Scottish Differences of Sex Development (SDSD)

Annual Report
2023/24

Lead Clinician: *Vacant*
Programme Manager: Jamie Nimmo
Programme Support Officer: Laura Craig

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.

In the 2022/23 reporting period, the network managed to progress all of its objectives, a few of which have follow up actions to be taken into the next business plan.

Dr Ruth McGowan (Consultant Clinical Geneticist, NHS Greater Glasgow and Clyde) stepped down from her role as Lead Clinician at the end of July 2023. SDSD would like to acknowledge and thank Dr McGowan for her valuable leadership and continued contribution to the network.

A National Services Directorate (NSD) proposal was taken to the SDSD Steering Group to look at joining with the Scottish Paediatric Endocrine Group (SPEG) clinical network on a more formal basis. The idea being that combining resources and stakeholders would safeguard the future of both networks by making them more resilient, with greater influence. Both networks worked together to deliver a joint education meeting in January 2024 and other examples of shared resources have also been emerging. Despite some initial trepidation, the networks have agreed to work together over the course of 2024/25 to determine how this could work long-term.

2. Current Position

The network achieved 10/10 (100%) of its ‘Business as Usual’ objectives and 10/10 (100%) of its ‘Service Development Plan’ objectives in 2023/24.

Several of the objectives will carry over into the next business plan, including the work around psychology support, the surgical coding audit and nurse resources. The three strategy documents will also need to be revisited in 2024/25.

Lead Clinician recruitment is currently on hold across all national clinical networks, however, Dr Harriet Miles (Consultant Paediatric Endocrinologist, NHS Lothian) has been providing clinical leadership on a temporary, voluntary basis but with limited capacity.

Without a Lead Clinician officially in post, this will hold up the proposed plan to bring together the SDSD and SPEG networks. There is also a risk that some of the objectives in the 2024/25 business plan will be impacted, such as the surgical coding audit.

3. Highlights

3.1 Effective Network Structure and Governance

Steering Group

Dr Miles has been chairing these meetings in the absence of a Lead Clinician and has also been supporting wider work around network developments and governance. Dr McGowan has also continued to offer her support where possible.

The network does not currently have any subgroups due to its relatively small size, but rather utilises task-focussed short-life working groups as required.

Strategies

The network has three strategy documents in place (Education, Quality and Communication). These will be redrafted completely in 2024/25 with longer-term strategic planning in mind.

Terms of Reference

A new Terms of Reference document has been drafted to replace the Service Level Agreement. This will be implemented from 2024/25.

SPEG

As outlined above, the network was approached by representatives from NSD to look at coming together with the SPEG network under a more formal arrangement.

In 2023/24 both networks have been working together on objectives around data, education and communication. They have delivered a successful joint annual education event, created nurse resources and collaborated on a business case to develop a data system that would benefit both networks. There are also a number of key stakeholders that are engaged across both networks.

There are some concerns about the potential loss of resources, identity and the engagement of some stakeholders who don’t fully align with endocrinology. To mitigate this risk, during the 24/25 year, there will be opportunities for the network to engage in shaping how the model develops.

3.2 Service Development and Delivery

Survey

A national survey was conducted in March 2024 to capture feedback on the network. The survey was issued to over 120 SDSD stakeholders, including Surgeons, Gynaecologists, Endocrinologists, Nurses, Radiologists, Clinical Scientists, Neonatologists, Paediatricians, Psychologists, Clinical Geneticists and patient/ third sector representatives. Only two health boards provided feedback (4 from NHS Lothian and 3 from NHS Greater Glasgow and Clyde) alongside one “other”. 75% were Steering Group members.

The main strengths that were highlighted were around education, collaboration and guidelines. 88% of respondents reported an increase in knowledge through the network's education programme.

Areas for improvement included addressing the gap in specialist psychology support, improved access to data and recruiting more members, especially a Lead Clinician. Respondents expressed concerns about the proposed "merger" with SPEG, the lack of funding, changes in NSD staffing and not having a clinical lead.

A summary of the survey responses around strengths, areas for improvement, priorities, and challenges, is included as Appendix 1.

