

**Scottish Paediatric & Adolescent Infection & Immunology National
Managed Clinical Network (SPAIIIN)**

ANNUAL REPORT 2019/20

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1. Executive Summary

2019/2020 has been a successful year for the SPAIIIN network with great steps forward in many of the clinical areas the network covers. The expansion into hepatitis B (HBV) and hepatitis C (HCV) has been a particular success nationally with the launch of effective treatment that was co-ordinated at network level. All known children in paediatric hepatitis treatment centres within the licensed age of medicine, which is 12 years old and over, have now been treated, cured and discharged. A large piece of work was also undertaken to identify any child under the age of 18 who has ever tested positive for HCV and may not be in care to re-engage and follow up. The appropriate legal paperwork has been carried out for this link clinicians have been identified and agreed from each board however access to this data had likely been delayed due to COVID-19.

We also held our most successful and best attended national education day in November and will follow this pattern in expanding further for 2020/21.

Due to huge time constraints on Infectious Disease steering group members, from the end of February, a decision was made to halt network business in the short term. Many of the network's healthcare professionals took on leadership roles with COVID-19 planning and management due to the nature of the speciality. Despite this loss of time and cancellation of steering group meetings we have been able to communicate via email when time allows and tie up the majority of the work priorities set out for 2019/2020.

The main work priorities for 2020/21 will be to:

1. Agree data collection mechanisms once the outcome of discussions on the legal basis for consent for the National Clinical Audit System (NCAS) under General Data Protection Regulation (GDPR) has been finalised.
2. Develop a care pathway for young adults over the age of 16 with Primary Immune Deficiency (PID) needing bone marrow transplant;
3. Continue to work with genetics services to progress formalising the process for the genetic testing service for patients with Primary Immune Deficiency in Scotland;
4. Identify via virology testing data and Health Protection Scotland (HPS) records anyone under 18 years who has ever tested positive with HCV and ensure every child/adolescent in Scotland is linked to care and offered treatment where appropriate.
5. Ensure all children with HCV, aged 6yrs -11yrs are entered into available trials.
6. Ensure all children with HCV, aged 3yrs-5yrs are entered into available trials.
7. continue to work with Waverley Care to deliver education and support to teenagers with HIV who are approaching transition.
8. Deliver both an education and communication and engagement strategy
9. Continue to take forward the recommendations of the Network review (please see [section 2](#) for more detail).
10. Pilot a program of Universal testing of HCV in pregnancy women to support better case finding in children.

2. Introduction

The Scottish Paediatric and Adolescent Infection and Immunology Network (SPAIIIN) was launched in February 2011 for the care of children and adolescents with HIV infection or a Primary Immune Deficiency (PID). The network was independently reviewed in 2016 as part of national commissioning governance. The outcome was SPAIIIN retained its status as a designated managed clinical network with an extension of scope to meet emerging priorities, specifically:

- a. To include children infected with other Blood Borne Viruses (BBV) and identification of children with Hepatitis B and C infection with the aim of:
 - Consolidating what is known about the children and standardising how they are managed.
 - Improving links with obstetric and neonatal units and adult ID clinics so children at risk can be offered testing, follow-up and management.
- b. To strengthen PID activities with respect to genetic testing and new treatment modalities to include care for (young) adults which includes:
 - Developing a pathway for genetic testing for PID
 - Developing a pathway for access to haematopoietic stem cell transplant for (young) adult patients where this is indicated by their condition.

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.

3. Report on Progress against Network Objectives in 2019/20

The network aims to support the best care for paediatric HIV infection and Hepatitis B and C infection as well as PID across Scotland, promoting engagement between adult and paediatric services to improve access to diagnosis and treatment.

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29¹:

1. Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) (Annex and national commissioning performance management and reporting arrangements; Annex C).
2. Support the design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
3. Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service User are involved in the Network and explicitly in the design and delivery of service models and improvements.
4. Improved capability and capacity in infectious diseases and immunology care through design and delivery of a written education strategy that reflects and meets stakeholder needs.
5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).

¹ Please see: https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

6. Generate better value for money in how services are delivered.

This report gives an overview of progress against these objectives in the year 2019/20.

3.1. Effective Network Structure and Governance

The Network continues to be overseen by a multi-disciplinary Steering Group that is accountable for the delivery of the Network workplan. Through its terms of reference and sub-group structure, SPAIIIN meets the core governance requirements of managed clinical networks as set out in CEL (2012) 29.

Workplans and reports are published on the Network website, and any documents produced by the Network are publically available for clinicians and patients to view.

The current SPAIIIN Lead Clinician is Ms Fiona Marra, Specialist Pharmacist in Infectious Diseases based in Glasgow. Her tenure is until March 2021.

The Network has a service level agreement with NHS NSS in place for 2019-2022.

The full list of current SPAIIIN Steering Group members is included in [Appendix 1](#).

The following workgroup leads have been identified under the network's governance structure: -

- Dr Hague - PID
- Dr Jones - Education & Training
- Ms Marra and Dr Doherty - HIV and Hepatitis B and C
- Dr Doherty – Data Collection and Audit

Patient engagement was to be taken forward as a cross-cutting theme in all the above workstreams rather than as a separate topic.

3.2. Service Development and Delivery

3.2.1 Primary Immune Deficiency (PID)

The network continues to strive to improve the diagnosis and treatment of PID.

The stem cell transplantation pathway was developed in conjunction with the Newcastle and Scottish transplant services; all patients who would benefit from a transplant are discussed at the quarterly clinic, and are offered a transplant as appropriate. These are mostly carried out at the Scottish Paediatric Stem Cell Transplant Service in Glasgow, with more complex cases referred to Newcastle. All known Scottish paediatric patients have been reviewed and those requiring a stem cell transplant have been offered one. SPAIIIN continues to work closely with the service in Newcastle to ensure that all appropriate patients are referred to Glasgow for treatment. This means that patients are treated as close to home as possible and enables resources to be directed within the Scottish Health services.

Adult services in Scotland are provided by five consultant immunology posts (one currently vacant) based in NHS Greater Glasgow and Clyde (GG&C), NHS Lothian, NHS Tayside and NHS Grampian. Engagement with adult services continues to evolve with joint case discussions and with the 4 current adult clinicians attending the SPAIIIN Education Day held in November 2019. Some progress has also been made in referring young adults for stem cell transplant but the referral process is on a case by case basis with no standard pathway. In contrast to children's services for HSCT, which have been well established for over 20 years, it is only recently that young adults have been offered transplant and criteria for suitability are therefore still evolving. With regards to genetic testing, there has been progress this year with links to the Aberdeen genetics laboratory having been strengthened. Work is progressing between the network and the laboratory to get some clinical/lab correlation and scrutiny around the process of testing and interpretation of results.

