Written evidence submitted by NHS Digital (DHS0041)

Summary

The below evidence submission has been prepared to support the Health and Social Care Committee's Independent Expert Panel in their evaluation work to support the ongoing digital transformation in the NHS inquiry.

Owing to the crossover in remits between organisations and the upcoming merger of the NHS ALBs, NHS Digital has supported the preparation of evidence submitted by the Department of Health and Social Care (DHSC). Where appropriate, we have also received contributions from the Department for our submission. As an organisation responsible for the delivery of policy, this response focuses on progress made towards targets and does not make comment on policy. This commentary will be provided by the Departmental submission.

About NHS Digital

NHS Digital (NHSD) is the national digital and technology delivery partner for the NHS and social care system. Our teams design, develop and operate the national IT and data services that support clinicians at work, help patients get the best care, and use data to improve health and care.

We are the data custodian for England's health and social care system, with responsibility for collecting, protecting, linking and disseminating some of the world's most valuable health and care data assets. As the primary provider of statistics and analysis to the NHS and social care, we also provide the trusted and independent insight that underpins the management and improvement of our system. Our most critical responsibility is maintaining the reliability, performance and security of the core infrastructure, platforms, and live services on which the NHS and social care system relies.

The Department for Health and Social Care (DHSC) has said the proposed transfer of NHS Digital's functions into NHS England (NHSE) which were due to happen at the end of March 2023 will now happen in early January 2023, subject to parliamentary approval and agreement with the devolved administrations.This means that all of NHSD's statutory functions under the 2012 Health and Social Care Act will in due course be passed over (with necessary modification) to NHS England through transfer regulations.

The care of patients and service users – NHS App

In February 2022 the former Health Secretary set out a target for the NHS App. He stated that, by the end of March 2024, he expected to see 75% of adults registered for the NHS App. The commitment was broken into two phases, expressed as: 'By 2024, 75% of adults will have registered for the NHS App with 68% (over 30 million people) having done so by March 2023.'

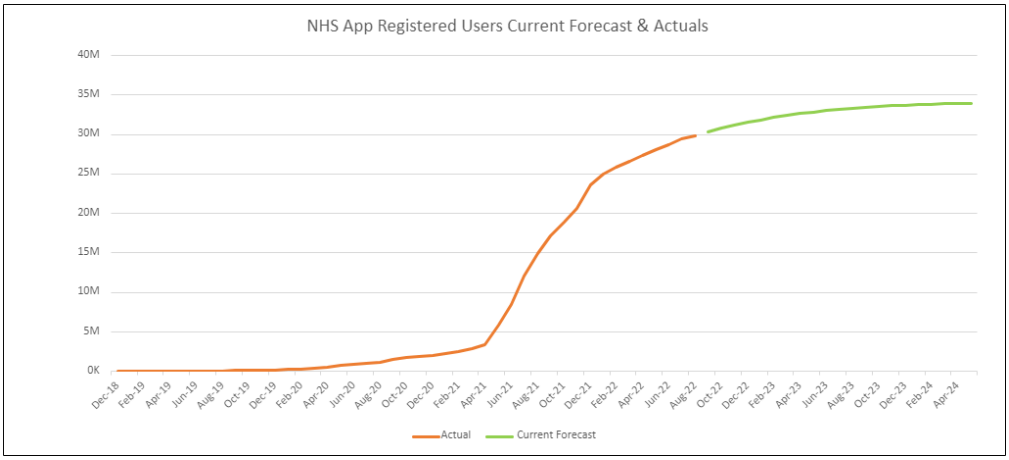
The period for which the targets of 68% (end March 2023) and 75% (end March 2024) equivalent of the English adult population being registered for the NHS App were set have not yet elapsed, however we have achieved the 68% target early, in September 2022, with over 30 million sign-ups* for the NHS App.

**Sign-ups are the recorded number of users with P5 verification (users with P5 verification can undertake a range of transactions including ordering repeat prescriptions, view their health record, manage their hospital or clinic appointments, register as an organ donor, view their COVID Pass). This total figure covers sign-ups across England and the Isle of Man, which includes those aged 13-*

15. Sign-ups do not necessarily map to individual users, as one person may use multiple email addresses to register for the NHS App. Work is underway to de-dupe to a person level, however we use 'sign-ups' as a proxy for equivalent % of the English adult population.

