National Patient, Public &
Professional Reference Group (NPPPRG)

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NHS
National Services Scotland

minutes

NPPPRG 2018/89

Subject:	**National Patient, Public & Professional Reference Group (NPPPRG) – 7 November 2018 – Gyle Square, Edinburgh**
Author:	Ms Jennifer Allen/Ms Kirstin Davidson
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Attendance:
Dr Mike Higgins, Medical Director, Golden Jubilee National Hospital ***(Chair)***
Mr Ed Clifton, Head of Scottish Health Technologies Group (SHTG)
Ms Carol Goodman, Regional Programme Manager, North of Scotland Planning Group (NoSPG)
Dr Phil Mackie, Consultant in Public Health, NHS Health Scotland (ScotPHN)
Mr Alex Munnoch, Consultant Plastic Surgeon, NHS Tayside
Mr Soumen Sengupta, Head of Planning – WoS Regional Planning (Deputising for Sharon Adamson)
Mr Wesley Stuart, Consultant Vascular Surgeon, NHS Greater Glasgow & Clyde

Video Conference:
Mrs Chris Anne Campbell, Nursing Director, NHS Western Isles

Observers:
Ms Vikki Milne, National Planning Manager, Strategic Planning & Clinical Priorities, Scottish Government Health & Social Care Directorates (SGHSC)
Ms Karen Grieve, National Planning, National Services Division (NSD)

Secretariat:
Ms Jennifer Allen, Assistant Secretary, Business Development Directorate
Mr Peter Croan, Financial Adviser, National Services Division (NSD)
Ms Kirstin Davidson, Assistant Secretary, National Services Division (NSD)
Ms Roseanne McDonald, Nursing & Quality Adviser, National Services Division (NSD)
Ms Fiona Murphy, Director, National Services Division (NSD)
Dr Craig Wheelans, Medical Director, National Services Division (NSD)

Apologies:
Mrs Sharon Adamson, Regional Planning Director, West of Scotland Planning Group (WoSPG)
Mrs Marianne Barker, Unit Head – Delivery of National Healthcare Priorities, (SGHSC)
Mr Alex Bennett, Consultant ENT Surgeon, University of Edinburgh
Mrs Julie Carter, Director of Finance, Golden Jubilee National Hospital
Ms Anne Marie Cavanagh, Nursing Director, Golden Jubilee National Hospital
Mr Daniel Connelly, Service Change Manager, Scottish Health Council
Dr Alasdair Forbes, General Practitioner, RCGP
Ms Natalie Frankish, Lay Representative and Development Officer, Genetic Alliance UK
Mr Colin MacIver, Consultant Maxillofacial/Head & Neck, NHS Greater Glasgow & Clyde
Mrs Fiona Marley, Director, Highly Specialised Services, NHS England
Mrs Jan McClean, Regional Healthcare Planner, South East and Tayside (SEAT)
Mrs Ruth Meechan, Assistant Secretary, National Services Division (NSD)
Mrs Anne Simpson, Lay Representative
Dr Ruth Stephenson, General Practitioner, British Medical Association (BMA)
Dr Mike Winter, Medical Director, National Services Division (NSD)

Presenters from NSD:
Dr Craig Wheelans, Medical Director*, for item 7.1 Scottish Familial Hypercholesterolaemia (FH) Service, 7.2 Primary Ciliary Dyskinesia (PCD) Diagnostic Service, 7.3 Complex Ehlers Danlos Syndrome (EDS), 7.4*

Focused Ultrasound for Essential Tremor (MRgFUS), 7.6 Scottish Cellular Therapy Service (Car-T) and 7.7 Scottish Molecular Radiotherapy Treatment Centre (SPMaRT).

Dr Anke Roexe, Programme Manager, *for item 7.5 Systemic Vasculitis Network*

Ms Karyn Robertson, Senior Programme Manager, *for item 8 Cleft Care Scotland (CCS)*

Ms Catriona Johnson, Programme Associate Director, *for item 8 Scottish Differences of Sex Development (SDSD) Network*

Mrs Liz Blackman, Senior Programme Manager, *for item 8 Scottish Pathology Network (SPAN) and Scottish Microbiology and Virology Network (SMVN)*

Mr Garrick Wagner, Senior Programme Manager, *for item 8 Thoraco & Supra-Renal Abdominal Aortic Aneurysms (TAAA)*

1. Welcome and Apologies and Declarations of Interest

Members were welcomed to the meeting and apologies were noted.

