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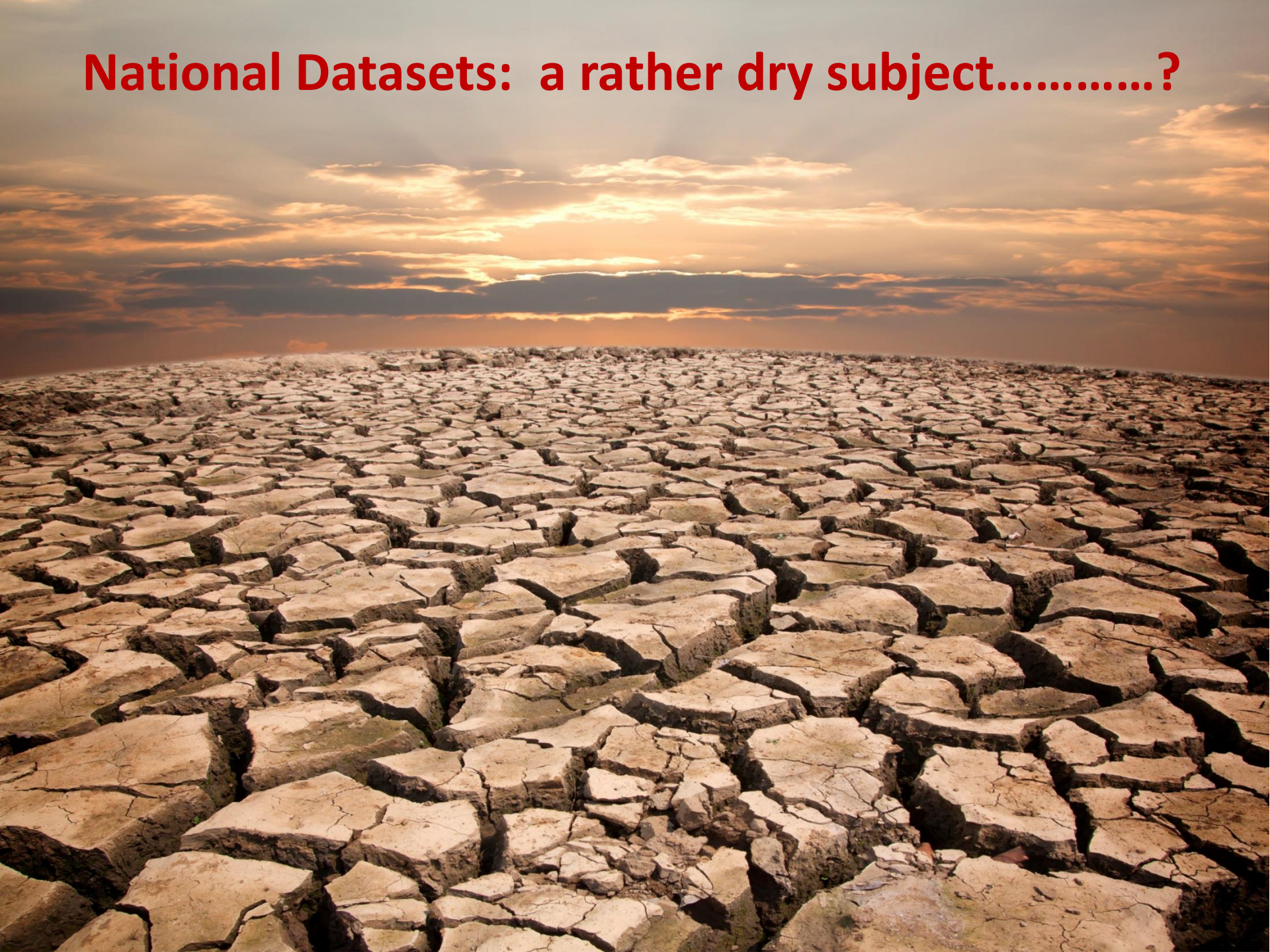
National datasets: a rich (and under-used) seam of information

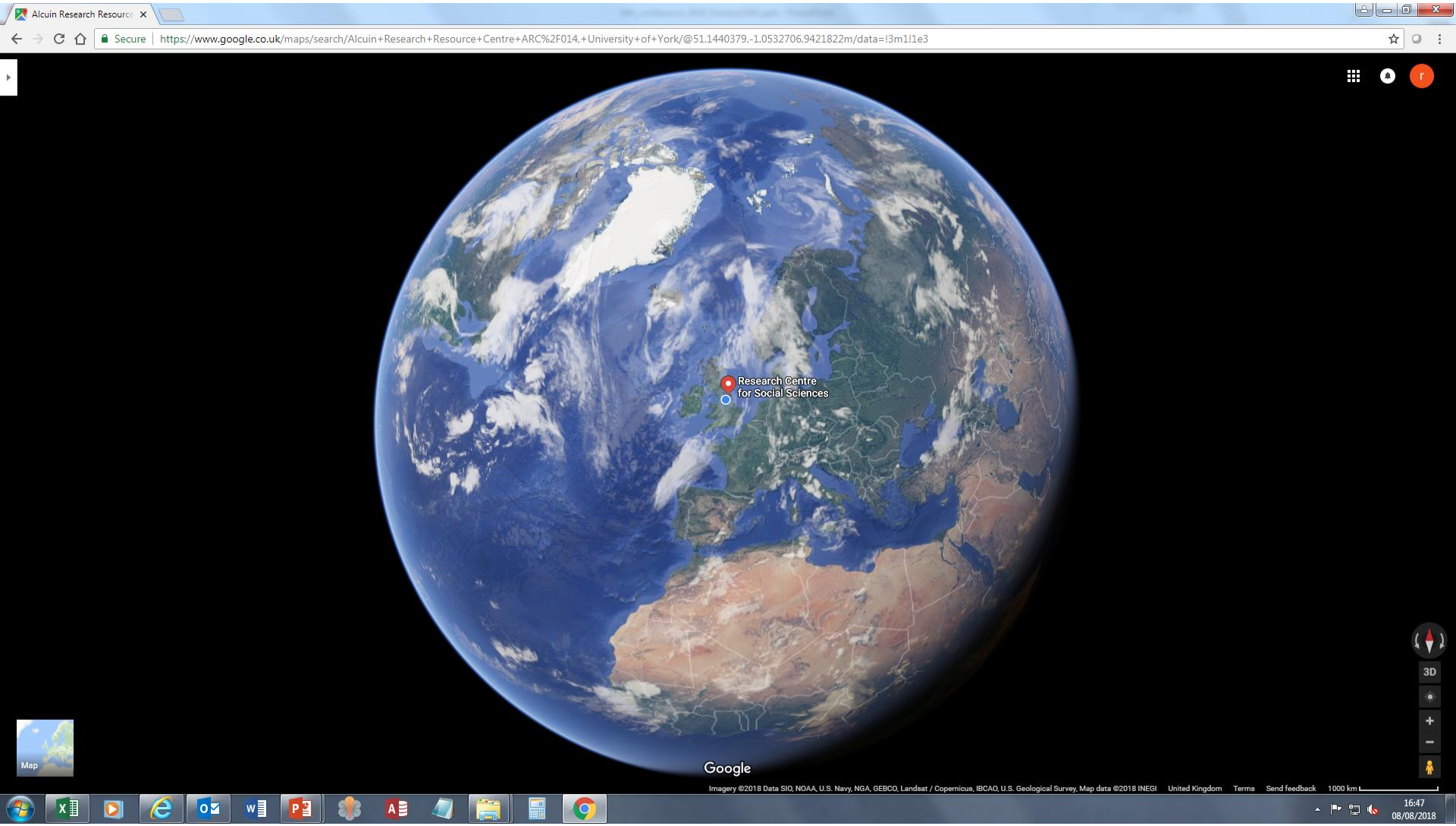
Roger Parslow, Senior Lecturer in Epidemiology.
School of Medicine

