National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) Workplan 2021-24

This plan sets out NCARDRS' priorities for the period 2021-24 within the context of the National Disease Registration Service's (NDRS) vision, building on what we have achieved since our launch in April 2015.

Background

NCARDRS exists to develop and run a comprehensive population-based registration service that collects and quality-assures data on congenital anomalies and rare diseases across the whole population in England.

Disease registration is key to intelligent public health and healthcare delivery. NCARDRS sits within the NDRS, alongside the National Cancer Registration and Analysis Service (NCRAS). We provide expert analysis and interpretation of the data we collect, which is used as a source of intelligence for a range of stakeholders.

NCARDRS is a much needed resource to support individual patients, their families, clinicians, research, service delivery, healthcare performance, commissioning and public health. We:

- support and empower patients and their carers by providing a national register of their disease or disorder
- provide a resource for clinicians to support high quality clinical practice
- provide epidemiology and monitoring of the frequency, nature, cause and outcomes of these disorders
- support research into congenital anomalies, rare diseases and precision medicine including basic science, cause, prevention, diagnoses, treatment and management through access to existing data and collaboration on new data streams
- inform the planning and commissioning of public health, and health and social care provision
- provide a resource to monitor, evaluate and audit health and social care services, including the efficacy and outcomes of screening programmes.

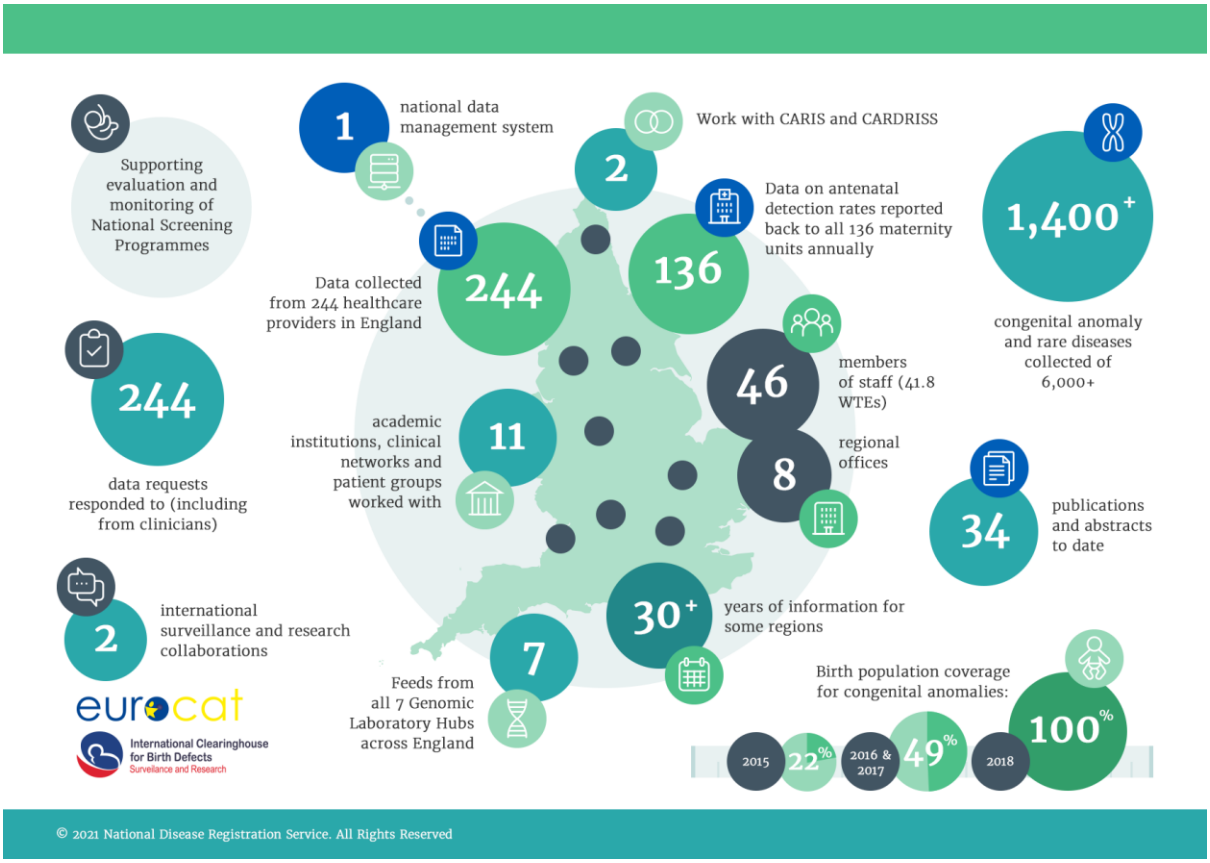
Our approach

Engagement with key stakeholders has been fundamental to delivering our achievements to date. Patients and their families lie at the heart of our work. We work with the Patient Empowerment Group of the Rare Disease UK campaign, managed by Genetic Alliance UK. Clinical champions work with us to ensure the robustness and relevance of our processes and output. Extensive engagement with clinicians, patient groups and other stakeholders have informed the priorities and the overall development of the service outlined within this plan. We will further focus our engagement on working with Genomics England, NHS England, NHS Digital and the Office for Life Sciences to inform and support policy initiatives and ensure alignment with the roll out of the Genomic Medicine Service (GMS). NCARDRS will also play a key role in the delivery and support of the UK Rare Disease Framework, working closely with the DHSC and other partners.

