

Scottish Paediatric and Adult Infection and Immunology Network (SPAIIN) Annual Report 2020/21

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Background

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

SPAIIN 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. In order 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

The pandemic caused huge time constraints on Infectious Disease steering group members from the end of February 2020. Many of the network's healthcare professionals took on leadership roles with COVID-19 planning and management due to the nature of the specialty. Regarding the 2020/21 workplan, although some elements have been delayed, there was significant progress over the latter part of the year in moving workstreams forward. This was despite the fact that Dr Jones, Dr Hague, Dr Doherty and Dr Thomas were still heavily involved in COVID-19 activity

The main areas affected were education and any projects involving Health Protection Scotland due to their resources being entirely committed to tackling the pandemic, particularly during the first half of the year. Nevertheless, good progress was made in progressing stem cell transplant pathway for adults as well as treating young HCV patients now that the medications are now licenced for 3-11 year olds

The network also made a significant contribution to the C-19 response during the year. Paediatric Multisystem Inflammatory Syndrome (PIMS-TS) is a rare and completely new paediatric disease characterised as a severe inflammatory reaction to SARS CoV-2, which has presented a novel challenge to paediatric services during the pandemic. The network was a major part of a collaborative approach between other specialist teams which allowed for the formation of a virtual 'hyperinflammatory' MDT. This important resource has supported local clinical teams in diagnosing, managing and transferring some very unwell children and adolescents.

Highlights

Improved engagement of adult Immunologists- this has been vital as the network's remit covers both paediatric and adults with PID's. Their collaboration has been important in driving forward the Stem Cell Transplant pathway for adults, to align with arrangements for children established through the network a few years ago.

Service Development-The network has lately made significant progress on a number of important workstreams:

- The network was reviewed in 2016, and from that review, it was recognised that adult PID care was evolving and that the network would be in a prime position to develop treatment pathways similar to what existed in paediatrics such as stem cell transplantation and gene therapy. During 2020/21 the network has:-
- Organised and hosted a successful meeting with a number of experts with the aim of developing a pathway for young adults and adults in Scotland who require stem cell transplant. This included input from Scottish paediatric and adult immunology teams, adult transplanters in Scotland, as well as the Stem Cell Transplant MDT from NHS England. The result is the development of a draft pathway that will be completed and implemented in 2021/22.
- Worked with the Aberdeen genetics laboratory to progress clinical/lab correlation and scrutiny around the process of testing and interpretation of results. This has resulted in huge progress with the gene panels available to the network and a more detailed referral form to complete enabling 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.
- Hepatitis C Virus (HCV)- despite the challenges the network has made significant progress in two major workstreams:-
- Treating children aged 3-12 yrs identified as positive with newly licenced medications. (Fig 3 below shows the outcomes with this cohort). All patients who are over 12 years old are either cured (have achieved a Sustained Viral Response (S.V.R.), which means there is no detectable virus after 6 months stopping treatment) or awaiting SVR. There are a few new patients diagnosed this year who have either a treatment plan in place or are being assessed for treatment.
- Continuing to work with Health Protection Scotland (HPS) in identifying children tested positive but not in care. HPS clarified that a separate Caldicott Data Release Form (CDRF) is required to be completed and submitted by the network for each board (with input from that board) before they would transfer this data to the respective board. This is required through information Governance (IG) rules. To date, five major boards (GGC, Lothian, Tayside, Ayrshire & Arran and Highland) have collaborated resulting in successful access to their patient lists. All boards in Scotland have a named link clinician so the network is continuing to work with all remaining boards to facilitate access to their own patient lists. This is a major project and its success will mean that all HCV positive children in Scotland, aged 3-17 years will have been identified, assessed, and if deemed suitable for treatment, be placed on a treatment pathway.

• Covid Response- Paediatric Multisystem Inflammatory Syndrome (PIMS-TS) is a rare and completely new paediatric disease characterised as a severe inflammatory reaction to SARS CoV-2, which has presented a novel challenge to paediatric services during the pandemic. The phenotype is severe and the importance of early recognition and aggressive early management became paramount but difficult as symptoms and signs were non-specific. A collaborative approach between paediatric infectious disease, rheumatology, cardiology and PICU teams allowed for the formation of a virtual 'hyperinflammatory' MDT involving the on-call members of specialist teams and has been resourced successfully to be available acutely across Scotland at any time for any paediatric team. This important resource has supported local clinical teams in diagnosing, managing and transferring some very unwell children and adolescents. To date 23 children in Scotland have been reported as having PIM-TS and more children were discussed at the forum and diagnosed with sepsis, other inflammatory conditions, drug reactions, malignancy etc. and alternate management instituted promptly.

