Data Provision Notice

National Disease Registration Service

Information Asset Owner: Sarah Stevens
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Contents

Change control

This is a revision of this Data Provision Notice to support the extension of scope of the collection.

The last version of this Data Provision Notice was issued by NHS England in February 2026 pursuant to a direction under section 254 of the Health and Social Care Act 2012 from the Secretary of State for Health and Social Care.

On 1 February 2023, the statutory functions of NHS Digital transferred to NHS England under the Health and Social Care Information Centre (Transfer of Functions, Abolition and Transitional Provisions) Regulations 2023 (Transfer Regulations). Under these Transfer Regulations, all directions from either the Secretary of State for Health and Social Care or NHS England to NHS Digital are now treated as directions from the Secretary of State for Health and Social Care to NHS England.

Consequently, the legal basis for this Notice is still the direction identified below, with its status now deemed to be a direction from the Secretary of State for Health and Social Care to NHS England under section 254 of the Health and Social Care Act 2012.

Background

The Health and Social Care Act 2012 (the **2012 Act**) gives NHS England statutory powers, under section 259(1)(a), to require data from health or social care bodies, or organisations that provide publicly funded health or adult social care in England, where it has been directed to establish an information system by the Secretary of State for Health and Social Care. NHS England may also request bodies that do not fall into one these categories to provide it with data to fulfil a direction.

The data, as specified by NHS England in this published Data Provision Notice, is required to support a direction from the Secretary of State for Health and Social Care to NHS England. Therefore, organisations that are in scope of section 259(1)(a) are legally required, and organisations in scope of section 259(1)(b) are requested, pursuant to section 259(5) of the 2012 Act, to provide the data in the form and manner specified below.

Purpose of the collection

On 1 October 2021, responsibility for the National Disease Registration Services (**NDRS**) transferred from Public Health England (PHE)[1] to NHS Digital as part of the government's reforms to the public health system announced in March 2021[2]. The Secretary of State for Health and Social Care directed NHS Digital to maintain and operate the NDRS from 1st

[1] PHE previously collected and analysed the data held in these Registries under section 2B of the National Health Service Act 2006 and Regulations 2 and 5 of the Health Services (Control of Patient Information) Regulations 2002 (**COPI**).
[2] https://www.gov.uk/government/publications/transforming-the-public-health-system

October 2021 under the National Disease Registries Directions 2021 https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/national-disease-register-service-directions (**Directions**).

On 1 February 2023, the statutory functions of NHS Digital transferred to NHS England[1] and the National Disease Registries Directions 2021 are now treated as Directions to NHS England.

The purpose of these Directions is to support the delivery for the operation and maintenance of the NDRS, which comprises the National Cancer Registration and Analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS), collectively the National Disease Registries.

The NCRAS aims to increase prevention and early diagnosis of cancer; and to improve the management of NHS cancer services, NHS cancer treatment and care, research and patient outcomes, including better quality of life and longer survival.

The NCARDRS aims to help the NHS in England, researchers, charities, people with congenital anomalies and rare diseases, and the public understand the prevalence of congenital anomaly and rare disease in England and to support wider understanding and treatment of these conditions.

The Directions enable NHS England to process confidential patient information for medical purposes[2] relating to:

- Individuals referred for the suspicion, diagnosis or treatment of cancer, including those being investigated for a possible inherited predisposition or with an inherited predisposition to cancer (the NCRAS), and
- Individuals with suspected, confirmed, or high genetic risk of congenital anomalies and rare or inherited diseases, and appropriate members of their family, such as where relevant, the parents of a child or fetus with a congenital anomaly and appropriate members of their family as determined by familial structure and or segregation of the condition within the family with a rare or inherited disease (the NCARDRS).

Such purposes include but are not limited to:

- the surveillance and analysis of health and disease;
- the monitoring and audit of health and health related care provision and outcomes where such provision has been made;
- the planning and administration of the provision made for health and health related care;
- medical research;
- the provision of information about individuals who have suffered from a particular disease or condition where:

[1] Under the Health and Social Care Information Centre (Transfer of Functions, Abolition and Transitional Provisions) Regulations 2023

[2] As defined in section 251(12) of the National Health Service Act 2006

- that information supports an analysis of the risk of developing that disease or condition, and
- it is required for counselling and support of a person who is concerned about the risk of developing that risk or condition or concerned about the risk of their child developing that risk or condition

- it supports identification of appropriate individuals for other direct care purposes such as targeted screening or access to testing

Benefits of the collection

Collection of data related to individuals referred for the suspicion, diagnosis, treatment or potential increased genetic risk of cancer aims to provide the following benefits:

- increase prevention and early diagnosis of cancer;
- support targeted screening initiatives for high risk groups;
- highlight and address inequalities in cancer diagnosis, treatment and outcomes;
- provide a real-world evidence-base to identify and enable best practice;
- improve the management of NHS cancer services;
- improve NHS cancer treatment and care; and
- improve patient outcomes, including better quality of life and longer survival.

