

Surgical Congenital Anomalies Network Scotland

ANNUAL REPORT 2019/20

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1. Executive Summary

Following an independent review of the Scottish Diaphragmatic Hernia Clinical Network (SDHCN) under routine national commissioning in 2018, it was agreed that the scope of the network be extended to include further congenital anomalies requiring surgery. In addition to patients with diaphragmatic hernia, the network now also includes patients with gastroschisis, exomphalos, oesophageal atresia and duodenal atresia rebranded as the Surgical Congenital Anomalies Network Scotland (SCANS).

The network reported on the first year of progress to the National Specialist Services Committee (NSSC) in December 2019. They noted the excellent progress made by SCANS and a further commissioning period was approved.

The major achievements during this period, as highlighted in the report to the NSSC have been:

1. Improved wider stakeholder engagement evidenced by a successful Strategic Planning Day in September 2019.
2. Completion of an ambitious and comprehensive five-year audit in across Scotland for all five conditions. This is the first of its kind in the UK and provided robust clinical evidence on which to design clinical pathways and other information for both clinicians and families.
3. Completion of a patient experience survey across all five conditions. Responses are being analysed to identify themes important to families which will be used by the network to inform services with the aim to deliver what matters to families.
4. Continuing engagement with Clevermed, developers of Badgernet, to identify new diagnosis and signpost clinical staff to relevant care pathways.
5. Development of a 3-year strategic plan to improve the care for babies, their mothers and families for these 5 conditions.

Despite the successes of the network there have also been some challenges around some of the scheduled activity taking longer than anticipated. This work continues, informed by the findings of the 5-year audit.

The main priority for next year is to progress the work already started with focus on:

1. completion of a post-discharge 2-year audit which, together with the results of the 5-year audit, will provide invaluable evidence to:
 - inform the development of guidelines, care pathways and patient information leaflets for all five conditions
 - develop robust key quality indicators and collection of robust data to measure against these
 - support for effective discharge management and communication
 - and collection of robust data to measure against the quality indicators.
2. Progress patient and family engagement, building on the feedback from the patient experience survey
3. Progress data collection through engagement with Clevermed and health boards
4. Continue to capture the impact of COVID-19 on the workplan

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). The view of both the network and an independent review panel was that the network would benefit from expansion and the network proposed adding four congenital anomalies requiring surgery. This would not only re-invigorate engagement but also allow the learning and developments from congenital diaphragmatic hernia (CDH) to benefit babies and their families affected by these other four conditions and enable the improvements identified for CDH to be progressed more effectively.

The NSSC supported this proposal with a number of key objectives to take forward, including:

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.

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.

Since February 2020, understandably NHS Scotland priority has been to prepare for and deal with COVID-19 impact and this has seen clinical and other resource diverted from network activity. The network has undertaken an exercise to not only capture the impact of this unprecedented situation on the current reporting period but also to assess the likely impact on delivery of the 2020/21 workplan.

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:

1. 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.

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

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.

This report gives an overview of progress against these objectives in the year 2019/20.

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 membership has expanded further from the initial momentum gained from the SCANS launch in February 2019. 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 until March 2020 and arrangements are under way to recruit a successor.

The Network has a service level agreement with NHS NSS in place for 2019 - 2020. A new SLA is under development and will include the revised 3-year strategic plan once it has been endorsed by the steering group.

The full list of current SCANS Steering Group members is included in [Appendix 1](#).

Expansion has had a significant positive impact on engagement from the wider network membership, demonstrated through the high attendance at the Strategic Planning Event (72 delegates) following a successful Launch Event in late February 2019 (60 delegates). Participation at these events in setting and delivering future priorities for the network demonstrated recognition of synergies between the conditions and renewed commitment to driving improvement.

The revised steering group has a wider geographical and multi-disciplinary representation and has met twice with consistently higher attendance, (21 at the June meeting and 24 at the December one). A meeting planned for March 2020 had to be cancelled due to COVID-19.

3.2. Service Development and Delivery

3.2.1 5-Year Audit

The priority for the network this year has been to collect evidence of outcomes for this group of patients across their care pathway by means of an extensive audit exercise. The expanded network agreed that the audit findings would be critical to underpin and inform the rest of the work to which it had committed. They therefore embarked on an ambitious and comprehensive audit exercise, the first in the UK, which would provide robust clinical evidence on which to design clinical pathways and produce high quality, tailored education and information resources for professionals and families.

The audit covered the demographic details and outcomes for the antenatal and in-patient stay for live born infants from January 2013 to December 2017. It included all live births for Gastroschisis, Exomphalos, Duodenal Atresia, Congenital Diaphragmatic Hernia and Oesophageal Atresia, collecting data from all three specialist centres; Glasgow, Edinburgh (including Dundee) and Aberdeen. It was a huge exercise involving the collection of 37 fields of data for each of 354 patients. Findings from the audit have been invaluable in

providing a clear, up to date picture of clinical presentation, care and experience at these key stages of the care pathway in Scotland. It also identified key areas for improvement:

- to develop repatriation pathways to facilitate a potentially earlier return to a hospital closer to home
- to improve post discharge communication, focusing on community health care staff, particularly health visitors who are often the first point of contact for parents after discharge.

A summary of the audit findings is shown in Appendix 3, figures 8-12. Key findings were:

- a) Antenatal diagnosis-this figure varied over the 5 conditions- from 100% to 20%. Recent feedback from families showed negative comments from families whose child's condition was not diagnosed antenatally. The steering group agreed that advances could be made in detection rates, recognising that not all abnormalities will be diagnosed. This is supported by Fetal Anomaly Screening Programme (FASP) standards for antenatal diagnosis of congenital anomalies which are below 100%. The network also recognises the need for managing expectations in families and avoiding reinforcement of the idea that not making an antenatal diagnosis represents a "failure".
- b) Repatriation – the results from the 5-year audit showed, of all patients who were discharged from specialist centres, more than 75% of them were discharged home instead of back to their local health boards. Results also showed that 67% of babies were treated in neonatal surgical units outwith their geographical health boards. There is therefore an opportunity to increase the proportion of patients that are repatriated to local hospitals prior to discharge home. Several possible challenges for this were identified:
 - Specialist centres may be reluctant to "release babies", preferring to hold on to them until ready for discharge.
 - Parents may receive unintended messages that care in the non-specialist centres has been sub-optimal compared to specialist units thus raising their anxiety levels.
 - Many local centres may not have the capacity with regard to neonatal cots.
 - Some local centres may have concerns about specific medical or nursing management of these patients as they have little experience of doing this in the past.
 - In some cases, many local units will not admit babies more than one month old to a neonatal cot, preferring them to be admitted to a paediatric unit.

Improving repatriation rates are a priority for the network, particularly since feedback from families indicated a preference for being treated nearer home. Other work by Dr Neil Patel has found that parental visits to specialist hospitals during neonatal stay cause a financial burden to the family budget with median costs around £2K per annum. There is a process in place for families to apply for financial help but many families don't. SCANS will work with the neonatal network to raise awareness of this fund.

The group agreed that good communication between specialist centre and local neonatal units well in advance of the transfer to allow planning was essential for successful repatriation. The neonatal network will be doing a piece of work around repatriation and the SCANS network will provide the neonatal network with data from the 5 year-audit to help evidence this.

- c) Discharge Planning –there was large variation with regard to who the discharge letters were sent to. GP's for example were universally included in discharge letter distribution whereas other professionals in community, secondary and tertiary care were frequently not included. In particular, letters to local hospitals and health visitors (<50% and <10% of letters respectively). The network agreed that this was another area that should be prioritised for improvement, particularly engagement with health visitors as they are usually the first point of contact for families after discharge. The network has already initiated engagement with Deirdre McCormack, Strategic Lead

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of Children's Services in Scotland to move this forward. During this engagement the network suggested having a representative from this group on the SCANS steering group. This piece of work will be as part of a Communication and Engagement Strategy and will be aligned with work done by the National Discharge Planning Group and the Neonatal Network.

- d) Recording Feeding Data – there were incomplete data collected for dates when feeding started and full feeds in Lothian due to the majority of patients not being located in a neonatal unit that uses Badger (i.e. a number of NHS Lothian babies were treated in PICU in RHSC). Data collected from the other centres included dates when feeds started, full feeds started and naso-gastric tubes removed. The network will start to collect this data prospectively rather than retrospectively and measure the recording of these feeding parameters as a KPI. This will give parents a realistic expectation of the feeding journey, allow benchmarking between centres and reduce encourage consistency of practice.
- e) CARDRISS-the data collected from the 5-year audit was recently benchmarked against Congenital Anomalies and Rare Diseases Registration and Information Services for Scotland (CARDRISS) data (same conditions and period) collected from boards across Scotland using their existing national datasets. The data figures were comparable (but not identical), but were more evident in DA (see table below)

| | SCANS Audit | PHI linked analysis |
|---------------|-------------|---------------------|
| CDH | 85 | 79 (93%) |
| Gastroschisis | 100 | 92 (92%) |
| Exomphalos | 37 | 34 (92%) |
| OA/TOF | 83 | 79 (95%) |
| DA | 51 | 42 (82%) |

One possible explanation was that PHI data sources don't always include all anomalies present in children with multiple anomalies and that genetic anomalies may take preference. There is a known association with DA and Downs Syndrome which may explain the variance in DA. Termination data collection was also discussed and once again CARDRISS figures were lower than expected for these five conditions. This was again explained by the difficulties in ascertaining multiple anomalies for Termination of Pregnancy due to Fetal Anomaly (TOPFA) cases due to the national abortion notification database only being able to record one ICD10 code. In addition, there was an indication that there is an incomplete return of termination notifications from some fetal medicine centres. PHI is planning to work with boards to improve this with a possibility of changes to the statutory reporting form so that multiple anomalies are reported.