Declarations of Interests – There were no Declarations of Interest.

2. Minutes of 22 August 2018 – NPPPRG 2018/69

The minutes were approved as a correct record.

3. Matters Arising and Action Tracker – NPPPRG 2018/71

There were no actions from the previous meeting. The Matters Arising paper updated on proposals made to the National Specialist Services Committee (NSSC). These had been added to the Business Case for 2019/20. The proposal to designate the Lutathera Treatment service in Glasgow would be presented to NHS Board Chief Executives (BCE's) on 13 November.

A brief review of the prioritisation for the Annual Business Case was provided and members noted that NSSC had ranked the proposals in a slightly different order to NPPPRG; however the differences were minor with the first four proposals prioritised by both groups.

Members noted the progress regarding Psychology Provision and the Oral Medicine Review and were asked to provide written feedback to the latter once it had been circulated.

3.1 New Service Implementation Update – NPPPRG 2018/72

This paper provided a brief update of newly designated services from 2017 and 2018. Members were informed that all were progressing as expected although some delays had occurred around the Neonatal Network. It was anticipated that this would be up and running over the winter.

4. Horizon Scanning – NPPPRG 2018/73

This paper reported on the early applications NSD had received and the work underway to find out more about the proposals.

It was noted that an Options Appraisal would be undertaken in mid November for the Complex Learning Disability for CAMHS Inpatient Care, looking at the pros, cons and costs of each feasible option. The Minister for Mental Health had requested that this be expedited. It was unclear as yet whether this would return for the attention of NPPPRG or whether it would addressed by the National Planning Board or Regional Planners.

An update was provided regarding Stem Cell Transplant (SCT) for Multiple Sclerosis (MS). NSSC had requested that the Scottish Health Technologies Group (SHTG) review the evidence base. This had now been added to their workplan.

5. Update from NHS England

Members were informed that NHS England was considering commissioning 2 units to provide Intrauterine Surgery for babies with Spina Bifida. Currently mothers can be referred to a centre in Belgium for treatment. Members were in agreement that if NHS England chose to commission these units, they would be happy for Scottish cases to be referred through NHS England.

It was noted that SHTG would be carrying out a review to determine whether a quicker turn around could be feasible in terms of organ re-perfusion with NHS Blood and Transplant (NHSBT). Members were aware that the Scottish National Blood Transfusion Service (SNBTS) may consider setting up a re-perfusion centre in Scotland.

6. NPPPRG/NSSC Workplan 2018/19 - NPPPRG 2018/74 & 74A

The purpose of these workplans was to provide members with an update on the 2018/19 workplan.

4 new Stage 1 Applications had been received bringing the total up to 22 services being considered during this period.

It was noted that most items were on track. The application for the Burns Hub Service was awaited although engagement meetings were underway. A draft application had been submitted for Craniofacial Specialist Surgery. Consultation and engagement was still required. Although Abdominal Sarcoma had submitted a Stage 1 Application, it had been decided that further work was required before presentation to NPPPRG.

Members were made aware that the Paediatric Stem Cell Transplantation Review was unable to progress due to NHS Greater Glasgow & Clyde (GG&C) carrying out an internal review. This would be addressed in due course.

7. New Proposals Submitted (for decision on recommendation)

Stage 1

7.1 Scottish Familial Hypercholesterolaemia (FH) Service – NPPPRG 2018/75

Familial Hypercholesterolaemia (FH) is a genetic condition which affects approximately 1 in every 250 people. FH results in high cholesterol levels from childhood with a resultant high risk of cardiovascular mortality and morbidity (heart attacks and strokes). Early identification of affected individuals however allows for access to relatively inexpensive generic statin drug therapy to reduce cholesterol levels and therefore reduce risk. It is estimated that FH affects over 21,000 people in Scotland with only 9% of patients currently being positively diagnosed (based on figures from British Heart Foundation (BHF). At present there is no clearly defined universal programme of care across Scotland to identify and treat individuals and their families and this outline proposal seeks to highlight the need to develop a strategic approach to deliver equitable FH care.

