

Cleft Care Scotland (CCS)

Annual Report 2021/22

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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 to ensure equitable provision of high quality, clinically effective services.

Approximately 100 children are born with a cleft lip and/or palate in Scotland each year. In 2021, there were 79 babies born with a cleft, of which 18 had a cleft lip, 35 have a cleft palate and 26 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 some progress against the 2021/22 workplan despite the challenges resulting from the continuing COVID-19 pandemic. Progress against Audit and Continuous Quality Improvement objectives has been limited due to the continued delay in cleft lip and palate services in Scotland joining the Cleft Registry and Audit Network (CRANE).

CRANE, the clinical registry for all children born with cleft lip and/or palate in England, Wales and Northern Ireland, 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. It is anticipated that NHS Scotland will join CRANE in 2022/23 and this will inform the Network's quality improvement initiatives.

Progress against the workplan is detailed in Appendix 1.

Lead Clinician Viewpoint

The last year has been difficult year for everyone in the cleft network especially the patients and their families with the continued impact of the COVID pandemic and its effects. The cleft service in Glasgow and clinicians across the network have continued to care for those born with cleft lip and palate. The network committees have continued with the use of remote meetings including delivery of a successful virtual network day for the second year. It is hoped that this year we can deliver a network day face to face this year.

I would like to thank all the families and patients in the cleft network for their patience and understanding during this difficult time. I would also like to thank all the staff, both clinical and support staff who have worked hard across Scotland to maintain the services of the network and care for our patients.

Highlights

vCreate

The COVID-19 pandemic resulted in greater emphasis on care being provided remotely using telephone consultations and NHS Near Me. However, for Speech and Language Therapy (SLT) services this new way of working has limitations as it does not offer the sound quality required to clinically assess speech development.

vCreate is a cloud-based service which enables secure transfer of short recorded (asynchronous) video in health and care settings. This technology is being used in several specialties across NHS Scotland and the Network was keen to explore whether this would be helpful in Cleft Care Specialist SLT services.

A six-month pilot of vCreate within Cleft Care Specialist SLT services in NHS Greater Glasgow and Clyde (NHSGGC) started in December 2021. This project will allow families to share videos of their child's speech patterns with the Cleft Care SLT team in NHSGGC for remote clinical interpretation, management advice, and for audit purposes.

Evaluation is central to the pilot process with feedback being sought from parents/carers after they have received comment on a video they have shared. This feedback will be analysed together with recording the reduction in number of in person appointments and subsequent reduction in travel time for patients/families. An evaluation will take place with the Speech and Language Therapists to gather feedback on the use of this technology to support patients/families and its use in consensus listening for clinical audit.

An evaluation report to assess whether vCreate brings additional benefit to Cleft Care SLT will be presented to Cleft Care Scotland Steering Group following the pilot. Any continuation or roll out of this system following the initial pilot will require discussions with the health boards responsible for providing cleft care SLT.

Commissioning and Cross Cover Arrangements

Cleft lip and palate services in Scotland operate as a 'Hub and Spoke' model with a nationally commissioned surgical element of the service covering specialist surgical input to all stages of assessment, inpatient hospital stay, and surgical follow-up. The nationally commissioned part of the service consists of the surgeons, specialist nurses and psychologists who support this service. All other aspects of care for people born with a cleft lip and/or palate is provided by the local NHS Boards and includes the specialities of speech and language therapy, orthodontics, paediatric dentistry, restorative dentistry, genetics, ENT and audiology. Nationally agreed care pathways are in place to ensure optimal outcomes are achieved.