Collection of data related to individuals with suspected, confirmed, or at increased genetic risk of congenital anomalies and rare or inherited diseases, aims to provide the following benefits:

- provide a resource for clinicians to support high quality clinical practice;
- support and empower patients, their carers and other family members by providing information relevant to their disease or disorder;
- through research and study determine the causes of congenital anomalies and rare diseases,
- improve diagnostics, treatment, and management of congenital anomalies and rare diseases; and

  inform the planning and commissioning of health and social care services for those affected or at risk.

More information about the NDRS and the benefits of the data collection are available on https://digital.nhs.uk/ndrs/.

Legal basis for the collection, analysis, publication and dissemination

Collection and analysis

NHS England has been directed by the Secretary of State for Health and Social Care under section 254 of the 2012 Act to establish and operate a system for the collection and analysis

of the information specified for this service. The direction and accompanying requirements specification are published on the NHS England website: https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/national-disease-register-service-directions

This information is required under section 259(1)(a) or requested under section 259(1)(b) of the 2012 Act in order for NHS England to comply with the above Directions.

In line with section 259(5) of the 2012 Act, all organisations in scope, in England, are required or requested (as indicated in the tables in Appendices A and B) to provide information to NHS England in the form, manner and period specified in this Data Provision Notice.

This Notice is issued in accordance with the procedure published as part of NHS England's duty under section 259(8).

Publication

Under section 260(1) of the 2012 Act, NHS England must publish all information it obtains by complying with a direction under section 254 or a request under section 255 of the 2012 Act unless the information falls within section 260(2).

In particular, in accordance with section 260(2)(d) of the 2012 Act, NHS England will not publish the information that is specified as not for publication in the Directions Requirements Specification.

Dissemination

NHS England will use its statutory powers, including those set out in Regulations 2 and 3 of COPI and section 261 of the 2012 Act to disseminate information it collects or obtains under these Directions via the Data Access Request Service (DARS) where there is a suitable legal basis.

All dissemination will follow established NHS England governance processes through the DARS including advice from the Advisory Group for Data (AGD) in accordance with the statutory guidance published by the Secretary of State for Health and Social Care under Section 274A of the 2012 Act.

Transparency

Transparency information about the National Disease Registration Service, providing information about the information collected, how it is used, the rights of individuals, including the right to opt-out and how to exercise these rights are published on the NHS England website: https://digital.nhs.uk/ndrs/transparency-notice

Those organisations within the scope of this Notice are also under an obligation to inform patients that their personal data is now being shared with NHS England for the purposes of providing the National Disease Registration Service. Providers of data should therefore update their patient transparency information to reflect that data which was collected previously by Public Health England and NHS Digital and will now be collected by NHS England.

Patient leaflets for both NCRAS and NCARDRS provide relevant and accessible information about cancer, rare disease and congenital anomaly registration for patients, carers and the public. Printed leaflets can be ordered from NDRS to give to patients by emailing ndrsenquiries@nhs.net. These leaflets are also available in digital form online at https://digital.nhs.uk/ndrs/patients/patient-leaflets.

The details of any data disseminations made by NHS England from this collection will be regularly published in the DARS Data Uses Register. DARS Data Uses Register: https://digital.nhs.uk/services/data-access-request-service-dars/data-uses-register For disseminations made before March 2024, these are available in the NDRS Data Release Register: https://digital.nhs.uk/services/independent-advisory-panel-on-data-release/data-release-register.

Persons consulted

NHS England has, as required under section 258 of the 2012 Act, consulted with the following persons in relation to the Directions and transfer of responsibility to NHS England of the NDRS:

Legacy Organisations:

- Public Health England (executive agency of the Department of Health and Social Care, formerly responsible for the National Disease Registration Service)
- NHSX (responsible for NHS data policy)
- NHS England and NHS Improvement

Current Organisations:

- Department of Health and Social Care (as the Directing organisation on behalf of the Secretary of State)
- The UK Health Security Agency (new executive agency of the Department of Health and Social Care)
- NHS Business Services Authority
- Office for National Statistics
- Representatives of those who are likely to use the information collected, e.g. researchers.

