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

Venue- Microsoft Teams Conference call

Date & Time- Wednesday 8 June 2022– 9:00 to 13:00

Present	Simon van Eeden (SvE) Chair	Cleft Development Group Chair
	Mary Bance (MB)	Network manager/co-ordinators representative, Network Manager, Cleft Net East
	Victoria Beale (VB)	Clinical Director, North West, IoM & North Wales Cleft Network
	Alistair Cobb (AB)	Clinical Director, South West Cleft Service
	Christine Couhig (CC)	Lead Clinical Nurse Specialist, Newcastle
	Claire Cunniffe (CCu)	CLAPA Chief Executive
	Sinead Davis (SD)	ENT & Audiology CEN Chair
	David Drake (DD)	Lead Clinician for Cleft Care Scotland
	Helen Extence (HE)	Clinical Director, The Welsh Cleft Lip and Palate unit
	Louisa Ferguson (LF)	Chair of the Cleft Training Interface Group
	Vanessa Hammond (VH)	Clinical Psychologist CEN Lead
	Norman Hay (NH)	Clinical Director, North Thames Cleft Service
	Peter Hodgkinson (PH)	Clinical Lead, Newcastle Site, Northern & Yorkshire Cleft Service
	Sarah Kilcoyne (SK)	Chair, NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies
	Kate Le Marechal (KLM)	Clinical Director, Evelina London Cleft Service
	Joanna May (JM)	Paediatric Dentistry CEN Chair
	Felicity Mehendale (FM)	President Craniofacial Society of Great Britain and Ireland
	Eilish O'Connor (EC)	Lead NI SLT Deputising for Chris Hill, Clinical Director, Northern Ireland Cleft Service
	Ginette Phippen (GP)	Representing the SLT CEN and Lead Groups
	Helen Robson (HR)	Representing Nursing led Nurse in North Thames Cleft Centre,
	Craig Russell (CR)	CRANE Clinical Project Lead
	Heather Sahunta (HS)	Cleft Nursing CEN Chair
	David Sainsbury (DS)	Representative for The British Association of Plastic, Reconstructive and Aesthetic Surgeons
	Siobhan Sawey (SS)	Paediatric audiologist. Northern Ireland Cleft service
	Julia Scott (JS)	Orthodontic CEN Lead
	Marc Swan (MS)	Clinical Director, The Spire Cleft Service
	Guy Thorburn (GT)	Representing the Surgical CEN
	Yvonne Wren (YW)	Chief Investigator, Cleft Collective
In Attendance	Catherine Foster	Project Manager, Clinical Effectiveness Unit, Royal College of Surgeons of England
Apologies	Neil Brierley	Lead Clinician, Cleft Net East
	Toby Gillgrass	Lead Clinician, Scotland
	Chris Hill	Clinical Director, Northern Ireland Cleft Service
	David Landes	Public Health Consultant
	David Orr	Plastic surgeon and cleft surgeon, Dublin Cleft Centre
	Alistair Smyth	Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service
	Martin Evans	Clinical Director, West Midlands Cleft Service

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, 1 February 2022	The minutes of the CDG meeting on 1 February 2022 were reviewed and approved as a true and accurate record of the meeting.
3. Research	**<u>Bristol-Cleft Collective</u>** YW provided an overview. The following update was circulated prior to the meeting: • Funding – we are pleased to report that we have been successful with a funding application to The Underwood Trust. An award of £1million will cover most costs required to continue the recruitment of participants and collection of data for another five years. Ultimately, this will lead to a sample size which is sufficient for most analyses to be carried out stratified by cleft subtype, important for questions relating to causes, treatment, and outcomes. It will also facilitate the collection of data into early adolescence. There is a small shortfall in the total funding required to cover all costs associated with running the study and we are in discussions with other potential providers to support this. • Recruitment to the birth cohort is up and running at 15 of the 16 recruitment sites. One site is not recruiting due to a lack of research nurse time. The CC and the PI are working with the site's R&D regarding this. Total numbers for recruitment are 9971 (January:9723) individuals from 3571 (January:3482) families across both the birth and 5-year-old cohorts. • Recruitment to the speech sub-study is improving but still behind pre Covid levels. As previously mentioned, we are now recruiting children up to age 36 months. Total numbers for recruitment are 938 (January:914) individuals from 467 (January:455) families. • Genotyping is ongoing and over 7000 individuals have been genotyped to date. We are in the process of recruiting a new post-doc research associate to continue our work on this, with funding awarded to Professor Sarah Lewis from the MRC. The focus has been on performing quality control analyses of the genotyped data and imputing the data using Haplotype Reference Consortium (HRC) and TopMed imputation platforms. Genome wide association study analysis (GWAS) meta-analysis investigating the contribution of maternal genetics to the development of cleft in their offspring is now proceeding with our collaborators at the University of Bonn. Additional projects using the genotyped data are in preparation. • Proposals to access and use the data continue to increase with 46 in total (see below for those submitted since last meeting). • A Research Nurse workshop took place in March for all those involved at the cleft centres with recruiting to the Cleft Collective. In this workshop, we provided an update to the Research Nurses and some cleft nurses on the study and reported on key research findings for attendees to share with potential participants. We also provided a chance to share best practice post-covid to support and increase recruitment and sample/questionnaire return rates. • Data sharing with CRANE is ongoing and is enabling us to validate cleft type for both the Cleft Collective and CRANE. We plan to publish a paper detailing this work in 2022. A new dataset containing cases where cleft classifications differ between sources has been sent to CRANE from the Cleft Collective. • A Policy Workshop took place in May with representatives from the clinical teams including five cleft surgeons, one ENT surgeon, four SLTs, two psychologists and one orthodontist as well as members of the Cleft Collective study team. The purpose of this workshop was to discuss four of our recent papers to determine core impact messages from the papers to inform policy briefing papers. We are hoping to make this an annual event and welcome clinicians to join us in this. • A panel presentation took place at the American Cleft Palate and Craniofacial Association Conference as part of the 'Guest Nation' Invitation, consisting of a question-and-answer

session with key members of the Cleft Collective team and partners (participants, site PI, data user).

- Cleft2022 – 17 papers including use of Cleft Collective data have been accepted for presentation (10 oral papers, 7 posters). We will also repeat the Panel presentation from ACPA at the Congress and run a workshop to enable attendees to explore the data dictionary and begin the process of submitting proposals to use the data.
- The MRC funded study to use Cleft Collective data to identify children most at risk of mental health needs is starting in September. A Research Associate has now been employed to work on this.

Data collection

Data collection is ongoing and is picking up again since the COVID pause.

- We are still monitoring the number of saliva samples returned as some teams need to send the kits home with parents rather than take the sample on site. This has an impact as parents sometimes forget to take the sample or saliva kits are lost. We are working with the recruitment nurses to ensure return rates are kept at their pre-covid rate.
- Our return rates for questionnaires remains consistent at 50% for our baseline questionnaires and a 39% return rate for our follow-up questionnaires.
- Surgical form return rate for first surgery is 93%, though for many sites it is at or close to 100% for first surgery. We are in contact with the two sites whose return rate is below 90% to explore ways to increase returns. We have been informed by many surgeons that the forms take no more than 2 minutes to complete.
- We are keen to increase the return rate for second and subsequent surgical forms. These data are requested and used – for example, one currently in consideration is keen to use data on palatal repair surgery but we do not have this for all participants. We welcome attempts by teams to determine how they can increase the return rate for these forms and are happy to assist you in any way we can.

• Return rate for speech sub-study

- LENA recordings - 85% (318 of 374 returned)
- 18/24 month assessment form - 94% (416 of 444 returned)
- 36-month assessment form - 71% (300 of 424 returned)

- We will submit an amendment regarding the online survey of speech and language therapy intervention this month to alter the process for requesting input from community teams.

YW updated on a new study proposal to be submitted to the NIHR looking at unmet needs of patients transitioning to adult care. Focus groups were held earlier in the year and the proposal based on these findings. The applicant team involves several clinicians from UK cleft teams. The intention is that the study will involve a research clinic in a couple of years' time, but YW did not want to spend more time on this topic as it is still to be approved and then funded. YW will feedback if stage 1 of the application/funding process is successful. HR thanked the CC for being able to provide recent research to be used in the reader material for the Cleft Nursing course at the Angela Ruskin University.