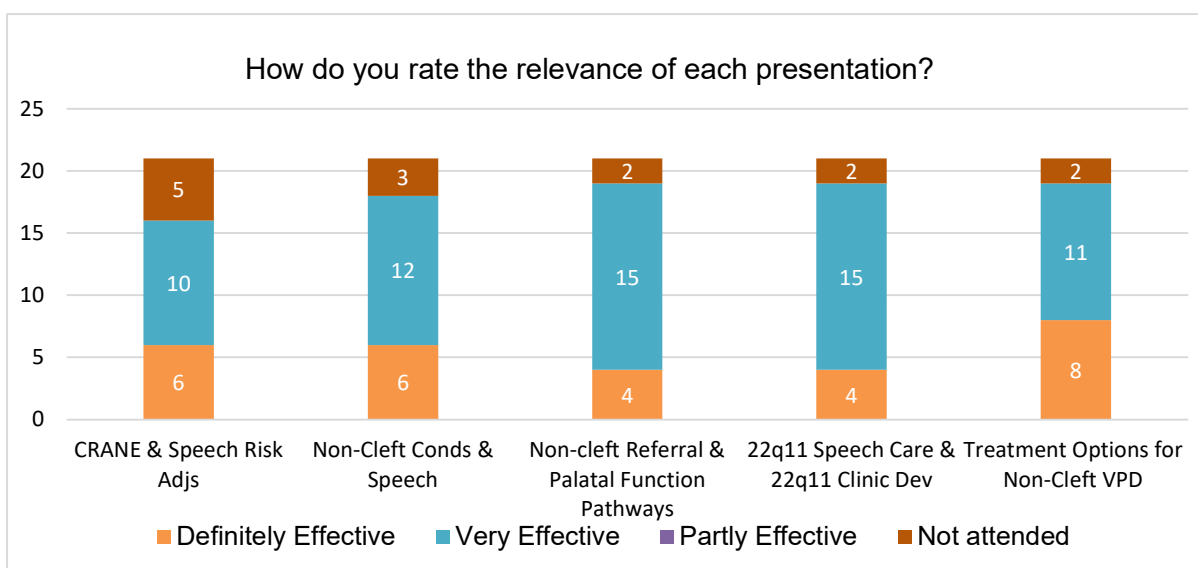
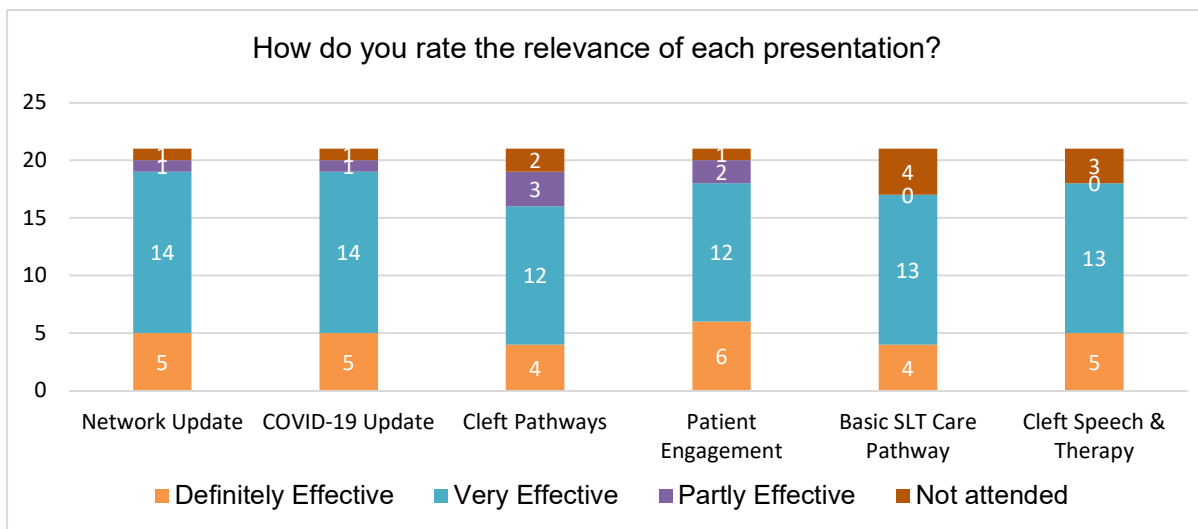
To ensure the best possible care is provided, there is a need to ensure that people born with a cleft lip and/or palate have equitable, timely access to all of the specialist services they require. NHS Boards have a duty to ensure that services they are responsible for are adequately staffed and contingencies are in place to ensure any periods of staff absence are covered appropriately.

Cleft Care Scotland has engaged with the commissioners of the National Managed Clinical Network to outline this issue to inform discussions with NHS Scotland’s Regional Planning Teams to ensure that all aspects of local cleft care services are supported appropriately across Scotland.

Education

The Network’s Annual Education Event took place virtually on 5th November 2021. This year’s event covered the theme of Speech and Language Therapy in Cleft while also including some general update sessions such as cleft care pathways, patient engagement and impact of COVID-19.

