

Cleft Care Scotland (CCS)

Annual Report 2020/21

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Background

Managed Clinical Networks are defined as co-ordinated groups of health professionals that support clinical services to continuously improve service delivery in order to ensure equitable provision of high quality, clinically effective services.

Around 100 children are born with a cleft lip and/or palate in Scotland each year. In 2020, there were 66 babies born with a cleft, of which 16 had a cleft lip, 31 have a cleft palate and 19 had a cleft lip and palate.

Cleft Care Scotland (CCS) provides a framework to facilitate delivery of standardised quality care for patients with cleft lip and/or palate throughout Scotland. The networks vision is that every patient with a cleft lip and/or palate is offered specialist cleft care from diagnosis to adulthood and families are offered the right care in the right place at the right time to produce the best possible outcome for the patient.

Current position

The network has demonstrated good progress against the 2020/21 workplan despite the challenges resulting from the COVID pandemic. All objectives relating to Network Structure and Governance, Communication and Engagement, and Education have been achieved. Progress against the Audit and Continuous Quality Improvement objectives has been limited however this will be a key focus of work planned for 2021/22

Progress against the workplan is detailed in Appendix 1 with particular attention drawn to the completion of the pathways covering the entire patient journey and the subsequent implementation of these. This year saw the development of the networks 2021-2024 workplan to support a shared vision and goals to work towards for network members, following re-establishing the network in 2019/20. The Networks Communication, Patient Experience and Engagement and Education Strategies were published in March 21 following engagement with stakeholders and will these will guide activity planned for 2021-22.

The COVID pandemic has resulted in a new way of working for everyone with the move to virtual meetings. All Steering Group and subgroup meetings have been taking place using MS Teams and this has worked well with participation across the network increasing. The annual education event took place virtually in October 2020 and plans are in place for this year's annual education event and a patient engagement event to take place virtually in the coming months.

Highlights

Patient Pathways

In March 2020, new care pathways for children born with a cleft lip and/or palate were agreed to address the clinical needs of the patients and to reduce the burden of care for patients and their families. Clinic reorganisation based on the new pathway model

commenced in June 2020 but the planned review of the impact of these pathways and patient feedback on these was delayed due to COVID-19. This activity will now be carried forward to the 2021-22 workplan.

Patient Experience and Engagement

The Networks Patient Experience and Engagement Strategy published in March 2021 outlines how the experiences of people born with a cleft lip and/or palate and their carers, and what matters to them, will inform the activities of the network. The Patient Experience and Engagement Strategy was developed by the newly established Patient Engagement Group which has representation from patients, carers and voluntary sector organisations with an interest in cleft care. Key priorities for this group include:

- Informing the development and review of patient resources to ensure these meet the needs of people attending cleft care services and their carers.
- Planning a patient/family event that provides an opportunity for networking, sharing information and for identifying priorities in cleft care.
- Developing a patient experience survey to gather feedback from people attending cleft care services and their carers to allow services to be tailored to their needs.

Education

The Annual Education Event took place virtually on 30th October 2020 with 36 people in attendance. This year's event covered a wide range of topics including the new patient pathways, virtual patient management, research, psychology and speech appliance services. Delegates reported that the event was an excellent opportunity to meet, discuss, learn and share information. Of the 25 respondents who returned an evaluation, 56% stated that the event had very much met their educational needs, expectations were very much met for 68% and 72% deemed that the event had been overall very effective (see Appendix 2).

A learning needs analysis (LNA) was conducted in August 2020 with the stakeholders of the network to inform the Education Strategy which was published in March 2021. This strategy outlines the approach the network will take in supporting continuing professional development of staff directly supporting cleft care. Consideration is also given to the education needs of professionals that do not have a direct role in cleft care, but are nonetheless important providers of support for patients and their families. Activities include the Network's annual education event, a programme of online education events covering a variety of topics relating to cleft care, and signposting to external educational opportunities where relevant.

COVID-19 and Remote Consultations

In March 2021, the Network issued a survey to staff involved in cleft care to gather views on how the service responded to the impact of COVID-19 and their experience of remote consultations to support the management of their patients. In total 23 health professionals from a range of specialties responded from seven health boards.

Feedback highlighted that COVID-19 impacted on cleft care services in a number of ways such as stopping routine patient care, access to clinical space, and redeployment of staff, which together led to delays in seeing patients. The majority of respondents reported an increased use of virtual consultations via NHS Near Me and telephone reviews but for some specialities virtual activity in this way was not practical (audiology, orthodontics, dentistry, restorative dentistry, speech assessment). The Network is currently exploring

the use of vCreate, which enables secure transfer of short recorded (asynchronous) video in health and care settings, to assess if this system provides the required quality to facilitate speech assessment remotely.