VH raised concerns the psychology CEN has about the 12 year old parent questionnaires and although she didn't want to go into too much detail at this meeting and mentioned that the Chair of the CEN is planning a meeting with YW as there are concerns about the process of agreeing measures and asking the CEN to sign off on those and the direction that the measures are going in in that they are becoming very individual child focussed and psychiatric, and VH felt it essential that children are considered in context; also there are concerns about the measures changing and not being able to do longitudinal follow up. YW responded saying that the measures agreed many years ago with Nicola Stock have been adhered to but now that children are getting older new measures are being considered and the CC are very keen to engage with the psychology CEN and CC are aware that there isn't a psychologist on the research team; YW went on to say that of all the specialities the cleft psychologists have been the most difficult to

	engage with despite multiple emails asking for engagement. YW went onto say that she accepts the points raised by VH and would welcome cleft psychology engagement and she asked VH how engagement could be improved? VH felt that the questionnaires had been sent for approval without prior psychology input, which she felt wasn't possible to do. YW re-iterated the fact that prior engagement had been sought without success and that as the children were getting older and deadlines had to be met and the questionnaires had to be formulated without prior psychology input. YW also confirmed that a meeting has been arranged with the Psychology CEN chair in the next week to discuss possible changes but she re-iterated that this is engagement late in the day and that YW hopes in the future that psychology input and engagement occurs early in the process. SvE brought the discussion to a close. ***New proposals since January 2022*** • CC046 S Simons - Dental care pathways and parent reported experiences and outcomes for 5-year-old children with cleft in the UK • CC045 A Langer – Patterns of speech sounds after surgery: investigating infants' **<u>Early Career Researchers Group / Cleft Multi-Disciplinary Collaborative</u>** DS provided an update. The following report was circulated prior to the meeting: **Background** The Early Career Researchers Group (ECRG) and Cleft Multidisciplinary Collaborative (CMC) exist to expand and enhance the opportunities for its members to engage with high quality research and quality improvement projects, benefiting NHS Trusts and ultimately our patients. It is open to all disciplines involved in cleft care, regardless of an individual's clinical or research experience. **Current membership** We currently have 30 members from a range of disciplines, with speech and language therapy and surgical specialties having the most representation. Since the two virtual meetings in 2021 we have had one combined face to face and virtual meeting (March 2022) with a fantastic CPD session on PPI. Sophie Butterworth has been appointed as the new Chair of the ECRG. **Current Projects** **1. Scoping Review of Outcomes for Children with Bilateral Cleft Lip and Palate** ***Current status*** Data extraction is complete in the different professional groups. There are large amounts of data from speech, surgery and dental. This will be written up over the course of the rest of the year as a broad scoping review identifying gaps in the research with regard to BCLP outcomes. These are likely to be separate publications. **2. Unrepaired Cleft Palate Survey and Audit** ***Current status - complete*** • Oral presentation at CFSGBI, April 2019 • Poster presentation at EACPA in Utrecht, June 2019 • Published in CPCJ 2021 A survey of cleft units in the UK was conducted. This project aimed to identify the number of children with intentionally unrepaired cleft palates in each unit within the UK. From the literature this has never been investigated. Each cleft team had a handful

of children, born with cleft palate, which were intentionally left unrepaired. The decision not to repair the palate in these children was often made in conjunction with many other healthcare professionals and the risks of surgery were weighed up against the perceived benefits. These children had very complex medical needs and spent lots of time in a hospital setting with many different specialists involved. Some of these children had a recognised syndrome such as Cornelia de Lange. All patients were found to be non-verbal and were PEG fed. Many of these patients are tricky consultations for clinicians and following the survey it was decided to continue this piece of work as a qualitative survey evaluation involving the specialist nurses and psychologists. This is to try and find out a little bit more about these patients to support some of the families that have found it difficult to accept that leaving the cleft palate unrepaired may be better for their child, particularly where the anaesthetic risk is high.
A second expansion of this study was to conduct a quadcentre audit, looking at the timing of primary lip and palate repair, any patients that had a delayed repair and the reasons for this and to pull out the actual numbers of deaths and intentionally unrepaired cleft palate patients. This was a retrospective audit involving 1826 patients over 5 NHS cleft sites. It was presented in November 2019 at the NorCleft meeting in Manchester and was published in 2021.

3. Non-Interventional Factors Influencing Outcomes in Velopharyngeal Function in Initial Cleft Palate Repair - A Systematic Review

Current status

- Protocol published (*Systematic Reviews* 2019 8:261)
- Funding received from CFSGBI to fund 8 licenses for Distiller SR (systematic review software) for 12 months.
- Three levels of screening completed and data extraction of 383 papers completed.
- Data analysis completed
- Manuscript in progress
- Poster presentation at CFSGBI 2021
- Accepted for presentation at International Cleft Meeting 2022

Background

This systematic review aims to inform the development of a screening tool which pre-operatively predicts which children are likely to develop velopharyngeal insufficiency, one of the causes of poor speech outcomes, following cleft palate repair. This would be highly beneficial as it would inform pre-operative counselling of parents, allow targeted speech and language therapy and enable meaningful comparison of outcomes between surgeons, techniques and institutions. Currently it is unclear which factors influence speech outcomes. A systematic review investigating the non-interventional factors which potentially influence speech outcomes following cleft palate repair is warranted. This may be inherently illuminating or provide foundations for future studies.

Methods

A systematic review will be carried out according to Cochrane methodology and reported according to PRISMA guidelines. Systematic review software will be used to facilitate three-stage screening by two independent reviews experienced in cleft lip and palate. Thereafter, data extraction and GRADE assessment will be performed in duplicate by five independent reviewers experienced in cleft lip and palate. Studies reporting the proportion of patients recommended for or who underwent secondary

speech surgery for velopharyngeal insufficiency following primary surgery for cleft palate will be included.
Study findings will be tabulated and summarised. The primary outcome measure will be further speech surgery (either recommended or performed). The secondary outcome measure will be perceptual speech assessment for the presence of velopharyngeal insufficiency. A meta-analysis is planned. However, if this is not possible, due to the anticipated marked heterogeneity of study characteristics, pre-operative assessment and the recorded outcome measures, a narrative synthesis will be undertaken.
This systematic review may provide sufficient data to inform the development of a screening tool to predict the risk of velopharyngeal insufficiency prior to cleft palate repair. However, it is anticipated that these findings will provide the foundation for future studies in this area.

4. Outcomes for Robin Sequence

Current status

- Presented at ECPCA, Utrecht, June 2019
- 10 centres involved in UK
- Data on 250 patients
- Accepted for oral presentation at International Cleft Meeting 2022

We are looking to describe a group of PRS patients born between 1st January 2005-31st December 2009. We would like to capture basic demographics, treatment details (for example, airway management, feeding methods, age of cleft repair, requirement for revisional surgery), and then record speech outcomes at 18 months (18-24 months), 3 years, 5 years and 10 years (where available). 5 year speech outcomes have been chosen as the primary outcome measure.
Data from patients across ten sites in the UK has been collected and analysed. This was presented at ECPCA, Utrecht last June. The sites that were included in this initial project were Newcastle, Liverpool, Northern Ireland, Oxford and Salisbury. Five more UK sites have contributed to this dataset. The definition as laid out by the international consensus – micrognathia, glossoptosis, airway difficulties (+ cleft palate in our case). RS subtype with cleft palate have poorer speech outcomes at 5 years compared to children with cleft palate only but there was no difference by age 10.

5. Impact of the COVID Pandemic on Cleft Surgery

Current status

- Study has been peer reviewed and is supported by the NIHR Cleft and Craniofacial Conditions Clinical Studies Group
- Funding granted from the Edinburgh Clinical Trials Unit for managing the RedCAP database
- Endorsed by the Royal College of Surgeons of England
- Data collection to date:
    - 8 units entering data
    - 651 operations details entered
    - Data entry closed on 7 June 2021
- Oral presentation at CFSGBI 2021 and ACPA 2022
- Accepted for oral presentation at International Cleft Meeting 2022

This study aims to determine the impact of COVID on cleft surgery. This the first time in the UK that a large cohort of patients will be undergoing cleft surgery with such large

delays in timing of surgery. Additionally, we do not know how the prevalence of COVID in the community and possibly in patients will affect the postoperative course of children undergoing surgery, particularly in the case of babies and procedures that may bring about a temporary reduction in airway volume. Given the relative rarity of COVID in babies and children, it is particularly important that we share data across the UK following the resumption of cleft surgery. This will enable better understanding of perioperative safety and outcomes. Additionally, it will provide data to guide practice, in particular the need to suspend/delay elective surgery during further waves of this pandemic.

This is also an opportunity to study the impact of delays to planned cleft surgery, in a large cohort and identify any impact on outcomes that may be related to such delays. This study will also examine cleft surgeons' experiences of wearing PPE with loupes, headlights or the operating microscope and will study solutions that may prove useful in similar situations. PPE is particularly relevant for cleft surgery because the surgeons face is close to the patient's mouth and the endotracheal tube (ET) for a considerable duration. Cleft surgery requires a Rae tube, curved to lie flat on a patient's chin. Not all units in the UK had access to cuffed Rae tubes in small sizes and this practice has been changing. Our study will report on these changes.

Primary Objective

- To determine the impact of the COVID pandemic, on elective cleft surgery timings and outcomes.

Secondary Objectives

- Study individual units screening processes, screening outcomes and their impact on clinical decision making regarding timing of surgery
- To determine prevalence of COVID positive tests in infants (and parents where testing is done as part of unit protocols)
- Incidence of post-operative complications
- Impact on patient follow up (remote or in person)
- Duration to return to usual protocol timelines
- Surgeons' reports of challenges of wearing PPE and operating with loupes/headlight/microscope

Primary Endpoint

- Point at which patients are able to have surgery in keeping with UK standards and unit protocols, in terms of timing of surgery.