The event was attended by 36 people of which 21 returned an evaluation. Feedback on the event was very positive with 16 respondents rating the event as very relevant (62%) or mostly relevant (14%) to their educational needs and 19 respondents rating the effectiveness of the meeting as very effective (62%) or mostly effective (29%). Feedback on each presentation in relation to relevance to attendee’s educational needs was very positive as noted in the graphs below:



Patient Experience and Engagement

The Network continues to ensure the experiences of people born with a cleft lip and/or palate and their carers, and understanding what matters to them, informs its activities as outlined in our Patient Experience and Engagement Strategy. Central to this is the direction and feedback provided by the Networks Patient Engagement Group which includes people born with a cleft, family representatives and voluntary sector organisations with an interest in cleft care.

Members of the Patient Engagement Group have been involved in informing the development and review of the Network's website to ensure this meets the needs of people born with a cleft and their families. The Group have supported the development of the patient experience survey which will be distributed across cleft care services in 2022/23 and will use the feedback from this to inform future activities.

Exceptions

Patient/Family Event

The online patient/family event to allow people to share information on the new patient pathways and find out more about the cleft care team has not taken place. This event, scheduled to take place in September 2021, was postponed due to limited numbers registering to attend. The event was rearranged to March 2022, but unfortunately did not take place due to unforeseen circumstances impacting on presenter availability. There was significant interest in this event, with 22 patient/families registered to attend and therefore the Network plans to reschedule this event as soon as possible.

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 2022/23 Network objectives are outlined in the workplan in Appendix 2. Key priorities for the coming year include:

- Developing and adopting the Networks Quality Improvement Strategy following NHS Scotland's entry into CRANE.
- Evaluating the pilot of vCreate to demonstrate whether vCreate offers additional value to Cleft Speech and Language Therapy services.
- Hosting the patient/family event to provide an opportunity for networking, sharing information and for identifying priorities in cleft care.
- Conducting the patient experience survey to gather feedback from people attending cleft care services and their carers to allow services to be tailored to their needs.
- Supporting the continuing professional development of staff directly and indirectly supporting cleft care.

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 2022/23. The joint review will engage with stakeholders to inform the best model of care moving forward for the Network and the Service to ensure these add value to people born with a cleft lip and/or palate, and to NHS Scotland.

Finance

Due to the restrictions in place and continued use of virtual meetings, costs normally associated from face-to-face meetings and education events have not been incurred this year.

The Network did use £2,430 from its budget this year to fund the pilot of vCreate in Cleft Speech and Language Therapy in NHS Greater Glasgow and Clyde.

Appendix 1 CCS Progress in 2021/22

Core Principle	Activity	End of Year Update	Start Date	End Date	Q4 RAG Status
Effective Network Structure and Governance	Core Team Meets Regularly	Core Team met fortnightly during 2021/22.	01/04/21	31/03/22	C
	Hold 3 Steering Group Meetings	Steering Group Meetings held on 7th June 21 and 4th October 21. Meeting scheduled for 7th March 22 was not quorate so formal meeting did not take place although some key actions discussed/progressed with attendees present.	01/04/21	31/03/22	C
	Subgroups meet regularly	Subgroups have taken place regularly during 2021/22.	01/04/21	31/03/22	C
	Finalise 3-5 year workplan	2021-24 Workplan endorsed at SG on 7th June 21.	20-21	07/06/21	C
	Annual Report	Annual Report submitted on 31st May 21. APR held on 4th October 2021.	01/04/21	31/05/21	C
	Mid-Year Report	Report submitted on 31st October 21.	01/09/21	31/10/21	C
	Finalise Quality Strategy	Draft Quality Strategy developed. Awaiting entry to CRANE before being finalised. Service taking forward entry to CRANE. Will be added to 2022/23 workplan.	20-21	30/06/21	R
	Quarterly monitoring of finance spreadsheet	No finance data provided. Only spend in 2021/22 on vCreate pilot.	01/04/21	31/03/22	N/A
	Purchase Orders received at the end of each quarter	No finance data provided. Only spend in 2021/22 on vCreate pilot.	01/04/21	31/03/22	N/A
	2022/23 Workplan Objectives	Network objectives to be drafted and shared with SG members for comment.	01/01/22	31/03/22	C
Service Development and Delivery	Develop Service Map. Plan to address gaps in provision and staffing.	Service Map developed. Gaps in service and how to address discussed at Steering Group on 04/10/21. Paper drafted to discuss appropriate cross cover shared with Steering Group on 7/03/22.	20-21	31/12/21	C
	Promotion of revised patient pathways to HCPs and patients/families.	Focus of patient event due to take place on 28/03/21. This was postponed due to unforeseen circumstances and will be rescheduled in 2022/23. Website updated to provide more information on pathways.	20-21	31/12/21	C
	Develop a patient educational video in conjunction with the Speech and Language	Put on hold due to COVID-19 pressures. Can be reconsidered at a later date if deemed helpful however in the interim focus is on vCreate pilot.	01/10/21	31/03/22	N/A

