

Scottish Paediatric and Adult Infection and Immunity Network (SPAIIIN)

Annual Report
2024/25

Lead Clinician:	Vacant
Programme Manager:	Hugh Kennedy (to 30/09/24) Gillian Kinstrie (from 01/10/24)
Programme Support Officer:	Mary Glen (to 30/09/24) Chris Williamson (from 01/10/24)

This document has been prepared by NHS National Services Scotland (NSS) on behalf of the Scottish Paediatric and Adult Infection and Immunology Network (SPAIIIN). Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. SPAIIIN is a collaboration of stakeholders involved in care of people with a Primary Immune Deficiency and children with blood borne virus who are supported by an NSS Programme Team to drive improvement across the care pathway.

Introduction

In 2011, the Scottish Paediatric and Adolescent Infection and Immunology Network was launched to improve access and the quality of services for children with HIV infection or a Primary Immune Deficiency (PID). In 2016 the scope of the network was expanded to reflect emerging priorities, specifically:

- To include children infected with other Blood Borne Viruses - Hepatitis B and C infection.
- To strengthen PID activities with respect to genetic testing and new treatment modalities to include care for adults which included developing pathways for stem cell transplant and genetic testing.

In 2016, the network was renamed as the Scottish Paediatric and Adult Infection and Immunology Network (SPAIIIN) to reflect the expanded remit for adults.

The network aims to support the delivery of an equitable high-quality service across Scotland, underpinned by evidence based clinical pathways and guidance, to deliver care as locally as possible and with the full involvement of patients and families. The early recognition of primary immunodeficiencies and children infected with blood borne viruses is key to delivering good clinical outcomes. To achieve this, the network raises awareness and knowledge at both primary care and general paediatric level to ensure that appropriate early referral occurs.

Current Position

A review of the network was undertaken between November 2023 and April 2024. The purpose of the review was to provide an independent and objective assessment of the network performance, make recommendations as to the best configuration of the network and inform future delivery. In June 2024, the National Specialist Service Committee (NSSC) approved the recommendation from NSD for continued designation of the national MCN. A number of recommendations were made with most of these completed and delivered within the deadlines agreed.

Dr Fiona Marra's tenure as Lead Clinician ended on 31 March 2024. Interim leadership arrangements have been in place during 2024/25, ensuring continuity of activity while formal recruitment is aligned with national review outcomes.

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development.

The actions prioritised for SPAIIIN were:

Priority Action	Progress
Design a national clinical pathway for Hepatitis B and develop KPI's to measure adherence to the pathway.	Pathway well established in NHS GGC, with all GGC patients identified adhering to pathway. National pathway being developed with NHS Lothian as only these two centres treat HBV patients in Scotland. All positive HBV children and young people have now been identified in Scotland, with KPI's developed and agreed. A CAS instance has been developed to measure treatment against these KPIs. Pathway expected to be endorsed in Q1, 2025/26
Engage with teenagers who have HIV and are nearing transition to understand their priorities for improvement. Develop an action plan which can be measured to assess effectiveness of plan.	This activity had been delayed due to service pressures however a patient experience survey has now been developed and the scope has been expanded to include all young people who attend a BBV clinic. The survey will be rolled out in Q1, 2025/26.
Deliver the recommendations of the network review	Most recommendations are complete and were delivered within the deadlines agreed. The two recommendations outstanding, the HBV Pathway and Adult HSCT Pathway, are both expected to be complete in Q1, 2025/26

All business as usual objectives on the 2024/25 workplan were completed.

The network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel and promoting economic and climate friendly practices.

Highlights

Education

Education is a core objective for all Managed Clinical Networks. In December 2024 the SPAIIN 2024-2026 Education Strategy was endorsed which outlines the objectives and outcomes of the education the network will deliver over the next three years. A review of the previous strategy by Steering Group members and a learning needs analysis with network stakeholders informed the development of this refreshed education strategy.

In January 2025, SPAIIN launched a programme of education sessions aimed at health care professions with an interest in infectious diseases and immunology. The education sessions last around an hour and take place at lunchtime on the last Thursday of alternate months via MS Teams. Sessions are recorded and available to watch at a later date via a dedicated SPAIIN Education MS Teams Channel which now has 84 members (as at 31st March 2025). Two sessions were held in 2024/25 - details of each session is provided below:

Date	Session	Attendees
27/02/2025	Updates from 'HIV Glasgow' <i>Dr Fiona Marra, Consultant Pharmacist, NHS Greater Glasgow and Clyde</i>	29*
27/03/2025	Reflections on a career in Paediatric Infectious Diseases <i>Professor Hermione Lyall, Consultant Paediatrician in Infectious Diseases, Imperial College Healthcare NHS Trust</i>	22*

*Known attendees – people shared screens in meeting rooms so numbers likely to be higher.

