

INTRODUCTION

Public Health England (PHE) has committed to the expansion of congenital anomaly and rare disease registration in England from 49% of births¹ to cover the whole population of England. NCARDRS now incorporates the previous seven regional congenital anomaly registers and the National Down Syndrome Cytogenetic Register (NDSCR). In those parts of the country where there was no data collection, new regional teams have been established.

The national registration service will provide a resource for clinicians to support high quality clinical practice and will empower patients and their carers through the provision of information relevant to their disease or disorder. Data will be collected to provide epidemiology and monitoring of the frequency, nature, cause and outcomes of these disorders. The development of the NCARDRS is integral to the UK Rare Disease Strategy.

There are over 6,000 recognised rare conditions and in the UK this amounts to approximately 3.5 million people. All rare diseases identified in the internationally recognised Orphanet Rare Disease classification system will be included in the register.

Data are collected under legal permissions granted under Section 251 of the NHS Act 2006. We have permission from the Confidentiality Advisory Group of the Health Research Authority to collect information on all suspected and confirmed cases of congenital anomaly and rare disease in England as defined by Eurocat and/or Orphanet. Patients have an absolute right of opt-out.

All data are collected onto a single national secure data management system, known as CARA. This system has been developed in order to provide a high degree of electronic data capture and standardised data entry across England. NCARDRS works on a multi-source model; In order to gain high case ascertainment and completeness of records we collect and process data from a number of national and regional data feeds.

OBJECTIVES

NCARDRS WILL:

- **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 all research** into congenital anomalies, rare diseases and precision medicine from basic science, cause, prevention, diagnostics, treatment and management.
- **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.

