

Introduction to Data Linkage

ECTU Statistics Methods Meeting

17th July 2020

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eCRUSADers – by Elizabeth Lemmon



by Elizabeth Lemmon APRIL 17, 2020

Using Administrative Data in a Clinical Trial



In this post, Catriona Kieria, Senior Statistician within Edinburgh Clinical Trials Unit (ECTU) talks to us about her work within ECTU and her involvement on a rare Scottish trial that used administrative health data. She provides some great diagrams to help along the way, which I can tell you are essential if you want to understand the complicated structure of the data! Catriona also highlights some of the key challenges the team faced in terms of data access and use and offers her reflections on what they learned from the project.

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[Research Data Scotland: A conversation with Roger Halliday, Chief Statistician \(Scottish Government\)](#)

by Elizabeth Lemmon MAY 21, 2020

Course Round Up: The Whys and Hows of applying to the Public Benefit and Privacy Panel for Health and Social Care (PBPP)



Date of course: Wednesday 11 March 2020

Organised by: Wellcome Trust Clinical Research Facility

Post summary: In this post I provide a run through of the course: *The Whys and Hows of applying to the Public Benefit and Privacy Panel for Health and Social Care (PBPP)*. As the title

suggests, the course – delivered by PBPP Manager Dr Marian Aldhous – covered two main areas: Why would you need to apply to the PBPP and how would you go about doing this. My thanks go to Marian, who has kindly let me use her slides to write this post.

In a rush? Check skip to the [Top Tips](#) for filling in your application and some of my [reflections on the course](#) (where you will also find links to an example Tooth fairy PBPP and associated documents!).

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[Using Administrative Data in a Clinical Trial](#)

[Researcher Experience: Dr David Henderson](#)

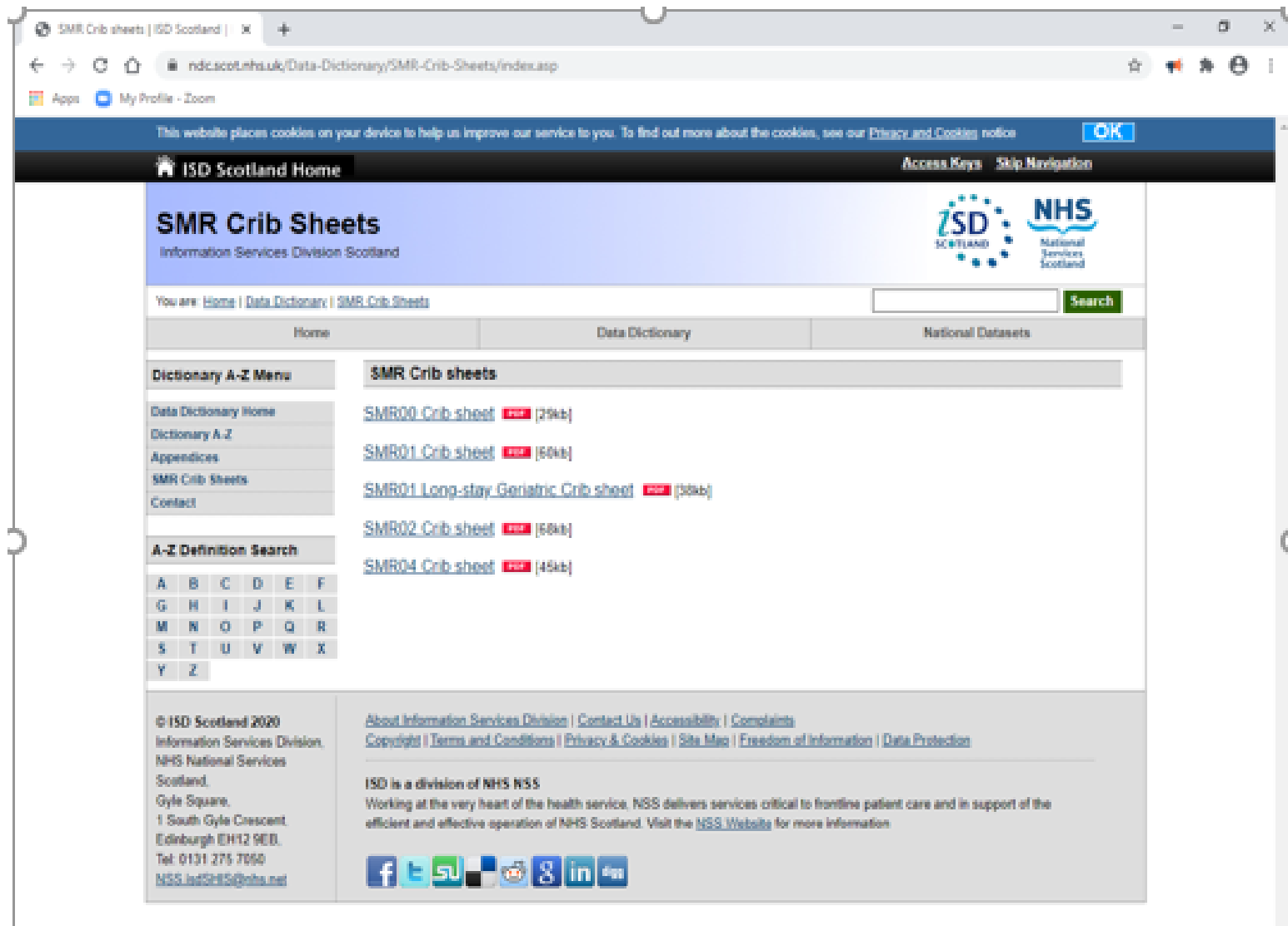
Post Contents:

