Round Table Paper: Trustworthiness, Quality and Value: how can English health and care statistics be enhanced to better serve the public good?

Paper for the Round Table meeting, 22 February 2016

1. National Statistics status means that statistics meet the highest standards of trustworthiness, quality and public value. They are trustworthy because they have been prepared by professionally-independent statisticians free from political pressure. They are of high quality because they are produced using sound methods and are based on reliable sources. They are valuable because they provide insight, support decision-making and inform debate.

2. Within this context, what is the aspiration for health and care statistics? What are the features of a health and care statistics system in England that delivers on trustworthiness, quality and public value? The UK Statistics Authority's strategy for UK Statistics – *Better Statistics, Better Decisions* – provides a framework for evaluating statistics in different policy contexts.

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 – 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 – greater availability of real time data and National Statistics used with confidence
    - **Efficient** – demonstrating value for money
    - **Capable** – building capability, working collaboratively across the health and care system, exploiting and integrating sources, adding value

4. The recent work by the Authority's regulatory function points to a system of National and official statistics about health and care in England that is diverging from these core aspirations and so is not delivering its full potential. While beacons of good practice exist, a sense of missed opportunities prevails; the value of health and social care statistics currently seem to be less than the sum of the parts. The degree of insight offered for decision makers in the NHS and government can be limited, particularly given the extensive data available; and serving the wider public interest in accountability and information may not always be given high priority.

5. Over the course of the last few months, the Authority's Regulation Team has taken the opportunity to sound out some expert stakeholders about our high-level analysis of the challenges and opportunities facing health and care statistics. Our analysis has resonated with those we have engaged with, who were able to flesh out the issues and offer important additional insights. Building on this dialogue, the themes and strategic

questions they pose might be broadly summarised as follows (with further background provided in Annex 1):

The world of health and care is ever changing and the health system in England is complex, delivered by a range of institutions – health statistics need to cut across this system and keep pace with change to help decision makers and the citizen

- What can the leaders of the health and care system do to cut across organisational boundaries and set a cohesive strategic direction for statistics that keeps pace with the changing landscape, while maintaining independence and objectivity for the statistics?
- How can leaders of the health and care system promote collaborative engagement and strengthen strategic partnerships to deliver change for users and citizens?

There is a need for strong and visible statistical leadership and coordination and greater clarity of roles and responsibilities

- How can we ensure that the professionalism and objectivity of statistical outputs, which is the bedrock of trustworthiness, are maintained and enhanced?
- How best can the leaders of the health and care system promote a publicly trusted statistical voice for health and care statistics?
- Who is best placed to provide leadership in an environment of multiple organisations who produce health statistics?

The presentation of health and care statistics is incoherent, with an imbalance in the reporting of the health and care landscape: some aspects are extensively covered, and there are gaps elsewhere

- What can leaders of the health and care system do to deliver an overarching framework for health and care statistics that addresses current overlaps and gaps in coverage and explains for users how the wealth of statistics and data interconnect?

There exists an abundance of statistics, indicators, management information and data but there is a lack of insight in the statistical outputs into the issues and underlying drivers within the system

- How can we move away from health and care statistics described as ‘chaotic’ and ‘quagmire’ towards a smaller portfolio of valued National Statistics that deliver strongly communicated high level messages and an insightful narrative, supported by more timely release of datasets and management information?
- What role do the leaders of the health and care system see for statisticians at the decision making table?
- How can we create an environment in which statistical outputs provide insight into drivers and issues?
- Would it be helpful to make a clearer distinction between outputs providing a snapshot (‘flash’ estimates) with those offering fuller analysis and deeper insight?

6. Conversely, the risk of inaction might be considered. What does the future look like if these concerns are not resolved?

7. With this background, the Round Table is asked to consider the following question:

Trustworthiness, Quality and Value: how can English health and care statistics be enhanced to better serve the public good?

