

Scottish Paediatric and Adult Infection and Immunology Network (SPAIIIN) ANNUAL REPORT 2023/24

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Introduction

The Scottish Paediatric and Adult Infection and Immunology Network (SPAIIIN) was launched in February 2011 as a Managed Clinical Network for the care of children with HIV infection or a Primary Immune Deficiency (PID).

SPAIIIN underwent a review in 2016, resulting in the network expanding its scope to reflect emerging priorities, specifically:

- To include children infected with other Blood Borne Viruses (BBV) - 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.

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

20/22 (91%) Business as Usual objectives were achieved. The two unachieved were a summer newsletter and restarting the teleclinic education sessions. Clinical pressures and competing workloads of staff were the cause. Both workstreams are being reinstated for the 2024/25 workplan.

6/7(86%) Service Delivery objectives were achieved. The development of a CAS core dataset to audit both paediatric and adult PID patients requiring a stem cell transplant was delayed due to staffing pressures on immunology clinicians with a nationwide shortage and recruitment crisis in the field. This work is now back on track with the dataset planned for completion by the end of April 2024.

Lead Clinician Reflection

SPAIIIN has continued to grow its services in 2023/2024 with key successes and new developments. We were delighted to add 2 new Consultants to the steering groups from Immunology and Neonatology. The sign off the Haematopoietic Stem Cell Transplant Pathway for Adults was a complex piece of work that will provide benefits in the integrated and equitable care of these patients in Scotland, particularly important as the adult immunology service faces a national staffing shortage. The genetics MDT in addition to this continues to be a success of the network with the optimisation of gene panels and the discussion of complex cases being just a few of the benefits of the national meeting.

Blood borne virus services in Scotland continue to flourish within paediatrics with all known children with HCV now cleared virus or offered treatment. This is a huge step in the WHO eradication targets set out globally. This year the network also mapped out HBV cases nationally to allow for all cases to be mapped and managed by the SPAIIIN hepatitis MDT. We await new treatment guidelines for the management of HBV in children. HIV care continues to the same high standard with no new vertical transmissions reported this year again and high level of HIV control, more than reaching the WHO 90:90:90 targets.

The network is in a strong place, and I look forward to a smooth handover to a new Lead Clinician to continue the growth. Thank you for all the support from NSS and a great steering group who have enabled all our successes.

Highlights

Service Development and Delivery

Development of a Haematopoietic Stem Cell Transplant (HSCT) Pathway for Adults

The pathway has now been completed and endorsed by SPAIIN. It has been sent to NSD for endorsement of Service Agreement with NHS England Adult HSCT Centres.

Guidelines and Pathways

The following guidelines and pathways were reviewed during the year, updated, and placed on the SPAIIN website:

- Haematopoietic Stem Cell Transplant for Children and Young People Pathway
- Annual Review of Patients with Hypogammaglobinaemia Guideline
- De George Pathway
- HIV Annual Review Guideline.

Development of Genetic Service Model

The network continues to work with the Aberdeen genetics laboratory to progress an improved model of care for genetic testing of children and adults affected by a PID. Three meetings were held during the year and again have again proved a great success. Improvements continues in the following areas:

- reviewing and updating request forms in relation to various genes and clinical phenotypes
- optimising gene panels, through updating them into common themes. This reduces the number of variants that need to be assessed by the genetics lab. It also makes it easier for the immunologists to select the relevant genes to be tested so that all patients are getting the same test requested encompassing all the relevant genes.
- formalising data collection-i.e., no of referrals, who referred, and panels requested.
- providing a forum for discussion of challenging immunological cases, professional peer support, and dissemination of medical knowledge. Both immunologists and the genetics lab have stated that joint case presentations have proved useful for learning both from the immunology and genetics perspective and very informative to gain a complete picture of the patient's presentation and outcomes of testing.

All these changes have improved the quality of PID genetic diagnosis leading to more robust ongoing management and care. Two specific cases that were very successful this year through the MDT process was where the case discussions identified a different approach leading to more appropriate care.