Informal feedback from staff who have attended the education sessions has been positive to date. An evaluation is planned to be undertaken following the third session in May to ensure these are meeting the needs of health care professionals and to inform the future of these.

The network also compiled a list of educational resources and podcasts which should be of interest to health care professionals working in infectious diseases and immunology and shared this on the website in January 2025.

Due to the current financial constraints within NHS Scotland, networks were asked to hold education events virtually to reduce costs to local NHS Boards for staff travel. SPAIIN members valued the opportunity network events offer to meet with staff from a range of specialties supporting immunology and infectious diseases working across Scotland and therefore agreed that the annual education event would not take place in 2024/25.

Genetic Pathway KPIs

The SPAIIN Genetics Pathway Subgroup has continued to meet with three meetings held during 2024/25. The purpose of this group is to support improvements in the genetics pathways for children and adults affected by PID as well as providing a forum for discussion of challenging immunological cases, professional peer support, and dissemination of medical knowledge.

In February 2025 the group agreed the following KPIs:

1. Discuss and provide justification for streamlining gene panels and addition of any new relevant genes. Proposed changes and justification to be collated on Meeting Action Tracker.
2. Discuss challenging patient cases utilising the clinical, scientific and laboratory expertise within the MDT to support patients who need accurate and timely genetic investigation in order to receive optimal treatment.
3. Review Request Form and put forward proposed amendments annually. Annual review supports panels to remain clinically relevant by removing variants that no longer need to be assessed and including new discovered genes and clinical phenotypes to improve diagnosis of patients with a PID.

Adult HSCT Pathway

In December 2023 the network endorsed a Haematopoietic Stem Cell Transplant (HSCT) Pathway for Adults, however, this guidance was paused due to discussions internally with NSD regarding the process around out of area transfers. In December 2024, work to finalise the pathway resumed and revised guidance was shared with the adult transplant team in Glasgow for feedback. The comments are currently being reviewed and it is anticipated that the pathway will be endorsed in Q1, 2025/26.

Adult immunology services are experiencing workforce pressures, with recruitment challenges impacting service sustainability and this may impact the viability of this pathway. Collaborative efforts are underway to explore solutions and support continuity of care.

Audit and Continuous Quality Improvement

In August 2024 the SPAIIN 2024-2026 Quality Strategy was endorsed which outlines the Networks approach to improving quality in the care of children and young people with HIV, Hep C and Hep B and children, young people and adults with PID across Scotland.

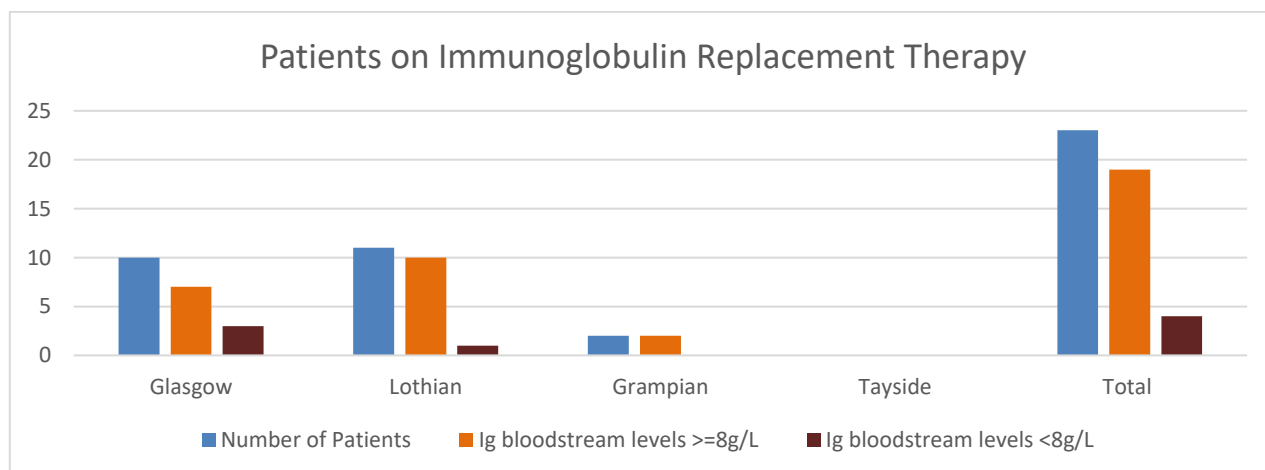
This year, a KPI for children with Hepatitis B Virus (HBV) was developed - All patients diagnosed should be discussed at an MDT twice per annum and ALT and APRI blood tests scored at the above. A CAS instance for collecting data on HBV was established but has not been used by network members to date due to discussions around the usefulness of CAS.