We have built positive working relationships with our data providers to improve data quality and completeness. We continue to review our data collection processes to ensure the burden on clinical staff is kept to a minimum, and are refining our tools and outputs to improve timely feedback to clinical teams. We continue to engage existing and potential data providers to allow us to understand the challenges to data sharing and work together to overcome them, seeking to capitalise on bulk data feeds that can be automated with a minimum of manual extraction for all parties without compromising data quality. These data liaison functions will be crucial to the success of implementing the rare disease data collection expansion and supporting the GMS. For this, we will take a pragmatic approach. We will prioritise collecting data that is currently available while working to identify sustainable systems and processes to collect information on other rare diseases where we have resource to do so.

We have Honorary Contracts in place with leading clinicians and academics in the field. We have established a process with PHE's Office for Data Release (ODR) through which we have managed 224 requests for data during the period 01/01/2015 to 01/12/2020. We have produced four annual congenital anomaly statistics reports, in which coverage of congenital anomalies has expanded from 21% of England in 2015 to full, national coverage in 2018. Our ambitions for the service have led to funded work programmes with partners including the DHSC, the National Screening Programmes and Orphanet.

Our achievements to date: 2015-2020



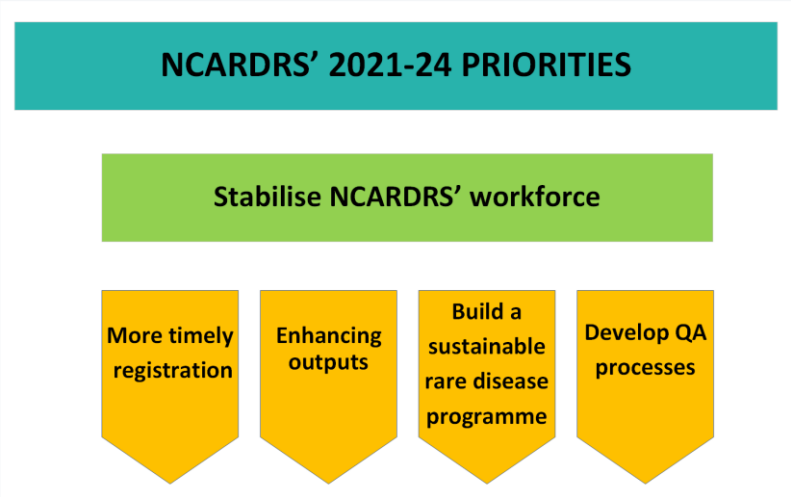
Our focus 2021-2024

High-quality data, and the information derived from it, is central to any healthcare system. We have made good progress in establishing the service over the first five years, with national coverage of over 1,400 congenital anomaly or rare disease data sets collected.

In the period to 2024, NCARDRS will focus on five key priority areas. Central to these is strengthening the service's foundations by stabilising the workforce. NCARDRS has been ambitious in its goals and outputs, and we now need to develop the functions within the service to meet these commitments in a sustainable way for the future. NCARDRS has developed strong collaborations with stakeholders since 2015, securing funding to develop work programmes. This has led to a growing number of short-term funded contracts which we want to sustain to ensure our business-as-usual capacity is appropriately resourced.

Whilst the Covid-19 pandemic highlighted our ability to rapidly generate answers to key clinical questions from within the largest rare disease population in Europe, it also highlighted the need for NCARDRS to position itself more strongly with external stakeholders and patients by becoming more responsive to clinical queries. We will achieve this by automating more registration processes to improve the timeliness of registration, and enhancing routine surveillance to improve understanding of congenital anomaly and rare disease prevalence, pathways and outcomes. NCARDRS is committed to the continuous improvement of data quality, and we will develop our quality assurance processes and continue to drive the development of national coding and classification guidance.

NCARDRS will build on the work from 2018 to expand its rare disease data sets by strengthening and expanding partnership work with stakeholders, including patients, clinicians, academia and the private sector, to deliver proactive and reactive, high-impact and novel output. We will develop automated systems that can deliver sustainable, high ascertainment, prospective reporting.



The deliverables behind each of these priorities are outlined in the following table, in order of importance. They will be labour intensive. The workforce resources that are available to NCARDRS will directly affect the extent of achievement of these aims and the pace of these achievements.

There is an internal plan in place that outlines the deliverables required to meet these 5 priorities.