If a formal service were to exist evidence suggests that for every 1,000 relatives tested, it is estimated that over 20 years, 46 myocardial infarctions, 50 cases of angina, 8 strokes and 16 deaths would be averted.

A great deal of inequity exists around diagnosis and treatment for this condition with no clear mechanisms in place. Previously NHS Grampian offered a nurse-led service to identify patients and their families with this condition. The funding for this had ceased and was now provided by a grant from a pharmaceutical group.

It was anticipated that due to the significant numbers of affected individuals/families the service would require to be delivered across multiple sites, NHS Boards and geographical areas across Scotland; therefore any formal proposal would require a scoping exercise to define who would deliver the service and the commissioning arrangements to do so.

Discussion ensued as to where this was best placed with suggestions including national commissioning, regional planning, and Public Health Scotland. Another suggestion was that this could be included through one of the existing Cardiac networks. The general consensus of opinion was that the numbers would be too large for this to be nationally commissioned. However it was recognised that this application had been submitted to NPPPRG due to difficulties in finding an appropriate platform for it to be addressed in, despite support from the National Advisory Committee for Heart Disease.

Members recognised that any future development of this application would involve a genetic testing element which would come under the remit of NPPPRG in terms of cascade testing through the Molecular Genetic Laboratories.

After further discussion members agreed that a Stage 2 Application was not appropriate due to the patient numbers being too large and the plan being too diffuse. Although the need for such a service was recognised, members decided that NPPPRG should write to the Directors of Planning to indicate their support and to request that it be added to their agenda. The applicant could also be encouraged to approach the Directors of Planning although it was recommended that the application be tightened up in terms of specifics. Potential costs for the genetic element could be separated out for NSSC at a later date.

In Summary, NPPPRG advised against a Stage 2 Application being submitted. NPPPRG recommended that the Directors of Planning be approached to lead on this work.

7.2 Primary Ciliary Dyskinesia (PCD) Diagnostic Service – NPPPRG 2018/76

The existing regional service for the West of Scotland undertook 30 ciliary biopsies in 2016 and 27 in 2017. These were performed in the RHC and analysed in the Pathology Department of the QEUH. The pathology service have intimated that they have the capability to increase this to 50 samples per year which would meet the anticipated needs of the paediatric patients residing in the North, East and South East of Scotland. Historically many of these non-WoS patients have been referred to PCD specialist services which are commissioned by NHS England with the costs of such investigation and follow up being funded from either NSD administered risk share funds or by individual Health Boards. In addition Boards have been required to reimburse travel and subsistence costs.

The Paediatric Scottish Diagnostic Centre for Primary Ciliary Dyskinesia would offer nasal ciliary biopsy to assist in the diagnosis of PCD for children and adults across Scotland. Samples would be taken in RHC, Glasgow and analysed by the Pathology Service on the Queen Elizabeth University Hospital Campus. This would offer equitable access to children across Scotland and reduce travel disruption and required time off work for family members.

In addition the service had suggested that their capability and capacity could offer biopsies for a specific group of adults who are suspected of suffering from PCD.

It was noted that NHS GG&C currently have the equipment, experience and capacity to see around 50 children per year, although at present around half that number were being seen. Members were informed that if these children were identified early their lung function could be protected through physiotherapy and other treatments.

It was anticipated that work would continue with colleagues in NHS England on a peer review basis in conjunction with a formal Multi Disciplinary Team (MDT) that would allow sharing of expertise.

Members discussed the fact that referrals to NHS England were funded through the Risk Share scheme; whereas if referrals were made within NHS Scotland through a Service Level Agreement (SLA), referring NHS Boards would be required to pay NHS GG&C for the complete cost of treatment.

It was noted that NHS England offered a Diagnostic Biopsy Service along with treatment. However, the proposal submitted by NHS GG&C outlined only a Diagnostic Biopsy Service with treatment being managed and delivered locally.