8. The objective is to develop a shared awareness, and to start to understand the possible barriers to, and levers for, change with a view to informing a larger 'Better Statistics, Better Decisions' summit in mid-2016 aimed at building a coalition and creating a shared commitment and momentum for action. The summit would centre on the priority themes that emerge from this Round Table.

9. This Better Statistics, Better Decisions summit would draw out the concerns, and would seek out and present ideas, opportunities, and examples of innovation and good practice. We expect much of the content of the summit to be delivered by producer bodies and users. The Authority will play a specific role in this summit by developing a set of principles for the development of health and care statistics and by helping producers to consider how they can deliver a smaller, more focused, balanced and insightful portfolio of National and official statistics.

10. Finally, the issue of consent and data privacy does not arise in this paper. This reflects the fact that it did not arise to any significant extent in our bilateral discussions. Moreover, a range of potential improvements in statistics can be secured without substantial increases in access to patient-level data. And it is of course ground that is well-trodden by others. That said, we would be happy to explore it in the Round Table should attendees think it appropriate.

3 February 2016

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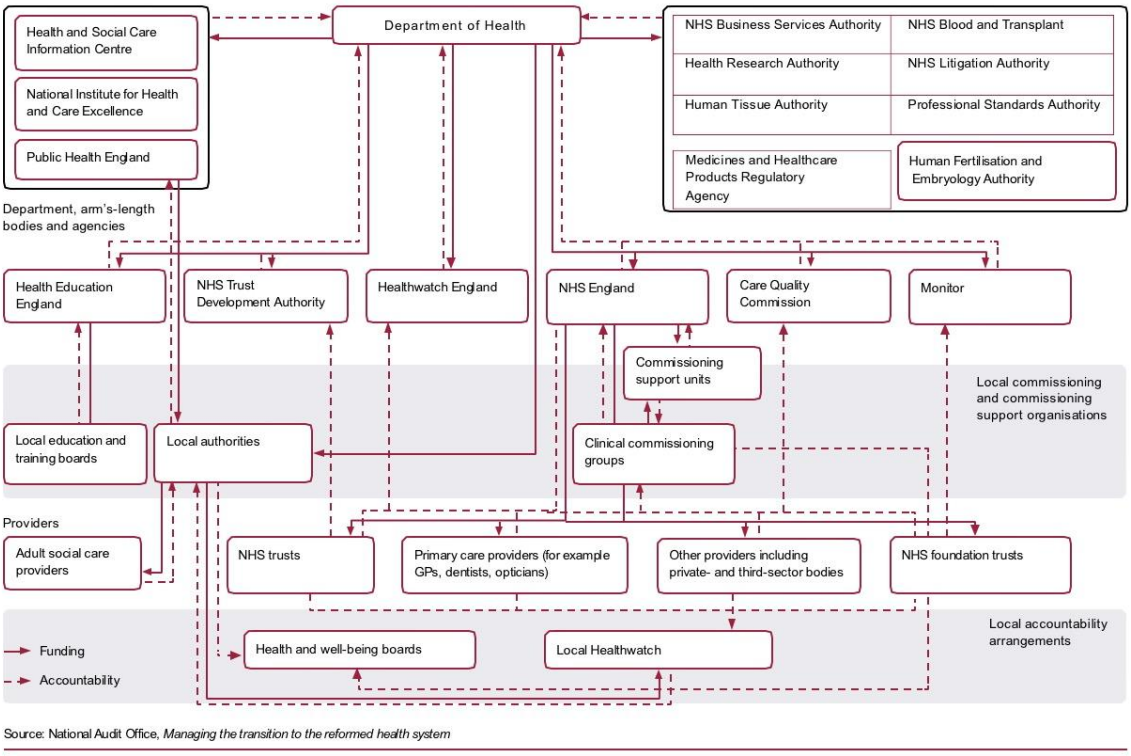
Annex 1 Concerns and Opportunities for Change – Background Information

1. The world of health and care is ever changing and the health and care system in England is complex, delivered by a range of institutions – health statistics need to cut across this system and keep pace with change to help decision makers and the citizen

The English health and care system is complex (see Figure 1) and evolving, reflecting the changing priorities and policies of successive governments and responding to different demands for services.

