

# minutes

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**Subject:** National Specialist Services Committee (NSSC) on 23 September 2021  
**File ref:** 09\Cttees & Grps\NSSC\Mins\2021\2021-09-23 NSSC Mins  
**Chair:** Ralph Roberts, Chief Executive, NHS Borders  
**Date:** 23 September 2021

## Attending:

Jennifer Armstrong, Medical Director, NHS Greater Glasgow & Clyde  
Colin Briggs, Director of Strategic Planning, NHS Lothian  
James Cotton, Consultant, Medicine & Cardiovascular, NHS Tayside  
Graham Foster, Director of Public Health & Planning, NHS Forth Valley  
John Keaney, Medical Director, Acute Division, NHS Lanarkshire  
Derek Lindsay, Director of Finance, NHS Ayrshire & Arran  
Phillip Lunts, General Manager, Transformation, NHS Borders  
Craig Pratt, Assistant Director of Finance, NHS Fife  
Ralph Roberts, Chief Executive, NHS Borders (**Chair**)  
Elizabeth Robinson, Public Health Principal, NHS Shetland  
Lorraine Scott, Director for Modernisation, NHS Grampian  
Maggie Watts, Director of Public Health, NHS Western Isles  
Louise Wilson, Director of Public Health, NHS Orkney

## Observers:

Alan Burns, Policy Manager, National Planning, Scottish Government  
Alison Harrison, Scottish Government  
Ann Pullar, Collaborative Services and Technologies for Health Team Leader  
Planning and Quality Directorate, Scottish Government  
Joanne Milne-Toner, Programme Manager, NSD

## Secretariat:

Peter Croan, Financial Adviser, NSD  
Roseanne McDonald, Nursing & Quality Adviser, NSD  
Ruth Meechan, Assistant Secretariat, NSD  
Craig Wheelans, National Medical Advisor, NSD

## Apologies:

Susan Buchanan, Director, NSD  
Mike Higgins, NPPPRG Chair  
Paul Nairn, Service Planning Manager, Planning & Performance, NHS Highland  
Boyd Peters, Medical Director, NHS Highland

## Presenters from NSD:

Aileen Ferguson, Programme Manager, *Item 9.1 – National Gender Identity Clinical Network Scotland (NGICNS)*  
Anna-Maria MacLeod, Programme Manager, *Item 9.2 – Scottish Pulmonary Vascular Hypertension*  
Anke Roexe, Senior Programme Manager, *Item 9.3 – Scottish Inherited Bleeding Disorders Network (SIBDN)*  
Louise Wilson, Senior Programme Manager, *Item 7.1 – Secure Adolescent Inpatient Service & Item 7.2 – Intellectual Disabilities Adolescent Inpatient Service*



Chair Keith Redpath  
Chief Executive Mary Morgan  
Director Susi Buchanan

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Common Services Agency for the Scottish Health Service

## **1. Welcome, Apologies and Declarations of Interest**

Ralph Roberts introduced himself to NSSC as the new Chair of the Group, taking over from Jeff Ace, who previously chaired the Group.

It was noted that Vicky Freeman, Head of Strategic Planning, NHS D&G, had informed NSSC's Secretariat that she would be standing down from NSSC. Vivian Gration is the deputy representative, but was unable to attend this NSSC. A replacement representative for NHS D&G would be sought.

Margo McGurk, Director of Finance, NHS Fife, was also standing down from NSSC. Craig Pratt, Assistant Director of Finance, NHS Fife, would now be NHS Fife's representative.

The Chair welcomed everyone to the meeting and apologies were noted.

### Declarations of Interest

There were no declarations of interest to note.

## **2. Minutes of 23 March 2021 – NSSC 2021/12**

The Minutes were approved as an accurate account of the meeting.

## **3. Matters Arising**

### **3.1 New Service Implementation – NSSC 2021/14**

The paper provided a brief update of newly designated services.