1. [What is the PBPP?](#)
2. [What is the legislation and principles covering aspects of information governance for the use of NHS Scotland data for purposes other than direct care?](#)



“What linked health data in Scotland is available?”

Common SMR datasets & crib sheets



The screenshot shows a web browser window displaying the 'SMR Crib Sheets' page from the Information Services Division (ISD) Scotland. The browser's address bar shows the URL ndc.scot.nhs.uk/Data-Dictionary/SMR-Crib-Sheets/index.asp. The page features a blue header with the ISD Scotland Home logo and a navigation bar with links for 'Access Keys' and 'Skip Navigation'. Below the header, the main content area is titled 'SMR Crib Sheets' and includes a search bar. The page is organized into a grid with a left sidebar containing a 'Dictionary A-Z Menu' and an 'A-Z Definition Search' table. The main content area lists several SMR Crib Sheets with their respective file sizes and download links. The footer contains copyright information for ISD Scotland 2020, contact details for the Information Services Division, and a list of social media links.

SMR Crib sheets | ISD Scotland | x +

ndc.scot.nhs.uk/Data-Dictionary/SMR-Crib-Sheets/index.asp

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A-Z Definition Search

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				

SMR Crib sheets

- [SMR00 Crib sheet](#) **PDF** (29kb)
- [SMR01 Crib sheet](#) **PDF** (60kb)
- [SMR01 Long-stay Geriatric Crib sheet](#) **PDF** (36kb)
- [SMR02 Crib sheet](#) **PDF** (68kb)
- [SMR04 Crib sheet](#) **PDF** (49kb)