UNIVERSITY OF LEEDS

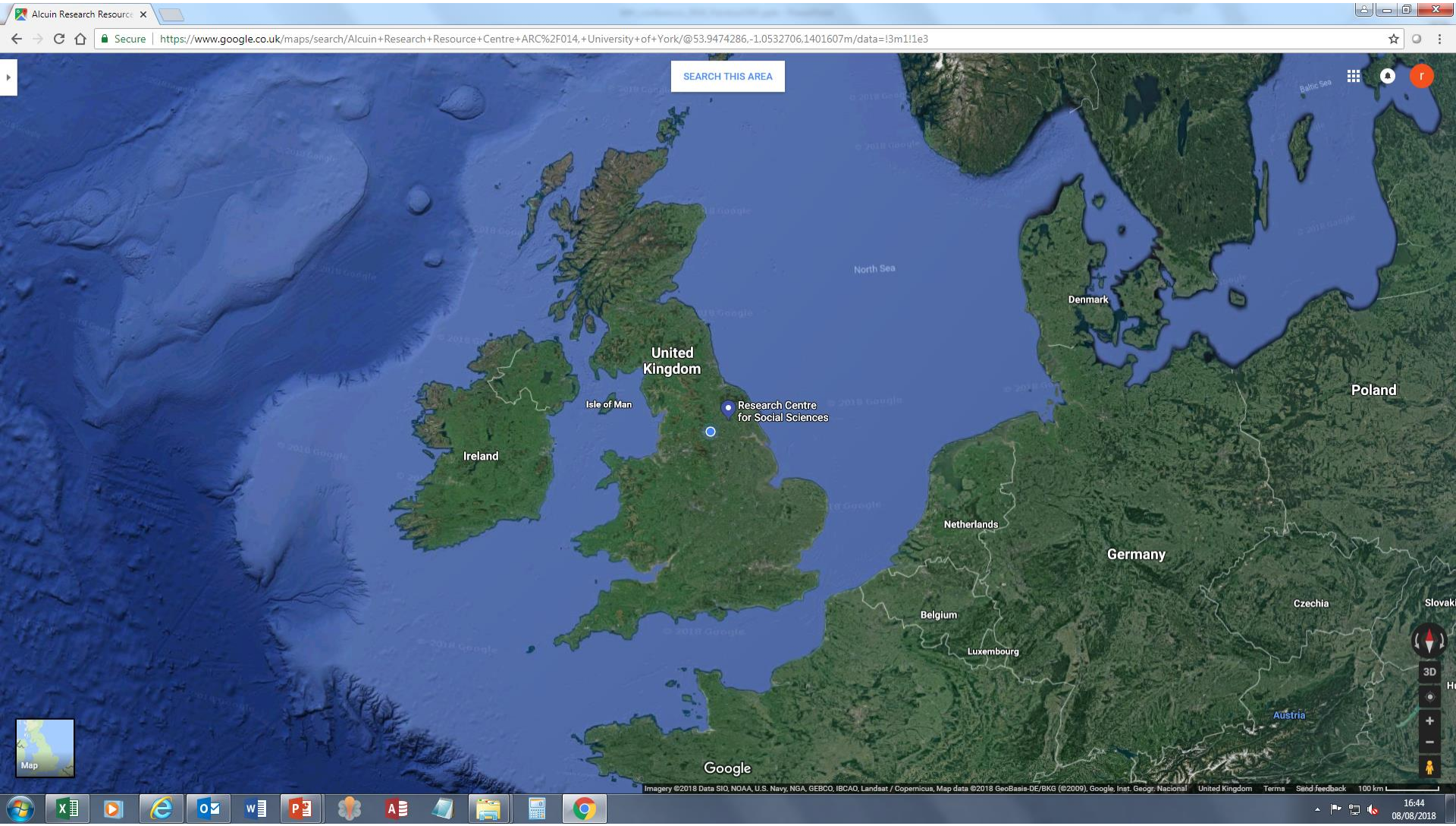
National Datasets: a rather dry subject……?



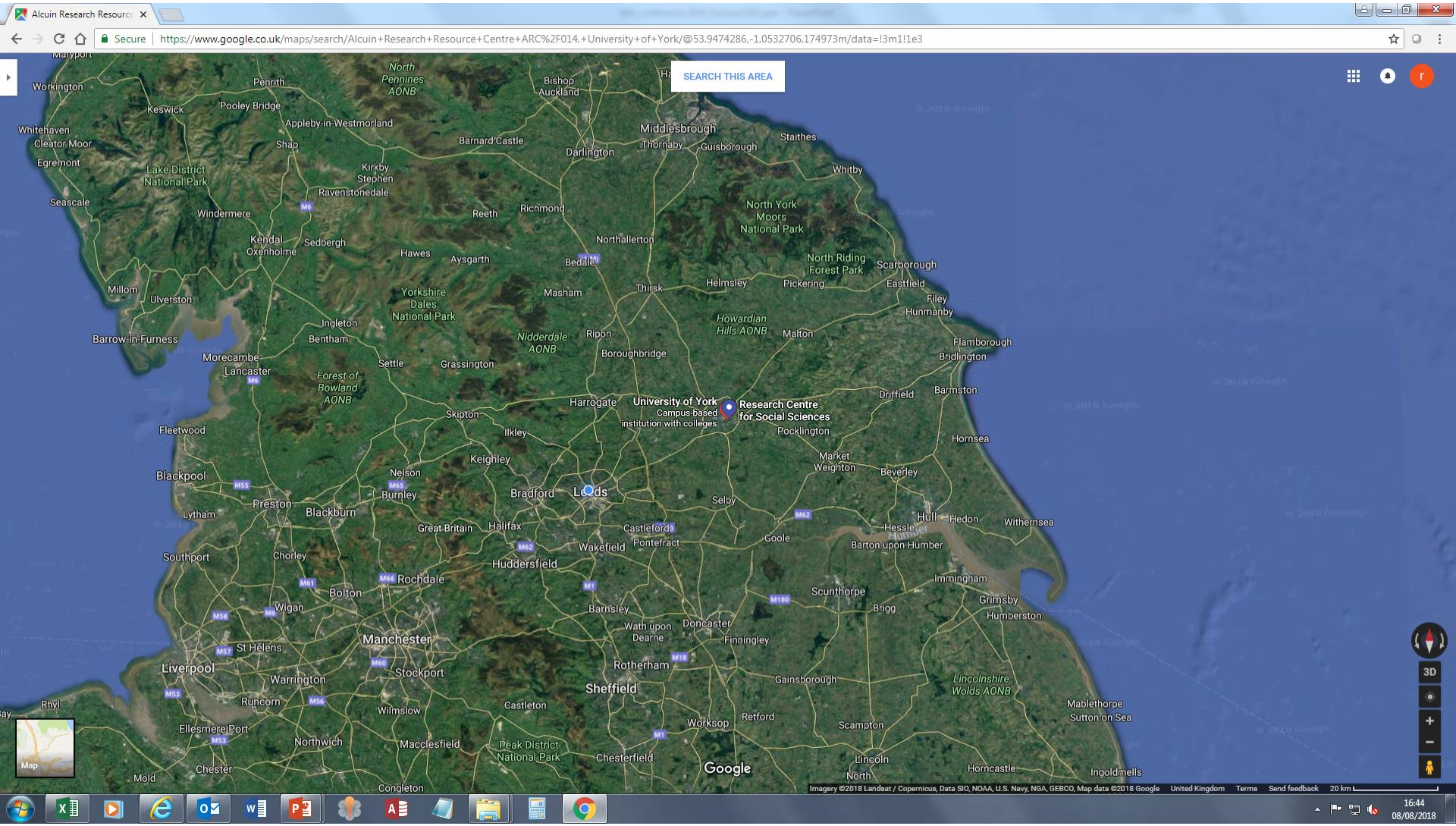
There is data about everything, everywhere



