

NHS Digital data sharing and access review: initial conclusions and scope for further review

Executive summary

- This report sets out the initial conclusions from the Office for Statistics Regulation's (OSR) Review of NHS Digital's data sharing and access processes, and the areas that will now be subject to further review.
- Enabling users to access data is one of the key ways that statistics producers can meet the Code of Practice for Statistics' expectations to fulfil the potential of the data they hold.
- The areas we will be focusing on have been identified following conversations with users of English health data about their experiences of accessing data from NHS Digital.
- We have identified some actions that OSR and NHS Digital can take now to address user concerns without needing further exploration.
- The main objective of the next stage of the Review is to identify ways to ensure that the full potential of NHS Digital's data can be realised. It will address two areas:
 - **How can users with innovative or complicated proposals be supported to access health data in England?**
 - **How can data users and NHS Digital work together to improve data quality and documentation?**

Background

In 2017, the Office for Statistics Regulation launched an investigation of the UK statistics system's ability to provide greater insight to users via data linkage. We are the independent regulators of the UK's official statistics system and our interest in this area is underpinned by the Code of Practice for Statistics' three pillars of trustworthiness, quality and value:

- Statistics add **value** when they answer society's questions. Many questions cannot be answered without sharing and linking data. As a result, a greater willingness and ability to share and link data is an essential prerequisite for improved official statistics.
- Without a focus on the **quality** of the data – their source, how they have been collected and processed, any biases and incompleteness in the data – the results could be misleading.
- Custodians of public data must demonstrate their **trustworthiness** by safeguarding data robustly during and after the sharing and linkage process, and by being open to public scrutiny. Organisational trustworthiness is at the core of OSR's work and is a key component of the first pillar in the Code of Practice.

The report of the review, [Joining up Data for Better Statistics](#), was published in September 2018. It included a commitment to scope the terms of an independent review of NHS Digital's health data sharing and access processes:

“With the launch of the [national data opt-out](#) programme in May 2018, the new Data Protection Act to implement GDPR, and NHS Digital's recent reforms to DARS, now would be a good time to take stock of user experiences and the wider terms under which NHS Digital's decisions are made, to help inform the direction of any future developments.” (p26)

This proposal was prompted by data users in universities, independent research institutes and government departments reporting difficulties accessing health data in England held by NHS Digital. Their experiences related to access for data linkage projects as well as requests for single data sources, which they reported becoming particularly difficult since 2014. This was in large part caused by new data access processes introduced in response to the [Partridge Review](#) of data releases by NHS Digital's predecessor body (the NHS Information Centre). It is important to acknowledge that the Partridge Review uncovered unacceptable practices that certainly warranted the introduction of a more robust approach to data safeguarding. However, it is also the case that valuable data resources have been diminished following changes to the health data access environment in England. For example, since the 1990s, people who participate in the [Health Survey for England](#) have been routinely asked to give consent for their survey data to be linked with mortality data, hospital records and cancer registry. This linkage supports analyses of the association between health and other life circumstances and outcomes of huge importance to policy makers and, more importantly, the public: the timing and cause of people's death, their use of hospital services, and their risk of developing cancer. Prior to 2014 these linked records were updated annually, but there has not been an update since 2014.

To help us identify the scope of the Data Access Review, we re-contacted some of the people we spoke to previously to find out what, if anything, has changed since then. We also met with key staff at NHS Digital, research funding bodies, and other data users with an interest in this issue. The issues identified in these conversations and our proposals for taking them forward are outlined below.

What is the Office for Statistics Regulations' remit for data access?

Our interest in data access is underpinned by the [Code of Practice for Statistics'](#) expectations of statistics producers to fulfil the potential of available data to serve the public good. Statistics producers should support users to access their data, providing there are appropriate and robust processes to safeguard data and scrutinise proposed

uses. This is one of the key ways that statistics producers can provide value to society via the data they hold.

Review objective

The Review's overarching objective is to identify ways to ensure that the full potential of NHS Digital's data can be realised.

Review scope

The issues raised with us as we scoped the terms of the Review covered six broad areas:

- 1) NHS Digital's communication of ongoing changes to their systems.
- 2) Escalation, appeal processes and redress.
- 3) Resources.
- 4) Streamlining access processes for existing users.
- 5) The need to improve data quality and documentation.
- 6) Handling complex proposals.