Members agreed that a Stage 2 Application should be provided with more detail given around patient numbers and provision of advice through a knowledge network.

In summary, NPPPRG reviewed the Stage 1 Application and recommended that a Stage 2 Application be submitted. However, clarity should be provided around patient numbers and provision of advice with an emphasis being placed on the service being primarily diagnostic.

7.3 Complex Ehlers Danlos Syndrome (EDS) – NPPPRG 2018/77

The aims of the service would be to provide a centre for the assessment, and management of patients with complex Ehler's Danlos Syndrome (EDS) whose needs are not being adequately met at a local level. The centre would offer a detailed evaluation of symptoms and needs of referred patients and develop an individualized care pathway for patients that would address the musculoskeletal and extra-skeletal manifestations of the disease.

A shared care model would then be developed with specialists from the referring NHS board so that care could be delivered locally on a longer-term basis. As the musculoskeletal system is almost invariably affected it is anticipated that most referrals would come from consultant rheumatologists.

It was noted that currently patients are often referred along different pathways with no MDT approach being taken to address all their symptoms. Some patients are referred, often unnecessarily, to a 3 week residential programme at significant cost. An MDT approach would minimise the need for this, given that expertise does exist at a local level. An assessment would be carried out for each patient and the treatment plan could be provided to a local physician for coordination.

A query was raised around the scope of the review and whether this was part of a wider group of non-inflammatory connective tissue disorders including Loeys-Dietz Syndrome (LDS) and Marfan Syndrome. Members were concerned that if the proposal was widened to include these, patient numbers would become too large for national designation. It was unclear how patients with other non-inflammatory connective tissue disorders were currently being managed as none were coming through the Risk Share Scheme.

In summary, NPPPRG cautiously supported a Stage 2 Application with the caveats that the patient group be defined more precisely, that consideration should be given to including other non-inflammatory connective tissue disorders, and that questions around diagnostic routes, referrals, staffing levels and relationships with existing services should be addressed.

7.4 Focused Ultrasound for Essential Tremor (MRgFUS) – NPPPRG 2018-78

Specialist treatment of patients with Essential Tremor using MRI-guided focused ultrasound (MRgFUS) to create small lesions within the brain (Thalamus). New MRgFUS technology would be targeted using the existing University of Dundee research MRI scanning facility. MRgFUS had recently gained the National Institute for Health and Care Excellence (NICE) approval for treatment of patients with essential tremor, targeting an area of the thalamus and for Parkinson's disease in a research setting. At present the approval was for unilateral treatment, and NICE recommended that the patient be advised of alternative interventions that offer bilateral treatment, and that the intervention was delivered under specific local clinical governance oversight using ultrasound.

Whilst the number of patients with essential tremor was high (~20 000) only 1 in 5 would seek treatment and of those only a small proportion would wish to proceed to MRgFUS. The only equivalent service in UK had a waiting list of over 200 people. It was suggested that the centre would be able to deliver 2 treatments / day on the one day / week that it would be available for NHS use.

It was noted that the Scottish Government had debated this issue earlier in the year and had raised concerns that the evidence base was insufficient. It was clarified that the NICE Interventional Procedures Guide had no major safety concerns, but had little around relative clinical and cost effectiveness. The guidelines also recommended that the equipment should only be used in conjunction with clinical research and members had concerns about investing a significant amount of money in something that would be primarily used for research on an experimental procedure in a non-NHS facility.

Discussion also ensued around the fact that being limited to treating 2 patients per week would likely mean that a substantial waiting list would develop due to this being a relatively common condition.

Members understood that it would be difficult to build an evidence base without the equipment and patients, but felt that NHS Tayside should be encouraged to talk to appropriate research funders.

In Summary NPPPRG did not endorse the development of a Stage 2 Application.

Stage 3

7.5 Systemic Vasculitis Network – NPPPRG 2018/79

This proposed network would cover adult patients with systemic vasculitis including ANCA associated vasculitis, large vessel vasculitis, Behcets disease and GCA. It is estimated that of the estimated 12500 patients with systemic vasculitis in Scotland, around 1500 would benefit from specialist input from a vasculitis service.