Establishing pathways for adults requiring stem cell transplant and for those who require genetic testing which mirror pathways already established for children remains one of the main objectives for 2020/2021

3.2.2 HIV

Improvements in HIV care continue for the treatment of children and young people.

There have been no cases of mother to child transmission of HIV among those who have progressed through maternity services in Scotland since 2011. The HIV Perinatal Care Pathway implemented in 2011 continues to strengthen national awareness of care in this group and re-enforces links with specialist centres in complex cases.

SPAIIIN also continues to support regular MDT's (involving neonates, obstetrics, paediatrics and adult ID services) for management of high risk HIV births born to HIV positive mothers. This can be due to late presentations, women who decline antenatal screening, or to poor compliance of mothers and a complex resistant virus all of which can cause problems for planning treatment for neonates.

SPAIIIN's work to support clinicians around the country to minimise the risk of perinatal transmission of HIV in Scotland is ongoing, facilitating compliance with the pathway. Other network aims focus on delivering education materials and expert advice via different specialists such as nurses, pharmacists and third sector to all children with HIV particularly teenagers undergoing transition to adult services.

SPAIIIN has also focused on auditing the impact on patient care of these measures which will be discussed in more detail below.

3.2.3 Hepatitis B and C

With the advent of new treatments, Hepatitis C Virus (HCV) is now curable in all children and adults infected with the virus that are 12 years old and over with 8-12 weeks of oral treatment, or under 12's via clinical trials. Very rough estimates suggest about 150 children in Scotland with HCV but only about 50 have so far been identified. HCV is not currently part of the routine antenatal screening programme, as at the point of assessing this criterion there was poor treatment options and no intervention could be made in pregnancy. This has changed and there are ongoing clinical trials looking at the treatment of HCV in pregnancy and certainly a quick and easy 8-week treatment course can be offered in the interim at the point of delivery to any mother who tests positive for HCV. Testing of high risk mothers has been identified as poor and missed opportunities to test children born to these mothers are frequent. SPAIIIN supports and will work in 2020/21 to establish universal testing of HCV in pregnancy in Scotland. Unrecognised perinatal transmission of HCV can result in liver disease manifesting as cirrhosis, liver cancer and the need for liver transplant potentially later in life.

SPAIIIN has developed very robust plans to meet this challenge:

- a) testing/management. SPAIIIN will provide support where required to facilitate this process. This will be a main focus for the network in 20/21. A treatment pathway for paediatrics has been developed in Glasgow, involving nurse and pharmacy led clinics. This was followed in NHS Lothian, Grampian and Tayside. The aim was to treat all known positive children age 12+ in Scotland with Hepatitis C by 2020. This has been measured as one of the networks QI's and results will be discussed below.
- b) A bigger challenge for the service is identifying children and young people who have tested positive and are not in a care pathway. Fiona Marra has been leading a large clinical team on this work alongside Alison Boyle, interim network pharmacist. The team comprises of paediatricians, adult liver specialists, virologists and a research team from Glasgow Caledonian University (GCU) led by Prof Sharon Hutcheson and Dr Norah Palmateer from Health Protection Scotland(HPS). HPS have a database of results of all children and adults in Scotland who have been tested for HCV. Due to Caldicott guardian rules, patient identifiable information may only be shared with a designated clinician in the individual's local health board. Data will be released following completion of a Caldicott Data Release Form (CDRF). Link clinicians have now been identified in each health board

who have agreed to review the patients identified in their board They will confirm the results, clarify whether subsequent testing or follow-up has occurred and whether the patient is still resident in the board. Thereafter, patients identified as having been lost to follow-up would be invited back to clinic locally to discuss the result and further action.

- c) Children known to service between the ages of 6 and 11 years are currently on clinical trials. This is being measured as one of the networks QI's. The aim is to obtain licence for the drug to be used on this age group so that they can be placed on the pathway and be placed on treatment pathways. Thereafter, the next group will be 3-5 yr. olds to follow the same route.
- d) Longer term objectives will be to achieve elimination of HCV in children and young people in Scotland by 2024. This will involve the following plans: -
 - SPAIIIN have linked with HPS/GCU and are assisting on a project to identify retrospectively all HCV positive women from their adult database to then be cross-checked with Scottish birth records to identify children who have not been tested for follow up. This is a large scale project which will likely run into 2022.
 - SPAIIIN has worked this year on better education of adult services on testing children of women who they are currently treating in a 'don't forget the children' campaign. This pathway will enable testing of children from mothers who were not tested in pregnancy. Lead clinician, Fiona Marra has spoken at 3 national HCV events in 2019/2020 on this topic. A CDRF for each board will be required as per the paediatric lost to follow up cases.
 - Currently, health boards have policies in place for antenatal HCV testing of pregnant females if they fall into a high risk category, such as current or previous injecting drug use. A recent review has indicated that uptake of this is relatively low in most boards. There have been ongoing discussions about the merit of introducing universal HCV testing in the antenatal setting, as with HIV and HBV. As mentioned, national screening groups have historically advised that HCV would not meet the criteria for universal testing. However, there is a growing body of evidence highlighting the cost effectiveness and high rates of patient acceptability of antenatal testing. SPAIIIN fully support universal testing and believe this is a missed opportunity for healthcare intervention in a hard-to-reach population.
 - Funding is available to pilot universal antenatal testing in North Glasgow at the Princess Royal Maternity and in NHS Lothian. The planned start date of this pilot was April 2020 but this has been delayed due to COVID-19. Once implemented, the outcomes will be reviewed with the aim of a national rollout throughout all health boards in Scotland.

Hepatitis B is less epidemiologically problematic as testing for Hepatitis B is part of the UK antenatal screening programme. Babies of positive mothers are given vaccination immediately after birth with follow up booster vaccinations. In addition, all babies are given vaccination as part of UK immunisation programme.

3.3. Stakeholder Communication and Engagement

3.3.1 Professional engagement

The main focus for communication and engagement within the Network has been:

- continuing re-establishing effective links with specialist and link clinicians throughout Scotland.
- engaging with adult services.
- Offer effective education strategies to reach out with core SPAIIIN members

These objectives continue to be challenging as both paediatric and adult immunology and infectious diseases workforce in Scotland is very small and faces numerous competing demands on their limited

capacity. However, improvements have been made over the year particularly regarding links with adult services as mentioned in the PID section above.

Ways to build on this will be considered within a Communication and Engagement Strategy, a draft of which has been developed.

3.3.2 Patient engagement

A key challenge for paediatric HIV patients is transition to adult services. This is a common issue in many life-long conditions where young patients need to take responsibility for their own treatment as they move into adulthood, and is especially difficult for young people with HIV who often have not had full disclosure of their condition until they are around 10 years old. Clinical practice is starting to change, and children are being informed of their condition at younger ages. With the stigma that still surrounds HIV, these young people often also live with a secret condition that they feel unable to discuss with their peers.

