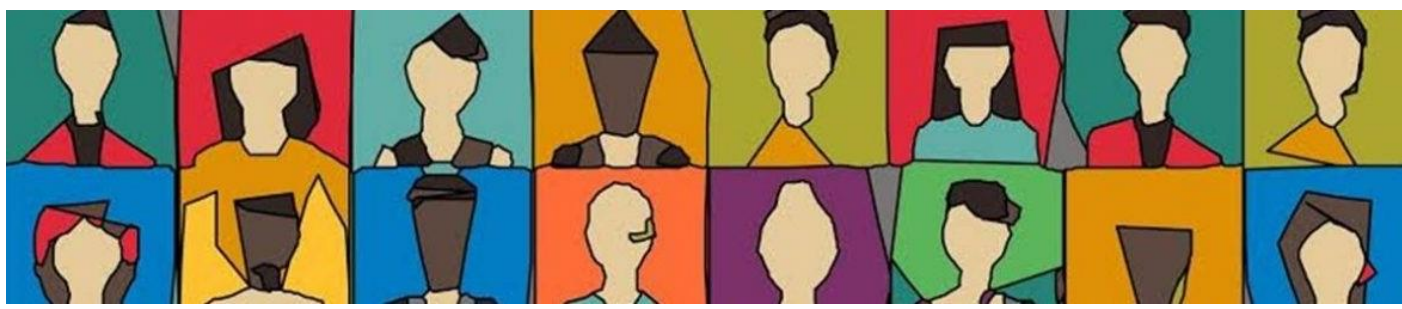


Scottish Differences of Sex Development Managed Clinical Network (SDSD) ANNUAL REPORT 2021/22



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Contents

1. Executive Summary.....	2
2. Lead Clinician reflection.....	2
3. Highlights.....	2
3.1. Effective Structure and Governance	2
3.2. Service Development and Delivery	2
3.3. Stakeholder Communication and Engagement.....	2
3.4. Education	3
3.5. Audit and Continuous Quality Improvement.....	3
4. Issues and risks.....	3
5. Finance.....	3
6. Looking forward.....	3
Appendix 1 – Detailed Description of Progress in 2021/22.....	5
Appendix 2 – Proposed Work Plan for 2022/23	11

1. Executive Summary

The Scottish Differences of Sex Development Network (SDSD), along with the other national managed clinical and diagnostic networks, continued to respond to the challenges of the global COVID-19 pandemic during 2021/22. The availability of some SDSD network members and stakeholders to be involved in network activity was reduced during the autumn and winter of 2021/22 because of the pressures of shoring up frontline services amidst the ongoing COVID pandemic.

Despite these challenges, the network was successful in progressing a number of tasks and workstreams. The network achieved 10 out of its 12 Business As Usual objectives, and 6 out of its 11 Development Projects. The work to strengthen the Clinical Psychology position paper is particularly noteworthy. Highlights are below, and full details of 2021/22 workplan achievement are in [Appendix 1](#).

2. Lead Clinician reflection

Despite the challenges resulting from clinical pressures imposed by the COVID pandemic, there has been a steady improvement in the restoration of out-patient services for individuals with DSD, from 2021 to 2022. There is also recognition that remote consultation by telephone or attend anywhere may be a preferable as well as clinically appropriate option for patients in certain circumstances, and these are likely to continue in the future.

In spite of the challenges, the SDSD Steering Group has continued to meet at quarterly intervals throughout the pandemic and the SDSD network has had a number of successes. These include: the complete update of patient as well as professional information resources available on the SDSD website, finalising the SDSD Clinical Psychology Position paper (in advance of the NHS England equivalent), and the highly successful annual SDSD symposium (March 2022) which had a Klinefelter syndrome focus, expert speakers from across the Scotland and a presentation from a patient representative and trustee of the Klinefelter Syndrome Association (KSA) who was the highlight of the event.

