

Scottish Differences of Sex Development (SDSD)

Annual Report 2022/23

Lead Clinician: Ruth McGowan
Programme Manager: Jamie Nimmo
Programme Support Officer: Stephanie Hales

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 the majority of its objectives, many of which have follow up actions to be taken into the next business plan.

2. Current Position

The network achieved 14/15 (93%) of its 'Business as Usual' objectives and 9/10 (90%) of its 'Service Development Plan' objectives in 2022/23.

Under 'Business as Usual', the network had an outstanding objective to update its strategy documents. This had been delayed due to process updates and a wider exercise to standardise templates. All three strategy documents will be reviewed and updated in 2023/24.

Under the 'Service Development Plan', the network had an objective to audit the uptake of the neonatal pathway, however this has not been possible due to the lack of capacity and resource and will need to be reviewed at a later date.

The network has faced some challenges this year, particularly around the Public Benefit and Privacy Panel (PBPP) request for surgical coding data taking so long to submit. There is also the perpetual issue around a lack of psychological support for differences of sex development (DSD) patients. However, despite some disappointment, progress has been made on both fronts as outlined in the highlights below.

The SDSD network has otherwise had a really positive year in progressing the majority of its objectives.

3. Highlights

3.1 Effective Network Structure and Governance

Steering Group

SDSD delivered all of its planned Steering Group meetings in 2022/23 and does not currently have any fixed subgroups due to the relatively small size of the network, but rather utilises task focussed short-life working groups as required. The Steering Group has been particularly active in its collaborative approach to organising the

next Education Symposium arranged for May 2023, with several Steering Group members set to deliver presentations.

Strategies

The network has its three strategy documents in place (Education, Quality and Communications). However, as they are overdue for review, they will be picked up in the 2023/24 Business Plan. This particular objective remained incomplete in 2022/23 due to a wider ongoing project to standardise these documents across all clinical networks.

3.2 Service Development and Delivery

Psychology Position

Lack of clinical psychology provision has been identified as a major gap in the current Differences of Sex Development (DSD) services in Scotland. Scotland is currently failing to meet recommendations for the provision of psychological support for DSD patients. Access to a DSD Psychologist is also inequitable. With this in mind, the network put extensive work into the development of a position paper to cover key guidelines and standards for psychological care in this area, as well as highlighting the current position.

The paper was submitted to the Senior Management Group within the National Services Division (NSD) and the network has subsequently been tasked with providing a further breakdown of data. A project has therefore been included in the 2023/24 business plan 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. The recommendation is that this 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.

Nurse Resources

It was highlighted that although there is access to a number of key resources for trainee Nurses on the SDSD website, the web page in question is unwieldy and difficult to navigate. A wider review of clinical network governance processes meant website activity was put on hold for some time. In the meantime, work has been done to outline a new layout for this section. This will include new subheadings, graphics and intuitive sections for ease of access.

SDSD have also begun working with the Scottish Paediatric Endocrine Group (SPEG) to incorporate some DSD information into a new specialist guidance document they have been developing for Nurses working across these specialist areas.

3.3 Stakeholder Communication and Engagement

Newsletters

The network continued to produce and circulate its quarterly newsletter 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 spring edition attracted 47 views, with 60% completing it and an average of 2 minutes spent reading. This was up from the previous (winter) edition, which attracted 25 views, with 73% completing it.



Image 1: Example of Newsletter

3.4 Education

Annual Symposium

The network was due to hold its Annual Education Symposium in March 2023. However, due to a number of challenges around availability of key stakeholders and the commitment to advertise such an event in plenty of time, a decision was taken to push this back to May 2023. This has meant it will fall into the next reporting year. All the preparatory work has been done. The focus of the event will be 'An Introduction to DSD: A Multi-disciplinary Approach'. This will provide learners with a broad overview of all of the key areas involved in the care of DSD patients. Steering Group members will be providing the majority of the talks, which include: terminology, surgery, genetics, endocrinology, psychology, gynaecology, biochemistry and radiology. At the time of writing, there are already over 100 people registered to attend.