Reporting Against SPAIIN Key Performance Indicators-Measuring performance has once again been a major objective for the network during 2020/21. 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. Those few patients identified where treatment has not been effective (the 11.8% below), are currently being followed up.

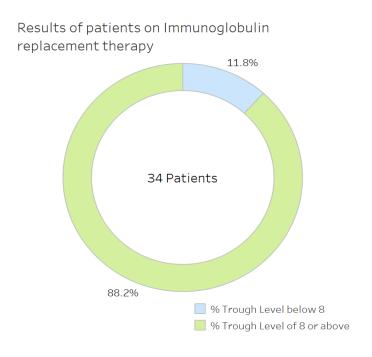


Fig 1 Effectiveness of Treatment on Immunoglobulin Replacement Therapy

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. There is still a patient with a detectable virus who is being followed up by the service.



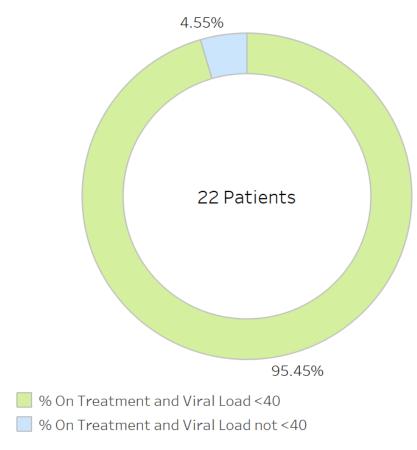


Fig 2 HIV patients virally supressed after 12 months on treatment

• **KPI 3.-Hepatitis Virus C (HVC)**All children and young people known to service with a diagnosis are followed up on a clinical pathway.

There is no HCV graphic for patients over 12 years old. This because the majority were treated last yaer and were either cured (have achieved a Sustained Viral Response (S.V.R.) or are awaiting SVR. There were only two new patients over 12 years of age recently diagnosed in 2020/21 and they have either a treatment plan in place or undergoing treatment assessment).

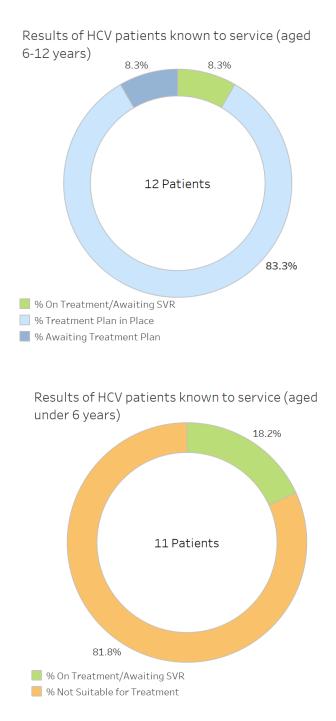


Fig 3 HCV patients known to service placed on a care pathway

This graphic above demonstrates that all children from the age groups 3 yrs-17 years known to the service have either been treated and discharged, are on/awaiting treatment or have been assessed for treatment and deemed not suitable. Unsuitable patients will be within the 3-5 yr. old range as the drug for this cohort is only licenced for children with genotype 1 of the virus. This cohort will be started on treatment when they reach 6 yrs. old.

Achieving this KPI has been a good example of the value in networking. Not all boards have expertise in treating these children. NHS GGC have now set up a monthly national MDT to coordinate treatment for all children identified.

CAS-work with IMS has resulted in CAS being developed to record relevant data on HCV. This detail will allow 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.

Website

Full year report

The network continues to raise awareness and increase the visibility of SPAIIN and its website www.spaiin.scot.nhs.uk to stakeholders. There are two new significant conduits; increased engagement with the adult immunologists in Scotland and the UK MDT and Scottish transplanters involved in developing the Scottish Stem Cell Transplant Pathway for adults

From April 2020 to March 2021, there were 1,171 more sessions (visits to the website) than the previous year and 1,842 more individual page views than the previous year.