Scope of the collection

Under section 259(1)(a) of the 2012 Act, this Notice is served in accordance with the procedure published as part of the NHS England duty under section 259(8) on the following persons:

- Data provider organisations specified in **Appendix A** who are:
    - a health or social care body in England; or

  - any person (other than a public body) who provides health services, or adult social care in England, pursuant to arrangements made with a public body exercising functions in connection with the provision of such services or care.

Under section 259(1)(b) of the 2012 Act, this Notice is served in accordance with the procedure published as part of the NHS England duty under section 259(8) on the following persons:

- Non health or social care public body providers specified in **Appendix A**. These data providers include, but are not limited to:
  - Private health care providers including laboratory services
  - The British Pregnancy Advice Service (BPAS)
  - Organisations that hold or operate Congenital Anomaly or Rare Disease registers
  - The Healthcare Quality Improvement Partnership (HQIP)

Form of the collection

NHS England is collecting patient level, identifiable data for the NDRS (confidential patient information). This includes both personal data and special categories of personal data including:

- Demographic data – such as name, address, postcode, date of birth & age, NHS number, gender, sexual orientation and ethnicity
- Health data – such as Body Mass Index (BMI), height and weight, smoking and alcohol habits, genetic data including genomic test result data, information about cancer diagnosis and treatment, information about rare diseases and congenital anomalies.

National Cancer Registration and Analysis Service (NCRAS) data

The NCRAS data from the data sets listed in **Appendix A**, must be provided in accordance with the Information Standards where listed, or with any subsequently approved version of the same standard(s). Where no Information Standard is listed, the data should be provided according to the data specification provided by NDRS and in a format agreed between NDRS and the data provider to ensure provision of all relevant information required to satisfy the Direction.

National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) data

The NCARDRS data from the data sets listed in **Appendix A** must be provided in accordance with the Information Standards where listed or with any subsequently approved version of the same standard(s). Where no Information Standard is listed, the data should be provided according to the data specification in **Appendix B** or any other agreed data

specification and in a format agreed between NDRS and the data provider to ensure provision of all relevant information required to satisfy the Direction.

Manner of the collection

Data providers will be required to make their submissions to NDRS using agreed processes that reduce burden on both parties. Private patient data can be requested to complete gaps in records.

Timing of the collection

The data should be submitted to NHS England in accordance with the timings specified in Appendix A.

Data quality

Feedback on data validation, quality control, data completeness and timeliness of submissions is returned to data providers via secure data portals/dashboards/reports. If necessary, NDRS staff will review primary sources of the data in order to find vital and missing information. They may do this by contacting staff in provider organisations or by logging on to NHS hospital systems, where direct access has been agreed with a trust.

Burden of the collection

In seeking to minimise the burden it imposes on others, in line with sections 253(2)(a) and 265(3) of the 2012 Act, NHS England has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This process is carried out by the Data Standards Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching Data Alliance Partnership Board (DAPB) approval process. The DAPB, acting under authority of the Secretary of State, oversees the assurance, approval and publication of information standards and data collections for the health and social care system in England.

Burden assessments have not taken place for this collection as it is effectively a continuation of an existing collection previously undertaken by PHE. The urgent requirement for the data to continue to be collected in order to maintain the National Disease Registration Service outweighs the requirement for such assessments at this time.

Notwithstanding this, NHS England in seeking to minimise the burden of the collection has:

- Continuously engaged with PHE, NHSD and the NDRS in relation to the data collection
- Sought to maintain all existing operational processes operated by the NDRS for the collection

- Employed existing technical means, already employed by NDRS, to collect the data.

Appendix A - Scope, Form, Manner and Timing of collection

National Cancer Registration and Analysis Service (NCRAS) data

Data Provider Organisation type	Data set	Data Specification / Information Standards which apply	Manner	Timing
Providers of NHS cancer services in England	Cancer Outcomes and Services Data set (COSD) and other bespoke data collections as required.	DAPB1521: Cancer Outcomes and Services Data Set Or the most recent standards available on Data outputs and publications – NDRS: https://digital.nhs.uk/ndrs/data	Providers of the data should make their submissions as per the dataset technical and User Guidance available at Data outputs and publications – NDRS: https://digital.nhs.uk/ndrs/data	Monthly collection on the date agreed
NHS Trusts in England providing cancer services to patients from England and Wales	Systemic Anti-Cancer Therapy (SACT) Data Set	DCB1533: Systemic Anti-Cancer Therapy Data Set Or the most recent standards available on Data outputs and publications – NDRS: https://digital.nhs.uk/ndrs/data	Providers of the data should make their submissions as per the dataset technical and User Guidance available at Data outputs and publications – NDRS: https://digital.nhs.uk/ndrs/data	Monthly collection on the date agreed

