

Minutes of a Meeting of the National UK NHS Cleft Development Group

Venue: Microsoft Teams conference call

Date & Time: Thursday 11 November 2022 – 9:00 to 13:00

Present	<p>Simon van Eeden (SvE) Chair Mary Bance (MB)</p> <p>Victoria Beale (VB)</p> <p>Christine Couhig (CC) Rebecca Crawford (RC) Claire Cunniffe (CCu) Sinead Davis (SD) Louisa Ferguson (LF) Toby Gillgrass Norman Hay (NH) Chris Hill Peter Hodgkinson (PH)</p> <p>Sarah Kilcoyne (SK)</p> <p>Kate Le Marechal (KLM) Joanna May (JM) Jason Neil-Dwyer (JND) Ginette Phippen (GP) Sandip Papat (SP) Helen Robson (HR) Craig Russell (CR) Heather Sahunta (HS) David Sainsbury (DS)</p> <p>Antonia Sinclair (AS) Imogen Underwood (IU) Rachel Willis (RW) Yvonne Wren (YW)</p>	<p>Cleft Development Group Chair Network Managers/Coordinators Representative, Network Manager, Cleft Net East Clinical Director, North West, IoM & North Wales Cleft Network Lead Clinical Nurse Specialist, Newcastle Clinical Psychology CEN Lead CLAPA Chief Executive ENT & Audiology CEN Chair Chair of the Cleft Training Interface Group Lead Clinician, Scotland Clinical Director, North Thames Cleft Service Clinical Director, Northern Ireland Cleft Service Clinical Lead, Newcastle Site, Northern & Yorkshire Cleft Service Chair, NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies Clinical Director, Evelina London Cleft Service Paediatric Dentistry CEN Chair Clinical Lead/Director, Trent Regional Cleft Network Representing the SLT CEN and Lead Groups Restorative CEN Chair Representing Nursing, Nurse in North Thames Cleft Centre CRANE Clinical Project Lead Cleft Nursing CEN Chair Representative for The British Association of Plastic, Reconstructive and Aesthetic Surgeons Community Engagement Coordinator, CLAPA Lead SLT, West Midlands Cleft Service Orthodontics CEN Chair Chief Investigator, Cleft Collective</p>
In Attendance	Claire Dunn (from 11:00)	Research Coordinator, Clinical Effectiveness Unit, Royal College of Surgeons of England
Apologies	<p>Neil Brierley Alistair Cobb David Drake Martin Evans Helen Extence David Landes Felicity Mehendale David Orr Siobhan Sawey Julia Scott Alistair Smyth Marc Swan Guy Thorburn</p>	<p>Lead Clinician, Cleft Net East Clinical Director, South West Cleft Service Lead Clinician for Cleft Care Scotland Clinical Director, West Midlands Cleft Service Clinical Director, The Welsh Cleft Lip and Palate Unit Public Health Consultant President Craniofacial Society of Great Britain and Ireland Plastic surgeon and cleft surgeon, Dublin Cleft Centre Paediatric audiologist. Northern Ireland Cleft service Orthodontic CEN Lead Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service Clinical Director, The Spire Cleft Service Representing the Surgical CEN</p>

Item	Notes
1. Apologies, absence and welcome to new members and invitees	The chair (SvE) welcomed the Cleft Development Group (CDG) to the meeting. The group joined the meeting via Microsoft Teams teleconference. Apologies were given for those unable to attend (see above). All attendees introduced themselves.
2. Minutes of the Cleft Development Group meeting, 8 June 2022	The minutes of the CDG meeting on 8 June 2022 were reviewed, and approved as a true and accurate record of the meeting.
3. Matters arising	
4. CDG Patient Engagement Group 5. (PEG)	<p>SvE opened the discussion and welcomed Antonia Sinclair, Community Engagement Coordinator from CLAPA to the meeting. SvE informed the meeting that GP, HR and Gillian McCarthy from CLAPA had met with the PEG on a few occasions and he asked GP to summarise the outcome of these. GP reported that there had been discussion about the expectations of the PEG, how the PEG can contribute to CDG and how they can request information that can be fed back out to the patient and parent communities. GP felt it was worth thinking about how best to integrate the PEG into CDG meetings and how also to be able to respond back to the group. GP said that the group had identified several questions that have broadly been categorised into 5 themes by AS. AS felt that the group would value answers to the questions within agreed timelines but didn't expect all the questions to be answered today.</p> <p>SvE screen-shared the questions with the group. He felt that CDG is too busy a meeting to try and get answers to all of the questions today but put forward the suggestion of a sub-committee, agreed at a meeting with SvE, GP and CC, to look at these outwith the CDG meeting with input from all stakeholders on the CDG? CC also suggested at the meeting with GP and SvE that, in view of the fact that some of these questions were likely to recur in the future, it might be useful for these to be posted on the CLAPA website under frequently asked questions with the answers and with updates if and when answers changed. AS felt that this would be a positive step.</p> <p>After SvE read out the questions from the spreadsheet and answered a few of these a discussion ensued about adult access to cleft services. AS felt that it would be made easier if patients were able to self-refer. All cleft units provide end of routine care advice and information on returning to the cleft team. Most cleft units apart from Scotland required GP referral back into the service and this would usually result in the patient seeing the multi-disciplinary team. AS questioned the reason for this and she felt that this created an extra layer that the patient had to negotiate to eventually be seen. It was felt by clinical directors that this was important from a tariff, medical history and electronic referral point of view. On re-referral some units provide the patient with a pre-clinic questionnaire to understand their reasons for returning to the cleft team for treatment and one other unit arranged a psychology appointment as the first appointment to then streamline subsequent appointments.</p> <p>As far as adult waiting lists are concerned it was felt that it would be difficult to publish these but there was universal agreement that adult patients were waiting a long time for surgery because of the pandemic. JND briefly explained the priority system brought about at the start of the pandemic that determines access to surgery.</p> <p>It was agreed that patients are always entitled to a second opinion and that mixing of NHS and private treatment is usually not recommended.</p> <p>With regard to current funding structures for cleft SvE briefly explained historical funding for cleft services but that this was changing. All the clinical directors agreed that funding had changed, was unclear, but was still continuing.</p>