Scottish Molecular Radiotherapy Treatment Centre (SPMaRt): which was designated in 2019 had not treated any patients to date. The Service had informed NSD that they were hoping to start the treatment of patients in January 2022.

Mesh Surgery: an SLA was in place with NHS Greater Glasgow & Clyde (GG&C) with Scottish Government (SG) funding for 2021/2022.

SG colleague reported that there had been 2 independent successful bidders who have experts to carry out the removal of mesh. These private providers are Spire Healthcare, Bristol and the Mercy Hospital, St. Louis in the USA.

Mesh reimbursement – SG would be taking a Bill to the Scottish Parliament, as some of the patients had paid for treatment themselves.

NSD provided clarification that the independent submission from the USA had been from Dr Veronikis directly not from Mercy Hospitals and that NSD were presently working through the associated due diligence in relation to this.

SG agreed to go back to colleagues for clarity around this.

### **3.2 Adult Cystic Fibrosis (ACF) De-designation – NSSC 2021/15**

NSD asked NSSC to consider if the National Planning Board (NPB) had a remit, in relation to establishing regional pathways, to provide the oversight and governance for the de-designation of AFC.

The accountable officers for delivery of the services are Board Chief Executives and Regional Planners.

If as at present services continue to be provided regionally, it was felt there would not be the need for major service redesign. A Short Life Working Group (SLWG) however would be put in place with the secretariat coming from NSD.

NSSC felt that NSD were best placed to lead the overarching Steering Group for ACF.

It was noted that ACF was due to be de-designated in March 2023.

### **3.3 Services analysis & update for Quarter 1 – NSSC 2021/16**

The majority of services are held to budget in the first Quarter, other than risk share, which reflects charging by Boards and Trusts.

This paper was presented to NHS Board Chief Executives on 17 August to make them aware of the Quarter 1 activity compared with SLA targets.

NSD's Quarter 1 2021/2022 Actual Costs represented in the slides = £59.28m.

Allocation received currently standing at £208m, 74% of the total anticipated allocation of £282m. Further allocations with value £50.3m have been requested.

It was agreed that NSD would update the paper for the next NSSC meeting and noted that NSD were giving regular updates into the capital finance network and upwards to the Board Chief Executives (BCEs) of any implications.

**Action: Peter Croan**

#### **4. Horizon Scanning – NSSC 2020/04**

As a result of Covid-19, Board Chief Executives had agreed that NSD should in the main pause applications for the designation of new services and national networks to allow for a full understanding of the new financial framework in which we are operating, core services to be preserved and allowed to recover from the effects of the pandemic and discussions to be held with SG in regards to how the financial envelope will be maintained in line with the affordability of new development. It was also noted that the implementation of designations at this time may also be hindered due to the challenges faced by boards remobilising to normal activity.

NSD have however continued to deal with enquiries which are relation to patient safety or cost neutral, and any new pro proposals received is being triaged and held on a waiting list until such time as new applications recommence Below is a list of those services which have approached NSD .

Over the last few months NSD have received requests for the consideration of their support in relation to the following services or likely service needs:

- Donor Breast Milk Bank, NHS Greater Glasgow & Clyde
- Meniscal Transplantation Service, NHS Golden Jubilee
- Autologous Hematopoietic Stem Cell Transplantation for Multiple Sclerosis
- Auto<sup>177</sup>Lu-PSMA-617\* Targeted Radioligand Therapy

Targeted Radioligand Therapy: NSSC asked about the interaction between national designation and if the numbers of patients rises.

NSD reported that with the neuroendocrine tumours (National Lutathera Therapy Service) there was continued agreement for a single national centre. As a result of adding this treatment for prostate cancer case numbers would increase significantly and having accommodated just 5-10 patients as part of the clinical trial had added a substantial clinical workload. The team in Glasgow had made it clear that they would not be able to absorb this for the whole of Scotland. If SG were to endorse this, there would need to be a plan put in place for the physical space and technical expertise required.