Data Provider Organisation type	Data set	Data Specification / Information Standards which apply	Manner	Timing
NHS organisations in England that provide radiotherapy services to patients from England, Wales and Scotland. NHS England subcontracted overseas proton radiotherapy activity for NHS patients.	Radiotherapy Data Set (RTDS) and other bespoke radiotherapy collections as required (overseas proton, molecular radiotherapy and BARD)	SCCI0111: Radiotherapy Data Set DAPB0111: Radiotherapy Data Set Or the most recent standards available on Data outputs and publications - NDRS	Providers of the data should make their submissions as per the dataset technical and User Guidance available at Data outputs and publications - NDRS	Monthly collection on the date agreed
NHS organisations that provide the following services: • Genomic Laboratory Hubs • Molecular Pathology and Haematology laboratories Genomics England Limited (GEL)	Somatic Dataset	N/A, the information to be provided is the same information that was provided to PHE as part of the NCRAS collection prior to 1st October 2021 Or the most recent standards available on Data outputs and publications - NDRS	Providers of the data should make their submissions as per the dataset technical and User Guidance. Data outputs and publications - NDRS Genomic laboratory Hubs (GLHs) are responsible for providing data generated by their subsidiary Local Genomic Laboratories (LGLs)	Monthly collection on the date agreed
NHS Genomic Laboratory Hubs and Genomics England Limited (GEL) (where relevant)	Germline Dataset	N/A, the information to be provided is the same information that was provided to PHE as part of the NCRAS collection prior to 1st October 2021 Or the most recent standards available on Data outputs and publications - NDRS	Providers of the data should make their submissions as per the dataset technical and User Guidance available Data outputs and publications - NDRS	Monthly collection on the date agreed

Data Provider Organisation type	Data set	Data Specification / Information Standards which apply	Manner	Timing
NHS Clinical Genetics Services	National Inherited Cancer Predisposition (including Lynch Registry)	Data is captured in accordance with the data template which is available when Trust staff log into the submission portal available on the website Data outputs and publications - NDRS	Providers of the data should make their submissions as per the dataset technical and User Guidance available Data outputs and publications - NDRS	As required
NHS Trusts providing colonoscopy services	Post Colonoscopy Colorectal Cancer (PCCRC) audit data	Data is captured in accordance with the data template which is available when Trust staff log into the Audit portal	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems.	As and when available

Data Provider Organisation type	Data set	Data Specification / Information Standards which apply	Manner	Timing
NHS Trusts providing endoscopy services	Post Endoscopy Upper Gastrointestinal Cancer (PEUGIC) audit data	Data is captured in accordance with the data template which is available when Trust staff log into the Audit portal	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems. New NHS providers who began submitting after 1st October 2021 can do as per the specification which is available when Trust staff log into the Audit portal.	As and when available
NHS Trusts providing pancreatic imaging services	Post Imaging Pancreatic Cancer (PIPC) audit data	Data is captured in accordance with the data template which is available when Trust staff log into the Audit portal	Per the specification which is available when Trust staff log into the Audit portal.	As and when available
NHS Business Services Authority (NHS BSA) via UK Health Security Agency (UKHSA)	Primary care prescriptions data	In accordance with the agreements between NHS BSA and UKHSA, the information to be provided by NHS BSA to NHS England via UKHSA is the same information that was provided to PHE as part of the NCRAS collection prior to 1st October 2021	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems	Monthly collection on the date agreed

Data Provider Organisation type	Data set	Data Specification / Information Standards which apply	Manner	Timing
Office for National Statistics (mortality data) via UK Health Security Agency	Mortality data	In accordance with the agreements between ONS and UKHSA, the information to be provided by ONS to NHS England via UKHSA is the same information that was provided to PHE as part of the NCRAS collection prior to 1st October 2021	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems	Daily collection

Data Provider Organisation type	Data set	Data Specification / Information Standards which apply	Manner	Timing
Laboratories testing cases of SARS-CoV-2 via UK Health Security Agency	SARS-COV-2 subset of the Second Generation Surveillance System (SGSS)	'A guide for diagnostic laboratories' (SGSS dataset specification)	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems	As and when available
UK Kidney Association	UK Renal Registry (UKRR) data	• KRT start date • KRT modality at start • AKI alert first date of episode • AKI severity (worst severity within episode) • Primary renal disease (PRD)	Using the same IT systems or in the secure manner agreed between NHS England and the providers of the data as updated by NHS England.	Submitted at regular intervals as agreed by both parties.

