



# USING DATA TO TRANSFORM MODELS OF CARE

**Johnny Skillicorn-Aston and Jeremy Hooper** explain why citizens are central to the data-driven transformation of healthcare

The NHS and other public services have a chequered history of using data in innovative ways. Now, more than ever before, we need to unlock the potential of data to drive new models of care. Where data-driven approaches have been successfully implemented, it has brought benefits to service users, public service professionals, and provider systems.

Perhaps the most critical example of the use of data for the common good is the NHS Test and Trace programme, a service intended to control the spread of COVID-19 by coordinating testing, isolation, and contact tracing for those exposed to coronavirus.<sup>1</sup>

Although questions persist about the design, implementation, and cost of the programme,<sup>2,3</sup> if we can get it right when capturing, sharing, and applying data to good effect during a pandemic, we can adapt this approach for use elsewhere.

In addition to specific concerns about the performance of Test and Trace, the programme has been criticised for the same issues at the heart of other data-driven transformations in public services—data sharing, information governance, security, and the involvement of private companies.

## About the authors

**Johnny Skillicorn-Aston (pictured)**

*Director of Engagement and Communications, Conclusio Limited*

**Jeremy Hooper**

*Health Analyst, Conclusio Limited*

[www.conclusio.org.uk](http://www.conclusio.org.uk)

 [@conclusioglobal](https://twitter.com/conclusioglobal)

Despite this, there have been good rates of uptake of health apps within the NHS App Library, such as the ‘Couch to 5K’ app, demonstrating that how patients engage with the health service is changing.<sup>4,5</sup>

There is a broader issue here about how we use data for the common good. We try to use data to give us answers, but data should be used to raise questions. Data available across the NHS give us an idea of general trends, and we should be using this information to ask what is happening in our populations.

## REALISING THE POTENTIAL OF DATA

In the context of integrated care, we should be combining intelligence from all available sources, not only to break

down the silos of primary, secondary, tertiary, and social care, but also to include local authority data. This is particularly relevant in the case of the wider determinants of health.

Engaging the citizen is paramount when it comes to data. How do people want to engage with the issue? What do they care about when it comes to sharing, storage, or use of their data? It could be argued that a common desire among patients is that their data are used for the common good—to minimise the burden of illness and disease. However, patients may also wish for minimal monitoring of their health, sufficient to manage their wellbeing with maximum effect and minimum intrusion—a silent ‘personal health assistant’, ensuring that regimes are followed, medicines adhered

to, appointments kept, experience reported on, and outcomes assured.

For citizens to be central to a ‘data revolution’, it is helpful to remember that a significant amount of data relates to studies or clinical trials, and is not gathered by the patient. Data that capture the lived experience of patients are vital; these data raise questions and aid further discovery. Empowering the patient by making data-driven innovation more patient-centred will help to challenge negative perceptions around the collection and use of data.

The development of practical approaches to how data sets are built, interrogated, and federated, including enrichment to overcome the limitations of primary and secondary data, is important. This is something that is in its infancy in the UK and will be challenging to achieve. However, communicating how real-time data sets will be connected, how genomic and healthcare data will be handled, and how this information will be aggregated will help people to understand how, through their data, they can participate in a common enterprise to reduce the burden of disease.

## DATA AND THE COVID-19 PANDEMIC

### Test and Trace

The data at the heart of the Test and Trace programme provide an opportunity to use the insights they afford to drive positive action. However, at present, faltering public confidence in the service may reflect a narrowing public outlook on what protecting public services means. Establishing that meaning requires all stakeholders in public health dynamics to find consensus on what we are protecting.

### Vulnerable patients

One constant throughout the many phases of the pandemic has been the need to protect the most clinically vulnerable members of society. This continues to be manifested in the way citizens interact with local services,



**App uptake shows that the way patients are accessing healthcare is changing**

where overnight change can be common. Although change is always difficult, some of the adopted changes are demonstrably beneficial and beg the question: why has it taken until now?