NSD were meeting with clinicians to talk this through. It was noted that there would need to be some consistency in the approach as there was not the infrastructure in place within all regions to support this service development.

NSSC noted that there were a number of other proposals for designation or service developments over the early part of 2021.

NSD would look at what comes in for commissioning and look at the process and redesign of how they go through the system, and do this on a national basis with national agreement.

High Consequence Infectious Diseases Planning Network – NSD were continuing in dialogue with Scottish Government, Public Health Scotland and clinicians to scope out how such work might be best accommodated.

Paediatric Chronic Pain – NSD had recently met with Scottish Government and clinical colleagues to discuss how best practice guidelines could be implemented. Informal discussion with Healthcare Improvement Scotland had identified some areas where a collaborative approach might be beneficial.

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

### Stage 1

#### **5.1 Navigation Bronchoscopy – NSSC 2021/18**

The service would allow the earlier detection of lung cancer in patients who have peripheral pulmonary nodules/lesions of unknown cause by using Navigation Bronchoscopy (ENB) and advance imaging (rEBUS) to direct biopsy samples. This will allow the early and accurate diagnosis or cancer, offering patients a curative treatment option.

The proposed service will be provided by NHS Lothian's Cardiothoracic Directorate, Royal Infirmary of Edinburgh.

Navigation Bronchoscopy (ENB) is now accepted as a safe and accurate alternative to CT biopsy and is now established in national guidelines as an adjunct to diagnosis.

Projecting to the national population, forecasts estimate >10 procedures/ month. Up to 120 procedures per year. However, with the advent of Lung Cancer screening it is anticipated a further increase in demand.

NPPPRG were not keen to propose this as a standalone position and requested a more worked up objective evidence base.

NSSC sought to see more clinical detail around the advantages of this being an alternative to CT biopsies. Whether or not it would be beneficial and would this expand into a very large number of patients being treated.

There was also concerned interest around the screening aspect. That this should be built into the screening development programme. It was felt a more strategic, rounded approach was required.

NHS Grampian's clinicians' feedback was that this was a very useful service, but would have a small number of patients. They would see one patient per month. It was highlighted that if this goes forward, who would be analyzing the samples and getting back to the MDTs.

It was also noted that if a service is set in one area, transport and accommodation for patients would have to be taken into consideration.

NSSC also asked where this would sit in the strategy of lung cancer screening.

NSSC felt that this was a short term fix until there was something in centres themselves. That in the future services similar to this would be looked at to develop them regionally. National designation was not suitable for short-term gaps in the service.

In summary: NSSC did not endorse the recommendation that a Stage 2 application be submitted, and advised to take this forward as a wider cancer development strategy.

#### **5.2 Paediatric Radiotherapy – NSSC 2021/19**

The proposal sought to establish a national service for Paediatric Radiotherapy. All steps in the patient pathway would continue to be provided locally where possible with the exception of planning and delivery of radiotherapy (including concomitant systemic anticancer therapy).

The proposed provider of the service will be the Beatson West of Scotland Cancer Centre, Glasgow.

The driver for the reconfiguration of Paediatric Radiotherapy Services and development of a National Centre based at the Beatson West of Scotland Cancer Centre originated from the CYPC MSN.

This was subsequently endorsed by NCCS in May 2018 and reiterated by the MSN in February 2020.

NPPPRG endorsed the Stage 1 proposal to proceed to a Stage 2 application.

NSSC had concerns around the implications for parents/families travelling from across Scotland to Glasgow as day cases and therefore needing to be able to stay overnight. They also asked that a piece regarding ongoing support be noted.

NSD agreed to go back to the applicants regarding this and noted that Ronald McDonald House, Glasgow, were there to give support if numbers were small.

SG reported:

- A Paediatric Cancer Management Service Network had been launched on 16 September 2021
- Radiotherapy Programme Board had convened
- A national policy had been drafted.

