

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

Venue- Zoom Conference call

Date & Time- Tuesday 2nd June 2020 – 9am to 1pm

Present	Simon van Eeden (SvE) Chair Lorraine Britton (LB) Alex Cash (AC) Mechelle Collard (MC) David Drake (DD) Yvette Edwards (YE) Helen Extence (HE) Toby Gillgrass (TG) Vanessa Hammond (VH) Norman Hay (NH) Chris Hill (CH) Nichola Hudson (NHu) Toni Kitchingman (TK) David Landes (DL) Cathy Marsh (CM) Jason Neil-Dwyer (JND) Ginette Phippen (GP) Sandip Popat (SP) Helen Robson (HR) Craig Russell (CR) Jonathan Sandy (JS) Julia Scott (JSc) Jackie Smallridge (JSm) Alistair Smyth (AS) Marc Swan (MS) Norma Timoney (NT) Imogen Underwood (IU) Rachael Willis (RW) <u>In Attendance</u> Catherine Foster	
Apologies, absence and welcome to new members	<u>Apologies:</u> Scott Deacon Sinead Davis The chair welcomed the Cleft Development Group to the meeting. The group joined the meeting via Zoom teleconference.	

Item	Notes	Actions
2. Minutes of the Cleft Development Group Meeting, November 2019	Amendments to the draft minutes from 11.11.19 were suggested by the committee.	
3. Matters arising	<ul style="list-style-type: none"> • 11/11/19: 3.1 – Due to delays related to COVID-19, this matter is still ongoing. TK will draft lay representation document ready for the next meeting. • 11/11/19: 5.1 – LB sent a revision of the Quality Monitoring and Evaluating Committee Terms of Reference to SvE, to be discussed at the next meeting. • 11/11/19: 7.1 – Quality improvement document was to be circulated, however the Quality Dashboard has been suspended by NHS England until further notice. 	02/06/20: 3.1 TK to draft CDG lay representation Job Description and circulate to the group for feedback.
4. Research	<p>Bristol https://www.youtube.com/watch?v=sX4F3aLB5Po (The above links to an animation about cleft genetics from Cleft Collective).</p> <ul style="list-style-type: none"> • The full report from Cleft Collective was circulated with the group prior to the meeting • JS is due to retire at the end of June 2020. Yvonne Wren will be replacing JS as PI for the Cleft Collective. <p>Cleft Multidisciplinary Collaborative</p> <ul style="list-style-type: none"> • Systematic Review: Non-Interventional Factors Influencing Speech Outcomes Following Primary Cleft Palate Repair: <ul style="list-style-type: none"> ○ Funding for 8 licenses for 1 year for Distiller SR from CFSGBI ○ Data extraction of 396 papers commenced April 2020 with 8 reviewers ○ Aiming to complete by end of 2021 • Delayed Primary Cleft Surgery and Unrepaired Cleft Lip and / or Palate in Five UK Cleft Centres <ul style="list-style-type: none"> ○ Currently being written up by Sophie Butterworth <p>Early Career Researchers Group</p> <ul style="list-style-type: none"> • Last face to face meeting at beginning of March just before lockdown. Cleft Collective updated them on what data was available; a few members keen to use the data, e.g. joint SLT/psych project looking at parent interaction and mood/depression scores at 13m. • BCLP review ongoing; data collection has started. Aim to complete by July and begin write up (that was before COVID however). • PRS national review – on hold • Next meeting due in September – likely to be virtual 	

5. Covid 19 – Updates and Resumption of services

- **Feedback from Cleft Centres (UK)**

Bristol – CM

Currently no surgery taking place, however paediatric inpatient may be returning at the end of June/beginning of July. The centre has created a priority list for this comprising of babies that will be 15 months old by July. Clinics have been taking place via Attend Anywhere, however there are some limitations with this i.e. unable to assess inside of mouth/palate. There have been no home visits, but they have been attending other maternity units. Bristol are currently updating their website to provide information for families regarding COVID-19. The team are adjusting to working from home and some clinicians are working rotationally in the office.

