

Scottish Differences of Sex Development (SDSD)

Annual Report 2025/26

This document has been prepared by the National Services Directorate (NSD) of Public Services Delivery Scotland (PSD Scotland) on behalf of the Scottish Differences of Sex Development (SDSD) network. Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. SDSD is a collaboration of stakeholders involved in the care of children and adults born with a difference in sex development or anomaly of the genitalia, who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

The network is supported by a dedicated programme team within Public Services Delivery Scotland (PSDS), consisting of:

Programme Manager: Jamie Nimmo

Assistant Programme Manager: 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.

2. Current Position

Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on a number of core priorities.

Looking ahead, and consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025), and recognising that Chief Executive Letter (CEL) 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks, SDSD will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives.

The priorities for SDSD in 2025/26 were:

- 1) To deliver an Annual Education Symposium on the topic of Turner Syndrome
- 2) To review all patient information leaflets and transfer them to a new standardised template.

3. Highlights

Steering Group

SDSD utilises task-focussed short-life working groups as required to progress specific pieces of work. The Steering Group has remained active throughout the year and continues to support the delivery of the network's priorities.

The network recognises the positive contribution that Dr Harriet Miles (Consultant Paediatric Endocrinologist, NHS Lothian) continued to make throughout 2025/26, including chairing Steering Group meetings and ensuring the network delivered on its priorities.

SDSD Resources

All professional resources remain up to date on the SDSD website, with useful links to external resources included in the 'healthcare professionals' section.

A key focus of 2025/26 was to get the SDSD patient resources back up to date and on a standard template. DSD conditions are often complex, sensitive and lifelong. By

providing patient information, the network is helping to support patients and their families to understand and manage their condition, whilst being able to make informed decisions.

A total of ten resources were updated, transferred to new templates and reviewed by the group. These included a mix of patient information leaflets, information sheets and a glossary of terms. These have all been formally approved by the network and will be published on the website after going through the appropriate NSD governance channels. The complete list is included below.

- Information sheet – genetic testing for families
- Patient information leaflet - genetic testing for families
- Patient information leaflet – congenital adrenal hyperplasia
- Patient information leaflet – genetic testing
- Glossary of terms
- Patient information leaflet – hypospadias for adolescents
- Patient information leaflet - hypospadias for parents
- Patient information leaflet - Mayer-Rokitansky-Küster-Hauser syndrome
- Patient information leaflet – undescended testes
- Patient information leaflet – vaginal dilation

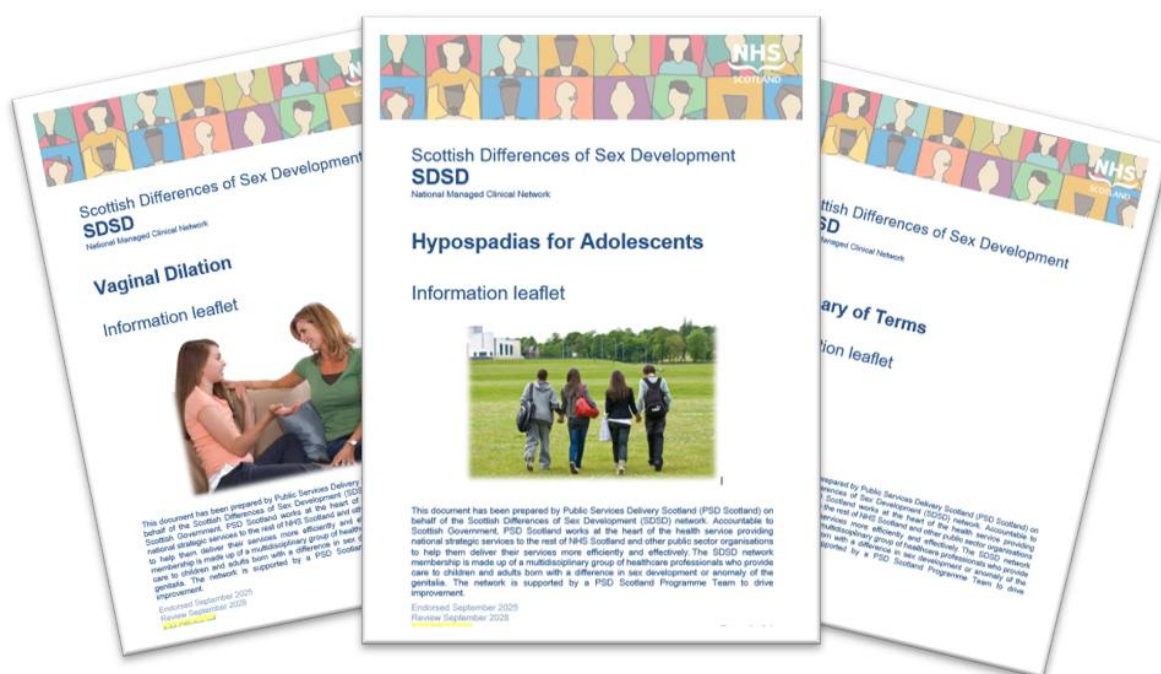


Image 1: Examples of SDSD patient information resources

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 December 2025 to ensure the website remained up to date.

Clinical Directory

The SDSD clinical directory remains up to date, after being introduced in early 2025. This document includes individual sections for each health board, containing 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. Individuals given the option to opt in or out of particular communications.

Annual Education Symposium

SDSD delivered its Annual Education Symposium on Friday 23 May 2025 via Microsoft Teams, with the recording later shared on the SDSD website. The event was centred around Turner Syndrome (TS) and included an introduction to TS as well as talks on fertility preservation, resources, a holistic approach to care, aortopathy and a patient perspective.

