



# Data for R&D PROGRAMME

Health Data User Group update

ISSUE NO 3 | MAY 2023

Our vision:  
by 2025 we will have a world leading NHS-wide,  
health data infrastructure that enhances patient care,  
sustains the NHS and supports innovation.



## About this update

This update outlines progress and key developments since our webinar in February. In this issue, we're excited to share news about funding approval taking us through to March 2025, how we're working with NHS England colleagues to support health research and the life sciences, and to give you an insight into our plans for 23/24.

### Use cases

We continue to welcome further use cases that would benefit from the Secure Data Environments and/or data-driven clinical trial operations to help shape the programme's development. Please submit any potential use cases via [this link](#), or use the form on the Data for R&D workspace on [FutureNHS](#).



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## News

### Treasury approval!

Firstly, we are delighted to announce that the Data for Research and Development's Programme Business Case was approved by HM Treasury this month (May 2023), signalling the ongoing commitment across government and NHS England to make privacy-protected data more accessible for research through Secure Data Environments (SDEs).

Business case sign-off means we are now able to finalise funding allocations for the remainder of the programme, taking us through to March 2025.

It enables us to make further investment in the newly formed 'NHS Research Secure Data Environment Network', ensuring coverage across England and support for a variety of research types, including clinical trials and artificial intelligence.



### Life sciences growth package and Lord O'Shaughnessy review of UK commercial clinical trials

On 25 May the Chancellor **announced investment of £650 million** for the UK's life sciences sector, the same day as the report from **Lord O'Shaughnessy's review** into commercial clinical trials in the UK was published.

Lord O'Shaughnessy's report makes 27 recommendations, including support for our SDE programme to proceed. This will help provide the data infrastructure required to underpin the reporting, data linkage and other services necessary to deliver improved clinical trials in England.

### Coming soon | Hold the dates



We would also like to invite you to our Summer webinar on **11th July 11am-12pm** and the Autumn update that will be an in-person event in London on **3rd October**.

### Data access policy consultation launched

In September 2022 DHSC published the **12 policy guidelines** for Secure Data Environments. A new consultation is seeking feedback on the latest draft policy update, which builds on the previous guidelines and sets out key policy proposals made so far.

The views and feedback gathered from the consultation will inform the final version of this policy update, as well as longer-term priorities and actions for data access policy. This policy update is intended for a technical audience, such as data controllers, data users and platform providers.

Find out more and respond [here](#).





### Innovation, Research and the Life Sciences

The Data for R&D programme spans both data architecture and clinical trial recruitment and we work closely with teams across NHS England to develop and enhance the health data and research ecosystem, as part of wider plans to [embed research in the NHS](#). This includes collaborating with the Innovation, Research and Life Sciences (IRLS) team whose mission is to ensure research and innovation meets the needs of the NHS, to improve NHS research efficiencies, and to accelerate adoption and spread of proven innovations to get the best treatments to patients faster.

Ali Austin, Deputy Director of Research within IRLS, explains the team's role as:

*“Our priority is increasing the scale, diversity, and pace of research in the NHS. We are making it easier for patients to volunteer for studies through the NHS app, raising the profile of research within our workforce plans, delivering changes to speed up trial set up, and supporting ICSs and their partners to increase research engagement with under-served communities.”*

To support delivery of these priorities, in March the IRLS team published its [Research Guidance for Integrated Care Systems](#) which aims to maximise the benefits of research for the NHS and NHS England became a signatory to the [Shared Commitment to further public participation in research](#). In addition last October the [National Contract Value Review](#) went live across the UK to facilitate faster costing of trials and contracting between commercial sponsors of clinical research and NHS sites. Early data shows that this new approach has reduced UK study set-up times by 45% and now takes 4 months instead of 7.

NHS England has also recently published a [good practice](#) guide to increasing diversity in research participation, focused on engaging with under-represented communities in research, which aims to:

- help researchers understand why research participation might be low in a group
- provide meaningful insights into working with groups where participation in research is low, and
- provide practical suggestions to increase participation in research.



## News

### NHS Research Secure Data Environment Network

In December last year [we announced](#) £13.5 million of investment for 11 Sub National Secure Data Environments (SNSDEs), which provide coverage for the whole of England. Since then, we have established the NHS Research SDE Network, which includes all the SNSDEs and the national SDE for England previously developed by NHS Digital with funding from our programme.



We have established a Community of Practice for the Network with working groups focusing on the urgent and immediate problem solving that's required to enable operational delivery. The groups cover areas such Information Governance and Ethics; Technology Infrastructure; and Communications and Patient and Public Involvement and Engagement. Each group contains national and local subject matter experts as well as members for the Data for R&D programme, Federated Data Platform (FDP) and DHSC to ensure alignment with wider policy and health data work.

