

# NSSC

NSSC 2018/70

## Minutes

**Subject:** National Specialist Services Committee (NSSC) on 4 December 2018  
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**Author:** Ms Fiona Murphy  
**Date:** 4 December 2018

### Attending:

Dr Graham Foster, Director of Public Health & Planning, NHS Forth Valley (**Chair**)  
Dr Jennifer Armstrong, Medical Director, NHS Greater Glasgow & Clyde  
Ms Clare Cartwright, Strategic Programme Manager, NHS Lothian  
(*deputising for Mr Colin Briggs*)  
Ms Kirstin Dickson, Director for Transformation and Sustainability, NHS Ayrshire & Arran  
(*deputising for Mr Derek Lindsay*) (**via v/c**)  
Dr Frances Elliot, Medical Director, NHS Fife  
Professor Colin Fleming, Consultant Dermatologist, Deputy Operational Medical Director,  
NHS Tayside  
Dr Mike Higgins, Medical Director, Golden Jubilee National Hospital  
Mr Colin Lauder, Director of Planning, Property & Performance, NHS Lanarkshire  
Mr Phillip Lunts, General Manager, Transformation, NHS Borders (*deputising for Mrs June Smyth*)  
Mr Paul Nairn, Service Planning Manager, Planning & Performance, NHS Highland,  
(*deputising for Ms Deb Jones*) (**via v/c**)  
Mr Graeme Smith, Director of Modernisation, NHS Grampian (**via v/c**)  
Dr Louise Wilson, Director of Public Health, NHS Orkney (**via v/c**)

### Observers:

Mrs Liz Sadler, Deputy Director Planning & Quality Division,  
Healthcare Quality & Improvement Directorate, Scottish Government

### Secretariat:

Ms Fiona Murphy, Director, NSD  
Ms Jenny Allen, Assistant Secretariat, NSD  
Mr Peter Croan, Financial Adviser, NSD  
Ms Roseanne McDonald, Nursing & Quality Adviser, NSD  
Mrs Ruth Meehan, Assistant Secretariat, NSD  
Dr Mike Winter, Medical Director, NSD

### Apologies:

Mr Jeff Ace, Chief Executive, NHS Dumfries & Galloway  
Mr Colin Briggs, Director of Strategic Planning, NHS Lothian,  
Ms Vicky Freeman, Head of Strategic Planning, NHS Dumfries & Galloway  
Ms Deb Jones, Chief Operating Officer, NHS Highland  
Mr Derek Lindsay, Director of Finance, NHS Ayrshire & Arran  
Mrs June Smyth, Director of Workforce Planning, NHS Borders  
Ms Hazel Sutherland, Head of Planning & Modernisation, NHS Shetland  
Dr Maggie Watts, Director of Public Health, NHS Western Isles

### Presenters from NSD:

Ms Karina O'Rourke, Programme Manager, *for item 5.1 Scottish Familial Hypercholesterolaemia*  
Dr Anke Roexe, Programme Manager, *for item 5.3 Complex Ehlers Danlos Syndrome and*  
*5.5 Systemic Vasculitis Network*  
Ms Karen Roberts, Programme Manager, *for item 5.7 Scottish Molecular Radiotherapy*  
*Treatment Centre*  
Mr Karyn Robertson, Senior Programme Manager, *for item 6.1 Cleft Care Scotland (CCS)*  
Ms Catriona Johnson, Programme Associate Director, *for item 6.2 Scottish Differences of Sex*  
*Development (SDSD) Network*

Mrs Liz Blackman, Senior Programme Manager, for item 6.3 Scottish Pathology Network (SPAN) and Scottish Microbiology and item 6.4 Virology Network (SMVN)

Mr Garrick Wagner, Senior Programme Manager, for item 6.5 Thoraco & Supra-Renal Abdominal Aortic Aneurysms (TAAA) and 6.7 Scottish Sacral Nerve Stimulation (SNS)

Mrs Anushka Govias-Smith, Programme Manager, for item 6.6 Oral Medicine

## **1. Announcements and Apologies**

Apologies were noted.

Declarations of Interest: There were no Declarations of Interest noted.

## **2. Minutes of Meeting held on 19 September 2018 - NSSC 2018/70**

It was noted that Lorraine Smith should read Lorraine Scott. The Minutes were approved as a correct record.