The areas of cleft clinical care that were able to be conducted effectively virtually and could continue beyond the pandemic were highlighted as triage, discussion on treatment plans and some clinical reviews. It was noted that virtual technology had been helpful in supporting engagement with patients/families and that it has enabled effective clinical working across staff groups. Informal feedback from patients and families on virtual appointments has been positive in that it has allowed treatment /reviews to continue, provided a facility to get answers to queries/concerns and they have reduced the burden of travelling to clinical appointments.

A key focus of the Network moving forward will be to support embedding these developments in the patient pathways and this will be considered when the new patient pathways are being reviewed.

Service Map

The Network has developed a service map noting all of the staff involved in providing cleft care across Scotland. Due to COVID-19 planned discussion around this to identify/address any gaps in provision did not take place and this has been carried over to the 2021/22 workplan.

Looking forward

Cleft Care Scotland will continue to support improvements in services for people born with a cleft lip and/or palate throughout their life through the delivery of its 2021-24 workplan. The 2020/21 Network objectives are outlined in the workplan in Appendix 3.

One of the key priorities for the coming year is to develop the Network's Quality Improvement Strategy and central to this is Scotland becoming part of the Cleft Registry and Audit Network (CRANE). CRANE is the national clinical registry for all children born with cleft lip and/or palate in England, Wales and Northern Ireland. It is a national clinical audit that is used to improve the care of patients and supports professionals to provide the best evidence-based cleft care. As part of the review of the national cleft service, agreement was reached for NHS Scotland to participate in CRANE, allowing benchmarking with services across the UK.

This year has been a transition year in terms of how data is collected. Work has been progressing to adapt the NCAS to align with the required fields in CRANE and this has resulted in little data being collected. Currently it is not possible to fully align this and the previously agreed process of collecting data in NCAS for upload to CRANE will have to be revisited in light of this.

Naturally the focus for the national surgical service over the past couple of years has been to establish a comprehensive database of all their patients to aid clinical care. This has drawn information from a number of sources including NCAS and is now the most

robust data source on cleft patients in Scotland. Whilst this has been the focus, the entry of births onto the NCAS has tailed off and it is therefore not possible to pull out an overview of the service in Scotland.

There remains frustration within the network about the pace of progress for Scotland's entry into CRANE. Once there is a clearer model for data collection, the network will be able to develop a clear plan around data collection and audit going forward.

Additional priorities for the network in the coming year include:

- Supporting the continuing professional development of staff directly and indirectly supporting cleft care. This will include developing a programme of online education events, hosting an annual Network education event and improving communication and understanding of the various roles across the multidisciplinary team.
- Continuing to use the experiences of people born with a cleft lip and/or palate and their families, and understanding what matters to them, to inform the activities of the Network.
- Developing the Networks website so that this is an effective communication, education and information resource for patients, families and health professionals.
- Production of the patient video on speech and language therapy exercises delayed due to the COVID-19 pandemic.

As part of National Services Division's commissioning process, Cleft Care Scotland will participate in a joint review of the Network and the National Cleft Surgical Service likely to take place in 2021/22. It is noted that at times network members and those involved in cleft care have difficulty in differentiating between the role of the network and that of the service. As part of this review, engagement with stakeholders will take place to inform the best model of care moving forward to ensure this adds value to people born with a cleft lip and/or palate, and to NHS Scotland.

Finance

There network did not utilise its budget this year. Due to the restrictions in place and the move to virtual meetings, anticipated costs associated from face to face meetings and education events have not been incurred. The planned video for Speech and Language Therapists is currently on hold due to staff capacity in responding to the COVID-19 pandemic and therefore the cost associated with this will now be incurred in 2021/22.

Appendix 1 Detailed Description of Progress in 2020/21

When defining network objectives please consider the NHS Scotland policy aims described in [Realistic Medicine](#), as well as the Institute of Medicine's six dimensions of quality, which are central to NHS Scotland's approach to systems-based healthcare quality improvement:

1. **Person-centred**: providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
2. **Safe**: avoiding injuries to patients from healthcare that is intended to help them;
3. **Effective**: providing services based on scientific knowledge;
4. **Efficient**: avoiding waste, including waste of equipment, supplies, ideas, and energy;
5. **Equitable**: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
6. **Timely**: reducing waits and sometimes harmful delays for both those who receive care and those who give care.

