

Scottish Differences of Sex Development (SDSD) Network

ANNUAL REPORT 2020/21

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1. Executive Summary

The global COVID-19 pandemic was a challenge that the Scottish Differences of Sex Development (SDSD) Network, along with the other national managed clinical and diagnostic networks, had to respond to during 2020/21. The availability of some SDSD network members and stakeholders to be involved in network activity was reduced during the first wave of the pandemic in the spring/summer of 2020, and from April to June 2020 the SDSD Programme Manager was deployed for 80% of their time to the Scottish Government to provide analytical support to the government's COVID-19 response.

SDSD responded to the challenges of the pandemic by transforming its ways of communicating, engaging, educating and daily operating. Furthermore, the SDSD Lead Clinician had no restrictions to their lead clinician session during 2020/21 and the network was successful in progressing a number of tasks and workstreams. Highlights are below, including the impact of work progress on access to and quality of specialist care. Full details of 2020/21 workplan achievement are in [Appendix 1](#).

2. Highlights

2.1. Effective Structure and Governance

SDSD maintained a full schedule of Steering Group meetings and updated the Strategic 3-year Workplan and the Education and Communication & Engagement Strategies.

Impact: Maintaining an effective governance and meetings structure empowered SDSD to make progress on its workplan objectives, which are designed to improve the accessibility and quality of care for patients with a difference of sex development (DSD).

2.2. Service Development and Delivery

SDSD published the updated Neonatal care pathway and linked it to the Bilateral Impalpable Testes care pathway.

Impact: The availability of the pathways to DSD clinicians will facilitate effective clinical decision making which will support equitable, evidence-based, high quality care for DSD patients. Both pathways are continuously audited through the Scottish Audit of Atypical Genitalia (SAAG) by monitoring Timing of sex assignment, Diagnosis, Investigations, Appropriate HCP involvement and provision of information to families.

The network produced a Clinical Psychology position paper with a view to addressing the insufficiency of clinical psychology provision to DSD patients in Scotland.

Impact: SDSD anticipates that if the paper's recommendations of further investment in DSD psychology services with at least 0.1WTE for each of the DSD specialist centres were implemented, it would significantly improve the provision of an essential service to meet the very specific needs of DSD patients.

2.3. Stakeholder Communication and Engagement

The network continued to provide high-quality information and resources through its website, and published regular newsletters with information and news for SDSD stakeholder groups. Website analytics show a 67% increase in SDSD website page views compared with 2019/20, and a 110% increase in sessions (see [Appendix 3](#)). The increase in website traffic may be a result of people turning to online media and resources on a large scale during the pandemic lockdowns.

Impact: Health care professionals, patients and their families were signposted to reliable, up-to-date, evidence-based information and resources. The newsletters kept stakeholders abreast of SDSD work and of news and developments in the wider realm of DSD care.

The network developed a Patient Experience Survey system to capture patients/parents/carers' views on their consultations, their care plan and the information they receive.

Impact: The data on patients' experience of care will be used to inform improvements in patient care and in communication with patients and families.

SDSD collaborated with the SPEG network in the area of Communication & Engagement by cross-posting news and information.

Impact: This collaboration means that more care professionals, patients, families and carers can benefit from the information, guidance and resources produced by both networks and from the events that they hold.

2.4. Education

SDSD held a successful online Education Symposium in March 2021 with a diverse range of speakers and topics.

Impact: DSD clinicians had an opportunity to improve their knowledge and skills base in DSD care, which will deliver direct benefits to their patients. The event was attended by 105 people from 11 NHS Scotland Health Board areas, NHS England, Third Sector organisations, and hospitals in Germany, Italy and Hong Kong. The online medium facilitated a considerably larger attendance than the face-to-face venues used hitherto for the Symposium. Four guest speakers were welcomed who presented on themes related to Fetal DSD. 91% of attendees who provided feedback rated the event as very good or excellent overall.

Further details of feedback on the Education Symposium are in [Appendix 4](#).