	<p>The PEG is keen to know how CRANE and the different groups fit into the cleft world? SvE answered by saying that all of the groups mentioned in the question would be reporting back in the meeting today, which will hopefully help answer this question.</p> <p>The PEG part of the meeting ended with agreement for SvE, HR and GP to meet to explore the setting up of a PEG sub-committee in more detail. SvE asked for those keen to be on the sub-committee to let him know. SvE agreed to send out the PEG questionnaire to CDG so that the questions can be appropriately answered and then returned to SvE. Some of these could then be put on the CLAPA website in the FAQ section.</p>
<p>6. Feedback from Cleft Centres (UK)</p>	<p>Scotland See Appendix 5.1 for a written update from the Cleft Surgical Service for Scotland.</p> <p>Welsh Centre for Cleft Lip and Palate See Appendix 5.2 for a written update from the Welsh Centre for Cleft Lip and Palate.</p> <p>Northern Ireland Cleft Service See Appendix 5.3 for a written update from the Northern Ireland Cleft Palate Service.</p> <p>North West, Isle of Man and North Wales Cleft Network See Appendix 5.4 for a written update from the North West, Isle of Man and North Wales Cleft Network.</p> <p>Newcastle Site, Northern and Yorkshire Cleft Service See Appendix 5.5 for a written update from the Newcastle Site, Northern and Yorkshire Cleft Service.</p> <p>Trent Regional Cleft Network See Appendix 5.6 for a written update from the Trent Regional Cleft Network.</p> <p>West Midlands Cleft Service IU advised that she had not received the new pro forma for CDG reports. SvE advised it had been sent to Martin Evans; IU requested that it be sent to her in future.</p> <p>Action 10/11/22:5.1: SvE to replace Martin Evans with Imogen Underwood for future circulation of/request for CD reports to the CDG.</p> <p>IU then provided the following update from the West Midlands Cleft Service:</p> <ul style="list-style-type: none"> • An appointment has been made to the new consultant role. • Surgery is now taking place close to national specifications. • Extra operating sessions have been allocated in order to address the backlog. • Extra weekend sessions are being run to bring the waiting list for investigations down. • There have been problems with clinic time and with accessing cleft and dental consultants. • RW has joined the team as an orthodontist. <p>Spires Cleft Lip & Palate Network GP spoke to the written update from the Spires Cleft Lip & Palate Network, included as Appendix 5.7. Key points were as follows:</p>

- Improvements have been made to the pre-surgical assessment pathway.
- Database needs for the service are being reviewed.
- The network has had a Cleft Fellow working with them, which has been invaluable.
- Waiting lists look good for primary surgery, but less good for bone grafts. There are long waiting lists for adult procedures.

North Thames Cleft Service

NH spoke to the written update from the North Thames Cleft Service, included as Appendix 5.8. Key points were as follows:

- There has been a large backlog of patients requiring cleft MDT appointments. Work has been undertaken to modify relevant protocols to rationalise the need for MDT review, to help address the backlog.
- Waiting times for alveolar bone grafts and osteotomies are now reasonable, with a regular operating slot now re-established after moving to an ad hoc arrangement during the pandemic.
- There remains a big orthodontic backlog.
- The consultant paediatric dentist role has not yet been appointed to, and has been re-advertised.
- There is a large backlog for VPI assessments, which is impacting waiting times.
- Psychology services are now provided on a referral basis only.
- Audiology services are now largely provided at local level.
- A mistake by the deanery meant the service was unable to appoint a new orthodontic post-CCST trainee registrar, meaning there will be a 1-year vacuum.
- The service received an outlier notification from CRANE and is currently doing a deep dive into the data to formulate a response.
- A new consultant cleft geneticist has been appointed which is proving of great benefit.
- There has been a lot of change at management level, with the need to educate new post-holders about cleft impacting the service.

