

Scottish Genital Anomaly Network



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Annual Report for National Services Division
April 2008 – March 2009

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1. Introduction

The Scottish Genital Anomalies Network (SGAN) is a national managed clinical network established in 2005/6 as a follow on from the Scottish Audit of Genital Anomalies study group. Network membership is made up of a multidisciplinary group of healthcare professionals who provide care to children and adults with a disorder of sex development (DSD) or who are born with an anomaly of the genitalia as well as parents and patients of these services. The Network is administratively hosted within the Managed Clinical Network Department of NHS Greater Glasgow and Clyde.

This annual report details the progress and development of the Network in the period April 2008 – March 2009.

2. Executive Summary

The year April 2008 – March 2009 has been a successful year for SGAN. A summary of the work undertaken is shown below:

- SGAN clinics were held in Aberdeen, Edinburgh and Glasgow. The Glasgow clinic is now held 4 times per year.
- Patients were registered on the SGAN database from Aberdeen, Dundee, Edinburgh, Glasgow and Inverness
- Information leaflets have been created for Congenital Adrenal Hyperplasia, Vaginal Dilatation, Cryptorchidism (Undescended Testes), SGAN Information leaflet adapted for over 16s. These leaflets will be available for distribution by end of 2009.
- A telemedicine link is now being used at 3 centres – Glasgow, Aberdeen and Edinburgh.
- The Network held another successful training Symposium in Stirling in March 2009

For the year April 2008 – March 2009, SGAN agreed the following objectives:

- (a) SGAN will undertake a service user satisfaction survey to assess the quality of service provided.

- (b) SGAN will create and disseminate information for Congenital Adrenal Hyperplasia and Vaginal Dilatation.
- (c) SGAN will aim to ensure continuous improvement of the SGAN Clinics, principally by improving on the use of telemedicine facilities.
- (d) SGAN will develop a web-based register with the help of the NSD following successful validation of the SGAN core dataset
- (e) The network will continue to develop information sheets for conditions which fall within the scope of the network.

3. Network Description

3.1 Background

Managed Clinical Networks

Managed Clinical Networks (MCNs) were first introduced in the Acute Services Review in 1998. The Scottish Executive (now Government) then issued a series of guidance documents on MCNs (NHS HDL (2002) 69 *"Promoting the Development of Managed Clinical Networks in NHS Scotland"*). These documents defined MCNs as:

Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland.

In addition they set out a list of core principles to which all MCNs must adhere. This was reiterated in the latest guidance issued, HDL (2007) 21 *"Strengthening the Role of Managed Clinical Networks"*. As well as confirming the commitment from the Government to the development of MCNs, this document emphasised the key role that MCNs should play in the planning and commissioning process, in delivering change and in involving service users.

Scottish Genital Anomaly Network

The Network is intended to encompass any individual where there may be concerns about sex development. Whilst most affected individuals present at birth, a substantial number of affected individuals may present in late childhood or young adulthood.

Genital anomalies, excluding isolated unilateral undescended testis, are reported to occur at an approximate rate of about 5 per 1000 live births. It is estimated that 1 in 4,500 live births may have a genital anomaly that is so abnormal that a decision about sex may be impossible at birth. Although there is a wide spectrum of DSD, they are usually identifiable and can be broadly classified into XX DSD and XY DSD. About 90% of cases of XX DSD are due to congenital adrenal hyperplasia (CAH) that may be as common as 1 in 14,000 live births in Scotland.

XY DSD is a more heterogenous group of conditions, and within this group, hypospadias is the commonest single defect occurring at a rate of 4 per 1000 live births in Scotland. The incidence of hypospadias has been reported to have risen over the last few decades but our studies in Scotland show that the birth prevalence of hypospadias has remained static over the last decade. Our studies have shown some regional differences in the birth prevalence of this condition in Scotland. Hypospadias can be of varying severity and can be classified as a proximal, mid or distal defect depending on the site of the meatus. Whilst some distal hypospadias may not require an intervention, mid and proximal forms invariably undergo surgery and are more likely to be associated with other genital anomalies such as micropenis, undescended testes and incomplete development of the scrotum and may require further investigation of gonadal function.

3.2 Network Function, Structure and Accountability

SGAN is organised around the 4 paediatric tertiary centres in Scotland – Aberdeen, Dundee, Glasgow and Edinburgh. There are recognised clinicians in each of these four centres who

are responsible for the local SGAN clinics and related network business. The SGAN Executive Group comprises of clinical SGAN members from all four areas.

The membership of the Network is included as Appendix 1 in this report.

Purpose of network (ie goals/aims)

The overall role of SGAN is to improve long-term clinical outcome.

Its function includes:

- provision of appropriate support to the affected person and their family
- guiding investigation and short-term management of the affected person
- developing a long-term management plan
- linking clinical personnel who are involved in patient management
- collection of data on affected cases through a national register
- provision of opportunity for clinical development of staff
- facilitate research and audit.

