

Surgical Congenital Anomalies Network Scotland ANNUAL REPORT 2018/19

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1. Executive Summary

As part of national commissioning policy, Scottish Diaphragmatic Hernia Clinical Network (SDHCN) was assessed as to whether it continues to meet stakeholder needs and adds value to healthcare in Scotland. The review process concluded in October 2018 with National Specialist Services Committee (NSSC) confirming network designation for a further year, with an expanded remit to include four further surgical anomalies in addition to congenital diaphragmatic hernia (CDH). The network was subsequently rebranded as Surgical Congenital Anomalies Network Scotland (SCANS) to reflect this extension. It is due to report back to NSSC for its December 2019 meeting to evidence that appropriate progress with implementing the review recommendations has been made.

A 12-15 month programme of work (starting in January 2019) has been developed to track and prioritise progress against the review recommendations.

Major achievements to date have been:

- Refresh of the Steering Group and improved stakeholder engagement.
- Hosting a successful SCANS Launch Event in February 2019.
- Identifying leads to take various workstreams forward.
- Completion of a five year audit in Glasgow for all five conditions, which is being rolled out Scotland wide. The roll out has been completed for two conditions: Gastroschisis and Exomphalos. Results from the audit will be used to inform new SCANS guidelines, care pathways and patient information leaflets.
- Good progress in the Badgernet project with all five conditions now on an alert system which will inform the network of new diagnosis.

The main challenges to date have been data collection and developing a suite of documents for all four additional anomalies based on updated CDH documentation within the timescales agreed. The five year audit in Glasgow is a key piece of work that will underpin SCANS work on quality improvement and service development going forward. Progress with the Badgernet project to implement automatic alerts about new patients in the system has been successful to date. However, work is still ongoing to get all health boards who use Badgernet signed up to the alert system, which will give the network up to date information on all new diagnoses. Finally, patient information leaflets for the four additional anomalies are in development.

The main priority for next year is to progress the workplan to be in a position to provide evidence to the NSSC for its December 2019 meeting. The focus will be on development of guidelines, care pathways and patient information leaflets for all five conditions, robust key quality indicators, support for effective discharge management and communication and collection of robust data to measure against the quality indicators.

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2. Introduction

The Surgical Congenital Anomalies Network Scotland (SCANS) was established as the result of a formal network review of the Scottish Diaphragmatic Hernia Clinical Network (SDHCN), which was concluded in October 2018.

The Expert Review Group (ERG) identified a number of areas for development and improvement but also recognised that the SDHCN had added value to NHS Scotland through:

- the development of guidelines, care pathways and patient information leaflets
- auditing care against agreed standards
- provision of professional education
- patient engagement through links with CDH UK and capturing of patient experiences

To improve engagement of professionals, the network proposed to extend its scope to include four additional congenital anomalies requiring surgery: Gastroschisis, Exomphalos, Oesophageal Atresia, and Duodenal Atresia. This would not only widen stakeholder engagement but also allow the learning and developments from congenital diaphragmatic hernia (CDH) to benefit these other conditions and enable the improvements identified for CDH to be progressed more effectively. The ERG supported this proposal.

The National Specialist Services Committee (NSSC) considered the findings and recommendations from the review and designated the network for a further year, with an expanded remit to include the four aforementioned anomalies in addition to CDH. The expectation is that through expansion the network will increase engagement and deliver measurable improvements for patients and families affected by these conditions. NSSC further recommended that this expansion should be done with a view to aligning the network in due course with the new Scottish Neonatal Network.

Key objectives for SCANS to take forward were identified as follows:

- 1. Improve communication and engagement with all stakeholder groups, including obstetrics and fetal medicine as well as secondary care and primary care staff
- 2. Explore expansion of Steering Group membership to include family and voluntary group representation.
- 3. Discharge planning should be a priority with robust communication channels to community health professionals including Health Visitors and GPs as well as the patient's local hospital and the family.
- 4. Data collection should be improved, focusing on continued engagement with Badgernet developers.
- 5. Audit should be across the whole care pathway including after discharge.
- 6. The network should engage with CDH UK to progress family engagement with the network.

SCANS was designated with its expanded scope for five congenital surgical anomalies in October 2018 with a remit from NSSC to provide an update on the network's progress in time for its December 2019 meeting. With this in mind the Network developed an agreed workplan, covering January 2019 – March 2020, to deliver these objectives and evidence impact on families and patients affected by these conditions.