SCANS have also shared their 5-year audit data with the neonatal network and fetal medicine colleagues.

3.2.2 Discharge Planning

The development of a discharge planning pathway and information provision will be a key priority for the network during 2020-21. This gap was initially identified from a patient experience survey a few years ago for CDH families which identified that families felt isolated after their baby was discharged from hospital, with health professionals in primary care and secondary care having little knowledge of their baby's condition. Feedback from the current survey of all 5 conditions as well as findings from the 5-year audit have supported this theme. The network plans to improve this area in a number of ways

- a) A follow up audit will be undertaken with the same cohort of patients, covering the first 2 years of the identified babies' lives (i.e. up to January 2015 for the earliest babies to December 2019 for

the later ones). This will look at the first 2 years of the baby's life and 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, hospital appointments and admissions (number/frequency/location and speciality), age and date of discharge. PHI have agreed to supply some of this information, e.g. hospital appointments and admissions if individual centres supply CHI numbers. The rest of the clinical information will be available on electronic case records. One vital piece of information that the network hoped to gather is families contact with primary care services after discharge.

- b) Once this audit is completed, the network will have met one of the main recommendations from the review, i.e. audit across the whole care pathway, including after discharge. As with the 5-year audit findings, this will be utilised to provide evidence based information to professionals and patients as well as identifying areas for improvement.
- c) Liaising with the National Neonatal Discharge Planning Group (NNDPG) whose remit is to develop a framework to support consistent and equitable discharge planning and delivery of neonatal community support. Dr Judith Simpson, Consultant Neonatologist in Glasgow is a member of the NNDPG and has agreed to represent the network on the group. SCANS will ensure that any planning and development work it does in this area aligns with the NNDPG aims.
- d) Improved engagement with health visitors as reported in 3.2.1

3.2.3 Guidelines and Care Pathways

The CDH antenatal and In-Patient guidelines have both been updated and revamped and both are under final review. Some changes with the antenatal guideline still to be agreed include timing of steroids, timing of MRI and the antenatal predictors indicating possible need for ECMO (to determine delivery location). In the In-Patient guidelines, further evidence on delayed cord clamping is being considered. Guidelines for Follow-Up Care have already been reviewed and agreed although transition now needs to be included as increasing numbers of patients are living into adulthood. Care pathways will also be reviewed for CDH. Completion of all these CDH documents will be prioritised in 2020/21. Similar documents will be developed over the next few years for the other 4 conditions once CDH has been finalised. Leads for each individual condition have been appointed to progress this work together with the development of patient information leaflets detailed in 3.3.3.

3.3. Stakeholder Communication and Engagement

3.3.1 Stakeholder Engagement

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

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

In response to the expansion of the network which stakeholders over a number of disciplines supported both the SCANS steering group and wider network membership expanded considerably since the review outcome. Figure 1 shows this clearly. The steering group currently has 24 active members from 8 health

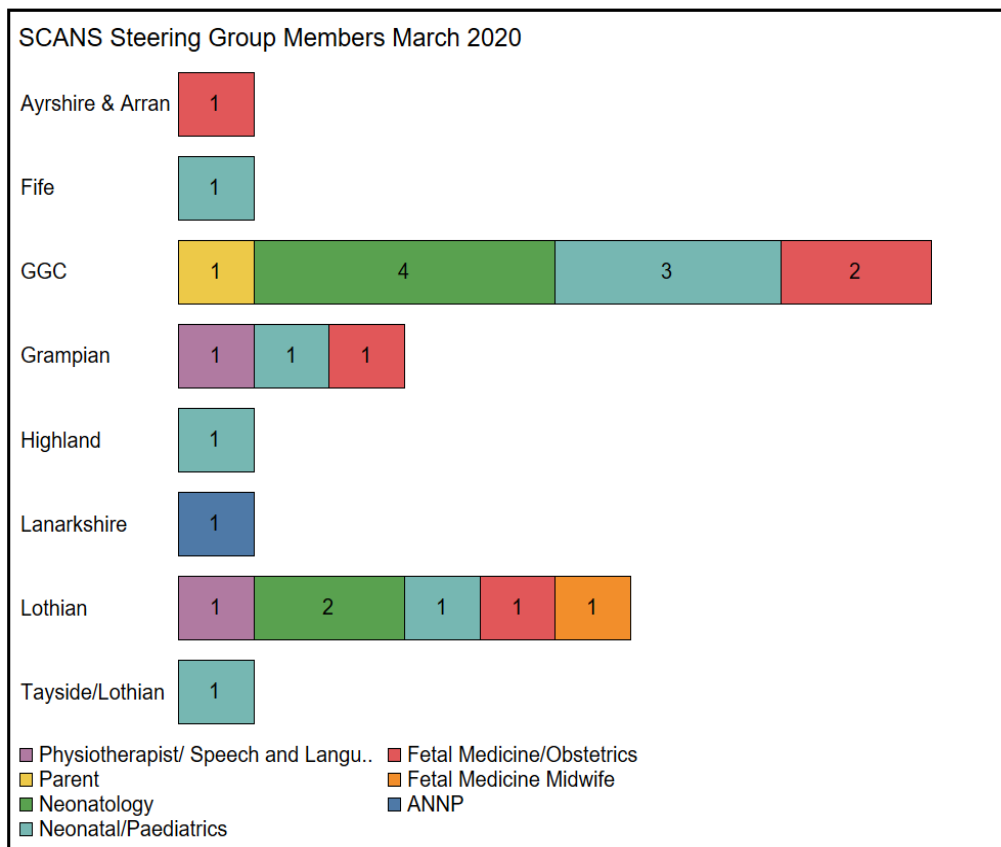
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boards covering 7 disciplines. This compares to 10 active members from 3 health boards covering 3 disciplines from the previous SDHCN.

There are still some gaps which the network will continue to try and fill. This includes: parents and patients, voluntary groups and specific health professionals i.e. psychologists, sonographers and health visitors.

The network will progress this next year. It has already made contact regarding health visitors (detailed in 3.2.1), has initiated contact with a list of voluntary groups for each condition and will use the expression of interest from various families to take forward engaging with that stakeholder group.

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SCANS Steering Group Members

SDHCN Steering Group Members

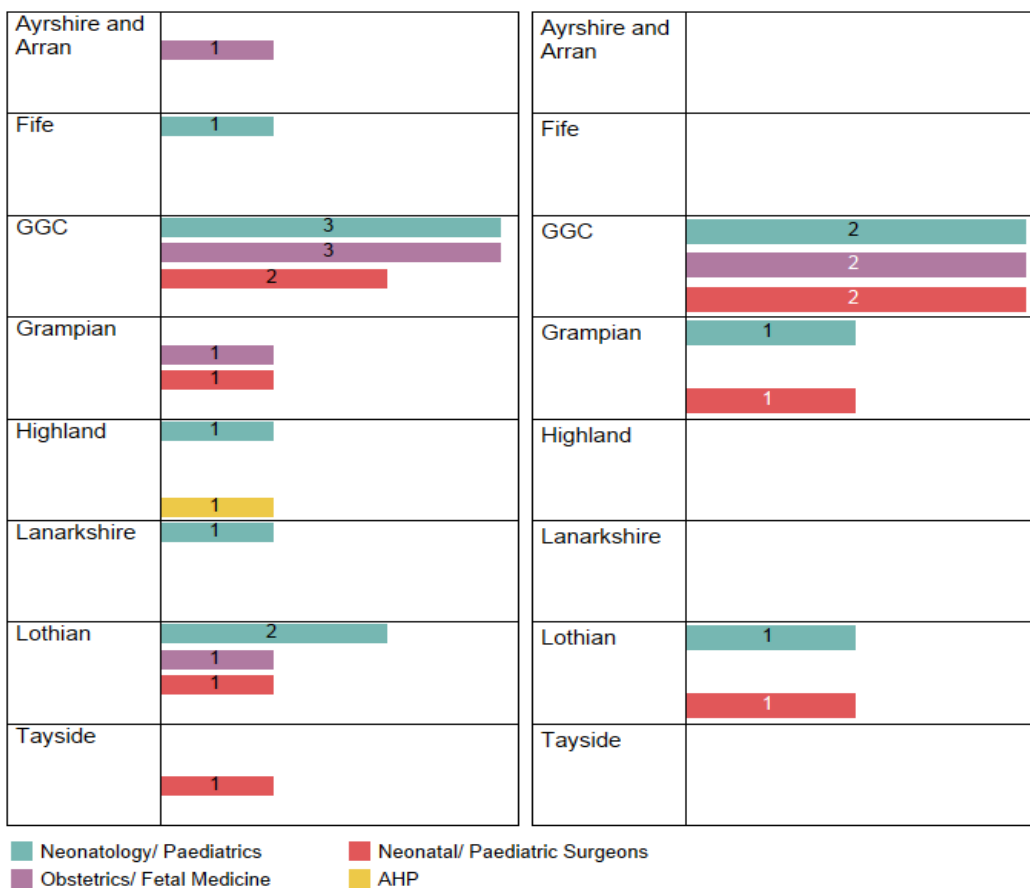


Figure 1: Current SCANS Steering Group Membership showing increased involvement from last year

3.3.2 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. The plan for this year will be to add to the website once finalised documents are available. Figure 2 below shows the full impact of the re-invigorated network evidenced by over 1,000 pages viewed and over 600 additional visits to the website compared with the same period last year since last year.