It can be national



Regional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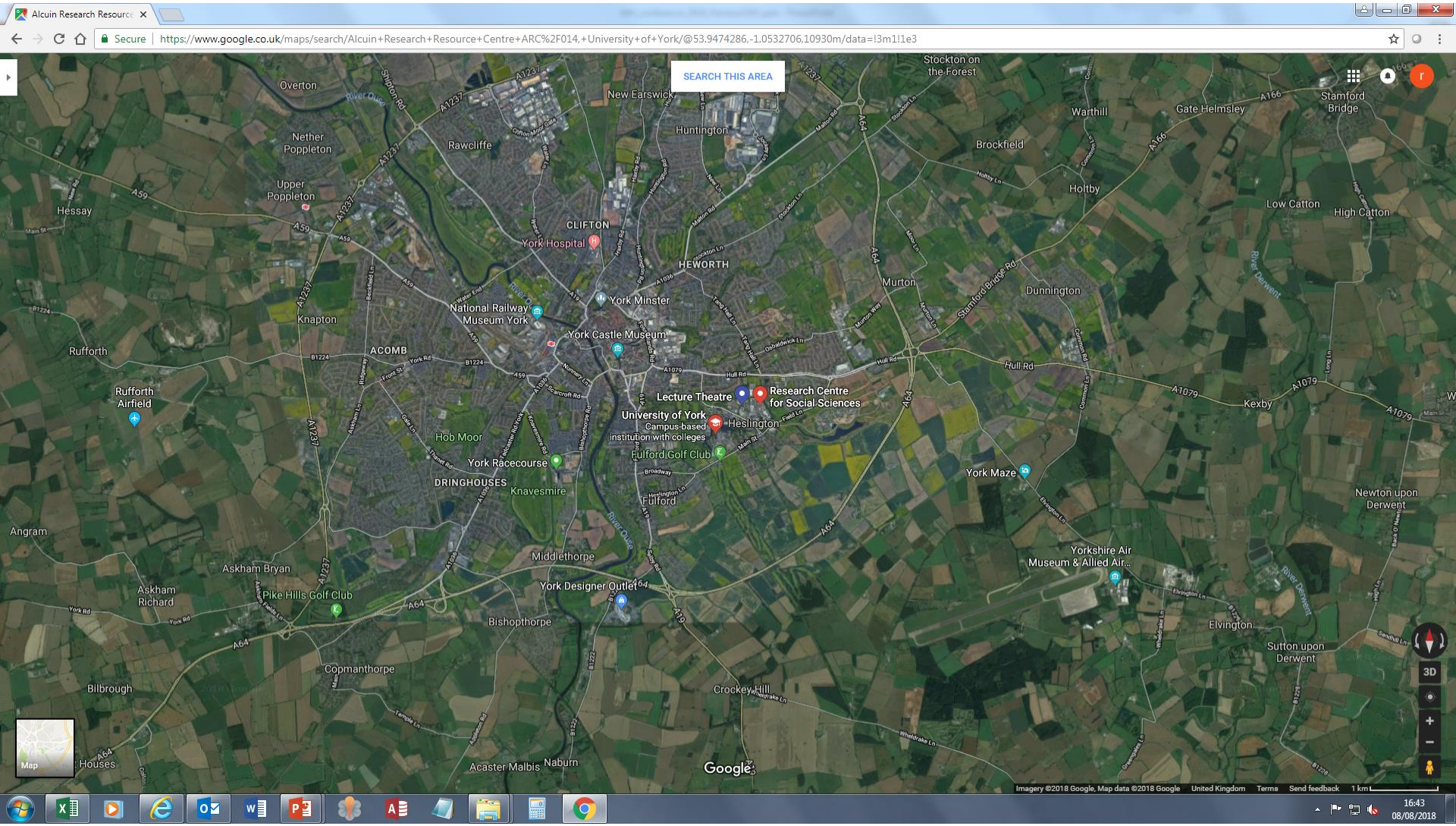
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High Catton
Hessay
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HEWORTH
York Minster
National Railway Museum York
York Castle Museum
Murton
Dunnington
Knapton
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ACOMB
Rufforth Airfield
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Research Centre for Social Sciences
University of York
Campus-based institution with colleges
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Hob Moor
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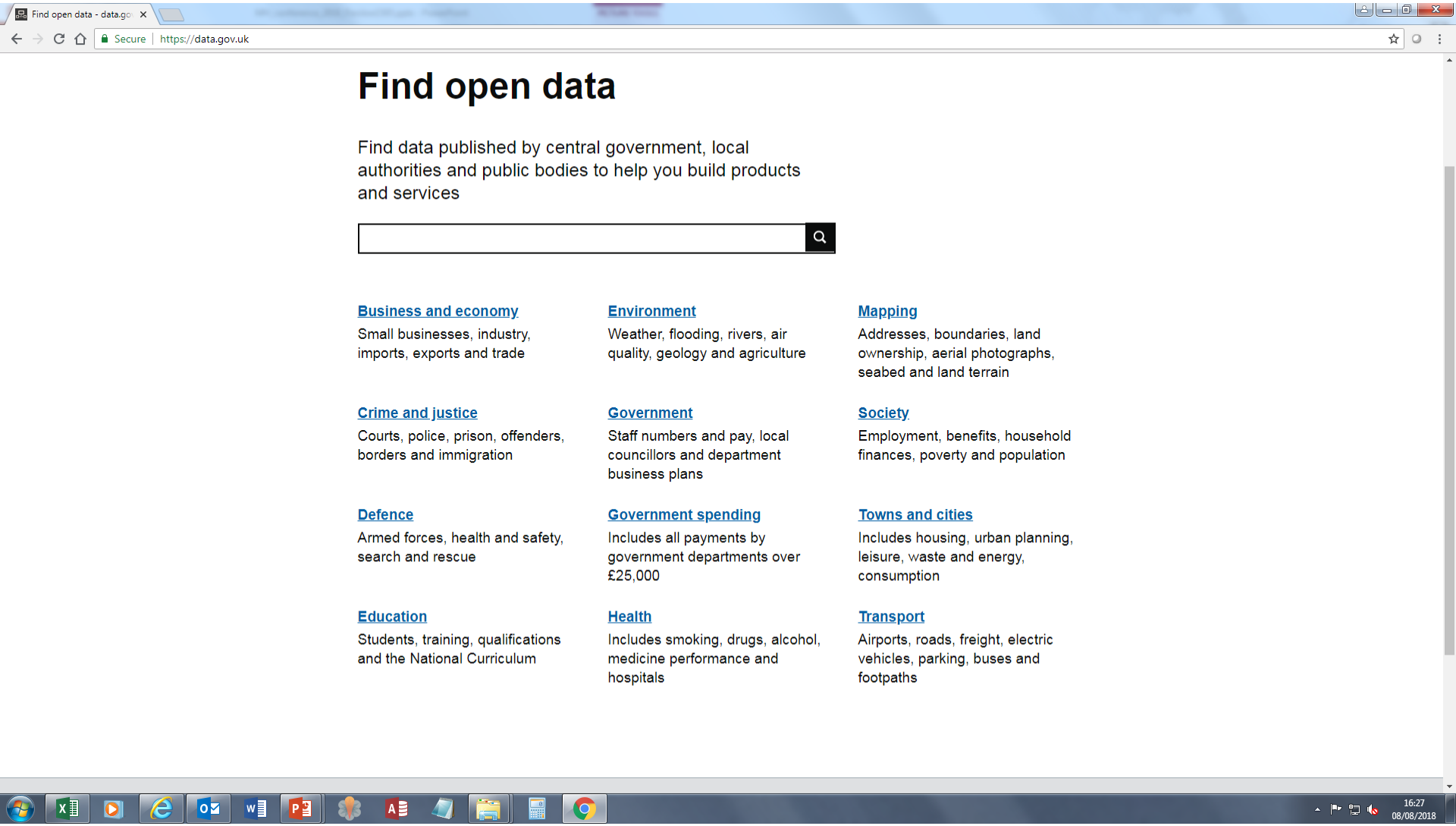
Institutional