2.5. Audit and Continuous Quality Improvement

The SDSD application to the Public Benefit Privacy Panel (PBPP) for access to the Community Health Index (CHI) numbers of genital surgery patients to support the proposed surgical data audit did not progress during 2020/21 because the panel had to prioritise COVID-related applications.

Impact: Once access to the CHI numbers is granted, the rectification of surgical coding anomalies will produce accurate clinical data which can be used to evidence that the recommended DSD pathways of care are being followed.

3. Risks and Issues

The impact of the COVID-19 pandemic and lockdown on SDSD network business in 2020/21 was not as severe as originally anticipated. Although the availability of clinician stakeholders for network activity was reduced during the first wave of the pandemic and the Programme Manager was largely absent for the first quarter of the year, a considerable amount of work was successfully progressed. However, the pandemic and the accompanying restrictions on our working lives are likely to remain a significant risk factor over next year or so. This is because:

- Care service delivery is unlikely to return fully to its pre-pandemic format, and as the NHS remobilises and we move towards the "new normal", it is likely to become a blend of face-to-face and online or telephone consultations. At this point, no-one can be sure exactly what that blend will look like or when it will stabilise in its new format.
- Effective planning for networks is compromised by the difficulty of predicting the pace of NHS remobilisation and when clinician availability for network activity will be fully restored.

The pandemic has also created a risk in relation to face-to-face network engagement with patients and families. In December 2020, SDSD organised an online children's Christmas party for children with a DSD, their families and carers. The intention of the party was to provide a source of cheer and reinvigorate a sense of togetherness amongst the younger DSD community in Scotland at a time of severe restrictions on

physical get-togethers. Unfortunately, despite individual invitations being sent to families, and the event being promoted through the Steering Group, social media channels and the Scottish Paediatric Endocrine Group (SPEG) network, the party attracted no sign-ups and had to be cancelled. This disappointing lack of interest could be attributed to online fatigue caused by a succession of protracted pandemic lockdowns. The risk to the network is that this fatigue will endure despite lockdown easing, and SDSD needs to take account of that in its patient and family engagement planning.

4. Finance

The backfill Purchase Order (PO) was in place for the SDSD Lead Clinician's 1 Programmed Activity (PA) session per week for 2020/21.

The SDSD network contributed £1,000 towards the production of a leaflet and video by the dsdfamilies charity for families of boys with a DSD, following national commissioning governance rules. SDSD did not make any other use of its £5,000 budget in 2020/21 because practically all network business, events and meetings were conducted in an online virtual format.

5. Looking forward

SDSD will support NHS remobilisation while driving forward its own strategic work priorities in 2021/22. This could include adjusting care pathways, guidelines, education and training materials and other resources to reflect the "new normal" of blended virtual and face-to-face NHS care delivery.

SDSD work priorities for 2021/22 include:

- Reinstating patient and family-related events.
- Recruiting a new Lead Clinician whose tenure will start in June 2021.
- Pursuing improved Clinical Psychology provision for DSD patients in Scotland.
- Seeking to increase collaboration with the SPEG network.
- Implementing the Patient Care Experience survey system (including tackling the challenges of gaining consent from patients to be approached for feedback), and using the data to improve delivery of what matters most to patients.
- Continuing the SDSD Website Quality Improvement (QI) project.
- Delivering an effective and informative education event.
- Making a plan to develop training resources for nurses, midwives and other care professionals.
- Developing a data plan in collaboration with IMS and pursuing progress on the PBPP application.
- Auditing the uptake of and adherence to the Neonatal Pathway to gather evidence of clinical value.

Full details are in [Appendix 2](#) – Proposed Work Plan for 2021/22.