Full year report: from 1/4/19 > 31/3/20

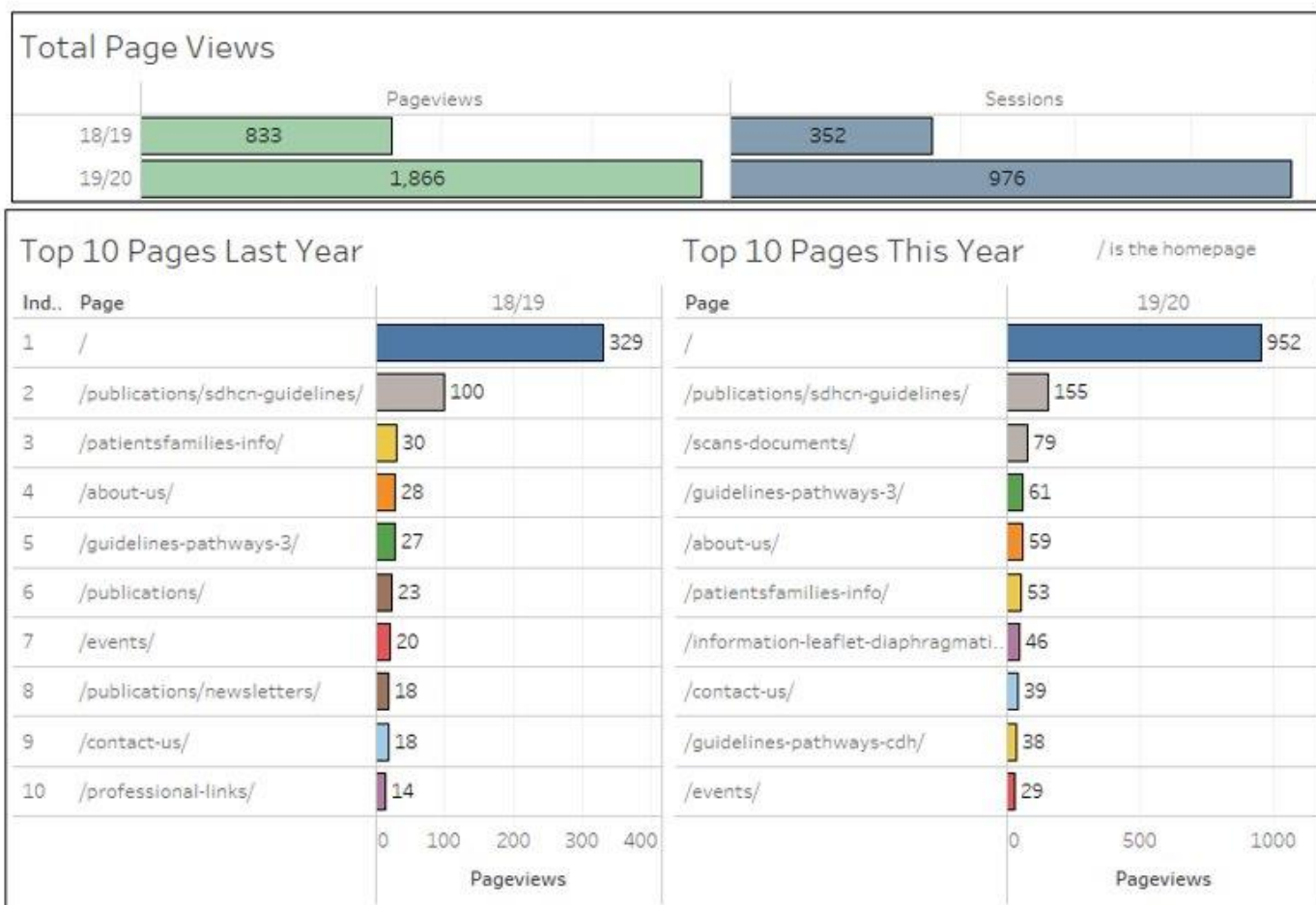


Figure 2: SCANS Website usage April 2019-March 2020 compared to previous year.

3.3.3 Information materials

SCANS are also reviewing and updating the CDH patient information leaflets. Three new leaflets will be developed for CDH: antenatal, in-patient and post-discharge care and again these will be used as templates to develop the same for the other 4 conditions. The network decided that this development would be more informative for families than the previous two leaflets, antenatal and postnatal. This development would add focus to post-discharge communication targeting both families and primary care staff as key audiences and will provide information on long term outcomes and potential complications.

To date the CDH antenatal leaflet has been updated and revamped and now includes some infographics from the 5-year audit findings that may be useful to the family for considering whether to continue with the pregnancy e.g. (survival %), and to explain any ongoing fetal investigations and location of care as well as other information that was agreed useful at the recent strategic planning event. The network has decided

that information from the forthcoming 2-year audit would also be useful for the antenatal leaflets. This means that none of the leaflets will be completed until the 2-year audit has been finalised as the network feels that all the network documentation should all be evidence based.

3.3.4 Patient/ Family Engagement

Parental feedback forms were sent to all families who had babies involved in the 5-year audit. 48 families responded. Feedback has been using qualitative methodology and a number of themes relating to of what is important to families identified. The network plan to use this information to look at ways on how the network can impact on these areas. In addition, 38 families indicated that they wanted to be involved in the network. These families have now been contacted to ask them how they would like to be involved, giving them various options, e.g. patient information leaflet review, parent forum groups with a representative from the group on the steering group etc.

3.3.4 Communication and Engagement Strategy

The network drafted a Communication and Engagement Strategy, which was presented at the strategic planning day. Feedback from that day has been influential in developing a revised draft plan.

3.4. Education

3.4.1 SCANS Strategic Planning Event

The network held a successful strategic planning event in September 2019 in Glasgow. The purpose of the event was to:

- Provide a summary of progress of the workplan
- Review of patient information leaflets and communication strategy
- Report the 5 year audit findings with presentations and infographics and what they tell us
- Review of progress of the new National Neonatal Network and its relationship with SCANS
- Review patient experience feedback
- Agree the main areas to focus on over the next few years

The event was attended by 72 people and 55 feedback forms were completed (76% response rate).

Figure 3 below shows event delegates split by profession.

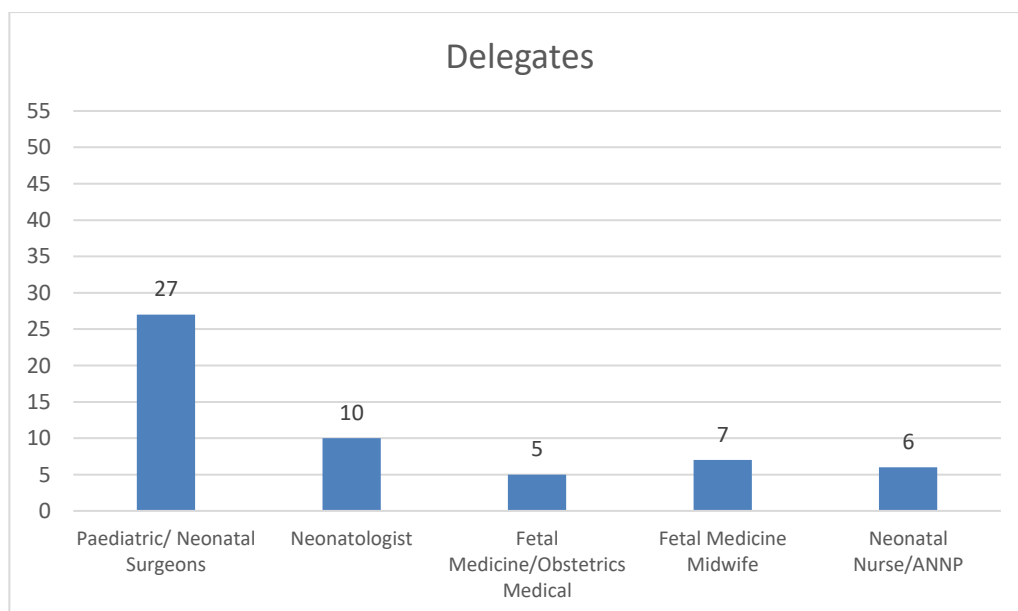


Figure 3: Delegate attendance at SCANS Launch Event

Figure 4 summarises how effective the event was in meeting the objectives of the day detailed above. Feedback shows the majority of delegates felt the event succeeded in this aspect.

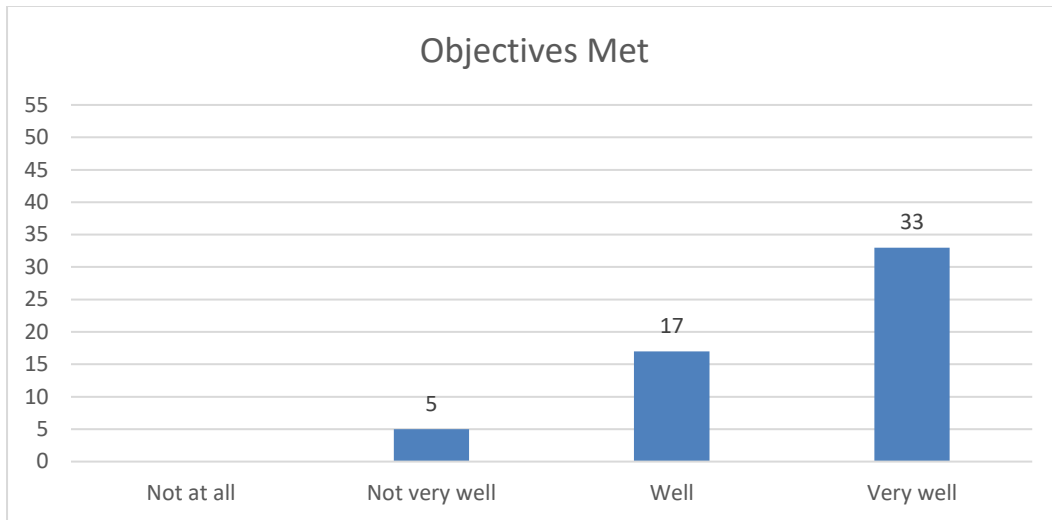


Figure 4: Evaluation responses from SCANS Launch Event showing how well objectives (delegates expectations, educational needs) met