Evelina London Cleft Service

KLM spoke to the written update from the Evelina London Cleft Service, included as Appendix 5.9. Key points were as follows:

- A new service manager and assistant service manager have been appointed. This has led to some delays and issues with gaining access to data and understanding waiting lists.
- At the last CDG meeting it was reported that the SLT team was struggling; this is now better, but not at ideal levels.
- The lead nurse has resigned and recruitment will begin shortly.
- There has been a large degree of turnover in the nursing team leadership and band 7 roles, so there is work to be done to restore stability.
- Waiting lists for primary surgery are generally on track. Alveolar bone grafts are more variable depending on the individual surgeon. More theatre capacity from April 2023, with an extra list each month, will help address any backlogs.
- Waiting lists for secondary surgery are more difficult to assess given the variability between surgeons. An additional issue for lip revisions is that the US has stopped supplying PermaLip implants to the UK, so patients are needing to be re-consented for an alternative procedure.

- In April 2023, Evelina will be moving to the EPIC database and also to a 4-week repeating ABCD theatre timetable, and it is anticipated this will impact on all services. The ABCD theatre timetable will mean some additional operating list time, but is logistically very difficult to organise, with the biggest issue being alignment with consultant job plans.
- Inpatient lists have been the focus for surgery, but attention is now moving to outpatient lists. A deep dive is under way, looking at 'appointment by' dates and other ways to address waiting lists, such as running extra clinics, running virtual clinics and switching staff from running one clinic to another where need is greater.
- The service is seeing an increasing number of non-cleft referrals, ie non-cleft patients who have been in a road traffic accident, cocaine users and patients with neurological issues, which the cleft service is not commissioned for.
- JND noted that a lot of services are looking at service specification pathways and it would be good to share these discussions nationally. SvE advised that at the last CDG meeting, each CEN was asked to look at the service specification for their area. KLM commented that the service specification provides the aspiration, but it would also be good to understand how services are making this work at a practical level.
- HR advised that North and South Thames groups are meeting regularly to share learning about issues such as the EPIC database.
- NH advised that one way to align the ABCD 4-week repeating schedule with consultant job plans would be to set out what the service needs to cover every 4 weeks, and then put the onus on the consultants on how this would be covered.
- PH commented that his service had seen a few non-cleft referrals, particularly for cocaine use – for example, more than half of rhinoplasty patients have used cocaine. KLM noted that a national discussion on how to address these referrals would be welcomed. SvE advised that this is something for the Surgical CEN to advise on.

Action 10/11/22:5.2: Surgical CEN to discuss how to manage non-cleft referrals and report back to CDG.

Leeds Site, Northern and Yorkshire Cleft Service

SvE spoke to the written update from the Leeds Site, Northern and Yorkshire Cleft Service, included as Appendix 5.10. Key points were as follows:

- Primary lip and palatal surgery is being delivered according to protocol.
- Waiting time for alveolar bone grafts has been reduced from 2 years to 18 months for the longest waiter, with further work planned to reduce this further.
- For secondary surgery, regular speech surgery has resumed, with a reduction in waiting times as a result.
- Cleft orthognathic surgery and lip/rhinoplasty surgery have also resumed, with no and very few patients on the respective waiting lists.

South West Cleft Service

SvE spoke to the written update from the South West Cleft Service, included as Appendix 5.11. Key points were as follows:

- The service continues to experience significant challenges in a number of areas.
- Staffing vacancies and pressures are felt at almost all levels, including Clinical Nurse Specialists, psychology, surgery, speech and language therapy, orthodontics and administration. Paediatric dentistry has a full