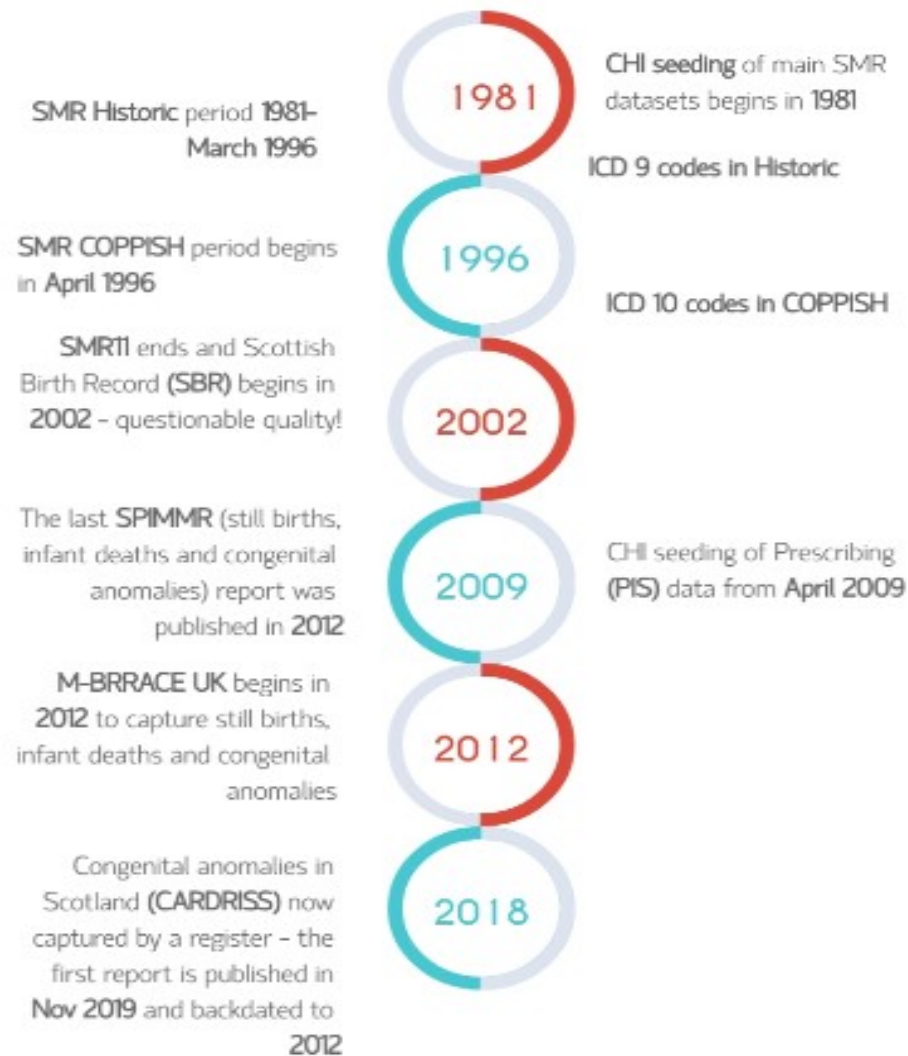
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Timeline of some datasets, in particular maternity

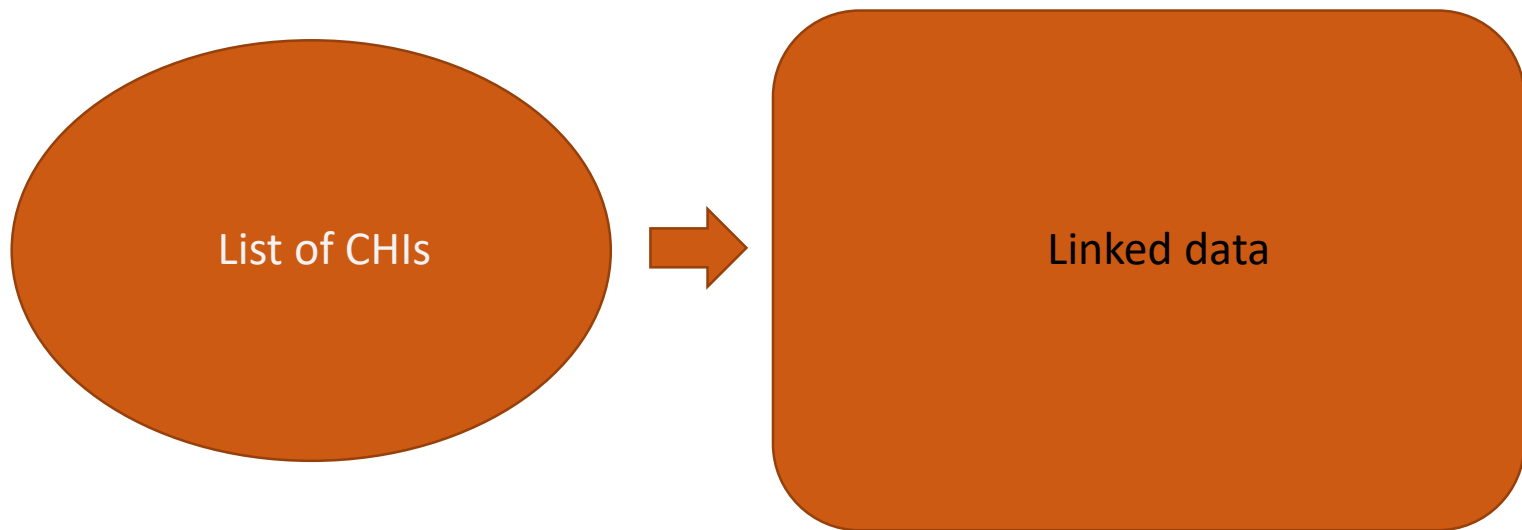




“How is a cohort identified?”