This was also reflected in delegate feedback about their intentions to change their clinical practice as a result of attending the event. Results shown below showed that the majority felt the education provided at the event had a positive impact on their clinical practice. Comments included:

- have more structured discussions with parents/families regarding the patient’s condition, treatment and counselling needs
- improve transition process for patients transitioning to adult services

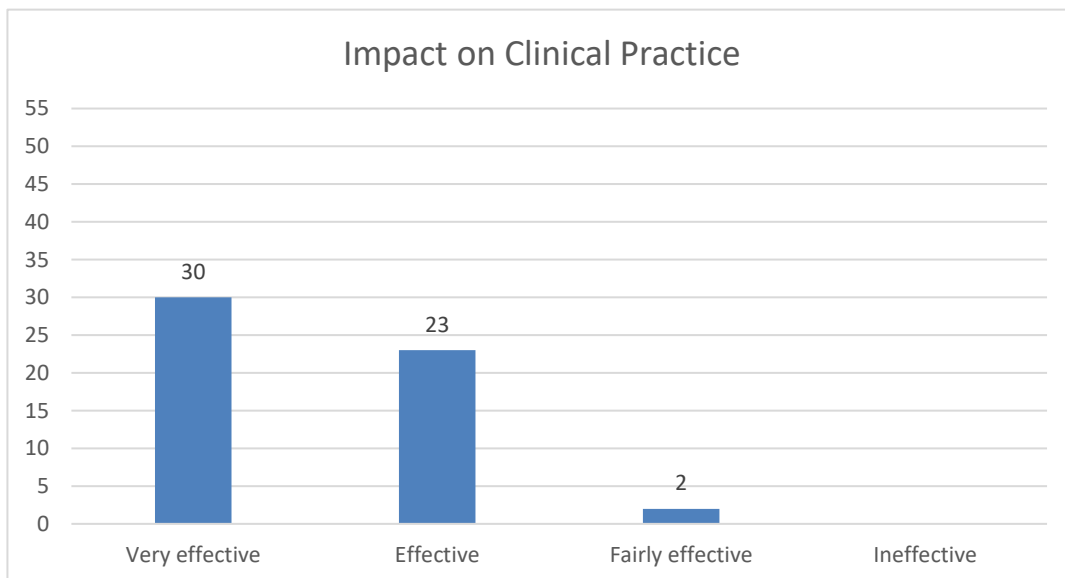


Figure 5: Evaluation responses from SCANS Launch Event showing how effective the event was on delegates clinical practice

3.4.2 Education Strategy

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

3.5. Audit and Continuous Quality Improvement

3.5.1 Data Collection

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 developed a mechanism to utilise both the Badgernet neonatal and maternity systems as a source of information.

An initial alert system trialled by the network and Badgernet had a number of technical issues so has been replaced with the following: as sections a) and b) below explains

- a) a new on-line system has been developed by Clevermed in which IMS have access to monitor all antenatal and neonatal diagnoses across all 5 conditions that are posted to Badgernet, for boards who have signed up to sharing their data (Figure 6). IMS have now completed a Public Benefit and Privacy Panel (PBPP) which will hopefully allow all Caldicott Guardians across all the boards to approve data sharing. This would mean the network could monitor all diagnosis across Scotland and measure whether QI's developed from the care pathways are being adhered to.

| 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 |

Figure 6 –Health Boards signed up to sharing data across Scotland from both Maternity and Neonatal Badgernet Systems

For the boards who have signed up to sharing data, 54 cases have been recorded for the period April 2019-March 2020. This includes both antenatal and postnatal diagnosis. Figure 7 shows numbers per condition.

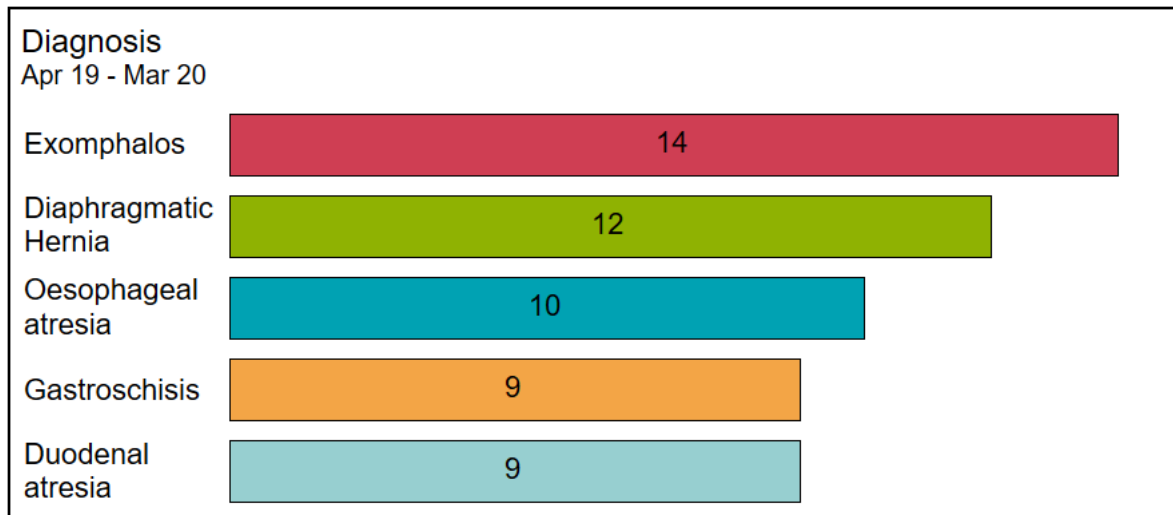


Figure 7-Diagnosis by condition for boards who have signed up to share data-see Figure 6 for list of boards

One of the key standards of the CDH network, which will apply to all 5 conditions, 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. This new Badgernet report now gives the network the tools to measure this by correlating antenatal diagnosis with subsequent delivery. This will be the first time that national outcome data are available for the whole journey from diagnosis. However, the network will wait until all boards across Scotland allow both their maternity and neonatal Badgernet data to be shared nationally before measuring this as interpreting data before then could be misleading. When this has been finalised, measuring this Quality Indicator will be a priority for 2020/21.

The on-line report also shows the badger ID number for each diagnosis. This will allow the three specialist centres to cross-reference with their clinical records to ensure all babies with one of the five diagnosis has been entered into the care pathways agreed.

Until all Boards have agreed to share their data automatically through Badgernet . the network will continue looking at ways to access their data.

- b) Care pathway 'pop-ups' are now available on screen where a diagnosis is input. This will mean that users of the Badgernet system will be able to view the antenatal care pathway on the maternity system and the postnatal care pathway on the neonatal system when they input a diagnosis. Once the guidelines are finalised, all users/clinical teams will have a signpost so that the optimum care will be given to the baby, based on evidence.

3.5.2 Quality Improvement

- a) As stated in section 3.2.1 one of the aims of the 5 Year audit was to identify areas of the service where improvements can be made. Several areas have already been identified e.g. repatriation, discharge planning, antenatal diagnosis and feeding) and KPI'S will be developed to measure these in 2020/21.
- b) In addition, standards of care with KPI's for CDH were developed a number of years ago and integrated into stages in both the antenatal and postnatal care pathways for CDH. These will be used to develop similar documents for the other four conditions over the next few years.

- c) Finally, a Quality Improvement Strategy will be developed for the network to plan and monitor these pieces of work.

3.6. Value

As demonstrated in the network review report, the SCANS provided value to NHS Scotland and families affected by these 5 conditions through:

- Completion of a 5-year audit which has provided an evidence base for the future development of standardised guidelines, care pathways and patient information leaflets for all 5 conditions– *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.*
- Progressing data collection methodology through engagement with Clevermed and utilising the data collected on the Badgernet systems-*identifying variation in care across services or against standards can lead to quality improvement in delivery of service.*
- provision of professional education and engagement at the Strategic Planning Event-*can achieve greater awareness of best practice amongst Scottish clinicians.*
- patient engagement through conducting a patient experience survey -*can identify patient's /family's needs, values views and preferences, identify areas of service improvement, provide valuable emotional support and improve patient centred care*

4. Plans for the Year Ahead

The work objectives for SCANS in 2020/21 are as follows:

1. Complete a 2 Year post-discharge audit across Scotland for all 5 conditions using the same patient cohort as the 5 –year audit
2. Develop antenatal patient information leaflets for all five conditions
3. Revise and update antenatal, in-patient and follow-up guidelines for CDH
4. Collect data collection and audit all five conditions across all sites in Scotland for all health boards.
5. Patient Experience Survey Analysis to be completed for all five conditions.
6. Develop key performance indicators for all five conditions that can measure improvement using data collected
7. Continue to liaise with the NDPG to improve discharge planning for families affected by these anomalies.
8. Continue to progress the specific recommendations from the Network Review.

5. COVID-19-Impact

The Surgical Congenital Anomaly Network of Scotland consists of a multidisciplinary and multi-agency staff group. Most of the clinical staff/steering group have remained their primary role, but they have significantly altered working practices, including picking up duties of other staff members who are either absent or self-isolating or have been re-deployed. Staff are learning new technologies and engaging in clinical activity in different ways and work output has changed. Staff are learning new strategies to work within the new C-19 structure within hospitals and the community.

The Lead Clinician is currently unable to devote any time to his Lead Clinician Role. He has been appointed to a managerial role with his department which will mean the planned appointment of another Lead

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Clinician needs to be expedited. It is understood that with a phased exit from lockdown, it may be some time before staff can return to their primary role.

