Scottish Differences of Sex Development (SDSD)

Annual Report 2024/25

This document has been prepared by NHS National Services Scotland (NSS) National Networks. Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHSScotland and other public sector organisations to help them deliver their services more efficiently and effectively. Working across professional and organisational boundaries, National Networks support the delivery of safe, effective healthcare that's designed around patients, carers and families.

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1. Introduction

The Scottish Differences of Sex Development network (SDSD) was originally established in 2005 as SGAN (the Scottish Genital Anomalies Network), a follow on from the Scottish Audit of Genital Anomalies study group. The SDSD network membership is made up of a multidisciplinary group of healthcare professionals who provide care to children and adults born with a difference in sex development or anomaly of the genitalia.

The 2024/25 reporting year has been a particularly challenging one for all NMCNs. This is mainly due to external factors that have impacted on the networks' ability to carry out key objectives.

2. Current Position

The Scottish Government have been undertaking a review of all national and regional networks. This will outline changes to the national planning structures in Scotland and it is anticipated that there will be proposed new models of networks.

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development.

SDSD prioritised the development of a clinical directory, drafting a new differences of sex development (DSD) nurses' resource and continuing with the psychology questionnaires (to evidence the gap in specialist DSD psychology support).

The network achieved 9/9 (100%) of its 'Business as Usual' objectives and 3/3 (100%) of its 'Service Development Plan' priority objectives in 2024/25, albeit with mixed results. Additionally, the network's three strategy documents (Education, Quality and Communication) were updated prior to identifying key priorities. SDSD also managed to deliver its Annual Education Symposium on 21 June 2024 and an online patient session on Mayer Rokitansky Küster Hauser (MRKH) Syndrome, with a very special guest speaker.

Dr Harriet Miles (Consultant Paediatric Endocrinologist, NHS Lothian) continued to take on a leadership role on a voluntary basis, also chairing the Steering Group meetings.

The Terms of Reference for the network replaced the service level agreement and covered the 2024/25 period.

3. Highlights

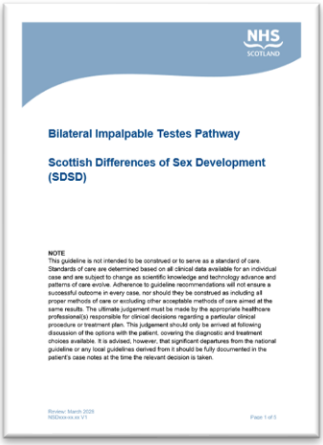
3.1 Effective Network Structure and Governance

Steering Group
SDSD does not currently have any subgroups due to its relatively small size but rather utilises task-focussed short-life working groups as required. The Steering Group has remained active throughout the year and plays a hands-on role in organising any education events.

Strategies
The network has its three strategy documents in place (Education, Quality and Communication). New strategy documents were developed in 2024/25 to align with the strategic planning objectives.

Terms of Reference
A new Terms of Reference document replaced the Service Level Agreement. This was implemented for 2024/25.

3.2 Service Development and Delivery


NHS SCOTLAND

Bilateral Impalpable Testes Pathway

Scottish Differences of Sex Development (SDSD)

NOTE
This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined based on all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

Review: March 2025
SDSDmay25 v1

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Clinical Guidelines
The 'Bilateral Impalpable Testes Pathway' was reviewed in March 2025 and is due to go onto the SDSD website in May 2025 All other guidance remains up to date. A tracker is in place to ensure all guidelines and patient information leaflets are reviewed in a timely manner.

Image 1: Example of SDSD Clinical Guideline

Nurses' DSD Resource
Last year, the Scottish Paediatric Endocrine Group (SPEG) NMCN developed an 'Endocrine Nurses' Guide to Growth Hormone' resource to assist Nurses with learning. The document provides a mix of information, useful signposting, templates and sections for Nurses to complete as they learn. As there is a crossover of stakeholders between the two networks, a suggestion was made that a further Nurses' resource covering differences of sex development (DSD) would also be beneficial. An objective was added to the 2024/25 business plan to begin developing this resource. A draft has been created, however, due to interdependencies with other external resources, this has not been finalised or published yet. It is anticipated that the resource will be completed in 2025/26.

Image 2: Example pages from SDSD Nurses' Resource

3.3 Stakeholder Communication and Engagement

Website

The SDSD website remains a useful resource for staff and patients alike, with access to a range of resources including patient information leaflets, reports, newsletters and clinical guidelines. A review was conducted in January 2025 to ensure the website remained up to date.