From the period April to September 2018, network activity focused on the network review, particularly on gathering support from the wider stakeholder group for the proposed extension. However, this report will focus on the activity in the period October 2018 to March 2019, following the designation of the network with an expansion in scope.

Within its extended remit it is estimated that the network now covers 70 - 80 live births per year for all five anomalies (compared to 20 - 25 previously for CDH alone). The network supports services in Scotland to provide equitable and prompt access to high quality care for all babies and children affected by these anomalies across their patient journey from antenatal, through perinatal, surgery, postnatal and long-term follow-up. Services for those affected by these conditions are delivered across three maternity units (Glasgow, Edinburgh and Aberdeen) allied to neonatal surgery units.

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3. Report on Progress against Network Objectives in 2018/19

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29¹. The network's core objectives are:

- Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) (Annex and national commissioning performance management and reporting arrangements; Annex C.
- 2. Support the design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
- 3. Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service User are involved in the Network and explicitly in the design and delivery of service models and improvements.
- 4. Improved capability and capacity the care of babies and children with congenital surgical anomalies through design and delivery of a written education strategy that reflects and meets stakeholder needs.
- 5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).
- 6. Generate better value for money in how services are delivered.
- 7. Key objectives identified in the review (please see section 2 on page 4 of this report for detail).

This report gives an overview of progress against these objectives in the year 2018/19.

3.1. Effective Network Structure and Governance

Building on earlier work to engage a much broader cross-section of relevant specialties in the work of the network, the SCANS steering group was established with a wider membership in October 2018 to reflect the extended scope agreed by NSSC. This is discussed in more detail under section 3.3.

Workplans, reports and other network documents are published on the new network website.

The current SCANS Lead Clinician is Mr Gregor Walker, Neonatal and Paediatric Surgeon based in Glasgow. His tenure is due to end in March 2020.

The Network has a service level agreement with NHS NSS in place for 2019 - 2020.

The full list of current SCANS Steering Group members is included in Appendix 1.

3.2. Service Development and Delivery

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¹ Please see: https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

Guidelines

It was agreed to develop guidelines and care pathways for the four additional surgical anomalies. A decision was made to first of all review and update the CDH documents, which includes the following:

- Antenatal Guideline
- Inpatient Guideline
- Follow-Up Guideline
- Antenatal Care Pathway
- Postnatal Care Pathway

Once finalised these will be used as a template for developing similar information leaflets, guidelines and care pathways for Exomphalos, Gastroschisis, Duodenal Atresia and Oesophageal Atresia. Four clinicians have now been identified to progress this workstream, with each leading on the development of documents for one of the additional conditions.

3.3. Stakeholder Communication and Engagement

Stakeholder Engagement

Recognising the challenge with professional engagement that was highlighted during the SDHCN network review the network has focused on:

- expansion of Steering Group membership to include better representation from fetal medicine as well as a wider geographical representation.
- expansion of the wider stakeholder group to include obstetrics and fetal medicine as well as secondary care and primary care staff (e.g. local hospital staff, Health Visitors, GPs).

In August and September 2018 the network surveyed clinicians from neonatology and fetal medicine to identify stakeholder support for the suggested expansion of the network. 26 clinicians from across a range of different specialities and Health Boards responded in support of this expansion.

In addition to this, NNMS staff supporting SDHCN participated in the 'Early Management of Rare Conditions for the Neonate' Conference in Glasgow on 3rd September 2018. Delegates at the conference were invited to complete a short questionnaire about their views on the network expansion proposal. 80 delegates responded with all of them supporting the expansion and no-one opposing the proposal.

A breakdown of responses is shown in Figure 1 below.

