



**Surgical Congenital Anomalies Network Scotland  
(SCANS)  
Annual Report  
2020/21**

**Lead Clinician – Mr James Andrews  
Programme Manager – Hugh Kennedy  
Programme Support Officer – Linda Watson  
Data Analyst – Louise Smith**

## **Summary of Year / Current Position**

The impact of the pandemic on SCANS was significant, with reduced capacity amongst members to contribute to workstreams and the Lead Clinician unable to devote time to the network during the first six months of the reporting period.

The network responded to this challenge in a number of ways. At the beginning of the year, the network had to adapt to an evolving situation and new ways of working via utilisation of online platforms - primarily Microsoft Teams. Although a number of meetings were put on hold due to the pandemic, there was still some engagement with network members using this technology. Other work progressed during this period included facilitating planning and preparation for starting an ambitious post discharge audit. Completion of this audit was the major priority for the network in 2020/21. Progress during this period included engaging with clinicians leading the audit, to agree and finalise data fields to be audited. Finally, the network managed to have useful engagement with Clevermed, developers of the Badgernet system, resulting in improvements to the report utilised by the network to access data.

Over the past six months, workstreams have progressed, in particular, the post discharge audit. However, completion of this audit requires information from Public Health and Intelligence (PHI). Access to this data has been delayed due to PHI's involvement in C-19. Nevertheless, the network will present progress to date at the June steering group meeting. Completion of this audit will be vital to progressing the networks workstreams moving forward.

A new Lead Clinician, Mr James Andrews, was appointed in October 2020 with dedicated network time. In addition, the majority of clinical staff have now returned to their primary roles. Both these changes have enabled the audit and other interdependent workstreams, previously on hold, to progress.

The 2020/21 workplan ([Appendix 1](#)) sets out details of progress while key highlights are outlined below.

## **Key Highlights**

### **Improvement in Steering Group structure and membership**

Improvement in professional engagement was one of the key recommendations from the 2018/2019 network review. Since then the steering group has been expanded to include a much wider geographical and multi-disciplinary representation. In particular, recent additions of a neonatal liaison nurse and health visitor will enhance the network's discharge planning workstream. This was set up in response to evidence from patient experience surveys that identified that parents/cares felt frightened and isolated, caring for a baby with a serious and rare condition at home without the support and the expertise of the tertiary centre clinicians. [Appendix 2](#) evidences how the network has delivered.

In addition to having a wider range of experienced clinicians represented on the steering group there has also been improved collaborative working over the last six months leading to an improvement in progressing a number of workplan objectives during that period. Five leads have taken on responsibility for completion of the post discharge audit and development of guidelines, care pathways and patient information leaflets, with each lead responsible for one condition. Each lead now has dedicated named support from other steering group members in driving these workstreams forward. In addition, the network has now formed a Communication and Engagement subgroup, led by Dr Neil Patel, whose remit is to lead the development and implementation a Communication and Engagement Strategy in 2021/22.

## **Service Development and Delivery**

A key recommendation from the Network Review in 2019/20 was that:

‘audit should be across the whole care pathway for these patients, including after discharge.’

The network embarked on an ambitious audit exercise to gather evidence which in turn would underpin and inform the rest of the work to which it had committed including clinical pathways and high quality, tailored education and information resources for all professionals. It also would identify key areas for improvement as well as providing valuable information for families.

During 2019/20, the network completed the first part of this exercise by completion of a five-year audit covering the demographic details and outcomes for the antenatal and in-patient stay for live born infants from January 2013 to December 2017.

During the past year, the network has undertaken the final part of this audit with the same cohort of patients, covering the first two years, after discharge, of the identified babies’ lives. This will again provide invaluable evidence that is not currently available in the UK on issues such as age and date of final discharge to home, the impact of associated anomalies, clinical status e.g. weight, feeding, respiratory support, medications at discharge all followed up at two years post discharge. At this stage, other areas audited include details of developmental status as well as data on hospital appointments and admissions (number/frequency/location and speciality), age and date.

Other data planned to be included in the audit are the number of hospital appointments and admissions during this period with details of hospital site, speciality and any interventions. PHI have agreed to supply this data to individual named clinicians in relevant boards; on receipt of the baby’s CHI. Due to Information Governance (IG), they can only do this with Caldicott approval as some of the patient cohort may have these follow-up episodes outwith their board of residence. Information Management Services (IMS) have submitted a Public Benefit and Privacy Panel (PBPP) application, which if successful will allow this data to be shared.

When completed, results from this audit will again identify additional key areas of improvement to add to workstreams already identified from the previous audit. These included:

- Development of antenatal and in-patient patient information leaflets for all 5 conditions which includes robust evidence based information from the audit
- Looking at improving Discharge Planning for SCANS patients, aligned with the work that is being undertaken by the National Perinatal Network as part of the Best Start recommendation from 2017. Both repatriation and post-discharge communication were key areas identified from the audit that needed improvement.
- Development of KPI's, to ensure improvements in both repatriation and post discharge communication to key stakeholders.

The complete list will form the basis of development of a suite of KPI's as part of the 2021/22 workplan, which will be used to measure continuous quality improvement going forward.

This audit (excluding PHI data) is almost complete. Findings to date will be analysed and presented at the June steering group meeting.

## Website

The network continues to raise awareness and increase the visibility of SCANS and its website [www.scans.scot.nhs.uk](http://www.scans.scot.nhs.uk). During 2020/21, the focus has been on engagement with third sector stakeholders, agreeing reciprocal website address hosting. Third sector organisations included Tracheo-Oesophageal Fistula Support (TOFS) and Down Syndrome Scotland (a common co-morbidity of Duodenal Atresia) in addition to Congenital Diaphragmatic Hernia (CDH) UK. From April 2020 to March 2021, there were 2,183 more sessions (visits to the website) than the previous year and 3,169 more individual page views than the previous year. (see Appendix 3)

## Audit and Quality Improvement

- Data Collection and Audit

The network has been utilising the Badgernet system over the past two years as a means of collecting antenatal and neonatal data for this cohort of babies. A new on-line report was developed last year that allows Information Management Services (IMS) to access this data on a monthly basis. Excellent progress has been made over the latter part of the year through IMS and the Lead Clinician engaging with a number of boards and having them agree to share their Badgernet data (see Appendix 4 for comparison with last year).