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

### 5.3 Interventional Cancer Pain Service – **NSSC 2021/20**

The service would allow patients, known to palliative care services with cancer pain uncontrolled by conventional analgesia to have their pain assessed by an interventional cancer pain team and if appropriate offered an intervention. The three main clinical interventions undertaken are intrathecal drug delivery, percutaneous cordotomy and coeliac plexus block.

The proposed provider of the service will be the Beatson West of Scotland Cancer Centre, Glasgow.

There is unanimous support from the palliative medicine community across Scotland for this service development.

There is support from NHS Greater Glasgow & Clyde (GG&C) Regional Services to expand this existing West of Scotland service currently located on the BWSCC to a national service.

NPPPRG were hesitant as to how the service would work around the regional set up, as well as issues around development of local confidences. It was felt that clarity and a stronger argument would be required for the Stage 2 application.

NSSC wondered if this might be something to look at regionally in supporting patients, or look at as a national service. One representative had scoped the views of his own board who said that in 15 years they had only needed this input twice and therefore there is most likely the need for national expertise however if any of the patient treatment or follow up (specifically refills) could be provided close to the patient this would be greatly appreciated.

NSD would write to the 3 Cancer Networks formally and ask them to submit their feedback to the team in Glasgow to allow this to be reflected in their Stage 2 application.

**Action: Craig Wheelans**

In summary, NSSC endorsed the recommendation that a Stage 2 application be submitted with the caveat that there was a need to understand how this would support services locally and regionally.

## **Stage 3**

### 5.4 Paediatric Renal Service – **NSSC 2021/21**

It was proposed to designate a specialist paediatric renal service that would formalise the commission of the existing national dialysis provision and will integrate with the commissioned paediatric renal transplant programme.

The service would deliver the renal pathway for dialysis (heamo and peritoneal) alongside specialist care for children with a range of conditions.

It is proposed that there is one provider, at the Royal Hospital for Children, Glasgow.

Funding gap of £456k requires to be considered. In relation to nursing pressures, (£363k) it is an acceptable ask, as these are largely due redesign of the renal ward and increase in baseline staffing establishment to reflect senior nurse recommendations around clinical safety and care. The psychology and play staffing, is a service development and whilst of high patient benefit, it would be acceptable to consider these posts in future years via CRES.

NPPPRG supported the application being submitted to NSSC.

In summary, NSSC approved the designation of the Paediatric Renal Service.

### 5.5 Scottish National Hilar Cholangiocarcinoma Surgery – **NSSC 2021/22**

Hilar Cholangiocarcinoma (HC) is a bile duct cancer arising at or near the biliary confluence. It is a rare cancer, accounting for approximately 2% of all cancers. Surgery for Hilar Cholangiocarcinoma is very specialised, requiring the ability to undertake complex vascular and biliary resections and reconstructions together with advanced management of liver dysfunction.

The proposed service will be provided at a single site by NHS Lothian, Royal Infirmary Edinburgh, HPB Unit. The team will include HPB surgeons also trained in liver transplantation, anaesthetists, critical care teams and interventional radiologists specialising in complex surgical HPB cases and liver transplantation.

The total current costs of the proposed service, based on 2019/20 activity numbers is £550,716, with the exception of £47,805 the costs and activity are already being incurred. The £47,805 is for an additional data manager and clinical nurse specialist.

The Hilar Cholangiocarcinoma service will continue to maintain close communication with referral units through regular update of referral forms, protocols, audit of results and outcomes, reports to the National HPB Educational meeting and presentation of results and outcomes at the National M&M Meeting.

NPPPRG supported the application being submitted to NSSC.

It was noted that NSSC felt this service was already incurring costs, and felt that this should not go forward for prioritisation.

NSD reported that an additional £48,000 of the costs were coming under national designation and that this was over and above what it was presently.

