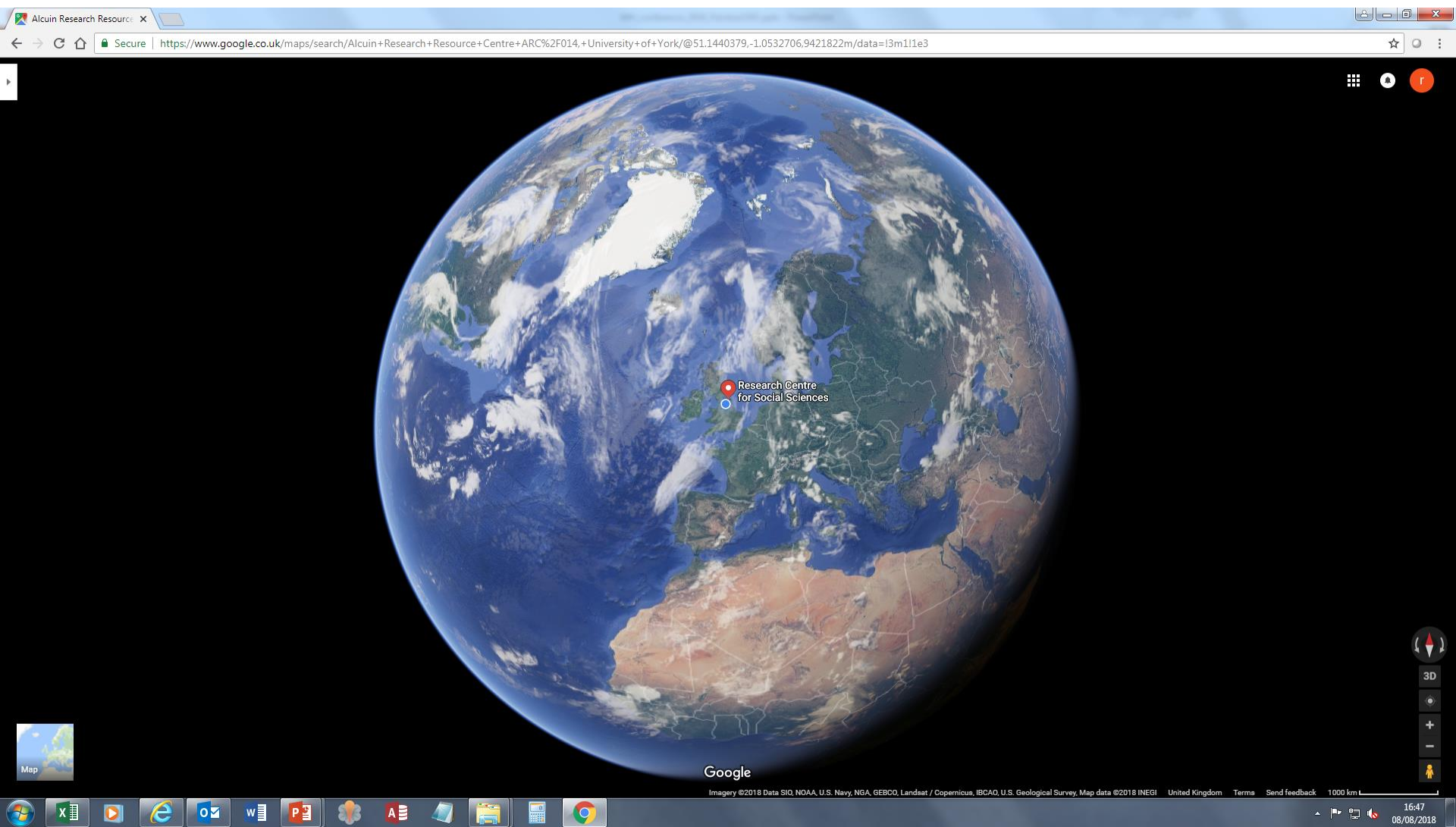


UNIVERSITY OF LEEDS

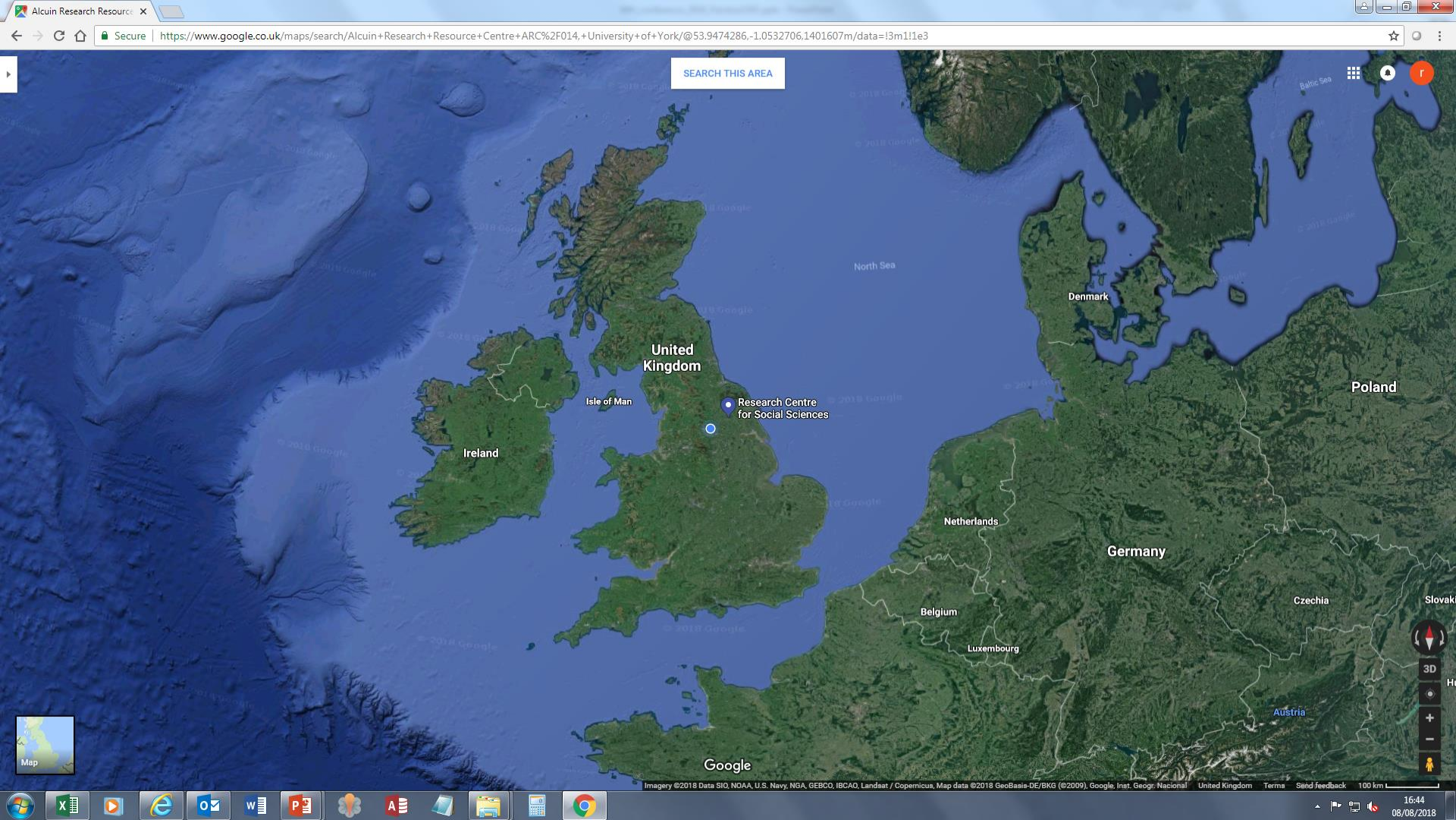
National Datasets: a rather dry subject.....?