A key clinical standard is that any baby diagnosed antenatally should have the remainder of the mother's pregnancy managed in a specialist centre and then transferred to the neonatal unit in that centre after birth. IMS have also engaged with Clevermed to develop the on-line report further to provide a complete audit of the care pathway from antenatal diagnosis through to neonatal admission and report terminations together with stillbirths and neonatal deaths. This means that babies diagnosed antenatally that do not survive to the stage of requiring specialist management are identified and services alerted to ensure that parents receive appropriate information and support. It also allows the network to investigate these episodes and, if relevant, through 'lessons learned' drive quality improvement for both patient and family

This project remains a work-in-progress as there are still a few boards not sharing their Badgernet data due to Information Governance rules. Approval of the PBPP will allow these boards to do this. A final challenge will be collecting meaningful antenatal data from NHS Lothian until they are using the Badgernet System. The network plans to engage with the National Perinatal Network (which includes both Maternity and Neonatal networks) to explore ways of collecting this data meantime

Despite these challenges, the Badgernet project has been a major success for the network. Identification of babies diagnosed antenatally and not surviving to the stage of requiring specialist management has been a major concern for the network for a number of years.

In analysing the data for the period April 2020-March 2021 Badgernet recorded 85 cases for boards who have signed up to sharing their data . This includes both antenatal and postnatal diagnosis. [Appendix 5](#) shows numbers per condition, and total diagnosis broken down by type of diagnosis, whilst [Appendix 6](#) shows how each condition was diagnosed.

The progress the network has made over the past 5 years in collecting data should be highlighted. [Appendix 7](#) shows the improvement of the network ability to gather robust data over the past five years in terms of numbers of diagnoses captured. [Appendix 8](#) demonstrates how the complete care pathway from antenatal diagnosis to neonatal admission showing outcomes is now captured on the current Badgernet report.

## **Exceptions**

The following objectives have not been fully delivered for the reasons explained in Section 1. The network however has progressed most of these over the past six months and are on schedule to be delivered during 2021/22.

### **Post Discharge Audit**

Planning and initiation delayed due to C-19 but now under way and scheduled for completion during 2021/22

### **Development of guidelines, care pathways and patient information leaflets**

Interdependency with post discharge audit has delayed the plan to review the CDH guidelines, care pathways and patient information leaflets and then use these as templates to produce similar documentation for the other four conditions. These pieces of work will be completed during 2021/22.

### **Communication and Engagement**

In addition to improving professional engagement, the network had also planned to progress family engagement. This workstream was another that was heavily impacted by the pandemic. The network formed a Communication and Engagement sub group, which had an initial meeting in March 2021.

The group considered feedback from a CDH questionnaire issued in 2017/18 and the more recent questionnaire in 2018/19 to families of the cohort of babies included in the five-year audit. Both of these identified a number of themes to be explored to improve services as well as families who wanted to engage with the network.

This workstream and others will be part of the Communication and Engagement Strategy that the sub group is taking forward in 2021/22.

### **Education**

SCANS has been unable to deliver its education event due to the impact of the pandemic. However, a virtual event is planned for September 2021, which will encompass both education and stakeholder engagement. The network is currently developing an education strategy focused on delivering educational needs to clinicians involved in caring for these patient at all stages of their care journey.

It plans to sign off both Communication and Education Strategies at the September event.

### **Looking forward**

Full details of the proposed workplan for 2021/22 are outlined in **Appendix 9**. Key workstreams will be;-

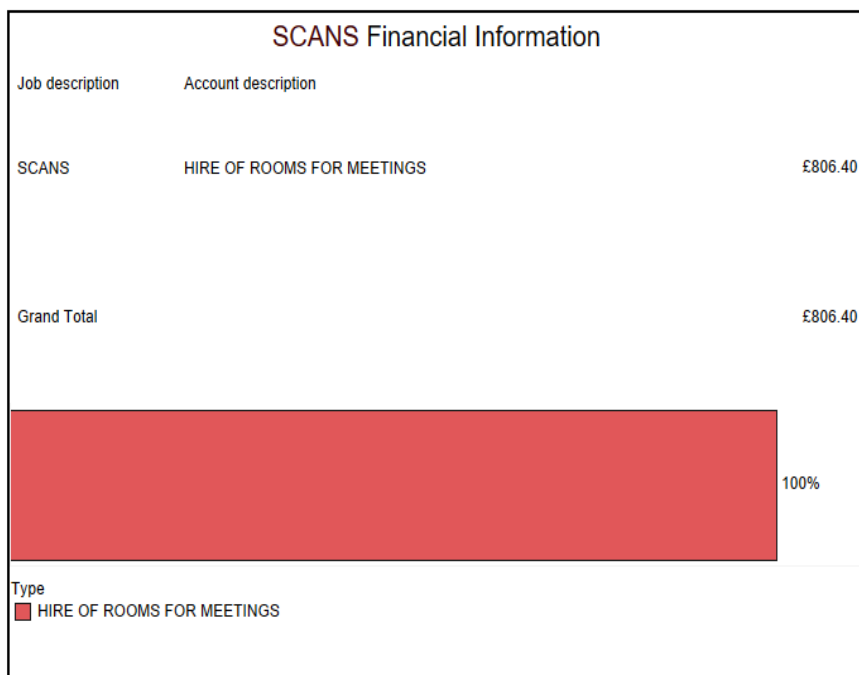
- Completion of the post-discharge audit, followed by analysis of the results. This work will then will drive other workstreams .e.g. guidelines and care pathways, patient information leaflets and KPI'S.
- Engaging further with Clevermed to progress the inclusion of data up to discharge on the on-line report.
- Whilst Badgernet supplies valuable data on antenatal and postnatal care, the network has been looking at ways of auditing post-discharge care prospectively. The use of the Clinical Audit System (CAS) to capture this data has been successfully explored with IMS. A CAS instance has been built based on data required to measure key points in the CDH Follow-up guidelines and other key milestones identified in the post discharge audit that are both important and measurable and relevant to all five conditions.

Together with the additional data from Badgernet this will mean prospective data will be collected from antenatal diagnosis to the first two years of the baby's post-discharge. The network will develop a suite of KPI's using the results and analysis of both the post discharge audit and the previous five-year audit to identify areas of improvement and measure against these using the data collected to drive continuous quality improvement

- Development of Communication and Engagement and Education Strategies

### **Finance**

Of the £5,000 annual budget, SCANS spend of £806.40 relates to a deposit made for an education event that was booked for June 2020 at the Studio Hotel in Glasgow which was cancelled due to Covid lockdown. The network has contacted the Studio who have offered a voucher for the value of the deposit.