Appendix 1 – Detailed Description of Progress in 2020/21

RAG status key

RAG status	Description
RED (R)	The network is unlikely to achieve the objective/standard within the agreed timescale
AMBER (A)	There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made
GREEN (G)	The network is on track to achieve the objective/standard within the agreed timescale
BLUE (B)	The network has been successful in achieving the network objective/standard to plan

The Institute of Medicine's six dimensions of quality are central to NHS Scotland's approach to systems-based healthcare quality improvement, therefore objectives should be linked to these dimensions:

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.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31.03.2021	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-01	The network will organise 4 Steering Group and 2 Data group meetings in 2020 to ensure effective delivery of the 2020/21 work plan.	31/03/2021	Steering Group and sub-group members	Steering Group meetings took place as planned in 2020/21. Data group activity is restricted by the delay in the PBPP application.	Effective delivery of the SDSD network workplan to ensure continued progress.	A
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-02	Complete the SDSD Neonatal care pathway review and link the pathway to the Bilateral Impalpable Testes care pathway.	March 2022	Lead Clinician Steering Group Programme Manager	The SDSD Neonatal care pathway was reviewed, published and linked to the Bilateral Impalpable Testes care pathway.	The updated pathway will be available to clinicians to promote effective clinical decision making.	G
2020-03	SDSD will seek to address the insufficiency of clinical psychology provision in meeting the specific needs of DSD patients in Scotland.	March 2023	Dr Rebecca Crawford Lead Clinician Programme Manager	After a period of waiting for progress in NHS England's investigations in this area, SDSD went ahead with finalising its own Clinical Psychology position paper with recommendations for improving provision in Scotland.	All patients presenting with a DSD will have appropriate psychological support and engagement with specialist care according to confirmed needs and conditions.	G

2020-04	SDSD will continue to collaborate with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network on service development areas of mutual benefit (eg. care pathways, clinical guidelines).	Ongoing	Lead Clinician Steering Group Programme Manager	Because of COVID-19 capacity constraints, no service development-related collaboration took place.	Stakeholders in both networks will benefit from productive collaboration on service development areas which will involve the sharing of expertise and best practice.	R
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2020-05	By March 2021 review the Communication Strategy to meet the needs of all stakeholders.	31/03/2021	Steering Group	The Communication Strategy was reviewed and updated in the second half of 2020/21.	Stakeholders across Scotland will inform the annual work plan to ensure a personalised approach to care.	B
2020-06	During 2020/21 hold one or more patient & family events.	31/03/2021	Steering Group Lead Clinician PM/PSO	The COVID-19 restrictions meant that no face-to-face events could be held. The online party organised for December 2020 attracted no sign-ups.	The DSD community in Scotland will have opportunities for sharing experiences, networking and mutual support.	R
2020-07	By March 2021 develop a survey capturing patients/parents/carers' views on their multidisciplinary clinic visit.	31/03/2021	Steering Group Lead Clinician PM/PSO	A Patient Care Experience survey system was devised which depends on gaining explicit consent from patients to be approached for feedback.	Through shared decision-making, SDSD will deliver what matters most to patients.	B
2020-08	During 2020/21 SDSD will co-fund the development of a leaflet and video produced by dsdfamilies for families of boys with a DSD.	31/03/2021	Steering Group Lead Clinician	SDSD contributed £1,000 towards these dsdfamilies resources.	Children, young people and families can learn and understand more about DSD conditions and how to overcome the challenges they bring.	B

2020-09	SDSD will issue regular newsletters.	31/03/2021	Programme Manager	SDSD issued its summer newsletter in July 2020, and its winter newsletter in the new Sway format in January 2021.	Stakeholders will receive regular updates on SDSD work and DSD care news and developments.	B
2020-10	Continue to develop the SDSD website as an information and educational resource for clinical stakeholders, and as an information and signposting resource for patients and families.	31/03/2021	Steering Group Lead Clinician PM/PSO	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, will take place in 2021/22. The Website QI project was started in autumn 2020, led by the SDSD PSO, but little progress was made because of unavoidable limits on her capacity.	SDSD will provide useful and accessible information and resources for clinicians, patients and families through its website.	A
2020-11	Collaborate with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network through cross-links between websites and cross-posting regular communications.	Ongoing	Steering Group Lead Clinician PM/PSO	SDSD and SPEG cross-posted some news and information in 2020/21.	Stakeholders in both networks will benefit from shared news, information and resources.	B
2020-12	Continue to collaborate and liaise with the Office for Rare Conditions (ORC).	Ongoing	Steering Group Lead Clinician	The network attended the Office for Rare Conditions education day in 2020/21 to raise awareness of the network, and advertised their April 2021 Fertility event at which some SDSD SG members are speaking.	There will be a greater awareness of SDSD within statutory and non-statutory organisations, and amongst health care professionals and 3rd sector services.	B

