

Scottish Paediatric and Adult Infection and Immunology Network (SPAIIIN) ANNUAL REPORT 2021/22

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Background

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.

The pandemic continued to cause huge time constraints on Infectious Disease steering group members, particularly from December 2021 through to February 2022. Many of the network's healthcare professionals continued to take on leadership roles with COVID-19 planning and management due to the nature of the specialty. Regarding the 2021/22 workplan, although some elements have been delayed, there was significant progress over the year in moving workstreams forward.

Current Position

The Network has continued to demonstrate good progress against the 2021/22 workplan despite the continuing challenges resulting from the COVID-19 pandemic. Progress against the workplan is detailed in Appendix 1.

Lead Clinician Reflection

It has been another successful but disrupted year once again due to huge staff pressures as a result of COVID. Indicators were met despite many services being affected and staff diverted to lead on other aspects of work however the core work continued and treatment targets for hepatitis C were still maintained. Case finding was delayed due to services being paused out with our control however we continued to move forward, establish national MDTs, and ensure care around the country in this area is equitable and uniform.

HIV care continues to be of a high standard, with joined up care around the country. We started the mapping of HBV services understanding how many children are in care in Scotland and how we are looking after them.

In response to covid pressures the network led on the co-ordination of PIMS-TS hyperinflammatory national MDTs which linked up the treatment of children with this covid related condition around Scotland. In line with current recommendations, our annual education day was virtual and met with great success.

I am keen to look ahead to 2022-23 and move further forward with standardising HBV in Scotland and look ahead to incorporating TB and the role of the network in Migrant health.

Highlights

Effective Network Structure and Governance

Throughout 2021-22 all commissioning activities were progressed as business as usual; an Annual Performance Review (APR) took place and minutes were approved by the Steering Group (SG). SG attendance at meetings was good, although the December meeting had to be cancelled due to covid impact on pausing workstreams. Membership continues to be well represented both by infectious diseases and immunology disciplines with continuing adult representation from immunology.

SPAIIIN is in the process of signing off a new Service Agreement for 2022-25 which includes a strategic plan for 2022-25.

Service Development and Delivery

- **Development of a Haematopoietic Stem Cell Transplant (HSCT) Pathway for Adults:** Further to a successful meeting with The National UK MDT November 2020 the network has progressed the development of a pathway for Scottish adults requiring transplant. Scottish clinicians met in June 2021 where they developed and agreed a pathway for referral to the National UK MDT. The remainder of the pathway has now almost been completed.
- **Development of Genetic Pathway:** Work with the Aberdeen genetics laboratory to progress clinical/lab correlation and scrutiny around the process of testing and interpretation of results continues. This has resulted in huge progress with clinicians to select a much greater selection of genes to be tested. from various panels. This will improve quality of PID genetic diagnosis via genetic testing leading to more robust ongoing management and care. The network plans to meet with geneticists from the laboratory three to four times per year from 2022/23 to have a more structured regime and approach to progress this development.
- **Hepatitis C (HCV) Service Development:** the network continues to make progress in three major workstreams:

Treating children aged 3-17 yrs. identified as positive with newly licenced medications: Fig 4 below shows the outcomes with this cohort.

Working with Health Protection Scotland (HPS) to identify any child under the age of 18 who has tested positive but not in a clinical care pathway: This major piece of work has now been successfully completed after all the challenges that the pandemic and, satisfying Information Governance (IG) requirements produced. HPS required a Caldicott Data Release Form (CDRF) to be completed by the network for each board and then signed off by a representative from that board before they would release a list of HCV positive children from their database to respective boards. All five major boards have collaborated resulting in successful access to their patient lists with data analysed and cross-checked. Only a few patients were identified requiring follow-up, and this is in hand. However, there were some patients who couldn't be traced and remain 'unknown' due to several factors, e.g., no, or incorrect CHI, no virology record in local boards. The network agreed that this had been a resource intensive piece of work and the way forward to ensure all positive cases were in a care pathway was antenatal screening.

Development of a national Hepatitis C pathway: this has just recently been completed and sent to steering group members for review and feedback. This will be implemented in 2022/23.

- **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 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. 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. This can lead to liver cirrhosis and hepatocellular cancer (HCC). A draft plan has now been agreed for implementation in 2022/23.

- Covid Response-** the network has continued to support NHS Scotland response to covid through facilitation of a monthly virtual hyperinflammatory MDT and the development and implementation of a care pathway for children with Paediatric Multisystem Inflammatory Syndrome (PIMS-TS), a severe inflammatory reaction to SARS CoV-2. This meeting involves collaboration between Paediatric infectious diseases, rheumatology, cardiology and PICU teams formed in 2020/21 supporting identification and treatment of children affected by this disease.