One of SPAIIIN’s main aims for 2019/20 was to ensure that these young people had sufficient knowledge about their condition before being passed through to adult services. The network had agreed that information packs developed by Children with HIV Association (CHIVA) was ideal for this purpose, and could be used over a year to measure gaps in knowledge for this cohort of patients. The network continues to work closely with Waverley Care and will use these packs to both assess knowledge and fill gaps where required via delivery of an educational program by different members of the team.

3.3.3 Website

The network continues to raise awareness and increase the visibility of SPAIIIN and its website www.spaiin.scot.nhs.uk to stakeholders through engagement with Waverley care and raising awareness at the education event. From April 2019 to March 2020 there were 429 more sessions (visits to the website) than from the previous year and 896 additional pages viewed, compared to the previous year.

Figure 1 below shows the increase in website usage.

Full year report: from 1/4/19 > 31/3/20

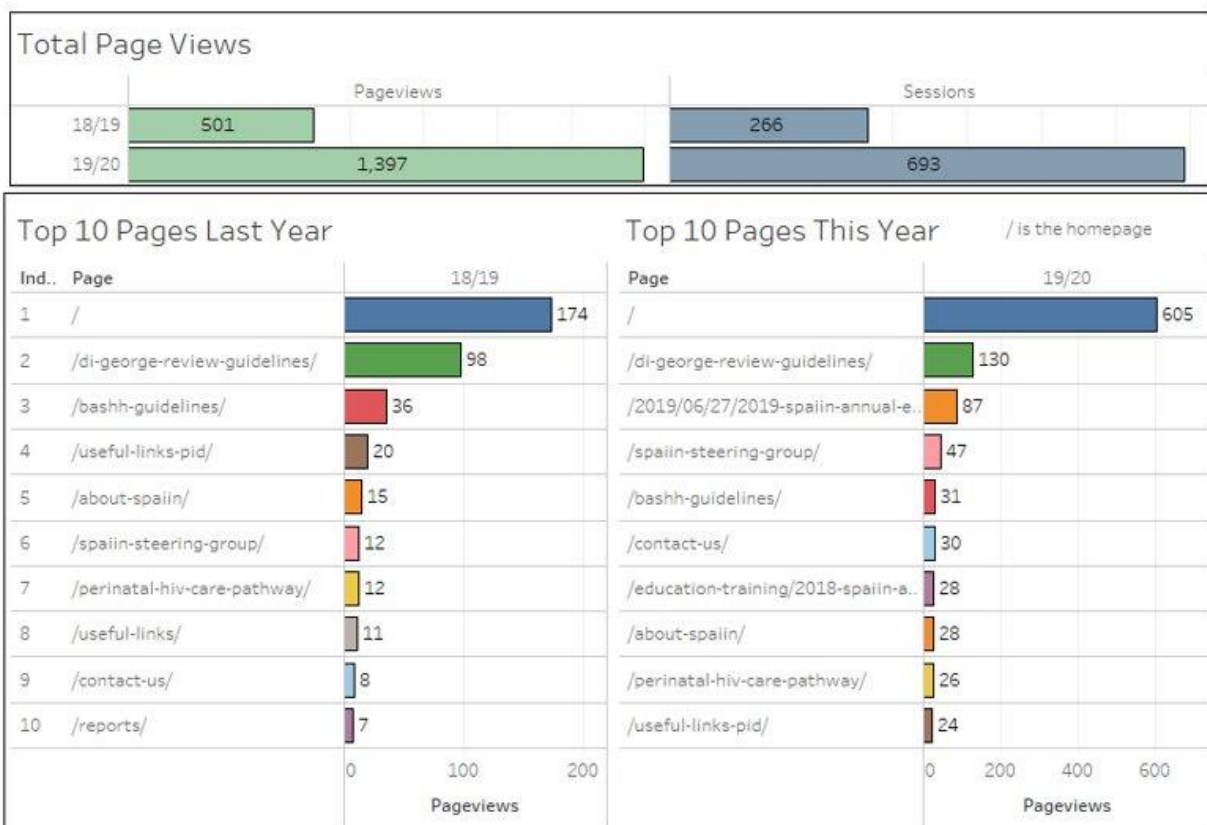


Figure 1 –SPAIIIN website usage April 2019-March 2020.

3.4. Education

The following programme of education has been developed to meet stakeholder needs and objectives identified by the network: These events/meetings are an integral part of the education strategy being developed by the network:

3.4.1 -An Annual Education Event. This is aimed to enhance knowledge in the management of paediatric infectious diseases and primary immunodeficiencies and the first event for two years was held in November 2019 in Glasgow. It was a great success with 52 delegates attending including a number of adult clinicians. There was also excellent input to the programme and discussions from both the adult sector and from the Health Protection Scotland (HPS) and the Glasgow Caledonian University (GCU) Research Team. Feedback response was almost 50% with the majority rating both the quality of education and relevance to educational needs very highly. More importantly, 50% stated that they would change their clinical practice as a result of attending the event. Comments included:

- Have more knowledge now to discuss with patients
- Better idea of BBV management in pregnancy and children
- Updated advice of management of HIV in newborns
- I'll be more mindful of checking lymphocyte count

A full evaluation analysis can be found in Appendix 3.

3.4.2- Other educational series planned for 2019/20 included:

- teleclinics for paediatricians, specialist nurses and paediatric trainees with a specific interest in paediatric infectious diseases and immunodeficiency across Scotland.
- Clinical Annual Review (CAR) meetings to discuss outcomes of annual reviews of both HIV and PID patients carried out within NHS Boards

The network however has not managed to hold these sessions but plans to re-establish them during 2020/21 as part of an Education Strategy that has been developed.

3.5. Audit and Continuous Quality Improvement

3.5.1 CAS

The ongoing use of the Clinical Audit System (CAS) remains under discussion to ensure that it provides value to the network. The network plans to agree data collection mechanisms once the outcome of discussions on the legal basis for consent for the National Clinical Audit System (NCAS) under General Data Protection Regulation (GDPR) has been finalised

3.5.2 Quality Improvement

The network agreed that its quality indicators (QIs) should be reviewed to focus on a smaller number of meaningful measures, reflecting the network's priorities to drive quality improvement. As a result, the following 4 QIs were agreed in 2019:

HCV

- a) all children and young people with a diagnosis are followed up on a clinical pathway.

HIV

- b) all children and adolescents infected are virally suppressed after 12 months on antiretroviral treatment.
- c) all adolescents have a documented assessment of their condition.

- PID**
- d) 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.