## **3. Matters Arising and Action Tracker – NSSC 2018/72 & 72A**

NSSC noted the Matters Arising and Action Tracker papers.

It was noted that the 2 actions within the Action Tracker were still ongoing.

### Neuro-endocrine Tumours – Lutathera Treatment

Board Chief Executives endorsed the recommendation of NSSC to nationally designate the service in Glasgow to provide the SMC accepted and evidence based protein receptor radiotherapy service for neuroendocrine tumours. The proposal had been approved by the Scottish Government and the designation would allow approximately 30 patients per year to receive this treatment at the Beatson Oncology Centre and recruitment to begin to new posts.

BCEs agreed that funding of the service element should be from anticipated savings in the NSD National Risk Share. The drug costs would be considered as part of the overall review of the National Risk Share Drugs Scheme.

### Psychology

Limited access to psychology interventions was an identified gap across a range of specialist services within NHS Glasgow and Clyde and NHS Lothian. Over the last decade, NSD baseline funding had increased to approximately 18wte psychologists in recognition of the added value of psychology input to the multi-professional team. Services had evidenced impact on the quality of life and wellbeing of patients from cognitive interventions. NSD was undertaking a review of specialist requirements, including engagement with the wider professional community to ascertain the planning approach to facilitate specialist and local access to psychology. It was anticipated that priority psychology funding would be requested in the 2019/2020 annual business case process. An interim request for funding from NSD had been declined until the full review was complete.

### 3.1 New Service Implementation Update – NSSC 2018/73

The paper provided a brief update of newly designated or de-designated services.

Members were informed that all were progressing as expected although some delays had occurred around the Neonatal Network, but this was now back on track.

There were 2 de-designations:

#### Paediatric Cystic Fibrosis Network

Approval was given by the Board Chief Executives in August 2018 to de-designate this network and by the Cabinet Secretary in October. A plan for de-designation was under development by NSD with a stakeholder group.

#### Sacral Nerve Stimulation Service

This would be discussed under Agenda item 6.7.

Clarity was sought regarding the formal commissioning of the Scottish Lyme Disease and Tick Borne Infections Reference Laboratory. It was confirmed that the existing service was

commissioned from 1 April 2018 with the enhanced service coming online 1 October 2018 to coincide with the validation of the equipment.

#### **4. NPPPRG/NSSC Workplan 2018/19 – NSSC 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.

Members were informed that an options appraisal exercise had taken place for CAMHS for LD Inpatient Unit. The favourite option was for a 5-6 bedded unit to be created to treat patients over the age of 12. All NHS Boards had been asked to indicate whether they had an interest in providing this with responses due by 5 December 2018.

#### **5. New Proposals Submitted (for decision on recommendation)**

##### **Stage 1**

##### **5.1 Scottish Familial Hypercholesterolaemia (FH) Service – NSSC 2018/75**

Familial Hypercholesterolaemia (FH) is a genetic condition which affects approximately one 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 was 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 was no clearly defined universal programme of care across Scotland to identify and treat individuals and their families and this outline proposal sought to highlight the need to develop a strategic approach to deliver equitable FH care.

Although the initial approach to NSD highlighting the need for this service came from a clinician employed by NHS Grampian, it was anticipated that due to the significant numbers of affected individuals/families the service would require to be delivered across multiple sites, 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.

It was the opinion of NPPPRG that the proposal would not fit with the designation criteria for a National Service. Whilst they felt that there was merit in identifying individuals affected by the condition and screening relatives they felt that it might be more appropriate to consider this within local Managed Clinical Networks and determine the most appropriate way to deliver this locally. It was suggested that NSD write to Directors of Planning. In addition the group had asked that cost implications for laboratory genetic testing be explored.

NSSC felt that this should be sent to the National Planning Executive Group meeting which was due to meet on 13 December 2018. This would allow for further discussion around where this was best placed to ensure equity of access.

In summary, NSSC endorsed NPPPRG's recommendation that a Stage 2 proposal should not be developed at this point until clarification had been sought regarding the most appropriate way to deliver this.

##### **5.2 Primary Ciliary Dyskinesia (PCD) Diagnostic Service – NSSC 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 Royal Hospital for Children (RHC) and analysed in the Pathology Department of the Queen Elizabeth University Hospital (QEUH). The pathology service had intimated that they had 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 West

of Scotland (WoS) patients had been referred to PCD specialist services which were 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 had 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 QEUH Campus.