As each region of the network designs and builds its SDE, we are working with them to ensure consistency with the target operating model and interoperability across the network.

## Data enabled clinical trials

### Be Part of Research hits 150,000 registrations!

Be Part of Research, the NIHR service that makes it easy for people to find and take part in health and care research happening across the UK, has introduced a new volunteer registry. The new service enables people to register their interest to take part in research across all health and care specialties or sign up as a healthy volunteer.



People can register for the service from the Be Part of Research website and via the NHS App (in England only). Since the service has been linked to the NHS App, a rapidly growing number of people from across the UK have registered their research interests, with 150,000 people currently signed up.

The registry gives researchers and sponsors free and easy access to research-engaged volunteers from across the UK - enabling study teams to recruit more quickly and effectively.

The service is actively seeking research studies that may benefit from accessing the registry of volunteers to support their study recruitment. Eligible studies can be either NIHR funded or on the NIHR Clinical Research Network Portfolio. If you are interested in finding out if your study could use the registry as a recruitment tool, please [complete this form](#). For more information please visit the [Be Part of Research](#) website.

### NHS DigiTrials

NHS DigiTrials has developed the [Feasibility Self Service](#) tool, which provides users with significantly faster routes to gaining feasibility insight for clinical trials, including potential sites. There is more information on our FutureNHS site, including a recording of the presentation about the tool from our webinar in February. You can read more about the team's approach to developing the tool in a blog ["Clinical trials get faster"](#) published to mark International Clinical Trials Day (20 May 2023) by James Gray, NHS DigiTrials Service Delivery Manager.

If you would like to hear more about the Feasibility Self service tool, you can [register](#) for the Feasibility Self-Service webinar on Wednesday 14 June from 11:00 – 12:00. You'll see how the tool works, understand the features and benefits, and have an opportunity to ask the team questions.

We are also a partner in the [Our Future Health](#) study which to date has sent over 10m invitations to encourage people to sign up.