2020-13	Continue to collaborate with the British Society of Paediatric Endocrinology and Diabetes (BSPED) DSD Special Interest Group (SIG) and the European Society for Paediatric Endocrinology (ESPE).	Ongoing	Lead Clinician	The SDSD lead clinician continued to work with the BSPED DSD Special Interest Group and the ESPE.	SDSD and its stakeholders will benefit from productive engagement with groups and societies at UK and international level which will promote the sharing of best practice and the exchange of research outcomes, information and other resources.	B
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-14	Deliver an annual national education symposium and link with stakeholders (eg. Office for Rare Conditions (ORC)) for regional teaching events.	31/03/2021	Steering Group Lead Clinician PM/PSO	SDSD delivered an effective and enjoyable education event in March 2021.	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	B
2020-15	Review and update the Education Strategy to support stakeholders' learning needs and address these in a range of formats, including regional teaching sessions.	31/03/2021	Steering Group/Lead Clinician PM/PSO	The SDSD Education Strategy was reviewed and updated in the second half of 2020/21.	The workforce is valued and has access to evidence-based specialist training and resources for improved health and care.	B

2020-16	By 2023 nurses and midwives (including neonatal nurses) who work with DSD will be able to access up-to-date and relevant training resources which make optimal use of communication systems, including the SDSA website.	March 2023	Steering Group Lead Clinician PM/PSO	SDSD did not develop a plan for producing online resources for midwives and neonatal nurses in 2020/21 as originally intended. The Steering Group will discuss and agree the way forward for this workstream in 2021/22.	Nurses and midwives can access up-to-date and relevant training resources which make optimal use of communication systems, including the SDSA website.	A
2020-17	By 2023 the SDSA network will have developed education and training resources for professionals other than nurses and midwives, in collaboration with a wide range of partners.	March 2023	Steering Group Lead Clinician PM/PSO	SDSD's plan to begin to scope what is currently available which can be used to provide remote and accessible education for professionals, including relevant learning from NHS Education for Scotland (NES), was not realised in 2020/21. The Steering Group will discuss and agree the way forward for this workstream in 2021/22.	Professionals working in DSD will have access to and opportunities to participate in relevant and up-to-date national education which will give them the knowledge, skills and confidence to provide effective care and support to patients and families.	A
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-18	By 2023 SDSA will have a robust data plan and a suite of useful quality measures and indicators.	March 2023	Data sub-group	Discussions took place between the network and IMS on the development of a data plan, which is somewhat hampered by the continued delay in the PBPP application. The use of SAAG to collect and report data on early years continued.	A robust data collection and reporting system that will support effective service delivery and pathways into care. The data reports and quality indicators accurately reflect the extent to which the network is: <ul style="list-style-type: none"> • doing what it is commissioned to do; • adhering to required quality criteria. 	A