Spires – GP

Currently no surgery taking place, but some elective surgery may restart in July following a prioritisation process. Two useful meetings have taken place with the Clinical Ethics Advisory Group in Oxford, which have aided the prioritisation process. Clinics are taking place virtually. There will be a change in surgeon in Salisbury in June; Adam Sawyer will be finishing at the end of June and Nefer Fallico will be starting on 15th June. A theatre refurbishment in Oxford is due to commence in the summer.

South Thames – AC

Outpatient clinics are taking place virtually, with outreach clinics closed for the foreseeable future. Early operating will begin from 8th June, although there is a lack in access to theatres. The centre has significantly struggled with staff redeployment. ST may lose some of their cleft nurse specialists to ward work in the long term, which they are trying to resist going forward.

North Thames – NH

North Thames have converted to EPIC, enabling them to access patient notes whilst working remotely. GOSH is now acting as the Paediatric referral service for North London, resulting in a loss of bed capacity. The ICU capability has increased to 120 beds for potential COVID referrals. All junior doctors are helping with the service, so any elective surgery is being performed by consultants. Post COVID spike, North Thames have seen 40 cases of Infant Inflammatory Syndrome. As the crisis is quieting, they are now looking at repatriation of patients to other North London hospitals. They have been performing emergency dental care for hospital staff and inpatients, proving to be successful. During the last few months they have been running 3 to 4 lists for elective surgery (cancer care and emergency) but are now up to 7, which are clinically prioritised. Outpatient clinics are being run remotely. Face-to-face appointments with new diagnoses have restarted this week. Inpatients are required to take a COVID test 48/72 hours prior. SLT and Psychology have been performing consultations over Zoom, performing well. Cleft Audit Clinics have been cancelled since March and the Team

are in a dilemma about when to recommence these. The Psychology service is coming under pressure as they are to be taken out of the cleft MDTs.

Cambridge – RW

Cambridge currently have no elective surgery taking place, although this could begin again towards the end of July/beginning of August. Minimal new babies during the lockdown period. They have been visiting new babies at home and have recently started home visits for urgent concerns. There have been some struggles with remote clinics, but towards the end of May they began to run clinics via Attend Anywhere. Psychology have done the majority of their care remotely. SLT have struggled without video. Their priority waiting lists is currently 44, so they have some concerns about how they can prioritise these.

Nottingham – JND

Surgery has started in the private sector. They are now looking at recommencing elective surgery, but their lists have been taken over by adult cancer surgeons who are in charge of list allocation. They have been allocated one day a week, commencing next week, but they are looking to raise this to two/three days. Due to ward restrictions, the utilisation of the lists will be 2/3 normal. They began with telephone consultations but have now moved to video. Nursing have been using video as a default model but have full PPE for home visits when medically indicated. Their one day of Psychology has stopped due to redeployment to staff support, but this should be restarting in June.

Birmingham – IU

Bruce Richards retired at the start of April. Ian Sharp, their Clinical Lead has been relocated, so IU is now covering Clinical Lead for the service. They are about to put forward their surgical prioritisation to request lists, but these a few and far between. AccuRx consultations have been taking place for outpatients. They will now be moving onto using Zoom, which will make the running of an MDT easier. Outpatients are now submitting groups of patients to come into the outpatient department. They will be using Zoom for clinical work via Trust accounts.