Going into 2020/21, some elements of the workplan will be impacted for the reasons above

Key areas of impact: -

1. 2020-04 –Undertake 2 Year Post Discharge Audit of all 5 conditions across Scotland-leads have been identified for each of the 5 conditions. Work had also started to identify data fields for the audit and for the leads to identify the CHI numbers to send to PHI who have agreed to provide data such as hospital appointments etc. from CARDRISS. This work has now halted with no date as yet to re-start.
2. 2019-05- Complete and publish guidelines for CDH –will be delayed
3. 2019-06-Revise antenatal and postnatal care pathways for CDH-will be delayed
4. 2019-08-Complete and publish antenatal patient information leaflets for CDH and use as template for the other four conditions-unknown as is dependent on evidence from the 2-year post discharge audit.
5. 2020-06-Hold an education conference-planned for June 2020-cancelled, re-scheduled date unknown at present.

6. Detailed Description of Progress in 2019/20 (Workplan April 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 Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small> | | | | | | |
| 2019-01 | Revise Steering Group and wider network membership to reflect expanded network scope | April 2019/ March 2020 | Programme Manager/ Steering Group | Both Steering Group and wider membership revised and engagement improved c/fwd | More effective network through involving additional key stakeholders | G |
| 2019-02 | Organise 3 Steering Group meetings to ensure effective delivery of the 2019/20 workplan | April 2019/ March 2020 | Steering Group | Steering Group Meetings: 10 June 2019 12 December 2019 23 March 2020-cancelled due to COVID-19 | Effective delivery of the SCANS work plan to ensure continuation of progress. | B |
| 2019-03 | The network will meet reporting requirements: - Mid-year Report - Annual Report | 31/10/19 31/05/20 | Lead Clinician/ Programme Manager | Mid-Year Report available Annual Report available | There are effective governance arrangements in place. | B |

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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 |
|---|--|--------------------------|---------------------------------|---|--|-------------|
| 2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2019-04 | Undertake 5 Year audit of all 5 conditions across Scotland covering: <ul style="list-style-type: none"> • Antenatal • In-Patient • Discharge | April 2019/ March 2020 | Steering Group | Audit successfully completed see Section 3.2.1 for details | Findings will be invaluable in informing network documents and patient information materials | B |
| 2019-05 | Revise the following guidelines for CDH: <ul style="list-style-type: none"> • Antenatal • In-Patient • Follow-Up Will be used to develop guidelines for other 4 conditions | April 2019/ March 2020 | Steering Group | Documents have been circulated to relevant clinicians for review. Still WIP. c/fwd. | Improved service delivery for mother and baby affected by any of these conditions | A |
| 2019-06 | Revise antenatal care pathway for CDH and use to develop care pathways for the other 4 conditions within scope: <ul style="list-style-type: none"> • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia | April 2019/ March 2020 | Steering Group | 5-year audit results will be used to develop pathways. This has not been prioritised this year c/fwd. | Improved service delivery for mother and baby affected by any of these conditions | A |
| 2019-07 | Revise postnatal care pathway for CDH and use to develop care pathways for the other 4 conditions within scope: | April 2019/ March 2020 | Steering Group | This exercise is now planned for 2020/21 and will now use results of 2-year post discharge audit as well as 5-year audit to inform pathways. c/fwd. | Improved service delivery for children and young people with these conditions | A |

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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. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6] | | | | | | |
| 2019-08 | <p>Revise antenatal patient information leaflets for CDH</p> <p>Use to develop similar leaflets for the other 4 conditions within scope:</p> <ul style="list-style-type: none"> • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia | April 2019/ March 2020 | Steering Group | Documents have been circulated to relevant clinicians for review. Network now wants to wait until results of 2-year audit have been analysed to incorporate findings into leaflets c/fwd. | Facilitate provision of better support for mother and baby affected by any of these conditions | A |
| 2019-09 | <p>Revise postnatal patient information leaflets for CDH. Network has now decided to replace this leaflet with more informative two new leaflets:</p> <ul style="list-style-type: none"> • in-patient • follow up after discharge <p>using results of 2-year post-discharge audit with post –discharge leaflet targeting families and primary care staff</p> | Jan 2019/ Dec 2019 | Steering Group | These will not be produced until 2-year audit has been completed and results analysed c/fwd. | Facilitate provision of better support for parents and patients after discharge affected by any of these conditions | R |
| 2019-10 | <p>Organise and hold a strategic planning event to: Present evidence of what the network has achieved to date</p> <p>Develop a strategic plan to take the network forward over the next 2 - 4 years aligned with the new Scottish Neonatal Network</p> | September 2019 | Steering Group | Successful event held-Sept 20 th 2019 –see Section 3.4.1 for details | Evidence provided that the network has demonstrated that it has achieved the objectives set by NSSC | B |

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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 |
|------------------|---|--------------------------|-----------------------------------|---|--|-------------|
| 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 2019/ March 2020 | Programme manager /Judith Simpson | The network plans to use findings from the 5-year audit and more specifically the 2-year post-discharge audit to identify particular issues to focus on. It will work in tandem with the NNDPG and the Neonatal Network to ensure a collaborative approach in improving this area. c/fwd. | Facilitate better support for parents and children after discharge affected by any of these conditions | A |
| 2019-12 | Develop a network Communication and Engagement Strategy | April 2019/ March 2020 | Programme Manager /Kirsty Young | Draft Strategy Developed c/fwd. | More effective network through involving additional key stakeholders | A |
| 2019-13 | Develop new SCANS Website | April 2019/ March 2020 | Kirsty Young | Website developed | Improved engagement with both patients and professionals | B |
| 2019-14 | Engage with patients and families affected by any of these conditions | April 2019/ March 2020 | Programme Manager | Patient experience questionnaire developed for CDH was used as a template for a survey sent to all families of babies who survived in the 5-year audit covering all 5 conditions - good number of responses with 38 families wanting to be involved in network. These families have been followed up to find out how they want to be involved. c/fwd. | Identified areas and action plan for improvements to service delivery and previously unmet needs associated with newly diagnosed condition | 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 |
|---|--|---------------------------|---|---|---|-------------|
| 4. Education [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2019-15 | Develop Education Strategy | April 2019/ March 2020 | Programme Manager | Draft Developed | Improved knowledge in these congenital anomalies for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice | A |
| 5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2019-16 | Improve identification of new cases to specialist services in the network | April 2019/March 2020 | Louise Smith/ Programme Manager | In partnership with Clevermed the network has been working with both Maternity and Neonatal Badgernet systems and health boards to get up to date accurate information for all 5 conditions. Work is ongoing to get all boards signed up to alerts. c/fwd. | Improved outcomes for babies with any of these conditions through identification and entry into pathways at appropriate stages of the patient journey. | G |
| 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 2019/March 2020 | Steering Group/ Louise Smith/ Programme Manager | Quality Indicators will be developed from areas identified from results of 5 year audit that network had identified for improvement. c/fwd. | Identified service improvements for patients with any of these conditions | A |

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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 |
|--|--|--------------------------|---------------------------------|--|--|-------------|
| 6. Value [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2019-18 | Providing added value to health care in Scotland | | | <p>Completion of a 5-year audit which has provided an evidence base for the future development of documentation all 5 conditions– will optimise all aspects of care can improve collaborative working across services and lead to a better outcome for families.</p> <p>Progressing data collection methodology and utilising the data collected will identify variation on care</p> | Providing added value to health care in Scotland for these groups of patients as well as cost savings for NHS Scotland | G |

6. Workplan April 2020- March 2021

| 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 Network Structure and Governance [linked to Quality Dimensions 3,4,5,6] | | | | | | |
| 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 | 3 Year Strategic Plan agreed | There are effective governance arrangements in place. | |
| 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 | b/fwd. Health Visitors representative, voluntary groups and families have already been approached. See section 3.2.1 and section 3.3.1 | More effective network through involving additional key stakeholders | |
| 2020-02 | Organise 3 Steering Group meetings to ensure effective delivery of the 2020/21 workplan | April 2020/ March 2021 | Steering Group | Steering Group Meetings: Still to be arranged | Effective delivery of the SCANS work plan to ensure continuation of progress. | |

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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 |
|---|---|---------------------------|--------------------------------------|--|--|-------------|
| 2020-03 | The network will meet reporting requirements: <ul style="list-style-type: none"> - Mid-year Report - Annual Report | 31/10/20-31/05/21 | Lead Clinician/ Programme Manager | | There are effective governance arrangements in place. | |
| 2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2020-04 | Undertake 2 Year Post-Discharge audit of all 5 conditions across Scotland: <ul style="list-style-type: none"> • Agree data fields to collect info • Leads to send CHI numbers to PHI who will use CARDRISS to provide hospital appointments and admissions. Clinical data will come from EPR's. • Consolidate on database • Analysis by IMS using Infographics | April 2020/ March 2021 | Steering Group | Network has engaged with PHI. Leads been identified for all 5 conditions. May run behind schedule due to COVID-19 | Findings will be invaluable in informing network documents and patient information materials | |
| 2019-05 | Complete and publish the following guidelines for CDH: <ul style="list-style-type: none"> • Antenatal • In-Patient • Follow-Up Use to begin development of guidelines for other 4 conditions <ul style="list-style-type: none"> • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia | April 2020/ March 2021 | Steering Group | b/fwd. Documents have been circulated to relevant clinicians for review. Completion will depend on availability of results and analysis of 2-year audit. Guidelines for all conditions planned to complete next few years | | |

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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 |
|--|---|---------------------------|---------------------------------|---|--|-------------|
| 2019-06 | Revise antenatal 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"> • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia | April 2020/ March 2021 | Steering Group | b/fwd. will use results of 2-year post discharge audit | Improved service delivery for mother and baby affected by any of these conditions | |
| 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"> • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia | April 2020/ March 2021 | Steering Group | b/fwd. CDH is planned for 2020/21 and will use 2-year post discharge audit as well as 5-year audit (Jan 2013 - Dec 2017) to inform pathway. Other 4 conditions will be planned for next few years | Improved service delivery for children and young people with these conditions | |
| 3. Stakeholder Communication and Engagement <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"> • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia | April 2020/ March 2021 | Steering Group | b/fwd. Documents have been circulated to relevant clinicians for review. Again dependant on completion of 2 year audit | Facilitate provision of better support for mother and baby affected by any of these conditions | |