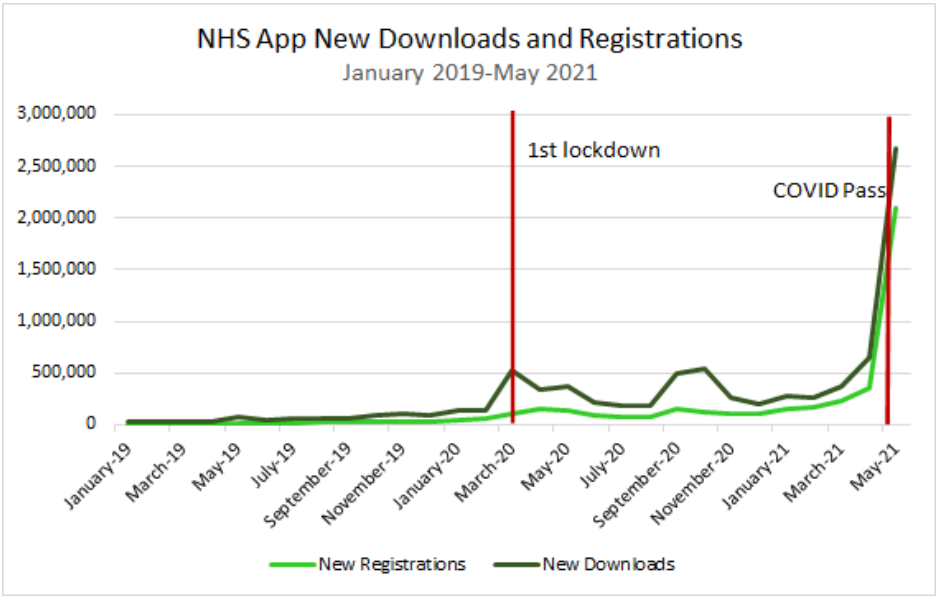
NHS England's Citizen Experience Team monitors this metric carefully, and are currently forecasting:

- 32 million sign-ups by the end of March 2023
- 33.8 million sign-ups by the end of March 2024



There were 260K sign-ups for the NHS App in January 2020, growing to 2.3 million in January 2021, with another spike in May 2021 after the introduction of the NHS COVID Pass – a universally available service only available via the NHS website or NHS App. Growth can be observed in the chart included above (figures in the table below).

Month / Year	No. NHS App sign-ups	% increase YoY
Jan 2020	260,000	
Jan 2021	2,285,874	779%
Jan 2022	25,000,834	994%
Sept 2022	30,204,227	17% at half way through FY



Beyond COVID Pass introduction, there was continued growth in the userbase, with another spike in November / December 2021, when COVID Pass was mandated for domestic use. Additionally, use of transactions within the NHS App continued to rise:

- App logins were 17 million during May 2021, peaking at 60 million in December 2021 and are now averaging out at 20 million per month.
- Primary care appointments managed (booked and cancelled) continue to remain low, due to not being made available by GP surgeries, but have increased from 57K in May 2021 to 287K in September 2022.
- GP health records viewed hit 9.3 million in May 2021, stoked by the influx of new registrations. This peaked at 11.4 million in December 2021, settling at 4.5 million monthly in recent months.
- Repeat prescriptions ordered was 517K in May 2021, increasing consistently month on month, most recently hitting 2 million in September 2022.

The ambition of our citizen-facing digital offer is to enable all adults in England to access digital health and care services in order to stay well, get well, and manage their health and care. The NHS App is front and centre of our offer (which also includes NHS website and NHS login).

On a monthly basis c. ¼ of userbase logs in to the NHS App (25% of user base logged in in September 2022), and 75% of userbase has logged in in the last 6 months, demonstrating a core userbase that remains engaged. Usage of NHS App transactions indicate that patients are opting to self-serve when given the opportunity to do so. In September 2022 alone there were:

- 2 million repeat prescriptions ordered via NHS App.
- 1 million referrals were managed via the NHS App.
- 430K secondary care appointments were managed by NHS App.
- 286K primary care appointments were managed via NHS App.

