

Scottish Paediatric and Adult Infection and Immunology Network (SPAIIIN) ANNUAL REPORT 2022/23

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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 reflecting 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

20/21 Business as Usual objectives were achieved. One objective, review of the De George pathway is behind schedule due to clinical pressures on staff.

5/8 Service Delivery objectives were achieved. Of the three that require extensions, two relate to the completion of the Adult Stem Cell Transplant Pathway, the other is completion of the National Hepatitis B (HBV). All of these workstreams are progressing but slower than anticipated, again due to pressures on clinical staff. It is anticipated that all will be completed by the end of 2023/24.

Lead Clinician Reflection

It has been another successful year and the first since 2019 without significant disruptions due to Covid-19 by our core steering group. Indicators were met and new members of the steering group embraced new roles. Hepatitis B case finding began in partnership with public health and virology colleagues as we map the known cases in Scotland in order to standardise follow up and treatment. Case finding to ensure any child with positive virology was in a dedicated service was piloted to success in larger boards.

HIV care continues to be of a high standard, with joined up care around the country. Attention has been given to education of the disease, in adolescents in particular, as we prepare them for transition to adults' services. Some complex resistance in new patients have highlighted the importance of the expert knowledge of the specialist teams in GGC and Lothian.

Similarly, Hepatitis C Virus (HCV) treatment continues around the country with progresses in medicine licensed, meaning treatment options for all children aged 3-5 (previously only genotype 1). The CAS system has made mapping of this around the country straightforward.

Relaxing Covid-19 pressures has also seen great progression in stem cell transplant pathways in adults and the national genetics testing MDT which has met 3 times with great success.

I am keen to look ahead to 2023-24 and handover to a new lead clinician to enable a continuous progression of quality indicators for SPAIIIN whilst maintaining a high level of clinical excellence amongst our medical areas around Scotland.

Highlights

- **Effective Network Structure and Governance**

SPAIIIN signed off a new Service Agreement for 2022-25 while a new strategic plan for 2022-25 has been endorsed by the network.

- **Service Development and Delivery**

Development of a Haematopoietic Stem Cell Transplant (HSCT) Pathway for Adults: The pathway has recently been endorsed by SPAIIIN, however still needs agreement of Scottish adult haematologists who will be involved in local care of these patients. Final step will be NSD endorsement of Service Agreement with NHS England Adult HSCT Centres. Progress has been slower than anticipated due to staffing pressures, however, the network aims to have all of this complete by the end of 2023/24.

Development of Genetic Pathway: the network has worked with the Aberdeen genetics laboratory to progress clinical/lab correlation and scrutiny around the process of testing and interpretation of results. One of the aims at the start of the year was for the network to establish an MDT to make this engagement more structured with robust workstreams and accountability in delivering these. Three meetings have taken place and proved a great success. Improvements noted to date include:

- 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, thus reducing workload of the genetics lab as well as making it easier for the immunologists to select the relevant genes to be tested.
- 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.

All of these changes improve quality of PID genetic diagnosis leading to more robust ongoing management and care.

Hepatitis C (HCV) Service Development: the network continues to make progress in two major workstreams:

-Treating children aged 3-17 yrs. identified as positive with newly licenced medications:

- Development of a national Hepatitis C pathway: a draft was completed last year and endorsed by the network in February 2023. This pathway includes guidelines for testing babies and children who may be at risk. This will mean improvement in outcomes for this cohort of patients as currently there is no universal antenatal screening for HCV in the UK. The network plans to measure impact of the implementation of this pathway over 2023/24.