## **Risk**

The network is dependent on the approval of the PBPP to complete two important pieces of work. The post discharge audit relies on information from PHI and a complete Badgernet report will rely on the boards not currently sharing their data to do so. The PBPP approval will allow both these pieces of work to progress. The document was submitted to the Data Protection Officer by IMS but the impact of C-19 has delayed the approval process. If the PBPP is not approved it would compromise the delivery of both these objectives.

## Appendix 1 – Annual Workplan

### SCANS Workplan April 2020- March 2021

RAGB status	Description
<b>RED (R)</b>	The network is unlikely to achieve the objective by the agreed end date.
<b>AMBER (A)</b>	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
<b>GREEN (G)</b>	The network is on track to achieve the objective by the agreed end date.
<b>BLUE (B)</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 2021	Anticipated Outcome	RAGB status
<b>1. Effective Network Structure and Governance</b> <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-01	Update and endorse Network Service Level Agreement so that Network continues to meet core principals of managed clinical networks as set out in CEL (2012) 29.	April 2020/ March 2021	Programme Manager/ Lead Clinician	New SA 2020/23 endorsed and signed including 3 year strategic workplan	There are effective governance arrangements in place.	<b>B</b>
2019-01	Continue to improve network stakeholder engagement: Target psychology, sonographers and health visitors and additional family rep to add to steering group membership	April 2020/ March 2021	Programme Manager/ Steering Group	Anaesthetist, Health Visitor, Sonographer and Neonatal Liaison Nurse added. GP, family rep and adult physician in progress. c/fwd.	More effective network through involving additional key stakeholders	<b>B</b>
2020-02	Organise 3 Steering Group meetings to ensure effective delivery of the 2020/21 workplan	April 2020/ March 2021	Steering Group	1 <sup>st</sup> meeting -August 2020 2 <sup>nd</sup> meeting -Dec 2020 3 <sup>rd</sup> meeting –March 2021	Effective delivery of the SCANS work plan to ensure continuation of progress.	<b>B</b>
2020-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/20- 31/05/21	Lead Clinician/ Programme Manager	MYR finalised , AR completed	There are effective governance arrangements in place.	<b>B</b>
<b>2. Service Development and Delivery</b> <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						



Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
2020-04	<p>Undertake 2 Year Post-Discharge audit of all 5 conditions across the 3 specialist centres in Scotland: This will mean the network will have a complete and robust audit over a 7-year period (2013-2019) of babies born between 2013-2017. This will include their antenatal and in-patient stay followed up by their first two years after discharge.</p> <ul style="list-style-type: none"> <li>• Agree data fields to collect info</li> <li>• Leads to send CHI numbers to PHI who will use CARDRISS to provide hospital appointments and admissions. Clinical data will come from EPR's.</li> <li>• Consolidate on database</li> <li>• Analysis by IMS using Infographics</li> </ul>	April 2020/ March 2021	Steering Group	<p>Data fields agreed, audit progressed and near completion</p> <p>PBPP submitted to allow PHI to send data relating to hospital app and admissions once sites send their relevant CHI numbers for all the surviving babies from the 5-year audit.</p> <p>PBPP still awaiting authorisation from Data Protection Officer –this has been delayed due to COVID</p> <p>Audit analysis however can still be progressed without this data C/fwd.</p>	Findings will be invaluable in planning services, informing network documents and patient information materials	A
2019-05	<p>Review, update and publish the following guidelines for CDH:</p> <ul style="list-style-type: none"> <li>• Antenatal</li> <li>• In-Patient</li> <li>• Follow-Up</li> </ul> <p>Use CDH docs to begin development of guidelines for other 4 conditions</p> <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2020/ March 2021	Steering Group	<p>b/fwd.</p> <p>Despite delay in starting this work CDH A/N Guideline complete and circulated for any final comment. Other CDH docs in progress.</p> <p>Guidelines for other four conditions planned to completed 2021/22 c/fwd.</p>	A suite of evidence based guidelines and continuing programme of audit will ensure high quality of care throughout Scotland for mothers and babies with these conditions	A
2019-06	<p>Revise antenatal care pathway for CDH and use to begin development of care pathways for the other 4 conditions within scope:</p>	April 2020/ March 2021	Steering Group	<p>CDH care pathway being reviewed, with template used to develop similar docs for other four conditions.</p>	Improved service delivery for mother and baby affected by any of these conditions	A

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
	<ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>			Timescale for completion of all 5 conditions 2021/22 c/fwd.		
2019-07	Revise postnatal care pathway for CDH and use to begin development of care pathways for the other 4 conditions within scope: <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2020/ March 2021	Steering Group	As with antenatal pathway c/fwd.	Improved service delivery for children and young people with these conditions	A
<b>3. Stakeholder Communication and Engagement</b> <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2019-08	Complete and publish antenatal patient information leaflets for CDH Use to develop and publish similar leaflets for the other 4 conditions within scope: <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2020/ March 2021	Steering Group	b/fwd. Documents have been circulated to relevant clinicians for review.	Facilitate provision of better support for mother and baby affected by any of these conditions	A
2019-09	Begin development of in-patient and post-discharge patient information leaflets for CDH using data collected from 2-year audit Use to begin development of similar leaflets for the other 4 conditions within scope: - <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2020/ March 2021	Steering Group	Plan is to produce leaflets for CDH initially then use template for other 4 conditions Completion of leaflets for all conditions will 2021/22. Post discharge leaflets will be informed by analysis of 2 year audit results c/fwd	Facilitate provision of better support for parents and patients after discharge affected by any of these conditions	A

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
2019-11	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.	April 2020/ March 2021	Programme Manager/ Judith Simpson	b/fwd Three SCANS steering group members are part of both the ; <ul style="list-style-type: none"> <li>Neonatal Dashboard sub group-looking to create a national core dataset. This would mirror an earlier piece of work looking at core requirements for a maternity dashboard. Both dashboards were part of the maternity and neonatal data hub as recommended by 'Best Start'</li> <li>Neonatal Repatriation sub group-looking to agree a set of national criteria that should be met before a baby is repatriated. Dr Judith Simpson, neonatologist with SCANS, leads the Repatriation group.</li> </ul> Both of these workstreams are work-in-progress c/fwd	Facilitate better support for parents and children after discharge affected by any of these conditions	A
2019-12	Produce a network Communication and Engagement Strategy	April 2020/ March 2021	Programme Manager	b/fwd. Network has formed a Comms Sub Group and is looking at various workstreams:- Website, Parent/Patient Engagement , Information packages for families and HV's as well as linking with Education Strategy Plan to	More effective network through involving additional key stakeholders	A

