Scottish Differences of Sex Development (SDSD) Network
ANNUAL REPORT 2019/20

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1. Executive Summary

The Scottish Differences of Sex Development Network (SDSD) made good progress against its workplan in 2019/20 and as part of network activities has:

- delivered a successful Families Day in June 2019 attended by patients and families, healthcare professionals and representatives from the Office for Rare Conditions (ORC) and the dsdfamilies charity. Feedback from the event indicated a clear appetite for similar events in the future;
- facilitated its annual education event in March 2020, the theme of which was Clinical Psychology in view of the recent investigation findings that current psychology provision in Scotland for DSD patients is failing to meet standards;
- liaised and collaborated productively with other bodies and organisations such as the Office for Rare Conditions (ORC), the Scottish Paediatric Endocrine Group (SPEG) Network and the dsdfamilies charity;
- compiled a report on the provision of adequate Clinical Psychology services for DSD in Scotland which recommended that more psychology input throughout Scotland should be provided;
- continued to provide useful and accessible information and resources for both clinicians and patients through its website, including two education videos for health professionals.

The network has ongoing challenges with the capacity of clinicians to meet workplan objectives due to their clinical commitments. Furthermore, the network had no Programme Manager between August 2019 and February 2020, and towards the end of 2019/20 the COVID-19 public health crisis arose which had an immediate impact on the network’s normal functioning and activities. Much network activity requiring clinician input was suspended or subject to delay. Along with other clinical networks, SDSD produced a COVID-19 Network Impact Report which identified the impact of the pandemic on network tasks and workstreams in this reporting period, and the likely impact in the subsequent reporting period. The true impact of the pandemic on the network in that subsequent period will be evaluated in the 2020/21 Annual Report. Despite the challenges, however, by building on its achievements in 2019/2020 and through an ambitious work programme for 2020/21, SDSD is well placed to achieve its long term objectives and provide truly equitable care and support to those living in Scotland with a DSD.

Going forward, the priorities for the SDSD network are to:

- deliver an effective and enjoyable Education Event in 2020/21 which builds on the success of its predecessors;
- devise a way of re-establishing the annual Family Day;
- seek to address the insufficiency of clinical psychology provision in meeting the specific needs of DSD patients in Scotland;
- make progress on the Patient Experience Survey which will capture the views of patients, parents and carers on their multidisciplinary clinic visit to guide the SDSD network in delivering what matters most to patients;
- undertake a stakeholder survey to obtain views on how the SDSD website can be improved to ensure that it continues to provide a wide range of relevant, useful and up-to-date information and other resources for clinicians, patients and families.
2. Introduction

2.1 Background

The SDSD Network, formerly the Scottish Genital Anomalies Network (SGAN), was established in 2005 to improve care and support for any individual with a difference of sex development from the point the difference is suspected, at all stages of their patient pathway, from antenatal care through to adulthood.

Sex is usually assigned immediately after birth. Whilst atypical genitalia are not uncommon and population studies using linked hospital datasets suggest that atypical genitalia may occur in 1 in 300 births\(^1\), delayed sex assignment is felt to be rarer. Currently, there are no published reports that describe the extent of delay in sex assignment. The prevalence of atypical genitalia and the time taken to assign sex in such cases remains unclear.

Information on term neonates who required specialist input for atypical genitalia was provided by the Scottish Audit of Atypical Genitalia (SAAG) survey between 2013 and 2019. In total, the study identified 171 term infants who required some investigation for atypical genitalia in the neonatal period, providing a birth prevalence of 1 in 1,881 term births. Of the 171, 97 (57%) had specialist input over the first 3 months of life, providing a birth prevalence of 1 in 3,318 term births that received specialist input for atypical genitalia. Of the 97, 92 (95%) had specialist input and complete 3-month follow-up data, and 62 of these (67%) presented within 24 hours of birth and age at presentation ranged from birth to 28 days. Age at sex assignment ranged from birth to 14 days and in 63 of the 92 cases (68%), sex assignment occurred at birth. Thus, the birth prevalence of a case of atypical genitalia where sex assignment was reported to be delayed beyond birth was estimated at 1 in 11,097 births. One case was re-assigned sex at 3 months.\(^2\)

Network membership is made up of a multidisciplinary group of healthcare professionals who provide care to children and adults with atypical genitalia. SDSD is focused on providing equitable care to all those living in Scotland with a DSD. The Network organises an annual Education Day, an annual Family Event and provides online resources for professionals working with families affected by a DSD.