Stakeholder Communication and Engagement

SPAIIIN continues to support patient and professional engagement through working with third sector organisations, distribution of Children with HIV Association (CHIVA) education booklets to nurses who see these patients in clinic and through its website and newsletters.

Education

Despite the continued impact of the Covid-19 pandemic on clinical staff availability and network activity, the network continued to prioritise and deliver a successful virtual education event. The Annual Conference was held in June 2021, using MS Teams. 48 delegates attended the event with 17 (37.5%) returning feedback. This was the second time a major virtual event had been held by SPAIIIN and like last year was again a great success as the charts below demonstrate. Delegate feedback reported that over 94% rated the virtual event a success in delivering education, whilst almost half it would definitely influence clinical practice going forward..(see Figure 1 below).

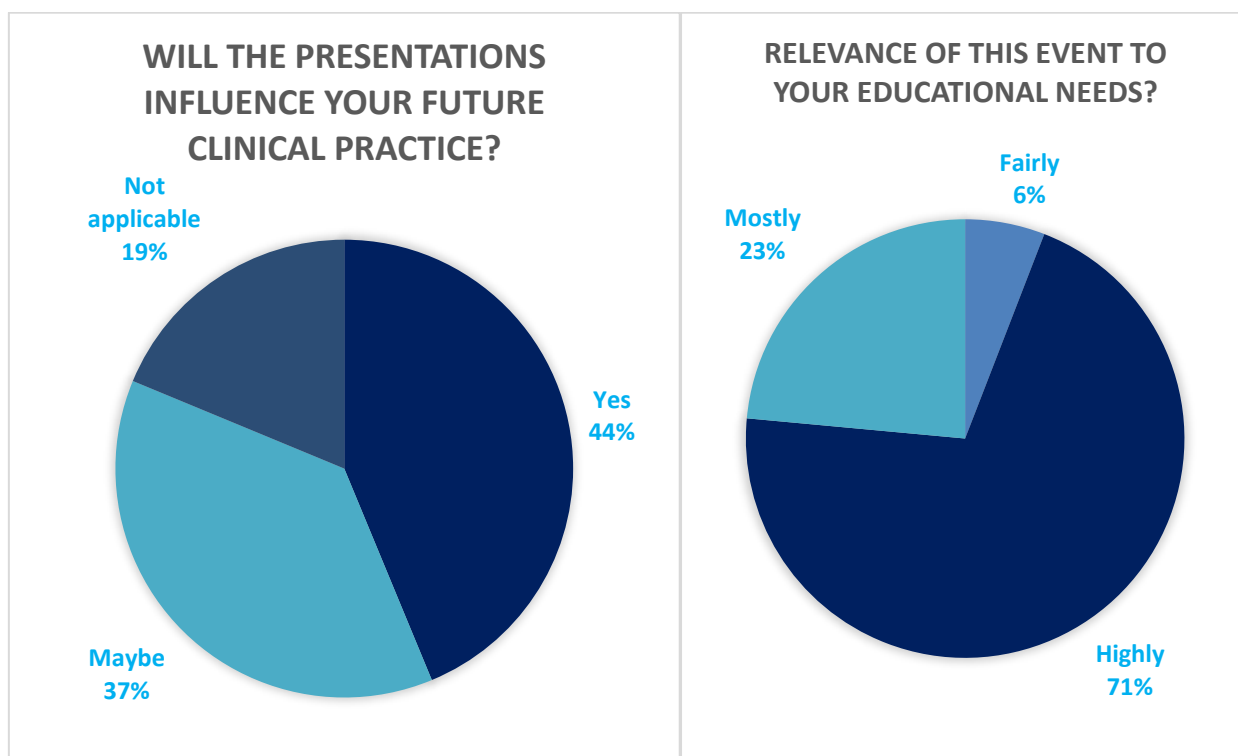


Figure 1 -Evaluation feedback

The 44% of respondents who answered 'Yes' were asked to clarify which areas of their clinical practice would be influenced by this event:

- Congenital CMV infection and the decision to treat when you have just an isolated Sign.
- Blood transfusion talk.
- Need to update practice with respect to transfusion special requirements for our PID cohort.
- New evidence and pathways discussed.

Audit and Continuous Quality Improvement

- **Reporting Against SPAIN Key Performance Indicators:** Measuring performance has once again been a major objective for the network during 2021/22. 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. Of the five patients identified that didn't reach this level, two had a dose increase and one patient was on treatment induction. The remaining two patients were on post bone marrow transplant, therefore were not aiming for troughs of >8 as it takes some time for immunoglobulin levels to get to a steady state for these patients.