Surgical Congenital Anomalies Network Scotland (SCANS): Annual Report 2019/20

| 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 |
|------------------|---|---------------------------|--------------------------------------|---|---|-------------|
| 2019-09 | <p>Begin development of in-patient and post-discharge patient information leaflets for CDH using data collected from 2-year audit</p> <p>Use to begin development of similar leaflets for the other 4 conditions within scope: -</p> <ul style="list-style-type: none"> • Gastroschisis • Exomphalos • Oesophageal Atresia • Duodenal Atresia | April 2020/ March 2021 | Steering Group | <p>b/fwd.</p> <p>Again dependant on completion of 2-year audit to analyse results and use for leaflets</p> <p>Plan is to produce leaflets for CDH initially then use template for other 4 conditions</p> <p>Completion of leaflets for all conditions may be over 2 years</p> | 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:</p> <p>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 2020/ March 2021 | Programme Manager/ Judith Simpson | b/fwd. | Facilitate better support for parents and children after discharge affected by any of these conditions | |
| 2019-12 | Endorse a network Communication and Engagement Strategy | April 2020/ March 2021 | Programme Manager | b/fwd. Draft Strategy Developed | More effective network through involving additional key stakeholders | |
| 2020-05 | Development and maintenance of SCANS Website | April 2020/ March 2021 | Programme Support Officer | b/fwd. Website developed-plan to develop and update | Improved engagement with both patients and professionals | |

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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 |
|--|---|---------------------------|--------------------------------------|---|--|-------------|
| 2019-14 | Engage with patients and families affected by any of these conditions | April 2020/ March 2021 | Programme Manager | <p>b/fwd.</p> <p>2 main obj: -</p> <ol style="list-style-type: none"> Analyse patient feedback with qualitative methodology – this will be used to identify issues important to patients /families so that network and service can focus planning on improvements for families these areas. Families who have responded to wanting to be involved will continue to be followed –up <p>Aim is to find out how the network can best support these families.</p> | Identified areas and action plan for improvements to service delivery and previously unmet needs associated with newly diagnosed condition | |
| 4. Education [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2019-15 | Endorse Education Strategy | April 2020/ March 2021 | Programme Manager/ Steering Group | <p>b/fwd.</p> <p>Draft Developed</p> | Improved knowledge for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice | |

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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 |
|---|--|---------------------------|--|---|---|-------------|
| 2020-06 | Hold annual education conference | April 2020/ March 2021 | Programme Manager/ Linda Watson | Planned for June 2020. Postponed –re-scheduled date unknown | Improved knowledge in these congenital anomalies for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice | |
| 5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2019-16 | Improve identification of new cases to specialist services in the network | April 2020//March 2021 | Data Analyst | b/fwd. Progress collection of data through Badgernet in partnership with Clevermed across all boards in Scotland. Use new report to measure QI's –See section 3.5.1 for details. | Improved outcomes for babies with any of these conditions through identification and entry into pathways at appropriate stages of the patient journey. | |
| 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 2019/March 2020 | Steering Group/ Data Analyst/ Programme Manager | b/fwd. Areas of improvement from 5-year audit already identified- <ul style="list-style-type: none"> • Antenatal Diagnosis • Repatriation • Discharge Planning • Feeding | Identified service improvements for patients with any of these conditions | |

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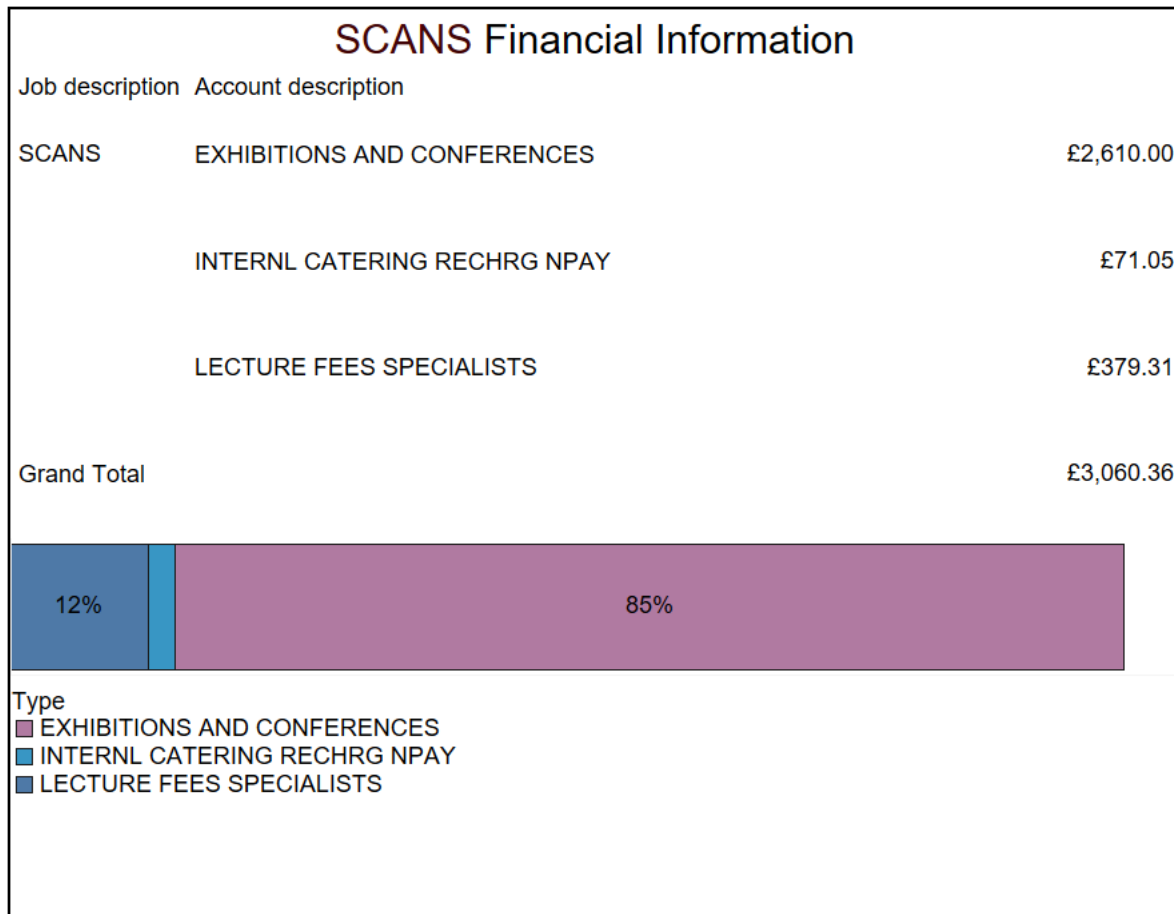
| Objective Number | Smart Objective | Planned start/end dates | Detailed Plan Available / Owner | Description of progress towards meeting objective as at March 31st 2019 | Anticipated Outcome | RAGB status |
|--|--|-------------------------|---------------------------------|---|--|-------------|
| | | | | Network will also look at current CDH standards and use to adapt for other 4 conditions | | |
| 2020-07 | Complete QI Strategy | | Programme Manager | | | |
| 6. Value [linked to Quality Dimensions 1,2,3,4,5,6] | | | | | | |
| 2020-08 | Providing added value to health care in Scotland | April 2020/March 2021 | Network | | Providing added value to health care in Scotland for these groups of patients as well as cost savings for NHS Scotland | |

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) |
| Mr James Andrews | Consultant Paediatric Surgeon | GGC |
| Dr Shona Cowan | Consultant Obstetrician | Lothian |
| Mr Carl Davis | Consultant Paediatric and Neonatal Surgeon | GGC |
| Carolyn Mc Connell | Neonatal Nurse | GGC |
| Dr Alan Webb | Consultant Neonatologist | Highland |
| Kirsten Cliff | Fetal Medicine Midwife | Lothian |
| Prof Allan Cameron | Consultant Obstetrician | GGC |
| Dr Neil Patel | Consultant Neonatologist | GGC |
| Dr Vix Monnelly | Consultant Neonatologist | Lothian |
| 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 |
| Andrea Wood | Physiotherapist | Lothian |
| Emma Wylie | Programme Manager-Neonatal Network | NNMS |
| John Collins | Parent | Glasgow |

Appendix 2: Finance

The annual budget for SCANS expenditure (not including staffing costs) is £5,000. Spending against this budget for 2019/20 was £3,060.36, the main cost being £2,610 for the Strategic Planning Event in September 2019, held in Glasgow. The network ended the year with an underspend of £1,939.64.