The health of the population – Data for Research and Development programme

NHS Digital is responsible for delivering two major elements of the Data for Research and Development programme: NHS DigiTrials and a Secure Data Environment for access to data.

NHS DigiTrials

NHS DigiTrials builds on existing NHS Digital data and is developing a range of data services designed specifically to support clinical trials. The service provides a single access point for the safe and secure access of linked national patient data for research to benefit patient care as well as delivering value add service that reduce burden on frontline NHS and increase speed and efficiency of clinical trials. Using this service, researchers and clinical trialists are able to work out if a trial is feasible, recruit eligible participants to take part, keep participants updated about the progress and results of trials and use routinely collected data to efficiently demonstrate the long-term safety and efficacy of new treatments. The NHS DigiTrials service aims to provide patients with more information and opportunity to join trials, together with enabling researchers to develop cutting edge treatments quicker.

Since its launch in November 2019, the service has supported vital research to improve care and outcomes for patients. This has included:

- NHS-Galleri trial– 140,000 volunteers were recruited in just 10 months for a trial designed to detect 50 different types of cancer from a single blood sample. Supported by the NHS DigiTrials recruitment service, it is one of the fastest recruited large-scale randomised trials.
- PANORAMIC – the service supported a study of antiviral treatments for COVID-19, testing whether they could reduce hospital admissions.
- Our Future Health – NHS DigiTrials is helping the UK's largest health research programme bring people together to develop new ways to prevent, detect and treat diseases.
- RECOVERY – the service also supported researchers who discovered an anti-inflammatory drug cut the risk of death from COVID-19 by one-third and saved an estimated 1 million lives worldwide.

The service is committed to transparency and hosts a diverse co-development panel made up of patients with an interest in clinical trials. The panel works to support service design, providing advice on ways to recruit into and communicate clinical trials to patients, the public and diverse communities and ensures that all our communications are clear and easy to understand. The panel is also looking at ways to widen participation among people and communities, particularly seldom-heard voices, who would not normally volunteer to take part in trials. NHS Digitrials is working collaboratively with clinical trialists to ensure services are developed based of their needs and are helping to address some of the key challenges facing trialists.

Secure Data Environment (SDE)

The NHS Digital Secure Data Environment (SDE) service will provide approved researchers and analysts with access to essential, de-identified health data from national health settings, to deliver quick answers to vital health related questions and will uphold the highest standards of privacy and security of NHS health and social care data when used for research and analysis. Only approved users, with approved projects, will be allowed to access and analyse data and only approved outputs can leave the environment. This Secure Data Environment will become a key platform to access NHS health and social care data for research into diseases and conditions affecting the population.

This Secure Data Environment will become a key platform to access NHS health and social care data for research into diseases and conditions affecting the population. New users will start to use the SDE in a beta phase from Autumn 2022 and users of NHS Digital's existing Trusted Research Environment service for England are expected to be migrated by the end of March 2023.

The NHS Digital SDE service is being built in line with the Five Safes framework and will comply with the Department for Health and Social Care's published Secure Data Environment guidelines. Users will be given access to the data approved under their data sharing agreements. The platform puts virtual walls around data under each agreement, to ensure that users can only access data for which they have been approved. All data is de-identified and so does not contain personal information such as names and addresses or NHS numbers. Findings that users wish to remove from the platform can be exported via the Safe Output Service, ensuring the formats and analyses are approved before they are released to authorised users. Researchers will only gain access to data they are permitted to see and all approved data flows are published on the Data Release Register.

SDE users will be provided with a virtual desktop, hosting powerful analysis and interrogation tools such as Databricks (a collaborative analytics platform that supports SQL and Python languages for the analysis of big data in the cloud), RStudio (a data analysis tool for R, a programming language for statistical computing and graphics and Gitlab (a code management and code version control tool that provides users with a secure, cloud-based repository to store and back-up versions of code when using Databricks and RStudio). Additionally, researchers with the same data sharing

agreement will be able to work collaboratively with their colleagues in shared project folders, using their preferred tool. The final intended output is checked for compliance with NHS Digital's Safe Output Service disclosure control rules before exports are approved.