There is data about everything, everywhere



It can be national



Regional

SEARCH THIS AREA

University of York
Campus-based
institution with colleges

Research Centre
for Social Sciences

Google

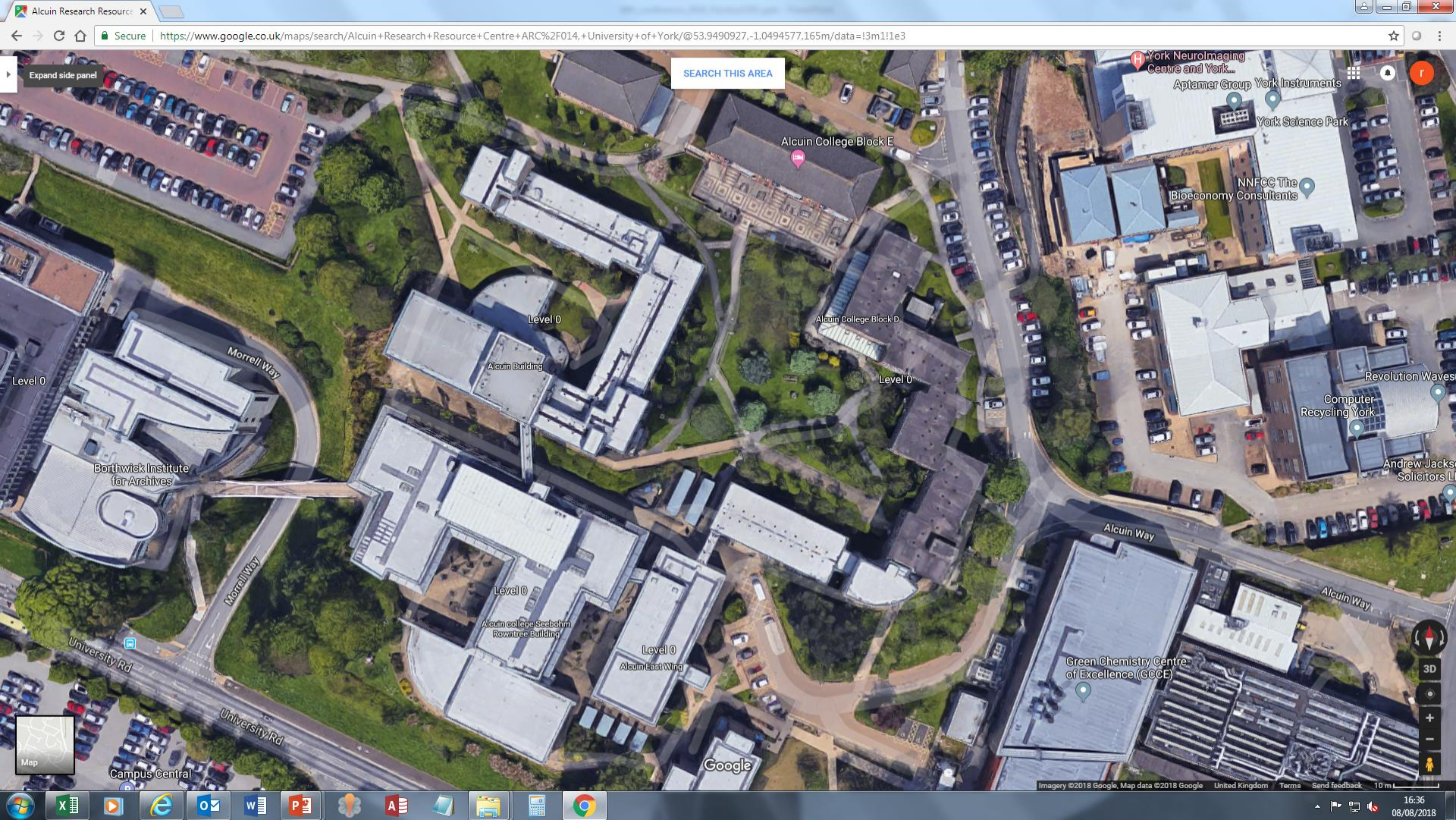
Map

16:44
08/08/2018

Local

The image shows a Google Maps browser window displaying a satellite view of York, UK. The map is centered on the University of York campus, with the Research Centre for Social Sciences highlighted in red. Other landmarks visible include York Minster, York Castle Museum, and the National Railway Museum York. The browser address bar shows the search URL: <https://www.google.co.uk/maps/search/Alcuin+Research+Resource+Centre+ARC%2F014,+University+of+York/@53.9474286,-1.0532706,10930m/data=!3m1!1e3>. The Windows taskbar is visible at the bottom, showing various application icons and the system clock displaying 16:43 on 08/08/2018.