Key

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 31/03/2020	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-01	The network will review its existing structure and ensure it is in alignment with the latest Service Level Agreement	May 2020	Network Team	Service level Agreement has been reviewed and has been signed off	There are effective governance arrangements in place for network activity	B
2020-02	The network will organise 3 Steering Group meetings and each subgroup will meet at agreed intervals to ensure effective delivery of the 2020-21 workplan	March 2021	Steering Group and Sub-Group membership	Steering Group met in September, December and March. Subgroups for speciality areas have taken place facilitated by subgroup leads.	Effective delivery of the CCS network workplan to ensure continuation of progress	B
2020-03	The Network will set out a workplan for the next 3-5 years.	End Dec 2020	Network team	Draft workplan for 2021 -2024 discussed at Steering Group in March 21. Additional content from subgroups added with Final Plan agreed in April 2021.	Network members have a shared vision and goals to work towards.	B
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-04	Map current network clinicians and plan to address gaps in provision and staffing	1 Sept 2020	Network Team	Mapping Exercise has taken place. Further discussion to identify/address any gaps in provision will take place in 2021/22.	There is equity of access to appropriately trained clinicians and services within NHS Scotland	A

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2020	Anticipated Outcome	RAGB status
2020-05	The network will agree a robust pathway covering the whole patient journey	31 Mar 2021	Steering Group	Cleft care pathways agreed and available on the CCS website.	Stakeholders are clear on what the expectations of care are	B
3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]						
2020-06	The network will develop a Communication Strategy to meet the needs of all stakeholders including provision of information and effective sign posting through the website	Sept 2020	Network Team/ Steering Group	The Communication Strategy has been approved and will inform the 2021/22 workplan.	Stakeholders across Scotland will have access to information to ensure a personalised approach to care and will have a route to engagement with the network	B
2020-07	The network will develop a small patient engagement planning group to develop a strategy to capture patient priorities and also to have patient input into specific pieces of work	Sept/Oct 2020 (start strategy)	Network Team/3rd Sector/Patient Group/Psychology	Patient Engagement Group Established and Engagement Strategy developed to inform 2021/22 workplan.	Patients/ needs/priorities drive the work of the network	B
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2020	Anticipated Outcome	RAGB status
2020-08	The network will arrange an Annual Educational Event	Nov 2020	Network Team/Steering Group	The Education Event took place virtually in October 2020.	Provide educational opportunities to specialist and non- specialist clinical staff to enhance knowledge of care of cleft lip and palate patients	B
2020-09	The network will develop an Education Strategy to explore different ways of delivering education to suit the needs of stakeholders, based on findings of Learning Need Assessment (LNA) and feedback from last study day.	Sept 2020	Network Team/Steering Group	The Education Strategy was finalised in March 2021 informed by the LNA and feedback from the Annual Education Event	The workforce has access to evidence based cleft care training and resources for improved health and care.	B
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-10	CCS will develop and adopt its Quality Improvement (QI) Strategy	Mar 2021	Network Team/Steering Group	The QI strategy is on hold due to delays in establishing links with CRANE.	Improvements to service delivery are progressed from audit	A
2020-11	The network will adapt Clinical Audit System (CAS) data fields to align with Cleft Registry and Audit Network (CRANE) which will audit performance	Nov 2020	Network members	Work is in progress with CRANE and NCAS to develop a robust system and methods of data input	Network and clinical work is supported by a robust system that meets is requirement	A

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2020	Anticipated Outcome	RAGB status
2020-12	The network will develop a patient educational video in conjunction with the Speech and Language Therapists (SLT) and audit evaluation of this	31/03/21	SLT Group	This has been put on hold due to COVID-19.	Improving education will lead to better outcomes for patients	R
6. Value [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-13	Implementation of pathways reduces clinic appointments and should release clinician's time for other clinical activity Quality Improvement should be utilised to deliver patient care of highest standard with efficient use of resources	1 March 2021	Network Team/ Steering Group	Clinic reorganisation based on the new pathway model has begun with clinics starting in June 2020. A review of the impact of these new pathways and patient feedback on these was delayed due to COVID-19 and this will now take place in 2021-22	Allow more clinical time in job plans by reducing unnecessary MDT attendance	A

Appendix 2 Annual Education Event Evaluation

The Cleft Care Scotland (CCS) Network held their annual education event on Friday 30th October 2020. There were 36 delegates who attended and evaluations were received from 25 attendees (69% response rate). Results from the evaluation are as follows:

Figures 1 and 2 below show the designations and Health Boards of respondents.