SPAIIIN have been collecting data to measure QI's a, b and d and this has been collated this into visual presentation with analysis as follows:

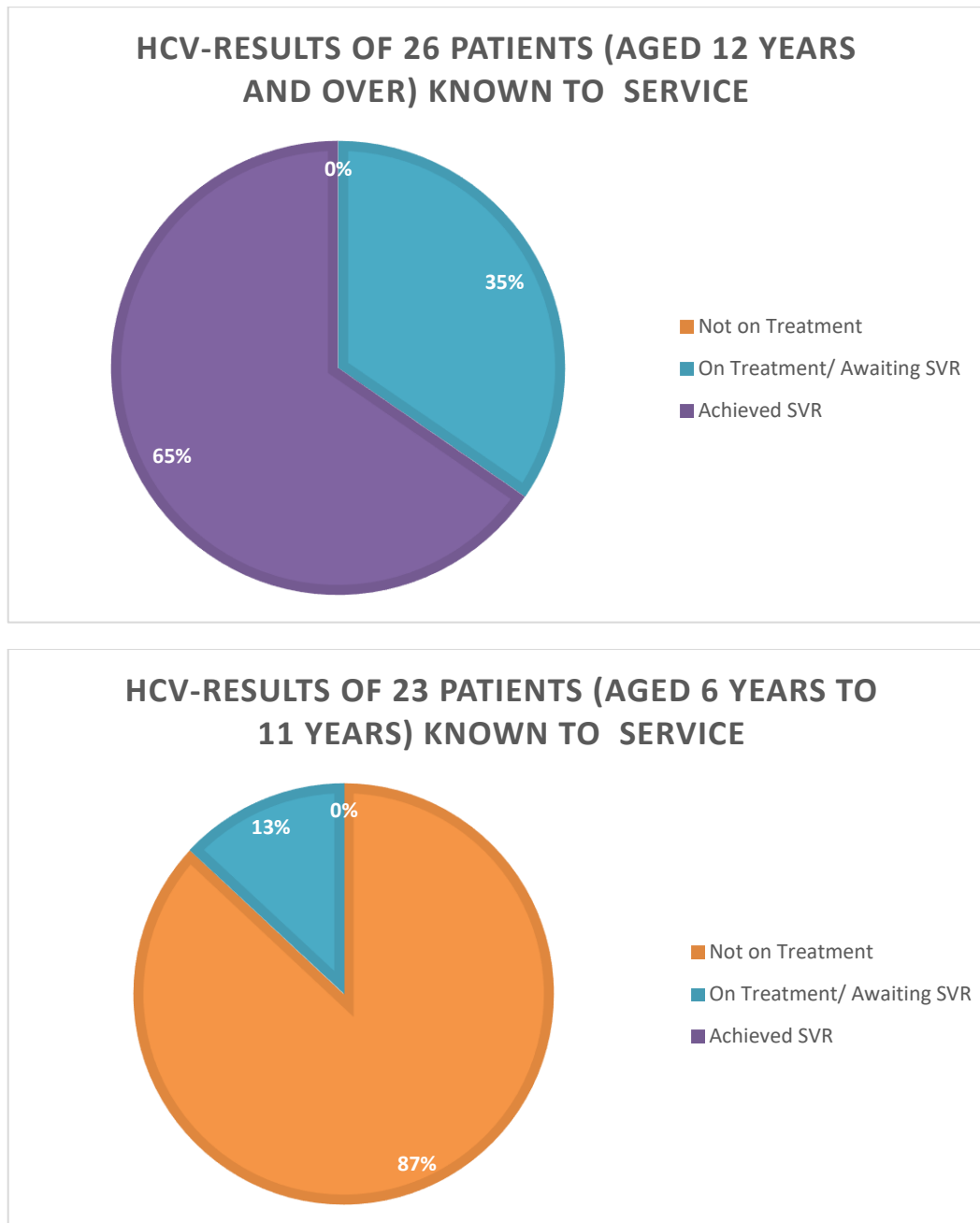


Figure 2 –SPAIIIN QI Measurements for HCV

- a) All patients who are 12 years old and over 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 are currently on treatment or awaiting SVR. There are 20 of 23 children under 12 years who have not yet been treated. 3 of the 23 have been treated via clinical trials. This may be because the

remainder are unsuited or due to spaces being limited. Licensed treatments are currently still only available for those 12 years and over but hopefully the outcome of these trials will allow 6-11 year olds to have licenced treatments.

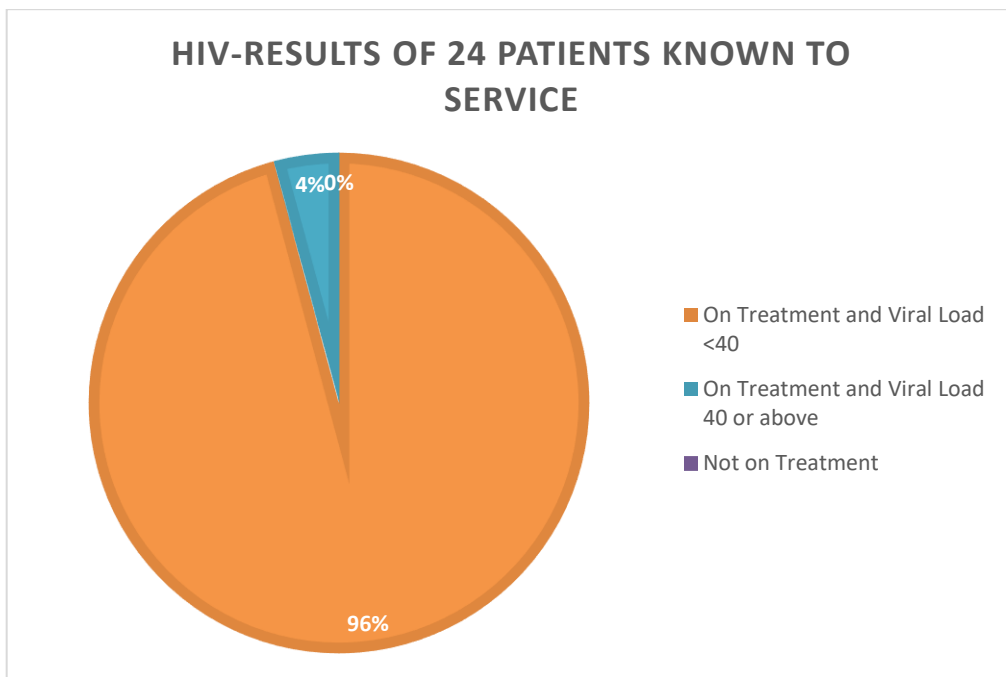


Figure 3 –SPAIIIN QI Measurements for HIV

- b) All patients have reached target apart from NHS GGC. However, they have a midyear transfer from England with other complex medical needs.