Ways to Identify a cohort

Pre-existing cohort – eg recruited clinical trial



Ways to Identify a cohort

Identified within an admin dataset eg births within a specified time period (with specified characteristics)



“Where is my data?”

Preparing for the data - SMR02 example extract

SUMMARY OF CODES - SMR02 (Last Update 22/02/19)

Induction of Labour

- 0 None
- 1 Artificial rupture of membranes (ARM)
- 2 Oxytocics
- 3 ARM + Oxytocics
- 4 Prostaglandins (includes cervical priming)
- 5 Prostaglandins + ARM
- 6 Prostaglandins and Oxytocics
- 7 Prostaglandins and ARM and Oxytocics
- 8 Other
- 9 Not known

Will grouped categories be?

0 None


1-8 Induced

9, blank or error – Not known

”How is linked data validated?”

Dataset validation guidance

- GUILD (2017) – paper and checklist
- RECORD (2015) – paper and checklist
- STROBE (2007) – paper and checklist

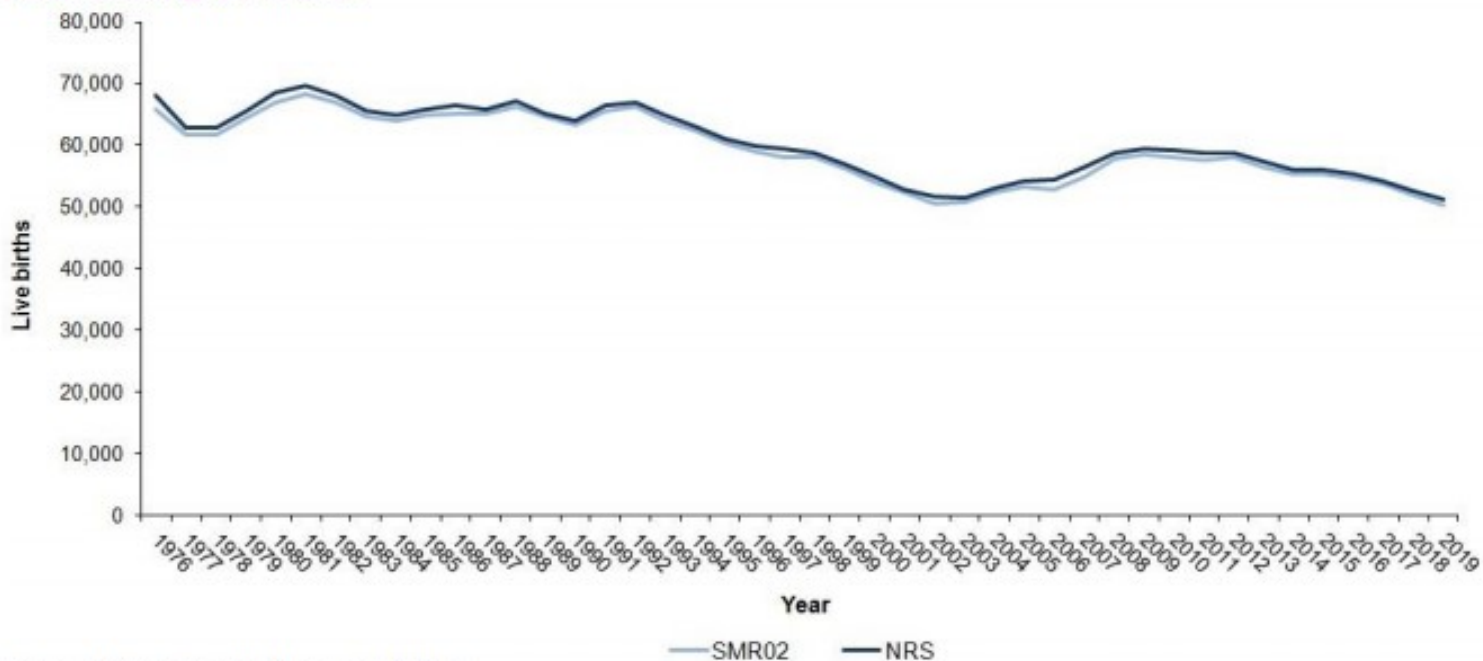


“this linked dataset has a record of all the cases of disease X in the population of interest during the specified time period”