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Stakeholder Support

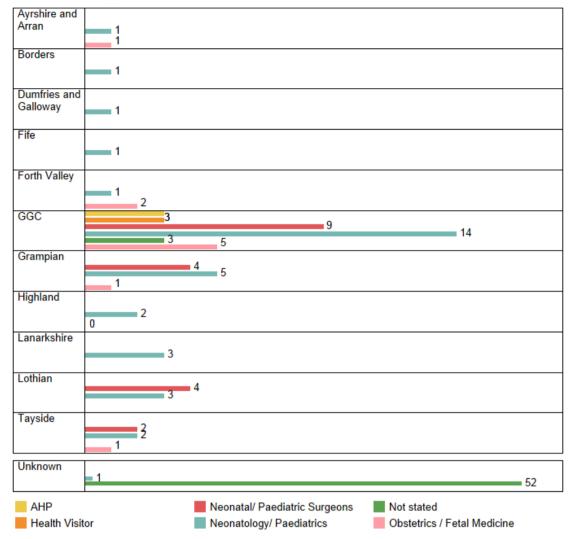


Figure 1: Stakeholder Support for Network Expansion

During these engagement activities, a number of clinicians were identified who would be interested to be directly involved in the work of an expanded network. They were subsequently invited to be part of the new Steering Group. Membership was formalised at the first SCANS Steering Group meeting in December 2018. The improvement in multi-disciplinary professional and geographical representation can be seen in Figure 2.

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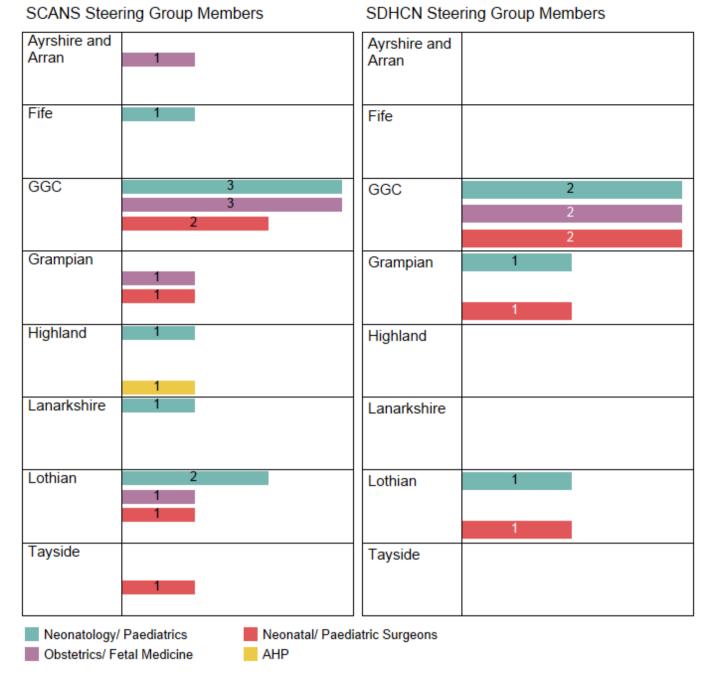


Figure 2: Current SCANS and former SDHCN Steering Group Membership

Website

A new SCANS website has been developed and is available at https://www.scans.scot.nhs.uk/.

The website currently contains CDH documentation (e.g. guidelines, care pathways and patient information leaflets) as well as some information on each of the four additional conditions.

Information materials

In addition to guidelines and care pathways SCANS is also reviewing and updating the CDH patient information leaflets, which cover antenatal and postnatal care.

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As with the guidelines and care pathways these will be used as a template for developing similar leaflets for the other four anomalies. The same clinicians will lead the work on development of guidelines and care pathways as well as patient information for each condition. Cognisance will be taken of the recommendations of the recent review to include long term follow up after discharge from hospital, targeting families and primary care staff as key audiences. This will provide information on long term outcomes and potential complications.

Patient/ Family Engagement

The network is currently looking at developing patient experience questionnaires for all five conditions covering the antenatal, in-patient and follow-up stages of the patient journey. This builds on previous work by the network to evaluate the patient experience for CDH in 2017/18.

Discharge Planning

One of the key findings from the CDH patient experience exercise last year was that many families felt isolated after their baby was discharged from hospital, with health professionals in primary and secondary care having little knowledge of the condition. This was reflected in the recommendations from the network review, which included making improvements to discharge planning by developing robust communication channels with primary care, in particular health visitors and GPs, local children's hospitals and the patient's family.

Dr Judith Simpson, Consultant Neonatologist in Glasgow, is a member of the National Neonatal Discharge Planning Group (NNDPG) and agreed to represent the network on that group. The NDPG aims to develop a framework for a consistent and equitable approach to discharge planning and neonatal community support and follow up throughout Scotland. This work supports the recommendations in *The Best Start: A five Year Plan for Maternity and Neonatal Care in Scotland*. The SCANS steering group agreed that liaison with this national workstream was the best mechanism to address the discharge planning challenges that had been highlighted by patients and during the network review.