Newsletters

The network continued to publish its newsletters via Microsoft Sway. This has allowed SDSD to share important information around leadership, surveys, upcoming dates, articles of interest, learning opportunities, patient resources and other wider clinical network activity. A decision was made to hold off on developing a newsletter for quarter 4, whilst awaiting an update on the Scottish Government's review of networks.

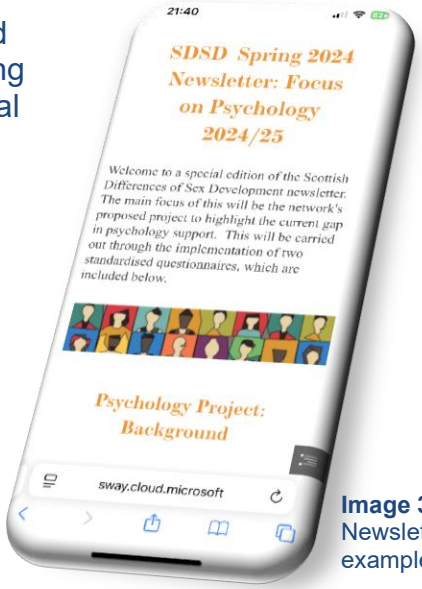

Image 3: Newsletter example

Clinical Directory

One of the other key objectives that was prioritised in the latter half of the year, was the development of a clinical directory for SDSD. This is contained within an Excel spreadsheet and includes individual 'sheets' for each health board. The sheets contain a list of key stakeholders across paediatric and adult services with an interest in DSD. Contact information is included to ensure that all stakeholders are kept up to date with news and events. This resource will remain a live document, with a thorough review carried out once a year to ensure details remain correct.

3.4 Education

Annual Education Symposium

SDSD delivered its Annual Education Symposium on Friday 21 June 2024 via Microsoft Teams. The event covered case studies, surgery, gynaecology, fertility, Vaginal Atresia and SDSD resources.

37 delegates attended the event on the day. In the feedback forms, they were asked to rate the extent to which their learning from this event would change their practice. The results are shown in the table below.

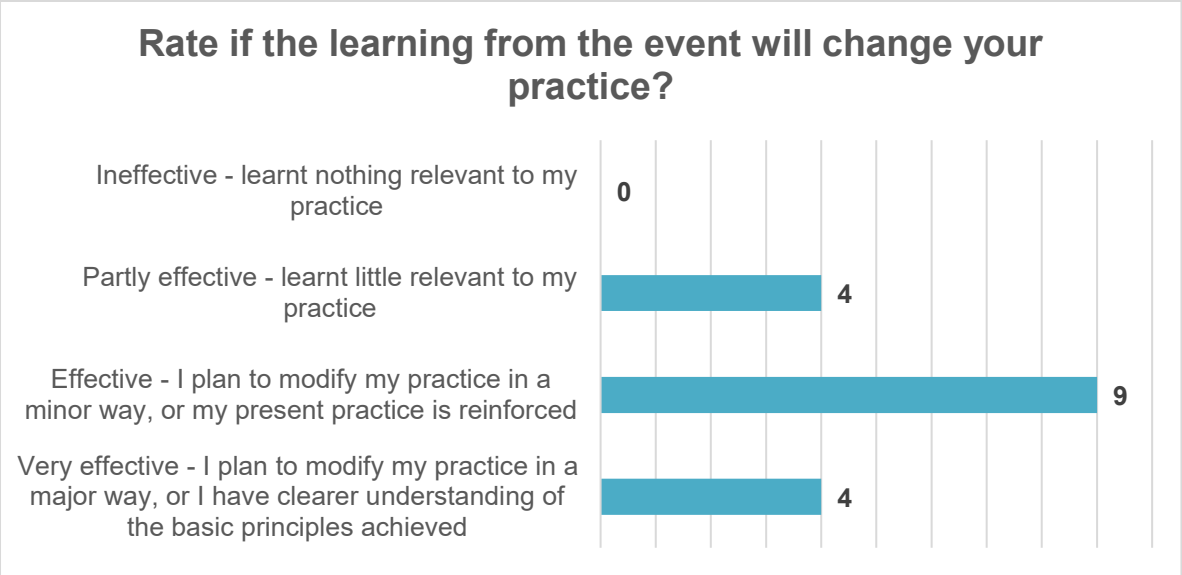

Figure 1: Feedback on extent to which education event will affect clinical practice

Below are some qualitative response highlights from the feedback

What are the key takeaways and insights you gained from the event?

