Health and Care Statistics in England – The Statistics Authority's direction of travel

Introduction

1. In February 2016 the UK Statistics Authority convened a meeting – a Round Table – of many of the leaders of the English health and care system to discuss how English health and care statistics could be enhanced to better serve the public good: how the statistics might be improved, in order to support better decision making. The attendees of the Round Table are listed in **Annex A**.

2. The Round Table discussed the features of a system of health and care statistics in England that would deliver on the core values of trustworthiness, quality and public value. There was support for the UK Statistics Authority's strategy for UK Statistics – *Better Statistics, Better Decisions* – which provides a framework for evaluating the characteristics of the service provided by the statistical systems in each domain (such as education, criminal justice, and health and care).

3. *Better Statistics, Better Decisions* starts from the independence and professionalism of statisticians as the essential pre-requisite to trustworthiness, and looks for systems of statistics which then demonstrate the following attributes:

    - **Helpful** – to those the statistics seek to serve – decision makers and the citizen
    - **Innovative** – innovating to make things better, for example mobilising the power of health and care data, and being responsive to rapid change in the health landscape
    - **Professional** – delivering high quality statistics that are trusted for their independence and objectivity, with greater availability of real time data and National Statistics used with confidence
    - **Efficient** – demonstrating value for money
    - **Capable** – building capability, for example working collaboratively across the health and care system, exploiting and integrating sources, adding value

4. The Round Table agreed that at its best the health and care statistical system in England satisfies these criteria. Statistics on cancer survival rates, aspects of patient experience and patient outcomes, and data on prescriptions are well-produced, high quality, and valuable (that is, useful, relevant), adding insight and knowledge. These statistics go beyond simple administrative counts to provide rich insights, based on linked datasets and deploying a wide range of analytical tools.

Key findings

5. The Round Table agreed that the English health and social care system is complex and is likely to become more complex with an increasing regional focus: it has the characteristics of an ecosystem. This complexity is reflected in the statistical infrastructure (see the Health Statistics Landscape diagram, at **Annex B**), but good work is being planned through the National Information Board (NIB) to bring organisations together to realise the full potential of health and care data.

6. The members of the Round Table concluded that, in the absence of an influential and high profile coordinating mechanism, the service (collection, presentation and dissemination, quality management and advice) provided by the decentralised health and care statistics system is incoherent and inconsistent. This manifests itself in a number of ways:

   i. **Official health statisticians often focus on servicing their immediate policy and operational users, and only within the NHS,** with insufficient effort devoted to working collaboratively to address the important issues of coherent and accessible statistics to support public understanding and accountability and insufficient opportunities to influence decision making. Generally, statisticians appear to be tentative about engaging with a broader user community.

   ii. **The health and care statistics landscape is data rich, but information poor: the importance of analysis has been neglected, as has been support for other analysts and researchers.**

      a. The NIB is commissioning a review into analytical capability across the Arms' Length Bodies that constitute the health and care system.
      b. Where there *is* analytical capability, the trend has been to reduce it – contrary to what is needed to make the most of increasing volumes of data.
      c. Administrative data sources are under-exploited. The system is exceptionally rich in both administrative data, generated within the system through the course of a patient journey, and in survey data. This presents opportunities for data analysts to perform triangulation between different sources, enabling a more comprehensive understanding of the performance of the health and social care system. Despite the abundance of statistics, indicators and management information, the range and quality of data in some areas - particularly social care and mental health - remains poor - and it is difficult to draw inferences about variations across the country.
      d. While there is an increasing demand from within the health and care system for information drawn from increasingly real-time data, there are delays in the publication of some data and analysis. More generally, there is a lack of clarity about the usefulness and relevance of the latest snapshot data and how it should be complemented by deeper analytical work: while both are needed, the value of each might be explored further in order to inform resourcing decisions.
      e. Researchers find it hard to access microdata and the implications (for access to data for research and subsequent statistical analysis) of the 2015 Caldicott Review remain a concern for some.

   iii. **Statistics are published on a variety of different websites, in different formats, with no single portal available to guide researchers or the public.** Almost 250 sets of statistics about health and care are produced by ten statistical producers. A piece-meal production approach is reflected in the fact that health and care statistics can be accessed via a range of websites and portals, but there is no single source to guide researchers or the public to the most appropriate statistics to meet their needs.