Hepatitis C (HCV) Service Development

the network continued to make significant progress in supporting clinical services to ensure children identified as positive are being treated with newly licenced medications. During the year it was verified that all children under 18 years old who tested positive for Hepatitis C have now been identified and offered treatment.

Advances in treatment mean there is a 98% cure rate, so this has enabled children in lifelong hospital services to be completely discharged.

There is also ongoing national initiative to build a case for Universal screening of Hepatitis C in pregnancy in combination with Prof Sharon Hutchison and team at Glasgow University. The

network provided data, presented at the December 2023 education event, to support the development of a case for change.

Hepatitis B (HBV) Service Development

One of the key priorities of the network continued to progress during the year was to identify all children in Scotland with an HBV infection and develop a national treatment care pathway to ensure all HBV positive children are treated appropriately. Unlike HCV, there is an antenatal screening programme for HBV in Scotland, with a follow-up vaccination protocol for any positive results to prevent any chronic infection. There is still a risk of failure to follow-up with some of these babies as well as overseas births (now resident in Scotland) where no immunisation programme was in place. Evidence has shown that 90% of babies and 30 to 50% of children under six years who carry the virus and are not on treatment will develop chronic infection which can lead to liver cirrhosis and hepatocellular cancer (HCC). The network developed and implemented a plan involving contacting the three regional virology laboratories in Glasgow, Edinburgh and Aberdeen who hold all the positive HBV diagnosis of babies and children in Scotland. This was successfully completed with results showing that all children had been followed up appropriately. The network has also developed a core dataset which it submitted to IMS to progress development of a system to monitor patients and their treatment against the pathway which will be developed in 2024/25.

HIV Service Development

The implementation of the HIV Perinatal Care Pathway continues to impact on children at risk of vertical transmissions (the most common cause of HIV infection in children and young people). The pathway has strengthened national awareness of care amongst centres who manage these pregnancies in this group and re-enforced linking in with specialist centres in the complex cases. Thus, as in every year since 2011, this year there has been no vertical transmission during the year in children who have progressed through maternity services in Scotland. Missed diagnosis is a particular issue for families from HIV endemic countries, particularly recent immigrants and/or asylum seekers. The network pharmacist continues to be involved nationally in prescribing or advising on safe, once daily antiretroviral (ARV) regimens that are cost effective.

Network Review

SPAIIIN was reviewed, between November 2023 and April 2024. The purpose 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. The methodology used was to assess the performance of the network from 2017/18 to 2023/2024 against the aims and objectives set out in the Service Agreement (SA).

In addition, the review looked at progress against the four recommendations made from the last SPAIIIN review in 2016.

SPAIIIN supported the review process by supplying information in line with queries raised by the review team.

The final report will be completed by April 24th and submitted for review at the SMG-C on May 2nd. If approved, it will then be submitted to NSSC on 17th June for final review. The final version of the report can be shared with the network after this approval.

Stakeholder Communication and Engagement

Website/Newsletter

The website moved to a new platform during the year making it easier to navigate with the aim of increasing use by stakeholders. The network has continued to monitor content to ensure it is kept updated with relevant and appropriate content for network stakeholders relevant to NNMS website guidance.

A winter newsletter was also produced and placed on the website.

<https://www.nn.nhs.scot/spaiin/news-and-events/news/>

Patient Engagement

SPAIIIN has acknowledged longstanding challenges as PID charities have limited paediatric patient/family involvement, and HIV stigma means that it is difficult to engage families living with HIV. SPAIIIN intends to carry out a patient engagement survey in April-June 2024, with the use of interpreters, if necessary, to gather views of patients with HIV whilst in clinics.

Stakeholder Survey

A stakeholder survey was shared in March 2024 to gather feedback from people who currently work within, are involved in, or are impacted by the network. The survey was shared with 140 stakeholders and 17 responses were received (12% response rate).

