PHE’s Vision for the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

To develop and run a national congenital anomaly and rare disease registration service for England

As a resource for:

Patients, families and carers, clinicians, researchers, commissioners and public health professionals.

To:

1. provide a resource for clinicians to support high quality clinical practice.

2. support and empower patients and their carers, through the provision of information relevant to their disease or disorder.

3. provide epidemiology and monitoring of the frequency, nature, cause and outcomes of these disorders.

4. support all research into congenital anomalies, rare diseases and precision medicine including basic science, cause, prevention, diagnostics, treatment and management.

5. inform the planning and commissioning of public health and health and social-care provision.

6. provide a resource to monitor, evaluate and audit health and social-care services, including the efficacy and outcomes of screening programmes.

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