SGAN Executive Group

In the past year there has been a change in the lead clinician for the network. Mr Chris Driver, Consultant Paediatric Surgeon based at the Aberdeen Children's Hospital has taken over from Dr Faisal Ahmed.

The purpose of the SGAN Executive Group is to support and steer the development of the Network and the services it encompasses. This includes the development of training opportunities for clinical staff and provides leadership and peer support for the local teams in the four centres. Executive Group members also have a key role in ensuring two-way communication between the Network and local teams of clinicians. The Executive Group tenure has been drawn up and those who have been on the executive for three or more years are being asked to review their tenure after discussion with their constituents and either continue their tenure or nominate a professional to replace them.

The Executive Group is accountable to National Services Division and the Health Boards for:

- Developing a strategic vision for the Network
- Developing strategic alliances for the Network to support and promote its work
- Ensuring the Network meets its agreed objectives
- Supporting the Network Management Team (Core Group)
- Accounting for performance against the National Services Division Service Level Agreement.

The Network encourages active service user representation, with involvement in activities such as the Executive Group meeting, assisting with the production of the information leaflets, commenting on documents produced by the Network and giving their opinions via surveys.

Network Management Team/ Core Group

The Network Management Team/ Core Group is made up of the SGAN Clinical Lead, SGAN Co-ordinator and MCN Department Manager. The Clinical Lead is accountable to the Executive Group for ensuring consistent clinical leadership of the Network and its services and is ultimately accountable for the MCN.

On a day to day basis the SGAN Co-ordinator is responsible for the operational management of the Network. The SGAN co-ordinator, who is full time, ensures the efficient organisation of the eight SGAN clinics per annum, services the Executive Group and related business, and maintains the SGAN register and website. The MCN Department Manager provides management support to the Clinical Lead and Co-ordinator and is responsible for the project and performance management of the Network and its finance.

SGAN Clinics

The SGAN clinics were established to provide an opportunity for multi-disciplinary working for key clinical staff. The multi-disciplinary team regularly attending SGAN clinics consists of

staff from Clinical Biochemistry, Clinical Genetics, Endocrinology (Paediatric, Adult), Psychiatry, Paediatric and Adult Psychology and Surgery (Gynaecology, Paediatric, Plastic and Urology). The SGAN clinics provide a 'one-stop' forum for discussion of complex cases by a multi-disciplinary highly specialised team. SGAN clinics also benefit patients and their families by reducing travelling, time spent away from home and attendance at multiple appointments, thus reducing stress. The SGAN clinic model can also help reduce the need for multiple procedures – for example a SGAN plastic surgeon and gynaecologist can be supported to travel to Aberdeen to work with a local SGAN paediatric surgeon, thus providing access to highest quality care as close to home as possible and maintaining local follow-up and care of the patient.

SGAN clinics in Glasgow are organised so that patients can be seen by two or three key team members in one consulting room while the consultation is relayed – with patient / parental consent - via telelink to the wider multi-disciplinary team (MDT) in another room, where the wider team continue with case discussion following a case presentation on that particular patient. A post-consultation discussion with the wider MDT can also take place. (See Appendix 2: Clinic Attendance)

SGAN REGISTER

SGAN has a register containing information on patients with DSD or genital anomaly enrolled by network members; this is an opt out register. Parents/carers & patients over 16 years are aware of the existence of the SGAN register, which is used for internal audits. In addition, the register is a useful resource for designing studies that are aimed at improving our knowledge of the prevalence, aetiology and management of these rare conditions. Over the past year the transfer of data from the old register onto the new register using the core dataset developed by the network has been ongoing. A trainee from Ayrshire & Arran Health Board Area assisted with this and then presented at the SGAN Scientific Meeting. This year a specialist registrar training in Genetics is using the register to obtain information for some research she is doing looking at the Spectrum of Clinical & Genetic Abnormalities In Women With Congenital Abnormalities Of The Mullerian Tract. Once the

results area available she will hope to present the findings to an SGAN meeting and have them published. (See Appendix 3: Registered Patients by 4 Regional Centres)

4. Financial Report

SGAN receives an annual budgetary allocation of £5000 from NSD to support the Network running costs. The following is a breakdown of the expenditure of the budget for April 2008 – March 2009.

Description	Cost
Communication & Stationery	£993
Hotel Services	£572
Other, non pay	£13
Travel, Expenses, Training	£2,712
Total	£4290
Underspend	£710

Audit Activity

The Endowment fund for the network will support and promote research and audit. Cash for the fund will be generated from income from events such as the SGAN symposium. It is hoped that trainees as well as other SGAN members will use this fund to develop research and audit that is based on the SGAN Register. The fund is also used to cover expenses for members attending conferences and expenses incurred where speakers have been invited to SGAN educational meetings.