Patients identified as clinically extremely vulnerable to COVID-19 were instructed to ‘shield’ from April to August 2020 as part of the initial response to the pandemic. Advised to socially distance from their families and remain in their own homes as much as possible, this was a big ask for these patients.<sup>6,7</sup> When surveyed by the Office for National Statistics (ONS), around a third of respondents from the shielding population said that the amount of care that they were receiving had decreased (see Figure 1).<sup>8</sup>

Towards the end of the shielding process, members of the shielding population were beginning to experience deterioration of their condition, with half of the patients surveyed indicating that they were no longer accessing some aspect of their care and that their mental health had worsened (see Figure 2).<sup>9</sup> This added to the burden on primary care: although the demand on primary care has not reverted to pre-COVID levels, the complexity of patients with chronic

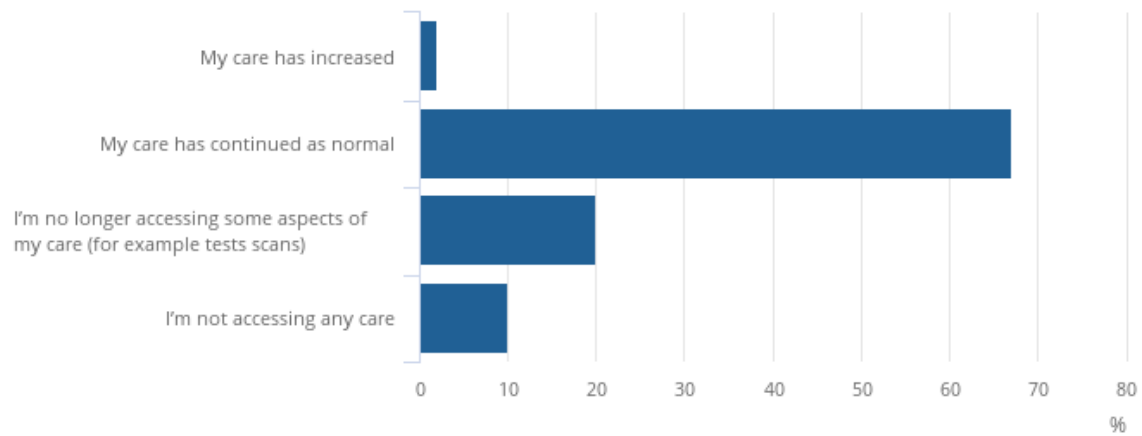
conditions requiring treatment in the community during the pandemic has resulted in an increased workload.<sup>10</sup>

However, after shielding started, primary care and local councils adapted the way that they delivered care to these patients as a result of the ONS data. Regular telephone calls from the GP to check all was going well became the norm.<sup>11</sup> In addition, local authorities established ‘vulnerability hubs’ that enabled these patients to get additional support,<sup>12</sup> whether in the form of food parcels or just a telephone call if they were feeling isolated. When a patient tested positive for COVID-19, the vulnerability hub would contact them to check if any additional support was required. This integrated response should not be lost as the pandemic winds down—it must be used to inform future models of care for patients who are vulnerable.

## APPLYING LEARNINGS FROM THE PANDEMIC

In future, the SARS-CoV-2 virus that causes COVID-19 may be of no greater concern than the flu virus. However, patients with complex conditions, particularly people with

**Figure 1: ONS Shielding Behavioural Survey—changes in access to care reported by the shielding population<sup>8</sup>**



Percentage of clinically extremely vulnerable by change in their GP or hospital care, England, 28 May to 3 June 2020.

Office for National Statistics. *Coronavirus and shielding of clinically extremely vulnerable people in England: 28 May to 3 June 2020*. [www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/28mayto3june2020](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/28mayto3june2020)

Contains public sector information licensed under the Open Government Licence v3.0.

impaired pulmonary function or immunocompromised individuals, will still require protection from transmissible infections that put them at risk. Our health estate, while a place of treatment, can also be a place of transmission.

### Case study: multiple sclerosis

An example of this risk can be found in how patients living with multiple sclerosis (MS) are managed in the NHS. Patients with the highly active form of MS are asked to attend hospital on a regular basis to receive infusions, but immunocompromise secondary to certain disease-modifying drugs places some patients with MS at increased risk of infection.<sup>13</sup> Other than advice to shield, no specific guidance has been issued on the management of MS during the COVID-19 pandemic.

However, care can be delivered to these patients just as effectively at home, either in tablet form or through the delivery of transfusions by community teams. This would provide better outcomes for patients with MS and their families, and release capacity in acute hospitals to enable them to

focus on patients with the greatest need. Alongside the support offered by local authorities and primary care, this approach may allow the health system to make inroads into tackling the backlog of patients awaiting treatment, be more cost-effective, and drive improvements in care.