Study Design

Study type: Observational

Setting: Tertiary cleft centres. All 11 cleft units (16 cleft surgical sites) in the UK will be approached for participation. This will include cleft surgery consultants and trainees. There is a well-established network and history of multicentre collaborative studies across the 11 UK cleft centres.

Study Duration: Until UK Cleft surgery has caught up with the COVID backlog.

Follow up duration: 3-4 months, until patients have had at least one post-op review

6. Delphi Fistula Project

Current Status

- Rounds 1 and 2 of Delphi Survey completed
- 35 members for expert panel
    - 14 cleft consultants
    - 6 SLTs
    - 6 Cleft specialist nurses

- 3 Paediatric Dentists
- 6 Orthodontists

- Accepted for presentation at ICCPCA 2022

The aim of this study is to provide a consensus opinion on how Cleft Teams in the UK report fistulae. An expert panel was invited to complete a short series of surveys, with results anonymised, to demonstrate an unbiased consensus opinion. The questions will not primarily be designed to give all answers to the many questions fistulae pose, but more to provide as close to a robust minimum data set as can be achieved.

7. **Assessing Learning Curve in Palatal Surgery using a Sommerlad Radical Intravelar Veloplasty**

Current Status

- This proposal is being redesigned and incorporated into a larger NIHR doctoral fellowship application being submitted by Sophie Butterworth
- To be submitted for peer review by the NIHR Cleft and Craniofacial Conditions Clinical Studies Group when complete

Aims

- To identify if a learning curve can be observed among surgeons performing a Sommerlad style palate repair
- Does the training pathway take account of the learning curve?

Methods

TBC

Completed Projects / Publications

1. **The Cleft Multi-Disciplinary Team Collaborative: Establishing a multidisciplinary network to support cleft lip and palate research in the United Kingdom**

   Sainsbury DCG, Davies A, Wren Y, Southby L, Chadha A, Slator R, Stock NM; Cleft Multidisciplinary Collaborative. *Cleft Palate Craniofac J* 2019;56(4):502-507.
2. **Non-Interventional Factors Influencing Velopharyngeal Function For Speech In Initial Cleft Palate Repair: A Systematic Review Protocol.**

   Sainsbury D, Williams C, Blacam C, Mullen J, Chadha A, Wren Y, Hodgkinson P. *Systematic Reviews* 2019 8:261
3. **A Closer Look at the Reasons for Delayed Primary Cleft Surgery and Unrepaired Cleft Lip and /or Palate in Five UK Cleft Centres.**

   Sophie Butterworth, Clare Rivers, Marnie Fullarton, Colm Murphy, Victoria Beale, Jason Neil-Dwyer, Simon Van Eeden, Stephanie Van Eeden, Peter D. Hodgkinson, Alistair Smyth, David C. Sainsbury

   Cleft Palate Craniofac J 2021 Jun 10:10556656211021700. doi: 10.1177/10556656211021700. Online ahead of print.

There were no questions for DS at the end of his presentation.

<u>Clinical Studies Group</u>

SK provided an overview.

	SK has been presenting to CENs and welcomes invites to CEN groups to provide CSG updates. Several members of the group have stepped down and SK welcomed applications for these vacancies and will send the application forms out to CDG members and she asked that these are circulated to all. The following update was circulated prior to the meeting: The CSG has continued to meet virtually via videoconference over the past year. The CSG continues to provide an opportunity for researchers to receive expert feedback on study design to support applications for funding. The CSG also continues to have invaluable PPI input to study reviews. In the context of the rarity of cleft and craniofacial conditions, the CSG continues to serve an important role in minimising the burden on patients and clinical staff in ensuring there is limited overlap in studies which may wish to recruit from the same, small population. The Early Career Researchers Group (ECRG) continues to provide a supportive and vibrant space for early-career researchers working in the field of cleft and craniofacial anomalies to formulate studies prior to submission to the CSG and to benefit from continuing professional development activities relating to research skills. The ECRG welcomed Dr Sophie Butterworth as Chair of the group. The ECRG works together with the Cleft Multidisciplinary Collaborative (CMC) to fulfil small scale projects and give opportunities to early-career researchers and trainees to develop their practical research skills as well. The CSG currently does not receive any financial support for the administration costs of the Cleft and Craniofacial Clinical Studies Group but receives support in kind from Lesley Bradley who is the specialty cluster administrator at the NIHR Clinical Research Network. CSG is currently providing a free service to the cleft community, and this may raise issues with sustainability in the future. 1. **New appointments.** After several years of service, some members have stepped down from the CSG. We are due to advertise for new PPI and clinical members shortly. 2. **The CCC CSG was promoted at the Craniofacial Five Centre Meeting in Birmingham on Friday 13th May, 2022.** Sarah Kilcoyne presented on behalf of the group about the role of the CSG and the craniofacial-related outputs (e.g. publications, studies submitted, booklets and presentations). of the CSG over the past year. 3. **The CCC CSG was promoted at the Cleft Clinical Excellence Network for Speech and Language Therapists on Friday 6th May, 2022.** Sarah Kilcoyne presented on behalf of the group about the role of the CSG and the current cleft-related outputs of the CSG. 4. **Seven study proposals were submitted since last report.** Feedback was not always provided in accordance with the NIHR timelines. The delays in feedback were due to gaps of time when a new administrator started, and the CSG mailbox was not monitored due to lack of administrative cover. The CSG Chair does not have access to this mailbox. These administrative difficulties appear to have been ironed out. 5. **Eleven studies were reported as completed through the CSG this year** (see appendix). **6. CSG members will continue to attend the ECRG meetings, with plans to have support from the multidisciplinary team represented on the CSG** (see below in outputs). **7. To continue collaboration with the Cleft Collective** **Outputs** • Submitted research proposals Seven research proposals have been submitted to the CSG since our last report. Two of these were from members of the Group. *The submissions relate to:* • Understanding and improving the decision-making process regarding surgery for parents of children with non-syndromic craniosynostosis. • Parents' experiences of empowerment throughout the treatment of syndromic craniosynostosis. • The cost of cleft care for the parent and child.

	• Sleep and language development in children with isolated cleft palate. • Exploring the Experience of Parents Whose Children Have Been Diagnosed with Single-Suture Craniosynostosis. • Caries in cleft palate • Transverse interdental arch outcomes of 5-Year-Olds born with a unilateral cleft lip and palate. • Attendance and presentation at the CFSGBI Annual Conference As the CFSGBI conference will be an international conference this year, it was not thought appropriate to present about the local UK CSG this year. A presentation will be made at the conference the following year. • Attendance and presentation at the National Five Centre Craniofacial Audit meeting. • Microtia UK Microtia UK are dedicated to supporting those born with microtia, and their families, by giving them the tools to make informed decisions. This includes giving charity members up to date information, enabling shared experiences amongst one another, by encouraging members to meet face to face or connect online, and Microtia UK also fund research to keep up to date on the latest procedures, technology, and information. We currently do not have any new research taking place. But we hope we will have funded more projects for 2023 in the near future. There were no questions for SK at the end of her presentation. **<u>SLUMBRS</u>** HR gave an update. The study is at risk of being cancelled by NIHR due to lack of lack of participants. This seems to be in part due to the fact that only some centres have been given approval to recruit and that these are encountering issues with the software and governance issues in their local trusts that was not anticipated by project management. CC reported that there had been an issue with sensors in her trust(Newcastle)and that this has now been overcome and they are about to recruit their first participant. HS fedback saying that Tent was also nearly able to start recruiting. GT reported that Oxford were close to starting and HE thought that South Wales is ready to start. SvE suggested that HR email the nurses to get an update and then contact Professor Bruce to update him of the progress to ensure that the study isn't closed by NIHR.
4. Matters arising	There were no outstanding actions. Crown dependencies data inclusion to be discussed under CRANE.
5. Feedback From Cleft Centres (UK)	**<u>North Thames Cleft Service (NH)</u>** Large backlog of patients requiring cleft MDT appointments in both the twin site centres. The list has been validated fully to assess the demand. This list has now been broken down into age groups for clinicians to assess relative urgency of the appointments. Further, changes have been implemented to rationalise the care pathway to reduce the burden on the Cleft MDT clinics for both the staff and patients. The possibility of the need for extra clinics to increase capacity is also being modelled on the new pathway. The rebuilding of the children's ward at Broomfield Hospital has been completed for approximately 5 months, following over one year of absence. This has led to a rebalancing of the primary surgery between the twin-sites reducing the burden on GOSH. Previous cancellation of P3 & P4 cases namely ABG's and Orthognathic surgery has resulted in a backlog of ABG's especially. Surgeons are attempting to catch up but obviously in competition with other services - delays in the ABG waits for surgery are currently running at 4-6 months. With regard to orthognathic surgery, some patients abandoned treatment, others were left frustrated by the delays. Gosh have now largely caught up on the orthognathic waiting list. This is because patients have been more understanding about surgery taking place when the opportunity has arisen - because of the general backlog in surgery, the operating access is less frequent and more ad-hoc.