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
				endorse by September 2021 Education /Stakeholder vent		
2020-05	Development and maintenance of SCANS Website	April 2020/ March 2021	Programme Support Officer	b/fwd. Website developed-and is being populated and updated in collaboration with Dr Neil Patel	Improved engagement with both patients and professionals	B
2019-14	Engage with patients and families affected by any of these conditions	April 2020/ March 2021	Programme Manager	b/fwd. This will be part of Communication and Engagement Strategy and has focused :- 1. Analysis of patient feedback already gathered from previous surveys. This had identified issues important to patients /families. How best to take this forward has been discussed but no plan yet in place how to take forward. Impact of Covid has delayed progress of this workstream. 2. Again group has discussed how to progress contacting families who have expressed interest in engaging but no decision made 3. These issues will be taken forward 2020/21 as part of Comms and Eng Strategy. c/fwd	The network objective priorities will be driven by parents and family members of patients with these conditions.  Identified areas and action plan for improvements to service delivery and previously unmet needs associated with newly diagnosed condition.	A

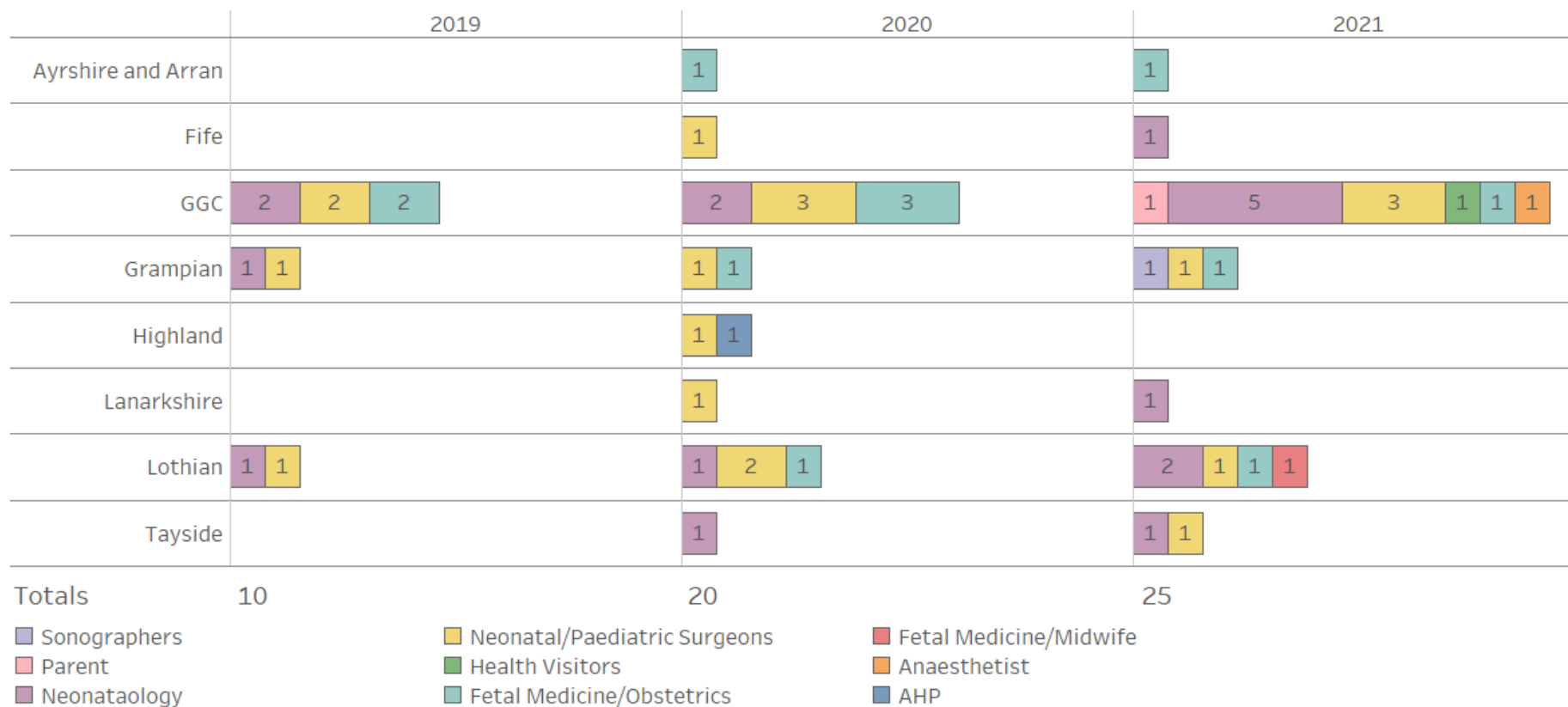
Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
<b>4. Education</b> <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-15	Produce an Education Strategy	April 2020/ March 2021	Programme Manager/ Steering Group	b/fwd.  Draft Developed. Plan to endorse by September 2021.	Improved knowledge for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	A
2020-06	Hold annual education conference	April 2020/ March 2021	Programme Manager/ Linda Watson	Planned for June 2020. Postponed –re-scheduled date September 2021. c/fwd	Improved knowledge in these congenital anomalies for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	R
<b>5. Audit and Continuous Quality Improvement</b> <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-16	Improve identification of new cases to specialist services in the network	April 2020//March 2021	Data Analyst	b/fwd. Good progress in collection and analysis of antenatal and postnatal data through Badgernet in partnership with Clevermed across all boards who have agreed to share their data. PBPP submitted to hopefully allow all boards on Badgernet to share data-delay in sign-off due to COVID. Network planning to use CAS to capture post-discharge data prospectively for audit	Improved outcomes for babies with any of these conditions through identification and entry into pathways at appropriate stages of the patient journey.	A

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
2019-17	Agree quality indicators and associate measures along the full pathway for all conditions within the network remit to underpin an ongoing programme of quality improvement	April 2020//March 2021	Steering Group/ Data Analyst/ Programme Manager	b/fwd. This exercise has three strands:- 1. Areas of improvement from 5-year audit already identified- • Repatriation • Discharge Panning 2. Analysis of post-discharge audit will identify addition areas 3. Generic CDH KPI's already endorsed will be used for all 5 conditions where relevant Plan for completion 2021/22 c/fwd	Identified service improvements for patients with any of these conditions	A
2020-07	Complete QI Strategy	April 2020//March 2021	Programme Manager	Draft completed	Develop and endorse a strategy to drive quality improvement	A
<b>6. Value</b> <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-08	Providing added value to health care in Scotland	April 2020//March 2021	Network	Ongoing SCANS has added value to health care in the following ways_ • Progressing development of care pathways and expectations of care that details the kinds of service that patients/families should have access too. • Collaborative working across services sing a multi-disciplinary approach	Providing added value to health care in Scotland for these groups of patients as well as cost savings for NHS Scotland	B