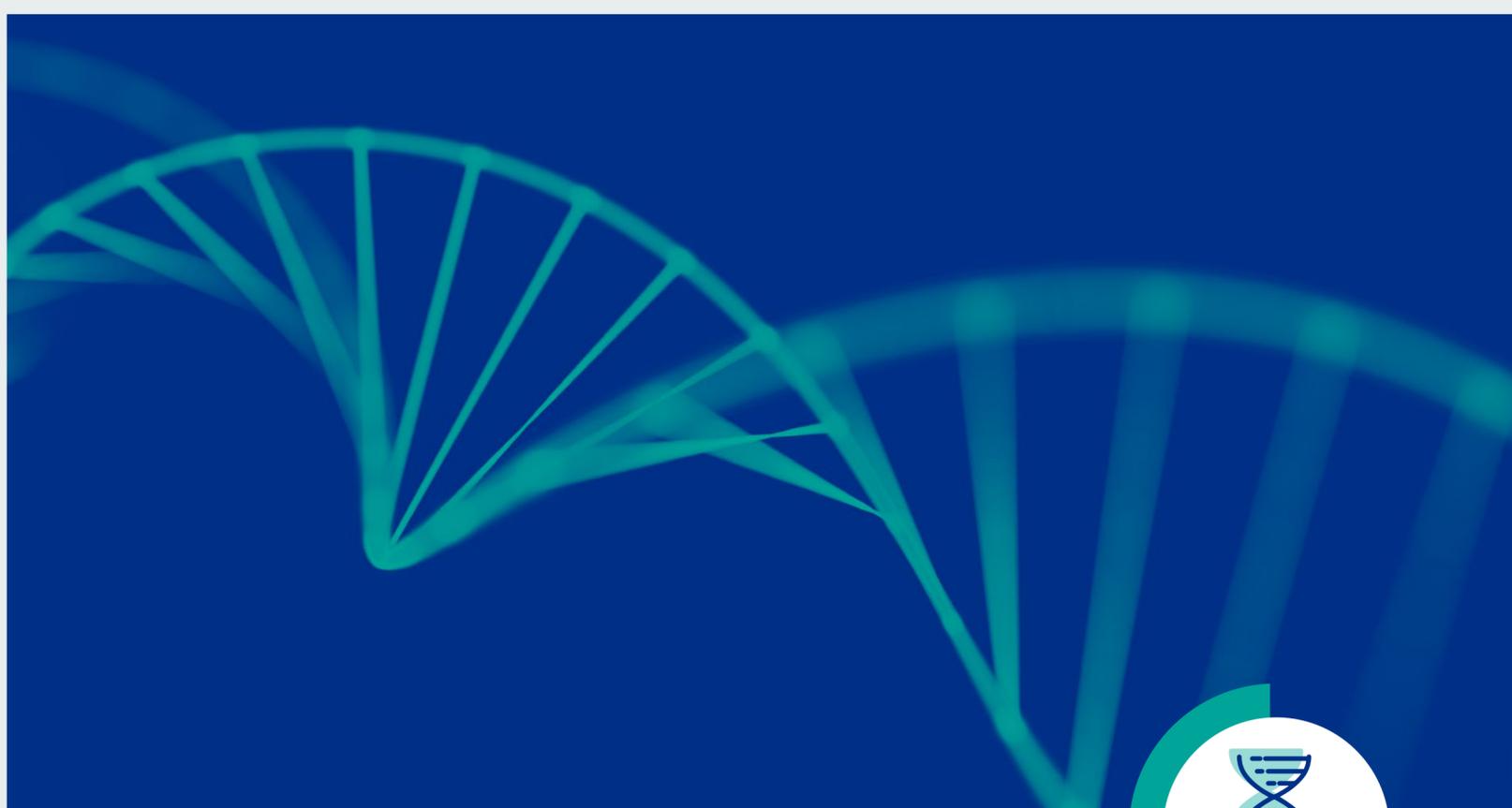


## Patient and Public Involvement and Engagement (PPIE)

Data for R&D has funded significant engagement on public expectations for use of NHS data for R&D purposes. This provides critical evidence on expectations, preferences, priorities and guardrails that will guide the programme as we move forward.

As part of this, NHS England commissioned Britain Thinks to conduct deliberative engagement sessions, including participants from across the country, to understand public views on draft commercial principles for access to NHS data. Summary findings include:

- A consistent set of commercial principles is welcomed by the public.
- The majority considers it appropriate that the NHS recoups its costs by charging for access to data.
- The majority support the NHS sharing in the value generated from any outputs that have used NHS data.



## Genomics driver projects



Data for R&D has allocated funding for three years to improve genomics data infrastructure and this is currently being explored through two driver projects to link and federate genomics datasets.

One project is focused on understanding cancer from both a molecular (genomic) and a spatial (histological and radiological) perspective and a team based at Genomics England is aiming to:

- Develop new technology to revolutionise digital pathology.
- Support access to integrated and comprehensive data set through a SDE.
- Develop interoperable systems that feature data from multiple healthcare organisations that will be stored in a standardised format so it can be analysed across multiple sources.
- Collaborate with industry and other centres of excellence in digital pathology and radiology to provide more precise diagnosis with AI tools applied to digital images.

We are also supporting the Cambridge based Bytes, Bench and Bedside Driver project that aims to build upon the proof-of-concept work that began during phase 1 of the DARE UK (Data and Analytics Research Environments UK) Sprint Exemplar by embedding automation of the airlock system between CYNAPSE and Genomics England, and begin to explore how to standardise OMOP mapping of large quantities of clinical data for clinical data science. The project has two aims: to develop an airlock automation for federation analytics and to map electronic health records data to a common data model (CDM).

You can find out more on the Data for R&D FutureNHS [workspace](#).



## Major conditions strategy: call for evidence

The major conditions strategy will build on government action to tackle major conditions and improve health outcomes. It includes work to tackle waiting lists for planned NHS treatments through the elective recovery plan and to improve cancer treatment and survival rates.