Some NSSC members felt that NSD should prioritise the additional costs within its existing budget and CRES saving rather than bringing these very small amounts to NSSC.

In summary, NSSC approved the designation of this service.

## **6. Prioritisation Exercise for 2022/23 funding**

The paper described the method and process for the prioritisation approach, which was undertaken firstly by NPPPRG and then would be undertaken by NSSC. The annual exercise supports the Committee to develop a prioritised list of developments and new services that require additional funding for Board Chief Executives in the context of limited resource. A cover sheet had been prepared for each of the four developments to be scored by members.

Some members expressed their reservations around the prioritisation exercise and whether it should be undertaken. It was considered that it could be difficult to score the proposals against each other as they varied in the type of service or development and the range of costs being requested. It was also felt that prioritisation was not needed for some as there were essential developments that should be supported (ie an additional PICU bed). For some it was felt that additional costs were so minimal, as per the earlier Hilar Cholangiocarcinoma service discussion, they could be met within CRES savings rather than NSSC prioritising.

NSD reported that the funding request to BCEs for 2022/23 was substantial (papers NSSC 2021/25 and NSSC 2021/26 detailed two services previously approved and prioritised) and the perceived smaller request for funded needed to be considered in that wider context.

NSSC felt that they should not be asked to make a judgement when a decision has been made elsewhere, in the case of CAR-T, where the decision had been made by the SMC.

There was also the suggestion that NSD should be prioritising proposals and advising NSSC of what is considered a 'must do', would be 'nice to do' and then others would be considered for debate.

NSD colleagues agreed to consider the discussion and bring back to the next meeting.

**Action: Susi Buchanan/Peter Croan/Roseanne McDonald**

The Committee discussed each of the proposals and would then consider the NPPPRG prioritisation ranking.

## **7. Annual Business Case: Funding Requirements for 2022/23**

### Services approved for designation - update

There were two designations already approved by NSSC and BCEs, they would not be included in the prioritisation exercise but required to be included in the funding requirements for 2022/23.

### Secure Adolescent Inpatient Service – NSSC 2021/25

### Intellectual Disabilities Adolescent Inpatient Service – NSSC 2021/26

Designation for both proposals had previously been approved by NSSC and BCEs. The Committee were content with the written updates provided on the service developments.

### New Services and Developments for Prioritisation

#### 7.1 CAR-T Capacity Planning – NSSC 2021/27

The nationally designated cellular therapy service for adults has been operational since January 2020 in Glasgow. It is the only unit in Scotland that is currently commissioned to administer two SMC approved CAR-T products.

Costs are difficult to estimate at this stage. Drug acquisition estimates below are very conservative as they assume that all patients will be fit enough to receive the product and survive for more than 6 months. However, not all eligible patients may be fit to complete their treatment which will lead to a partial refund. Rebates are also due for patients which do not survive past 6 months.

Assuming a CAR-T therapy for myeloma product gets approved by SMC, the additional impact could be in the region of £7.6m (£5,06m drug acquisition costs and £2m additional service costs) if additional 20 patients receive treatment. The estimates for myeloma are subject to a significant level of uncertainty.

NSD reported that CAR-T had been put forward and approved by the Scottish Medicines Consortium (SMC). It was noted that there is a Scottish Policy whereby if SMC endorses something, then it should be carried out.

NSD confirmed that part of the prioritisation was the drug cost and should they be asking for this as part of their top slicing.

It was noted that Tecartus had already been approved and NSD were looking at whether they could accommodate Tecartus in a year's time. Capacity issues meant that there was the potential need for patients to be referred to England which comes with a cost premium of approximately 30% more than attending the current service in Scotland. It was felt that a second centre might be considered with a step up to a third centre eventually.

NSD are presently doing more national planning regarding the specifications and were asking NSSC to fund Tecartus for this year and would they sanction further costs for this product for the following year.