We have experienced disappointing news about lack of progress with our PBPP application relating to genital surgeries; however, we have a number of alternative strands to our SDSD dataplan and seek to progress these in 2022/2023. Furthermore, we plan to collaborate with the Office for Rare Conditions and the Scottish Paediatric Endocrinology Group (SPEG) on the delivery of patient-focused and educational events.

3. Highlights

3.1. Effective Structure and Governance

All planned meetings of the Steering Group and took place during 2021/22, and an active Service Agreement is in place for 2020 – 2023. The network acquired a new Lead Clinician, Dr Ruth McGowan of NHS Greater Glasgow & Clyde, in July 2021.

3.2. Service Development and Delivery

The SDSD Clinical Psychology position paper aimed at addressing the insufficiency of clinical psychology provision in meeting the specific needs of DSD patients in Scotland was significantly strengthened by the addition of NHS Board-specific indicative demand data for each of the main DSD conditions. The revised paper has been approved by the SDSD Steering Group and the next step is to submit it to NSS planners.

3.3. Stakeholder Communication and Engagement

Despite sustained efforts on the part of the SDSD Core Team and Lead Clinician during 2021/22, the SDSD Patient Care Experience survey capturing patients/parents/carers' views on the care and information they receive did not gain momentum and little data was recorded. A new approach has been devised using

printed cards handed to patients by clinicians at the end of consultations which will be deployed and promoted during 2022/23.

Under the SDSD Website Quality Improvement project, four patient/family leaflets were updated and placed on the SDSD website during 2021/22.

3.4. Education

SDSD held a successful online Education Symposium in March 2022 with a specific focus on Klinefelter Syndrome, which was attended by 76 people and attracted very positive feedback. The highlight of the symposium was a talk on “Living with Klinefelter Syndrome” by a trustee of the Klinefelter Syndrome Association (KSA) which was informative and moving. A full summary of delegate feedback is available on request.

3.5. Audit and Continuous Quality Improvement

Unfortunately 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 2021/22.

During 2021/22 SDSD started work on a data plan by creating a structured, comprehensive inventory of the disparate data sources that it uses.

4. Issues and risks

Issues:

- It is challenging for clinician stakeholders, including Steering Group members, to find the capacity to support network tasks and workstreams.
- Network members are frustrated by the lack of progress with the PBPP application for the surgical data audit.

Risks:

- If stakeholders don't step forward to support them, progress with network tasks and workstreams may be compromised or even stalled. **Mitigating action:** the SDSD Core Team will emphasise the importance of sustained support for and commitment to network activity. The team will also investigate whether members whose capacity is constrained should stand down and be replaced.
- Frustration with the PBPP application may undermine the credibility of the network. **Mitigating action:** SDSD stakeholders will be reminded that during the COVID pandemic, the PBPP committee have only been able to consider COVID-related applications. Further discussions will take place within NSD on how to take this forward and the network will also explore alternative ways of carrying out the surgical data audit.

5. Finance

A Purchase Order (PO) for one Programmed Activity (PA) session per week for Dr McGowan for 2022/23 is in place.

SDSD spent £380.20 on cards and patient information leaflets in 2021/22.

6. Looking forward

SDSD will continue to support NHS remobilisation while driving forward its own strategic work priorities in 2022/23. 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. Along with this, the network will seek to strengthen synergies and collaboration with the Scottish Paediatric Endocrine

Network (SPEG) which will produce economies of scale, improved value for patients, families and clinicians and other efficiencies and benefits. This initiative will be done carefully and sensitively in order to preserve identity and branding of which each network is understandably protective.