Institutional

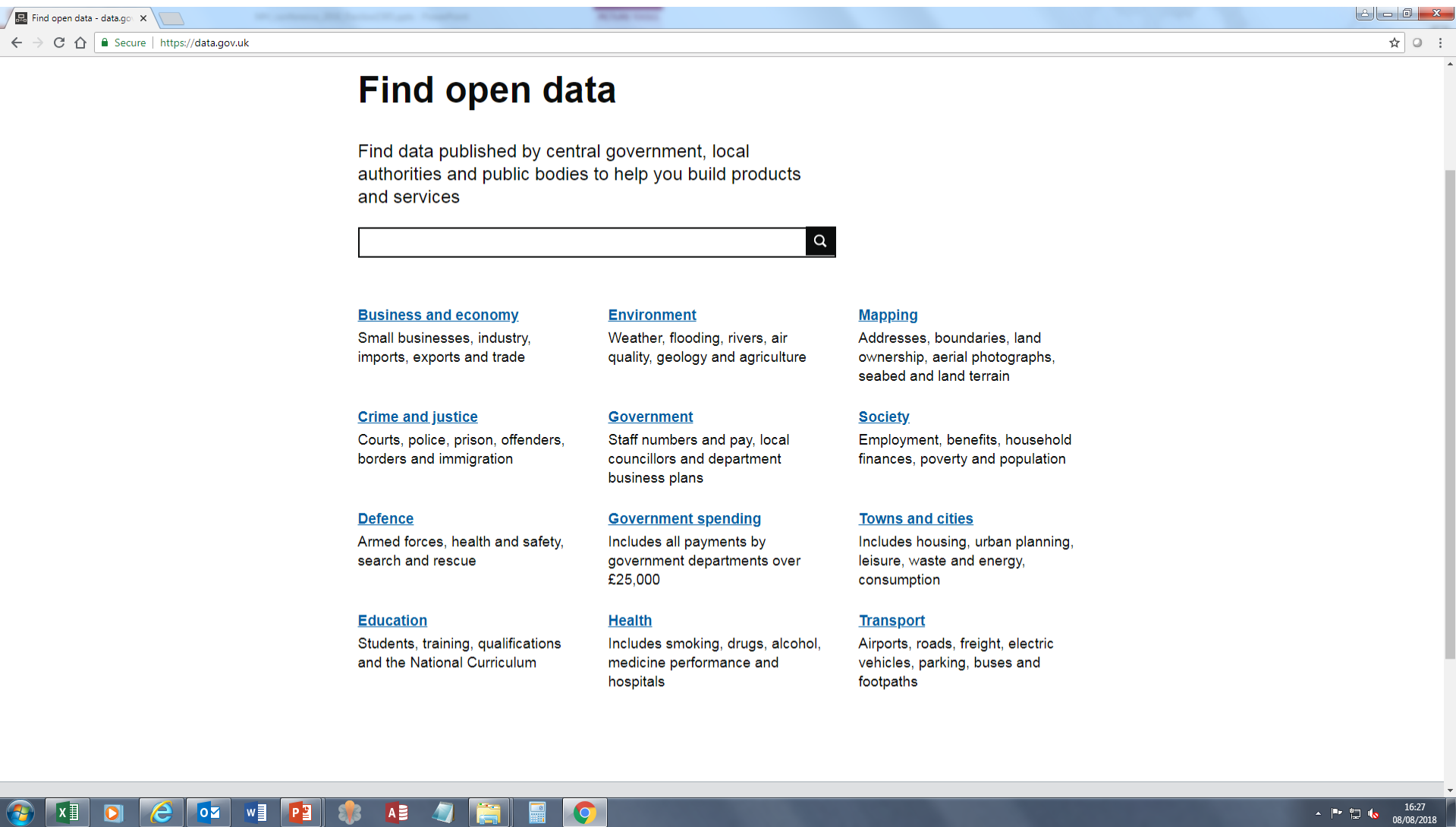


Or individual



What do we mean by National datasets?


The government publishes data...



The screenshot shows a web browser window with the URL <https://data.gov.uk>. The page title is "Find open data". Below the title is a search bar with a magnifying glass icon. The main content area is a grid of data categories, each with a blue underlined title and a brief description.

Find open data

Find data published by central government, local authorities and public bodies to help you build products and services



<p>Business and economy Small businesses, industry, imports, exports and trade</p>	<p>Environment Weather, flooding, rivers, air quality, geology and agriculture</p>	<p>Mapping Addresses, boundaries, land ownership, aerial photographs, seabed and land terrain</p>
<p>Crime and justice Courts, police, prison, offenders, borders and immigration</p>	<p>Government Staff numbers and pay, local councillors and department business plans</p>	<p>Society Employment, benefits, household finances, poverty and population</p>
<p>Defence Armed forces, health and safety, search and rescue</p>	<p>Government spending Includes all payments by government departments over £25,000</p>	<p>Towns and cities Includes housing, urban planning, leisure, waste and energy, consumption</p>
<p>Education Students, training, qualifications and the National Curriculum</p>	<p>Health Includes smoking, drugs, alcohol, medicine performance and hospitals</p>	<p>Transport Airports, roads, freight, electric vehicles, parking, buses and footpaths</p>

The Windows taskbar at the bottom shows the Start button, taskbar icons for Excel, PowerPoint, Word, and other applications, and the system tray with the date and time: 16:27 08/08/2018.

There are National Statistics...

The screenshot shows the Office for National Statistics website. At the top, there is a navigation bar with the logo and menu items: Home, Business, industry and trade, Economy, Employment and labour market, People, population and community, and Taking part in a survey?. A search bar is located below the navigation bar. The main content area features a large blue banner with the text 'Welcome to the Office for National Statistics' and 'The UK's largest independent producer of official statistics and the recognised national statistical institute of the UK.' To the right of the banner is a grid of letters 'A to Z of statistical bulletins'. Below the banner is a section titled 'Headline news, figures and publications' containing four cards: 1. A line chart showing data from 2006 to 2018. 2. A bar chart showing employment rate (aged 16 to 64, seasonally adjusted) at 75.7% for 2018 MAR-MAY. 3. A bar chart showing CPIH ANNUAL RATE 00: ALL ITEMS 2015=100 at 2.3% for 2018 JUN. 4. A line chart showing unemployment rate (aged 16 and over, seasonally adjusted) at 4.2% for 2018 MAR-MAY. To the right of these cards is a link to 'Looking to download time series? Try our time series explorer'. At the bottom right is the GOV.UK logo. The browser's taskbar is visible at the bottom, showing various application icons and the system clock (16:28 08/08/2018).

Office for National Statistics

English (EN) | [Cymraeg \(CY\)](#)

[Release calendar](#) | [Methodology](#) | [Media](#) | [About](#) | [Blog](#)

Home | Business, industry and trade | Economy | Employment and labour market | People, population and community | Taking part in a survey?

Search for a keyword(s) or time series ID

Welcome to the Office for National Statistics

The UK's largest independent producer of official statistics and the recognised national statistical institute of the UK.

A to Z of statistical bulletins

A	B	C	D	E	F	G
H	I	J	K	L	M	N
O	P	Q	R	S	T	U
V	W	X	Y	Z		

Headline news, figures and publications

2006 JAN 2018 JUN

1971 JAN-MAR 2018 MAR-MAY

Employment rate (aged 16 to 64, seasonally adjusted)

75.7%

2018 MAR-MAY

CPIH ANNUAL RATE 00: ALL ITEMS 2015=100

2.3%

2018 JUN

2018 MAR-MAY

Unemployment rate (aged 16 and over, seasonally adjusted)

4.2%

2018 MAR-MAY

Looking to download time series?

Try our time series explorer



The NHS publishes data...

Home - NHS Digital x
Secure | https://digital.nhs.uk

NHS Digital **70 YEARS OF THE NHS 1948-2018**

[Data and information](#) [Systems and services](#) [News and events](#) [About NHS Digital](#)

NHS Digital is the national information and technology partner to the health and care system

What are you looking for today? **Search**

Data and information

Find data and information

We collect, process and publish data and information from across the health and social care system in England. Search for our publications and indicators.