The Discharge Planning subgroup of National Discharge Planning have so far made recommendations to focus on:

- Communication: early, regular effective communication with parents/carers including a discharge package, relevant community and hospital teams including both specialists and local base hospital.
- Collaboration/Coordination: development of a standardised pathway based on good practice and adapted to suit service provision with early identification of babies requiring a more formalised multi-disciplinary team/discharge planning meeting with complex medical/surgical needs or psychosocial concerns.

These recommendations await ratification by the wider NNDPG.

Within its five year audit, the network looked at the extent to which hospital discharge letters were sent to various health professionals who would likely be involved in the follow-up care pathway of babies affected by these conditions. So far this has been completed for two of the five conditions: Gastroschisis and Exomphalos.

The results of this audit are shown in Appendix 3. Key findings are as follows:

- Communication to both primary care and secondary care was highly variable:
 - GPs for example, were nearly universally included in discharge letter distribution (100% of Gastroschisis letters and 94% of Exomphalos letters).
 - o Other professionals in community, secondary and tertiary services were frequently not included in discharge letters for the two conditions. In particular, letters to local hospitals

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- and health visitors (< 50% and <10% of letters, respectively) were areas of concerns as these are often the first port of call for families after discharge.
- Taking into account CDH patient feedback about non-specialist healthcare professionals often not being informed about their condition, it is highly probable that within the other three conditions similar trends will be found. This will inform SCANS work on discharge communication as a key priority going forward.

Communication and Engagement Strategy

The network drafted a Communication and Engagement Strategy, which will be presented to the steering group for endorsement at the June 2019 meeting.

3.4. Education

SCANS Launch Event

The network held a successful launch event on 22nd February 2019 in Glasgow. The purpose of the event was to:

- Introduce the SCANS network including the outcome of the recent network review
- Present an overview of the SCANS 12-15 month workplan and progress against it
- Present an overview of challanges of data collection within the network
- Present a five year audit of care for the five anomalies
- Provide a Clinical Overview of the five conditions
- Present Case discussions for all five conditions

The event was attended by 55 people and 22 feedback forms were completed (36% response rate).

Figure 3 below shows event delegates split by profession.

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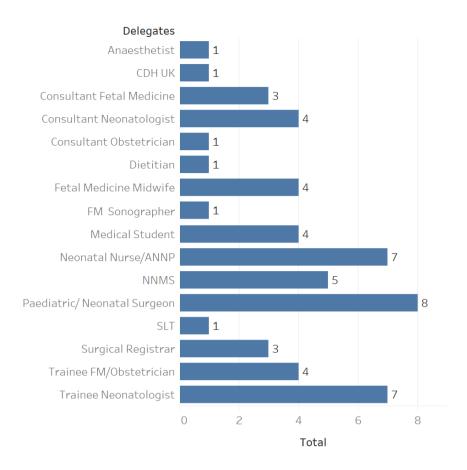


Figure 3: Delegate attendance at SCANS Launch Event

Figure 4 summarises how effective the event was in meeting delegates' expectations, CPD needs and educational needs. Across all measures delegate feedback was very positive.

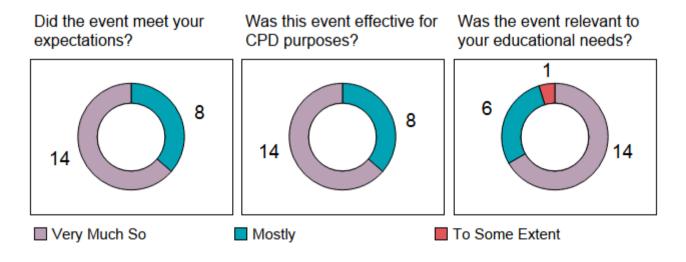


Figure 4: Evaluation responses from SCANS Launch Event

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This was also reflected in delegate feedback about their intentions to change their clinical practice as a result of attending the event. Learning points were summarised under the following headings:

- Change of clinical practice
 - have more structured discussions with parents/families regarding the patient's condition, treatment and counselling needs
 - improved transition process for patients transitioning to adult services
 - more involvement in the development of patient information leaflets
 - improve data collection and audit
- How could future SCANS events be improved
 - use of VC
 - small discussion groups when developing /reviewing pathways
 - MDT presentation of cases
- What topics would you like to see covered in future SCANS events
 - developmental follow-up
 - presentation of data from UK wide/EU databases

Strategic Planning Event 2019

The network is currently organising a Strategic Planning Event to be held in Glasgow in September. To date over 20 people have registered, all exclusive of the SCANS steering group membership. The purpose of the event is to:

- Provide evidence of progress within the workplan, including workstreams that have been completed and updates on others that remain in progress with realistic timescales.
- Develop a 3 5 year strategic plan to take the network forward with a view of alignment with the new Scottish National Neonatal Network.