SGAN ENDOWMENT FUND	
Opening balance Apr 2008	1, 880.00
INCOME	
SGAN Event Registration 2009	440.00
	<i>TOTAL INCOME</i> £2,320.00
OUTGOINGS	
Dr A Robertson attending Conference	233.64
Mrs G Coyle, Attending CAH Conference	109.00
Prof Richard Sinnott SGAN Symposium Speaker	29.70
Prof Olle Soder SGAN Symposium Speaker	360.00
	<i>TOTAL OUTGOING</i> £732.34
	SGAN BALANCE £1,587.66

5. Progress April 2008 – March 2009

The service level agreement between SGAN and National Services Division for the period April 2008 – March 2010 set out the key network objectives.

This section will provide a report on performance against these objectives. Other performance information in terms of the network's achievements is included.

Objective	Narrative	2008-09 Status	2009-10 Status
<p>1. The network will develop a web-based register with the support of NSD using the SGAN core dataset.</p>	<p>A sub-group was set up to take this forward and a core dataset was developed by the network to be submitted for consideration for the GCS system. The GCS system has now been put on hold.</p> <p>A new system is in the development stage and SGAN have developed a core dataset mapping to the NSD's 7 screen template for the new system.</p>	<p>Not achieved</p>	<p>Ongoing</p>
<p>2. The network will continue to support and promote the participation of service users in the work of the network.</p>	<p>Multi-disciplinary clinics take place at 3 sites in Scotland: Aberdeen, Edinburgh & Glasgow. These clinics take the form of discussing specific cases and opinions sought from the peer group. These clinics are linked to all sites through the use of telemedicine links.</p> <p>There is also an annual symposium where all the network members have the opportunity to hear invited speakers presenting on topics of interest to the network.</p> <p>There is a quarterly newsletter distributed to all members, who are also asked for contributions to be included.</p> <p>The website also has information about the network and all clinic dates, newsletters, minutes, etc can be found along with links to other</p>	<p>Ongoing</p>	<p>Ongoing</p>

<p>The network is also organising awareness sessions for patients/ parents/carers to get involved in the network.</p>	<p>websites for further information.</p> <p>A leaflet has been developed and has been approved by the Caldicutt Guardian. This leaflet will explain the network and how to get involved. This will be sent out over the next few months.</p>		<p>To start in July 2009</p>
<p>3. The network will undertake a service user satisfaction survey to assess the quality of the service provided.</p>	<p>A user satisfaction survey was developed in Spring 2009 in the form of a "<i>Survey Monkey</i>" questionnaire. The link to this was sent to all network users and a link posted on the website. The results are appended to this report. (See Appendix 5)</p> <p>This will help the network decide where improvements can be made and what can be achieved in the future.</p>	<p>Achieved</p>	
<p>4. The network will create and disseminate information for Congenital Adrenal Hyperplasia, Vaginal Dilatation and Bilateral Undescended Testes (BUDT). The SGAN information leaflet has been adapted for over 16's and this will be sent out to all registered patients in this age-group.</p>	<p>An information leaflet for Congenital Adrenal Hyperplasia is in the final development stage, and will be distributed for endorsement to the target group and peer group before being submitted to FILES at Yorkhill for approval. The information leaflet for BUDT is in the initial stages of development, with the first draft to be sent out to the network for comment at the end of May 2009. Once these information leaflets have been approved they will be distributed to patients/ parents/carers and will be available on the website for information.</p> <p>The network is also planning to make all information leaflets available in other languages, in line with the Equality & Diversity Policies.</p>	<p>Partially achieved</p>	<p>To be achieved by 2010.</p>
<p>5. The network will aim to ensure continuous improvement of the</p>	<p>A record of attendances at the SGAN clinics will be kept and presentations will also be recorded for audit purposes. The telemedicine link is</p>	<p>Ongoing</p>	<p>Ongoing</p>

<p>SGAN clinics, principally by improving on the use of telemedicine facilities.</p>	<p>now being used at 3 centres – Glasgow, Aberdeen & Edinburgh – and any problems will be highlighted and brought to the attention of the Telemedicine manager.</p>		
<p>6. The network will develop a Quality Assurance Framework (QAF)</p>	<p>The guidance issued by NHS QIS defines the functions of a MCN QAF as:</p> <ul style="list-style-type: none"> ➤ To measure performance against agreed standards. ➤ To support improvements in care and services ➤ To learn openly from challenges and share strengths ➤ To report openly 		<p>To be Completed end 2009</p>
<p>7. The network will develop an Equality Impact Assessment Tool (EQIA) for patient services</p>	<p>The NHS is committed to realising the aims of equality legislation; these are</p> <ul style="list-style-type: none"> ➤ Address unlawful discrimination ➤ Eliminate Harassment ➤ Promote equality ➤ Ensure consultation and dialogue with a diverse community <p>Therefore in order to test out whether the network is able to meet a range of needs and making them accessible and effective for all an EQIA will be developed.</p>		<p>Set for completion end 2009</p>

Additional Progress

SGAN Symposium

The 3rd SGAN Symposium took place in Stirling on 13th March 2009 and, once again, was again well attended. A substantial audience from a wide variety of clinical backgrounds were rewarded with outstanding contributions from leading authorities in their fields.