				<p>Capturing and reporting cases discussed at DSD Diagnostic Meetings continued.</p> <p>Work on surgical coding anomalies rectification did not take place because of the continued delay in the PBPP application.</p>		
2020-19	Explore the potential for common data reporting with the Scottish Paediatric Endocrine Group (SPEG).	March 2022	<p>Steering Group/Lead Clinician</p> <p>PM/PSO</p> <p>Data analyst</p>	Discussions took place between the SDSD and SPEG Lead Clinicians on common data reporting, and the view was taken that there is little value in it at this time.	Stakeholders in both networks will benefit from data collection and reporting systems that reflect the quality levels of service delivery areas of mutual benefit.	G
2020-20	Review and update the network's Quality Strategy.	31/03/2021	<p>Steering Group</p> <p>Lead Clinician</p> <p>Programme Manager</p>	The SDSD Quality Strategy was not reviewed and updated in 2020/21 because of COVID-19 and PSO capacity constraints.	The Quality Strategy governs the development of effective and relevant measures for evidencing the quality of DSD care delivery in Scotland.	A
6. Value <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-21	Audit uptake of and adherence to the Neonatal Pathway to gather evidence of clinical value.	March 2022	<p>Steering Group/Lead Clinician</p> <p>PM/PSO</p>	Auditing uptake and adherence to the Neonatal Pathway is rolled forward to 2021/22.	Patients will benefit from centres working together to provide optimum care and manage risk better. The audit will highlight level of awareness and how consistently pathway is utilised across Scotland.	A

2020-22	<p>Reducing Carbon Footprint</p> <p>By 2023 SDSD will have added value by reducing its carbon foot print, the network will facilitate virtual on-line meetings and minimising the printing of papers such as agendas and meeting papers.</p>	Mar 2023	Steering Group	<p>During 2020/21 SDSD used MS Teams videoconferencing for all its meetings because of the COVID pandemic lockdown. This had the effect of:</p> <ul style="list-style-type: none"> • reducing the carbon footprint and saving travel costs and time as no travel to meetings was required. • saving printing costs as attendees viewed documents on screen. 	SDSD will have been able to demonstrate that it has worked with other agencies using a “Once for Scotland” approach. Thus the network will complement but not replicate established work on care being carried out by other key groups and agencies.
2020-23	<p>Activity and Process efficiency</p> <p>By 2023 SDSD will have maximised the efficiency of its activities and processes.</p>		Lead Clinician	SDSD constantly seeks to maximise the efficiency of its activities and processes on an ongoing basis through effective planning, communication and evaluation.	
2020-24	<p>Other Strategic National Programmes</p> <p>By 2023 SDSD will be contributing actively and productively to other strategic national programmes which it deems to be relevant.</p>		Programme Manager	During 2020/21 SDSD continued to contribute to other strategic national and international programmes as detailed elsewhere in this workplan.	
2020-25	<p>Once for Scotland</p> <p>By 2023 SDSD will have minimised unwarranted variation in practice by taking a Once for Scotland approach.</p>		Programme Support Officer	During 2020/21 SDSD sought to minimise unwarranted variation in practice in line with the “Once For Scotland” approach, and will continue to do so.	

G

Appendix 2 – Proposed Work Plan for 2021/22

a) SDSD Business as Usual (BaU) Action Plan		
Core Principle	Programme of Work	Owner
Effective Network Structure and Governance	The network will organise 4 Steering Group and 2 Data group meetings in 2021 to ensure effective delivery of the 2021/22 work plan.	Core team
Service Development and Delivery	SDSD will continue to collaborate with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network on service development areas of mutual benefit (eg. care pathways, clinical guidelines).	LC/Core team
Stakeholder Communication and Engagement	SDSD will issue two newsletters during 2021/22.	Core team
	SDSD will continue to develop the SDSD website as an information and educational resource for clinical stakeholders, and as an information and signposting resource for patients and families.	Core team
	SDSD will collaborate with colleagues in the SPEG Network through cross-links between websites and cross-posting regular communications.	Core team
	SDSD will continue to collaborate and liaise with the Office for Rare Conditions (ORC) and attend the ORC education day in 2021/22 to raise awareness of the network.	LC/SG
	SDSD will continue to collaborate with the British Society of Paediatric Endocrinology and Diabetes (BSPED) DSD Special Interest Group (SIG) and the European Society for Paediatric Endocrinology (ESPE).	LC/SG
Education	SDSD will deliver an annual national education symposium and link with stakeholders (eg. Office for Rare Conditions (ORC)) for regional teaching events. The symposium preparation will take account of delegate feedback from previous symposia, and this event will be evaluated through delegate feedback to inform future symposia.	LC/Core team/SG