While the number of responses was disappointing, a lot of positive feedback was received and highlights the value added by the network:

- 71% responses 'strongly agreed' or 'agreed' that the network provided a structure to make service improvements in immunology and infectious disease care.
- 70% responses 'strongly agreed' or 'agreed' that the networks service development activity adds value to immunology and infectious disease care.
- 82% responses 'strongly agreed' or 'agreed' that the networks education offering adds value to immunology and infectious disease care.
- 50% responses 'strongly agreed' or 'agreed' that the networks audit and continuous quality improvement activity adds value to immunology and infectious disease care.

This table includes a summary of all survey responses. However, it is acknowledged that some response views may not be relevant to the role and or remit of the National Managed Clinical Network.

Strengths	Areas for Improvement
<ul style="list-style-type: none">• Peer support and networking.• Conduit for sharing information to and from clinical services.• Provision of specialist information.• Facilitates connections and collaboration.• Shared vision and purpose.• Education, for example, education day event.• Ensuring best practice evidence-based care available across Scotland regardless of geographical location.• National MDT approach to decision-making.	<ul style="list-style-type: none">• Despite some positive responses to the questions around NSD support, there are a number of neutral or disagree responses from Steering Group members (three responses) which could indicate potential room for improvement.• Improve collaborative working across Scotland.• Develop priorities based on changing epidemiology of BBV and new developments in the management of immune deficiency.• Stronger presence and leadership for adult immunology.• More teaching events.
Future Priorities (3-5 years)	Network Challenges/Threats
<ul style="list-style-type: none">• Engaging consultant colleagues.• Inclusion of TB, migrant health and CMV in NMCN activities.• Continue to strengthen professional and personal networks.• Provision of guidelines and education to allow local clinicians to deliver care closer to home for some patients.	<ul style="list-style-type: none">• Low number of immunologists.• Lack of time to commit to NMCN activity from small number of clinicians involved.• Lack of patient representation in the NMCN due to a diverse patient group with very different conditions, meaning

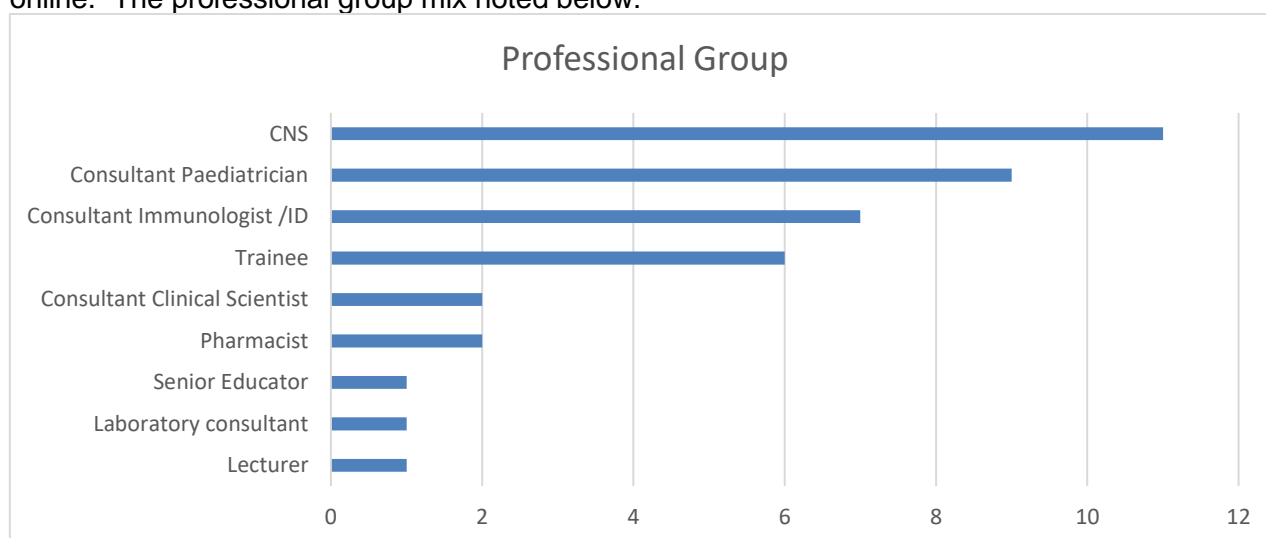
<ul style="list-style-type: none"> • Support colleagues to develop in to local and national leadership roles. • Formalise specialist pathways for care i.e. BMT for adult PID, HBV pathway and CAS. • Improved online resources. • New leadership • Encourage wider participation through advertising the objectives of the NMCN across Scotland. 	<p>no one group can represent the journey of others.</p> <ul style="list-style-type: none"> • Patients unaware of the positive impact of the NMCN to their care, as the NMCN is not visible to them and it is difficult to communicate this to them. • Work pressure and unrealistic expectations may lead to loss of experienced staff in the field. • Lack of opportunity for face-to-face education meetings and national strategic planning.
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The feedback received will be considered by the SPAIIN Steering Group and an action plan to support areas for improvement will be developed.