Appendix 3: Five Year Audit Results

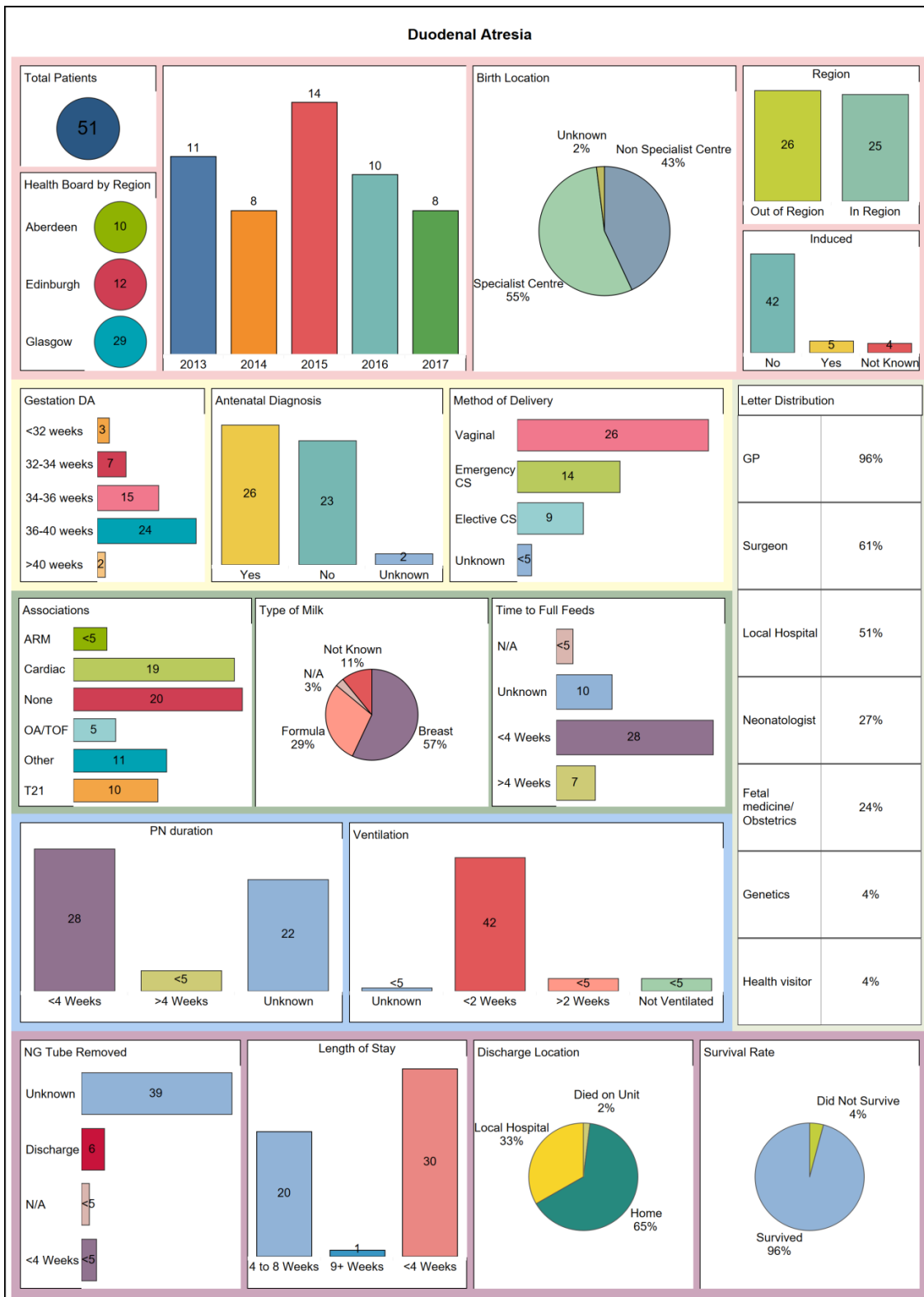


Figure 8 Duodenal Atresia-Results of Five Year Audit for Scotland, Jan 2013-Dec 2017

Note: The denominator for letter distribution for “local hospital” refers only to babies treated/having surgery ‘Out of Region’ i.e. outwith their family health board.

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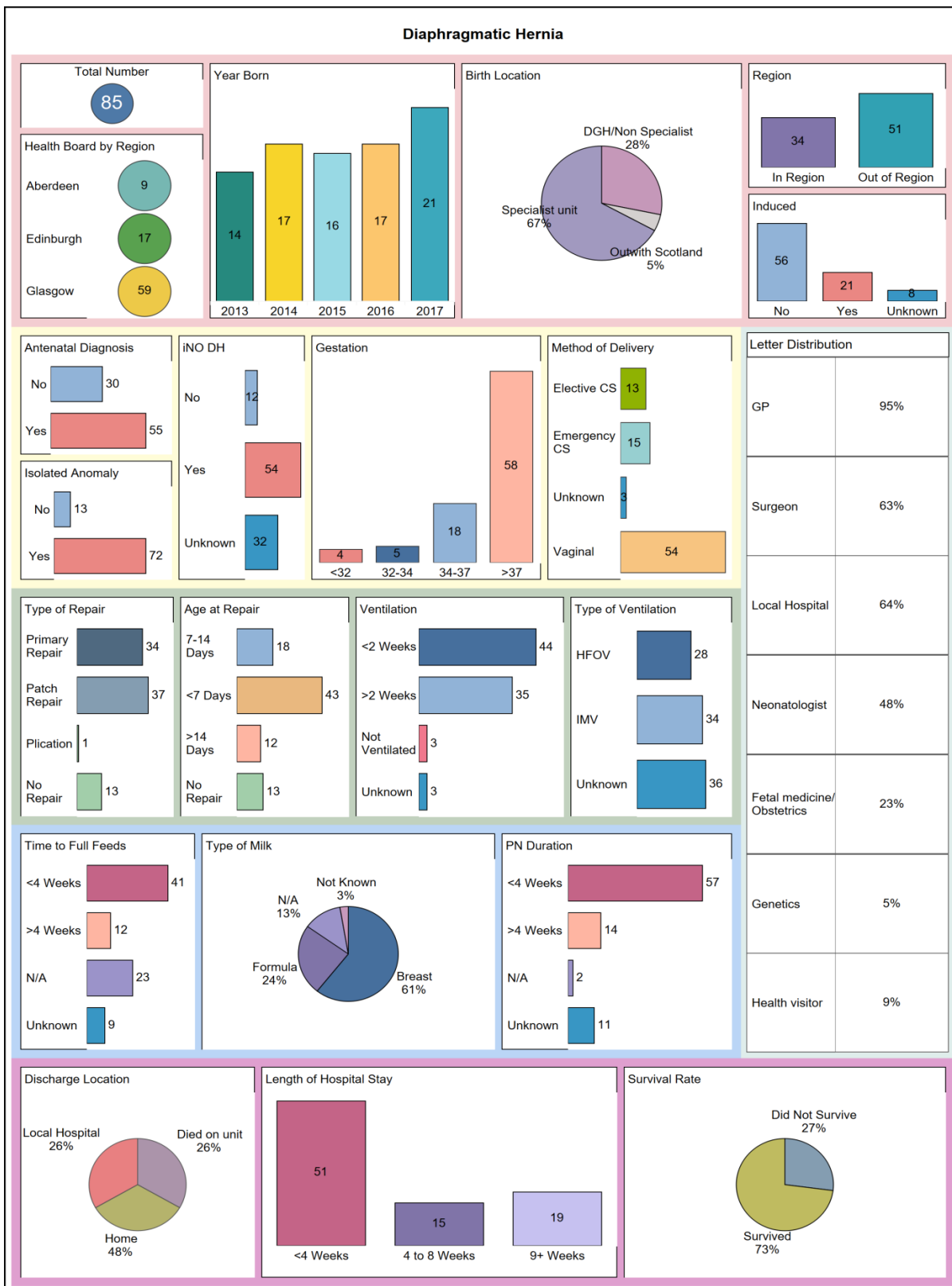


Figure 9 Diaphragmatic Hernia-Results of Five Year Audit for Scotland, Jan 2013-Dec 2017

Note: The denominator for letter distribution for “local hospital” refers only to babies treated/having surgery ‘Out of Region’ i.e. outwith their family health board.

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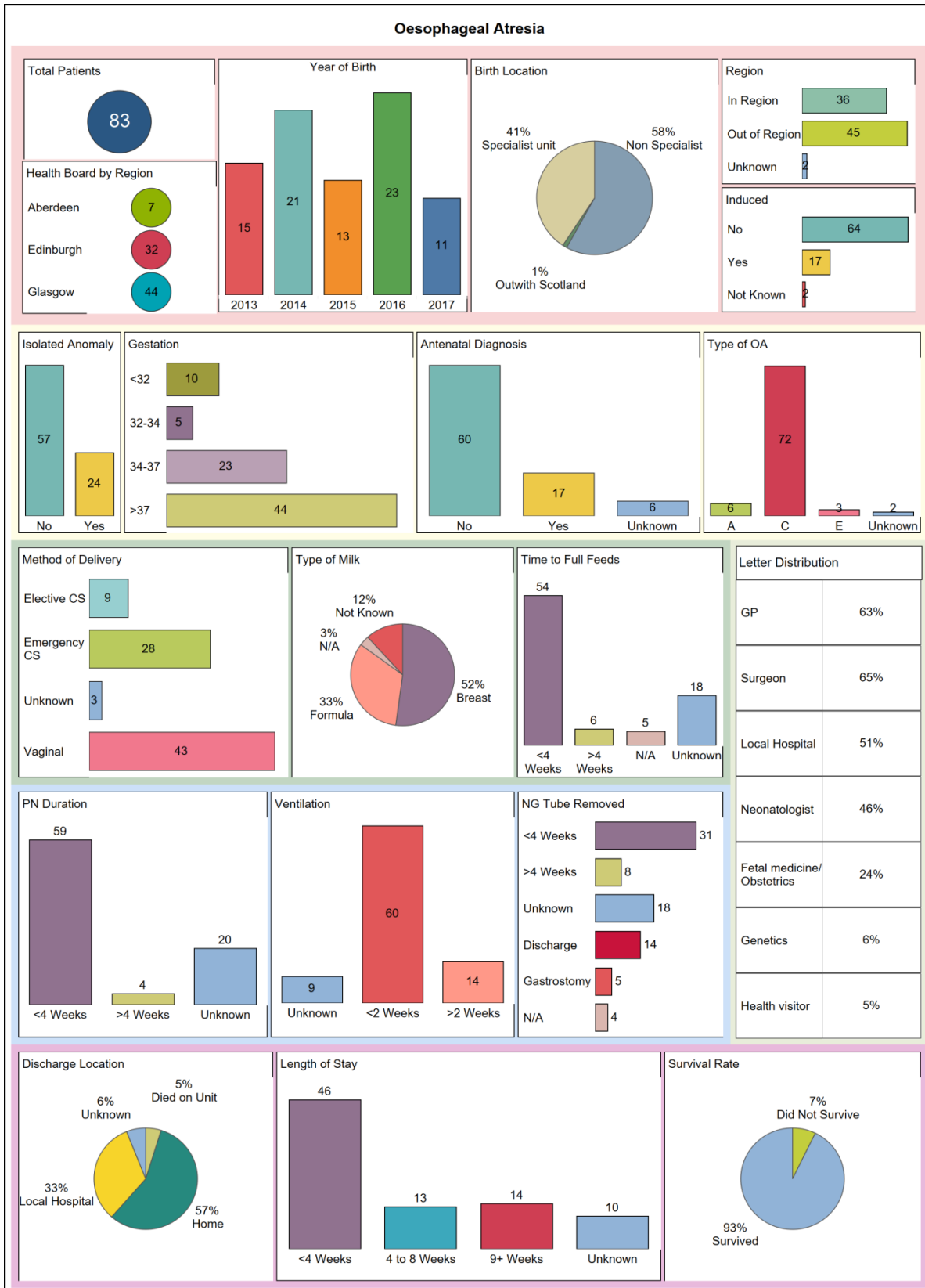