The SGAN AGM was held during the meeting. It focused on the development of SGAN and noted goals that have been reached. The next steps in the development of the Network were discussed.

Case Presentations which precipitated considerable discussion completed the Clinical side of the meeting and highlighted the value of the network. The meeting was well received and again emphasised the merit of SGAN in encouraging debate and offering patients truly multidisciplinary care.

A programme of the event and the feedback is attached as an Appendix. (see Appendix 6)

6. Forward Plan

In the period to end March 2010 the network will continue to strengthen the relationships within SGAN, thus fostering the good working relationships and improvements in patient care encouraged by collaboration through the MCN. In the main SGAN plans to continue to deliver highly quality clinical opinion and advice at the SGAN clinics held at the 3 sites, support activity in Dundee, and support continuous service improvement in the relevant disciplines. We will continue to develop high quality written information for our clinicians, patients and carers and ensure that the SGAN website is effective.

In addition to these overarching commitments SGAN plans to address some specific issues in the next 12 months, these are outlined below:

- (a) SGAN will aim to ensure continuous improvement of the SGAN Clinics, principally by improving on the use of telemedicine facilities.
- (b) SGAN will develop a web-based register with the help of the NSD team, following successful validation of the SGAN core dataset
- (c) The network will develop information sheets for conditions that fall within the scope of the network.
- (d) The Network will develop a Quality Assurance Framework.
- (e) The Network will develop an Equality Impact Assessment for patient services.
- (f) The network will organise patient/parent/carer forums to gauge what users would like to see the network achieving in future and how they can become involved. This is in line with PFPI policy

7. Conclusions

After a busy year SGAN looks forward to continued success in 2009/2010. The network membership is increasing and we are excited about encouraging more service user representatives to become involved. The development of the online register of our patients is a real opportunity and we are confident of increasing our registered cases by similar or greater numbers in 2009/2010.

APPENDIX 1: SGAN MEMBERSHIP AND EXECUTIVE

Aberdeen				Glasgow						
Endocrinology	Bevan	John	Cons Adult Endocrinologist	ARI	Endocrinology	McNeill	Ethel	Endocrine Specialist Nurse		Yorkhill
Endocrinology	Mayo	Amalia	Cons Paed Endocrinologist	RACH	Endocrinology	Mason	Avril	Trainee in Paediatrics		Yorkhill
Endocrinology	Reid	Jacquie	Endocrine Specialist Nurse	RACH	Endocrinology	Kerr	Lindsay	Trainee in Paediatrics		Yorkhill
Surgery	Driver	Chris	Cons Paed Surgeon	RACH	Endocrinology	McDevitt	Helen	Trainee in Paediatrics		Yorkhill
Surgery	Youngson	George	Cons Paed Surgeon	RACH	Endocrinology	Wong	Jarod	Trainee in Paediatrics		Yorkhill
Psychology	Dutch	Susan	Cons Clin Psychologist	RACH	Genetics	Murday	Victoria	Cons Clin Geneticist		Yorkhill
Psychology	Darbyshire	Corrie	Cons Clin Psychologist	RACH	Genetics	Tolmie	John	Cons Clin Geneticist		Yorkhill
Psychiatry	Gilmour	Carol	Cons Child Psychiatrist	RACH	Gynaecology	Deeny	Miriam	Cons Gynaecologist		GRI
Gynaecology	Logan	Susie	Cons Adol Gynaecologist	RACH	Gynaecology	Ida	Ismail	Trainee in Gynaecology		GRI
Genetics	Dean	John	Cons Geneticist	RACH	Gynaecology	Lyll	Helen	Cons Gynaecologist		GRI
Endocrinology	Sun	Angela	Specialist Registrar	RACH	Psychiatry	Jason	Westwater	Cons Psychiatrist		Sandyford Clinic
Endocrinology	Maheshwari	Abha	Specialist Registrar	RACH	Psychology	Green	Lyndia	Cons Clin Psychologist (Adult)		GRI
Paediatrics	Oxley	Craig	Cons Paediatrician	RACH	Psychology	Robertson	Alison	Cons Clin Psychologist (Paed)		Yorkhill
Edinburgh					Surgery	O'Toole	Stuart	Cons Urologist		Yorkhill
Biochemistry	Crofton	Pat	Principal Biochemist	RHSC	Surgery	Ray	Arup	Cons Plastic Surgeon		GRI/Yorkhill
Psychology	Wesson	Caroline	Cons Clin Psychologist	RHSC	Surgery	Sabharwal	Atul	Cons Paed Surgeon		Yorkhill
Endocrinology	Bath	Louise	Cons Paed Endocrinologist	RHSC	Surgery	Telfer	John	Cons Plastic Surgeon		GRI
Endocrinology	Drake	Amanda	Trainee in Paediatrics	RHSC	Surgery	Flett	Martyn	Cons Paed Surgeon		Yorkhill
Endocrinology	Kelnar	Chris	Cons Paed Endocrinologist	RHSC	Surgery	Brindley	Nicola	Cons Paed Surgeon		Yorkhill
Endocrinology	Wardhaugh	Barbara	Endocrine Specialist Nurse	RHSC	Surgery	Senior	Mike	Cons Plastic Surgeon		GRI
Geneticist	Lam	Wayne	Cons Clin Geneticist	WGH	Surgery	Cascio	Salvatore	Cons Paed Surgeon		Yorkhill
Neonatology	Midgley	Paula	Cons Neonatologist	RIE						
Surgery	MacKinlay	Gordon	Cons Paed Surgeon	RHSC	Stirling					
Surgery	Orr	John	Cons Paed & Urol Surgeon	RHSC	Endocrinology	Schulga	John	Cons Paediatrician		SRI
Surgery	Stewart	Ken	Cons Plastic Surgeon	RHSC	Ayrshire & Arran					
Surgery	Lam	Jimmy	Con Paed & Urol Surgeon	RHSC	Endocrinology	Williamson	Scott	Cons Paediatrician		A&A
Surgery	Anderson	William	Cons Plastic Surgeon	RHSC	Support Groups					
Dundee						Cull	Melissa	CAH Support Group		
Endocrinology	Greene	Steve	Paed Endocrinologist	Ninewells		Simmonds	Margaret	AIS Support Group		
Surgery	Stevenson	Howard	Cons Plastic Surgeon	Ninewells	Executive Group					
Gynaecology	Madhurima	Rajkhowa	Cons Gynaecologist	Ninewells	Driver C	Clinical Lead		Midgley P		Neonatology
					Kinney M	Network Co-ordinator		O'Toole S		Surgery
Glasgow					Deeny M	Gynaecology		Robertson A		Psychology
Biochemistry	Wallace	Mike	Cons Clin Biochemist	GRI	Ahmed F	Endocrinology		Stewart K		Surgery
Biochemistry	McNeilly	Jane	Clinical Biochemist	Yorkhill	Greene L	Psychology		Telfer J		Surgery