Figure 1: Health and Care System in England (and producers of official statistics outside the system)



Source: National Audit Office, *Managing the transition to the reformed health system*

The statistical system is similarly complex and subject to change with ten organisations producing National and Official Statistics. The Health and Social Care Information centre's (HSCIC) Strategy 2015-2020 effectively communicates the challenge for official statistics:

'…*given the numbers of different organisations involved across the health and care systems, we do not under-estimate the challenge of creating a health and social care environment that is centred on the citizen*'.

Generally, the statistical community remains compartmentalised, with little engagement between the contiguous teams and their common stakeholder and user groups. While each organisation needs to plan its own path, there is scope for greater harmonisation. The Health and Social Care Theme Group used to facilitate user engagement but it does not now involve user representatives such as the Health Statistics User Group.

This compartmentalisation means that it is hard for statistics to evolve as society's needs, and the health and care system itself, evolve. Our analysis suggests that 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. Statisticians are tentative in engaging with a broader user community, although we have started to see HSCIC embrace this important user dialogue more actively and strategically in the last year.

While good practice is inconsistent across health and care statistics in England, there are beacons of good practice. These beacons demonstrate the potential for innovation, for example:

- One characteristic underpinning the innovation process is standardisation; of processes; datasets, platforms and interfaces. In some cases, the standardisation is formal, with the mandatory adoption of industry-wide standards. In other cases, standards evolve through convention and informal adoption. Standardisation enables innovation, reduces development costs, lowers barriers to adoption, speeds up wide-scale adoption and supports an almost infinite variety of bespoke and personalised service offerings.

- By introducing new data extraction services HSCIC will minimise the administrative burden of data collection on care providers which will be more efficient for them and will help the trade off between the speed with which data can be made available and its quality and completeness when it is initially available. Expecting care providers to submit data through national data collection tools may become a thing of the past. Technology can now support routine data extraction at source from local systems, and HSCIC is already doing this for some types of data.

- Metrics for acute activity- there are excellent current metrics that measure acute activity- the problem is that they are used to judge organisations rather than whole system performance. Work has been developed in the Northwest by Association of Directors of Adult Social Services (ADASS) and Advancing Quality Alliance (AQUA) in a scorecard currently produced by the Utilisation team. It takes core data and cuts it by postcode to the boundaries of local government. In revealing the system, it helps to show the experience of the people of Wigan or Trafford: how many people go straight to residential care, how many die at home etc.

- An often cited limitation of statistics about health is the lack of comparable data about private sector providers (including procedures and services provided privately but funded by the NHS). The Private Healthcare Information Network has been collecting data on a consistent basis with the NHS since 1 January 2016 with a view to publishing first statistics in April 2017 – as this work develops, the more it can be supported by HSCIC and other producers of official statistics, the greater opportunities there will be to exploit the data to present a more complete and coherent picture for decision makers and citizens.

These beacons have in common a focus on cutting across institutional boundaries to focus on what the health and care system needs in terms of data and statistics, and then identifying the partnerships necessary to deliver change. The challenge is how to ensure that these cases are not isolated but become the norm.

2. There is a need for strong visible statistical leadership and coordination and greater clarity of roles and responsibilities

In considering any area of statistics, the Authority starts by looking for signs of trustworthiness – that statistics are produced by statistical professionals forming independent and objective judgements. This trustworthiness enhances public confidence because it provides a clear public voice, separate from managerial or policy imperatives. Clarity of voice, roles and responsibilities is therefore an essential starting point for any statistical system.

In terms of this clarity, the English health and social care system is relatively complex, and it will potentially become more complex with an increasing regional focus e.g. DevoManc. This complexity is reflected in the statistical infrastructure.