There are similar delays in secondary cleft surgery including lip, nose and speech revision surgery - this is being addressed however and waiting list times are reducing.
Orthodontic clinics, MDT, ABG and audit clinics running as normal (Face to face) however, large gaps between orthodontic appointments due to the backlog, is contributing to increased treatment times.
Still to appoint a consultant paediatric dentist despite having been approved for a year now, but NH managed to partially address the problem of data collection to satisfy cleft dashboard and CRANE outcomes by the incumbent paediatric dentist changing her job plan meaning that she is available when audit clinics take place.

- Speech and language therapy have largely returned to a normal service but continue to struggle to deliver therapy with a reduction in community service provision.
- They is still no qualified psychological service attending the cleft MDT's at GOSH following reorganisation of the psychology service. This is now provided on a referral only basis. This has made provision of this service significantly less effective and has significantly reduced the quality of the service provided in MDT's although every effort is being made to change this. There is still psychology attendance in the Broomfield MDT clinics.
- Audiological services are now largely provided at a local level with oversight from the hub centre
- Training – There has been a definite negative effect on clinical training programs in orthodontics and surgery over the covid period, the effects of which are still being felt.

Staffing
A longstanding and devoted consultant cleft geneticist has recently retired from the team and they have successfully reappointed to this position with a substantive post.
They have recently appointed a substantive consultant paediatrician to support the cleft team as a replacement for a long-term locum in this role.
One of the longstanding devoted CNS's has retired after years of tremendous support for cleft patients and they have successfully managed to appoint 2 nurses to this position. The Cleft CNS's are therefore currently at full quota but one of the band 7 nurses is due to go on extended leave soon.
The team still in the process of recruiting a paediatric dental consultant, which has significantly impacted on the submission of paediatric dental NHS England and CRANE data.
A new director of surgical services has been appointed following the retirement of another longstanding director and supporter of the cleft service.
New general and service managers have been appointed to the surgical division managing cleft services.
JM asked for the name of the paediatric dentist so that audit data can be collected.
VH mentioned that it is very disappointing about the news of the lack of GOSH psychology MDT input despite the CEN giving support and she advised cleft units to keep the psychology budget within the cleft budget and not to let it go into general psychology as there is a shortage of paediatric psychologists nationally and budgets are being spread across the whole of psychology-NH and PH agreed with this.

<u>Evelina London Cleft Service (KIM)</u>
Evelina is constantly changing and has now developed a fifth directorate for children's' cardiac /respiratory care which has resulted in changes in management. The service manager has recently left and the new service manager, who comes from community starts on 13 June. The assistant service manager will not be returning from maternity leave, so the centre will be recruiting for a replacement.
An Evelina expansion programme which aimed to dramatically increase the number of beds and physical space, has been suspended. Evelina will no longer be expanding physically but will be expanding without buildings. Although this does not directly affect the cleft service, the physical expansion could have resulted in more operating space and time. The building of the new day surgery unit is underway but with some delays and the hope is that this might result in more

operating. Evelina now considers the pandemic over and now that there is a fifth surgeon the expectation is that operating will increase to 120%, which in itself is a challenge.
There are currently still some long waiters for surgery. Primary surgery is almost back on track. Orthognathic remains an issue.
The service will move to an ABCD four week repeating pattern for theatres, rather than a week 1-5 schedule. This will have a huge impact on the regional service and outpatient clinics as when operating moves to 4 weeks repeating pattern, surgeon availability will change and therefore outpatient clinics will need to be rearranged/renegotiated, which is a major challenge for the team.
The team are moving to the EPIC database in February 2023, which is causing some concerns around productivity during the move and in the long-term.
There are some staffing issues mainly within the SLT team (particularly for short term contracts (2 maternity leave, 1 long term sickness). There is also a shortage of junior doctors with a fellow off for maternity leave and a lack of Junior Doctors to cover on-call. SvE agreed that the 4 week rolling rota at the cleft centre raises lots of issues when trying to fit in with a monthly rota in peripheral hospitals. There were no questions for KLM

Spires Cleft Lip & Palate Network (MS)
MS started as CD for Spires in January 2022 and he thanked GP for her hard work as the retiring CD. A commissioner deep-dive of the ODN for paediatric surgery has taken. This was triggered in response to a spike in Primary P2 cases, in the service but particularly in Salisbury. A virtual meeting took place on the 9th March focusing on Oxford, and a f2f visit took place at Salisbury on 19th May. The formal report is currently pending but is expected at the end of June. MS will feedback to the CDG in due course. The panel on dual site fluidity and is keen to introduce an integrated surgical waiting list across both sites with dual waiting list across the two sites, so that patients can relocate when a list becomes available. MS felt that the service would push back against this, as it is against the centre's modus operandi and would make co-ordination difficult. The centre however felt that if a patient was breaching a timing threshold, then this approach would be suitable but there are concerns about this becoming routine for all patients, but MS will report back about this in due course.
As far as staffing is concerned Helen Moreland, lead nurse, will be returning from maternity leave in July. MS thanked Jane Sibley who has operated as interim lead nurse. The centre are beginning succession planning for the Lead Orthodontist in Oxford, and for the secondary maxillofacial surgeon in Salisbury. There is no paediatric dentistry support at either hub, although there is some peripheral paediatric dentistry input. There is no formal restorative dentistry presence in Salisbury. There are huge pressures in the community with S&LT, and patients are having major issues accessing GDP care. Nurses are reporting difficulties in accessing community dietician input for complex babies. In some spoke centres, particularly Swindon and Bournemouth, there are difficulties in recruiting orthodontic expertise; this has been raised with commissioners.
As far as surgical covid recovery is concerned P2 cases have been largely caught up and Lips are being done before 6 months and palates before 13 months. The centre has had some limited additional theatre capacity and are fighting to maintain this. Adam Sawyer has returned in a Locum capacity to Salisbury for 1 year in the first instance to assist with some long-waiting secondary surgery P2 cases (speech & bone graft). There is still a major issue across both sites with bone graft cases, and many adult P4 cases have yet to be addressed. MS thanked the speech therapists and orthodontists for carrying out a harm review for patients waiting for speech and alveolar bone graft surgery, which has been instrumental in stratifying the surgical waiting list for these patients. There is immense summer pressure on beds due to nursing issues, particularly at the Oxford site. There is also increased pressure on both ward and critical care paediatric beds due to RSV and other respiratory illnesses which is having a direct impact on cleft operating lists.
Virtual appointments remain valuable, particularly for Psychology, Genetics, and S&LT. The centre is looking at the value of patient initiated follow-up and MS would be interested to hear from the Trent team as they are apparently advanced in this regard, and this is with particular reference to interim appointments for later age groups for isolated lips and palates without

dento-alveolar involvement. Pre-operative assessment clinics, that were lost during Covid, are slowly being reintroduced following guidance from the Royal College of Anaesthetists.
A senior plastic surgery trainee from Northern Ireland has assimilated nicely into the service as a non-TIG fellow. The centre is still keen to be accredited as a TIG training centre and there are ongoing discussions regarding this particularly about funding. The centre is looking forward to the Cleft 2022 meeting in July.
NH asked if there is an SLA across the network; MS thought that there was one but this is apparently not so and is being sorted out at the moment.
There were discussions regarding the dual waiting list. DD and PH supported the movement of patients between surgeons even if the family saw a different surgeon in clinic and felt that it would be an appropriate and efficient way to operate moving forward. MS felt that there would be concerns from families regarding the move from one hospital to another especially when significant distances are involved, and that it would impact hugely on clinical nurses. GP suggested taking the matter to the Patient Engagement Group (PEG) for their input. CC added that this would be useful and further added that it would be important to put the question into context about timings and surgeon availability; CC agreed that it is something worth taking back to the PEG .
Action 08/06/22:5.1: Twin site dual waiting lists to be discussed with the PEG.

South West Cleft Service (AC)
The team wanted to express their thanks for all the support they have received from other UK Cleft Services, and in particular to SvE for his support and help contacting the chief executive of the trust.
The service has reduced their children's waiting list by about 15 cases since November. This is mostly from work in Derriford (Plymouth). It now sits at about 180 cases. AC estimates that their recovery to operating in Service-determined ideal ages (3 month lips, 6 months palate etc) will take 4.5 years, subject to other factors meaning that he doesn't think that recovery is possible unless further action is taken. Primary palate surgery is being undertaken at 13.5 months. There is a backlog in clinics in both Bristol and Spoke units which will initially raise the waiting list as they see these patients and list them for surgery. The worst wait for adult surgery is 109 weeks for adult ABG. The wait for orthognathic patients is 79-80 weeks. In terms of theatre capacity, the service is operating alternate weeks in Derriford Hospital, Plymouth (2 ABGs Tuesday, and two Wednesday). This will step up to 3 (maybe 4) when beds become available; they have done the occasional lip revision as a day case but have very few of these. 35 cases have been done since November. This arrangement with Derriford has been extended until April 2023. They are considering starting speech surgery for older children in Derriford as these patients have been waiting a long time for surgery, but this needs careful consideration. Bristol Children's Hospital (BCH) lists are on alternate Monday and Wednesdays once a month and Friday mornings. It is only possible to do 1 case per 4 hour session because of beds and staffing. These lists are subject to cancellation due to staffing - BCH Friday lists have all, but for 5 lists, been cancelled this year due to staffing issues. UHBW Trusts are looking to move other paediatric surgical cases (mainly orthopaedic and ENT cases) to other trusts mostly Derriford due to capacity issues. They do not have adequate solutions for adult surgery, particularly orthognathic surgery, as they still have a reduced number of lists per month. This is because of backlogs in adult endoscopy and other priority surgery.
The service still do not have a functional speech investigation service and this has been the case since October 2019; the digital transformation team engagement has been started to resolve this-AC is of the opinion that the solution to this problem is funding and he estimates that it would need in the region of 80-100K. The current wait for Speech investigation is 11 months for VF radiography and 2.5 years for nasendoscopy. Speech surgery has been doubly hit by the backlog and the prioritisation of primary palate surgery. The current wait for speech surgery is 15 months; there are however cases that were referred 3 years ago for speech investigation and once they have had their speech investigation, they will have to wait a further 15 months for their surgery. This is devastating psychologically for the patients and their families.
In terms of mutual aid, meetings have been held with Swansea, Cardiff, Nottingham, Birmingham, Newcastle and Addenbrookes and 6 cases were carried out in Swansea for which the Bristol service is very appreciative. It is difficult to move cases from Bristol to Swansea based