Endocrinology	Ahmed	Faisal	Cons Paed Endocrinologist	Yorkhill		Lam W	Genetics		Coyle G	Lay Representative
Endocrinology	Connell	John	Cons Adult Endocrinologist	WIG						
Endocrinology	Donaldson	Malcolm	Cons Paed Endocrinologist	Yorkhill						
Endocrinology	Shaikh	Guftar	Cons Paed Endocrinologist	Yorkhill						

Appendix 2: SGAN Clinics Specialty Attendance

Edinburgh 2008/2009

Date	Patients Seen / Discussion	ATTENDEES		
02/05/2008	7	Biochemist	1	Edinburgh
		Endocrinology	3	Glasgow/Edinburgh/ Aberdeen
		Plastic Surgery	2	Edinburgh
		Surgical	2	Edinburgh/Aberdeen
		Specialist Nursing	1	Edinburgh/Aberdeen
		Geneticist	1	Edinburgh
		Trainees		Edinburgh
Date	Patients Seen / Discussion	ATTENDEES		
23/01/2009	5	Biochemist	1	Edinburgh
		Endocrinology	4	Edinburgh/Aberdeen/Glasgow
		Plastic Surgery	0	
		Surgical	1	Edinburgh
		Specialist Nursing	1	Edinburgh
		Geneticist	1	Edinburgh
		Trainees	1	Edinburgh
		Medical Student	1	Aberdeen

Aberdeen 2008/2009				
Date	Patients Seen / Discussion	ATTENDEES		
08/05/2008	5	Endocrinology	2	Glasgow/Aberdeen
		Gynaecology	3	Glasgow/Aberdeen
		Plastic Surgery	1	Glasgow
		Surgical	3	Glasgow/Aberdeen
		Specialist Nursing	1	Aberdeen
		Psychology	2	Glasgow/Aberdeen
		Paediatrics	1	Aberdeen
		Trainee Staff	5	Glasgow/Aberdeen
13/11/2008	4	Endocrinology	2	Glasgow/Aberdeen
		Gynaecology	2	Glasgow/Aberdeen
		Plastic Surgery	1	Glasgow
		Surgical	2	Aberdeen
		Specialist Nursing	1	Aberdeen
		Psychology	1	Aberdeen
		Psychiatry	1	Aberdeen
		Trainee Staff	3	Aberdeen/Glasgow

