

NHS Digital data sharing and access review: update

Background

The [Code of Practice for Statistics](#) promotes an organisational commitment to fulfil the potential of available data. Statistics producers can promote this principle by enabling safe onwards access to the microdata used in official statistics production. We have been working with health data users and NHS Digital to help identify ways to address concerns raised with us about data access.

This update sets out our current assessment of data access provision at NHS Digital and outlines the areas where we will continue to support users and NHS Digital to help fulfil the potential of data for the public good.

Coronavirus impact

NHS Digital's statistics production and data access teams are under considerable additional pressure at the moment supporting NHS England's response to coronavirus. New powers have been granted so that NHS Digital can ensure data are being used effectively to tackle the pandemic. This work is clearly their priority now and we appreciate that the suggested actions below will not be progressed until the organisation has returned to business as usual. Applications for data unrelated to the pandemic will inevitably now take longer to process. We hope that researchers will be understanding of these additional demands and welcome the steps that NHS Digital, and other data providers, are taking to keep users informed about the likely impact on their work.

User engagement

We noted last year that NHS Digital's [Data Access Request Service](#) (DARS) is clearly committed to seeing data being used more effectively to provide important insights about the population's health.

However, it remains the case that some users had continued to raise concerns with us about their experience of accessing data via DARS. Improved communication is one solution to this. Direct and ongoing engagement with users will also help to raise confidence among the research community that DARS understands their needs.

Health Survey for England data access

Since our last update, our work in this area has focused on population survey data access arrangements, reflecting NHS Digital's decision to provide access to the data from the surveys it commissions via DARS rather than solely via the [UK Data Service](#) (a data provider to researchers, students and teachers funded by the Economic and Social Research Council). We convened a workshop in October 2019 with academic users of the [Health Survey for England](#) (HSE) data and NHS Digital (from DARS and the population health survey team) to help raise

awareness of each other's needs and concerns about data access. We have published a report of that workshop alongside this update today.

A Working Group was formed after our workshop to identify access arrangements that will meet different user needs and ensure appropriate safeguarding of the data. In light of their current additional demands, NHS Digital is reviewing whether to continue depositing a reduced HSE dataset with the UK Data Service under End User Licence for another year. Users will be informed when a decision has been made. The Working Group will continue to explore options for future data and we will work with users and your team as this work progresses.

Mental health survey data access

Alongside our work with data users we have also been conducting a systemic review of mental health statistics in England. The report from that work will be published shortly. Many of the users we have spoken to raised concerns about mental health data access, in particular in relation to the Adult Psychiatric Morbidity Survey (APMS) and Mental Health of Children and Young People Survey (MHCYPS). There has been a dramatic decline in use of the APMS data since DARS became responsible for its distribution. Figures cited in a [Lancet Psychiatry editorial](#) show that the most recent survey, conducted in 2014, which is available via DARS had been accessed by 22 unique users as of August 2019, whereas its 2007 predecessor, which is still available via UKDS, had 288 new downloads between 2016 and 2019. Plans are in place to redesign the application form to reduce some of the burden on applicants and help address this decline in use. Understandably, this work will be delayed while the DARS prioritises pandemic work. When this work resumes, in our view this activity would benefit from much closer engagement with the research community and more proactive communication about what steps are being taken to improve access.

The official statistics based on the MHCYPS were released in [November 2018](#) but the data has not yet been made available to researchers. We have raised our concerns about this lack of timeliness with NHS Digital, highlighting that it does not align with the principles in the Code of Practice. We understand that work is underway with Information Governance colleagues to resolve this situation and we look forward to seeing this communicated to users as soon as a solution is agreed and can be actioned. We will monitor progress on MHCYPS and APMS data access as part of our mental health systemic review follow-up actions.

Positive developments

There are positive developments to note. We welcome the [work](#) underway, funded ADR UK, to link NHS Digital and Department for Education data to create a new research data resource to help understand more about children's school attainment and their health. The data will be available for researchers to access securely via the ONS Secure Research Service, subject to appropriate approvals being granted (and the service being available again for users to access). This innovative work highlights the unique contribution that data linkage can make to answering important questions for society.

NHS Digital is also supporting [HDR UK's](#) creation of a [Health Data Research Innovation Gateway](#) that will bring together all of England's health data sources and establish a single application pathway for all the different approvals that need to be sought to use health data. Allied to this, HDR UK is also supporting work to improve data quality, its documentation and metadata. These developments will help transform users' ability to maximise the value of health data. However, they will obviously take time to be developed. It will be important to ensure that users' experience of accessing health data via DARS continues to be improved in the meantime.

Next steps

We have written new regulatory guidance to increase awareness among statistics producers and users that the Code of Practice's principles extend to data sharing and access. The guidance outlines what kinds of practices and processes would uphold the principles set out in the Code of Practice. When NHS Digital and other statistics producers who provide data have returned to business as normal after the coronavirus pandemic, we will use the principles set out in the guidance to frame our ongoing engagement with them.