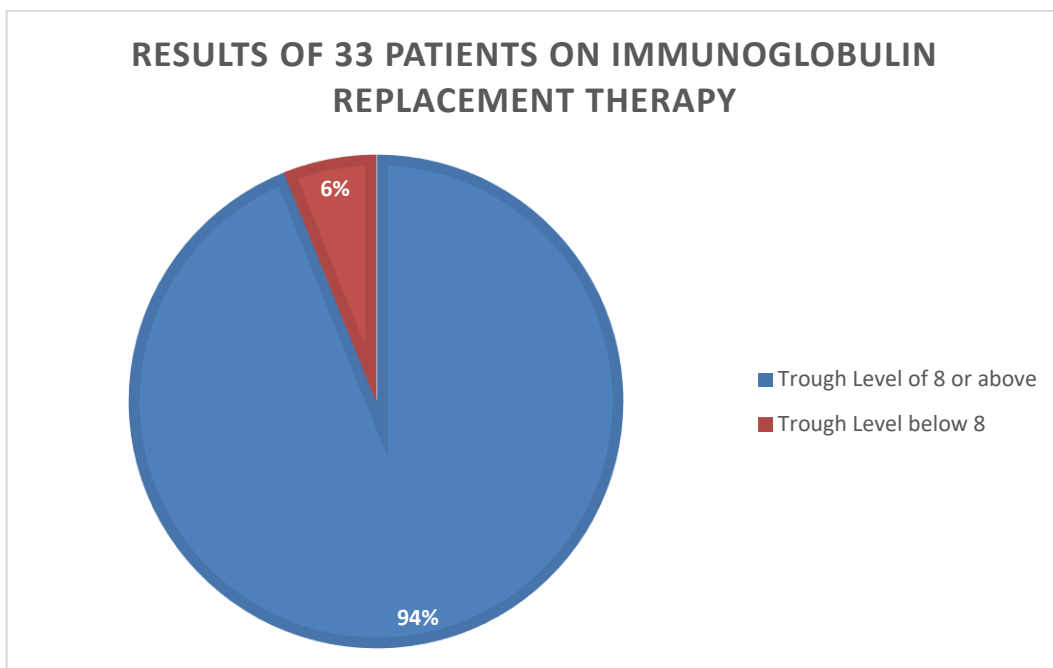


Figure 4 –SPAIIIN QI Measurements for PID

d) 31 of the 33 patients on immunoglobulin (Ig) replacement therapy had reached the trough level of >8g/l (this is minimum level of Ig required in the bloodstream for the drug to be deemed effective for these patients). The 2 patients who had not reached this trough level are being followed up by their local service.

3.6. Value

There continues to be a very robust and successful pathway for children with PID requiring a stem cell transplant. SPAIIIN continues to work with the service in Newcastle and the Scottish Stem Cell Transplant Services in Glasgow to increase the proportion of patients referred to the Scottish service for treatment. This saves money, and where clinically appropriate, patients are treated closer to home. Stem cell transplants undertaken in Scotland save around £100,000 per patient when compared with referral to the Newcastle service

The network has produced a Scottish integrated care pathway for the perinatal management of HIV, which is being used across the main health boards where HIV pregnancies are being managed. This pathway helps to reduce the likelihood of mother-to-child transmission to zero, improving outcomes for the child, and resulting in significant savings for the NHS where treatment would be hundreds of thousands of pounds in the life of that child. The network pharmacist continues to be involved in prescribing or advising on safe, once daily ARV regimens that are cost effective and patient friendly to avoid the development of resistance.

Ensuring all paediatric Hepatitis C patients are linked into care and a plan is in place for treatment in local or regional centres will result in cure for 100% of children with this virus in Scotland. In the vast majority this will result in discharge from medical services. The consequence of not getting all of these children on these pathways will result in significant liver disease in adolescence or adulthood leading to cirrhosis, liver cancer or transplant. The cost of managing these largely irreversible conditions is in the hundreds of thousands of pounds. For example, transplant costs are approximately £50,000 per transplant, not including pre-transplant treatment requirements.

4. Plans for the Year Ahead

Key priorities for year ahead as previously mentioned include:

1. Agree data collection mechanisms once the General Data Protection Regulation (GDPR) outcome has been finalized.
2. Develop a care pathway for young adults over the age of 16 with Primary Immune Deficiency (PID) needing bone marrow transplant;
3. Continue to work with genetics services to progress formalising the process for the genetic testing service for patients with Primary Immune Deficiency in Scotland;
4. Identify via virology testing data and Health Protection Scotland records anyone under 18 years who has ever tested positive with HCV and ensure every child/adolescent in Scotland is linked to care and offered treatment where appropriate.
5. Ensure all children with HCV, aged 6yrs -11yrs are entered into available trials.
6. Ensure all children with HCV, aged 3yrs-5yrs are entered into available trials.
7. continue to work with Waverley care to deliver education and support to teenagers with HIV who are approaching transition.
8. Deliver both an education and communication and engagement strategy
9. Continue to take forward the recommendations of the Network review (please see [section 2](#) for more detail).

10. Pilot a program of Universal testing of HCV in pregnancy women to support better case finding in children.

5. COVID-19

Since February 2020, understandably NHS Scotland priority has been to prepare for and deal with COVID-19 impact and this has seen clinical and other resource diverted from network activity. The network has undertaken an exercise to not only capture the impact of this unprecedented situation on the current reporting period but also to assess the likely impact on delivery of the 20/21 workplan. Due to huge time constraints on Infectious Disease steering group members, from the end of February, a decision was made to halt network business in the short term. Many of the network's healthcare professionals took on leadership roles with COVID-19 planning and management due to the nature of the speciality. Despite this loss of time and cancellation of steering group meetings we have been able to communicate via email when time allows and tie up the majority of the work priorities set out for 2019/2020. Going into 2020/21, some elements of the workplan will be delayed whilst other can be progressed for the reasons above.