Figure 10 Oesophageal Atresia-Results of Five Year Audit for Scotland, Jan 2013-Dec 2017

Note: The denominator for letter distribution for “local hospital” refers only to babies treated/having surgery ‘Out of Region’ i.e. outwith their family health board.

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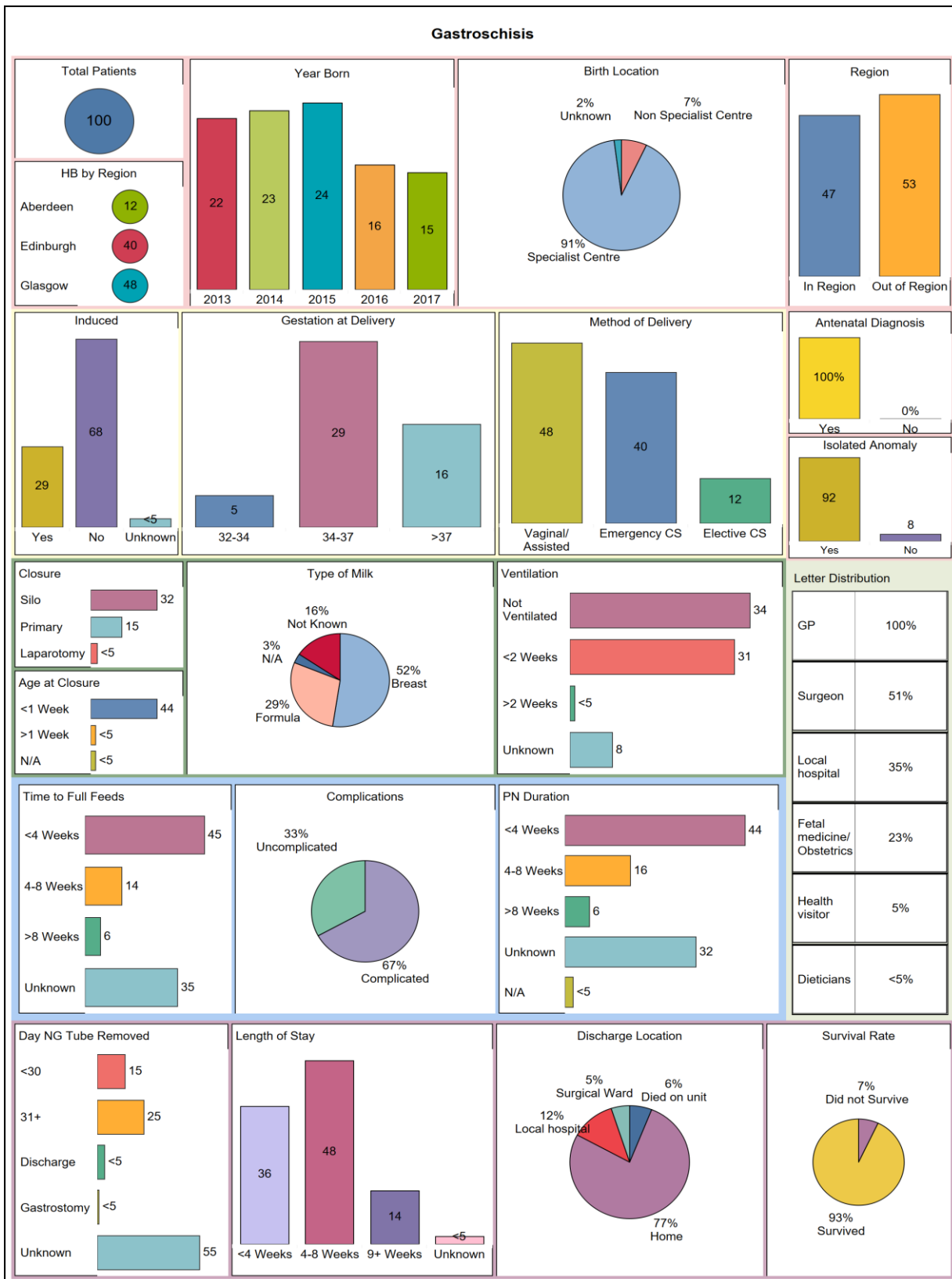


Figure 11 Gastroschisis-Results of Five Year Audit for All Scotland, Jan 2013-Dec 2017

Note: The denominator for letter distribution for "local hospital" refers only to babies treated/having surgery 'Out of Region' i.e. outwith their family health board.

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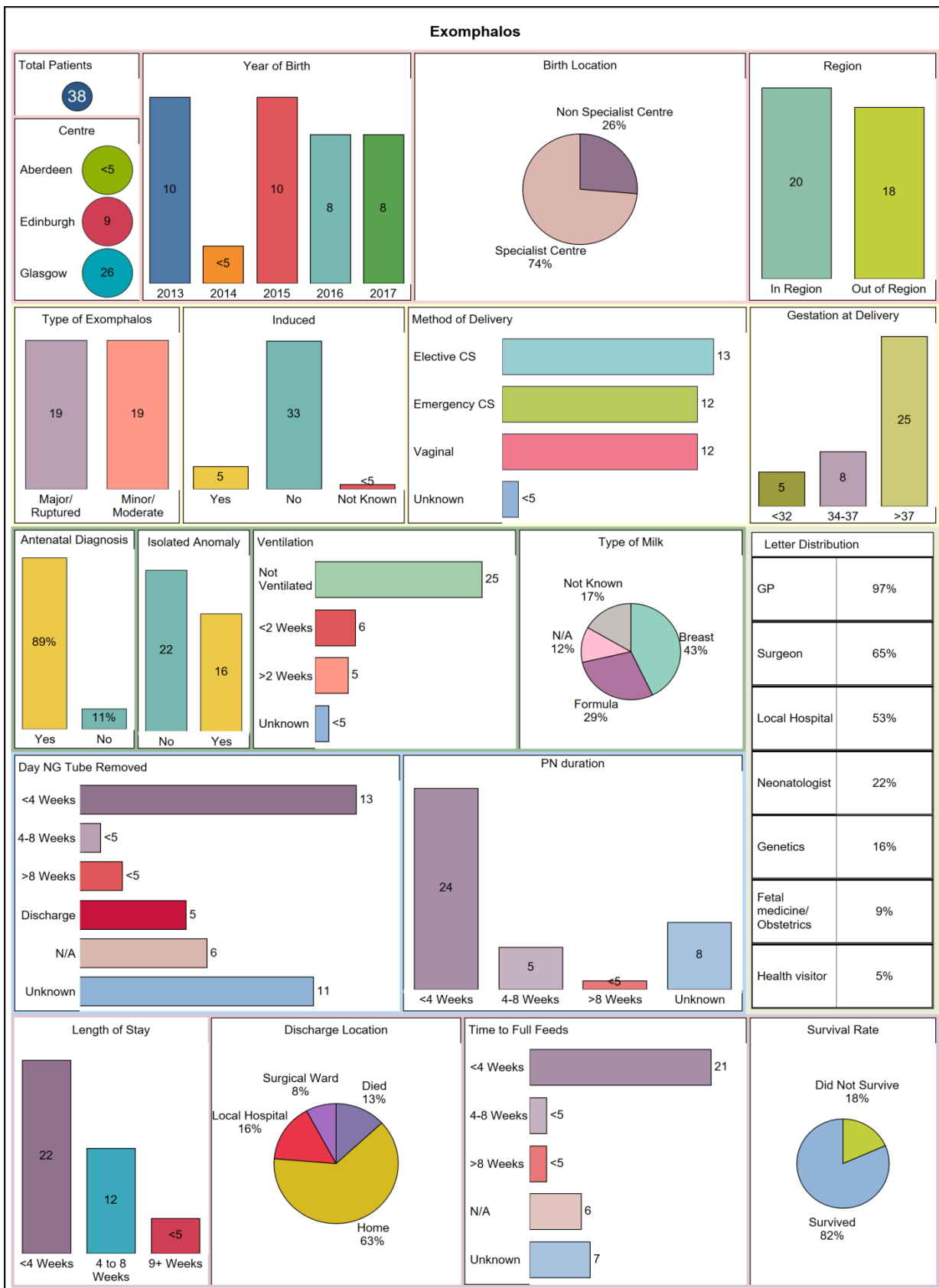


Figure 12 Exomphalos-Results of Five Year Audit for All Scotland, Jan 2013-Dec 2017

Note: The denominator for letter distribution for “local hospital” refers only to babies treated/having surgery ‘Out of Region’ i.e. outwith their family health board