The challenge is to ensure that the presentation of health and care statistics and data are not fragmented as a result. It should be possible (and it would be desirable) to achieve coherent, insightful and accessible statistics without the need for constant reorganisation. Clarity is needed about roles and responsibilities, by producers and by users, about how each organisation adds value and how this sums to an effective statistical system for health and social care.

The National Information Board is at an embryonic stage but a positive development in respect of bringing organisations together to realise the full potential of health and care data. For National and Official statistics, there is a similar need for a strong co-ordination function to bring together the professional community to effect change. In the past the Department of Health (DH) had a Director of Statistics to provide leadership, and other functions have visible senior roles, such as Chief Economist, Chief Statistician or Data Scientist. For statistics, it is not entirely clear at present whose role it is to:

- Be a publicly trusted statistical voice for health and care statistics - for example, to avoid miscommunications around issues such as weekend deaths, cancer screening and dangerous levels of alcohol consumption.

- Provide the leadership to statistical professionals across the multiple organisations who produce health and care statistics.

- Fix data quality problems - the Authority's assessments have exposed risks due to data quality issues. In the absence of leadership, drivers for better data may be less pronounced and there is the risk that data are simply produced to feed a performance management machine. When data quality issues emerge, as they will

do on a sporadic basis (through, for example, NAO reports), they can damage public confidence.

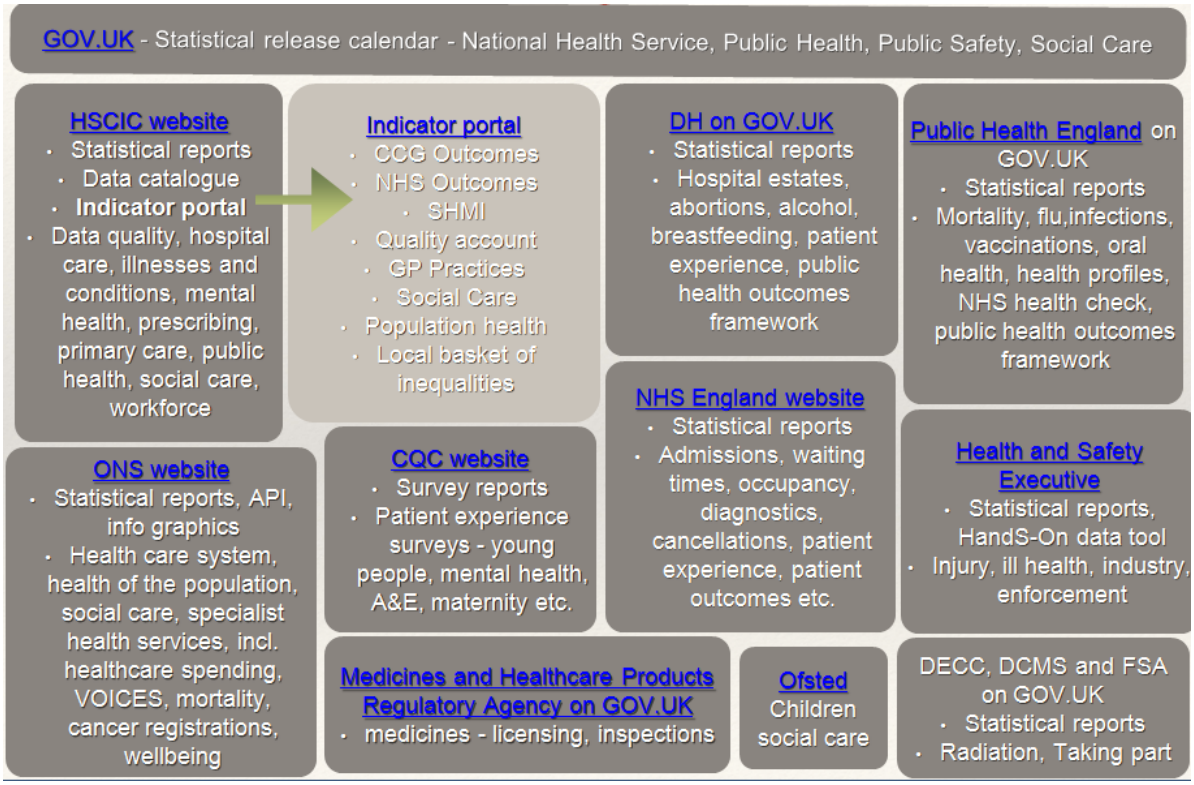
3. *The presentation of health and care statistics is incoherent, with an imbalance in the reporting of the health and care landscape*