[View data and publications](#)

Indicator library

We publish over a thousand health and social care indicators in England. Add your indicator to our methodology library, search for existing indicator methodologies or apply for independent assurance.

[Find methodology](#)

Latest publications

Practice Level Prescribing May 2018 03 August 2018	General Pharmaceutical Services in England - 2007/2008 to 2017/2018 02 August 2018	NHS Sickness Absence Rates - January 2018 to March 2018 and Annual Summary 2009-10 to 2017-18 26 July 2018
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Windows taskbar: 16:30 08/08/2018

So do National Audits..



UNIVERSITY OF LEEDS

UNIVERSITY OF LEICESTER

General Enquiries
picanet@leeds.ac.uk
0113 343 8125

About ▾

Governance ▾

Annual Reporting and publications ▾

Annual Meeting ▾

Patients and Families Information



About

Welcome to the new look PICANet website!

All the content you know and trust is still accessible here, but we have spent time to try and organise it in a more user-friendly manner, in line with other modern websites.

If you have any questions, please get in touch s.butler1@leeds.ac.uk

Please note that many of the menu titles hold pages themselves, so if you click on "Governance" it will take you to a page about PICANet team members, however if you click the arrow next to the title it will provide you with more options to explore. This is the same for all menus displaying a little arrow next to the title.



Data Collection

Data Manuals and Guidance

Customised Data Collection

Data Requests

Contact Us

Patients and Families Information

News

Newsletters

Useful websites

BUT:

- The published data do not always provide exactly the information we want
- Researchers need to make bespoke requests for raw/individual level data
- there is no dedicated set of data collected for paediatric palliative care....
-how have national data sets been used to investigate epidemiology and service delivery in paediatric palliative care?
-and what can be done to improve use of these datasets?

In 2007, this wide-ranging report was published:

PALLIATIVE CARE SERVICES FOR CHILDREN AND YOUNG PEOPLE IN ENGLAND



An independent review for the Secretary of State for Health by Professor Sir Alan Craft and Sue Killen

Available from:

http://webarchive.nationalarchives.gov.uk/20080817153128/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPolicyAndGuidance/DH_074459

It noted that....

.....‘We found a poor information base with no nationally agreed figures on prevalence and little evidence of good needs assessments at either regional or local level. Services are generally commissioned at PCT level, but our evidence indicates that numbers requiring services at PCT level are generally too low to support sustainable services’

But to accompany the palliative services report the DH did use routine national health data:

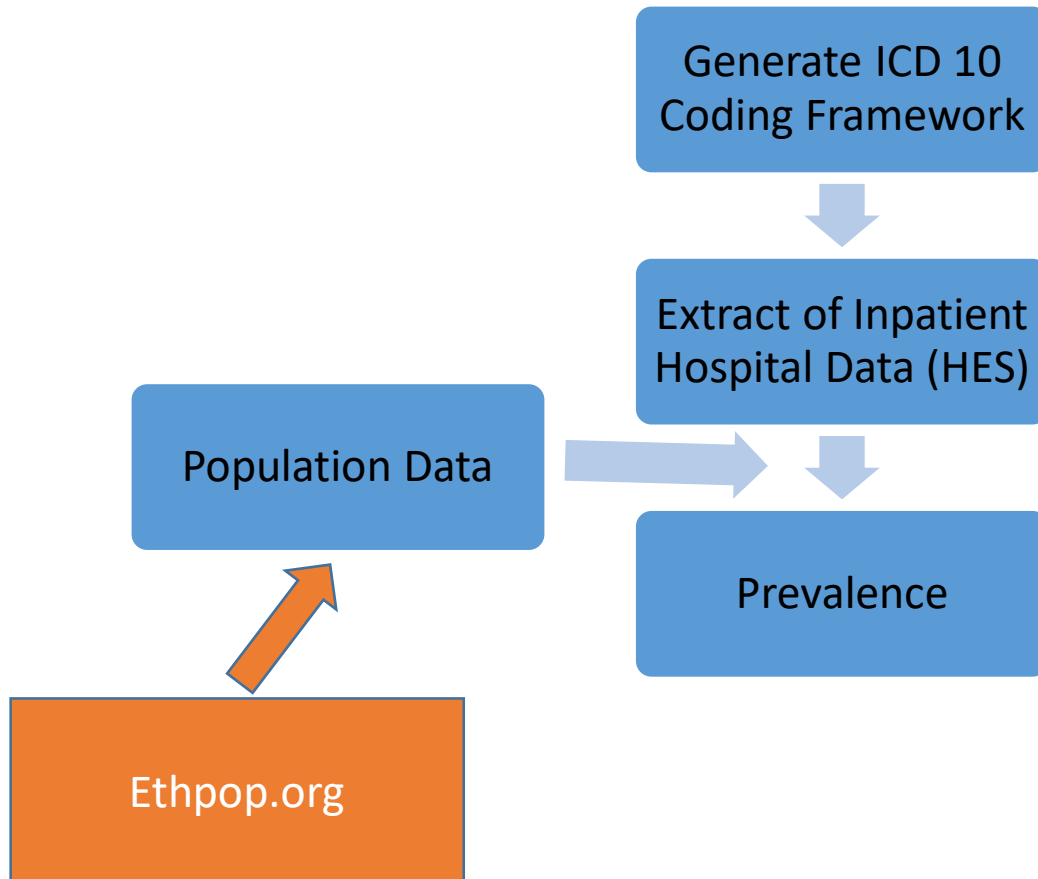


Palliative Care Statistics for Children and Young Adults

- Analysed routine mortality data and hospital admission data, for children and young adults **with conditions likely to require palliative care services in England** *[my emphasis]*
- They compiled a list of ICD codes of these conditions, but the evidence base for their selection was not systematic
- Estimated prevalence at 16 per 10,000 population aged 0-19
- This was an excellent report – but acknowledged shortcomings in the data