This evidence will form the basis of a report to the NSSC in time for its December 2019 meeting to demonstrate the network's positive impact and ongoing role in improving care for families affected by congenital surgical anomalies.

Education Strategy

The network completed a draft Education Strategy, which will be presented to the steering group for endorsement at the June 2019 meeting.

3.5. Audit and Continuous Quality Improvement

Quality Improvement relies on collection and audit of accurate, robust data and the establishment of meaningful quality indicators. Once guidelines and care pathways have been developed and agreed for all five conditions, key quality indicators will be developed to audit and improve care, based the expectations described in the guidelines and care pathways.

Data Collection

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Prospective data collection for CDH has always been challenging with previous practice being to review cases collectively at the annual education event. Although this is a robust method of identifying data from cases presenting at specialist centres, the potential remains to miss babies diagnosed antenatally that do not survive to the stage of requiring specialist management. The network has developed a mechanism to utilise both the Badgernet neonatal and maternity systems as a source of information. Progress to date with rolling this out across Scotland is as follows:

- From July 2018, an alert was established for CDH within both systems to notify the network of anonymised new cases and to signpost clinical staff to the CDH guideline, care pathway and patient information leaflet. However in order for the alert process to be activated, the relevant clinical teams in each Health Board need to opt in to the alert system for their unit (i.e. they need to opt in separately for neonatal and maternity Badgernet if both are used in one Health Board). Figure 5 shows Health Boards who use the Badgernet systems and those who have signed up to the alerts.
- Through the Information Management Service (IMS), the network has engaged with Clevermed and now alerts are set up for all five diagnoses from March 2019.
- Local leads continue to be identified to provide liaison between Badgernet users in each Board and SCANS.
- IMS plan to engage with all boards who have not yet signed up to the alerts and provide them with a Public Benefit and Privacy Panel (PBPP) document.



Figure 5: Health Boards who use Badgernet systems and those who have signed up to alerts

Audit

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The network completed five year audits from January 2013 to December 2017 for all five conditions, initially just looking at data from Glasgow. The audit is being rolled out Scotland wide and has so far been completed for Gastroschisis and Exomphalos. Results of the audit so far are shown in Appendix 3. Once completed this data will be used to inform standards, guidelines, care pathways and patient information leaflets, as well as the development of network quality indicators.

3.6. Value

As demonstrated in the network review report, the SDHCN provided value to NHS Scotland and families affected by CDH in Scotland through:

- the development of standardised guidelines, care pathways and patient information leaflets –
 provides evidence-based care for mother and babies where a multidisciplinary approach to optimise
 all aspects of care can improve collaborative working across services and lead to a better outcome
 for families.
- auditing against standards in the face of challenging data collection-identifying variation in care across services or against standards can lead to quality improvement in delivery of service.
- provision of professional education-can achieve greater awareness of best practice amongst Scottish clinicians.
- patient engagement through links with CDH UK and collection of patient experience-can identify patients /families needs, values views and preferences, identify areas of service improvement, provide valuable emotional support and improve patient centred care

In addition, the *Mothers and Babies – Reducing Risk through Audit and Confidential Enquiries across the UK* (MBRRACE-UK) report, published in December 2014, highlighted the SDHCN clinical pathways as examples of good practice as they centred around patients.

Since the designation of SCANS as a network with a broader remit for congenital surgical anomalies in October 2018, there has not yet been sufficient opportunity to similarly demonstrate added value in relation to the expanded scope of the network. The expectation is to provide this evidence in time for the report back to NSSC in December 2019.

4. Plans for the Year Ahead

The work objectives for SCANS in 2019/20 are as follows:

- Develop patient information leaflets, guidelines and care pathways for all five conditions
- Collect data collection and audit all five conditions across all sites in Scotland.
- Patient Experience Survey to be completed for all five conditions.
- Facilitate sign-up by all Health Boards who use Badgernet to the alert system
- Develop key performance indicators for all five conditions that can measure improvement using data collected
- Continue to liaise with the NDPG to improve discharge planning for families affected by these anomalies.
- Continue to progress the specific recommendations from the Network Review.