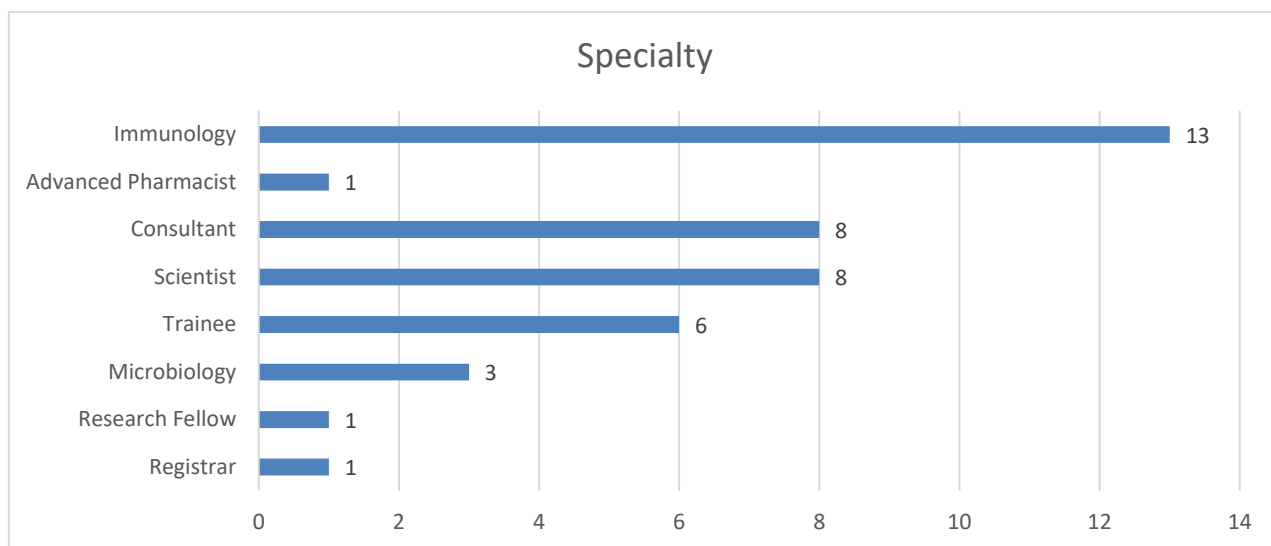
Hepatitis B (HBV) Service Development: One of the key priorities of the network is to develop a treatment care pathway for children with Hepatitis B (HBV) infection and ensuring all HBV positive children are on it. Unlike HCV, HBV is screened for antenatally in Scotland. Any infected babies are vaccinated at birth, and then followed up at 4 weeks and 12 months in addition to routine HPS HBV immunisation programme 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 be fatal. This can lead to liver cirrhosis and hepatocellular cancer (HCC). The network has developed 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. They will request the list of all positive children and then check if they have been followed up appropriately. NHS GGC already has a local pathway in place and has followed

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this process which resulted in clarifying that all children had been followed up. Numbers outside NHS GGC are unknown; therefore, the network will contact leads in all remaining boards and ask them to follow the same process and feedback to SPAIN with the results. SPAIN will then develop a national HBV pathway when all HBV positive children across Scotland are identified, ensuring all can be entered into a treatment pathway.