Almost 250 sets of statistics about health and care (see Figure 3) are produced by the 10 statistical producers representing a little under 15 per cent of all National and Official statistics produced in the UK. The NHS in England generates and disseminates an unprecedented amount of data – because of this the Health Secretary has described it as 'the most open and transparent healthcare system in the world'.

The system is exceptionally rich in both administrative data, generated within the system through the course of a patient journey, and in survey data (for example, with very large surveys of primary care experience).

Over 70 per cent of National Statistics about health and care relate to demographics, health status, and illness prevention. Nearly a quarter are related to care and quality and less than five per cent to funding and efficiency. A piece-meal production approach means that health and care data can be accessed via a range of websites and portals (see Figure 2), and as well as overlaps where a number of different producers are publishing statistics on the same topic, there are gaps in important areas.

Figure 2 – Overview of official statistics published through different websites



Source: Produced by the Statistics Authority's Monitoring and Assessment team

Some examples of incoherence:

- Lack of overarching framework and typology – there is more data than ever before and so more thought is needed about how it interconnects
- There is little triangulation between administrative sources (based on the data generated within the system) and survey sources (based on direct testimony from patients themselves)
- Official statistics are often based on those things that are easiest to count such as output measures – historically based around episodic care
- Official statistics do not typically examine the relationship between inputs, processes, activities and outcomes
- There are important gaps – for example statistics about mental health are not as developed as those relating to physical health and performance frameworks do not give sufficient weighting to mental health
- There are also overlaps - for example, 5 separate HSCIC sets of official statistics on prescribing; 4 sets of seasonal influenza outputs from Public Health England (PHE), 4 producers publish 10 sets of official statistics on children and infant health
- Other gaps include a lack of coherent financial information, community services, GP services, data on independent providers, wider Patient Reported Outcome Measures (PROMs) measures, transparent statistics comparing the performance of Trusts and Clinical Commissioning Groups (CCGs), geographies that are the most helpful for decision making (often just NHS regions) - while the NHS Atlas of Variation[1] is an excellent tool, the maps are not consistently featured alongside the relevant datasets and rely on users being aware of their existence
- HSCIC indicators portal has the potential to be helpful but lacks a coherent set of national data on topics including mortality rates, length of stay, and re-admission rates

There are clear opportunities for improvement. With a wealth of data and a commitment to intelligent transparency, the English health and care system is already one of the most open and transparent in the world, and it is easier to build coherence when there is a wide range of sources than in a vacuum. Opportunities to explore include:

- Taking a top down strategic approach which looks at the infrastructure of health and care statistics as whole, and also a bottom up output based approach which requires statisticians to make clearer links between individual outputs
- From a top-down perspective, publishing an overview of available health and care statistics for users (potentially linking in with development work ONS is leading around official statistics themes) and providing guidance for users on interpreting statistics and data from various sources – this could help illustrate and help users unlock the immense latent transparency of the health and care system
- Using the overview to understand and explain where statistics complement each other and to identify where the overlaps lie and work to consider if there is scope for rationalisation, removing analytical duplication, and/or more coherent presentation e.g. joint outputs

[1] http://www.rightcare.nhs.uk/index.php/nhs-atlas/

- Understanding where the important gaps lie and deliver a strategy for addressing those gaps
- Developing clearer triangulation between survey and administrative sources to create fuller pictures of patient journeys and outcomes

4. There exists an abundance of statistics, indicators, management information and data but there is a lack of insight in the statistical outputs into the issues and underlying drivers within the system

As noted above, almost 250 sets of statistics about health and care (see Figure 3) are produced by 10 statistical producers.