Core Principle	Programme of Work	Owner
Audit and Continuous Quality Improvement	The use of SAAG data on early years and DSD Diagnostic Meetings data for monitoring access to and quality of care will continue.	LC/Core team/SG
	SDSD and SPEG will continue to explore the potential for common data reporting.	LC/Core team/SG
	The SDSD Quality Strategy will be reviewed and updated in 2021/22.	LC/Core team/SG
Value	During 2021/22 SDSD will continue to use MS Teams videoconferencing for meetings in order to reduce the carbon footprint, save travel costs and time, and to save printing costs.	ALL
	SDSD will continue to seek to maximise the efficiency of its activities and processes on an ongoing basis through effective planning, communication and evaluation.	ALL
	During 2021/22 SDSD will continue to contribute to other strategic national and international programmes as detailed elsewhere in this workplan.	ALL
	During 2020/21 SDSD will continue to seek to minimise unwarranted variation in practice in line with the “Once For Scotland” approach.	ALL

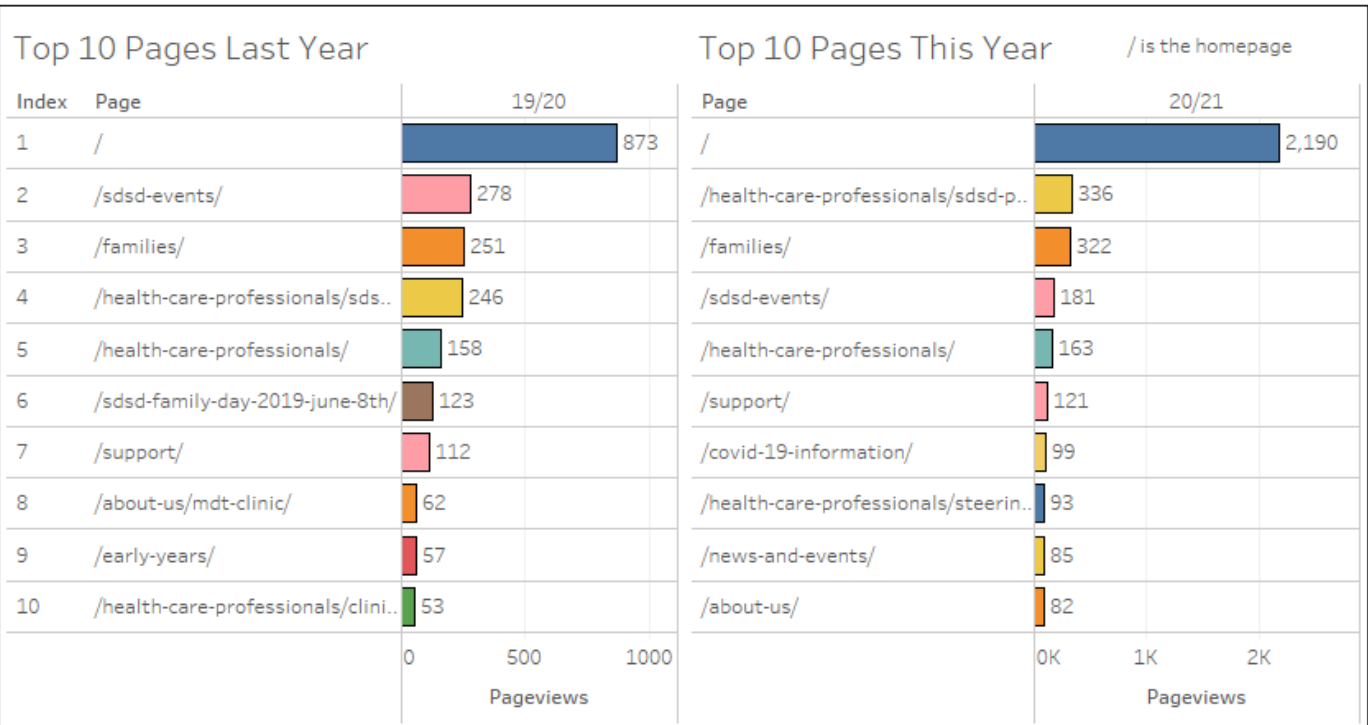
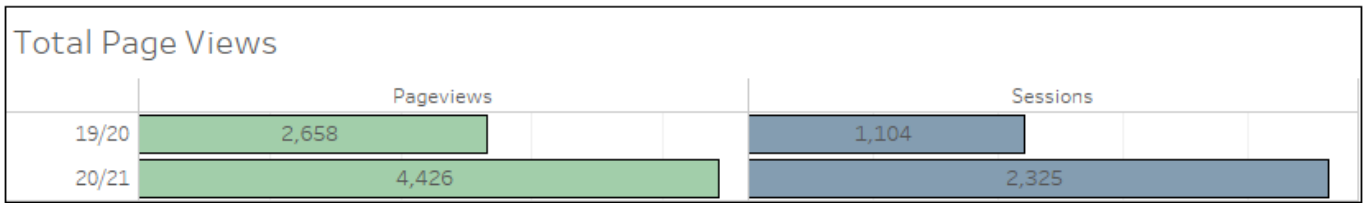
b) SDSD Special Programmes Action Plan