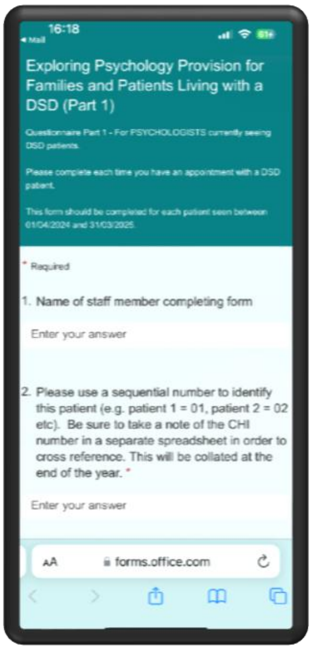
Psychology Position

Lack of clinical psychology provision has been identified in recent years as a major gap in DSD services in Scotland. 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.

A position paper was submitted to the Senior Management Group within the National Services Directorate (NSD) last year. The network was subsequently tasked with providing a further breakdown of meaningful data. A project was implemented in 2023/24 to capture real time data around current psychology provision for DSD patients and a note of all patients that *would have* benefited from a referral but could not get one.

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

- The first questionnaire[1] is for the Psychologists (currently seeing a limited number of DSD patients in NHS Greater Glasgow and Clyde) to complete. They are asked to log any actual DSD patient appointments/ interventions. The questionnaire does not require patient level detail, only high-level information such as age and diagnosis.
- The second questionnaire[2] is for clinicians to complete, also in real-time. This will capture similar data for any patients that *would have benefitted* from psychology support, whether they have been referred or not.



Exploring Psychology Provision for Families and Patients Living with a DSD (Part 1)

Questionnaire Part 1 - For PSYCHOLOGISTS currently seeing DSD patients.

Please complete each time you have an appointment with a DSD patient.

This form should be completed for each patient seen between 01/04/2024 and 31/03/2025.

* Required

1. Name of staff member completing form

Enter your answer

2. Please use a sequential number to identify this patient (e.g. patient 1 = 01, patient 2 = 02 etc). Be sure to take a note of the CHI number in a separate spreadsheet in order to cross reference. This will be collated at the end of the year. *

Enter your answer

Image 1: Screenshot of Questionnaire on Microsoft Forms

The recommendation is that a report with the outcomes is then taken to the Child Health Commissioners and territorial boards to seek investment. Psychology provision in NHS England is currently under review and a commissioning report is expected imminently. The network will review the report as soon as it is published.

---

[1] Exploring Psychology Provision for Families and Patients Living with a DSD (Part 1) (office.com)

[2] Exploring Psychology Provision for Families and Patients Living with a DSD (Part 2) (office.com)

Nurse Resources

The Nurse representatives on the SDSD Steering Group did some work on the patient and family resource page of the SDSD website to make it more user friendly, however, the website has since moved to a shared web offering alongside the other clinical networks and now uses standard formatting. In the meantime, the Nurses have also been supporting the SPEG Nurses' Subgroup in developing a learning resource for growth hormones. This is about to be published on the SPEG website, and the expectation is that the format will be replicated to develop other resources for DSD-specific learning.

3.3 Stakeholder Communication and Engagement

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. The most recent edition attracted 32 views.

3.4 Education

Annual Symposium

The focus of the SDSD Annual Education Symposium, which was carried over from last year, was 'An Introduction to DSD: A Multi-disciplinary Approach'. The event took place on 15 May 2023.

A broad overview of the key areas involved in DSD care were covered through talks delivered mostly by Steering Group members. Topics included: terminology, endocrinology, genetics, radiology, surgery, gynaecology, fertility and psychology.

Feedback was really positive and the event was attended by around 70 people.

Delegates were asked to rate the extent to which they considered learning from this education event would change your practice: (1 = no change to my practice, 5 = will change my practice in a significant way). The table below shows outlines the responses, with an average score of 3.9/5.