Figure 1 - Designation

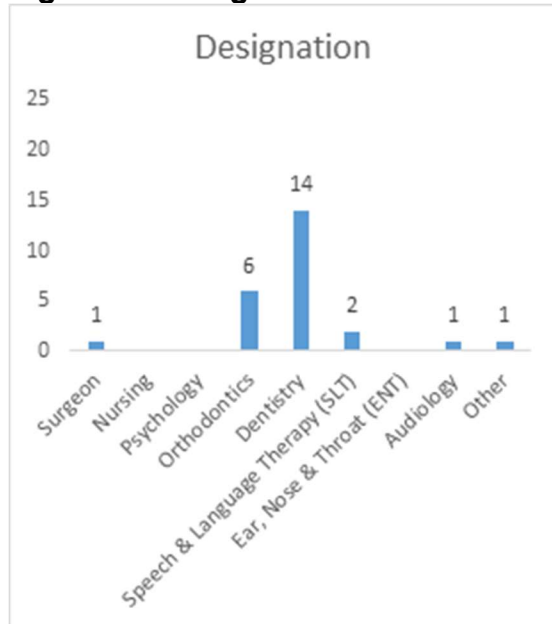
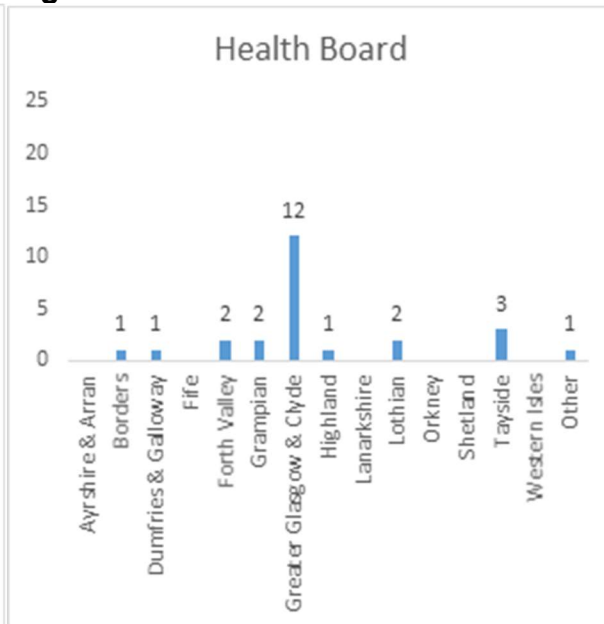


Figure 2 - Health Board



Figures 3 and 4 illustrate how respondents rated the event.