	Therapists (SLT). Audit evaluation of this.				
	Pilot vCreate in Speech and Language Therapy	Six-month pilot started on 01/12/21. Limited formal feedback to date but positive from clinicians and parent/carers. Pilot will continue into 2022/23 workplan.	01/09/21	30/06/22	G
	Review of the impact of the new pathways through clinician and patient feedback.	Carried over from 2020/21 to allow time for new pathways to embed given COVID-19 restrictions. Will be carried over to 2022/23 workplan given ongoing impact of COVID-19 on service delivery.	01/10/21	30/09/22	A
Stakeholder Communication and Engagement	Issue Two Newsletters	One Network newsletter developed. Shared in February 2022.	01/04/21	31/03/22	A
	Development of website	Website reviewed with Patient Engagement Group. Additional information provided by subgroup leads. Website updated and will be updated on an ongoing basis.	01/04/21	31/03/22	C
	Hold Patient Engagement Event	Event planned for 6th September 2021 postponed due to limited numbers attending. Event due to take place on 28/03/21 with 22 people registered. Event postponed due to unforeseen circumstances and will be rescheduled in 2022/23.	01/06/21	06/09/21	A
	Patient Experience Survey	Discussed at Steering Group with concerns raised around purpose. Discussed further with PEG on 23/11/21 and further updates made. Final sign off and discussion on dissemination to take place. Will be added to 2022/23 workplan.	01/10/21	31/01/22	A
Education	Host Annual Educational Event	Event held on 5th November 2021 with a focus on SLT. Around 35 people attended and feedback was positive. Evaluation Report shared on 17/12/21 and recordings available on the website.	01/08/21	05/11/21	C
Audit and Continuous Quality Improvement	Support Effective Audit via CRANE	Entry to CRANE pending. Agreed that this will now be taken forward by the Service. Paper outlining existing approach to collecting audit data from each specialty drafted discussed at SG 07/03/22. Will be added to 2022/23 workplan.	20-21	30/06/21	R
	Adopt the Quality Improvement Strategy	Quality Improvement Strategy to be finalised and adopted post CRANE entry. Delayed due to delays with entering CRANE. Will be added to 2022/23 workplan.	01/07/21	31/03/22	R

Appendix 2 2022/23 CCS Workplan

Core Principle	Activity	Start Date	End Date
Network Structure and Governance	Core Team Meets Regularly	01/04/2022	31/03/2023
	Hold 3 Steering Group Meetings	01/04/2022	31/03/2023
	Subgroups meet regularly to drive forward workplan	01/04/2022	31/03/2023
	Ensure all finance requirements are met	01/04/2022	31/03/2023
	Submit Annual Report	01/04/2022	31/05/2022
	Submit Mid-Year Report	01/10/2022	31/10/2022
	Develop 2023/24 Workplan	01/02/2023	31/03/2023
Service Development and Delivery	Complete and evaluate pilot of vCreate in Speech and Language Therapy.	01/09/2022	30/06/2022
	Review of the impact of the new pathways through clinician and patient feedback.	01/04/2022	31/03/2023
	Explore how best the National Service and Network can work together to complement one another and avoid duplication.	01/04/2022	31/03/2023
Stakeholder Engagement and Communication	Hold Patient Engagement Event	01/04/2022	31/03/2023
	Share patient experience questionnaire and develop action plan in response to feedback	01/04/2022	31/03/2023
	Website is useful resource for patients/HCPs	01/04/2022	31/03/2023
	Issue at least 2 Newsletters	01/04/2022	31/03/2023
Education	Host Annual Educational Event for HCPs	01/04/2022	30/11/2022
Audit and Continuous Quality Improvement	Finalise and Adopt Quality Strategy	01/04/2022	31/03/2023