Total number of live births in Scotland

<https://www.isdscotland.org/Health-Topics/Maternity-and-Births/Publications/data-tables2017.asp?id=2553#2553>

Figure 1: Comparison of National Records of Scotland and SMR02 live births, Year ending 31 March

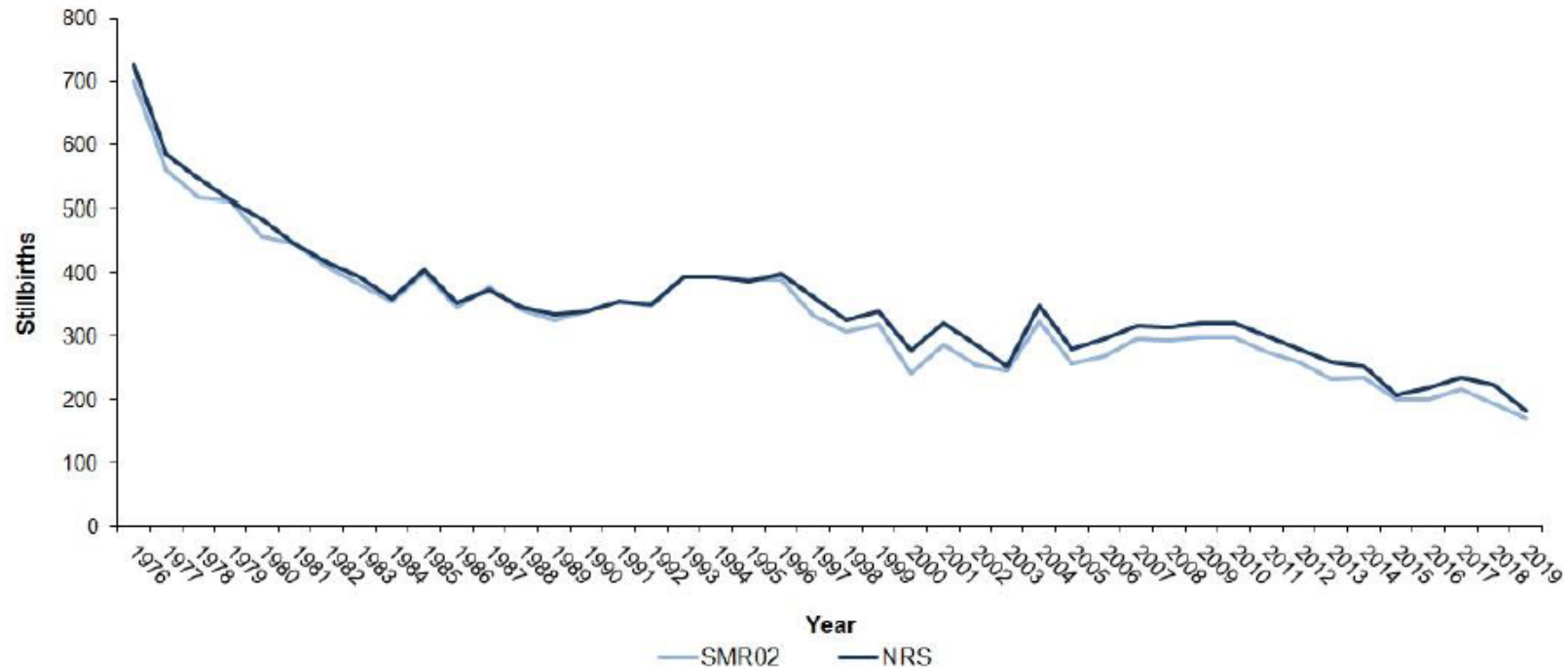


Source: NRS birth registrations and SMR02.

