NDRS user research response plan

October 2023

About the NDRS

The National Disease Registration Service (NDRS) is part of NHS England. Its purpose is to collect, collate and analyse data on patients with cancer, congenital anomalies, and rare diseases. It provides robust surveillance to monitor and detect changes in health and disease in the population. NDRS is a vital resource that helps researchers, healthcare professionals and policy makers make decisions about NHS services and the treatments people receive.

The NDRS includes:
- the National Cancer Registration and Analysis Service (NCRAS) and
- the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Healthcare professionals, researchers and policy makers use data to better understand population health and disease. The data is provided by patients and collected by the NHS as part of their care and support. The NDRS uses the data to help:
- understand cancer, rare diseases, and congenital anomalies
- improve diagnosis
- plan NHS services
- improve treatment
- evaluate policy
- improve genetic counselling

National Disease Registration Service
The Leeds Government Hub
7&8 Wellington Place
Leeds LS1 4AP
NDRSenquiries@nhs.net

Contents

1. Overview

In our strategic plan 23 – 24 we outlined our pledge to become an increasingly user-led service, with a commitment to embed user-needs led approaches and to continue to gain a better understanding of user needs to identify new opportunities for innovation and to continually improve the service.

The move of NDRS from NHS Digital, as part of the merger to the new NHS England in January 2023, provided an opportunity to gain a fresh insight from current and potential users, and their needs and challenges in utilising NDRS and its outputs. We commissioned CapGemini Invent to work with us to undertake user research with the broad range of NDRS stakeholders, redefining our stakeholder categories, better determining their needs for data and the service, and hearing their potential suggestions for improving the service for all.

This work will not standalone. We will continue to seek and implement opportunities to embed user needs led approaches in NDRS and continually assess and improve the service based on user feedback and needs. As we embed in the new NHS England this will include a review of our governance, our processes around partnership and project approvals and with our wider engagement and priority setting.

We are very grateful for everyone that took the time to participate and provide us with their insight and feedback. The final report can be found on the NDRS website.

A few things to note:

1. We continue to strive to improve our transparency in our role as data curator for cancer, congenital anomalies, and rare diseases. We gave a lot of consideration about including patients and the public as part of this user research. The focus of this project was on the data outputs and products of the service, and we knew that we want to have a wider conversation with patients and the public; to encompass the outputs and data aspects, but also to allow for other areas of interest and concern such as the opt-out and patient involvement. We have committed to undertake this in phase 2. We will share more information about when this will be starting in due course.
2. While the level of clinical engagement was low due to the timescales, we have shared the report with the NDRS clinical leads and gained their feedback as part of the process. Similar projects in the future will engage with clinical stakeholders earlier to allow them time to participate should they wish.
3. Users provided insight and feedback around the issues with accessing NDRS data via the Data Access Request Services (DARS.) We have shared this with colleagues in the Transformation Directorate responsible for DARS and have included more details in the response plan.

2. Our response

Below you will find our response to the findings of the user research. A significant part of the feedback was about navigating NDRS systems and platforms and for users to gain a better understanding of NDRS outputs and resources, therefore we have worked to create a response to each user need identified and provided the most up-to-date resources and contact information. This will continue to be a live document which we will update regularly. We hope that this provides clarity and guidance on some issues, and we will continue to work to improve the experience for all users and to do our part to address the wider systems issues.

We continue to welcome feedback and suggestions. Please email us at NDRSenquiries@nhs.net

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
Communication & Engagement			
1.1	Enhancing NDRS' general engagement with user communities	• We launched our new NDRS website in September 2022 which provides a single point of access to all NDRS online information and resources bringing together the cancer, rare disease and congenital anomaly work to one location for the first time. Our aim is that this will allow improved discoverability and easier navigation of NDRS information, resources, data products and services. • We have a network of Clinical and Scientific Leads who work to advocate and representation of NDRS within relevant communities. We are currently in the process of adding all our clinical leads details to the website and will update this document with a link to this information when available.	• There are a number of engagement activities taking place in the next few months. These include: • NDRS COSD Roadshows visiting all NDRS regions and engage with Trusts and regional colleagues. These will start in January 2024 and more details will be available on our website and via our newsletters soon • Workshops and stakeholder engagement activities to review datasets and data outputs. For example, the SACT dataset review. Information about new opportunities will be circulated via the NDRS newsletter.

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
		• We have an NDRS monthly newsletter available to anyone that subscribes capturing recent publications, data releases, events, and other news. • In addition, we have newsletters specifically relating to the Cancer Outcomes and Services Dataset (COSD), Systemic Anti-Cancer Therapy Dataset (SACT) and from our Data Liaison team. For more information on these please email NDRSenquiries@nhs.net • We work closely with user networks and communities including: – The United Kingdom and Ireland Association of Cancer Registries (UKIACR) – European Registration of Congenital Anomalies and Twins (EUROCAT) – UK Health Statistics Steering Group (UKHSSG) – The National Cancer Audit Collaborating Centre (NATCAN) – The National Institute for Health and Care Excellence (NICE) – Cancer Research UK (CRUK) – MacMillan Cancer Support – Cancer 52 – Wider third sector – Royal Colleges (including Royal College of Pathologist, Royal College of Radiologists and Royal College of Surgeons England) Please do reach out to us if there are other networks you feel we would be of value to or vice versa.	• NDRS colleagues will be attending a range of conferences and other relevant events to showcase our work and networks. Please contact us at NDRSenquiries@nhs.net if you are hosting a conference or event and would like an NDRS speaker, exhibition stand or to collaborate. • We will also be exploring other in person events to support networking and showcasing.