Data Provider Organisation type	Data set	Data Specification / Information Standards which apply	Manner	Timing
NICOR	National Institute for Cardiovascular Outcomes Research Datasets – NICOR: https://www.nicor.org.uk/datasets	Datasets – NICOR: https://www.nicor.org.uk/datasets	Using the same IT systems or in the secure manner agreed between NHS England and the providers of the data as updated by NHS England.	Submitted at regular intervals as agreed by both parties.

National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Data Provider Organisation type	Services provided / Data set	Data Specification / Information Standards which apply	Manner	Timing
NHS organisations in England	Screening and diagnostic clinical laboratories, including NHS Genomic Laboratory Hubs, Genomics England (GEL), biochemistry, NIPT (including private patients) and cytochromes laboratory data.	N/A, the information to be provided is the same information that was provided to PHE as part of the NCARDRS collection prior to 1st October 2021 or as updated at Data outputs and publications - NDRS or in the rare diseases minimum dataset available Data outputs and publications - NDRS	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems or in the secure manner agreed between NHS England and the providers of the data as updated by NHS England.	Submitted at intervals agreed with individual laboratories
NHS (and private provider) organisations in England	Clinical Genetics Services, Specialised and Highly Specialised Services, maternity services, immunology services and other diagnostic and treatment clinical services including ultrasound, Badgernet data, manual individual notifications, post	N/A, the information to be provided is the same information that was provided to PHE as part of the NCARDRS collection prior to 1st October 2021 or as updated at Data outputs and publications - NDRS or in the rare diseases minimum dataset available at Data outputs and publications - NDRS	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems New NHS providers who begin submitting after 1st October 2021 can do so as per the following commissioning	As and when available

	mortem reports, case lists and PAS data.		documents: Data outputs and publications - NDRS	
NHS rare disease centres in England	Rare disease clinical services Rare disease minimum dataset available on: Data outputs and publications - NDRS	N/A, the information to be provided is the same information that was provided to PHE as part of the NCARDRS collection prior to 1st October 2021 Or the most recent standards available on: Data outputs and publications - NDRS	Providers of the data should make their submissions as per the dataset technical and User Guidance available at https://digital.nhs.uk/ndrs/ Additional data from charities, universities or other organisations is considered through the information governance Data Protection Impact Assessment process.	As and when available

Office for National Statistics (Births and mortality data) via UK Health Security Agency	Births and mortality data, ONS births and death data.	In accordance with the agreements between ONS and UKHSA, the information to be provided to NHS England by ONS via UKHSA is the same information that was provided to PHE as part of the NCARDRS collection prior to 1st October 2021	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems	Daily collection
The British Pregnancy Advice Service (BPAS)	Terminations due to fetal anomaly (BPAS data)	N/A, the information to be provided is the same information that was provided to PHE as part of the NCARDRS collection prior to 1st October 2021 or as updated at Data outputs and publications - NDRS	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems or in the secure manner agreed between NHS England and the providers of the data as updated by NHS England.	Quarterly collection on the date agreed

NHS Trusts in England providing cancer services to patients from England and Wales	Systemic Anti-Cancer Therapy (SACT) Data Set	DCB1533: Systemic Anti-Cancer Therapy Data Set Or the most recent standards available on Data outputs and publications - NDRS	Providers of the data should make their submissions as per the dataset technical and User Guidance available Data outputs and publications - NDRS	Monthly collection on the date agreed
Laboratories testing cases of SARS-CoV-2 via UK Health Security Agency	SARS-COV-2 subset of the Second Generation Surveillance System (SGSS)	'A guide for diagnostic laboratories' (SGSS dataset specification)	Providers of the data should continue to make their submissions of data in the same manner as they did prior to 1st October 2021 and using the same IT systems	As and when available
The Healthcare Quality Improvement Partnership (HQIP)	NCARDRS will collect data from HQIP relating to patients identified with congenital diseases to ascertain cases with suspected or confirmed congenital anomaly and/or rare disease and to complete data fields for cases	N/A data will be shared in line with Data Sharing Arrangements established between NHS England and HQIP established by virtue of the HQIP Data Access Request Process	Data shall be securely shared in the manner agreed between NHS England and HQIP	Data shall be securely shared in the timing agreed between NHS England and HQIP