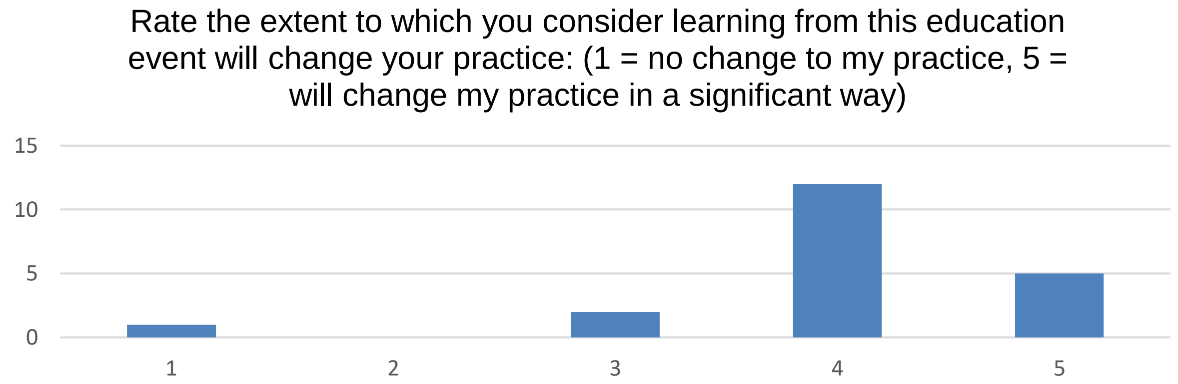


Figure 1: Education Symposium – change in practice through learning – scoring out of 5

Of the 22 feedback responses, eighteen delegates gave the event an overall score of 5/5 and four gave it a score of 4/5 (average of 4.8/5 or 96%).

Joint Annual Scientific Meeting with SPEG

Image 2: SPEG/ SDSD Annual Scientific Meeting

The network worked with the SPEG clinical network to deliver its 25th Annual Scientific Meeting in January 2024 at the Stirling Highland Hotel. The chosen topic of focus was Congenital Adrenal Hyperplasia (CAH) as it is a condition of interest for both networks.

There were 48 delegates in attendance from across Scotland. Evaluation feedback was received from 37 delegates. The below table outlines the overall impression of the event, with most delegates scoring the programme, organisation, and venue as “excellent”.

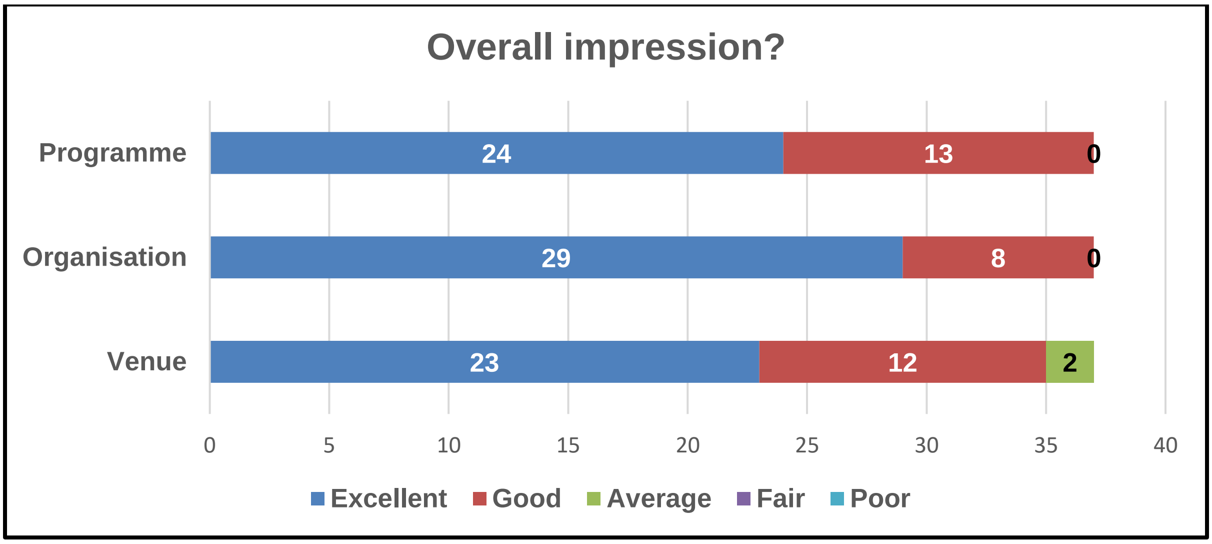


Figure 2: SPEG ASM Feedback – Overall Impression

The word cloud on the left has been generated based on the qualitative feedback received.