SDSD work priorities for 2022/23 include:

- Following up the submission of the Clinical Psychology paper to NSS planners and monitoring the progress of NHS England's investigations in this area to see if their resource modelling approach could be adapted for use in Scotland.
- Seeking to reinstate patient & family events, considering both virtual and face-to-face formats.
- Developing an information sheet for patients about genetic testing to improve their understanding of the process and purpose of the testing, as well as a questionnaire for clinicians to determine how useful they find, and how well they understand, genetic reporting data.
- Continuing the Website QI project by conducting a stakeholder survey to obtain views on the usefulness of the website and how it can be improved to ensure that it is accessible and user-friendly, and that its content is relevant, useful and up-to-date.
- Developing the SDSD data plan by weaving the sources itemised in the inventory together in a structured way to form a robust evidence base for the impact of the network on access to and quality of specialist care.

Full details are in [Appendix 2](#) – Proposed Work Plan for 2022/23.

Appendix 1 – Detailed Description of Progress in 2021/22

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.

a) Business as Usual

Core principle	Description of Work	End of year status	Start date	End date	RAG status
Effective Network Structure and Governance	The network will organise 4 Steering Group and 2 Data group meetings in 2021/22 to ensure effective delivery of the annual work plan.	All aspects of governance were in place and all planned meetings and mandatory reporting took place, apart from revising the Quality Strategy due to capacity constraints. This will be done in 2022/23.	01/04/2021	31/03/2022	A
Stakeholder Communication and Engagement	SDSD will issue two newsletters during 2021/22.	Summer newsletter issued. Winter newsletter not issued in line with directive to defer some network activity in Feb and March 2022 because of pandemic pressures.	01/04/2021	31/03/2022	A
Stakeholder Communication and Engagement	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.	Website was kept refreshed and up to date.	01/04/2021	31/03/2022	G
Stakeholder Communication and Engagement	Collaborate with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network through cross-links between websites and cross-posting regular communications.	Cross-links between websites and cross-posting regular communications took place as planned.	01/04/2021	31/03/2022	G
Stakeholder Communication and Engagement	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.	Relevant collaboration and liaison with ORC took place as planned through Dr Martina Rodie.	01/04/2021	31/03/2022	G
Stakeholder Communication and Engagement	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).	Relevant collaboration with BSPED DSD SIG and ESPE took place as planned through Dr Martina Rodie.	01/04/2021	31/03/2022	G

SDSD Annual Report 2021/22

Education	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.	March 2022: education symposium delivered successfully with good attendance levels.	01/04/2021	31/03/2022	C
Audit and Continuous Quality Improvement	SDSD will continue to use Scottish Audit of Atypical Genitalia (SAAG) data on early years and DSD Diagnostic Meetings data to monitor access to and quality of care.	SDSD continued to use these data sources to monitor access to and quality of care. It is a network priority to formulate a data plan during 2021/22.	01/04/2021	30/09/2021	G
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 meetings conducted using MS Teams with papers sent electronically.	01/04/2021	31/03/2022	G
Value	SDSD will continue to seek to maximise the efficiency of its activities and processes on an ongoing basis through effective planning, communication and evaluation.	SDSD continued to seek to maximise the efficiency of its activities and processes.	01/04/2021	31/03/2022	G
Value	During 2021/22 SDSD will continue to contribute to other strategic national and international programmes as detailed elsewhere in this workplan.	SDSD actively sought to contribute to other relevant strategic programmes.	01/04/2021	31/03/2022	G
Value	During 2020/21 SDSD will continue to seek to minimise unwarranted variation in practice in line with the “Once For Scotland” approach.	SDSD actively sought to minimise unwarranted variation in practice.	01/04/2021	31/03/2022	G