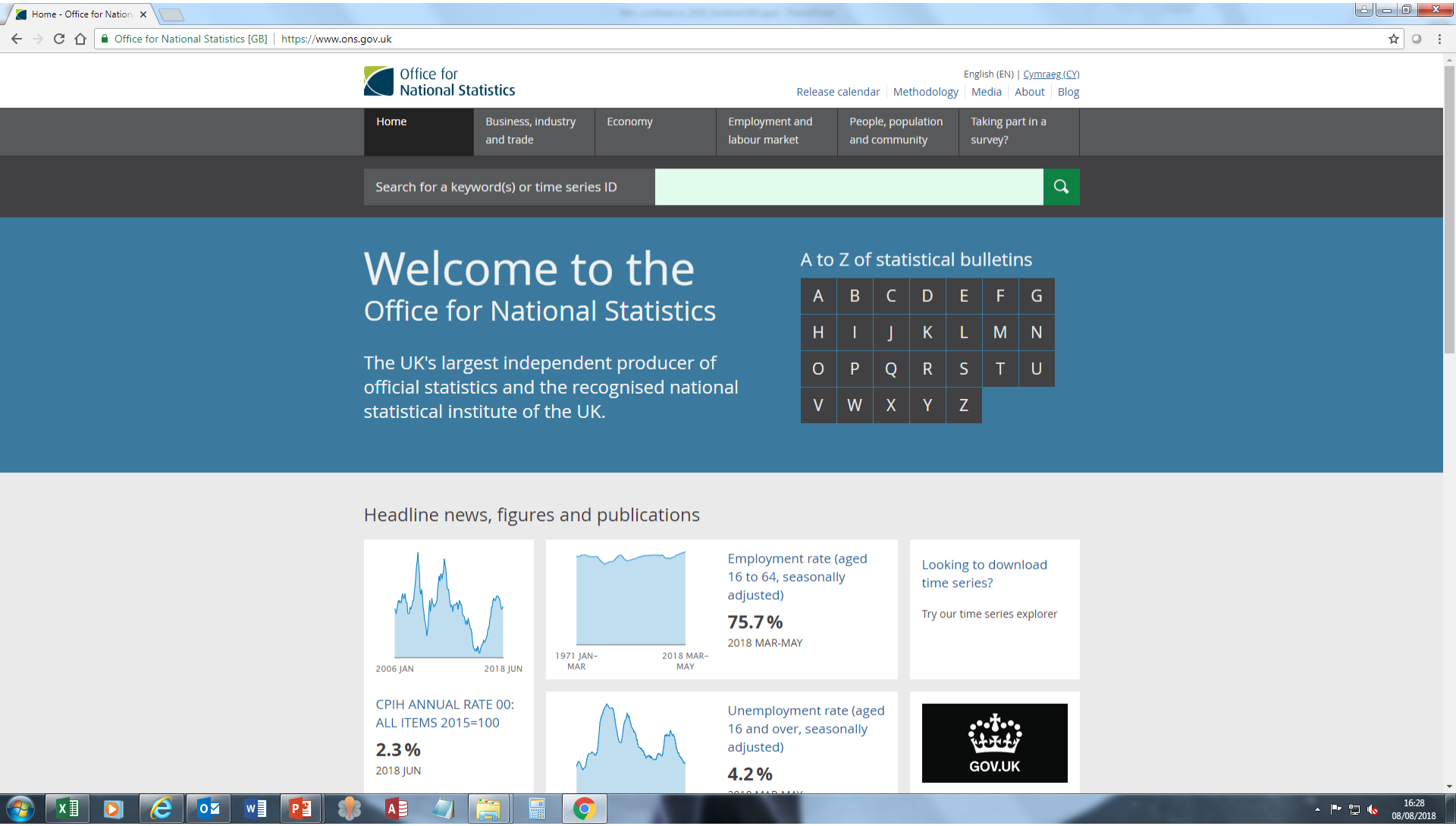
Or individual

What do we mean by National datasets?