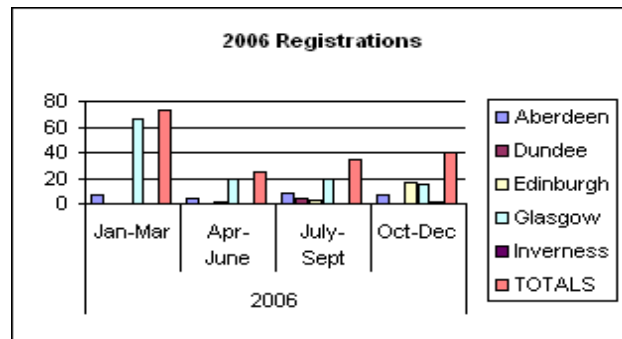
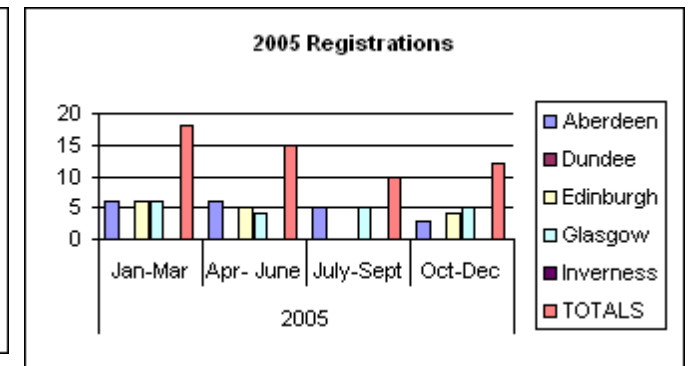
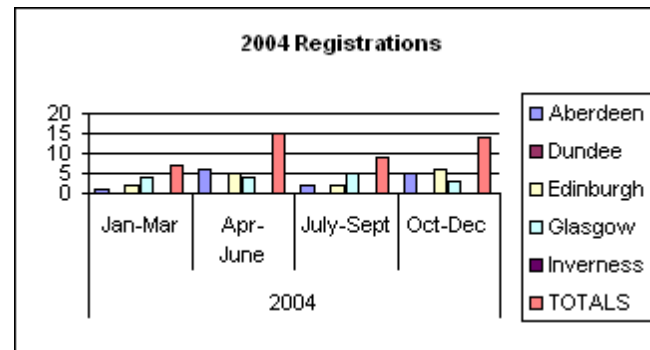
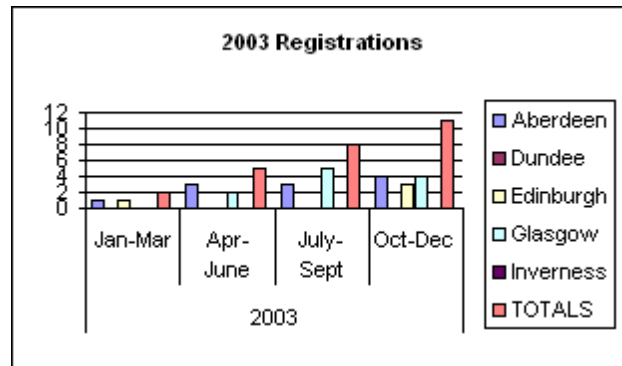
GLASGOW CLINICS 2008/2009

Date	Patients Seen / Discussion	ATTENDEES		
02/06/2008	6	Endocrinology	2	Glasgow/Aberdeen
		Surgical	2	Glasgow/Aberdeen
		Plastic Surgery	2	Glasgow
		Gynaecology	0	Glasgow/Aberdeen
		Neonatology	1	Edinburgh
		Psychology	2	Glasgow
		Nurse Specialist		Aberdeen/Edinburgh/Glasgow
		Trainees	6	Glasgow
06/10/2008	6	Endocrinology	3	Glasgow/observer from Israel
		Surgical	3	Glasgow/Aberdeen
		Plastic Surgery	1	Glasgow
		Gynaecology	1	Glasgow
		Neonatology	1	Edinburgh
		Psychology	2	Glasgow
		Nurse Specialist	2	Glasgow
		Trainees	1	Glasgow
12/01/2009	4	Biochemistry	2	Glasgow
		Endocrinology	4	Glasgow/Edinburgh
		Surgical	3	Glasgow/Aberdeen
		Plastic Surgery	1	Edinburgh
		Gynaecology	1	Glasgow
		Psychology	3	Glasgow
		Genetics	1	Edinburgh
		Nurse Specialist	2	Glasgow
		Trainees	4	Glasgow