Figure 3 - Effectiveness of Topics

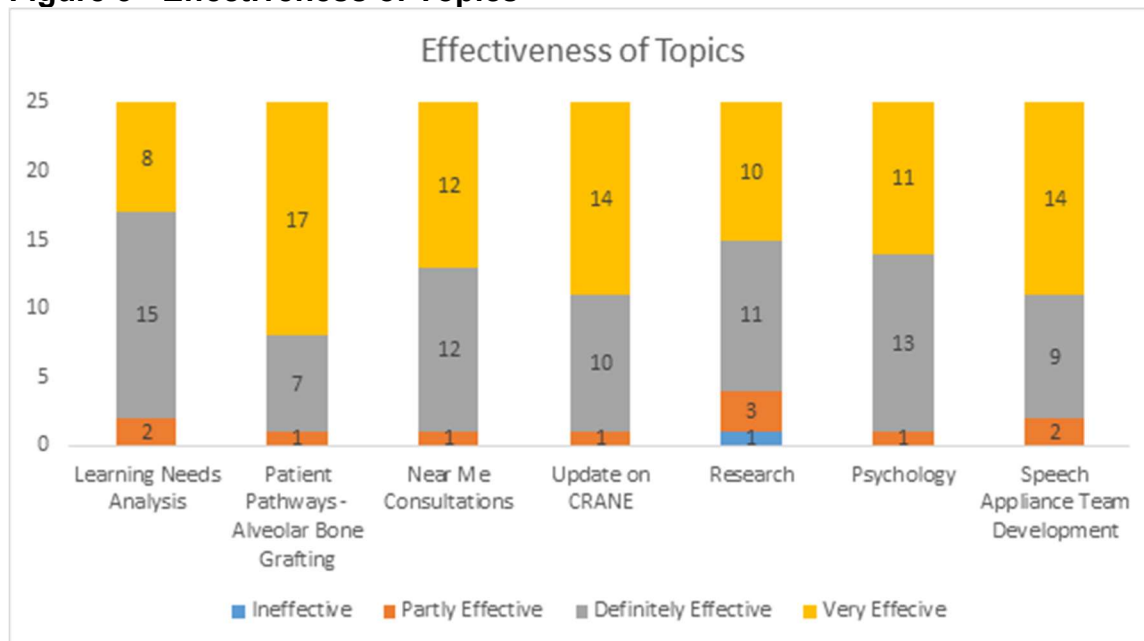
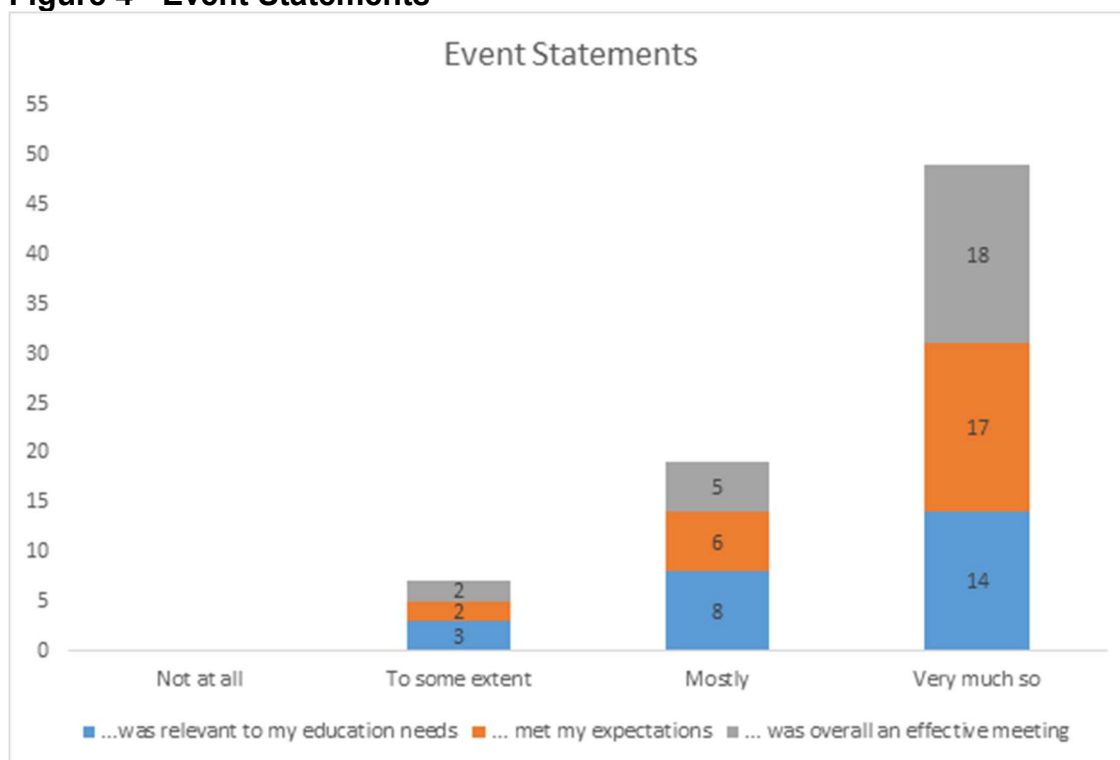


Figure 4 - Event Statements



What was good about the event?

Overall, delegates stated that the event was an excellent opportunity to meet, discuss, learn and share information from the multi-disciplinary team perspective. Virtual access to the event was well received and allowed colleagues to attend who would have otherwise not been able to. Although face to face meetings were good for networking and perhaps having some more detailed discussions, there was a sense that virtual meetings would improve as colleagues became more familiar/comfortable with this new way of working.

What could have been better?

Suggested improvements included more orthodontic topics, reducing technical issues, earlier advertisement, increasing interactions by perhaps breakout rooms or chat at break, having handouts and hosting event over shorter period of time..

What was gained from attending the event?

The majority of attendees gained a better knowledge and understanding of areas such as management of cleft care (pathways), the multi-disciplinary approach, data and research associated with cleft. Other attendees indicated that they acquired updates and overviews.