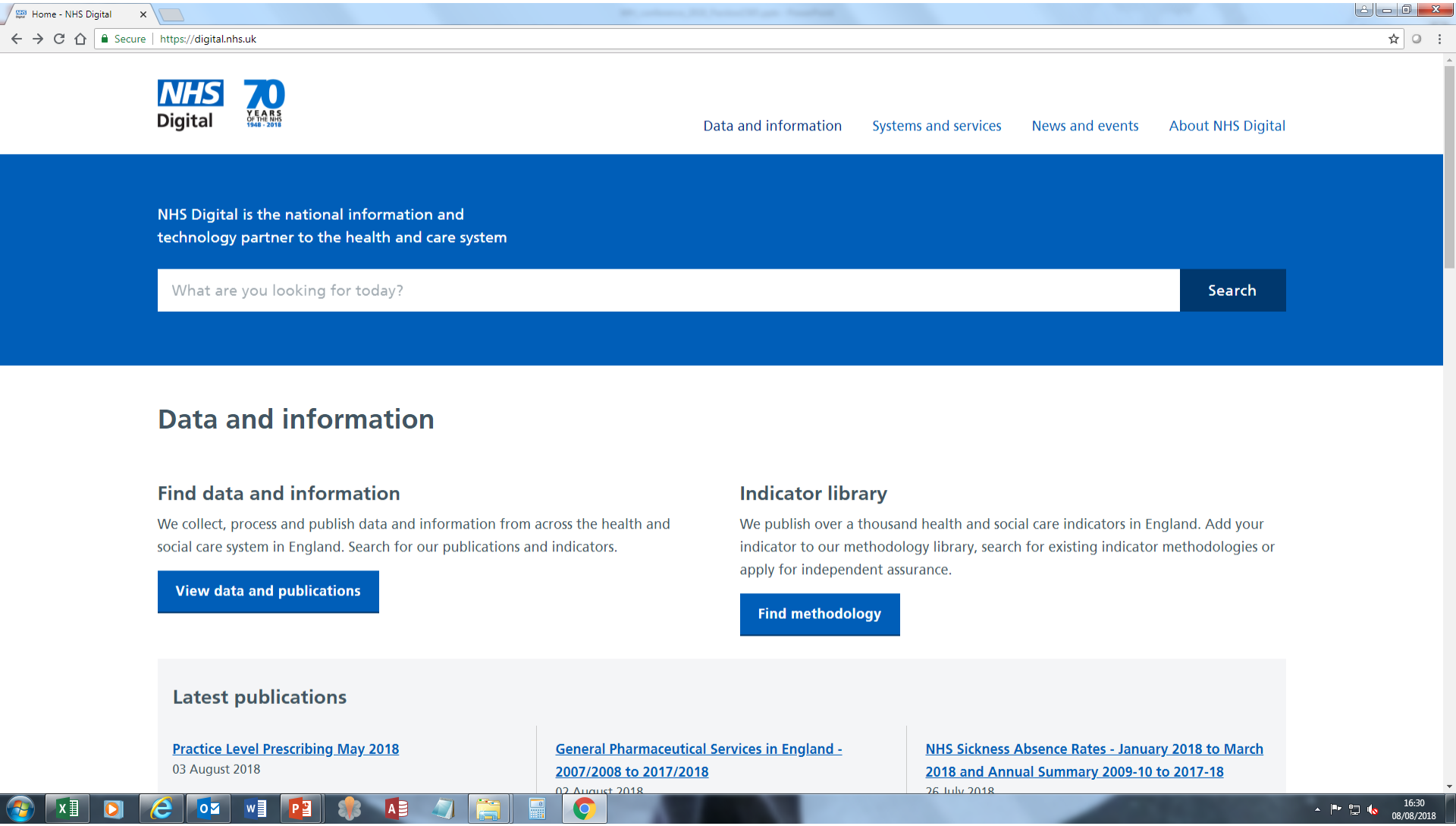
The government publishes data…



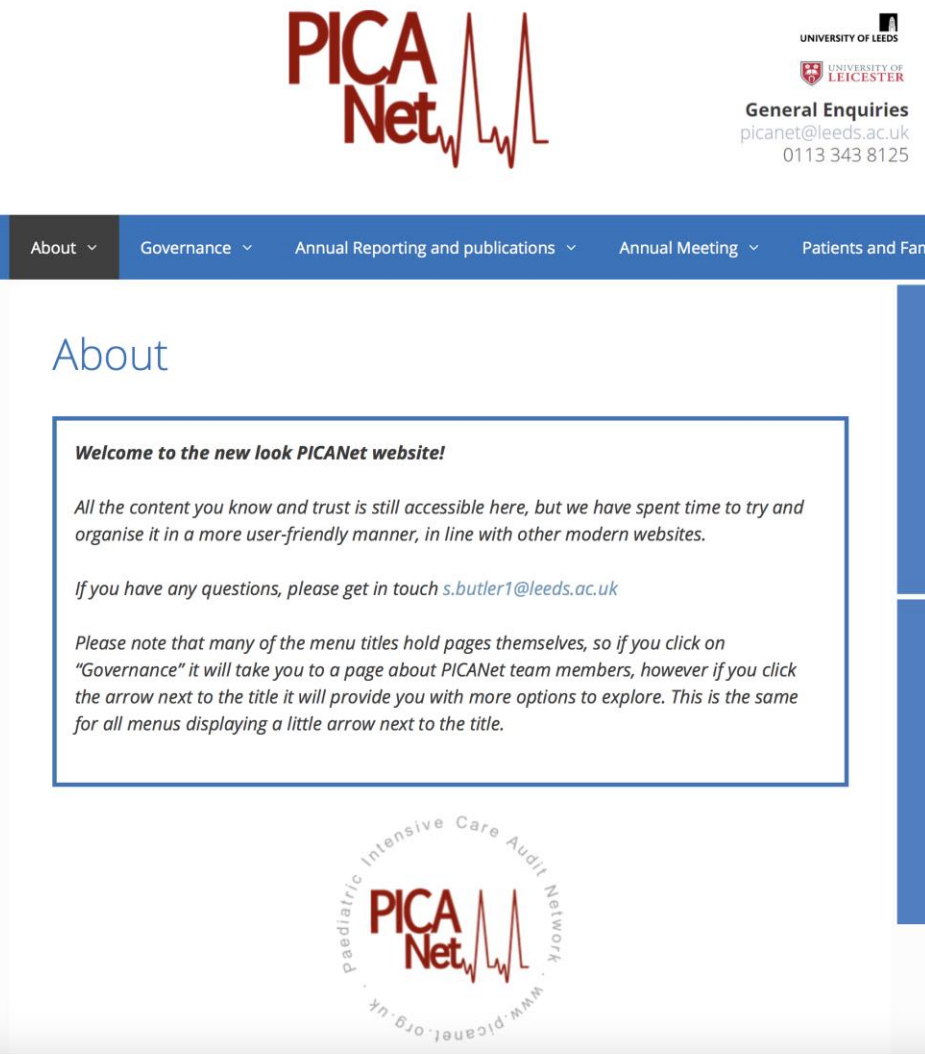
There are National Statistics…



The NHS publishes data…



So do National Audits..



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:

Available from:
http://webarchive.nationalarchives.gov.uk/20080817153128/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/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’

PALLIATIVE CARE SERVICES FOR CHILDREN AND YOUNG PEOPLE IN ENGLAND. Executive summary, p4

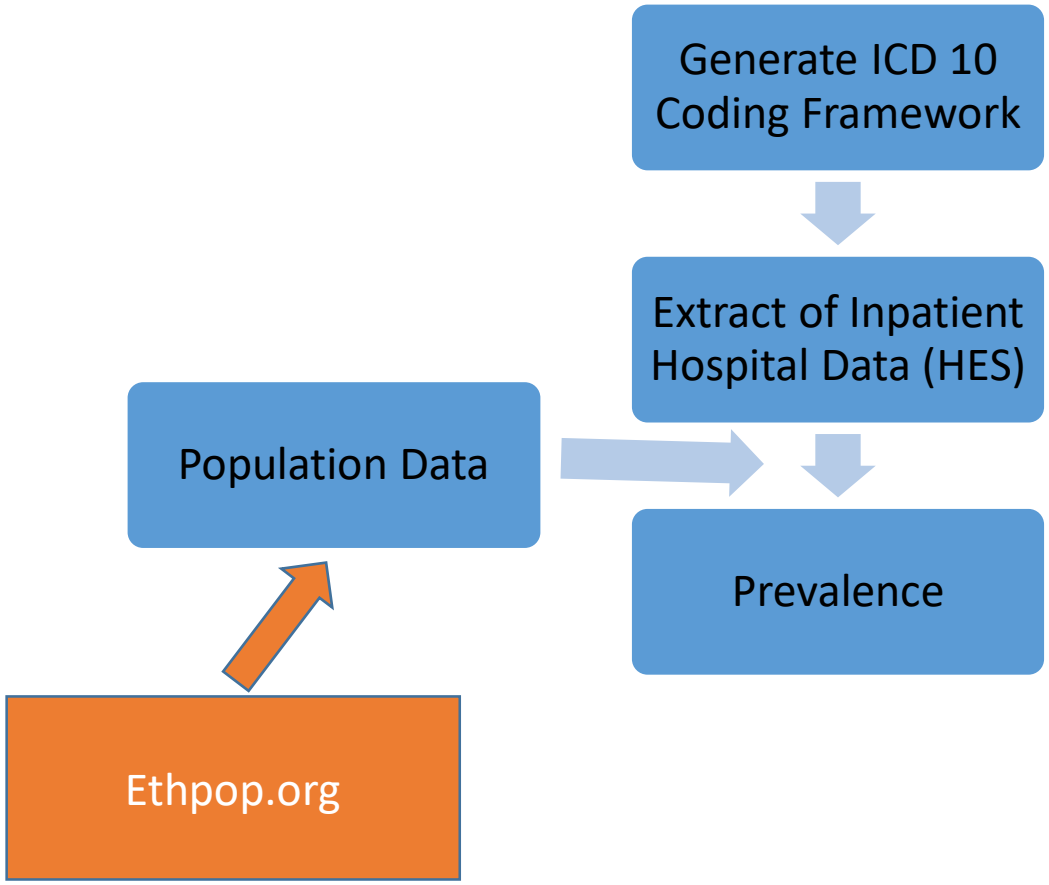
But to accompany the palliative services report the DH did use routine national health data:

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

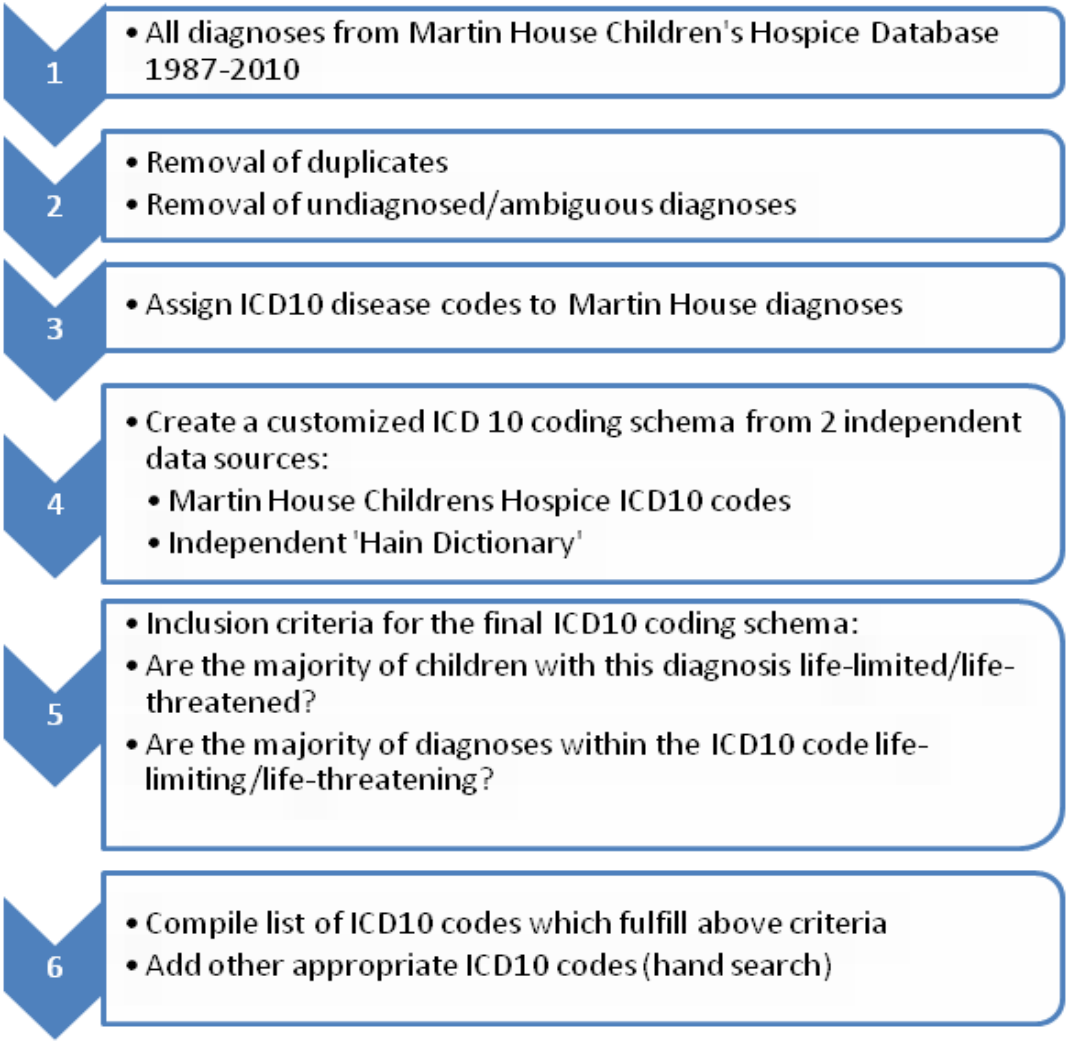
We hoped to improve the of use routine national health data to estimate the prevalence of children and young people living with life limiting or life threatening conditions by tightening up definitions…..