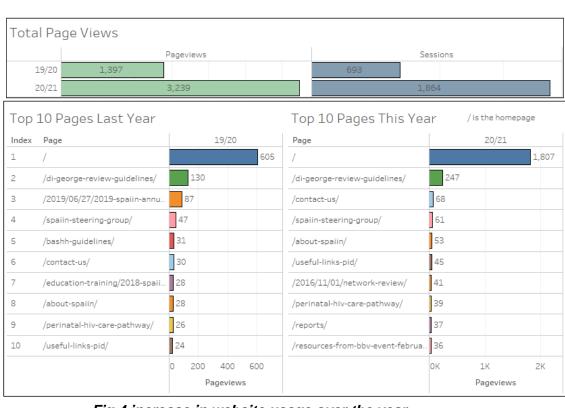


Fig 4 increase in website usage over the year

Exceptions

The following objectives have not been fully delivered due to reduced capacity amongst clinicians due to the C-19 pandemic as explained in the Current Position section.

Universal Antenatal Screening

The network's original plan to pilot HCV Antenatal Screening in Princess Maternity to gather evidence of its cost –effectiveness has been paused as it involved support from HPS. The network has engaged with NHS England HCV paediatric services who are

planning various pilots with a view to a joint application to the National Screening Committee.

Annual Education Event

Planned for September 2020. Agreed to postpone due to pressure on staffing during Covid-19 pandemic and second wave pressures. Teleclinics were also postponed. Both will be picked up in 2021/22.

HIV Patient Engagement

The network planned to continue engagement with young adults with HIV providing them both support and education. They procured and distributed Children with HIV Association (CHIVA) leaflets last year and collaborated with the Waverly Care charity who organised group meetings in various locations where individuals could engage with their peers facilitated by professional support. This arrangement however depended on the support from Lynn Williamson in Waverley Care. Lynn has now left this organisation and the network has been informed that this service is now withdrawn. This has been a major disappointment to SPAIIN and the network is now exploring alternative third sector support to provide a similar type of support.

Looking forward

Full details of the proposed workplan for 2021/22 are outlined in Appendix 2. Key workstreams will be:-

- Endorsement of both stem cell transplant pathways for adults and genetic pathway for adults
- Completion of the identification and treatment of all HCV positive children between the ages of 3-17 yrs.
- Developing care pathways for children with Hepatitis B (HBV) infection-this will be a major challenge for the network. 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. This is in addition to routine HPS HBV immunisation programme introduced in October 2017 which offers vaccination to all babies at 8, 12 and 16 weeks. However, 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). While treatment doesn't cure hepatitis B, it can be used to suppress the replication of the virus and, therefore, the person's infectivity. The challenge for the network is to identify all children who are infected and ensure they are in care.

Finance

Of the £5,000 annual non-pay budget received, SPAIIN has not spent anything during the year. Whilst planned meeting costs have not been incurred, SPAIIN plans to utilise budget to raise awareness of the network amongst its stakeholder communities.

Appendix 1 -

SPAIIN Workplan April 2020- March 2021

RAGB stat	us	Description						
RED (R)		The network is unlikely to achie	chieve the objective by the agreed end date.					
AMBER (A	7)	There is a risk that the network	will not achieve	the objective by the a	greed end date but progress ha	as been made.		
GREEN (G	The network is on track to achieve the objective by the agreed end date.							
BLUE (B)	JE (B) The network has been successful in achieving the network objective to plan.							
Active Number	Smart	Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31 st March 2021	Anticipated Outcome	RAGB status	
1. Effective	e Networl	k Structure and Governance ^{[lin}	ked to Quality Dimensio	ns 3,4,5,6]				
2020-01	multi-dis Lead Cli Network and wor Network	c continues to be overseen by sciplinary steering group with inician and Chair. It has Service Level Agreement is plan in place a meets core principals of ad clinical networks as set out in place 29.	April 2020/ March 2021	Hugh Kennedy/Steering Group	SA updated with 3 year work plan to reflect change in scope and signed off by SG.	Effective delivery of the SPAIIN work plan to ensure continuation of progress.	В	
2020-02	Organis	e 3 Steering Group meetings to effective delivery of the 2020/21	April 2020/ March 2021	Steering Group	4 Steering Group Meetings held: 16 June, 29 th Sep 10 th Dec all 2020 & 9 th March 2021-this model has worked well in progressing workstreams. Steering Group decided there were too few numbers to have separate sub-groups	Effective delivery of the SPAIIN work plan to ensure continuation of progress.	В	
2020-03	requiren - Mid-y	work will meet reporting nents: /ear Report al Report	31/10/20 31/05/21	Lead Clinician/ Programme Manager	MYR and AR completed.	There are effective governance arrangements in place.	В	