The proposed network of clinicians from various specialties across Scotland would ensure that pathways for referral and management of systemic vasculitis were clearer, and patient outcomes improved. The network would aim to ensure appropriate coordination of care and use of expensive medicines. It would facilitate patient access to timely specialist knowledge.

It was anticipated that clinical outcomes would be improved by earlier diagnosis and the development of agreed treatment protocols based on current evidence based guidelines and with harm reduction strategies embedded.

The overarching goal of the network was to improve outcomes, reduce geographical variation and ensure safer, more cost-effective care across Scotland. The proposed network also aligned well with the current national emphasis on realistic medicine and shared decision making as it would reduce inappropriate therapy and ensure access to experienced clinicians.

NPPPRG agreed that an MDT approach would be more beneficial and recognised that a great deal of effort had been put into developing this proposal.

It was noted that the proposal had broad and good support across clinical specialties; however, NPPPRG observed that written support had only been provided from the Chief Executives of 2 of the regions. It was decided that written support should be obtained from all of the regions to ensure good regional connections.

Action: Dr Roexe

In summary, NPPPRG endorsed the commission of this proposed National Managed Clinical Network (NMCN) once complete written support had been obtained from the regions.

7.6 Scottish Cellular Therapy Service (Car-T) – Update – NPPPRG 2018/80

Reviewing NHS GGC&C's Stage 2 application, NSSC agreed that, subject to approval by the SMC, a Stage 3 Application for a single site service for adults should be developed in the first instance.

NSD were asked to formally appraise the capabilities of the Allogeneic Stem Cell Service in Glasgow and Autologous Stem Cell Services in Edinburgh and Aberdeen to deliver the two products for the treatment of Diffuse B Cell Lymphoma in line with the Commissioning Service Specification which has been prepared in conjunction with the manufacturers of the therapy and UK clinical experts experienced in this therapy by NHS England.

Whilst there were strengths and weaknesses in both the submissions from NHS Lothian and NHS Greater Glasgow, it was the recommendation of NSD that the initial commissioning of this service should be in line with the opinion of both the clinical reference group in England and the manufacturers that the service would be initially delivered in an allogeneic centre. In order for this to take place there would be the requirement that NHS GGC were formally accredited in this form of therapy by the Joint Accreditation Committee ISCT and EBMT (JACIE). In preparation for the introduction of the therapy there would be a requirement that the clinicians in all centres within Scotland work together to define the care pathway for patients, work up for treatment, follow up post therapy and scope how the delivery of therapy would look in the future following this initial roll out.

It was noted that NHS GG&C had submitted their formal application for JACIE accreditation and an inspection was anticipated in May 2019. The stem cell laboratories had already been inspected in January 2018. NPPPRG recognised that the reapplication for JACIE accreditation had been necessary due to having moved to a new facility.

NPPPRG were aware of the fact that commissioning could not take place until the Scottish Medicines Consortium (SMC) had given approval for the two products but wanted to be prepared, assuming that Scotland would be offered the products at the same price as England. Members recognised the fact that if they did not recommend designation, patients would have to be referred to NHS England, thereby causing capacity issues.

Members queried if every new drug was likely to come through NPPPRG but clarification was provided that only those drugs that required specialist treatment would take that route.

Discussion ensued around future roll out of these products in other Scottish centres. It was confirmed that this would not be presented as part of the Stage 3 Application, but that after designation the service would bring groups together to further understand the referral pathway and to discuss training and development.

In summary, NPPPRG noted the recommendation from NSD that NHS GG&C progress to a Stage 3 Application and awaited its circulation for comments prior to NSSC.

7.7 Scottish Paediatric Molecular Radiotherapy Treatment Centre (SPMaRT) - Update – NPPPRG 2018/81

The Stage 3 application from NHS GG&C was considered by NPPPRG and NSSC in August/September 2018; however both the reference group and committee raised concerns around the costs of delivering the service in relation to staff costs and the number of patients that would be treated each year. Such low numbers, it was felt, could make the service prohibitively expensive in comparison to the costs charged by the current providers in NHS England and would not give the clinical team adequate case volumes to gain confidence in delivering the treatment and maintain the developed skills.