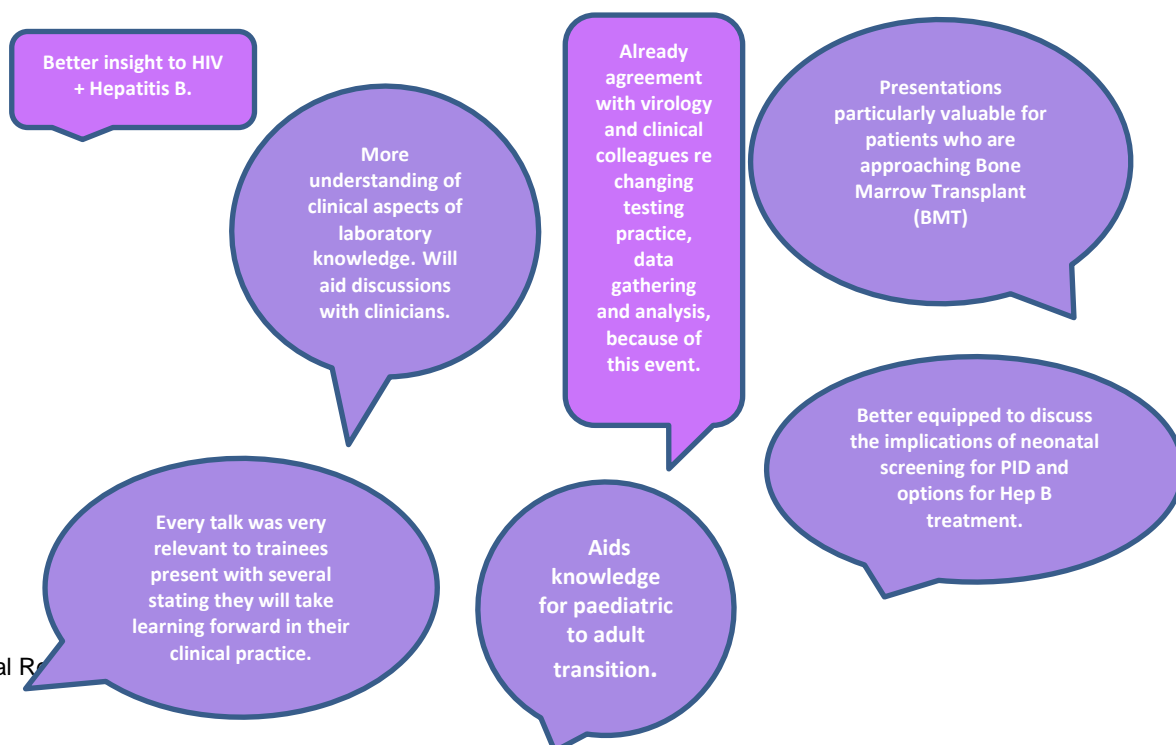
- Education**

The SPAIN Annual Education Event was held at COSLA Edinburgh in November 2022. 61 people attended the event (32 in person, 29 virtual) from a wide range of specialties and disciplines as shown below:



41 delegates (67.2%) provided feedback which was very positive. All the respondents rated the quality of education provided as either excellent (80%) or good (20%), with 78% adding that there was sufficient time for discussion between presentations. Respondents also liked the format with 90% saying they would prefer hybrid for future events.

When asked about what impact the event had on their future practice, responses were again positive. The main themes identified are included below:



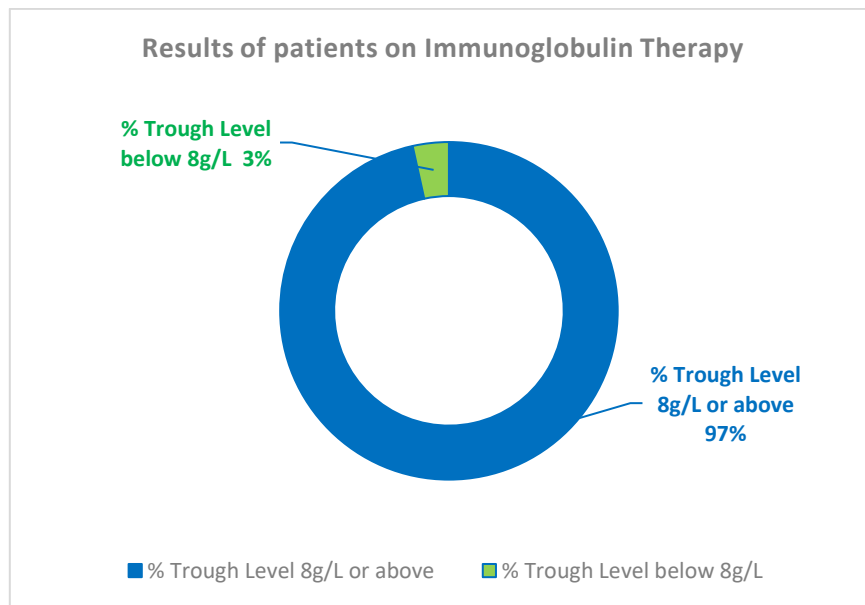
- **Audit and Continuous Quality Improvement**

Reporting Against SPAIN Key Performance Indicators: Measuring performance has once again been a major objective for the network during 2022/23. Clinicians have continued to provide data to measure against three Key Performance Indicators (KPIs) shown below.