2.2 Core Objectives

National networks have agreed core objectives that reflect the Scottish Government’s expectations for managed clinical networks, as described in CEL (2012) 29\(^3\). The network’s core objectives are:

1. The design and ongoing development of an effective network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) and national commissioning performance management and reporting arrangements.

2. To support the design and delivery of services that are evidence-based and aligned with current strategic and local and regional NHS planning and service priorities.

3. Effective Stakeholder Communication and Engagement through the design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service Users are involved in the Network and explicitly in the design and delivery of service models and improvements.

4. Improved capability and capacity in DSD care through the design and delivery of a written education strategy that reflects and meets stakeholder needs.

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5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).

6. To generate better value for money in how services are delivered.


3.1. Effective Network Structure and Governance
SDSD has an established network structure in line with National Commissioning Governance for National Networks. The network has clear management arrangements and is held accountable for its performance through National Services Division (NSD) annual performance management and reporting cycle. It has consistently fulfilled its responsibilities, producing annual and mid-year reports and participating in Annual Performance Review meetings with NSD Commissioners. The networks annual and midyear reports are available to the public through the network website: http://www.sdsd.scot.nhs.uk

3.2 Service Agreement
SDSD has a Service Level Agreement in place covering the period 2020 - 2023.

3.3 Strategies

3.3.1 Communication and Engagement Strategy
The SDSD Communication and Engagement Strategy was issued in November 2018, and updated by the Steering Group in January 2019 to guide work on service user and voluntary sector engagement. The strategy will be reviewed and updated in 2020/21.

3.3.2 Education Strategy
The SDSD Education Strategy which governs the delivery of the network’s education plan was issued in June 2018, and will be reviewed and updated in 2020/21.

3.3.3 Quality Strategy
The SDSD Quality Strategy which governs the delivery of the network’s quality improvement plan was issued in June 2018, with an unpublished update in February 2019. The strategy will be reviewed and updated in 2020/21.

3.4 SDSD Core Team
The SDSD core team consists of a Programme Manager (0.5 WTE) and a Programme Support Officer (0.2 WTE) who are responsible for the day-to-day running of the network alongside a Lead Clinician who provides 1 Programmed Activity (PA) per week and has responsibility for overseeing the work of the network.

Between August 2019 and February 2020, the network operated without a dedicated Programme Manager pending recruitment of a successor to Mrs Mungall. To mitigate the impact of this unexpected and unavoidable gap, the network undertook an exercise to identify priorities to be progressed. These are reflected in this report.

3.5 Steering Group
The network delivered its scheduled programme of steering group meetings in full with four meetings during 2019/20.
The Steering Group is chaired by the Lead Clinician, Dr Martina Rodie (Greater Glasgow & Clyde), and has up to date Terms of Reference which were last reviewed in May 2019.

The Steering Group has representation from multidisciplinary healthcare professionals providing direct care and support to children and adults affected by a DSD from four NHS Boards: NHS Greater Glasgow & Clyde, NHS Lothian, NHS Grampian and NHS Highland. The group also includes a patient representative who actively contributes to the delivery of the workplan (see Appendix 1: Steering Group Membership).

All NHS Boards refer DSD patients to the three specialist centres for DSD care provision (Glasgow, Edinburgh and Aberdeen) and are essentially the “customers” of the three care delivery Boards. Accordingly, SDSD seeks to maximise input from all Boards to the Steering Group to ensure that their perspective is captured and informs how services are delivered.

The network currently has one working group, a Data Subgroup that works to identify data requirements to measure performance against Quality Indicators and pursues other data-related projects.

3.6 Service Development and Delivery

3.6.1 Pathways into Care
During 2019/20, the SDSD network liaised with colleagues in the Scottish Paediatric Endocrine Group (SPEG) network to develop the Bilateral Impalpable Testes (BIT) pathway. In addition, in view of the fact that the Undescended Testes Guidelines do not contain enough relevant information for BIT, specific guidance for clinicians was developed which included information for parents.