While this abundance of information is welcome, it is sometimes difficult to appreciate the full extent of the insight that the latest statistics reveal from that data. For example, the Authority has heard concerns from some decision-makers that they are not getting the information they need. The Department of Health (DH) talks of a need for 'intelligent transparency'. There is work to be done to offer insight through the narrative supporting the statistics and to present statistics that deliver the accountability and trustworthiness important to decision makers and to the citizen. While the development of a range of measurement frameworks has been well-intentioned, the number of competing frameworks can diminish their usefulness, as can the constant changes to those frameworks. There are some good examples (PHE) but too many are of inconsistent quality. The Authority has heard words such as 'chaotic', 'quagmire' and 'haphazard' being used to describe the current situation.

This frustration may reflect the lack of a clear distinction between the latest snapshot data and deeper analytical work that we see in other sectors. The snapshot data on a standard cycle – weekly, monthly, annual – presents what is called in other sectors a flash estimate: the latest 'news' on what is emerging from the system, a leading indicator of emerging trends. The deeper analytical work synthesizes a range of indicators to highlight the patterns, drivers and questions thrown up by the indicators.

A concern the Authority has heard repeatedly is that statisticians are constrained to measure what they are told to by DH and NHS England because they are not present at the decision making tables when performance frameworks and indicators are designed and reviewed. Statisticians are not always involved in developing the methods to deliver the indicators and often the priorities for development are outside their control. This impact of the late involvement is potentially twofold. Firstly, the statisticians are playing a passive role in determining holistically what is needed to inform decision making and how to achieve that insight and as a result the quality and value of the statistics to decision makers and the citizen is diminished. Secondly, it creates a perception risk: that performance frameworks are perceived as lacking the independence and objectivity that comes from the strong professional input of statisticians. Even if this perception is without foundation, it damages the trustworthiness of the frameworks and the statistics based on them.

Not all data requires a statistical report. There is a case for putting out datasets in a timely manner with strong metadata. At the same time, there are cases where data needs greater explanation and interpretation. There is also cause to consider how frequently the narrative needs to be reviewed. For example, for weekly data, it may change little from week to week or conversely, it could be highly volatile and so nothing helpful can be inferred. In either

circumstance a weekly data release with a less frequent but insightful statistical narrative (National Statistics) might represent a good balance. HSCIC's Publication Strategy indicates that it is starting to review its portfolio of National and Official Statistics in this light. PHE is also considering its next generation of statistical products. NHS England has created 'super Thursday' bringing together its headline performance data on a monthly basis, including Accident and Emergency waiting times and cancer treatment times that used to be quarterly, allowing the potential for a broader judgement of overall NHS performance.

Examples where more data is not currently equating to greater insight:

- There are many attempts to aggregate health indicators in various scorecards. The NHS has a plethora of indicators of care, for example MyNHS has 36 indicators and the NHS Outcomes Framework 71 indicators. There will be: a new scorecard on CCGs, highlighting the key role of commissioners in improving the health of their local populations; a new scorecard on providers of adult social care, covering residential and nursing homes; a new scorecard on dentists; additions and updates to existing scorecards, both to reflect routine data refreshes and to add new areas, such as Improving Access to Psychological Therapies on the Mental Health Scorecard, and consultant team or unit level outcomes for the Consultant's scorecard.
- NHS Outcomes Framework – such an overarching Framework has the potential to offer great insight and to enable the government to be held to account, but the 71 indicators published in a portal are at different stages of development and the statistical reports and dashboards only analyse a snapshot of latest subset of indicators for which new data are available – HSCIC is now working towards providing an official annual position for each domain and comparisons over time.
- During last winter the NHS England Emergency Care Weekly Situation Reports reported failures to meet the 95 per cent performance target for 4 hours arrival to admission, transfer of discharge but were unable to offer insight as to the reasons, leading to frustration for officials and Ministers.
- Local Health and Wellbeing Boards are not always aware of the range of available statistics and the risk is that they rely on management information generated from within the systems they oversee. The benefit of official statistics in providing in independent view and a wider picture is lost.
- The National Information Board is tasked with examining how the NHS in England can harness the power of data and technology to transform citizens' experiences of health and care services and deliver greater quality and efficiency. It has stated that '*at present, health and care data is often fragmented, incomplete and inaccessible. Its full potential to inform what the system needs to do to deliver the Government's priorities for health and care and meet the challenges of the Five-Year Forward View cannot be realised. Neither is it fully available to researchers to help them develop new medicines and treatments to benefit citizens and patients*.'

