NHS Providers' submission to the Commons Public Administration and Constitutional Affairs Committee
Covid-19 – Data transparency and accountability
30 October 2020

Introduction

NHS Providers is the membership organisation for the NHS hospital, mental health, community and ambulance services that treat patients and service users in the NHS. We help those NHS trusts and foundation trusts to deliver high-quality, patient-focused care by enabling them to learn from each other, acting as their public voice and helping shape the system in which they operate. NHS Providers has all trusts in voluntary membership, collectively accounting for £87bn of annual expenditure and employing more than one million staff.

Key points

1. As the first wave of the pandemic unfolded, the need to evidence what was happening in real time was immediately clear and there has been growing pressure for more information and data relating to COVID-19 since then. Together, agencies such as Public Health England, NHS England and Improvement and the Office of National Statistics have shown a broad commitment to transparency and have significantly increased the volume and frequency of the data being published. As we enter a phase of local surges, it is imperative that the data and rationale on which the Government bases decisions around local lockdowns is clearly explained and accessible to the public and local leaders.

2. Secondary care providers are major contributors to regular data collection relating to COVID-19. However, requests for data returns from trusts should be coordinated across government agencies and arm's length bodies (ALBs) to avoid duplication. Requests must be proportionate, and key data should be published to help improve the public's understanding of the virus and its impact, including on the NHS.

3. COVID-19 has resulted in a rapid expansion of digital capability in the NHS. However, more capital investment is needed to sustain this and to improve data sharing and data interoperability between different NHS organisations and across health and care systems.

4. The pandemic has highlighted two gaps which should be addressed:

    a. The death registration and certificate process should be amended to help us better understand the impact of COVID-19 on Black, Asian and minority ethnic (BAME) groups. It is crucial we collect this information to help us better understand and help reduce health inequalities and we therefore welcome the recent recommendation from the Government's Race Disparity Unit and subsequent commitment from the Government to introduce a new mandate for ethnicity to be recorded as part of the death certification process.

    b. There must be better joined up use of data between health and social care providers to help manage patient flow and discharge processes. The Department of Health and Social Care should consider working with the social care sector to develop data returns for social care providers which go beyond the voluntary Skills for Care National Minimum Data Set for Social Care to ensure complete national coverage and accurate data. In our view, such a data set would help all stakeholders across health and care systems better understand the demand for social care provision and the interdependencies between the NHS and care homes in particular.

5. Throughout the evolution of the Test and Trace system there have been widespread concerns about the accuracy and completeness of the data. Accurate and timely data is needed to grow public confidence in the system and NHS app. There have also been concerns as to whether the national testing data is being provided to local authorities in sufficient detail to allow them to do their job 'on the ground'. Additionally, there are concerns that data from Pillar two tests (swab testing for the wider population) is not being integrated with all relevant patient health records at sufficient speed and with sufficient consistency, which means subsequent treatment is less efficient for some patients. We need the right data to get to the right point, in the required format, to the time and quality that is needed. Feedback and levels of satisfaction or dissatisfaction from both NHS clinicians, and local public health directors, would be a good measure of success here.

The NHS provider sector and the important role of data

6. The NHS continues to be a major contributor to regular data collection and analysis relating to COVID-19. The provider sector, comprising hospitals and specialist

hospitals, the ambulance service, community services and mental health services, has played a central role in helping us better understand COVID-19. To ensure that trust boards had continuous oversight of the operational picture stemming from COVID-19, trusts rapidly developed internal dashboards to track capacity, demand, supplies, staffing and testing. Examples of these high-level dashboards capture information on the following metrics:

a. patients tested for COVID-19 including results – positive, negative, pending
b. beds occupied by patients with confirmed COVID-19 (ward/location specific)
c. total beds occupied with confirmed COVID-19 patients
d. deaths of patients with confirmed COVID-19
e. staffing fill rates, staff sickness and staff self-isolating
f. personal protective equipment stock and procurement chain
g. local population data for modelling future demand.

7. Trusts are data driven in what they do and they provide a vast amount of real time reporting measures via NHS England and NHS Improvement. Much of the data trusts collate internally is fed into national data returns. This is used in daily national reporting and supports decisions taken by government. Trusts want to play a central role in the collection of data to drive evidence-based policy decisions. However, the need for data from trusts should be coordinated across government agencies to avoid duplication. Requests should also be proportionate, and the data should be published to help to improve public understanding of the virus and its impact on the NHS.

8. It is important that the government accompanies public messaging and data releases about the risk of NHS services being overwhelmed with reassurances that the NHS is open for all those who need it and that adherence to lockdown and social distancing rules will enable the NHS to cater for more patients needing different care and treatments, alongside patients with coronavirus. We know that the NHS did continue to support a range of non COVID throughout the first peak of the pandemic, sustaining most mental health and community services and meeting a peak in demand for ambulance services for example. However, it is also true that many patients and families continue to suffer disruption to their care because of the virus. Since early summer, NHS activity levels across a range of services have improved significantly and everyone is working incredibly hard to restore all non-COVID services.[1] Trust leaders are increasingly worried about the pent-up demand in the

[1] NHS Providers, Restoring Services, https://nhsproviders.org/restoring-services-nhs-activity-tracker/october-2020

community for both physical and mental health services if the public delay seeking treatment when it is needed.[2]

9. Many trusts are using their data and working collaboratively with academic institutions and other partners, leading the research in many areas such as the impact of COVID-19 on BAME communities, drug trials for COVID-19 treatments and in search of a vaccination.