Total number of stillbirths in Scotland

<https://www.isdscotland.org/Health-Topics/Maternity-and-Births/Publications/data-tables2017.asp?id=2553#2553>

Figure 2: Comparison of National Records of Scotland and SMR02 stillbirths, Year ending 31 March

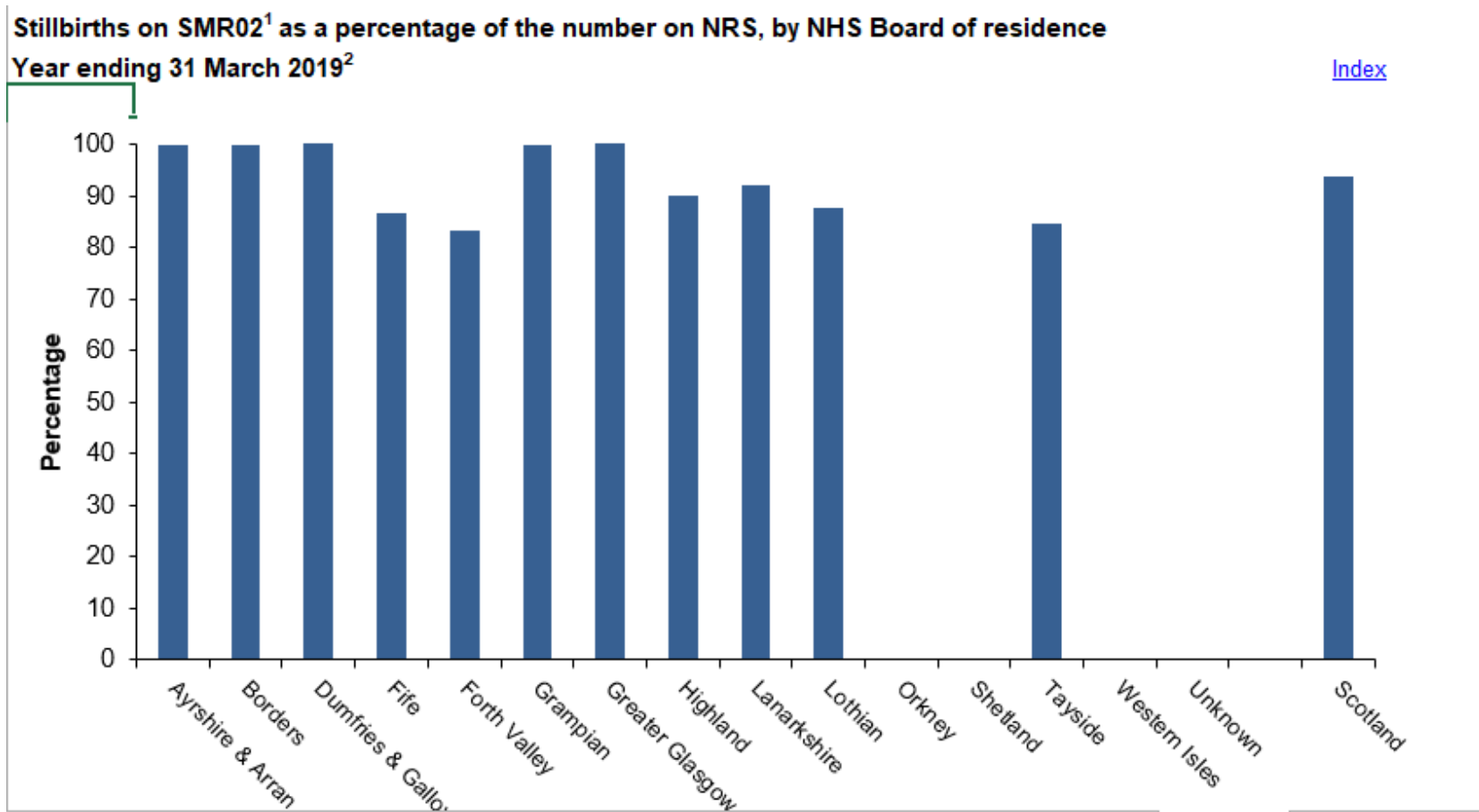


Source: NRS birth registrations and SMR02.



