

1 June 2026

Service Configuration, Governance and Strategic Priorities

Section 1: System Structure & Governance

- 1. Have there been any changes to your commissioning or service delivery structures in the past 24 months (including mergers, hosted services, or collaborative arrangements)?**

Nephrology and Transplant: No

Respiratory: No

Regional Molecular Diagnostics Service (RMDS) : No. RMDS is the pathology service that delivers genetic testing for rare genetic disorders but delivery of rare disease services is the responsibility of a wide range of medical disciplines.

- 2. Are any services related to respiratory, transplant, or rare diseases commissioned or managed collaboratively (e.g. regional networks, hosted models, or lead-commissioner arrangements)?**

Nephrology and Transplant: No

Respiratory: No

RMDS: This is a regional laboratory service for delivery of genetic testing for rare genetic diseases and is commissioned directly to deliver genetic testing for the Region.

- 3. Are there any planned organisational or governance changes affecting these service areas over the next 12–24 months?**

Nephrology and Transplant: No

Respiratory: No

RMDS: No

Section 2: Roles, Committees & Decision-Making

- 4. Which committees or governance groups hold responsibility for pathway design and medicines optimisation in:**
 - **respiratory services – Drug and Therapeutics Committee**

1 June 2026

- **transplant services**
- **rare disease services?**

Service groups

5. Are there any named clinical leads, programme leads or specialist roles associated with these service areas?

Nephrology and Transplant : Yes there are a number of clinical lead or specialist roles within Nephrology and Transplant services:

- Patient Safety and Governance Lead – Transplant Surgery and Nephrology
- Organ Utilisation Lead
- Surgical Vascular Access Lead
- Transplantation and Living Donor Lead
- Clinical Lead for Nephrology
- Clinical Director

Respiratory: Yes

- Patient Safety and Governance Leads
- Service Improvement Lead
- Clinical Director

RMDS:

- Clinical Lead
- Service Improvement Lead
- Adult Rare disease Lead
- Childhood Rare disease Lead
- Clinical Director
- Other medical disciplines

6. Have any new roles or groups been established in the past 18 months that influence pathway design or medicines decision-making?

Nephrology and Transplant: No

Respiratory: No

RMDS: No, however, the establishment of a Clinical Advisory group to genomics is an absolute requirement in determining the priority for funding and delivering genomic testing to support pathway design and medicine decision making.

1 June 2026

Section 3: Strategic Priorities & Pressures

7. Please list any published strategies, transformation programmes or priority documents currently relevant to:

- **respiratory services**
- **transplant services**
- **rare disease services**

Nephrology and Transplant: Within NI Organ and Tissue Donation Act 2022, known as “Daithi’s Law” effective from 1 June 2023 which established an opt out system.

Public awareness campaigns by the DOH to include organ donation education in schools to increase awareness.

PHA Regional Strategy – introduced to address the shortage of organ donors

NHSBT Strategies – provide strategic planning for donation and transplantation across the UK

Respiratory: No current transformation programme

RMDS:

- Northern Ireland Rare Disease Action Plan 2022/23
- A Cancer strategy for Northern Ireland 2022-2032
- Genome UK: the future of healthcare
- Genome UK: shared commitments for UK-wide implementation 2022-2025
- Fit for Future: 10year health plan for England

8. Are any of these services currently subject to financial recovery, service sustainability review, or workforce mitigation activity?

Nephrology and Transplant: No

Respiratory: No

RMDS: The service is currently running at a cost pressure to the Belfast Trust. An outline business case is in development to address service requirements for future service delivery and to provide equity of testing for Northern Ireland patients.

1 June 2026

9. Are national or regional policy initiatives currently influencing planning in these areas?

Nephrology and Transplant: Yes

- [Substances of human origin \(SoHO\): review of UK legislation - call for evidence document - GOV.UK](#)
- [Travelling outside the UK for organ transplantation | Human Tissue Authority](#)

Respiratory: Yes, Sub-specialty specific guidance on services eg. asthma, lung cancer

RMDS: Yes

- Northern Ireland Rare Disease Action Plan 2022/23
- A Cancer strategy for Northern Ireland 2022-2032
- Genome UK: the future of healthcare
- Genome UK: shared commitments for UK-wide implementation 2022-2025

Section 4: Respiratory Services

10. Are respiratory services currently undergoing pathway review or service redesign (e.g. community respiratory, diagnostics, prevention, or virtual wards)?

Yes – respiratory is involved with the virtual ward pilot starting later this year.

11. Which respiratory disease areas are identified as priorities within current planning documents (if applicable)?

N/A

Section 5: Rare Disease & Transplant Services

12. How are rare diseases and transplant services overseen within your organisation (e.g. specialist pathways, regional networks, named leads, or national commissioning arrangements)?

By the service in conjunction with HTA and NHSBT