As a result of the concerns which were raised, NHS GG&C had revised their costs, had sought support of clinicians from North East England and Northern Ireland with a view to increasing patient numbers referred for treatment in Glasgow and had provided some additional reassurance regarding governance arrangements for the delivery of treatment.

NPPPRG noted that in order for the service to be cost effective it would need to undertake 6 treatments on 4 children per year. This was deemed likely given existing patient numbers.

Discussion ensued around the implementation of the service with concerns raised as to how many patients would actually receive treatment per year as the service developed, given that it would take a while to get referrals. It was suggested that a 12 month review should take place after designation to assess and monitor the patient numbers and referral patterns. It was acknowledged that with small numbers it would be difficult to demonstrate outcomes quickly and review should include process measures of clinical governance. It was noted that NSD would perform annual review of the service as part of the commissioning process.

In summary, NPPPRG supported the application and recommended designation to NSSC.

8. Service Reviews/Developments

8.1 Cleft Care Scotland (CCS) – NPPPRG 2018/82

The Cleft Care Scotland (CCS) network was originally established in April 2000 as CLEFTSiS, a national paediatric network for children born with a cleft lip and/or palate. Following reviews of the network in 2009 and 2011, it was rebranded as Cleft Care Scotland and expanded to encompass the full patient pathway.

Around 100 children were born with some form of cleft lip/palate in Scotland each year. Care was delivered by a multi-disciplinary team of professionals including surgeons, orthodontists, SLTs, specialist nurses, psychologists and dentists throughout childhood and into adulthood.

The Network had been challenged for some time, with fractured relations within the cleft care community affecting engagement and participation in the network. Many of the professionals involved had stated they struggled to identify a meaningful role for the network that was separate to that of the nationally designated surgical service.

In 2015 NSSC directed a further review of the nationally designated surgical service. The outcome was approval from the Cabinet Secretary for Health and Sport that cleft surgery should be provided on a single site (NHS GG&C), supported by the existing national network. This process and outcome proved very contentious and exacerbated already strained relations within the network.

This review had been undertaken due to changing circumstances within cleft services in Scotland necessitating a review of the role of the network going forward. Given that many of the same stakeholders had recently participated in the review of the national cleft surgical service, this review had assessed the available evidence from documentation and stakeholder engagement and had not convened a full expert review group. The conclusions and recommendations drawn from the evidence had been provided by a review team from NSD as commissioners of the network with external oversight from Simon Hilton, Consultant in Public Health Medicine, NHS Grampian.

The review found a continued need for the network and a willingness of members to re-engage and refresh the network to support services and patients across Scotland.

NPPPRG noted the review findings, endorsed the recommendations and recommended to NSSC that the network retain its national designation for a further 3-5 years.

8.2 Scottish Differences of Sex Development (SDSD) Network – NPPPRG 2018/83

The Scottish Differences of Sex Development (SDSD) Managed Clinical Network (MCN) was established in 2005 to improve access to high quality care for all those living in Scotland born with a DSD. The Network had been reviewed twice since its original designation in 2007; once in 2009 as part of a review of nine national managed clinical networks which identified an ongoing role for the network, and again in 2015.

The aim of this review was to ascertain the extent to which the network continued to achieve the objectives and recommendations agreed following the 2015 review. Given the additional period of scrutiny this review had been undertaken using a modified network review model whereby a review team from NSD, with external oversight from Ms Alex Little, Child Health Commissioner, NHS Dumfries and Galloway, assessed the available evidence from documentation and stakeholder engagement.

NPPPRG noted the review findings, endorsed the recommendations and recommended to NSSC that the network retain its national designation for a further 3-5 years.

8.3 Scottish Pathology Network (SPAN) – NPPPRG 2018/84

The Scottish Pathology Network (SPAN) National Managed Diagnostic Network (NMDN) was reviewed in October 2016. The review highlighted notable successes for the network, including the creation of a cohesive dataset and the bringing of pathologists together to share best practice. However, there were extensive recommendations from the Expert Review Group which required significant change in the network approach and workplan. NSSC therefore approved a two-year extension to enable the network to address these matters and provide a further report.