The Data Saves Lives Strategy sets out a commitment for the implementation of Secure Data Environments as the default way to access NHS health and social care data for research and analysis. The NHS Digital Secure Data Environment will be a key platform to support the NHS deliver on these commitments. It will also meet the requirements set out in the UK's Life Sciences Vision and a number of recommendations in the Goldacre review.

Funding announced in March 2022 as part of the NHS England Data for Research and Development Programme is enabling NHS Digital to accelerate the work that was already underway to evolve the existing Trusted Research Environment (TRE) service for England created during COVID-19 into the Secure Data Environment.

Working in partnership with Health Data Research UK (HDR UK) and our first user, the British Heart Foundation Data Science Centre (BHF DSC), the current NHS Digital TRE service has grown into a powerful environment, capable of answering complex research questions. The service offers the tools and data needed to support teams of researchers from UK universities and other research organisations to perform analyses on a variety of linked, pseudonymised data sources.

There are currently 201 users, made up of 73 BHF DSC users, 79 DHSC users, 9 DataCan users, 11 NHSE users, 16 AstraZeneca users, 7 NICE users and 6 NHS Digital users. There are 91 datasets in use and a further 78 priority datasets are in the process of being onboarded. These users are carrying out a range of projects with 10 papers published or under review.

The health of the population – GP Data for Planning and Research (GPDPR)

NHS Digital is already able to extract de-identified data from GP practices through the General Practice Extraction Service (GPES), which is able to interrogate data within the GP system and produce aggregate results. This system, however, is ten years old, operating over capacity, lacks modern capabilities for data processing and so needs to be replaced. GPES operates on a 'collect once, use once' basis, so every single use case requires a separatee extraction. This is costly, uses more processing power and bakes in a reliance on third party suppliers to provide the data.

The specific commitment around de-identified data leaving GP practices was linked to the General Practice Data for Planning and Research (GPDPR) programme. This programme aims to support and enable the movement of de-identified patient data from GP practices to NHS Digital, where it would then be safely stored, processed and used transparently and in line with the Health and Social Care Act.

Privitar, the technology to enable pseudonymised data to be extracted, was successfully implemented within GP systems in May 2021. Privitar has undergone penetration testing as part of the wider IT security review within NHS Digital with the report being submitted to NHS Digital in May 21. However, Privitar has never been activated into live use and data is not being extracted using this tool. This is partly due to concern about the wider programme that was raised by the public, patients and professionals about the proposed changes in summer 2021. The GPDPR programme was paused following these concerns.

The pause in July 2021 presented an opportunity for the health and social care system to improve transparency and public engagement on use of patient data. The programme identified that it

needed to listen, understand, engage and act on what we learnt. We are working with partners such as health and care professionals including the Royal College of GPs (RCGP) and the British Medical Association (BMA), research organisations, patient charities, data experts, the National Data Guardian (NDG), patients and the public to establish how best to address the concerns raised.

We have listened to some critical feedback and we are working more closely with our partners to make sure they are confident that data is kept secure, the workload for general practice staff is reduced so they can concentrate on patients, and to communicate better with everyone.

With Ministers, we have developed a set of commitments that we will work to and the programme will only begin data collection when:

- Patients are able to opt out or back in to sharing their GP data with NHSD, with data being deleted even if it has been uploaded.
- A Trusted Research Environment is available where approved researchers can work securely on de-identified patient data.
- A campaign of engagement and communication has increased public awareness, explaining how data is used and patient choices.

The commitment to be able to use data from GP systems to support the NHS and to enable research remains and, as we set out in *Data Saves Lives,* the Government's data strategy for health and care data, subject to HM Treasury approval, we expect that the GP Data for Planning and Research programme will be a flagship example of a service where data will only be accessible via a secure data environment.

Due to ongoing challenge to the programme ambition, continuing stakeholder engagement and budget constraints GPDPR will not be delivered this year.

Nov 2022