Core Principle	Description of Work	BOSCARD (Yes / No)	Owner	Start Date	End date
Effective Network Structure and Governance	SDSD will recruit a new Lead Clinician whose tenure will start in June 2021.	No	Core team	01/04/2021	31/05/2021
Service Development and Delivery	SDSD will seek to address the insufficiency of clinical psychology provision in meeting the specific needs of DSD patients in Scotland. In 2021/22 SDSD will submit the Clinical Psychology position paper with recommendations for improving provision in Scotland to NSS planners. Improvements in provision will be measured by monitoring the relevant clinical psychology staff WTE levels and reported on in relevant mid-year and annual reports. The network will also monitor the progress of NHS England's investigations in this area.	No	LC/PM/SG	01/04/2021	31/03/2023
Stakeholder Communication and Engagement	During 2021/22 SDSD will seek to reinstate patient & family events, and will consider both virtual and face-to-face formats	No	LC/Core team/SG	01/04/2021	31/03/2022
	By March 2022 SDSD will implement the Patient Care Experience survey capturing patients/parents/carers' views on their consultations, and address the challenges of gaining consent from patients to be approached for feedback.	Yes	LC/Core team	01/04/2021	31/03/2022
	SDSD will pursue the Website QI project, part of which will be to carry out 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.	Yes	LC/Core team/SG	01/04/2021	31/03/2022
	SDSD will obtain and assess stakeholders' views of the effectiveness of the collaborative cross-posting of news and information by SDSD and SPEG.	No	LC/Core team/SG	01/04/2021	31/03/2022

Core Principle	Description of Work	BOSCARD (Yes / No)	Owner	Start Date	End date
Education	By 2023 nurses and midwives (including neonatal nurses) who work with DSD will be able to access up-to-date and relevant training resources which make optimal use of communication systems, including the SDSA website. The SG will discuss and agree the way forward for this workstream in 2021/22.	Yes	LC/Core team/SG	01/04/2021	31/03/2023
	By 2023 the SDSA network will have developed education and training resources for professionals other than nurses and midwives, in collaboration with a wide range of partners. The SG will discuss and agree the way forward for this workstream in 2021/22.	Yes	LC/Core team/SG	01/04/2021	31/03/2023
Audit and Continuous Quality Improvement	By 2023 SDSA will have a robust data plan and a suite of useful quality measures and indicators. In 2020/21 the data group will pursue the formulation of a data plan and the PBPP application. SDSA will start work on surgical coding anomalies rectification as soon as the PBPP application is approved and the patient CHI numbers are acquired.	No	Data group	01/04/2021	31/03/2022
Value	SDSA will audit the uptake of and adherence to the Neonatal Pathway in 2021/22	No	LC/Core team/SG	01/04/2021	31/03/2022