The next stage of the Review will focus on the final two areas - data quality and complex proposals. They represent the most challenging aspects raised and do not have immediate solutions. Based on our conversations with NHS Digital, many of the other issues raised with us can be addressed by actions that OSR and NHS Digital can take now that do not require further exploration. These actions, and our recommendations for NHS Digital, are detailed in the annex to this report.

Review question one: how can users with innovative or complicated proposals be supported to access health data in England?

NHS Digital currently receives over 1,000 applications for data a year. The most recently available [published estimates](#) (up to May 2018) showed that median turnaround time was around 50 days, but with some notable outliers with longer times. The volume of applications has increased markedly in recent years (doubling between 2016 and 2017). So far, turnaround speed does not appear to have been affected.

However, most of the examples of issues people raised with us related to data requests that do not fit this pattern. Some of which had innovative or complicated aspects that meant a data request could not be submitted because the legal basis for conducting the work could not easily be established, or involved a very lengthy approvals process.

NHS Digital has a structure in place to support users navigate the application process once their request has been submitted, and there is some scope for users to speak to case officers while they prepare their application. However, there is no mechanism at

present to support the development of more challenging or innovative proposals. This particularly affects projects seeking to link data from multiple sources, including non-NHS data, where the complex legislative framework governing English health data access (over which NHS Digital has no control) needs to be navigated before data can be applied for. Proposals for UK-wide studies are similarly challenging, given the different legal frameworks for data access in each country. Proposals for broad ranging analyses spanning multiple topics using the same dataset also present challenges for data providers. A careful balance needs to be struck between supporting valuable research and fulfilling important duties to ensure data requests are proportionate and specific research questions are given appropriate scrutiny.

We will work with interested parties to identify solutions that will enable more projects with innovative or complicated characteristics to be conducted. As part of this work we will build-on (and extend, if necessary) existing work to map out the legal frameworks that operate in each UK country to help users better understand the landscape.

Review question two: how can data users and NHS Digital work together to improve data quality and documentation?

Gaining access to data is the fundamental requirement for realising its potential. However, poor quality data, metadata and documentation are also major barriers that hinder users' ability to maximise the value of their analyses. For this reason, quality is one of the Code of Practice's three pillars.

Data quality encompasses multiple aspects, starting with how systems have been designed to capture it at source, through to the documentation available to end users describing the properties of the data. Significant work is currently underway at NHS Digital to reform and improve data quality across the NHS as part of a wider move to increase the use of digital technology and data to improve health care and outcomes in England. However, users told us about the time-consuming data cleaning that they often need to undertake before the data they have received can be used, and of resources they have developed themselves to assist in that process. We believe there would be value in users and NHS Digital working together to identify ways to enhance the source data and improve its documentation. We will use this part of the Review to identify potential ways to facilitate this process, including exploring the feasibility of external funding sources to support data enhancement.

Review timelines and outputs

- Meetings with key stakeholders: April-June 2019
- Progress update and provisional recommendations: July 2019
- Final report: no later than September 2019

Annex – Actions for OSR and recommendations for NHS Digital that need no further investigation

NHS Digital’s communication of ongoing changes to their systems.	
<p>Details</p>	<p>NHS Digital’s Data Access Request Service (DARS) was established in 2016. Their processes continue to evolve and more support for users is being rolled-out. The Research Advisory Group (RAG) that supports DARS has two sub-groups looking to improve the application process and support research. One is focusing on streamlining approvals and the other on data and service innovations. Some examples of recent or planned changes include:</p> <ul style="list-style-type: none"> • More resource has been provided to support users navigate the system, including dedicated case officers for specific institutional users to enable expertise and relationships to develop. • User roadshows, supported by the Medical Research Council, are happening across the UK. • A faster process has been introduced for data access requests deemed low risk that avoids the need for the Independent Group Advising on the Release of Data (IGARD) to review every application. The long-term aim is for IGARD to review only a minority of applications and for the majority to be approved based on precedent. • There are plans to introduce a secure Data Access Environment (a virtual safe setting). This will reduce the need for data to be transferred to users’ own systems, and will help users in organisations with systems that do not meet the necessary information security standards. • Access to the data relating to NHS Digital’s commissioned surveys that are held in the UK Data Archive will in future require a DARS application. The transfer of the data from the Archive to NHS Digital is being considered as well. • A number of registries held by other organisations are also being moved into NHS Digital, reducing the number of organisation that users need to approach to access data. <p>Many of these developments are positive for users, but some, particularly relating to survey data access, have raised concerns among the very active health research community. Their worries include a reduction in data-use, prompted by what happened when the Adult Psychiatric Morbidity Survey moved to this new model.</p>