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
				<ul style="list-style-type: none"> <li data-bbox="1279 284 1671 357">Auditing care against standards</li> </ul>		

## Appendix 2 – Increase in Steering Group membership March 2019-March 2021

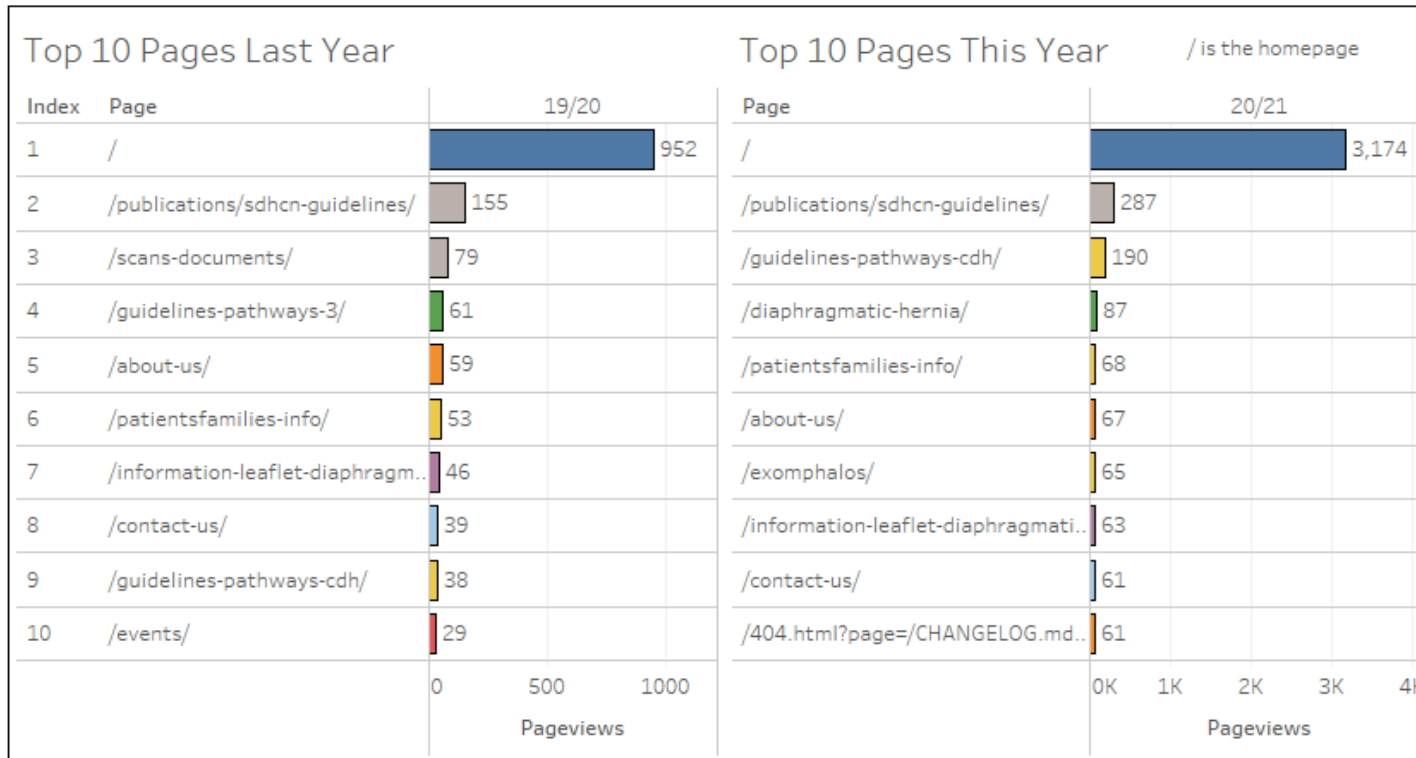
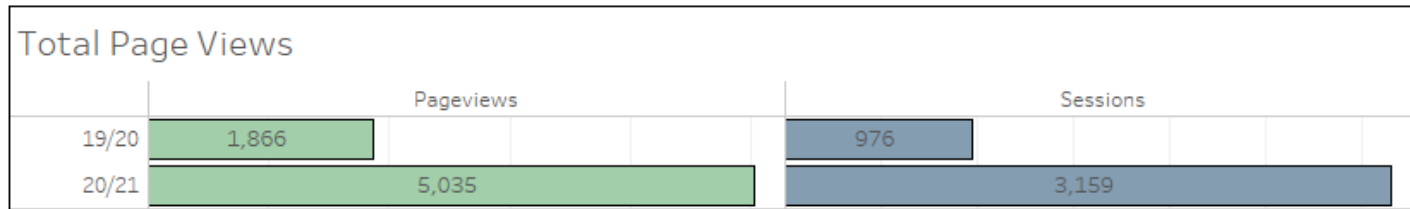
Steering Group Membership 2021





## Appendix 3 – Increase in SCANS Website usage 2019/20-2020/21

Full year report



## Appendix 4 – Comparison of number of Health Boards sharing Badgernet data. March 2020-March 2021

March 2020

Health Boards signed up to Badgernet data being shared with SCANS		
	Maternity	Neonatal
A&A	No	No
Borders	Yes	No
D&G	No	No
Fife	Yes	Yes
Forth Valley	Yes	No
GGC	Yes	Yes
Grampian	No	Yes
Highland	No	No
Lanarkshire	Yes	No
Lothian	No	No
Orkney	No	Yes
Shetland	No	Yes
Tayside	No	No
Western Isles	Yes	No