- Important take home messages about risk of cancer and counselling for gonadectomy.
- Good to hear about surgery and changes in processes as it helps us counsel families about what to expect.
- Continuity of care and MDT approach.
- I did not how many people are affected by this condition or the implications of delaying surgery.
- I have a better understanding of both the surgical and non-surgical aspects of DSD.
- I feel more confident knowing what the pathway should be for patients and have a better idea of what blood tests are needed for the workup.

How will your practice change after the event?

- Better understanding risks of gonadal tumours.
- improved understanding re counselling for gonadectomy vs preservation.
- As a paediatric trainee with not much experience in patients with DSD, it was very useful to hear about the evidence basis of gonadectomy and cancer risk in AIS and about how the surgical approach to DSD

- The huge importance of working collaboratively with other disciplines to provide good care to patients.
- Having a parent talk about the patient perspective was also eye-opening, as we are often focused on patient outcomes as doctors and forget the patient journey and experience is perhaps one of the most important outcomes
- Much more empathy for families I meet with a child with DSD. There is so much more to think about than I had realised
- I will be aware of who I need to contact, as well as why and when I need to do so.
- A more informed discussion with parents re: future surgical options and rationale for delaying these.
- Being more conservative and less plans for surgery.
- Better knowledge of the updates on CAIS malignancy and gonadectomy.
- Improved understanding of surgical management.
- More awareness of surgical timings when counselling families.
- Greater awareness of patient impact of vaginal atresia.

3.5 Audit and Continuous Improvement

Psychology

Lack of clinical psychology provision has been identified in recent years as a major gap in DSD services in Scotland and DSD services are failing to meet international standards for the provision of psychological support for patients. Access to a DSD Psychologist is also inequitable, with specialist support only currently available in NHS Greater Glasgow and Clyde.

Last year, an approach was developed to try and capture the gap in specialist support through recording the number of patients (and families) that were able to access this, alongside the number of patient (and families) that were unable to be referred for support.

Two Microsoft Forms were set up to capture this information throughout 2024/25.

- The first questionnaire was set up for the Psychologists (currently seeing a limited number of DSD patients in NHS Greater Glasgow and Clyde) to complete. They were asked to log any actual DSD patient or family appointments/ interventions. The questionnaire did not require patient level detail, only high-level information such as age and diagnosis.
- The second questionnaire was for 'referring' clinicians to complete, also in real-time. This would capture similar data for any patients and families that *would have benefitted* from specialist psychology support, whether they had been referred or not.

The recommendation was that a report with the outcomes would then be taken to the Child Health Commissioners and territorial boards to seek investment. Unfortunately, completion rates remained low throughout the year, with Steering Group members agreeing that the numbers were not an accurate reflection. A decision was taken to extend the questionnaires into 2025/26, however, it has also been recognised that this approach may not yield the intended results, given the

extensive push throughout 2024/25. For example, one of the SDSD newsletters was focused specifically on this project.

3.6 Value

Image 4: MRKH event leaflet

Mayer-Rokitansky-Kuster-Hauser (MRKH) Patient / Family Event

SDSD delivered an online event for MRKH patients and families. Although there was a low turnout on the day, the event was recorded and shared on the SDSD website for the benefit of staff and patients/ families alike. Despite the limited numbers, the contribution from people was insightful and supported quality conversations throughout the event.

Topics covered included dilation, uterus transplantation, the role of the GP, psychology and surrogacy.

The network was also delighted to host a special guest speaker, Betty Mukherjee, who courageously spoke about her own experience of having MRKH on the BBC television show "Race Across the World". Betty delivered a very honest and engaging talk about her personal experience of living with MRKH.

Sustainability

The SDSD network has continued to run all of its meetings online, which has cut down on costs as well as reducing the network's carbon footprint.

All resources are accessible on the website and most forms are now completed online, reducing the need to print copies.

Looking forward – 2025/26

The network will continue with its 'business as usual' activity throughout quarter one in 2025/26, with further updates expected from the Scottish Government via NSD in the near future. The usual Business Plan will not be populated at this time.

Finance

The network operated within its allocated budget in 2024/25, focusing on low-cost, high-impact activities such as virtual education and digital resource development.

Risks and Issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals.

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits.

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