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
1.2	Fostering collaborative relationships with users	• NDRS has worked with a range of academic, third sector, clinical and public sector partners for many years to deliver high quality research, statistics, and data access. The details of our current partnerships can be found on our website.	• We are in the process of reviewing our partnerships process as a result of transferring to NHS England. We aim to develop an equitable partnership framework detailing the current opportunities for working with us and how to initiate contact and start discussions. More information will be publicised on the NDRS website when ready. • In line with our strategic plan we are also exploring targeted engagement with other sectors and communities to raise awareness of existing NDRS information, resources and opportunities and to facilitate continued understanding of user needs to inform our service and products.
1.3	Improving communication on data releases and publications and timelines for approvals	• The NDRS newsletter provides a regular feed about what has been released each month, as does the SACT newsletter. • The NDRS website has a comprehensive library of academic publications dating back to 2018 and we will expand this over time. • The website also signposts to many other data products and outputs including those on currently hosted on Cancerdata. • If you have a question about a particular data product you can email us at NDRSenquiries@nhs.net	• We are currently developing a data release and outputs timetable which will be updated each quarter and available on the NDRS website. Due to be published in November 2023. • We will continue to explore other ways to improve our communication and promotion of data releases and publications. Please email us with any suggestions.

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
1.4	Improving the user’s awareness and understanding of NDRS materials and resources	• Since 2020, we have been running a regular webinar series taking a deeper dive into NDRS work and collaborations with partners. They can all be found on the NDRS website. • The retirement of the legacy websites in October 2023 will remove the fragmented online presence and create a single point of information via the new website, making it easier for users to find information and resources. • The launch of the Bitesize series in July 2023 is aimed at those new to NDRS, but with up-to-date information that will also be useful to regular users. Topics include datasets, data outputs, platforms, and other relevant resources. We will continue to add to these so if there is a particular topic you would like to hear about, please drop us an email NDRSenquiries@nhs.net	• For work to enhance the transparency of our analytical outputs please see item 2.2 below. • The introduction of Search Engine Optimisation (SEO) as part of the ongoing digital transformation project and new website maintenance will enable easier searches and navigation of NDRS tools and resources. • We have started and will continue to engage with users to develop an accessible and easy to follow guide of NDRS data products. We will add more information here when this is available.
	Governance and data access		
2.1	Improving transparency of decision making and priority setting within the NDRS systems of operation	• In April 2023 we launched and published the NDRS Strategic Plan for 2023 – 24. This sets out the NDRS priorities including our commitment to becoming increasingly user needs led and more transparent about how we work. We will publish a 6-month update on our progress against the strategic priorities on the website. The first 6-month update report will be in October 2023. • There is an NDRS clinical and scientific leads group with whom we meet regularly and who act in an advisory capacity with the senior team and as subject	• As part of the new NHS England, we are beginning to review the governance framework and accountabilities for NDRS. We are exploring the possibility of an external advisory group and will share more information in due course. • We are working closely with the Data and Analytics Directorate to address issues around data access. Please see 2.5 for further information.

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
		matter experts on many NDRS programmes and projects. More widely there are a number of programme boards with external representation. More information about our governance structure, terms of reference and opportunities to get involved will be published on our website in due course. • We have a rigorous process for assessing new analytical requests. New proposals are assessed by our panel of clinical, statistical, and operational leads on a fortnightly basis for feasibility and appropriateness and we work with requestors to facilitate their proposal being delivered, either in partnership or through our core work programme.	
2.2	Optimising outputs	• We are applying Reproducible Analytical Pipelines (RAP) principles to publications: reusable code functions, publication of code which will make our outputs more efficient and more transparent to users, allowing them to understand the methodology and scrutinise our processes. • We are applying the highest accessibility standards across all platforms and web content to make all content and products accessible to all. And we will continue to monitor this standard as part of our publication framework. Accessibility - NDRS (digital.nhs.uk) • We are embedding user feedback processes into our work so that we continue to improve outputs and ensure they are meeting user needs. This will create further opportunities for stakeholders and the public to	• In phase 2 of the digital transformation programme, we are reviewing and further consolidating platforms and webpages so that they are easier to find and navigate, supporting users to get the most from our outputs. This includes the transfer of outputs from the CancerData platform to the new website. Following this we will carry out a review of the CancerStats2 platform and how we can potentially make the data improvement dashboards more publicly available. This work will begin in the Autumn 2023. • We will also review web usage data to monitor what is being accessed and used and where we might need to improve