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

NPPPRG members agreed that there was merit in asking the applicant to prepare a Stage 2 Application. Such an application should provide clarity around patient numbers from elsewhere in Scotland and should describe how advice would be given and a knowledge network developed. The proposal should place emphasis on the service primarily being diagnostic with ongoing care provided by referring clinician locally.

Members were informed that the service was currently provided for children, but there was the capacity within the system for the occasional adult. Clinicians in Scotland were using this service through the Cross Border system.

NSSC endorsed the recommendation that a Stage 2 application be submitted.

### **5.3 Complex Ehlers Danlos Syndrome (EDS) – NSSC 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 were 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 individualised 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 was almost invariably affected it was anticipated that most referrals would come from consultant rheumatologists.

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.

NSSC agreed that the main issues were around co-ordination and ownership of care for patients with complex EDS and were clear about the fact that the proposed service would provide an assessment of patient needs with treatment being delivered locally.

Members agreed with NPPPRG that clarity was required around other non-inflammatory connective tissue disorders, the clinical benefit to patients and referral criteria. It was noted that input should be sought from rheumatology and orthopaedic colleagues and that a clear de-designation plan developed.

NSSC endorsed the recommendation that a Stage 2 application be submitted which addressed the issues highlighted.

### **5.4 Focused Ultrasound for Essential Tremor (MRgFUS) – NSSC 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 can be targeted using the existing University of Dundee research MRI scanning facility. MRgFUS has recently gained National Institute for Health and Care Excellence (NICE) approval for treatment of patients with essential tremor targeting an area of the brain. 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 1:5 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 waiting for MRgFUS. It was suggested that the centre would be able to deliver 2 treatments per day on the one day per week that it would be available for NHS use.

NPPPRG advised concern about limited evidence with regard to efficacy and long term outcomes. It was accepted that there was evidence of this intervention being safe and effective in short-term follow up. Gathering this evidence required further clinical research and until this was generated NPPPRG members did not feel that NHS core funding could be committed. In addition, they felt that the contribution being asked for was disproportionate based on the proposed profile of clinical research/NHS treatments.

NSSC recognised the benefits of a research programme but agreed that this proposal was beyond the scope of NSSC. Despite the interest of a lobby group, Scottish Government representatives agreed that this should go through the proper process.

NSSC endorsed the recommendations of NPPPRG that the applicants be asked to seek alternative funding to allow the University of Dundee (UoD) to progress the research needed to address the issues highlighted.

### **Stage 3**

#### **5.5 Systemic Vasculitis Network – NSSC 2018/79**

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

The network would cover adult patients with systemic vasculitis including ANCA associated vasculitis, large vessel vasculitis, Behcets disease and GCA. It was 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 would have 3 regional subgroups to support implementation of network initiatives across Scotland.

NPPPRG supported the application. The group requested that additional letters of support should be sought to ensure that this proposal was supported by all three regions. An additional letter of support had been received from Dr Tracy Gillies, Medical Director, NHS Lothian.

It was noted that since the paper was produced, a letter of support had been received from NHS Greater Glasgow & Clyde (GG&C).

NSSC endorsed the NPPPRG's recommendation and supported the commissioning of the proposed NMCN.

#### **5.6 Scottish Cellular Therapy Service (Car-T) - Update – NSSC 2018/80**

Reviewing NHS GG&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 recently developed products for the treatment of Diffuse B Cell Lymphoma in line with the Commissioning Service Specification which had 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 GG&C, 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 initially should be delivered in an allogeneic centre. In order for this to take place there would be the requirement that NHS GG&C are formally accredited in this form of therapy by Joint Accreditation Committee – ISCT & 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.

This proposal was not ready to be submitted to NPPPRG on 7 November. Given Scottish Medical Council (SMC) timelines, NPPPRG agreed that the application should be considered by NSSC in December. The application was shared with NPPPRG members.

A paper had been presented to NHS Board Chief Executives (BCE's) on 13 November 2018 informing them of the situation. They had requested that a forward view of ATMPs be looked at by NHS Medical Directors, Pharmacy Directors and Directors of Finance, but recognised that if approved by the SMC, it would likely be necessary to commission this service in the meantime.

