

Dear

**FREEDOM OF INFORMATION – SERVICE CONFIGURATION**

I write in response to your request for information in relation to service configuration.

Question:

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

Answer:

1.	Yes. Transplant services commissioned by National Services Division which was previously part of National Services Scotland. As of 1 April 2026, National Services Scotland has merged with NHS Education for Scotland, forming Public Services Delivery Scotland. No - respiratory services, transplant services
2.	Liver, kidney, pancreas and islet transplant are commissioned by National Services Division. Yes - Respiratory has Regional Networks for Lung Cancer Diagnostics, Managed Clinical Networks for Respiratory, Regional ILD MDT, Regional Sleep Centre, Lung Transplant Links are with Newcastle, Pulmonary Vascular Service is provided by Golden Jubilee Hospital, GGC and Rare Disease advice is sought Nationally. (NHS Lothian Respiratory does not lead commissioner arrangements as our funding model is not commissioning based as in NHS England - so not applicable)
3.	No – transplant services Yes – for respiratory - Sleep Pathways are in redesign phase and undergoing sustainability and value project. TB GIRFT report implications are being considered.

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Chair Professor John Connaghan CBE  
 Chief Executive Professor Caroline Hiscox  
 Lothian NHS Board is the common name of Lothian Health Board





Question:

**Section 2: Roles, Committees & Decision-Making**

4. Which committees or governance groups hold responsibility for pathway design and medicines optimisation in:
  - o respiratory services
  - o transplant services
  - o rare disease services?
5. Are there any named clinical leads, programme leads or specialist roles associated with these service areas?
6. Have any new roles or groups been established in the past 18 months that influence pathway design or medicines decision-making?

Answer:

4.	<ul style="list-style-type: none"> <li>• Local HMG, Resp MCN, SMC, Regional and Local Pharmacy Networks, Respiratory conditions - quality prescribing strategy: improvement guide 2024 to 2027. Respiratory Prescribing Strategy. NHS Sustainability Action. Scottish Polypharmacy Document. Respiratory Care Action Plan.</li> <li>• RIE Site CMG, Acute CMG, Acute Prescribing Forum, UHD Drugs and Therapeutics Committee. East Region Formulary. Scottish Medicines Consortium</li> <li>• Expert advice sought regionally and nationally when required.</li> </ul>
5.	<p>In some Respiratory subspecialties there is a named Clinical Lead eg - Sleep, Pulmonary Physiology. There are Lead Consultants for each of the Subspecialty Services available in Lothian. Our unit has the Consultant who is the National Clinical Lead for COPD. There is One Respiratory Clinical Director for each of the 3 Hospitals in Lothian.</p> <p>In Transplant the referring Consultant remains responsible for referral to Newcastle and providing on going shared care.</p> <p>We currently do not have a designated lead for Rare Diseases. Rare diseases remain under the referring Consultants - shared care agreement with National Specialist units.</p>
6.	<p>National Clinical Lead for COPD is from RIE Respiratory Unit.                  Redesign of Sleep Pathways - in progress.                  TB Gift Report - considering implications of this in terms of resource - in progress.</p>

Question:

**Section 3: Strategic Priorities & Pressures**

7. Please list any published strategies, transformation programmes or priority documents currently relevant to:
  - o respiratory services
  - o transplant services
  - o rare disease services.

8. Are any of these services currently subject to financial recovery, service sustainability review, or workforce mitigation activity?
9. Are national or regional policy initiatives currently influencing planning in these areas?

Answer:

7.	<ul style="list-style-type: none"> <li>• TB National Gift Report, CFSD Severe Pathway Document, CFSD Sleep Apnoea Services, CFSD Innovation Team - OSAHS wearable devices, Lung Cancer Diagnostic Pathways - Navigational Bronchoscopy Service and Robotic Bronchoscopy, Lung Volume Reduction Surgery and Endobronchial Valve Placement.</li> <li>• NHS Lothian does not have a transplant specific strategic document</li> <li>• NHS Lothian does not have a rare disease specific strategic document</li> </ul>
8.	<p>Yes</p> <p>Sleep Services are about to undertake a sustainability and value review process.</p>
9.	<p>Yes</p> <p>Yes - efforts are taken to keep abreast of National and Regional policies and adjust services to meet recommendations. eg The National Performance Framework (NPF) is Scotland's wellbeing framework and sets the vision for Scotland, Scottish Access Collaborative &amp; Modernising Patient Pathways Programme.</p>

Question:

**Section 4: Respiratory Services**

10. Are respiratory services currently undergoing pathway review or service redesign (e.g. community respiratory, diagnostics, prevention, or virtual wards)?
11. Which respiratory disease areas are identified as priorities within current planning documents (if applicable)?