Key areas of impact: -

1. 2019-05 –Identify via virology testing data and Health Protection Scotland records anyone under 18 years who has ever tested positive with HCV and ensure every child/adolescent in Scotland is linked to care and offered treatment where appropriate-this work involves engaging with HPS and link clinicians and has been delayed.
2. 2019-07- Pilot a program of Universal testing of HCV in pregnancy women to support better case finding in children-planned to start in April 2020-has been delayed
3. 2019-08-Continue to assess the knowledge of young people with HIV who are undergoing transition-involves interviewing teenagers-has been delayed.
4. -Provide multi-disciplinary paediatric study day for healthcare professionals-planned for late Autumn

5 Detailed Description of progress 2019/20

RAGB status	
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	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 network is on track to achieve the objective by the agreed end date.
BLUE (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 March 31st 2020	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2019-01	<p>Network continues to be overseen by multi-disciplinary steering group with Lead Clinician and Chair.</p> <p>Network has Service Level Agreement and workplan in place</p> <p>Network meets core principals of managed clinical networks as set out in CEL (2012) 29.</p>	April 2019/ March 2020	Hugh Kennedy/ Steering Group	<p>Steering Group in place with LC and Chair which oversees workplan.</p> <p>The Network has a service level agreement with NHS NSS in place for 2019-2022. This is currently being updated</p>		B
2019-02	Organise 3 Steering Group meetings to ensure effective delivery of the 2019/20 workplan	April 2019/ March 2020	Steering Group	Steering Group Meetings: 18 June 2019 10 December 2019	Effective delivery of the SMN work plan to ensure continuation of progress.	B

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
				March meeting cancelled due to COVID-19		
2019-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/19 31/05/20	Lead Clinician/ Programme Manager	Mid-Year Report available Annual Report available	There are effective governance arrangements in place.	B
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-04	Development of young adult PID Stem Cell Transplant pathway for Scotland-mimicking and/or using the pre-existing paediatric pathway	April 2019/ March 2020	Rosie Hague	Has not progressed as well as expected. Some referrals have been made but they have been case by case without a recognised pathway in place. Transplant criteria more challenging for adults c/fwd	Improved service delivery for young people with PID	A
2019-05	Developing a pathway for genetic testing for adolescents with PID	April 2019/ March 2020	Rosie Hague	Links with the Aberdeen lab have been strengthened and a new request form developed c/fwd	Improved service delivery for young people with PID	G
2019-06	Continue to establish better links with adult immunology service	April 2020/	Rosie Hague	Initial links established through education event, joint clinics and regular	More effective networking through	G

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
		March 2021		teleconferences. Need to build on this-c/fwd	involving key additional stakeholders	
2019-07	Develop care pathways for children and young people with hepatitis B and C infections in Scotland improving access to treatment	April 2019/ March 2020	Connor Doherty/ Fiona Marra	Care pathway developed in Glasgow and rolled out to other specialist centres. Focus has been to ensure all children from 12-17 yrs of age known to services across Scotland are on a pathway of care. This has been successful.	Improved service delivery for children and young people with Hepatitis B and C	B
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2019-08	Develop and Implement a Communication and Engagement Strategy	April 2019/ March 2020	Hugh Kennedy	Draft developed c/fwd to next year	More effective network through involving additional key stakeholders	A
2019-09	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 -	April 2019/ March 2020	Fiona Marra/ Connor Doherty	This is WIP with the network working with these groups to develop plans to identify all of these children. This work will be c/fwd to next year	More effective network through involving additional key stakeholders	G

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2019-10	Assess the knowledge of young people with HIV who are undergoing transition	April 2019/ March 2020	Fiona Marra	Network are using CHIVA tool to measure knowledge and collaborating with Waverley Care to assess patents. This work has started and will be c/fwd to next year	Improved transition service delivery for young people with HIV	G
2019-11	Review information currently on SPAIIIN website and ensure it is relevant and up to date	April 2019/ March 2020	Mary Glen	This has been done	Improved engagement with both patients and professionals	B
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-12	Develop and implement SPAIIIN education strategy –	April 2019/ March 2020	Hugh Kennedy	Draft Developed. c/fwd to next year.	Improved knowledge in childhood immunology/infectious diseases for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	A
2019-13	Provide multi-disciplinary paediatric study day for healthcare professionals	April 2019/ March 2020	Mary Adams/ Laura Jones	Successful event held in Glasgow in November 2019. See section 3.4 and Appendix 3 for details	Improved knowledge in childhood immunology/infectious diseases for relevant healthcare professionals that either reinforce existing	B

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
					best practice or results in changes in practice	
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-14	Collect meaningful data on PID, HIV and Hep C by developing 6 KPI's	April 2019/March 2020	Hugh Kennedy/ Mike Gunn	4 QI's currently being measured. See section 3.5 for more details. Plan to continue to measure and develop more next year	Identified service improvements for patients with these conditions	G
6. Value <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-15	Providing added value to health care in Scotland			<p>Scottish Stem Cell pathway for children with PID requiring transplant saves around £100,000 per patient.</p> <p>Care Pathway for Perinatal Management of HIV will save hundreds of thousands of pounds per child.</p> <p>Ensuring all paediatric Hepatitis C patients are linked into treatment plan will save hundreds of thousands of pounds per</p>	Providing added value to health care in Scotland for these groups of patients as well as cost savings for NHS Scotland	G

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
				patient in avoidance of liver disease.		

Proposed Work Plan for 2020/21

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	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 network is on track to achieve the objective by the agreed end date.
BLUE (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 March 31st 2020	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-01	<p>Network continues to be overseen by multi-disciplinary steering group with Lead Clinician and Chair.</p> <p>Network has Service Level Agreement and workplan in place</p> <p>Network meets core principals of managed clinical networks as set out in CEL (2012) 29.</p>	April 2020/ March 2021	Hugh Kennedy/ Steering Group		Effective delivery of the SMN work plan to ensure continuation of progress.	
2020-02	Organise 3 Steering Group meetings to ensure effective delivery of the 2020/21 workplan	April 2020/ March 2021	Steering Group	Steering Group Meetings: 16 June 2020	Effective delivery of the SMN work plan to ensure continuation of progress.	

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
2020-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/20 31/05/21	Lead Clinician/ Programme Manager	Mid-Year Report available Annual Report available	There are effective governance arrangements in place.	
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-04	Continue with development of young adult PID Stem Cell Transplant pathway for Scotland-mimicking and/or using the pre-existing paediatric pathway	April 2020/ March 2021	Rosie Hague	b/fwd from 2019/20	Improved service delivery for young people with PID	
2019-05	Continue to developing a pathway for genetic testing for adolescents with PID	April 2020/ March 2021	Rosie Hague	Build on the progress made last year.	Improved service delivery for young people with PID	
2019-06	Continue to establish better links with adult immunology service	April 2020/ March 2021	Rosie Hague	b/fwd from 2019/20-initial links need to be progressed	More effective networking through involving key additional stakeholders	
2019-07	Develop care pathways for children and young people with hepatitis B and C infections in Scotland improving access to treatment For 2020/21 this includes: -	April 2020/ March 2021	Connor Doherty/ Fiona Marra	b/fwd from 2019/20 <ul style="list-style-type: none"> Network have liaised with HPS to identify HCV positive children not in care. 	Improved service delivery for children and young people with Hepatitis B and C	