March 2021

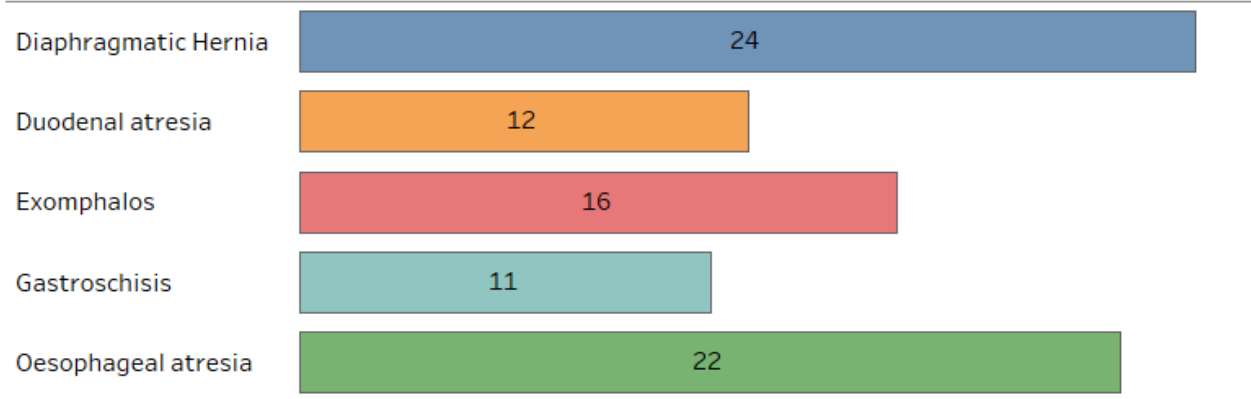
Health Boards signed up to Badgernet data being shared with SCANS		
	Maternity	Neonatal
A&A	Yes	Yes
Borders	Yes	No
D&G	No	No
Fife	Yes	Yes
Forth Valley	Yes	Yes
GGC	Yes	Yes
Grampian	No	Yes
Highland	No	Yes
Lanarkshire	Yes	No
Lothian	No	Yes
Orkney	No	Yes
Shetland	No	Yes
Tayside	Yes	Yes
Western Isles	Yes	

- Western Isles does not have a neonatal unit.
- NHS Lothian Maternity Badgernet not yet live in March 2021
- D&G Neonatal have just recently approved but this was post March 2021 and has not yet been actioned on spreadsheet

## Appendix 5 – Badgernet Diagnosis by condition and system 2022/21

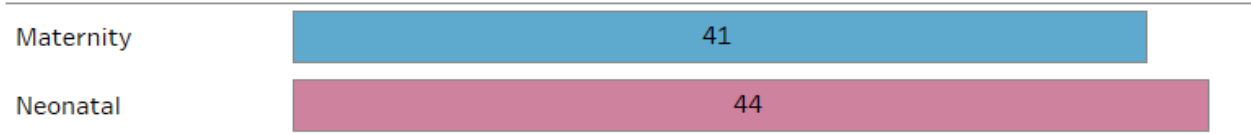
### Number of Patients

*Apr 2020 - Mar 2021*



### Number of Alerts per System

*Apr 2020 - Mar 2021*



The above two graphics show the number of patients who have had a diagnosis entered into the Badgernet system. The top graphic shows this by condition; whilst the bottom one shows total numbers of patients diagnosed antenatally (41) and postnatally (44) , represented by the system they were initially capture on. Patients with an antenatal diagnosis who first presented on the maternity system will remain during the mother’s pregnancy. Once they are born and survive to be admitted to a neonatal unit, they will be entered into the neonatal system. However, the Badgernet report has been designed so that these babies will not be double-counted. The Neonatal figure of 44 therefore only represents babies with a postnatal diagnoses who will first present on the neonatal system.

## Appendix 6 – Badgernet Diagnosis by condition analysed by system 2022/21

### Source of Diagnosis

*Apr 20 - Mar 21*

	Maternity	Neonatal
Diaphragmatic Hernia	58%	42%
Duodenal Atresia	25%	75%
Exomphalos	81%	19%
Gastroschisis	73%	27%
Oesophageal Atresia	14%	86%

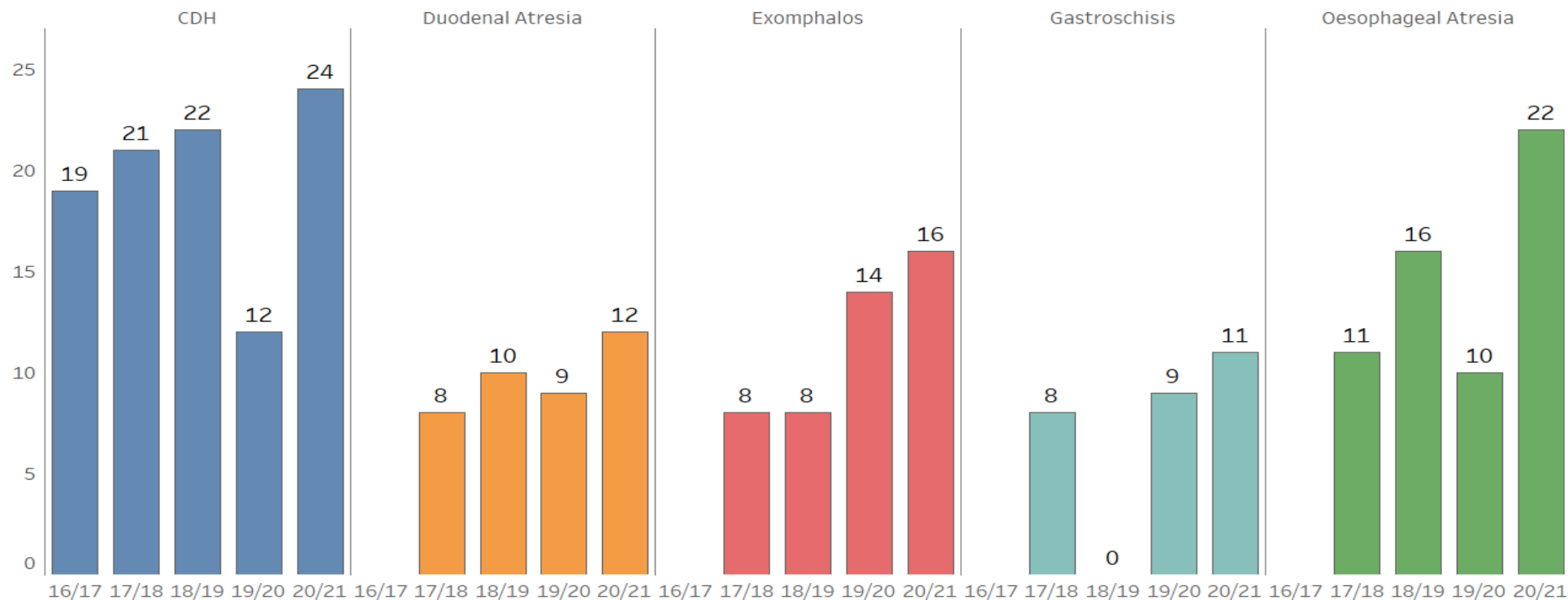
The above graphic depicts the number of children who initially presented on either maternity Badgernet or the neonatal Badgernet system by condition, showing the spread of antenatal and postnatal diagnosis. (i.e. 14 (58%) of the 24 Diaphragmatic Hernia (DH) diagnosis were antenatal)