#### 7.2 PICU: Additional Bed – NSSC 2021/28

The business case sets out the proposal for the PICU capacity phase 1 requirement for an additional PICU bed in NHS GG&C.

Modelling of GGC PICU activity on PICA-net 80% occupancy standard indicates the requirement of 22.8 beds. During the pandemic PICU occupancy was low in Scotland and across the UK. Therefore the evidence for increasing capacity is based on data up to 2019.

Recurring costs: £780,000 for 1 PICU bed/cot.

NSSC asked if this was more Winter pressure or Covid related. NSD informed NSSC that this was a split between HDU and ITU – the balance between HDU and ITU had shifted.

NSD reported that this quarter's activity was not like previous years data. There had been a shift in complexity in both Units, but a higher level in Glasgow related to their cardiac and ECMO service.

It was noted that this was Phase 1 of the initial analysis of 30 beds for Scotland. The split between Glasgow and Edinburgh was unknown. The data for Edinburgh was purely for paediatric intensive care. The first step of the plan would be to get buy in and go forward to get intensive care and HDU.

#### 7.3 Paediatric Renal Service – NSSC 2021/29

The proposal is for the designation of a specialist paediatric renal service that would formalise the commissioning of the existing national dialysis provision and will integrate with the commissioned paediatric renal transplant programme. The service will treat patients with a range of diseases.

Estimated costs will be £3.7m which includes the paediatric transplant service of £1m which is already nationally designated and funded.

There are no potential financial savings to NHS Scotland. Current NHS funding totals £3.3m (£2.3m excluding the paediatric transplant service). An overall increase in funding of £0.4m is therefore required to support, psychology and play service developments and the current ward nursing pressure.

#### 7.4 National Hilar Cholangiocarcinoma Surgery – **NSSC 2021/30**

The total current costs of the proposed service, based on 2019/20 activity numbers is £550,716, with the exception of £47,805 the costs and activity were already being incurred. The £47, 805 is for an additional data manager and clinical nurse specialist.

### 8. **Prioritisation - Discussion and decision making**

NSD provided with the results of the NPPPRG prioritisation exercise, which were:

1. PICU additional bed
2. Paediatric Renal Service
3. Hilar Cholangiocarcinoma Surgery
4. CAR- T

After consideration of each of the cases, NSSC discussed the terms of what they were prioritising:

1. PICU: Additional Bed – there was agreement that this was priority.
2. Paediatric Renal Service – prioritising the designation and the additional nursing costs but not the psychology support and play costs
3. National Hilar Cholangiocarcinoma Surgery – prioritising the designation but not supporting the additional clinical nurse specialist and data manager costs
4. CAR-T – cost of drugs and some of the in service delivery costs. NSSC recognised the SG policy position around but the affordability of it meant the ranking was low.

### 9. **Service Reviews (for decision on recommendation)**

#### 9.1 National Gender Identity Clinical Network Scotland (NGICNS) – **NSSC 2021/31**

The National Gender Identity Clinical Network Scotland (NGICNS) was set up in 2014. Its remit was to facilitate the implementation of the 2012 Gender Reassignment Protocol (GRP)<sup>1</sup> on behalf of NHS Boards and Scottish Government.

The Network was reviewed in 2018 and progress against the recommendations from that review has been considered alongside performance against the core objectives of the network by the Expert Review Group (ERG).

The ERG noted the wealth of evidence of the good work achieved by the network and felt there was a valuable role for the network to play in the future.

The ERG recognised the urgent need to tackle waiting lists and noted the importance of service reconfiguration as part of this work.

The ERG recommended the continued designation of the NGICNS network for a further 3 to 5 years.

NPPPRG endorsed the decision to continue designation of the network.

It noted that while it was the recommendation of the ERG that NGICNS become a strategic network, this was not accompanied by funding and at this time no funding routes had been explored. This recommendation was therefore moved from 'short-term' to 'long-term'. Clarity was also requested on the wording on recommendation 8; as to who would be carrying out the quality improvement work. This level of detail had not been discussed by the ERG, however, the wording in this recommendation was amended slightly to provide greater clarity.