b) Development Projects

Core principle	Description of Work	End of year status	Start date	End date	RAG status
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. The network will also monitor the progress of NHS England's investigations in this area.	Population prevalence data was provided by network clinicians, processed by the PM and added to the position paper as an indicator of regional demand for DSD-related CP services. The modelling work required to quantify required CP resources for Scotland will be based on the NHS England study which has still not been published.	01/04/2021	31/03/2023	G
Service Development and Delivery	SDSD will create an information sheet for patients about genetic testing to improve their understanding of the process and purpose of the testing. The network will also create a questionnaire for clinicians to determine how useful they find, and how well they understand, genetic reporting data. The extent to which the clinicians successfully interpret the data directly affects how well the information is conveyed to patients.	The component of this project for 2021/22 was that drafts of the patient information sheet and the clinician questionnaire should be reviewed and discussed by the SDSD SG, which was achieved. The project will continue in 2022/23.	01/08/2021	31/03/2023	G
Service Development and Delivery	SDSD will explore the potential for collaborating with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network on service development areas of mutual benefit (eg. care pathways, clinical guidelines).	A project proposal was created in Q4 setting out the specifics of the development of SPEG/SDSD synergies. The project will continue in 2022/23.	01/01/2022	31/03/2023	G

SDSD Annual Report 2021/22

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	SDSD Steering Group decided to aim for a face-to-face patient event in the summer of 2022.	01/07/2021	31/03/2022	G
Stakeholder Communication and Engagement	By March 2022 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.	This initiative did not get off the ground because despite efforts by the SDSD Core Team, very few patient contact details were sent to them by DSD clinicians. In Q4 a different approach was devised using cards to be given to patients at the end of consultations, which will be implemented in Q1 of 2022/23.	01/04/2021	31/03/2022	A
Stakeholder Communication and Engagement	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.	In Q4 SDSD patient/family leaflets were revised and updated.	01/10/2021	31/03/2022	G
Stakeholder Communication and Engagement	SDSD will obtain and assess stakeholders' views of the effectiveness of the collaborative cross-posting of news and information by SDSD and SPEG.	This workstream is rolled forward to 2022/23.	01/11/2021	31/03/2022	A
Education	By 2023 nurses, midwives (including neonatal nurses) and other health professionals 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 SDSD website.	The SG is in the process of assessing the need for these specific resources.	01/10/2021	31/03/2023	A

SDSD Annual Report 2021/22

<p>Audit and Continuous Quality Improvement</p>	<p>By 2023 SDSD 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. SDSD will start work on surgical coding anomalies rectification as soon as the PBPP application is approved and the patient CHI numbers are acquired.</p>	<p>The LC and Core Team compiled an inventory of DSD-related data sources in 2021/22 with a view to combining outputs to produce intelligence. As the PBPP application made no progress in 2021/22, alternative ways of carrying out the surgical data audit will be explored in 2022/23.</p>	<p>01/04/2021</p>	<p>31/03/2022</p>	<p>A</p>
<p>Audit and Continuous Quality Improvement</p>	<p>SDSD and SPEG will continue to explore the potential for common data reporting and will report the findings. Phase 1: by 31/03/2022 evaluate and report on potential; Phase 2: during 2022/23 agree common data reporting areas and develop them.</p>	<p>In Q4 work commenced to explore and develop SPEG/SDSD synergies. The project will continue in 2022/23.</p>	<p>01/01/2022</p>	<p>31/03/2023</p>	<p>G</p>
<p>Value</p>	<p>SDSD will audit the uptake of and adherence to the Neonatal Pathway in 2021/22</p>	<p>This task is rolled forward to 2022/23.</p>	<p>01/01/2022</p>	<p>31/03/2022</p>	<p>A</p>