To support collection of data for HSCT, a Data Collection Template was agreed on Excel and IMS have agreed template/process from an information governance perspective. The template has been shared for roll out beginning Q1 2025.

Performance against the KPIs in 2024/25 is noted below:

- KPI1: Paediatric Immune Deficiency (PID)

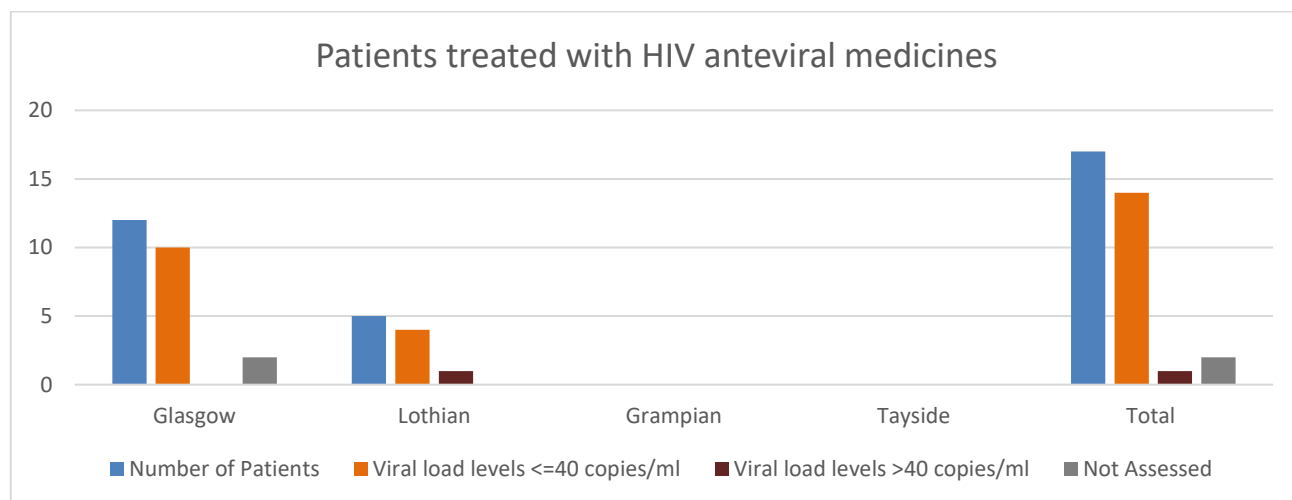
Treatment for all children and adolescents on immunoglobulin replacement therapy is effective. This is measured through testing patients to establish the amount of immunoglobulin in their bloodstream. A count of $>8\text{g/L}$ is deemed effective.



Glasgow	10 patients, 3 of whom are just below target level. All 3 have had dose increased and repeat monitoring arranged.
Lothian	11 patients, 1 of whom has just dropped below the target level.
Grampian	2 patients. One patient has variable levels but currently above target.
Tayside	No patients.

- KPI2: HIV**

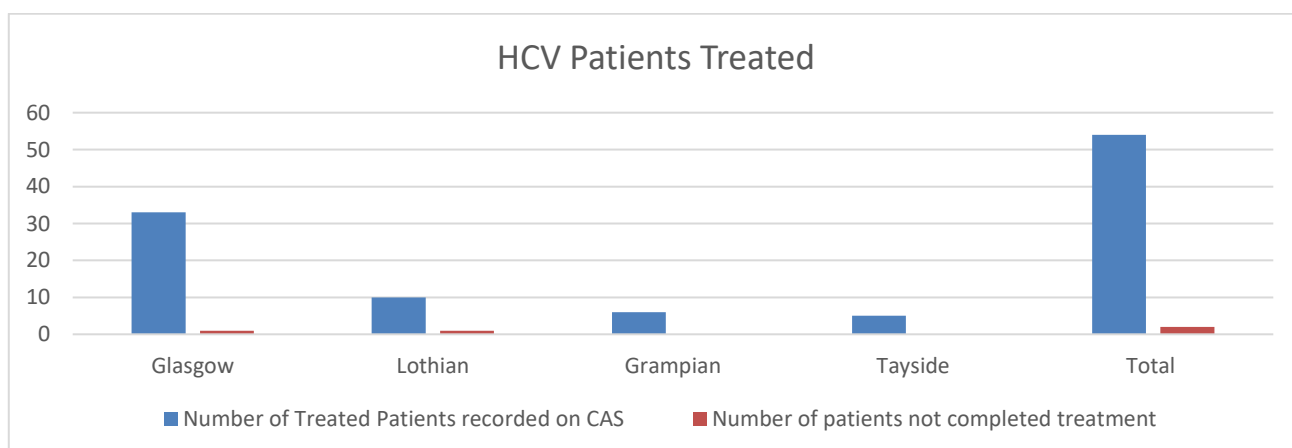
All children and adolescents infected are virally suppressed after 12 months on antiretroviral treatment. This is indicated by a viral load <40 copies/ml.