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

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

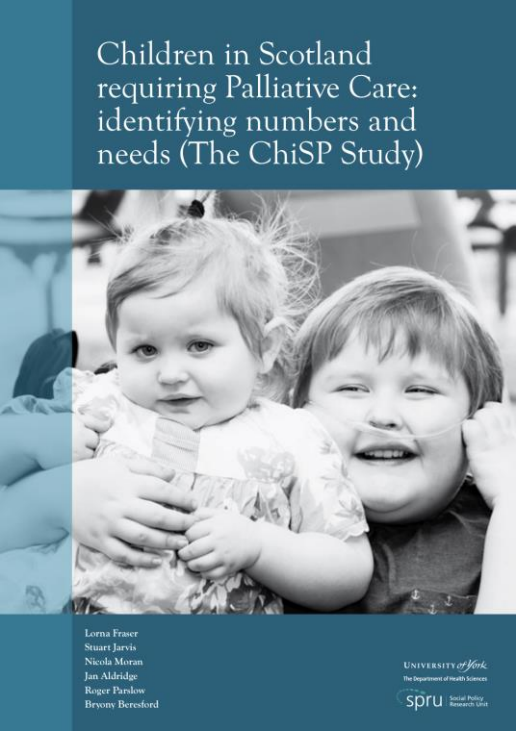
Prevalence of Life Limiting Conditions in England per 10,000 population (0- 19 years)

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**

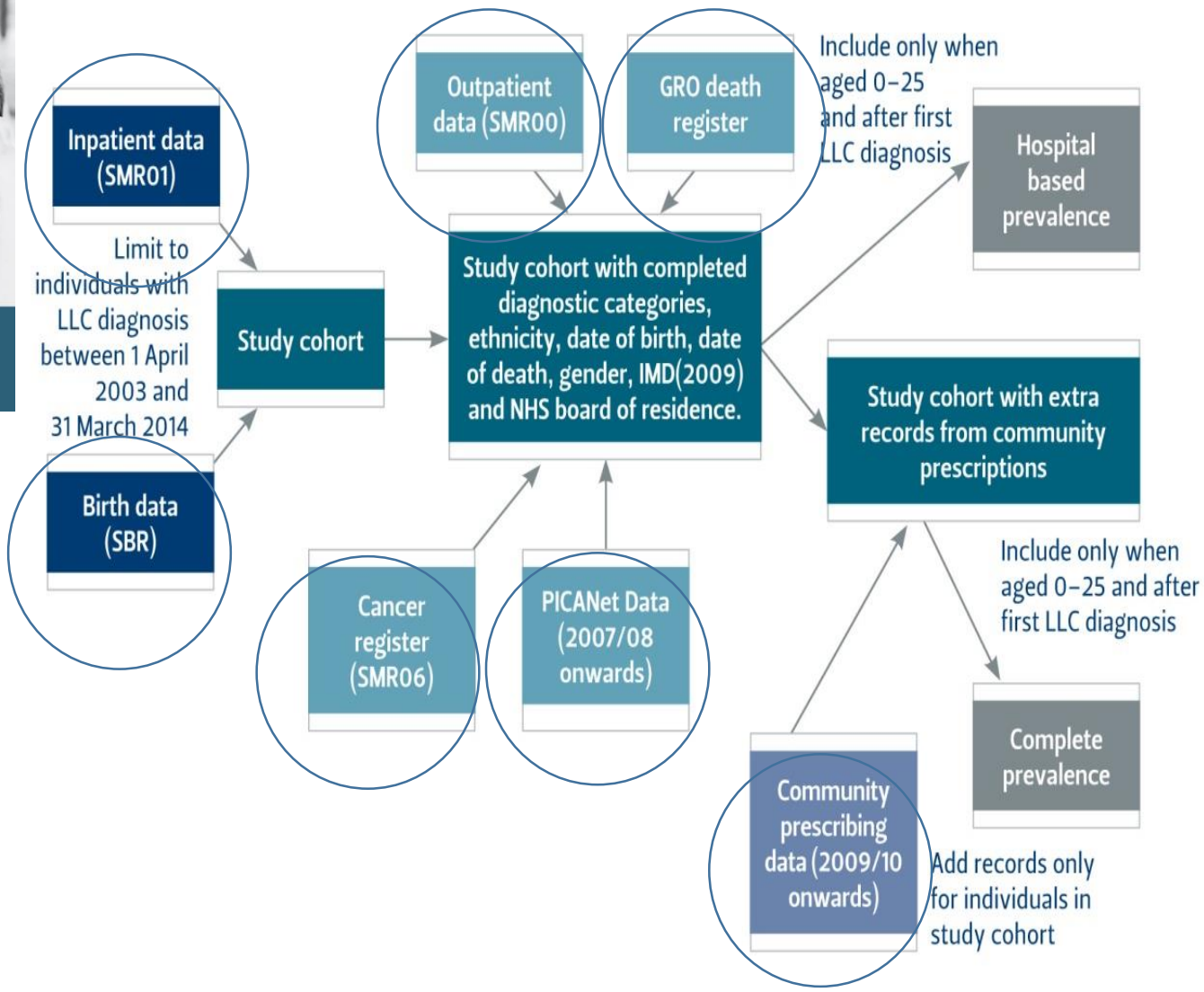
Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA Parslow RC. Rising national prevalence of life-limiting conditions in children in England. Pediatrics. 2012 Apr 1;129(4):e923-e929. DOI: 10.1542/peds.2011-2846

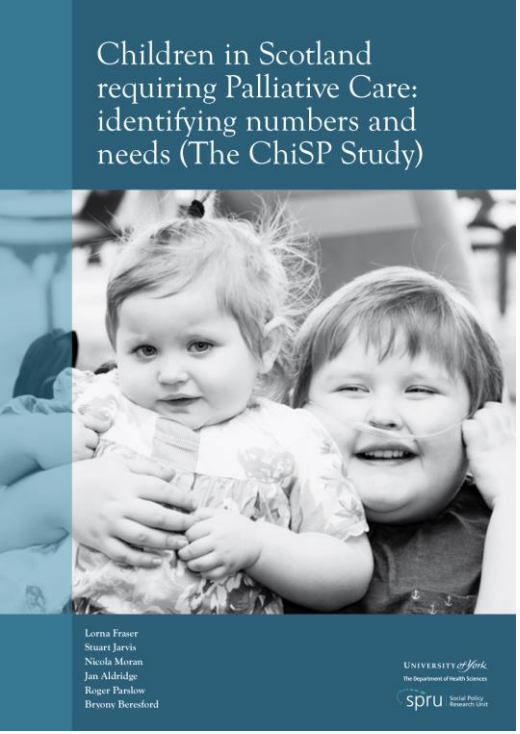
We seem to have mined this rich seam of national data quite well and produced some important results: the Pediatrics paper on the increase in prevalence has been cited in over 80 journals. It prompted Scotland to request a similar piece of work, including a qualitative element, an extremely important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

Children in Scotland requiring Palliative Care (ChiSP Study)



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





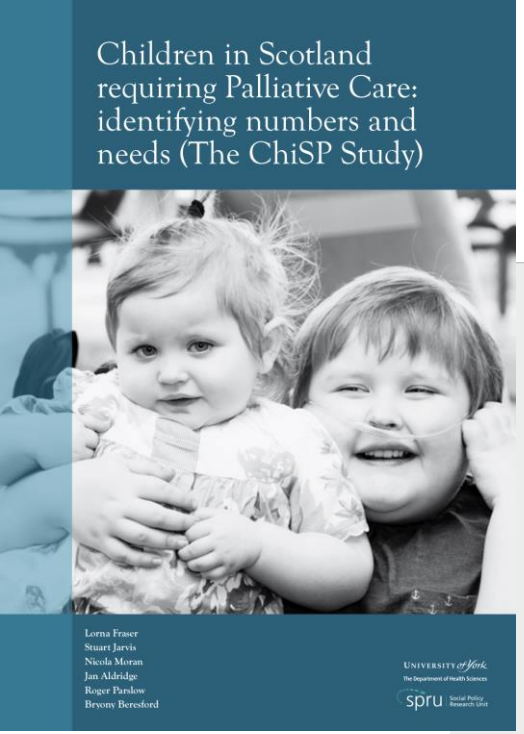
Children in Scotland requiring Palliative Care (ChiSP Study)