Appendix 2 – Proposed Work Plan for 2022/23

a) Business as Usual

Core principle	Description of Work	Owner	Start date	End date
Effective Network Structure and Governance	The network will organise 4 Steering Group and 2 Data group meetings in 2022/23 to ensure effective delivery of the 2022//23 work plan.	Core team	01/04/2022	31/03/2023
Stakeholder Communication and Engagement	SDSD will issue two newsletters during 2022/23.	Core team	01/04/2022	31/03/2023
Stakeholder Communication and Engagement	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	01/04/2022	31/03/2023
Stakeholder Communication and Engagement	Collaborate with colleagues in the Scottish Paediatric Endocrine Group (SPEG) Network through cross-links between websites and cross-posting regular communications.	Core team	01/04/2022	31/03/2023
Stakeholder Communication and Engagement	Continue to collaborate and liaise with the Office for Rare Conditions (ORC) and attend the ORC education day in 2022/23 to raise awareness of the network.	LC/SG	01/04/2022	31/03/2023
Stakeholder Communication and Engagement	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	01/04/2022	31/03/2023
Education	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	01/04/2022	31/03/2023
Audit and Continuous Quality Improvement	SDSD will continue to use SAAG data on early years and DSD Diagnostic Meetings data to monitor access to and quality of care.	LC/Core team/SG	01/04/2022	31/03/2023
Value	During 2022/23 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	01/04/2022	31/03/2023
Value	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	01/04/2022	31/03/2023

SDSD Annual Report 2021/22

Value	During 2022/23 SDSD will continue to contribute to other strategic national and international programmes as detailed elsewhere in this workplan.	ALL	01/04/2022	31/03/2023
Value	During 2022/23 SDSD will continue to seek to minimise unwarranted variation in practice in line with the “Once For Scotland” approach.	ALL	01/04/2022	31/03/2023

b) Development Projects

Core principle	Description of Work	Owner	Start date	End date
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 2022/23 SDSD will submit the updated Clinical Psychology position paper with recommendations for improving provision in Scotland to NSS planners. The network will draw on the outcomes of NHS England’s investigations in this area to model the required provision, and improvements in provision will be measured by monitoring the relevant clinical psychology staff WTE levels.	LC/PM/SG	01/04/2022	31/03/2023
Stakeholder Communication and Engagement	SDSD will continue to develop an information sheet for patients about genetic testing to improve their understanding of the process and purpose of the testing. The network will also continue to develop a questionnaire for clinicians to determine how useful they find, and how well they understand, genetic reporting data.	LC/Core team/SG	01/07/2022	31/03/2023
Stakeholder Communication and Engagement	During 2022/23 SDSD will seek to reinstate patient & family events, and will consider both virtual and face-to-face formats	LC/Core team/SG	01/06/2022	31/03/2023
Stakeholder Communication and Engagement	Boost responses to the Patient Care Experience survey capturing patients/parents/carers’ views on their consultations. The achievement of good data volumes will allow the network to evidence levels of and improvements in care quality.	LC/Core team	01/05/2022	31/03/2023
Audit and Continuous Quality Improvement	The SDSD Website QI project will be continued, including a stakeholder survey to obtain views on the usefulness of the website and how it can be improved to ensure that it is accessible and user-friendly, and that its content is relevant, useful and up-to-date.	LC/Core team/SG	01/04/2022	31/03/2023

SDSD Annual Report 2021/22

Education	Produce up-to-date and relevant training resources, which make optimal use of communication systems, for nurses, midwives (including neonatal nurses) and other health professionals who work with DSD.	LC/Core team/SG	TBD	TBD
Audit and Continuous Quality Improvement	By 2023 SDSD will have a robust data plan and a suite of useful quality measures and indicators, as follows:	SG/IMS/Data group		
	a) Develop the SDSD data source profile to show how data from the different sources might be combined or synthesized to produce useful intelligence on DSD-related care.	Data group	01/04/2022	31/03/2023
	b) Start work on surgical coding anomalies rectification as soon as the data is available, either via the PBPP application or an alternative route.	IMS/Data group	TBD	TBD
Value	Audit the uptake of and adherence to the Neonatal Pathway.	LC/Core team/SG	01/06/2022	31/03/2023
Value	Develop and implement synergies with the SPEG network which will produce economies of scale, improved value for patients, families and clinicians and other efficiencies and benefits. This initiative must be done carefully and sensitively in order to preserve identity and branding of which each network is understandably protective.	SDSD and SPEG Core Teams	01/06/2022	31/03/2023