The Network will need to show evidence of good progress for the NSSC meeting in December 2019. This presents challenging timescales for completing the current network work programme to be able to provide this evidence. There are risks to timely progress with the network work programme within those timescales, in particular as work on guidelines and care pathways relies heavily on the input of many different clinicians who have competing demands on their limited time.

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5. Detailed Description of Progress in 2018/19 (Workplan Jan 2019 - March 2020)

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
GREEN (G)	The network is on track to achieve the objective by the agreed end date.
BLUE (B)	The network has been successful in achieving the network objective to plan.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2019	Anticipated Outcome	RAGB status
1. Effective	ve Network Structure and Governance	[linked to Quality Dir	mensions 3,4,5,6	3		
2019-01	Improve network stakeholder engagement: Revise Steering Group and wider network membership to reflect expanded network scope	Jan 2019/ Dec 2019	Hugh Kennedy	Both Steering Group and wider membership revised	More effective network through involving additional key stakeholders	G
2. Service	e Development and Delivery [linked to Quali	ty Dimensions 1,2,3,4	4,5,6]			
2019-02	Revise the following guidelines for CDH: • Antenatal • In-Patient • Follow-Up	Jan 2019/ March 2020	Steering Group	Documents have been circulated to relevant clinicians for review	Revised CDH guidelines will be used as a basis of developing guidelines for 4 other conditions within scope in	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2019	Anticipated Outcome	RAGB status
	Use to develop guidelines for other 4 conditions Gastroschisis Exomphalos Oesophageal Atresia Duodenal Atresia				strategic plan.	
2019-03	Revise antenatal care pathway for CDH and use to develop care pathways for the other 4 conditions within scope: • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia	Jan 2019/ March 2020	Steering Group	5 year audit (Jan 2013 - Dec 2017) performed in NHS GGC of patient journey for all 5 conditions - will be used to inform pathways	Improved service delivery for mother and baby affected by any of these conditions	G
2019-04	Revise postnatal care pathway for CDH and use to develop care pathways for the other 4 conditions within scope: • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia	Jan 2019/ March 2020	Steering Group	5 year audit (Jan 2013 - Dec 2017) performed in NHS GGC of patient journey for all 5 conditions - will be used to inform pathways	Improved service delivery for children and young people with these conditions	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2019	Anticipated Outcome	RAGB status
3. Stakeh	older Communication and Engagemer Revise antenatal patient information	nt [linked to Quality [Dimensions 1,3,4	l,5,6]		
2019-05	leaflets for CDH Use to develop similar leaflets for the other 4 conditions within scope: • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia	Jan 2019/ Dec 2019	Steering Group	Documents have been circulated to relevant clinicians for review	Facilitate provision of better support for mother and baby affected by any of these conditions	G
2019-06	Revise postnatal patient information leaflets for CDH Incorporate follow up after discharge into postnatal leaflet targeting families and primary care staff Use to develop similar leaflets for the other 4 conditions within scope:- Gastroschisis Exomphalos Oesophageal Atresia Duodenal Atresia	Jan 2019/ Dec 2019	Steering Group	Documents have been circulated to relevant clinicians for review	Facilitate provision of better support for parents and patients after discharge affected by any of these conditions	G
2019-07	Organise and hold a strategic planning event to:	September 2019	Steering Group	Date agreed-Sept 20 th 2019	Evidence provided that the network has demonstrated that it	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2019	Anticipated Outcome	RAGB status
	Present evidence of what the network has achieved to date Develop a strategic plan to take the network forward over the next 2 - 4 tears aligned with the new Scottish Neonatal Network				has achieved the objectives set by NSSC	
2019-08	Support effective discharge management and communication: Engage with National Discharge Planning Group whose function is to develop framework to support consistent and equitable discharge planning and delivery of neonatal community support and follow up throughout Scotland.	Jan 2019/ Dec 2019	Hugh Kennedy/ Judith Simpson		Facilitate better support for parents and children after discharge affected by any of these conditions	G
2019-09	Develop a network Communication and Engagement Strategy	Jan 2019/ Dec 2019	Hugh Kennedy/ Kirsty Young	Draft Strategy Developed	More effective network through involving additional key stakeholders	G
2019-10	Develop new SCANS Website	Jan 2019/ Dec 2019	Kirsty Young	Website framework developed	Improved engagement with both patients and professionals	G
2019-11	Engage with patients and families affected by any of these conditions	Jan 2019/ Dec 2019	Hugh Kennedy	Patient experience questionnaire developed for CDH will be used as a template. Patents identified	Identified areas and action plan for improvements to service delivery and previously unmet	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2019	Anticipated Outcome	RAGB status
					needs associated with newly diagnosed condition	
4. Educat	ion [linked to Quality Dimensions 1,2,3,4,5,6]					
2019-12	Hold annual education conference	Feb 2019	Hugh Kennedy/ Kirsty Young	Event took place on Feb 22 nd 2019-Evaluations in main body of report	Improved knowledge in these congenital anomalies for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	G
5. Audit a	nd Continuous Quality Improvement ^{[I}	inked to Quality Dime	ensions 1,2,3,4,5	,6]		
2019-13	Improve identification of new cases to specialist services in the network	April 2019/March 2020	Louise Smith/ Hugh Kennedy	In partnership with Clevermed the network has been working with both Maternity and Neonatal Badgernet systems to get alerts set up for CDH and other four conditions. This has now been completed. Work is ongoing to get all boards signed up to alerts.	Improved outcomes for babies with any of these conditions through identification and entry into pathways at appropriate stages of the patient journey.	G
2019-14	Agree quality indicators and associate measures along the full pathway for all	April 2019/March	Steering Group/	Quality Indicators already developed for CDH to be	Identified service improvements for	G