2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6] h/fwd Work initially delayed by effect of Covid but now progressing. Initial MDT meeting held on November 24th. Draft pathway Continue with development of young developed by adult Improved service adult PID Stem Cell Transplant immunologists in April 2020/ Rosie Hague pathway for Scotland-mimicking and/or 2019-04 collaboration with the two delivery for adults with Α March 2021 using the pre-existing paediatric Glasgow transplanters. PID Follow up meeting planned pathway for June 2021 to finalise pathway, which will then be shared with UK MDT and NSD Commissioners to endorse. c/fwd b/fwd Again delayed by Covid but now progressing. Meeting held in November 2020 with Aberdeen genetics lab. Continue developing a pathway for Number of gene panels has Improved service genetic testing for adolescents with April 2020/ been increased with 2019-05 Rosie Hague Α delivery for young people PID March 2021 agreement between the and adults with PID network and lab in achieving clinical/lab correlation and scrutiny around the process of testing and interpretation of results. progressing c/fwd b/fwd More effective Dr Thomas is a SG member. April 2020/ Continue to establish better links with networking through 2019-06 Rosie Hague В Other three adult involving key additional adult immunology service March 2021 immunologists have stakeholders indicated they want to be

				involved in the network and have engaged and collaborated in Stem Cell Transplant pathway development.		
2019-07	Develop care pathways for children and young people with hepatitis C infections in Scotland improving access to treatment For 2020/21 this includes: - • Identify via virology testing data and Health Protection Scotland (HPS) records anyone under 18 years who has ever tested antigen positive with HCV and ensure every child/adolescent in Scotland is linked to care and offered treatment where appropriate. • Ensuring all 6-11 year olds are entered into care pathways • Ensuring all 3-5 year olds are entered into care pathways	April 2020/ March 2021	Connor Doherty/ Fiona Marra	This work was delayed during the first half of the year due to Covid. Has now progressed: Care Pathways in place for all children aged 3-17yrs. of age known to services Medications for 3-12 year olds have recently been licenced. This cohort have now started either started treatment, awaiting treatment or deemed unsuitable at present treatment. See graphics in Highlights for details Access to HPS data was delayed due to HPS involvement in COVID-19. This work is now progressing with 5 boards now having access to patient lists through SPAIIN submission of a Caldicott Data Release Form (CDRF) in collaboration with these specific boards.	Improved service delivery for children and young people with Hepatitis C	A