The approach will require underpinning with firm data reporting and, in terms of patients, self-reporting of data on their own service utilisation, adherence to treatment regimens, and experiences. Patient-initiated contributions to the process of capturing and recording data will be an essential component of improving care planning and delivery.

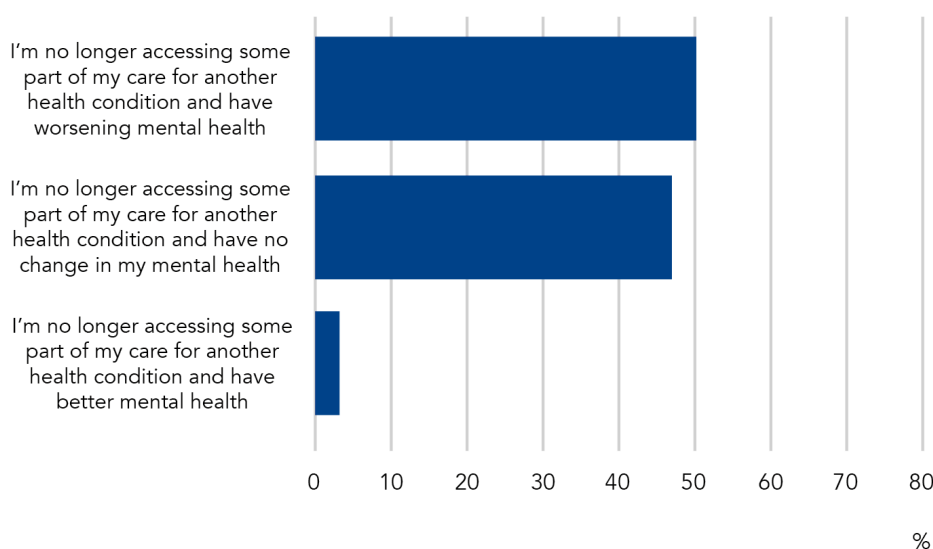
### A long-term partnership approach

There are many complex conditions that can be managed in this way: home-based administration of medicines is possible for patients with cystic fibrosis, myoclonic astatic epilepsy, and cancer, to name but a few examples. Developing a community-based workforce to deliver effective care—supported by technology and under the direction of a consultant—has the potential to reduce the risk of infection and will allow

patients to ‘normalise’ their lifestyle, increase capacity for patient care, and deliver better patient outcomes. The ‘every contact counts’ mantra is just as important in the digital realm: each interaction creates data that, when harvested and evaluated, can shape existing or new technologies in ways that allow improved care to flourish.

To make this a success requires partnership working between the pharmaceutical industry and emerging Integrated Care Systems to examine longer-term investment appraisal models, as outlined in the HM Treasury *Green Book*,<sup>14</sup> rather than simplistic single-year, single-patient costing models. The current approach does not take into account the longer-term benefits of reduced treatment or care needs, but instead tries to deliver artificial in-year savings. A long-term partnership approach, incentivised to reduce broader fixed costs over a number of years rather than short-term, in-year revenue savings, will give industry a better understanding of need, and enable the development of pathways sustainable in the long term that deliver better, cost-effective patient outcomes.

**Figure 2: ONS Shielding Behavioural Survey—mental health changes reported by members of the shielding population who were no longer accessing some aspect of their care<sup>9</sup>**



Percentage of clinically extremely vulnerable people by change in mental health, underlying health condition, and level of GP or hospital care they are receiving, England, 9 to 18 June 2020.

Adapted from: Office for National Statistics. *Coronavirus and shielding of clinically extremely vulnerable people in England: 9 June to 18 June 2020*. [www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/9juneto18june2020](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/9juneto18june2020)

Contains public sector information licensed under the Open Government Licence v3.0.