	on the twin-site model because they are governed by different health services but this can be overcome with appropriate planning etc . No other cases have been possible elsewhere due to worsening capacity across the country. Some patients have taken their children to Great Ormond Street or the Portland privately, which Bristol supports. 5 different private providers of adult surgery have been approached for help but the reduced tariff, since block contracts, means that only Nuffield Hospitals are willing to engage with Bristol. This means that only a few cases will be accommodated privately in the future. The service has started a harm assessment and mitigation plan for all patients (children and adults) operated on since starting in the Trust in 2014. The report on this is due in the Summer. The Harm review is part of the Root Cause Analysis of why they are in the current position and how they can correct this – this is due to report later this year. There are alternate week meetings with the local Commissioners and the SW Paediatric Surgery ODN. The focus has shifted from solutions to ongoing assurance of the recovery. Here is the first documented case of pre-orthognathic surgery harm in the harm review caused by the wait: generalised dental root resorption whilst waiting for cleft orthognathic surgery. The OPCS code lead in NHS England has been approached about designating a new OPCS code for SMCP to clean up the data on the waits for surgery. They have been informed that this was not possible, and that needed to use the same OPCS code with the Snomed pathology code for SMCP. Work has begun on changes to how they function in the network. This would be modelled on the Scottish Service set up of a surgical hub and Network, but with the addition of the sub-hub. They are looking to establish a more robust Network between the Bristol and a sub-hub at Derriford in Plymouth. Derriford hospital has recently been recognised by NHS England as a specialisation centre for secondary paediatric services and if co-location of intensive care services occurs then Bristol might see its role in the provision of cleft services diminish. The welfare of the Cleft team remains a priority. 2 out of 4 Cleft CNSs have resigned meaning a significant loss of experience including the loss of the lead for Pierre Robin sequence. The difficulty of dealing with angry and upset parents and families is certainly a factor in this and this is likely to continue for the duration of their recovery for several years to come. 3 senior leads of the Cleft service are close to retirement. 2 rounds of recruitment for 2 vacant psychology posts were not successful but they have now recruited to a lower banded post with the stated aim of mentoring the post holder to develop the necessary skills. They are yet to finalise a speech therapy post for Devon, which has been vacant for 4 years. They are planning for an additional surgeon-whilst the original commissioning requirement of 35 new cases minimum per year would not be met, they have operating need and catch up clinics to run for the next few years. Kind offers of colleague surgeons in the UK to help with operating is only part of the solution– the clinics in the Spokes need attending to, and operating lists are regularly cancelled the night before or on the day of surgery meaning that this would not work for visiting surgeons. The previous Cleft fellow is now working as a locum consultant cleft surgeon doing new and post-operative review clinics, straight forward lips, CPO palates and bone grafting. Any definitive job will be put out to national advert for open application and interview. SvE wondered if the use of private hospitals in London with previous experience of doing clefts might be an option worth exploring-AC replied saying that the trust doesn't have the money to fund private care. CCu queried what is be communicated to patients and families waiting for surgery so that CLAPA can respond to any questions accordingly. She further queried if AC and herself should meet separately to explore how CLAPA can further assist. AC welcomed the offer to meet with CCu outside of this meeting; AC went on to say that hospital parking, congestion charging, and house costs are resulting in nurse recruitment difficulties for the trust as a whole which has a knock on effect on staffing for theatres etc. SvE commented that Derriford might in the future become the hub for cleft services if all the issues highlighted by AC in Bristol aren't addressed. **<u>The Welsh Centre for Cleft Lip and Palate (HE)</u>** HE started by saying that The Health Board management and Swansea cleft service continue to explore ways in which they can provide mutual aid to Bristol. Tom O'Neill will support further lists but these cannot be undertaken in the week, but they are exploring weekend capacity and

	are currently putting costs together for Bristol and plan to meet Bristol management in 3 -4 weeks' time. The Centre continue to have 4 lists per month instead of the usual pre-covid 6 lists. An argument has been put forward for more lists along with all the other paediatric surgeons and the paediatric group have been told more capacity will be released but they are yet to see this but remain hopeful that they will be able to increase their capacity. They were back to their usual 6-month protocol but due to staffing issues and patient cancellations due to covid, primary palate repairs are now taking place around 9 months and speech surgery and ABGs are approximately waiting 4-5 months after listing. Some of the cleft lists have needed to be used for dental patients due to delays in dental lists in the community. Delays in dental treatment have particularly affected ABG patients who require dental input before ABG surgery. A few adult lists have taken place in the private sector but Tomas O'Neill, due to tax issues is unable to undertake any additional WLI lists so this agreement has ceased. A regular list on a different site has been offered for adult rhinoplasties and lip revisions(Singleton site) but as this is the day after the paediatric list on a different site, the surgeon is unhappy from a safety point of view, to use this list; they are waiting for this list to be timetabled to a different day and in so doing hope to be able to do the rhinoplasties and lip revisions on this list during the remainder of this year to address the waiting list for these patients. The adult speech surgery cases are more problematic as these need to be undertaken on the Morriston site and they are unable to secure lists or beds for this group. This group is being flagged continually as some have been waiting nearly 3 years-these patients have been contacted and are aware of the ongoing status and issues. The Orthognathic patients have been listed under the care of the Oral and Maxillofacial service. All outpatient clinics are running and whilst they can put more patients on clinics, they are requiring longer clinic slots as patients are more complex and they are therefore not getting through patients requiring clinic appointments. Despite some extra clinics being allocated, further additional clinics will be required to get back to pre-covid levels. Orthodontic outpatients continue to have the longest wait to be seen. The service will be advertising a locum cleft surgeon position for 7 sessions for a fixed term of 12 months. It is hoped that recruiting will help support surgeries particularly with regards to extra paediatric lists, adult surgeries, and outpatients. Paperwork is in the final stages of completion and should go to advert soon. Still waiting for a restorative dentist to be appointed but there are issues with dental space and dental nurses that have not been resolved and therefore the post cannot be advertised for Swansea. They have RD for Cardiff. The service has recruited to Band 6 and 7 SLT posts but have 2 SLTs on maternity leave and currently have a vacant 0.4 wte Band 7 post which they are hoping to recruit to as soon as possible. The Lead psychologist, Dr Vanessa Hammond will be leaving the cleft service as she has been successful in a recent promotion to lead the child psychology service for the Health Board and will be looking to appoint as soon as possible to 0.5 8C post. SvE thanked the Swansea service and the surgeon Tom O'Neill for their continued support of the Bristol service. **<u>West Midlands Cleft Service</u>** No update from West Midlands Cleft Service. **<u>Cleft Net East (MB)</u>** There has been a reduction in theatre allocations due to pressures within paediatrics elsewhere. The service isat 54% of their usual theatre allocations. Reduced capacity and an increase in babies (there have been as many new babies this year as the whole of last year already) has meant that the service can only focus on primary surgery now and the service is being pushed to deliver these on target. The secondary surgery waiting list is now growing, with no opportunity at the moment to list these patients. Discussions are taking place with the trust to explore how to increase theatre allocation.