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

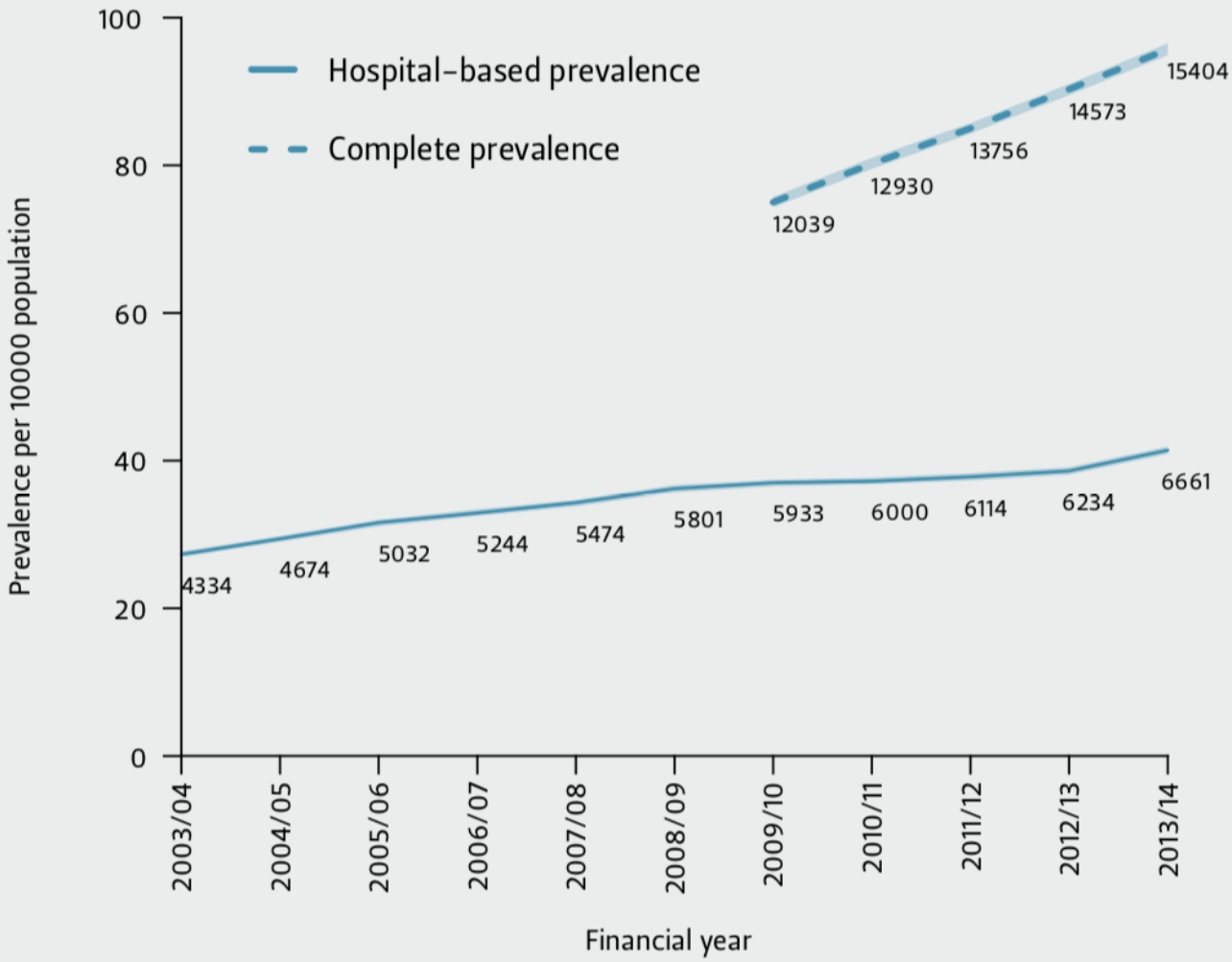
Increase from 27.3 per 10,000 population in 2003/4 to 41.4 per 10,000 population in 2013/14

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 (ChiSP Study)



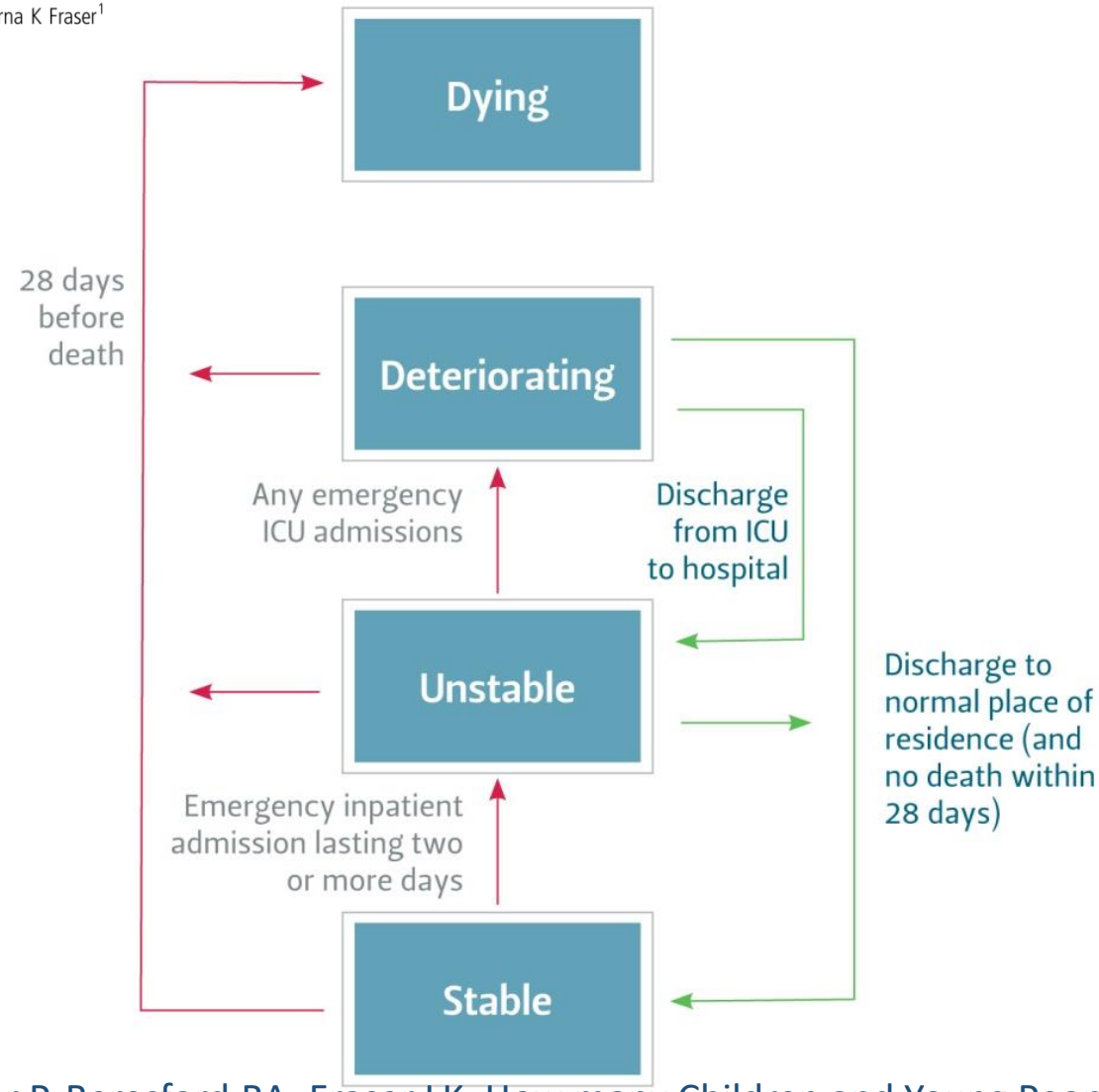
Original article

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 Fraser[1]