Contribute to COVID-19 Response			The network has collaborated with other specialties in Scotland in leading the response to PIMS-TS. This has been through involvement in monthly Hyperinflammatory meetings to discuss various cases in a national forum, patients with the post covid PIMS-TS.	Improve treatments for children and young people with PIMS-TS	В
older Communication and Engagement	[linked to Quality Dimens	sions 1,3,4,5,6]			
Endorse and implement a Communication and Engagement Strategy	April 2020/ March 2021	Hugh Kennedy	This has been endorsed by SG.	More effective network through involving additional key stakeholders	В
Improving links with obstetrics and neonatal units and adult ID clinics so children at risk of Hep B and C can be offered testing, follow-up and management. This includes: • Develop pathway for testing children of women currently being treated for HCV	April 2020/ March 2021	Fiona Marra/ Conor Doherty	 b/fwd The network continues to raise awareness to adult ID neonatal and obstetrics of the importance ensuring that children of mothers who are currently being treated for HCV have been tested and place on the care pathway if positive. There is pathways in place now for a more direct referral to paediatric services for testing of children. c/fwd The planned pilot in 	More effective network through involving additional key stakeholders	A
	Endorse and implement a Communication and Engagement Strategy Improving links with obstetrics and neonatal units and adult ID clinics so children at risk of Hep B and C can be offered testing, follow-up and management. This includes: • Develop pathway for testing children of women currently being	Endorse and implement a Communication and Engagement Endorse and implement a Communication and Engagement Strategy Improving links with obstetrics and neonatal units and adult ID clinics so children at risk of Hep B and C can be offered testing, follow-up and management. This includes: • Develop pathway for testing children of women currently being treated for HCV April 2020/	Endorse and implement a Communication and Engagement Communication and Engagement Strategy Improving links with obstetrics and neonatal units and adult ID clinics so children at risk of Hep B and C can be offered testing, follow-up and management. This includes: • Develop pathway for testing children of women currently being treated for HCV April 2020/ Fiona Marra/	Contribute to COVID-19 Response Contribute to COVID-19 Response to PIMS-TS. This has been endorsed to SG. Contribute to COVID-19 Response Contribute to COVID-19 Response to PIMS-TS. This has been endorsed by SG. Contribute to COVID-19 Response to PIMS-TS. Confider and Engagement Contribute to COVID-19 Response to PIMS-TS. This has been endorsed by SG. Contribute to CovID-19 Response to PIMS-TS. Confider and Engagement Contribute to COVID-19 Response to PIMS-TS. This has been endorsed by SG. Contribute to CovID-19 Response to PIMS-TS. Confider and Engagement Contribute to COVID-19 Response to PIMS-TS. Confider to Contribute to CovID-19 Response to Information PIMS-TS. Confider to CovID-19 Response to to CovID-19	Contribute to COVID-19 Response Communication and Engagement Communication and Engagement Communication and Engagement April 2020/ March 2021 April 2020/ March 2021 April 2020/ March 2021 Fiona Marra/ Conor Doherty Conor Doherty Collaborated with other specialized in response to PIMS-TS. Improving this with observable and place on the care pathway if positive. There is pathways in place now for a more direct referral to paediatric services for testing of children. c/fwd b/fwd Collaborated with other specialized in Response to PIMS-TS. This has been children and young people with PIMS-TS Improving Influence in April 2020/ March 2021 April 2020/ March 2021 Fiona Marra/ Conor Doherty Fiona Marra/ Conor Doherty Conor Doherty Collaborated with of the response to PIMS-TS. This has been choiced by children and young people with PIMS-TS Improving Influence in April 2020/ More effective network through involving additional key stakeholders Conor Doherty Conor Doherty Conor Doherty Collaborated with clearing in Response to PIMS-TS. This has been choiced by children and young people with PIMS-TS Improving the With PIMS-TS More effective network through involving additional Rey stakeholders Conor Doherty Conor Dohert

	Pilot a universal testing of HCV in pregnancy to support better case finding in children			at Princess Royal Maternity to gather evidence on its cost effectiveness has been delayed due to COVID. The network is now looking at an alternative workstream in collaboration with NHS England to establish Universal testing. c/fwd		
2019-10	Continue to assess the knowledge of young people with HIV who are undergoing transition	April 2020/ March 2021	Fiona Marra	b/fwd Work had re-started in clinics using CHIVA booklets to assess teenager's knowledge. Waverley Care however is currently being re-organised therefore progress will be slower. The network is exploring other options of third sector organisations that can step in for the social aspect of care provided by Waverly care including outings for children. c/fwd	Improved transition service delivery for young people with HIV	A
2020-05	SPAIIN Website-Continue to develop and maintain	April 2020/ March 2021	Mary Glen	Ongoing		В
4. Education	On [linked to Quality Dimensions 1,2,3,4,5,6]					
2019-12	Endorse SPAIIN education strategy –	April 2020/ March 2021	Hugh Kennedy	This has been endorsed by the SG	Improved knowledge in childhood immunology/infectious diseases for relevant	В