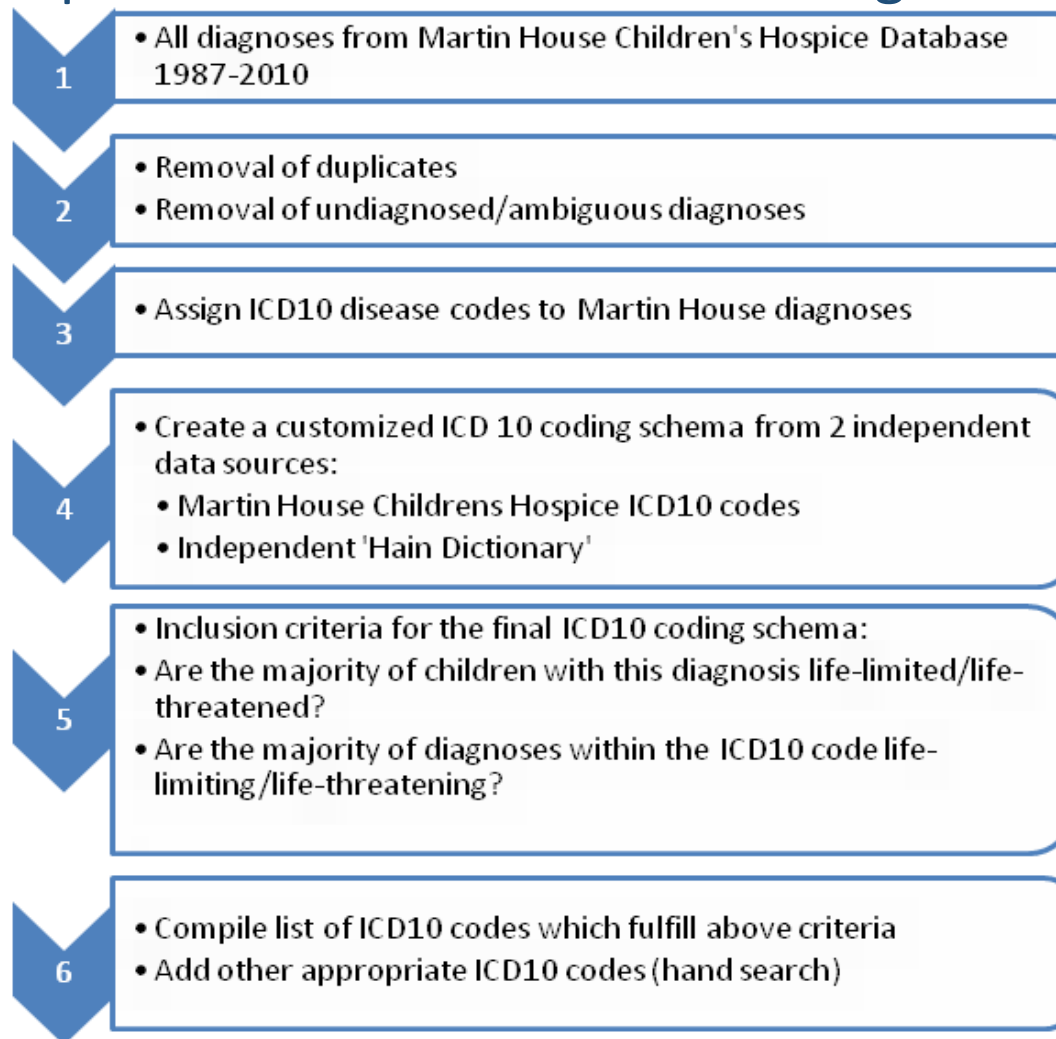
We hoped to improve the of use routine national health data to estimate the prevalence of children and young people living with life limiting or life threatening conditions by tightening up definitions.....

Prevalence of Life Limiting Conditions in England: combining national datasets:



Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA Parslow RC. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*. 2012 Apr 1;129(4):e923-e929. DOI: [10.1542/peds.2011-2846](https://doi.org/10.1542/peds.2011-2846)

Prevalence of Life Limiting Conditions in England: creating a paediatric palliative care definition coding frame:



Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA Parslow RC. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*. 2012 Apr 1;129(4):e923-e929. DOI: [10.1542/peds.2011-2846](https://doi.org/10.1542/peds.2011-2846)

Prevalence of Life Limiting Conditions in England per 10,000 population (0- 19 years)

Year	2000/01	2001/02	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10
Number of Patients	30643	29443	30503	31280	31639	34066	36013	37447	37601	40042
Total	24.9	23.8	24.7	25.3	25.6	27.6	29.1	30.2	30.3	32.2
Age under 1	116.7	105.9	104.2	104.1	102.1	106.7	123.4	113.5	117.5	125.7
1-5 years	29.1	28	29.5	29.9	29.9	31.1	31.4	32.9	32.4	34.1
6-10 years	18.8	18.1	19.1	19.6	20.1	21.8	22.3	23.5	23.6	24.8
11-15 years	17.4	17	18	18.5	18.4	20.4	21	22.4	22.5	24
16- 19 years	16.3	16.2	16.5	17.5	17.9	19.5	19.7	21.1	22	23.6

Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA Parslow RC. Rising national prevalence of life-limiting conditions in children in England. Pediatrics. 2012 Apr 1;129(4):e923-e929. DOI: [10.1542/peds.2011-2846](https://doi.org/10.1542/peds.2011-2846)

We seem to have mined this rich seam of national data quite well and produced some important results: the Pediatrics paper on the increase in prevalence has been cited in over 80 journals. It prompted Scotland to request a similar piece of work, including a qualitative element, an extremely important part of research into paediatric palliative care needs.

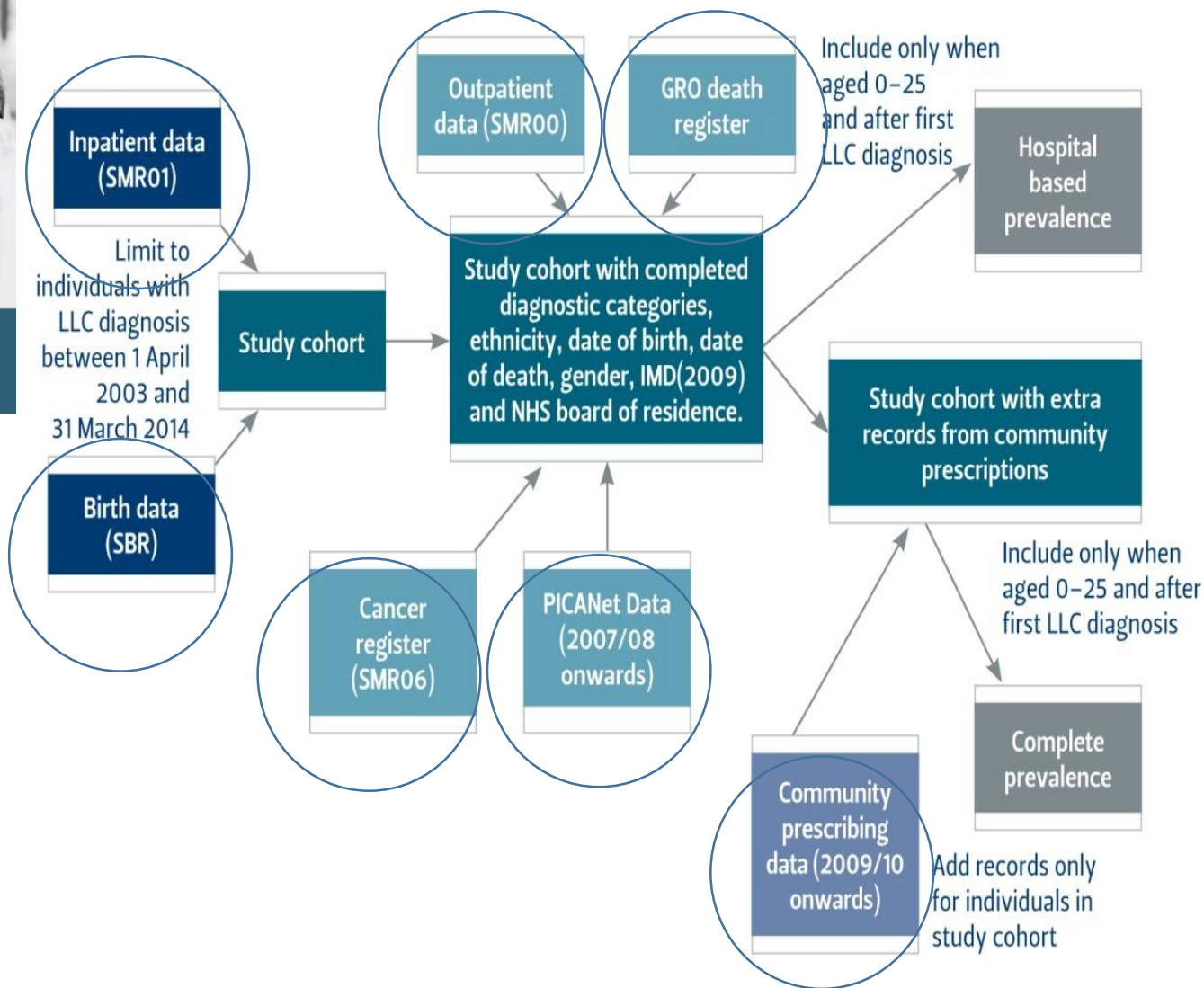
Children in Scotland requiring Palliative Care (ChiSP Study)