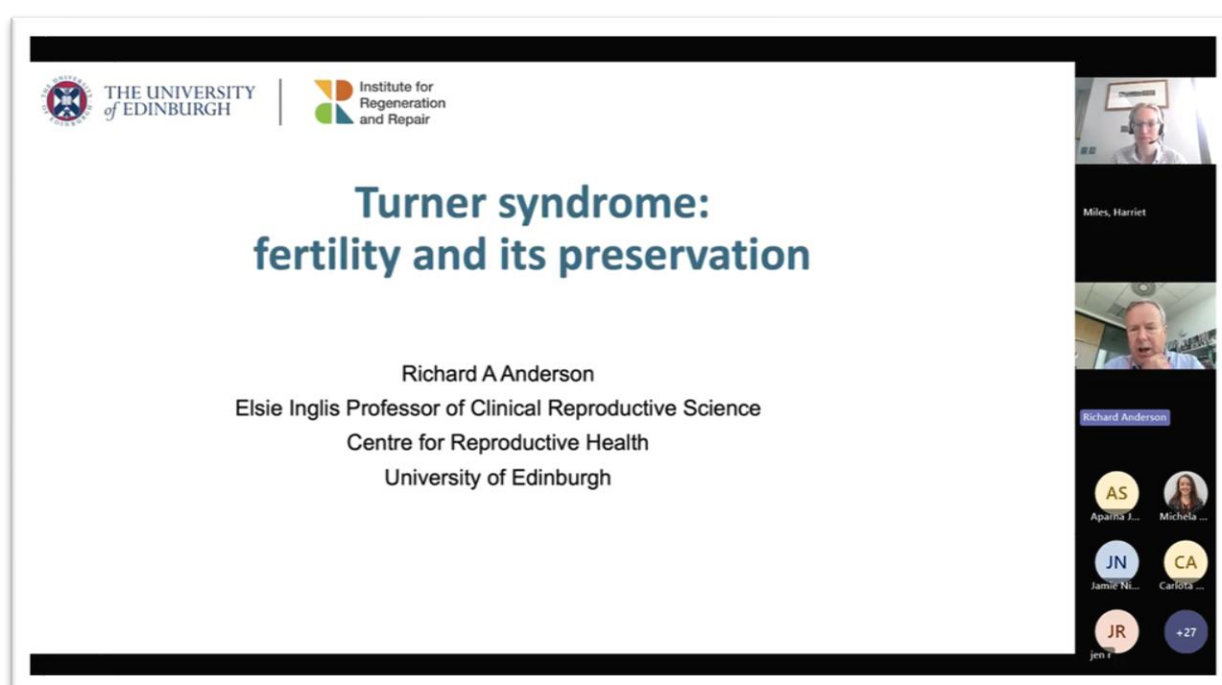


Image 2: Screenshot of one of the talks from the 2025 SDSD Annual Education Symposium

34 delegates attended the event on the day. Each of the five talks were rated as “excellent” within the feedback responses.

When asked about the extent to which learning from the event would change the individual’s practice, 50% of the respondents selected, *“effective - I plan to modify my practice in a minor way, or my present practice is reinforced”* and 50% selected, *“Very effective - I plan to modify my practice in a major way, or I have clearer understanding of the basic principles achieved”*.

Some of the specific changes clinicians noted they would make going forward included:

- Cardiology reviews for mosaics
- Discussing the number of people in the room in advance during transition
- Reminder about the importance of risk modification in cardiovascular disease, starting in the paediatric clinic

Other key takeaways included:

- Importance of cardiology
- Importance of thinking in advance about who might be in the room during transition
- More clarity for having initial discussion about fertility options for girls with TS
- Multidisciplinary teamwork is essential for turner patients
- More to do in transition

Some other qualitative feedback included:

- “Excellent presentations, thank you.”
- “I thought they were all excellent and it was very informative.”
- “Overview of cardiovascular risks was excellent.”

Audit and Continuous Improvement

Lack of clinical psychology provision for DSD patients has remained a priority for the network, however, capturing more data around this was paused due to capacity issues with clinical stakeholders, particularly from psychology colleagues.

A surgical coding audit has also been put on hold due to a lack of clinical stakeholder capacity within the network. The clinicians that were heavily involved in steering this work have since moved on from the network.

Sustainability

The SDSD network has continued to run all its meetings online, which has cut down on costs as well as reducing the network’s carbon footprint. One of the other main benefits is that is the ability to support wider participation from professional across Scotland, who may otherwise face challenges attending in person.

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

Looking forward – 2026/27

The network will continue with its ‘business as usual’ activity in 2026/27, including:

- Reviewing professional resources and ensuring they are fit for purpose and meet governance requirements
- Maintain patient information leaflets
- Produce and publish bi-annual newsletters
- Maintain the SDSD website and all its contents.

The network will also undertake a strategic needs assessment (SNA) to prioritise future planning. The SNA will assess SDSD’s impact and how it benefits service users, and will include looking at the patient pathway, a review of available data, a look at workforce requirements and engagement with all stakeholders.

Other priorities will include:

- Delivering an Annual Education Symposium
- Delivering a patient and family event
- Reviewing options to take forward recommendations to improve DSD specialist psychology provision.

Finance

The Network is funded through Public Services Delivery Scotland and operated within its approved budget during 2025/26.

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Contact email address: nss.sdsd@nhs.scot