KPI 1.-Paediatric Immune Deficiency (PID)

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

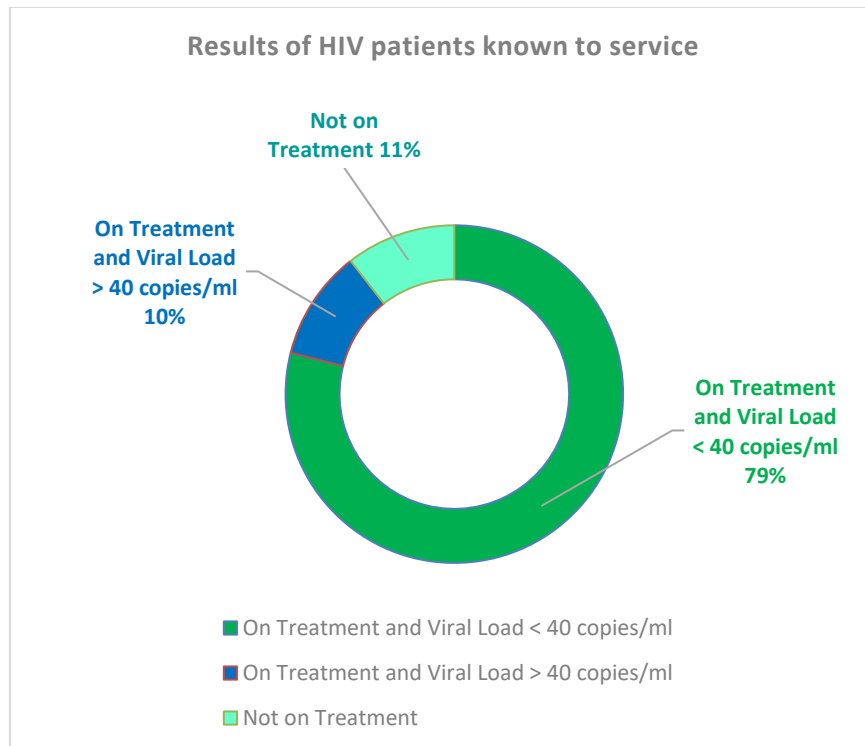
This is measured through testing patients to establish the amount of immunoglobulin in their bloodstream. A count of >8g/L is deemed effective. 29 patients were on treatment, the one patient identified that didn't reach this level was given a dose increase.



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. 19 patients are known to services with 17 on treatment, with two new patients not yet started treatment. Of those on treatment two patients have compliance to treatment issues and are being offered support by the MDT.