Whilst Appendix 5 showed that overall alerts are roughly equal between maternity and neonatal systems, Appendix 6 shows there were large variations in the type of diagnosis between different conditions (apart from DH). ((Percentages had to be used for General Data Protection Regulation (GDPR) as some numbers were <5)). Feedback from recent surveys showed that families whose child was not diagnosed antenatally gave negative comments regarding why this did not happen. Their perception was that they would have had more information at an earlier stage regarding the condition and the probable prognosis as well as being better supported by the clinical team. The steering group agreed that advances could be made in detection rates whilst recognising that not all abnormalities will be detected. This is supported by the Fetal Anomaly Screening Programme (FASP) standards for antenatal diagnosis of congenital anomalies that are below 100%

These figs per condition will therefore be used as a base line to measure against future measures.

## Appendix 7 – Comparison of Data captured by the network over the past 5 years-2016/17- 2020/21

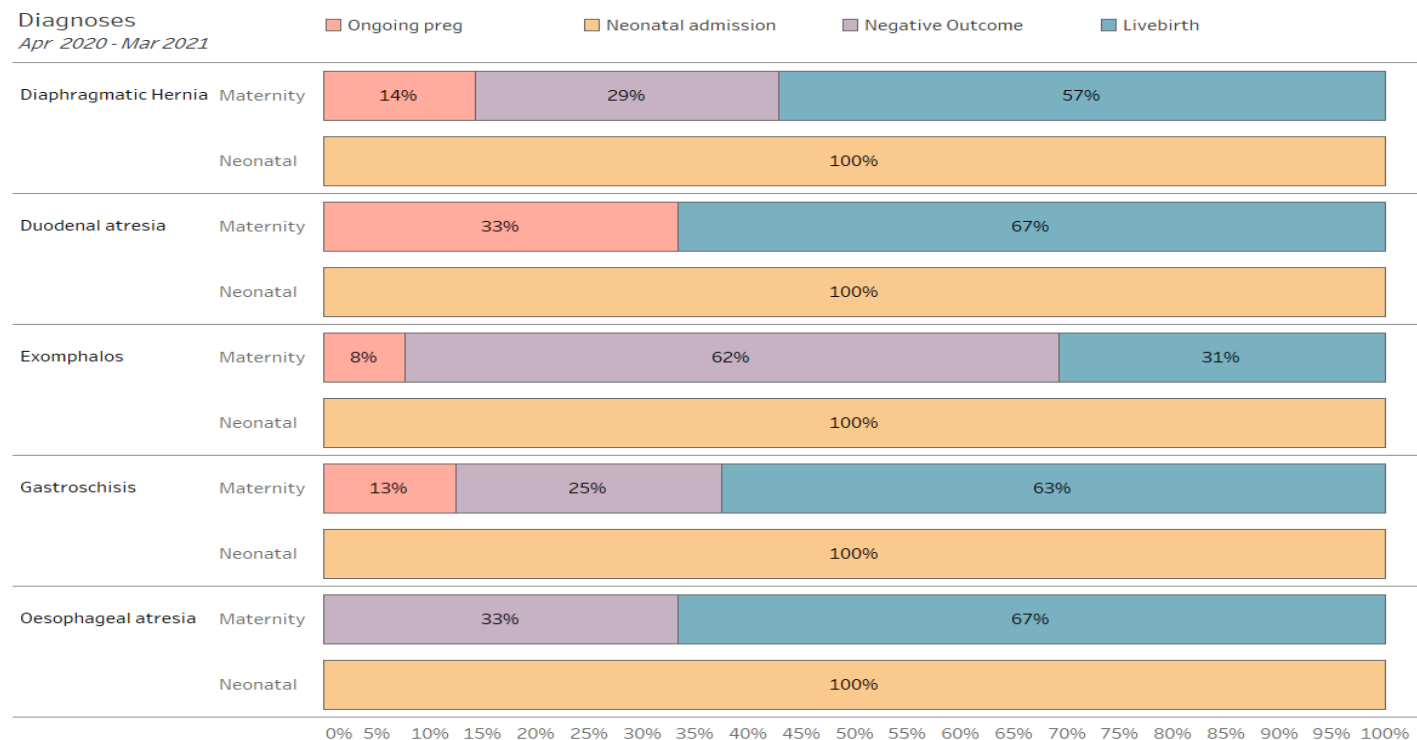
All Scotland Figures  
2016 - 2021



\* Previous year's figures are not a complete representation of Scotland SCANS patients due to health boards only recently signing up to Badgernet. 2020/21 financial year is the most accurate data collected to date.

Detailed on-line Badgernet data has only been available since April 2019. Previously the data gathered from Clevermed was simply a Scotland wide figure supplied at the year-end of total diagnosis. These figures had no breakdown of board, antenatal/postnatal details or month of diagnosis behind them and as the graphic shows, in some of these years here was no data supplied for some conditions. The improvement in quality of data accessed can be seen more clearly in [Appendix 8](#) below.

## Appendix 8 – Breakdown of condition by outcome reported on Badgernet- 2020/21



Analysis of [Appendix 8](#) shows outcome of babies diagnosed antenatally. This detail has only been available since February 2021 and demonstrates the improvements made by the network in accessing useful Badgernet data. The graphic highlights that there are some cases that require further investigation. e.g. 29% of CDH antenatal diagnoses had a negative outcome. A negative outcome includes termination, antepartum stillbirth, neonatal death, an episode 'Automatically Closed by Badgernet' or outcome unknown. An episode 'Automatically Closed by Badgernet' occurs when an antenatal diagnosis is recorded but there is no delivery of the baby after a reasonable period so the system closes the record. This will be due to an early miscarriage where the mother has not informed the hospital or where the mother moves away after the antenatal diagnosis. Outcome unknown refers to an antenatal diagnosis where there has been no delivery recorded after a reasonable period but the record has not been closed by the system. A more detailed breakdown showing these different outcomes by actual numbers is available to individual centres on request to IMS. This will allow local investigation so that the network can consider what further action needs to be taken to improve outcomes. Neonatal diagnosis currently only shows 100% neonatal admission as an outcome with no other information. The network has requested additional information regarding survival at discharge from Clevermed for 2021/22. This report will then show the complete pathway from antenatal diagnosis to discharge for this cohort of babies.