	<p>complement of consultants, but there are access issues to dental care across the south-west.</p> <ul style="list-style-type: none"> • Paediatric waiting lists have reduced since last year; however, this is likely not sustainable particularly for alveolar bone grafts. The service is keeping primary palate repairs to 12 months, but this is impacting speech surgery. • Adult waiting lists remain high, with operating lists still reduced. • Speech investigation equipment has still not been replaced after being broken for 3 years. Emergency funding has been requested. • There is an obvious need for an increased number of operating lists for the cleft service at Bristol Children’s Hospital, but it is not clear how this might be achieved. • No mutual aid opportunities have been identified since the last CDG meeting. • PH noted that Bristol has a large waiting list for speech patients. It had previously been agreed that some patients could be transferred to Newcastle, but Newcastle has suddenly lost capacity. The problem is that no other service has capacity to assist Bristol, but that Bristol will not be able to address its issues alone. This is a national issue, not a local one, and needs a national solution – for example, giving all units extra capacity to allow them to support Bristol. PH queried: whether SvE could raise the issue at a national level; whether the SLT CEN could help to lobby to prioritise speech operations; and whether the CENs could consider producing a risk document to be used nationally to advocate for priority patients (eg, ensuring children are seen before they start school, to minimise the impact on educational attainment). • CR commented that there will not be a quick fix, and that a 5-year plan is needed to get back to acceptable waiting times. • CR further noted that a team at the London School of Hygiene & Tropical Medicine (LHSTM) is looking at the impact of Covid on primary surgery, and that Bristol is a significant outlier. • VB queried the degree to which the Bristol figures are skewing the Quality Dashboard and therefore the levels deemed acceptable for other Trusts. <p>Action 10/11/22:5.3: SvE to consider how to respond to the questions and discussion around how best to support Bristol.</p> <p>Cleft Net East MB spoke to the written update from Cleft Net East, included as Appendix 5.12. Key points were as follows:</p> <ul style="list-style-type: none"> • A new TIG Fellow joined the service in August 2022. A number of other posts have been filled or are being actively recruited to. • MB will be leaving for a 1-year secondment, starting January 2023. The cover post will be advertised shortly. • Primary surgery waiting lists are broadly okay, but the service is not receiving sufficient lists to manage demand for secondary surgery. • The Trust is not using pre-Covid levels as a target for theatre time allocation, but is rather basing allocation on demand. This means the amount of theatre time allocated to the cleft service has been reduced, with traction only being gained for patients who breach the 72-week waiting time.
<p>7. Feedback from CENs</p>	<p>ENT & Audiology CEN SD spoke to the written update submitted by the ENT & Audiology CEN, included as Appendix 6.1. Key points were as follows:</p>

- Overall, engagement with the ENT & Audiology CEN has been limited. Meetings will be kept as brief as possible in future to make it easier to engage. SvE suggested CDs should speak to their local ENT and audiology teams to boost engagement.
- Work is under way with CRANE to determine what would be the most useful 5-year data to collect, and to develop an SOP to get the information from CRANE.
- Work to standardise the information provided by different centres, eg on their websites, is under way to ensure consistent basic knowledge is available to stakeholders.
- Discussion is needed around data collection for CRANE, particularly in terms of administrative support.

Action 10/11/22:6.1: CDs to promote the ENT & Audiology CEN to relevant colleagues and suggest booking the CEN meetings into study leave.

Speech & Language Therapy (SLT) CEN

GP spoke to the written update submitted by the Speech & Language Therapy (SLT) CEN, included as Appendix 6.2. Key points were as follows:

- Work is ongoing to update information about roles and responsibilities across clinical networks and capacity for interventions. There are general capacity issues at a national level.
- The SLT CEN is keen to review the service specification. One issue that will need to be addressed is the lack of specific recommendations on how to engage local services and what is expected of them.
- The autumn study day is taking place on 11 November, focusing on the evidence base for interventions.
- The CEN has made a recommendation about how to manage the 2015 speech data, which was supported by the CDG.

Clinical Psychology CEN

RC, the new CDG representative for the Clinical Psychology CEN replacing Vanessa Hammond, spoke to the written update submitted by the Clinical Psychology CEN, included as Appendix 6.3. Key points were as follows:

- Work is under way in collaboration with CRANE about new data to be collected.
- Work is under way to ensure consistency across units.
- A review of the service specification is in progress.
- The new CEN Chair is Jen Rundle (Evelina) and the new CEN Assistant Chair is Katherine Berlouis (Scotland).

Nursing CEN

HS spoke to the written update submitted by the Nursing CEN, included as Appendix 6.4. Key points were as follows:

- The main focus at present is to reignite and enthuse Nursing CEN members following the impact of Covid.
- An education/study day event was held in October, focusing on feeding and complex cases. CRANE, CLAPA and CFSGBI updates were also included. HR wished to formally record her thanks to Jenny Williams for her unpaid work in organising the study day.
- The CEN is supporting HR/CFSGBI in the planning of their 2023 conference.
- Updates to the CEN Nursing Standards are under way.
- Work to review the service specification is also being planned.

Orthodontics CEN

RW spoke to the written update submitted by the Orthodontics CEN, included as Appendix 6.5. Key points were as follows:

- Meetings remain virtual at present – in future, the plan is to meet face-to-face at the annual CFSGBI conference each spring, and virtually each autumn. There is a lot of interest in the meetings, but it seems to be a struggle to manage attendance alongside clinical tasks, and to get study leave for the meetings.
- CR is due to join the CEN meeting on 11 November to discuss the timing of the two data collection points used to assess growth.
- An ongoing concern is the lack of adult orthodontic surgery provision. The CEN has collected data to look at waiting times for cleft and non-cleft and agrees it would be useful to have an orthognathic paper to present to service managers to prioritise these patients. Input from the Surgical and Psychology CENs would be welcomed.
- The Orthodontics CEN gave a number of presentations and posters at the Cleft 2022 conference.
- A review of the service specification will be added to the agenda for the 11 November CEN meeting.