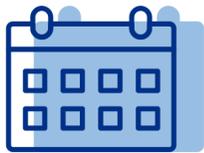
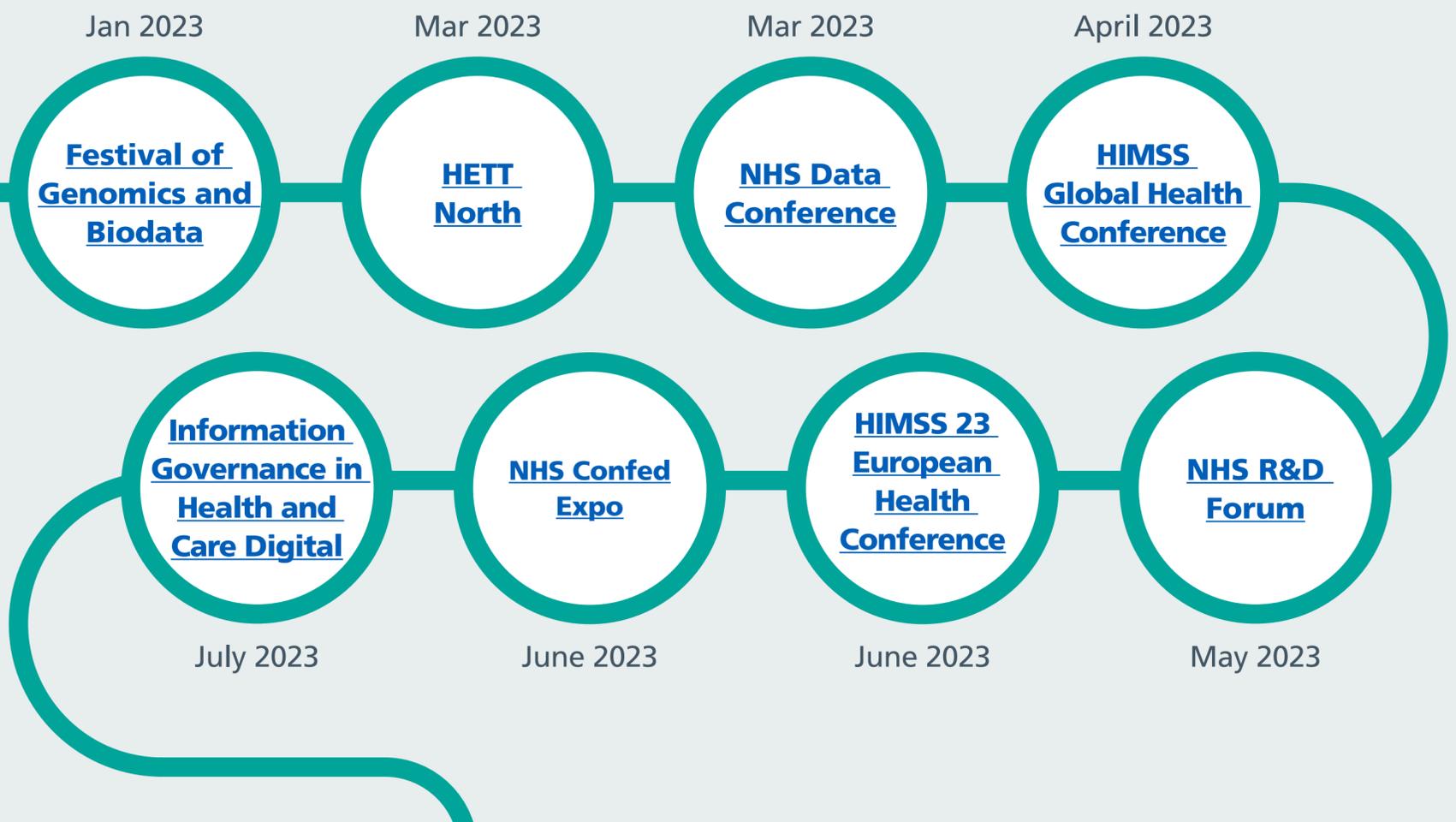
A consultation was launched in May asking for views and ideas on how to prevent, diagnose, treat and manage the groups of major conditions that contribute to ill health in England, namely:



- cancers
- cardiovascular disease (CVD), including stroke and diabetes
- chronic respiratory diseases (CRDs)
- dementia
- mental ill health
- musculoskeletal (MSK) disorders.

You can submit your views and ideas [here](#). The consultation closes at 11:59pm on 27 June.

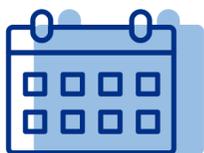
## A snapshot of recent and future events



### Webinar

Tuesday 11 July from 11:00 to 12:00.

We'll confirm the agenda nearer the time, but you can [register now](#)



### Face-to-face event | Hold the date

Tuesday 3 October

We are currently planning a face-to-face event in London on Tuesday 3 October. Please hold the date in your diary.



## FutureNHS workspace

Stay up to date, and access key information and documents relating to the Data for R&D Programme using our new FutureNHS workspace. We've been delighted to welcome over 100 colleagues so far and if you're not one of them, then now is a great time to join and get easy access in one place to everything we share.

Follow [this link](#) for instructions on how to get started. Once you have set up an account, look out for an invite to join the Data for R&D workspace (this email may end up in your junk inbox). If you have any problems or do not receive the invitation email, please email [Lucy Armstrong](#).

### What you'll find on our FutureNHS space:

- Our latest news
- Resources, including presentations and documents from our events
- How to submit a use case and supporting documents
- Discussion forum.

## Meet the team

Since our last newsletter, Claire Bloomfield has been appointed as Director of the Centre for Improving Data Collaboration at NHS England, a position she has taken on in addition to her role as Senior Responsible Officer for the Data for R&D programme.



### Dr Claire Bloomfield

Senior Responsible Officer



### Humaira Ali

Interim Programme Director



### Dr Chris Russell

Head of Delivery



### Jonathan Darley

Senior Policy Advisor



### Becca Cosgriff

Head of Strategy



### Asif Khan

Senior Project Manager



### Dr Cathy Kelly

Clinical Advisor



### Georgie Appleyard

Project Manager



## CONTACT US

If you have any questions or would like further information please get in touch with [Lucy Armstrong](#).

You are receiving this newsletter as you've previously attended one of our Data User Group events, or expressed interest in doing so. Please [email us](#) at any time if you no longer wish to receive information from the Data for R&D programme.