Members were informed that the Network was now working well collaboratively with strategic partners. Steering groups and working groups had also been successful. An annual education event had now been instigated and had been very well attended with tremendous feedback. Funding for the digital path rollout had also been secured.

NPPPRG recognised the hard work and effort that had been put in by members of the network.

NPPPRG noted the significant progress made in implementing the recommendations of the SPAN review report and the value SPAN added in supporting NHS Scotland to progress current strategic initiatives. NPPPRG recommended to NSSC that the network retain its national designation for a further 3-5 years and that the network should be returned to routine review.

8.4 Scottish Microbiology and Virology Network (SMVN) – NPPPRG 2018/85

The Scottish Microbiology and Virology Network (SMVN) was established in 2012. The network differs from other national networks in that management is provided through a service agreement with NHS Grampian and was not fully integrated into the NNMS.

SMVN was reviewed in 2017 as a part of routine commissioning processes and several key successes were noted, including the creation of a strong sense of community in Microbiology and Virology in Scotland, highly regarded education events, best-practice sharing; development of policy and guidelines, and procurement and ongoing support of the VITEK systems (for microbial identification and antimicrobial susceptibility testing).

The Review concluded that the SDSD network had made significant progress within this review period in all of the core principles identified in SGHSCD guidance on MCNs. It commended the work undertaken to expand the evidence base and explore an appropriate range of approaches and data sources to identify and measure improvement.

In December 2017 NSSC endorsed the findings and recommendations within the Review Report for the Scottish Microbiology and Virology Network (SMVN), with the additional requirement that the Network address a number of key recommendations within twelve months. This paper highlights the significant progress that had been made over the past year towards implementation of the recommendations, and made recommendations about the future of the network.

NPPPRG were satisfied that good progress had been made around distributed leadership, better use of resources, engagement with stakeholders, website development and the 5 year work plan. A business case had recently been submitted for Tuberculosis (TB) work which would provide a potential for cost savings and would ensure consistent standardization across all the laboratories for TB cases.

It was confirmed that work was well under way to convert the structural set up of the network to a more conventional framework.

NPPPRG noted the significant progress made and recommended to NSSC that the network retain its national designation for a further 3-5 years and that the network should be returned to routine review.

8.5 Thoraco & Supra-Renal Abdominal Aortic Aneurysms (TAAA) – NPPPRG 2018/86

NHS Lothian was designated in 2001 to provide a comprehensive Thoraco-Abdominal Aortic Aneurysm surgical service for the population of Scotland.

A Thoraco-Abdominal Aortic Aneurysm (TAAA) is an aneurysm of the descending thoracic aorta extending into the abdominal aorta. Should bulging and weakening of the wall continue unchecked or untreated the artery may go on to rupture (burst). The mortality associated with the natural history of TAAA is significant, but there is also substantial risk of mortality and morbidity associated with its repair.

The TAAA Service was due for a planned review and the Service has also requested a review of baseline funding for the current service model. In light of this, NSD requested that the National Specialist Services Committee (NSSC) agree a Major Review for the Service. It was agreed that the Review would also consider changes to the referral pathway for TAAA and new technologies, including complex endovascular devices (EVAR, FEVAR and BEVAR), which had increased in usage since 2012.

The aim of this review was to assess how the TAAA Service might meet the requirements of the current Service Agreement and the ongoing needs for the Service, using evidence from the current service and from a wider review. It was agreed that the Review would consider changes to the referral pathway for TAAA and new technologies.

The Review Group assessed the current service against NSSC criteria for national designation as well as the extent to which the Service was clinically and cost effective, and was meeting the identified need. The Review Group concluded that:

- there was an ongoing need for a nationally commissioned TAAA service for Scotland;
- the service was clinically effective and cost effective
- the service continued to meet the identified need and to meet the NSSC criteria for designation, but that there were geographical variations in uptake of the service. To reduce the risk of unwarranted variation and ensure equity of access, the Review Group explored the options facing NHS Scotland for an enhanced patient pathway for patients identified with a TAAA
- the patient pathway for the Service should be altered, with the introduction of a Pan Scotland TAAA MDT.