Lorna Fraser
Stuart Jarvis
Nicola Moran
Jan Aldridge
Roger Parslow
Devon Beresford

UNIVERSITY of York
The Department of Health Sciences
spru Social Policy Research Unit

1. Inpatient data
2. Birth data
3. Outpatient data
4. GRO death register
5. Cancer registry data
6. PICANet data
7. Prescribing data





Children in Scotland requiring Palliative Care (ChiSP Study)

Hospital-based prevalence (had an inpatient episode in that year aged 0-25):

Increase from 27.3 per 10,000 population in 2003/4 to 41.4 per 10,000 population in 2013/14

Complete prevalence estimates: also includes children and young people with a LLC who were still alive and resident in Scotland but who had not received inpatient care in that year:

Increase from 75.0 per 10,000 in 2009/10 to 95.7 per 10,000 in 2013/14.

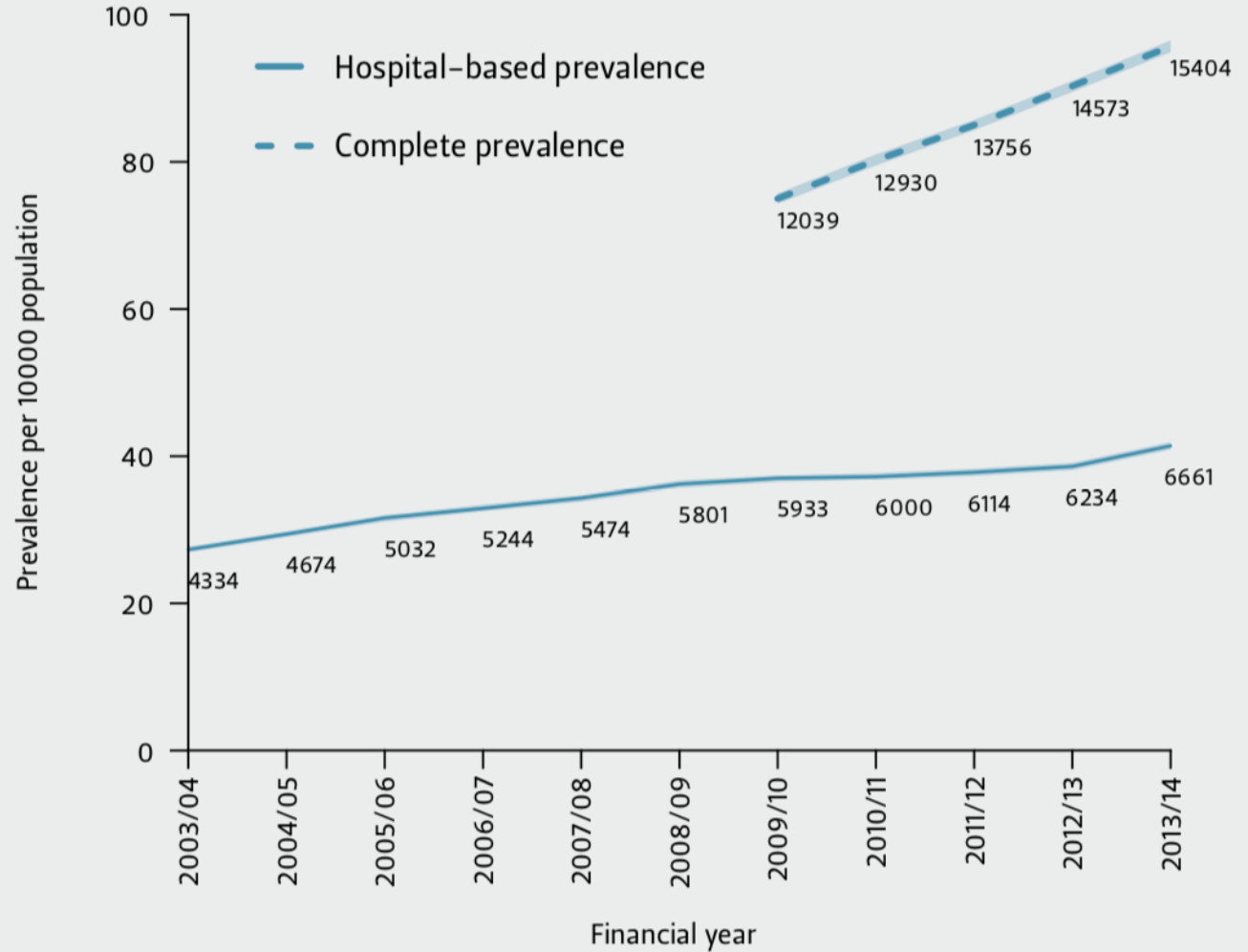
Children in Scotland
requiring Palliative Care:
identifying numbers and
needs (The ChiSP Study)

Children in Scotland requiring Palliative Care (ChiSP Study)



Lorna Fraser
Stuart Jarvis
Nicola Moran
Jan Aldridge
Roger Parslow
Devon Beresford

UNIVERSITY of York
The Department of Health Sciences
spru Social Policy
Research Unit