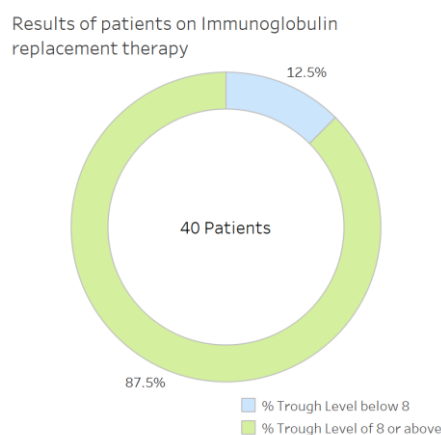


Fig 2 Effectiveness of Treatment on Immunoglobulin Replacement Therapy

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. Four patients did not achieve this target. Three have received additional counselling and adherence support. The remaining patient has just commenced on therapy, therefore wouldn't be expected to be virally suppressed at this stage.

Results of HIV patients known to service

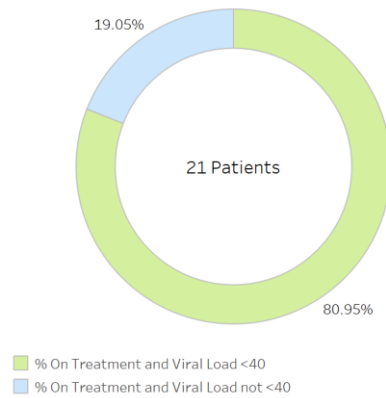


Fig 3 HIV patients virally suppressed after 12 months on treatment

KPI 3.-Hepatitis C Virus (HCV)

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

Following the network working with IMS to develop a CAS instance to collect relevant data on HCV patients at the end of last year, patients are now being successfully collected on the system. This detail allows clinicians to have a summarised dashboard 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.

In total, 37 patients out of 53 diagnosed have been either cured i.e. have achieved a Sustained Viral Response (S.V.R.) or are on treatment / awaiting SVR. One patient was lost to follow-up and the 15 remaining patients either have been assessed and are awaiting starting treatment or are not suitable for treatment. 7 of these patients are under 6 years of age and the drug for this cohort is only licenced for genotype 1 of the virus. If suitable, they will start treatment when they reach 6 years old.

- **Developing a CAS instance to measure patients requiring HSCT:** working with IMS, the network have started to plan to document both paediatric and adult patients requiring this treatment and audit against both HSCT care pathways.

Exceptions

Universal Antenatal HCV Screening

The Network's original plan to pilot HCV Antenatal Screening in Princess Maternity to gather evidence of its cost –effectiveness was put on hold as it involved support from HPS who were heavily involved in the pandemic. The network has recently engaged with NHS England HCV paediatric services who are planning various pilots with a view to a joint application to the National Screening Committee. This, however, has progressed slower than expected due to covid-19

Looking forward

Full details of the proposed workplan for 2022/23 are outlined in Appendix 2. 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 document and audit both paediatric and adult patients requiring HSCT treatment
- Continue to monitor KPI's and develop additional ones for HSCT and HBV
- The network will submit a proposal to incorporate Tuberculosis within its Infectious Diseases remit.

Appendix 1- Detailed Description of Progress in 2021/22

Core Principle	Description of Work/Activity	End of Year Update	Start Date	End Date	Q4 RAG Status
Effective Network Structure and Governance	Core Team meets regularly	Core Team met fortnightly during 2021/22 apart from the few months at the start of 2022 due to covid restrictions.	01/04/21	31/03/22	C
	Hold 3 Steering Group Meetings	Steering Group Meetings held on Aug and March 2022. Dec meeting cancelled due to covid restrictions	01/04/21	31/03/22	A
	Annual Report	Submitted 31/05/21.	01/04/21	31/05/21	C
	Mid-Year Report	Mid-Year Report submitted on 31st October 21	01/09/21	31/10/21	C
	Quarterly monitoring of finance spreadsheet	No finance data provided. Network holds local record for budget spend.	01/04/21	31/03/22	N/A
	Purchase Orders received at the end of each quarter	No finance data provided. Network holds local record for budget spend.	01/04/21	31/03/22	N/A
	2022/25 SA and 3-year Workplan Objectives	Objectives discussed at March 2022 SG Meeting. Awaiting sign off by Steering Group	01/01/22	31/03/22	G
Identification of all HCV positive children in Scotland	Identification of all HCV positive children in Scotland	SPAIIN worked with HPS to identify any child <17 yrs. old who had tested positive and was not in care pathway. Only a few identified, these patients will be followed up	01/04/21	31/03/22	C
	Development of HCV Care pathway	Pathway developed and sent to Steering Group for review	01/04/21	31/03/22	G
	Develop Stem Cell Transplant pathway for young adults and adults	Stem Cell Pathway in final draft stage	01/04/21	31/03/22	G