Restorative CEN

SP spoke to the written update submitted by the Restorative CEN, included as Appendix 6.6. Key points were as follows:

- This is the newest CEN, and interest has continued to grow, with 33 dentists treating patients with cleft currently part of the Network.
- There has been, and continues to be, good collaboration with speech and language therapists around speech problems. A joint training day has been planned seeking to demystify these issues.
- The British Dental Journal has commissioned SP and Prof Martin Ashley to edit a series on the multidisciplinary management of patients with cleft lip and/or palate. A collaborative approach has been taken, with various other cleft CENs contributing. The series is due to be published in May 2023.

Paediatric Dentistry CEN

SvE spoke to the written update submitted by the Restorative CEN, included as Appendix 6.7. Key points were as follows:

- No meeting has been held since the last CDG meeting.
- The Paediatric Dentistry CEN has found that virtual meetings help boost attendance.
- The main issues at present are the backlog in restorative dentistry (for both cleft and non-cleft patients), and the lack of access to NHS dentistry services, especially for paediatric patients.
- There have been some glitches with entering the dental anomalies data for 5- and 10-year-olds into CRANE. These issues will be discussed and resolved by consensus view at the next CEN meeting.

Surgical CEN

SvE spoke to the written update submitted by the Surgical CEN, included as Appendix 6.8. Key points were as follows:

- Meetings continue to take place virtually. Going forward, the model will be one face-to-face meeting each year (coinciding with the CFSGBI conference) plus one virtual meeting in the autumn.
- A key issue being looked at by the Surgical CEN is the high proportion of cleft surgeons developing spine, and especially neck, problems.

Questions and discussion

	<ul style="list-style-type: none"> AS asked if there was a Genetics CEN. SvE advised there was not, as genetics falls outwith the core cleft team membership. NH asked if there was a Paediatric CEN. SvE advised there was not.
<p>8. Feedback from CRANE</p>	<p>CR reminded all CDG members that they had been sent a first draft of the 2022 CRANE Annual Report and asked for any comments to be returned by 25 November.</p> <p>CR then spoke to the key points of a PowerPoint presentation to provide an update on CRANE. The full presentation is included as Appendix 7.</p> <p>Contract and funding</p> <ul style="list-style-type: none"> The new contact with NHS England (NHSE) was finalised in March 2022. While the new contract represents a small funding increase on previous years, there remains a significant gap between the cost of CRANE and the funding available. The Clinical Effectiveness Unit (CEU) at the Royal College of Surgeons of England (RCSEng) has effectively been underwriting this shortfall for a number of years, but this arrangement is no longer viable. The CEU is therefore engaging with NHSE to explore options for the future of CRANE: (1) for the CEU to develop a full business case for the true cost of CRANE, or (2) for the CEU to host CRANE until the end of the next financial year, at which point activity would either be transferred to a new provider or cease. CR asked for written support from the CDG and individual CDs to support the CEU's ongoing negotiations with NHSE. There was strong support for this from the CDG, with JND commenting that Cleft 2022 made it clear that thanks to CRANE, the UK is the only country with 100% registration of patients with cleft and with longitudinal data on outcomes. CRANE is the international gold standard in cleft care and it is imperative to ensure it continues. <p>Action 10/11/22:7.1: CR to provide information to CDG members as to the kind of points it would be useful to include in their letters of support.</p> <p>Action 10/11/22:7.2: CDG members to draft letters of support and send to CRANE for collation and submission.</p> <p>Website updates</p> <ul style="list-style-type: none"> Website information has been updated in response to information governance changes (eg, compliance with the National Data Opt-out) and stakeholder engagement and feedback (eg, infographics summarising key messages and information for patients and the public). The CRANE website holds a large amount of information that would be of use to CDG members, but use is currently somewhat limited. The CRANE Database has been enhanced with additional data items around ethnicity, syndromes/congenital malformations, and developmental defects of enamel (DDE). Further enhancements in the pipeline include psychology, commissioner requests, LAHSHAL, surgery, orthodontics, and hearing. CR noted that such enhancements carry a cost, and that some previous enhancements paid for by CRANE are not well used; he therefore asked that CENs ensure any future enhancements they request will be well used, to ensure optimal use of CRANE resources. <p>Cleft 2022 conference</p>

- CRANE had a very successful Cleft 2022 conference, with 9 presentations using CRANE data delivered.
- The CRANE team also received very positive feedback from both national and international attendees on the work of CRANE, including some interest from non-UK countries in joining the database.

Research and development

- There have been a total of 11 publications from the CRANE team, all available on the [CRANE website](#). Recent topics include risk adjustment, longitudinal educational attainment, and risk determinants in cleft outcomes.
- CR noted that cleft lip and palate is one of the few clinical areas within paediatrics that is looking at educational outcomes, again demonstrating the value of CRANE in setting the standard.