Glasgow	12 patients, 10 of whom met target for viral suppression. 2 patients have not yet been on treatment for 12 months to assess.
Lothian	5 patients, 4 of whom met target for viral suppression.
Grampian	No patients.
Tayside	No patients.

- KPI3: Hepatitis C Virus (HCV)**

All children and young people known to service with a diagnosis are followed up on a clinical pathway.



Glasgow	1 patient untreated - ASD and currently cannot tolerate treatment. Revisiting every 6 months.
Lothian	1 patient untreated - refusing treatment.

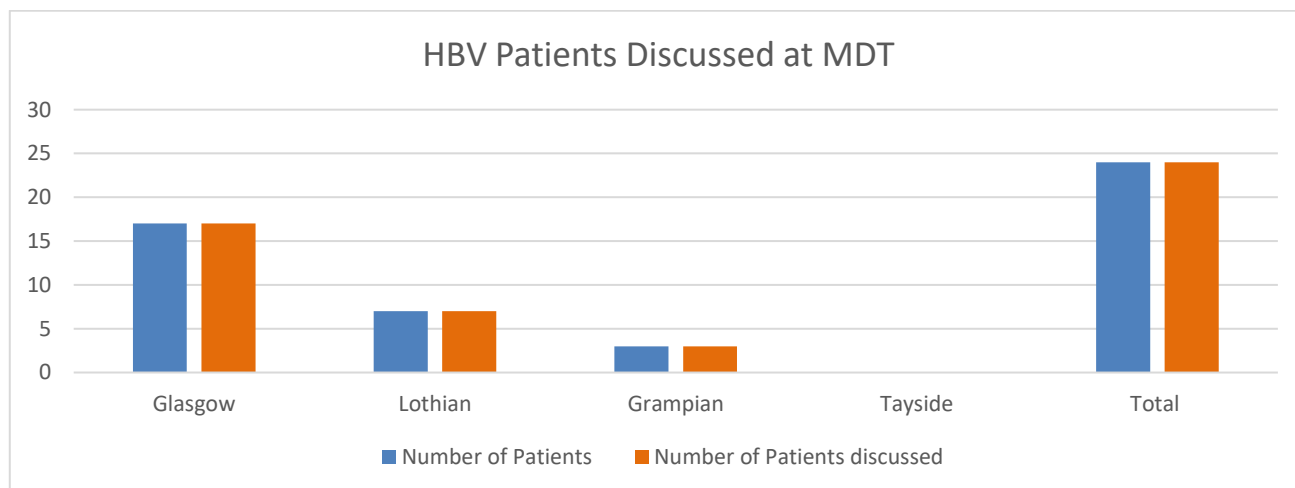
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Grampian	All patients completed treatment.
Tayside	All patients completed treatment.

- KPI4: Hepatitis B Virus (HBV)**

All patients diagnosed should be discussed at an MDT twice per annum and ALT and APRI blood tests scored at the above.



Glasgow	17 patients. All discussed at first paediatric national HBV MDT with plan in place for next 12 months.
Lothian	7 patients. All discussed at first paediatric national HBV MDT with plan in place for next 12 months.
Grampian	3 patients. All patients discussed with Hepatologists from King's. From 2025 all patients will be discussed at paediatric national HBV MDT.
Tayside	No patients.

Looking forward – 2025/26

Due to ongoing review of national networks, networks have been asked to only plan activity for Quarter 1, 2025/26. SPAIIN have agreed the following activities:

Carried forward from 2024/25:

- Publication of HBV Pathway
- Publication of Adult HSCT Pathway

Network Business as usual activity:

- Steering Group Meeting
- Genetic Pathway Meeting
- SPAIIN/SPARN Joint Education Session
- Evaluation on Education Sessions
- Roll out of HSCT Data Collection template
- Roll out of patient experience survey

Finance

The network operated within its allocated budget in 2024/25, focusing on low-cost, high-impact activities such as virtual education and digital resource development.

Risks & Issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals.

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits.

Adult immunology services are experiencing workforce pressures, with recruitment challenges impacting service sustainability. Collaborative efforts are underway to explore solutions and support continuity of care.

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