What would be done differently?

A number of suggestions for what would now be done differently were highlighted. These included using training videos, applying knowledge with confidence, improved networking and sharing of information and further reading on CRANE.

Future topics

The top three suggested future topics were:

- Paediatric Dentistry
- Psychology and Speech & Language Therapy
- Orthodontics, Case Discussions, Outcomes, Service Delivery and Cleft Pathway

Other areas of interest included Audiology, Restorative Dentistry and data.

Summary & Conclusion

There were 36 delegates who attended of whom 25 responded to the evaluation thus giving a response rate of 69%.

The vast majority of respondents indicated that the topics were definitely or very effective. 56% stated that the event had very much met their educational needs, expectations were very much met for 68% and 72% deemed that the event had been overall very effective.

The virtual platform was well received although there was a sense that networking opportunities were reduced but this may improve over time.

Many colleagues had improved understanding and knowledge as a result of attending the event. Flexibility in treatment of patients to suit individual needs was a theme from doing things differently with research, networking and highlighting issues with delayed surgery also being mentioned.

Recommendations:

- To increase virtual networking opportunities.
- Earlier advertisement of event.
- Hosting event over shorter period of time.
- Covering suggested topics at future events.

Appendix 3 2021/22 CCS Workplan

When defining network objectives please consider the NHS Scotland policy aims described in [Realistic Medicine](#), as well as the Institute of Medicine's six dimensions of quality, which are central to NHS Scotland's approach to systems-based healthcare quality improvement:

1. **Person-centred**: providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-03	The Network will finalise its workplan for the 2021-24.	June 2021	Network Team/Steering Group		There are effective governance arrangements in place for network activity	
2021-01	The network will organise 3 Steering Group meetings and each subgroup will meet at agreed intervals to ensure effective delivery of the 2021-22 workplan	March 2022	Steering Group/ Sub-Groups		Effective delivery of the CCS network workplan to ensure continuation of progress	
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-04	Map current network clinicians and plan to address gaps in provision and staffing	March 2022	Network Team		There is equity of access to appropriately trained clinicians and services within NHS Scotland	
2021-02	The network will promote the revised patient pathways to HCPs and patients/families. Feedback on the pathways will be sought to inform future service development.	March 2022	Steering Group		Stakeholders are clear on what the expectations of care are	
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2021-03	Network communications will meet the needs of all stakeholders including in line with the Communication Strategy	March 2022	Network Team/ Steering Group		There will be effective, clear lines of communication between the network and all stakeholders.	
2021-04	Develop the website to ensure it provides an effective communication and information resource for patients, families and professionals.	Ongoing	Network Team			

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at	Anticipated Outcome	RAGB status
2021-05	Network activity will be informed by people born with a cleft lip and/or palate and their carers. Activity will be guided by the Patient Engagement Group and will include a patient engagement event and patient experience survey.	March 2022	Network Team/ PEG		Patients/ needs/priorities drive the work of the network	
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2021-06	The network will arrange an Annual Educational Event	Autumn 2021	Network Team		Provide educational opportunities to specialist and non- specialist clinical staff to enhance knowledge of care of cleft lip and palate patients	
2021-07	The network provide education opportunities for staff directly and indirectly involved in cleft care in line with the Education Strategy	March 2022	Network Team/ Steering Group		The workforce has access to evidence based cleft care training and resources for improved health and care	
5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-10	The network will develop and adopt its Quality Improvement (QI) Strategy	June 2021	Network Team/ Steering Group		Improvements to service delivery are progressed from audit	
2020-11	The network will adapt Clinical Audit System (CAS) data fields to align with Cleft Registry and Audit Network (CRANE) which will audit performance	June 2021	Network members		Network and clinical work is supported by a robust	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at	Anticipated Outcome	RAGB status
2021-08	Cleft Care services will collect and record the required data within the national systems to ensure effective audit can take place.	March 2021	Network members		system that meets is requirement	
2020-12	The network will develop a patient educational video in conjunction with the Speech and Language Therapists (SLT) and audit evaluation of this	Dec 2021	SLT Group		Improving education will lead to better outcomes for patients	
2021-09	Review of the impact of these new pathways through clinician and patient feedback.	March 2021	Network Team/ Steering Group			
2021-10	The network will use the findings from national audit and patient feedback to support improvements in patient care with efficient use of resources.	Ongoing	Network Team/ Steering Group		Providing added value to health care in Scotland as well as cost savings for NHS Scotland	
6. Value <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						