National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) Privacy notice

May 2018
About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.
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Introduction

This document contains the key information to be communicated to data subjects under the General Data Protection Regulation (GDPR).

Data controller and data protection officer

The data controller for NCARDRS is Public Health England:

Public Health England
Wellington House
133-135 Waterloo Road
London SE1 8UG

The data protection officer is the PHE director of corporate affairs.

Purpose of the processing

The data is processed for the purposes of congenital anomaly and rare disease registration.

This registration service:

- provides a resource for clinicians to support high quality clinical practice
- supports and empowers patients and their carers, by providing information relevant to their disease or disorder
- provides epidemiology and monitoring of the frequency, nature, cause and outcomes of these disorders
- supports all research into congenital anomalies, rare diseases and precision medicine including basic science, cause, prevention, diagnostics, treatment and management
- informs the planning and commissioning of public health and health and social care provision
- provides a resource to monitor, evaluate and audit health and social care services, including the efficacy and outcomes of screening programmes
Legal basis for the processing

Under GDPR, the lawfulness of processing personal data for the PHE NCARDRS is under:

Article 6 e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

Under GDPR, the lawfulness of processing special categories of personal data for the PHE NCARDRS is under:

Article 9 h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services

AND

Article 9 i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices

NCARDRS also holds section 251 approval from the Secretary of State for Health and Social Care to collect this data.

The legitimate interests of the data controller

PHE has a legal duty to improve and protect the health of the population.

Categories of personal data collected

The categories of personal data collected include: name, address, demographics, diagnosis, tests and treatment data. This data is collected for the patient (and parents of the patient in cases of congenital anomaly).
Recipients of the personal data

Data can be sent to NHS organisations and research institutions where legal and ethical conditions have been met.

No transfers are made outside of the EU.

Retention period for the data

The nature of congenital anomaly and rare disease registration is such that the data collected now and in the past increases in relevance and usefulness over time.

The purpose of the registration process is to monitor congenital anomaly and rare disease prevalence, detection and outcomes over time in addition to monitoring changing environmental risks.

Consequently patient case records will be continually amended and updated. For this reason data are retained indefinitely but we will continue to review this requirement on an annual basis.

Data subject’s rights

Data subjects have the right to be informed about the processing of their data, the right to access their data and the right to opt out of the register.

Complaints

Complaints can be made direct to the registration service by emailing the PHE complaints department via complaints@phe.gov.uk

Or by writing to: Complaints manager, Strategy directorate, Public Health England, Wellington House, 133-155 Waterloo Road, London SE1 8UG
The source of the personal data

The data is collected from NHS organisations where the patient is diagnosed and/or treated. It is confidential data and therefore not publically available.

The data is held within the N3 (NHS) secure network and there are extensive and robust security controls in place to protect the data.