2020-06	Provide multi-disciplinary paediatric study day for healthcare professionals	April 2020/ March 2021	Mary Adams/ Laura Jones	2020 event postponed due to COVID-19. Early 2021 event agreed by SG and will now be planned alongside an additional congenital health study around May/June c/fwd	healthcare professionals that either reinforce existing best practice or results in changes in practice Improved knowledge in childhood immunology/infectious diseases for relevant healthcare professionals that either reinforce existing best practice or results in changes in	R
2020-07	Educational series for paediatricians, specialist nurses and paediatric trainees with a specific interest in paediatric infectious diseases and immunodeficiency across Scotland Clinical Annual Review (CAR) meetings. These meetings are used to discuss the outcomes of the annual reviews of both HIV and PID patients and are carried out within NHS Boards.	April 2020/ March 2021	Mary Adams/ Laura Jones	Events postponed due to COVID-19. c/fwd Successful reviews were held	practice Improved knowledge in childhood immunology/infectious diseases for paediatricians, specialist nurses and paediatric trainees with a specific interest in paediatric infectious diseases and immunodeficiency across Scotland	Α
5. Audit ar	nd Continuous Quality Improvement [link	ed to Quality Dimension	s 1,2,3,4,5,6]			
2020-08	Collect meaningful data on PID, HIV and Hep C through measurement of the QI's	April 2020/March 2021	Hugh Kennedy/ Mike Gunn	This work was initially delayed by C-19 however, work progressed and data collected. CAS has been developed to record more detailed data on HCV.	Identified service improvements for patients with these conditions	В
2020-09	Develop and implement a Quality Improvement (QI) Strategy	April 2020/March 2021	Hugh Kennedy	Draft prepared	Identified service improvements for patients with these conditions	A

6. Value [lir	nked to Quality Dimensions 1,2,3,4,5,6]		
2020-10	Providing added value to health care in Scotland	Scottish Stem Cell pathway for children with PID requiring transplant saves around £100,000 per patient. Care Pathway for Perinatal Management of HIV will save hundreds of thousands of pounds per child. Ensuring all paediatric Hepatitis C patients are linked into treatment plan, cured, and discharged will save hundreds of thousands of pounds per patient in avoidance of liver disease in later life as a result of untreated hepatitis C which will manifest as cirrhosis, liver cancer or the need for liver transplant.	nd B

Appendix 2 -

SPAIIN Workplan April 2021- March 2022

RAGB stat	tus Desci	Description							
RED (R)	The n	The network is unlikely to achieve the objective by the agreed end date.							
MBER (A	There	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.							
GREEN (G	The n	The network is on track to achieve the objective by the agreed end date.							
BLUE (B)	The n	etwork has been succe	ssful in achieving	the network objectiv	e to plan.				
Active Number	Smart Objective		Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status		
. Effective	e Network Structur	e and Governance ^{[link}	ked to Quality Dimensions	s 3,4,5,6]					
2021-01	multi-disciplinary s Lead Clinician and Network meets co	Chair.	April 2021/ March 2022	Hugh Kennedy/Steering Group		Effective delivery of the SMN work plan to ensure continuation of progress.			
2021-02		ng Group meetings to elivery of the 2021/22	April 2021/ March 2022	Steering Group	Steering Group /APR Meeting in June 2021 planned	Effective delivery of the SMN work plan to ensure continuation of progress.			
2021-03	The network will m requirements: - Mid-year Report	, ,	31/10/21 31/05/22	Lead Clinician/ Programme Manager		There are effective governance arrangements in place.			
2. Service	Development and	Delivery [linked to Quality Di	mensions 1,2,3,4,5,6]						
2019-04		ell Transplant pathway cking and/or using the	April 2021/ March 2022	Rosie Hague	b/fwd Work is progressing. Plan to finalise Pathway. Final draft will then be discussed with key stakeholders from transplant centres in NHS England and NSD Commissioners.	Improved service delivery for young people with PID			

2019-05	Continue to developing a pathway for genetic testing for adolescents with PID	April 2021/ March 2022	Rosie Hague	b/fwd Work progressing. Updated gene panel developed by Aberdeen labs to make identification of PID's less challenging. Further meeting planned to progress	Improved service delivery for young people with PID	
2019-06	Continue to establish better links with adult immunology service	April 2021/ March 2022	Rosie Hague	b/fwd - All four adult clinicians have been involved in workstreams. A deputy for Dr Thomas will be invited to join SG	More effective networking through involving key additional stakeholders	
2019-07	Develop care pathways for children and young people with hepatitis C infections in Scotland improving access to treatment For 2021/22 this includes: - Identify via virology testing data and HPS records anyone under 18 years who has ever tested antigen positive with HCV and ensure every child/adolescent in Scotland is linked to care and offered treatment where appropriate.	April 2021/ March 2022	Connor Doherty/ Fiona Marra	b/fwd due to HPS involvement in COVID response pathways now in place for all children 3-17 yrs of age been recently licenced. This will allow:- All children 3-11 yrs old already identified and not treated 2020/21 to be prioritised. New patients over 12 years of age to be treated Children identified by HPS not yet treated to be placed into care pathways-5 boards have completed the Caldicott Data Release Form (CDRF) and accessed HPS data relating to their own boards. Plan for other boards to follow	Improved service delivery for children and young people with Hepatitis C	