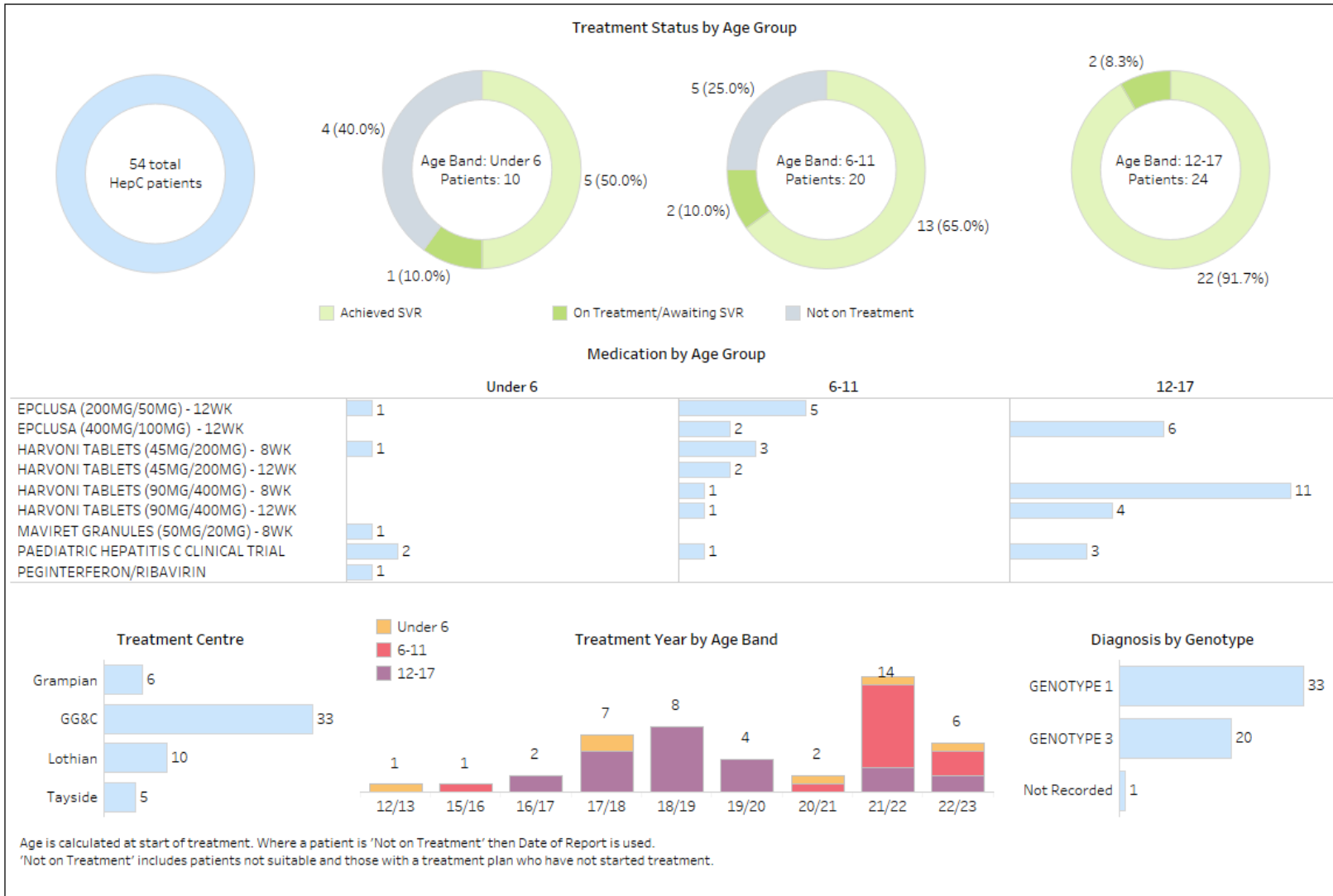
KPI 3.-Hepatitis C Virus (HCV)

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

The dashboard 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.

The dashboard below shows results of the audit to date. In total, 45 (83%) 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. Of the 9 remaining patients, they either have been assessed and are awaiting starting treatment or are currently not suitable for treatment. 4 of these patients are under 6 years of age and the drug for this cohort is only newly licensed in 3-5 years olds across all genotypes.

SPAIIN - National HCV CAS Data Summary at 11/04/2023



Developing a CAS instance to measure patients requiring HSCT: working with IMS, the network have progressed development of a core dataset on CAS 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 answer questions from other stakeholders about this group of patients.

- **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 to audit both paediatric and adult patients requiring HSCT treatment
- Continue to monitor current KPI's and develop additional ones for HSCT and HBV
- Work with clinicians in boards through the new HCV Pathway to identify babies and children from 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 2022/23 is given below:

Item	Spend
Venue Hire/Catering for Annual Event	£1,111
Accommodation/Travel for Annual Event External Speaker	£142
TOTAL SPEND	£1,253

Risks & Issues

None identified