APPENDIX 3: SGAN REGISTER

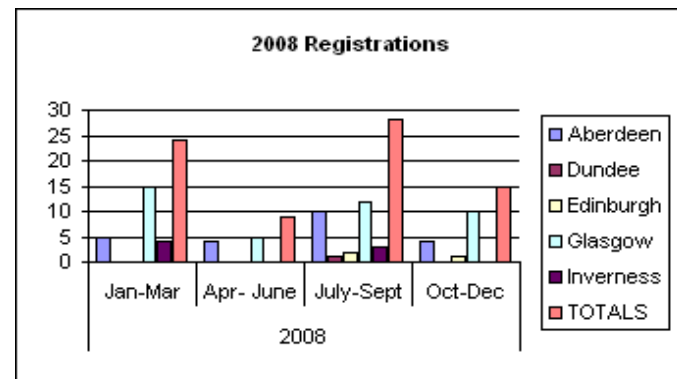
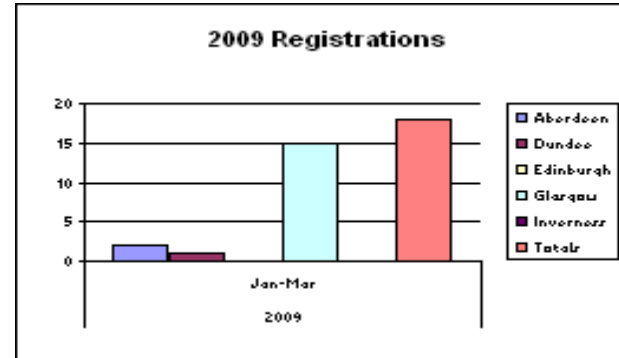
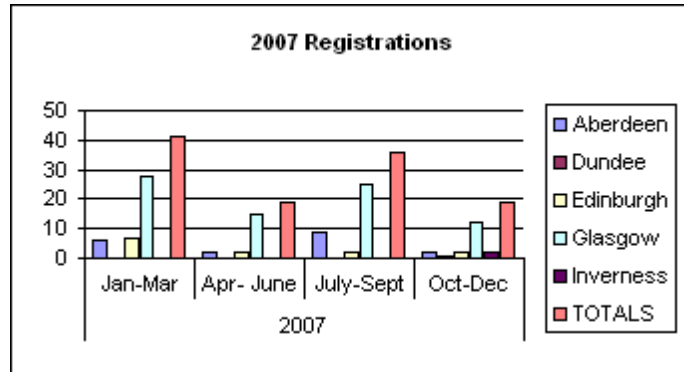
SGAN REGISTERED CASES 2003-2009

	2003					2004					2005					2006				
	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Tot	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Tot	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Tot	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Tot
Aberdeen	1	3	3	4	11	1	6	2	5	14	6	6	5	3	20	7	4	8	7	26
Dundee	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	4	0	4
Edinburgh	1	0	0	3	4	2	5	2	6	15	6	5	0	4	15	0	1	3	17	21
Glasgow	0	2	5	4	11	4	4	5	3	16	6	4	5	5	20	66	20	19	15	120
Inverness	0	0	0	0	0					0					0				1	1
TOTALS	2	5	8	11	26	7	15	9	14	45	18	15	10	12	55	73	25	34	40	172



SGAN REGISTERED CASES 2003-2009
(CONT)

	2007					2008					2009					CENTRE TOTAL
	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Tot	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Tot	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Tot	
Aberdeen	6	2	9	2	19	5	4	10	4	23	2				2	25
Dundee	0	0	0	1	1	0	0	1	0	1	1				1	2
Edinburgh	7	2	2	2	13	0	0	2	1	3	0				0	3
Glasgow	28	15	25	12	80	15	5	12	10	42	15				15	57
Inverness				2	2	4	0	3	0	7	0				0	7
TOTALS	41	19	36	19	115	24	9	28	15	76	18				18	94



Response Summary

Appendix 4: Survey response summary

Total Started Survey: 20

Total Completed Survey: 19 (95%)

1. SGAN Clinics							
	<i>answered question</i>						18
	<i>skipped question</i>						2
	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied	Rating Average	Response Count
Are you satisfied with the organisation of the SGAN clinic?	33.3% (4)	50.0% (6)	16.7% (2)	0.0% (0)	0.0% (0)	1.83	12
Are you satisfied with the use of the telemedicine equipment?	7.1% (1)	42.9% (6)	21.4% (3)	28.6% (4)	0.0% (0)	2.71	14
The clinics provide effective access to many specialists?	63.6% (7)	36.4% (4)	0.0% (0)	0.0% (0)	0.0% (0)	1.36	11
The clinics are a valuable source of education and professional development?	46.7% (7)	46.7% (7)	0.0% (0)	6.7% (1)	0.0% (0)	1.67	15

2. Are you satisfied with the overall level of clinical support provided by the network?

		<i>answered question</i>	19
		<i>skipped question</i>	1
		Response Percent	Response Count
Very satisfied		47.4%	9
Satisfied		52.6%	10
Neutral		0.0%	0
Dissatisfied		0.0%	0
Very dissatisfied		0.0%	0