NSSC endorsed the recommendations of NPPPRG and supported national designation, contingent on SMC drug approval.

#### 5.7 Scottish Molecular Radiotherapy Treatment Centre (SPMaRT) - Update – **NSSC 2018/81**

This was an update to a Stage 3 application previously considered by NSSC. Concerns were raised around the costs and the small number of patients that would be treated.

These concerns had been addressed by the team in Glasgow; costs had been revised and were now reduced to make it comparable with the service in London if the service delivered 6 treatments per year.

This application was supported by Northern Ireland and Northern England; potential referrers in both areas had confirmed they would refer to the service in Glasgow. It was anticipated that there would be one patient per year from each area, taking the predicted patient treatments to 10 per year.

The current provider in London had also now endorsed the application and felt that a service in Glasgow would provide additional capacity to the wider NHS in England with a view to reducing waiting times for treatment. This again would increase the numbers. It had also been noted that having a facility available in Scotland might allow access to clinical trials for more children.

NPPPRG were supportive of the designation, although there were still concerns around the small numbers who would receive treatment as the service developed. It was suggested that numbers be closely monitored and a review should be carried out following the service being in place for a year.

NSSC was asked to consider the updated costs and information regarding additional referrals from Northern Ireland and England, and advise if the service should be designated.

Members agreed that it would be beneficial to carry out process outcome checks, but also recognised the importance of allowing 3-5 years to collect a significant amount of patient outcome data. It was noted that the clinical team had been asked to benchmark against London.

NSSC endorsed the recommendations of NPPPRG and supported the designation of the service.

## **6. Service Reviews/Developments**

### 6.1 Cleft Care Scotland (CCS) – NSSC 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 are born with some form of cleft lip/palate in Scotland each year. Care is 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 approved 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, polarising those working with the surgical team based in NHS Lothian and those working with the surgical team based in NHS GG&C.

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 National Services Division as commissioners of the network with external oversight from Simon Hilton, Consultant in Public Health Medicine, NHS Grampian.

NPPPRG endorsed the recommendations of the review to be put forward to NSSC.

It was noted that ongoing efforts were being made to ensure good interaction between the 2 NHS Boards with a shared workplan to minimise duplication.

NSSC endorsed NPPPRG's recommendation for ongoing designation for a further 3-5 years.

## **6.2 Scottish Differences of Sex Development (SDSD) Network – NSSC 2018/83**

The Scottish Differences of Sex Development (SDSD) Managed Clinical Network (NMCN) 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 9 national managed clinical networks and again in 2015. Both reviews identified an ongoing role for the network.

The aim of this review was to ascertain the extent to which the Network continued to achieve the objectives and recommendations agreed at the 2015 review following which the network was subject to a 12 month period of additional scrutiny to assure NHS Boards and Scottish Government that it was successful in implementing the review recommendations. 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.

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 particularly commended the work undertaken to expand the evidence base and explore an appropriate range of approaches and data sources to identify and measure improvement.

Since the last review there had been a number of strategic developments in relation to neonatal and rare disease policy and practice, and the review group noted that collaboration

with a range of partners, including the Office for Rare Conditions, had enabled the Network to extend its reach in engaging stakeholders and educating health and other professionals in DSD care. This had also resulted in more effective use of limited human and financial resources. The review had identified further opportunities to collaborate with other Networks in pursuit of shared aims.

NSSC noted that in due course this Network might be aligned with the new Neonatal Network.

NSSC endorsed NPPPRG's recommendation that SDSD NMCN retain its national designation for a further 3-5 years.

### **6.3 Scottish Pathology Network (SPAN) – NSSC 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 bringing 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. The National Specialist Services Committee (NSSC) therefore approved a 2 year extension to enable the Network to address these matters and provide a further report.

NPPPRG noted the progress made by the Network and ratified the recommendation that SPAN retains designation as a NMDN, with further review within the routine review cycle.

NSSC commended SPAN for the progress that they had made and noted marked improvements in many areas. Members agreed that it would be useful to have a focus on Artificial Intelligence (AI) to support service transformation in the future.

NSSC endorsed the recommendations of NPPPRG to continue the designation of the Network.