Data linkage

- CRANE links to other datasets to avoid asking for additional data input from cleft teams, and to add value to CRANE by linking to other outcome data (eg, educational). However, the current contractual situation of CRANE makes data linkage more difficult. For example, if CRANE had a 3-5-year funding contract as opposed to its current 1-year contract, the cost of data linkage would be substantially reduced.
- Linkage completion to the Newborn Hearing Screening Programme (NHSP) is expected in November 2022. Initial analysis will be of congenital deafness in cleft patients.
- Linkage to Hospital Episode Statistics (HES) for England is in place to end 2012, but not thereafter due to CRANE's above-mentioned contractual/funding issues.
- Linkage to the National Pupil Database (NPD) has enabled analysis of educational deficit in patients with cleft, deficit associated with school absence, and deficit maintained through schooling. As with HES, the current arrangement is coming to an end due to CRANE's contractual/funding issues.

Action 10/11/22:7.3: Audiology/ENT CEN to advise CR if they know of anyone who would want to liaise with CRANE on analysis of the NHSP data linkage.

Outlier policy

- CRANE's outlier policy was developed in line with HQIP guidance, with the support of the CDG, and piloted in 2021. The policy is designed to support cleft services by developing a shared understanding of what influences outcomes and how these can be improved.
- The outlier policy was followed again this year for the most recent birth cohort (2012-14 births). A number of centres have been alerted as being outliers on one or more outcome; CR will follow up to discuss.

Consent

- As an example of the findings in the 2022 Annual Report, CR presented the results for consent to demonstrate the impact of the time lag between current practice and the reporting period. Evelina has remained a negative outlier between the 2011-13 and 2012-14 birth cohorts; however, in the data for 2021 Evelina is a positive outlier, showing significant progress between the reporting period and today.

Governance and QMIC

- CR highlighted the [2021 local action plan template](#), available on the website and designed to support cleft services to drive quality improvement based on the findings of the Annual Report. A similar plan will be developed to support the 2022 Annual Report.

2023 CRANE timeline

- The 2023 CRANE timeline, which includes data collection milestones and dates for the outlier process, is now available on the [CRANE website](#).

Annual reporting

- The 2022 Annual Report is due to be published on 9 December 2022. CR asked CDG members to send any amends (via email or tracked changes in the document) by 25 November 2022.
- For the 2023 report, key issues will be considering how CRANE reports, and dental and speech outcome 2A outliers.
- For 2024 and beyond the ambition is to incorporate risk adjustment.

Action 10/11/22:7.4: CDG members to return comments on CRANE 2022 Annual Report by 25 November.

Hopes for 2023 and beyond

- Secure a funding position that reflects the activity and ambition of CRANE.
- Reduce the burden of data collection.
- Improve the reliability and relevance of reporting.
- Demonstrate the practical and financial value of CRANE to a range of stakeholders.

Other issues

- CR explained that the mismatch between the dashboard and the annual report is due to the timing of data extraction: CRANE extracts data twice yearly for the annual report (April and June), while dashboard data is extracted quarterly.
- CR advised that there were several queries at Cleft 2022 about patient input into CRANE. Currently the CRANE team liaises with CLAPA regarding each annual report. The team is also exploring other ways to improve patient engagement, including learning from other CEU audits.

Making it Better events

- The next Making it Better event, which will reflect on the findings of the 2022 Annual Report, will take place on 30 January 2023 at 10:30-12:00.
- There will be a CRANE data Q&A on 28 February 2023 at 10:00-11:30, supporting data issues before the deadline for interim report data submission.
- Resource depending, there may also be a further session in May to support data issues after interim report data submission.

Action 10/11/22:7.5: CDG members to note date of CRANE events and email crane@rcseng.ac.uk to register.

Action 10/11/22:7.6: CR to circulate full presentation to all CDG members following the meeting.

Action 10/11/22:7.7: CDG members to contact CR if they would like assistance with interpreting the funnel plots in the presentation.