3. COMMUNICATION AND SUPPORT

	<i>answered question</i>						18
	<i>skipped question</i>						2
	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied	Rating Average	Response Count
Are you satisfied with the overall level of communication of the network?	57.1% (8)	42.9% (6)	0.0% (0)	0.0% (0)	0.0% (0)	1.43	14
Are you satisfied with the overall level of progress of the network?	35.3% (6)	64.7% (11)	0.0% (0)	0.0% (0)	0.0% (0)	1.65	17

Scottish Genital Anomaly Network Symposium

Friday 13th March 2009

Stirling Highland Hotel, Stirling

The Scottish Genital Anomaly Network is a managed clinical network supported by NSD Scotland and is dedicated to the management of congenital disorders of sex development and associated genital anomalies. Its mission includes the provision of education and opportunities for continuous professional development of its members as well as others involved in the delivery of health care.

1000-1030	Registration & Coffee	
1030-1100	Supporting Collaborative Clinical Research	Prof Richard Sinnott Professor and Technical Director National e-Science Centre University of Glasgow
1100-1130	Report from the Testis: Role of paracrine cytokines for testicular development and function	Professor Olle Soder MD; PhD Chairman of Dept of Women's and Children's Health Peds Endo Reproductive Research Unit Karolinska Institute & University Hospital Stockholm
1130-1200	'Role of AMH and the hCG stimulation test in evaluating Disorders of Sex Development'	Dr Faisal Ahmed SGAN
1200-1230	Psychosexual issues in DSD	Caroline Sanders Nurse Consultant Alder Hey Children's Hospital
1230-1300	AGM	
1300-1345	LUNCH	
1345-1415	Laparoscopy and DSD	Mr Gordon MacKinlay SGAN
1415-1445	Surgical and Medical approaches to Vaginal Atresia	Prof Anne Garden Centre for Medical Education Lancaster University
1445-1500	Coffee	
Research / Audit / Clinical Cases		
1500- 1600	Case presentations	
1600-1615	Close	

Registration fee: £40 as cheque payable to SGAN Fund

For further enquiries, contact:

Maureen Kinney SGAN Co-ordinator
MCN Department, 9th Floor QM Tower
Yorkhill, Glasgow G3 8SJ
email: maureen.kinney@ggc.scot.nhs.uk
Telephone: 0141 201 0693

Hotel details:

www.barcelo-hotels.co.uk/hotels/scotland/barcelo-stirling-highland-hotel

Analysis of Symposium Evaluation forms

21 evaluations received

1. How do you rate the relevance of this meeting to your need to keep informed about Genital Anomalies/DSDs?

No part relevant	Little of relevance	Fairly relevant	Mostly of relevance	Highly relevant
		14%	52%	33%

2. How do you rate the overall quality of education provided by this meeting?

Poor	Mediocre	Satisfactory	Good	Excellent
		4.76%	47.62%	47.62%

3. Have you any comments about individual presentations? Please use overleaf if necessary.

Very high quality presentations

More time for questions and awareness that not all participants are medical practitioners

4. How useful to you personally was this event?

Extremely useful	Useful	Fairly useful	Not useful	Not directly relevant in current post but of interest
33.33%	47.62%	9.52%	4.76%	4.76%

5. What impact will this event have on your future practice?

Wider understanding of issues & current practice

More awareness about psychosocial issues/surgical options for UA

Greater background knowledge useful to interpret biochem results

Further discussions

Know colleagues who can help

Good networking

Maybe use the network to consult on difficult gendo-assignments

Renewed enthusiasm to get involved in SGAN

Yes - but not in the way you think!

Increased awareness

Serious

6. What did you like best about the event?

Prof Soder's talk

Informality

Multidisciplinary

Case presentations

Surgical presentations & case studies

Get to know colleagues and their thinking

Psychosexual presentation and lunch!

Meeting folk & hearing interesting presentations

Dialogue with colleagues

Clear presentations - wide scope

Prof Soder's talk

SGAN

Discussions among professionals

7. What did you like least about the event?

Rushed

Too much science

8. What was your overall impression of this event?

	Poor	Mediocre	Satisfactory	Good	Excellent
Programme			9.52%	47.62%	14.29%
Organisation			4.76%	38.10%	28.57%
Catering			9.52%	52.38%	9.52%
Venue			9.52%	47.62%	14.29%

9. How could the symposium be improved?

Workshops/small group work.

More case studies, less highly technical; patient presentations

10. Have you any comments about the symposium in general?

Good, valid speakers and mix of disciplines; Anne Garden's presentation

Alert that there are patient representatives

Good all round

Patient experiences of network

Covered the multidisciplinary remit

11. Have you any topics you would like discussed at the next meeting?

Fertility options - surrogacy (law/ethics); donor eggs/sperm

12. Additional Comments:

Copies of presentations would be useful

Need to see more linked network support for children & families with problems

"Rota for case management" across Scotland - ambiguities