Work also began on a review of the SDSD Neonatal care pathway during 2019/20. Once this is complete, the BIT pathway will be linked to the Neonatal care pathway as they are interdependent, which will ensure consistency in terms of quality of and access to care.

3.6.2 Clinical Psychology Provision
As described in the 2018/19 SDSD Annual Report, the British Society for Paediatric Endocrinology & Diabetes (BSPED) recommends that early psychological input and support by a specialist clinical psychologist with experience of DSD is beneficial for young people with a DSD and provides a pathway to an optimal long-term outcome⁴. Accordingly, the network commissioned a Psychology report to advise on current DSD psychology provision in Scotland which highlighted that current provision is insufficient to meet the often very specific needs of DSD patients. At the SDSD Education Symposium in March 2020, the keynote speaker, Dr Julie Alderson (Clinical Psychologist, NHS England), explained that England was in a similar position to Scotland in its lower than recommended level of psychology provision.

As part of an exercise to scope psychology requirements for nationally commissioned specialist services, National Services Division colleagues met with stakeholders. While psychology provision for SDSD services is a matter for individual NHS Boards, a position paper was invited from the Heads of Psychology Group to inform discussions with planners.

4. Stakeholder Communication and Engagement

4.1 Newsletters
The network issued two newsletters during 2019/20 which provided the SDSD community and its stakeholders with engaging accounts of work that the network had undertaken. The newsletters are available at: https://www.sdsd.scot.nhs.uk/news-and-events/

4.2 Website
Figure 1 below compares SDSD website page views and sessions for 2018/19 and 2019/20. There are marked increases in page views (75%) and sessions (86%) in 2019/20 compared to 2018/19. Particular pages which saw a marked increase in views are Healthcare Professionals (62%), Events (54%) and Families (44%). This comprehensive increase in website activity is a measure of the success of the network’s efforts in increasing the appeal and accessibility of the SDSD website not only to healthcare professionals, but also to patients and families.

![Figure 1]

4.3 Patient Engagement: 2019 Families day
The 2019 SDSD Families Day took place on 8th June 2019. The purpose of the day was to provide patients and families with a relaxed, confidential and safe space in which they could:

- meet each other to share experiences and create support networks;
- learn more about the treatment, support and information available from NHS Scotland and other agencies and charities.

The event was attended by 26 people comprising patients, families, a range of healthcare professionals, SDSD network representatives and representatives from the Office for Rare Conditions (ORC) and the dsdfamilies charity. The day was structured as a series of talks and discussion sessions, interspersed with opportunities for free-form networking and interaction. The network’s lead clinician set the tone for the day by asking everyone to share all experiences in a constructive way while recognising the challenges and hurdles that many have faced on their journeys.

The event was a success with 92% of attendees who provided feedback indicating their overall assessment of the event as ‘Very Good’. All feedback respondents gave a score of ‘Very Satisfied’ to the following aspects of the day:

- Booking process and pre-event organisation
- Organisation of the day
- Range of speakers and topics
- Relevance of the topics
- Presentations that were delivered
- Chance to participate in the discussion sessions

Feedback responses to the question ‘What aspects of the day will be of most benefit to you?’ revealed the following themes:
- A desire for similar events in the future
- Speaking about surgery
- Speaking to other parents in the same position
- Hearing from other people living with DSD and learning from their experiences
- Discussions/information about fertility and starting a family

SDSD will use feedback from the event to improve the design and delivery of its next Family Day.

5. Education
The network has committed to optimise education and training potential of network members through developing and maintaining training and educational events to meet the knowledge and skills requirements of those involved in the treatment and care of DSD patients.

5.1 Education Strategy
An Education Strategy was produced in 2018 which identified that the network needed to extend and promote its education events amongst midwives and nurses. The network advertises the events that it facilitates on its website and through collaboration with a range of partners works to extend its reach in delivering education beyond the highly specialist centres.