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

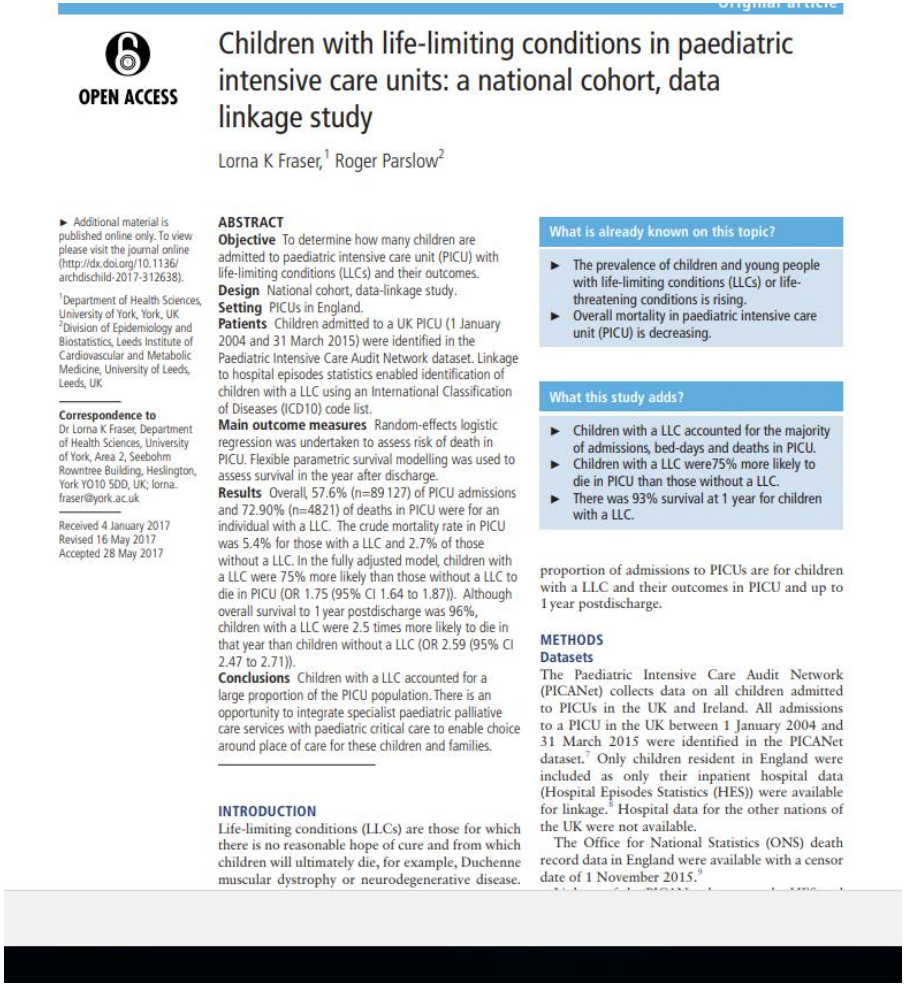
Original article

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 Fraser[1]

- 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



OPEN ACCESS

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

Lorna K Fraser,[1] Roger Parslow[2]

► 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.

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 were75% more likely to die in PICU than those without a LLC.
- There was 93% survival at 1 year for children with a LLC.

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. 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

Fraser LK, Parslow R. Children with Life-Limiting Conditions in Paediatric Intensive Care Units:: a national cohort, data linkage study. Archives of Disease in Childhood. 2017 Jul 13;1-9. Available from, DOI: 10.1136/ archdischild- 2017-312638

So why might national datasets be underused?

Have other nations taken the initiative?

Scotland


scot-ship.ac.uk
SHIP
ScottisH
Informatics
Programme
The collation, management, dissemination and research analysis of anonymised Electronic Patient Records
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About
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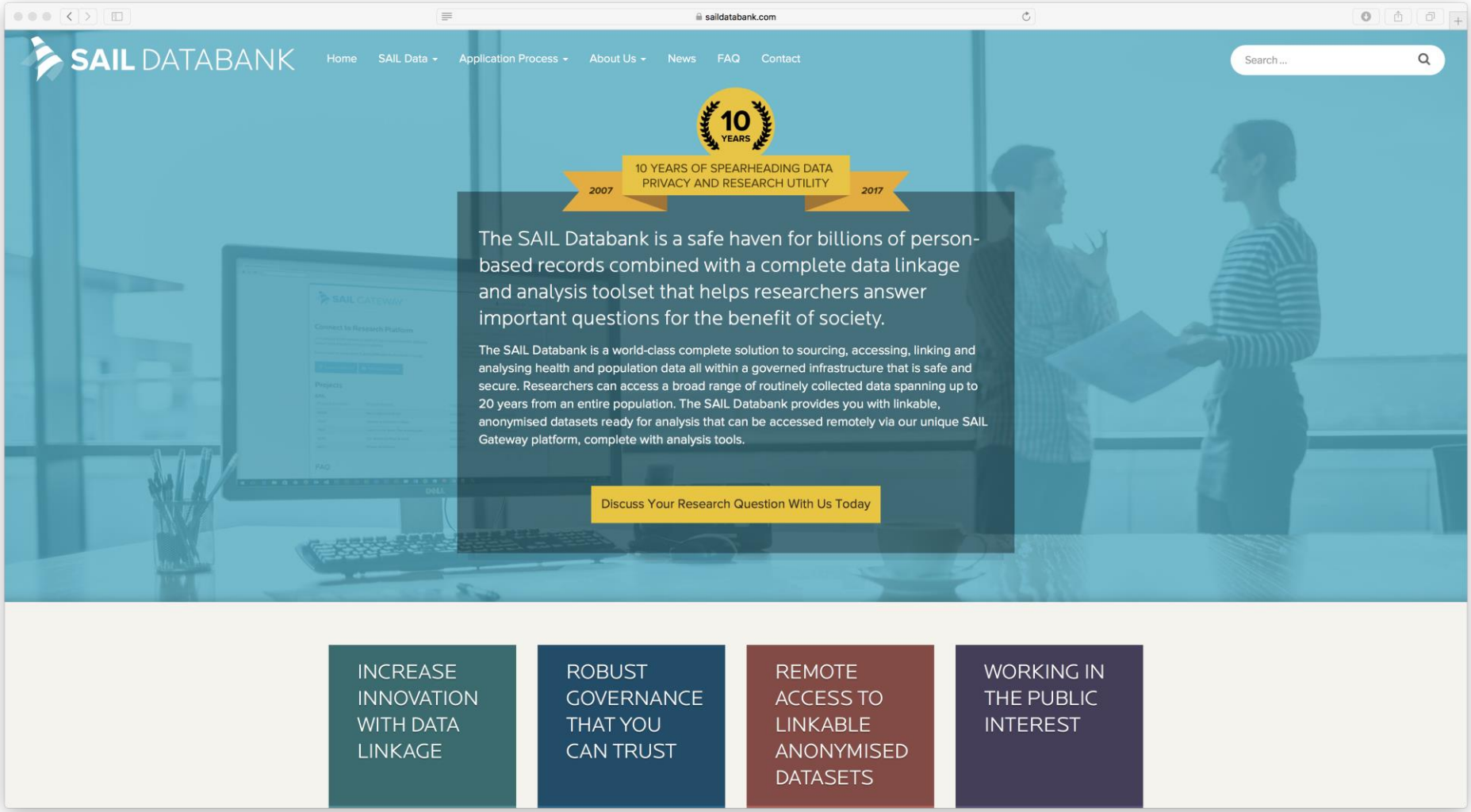
Conference
Publications
Data Access
Toolkit
Public Interest
Contact
Overview
Core Programmes
Research Programmes
SHIP Investigators
Dr Marion Bain
Professor Paul Boyle
Professor Helen Colhoun
Professor Sarah Cunningham-Burley
SHIP Investigators
SHIP brings together the Information Services Division (ISD) of NHS Scotland and a genuinely inter-disciplinary 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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News
FAQ
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10 YEARS
10 YEARS OF SPEARHEADING DATA PRIVACY AND RESEARCH UTILITY
2007
2017
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 INNOVATION 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…

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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...

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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

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.