2021-04	Develop care pathways for children and young people with hepatitis B infections in Scotland improving access to treatment For 2021/22 this includes: - • Identify via virology testing data and HPS records anyone under 18 years who has ever tested antigen positive with HBV and ensure every child/adolescent in Scotland is linked to care and offered treatment where appropriate.	April 2021/ March 2022	Connor Doherty/ Fiona Marra		Improved service delivery for children and young people with Hepatitis B	
2019-09	Continue the drive for universal testing of HCV in pregnancy to support better case finding in children	April 2021/ March 2022	Fiona Marra/ Connor Doherty	Plans in place to collaborate with NHS England HCV paediatric network to gather sufficient evidence submit joint application	More effective network through involving additional key stakeholders	
2020-04	Continue to support COVID-19 response	June 2020/ongoing	Mary Glen/Steering Group	Ongoing	Improve treatments for children and young people with PIMS-TS	
3. Stakeho	older Communication and Engagement ^{[li}	nked to Quality Dimensi	ons 1,3,4,5,6]		'	
2019-10	Continue to assess the knowledge of young people with HIV who are undergoing transition	April 2021/ March 2022	Fiona Marra	b/fwd from 2019/20 Currently exploring what third sector are offering	Improved transition service delivery for young people with HIV	
2021-05	Develop and circulate SPAIIN Newsletter, then update every 6 months		Mary Glen	Draft newsletter developed for review		
2021-06	SPAIIN Website-Continue to develop and maintain	April 2021/ March 2022	Mary Glen	Ongoing		

2020-06	Provide multi-disciplinary study day for healthcare professionals	April 2021/ March 2022	Mary Glen/ Laura Jones	bfwd Planning for June 2021 virtual meeting	Improved knowledge in childhood immunology/infectious diseases for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice
2020-07	Educational series for paediatricians, specialist nurses and paediatric trainees with a specific interest in paediatric infectious diseases and immunodeficiency across Scotland Clinical Annual Review (CAR) meetings. These meetings are used to discuss the outcomes of the annual reviews of both HIV and PID patients and are carried out within NHS Boards.			b/fwd. First meeting planned May 2021	
5. Audit ar	nd Continuous Quality Improvement [links	ed to Quality Dimensions	1,2,3,4,5,6]		
2020-08	Collect meaningful data on PID, HIV and Hep C through measurement of the QI's Continue to collect meaningful data on HCV using CAS.	April 2021/March 2022	Hugh Kennedy/ Hugh O'Pray	Continue to measure 4 QI'S from 2019/20 CAS currently being populated with HCV data.	Identified service improvements for patients with these conditions
2021-07	Develop new QI-Standardisation of paediatric flow cytometry across Scotland'.				Standardise flow tests across Scotland. This would involve Glasgow, Tayside and Aberdeen to work together to agree which health board would be responsible for each part of the process, to agree common panels and agree a standard process across Scotland.

2020-09	Develop and implement a Quality Improvement (QI) Strategy	April 2021/March 2022	Hugh Kennedy	Ongoing	Identified service improvements for patients with these conditions
6. Value ^{[lir}	nked to Quality Dimensions 1,2,3,4,5,6]				
2020-10	Providing added value to health care in Scotland			Scottish Stem Cell pathway for children with PID requiring transplant saves around £100,000 per patient. Care Pathway for Perinatal Management of HIV will save hundreds of thousands of pounds per child. Ensuring all paediatric Hepatitis C patients are linked into treatment plan will save hundreds of thousands of pounds per patient in avoidance of liver disease.	Providing added value to health care in Scotland for these groups of patients as well as cost savings for NHS Scotland