5.2 Collaborative Education and Training
The network works in partnership with the Office for Rare Conditions Glasgow (ORC). The ORC was established in Scotland in 2017 to raise awareness of rare conditions, enhance the quality of care provided and promote participation in multi-centre research. It is based at the Royal Hospital for Children (NHS Greater Glasgow and Clyde) and the University of Glasgow. Given the rare nature of DSD conditions and that both ORC and SDSD have aims and stakeholders in common, the partnership provides both the network and the ORC with a valuable opportunity to share resources and maximise impact on clinical colleagues as well as patients and families.

In addition, the SDSD lead clinician works with the British Society of Paediatric Endocrinology and Diabetes (BSPED) DSD Special Interest Group (SIG) and the European Society for Paediatric Endocrinology (ESPE). This productive engagement with groups and societies at UK and international level promotes the sharing of best practice and the exchange of research outcomes, information and other resources.

5.3 Online Education
In 2019/20 SDSD facilitated the production of two education videos for health professionals which can be accessed through the professional resources page of the SDSD website:
https://www.sdsd.scot.nhs.uk/health-care-professionals/sdsd-professional-resources/

- How to assess newborns with atypical genitalia (251 views as at end August 2020)
- Atypical genitalia: theory and management (77 views as at end August 2020)

SDSD is pleased to report that the two videos have amassed 328 views between them in eight months.
5.4 Annual Education Symposium

The SDSD 2020 education symposium was held on 6th March 2020 in Edinburgh, and was attended by 46 delegates from across Scotland and England. Like the year before, the symposium carried Continuing Professional Development (CPD) approval from the Royal College of Paediatrics and Child Health (RCPCH).

The geographical spread of delegates was modest with four territorial NHS boards in central Scotland represented. Delegates’ professional areas included Clinical Psychology, Neonatology, Endocrinology and Clinical Genetics, and nearly a fifth of delegates were students. The theme of the day was Clinical Psychology in view of the recent investigation findings that standards of current psychology provision for DSD patients in Scotland need to be improved. The SDSD lead clinician chaired the symposium and encouraged a positive tone with a focus on how to drive improvement in and access to services. There were six presentations, four from clinicians, one from a trainee clinician and one from a patient on her experience of living with Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome, a congenital disorder affecting the female reproductive tract. The keynote speaker was Dr Julie Alderson, Clinical Psychologist, University Hospitals Bristol NHS Foundation Trust.

Feedback from the event was very positive, and the talk by the patient on the challenges and triumphs she has experienced on her journey living with MRKH syndrome was particularly well received. 70% of responding delegates reported that learning objectives were fully met with respect to increased awareness of the SDSD network, and 65% reported that they were fully met with respect to increased conversancy with patient management and care (see Figure 2 below).

![Extent to which learning objectives were met](image)

Figure 2

56% of responding delegates reported that their learning needs were fully met, and 60% reported that their practice would change substantially thanks to the event (see Figures 3 and 4 below). The learning needs of nearly half of responding delegates were partially met, and three reported little or no predicted change to their practice as a result of the event. Accordingly, the SDSD network will consider carefully whether it is possible to increase the extent to which learning needs are met and relevance to clinical practice in future education events, without unduly narrowing the overall appeal of such events.
Here is a selection of the comments received:

“‘Living with MRKH’ was extremely interesting; I felt it was really beneficial to see things from a patient’s point of view.”

“The best aspect of the entire day was the presentation by the patient on her journey with MRKH.”

“Would be keen to hear more about possible networking opportunities and contact with other psychologists working with DSD.”

“Really good to get perspective of psychology in this area as a clinician.”

“It would be useful to develop a network of psychology contacts working in the area of DSD in Scotland, and hold connection/skills-based workshops that focus on different conditions. We should also look at how, as clinical psychologists working in DSD, we can contribute to strengthening the evidence base.”

“Really surprised by the consistently high quality of presentations at this event and how useful each presentation was.”
“It really increased my awareness and I am amazed at how committed and incredible all the professionals here are.”

“This learned knowledge will definitely improve my practice. DSD babies are a rare occurrence within my unit so familiarisation of available services is of great use.”

“Convenient venue! A very worthwhile educational day. It would be interesting to hear from a wider team.”

Frequently used words within the collated feedback:

**MOVING INFORMATIVE EXCELLENT STIMULATING ENGAGING**

6. Audit and Continuous Quality Improvement

6.1 Data Group

The SDSD data subgroup collaborates with the Networks Information Management Service (IMS) to identify data requirements to measure performance against Quality Indicators. It also pursues other data-related projects to support audit and continuous quality improvement.

