

Health and Care Statistics User conference: putting users' needs at the heart of improving health and social care statistics

Held on the **28 November 2017** at etc venues, Drummond Gate, London

Eight major themes were chosen and conference participants selected the one they would most like to contribute to, with a facilitator at each table to drive discussions, who would take the work forward. The table themes were:

- Smoking
- Child and maternal health
- Adult social care
- Mental health, including dementia
- UK health and care data
- NHS and social care workforce data
- Health inequalities
- Primary and dental care

Ed Humpherson, Director General for Regulation, opened the conference with an introductory talk emphasising that statistics are a public good and that one of the purposes of the Office for Statistics Regulation is to improve statistics to help people make decisions. Ed noted that the user voice is key, and the conference continued the joint working of users and producers to help:

- drive improvements to statistics
- ensure the usability of statistics
- create new statistics

Our next speaker was John Morris, Chair of the Four Nations Statistics Group, who updated the audience about the work of the group. The most recent work has focused on the development and submission of [the OECD Healthcare Quality Indicators](#). The aim of these indicators is to measure and compare the quality of health service provision in different countries. An OECD Expert Group has developed a set of quality indicators at the health systems level, to assess the impact of particular factors on the quality of health services. The Department of Health is the UK representative, with input from the devolved nations. Experimental statistics have been developed and data was provided by the devolved nations to NHS Digital who compiled UK figures which have been submitted to the OECD for 2016. John noted that the primary purpose for the product was to invite user feedback, and in particular to receive comments on how the product might be developed further.

Abigail Self, Head of Health Analysis for ONS spoke next, summarising the work of the English Health Statistics Steering Group (EHSSG). Abigail started her presentation noting that the OSR had set statistics producers a challenge to work collaboratively to improve the information available to users to better meet their needs. EHSSG was set up to deliver improvements to health and care statistics. The [Health and Care Landscape](#) document was published on the Government Statistical Service (GSS) website in May 2017 and reflects the fact that this is a

collaboration with all health statistics producers across the GSS. ONS maintains and updates it monthly with latest information. As well as improving accessibility to existing data, Abbie noted that there had been increased focus on meeting users' needs for additional data for research purposes. There have been a number of new collaborations between departments, involving outputs about smoking, cancer, urgent and emergency care, learning disabilities and comparable indicators for the four nations of the UK. Abbie finished her presentation with a summary of the different projects that ONS has been undertaking with users to improve the collection and presentation of statistics about very personally sensitive subjects.

Following this presentation, the topic tables broke into facilitated discussions about what changes users have noticed about the statistics in each thematic area in the last year or so and what producers are now planning to do to improve health and social care statistics in that topic area. The Mental Health, Dementia and Learning Disabilities table had an active discussion about how there has been a noticeable increase in the availability of data available including through the MH 5 year forward view dashboard. Other examples include that some table members had noticed that some of the statistics were provided in a more machine readable form and also that the frequency of some publications had been increased. Awareness of the Landscape document is mixed, but those who have used it found a very helpful as a way of navigating to relevant data or publications. The main suggestions for improving it were to add depth and breadth (more metadata and other data sources). Infographics and other more visual ways of presenting statistics were felt to be helpful – particularly on Twitter – although they should not be instead of providing full data sets and narrative reporting.

After a short break, our next speakers were Scott Heald and Maighread Simpson representing NHS Scotland Information Services Division (ISD) who gave an interesting overview of the landscape of health statistics in Scotland. Since 2015, ISD are able to collect social care data from local authorities, as well health data from NHS bodies, so are able to publish statistics about the whole care journey. Traditionally, their focus was on reporting on health data in silos, but they are now able to tell more of the story through an incremental programme of work to change how and what they publish. Users have been fundamental to these developments and ISD are engaging widely, with a broad range of groups. The team have divided the various user personas into four types, depending on their need, and which led to four main types of behaviour, that they have classified as: Curious, Focused, Detailed and Digging.

Next, Claire Milne gave us an update about the work of FullFact, the fact-checking organisation and its Need to Know Project. Questions they are posing include:

- Where are the data and analysis gaps?
- How well are we communicating what we know?

FullFact's key pointers for statistics producers are:

- Pre-empt the questions people have and what they want to use the data for
- Make it easy to find the right figures quickly
- Explain trends and communicate clearly

The second facilitated table discussion aimed to provide producers and users a chance to discuss what government statisticians could be doing to improve the insight provided by health and care statistics. We invited users to discuss the priority gaps to fill and identify the insight that already exists. Examples of questions that the current statistics do not answer include 'Do we spend enough on prevent in of mental ill health?'; 'How does salary affect retention of staff?'; 'How much do patients spend on private dentistry?'; 'Who needs to attend A&E?' One suggestion was to encourage opportunities for collaboration between analysts / academic researchers and in-house software development teams, by linking the analytical work carried out by individual researchers / analysts on centrally held health and care datasets, with the work carried out by the in-house software development teams that support these datasets. Improvements discussed include the need for more data about mental well-being, data to better under ethnicity issues and more data linkage to understand mental health within schools, during pregnancy and in care homes. All tables identified a lack of "joined up" data that can reflect patient journeys between different parts of the system. This is a challenge to be addressed across all the theme groups, but particularly between Primary, Secondary and Social care themes.

After a buffet lunch, Professor David Spiegelhalter, Winton Professor for the Public Understanding of Risk in the Statistical Laboratory at Cambridge University, entertained the audience with a very lively talk about the importance of making statistics accessible, usable and assessable. He noted that it is important for producers to demonstrate trustworthiness and people must be able to assess that trustworthiness. David summarised some work he had done with parents to enable them to understand statistical uncertainty. He felt it was key that statistics producers understood their audience and considered multiple formats for disseminating their information.

A plenary question and answer session was scheduled, and the producer panel assembled. The panel included representatives from Public Health England, ONS, NHS Digital, ISD Scotland, and Welsh Government. Firstly, the plenary heard a short summary of the common themes from the topic tables, including a plea for more data linking and analysis of linked data; keeping users up to date with developments and to engage with a wider range of users. These are some of the themes arising from the question and answer session, which statistics producers will consider:

- The need for more data linkage
- The need for sharing low level highly granular raw data, rather than merely aggregated data
- Developing the statistical capability of leaders and policy-makers
- The need to drive up healthcare quality in small organisations
- The importance of UK-wide outcomes
- The importance of data about protected characteristics
- The challenge of more than one data source for some statistics
- The need to engage users at every step of the statistics process and to make users more aware of changes
- The need for data about the prevalence of mental ill health by GP geographic area

Iain Bell, Deputy National Statistician for Population and Public Policy at the Office for National Statistics, closed the conference with a promise to lead the collaborative work to improve health and care statistics, to better meet user need.