	Hub clinics are on track, with minimal backlog. Spoke clinics have caused some difficulties due to lack of physical space meaning that they are struggling to get back to pre-covid levels. SLAs have been reviewed as they are currently not very prescriptive as to what they are getting from other services and they are hoping that by doing this and being more prescriptive they will be able to claw back some of the physical space in the spoke hospitals. Dental outpatient appointments and treatments are impacted by staffing. There is a backlog of patients needing joint ABG reviews, which is impacting on CRANE results. Staffing: Cleft consultant is due to return from maternity leave in September and this has been covered by a locum. A TIG fellow is due to start at the end of August and the centre will soon have two vacant orthodontic posts. The first round of recruitment has recently closed. Permission has been given for an additional speech therapist which will help with cover for MDT clinics and therapy. Psychology staffing is slightly down, with one small vacancy. The service were hoping to help Bristol, but due to reduction in theatre allocation, this has been made difficult. There were no queries for Mary; SvE thanked CleftNet East for their offer of help to Bristol. **Trent Regional Cleft Network (HS)** HS gave an informal update in JND absence. The service is continuing to work on their primary surgery but are struggling at times with anaesthetic cover and list certainty with a lot of last minute decisions. A Psychologist has been appointed and will be starting at the end of June 2022. **North West, North Wales & Isle of Man Cleft Network (VB)** Surgery: Manchester - Reduced access to paediatric theatre, average 3 sessions per week, cancelled cases due to bed / staff shortages is an ongoing issue. Primary surgery still at upper end of Quality Dashboard timings with palate repairs largely by 13 months. Speech surgery wait is approximately 4-5 months, ABGs appropriately prioritised with surgery before canine eruption. There is limited access to Ad hoc adult lists for 104 week waiters and there is pressure from Trust to get all waits under 104 weeks by late June. No cleft orthognathic surgery done yet as they haven't reached the 104 week threshold yet and the WL clock starts ticking at end of orthodontics, anticipating reduction to 1 year wait for these patients once Trust has dealt with the 104 weeklong waiter backlog. Liverpool - paediatric lists are as per pre-Covid and are operating to normal protocol. There is some access to adult operating including orthognathic cases, but list cancellations have been an issue. Nursing: Vacant lead nurse post. Advertised but no applicants. Back out to advert, closing date is the 18th of July after the international conference. One CNS is on long term sickness. Paediatric Dentistry: There is a backlog of Paediatric dental patients in Manchester -a fixed term specialist dentist for 1 day a week to support the consultant paediatric dentist / dental therapist has been appointed with funding until end of financial year using money from vacant posts. HIVE: EPIC EPR launch September in Manchester. Working on digitisation of the GOSPASS form, ideally want to avoid scanning as a solution. Alder Hey is on Meditech EPR, Manchester EPIC, meaning 2 different systems cross the Network, so will need to ensure appropriate team members have access to systems across the network particularly CNS. Births: Reduced births by 2/3 from the 10 year average births over the past couple of years but last week there were 12 births in 12 days; it this the start of a rebound? Clinics: Face to face when advantageous, some older patients still being seen virtually and will continue this in the long term. There were no queries for VB. **Leeds Site, Northern and Yorkshire Cleft Service** No report from Leeds site, Northern and Yorkshire Cleft Service. **Newcastle Site, Northern and Yorkshire Cleft Service (PH)** Staffing remains stable. The service fought against Psychology becoming generic across the Trust. Team meetings continue to take place virtually and they are quick and efficient.

	Protocols have been adjusted and "in-between" appointments have been removed unless absolutely needed. A restricted number of f2f clinics are taking place, seeing roughly 15 patients a week in a single clinic and have yet to return to their spoke clinics f2f. DNA rates have been reviewed and they haven't gone up and some of these have gone down, so the service is not feeling too much pressure to return to Spoke clinics. Primary lip repairs were moved to 6 months but are being moved back down to 3 months. Children's surgery (primary surgery, speech surgery, alveolar bone grafts) is largely up to date with some delay in orthognathic and adult secondary revisions, but this is improving. Ward closures and bed unavailability continue due to a shortage of staff. PH thanked their Specialist Lead Nurses who have taken on the role of list officers, and this is working well. The service has been unable to support Bristol after the 3 families that were initially referred and treated due to difficulties with beds. PH continues to push to be able to help Bristol and it would appear that there is a glimmer of hope from the directorate manager, and she will hopefully be in contact with Bristol to offer this help soon. Issues with supporting tongue and lip tie referrals continue. The service is considering not seeing these patients. DD noted that Scotland have generic letters that are sent in response to referrals but will see patients if referred by a speech and language therapist. DD agreed to share these with PH. AC echoed the tongue tie issue in the South West and thanked PH for his help regarding the Bristol waiting list. **<u>Scotland (DD)</u>** The service is on target for lip repair at 6 months and palate repair at 12 months. ABGs are delivered within 6 months of decision to graft and they go from P3 to P2 once that decision is made. There are pressures around operating capacity due to nurse staffing issues. This is having an effect on speech patients. Adult surgery is just returning with some lists are arising; there is a waiting list of over 80 adult patients. Peripheral clinics are back to pre-covid level with mostly f2f clinics and some remote sessions for families. There are concerns surrounding paediatric dental access in general across the network due to the impact of Covid and changes in dental contracts. Staffing remains stable. The service has received sign off from the Scottish Government to enter CRANE. They will be appointing a data coordinator to support this and DD thanked Toby Gilgrass for securing the funding for this; they hope to add data to CRANE later in the year. There were no questions for DD. **<u>Northern Ireland Cleft Service (EC)</u>** EC provided an updated on behalf of Chris Hill, Clinical Director of the Northern Ireland Cleft Service. The service still do not have regional cleft orthodontists with no MDT attendance, which is putting huge pressure on consultant orthodontists who cover other specialties. Unlike other services across the UK, Northern Ireland do not hold their own budget and this causes issues with funding. The cleft service secured funding for an orthodontist for 0.4 WTEs but The Royal College of Surgeons would only approve a 0.6 WTEs because of the workload, meaning that the additional funding will have to come from elsewhere – efforts are still being made to find funding for this. There is no direct cleft access to restorative dentistry which means that many patients are sitting on a generic waiting list. The main issues though are to do with ABG and orthognathic surgery; these usually take place in the Ulster hospital and none have taken place since December 2021 in NI. EC and CH have been in discussions with senior management at Ulster hospital and hope to meet next week to confirm a plan; EC forwards all patient queries about this to these managers so that they can deal with them. There are currently 41 patients waiting for an ABG, and 54 waiting on ABG clinic appointments. The NI team has been in contact with the Dublin cleft team and UK cleft centres to discuss willingness management. Primary surgery has reduced lists in the children's hospital. There is only one secured list per week with an occasional second list if available; 3 children need primary repairs by the end of July, 6 are on the waiting list for speech surgery, and 31 for other surgeries (lip revision, rhinoplasty etc). There are no fixed lists for adults. EC has contacted everyone on the waiting list to rearrange an appointment with S&LT if necessary. Community S&LT is an issue due to pressures on community staff. The service is planning on developing a regional SLT approach to avoid children sitting on a waiting list. A full time cleft nurse specialist joined the team in May. A specialist dentist has gone on maternity leave so they only have part-time consultant dentist

	cover at the moment. Due to an increase in SLT staffing they are up to date with videofluoroscopies, review clinics and therapy and they have acquired a new nasal endoscopy suite and vidiview. SvE asked to be kept update about ABG and orthognathic surgery backlogs.
6. CLAPA	The following updated was provided by CCu: • CLAPA have now launched the new Organisational Strategy for 2022-2025 and CCu is very happy to attend Cleft Centre team meetings or CEN meetings to talk to people about it in more detail - https://www.clapa.com/wp-content/uploads/2022/05/CLAPA-STRATEGY-2022-25.pdf. There have been numerous staffing changes over the las few months: • Following the retirement of Cherry LeRoy at the end of April as Engagement and Services Manager, Ellie Dale has been appointed and started in post at the beginning of May. Also new in Ellie's team is Antonia Sinclair who has replaced Joy Mason as Community Engagement Coordinator. • The former Head of Fundraising, Toni Kitchingman, moved on in April and will be succeeded by Mikaela Conlin-Hulme as Head of Income on 22nd August. Finally, Anna Lockey has started as the new Communications Officer. One of the team members Laura , the adult services manager, was sadly lost to cancer. All the new staff members are based from home in various locations around the UK. • Finally, in terms of staffing, a key member of the SMT has Post COVID Fatigue and is currently working reduced hours so this has impacted on their ability to drive things forward in the way that CLAPA would have liked. • CCu thanked all who supported this year's Awareness Week. This year was quite a challenge with staff sickness absence and the recent staff turnover, but CLAPA is really pleased with how the week went: o We shared 30 stories from people at all stages of their cleft journey o posts were shared 1,850 times to 275,850 people on social media throughout the week o The Step Up campaign raised £13k with more still coming in on other platforms o Currently reviewing the format of cleft awareness week for next year • A recent appeal was launched to recruit 250 new CLAPA Champions (regular giving campaign) by Christmas - https://www.clapa.com/news-item/a-letter-from-clapas-chief-executive/. There has been a fantastic response so far (51 so far) and CCu would be grateful if this could be shared amongst the cleft networks. This is guaranteed and unrestricted funding meaning that it can be used as necessary. CLAPA will keep promoting this appeal and this appeal will be highlighted again in June when it will be CLAPAs 43rd birthday. • Safeguarding – there has been a dramatic increase in the number of safeguarding issues they are dealing with as an organisation which is time consuming and difficult. This year, they have already dealt with 10 issues which compares with only 5 for the whole of 2021 and 6 in 2020. Issues include the following: o Young people with mental health issues – contacted by either young person themselves, parent or grandparent. o Older adults with mental health issues o International adult with a cleft with mental health issues • Also, related to the above, they have re-started running Residential Weekends and have delivered one so far which was very successful; they have however identified a number of challenges in relation to how support is provided to young people with additional needs and they are addressing these internally to ensure that here is adequate staffing on these weekends. There were no questions for CCu. **Feedback from Patient Engagement Group (GP)**