Stillbirths captured in SMR02, by health board

<https://www.isdscotland.org/Health-Topics/Maternity-and-Births/Publications/data-tables2017.asp?id=2553#2553>



Some of the Challenges

- Lack of technical guidance / references
- Data set validation
- Messy data! Or just lots of it
- Known missing values + records (at random?)
- Unknown missing values + records
- **Time taken to receive data**

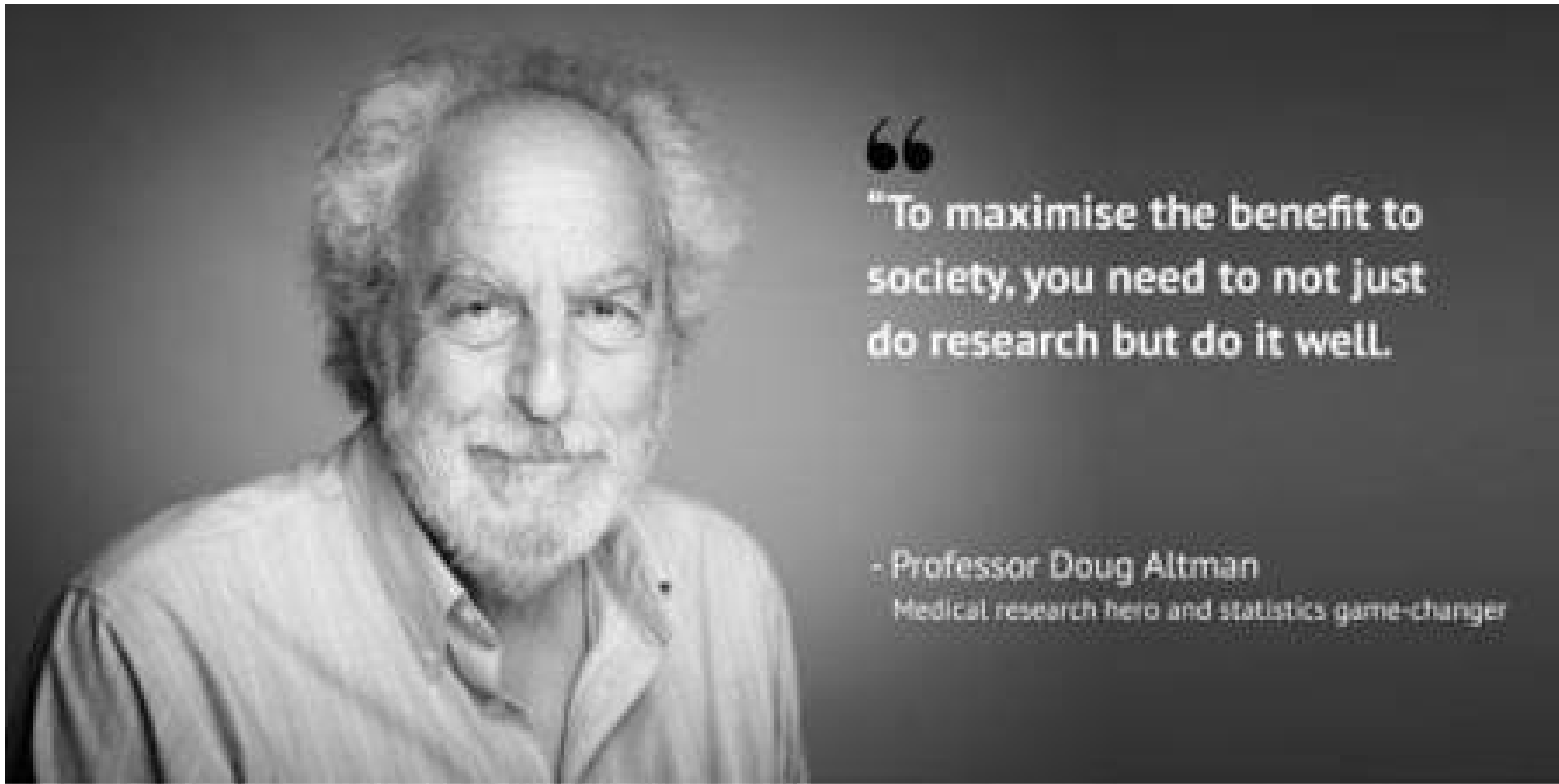
Some of the Advantages

- Lookback + look forward
- Relatively low cost
- Good population coverage
- Big data and big populations
- Opportunity to study rare diseases
- 'Real life' data

Opportunities....

- More sharing of good practice and technical guidance
- Research ready databases – has relevant data already been pulled together?
- COVID research
- Primary care?
- Standard Data Sharing agreements between organisations

The late, Great Professor Doug Altman



“

“To maximise the benefit to society, you need to not just do research but do it well.

- Professor Doug Altman

Medical research hero and statistics game-changer



Thank you for your attention!

Any questions?