7. Taking these findings together, the Round Table concluded that the value of the health and social care statistical system is less than the sum of its parts. Data collections impose burdens on providers and the bodies who produce data, and the production of statistics themselves incurs significant cost. There is unnecessary duplication of data collection and statistical production between and within bodies, leading to a question about value for money.

Next steps toward a coherent system

8. The members of the Round Table agreed that there is no magic bullet to address these issues: instead the issues should be reviewed, including in discussion with the expert user community, as a prelude to identifying and implementing a range of activities which will lead to better health and care statistics.

Coordination and engagement

9. **A coordinated system-wide health and care approach is vital with further Health Statistics Round Table meetings needed, as well as user-focussed events such as a Better Statistics, Better Decisions summit**. The leadership group which met at the inaugural Health Statistics Round Table should convene on a regular basis, to:
    - establish the key statistics needed to monitor the effectiveness of the health and care system;
    - develop a principle-based approach to the statistical responsibilities of the different organisations which currently produce official statistics (including ONS);
    - clarify the organisational responsibilities around the production of primary data and secondary analysis; agree steps to ensure that health and care statisticians have sufficient influence – a seat at the table – to enhance policy and operational decision making; and
    - consider the merits of commissioning an independent review of the state of health and care statistics, building on the Round Table and the summit.

10. A Better Statistics, Better Decisions summit would draw out the concerns of researchers and patients, and would seek out and present ideas, opportunities, and examples of innovation and good practice. The content will be presented by producer bodies and researchers, with two immediate goals: to move toward a more focused, balanced and insightful portfolio of National and official statistics; and to establish the architecture of future producer-user engagement about statistical needs. A longer term outcome would be to inform decisions about how the health and care statistics system should be resourced and governed. The summit will need to address participants' expectations carefully, in presenting a realistic sense of the timescales involved in making substantial progress towards the goal of trustworthy, high quality and valuable health and care statistics.

Data and analysis

11. **There are huge opportunities in combining administrative data from different sectors and there are no technical barriers to near-real time data flows.** Yet these

are not sufficiently exploited. Currently there are significant gaps in the data from different sectors that are needed to make well-informed decisions. Using administrative data alongside survey data would provide decision makers across the system with better information to tackle key problems, such as winter planning; providing insight to both decision makers and statistical users on complex issues, such as rising emergency admissions. At present, accident and emergency statistics are produced on a monthly basis and lag the month of activity by over four weeks, which limits their usefulness. The delay also creates a risk that the management information available within the NHS, but not publicly available, will be inadvertently released. Such inadvertent release would constitute a failure to release statistics in an orderly way, and would demonstrate the danger that official statistics are out of step with the pace of management information within NHS organisations

12. The good work planned by the NIB will help to drive strategic improvements in data quality and analytical value added; leaders of the health and care system might overcome the current degree of inertia by actively supporting the Board's endeavours.

13. Health statistics producers should engage with the Administrative Data Research Network and establish a detailed communications plan to engage with the public on the issue of access to microdata and data sharing.

Presentation

14. **The presentation of statistics to patients and researchers should be enhanced – for example, the creation of a portal covering all official health statistics might support the needs of the public, whilst post-web 2.0 approaches might be more appropriate to meet the needs of expert users.** Publishing an overview of existing health and care statistics for users and providing guidance for users on interpreting statistics and data from various sources would help users unlock the latent transparency of the health and care system. The overview – a framework for health and care statistics – will help to clarify where statistics complement each other while also identifying the gaps, duplications, and scope for more coherent presentation (such as joint outputs, and regular analytical compendium publications).

List of Annexes

Annex A **Round table attendees**

Annex B **Health statistics landscape**

Annex C **Paper for the Round Table meeting, 22 February 2016: *Trustworthiness, Quality and Value - how can English health and care statistics be enhanced to better serve the public good?***