	The minutes from the first meeting will be circulated to the CDG; these have been sent to CF and can go out with the CDG minutes. The meeting had great attendance and GP suggested that the meeting be fully discussed during the next CDG meeting. The group met on 19th May 2022 with a mixture of parents with young children recently treated, and adults who had cleft treatment themselves. Gillian McCarthy from CLAPA is supporting the group and has pulled together the main themes from the meeting that covered cleft treatment, cleft care funding, recruitment, and vacancies, mixing private and NHS care, access to treatment (particularly the adult perspective), postcode lottery and variation in information on access to teams, genetics, and education for GPs and GDPs. The minutes from the October CDG meeting and the standing agenda were circulated to the group. GP shared a very positive email from one of the participants about validation. HR reported that there was good representation from around the country and re-iterated the content of the discussions described above. GP went on to say that there was a lot of interest in how services were run and whether it was the same around the country. They liked the detail and honesty in the minutes about the cleft centres and the fact that this is shared on a national basis. Two members of the group are willing to attend CDG meetings where possible and GP suggested that CDG needs to decide how information will be shared with the group. SvE replied saying that CDG has always sought to have patient/parent representation on CDG so if there are 2 volunteers, he felt that this should be encouraged. GP suggested that the current process continue with Gillian McCarthys help and they can feedback to CDG; CDG can make a decision about the form of this representation once CDG has been able to appraise the minutes from this inaugural meeting. It was agreed that the Patient Engagement Group meeting would be added to the agenda for the next CDG meeting. **Action 08/06/22:6.1:** Minutes from the Patient Engagement Group are to be circulated to the membership. Concerns raised during the PEG group meeting are to be discussed during the next CDG meeting.
7. Feedback from CENs	**Nursing CEN (HS)** The CEN continues to liaise closely with the lead Nurse group with both groups in the process of supporting with the preparation and delivery of conference next year where Helen Robson will be President representing nursing. The Cleft Nursing course continues to move forward in association with Angela Ruskin University although not yet finalised as issues with content, duration and credits plus costing has not been formally discussed. This has hit a bit of a brick wall this week but the nurses are hopeful that his can be resolved for a September intake - a meeting is scheduled with ARU next week. Thanks, and credit also needs to be given to Jenny Williams, known to many as a previous Lead Nurse, as through her continued passion and drive for cleft nursing she has been the driving force in the progression of this course through many months and hours of hard work and negotiations. The CEN has intentions to hold a meeting to share experiences and practice in the autumn and the usual CEN day at the CFSGBI conference the following year. HR added that the dates for the course have now been finalised and offered support to the Bristol team following AC's feedback about cleft nursing issues. AC asked about the course-HS replied saying that it hasn't been publicised yet, but it will be on the Angela Ruskin University website. AC said that he will need help about recruitment and mentioned that he is thinking of "upbanding" the lead nurse post to recruit from band 8 nurses with leadership experience rather than looking for those with cleft experience to then offer cleft experience once appointed. **Audiology and ENT CEN (SD)** SD apologised for her 6 month absence and thanked Victoria Parfitt in CleftNet East for maintaining the CEN in SDs absence and fedback that she was involved with the CLAPA Q&A before Christmas, which had great attendance and response. The team have been involved in work with the YW and the Cleft Collective-there was a representative that went to the CC policy workshop and Colette Hall attended the optimising cleft outcomes for young people meeting-this reflects increased involvement of the CEN. The CEN hope to meet virtually at the end of

July. They were hoping to have completed multicentre data collection of 5 year data to present at the International cleft conference in July but unfortunately this has not been completed. There are still plans to complete this piece of work.

Paediatric Dentistry CEN (JM)

The CEN met virtually on 27th April, and there was an online calibration day on 6th May which was open to non-paediatric dentists. The CEN discussed plans for the online calibration which they'd hoped would be hosted on the CFSCBI website. Due to funding issues this was not possible, so they are looking for alternative sources of funding. It will cost £3900 to set up on the website and maintain it. Hopefully this will allow people to freely access this to get the training when it suits them and will also keep a database of all who are calibrated. The dental anomaly scores have been uploaded to CRANE and they are discussing how far back into the data to go. It would be useful to have historic data, but resources are not available. The CEN have agreed at present that they will back date to 2016 births for 5 year data. There were discussions regarding CRANE 10 year data. A number of units aren't seeing patients routinely (F2F) at 10 years, so there is limited data and is not currently being added to CRANE. The CEN has offered a few names to be involved in the cleft laterality and missing teeth study as they have concerns about discerning between congenitally missing teeth and missing teeth following extraction. There are several multicentre projects being presented at the Cleft 2022 conference including access to general dental care during Covid.

Orthodontic CEN (JS)

The CEN met virtually in April 2022 and the next F2F meeting will take place in Liverpool on 11th November. The OCEN leads met in April 2022 and will continue to meet on a quarterly basis. The CEN had a recent presentation from Mike Mars about data collection and growth. The group agreed with Mike's request to collect data on at least two occasion to assess growth. JS is to meet with CR on how to take this forward. There are ongoing concerns about the lack of adult surgery. The CEN are currently collecting data to look at waiting times for cleft and non-cleft orthognathic cases with a deadline for submission at the end of the month and JS will share the results in due course. OCEN have several oral presentations and posters accepted for Cleft 2022.

Psychology CEN (VH)

The CEN met recently and had discussions about Cleft Collective, and CRANE and the outlier process and VH feels that the CEN members now have a good understanding of the importance of CRANE data submission so as not to be an outlier inadvertently. TIM calibration is ongoing, and KLM is leading on this. The CEN have several presentations at Cleft 2022 and there will be good cleft psychology attendance at the conference. One of the papers at the conference looks at national data - the paper found that 63% of 10 year olds and 50% of 15 years olds received psychological input as an outcome from clinics. VH stressed the importance of picking up on any psychological issues early on and if f2f clinics are replaced with virtual clinics this may not happen. VH raised the issue of moral injury and psychological distress in teams and noted that teams need to address this early on rather than working through it as failure to address this can lead to burnout. She added that most well-being services will offer support to teams in their hospitals. This will be the last CDG meeting for VH. She thanked they group for their support of the CEN. Rebecca Crawford will be taking over from VH. SvE thanked VH for her contributions over the years and he wished her the best of luck in her new role.

Speech and Language Therapy CEN (GP)-feedback from the leads group and the CEN

CEN study day 6th May – another successful virtual meeting organised by CEN committee

- Speech, Language, Hearing and Communication in children with Craniosynostosis: An overview - Sarah Kilcoyne, Principal Specialist Speech and Language Therapist in the Oxford Craniofacial Unit.
- Assuring the quality of speech assessment of velopharyngeal function via telehealth - Niamh Ward, Highly Specialist SLT, Cleft Services in Dublin and Galway in Ireland.

- 'Gen up on speech' – the difficulties related to generalisation and overview of resource book to encourage generalisation of sounds into children's everyday conversation - Lisa Farquhar, Specialist Speech and Language Therapist, Welsh Centre for Cleft Lip and Palate
- Updates from regional units
- Case study presentations

These study days are working very well virtually and thanks go to the CEN committee for organising this.

Lead SLT meeting 10th May 2022 – topics discussed:

- Regional unit and community SLT roles and responsibilities – ongoing work
- Continuing to look at scoping intervention demand and provision to support retention and access to resources in regional units and across community networks
- Full CAPS-A training rescheduled to September 29-30th in Oxford and should help with consensus listening for audit in the future
- Non-cleft VPD outcomes – felt that formal audit is not indicated due to the heterogeneity of the group and lack of resources i.e. no capacity for additional recording & consensus listening, to do so but it was agreed useful to have process data on referrals, surgery demand, SLT & MDT workload.
- Lots of discussion and ongoing concerns about audit data collection and submission to CRANE, in relation to birth years 2015. All units striving to account for all patients.
  - There is considerable variation in units' speech data due to variable impact of covid across UK, plus other factors impacting on workforce and consensus listening. This has been highlighted to CDG and CRANE and was documented in the CRANE annual report 2021
  - Some units have only 3 or 4 cases for 2015 – how representative and relevant is this?
  - Where units have been in a position to collect and analyse more speech data for 2015, this may be skewed as families were asked only to attend hospital appointments if high level of concern
  - Full implementation of outlier policy this year feels mis-timed, although in some units the lack of data submitted will be important feedback to Trust managers & commissioners
  - Feeling that they need to move on from 2014 & 2015 data and focus resources and efforts (where available) on a 'good 2016' – this would allow services to regroup

- Use of Cleft-Q speech measures across UK – not currently in use
- Cleft Speech Modules (MSc level) – previously ran at University of Sheffield, exciting new opportunity at Cardiff Met University being explored-grateful to YW for supporting with that
- Next meeting July 5th 2022

Restorative Dentistry CEN

Sandip Popat was not in attendance and a report was not submitted.