Education

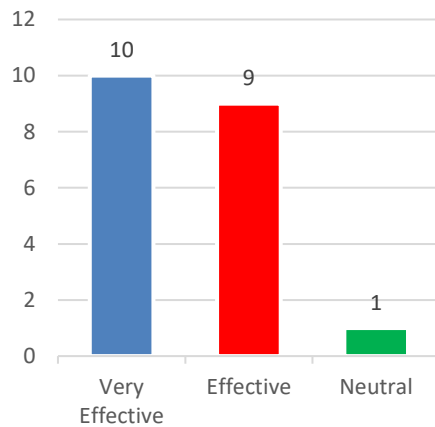
Annual Conference

SPAIIN hosted their Annual Education Event on Monday 11th December 2023 at the National Education for Scotland (NES) venue in Glasgow. In total, 40 people attended - 22 in person, 18 online. The professional group mix noted below:

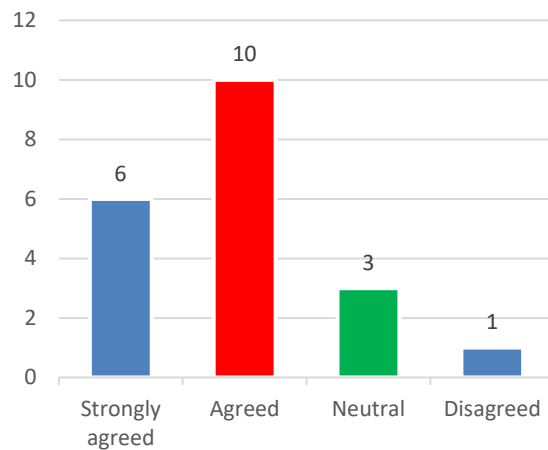


20 of the 40 attendees completed the networks Post-Event Evaluation:
Results are graphically shown below:

Impact on knowledge of immunology and infectious diseases

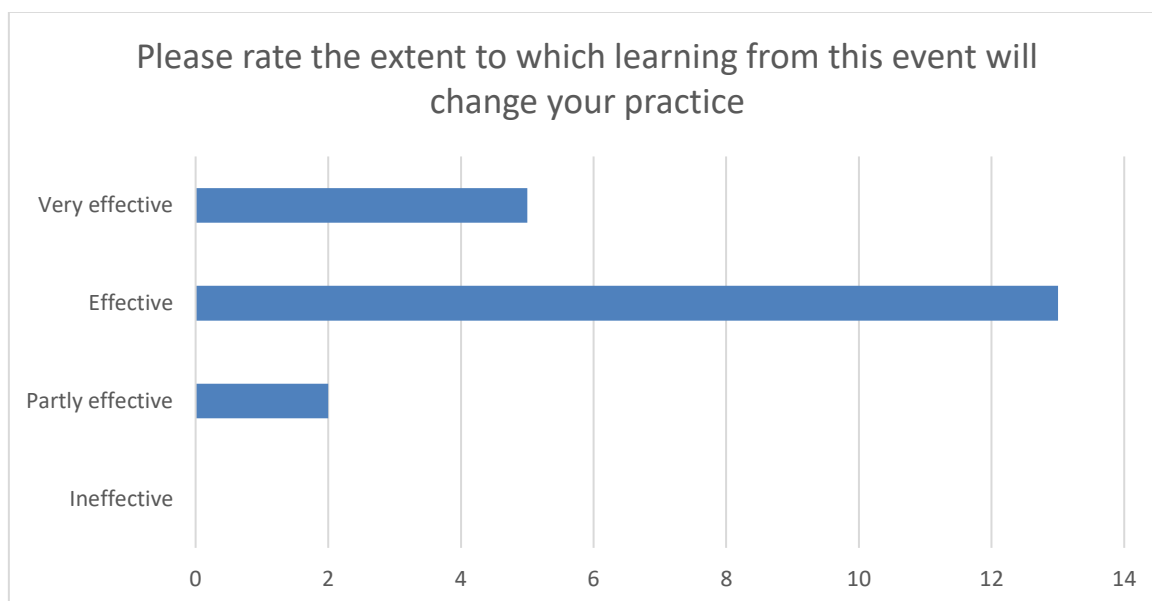


Impact on opportunity to network and learn from each other



Attendees were asked to score each presentation. The results reflected that most attendees agreed that the 'delivery' and 'content' of each was well received and to a high standard and met their learning needs.

The table below reflects how the learning from this event would effectively change practice:



Examples included:



The network has made both these presentations and those from the 2022 event available on its Education channel on MS Teams. All members of the wider network distribution list have been made aware of this and given instructions on how to access them.

Audit and Continuous Quality Improvement

The network recently developed its Quality Improvement Strategy, focusing on the delivery of the following:

Reporting Against SPAIN Key Performance Indicators

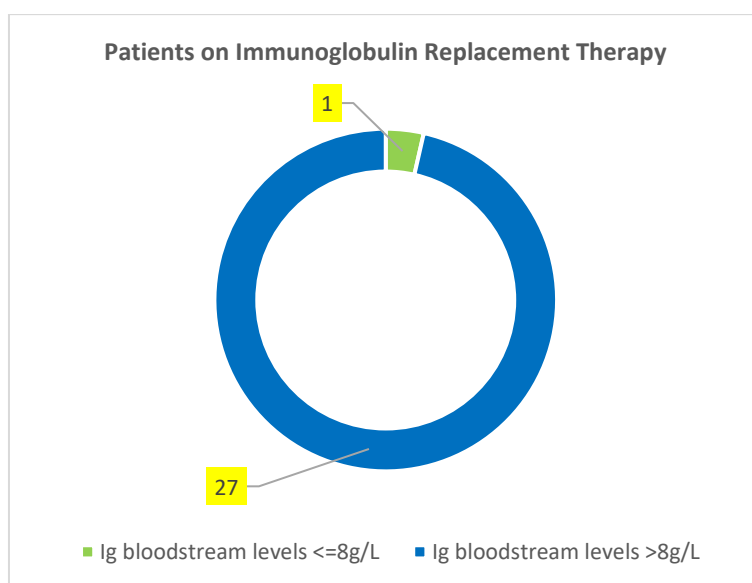
Measuring performance has once again been a major objective for the network during 2023/24. Clinicians have continued to provide data to measure against three Key Performance Indicators (KPIs) shown below.

The impact of pathways is monitored through measuring data collected against KPIs for the workstreams: PID, Hepatitis C and HIV.

KPI 1.-Paediatric Immune Deficiency (PID)

Treatment for all children and adolescents on immunoglobulin replacement therapy is effective.