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
	<ul style="list-style-type: none"> 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. Ensuring all 6-11 year olds are entered into available trials Ensuring all 3-5 year olds are entered into available trials 			<ul style="list-style-type: none"> Three 6-11 yr olds tested positive are currently on clinical trials 		
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2019-08	Endorse and implement a Communication and Engagement Strategy	April 2020/ March 2021	Hugh Kennedy	b/fwd from 2019/20	More effective network through involving additional key stakeholders	
2019-09	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: <ul style="list-style-type: none"> Develop pathway for testing children of women currently being treated for HCV 	April 2020/ March 2021	Fiona Marra/ Connor Doherty	b/fwd from 2019/20. This is a long term objective.	More effective network through involving additional key stakeholders	

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
	<ul style="list-style-type: none"> Pilot a universal testing of HCV in pregnancy to support better case finding in children 					
2019-10	Continue to assess the knowledge of young people with HIV who are undergoing transition	April 2020/ March 2021	Fiona Marra	b/fwd from 2019/20	Improved transition service delivery for young people with HIV	
2020-04	SPAIIIN Website-Continue to develop and maintain	April 2020/ March 2021	Mary Glen			
4. Education <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-12	Endorse SPAIIIN education strategy –	April 2020/ March 2021	Hugh Kennedy	b/fwd from 2019/20	Improved knowledge in childhood immunology/infectious diseases for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
2020-05	Provide multi-disciplinary paediatric study day for healthcare professionals	April 2020/ March 2021	Mary Adams/ Laura Jones	Possible risk due to COVID-19	Improved knowledge in childhood immunology/infectious diseases for relevant healthcare professionals that either reinforce existing	

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Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
					best practice or results in changes in practice	
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-06	Collect meaningful data on PID, HIV and Hep C through measurement of the QI's	April 2020/March 2021	Hugh Kennedy/ Mike Gunn	Continue to measure 4 QI'S from 2019/21 Start to measure additional QI' s for PID Develop new QI's for HCV children not currently in care.	Identified service improvements for patients with these conditions	
2020-07	Develop and implement a Quality Improvement (QI) Strategy	April 2020/March 2021	Hugh Kennedy		Identified service improvements for patients with these conditions	
6. Value <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-08	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	Providing added value to health care in Scotland for these groups of patients as well as cost savings for NHS Scotland	

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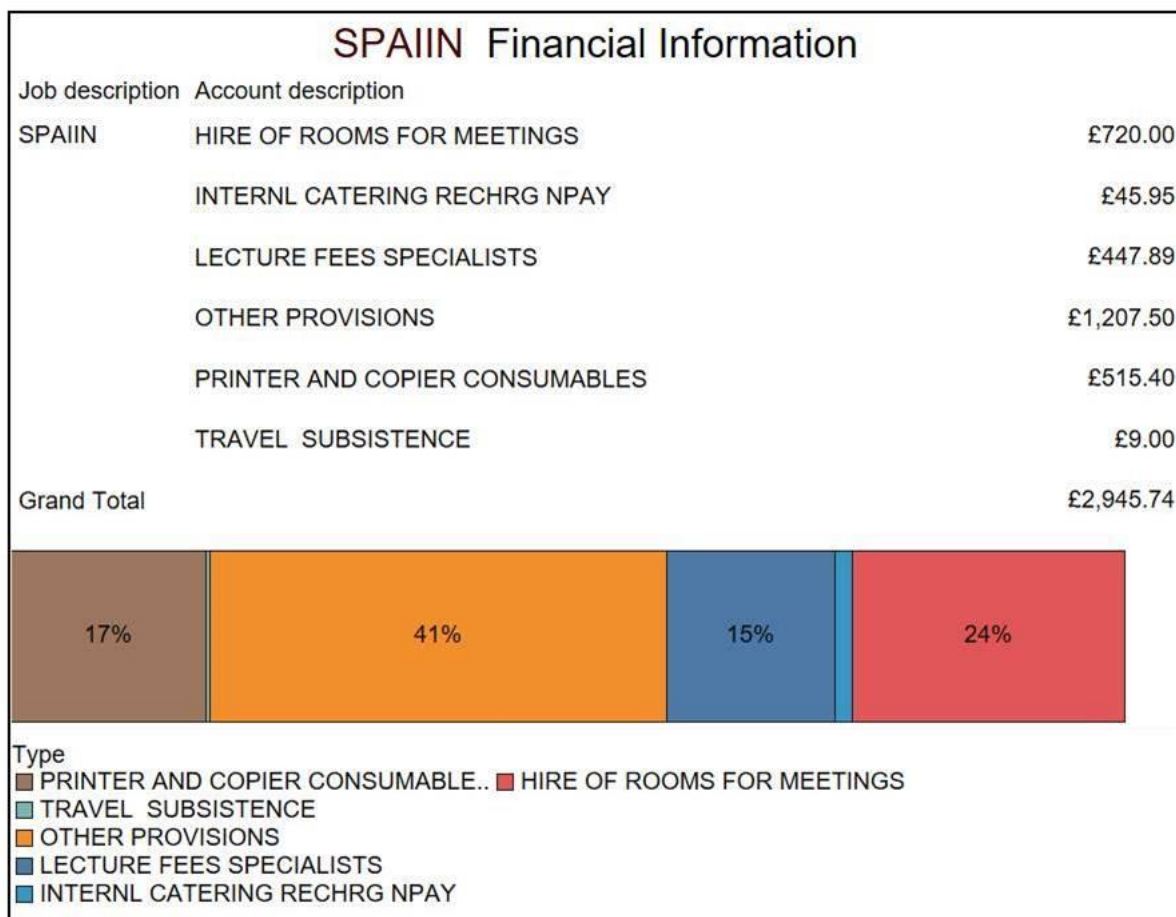
Active Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
				<p>thousands of pounds per child.</p> <p>Ensuring all paediatric Hepatitis C patients are linked into treatment plan will save hundreds of thousands of pounds per patient in avoidance of liver disease.</p>		

Appendix 1: Steering Group Membership

Mrs Fiona Marra	Lead Clinician, Specialist Pharmacist
Dr Conor Doherty	Consultant Paediatrician, NHS GG&C
Dr Rosie Hague	Consultant Paediatrician, NHS GG&C
Dr Moira Thomas	Consultant Immunologist, NHS GG&C
Dr Laura Jones	Consultant Paediatrician, NHS Lothian
Ms Lorraine Clark	Immunology Nurse Specialist, NHS Grampian
Ms Lynne Williamson	Children and Families Project Worker, Waverley Care
Ms Sarah Goodyear	Parent representative-- resigned as of Feb 2020
Ms Elizabeth Furrie	Lead Clinical Scientist, NHS Tayside
Ms Alison Boyle	Specialist Pharmacist, NHS GG&C