Answer:

10.	<p>Yes - pathway review is an ongoing process and service redesign.</p> <p>In RIE we have an active Community Respiratory Team and have developed strong links with IJB's and community services. The Hospital at Home team have specific dedicated Respiratory Consultant Input. RIE fund and oversee Oxygen prescribing in Lothian. Hospital at Home Service run a virtual ward model. Simple spirometry has been encouraged to be undertaken by diagnostic hubs in GP clusters. We will improve equitable access to evidence based diagnostic tests by working with partners to reduce variation in the quality of spirometry testing across the area and design pathways for complex respiratory function testing.</p> <p>We are increasing access to pulmonary rehabilitation. We will design pulmonary rehabilitation pathways based on examples of best practice and test them in areas where improvement is required. We will look at ways of providing support to a wider group of people with rehabilitation and self-management support.</p> <p>We support clinicians and third sector to promote good practice and reduce variation in the quality of mental health support access.</p>
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	<p>We develop policies and procedures for a good transition from children and young people services to adult services for asthma, bronchiectasis, sleep, respiratory failure and ventilation.</p> <p>We are providing best practice palliative care for people with a lung condition as they near the end of life.</p> <p>We will work with stakeholders, in the context of the work taking place under the National Health and Social Care Workforce Plan, to explore how best to further support the development of appropriate expertise in the health and social care and support workforce for those working with people with respiratory conditions.</p> <p>We will modernise and keep up with modern lung cancer diagnostic techniques.</p>
11.	<p>As per Scottish Government Respiratory Care Action Plan Document - 2020 to 2026 - Dr Tom Fardon.</p> <p>The Plan focuses on 5 conditions: • Asthma • Bronchiectasis • Chronic Obstructive Pulmonary Disease (COPD) • Idiopathic Pulmonary Fibrosis (IPF) • Obstructive Sleep Apnoea Syndrome.</p>

Question:

**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)?

Answer:

There are nationally commissioned services for liver, kidney, pancreas and islet.

Rare diseases are managed by individual clinician with expert advice sought from National centres/ clinicians. We have access to regional networks and national centres as required on case by case basis.

eg:

**Genetic and Congenital Disorders**

- **Pulmonary Agenesis:** Absence or underdevelopment of one or both lungs, often diagnosed in infancy.
- **Alpha-1 Antitrypsin Deficiency (AATD):** Genetic deficiency leading to early-onset emphysema and liver disease. - COPD Consultant manages these cases.
- **Cystic Fibrosis (CF):** Causes thick mucus accumulation in lungs and other organs, managed with airway clearance and medications.- CF Unit is based @ WGH hospital.
- **Birt-Hogg-Dubé Syndrome (BHDS):** Genetic disorder causing lung cysts, spontaneous pneumothorax, and kidney tumors.

### **Interstitial and Fibrotic Lung Diseases**

- **Idiopathic Pulmonary Fibrosis (IPF):** Progressive scarring of lung tissue causing severe breathing difficulties. - ILD Consultant manages these cases.
- **Nonspecific Interstitial Pneumonia (NSIP):** Inflammation of alveolar walls, often linked to autoimmune conditions. - ILD Consultant manages these.
- **Diffuse Pulmonary Ossification:** Rare formation of bone tissue within the lungs.

### **Autoimmune and Inflammatory Disorders**

- **Sarcoidosis:** Formation of granulomas in lungs and other organs, potentially leading to fibrosis. - ILD Consultant manages these.
- **Pulmonary Alveolar Proteinosis (PAP):** Accumulation of surfactant in alveoli due to autoimmune or genetic causes. - ILD Consultant manages these.
- **Granulomatosis with Polyangiitis (GPA):** Rare vasculitis affecting small blood vessels in the lungs. - ILD Consultant Manages these with Input from Renal Vasculitis Team
- **Antisynthetase Syndrome (ASS):** Autoimmune disease involving interstitial lung disease, muscle inflammation, and arthritis. - ILD team manage these.

### **Vascular and Circulatory Disorders**

- **Pulmonary Arterial Hypertension (PAH):** Narrowing of lung arteries, leading to high pulmonary blood pressure. - Referred to GGC Golden Jubilee SVPU.
- **Beryllium Disease (Chronic Beryllium Disease):** Granulomatous lung disease caused by beryllium exposure. - Seen by General Respiratory Team.

### **Rare Cystic and Neoplastic Conditions**

- **Lymphangiomyomatosis (LAM):** Abnormal smooth muscle growth in lungs, primarily affecting women of childbearing age. - seen by ILD team.
- **Mesothelioma:** Rare lung cancer caused by asbestos exposure- seen by Lung Ca team - feed into National Mesothelioma MDT.
- **Pulmonary Alveolar Microlithiasis (PAM):** Calcium phosphate deposits in alveoli, extremely rare.
- **Diffuse Idiopathic Pulmonary Neuroendocrine Cell Hyperplasia (DIPNECH):** Overgrowth of pulmonary neuroendocrine cells, underdiagnosed and rare. - Seen by General Respiratory Team.

**Environmental and Occupational Causes**

- **Asbestosis:** Chronic lung scarring from asbestos exposure - managed by ILD Team.
  - **Hypersensitivity Pneumonitis (HP):** Lung inflammation from inhaled allergens like mold or chemicals - managed by ILD team.
- Acute Chest Syndrome:** Complication of sickle cell disease affecting the lungs - managed by Haematology.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at [www.itspublicknowledge.info/Appeal](http://www.itspublicknowledge.info/Appeal). If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhslothian.scot/FOI/Pages/default.aspx>

Yours sincerely

**ALISON MACDONALD**  
**Executive Director, Nursing**  
Cc: Chief Executive