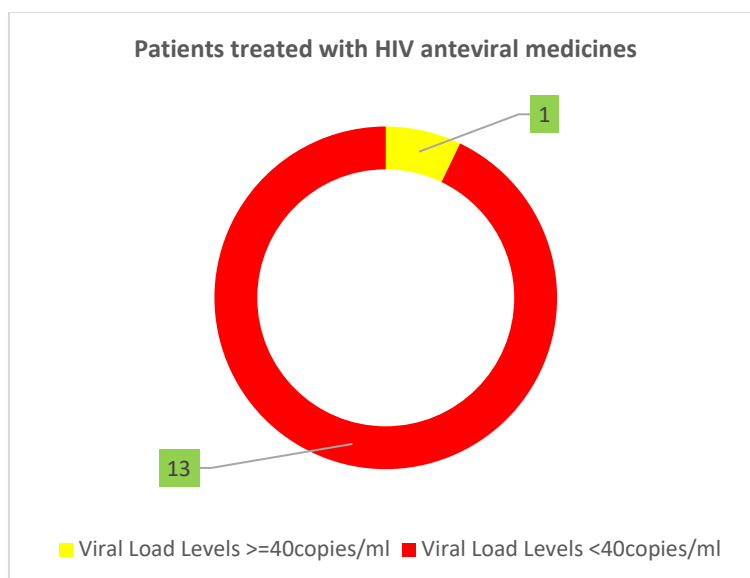
This is measured through testing patients to establish the amount of immunoglobulin in their bloodstream. A count of >8g/L is deemed effective. 28 patients were on treatment, the one patient identified that didn't reach this level was given a dose increase.



KPI 2.-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. All 14 patients known to services are on treatment with 13 patients virally suppressed. The other patient has compliance to treatment issues and are being offered support by the MDT.



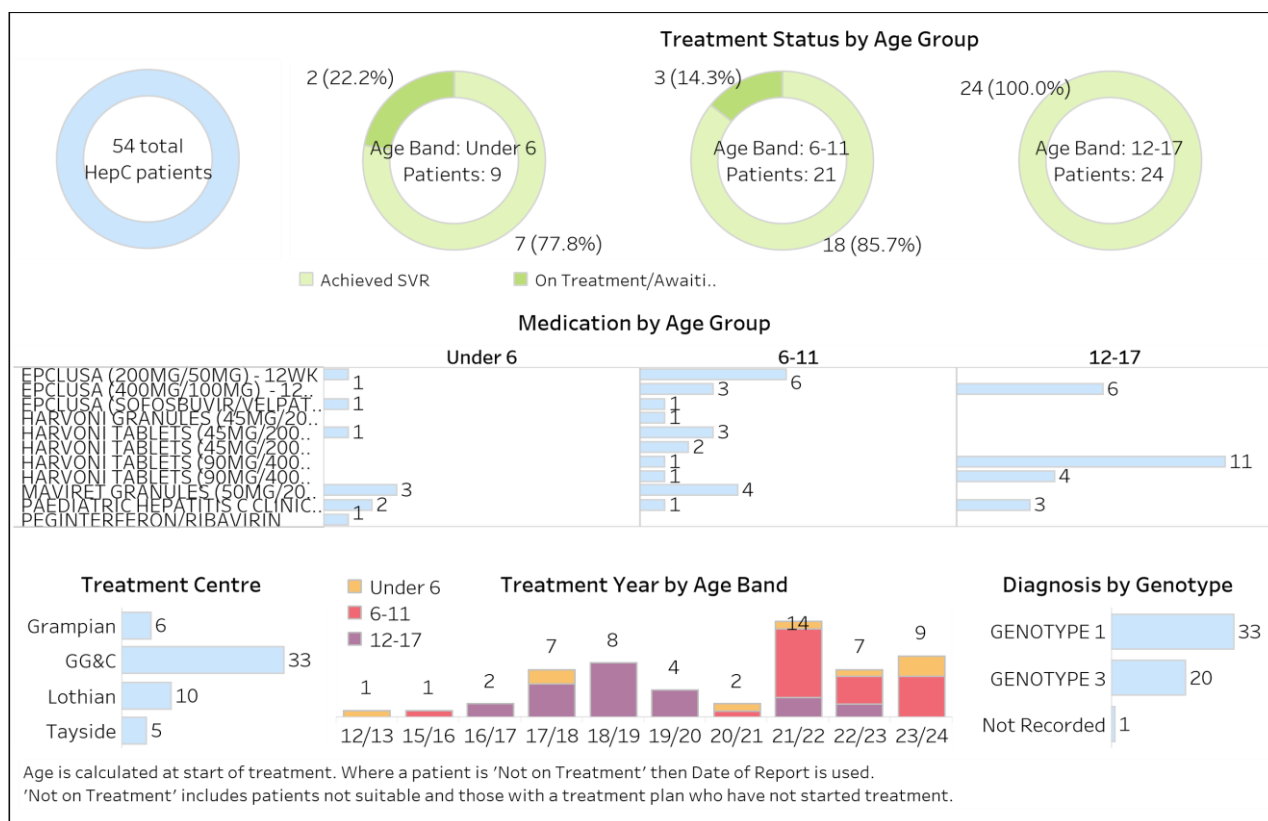
KPI 3.-Hepatitis C Virus (HCV)