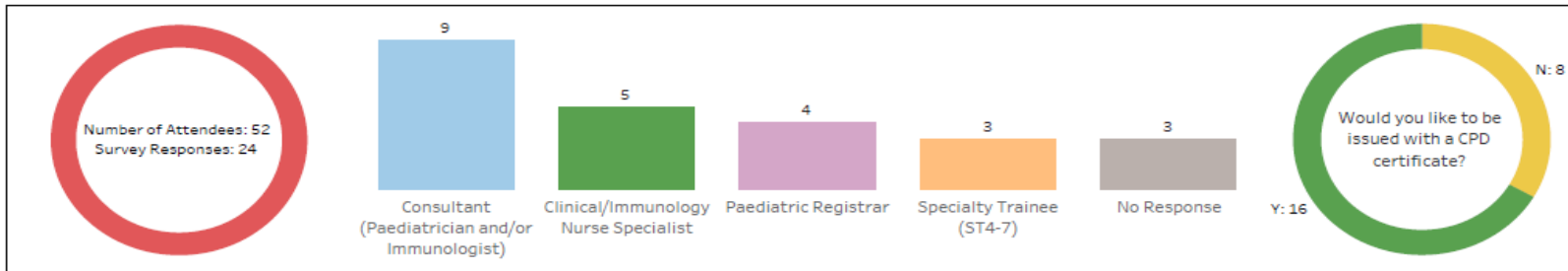
Appendix 2: Finance

During the reporting period SPAIIIN were allocated a budget of £5000, the chart below contains a breakdown of how this was spent. The network held their first annual education event in two years in Glasgow which was a significant spend at £1927.50. This has been split into Hire of Rooms and Other provisions in the report below. The other main cost was the Printer and Copier Consumables of £515.40 which was due to the printing of the CHIVA booklets to help educate teenagers with HIV being transitioned into adult services. The network final position was an underspend of £2,045.26.

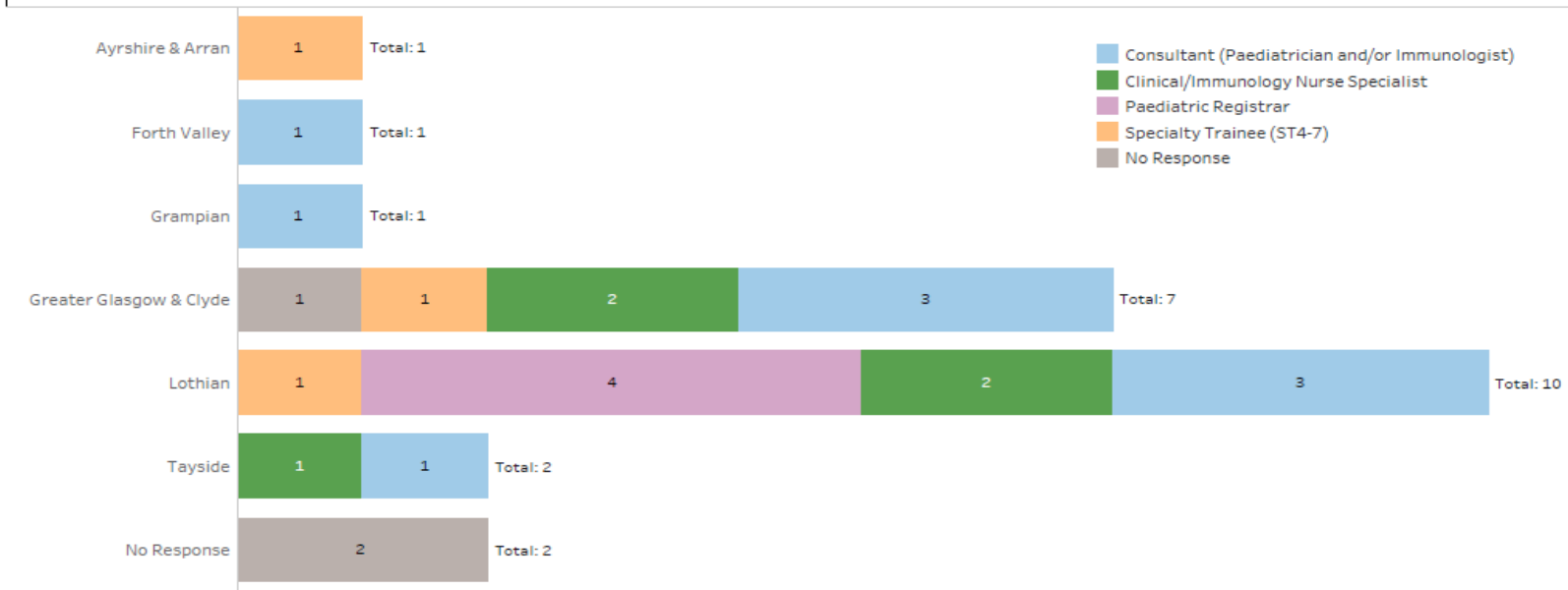


Appendix 3: Annual Education Event-Evaluation Results

SPAIIIN Education Event Attendees



Job Titles by Health Board



Page

Figure 5-Delegate breakdown by board

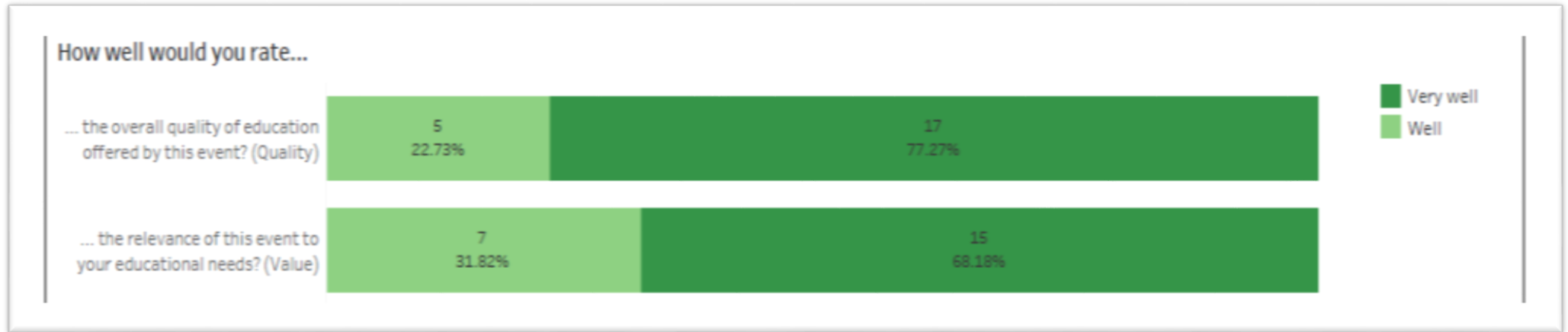


Figure 6-Feedback on quality of education and relevance to educational needs

Figure 7- Relevance of education to impact on clinical practice

Delegate Gains and Changes