	<p>Questions and discussion</p> <ul style="list-style-type: none"> AS expressed her support for enhanced patient engagement, and asked (1) whether adults are included in patient and public engagement work; and (2) whether patients could self-report to CRANE, eg their outcomes. CR advised that (1) data is currently collected for 5-year-olds and 10-year-olds, but that work was under way with the University of Bristol to determine what could be collected for adolescents and adults – noting that this was not financially possible at present; and (2) that patients cannot self-report to CRANE as a database login is required, but the CRANE team are exploring the possibility of including patient-reported outcome measures (PROMs). JND queried the timeline and process for the outlier policy, noting that the minutes of the last CDG meeting recorded that: ‘CRANE will suspend writing letters regarding alerts and outliers of process until after the publication of the 2025 report based on the impact of Covid on the process, but where invited to by any individual unit, CRANE will write on their behalf to highlight where they may be having challenges in comparison to the rest of services across the UK.’ CR confirmed that the letters written to cleft services this year were informal rather than the formal outlier process, which would not commence until publication of the 2025 report. JND advised that having this documented formally outwith the CDG minutes would be helpful. It was agreed that a statement on the CRANE website would be sufficient. It was suggested that an external review of the outlier process, in particular the validity of the risk stratification model, would be useful. CR agreed to progress this. <p>Action 10/11/22:7.8: CR and SvE to agree wording for CRANE website about the timing and nature of the outlier process and the informal approach being used in the interim.</p> <p>Action 10/11/22:7.9: CR to arrange external review of the CRANE outlier process.</p>
<p>9. Quality Monitoring and Improvement Committee (QMIC)</p>	
<p>10. Feedback from CLAPA</p>	<p>See Appendix 9 for a written update from CLAPA. #saveCLAPA</p> <p>Fundraising income has plummeted since the pandemic and we have until the end of this year to turn things around before we look at making serious cuts to our vital services. Last month, we launched #SaveCLAPA - https://www.clapa.com/saveclapa/ and we really need your help and support to enable us to continue to in our current form.</p> <p>The appeal has included a video from our Chair of Trustees, Nick Astor - https://www.youtube.com/watch?v=rV4ECSFZ0nY, one from our Patron, Carol Vorderman - https://www.youtube.com/watch?v=u6hXHDDP-DM and today, we will be launching a video using paid for social media advertising, about the feeding service which is aimed at the general public.</p> <p>In addition, this week, we are sending out a direct mail, something we haven’t done for 5 years.</p>

We have been extremely touched by the responses to date which have resulted in a real increase in one-off and regular donors (CLAPA Champions) and we have also had a number of very helpful offers of pro bone support.

This appeal is the start of a new approach for CLAPA. In order for us to be sustainable, we will need to ensure that we continue to shout about the need for donations in all of our communications from now on.

Fundraising Strategy

Our previous Head of Fundraising left in April and we then employed a fundraising consultant to carry out a review of our fundraising and governance whilst also recruiting for a new Head of Income. Our new Head of Income, Mikaela Conlin-Hulme, who joined us at the end of August is now leading on the development of a Fundraising Strategy using the findings from the Fundraising Review. This will focus on April 2023 onwards and is likely going to focus on diversifying our fundraising to ensure we are maximising all possible income generation opportunities.

Mikaela joined CLAPA in August 2022 as Head of Income, leading on income generation and donor care and stewardship and is part of the Senior Management Team. Mikaela has 15 years' experience in the fundraising and supporter care sector supporting a range of small and medium charities in the UK and abroad.

Mikaela has a little girl so has limited 'free time' but when she can normally be found baking or planning her next travel adventure! You can contact Mikaela with any fundraising idea or opportunity, she would love to hear from you.

Email: mikaela.conlin-hulme@clapa.com

Other Staffing Changes

Becky Croft joined CLAPA in October 2022 as an Adult Services Coordinator and is part of the Engagement and Services Team.

Becky has over ten years of experience working within mental health services in the NHS and has a degree in Psychology and Sociology. Becky has previously worked as a Mental Health Nurse and has spent time volunteering within different charities and organizations. Becky is passionate about supporting people and will be creating events and developing the service CLAPA provides for adults in the cleft community with the support of CLAPA volunteers and staff.

When Becky isn't at work, she enjoys walks in the local countryside with her family, including two sausage dogs. You can contact Becky with any suggestions or questions about the Adult Services CLAPA provides.

Email: becky.croft@clapa.com

Rashna Choudhury, Fundraiser, has now gone on maternity leave and we are not recruiting anyone to cover the role in her absence.

	<p>For the full staff team, please go to https://www.clapa.com/about-us/meet-the-team/.</p> <p><u>CLAPA Link people</u></p> <p>Thank you to those of you whose teams have put forward a point of contact as a CLAPA Link person. We are keen to understand if this role is working and if the information that we are sharing is being disseminated within teams.</p> <p>We are also still looking for Link People from the following Cleft Teams:</p> <ul style="list-style-type: none"> • Northern and Yorkshire Cleft Service • North West England, Isle of Man and North Wales Cleft Service • National Cleft Surgical Service for Scotland • South West Cleft Service <p>Please contact Ellie Dale, Engagement and Services Manager, at ellie.dale@clapa.com for more information or to nominate someone as the link to your service.</p>
11. Research	<p>Bristol Cleft Collective See Appendix 10.1 for a written update from the Bristol Cleft Collective.</p> <p>Early Career Researchers Group/Cleft Multi-Disciplinary Collaborative See Appendix 10.2 for a written update from the ECRG/CMC.</p> <p>Cleft and Craniofacial Conditions Clinical Studies Group See Appendix 10.3 for a written update from the CCC CSG.</p> <p>SLUMBR See Appendix 10.4 for a written update on the SLUMBR study.</p>
12. Quality Dashboard	
13. CFSGBI Feedback	<p>HR spoke to the written report included as Appendix 12. Key points were as follows:</p> <ul style="list-style-type: none"> • The new CFSGBI website is due to go live on 1 December 2022. • At the November Council meeting there was a discussion about the possibility of combining the spreadsheet alongside the website membership. • CFSGBI has received hard copies of historical treasurer's information and minutes which will be scanned and archived. • The potential to use the website as a repository for research and available funding is being discussed.
14. Training	<p>LF provided the below update on training:</p> <ul style="list-style-type: none"> • Five training posts are available in the next recruitment round, with interviews due to take place in January 2022. However, if no units are willing to take a trainee, the interviews will not be allowed to proceed. LF has already emailed all services which have previously hosted a trainee but as yet has had no response. LF will follow up following the CDG meeting. • There is a backlog getting people into jobs post-training, exacerbated by the fact that some jobs are going to non-TIG individuals. LF asked if the