	<p>Key stakeholders certainly recognise the positive changes that NHS Digital has made, and their commitment to making the data access process less frustrating. However, awareness of these developments is not universal, so some users' attitudes to NHS Digital as a data provider continue to be shaped by their previous less positive experiences. The changes introduced so far have yet to provide a solution to the halted Health Survey for England data linkage issues outlined in this report.</p>
Next steps for OSR	<ul style="list-style-type: none"> • Regular scheduled meetings with senior staff in DARS to become part of OSR's core health and social care domain work. These meetings will give NHS Digital an opportunity to share details of progress on current reforms, further planned changes, and any other relevant issues. OSR will share concerns raised by users.
Recommendations for NHS Digital	<ul style="list-style-type: none"> • Consider using the main DARS webpage to highlight recent innovations and planned changes to access processes (some of which is set out in the RAG pages). This would reinforce the message that NHS Digital is committed to improving user experiences. • Engage directly with the Health Statistics User Group and the UK Data Service's health studies users about planned changes to access arrangements. • Work closely and proactively with the ONS Secure Research Service, and other secure data providers, to share experiences and learning about developing secure data access environments.

Escalation, appeal processes and redress.	
Details	<p>Users who felt that their applications had not been handled correctly, or who were unhappy with the outcome, reported that there were no opportunities to raise this with NHS Digital. NHS Digital had already begun to introduce an appeal process when we raised this with them in late 2018, its details have yet to be published. Escalation processes also exist, but they are not well known.</p>
Next steps for OSR	<ul style="list-style-type: none"> • Signpost users to escalation channels and the new appeal procedures when they are live. • Monitor how the system is working via conversations with users and in the OSR-DARS meetings.
Recommendations for NHS Digital	<ul style="list-style-type: none"> • Communicate with users about escalation channels and the new appeals process and add details to the DARS website.

Streamlining access processes for existing users.	
Details	<p>Most of the people we spoke to are long-term heavy users of English health data who feel they can demonstrate a strong record of being safe and therefore trusted data users. They feel that the application process should do more to recognise the status of trusted users. NHS Digital recognises that a lot of information is known about existing users and is adapting its application processes to make better use of that. Health data users in government departments voiced particular concerns about the lack of a process to recognise their particular user needs. As noted above, work is underway to streamline processes, which will benefit all users, but awareness of this activity is low.</p>
Recommendations for NHS Digital	<ul style="list-style-type: none"> • Communicate more effectively with users about any new processes introduced that will help streamline applications. • Continue to invite feedback from users and NHS Digital case officers about additional ways to streamline processes, harnessing technology to support this wherever possible.
Next steps for OSR	<ul style="list-style-type: none"> • Active monitoring via regular OSR-DARS meetings. • Address the access issues raised by government departments in the innovative or complicated proposals strand of the Review.

Resources and charges	
Details	<p>Users provided examples of access requests that they believed had progressed slowly due to resource constraints at NHS Digital. They also raised concerns about the potential impact of NHS Digital's restructuring programme on data access and supply, both in terms of overall staff numbers and turnover of key people.</p> <p>In common with NHS data providers elsewhere in the UK, NHS Digital charges for data access on a cost recovery basis. Organisations supporting health research therefore spend significant sums each year on data access, in many cases funded via charitable donations from the public. Some feel these charges aren't proportionate. NHS Digital's charging policy for 2019 is changing to align its costs more closely with the time that tasks take.</p>

	<p>Different funding models exist for the data held by providers such as the UK Data Archive or ONS Secure Research Service (SRS) who do not charge non-commercial users for data access. The new Administrative Data Research Partnership will increase the amount of research data available via the ONS SRS. This has heightened user concern about the costs of analysing health data which is not held in the SRS.</p>
<p>Next steps for OSR</p>	<ul style="list-style-type: none"> • Ensure that proposals from the Review are affordable for NHS Digital, given the current funding environment. • Initiate discussions with the Office for Life Sciences about the wider landscape of charges for access to research data, and with UKRI about funding for data access.
<p>Next steps for NHS Digital</p>	<ul style="list-style-type: none"> • Communicate effectively with users about changes to the charging policy. • Monitor the impact of the new policy on users' costs to identify users who are disproportionately affected.