Surgical CEN (GT)

The CEN met virtually on 20th May 2022 with good attendance. The CEN discussed consensus documents for protecting surgeon's spines, as a number have been off work due mainly to neck issues, and work adjustments. The next meeting will take place virtually on 21st November. The meetings will return to F2F with the spring CFSGBI scientific meetings, and then virtually in the autumn every year-the CEN are hoping to form a working group to ensure this is sustainable in

	the future. The CEN are also looking to put together a working group to work with CR and CRANE
8. Feedback from CRANE	CR provided a power point update from CRANE: Contract and Funding: A contract is now in place, for the first time since 2008, but still reflects the same 2008 funding arrangements with no inflationary uplift. The costs have significantly outweighed income for a number of years and CRANE has been supported with funding from the CEU but this is not sustainable in the long-term. CRANE are working with NHS England to secure improved arrangements that will reflect the activity requirements. Once outputs have been agreed, CRANE will put together a business case for activity enhancements. Team: CF will be leaving the CRANE team. CR thanked CF for her time and administration support especially her support for Jibby Medina and he wished her well in her new role as a project manager for one of the cancer audits. The RCSEng has reopened, and the team are in the office on an adhoc basis. Team continues to meet virtually. Stakeholder engagement: CRANE is actively trying to meet with all stakeholders and the team ran a Making it better session with CRANE users. A second session was run focusing on the preliminary report presentation and review. The team are in discussion rabout setting up a Database users' group for service managers/data inputters. The team have produced a series of online video database demonstrations namely: • Managing patient transfers • Recording syndromes and additional diagnoses • Importing data • Identifying missing outcome data • Finding patients without verified consent CR hoped that these have been helpful to teams. Database Enhancements: Achieved: Ethnicity, syndromes/congenital malformations, and DDE have been added to the database. CR welcomed any feedback on these.

	In the future, the team hope to develop in the following areas: commissioner requests, LAHSHAL (on hold until inter and intra relator reliability better understood), surgery, psychology, orthodontics, and hearing. Outlier Policy: The CRANE outlier policy has been developed in conjunction with CD, in-line with HQIP guidance over the last 18 months. A positive response was received for the 2021 pilot. CRANE plan to introduce de novo this year. This means that CRANE will identify alerts and true outliers. They do not plan to use any of the information from the pilot process. CR stressed that this is a supportive process to services, and not a league table and highlights differences, and the aim is to help cleft teams to improve. CR said that CRANE will be reporting on the 2012-2014 as funnels and the 2015 cohort as tables because of the lack of data collection because of the pandemic. CR posed a number of questions to CDG: -do we wish to catch up? -if so when-is it next year, the year thereafter or the year after that? -if we do plan to catch up how do we plan to catch up-would that be to miss a year and go to 2014-2016 and miss 2013-2015 as funnels, or do we do a 4 year cohort 2013-2016 next year? The group discussed the catch up. GP reported that speech data collection for the 2015 was at best 50% complete in some units while others having only managed to collect 3 to 4 cases and she wondered if that was true for other specialities and if it is the case for other specialities then she suggested missing a year or absorb 2015 in the 4 year cohort. She felt that if a record of a child is taken, then there is a duty to submit this. She also added that that perhaps those patients that attended during this period may have skewed data as they will have only attended due to complex issues i.e cases are not representative. CR responded saying that CRANE will look at the data received and if for example, on analysis the spread is greater or if there is a shift in the mean in a downward direction CRANE will add a narrative to explain this. CR invited services to get in touch if they had any issues regarding their preliminary data so that the relevant narrative can be added. DD supported reporting on 2015 data with the accompanying narrative as he felt it could support units that are struggling and highlight differences. This will highlight the issues that the pandemic has given rise to. CR reported that CRANE do not intend changing how they report on data completeness but will include a narrative. SvE added that the narrative was important and that it was necessary to include the fact that CDG agreed to halt data collection during the covid pandemic although some did manage to collect data as their service model allowed this to occur. The group agreed that there will be no outliers this year but there will be alerts (2022 CRANE report) and if this follows with an alert in 2023 then this will become an outlier; the outlier process will then be followed but with the accompanying supportive narrative. CR went onto say that his is about showing what has happened even though there will probably be bias in the data as some units continued to audit and others didn't. The discussion continued with contributions from CR, SvE, GP, GT, JM and JS and thereafter CDG agreed to suspend CRANE letters about process alerts and outliers until the 2025 CRANE report based on the impact of the covid pandemic. Where invited by any individual unit CRANE will write on their behalf to highlight where they may be having challenges in comparison to other services in the UK. Outlier Policy and risk adjustment: The team are close to being able to present a risk adjustment model for speech and dental. All will be presented at Cleft 2022. Annual Report: The deadline for data input is 24th June. The team aim to get the 1st draft to the CDG as early as possible. Cleft 2022: CR, Jibby Medina and Kate Fitzsimmons will be attending the Cleft 2022 conference. The team will be giving the following oral presentations: • Timing of Cleft palate diagnosis • Determinant of dental outcomes

	• Range and frequency of congenital malformation in persons with cleft • Laterality of cleft and additional congenital malformations • Laterality of cleft and clinical outcomes • Longitudinal Educational Outcomes • Determinants of speech outcomes • Determinates of Dental outcomes • Improvements in speech outcomes (E,W & NI) Challenges for the future: • Funding • Staffing • Expectations from outwith **Action 08/06/22:8.1:** 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 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.
9. Quality Monitoring and Improvement Committee (QMIC)	**March 2022 meeting** The QMIC asked all of those with outcome positive alerts to speak. A presentation was given from Belfast (stable team, pick up on speech issues early, intervene early), Trent (Standardised procedure, benchmarking against one another on a regular basis, early involvement of SLTs), West midlands and Evalina (stable team and uniform protocols), and GOSH (teams and protocol). The Leeds review team also presented. SvE has since been in contact with the Leeds lead for children's services and SvE has feedback to the Leeds review team in terms of what has been put in place since the review.
10. Quality Dashboard	Nothing to report apart from CR highlighting the reducing cleft birth-rate which might have a knock on effect on funding via commissioners in the future.
11. CFSGBI Feedback	FM provided an update from the CFSCBI. An email was circulated to announce the launch of the new website. FM noted that if anyone has not received the email then this is because the email on record is not accurate. FM encouraged everyone to use the website and keep it updated. Mathew Fell is the new website officer. The society are working to add access to the CPCJ for all members. The Sage team are currently drafting the contract but this has already been agreed verbally. Covid and uncertainty around Cleft 22 attendance (difficulties with visas meaning late cancellations etc) are making financial predictions difficult, but the society are creeping towards making a surplus. The society have many surgeons, orthodontists, and speech pathologists/therapists attending, but fewer from other specialties especially nurses -CFSGBI is keen to encourage a truly multi-disciplinary conference. There will be 5 rooms streamed live but more than 5 parallel conference rooms with a wide international reach. There will also be a tweet chat. There are currently 4 countries bidding for cleft 2029; Brazil, Australia, Turkey, and the USA. This will be voted for on the last day.
12. Training	LF provided an update on training. Two fellows are in post; one in Scotland and one in South Thames and the South Thames fellow is currently on maternity leave. 1 TIG fellow has been appointed and will be starting in Cambridge in August, 2022. Two past fellows are currently in locum appointments and will soon be looking for jobs. Now that the TIGs are post-CCT oversight of any issues will now come from the TIG committee along with the clinical supervisors in their TIG approved units. A new HAFF form will be coming out at the end of June, 2022 and LF stressed that all teams wishing to train a TIG fellow will need to complete this. LF will email all units with the new form once available. The new curriculum has been approved and is very similar to the previous curriculum but there is now a check list that will need to be filled in and signed off at the end of the TIG fellowship -this will apply to new fellows starting in August, 2022. **Action 08/06/22:12.1:** LF will email all units with the new HAFF form once available.

13. Any other business – CDG & dates of next meeting	SvE raised the updating the Cleft Service Specification and suggested that each section is looked at by individual CENs for discussion at the next meeting. KLM queried if we were allowed to change the specification and if so who does CDG answer to in this regard? SvE agreed to try and find out what the process might be. The next meeting of the Cleft Development Group will take place virtually on Thursday 10 November 2022 from 9am-1pm. **Action 08/06/22:13.1:** CENs are to assess individual sections in the Cleft Service Specification for discussion during the next meeting.

The next meeting of the Cleft Development Group will take place virtually on Thursday 10th November 2022 (9am-1pm).

Actions from Cleft Development Group meeting: 8th June 2022	Owner	Due Date
Action 08/06/22:5.1: Twin site dual waiting lists to be discussed with Patient Engagement Group	GP/HR	
Action 08/06/22:6.1: Minutes from the Patient Engagement Group are to be circulated to the membership. Concerns raised during the PEG group meeting are to be discussed during the next CDG meeting.	SvE	10th November 2022
Action 08/06/22:8.1: 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 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	10th November 2022
Action 08/06/22:12.1: LF will email all units with the new HAFF form once available.	LF	Once available
Action 08/06/22:13.1: CENs are to assess individual sections in the Cleft Service Specification for discussion during the next meeting.	CEN Leads	10th November 2022