## THE FUTURE

Going forward, pharmaceutical companies must adapt their approach to budget impact modelling to reflect the new 5-year commissioning cycle within the NHS.<sup>15</sup> They will also likely need to move away from simple acquisition cost savings to include wider information around community-based care, patient outcomes, and capacity-releasing benefits. Companies must be encouraged to work in partnership with the NHS to deliver value and ensure equity in outcomes for all patients as part of corporate social responsibility. The key to achieving this will be a willingness to engage patients on the issue of their data and its potential to make a difference. **SM**

## REFERENCES

- DHSC. *NHS Test and Trace: how it works*. [www.gov.uk/guidance/nhs-test-and-trace-how-it-works](http://www.gov.uk/guidance/nhs-test-and-trace-how-it-works) (accessed 14 January 2021).
- McKee M. *Martin McKee: "NHS" Test and Trace under fire—a system flawed by design*. [blogs.bmj.com/bmj/2020/12/11/martin-mckee-nhs-test-and-trace-under-fire-a-system-flawed-by-design/](https://blogs.bmj.com/bmj/2020/12/11/martin-mckee-nhs-test-and-trace-under-fire-a-system-flawed-by-design/) (accessed 14 January 2021).
- National Audit Office. *The government's approach to test and trace in England – interim report*. London: NAO, 2020. Available at: [www.nao.org.uk/wp-content/uploads/2020/12/The-governments-approach-to-test-and-trace-in-England-interim-report.pdf](http://www.nao.org.uk/wp-content/uploads/2020/12/The-governments-approach-to-test-and-trace-in-England-interim-report.pdf)
- NHS. *NHS Apps Library*. [www.nhs.uk/apps-library/](http://www.nhs.uk/apps-library/) (accessed 14 January 2021).
- NHS Digital. *NHS Apps Library reaches 70 apps in honour of the NHS birthday*. [digital.nhs.uk/news-and-events/latest-news/nhs-apps-library-reaches-70-apps-in-honour-of-the-nhs-birthday](https://digital.nhs.uk/news-and-events/latest-news/nhs-apps-library-reaches-70-apps-in-honour-of-the-nhs-birthday) (accessed 14 January 2021).
- British Foreign Policy Group. *COVID-19 timeline*. [bfpgrp.co.uk/2020/04/covid-19-timeline/](https://bfpgrp.co.uk/2020/04/covid-19-timeline/) (accessed 14 January 2021).
- NHS. *Advice for people at high risk from coronavirus (shielding)*. [www.nhs.uk/conditions/coronavirus-covid-19/people-at-high-risk/advice-for-people-at-high-risk/](https://www.nhs.uk/conditions/coronavirus-covid-19/people-at-high-risk/advice-for-people-at-high-risk/) (accessed 14 January 2021).
- DHSC, Public Health England. *Guidance on shielding and protecting people who are clinically extremely vulnerable from COVID-19*. [www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19](http://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19) (accessed 14 January 2021).
- Office for National Statistics. *Coronavirus and shielding of clinically extremely vulnerable people in England: 28 May to 3 June 2020*. [www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/28mayto3june2020](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/28mayto3june2020) (accessed 14 January 2021).
- Office for National Statistics. *Coronavirus and shielding of clinically extremely vulnerable people in England: 9 June to 18 June 2020*. [www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/9juneto18june2020](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/9juneto18june2020) (accessed 14 January 2021).
- Park S, Elliot J, Berlin A et al. Strengthening the UK primary care response to covid-19. *BMJ* 2020; **370**: m3691.
- NHS Digital. *Shielded patients list: guidance for general practice*. [digital.nhs.uk/coronavirus/shielded-patient-list/guidance-for-general-practice](https://digital.nhs.uk/coronavirus/shielded-patient-list/guidance-for-general-practice) (accessed 14 January 2021).
- Local Government Association. *Protecting vulnerable people during the COVID-19 outbreak*. [www.local.gov.uk/protecting-vulnerable-people-during-covid-19-outbreak](http://www.local.gov.uk/protecting-vulnerable-people-during-covid-19-outbreak) (accessed 14 January 2021).
- Multiple Sclerosis Trust. *Coronavirus, Covid-19 and multiple sclerosis*. [mstrust.org.uk/a-z/coronavirus-covid-19-and-multiple-sclerosis](https://mstrust.org.uk/a-z/coronavirus-covid-19-and-multiple-sclerosis) (accessed 14 January 2021).
- HM Treasury. *The green book (2020)*. London: HM Treasury, 2020. Available at: [www.gov.uk/government/publications/the-green-book-appraisal-and-evaluation-in-central-government](http://www.gov.uk/government/publications/the-green-book-appraisal-and-evaluation-in-central-government)