SERVICE CONFIGURATION

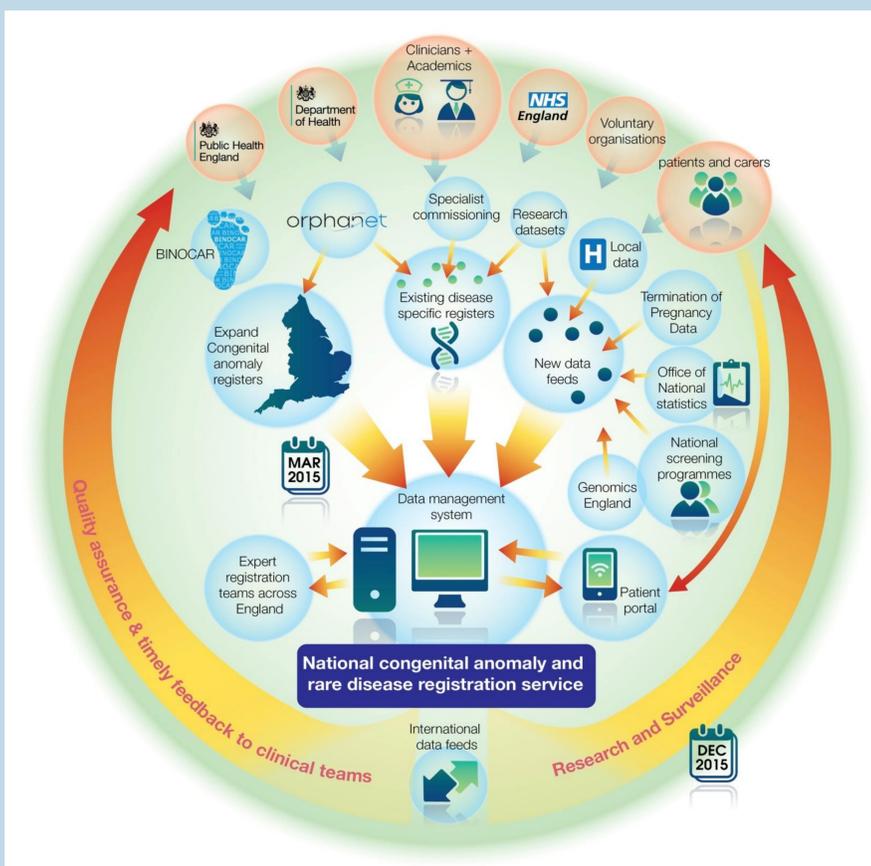


Figure. 1 NCARDRS Data flows and Interactions

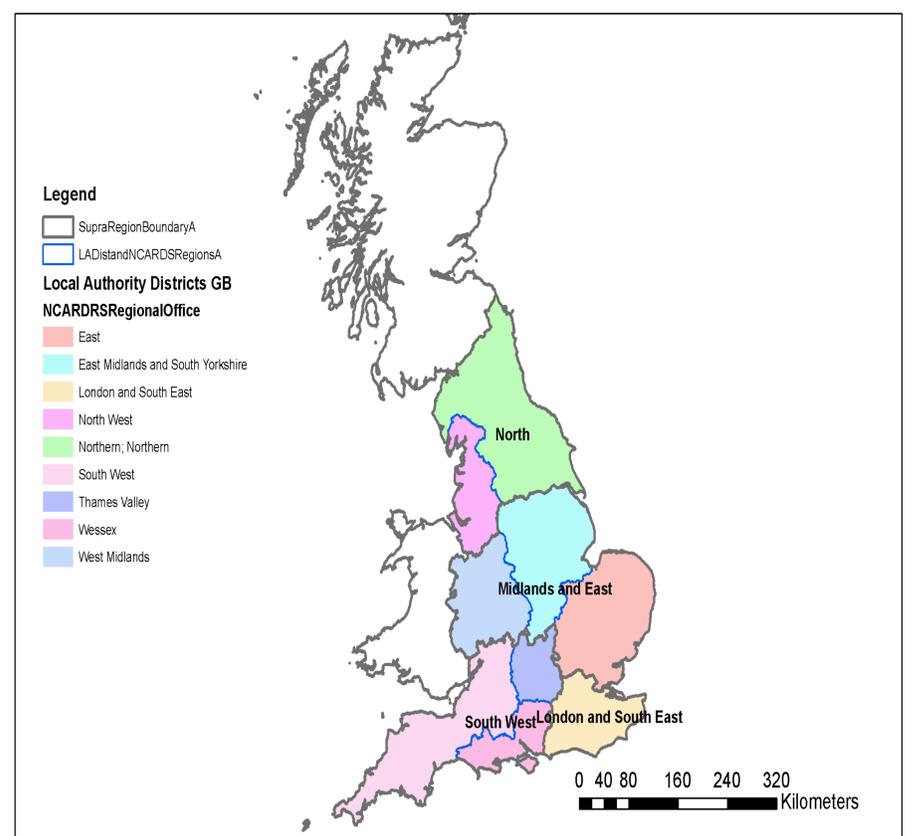


Figure. 2 NCARDRS Regional coverage map

PLANNED OUTPUTS

Planned outputs from the NCARDRS are to include data sharing with international organisations;

EUROCAT (European Surveillance of Congenital Anomalies) is a European network of population-based registries for the epidemiologic surveillance of congenital anomalies.

NCARDRS shares data with EUROCAT in order to pool data across a wider geographical area, make comparisons across Europe and share expertise.

Orphanet is an international rare disease and orphan drugs portal which aims to increase awareness of rare diseases and improve diagnosis, care and treatment of patients with rare diseases.

NCARDRS includes Orphanet UK, thereby creating an avenue for integrating global standards; Orphanet being an international rare disease and orphan drugs portal.

National and regional outputs are to include a national annual report, regional feeds for NHS Trusts, and specialised reports for patient groups.

Key stakeholders for all outputs:

- Researchers & research programmes
- Specialist clinical groups
- Patient groups and charities
- NHS commissioning bodies
- Specialist NHS Centres
- European registries & reference groups

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Reference:

1. www.binocar.org