Service Development and Delivery	Develop Genetic Testing Pathway for adolescents with PID's	Pathway developed and will include arranging 3 to 4 meetings p.a. between Immunology and Genetics staff at Aberdeen labs.	01/04/21	31/03/22	G
	SPAIN to work with HCV services in NHS England who will gather evidence in support of submission for Universal HCV antenatal testing across the UK	Still behind schedule due to covid impact on key staff involved Carried forward to 2022/23	01/04/21	31/03/22	A
	Identify all children in Scotland who are HBV positive. Ensure they are in care pathways	Plan developed. Implementation behind schedule due to covid impact on key staff Carried forward to 2022/23	01/04/21	31/03/22	A
	Continue to support Covid-19 Response	Network clinicians continue to lead on this	01/04/21	31/03/22	G
	Develop Networks Quality Improvement Strategy	Quality Improvement Strategy scheduled to be developed following development /review/update to Guidelines and Care Pathway	01/04/21	31/03/22	A
Stakeholder Communication and Engagement	Development of website	Website updated on an ongoing basis.	01/04/21	31/03/22	C
	Development of Newsletter	Newsletter produced and sent to Steering Group for content to populate.	01/04/21	31/03/22	G
	Patient /Family Engagement	Contact made with third sector including Waverley Care to scope resources to support needs of HIV teenagers. Network asked to engage with patients to establish needs and then respond to Waverley Care with info. This has been done but no response yet from Waverley care. Carried forward to 2022/23. CHIVA leaflets issued to nurses who see HIV patients	01/04/21	31/03/22	G

Education	Host Annual Educational Event	Education Event held on 18th November 2021.	01/04/2021	31/03/2022	C
Data Collection and Audit	Audit quarterly HCV reports produced by IMS to ensure they report accurate data	Dashboard produced from CAS input	01/04/2021	31/03/2022	C
	Audit other KPI's annually: HIV- all patients on treatment have an undetectable viral load Immunology-all patients receiving Immunoglobulin Replacement Therapy (IVIg)have a trough level > 8	All audited	01/04/2021	31/03/2022	C
	Develop CAS instance to document patients requiring HSCT	Work has started	01/04/2021	31/03/2022	A

Appendix 2- Proposed Work Plan for 2022/23

Core Principle	Activity	Start Date	End Date
Network Structure and Governance	Core Team Meets Regularly	01/04/2022	31/03/2023
	Hold 3 Steering Group Meetings	01/04/2022	31/03/2023
	Ensure governance in place for Guidelines/Pathways	01/04/2022	31/03/2023
	Ensure all finance requirements are met	01/04/2022	31/03/2023
	Submit Annual Report	01/04/2022	31/05/2022
	Submit Mid-Year Report	01/10/2022	31/10/2022
	Develop 2023/24 Workplan	01/02/2023	31/03/2023
Service Development and Delivery	Continue to assess and treat if appropriate any child <17 yrs. old who had tested positive for HCV.	01/04/2022	31/03/2023
	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 place these children on it.	01/04/2022	31/03/2023
	Complete Stem Cell Pathway for adults stage	01/04/2022	31/03/2023
	SPAIN to continue work with HCV services in NHS England who will gather evidence in support of submission for Universal HCV antenatal testing across the UK	01/04/2022	31/03/2023
	Develop Networks Quality Improvement Strategy	01/04/2022	31/03/2023
Stakeholder Communication and Engagement	Continue to develop the SPAIN website so that it is a useful resource for patients/HCPs	01/04/2022	31/03/2023
	Issue at least 2 Newsletters	01/04/2022	31/03/2023
	Review Communication Strategy	01/04/2022	31/03/2023
Education	Host Annual Educational Event for HCPs	01/04/2022	31/03/2023
	Review Education Strategy	01/04/2022	31/03/2023
Audit and Continuous Quality Improvement	Continue to monitor data against the 3 KPI'S already agreed i.e.:		
	HCV HIV IVlg	01/04/2022	31/03/2023
	Develop CAS Instance to monitor patients (paeds and adults) requiring HSCT	01/04/2022	31/03/2023

	Develop additional KPI'S based on – HSCT Pathways (Paeds and Adults) HBV Care Pathway	01/04/2022	31/03/2023
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