6.2 Prevalence of genital surgery

In 2018/19 SDSD started to analyse clinical data from NHS Scotland’s Information Services Division (ISD) on the prevalence of DSD-related surgeries in Scotland by age range and surgery type. However, the network’s analyses revealed that this data did not accurately reflect the actual surgeries performed. This gave rise to concerns that the procedures were being incorrectly coded. Accordingly, the network formed a plan to audit the surgical notes of all the patients to ensure that they are being coded properly in ISD’s data. Only by having accurate clinical data can it be evidenced that the recommended pathways of care are being followed.

During 2019/20 the work of the group was confined to the Public Benefit Privacy Panel (PBPP) application to be given access to the Community Health Index (CHI) numbers of patients who have undergone genital surgery. The granting of this access will enable historical national clinical data to be audited so that surgical coding anomalies can be rectified. Unfortunately, the panel’s consideration of the application has not yet taken place, so the data subgroup was unable to do much substantive data work in 2019/20.

6.3 Quality Indicators

**Quality Indicator 1:**

**Number and proportion of families in Scotland whose newborn baby had atypical genitalia in the last 5 years, who had a face to face discussion with a healthcare professional with the relevant expertise and knowledge of DSD**

The network is able to report from SAAG data that from July 2013 to December 2019 there were 92 cases of newborns diagnosed with DSD, 100% of whom have met someone face to face with expertise in DSD.

**Quality Indicator 2:**

**Number of families in Scotland whose newborn baby had atypical genitalia in the last 5 years, who met a psychologist**

The SAAG data highlights that only 12 out of 92 families (13%) from July 2013 to December 2019 have met a psychologist.

In 2019/20, there were five cases of newborns diagnosed with DSD, and two of these families met a psychologist. Although this is a higher proportion (40%) than the overall 2013 – 2019 period (13%), the numbers are very small. Overall, these findings continue to reinforce the findings of the report on Clinical Psychology services for DSD in Scotland (see page 4).
Quality Indicator 3:
How good were health professionals at listening/explaining/communicating shortly following the birth of your baby?

This indicator is based on data collected through the Patient Experience Survey which was not conducted during 2019/20, so it is not included in this report.

The network will consider the implications of all these findings in its work to identify service developments.

6.4 DSD Diagnostic Meetings data
Data on DSD cases discussed at Diagnostic Meetings is provided to the SDSD network by the Child Health Research Team at the University of Glasgow. A total of 67 cases was reported for 2019/20, and the breakdown by case type and NHS Board is shown below:

New cases (Figure 5): Newly-discussed cases

NGS results (Figure 6): Cases where the Next Generation Sequencing (NGS) extended panel has been carried out and the results have been discussed. Patients will have been presented before at the DSD meeting.

![Figure 5](image_url)
7. Value

As part of the National Network Management Service (NNMS), SDSD operates a structure that is designed to maximise the use of limited financial, physical and human resources by sharing knowledge and reducing unnecessary duplication of effort. The network continues to maximise opportunities to raise awareness of its work through NNMS events which reach a broader audience. Furthermore, the SDSD Quality Indicators were developed with the intention of generating better value for money and increasing the reach and impact of the network.

During 2019/20 the SDSD network has sought to create best value for its stakeholders in the following ways:

- Addressing lack of awareness of DSDs and their management and treatment by providing access to evidence-based information and resources for clinicians, patients and families. This is done through the SDSD Quality Improvement (QI) strategy with its focus on improved communication and awareness of the network, its resources and its activities. Thus during 2019/20 SDSD has:
  - ensured that the content of the network’s website is relevant and useful, and maximised its accessibility;
  - issued regular clinician and patient newsletters;
  - maximised its use of the Children and Young People’s Twitter account.

- Addressing deficiencies in DSD training and expertise by providing access to high quality DSD education and training through the SDSD Education Symposium and the production of two online education videos for health professionals.
• Minimising duplication of effort by:
  ➢ collaborating productively with the Office of Rare Conditions (ORC) to share resources and maximise impact on clinical colleagues as well as patients and families;
  ➢ working with groups and societies at UK and international level to share best practice and exchange research outcomes, information and other resources.