Digital capability of the NHS

10. Although the NHS has made a huge jump forward in terms of its digital capability as a result of the pandemic, more investment is needed to sustain this consistently across the country. Additional investment is also critical to ensure the NHS and stakeholders can access information across the NHS. There are still a significant proportion of trusts that do not have Electronic Patient Record (EPR) systems. Data sharing and data interoperability limitations are also widespread, and often act as a barrier to more joined up working across different NHS organisations and across local health and care systems. Examples include different trusts not being able to access patient health records which can directly impact patient experience and joined up care.

11. Although the pandemic has meant that some progress is being made, we must maintain momentum to continue to ensure better use technology and data across the NHS. The NHS will require additional capital funding in the forthcoming Comprehensive Spending Review to further drive the digital agenda.

Death certificate data

12. Tracking the number and location of COVID-19 deaths has been central to improving our understanding of the virus. During the first wave there was some ambiguity around COVID-19 deaths data. The Government published the number of deaths in hospitals only, but very quickly the ONS registered deaths data set became the clear authority highlighting the total numbers of all direct and indirect COVID-19 deaths. This is a complex area which shone a spotlight on the death registration and death certificate process. The ONS acted responsively and ensured the speed at which data was published was accelerated. The ONS has published clear data on excess deaths, deaths by condition, deaths by location and has published bespoke pieces looking at

[2] NHS Providers, The State of the NHS Provider Sector 2020, https://nhsproviders.org/the-state-of-the-nhs-provider-sector-2020

COVID deaths compared to flu and pneumonia which has been helpful in putting the data into context.

13. Ethnicity or religious belief information is not currently captured on a death certificate. Many trusts and their partners in local authorities continue to work hard to identify this information from their own records and carry out local analyses to fill this data gap. If this information was captured, we would have a much fuller and accurate picture of the trends in this area, which would in turn help us to tackle health inequalities. We therefore welcome the recent recommendation from the Government's Race Disparity Unit and subsequent commitment from the Government to introduce a new mandate for ethnicity to be recorded as part of the death certification process.

Social care data

14. There must be better joined up use of data between health and social care providers to help manage patient flow and discharge processes. The fragmented and varied nature of social care provision meant that a process for local and national reporting of COVID-19 cases was delayed and difficult to implement. During this time cases in care homes rose significantly. The CQC used its regulatory powers to establish a process in response to capture data around outbreaks. The Department of Health and Social Care should consider working with the social care sector to develop data returns for social care providers beyond the voluntary Skills for Care National Minimum Data Set for Social Care to ensure complete national coverage and accurate data.[3] In our view, such a data set would help all stakeholders across health and care systems better understand the demand for social care provision and the interdependencies between the NHS and care homes in particular.

Test and trace system

15. National NHS leaders faced a difficult task in establishing the Test and Trace system from a standing start during the pandemic. Throughout its evolution, NHS Test and Trace has faced concerns about the accuracy and completeness of its data. Accurate and timely data is essential to help control the virus and grow public confidence in the system and NHS app.

16. Earlier in the pandemic the government's focus was on delivering a national figure for daily testing, obscuring variable performance and capacity across the country and

[3] Skills for Care, National Minimum Dataset for Social Care (NMDS-SC), https://data.gov.uk/dataset/9cd42409-1a44-4e6c-9696-29d6a760e746/national-minimum-dataset-for-social-care-nmds-sc

problems with the implementation of a broader system that provided the ability for NHS trusts to get regular, consistent, access to tests for all their patients and staff within the turnaround times they needed. We acknowledge that the government target of 100,000 tests by 30 April had a galvanising effect on building testing capacity, but there was a need for a more sophisticated and long-term view.[4]

17. A lot of effort has gone in to developing the regularly published NHS Test and Trace data, working with stakeholders including the Office for National Statistics (ONS). Thanks to this work, we are well past the legitimate debate that surrounded the veracity and accuracy of the statistics on whether the government met its various capacity targets or not. But, in our view, wider measurements of success and regular reports against NHS Test and Trace's end July business plan are now needed.

18. There have been longstanding concerns that the national testing data is not being provided to local authorities in sufficient detail to allow them to do their job 'on the ground'. Additionally, there are concerns that data from Pillar two tests (swab testing for the wider population) is not getting into all relevant patient health records at sufficient speed and with sufficient consistency, which means subsequent treatment is less efficient for some patients. We need the right data to get to the right point, in the required format, to the time and quality that is needed. Feedback and levels of satisfaction or dissatisfaction from both NHS clinicians, and local public health directors, would be a good measure of success here.

[4] NHS Providers, We need an updated testing strategy, https://nhsproviders.org/news-blogs/blogs/we-need-an-updated-testing-strategy