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

The dashboard below allows clinicians to have a summarised position showing investigations, genotype, and medications. This will drive improvements in treatments for this patient group through monitoring the efficacy of different regimens in paediatrics, particularly with the newly licenced medications.

Results of the audit to date show in total, all (100%) patients out of 54 diagnosed have been either cured i.e. have achieved a Sustained Viral Response (S.V.R.) or are on treatment / awaiting SVR. This has been a tremendous achievement by the network with Scotland the first country in Europe to offer all children with a positive Hep C RNA PCR test result treatment.

Year ended March 2024



Developing a CAS instance to measure patients requiring HSCT.

Working with IMS, the network has developed and agreed a core dataset to document both paediatric and adult patients requiring this treatment. The focus of data recording will be to keep a registry to make it easier for clinicians/Network to inform service planning.

Climate Sustainability

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.

Looking forward

Key workstreams will be:

- Identify children across Scotland who have tested positive for HBV and have not been followed up by Public Health. Develop an HBV Treatment Care Pathway and ensure all children who are HBV positive, are being treated through this pathway.
- Complete CAS instance, or other methodology, to audit both paediatric and adult patients requiring HSCT treatment.
- Continue to monitor current KPI's and develop additional ones for HSCT and HBV
- As universal testing of pregnant women has not been adopted, individual health boards and hospitals offer selective antenatal screening strategies. SPAIIN will continue to work with clinicians in boards through the HCV Pathway to identify babies and children from women with an undiagnosed positive HCV, where the child is at risk
- Continue to work with NHS England to advocate universal HCV antenatal screening. Up until recently there had been no cure for Hepatitis C, therefore testing during pregnancy did not meet the UK Screening Committee criteria. As the landscape had now changed the network was more hopeful of success in the future.

Finance

The itemised costs and total spend for 2023/24 is given below:

Item	Spend
Venue Hire/Catering for Annual Event	£,131
TOTAL SPEND	£131

Risks & Issues

The following have been identified:

- The network will be without dedicated clinical leadership from April 1st, 2024. The colleague who backfilled the Lead clinician's sessions has had to step down from steering group membership due capacity issues. This individual successfully led on both HCV and HBV workstreams detailed above. Both losses may impact the delivery of the network's business plan for 2024/25.
- Due to the current financial constraints within NHS Scotland, networks have been asked to hold events virtually to reduce costs to local NHS Boards for staff travel. SPAIIN members value the opportunity network events offer to meet with staff from a range of specialties supporting immunology and infectious diseases working across Scotland.
- The adult immunology services face difficult challenges due to depleted staffing levels. There have been continued vacancies in NHS GGC, Grampian, and Tayside, meaning currently there are only two adult immunologists covering all of Scotland.