• Maximising its use of video conferencing and other audio-visual technology in meetings and events to reduce travel and ensure equitable access regardless of location.

8. Finance
All national managed clinical and diagnostic networks receive an annual budget of £5,000 to undertake network activity, Figure 7 provides a breakdown of network expenditure for 2019/20 and shows that the network remained within its allocated budget.

9. Plans for the Year Ahead

9.1 Service Development

9.1.1 Pathways into Care
Complete the SDSD Neonatal care pathway review and link the pathway to the Bilateral Impalpable Testes care pathway.
Audit uptake and adherence to the Neonatal pathway.

9.1.2 Clinical Psychology Provision
Seek to address the insufficiency of clinical psychology provision in meeting the specific needs of DSD patients in Scotland.

9.1.3 SDSD/SPEG common Service Development ground
Continue to collaborate with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network on service development areas of mutual benefit (e.g. care pathways, clinical guidelines).

9.2 Communication and Engagement

9.2.1 Patient Engagement
Plan and facilitate a Families day during 2020/21 through an appropriate virtual medium such as the Zoom videoconferencing program.
Make progress on the Patient Experience Survey which will capture the views of patients, parents and carers on their multidisciplinary clinic visit to guide the SDSD network in delivering what matters most to patients.

9.2.2 Website
Continue to develop its website as an information and educational resource for clinical stakeholders, and as an information and signposting resource for patients and families. SDSD will undertake a stakeholder survey to obtain views on how the SDSD website can be improved to ensure that it is accessible and user-friendly, and that its content is relevant, useful and up-to-date.

9.2.3 Clinical Stakeholder Engagement
Continue to collaborate with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network through cross-links between websites and cross-posting regular communications.

Continue to collaborate and liaise with the Office for Rare Conditions (ORC), the British Society of Paediatric Endocrinology and Diabetes (BSPED) DSD Special Interest Group (SIG) and the European Society for Paediatric Endocrinology (ESPE).

9.2.4 Communication and Engagement strategy
Review and update the SDSD Communication and Engagement strategy.

9.3 Education and Training

9.3.1 Education event
Deliver an effective and enjoyable education event in 2020/21 which builds on the success of its predecessors.

9.3.2 Education strategy
Review and update the SDSD Education strategy.

9.4 Continuous Quality Improvement

9.4.1 Data group
Reinvigorate the SDSD Data Group which will:

- expedite the PBPP application approval so that surgical coding anomalies can be rectified in national data on DSD patients;
- refresh the SDSD CQI and Data plan for the collection, analysis and reporting of key data and quality indicators;
- explore the potential for common data reporting with the Scottish Paediatric Endocrine Group (SPEG).

9.4.2 Quality strategy
Review and update the SDSD Quality strategy.

9.5 Value
Continue to create best value for SDSD stakeholders by addressing lack of awareness of DSDs and their management and treatment, addressing deficiencies in DSD training and expertise and minimising duplication of effort.
9.6 Risks /Issues
The precise duration of the impact of the COVID-19 public health crisis is currently unknown. However, in order to mitigate uncertainty and anticipate risks, a COVID-19 Impact Assessment report is produced every quarter for the network. In the short term, the main effects will potentially be the unavailability of front line staff to attend meetings and progress network work, and the ‘catch-up’ required from meetings and events missed during the lockdown period.
10. Detailed Description of Progress in 2019/20

When defining network objectives, please consider the Institute of Medicine’s six dimensions of quality, which are central to NHS Scotland’s approach to systems-based healthcare quality improvement:

1. **Person-centred**: providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
2. **Safe**: avoiding injuries to patients from healthcare that is intended to help them;
3. **Effective**: providing services based on scientific knowledge;
4. **Efficient**: avoiding waste, including waste of equipment, supplies, ideas, and energy;
5. **Equitable**: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
6. **Timely**: reducing waits and sometimes harmful delays for both those who receive care and those who give care.