	<p>CDG supported maintaining TIG posts as the gold standard for cleft training in the UK, and received strong support for this, with a fuller discussion to be scheduled for the next CDG meeting.</p> <p>Action 10/11/22:13.1: CDG members to advise LF if they are able to host a trainee asap.</p> <p>Action 10/11/22:13.2: SvE to add discussion about how to ensure TIG remains the gold standard for UK cleft training to the agenda for the next CDG meeting.</p>
<p>15. AOB</p>	<p>Government information for parents about cleft RW queried whether CDG members were aware of the government's information for parents about cleft lip and palate and if any members had an opinion as to what had been included/excluded.</p> <p>Action 10/11/22:14.1: SvE to add a discussion about the government's information for parents about cleft lip/palate to the agenda of the next CDG meeting.</p> <p>Data about non-accidental injury/death in children with cleft VB advised that a review of a non-accidental injury/death had stated that children with cleft are more likely to be shaken or have a non-accidental injury, and asked if any CDG members had any data to support or refute this.</p> <p>Action 10/11/22:14.2: CDG members to share any data/information they are aware of in relation to non-accidental injury/death in children with cleft.</p>

The next meeting of the Cleft Development Group will take place virtually on Friday 12 May 2023 (9am-1pm).

Actions from Cleft Development Group meeting: 10th November 2022	Owner	Due Date
Action 10/11/22:5.1: SvE to replace Martin Evans with Imogen Underwood for future circulation of/request for CD reports to the CDG.	SvE	23 May 2023
Action 10/11/22:5.2: Surgical CEN to discuss how to manage non-cleft referrals and report back to CDG.	Surgical CEN Chair	23 May 2023
Action 10/11/22:5.3: SvE to consider how to respond to the questions and discussion around how best to support Bristol.	SvE	TBC
Action 10/11/22:6.1: CDs to promote the ENT & Audiology CEN to relevant colleagues and suggest booking the CEN meetings into study leave.	CDs	December 2022
Action 10/11/22:7.1: CR to provide information to CDG members as to the kind of points it would be useful to include in their letters of support.	CR	December 2022
Action 10/11/22:7.2: CDG members to draft letters of support and send to CRANE for collation and submission.	All	CR to advise
Action 10/11/22:7.3: Audiology/ENT CEN to advise CR if they know of anyone who would want to liaise with CRANE on analysis of the NHSP data linkage.	Audiology/ENT CEN Chair	CR to advise
Action 10/11/22:7.4: CDG members to return comments on CRANE 2022 Annual Report by 25 November.	All	25 November 2022
Action 10/11/22:7.5: CDG members to note date of CRANE events and email crane@rcseng.ac.uk to register.	All	30 January 2023
Action 10/11/22:7.6: CR to circulate full presentation to all CDG members following the meeting.	CR	Immediate (completed 14 November 2022)
Action 10/11/22:7.7: CDG members to contact CR if they would like assistance with interpreting the funnel plots in the presentation.	CR	December 2022
Action 10/11/22:7.8: CR and SvE to agree wording for CRANE website about the timing and nature of the outlier process and the informal approach being used in the interim.	CR/SvE	December 2022
Action 10/11/22:7.9: CR to arrange external review of the CRANE outlier process.	CR	TBC
Action 10/11/22:13.1: CDG members to advise LF if they are able to host a trainee asap.	All	1 December 2022
Action 10/11/22:13.2: SvE to add discussion about how to ensure TIG remains the gold standard for UK cleft training to the agenda for the next CDG meeting.	SvE	23 May 2023
Action 10/11/22:14.1: SvE to add a discussion about the government's information for parents about cleft lip/palate to the agenda of the next CDG meeting.	SvE	23 May 2023
Action 10/11/22:14.2: CDG members to share any data/information they are aware of in relation to non-accidental injury/death in children with cleft.	All	TBC