

Stakeholder engagement and user needs with a focus on health and care statistics

**International Workshop on User Engagement - Amman, Jordan
17th June 2019**

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Background – UK Health Care System

- UK health care system
 - Department of Health and Social Care
 - ❖ Helping people to live better for longer
 - ❖ Supported by over 27 agencies and public bodies incl. National Health Service (NHS)
 - NHS is responsible for arranging the provision of health services.
- Health and Care – Devolved Policy
- Health and care decentralised
 - Allowing for healthcare that is tailored to the local landscape

Implications for Official Statistics Production

- Multiple Producers
- Methodological issues
- Numerous publications
- Publication formats
- Duplication

To put it in context

Users had to navigate through;

- **Around 400 official statistics publications relating to health and care, covering England alone**
- **Published by around 20 different government organisations**
 - **each with its own websites**
 - **each with own processes on how users can requesting data**
- **Not all the producers are obvious health providers**
 - **Office for Standards in Education – child social care**
 - **Department for Transport - road casualties**
 - **Home Office - drug misuse**
 - **MoJ – Safety in custody statistics**
 - **MoD - Casualties, PTSD statistics**
- **Separate smoking publications by ONS and PHE**

Impact on users:

“Statistics published on a variety of different websites, in different formats, with no single portal available to guide users”

“The health and care statistics landscape was data rich, but information poor”.

“Statisticians often focus on servicing their immediate policy and operational users with insufficient effort devoted to working collaboratively to understand user needs”.

Solutions – (England)...

English Health Statistics Steering Group (EHSSG)

set up to:

“deliver improvements in health and care statistics”



Department
of Health &
Social Care



Office for
National Statistics



Public Health
England

NHS

England

NHS

Digital

Successes...



Health and Care Monthly Update England, June 2019

This monthly knowledge update brings together information, resources and official statistics on health and care in England. For further queries, or to propose a publication to include in a future knowledge update, contact us.

GSS > User-facing pages > Health and care statistics

Health and care statistics

Sub-sections:

- Health and Care Monthly Knowledge Update Archive
- Health and Care statistics landscape for England
- Health Waiting Time Statistics
- The English Health Statistics Steering Group
- The English Health Statistics Theme Groups

Health and social care are devolved matters in the UK. Within England, the decentralised nature of the official health and care statistics system means that a number of organisations are involved in the collection of data and the publication of a range of statistical outputs. As noted by the Office for Statistical Regulation in 2016: [“Statistics are published on a variety of different websites, in different formats, with no single portal available to guide researchers or the public”](#).

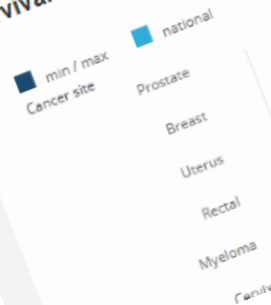
To help users find the information they need, we have introduced:

- a [Health and Care Statistics Landscape for England](#) – this experimental output provides links to a range of official statistics produced across government

For most cancer sites and geographies, there were increasing trends in 1-year and 5-year survival


However, for 1-year survival there was a statistically significant decrease for bladder cancer, and some combinations of geography and cancer site appeared to show a fall. 1-year survival estimates were above 75% and 5-year survival estimates were above 50% for the majority of the 14 cancer sites and 67 geographies examined. As shown in the chart, the range of 1-year survival estimates varied from 1.7 percentage points for prostate cancer to 11.8 percentage points for stomach cancer.

Age-standardised 1-year net cancer survival (%) for adults diagnosed in the period 2012 to 2016 and followed up to 2017, and the range of survival estimates for Cancer Alliances: England, by cancer site




Successes...

One stop portal for health and care statistics



Health and Care Statistics Landscape for England Beta V2.0



Using the theme and geography filters, or typing in the search bar, will change the list of publications shown below.
For further information, see the [notes](#) ⓘ

Search keyword:

↵

← Clear filters

Theme:

Adult social care & older people	Child & maternal health	Cross-cutting	End of life care	Health inequalities	Learning disabilities	Mental health & dementia	Prescribing	Secondary & hospital care	Workforce
Cancer	Chronic illness	Disability and Unpaid Care	Finance, estates, and efficiency	Infectious disease	Lifestyles & behaviours	Mortality	Primary & Dental Care & Oral Heal...	Sexual health	

Geography:

Below Local Authority	Clinical Commissioning ...	England	Local Authority	NHS England Region	Other Region	Public Health England Centre	Public Health England Region	Region (formerly GOR)	Trust
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Publication Name	Link	Organisation	Theme	Frequency	Discontinued	Date Last Published	Next Publication Date
12 week maternal assessment	https://www.gov.uk/...	NHS England	Child & maternal health	Quarterly	Discontinued	20 October 2017	
2011 Census analysis: General Health in O...	https://www.gov.uk/...	Office for National Statis...	Health inequalities	One off	Not applicable	19 February 2015	
30 Hours Free Childcare	https://www.gov.uk/...	Department for Education	Child & maternal health	Monthly	Not discontin...	27 September 2018	
30 Hours Free Childcare	https://www.gov.uk/...	Department for Education	Child & maternal health	Quarterly	Not discontin...	27 September 2018	
A safer place to be	http://www.cqc.org.u...	Care Quality Commission	Cross-cutting	One off	Not applicable	01 October 2014	
A&E attendances and emergency admissi...	https://www.gov.uk/...	NHS England	Secondary & hospital ...	Monthly	Not discontin...	09 May 2019	13/06/2019
Abortion statistics for England and Wales	https://www.gov.uk/...	Department of Health an...	Child & maternal health	Annual	Not discontin...	07 June 2018	13/06/2019
Abuse of Vulnerable Adults in England	http://digital.nhs.uk/...	NHS Digital	Adult social care & ol...	Annual	Discontinued	06 February 2014	
Adult Dental Health Survey	https://digital.nhs.uk...	NHS Digital	Primary & Dental Car...	One off	Not applicable	08 December 2018	
Adult drinking habits in Great Britain	https://www.gov.uk/...	Office for National Statis...	Lifestyles & behaviours	Annual	Discontinued	01 May 2018	
Adult inpatient survey	https://www.cqc.org...	Care Quality Commission	Secondary & hospital ...	Ad-hoc	Not applicable	01 June 2018	
Adult Psychiatric Morbidity Survey: Surve...	http://content.digital...	NHS Digital	Mental health & dem...	Ad-hoc	Not applicable	29 September 2016	