<table>
<thead>
<tr>
<th>RAGB status</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>RED (R)</td>
<td>The network is unlikely to achieve the objective by the agreed end date.</td>
</tr>
<tr>
<td>AMBER (A)</td>
<td>There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.</td>
</tr>
<tr>
<td>GREEN (G)</td>
<td>The network is on track to achieve the objective by the agreed end date.</td>
</tr>
<tr>
<td>BLUE (B)</td>
<td>The network has been successful in achieving the network objective to plan.</td>
</tr>
</tbody>
</table>

Please note that where an item is flagged as red or amber in the workplan below, remedial action is described in blue text in the “Description of progress towards meeting objective as at 31.03.2020” column.
<table>
<thead>
<tr>
<th>Objective Number</th>
<th>Smart Objective</th>
<th>Planned start/ end dates</th>
<th>Detailed Plan Available / Owner</th>
<th>Description of progress towards meeting objective as at 31.03.2020</th>
<th>Outcome</th>
<th>RAGB status</th>
</tr>
</thead>
</table>
| 1. Effective Network Structure and Governance  
linked to Quality Dimensions 3,4,5,6 | The network will organise 4 Steering Group and 3 Data group meetings by 2020 to ensure effective delivery of the 2019/20 work plan. | 31/03/2020 | Steering Group and Sub - group member - ship | Steering Group meetings took place as planned in 2019/20. Data group did not meet because of PBPP application delay. The data group will be reinvigorated in 2020/21. | Effective delivery of most of the SDSD network workplan to ensure continued progress. | A |
| 2. Service Development and Delivery  
linked to Quality Dimensions 1,2,3,4,5,6 | By December 2019 provide a benchmarking report of the psychological support requirements for all patients against other UK services. | 31/03/2020 | Dr Rebecca Crawford  
Lead Clinician  
Programme Manager | This work was completed by December 2019. | All patients presenting with a DSD will have appropriate psychological support and engagement with specialist care according to confirmed needs and conditions. | B |
<table>
<thead>
<tr>
<th>Objective Number</th>
<th>Smart Objective</th>
<th>Planned start/ end dates</th>
<th>Detailed Plan Available / Owner</th>
<th>Description of progress towards meeting objective as at 31.03.2020</th>
<th>Outcome</th>
<th>RAGB status</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019-03</td>
<td>By December 2019 develop new clinical Care Pathway for Bilateral Undescended Testes.</td>
<td>31/12/2019</td>
<td>Dr Paula Midgley</td>
<td>Completed on time.</td>
<td>Delivery of evidence-based practice and equity of access to high quality care across Scotland to reduce harm and unwarranted variation</td>
<td>B</td>
</tr>
</tbody>
</table>

### 3. Stakeholder Communication and Engagement
[linked to Quality Dimensions 1,3,4,5,6]

<p>| 2019-04          | By March 2020 review the Communication Strategy to meet the needs of all stakeholders, including provision of information and effective sign-posting through the website | 31/03/2020               | Steering Group                  | Not achieved due to absence of PM. <strong>The Communication Strategy will be reviewed in 2020/21.</strong> | Stakeholders across Scotland will inform the annual work plan to ensure a personalised approach to care | R           |
| 2019-05          | By March 2020 develop a survey capturing patients/parents/carers views on their multidisciplinary clinic visit | 31/03/2020               | Steering Group Lead Clinician PM/PSO | No progress due to absence of PM. <strong>Progress on the survey will be made in 2020/21.</strong> | Through shared decision-making, SDSD will deliver what matters most to patients | R           |</p>
<table>
<thead>
<tr>
<th>Objective Number</th>
<th>Smart Objective</th>
<th>Planned start/ end dates</th>
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<th>Outcome</th>
<th>RAGB status</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019-05</td>
<td>By the end of 2019, SDSD will co-fund and contribute to the content and design of the Story of Sex Development families’ education resource produced by dsdfamilies</td>
<td>31/12/2019</td>
<td>Steering Group Lead Clinician</td>
<td>Resource launched by dsdfamilies in November 2019</td>
<td>Children, young people and families can learn more about their bodies, and understand more about sex development, the terms that doctors use to describe it and the tests that doctors sometimes carry out</td>
<td>B</td>
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</tbody>
</table>