The SDSD network has been collaborating with the SPEG network on education, with a joint event planned for January 2024 with a focus on Congenital Adrenal Hyperplasia (CAH). Steering Group member, Harriet Miles also presented a talk on DSD at SPEG's September 2022 Clinical and Academic Meeting.

3.5 Audit and Continuous Improvement

PowerApps

In recent months, the network has explored the option of a joint business case with the SPEG clinical network to develop a new database on PowerApps. This new platform allows networks to have more influence over what data points are included, whilst presenting them in a more intuitive order than the current Clinical Audit System (CAS) used by SPEG. It would also allow 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 in Scotland mainly used by NHS Greater Glasgow and Clyde. Some risks remain around capacity to input data as well as duplication of effort. It is anticipated that the business case will be submitted in early 2024.

Public Benefit and Privacy Panel (PBPP)

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. The SDSD Lead Clinician and Steering Group were unaware of the reasons for the delay. An enquiry found that the delay was due to a breakdown of communication between the Programme Manager, PBPP committee and eDRIS team.

However, the application has now been submitted and the following objectives can progress once the data is received.

- 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

3.6 Value

Clinical Network Synergies

The SDSD clinical network has been engaging with the SPEG clinical network around shared data interests, nurse resources and education events. Communications have also been cross-posted on a more frequent basis.

Patient and Family Event

The network delivered a highly successful patient and family event on 'Hypospadias' in collaboration with the Office for Rare Conditions (ORC) in November 2022. The event took place at Quarriers in Glasgow. 16 adults and 10 children attended the event, with 24 and 20 registered to attend respectively. The programme included talks on genetic, surgical, hormone and psychology aspects and allowed plenty of time for questions and discussion. Children's entertainment was also provided in

separate rooms.



Image 2: Hypospadias Patient and Family Event Speakers

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

“It was great to have the opportunity to ask questions in an informal all setting and to chat to other parents and share experiences.”

“Opportunity to ask questions and meet with other parents to talk about their experiences.”

“Understanding more about the condition and connecting with other families.”

Genetic Testing Leaflets

Information for patients and professionals about genetic testing for DSD has been updated and is available on the website. Furthermore, a new genetic testing information leaflet aimed at patients and families with DSD has been developed this year.

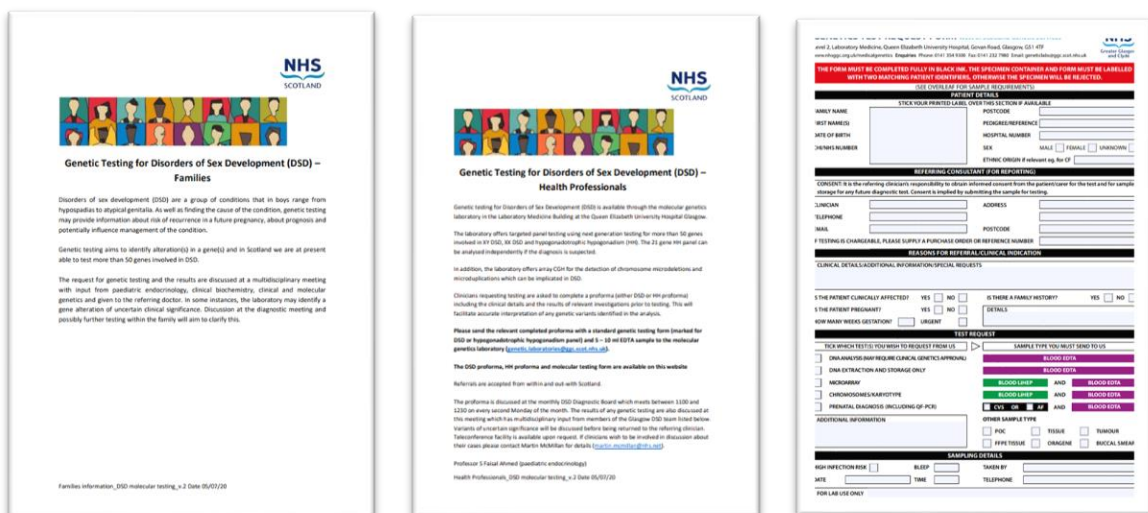


Image 3: Genetic Testing Leaflets and Form

Patient Survey

The network created a patient survey to seek feedback on DSD care in Scotland. A 'business card' with a QR code was created to share with patients to provide easier access to the online survey. Despite the team's best efforts, the response rate has remained low.