Appendix 3 – SDSL Website Analytics 2020/21

Full year report



Appendix 4 – SDSD Education Symposium Feedback, 5th March 2021

The Education Symposium theme this year was Fetal and Neonatal DSD, and the programme was as follows:

Perspectives on DSD as a patient, parent and healthcare professional Presentation recording available HERE .	Dr Jo Williams, <i>dsdfamilies</i>
Lessons Learnt from Routine Data Collection in DSD Presentation recording available HERE . Presentation slides available HERE , to accompany the recording.	Professor Faisal Ahmed, Consultant Paediatric Endocrinologist, <i>NHS Greater Glasgow & Clyde</i>
SDSD Neonatal pathways Presentation recording available HERE .	Dr Martina Rodie, Consultant Neonatologist, <i>NHS Greater Glasgow & Clyde</i>
Prenatal DSD conditions (eg. Turner Syndrome, Dysplasia)	Dr Tessa Homfray, Consultant in Medical Genetics, <i>St George's University Hospitals</i>
Dexamethasone as a prenatal treatment for Congenital Adrenal Hyperplasia (CAH)	Professor Nicole Reisch, <i>University of Munich, Germany</i>

Feedback was collected via the Forms application on Microsoft Teams. Written feedback was also collected via email after the event.

A total of **105 people** attended the 2021 SDSD Education Day, with **23** providing feedback. All those who provided feedback said that there was **no bias or conflict of interest** in the event content.

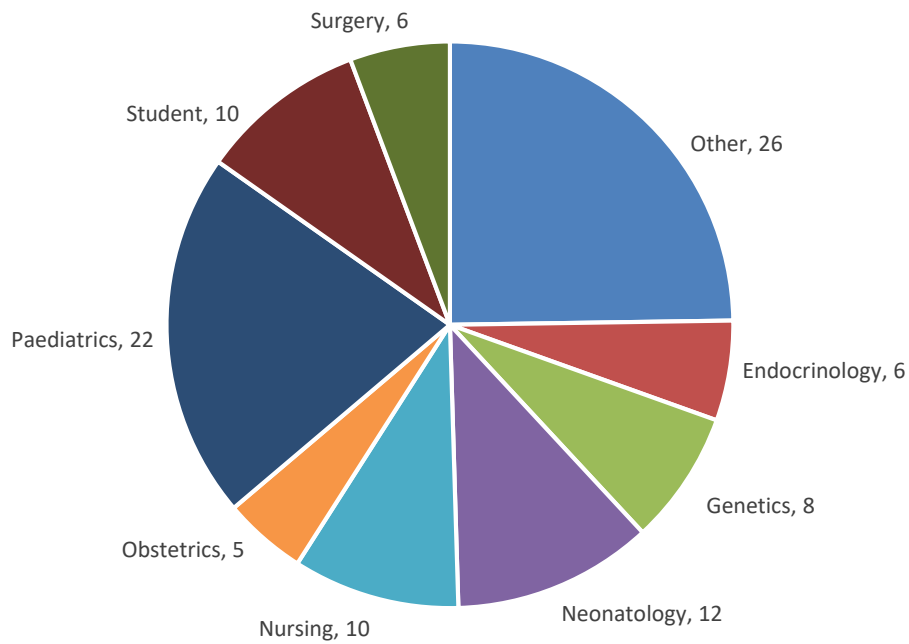
The event scored **4.6 out of 5** overall.

Over **50 new people** requested to be added to the SDSD distribution list to receive information about the network's activities and future events.

Of those who gave feedback:

- **91%** rated the event as **very good or excellent** overall.
- **90%** stated that learning from the event would result in **moderate to significant change** in their practice.
- **91%** rated the learning objective of increasing their knowledge of the care of DSD patients as **mostly or fully met**.
- **100%** rated the learning objective of increasing their awareness of the SDSD network as **mostly or fully met**.
- **95%** rated the quality of delivery for all speakers as **very good or excellent**.
- **95%** rated the quality of session content for all speakers as **very good or excellent**.

105 Attendees, by Professional Area



Frequently used words within the collated feedback