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2019	Anticipated Outcome	RAGB status
	conditions within the network remit to underpin an ongoing programme of quality improvement	2020	Louise Smith/ Hugh Kennedy	used as a base.	patients with any of these conditions	
6. Value [inked to Quality Dimensions 1,2,3,4,5,6]					
None						G

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Appendix 1: Steering Group Membership

Name	Designation	Health Board Area
Ms Lisa Steven	Consultant Paediatric Surgeon	Tayside
Mr Yatin Patel	Consultant Paediatric Surgeon	Grampian
Dr Ben Stenson	Consultant Neonatologist	Lothian
Mr Fraser Munro	Consultant Paediatric Surgeon	Lothian
Dr Judith Simpson	Consultant Neonatologist	GGC
Mr Gregor Walker	Consultant Paediatric and Neonatal Surgeon	GGC(Lead Clinician)
Dr Shona Cowan	Consultant Obstetrician	Lothian
Mr Carl Davis	Consultant Paediatric and Neonatal Surgeon	GGC
Cindy Sykes	Neonatal Transport	Lothian
Morag Liddell	Neonatal Nurse	GGC
Dr Alan Webb	Consultant Neonatologist	Highland
Sandra Whitelaw	Fetal Medicine Midwife	GGC
Prof Allan Cameron	Consultant Obstetrician	GGC
Dr Neil Patel	Consultant Neonatologist	GGC
Dr Lena Crichton	Consultant Obstetrician	Grampian
Dr Janice Gibson	Consultant Obstetrician	GGC
Lynnette Mackenzie	Neonatal/Paediatric Nurse	Fife
Dr Innis Osman	Consultant Obstetrician	Ayrshire & Arran
Deborah Smith	Neonatal Nurse	Lanarkshire
Sue-Ann Grant	Speech and Language Therapist	Highland
John Collins	Parent	Glasgow

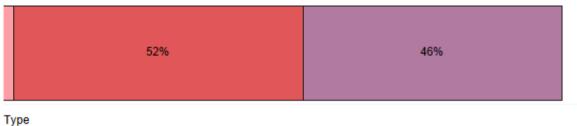
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Appendix 2: Finance

The annual budget for SCANS expenditure (not including staffing costs) is £5,000. Spending against this budget for 2018/19 was £4,214.80, covering costs of £1,950 for an educational conference and the SCANS launch event cost of £2,185. The educational conference took place in December 2017; however the payment was not processed until April 2018.