Image 4: SDDS Patient Feedback Business Card

The responses are included below.

Question	Average Rating
How well did you understand your child's/ your consultation with professionals and the information they provided?	4.4/5
To what extent did the professionals understand and deal with your concerns?	4.6/5
Were you satisfied with the plan for your child's/ your care at the end of the consultation?	5/5
Do you have someone you can contact for further information?	5/5 "yes"

Table 1: Patient Survey Responses

Comments
"Have nothing but praise for all the professionals involved in my son's care. In particular, Mr Flett who has been fantastic throughout."
"I feel all aspects of the care we have received at the RHC has been exceptional. There were unavoidable delays/communication issues during the pandemic but aside from that everything went very smoothly."

Sustainability

The SDDS network has moved all of its meetings online, with the exception of patient and family events. This will significantly 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 – 2023/24

SDDS's 2023/24 business plan objectives include:

- Organise and deliver an Education Symposium on an introduction to DSD
- Organise and deliver a patient and family event on hypospadias
- Submit a PowerApps business case
- Annual Scientific Meeting with SPEG on CAH
- Expand on nurse guidance resource with SPEG
- Review of website content and layout
- Update all strategy documents
- Follow up on surgical data outcome objectives once received
- Carry out a QI project around psychology support data

Finance

The network spent £1953.25 on the Hypospadias Patient and Family Event, as well as £200 on a Plain English patient information leaflet review, totalling a spend of £2153.25. This left the network with an underspend of £2846.75.

Risks and issues

There is a risk that survey responses remain low when the network seeks feedback from staff or patients. SDSD will seek to expand on its communication channels and widen its distribution list to include more general staff as well as those working in primary care.

There is a risk in submitting the PowerApps business case that there will not be capacity for staff to input the data once the system is in place. This will have to be scoped properly, given the cost and development time involved.

There remains a risk to patients around the lack of psychology support. The network will carry out a data collection project to provide further evidence of the desperate need for more provision, alongside the imminent publication of an NHS England paper.

Appendix 1 – Patient and Family Event Programme



The Scottish Differences in Sex Development (SDSD) Network and the Office for Rare Conditions Family Day

Saturday 19th November 2023 10.00am – 14.00pm

William Quarrier Conference Centre, 20 St. Kenneth Drive, Glasgow,
G51 4QD

- 10:00 Introduction and Welcome**
Dr Ruth McGowan, Consultant in Clinical Genetics, SDSD Lead Clinician
- Chair**
Professor Faisal Ahmed, Professor in Child Health
- 10:10 What is Hypospadias, surgical aspects and long-term outlook (10-minute presentation and short Q & A session)**
Mr Stuart O'Toole, Consultant Paediatric Surgeon and Urologist
- 10:40 Hormone aspects of Hypospadias (10-minute presentation and short Q & A session)**
Dr Angela Lucas-Herald, Clinical Lecturer
- 11:00 Coffee break**
- 11:20 Genetic aspects of Hypospadias and SDSD network (10 minute presentation and short Q & A session)**
Dr Ruth McGowan, Consultant in Clinical Genetics, SDSD Lead Clinician
- 11:40 Supporting boys with Hypospadias and their families (10-minute presentation and short Q & A session)**
Dr Emily Fraser, Clinical Psychologist
- 12:00 Questions and answers**
- 12:30 Lunch**
- 13:00 Round table discussion**
- 13:50 Close**
Professor Faisal Ahmed

Children's entertainment will be provided throughout the day including sessions from Jo Jingles and Magic Mark!