### **6.4 Scottish Microbiology and Virology Network (SMVN) – NSSC 2018/85**

The Scottish Microbiology and Virology Network (SMVN) was established in 2012, directly commissioned by Scottish Government as the fourth National Managed Diagnostic Network (NMDN). Commissioning transferred to NSD in 2013, ahead of the establishment of the National Network Management service (NNMS) in April 2014. The Network differed from other National Networks in that management was provided through a service agreement with NHS Grampian and was not fully integrated into the NNMS.

The 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).

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 12 months. The paper highlighted 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 noted the progress and sought assurance that the specialist expertise provided by the Network Manager was being utilised appropriately. It was confirmed the Network was now supported by a wider team playing appropriate roles.

NSSC noted the significant progress made in implementing the recommendations of the SMVN review report and supported the continuing designation of the Network.

### **6.5 Thoraco & Supra-Renal Abdominal Aortic Aneurysms (TAAA) – NSSC 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. 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 had 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

NPPPRG endorsed the recommendations of the review to be put forward to NSSC, with the added recommendations that a progress report on the Pan Scotland TAAA Multidisciplinary Team (MDT) was submitted back to the NPPPRG and NSSC a year after it is set up (this would mean the Report would be submitted in April 2020).

NSSC recognised that there would be difficulties in setting up the MDT and ensuring good functionality, and recommended that the Independent Chair would be appointed through NHS Lothian. Members agreed that reviewing the MDT in 2020 would be beneficial as it was recognised that having a functioning PAN Scotland MDT was critical in ensuring equity of access for patients across NHS Scotland. It was also noted that the new NICE Guidance would be available at this point.

In summary, NSSC endorsed the recommendations of NPPPRG that the TAAA service retain its national designation for a further 3-5 years with the caveat that a progress report on the MDT be submitted in April 2020.

#### **6.6 Oral Medicine Review – NSSC 2018/87**

Following prolonged difficulties encountered by NHS Lothian in the recruitment of a Consultant in Oral Medicine (OM) with the resultant inability to provide specialised Oral Medicine expertise, NSD was asked to lead on a review of Scottish Oral Medicine services.

OM is the specialty of dentistry concerned with the oral healthcare of patients with chronic, recurrent a medically related disorders of the oral and maxillofacial region; diagnosis and non-surgical management. It sits at the interface between Dentistry and Medicine.

OM services in NHS Scotland are delivered within three specialist dental facilities; Edinburgh, Glasgow and Dundee. Patients might be referred to services directly by General Dental Practitioners, General Medical Practitioners or secondary care clinicians.

The report and cover paper were circulated electronically to NPPPRG for their comments which were included in the cover paper.

NSSC recognised that OM sits within a wider portfolio of services that can be delivered in Primary Care. Concerns were raised that the numbers were too large for an NMCN and members agreed that this should be addressed by the NHSS National Planning Board in conjunction with the Chief Dental Officer and Regional Planners.

NSSC supported NPPPRG in endorsing the recommendations of the Expert Review Group.

#### **6.7 Scottish Sacral Nerve Stimulation (SNS) – NSSC 2018/88**

In December 2017, NSSC supported the recommendation for de-designation of the Scottish Sacral Nerve Stimulation (SNS) service for Urinary Dysfunction and agreed that NSD should assist regional service leads in developing implementation plans for regional SNS services.

Whilst NSD was hopeful that all Regional SNS services would be accepting patients from April 2019, there was a risk that this may not be the case and that the current national SNS service might need to be commissioned and funded by NSD for a further 3 month period (to the end of June 2019) in order to ensure a smooth transition to a regional service provision.

At present NSD and NHS GG&C management/clinicians were working to mitigate the risk of delay by considering alternative arrangements to reduce the current waiting list using clinical personnel from other NHS Boards who would subsequently deliver the regional service. The aim of such work being to smooth the transition and reduce any backlog of cases for the new provider.

NSSC noted the update on the progress to implement the regional SNS service and the risk of delay in the implementation of regional provision. It was agreed that a further 3 month period would be funded if required although all effort should be made to reach the agreed March 2019 deadline.

## **7. National Planning Update – NSSC 2018/89**

The new NHSS National Planning Board met for the first time on 19 October 2018. The Governance Framework for national planning describes 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 – finance, workforce, and infrastructure.