SCANS Financial Information

Job description	Account description	18/19
SCANS	EXHIBITIONS AND CONFERENCES	£1,950.00
	HIRE OF ROOMS FOR MEETINGS	£2,185.00
	INTERNL CATERING RECHRG NPAY	£79.80
Grand Total		£4,214.80



Type

EXHIBITIONS AND CONFERENCES

HIRE OF ROOMS FOR MEETINGS

INTERNL CATERING RECHRG NPAY

Fig. 6: SCANS Budget 2018/19

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Appendix 3: Five Year Audit Results

Glasgow Only

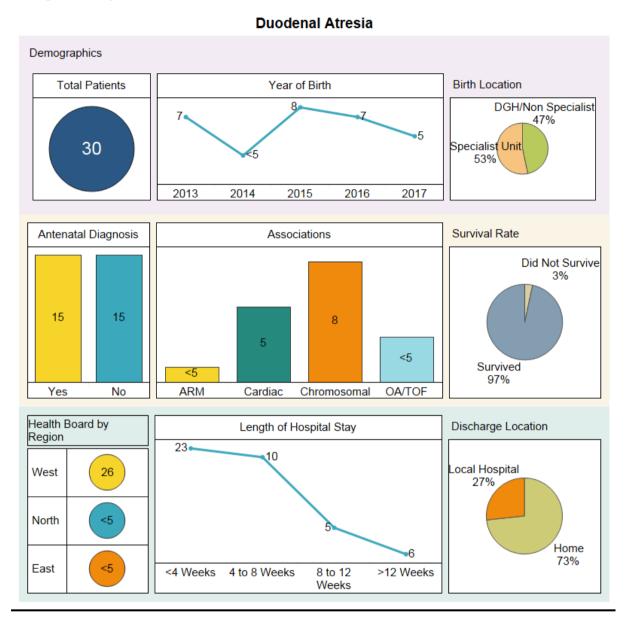


Fig. 7: Duodenal Atresia-Results of Five Year Audit for Glasgow, Jan 2013-Dec 2017

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Glasgow Only

Diaphragmatic Hernia Demographics **Total Patients** Year of Birth Birth Location 10% **•**16 Outwith Scotland 25% 60 DGH/Non Specialist 65% Specialist unit 2013 2014 2015 2016 2017 Antenatal Diagnosis Type of Surgery Survival Rate Did Not Survive 30% 29 44 21 10 Survived 16 70% Patch Repair Primary Repair No Repair No Yes Health Board by Region Discharge Location Length of Hospital Stay 30 West 41 Local Hospital Home 23% East 8 42% Outside Scotland Died on unit 30% 8 to 12 >12 Weeks North <4 Weeks 4 to 8

Fig. 8: Diaphragmatic Hernia-Results of Five Year Audit for Glasgow, Jan 2013-Dec 2017

Weeks

Weeks

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Glasgow Only

Osophogeal Atresia Demographics Total Patients Year of Birth Birth Location 17 100% 44 DGH/Non Specialist <5 2013 2014 2015 2016 2017 Survival Rate Associations Antenatal Diagnosis 5% Did Not Survive 11 42 <5 95% VACTERL Musculoskel. Cardiac Chromosomal Duodenal Survived Atresia Yes No Health Board by Birth Location Length of Hospital Stay Region 23• 5% RHC West 39 30% Local Hospital North 61% East 5% Home Died in unit Outside <4 Weeks 4 to 8 Weeks 8 to 12 Weeks >12 Weeks Scotland

Fig. 9: Oesophageal Atresia-Results of Five Year Audit for Glasgow, Jan 2013-Dec 2017

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All Scotland



Fig. 10: Gastroschisis-Results of Five Year Audit for All Scotland, Jan 2013-Dec 2017

<u>Note</u>: The denominator for letter distribution for "local hospital" excludes cases where the tertiary centre is the local hospital (rendering a discharge letter redundant).

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Exomphalos Letter Distribution Demographics **Total Patients** Year of Birth Birth Location GΡ 94% AMH SGH* 9% 20% PRM 10 35 8 RIE 6 Surgeon 69% QEUH <5 43% 2013 2014 2015 2016 2017 47% Antenatal Diagnosis Type of Exomphalos Local Hospital Survival Rate Did Not Survive 89% 18 23% Neonatologist 12 <5 Survived 11% 83% Yes No Minor Major Ruptured Moderate Genetics 17% Health Board by Length of Hospital Stay Discharge Location Region Various/Transferred Died on unit East 6 Fetal 9% Local Hospital medicine/Obstetrics 13 14% 5 North 6 <5 <5

Fig. 11: Exomphalos-Results of Five Year Audit for All Scotland, Jan 2013-Dec 2017

8 to 12

Weeks

4 to 8

Weeks

West

24

<4 Weeks

<u>Note</u>: The denominator for letter distribution for "local hospital" excludes cases where the tertiary centre is the local hospital (rendering a discharge letter redundant).

>12 Weeks

Home

63%

Health visitor

6%

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