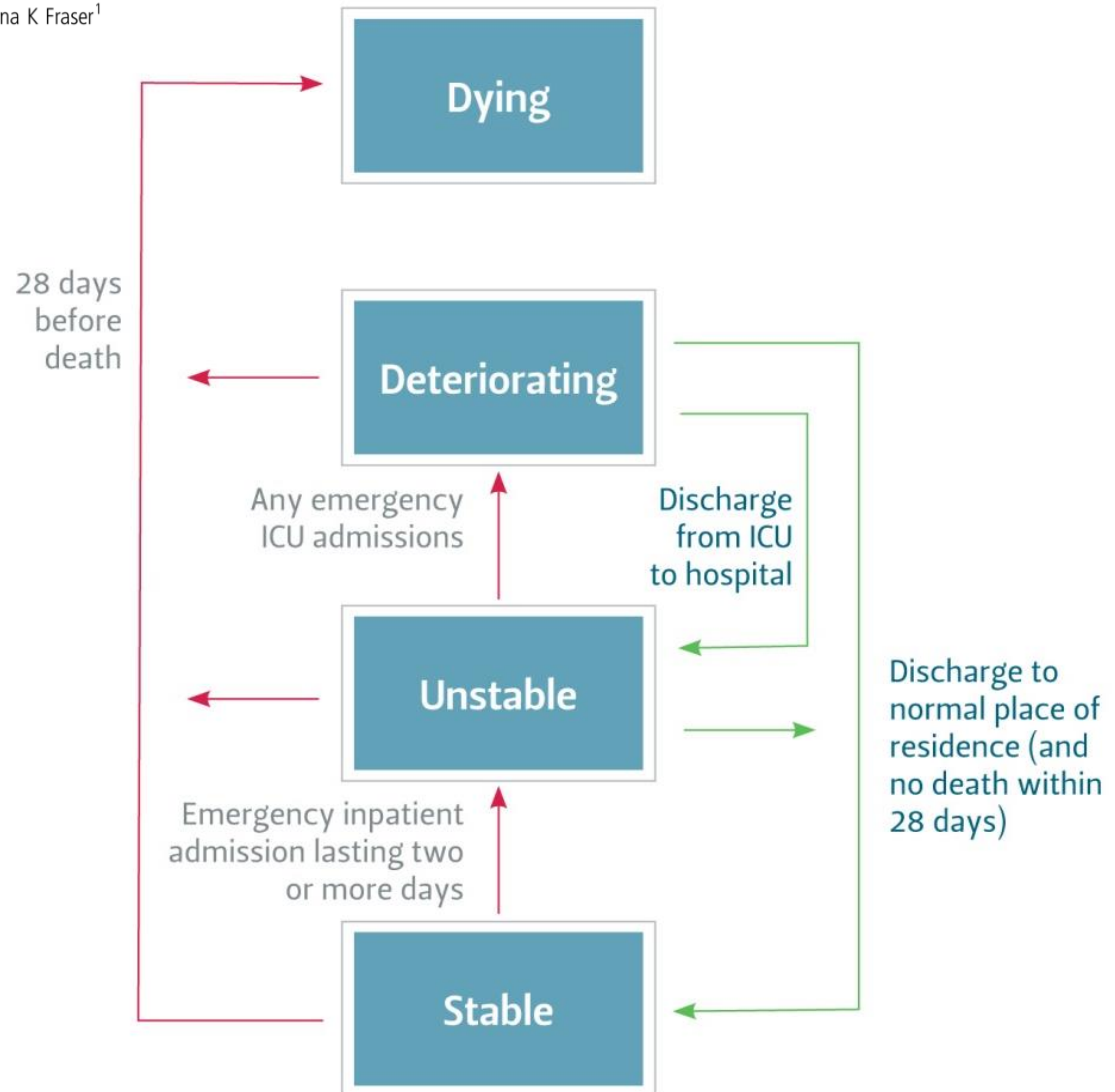


How many children and young people with life-limiting conditions are clinically unstable? A national data linkage study

Stuart Jarvis,¹ Roger C Parslow,² Pat Carragher,³ Bryony Beresford,⁴ Lorna K Fraser¹

Datasets used:

1. Inpatient data
2. Birth data
3. Outpatient data
4. GRO death register
5. Cancer registry data
6. PICANet data
7. Prescribing data



Jarvis SW, Parslow RC, Carragher P, Beresford BA, Fraser LK. How many Children and Young People with Life Limiting Conditions are clinically unstable?: a National data linkage study. Archives of Disease in Childhood. 2016 Sep 28. Available from, DOI: [10.1136/archdischild-2016-310800](https://doi.org/10.1136/archdischild-2016-310800)

How many children and young people with
life-limiting conditions are clinically unstable?
A national data linkage study

Stuart Jarvis,¹ Roger C Parslow,² Pat Carragher,³ Bryony Beresford,⁴ Lorna K Fraser¹

- Each year between April 2009 and march 2014, over 2200 CYP with LLCs in Scotland were unstable, deteriorating or dying.
- Children under 1 year of age are more likely than older children to be unstable, deteriorating or dying.
- CYP from South Asian, Black or Other ethnic groups are more likely to be unstable, deteriorating or dying than White children.

Children with Life-Limiting Conditions in PICU: linking audit, mortality and HES data



Children with life-limiting conditions in paediatric intensive care units: a national cohort, data linkage study

Lorna K Fraser,¹ Roger Parslow²

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/archdischild-2017-312638>).

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Received 4 January 2017
Revised 16 May 2017
Accepted 28 May 2017

ABSTRACT

Objective To determine how many children are admitted to paediatric intensive care unit (PICU) with life-limiting conditions (LLCs) and their outcomes.

Design National cohort, data-linkage study.

Setting PICUs in England.

Patients Children admitted to a UK PICU (1 January 2004 and 31 March 2015) were identified in the Paediatric Intensive Care Audit Network dataset. Linkage to hospital episodes statistics enabled identification of children with a LLC using an International Classification of Diseases (ICD10) code list.

Main outcome measures Random-effects logistic regression was undertaken to assess risk of death in PICU. Flexible parametric survival modelling was used to assess survival in the year after discharge.

Results Overall, 57.6% (n=89 127) of PICU admissions and 72.90% (n=4821) of deaths in PICU were for an individual with a LLC. The crude mortality rate in PICU was 5.4% for those with a LLC and 2.7% of those without a LLC. In the fully adjusted model, children with a LLC were 75% more likely than those without a LLC to die in PICU (OR 1.75 (95% CI 1.64 to 1.87)). Although overall survival to 1 year postdischarge was 96%, children with a LLC were 2.5 times more likely to die in that year than children without a LLC (OR 2.59 (95% CI 2.47 to 2.71)).

Conclusions Children with a LLC accounted for a large proportion of the PICU population. There is an opportunity to integrate specialist paediatric palliative care services with paediatric critical care to enable choice around place of care for these children and families.

INTRODUCTION

Life-limiting conditions (LLCs) are those for which there is no reasonable hope of cure and from which children will ultimately die, for example, Duchenne muscular dystrophy or neurodegenerative disease.

What is already known on this topic?