	already notified to the NCARDRS for the purpose of improving the quality of the dataset. Including but not limited to, data from the National Child Mortality Database (NCMD), Maternal, newborn and infant clinical outcome review programme – MBRRACE and Paediatric Intensive Care Unit – PICANet			
UK Kidney Association	UK Renal Registry (UKRR) data	• KRT start date • KRT modality at start • AKI alert first date of episode • AKI severity (worst severity within episode) • Primary renal disease (PRD)	Using the same IT systems or in the secure manner agreed between NHS England and the providers of the data as updated by NHS England.	Submitted at regular intervals as agreed by both parties.

NICOR	National Institute for Cardiovascular Outcomes Research Datasets - NICOR	Datasets - NICOR	Using the same IT systems or in the secure manner agreed between NHS England and the providers of the data as updated by NHS England.	Submitted at regular intervals as agreed by both parties.
Rare disease patient charities	Rare disease patient charities membership or registry data (for members diagnosed with the indicated rare disease and who consent for their data to be shared with the NDRS)	Where available: • Full name • Date of birth • Self-reported gender • Postcode • NHS number • Diagnosis • Date of diagnosis	Data shall be securely shared in the manner agreed between NHS England and the providers of the data	Submitted at regular intervals as agreed by both parties.
NHS Trusts that submit data to the National Haemoglobinopathy Register: https://nhr.mdsas.com/ (NHR) (collection via MDSAS)	Sickle cell and thalassemia data from the NHR	Rare diseases minimum data set https://digital.nhs.uk/ndrs/data/data-sets/rdds	Data shall be securely shared in the manner agreed between NHS England and MDSAS	Data shall be securely shared in the timing agreed between NHS England and MDSAS

NHS Trusts and GP practices that submit data to the Universal Care Plan (UCP) (collection via North East London Integrated Care Board (NEL ICB)	Sickle cell and thalassemia data from the UCP	Rare diseases minimum data set https://digital.nhs.uk/ndrs/data/data-sets/rdds	Data shall be securely shared in the manner agreed between NHS England and NEL ICB	Data shall be securely shared in the timing agreed between NHS England and NEL ICB

Appendix B - NCARDRS Data Specification

Data items collected (where available) for the NCARDRS:

Data items:

1. Local ID
2. Baby's name
3. Baby's hospital number
4. Baby's NHS Number
5. Baby's address and postcode if different from mother
6. Date of booking (first check up in pregnancy)
7. Date of birth
8. Date of death
9. Place of booking
10. Place of delivery
11. Mother's name
12. Mother's hospital number
13. Mother's NHS Number
14. Mother's address and postcode at conception, booking and birth
15. Mother's date of birth
16. Father's name
17. Sex
34. Mother's drug use
35. Mother's alcohol use
36. Mother's medical history
37. Method of labour
38. Method of delivery
39. Type of birth
40. Survival
41. When anomaly/ rare disease was discovered
42. First positive prenatal test
43. Karyotype
44. Post-mortem performed
45. Syndromes and malformations
46. Estimated Date of Delivery (EDD)
47. Tests carried out and results
48. Screening, anomaly scan, diagnostic test (including private providers to complete NHS records)
49. Syndromes and malformations prenatally diagnosed
50. Outcome of pregnancy (including miscarriage/stillbirth/termination)
51. Consultant

18. Number of babies delivered	52. Details about post-mortems
19. Birth weight	53. Cause of death
20. Gestation	54. Procedures
21. Number of previous pregnancies	55. Mother’s country of birth
22. Number of previous pregnancies with anomalies	56. Place of death
23. Assisted conception	57. Referral
24. Consanguinity	58. Date of admission/discharge
25. Siblings with anomalies	59. Ethnicity of baby
26. Mother’s ethnicity	60. Rare diseases
27. Mother’s smoking habits	61. Morbidities association with condition
28. Mother’s BMI	62. GP details
29. Mother’s occupation	63. Prescription drugs
30. Father’s occupation	64. Father’s identifiers: DOB, address, NHS number
31. Father’s age	65. Family history of congenital anomalies and rare diseases
32. Family history of anomalies	
33. Mother’s folic acid use	