4. Education [linked to Quality Dimensions 1,2,3,4,5,6]

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<thead>
<tr>
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<th>Outcome</th>
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</tr>
</thead>
<tbody>
<tr>
<td>2019-06</td>
<td>By March 2020 deliver one national symposium and link with stakeholders (eg. Office for Rare Conditions (ORC)) for regional teaching events</td>
<td>31/03/2020</td>
<td></td>
<td>The Annual Symposium was held in March 2020.</td>
<td>Healthcare professionals across Scotland share and increase their knowledge, skills and awareness of DSD management Improved quality of patient care due to better trained clinicians</td>
<td>B</td>
</tr>
<tr>
<td>Objective Number</td>
<td>Smart Objective</td>
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<tr>
<td>2019-07</td>
<td>By June 2019 review and update the Education Strategy to support stakeholders’ learning needs and address these in a range of formats, including regional teaching sessions</td>
<td>31/03/2020</td>
<td>Steering Group</td>
<td>Not achieved due to absence of PM.</td>
<td>The workforce is valued and has access to evidence-based specialist training and resources for improved health and care</td>
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<td></td>
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<td>Lead Clinician</td>
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<td></td>
<td>Barbara Wardhaugh</td>
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<td></td>
<td>Dr Harriet Miles</td>
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<td></td>
<td>Programme Manager</td>
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<tr>
<td>5. Audit and Continuous Quality Improvement</td>
<td>[linked to Quality Dimensions 1,2,3,4,5,6]</td>
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<td>2019-08</td>
<td>By March 2020 the network will continue to improve the established dataset</td>
<td>31/03/2020</td>
<td>Data Group</td>
<td>Ongoing work with Data group.</td>
<td>To enable data collection, audit and research into DSD conditions to drive future service improvement to improve patient outcomes</td>
<td>A</td>
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<td>Continue use of SAAG to collect data on early years.</td>
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<td>Continue capturing number of cases discussed at DSD Diagnostic Meetings.</td>
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<td>Analysis of surgical data pending approval from Public Benefit and Privacy</td>
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<td>Panel for Health and Social Care – not achieved because PBPP application not considered.</td>
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<td>The PBPP application will be expedited in 2020/21 and work begun on surgical coding anomalies rectification.</td>
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</tbody>
</table>

6. Value [linked to Quality Dimensions 1,2,3,4,5,6]

| 2019-09          | By March 2020 audit uptake and adherence to the Neonatal Pathway to gather evidence of clinical value | 31/03/2020 | Steering Group Lead Clinician Programme Manager Programme Support Officer | The neonatal care pathway has been distributed to all Neonatal Units in Scotland. Work began on a review of the pathway during 2019/20. The Neonatal care pathway review will be completed in 2020/21. | Patients will benefit from centres working together to provide optimum care and manage risk better Audit will highlight level of awareness and how consistently pathway is utilised across Scotland | A          |
Appendix 1: Steering Group Membership

Dr Martina Rodie, Consultant Neonatologist, Lead Clinician, NHS Greater Glasgow and Clyde (GGC)
Miss Alex Brown, Programme Support Officer, NHS National Services Scotland (NSS)
Dr Tarini Chetty, Paediatric Endocrinology Trainee, NHS Lothian
Dr Shiona Coutts, Consultant in Obstetrics and Gynaecology, NHS Lothian
Dr Kathryn Cox, Paediatric Trainee, NHS Lothian
Dr Rebecca Crawford, Consultant Clinical Psychologist, NHS GGC
Mr Chris Driver, Consultant Paediatric Surgeon, NHS Grampian
Dr Stuart Henderson, Consultant General Paediatrician, NHS Highland
Mrs Claire Lawrie, IMS Senior Programme Manager, NHS NSS
Ms Morag Liddell, Senior Charge Nurse / Ward Manager NICU, NHS GGC
Ms Michelle McFall, Staff Nurse, NHS GGC
Dr Ruth McGowan, Consultant in Clinical Genetics, NHS GGC
Mr Phil McNicol, Programme Manager, NHS NSS
Dr Harriet Miles, Consultant Endocrinologist, NHS Lothian
Dr Aparna Sastry, Consultant Obstetrics and Gynaecology, NHS GGC
Ms Michelle Tamburrini, Patient Representative
Sr Barbara Wardhaugh, Endocrine Nurse Specialist, NHS Lothian