- The prevalence of children and young people with life-limiting conditions (LLCs) or life-threatening conditions is rising.
- Overall mortality in paediatric intensive care unit (PICU) is decreasing.

What this study adds?

- Children with a LLC accounted for the majority of admissions, bed-days and deaths in PICU.
- Children with a LLC were 75% more likely to die in PICU than those without a LLC.
- There was 93% survival at 1 year for children with a LLC.

proportion of admissions to PICUs are for children with a LLC and their outcomes in PICU and up to 1 year postdischarge.

METHODS

Datasets

The Paediatric Intensive Care Audit Network (PICANet) collects data on all children admitted to PICUs in the UK and Ireland. All admissions to a PICU in the UK between 1 January 2004 and 31 March 2015 were identified in the PICANet dataset.⁷ Only children resident in England were included as only their inpatient hospital data (Hospital Episodes Statistics (HES)) were available for linkage.⁸ Hospital data for the other nations of the UK were not available.

The Office for National Statistics (ONS) death record data in England were available with a censor date of 1 November 2015.⁹

154,667 PICU admissions
Children with a LLC accounted for:

- nearly 58% of all admissions to PICU
- 72% of PICU bed-days
- 87.5% of all PICU admissions that lasted >28 days
- 73% of all in-PICU deaths
- Children with LLC 2.5 times more likely to die in the year after discharge

So why might national datasets be underused?

Have other nations taken the initiative?

Scotland



scot-ship.ac.uk



**Scottish
Informatics
Programme**

The collation, management, dissemination and research analysis of anonymised Electronic Patient Records

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[Core Programmes](#)

[Research Programmes](#)

[SHIP Investigators](#)

[Dr Marion Bain](#)

[Professor Paul Boyle](#)

[Professor Helen Colhoun](#)

[Professor Sarah
Cunningham-Burley](#)

SHIP Investigators

SHIP brings together the Information Services Division (ISD) of NHS Scotland and a genuinely interdisciplinary group of academics providing a breadth of expertise in medicine and social science. The team includes leading international experts in the field who have skills in record linkage; the statistical analysis of routine data; longitudinal studies; social science; legal, ethical and confidentiality issues; genetic studies; and clinical trials design and execution. The strong collaboration between academics and experts in the Scottish NHS are driving the successful implementation of this ambitious endeavour.

The Principle Investigator is Professor Andrew Morris. He has extensive experience in the management of large inter-institutional research programmes. He is also eHealth Director of NHS Tayside and a member of the NHS Scotland eHealth Strategy Board.

Wales

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Search...

10 YEARS
2007 2017
10 YEARS OF SPEARHEADING DATA
PRIVACY AND RESEARCH UTILITY

The SAIL Databank is a safe haven for billions of person-based records combined with a complete data linkage and analysis toolset that helps researchers answer important questions for the benefit of society.

The SAIL Databank is a world-class complete solution to sourcing, accessing, linking and analysing health and population data all within a governed infrastructure that is safe and secure. Researchers can access a broad range of routinely collected data spanning up to 20 years from an entire population. The SAIL Databank provides you with linkable, anonymised datasets ready for analysis that can be accessed remotely via our unique SAIL Gateway platform, complete with analysis tools.

Discuss Your Research Question With Us Today

INCREASE
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WITH DATA
LINKAGE

ROBUST
GOVERNANCE
THAT YOU
CAN TRUST

REMOTE
ACCESS TO
LINKABLE
ANONYMISED
DATASETS

WORKING IN
THE PUBLIC
INTEREST

No: the FARR institute covers the UK...

The screenshot shows the website for the Farr Institute of Health Informatics Research. The browser address bar displays 'farrinstitute.org'. A search bar in the top right corner contains the text 'Looking for something?'. The main navigation menu includes links for 'About', 'News', 'Events + Courses', 'Research + Education', 'Public Engagement + Involvement', 'Partnerships', and 'Contact us'. A large orange banner with the word 'News' is positioned below the navigation. The featured article is titled 'Health Data: First UK Snapshot Review of Research Activity and Key Investments', published on 24th May 2018. The article's main image shows a grid of blue and white numbers. The text of the article describes a landmark report from the Medical Research Council, highlighting the work of the Farr Institute and major investments in health data research across the UK. Below the main article, there are four smaller news items, each with a thumbnail image, a date, a title, a short description, and a 'Read more +' link. The items are: 'Smoking and Drinking in...' (29.08.2018), 'Thinner Retinas Are Early...' (24.07.2018), 'Decent Housing Means Fewer...' (02.07.2018), and 'Most People with Asthma...' (25.05.2018). At the bottom of the page, a cookie consent banner states: 'This website uses cookies to improve your experience. By continuing to use this site, you agree to our use of cookies. | Understand'.

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News

Health Data: First UK Snapshot Review of Research Activity and Key Investments

Published on: 24th May 2018



Mapping the Landscape of UK Health Data Research and Innovation is a new landmark report published by the Medical Research Council. The report highlights the complex and flourishing area of health data research in the UK, detailing key activities, **including work from The Farr Institute**, and major investments made by UK public funders, government, charities and universities from across the country.

Commissioned in 2017, the review provides a unique window into major investments made by 26 research organisations, and informed the establishment of the new national institute – **Health Data Research UK** – whose mission is to make game-changing improvements in the health of patients and populations through data science research and innovation. The report acts as an important benchmark to help inform funder strategy, prevent duplication of effort and encourage collaboration in

29.08.2018
Smoking and Drinking in...
The arteries of teenagers who drink alcohol and smoke, even very occasionally, are already beginning to...
[Read more +](#)

24.07.2018
Thinner Retinas Are Early...
Thinner retinas in the human eye are a clear sign a person is at significant and...
[Read more +](#)

02.07.2018
Decent Housing Means Fewer...
Britain has a housing crisis, not just in terms of a shortage of homes and sky-high...
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25.05.2018
Most People with Asthma...
Asthma UK's new report suggests the willingness of people with asthma to share their data, coupled...
[Read more +](#)

23.05.2018

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Our Future Vision

The Farr Institute is proud to be a part of the UK's vision to become a global leader in health data science by accelerating the understanding of disease and improving health and care for patients and the public.

By connecting diverse molecular, phenotypic, health and non-health datasets at scale, the core activities of the UK's health and medical bioinformatics research community will apply cutting-edge data science approaches to address major challenges across the nation's 65 million population in the areas represented below.



Or is the process of requesting
and obtaining health data too
onerous?

(This is the part of my talk with no
slides.)

A modest proposal:

- Add to patient records a flag that clearly identifies children, young people and adults who have a life-limiting or life threatening condition.
- Create an *accessible* data repository that allows researchers access to ALL administrative and specialist health datasets
- Make it possible to use this data at an individual level without undue hindrance (we need to deal with the issue of the use of individual health data)

Acknowledgements

Thank you to Lorna Fraser for the use of some images from her slides.