The Review Group were in unanimous agreement that the TAAA Service should continue as a designated national service. However, there was also agreement that the pathway into the Service had scope for improvement and that it should include a MDT with input from other vascular/interventional radiologist services in NHS Scotland.

A query was raised around the fact that no mention had been made regarding improved communications. It was noted that the Pan Scotland MDT should address this.

Discussion ensued around the variation between endovascular and open procedures and the fact that there is a variance across NHS Boards as to their preferred method. Members recognised that this split became more polarized at the specialist end of the field. It was noted that the Pan Scotland MDT would have all the relevant data and would monitor and report on both procedures which would go some way to providing a clinical governance framework for when the NICE guidelines were published.

Further discussion was had around the Pan Scotland MDT and how much buy in there had been to this suggestion. NPPPPRG were informed that the clinicians on the review group had all supported this move and the recommendation had been made that NHS Boards enter into their workplan that each consultant would be a member of the Pan Scotland MDT. Efforts were underway to identify an independent chair from external sources. It was estimated that the MDT would be created in March 2019.

In summary, NPPPRG noted the review findings and recommended to NSSC that the network retain its national designation for a further 3-5 years with the caveat that an interim 12 month review be carried out in March 2020 to evaluate the progress on the Pan Scotland MDT.

9. National Planning Update – NPPPRG 2018-87

The new NHSS National Planning Board met for the first time on 19 October 2018. The Governance Framework for national planning described the remit, governance, membership, meeting arrangements, review period and ways of working.

The NHSS National Planning Board would provide oversight, governance and decision making in relation to national planning of NHSS services and set the strategic direction for the medium to long term, taking account of the enabling resources, namely finance, workforce, and infrastructure.

The purpose of this report was to inform the NPPPRG about the NHSS National Planning Board's remit and new work plan and to inform NPPPRG about the outcome of the NHSS National

Planning Board decision relating to the connections and processes between the board and the NSSC.

Members were reminded that the new NHSS National Planning Board was a refreshed version of the previous National Planning Forum. It would be coordinated by NSD with Ms Grieve leading as Programme Associate Director.

It was noted that it might be appropriate for NPPPRG/NSSC to refer things to the NHSS National Planning Board and vice versa. It was intended that NHSS National Planning Board would scope out future need and therefore potentially be able to predict areas for commissioning ahead of applications being submitted by individual NHS Boards as happens presently.

Members were informed that the NHSS National Planning Board had chosen not to have sight of Stage 1 Applications or Horizon Scanning documents from NPPPRG/NSSC and would allow applications to be directed to them after scrutiny and rejection by these groups.

In summary, NPPPRG noted the NHSS National Planning Board's decision and took cognizance of the need to consider NSSC proposals and applications in the context of the new NHSS National Planning landscape.

10. NSSC Business Case – NPPPRG 2018-88

This paper detailed the projected funding requirement for national services in 2019/20 within a context of **delivering 5% CRES** and ensuring long term financial balance on specialist services.

NSD budget for national specialist & screening services, risk share schemes & networks in **2018/19 is £232.4m**

For **2019/20**, after uplifts and other previously agreed funding changes were applied, despite continued significant increases in activity, no additional funding was required for existing specialist services.

Due to significant CRES, it was estimated that Risk Share costs will fall in 2019/20. However, it was recommended that the funding remains at the 2018/19 level, and that the CRES was redeployed to recurrently fund a number of new services as prioritised by NSSC.

In addition to this, the group were asked to note the potential requirement to fund CAR-T cell therapy (either as a new service in Scotland or through referral to England) and were asked to consider whether the costs for this and the drug costs for the Lutathera service should be included within the National Risk Share funding.

NPPPRG were in agreement that the CRES should be redeployed as recommended and confirmed that funding would not be available for Lutathera drug costs or Car-T drug costs or service. It was also agreed that the Systemic Vasculitis Network and the SPMaRT Centre would be added into the figures.

11. Any Other Business

No other business.

12. Date of Next Meeting:

Wednesday, 20 February 2019 (at Gyle Square, Edinburgh) – 10am-1pm.