Successes...

Benefits:

- Uses R and Microsoft Power BI – both free
- Automated using webscraping = more time to improve other parts
- Allows users to search by: keyword, theme, geography
- More visually appealing than previous version (PDF)

Issues:

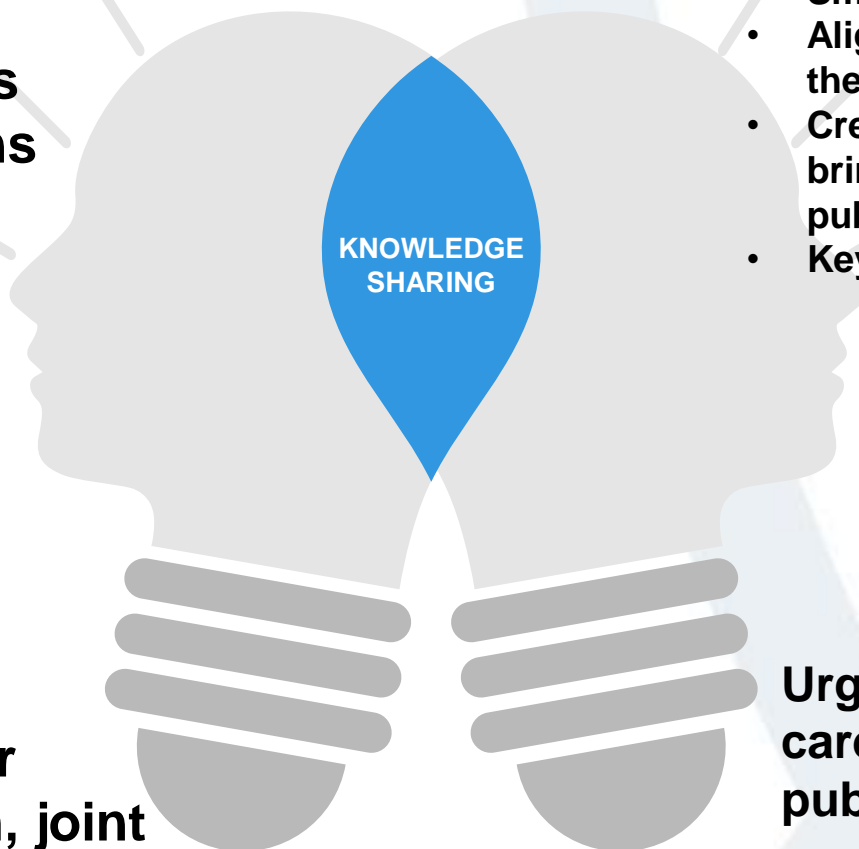
- Free software means little service support
- Upskilling of staff to use software
- Webscraping relies on websites not changing their format – initial set up if things change can be resource-intensive
- Accessibility – balancing information with ease of access

[Health & Care Statistics Landscape for England](#) < make sure we use this link if sharing it, due to the Power BI issues

Collaborative successes...

- **Aligned publication dates**
- **Joint publications**
- **Theme groups**
- **Data sharing**
- **Secondments**
- **Apprenticeships**

- **Smoking – NHS D, PHE, ONS**
- **Aligning smoking publications for the same day**
- **Creating a slide pack which brings stories from three publications together**
- **Key user events**



**Cancer – ONS/PHE
rationalising cancer
registration system, joint
publication and QA of
statistics**

**Urgent and emergency
care –joint NHSD/ NHSE
publication**

Secondments and Apprenticeships

Collaboration – snapshot of user feedback

Landscape - A local council: “We've found this resource to be an excellent benefit in sourcing information”

Landscape - NICE: “Our team of analysts often review nationally available data sources ... were very pleased to see the resource you had produced.

On the newsletter: “Really excited to finally have a single publication pulling together information about health and care data from all the government publishers (rather than having to rely on lots of individual bulletins).”

But there is no room for complacency....

- To this end we are moving to the next phase
- Workplan to focus on evidence gaps in health and social care.
- Will work with the 4 Nations Group as those gaps are filled to improve the health and care evidence base of the whole UK

Methods of engagement

- Consultations and surveys - Periodically
- Meetings, workshops, seminars - Monthly
- Newsletter - Monthly
- User groups – Regular minimum monthly
- User research – Before any change or update
- Answer questions - Regular
- Online forums – StatsUserNet
- Social media – Coming very soon!!