In summary, NSSC endorsed to continue designation of the National Gender Identity Clinical Network Scotland (NGICNS).

#### 9.2 Scottish Pulmonary Vascular Hypertension (SPVU) – **NSSC 2021/32**

This is a minor Review hosted by NHS Greater Glasgow & Clyde (GG&C) and the Golden Jubilee Foundation, and was nationally designated in 1999 for the investigation, management and treatment of all patients with severe pulmonary hypertension in Scotland.



The primary aim of the service is to achieve improved quality of life by providing accurate diagnosis; ensuring people are offered the appropriate medicines / surgical treatment pathway and monitoring effectiveness of treatment.

The specific aims and objectives of the review were to assess the service's performance against the National Specialist Services Committee (NSSC) designation criteria.

The review concluded that the Pulmonary Vascular Hypertension service continues to meet the criteria for designation.

While the service continues to meet the criteria for designation, the review recommended some actions.

NSD considered the growth in prevalence of patients within the service and is cognisant that a regional model of delivery may need to be considered in the future should the number of active patients continue to increase.

Further, NSD is to include the question regarding drug costs being transferred into the 'risk share' model of funding within the 2022/23 business plan for consideration.

NPPPRG unanimously endorsed the review recommendations and continued designation of the SPVU Service.

NSSC queried the proposal on the drug costs becoming part of the risk share rather than the parent Board of the patients incurring these costs, and would NSSC be setting a precedent with this model.

NSD informed NSSC that this was the only service set up whereby the actual drug costs were included in the service. For other services NSD would only pay for the inpatient cost and for the week after discharge and after that costs were incurred by the host Board. This service had been an anomaly. The other option would be to de-designate the drugs costs back to the Boards. This had not been fully explored but it was agreed that NSD would consider to allow Boards to understand the implications for them. NSD would pick this up and build this into the Business Case for Chief Executives consideration.

In summary, NSSC noted the service continued to meet the criteria for designation but expected further work to be carried out around the drug funding model.

### **9.3 Scottish Inherited Bleeding Disorders Network (SIBDN) – NSSC 2021/33**

The Scottish Inherited Bleeding Disorders Network (SIBDN) was formally commissioned in April 2016. It is a life span network and encompasses care for individuals with an inherited or acquired bleeding disorder (IABD) at all stages in the patient pathway from childhood through to adulthood. These conditions are rare in the general population and most are genetically inherited. They are treated by replacing the missing clotting factor.

The Independent Review Group (IRG) concluded that the risk sharing scheme meets the commissioning criteria for risk sharing and there are no concerns in relation to unwarranted divergence in practice.

It should be noted that the review report was finalised in January 2021 but submission was delayed due to a challenge from the patient group in regard to one of the recommendations. The May and June meetings of NPPPRG/NSSC were cancelled.

NSD's clinical SMG is of the opinion that the strategic landscape has changed significantly since January 2021. As a result, the group has reservations about supporting the recommendations around expanding the scope of the risk sharing scheme. Other routes for ensuring appropriate investment in psychology and physiotherapy services may be more appropriate.

NPPPRG were of the opinion that this was a risk share and not a national commissioned service hence extending the scope to include posts for physiotherapy and psychology were not warranted.

Improving psychology and physiotherapy services should be progressed through regional or local planning processes.

NPPPRG supported the continuation of one PA and adequate PM support and endorsed the SIBDN Review.

NSSC were in agreement with NPPPRG's opinion that the risk share was for the cost of the drugs and the service and not physiotherapy and psychology.

In summary, NSSC endorsed the continued designation of the SIBDN service.

**10. Any Other Business**

NSD has not been notified of any other business.

**11. Date of Next Meeting:**

Thursday, 9 December 2021 – 1.30pm (Via Teams calendar invite)