Opportunities to explore might include:

- Reviewing the portfolio of National and Official Statistics within the context of the increasing availability of real time data and different types of management information - engage users about the rationale for focusing resources on adding

value and providing the highest quality insight through a core set of topic-based releases. The Welsh Government is exploring this approach

- Considering how the Authority can provide greater clarity about what should be National and Official Statistics while at the same time issuing standards for management information – for example, in respect of release practices, quality assurance and metadata
- Communicating high level messages more directly – for economic statistics, ONS provides a high level assessment of the current economic position through its Economic Review, which draws several sources together into a coherent overview. This might be a model for health and care statistics to adopt.
- Considering the different vehicles that can be used to deliver impactful statistics – to stimulate interest while offering harmonised messages
- Reviewing the role of dashboards as part of the story – dashboards have the scope to provide quick and easy insight about performance, experience and outcomes that can inform decisions and individual choice in an accessible way - poor choices of indicators though can also mean dashboards have the potential to mislead. MyNHS has a potentially important role to play in informing patients but the quality and relevance of the indicators and metadata is currently mixed – MyNHS indicators may be informed by different types of sources, some less reliable than others. Strengths and limitations need to be understood to inform their interpretation, and concern has been raised that there should be a focus on getting the basic methods and quality measures right rather than continually increasing the available metrics
- Considering the role that ONS takes in the future – its compendia have added value at a UK level in the past and publications such as Health Trends were generally well-received. Might ONS be able to work with other actors in the health and care system to redevelop its complementary analytical role and thereby help draw the picture together for users?
- Considering the distinction between snapshots and deeper analyses - Would a clearer demarcation between these different types of output balance the need for quick overviews of the system with the need for deeper insight?

Annex 2 People we have spoken to in the run up to the Round Table

Sir Malcolm Grant (Chair), Mark Svensson (HoP), and Lorraine Hawkins, NHS England

Dame Moira Gibb, Non-Executive Director, NHS England Board and UK Statistics Authority

Kingsley Manning (Chair), Professor Martin Severs (Interim Director of Information and Analytics), and Chris Roebuck (Acting HoP), HSCIC

Will Cavendish, Director General of Innovation, Growth and Technology, DH

Alex Kafetz, Lay member of the National Information Board

Ed Smith, Chair, Monitor

Veena Raleigh, Kings Fund

Sam Hunt, NHS Confederation

Matt James, Private Healthcare Information Network (PHIN)

Professor David Rhind CBE FRS Hon FBA

Deana Leadbeter, Chair, HSUG

Mike Hughes, Chair, RSS National Statistics Advisory Group

Roeland Beerten, Director of Policy and Public Affairs, RSS

Rachael Harker, House of Commons Library

Dr Mark Bush, Young Minds

Jennet Woolford and Jamie Jenkins, Life Events and Population Sources, ONS

Hugh Pym, Health Editor, BBC

Laura Brackwell and Will Palmer, NAO

Elaine Kelly, IFS

Anita Charlesworth, Health Foundation

Gwyn Bevan, London School of Economics and Political Science

Stephen Buckley, Head of Information and Expert Spokesperson on Mental Health, MIND

GSS Health and Social Care Theme Group