The purpose of this report was to inform NSSC about the NHSS National Planning Board's remit and new workplan and to inform NSSC about the outcome of the NHSS National Planning Board decision relating to the connections and processes between the Board and the NSSC.

Members recognised that there was interdependence between some of the work of the NHSS National Planning Board and the NSSC, eg, new developments involving recently proven techniques or where it may be unclear at the outset if a single site or regional model of service may be preferred.

The NHSS National Planning Board agreed that there was no formal role for them when a proposal clearly met the criteria for specialist services planning as NSSC/NPPPRG processes were well established

Where proposals do not meet the NSSC criteria or where there was contention regarding how things should be planned or progressed; there should be:

- Internal NSD discussion via the Director of NSD and the Senior Management Team (which includes the Programme Associate Director for National Planning),
- Items escalated as required to the National Planning Core Group or National Planning Executive Group (depending on timing and level of need)

NSSC noted the NHSS National Planning Board decision; and took cognisance of the need to consider NSSC proposals and applications in the context of the new NHSS National Planning landscape.

## **8. NSSC Business Case**

Due to significant Cash Releasing Efficiency Savings (CRES), it was estimated that Risk Share costs would fall in 2019/20. It was recommended that the funding remained at the 2018/19 level, and that the CRES would be redeployed to recurrently fund the new services as prioritised by NSSC.

The Group were asked to note that the existing costs of the Retro-peritoneal Lymph Node Dissection Service (£245k) would need to be top-sliced from NHS Boards.

The Group was asked to decide whether a Car-T Cell Therapy Service should be nationally funded (either as a new service in Scotland or through referral to England), and whether drug costs relating to Car-T Therapy and Lutathera treatment should be funded through the national risk share arrangement.

Discussion ensued around the drug costs relating to Car-T Therapy with clarity being sought around the price parity between NHS England and NHS Scotland. It was agreed that once the SMC had made their decision, further negotiations would take place around this.

In summary, NSSC agreed and approved the Business Case.

## **9. Horizon Scanning – NSSC 2018/91**

Dr Winter spoke to the paper and highlighted the following new notifications:

Gender Affirmation Centre (October 2018) – initial contact from surgeon in NHS Tayside who wished to explore development of a surgical centre to offer gender reassignment surgery: F>M chest in first phase, and subsequently F>M and M>F genital surgery. The initial contact suggested outlining support from NHS Tayside management and the model advised would mirror a service provided in Helsinki for the whole population of Finland. NSD intended to align any application with existing work to align commissioning for specialist gender surgery with NHS England and work within the National Gender Identify Clinical Network for Scotland (NGICNS).

Organ Reperfusion Centre - ORC (October 2018) – initial contact from a surgeon in NHS Lothian and the Medical Director of SNBTS who wished to explore the option of commissioning an ORC that would offer the Transplant Organ retrieval programme, managed on a UK basis by NHS BT in Bristol, although funded by all 4 nations. The outline was for organs retrieved in Scotland to be transported to the ORC for reperfusion using a variety of current technologies. There was strong evidence of benefit for lung transplant with emerging evidence of benefit for use with other organs. Any discussion would be taken forward with input from the Scottish Transplant Group.

Alpha 1 Antitrypsin Service (October 2018) – Clinicians from NHS Lothian had provided an outline submission describing the need to develop a specialist service for patients suffering from Alpha 1 Antitrypsin Deficiency. NSD had agreed to support the clinicians in developing a Stage 1 Application in conjunction with their management colleagues and anticipate that this would be shared with this group early in 2019.

Abdominal Sarcoma Surgery (October 2018) – NHS Greater Glasgow and Clyde had submitted a Stage 1 application for a proposal to provide a national specialist Abdominal Sarcoma Surgery Service in Glasgow Royal Infirmary. Having been reviewed by the NSD SMT it was felt that the submission required further work before being considered by NPPPRG/NSSC and NSD would now work with NHS GG&C management and clinicians to prepare this for consideration in early 2019.

In addition to the paper, Dr Winter mentioned that the Scottish Government had approached the Perinatal Mental Health Network (PMHN) for advice on how to develop PMH services. NSD had noted that PMHN would require an infrastructure investment to do so.

## **10. Any Other Business**

NSD has been not been notified of any other business.

## **11. Date of Next Meeting:**

Tuesday, 19 March 2019 (at Gyle Square, Edinburgh) – 1:30pm