## Appendix 9 – Workplan April 2021- March 2022

RAGB status	Description
<b>RED (R)</b>	The network is unlikely to achieve the objective by the agreed end date.
<b>AMBER (A)</b>	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
<b>GREEN (G)</b>	The network is on track to achieve the objective by the agreed end date.
<b>BLUE (B)</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 2021	Anticipated Outcome	RAGB status
<b>1. Effective Network Structure and Governance</b> <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2019-01	Continue to improve network stakeholder engagement: Target psychology, adult physicians GP and family rep	April 2021/March 2022	Programme Manager/ Steering Group	b/fwd Good progress already made. Network plans to target GP, psychology and adult physician	More effective network through involving additional key stakeholders	
2021-01	Organise 3 Steering Group meetings to ensure effective delivery of the 2021/22 workplan	April 2021/March 2022	Programme Manager/ Steering Group	2 Steering Group Meetings have already been arranged: June and November 2021	Effective delivery of the SCANS work plan to ensure continuation of progress.	
2021-02	The network will meet reporting requirements: - Mid-year Report - Annual Report	April 2021/March 2022	Lead Clinician/ Programme Manager		There are effective governance arrangements in place.	
<b>2. Service Development and Delivery</b> <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-04	Analyse results of the 2 Year Post-Discharge audit of all 5 conditions across Scotland: This will mean the network will have a complete and robust audit over a 7-year period (2013-2019) of babies born between 2013-2017. This will include their antenatal and in-patient stay followed up by their first two years after discharge.	April 2021/March 2022	Leads/IMS Programme Manager	b/fwd Audit almost completed for all 5 conditions. PBPP application with DPO but endorsement delayed by COVID. However analysis can begin without this data	Findings will be invaluable in informing network documents and patient information materials	

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
2019-05	<p>Complete and publish the following guidelines for CDH:</p> <ul style="list-style-type: none"> <li>• Antenatal</li> <li>• In-Patient</li> <li>• Follow-Up</li> </ul> <p>Use to develop guidelines for other 4 conditions</p> <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2021/March 2022	Leads	<p>b/fwd CDH Antenatal complete and circulated for comments. Other documents have been circulated to relevant clinicians for review.</p> <p>Completion for other 4 conditions will use CDH template-already started.</p>		
2019-06	<p>Revise antenatal care pathway for CDH and use to develop care pathways for the other 4 conditions within scope:</p> <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2021/March 2022	Leads	<p>b/fwd CDH care pathway being reviewed, with template used to develop similar docs for other four conditions.</p>	Improved service delivery for mother and baby affected by any of these conditions	
2019-07	<p>Revise postnatal care pathway for CDH and use to develop care pathways for the other 4 conditions within scope:</p> <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2021/March 2022	Leads	<p>b/fwd Will be informed by analysis of post-discharge audit results-</p>	Improved service delivery for children and young people with these conditions	

### 3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]



Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
2019-08	<p>Complete and publish antenatal patient information leaflets for CDH Use to develop and publish similar leaflets for the other 4 conditions within scope:</p> <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2021/March 2022	Leads	b/fwd. Documents have been circulated to relevant clinicians for review.	Facilitate provision of better support for mother and baby affected by any of these conditions	
2019-09	<p>Begin development of in-patient and post-discharge patient information leaflets for CDH using data collected from 2-year audit Use to begin development of similar leaflets for the other 4 conditions within scope: -</p> <ul style="list-style-type: none"> <li>• Gastroschisis</li> <li>• Exomphalos</li> <li>• Oesophageal Atresia</li> <li>• Duodenal Atresia</li> </ul>	April 2021/March 2022	Leads	b/fwd Plan is to produce leaflets for CDH initially then use template for other 4 conditions Completion of leaflets for all conditions will 2021/22. Both will be informed by analysis of post discharge audit results	Facilitate provision of better support for parents and patients after discharge affected by any of these conditions	
2019-11	<p>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.</p>	April 2021/March 2022	Programme Manager/ Lead Clinician /Judith Simpson	b/fwd  In progress	Facilitate better support for parents and children after discharge affected by any of these conditions	
2019-12	Produce and implement a network Communication and Engagement Strategy	April 2021/March 2022	Comms and Eng Sub Group	b/fwd In progress. Comm and Eng sub group formed to complete. Planned for September 2021	More effective network through involving additional key stakeholders	

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
2021-03	Development and maintenance of SCANS Website	April 2021/March 2022	Comms and Eng Sub Group	Continued development	Improved engagement with both patients and professionals	
2019-04	Engage with patients and families affected by any of these conditions	April 2021/March 2022	Comms and Eng Sub Group	b/fwd part of Comm and Eng Sub Group	Identified areas and action plan for improvements to service delivery and previously unmet family needs associated with newly diagnosed condition	
<b>4. Education</b> [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-15	Develop and endorse Education Strategy	April 2021/March 2022	Programme Manager/ Steering Group	b/fwd In progress. Planned for September 2021	Improved knowledge for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
2020-06	Hold annual education conference	April 2021/March 2022	Programme Manager/ Linda Watson	b/fwd Planned for September 2021	Improved knowledge in these congenital anomalies for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
<b>5. Audit and Continuous Quality Improvement</b> [linked to Quality Dimensions 1,2,3,4,5,6]						
2021-04	Improve identification of new cases to specialist services in the network	April 2021/March 2022	Data Analyst	Continue the good progress already made. Look to develop Badgernet report to capture pathway from	Improved outcomes for babies with any of these conditions through identification and entry	

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2021	Anticipated Outcome	RAGB status
				neonatal admission to discharge Plan to have all boards across Scotland sharing antenatal and postnatal Badgernet data once PPBP approved. Network will also use CAS to capture and audit post-discharge data prospectively	into pathways at appropriate stages of the patient journey.	
2019-17	Agree suite of quality indicators and associate measures along the full pathway for all conditions within the network remit to underpin an ongoing programme of quality improvement	April 2021/March 2022	Steering Group/ Data Analyst/ Programme Manager	b/fwd Network will develop a complete suite of KPI's from both audits and generic KPI's already developed for CDH	Identified service improvements for patients with any of these conditions	
	Complete QI Strategy		Programme Manager	In Progress. KPI's will be used to drive quality improvement.		
<b>6. Value</b> [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-08	Providing added value to health care in Scotland		Network		Providing added value to health care in Scotland for these groups of patients as well as cost savings for NHS Scotland	