Suggested topics for future events included:

- DSD, late effects
- Hyperthyroid management
- Diabetes insipidus
- Obesity management
- General endocrinology
- Calcium metabolism
- Pseudo parathyroid
- Lab talks
- Pituitary pathology
- Genetics of hypopit
- Precocious puberty
- Hypopituitarism
- Transition to adult services
- MRKH/ AIS
- Genetics of short stature
- Hyperinsulinism
- Growth hormone treatment outcomes

Figure 3: SPEG ASM feedback – word cloud

3.5 Audit and Continuous Improvement

PowerApps

In 2023/24, SDSD continued to engage with SPEG colleagues to produce a joint business case to develop a new Power Apps instance, which could capture useful data for both networks. Power Apps allows networks to have more influence over what data fields are included, whilst presenting them in a more intuitive order than the current Clinical Audit System (CAS) used by SPEG. It also allows access to outputs via interactive dashboards, thus providing more incentive to input data. SDSD's main focus has been on the viability of such a solution and how this might link up with the International-DSD (I-DSD) system currently available to users across the UK, but mainly used by NHS Greater Glasgow and Clyde.

Due to the risks raised around capacity to input data as well as duplication of effort, SDSD decided to pull out of the business case, which would be submitted by SPEG, with a note that it could benefit SDSD in the long run.

Surgical Coding Audit

A PBPP application was completed by the SDSD network to request a specific national dataset on ICD10/OPCS4 codes. The application was held up for a significant period of time and was finally approved towards the end of 2023/24.

The following objectives were outlined.

1) Check if the ICD10/OPCS4 codes entered in the patient's data record accurately reflect the surgery performed
2) Promote discussion on whether or not the surgery performed was the right surgery to address the patient's clinical needs at the time
3) Analyse the range and frequencies of surgeries being carried out by category and by area
4) Analyse the impact of COVID-19 on surgeries and the subsequent recovery period
5) Use data as the basis for future data capture
6) Stratify actions by geographical location

It is anticipated that the network will get a hold of the data from Public Health Scotland (PHS) in 2024/25 to begin the audit process.

3.6 Value

Clinical Network Synergies

As outlined throughout this report, SDSD has been engaging with SPEG on a more formal basis around shared data interests, resources and education. Communications have also been cross posted on a more frequent basis. By bringing the networks together, this will provide a more sustainable future and natural progression of shared infrastructure and interests.

Patient and Family Event

The network delivered another successful patient and family event on 'Hypospadias' in collaboration with the Office for Rare Conditions (ORC) in November 2023. The event took place at the Advanced Research Centre, Glasgow University. 16 adults and 9 children attended the event. 64% of attendees were from Greater Glasgow & Clyde with the remaining 36% from other health boards across Scotland.
The programme included talks on genetic, surgical, endocrine and psychology aspects and allowed plenty of time for questions and discussion. All of the talks were rated "excellent" (91% of responses) or "good" (average 9% of responses) in the feedback. 100% of the respondents agreed that the event met their expectations. Children's entertainment was also provided in separate rooms.

Feedback from the event was really positive, with some of the perceived benefits quoted below.

- listening to other parents
- similar concerns – pre/post-surgery questions
- seeing the step-by-step operation pictures
- information and opportunity to ask questions

- finding out about genetic aspects - we have never come across this and did not know about future hormone issues
- wider network of support

Delegates were also asked to provide feedback on their experience of the DSD service in general, and what provided the most value. Responses are included below.

- being able to contact the secretary with any concerns and being contacted to discuss by surgeon
- all experiences with paediatric urology and endocrinology here have been excellent
- the continued follow-ups are very much of value to us as we learn more about hypospadias
- the support from cross disciplines and also play therapists

Suggested improvements for DSD services included the following.

- information when baby is born
- possibly more support after surgery - community?
- information pre-surgery regarding what to expect post-surgery e.g. advice of what to do if dressing falls off early
- images of post-surgery so you have an idea of what is "normal".
- I'd like to see improvements in waiting times for CAMHS
- perhaps a "what to expect” medical photograph info leaflet/ images of post-surgery so you have an idea of what is "normal".
- timescales of operations

Sustainability

The SDSD network has moved all of its meetings online. This will significantly cut down on costs as well as reducing the network’s carbon footprint.