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
		inform our service in the future. More information will be published on the website when available.	visibility of outputs and resources that are not as well used. • We will build and release a set of standard data outputs for an initial set of rare diseases and will aim to expand this over time. More information will be published in due course.
2.3	Creating systems for equitable opportunities of access	• We are working closely with colleagues in the Data & Analytics Directorate to ensure we are providing consistent messaging to stakeholders about the progress and developments in relation to NDRS data being available in the Trusted Research Environment (TRE) and Safe Data Environment (SDE) services. You can find the latest information on the SDE here.	• We will be exploring how we can better promote and improve the accessibility of our outputs – see section 1.3 and 2.2 above.
2.4	Providing assistance with navigating a complex system	• We have a dedicated points of contact via NDRSenquiries@nhs.net for general enquiries. • NHSDigital.NDRSanalysis@nhs.net for analytical enquiries • We also have a dataset specific address ndrs.datasets@nhs.net for data liaison or other dataset specific enquiries. • We have also updated the Data Access and Release Services (DARS) data dictionary and Rapid Cancer Registration Dataset (RCRD) data dictionary to ensure they are as user friendly and accessible as possible,	• With user input, we will be developing a comprehensive guide of NDRS products to support user understanding of what is available and what the resource is. We will update further when this work is underway.

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
		and up to date with the data that is available from NDRS.	
2.5	Addressing issues with DARS	• We are working closely with the Data Access Request Service (DARS) to improve access to NDRS data. *We have liaised with DARS who have provided the following update:* • The DARS team has been restructured to make best use of reduced capacity with new ways of working to simplify the application review process and increase efficiencies. • DARS is also exploring investment by external Research and Life Sciences stakeholders to support increasing capacity to match demand.	• As part of the work moving DARS into the new NHS England, we are creating a separate account management team who will support users to understand more about the data we hold, the applications process, and how their applications for data are progressing. This team is currently being established, and is likely to become operational from Spring 2024. • The creation of an account management team will also enable our applications staff to focus on reviewing and processing applications (they are currently spread across a multitude of complex activities). • In addition to creating efficiencies and new ways of working, our work continues with external stakeholders to explore options to increase capacity which will help us to develop further improvements.
2.6	Creating opportunities for accessing lower-level data	• The Get Data Out programme publishes statistics on smaller groups of patients, in particular for rare and less common cancers. For each group of patients, we routinely publish statistics about incidence, routes to diagnosis, treatments and survival. Recently we have published data on haematological cancers.	• We continue to look at other options for supporting users to access lower-level data. As part of Phase 2 of the Digital Transformation project (see section 2.2 above) we will be undertaking a review of the products on the CancerStats2 platform

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
			and how we can potentially make the data improvement dashboards more publicly available. This data is intended to support NHS organisations to monitor and improve the quality and completeness of their data upon submission to NDRS. This work will begin in the Autumn 2023.
	Knowledge sharing		
3.1	Providing guidance to help navigate datasets and routine outputs	Previous activities as mentioned: • catalogue of NDRS outputs • timetable of data releases • easier online navigation • webinars • email enquiries We are always happy to hear from you if your query is not resolved by the above resources. Please drop us an email at NDRSenquiries@nhs.net	• We have begun to publish code for our routine analytical outputs on GitHub and will expand this over time. Doing this will grant users full transparency of our methodologies and we invite users to comment on published code. Our aspiration is to organise the published content such that code can be reused by those who have access to relevant data extracts through the Data Access Request Service (DARS). For information about data access please also see item 2.5 below. • We will further promote and signpost to the NDRS Data Profiles. • See section 2.4 above for the plans to create an online catalogue of outputs.
3.2	Additional considerations: Increasing opportunities for data linkage	• This is a key priority for us (see NDRS Strategic Plan: Strategic Priority 3: Our Infrastructure/ data linkage and the right technology)	• We are working closely with colleagues developing the Secure Data Environment (SDE) to deposit NDRS data, which will

User need identified		What is already in place that could help address this need?	Additional activities for 2023/24 and beyond
		• The merger to the new NHS England provides optimum opportunity for greater data linkage and we have already begun discussions to link data within our priority datasets Hospital Episodes Statistics (HES), Emergency Care Dataset (ECDS), ONS births and mortality data, Diagnostic Imaging Dataset (DIDS), Prescriptions, Maternity Services Dataset (MSDS), Primary Care data. We will share more information as this progresses.	enable more linkage. By moving cancer and congenital data products closer to the SDE opens more linkage and collaboration opportunities. The SDE will have elastic compute* providing a platform responsive to user requirements.
3.3	Additional considerations: Data-specific requests for example more data about inequalities such as age, gender, ethnicity, socioeconomic group, sexual orientation	• Within our Strategic Plan we have stipulated our commitment to identifying and reporting on inequalities to improve population health. We have an ongoing programme of work to review health inequalities and include these routinely in our outputs.	• We have published a summary guide showing which of our outputs include different patient demographic factors so far and will update this on a regular basis.

*Elastic compute is cloud technology that can increase and decrease processing capacity, processing and memory based on changing demands.