The CAH education event was delivered jointly with SPEG this year, which has saved money and cut down on the number of face-to-face meetings even more.

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

Looking forward – 2024/25

A summary of the draft Service Development objectives for 2024/25 is included below.

Description of Work
Work with the Scottish Paediatric Endocrine Group NMCN to bring the networks together on a more formal basis. The 2024/25 reporting year should be utilised as a period of transformational change. The networks should identify common areas of interest/ focus as well as areas that do not align. Consideration to be given as to how formal arrangements will work from 2025/26. (LOGIC MODEL)
Organise and run an online education symposium for any staff with an interest in differences of sex development based on requirements/ feedback. Speakers to be organised between Steering Group members and should include patient/ family perspective.
Organise and run an online patient and family engagement event based on requirements/ feedback. Speakers to be organised between Steering Group members and should include patient/ family perspective.
Once surgical coding data is made available via Public Health Scotland, scoping to get underway around auditing the data to drive quality improvement and to address any errors in coding. This is expected to take 3 years.
Continue with psychology project to identify gaps in service provision. This will be done through the capture of real time data on patients that have either attended a specialist DSD psychology appointment or that have engaged with a clinician and *would have* benefitted from a referral, whether or not the option was available. 2 questionnaires are currently live on Microsoft Forms and are open for the 2024/25 reporting period. It is expected that the data will help to provide further evidence around the lack of equal access to specialist DSD psychology support. Scoping took place in 2023/24 and reporting will be done in 2025/26.
Using the new growth hormone nursing resource created via the SPEG Nurses' Group, develop further resources in a similar format that focus more on differences of sex development. Content should include guidance, sign off sheets, learning resources and other useful information.

Finance

The network spent £495.80 on catering for the patient and family day. The venue was free to hire.

No costs have been allocated the SDSD for the joint meeting between SPEG and SDSD as of yet. However, the event cost £2159.35 in total, including expenses for speakers.

Risks and issues

The main risks that stakeholders have raised concerns about are around the proposed formal arrangement between SDSD and SPEG coming together. There is a risk that SDSD loses its identity and that it gets swallowed up by the larger network. There is a risk that any cuts to resources as a result of the move will have a negative impact on the network being able to deliver its objectives.

There is a risk that the prolonged gap in clinical leadership will have a negative impact on the network being able to deliver its objectives and engagement may fall off. Dr Miles has been providing some clinical leadership on a voluntary basis, however this is not sustainable and several members of the Steering Group have voiced their concerns around this.

Ther is a risk that the impact of the points highlighted above lead to reputational damage for both NSD and the network itself. There is also a risk that this will further impact morale within the network, which could lead to disengagement.

Unless the concerns raised by the network members are addressed in a timely fashion, there is a risk that the future of the network could be at stake.

Appendix 1 – Network Survey: Summary of Responses

Strengths	Areas for Improvement
• Shared knowledge, experience and collaboration. • Scotland wide. • Shared protocols, ensuring equitable service and access to information. • Providing education and guidelines to the wider paediatric/ gynae/ neonatal/ surgical workforce. • Providing a voice for patients to ensure that needs are addressed (e.g. psychology) • Education. • Opportunity to attend patient specific condition events. • Best practice. • Reliable source of information and access point. • Education day for health professionals. • Up to date guidelines. • Good website.	• Improved use of database. • Psychology input for Scotland as a whole. • Formally appointing a chair to ensure continuation of network services. • Developing a list of stakeholders to ensure that information and education reaches a wider audience. • Remaining independent of SPEG.
Suggested Future Priorities (3-5 years)	**Network Challenges/Threats**
• Assessing access to psychology for all DSD patients in Scotland. • Ensuring best quality care for patients with DSD. • Continuing to support clinical practice and excellence. • Recruiting more members. • Clinically relevant data outputs in a meaningful timeframe.	• Merging with SPEG. • Crisis in funding resulting in withdrawal of support. • Changing NSS/NSD staff support. • Slow data protection processes. • Budget freeze • Peer to peer support cannot be achieved with just online meetings. • No official Clinical Lead • No planned job time.