North West – VB

Alder Hey have started their first Attend Anywhere clinic successfully, and Manchester are moving towards Attend Anywhere but are yet to trial any clinics for face-to-face MDT. A new nurse started at the beginning of March but was redeployed to the Nightingale Hospital and is yet to be released. Other nurses that had been redeployed have now returned to the cleft service. Nurses have been doing essential home visits using PPE but have been largely using telephone and video support. There is a nurse retirement coming up in July. SLT have adapted well to video consultations. There is a backlog of surgery having not operated

since March. There are 7 patients that are past protocol at Alder Hey and 28 in Manchester. Surgery is restarting in Manchester on 3rd June, with one day a week of operating. At Alder Hey there will be two days a week of operating from 8th June. It will take Manchester longer to catch up with their backlog than Alder Hey, causing a discrepancy across the service, so they are looking at whether they can take some of their patients to Alder Hey. There are also some discrepancies in patient COVID advice between the two centres. Orthodontics have been offering telephone support, but they will be starting a phased return to face-to-face in mid-June. Manchester have been offering dental support via telephone but Alder Hey have been operating an emergency service throughout the lockdown. Psychology has been offering telephone and video with some face-to-face with urgent CAMHS patients.

Leeds – AS

CNS have continued to visit patients on maternity and postnatal units. Nurses have made some home visits but the majority being dealt with via telephone. They have been running virtual clinics since March, with some success. They have continued to contact new patients, particularly new babies. They have been using Attend Anywhere in Leeds which has been successful with most patients. Urgent elective Paediatric surgery restarted last week. The urgent elective surgery includes cleft surgery and the first list is taking place on 5th June, at a significantly reduce capacity. They are prioritising primary surgery over secondary surgery, particularly children with cleft palates. Patients and their household must self-isolate for 14 days prior to admission and must be tested for COVID 48-hour pre-surgery. They have continued to run team meetings via Microsoft Teams. They are now looking at redesigning their service provisions for the future.

Newcastle – PH

Nurses have continued home visits and seeing new babies, working the PPE. They have been using Attend Anywhere for single patient clinics and will be starting to use it for running MDTs. As a default they have been deferring patients for at least 6 months. SLT have been working from home, using StarLeaf to deliver therapy. Orthodontics and dentistry have stopped, apart from emergency work. Clinical Psychology are working remotely. Children services will be opening offering one and a half session a week. Orthodontics will be starting work on Alveolar bone graft in two weeks. Although they have no concrete protocol for patient COVID advise, patients are being told to isolate for two weeks and are tested 48 hours prior to surgery. They are also working on some service adjustments.

Scotland – DD

Scotland have been operating for 5 weeks, prioritising lip and palate, but have seen a significant reduction in their surgical capacity. The Children's Hospital in Glasgow has lost many of their surgical theatres and is now prioritising lists on an ad-hoc basis based on

agency of surgery. They are currently wearing 3M PPE masks and loops, and using the microscope as normal. Patients are tested 48 hours prior to surgery and are advised to isolate as much as possible. They have been running Attend Anywhere clinics for new babies and urgent post-op reviews. SLT have struggled with the delivery of speech therapy via Attend Anywhere due to broadband issues. There are no face-to-face clinics other than for urgent patients. Cleft nurses are visiting new babies and collecting pre-operative swabs.

Northern Ireland – CH

The spread of COVID has been lower in NI so CH has been back operating for the last five weeks. Children and households are being asked to isolation for seven days, and are then tested 24 hours prior to surgery. Surgery is slower due to PPE and anaesthetic. They have been using Microsoft Teams for their MDT meetings. They are looking to get face-to-face clinics running for their older patients, but the patient number will need to be significantly reduced. Dentistry is looking towards setting up face-to-face clinics, but they are investigating what PPE is necessary. Psychology have been delivering their service via video and SLT have been using Microsoft Teams for delivering therapy.

Wales – HE

Wales have some ad-hoc cleft baby lists. Two of their recent lists have had to be cancelled due to the Surgeon self-isolating following familial COVID symptoms. They have another list for 15th June. They are testing patients 24 hours prior surgery and advising that they self-isolate for 14 days. There are no plans for adult surgery and speech surgery at the moment. The CNS are visiting maternity hospitals with nurses carrying out follow up telephone calls. There have not been any virtual MDT clinics but there are virtual speech clinics for assessment and therapy. Psychology have been operating via telephone and have been working within the main hospital under the staff wellbeing service. Orthodontics and dentistry have been available for urgent care.

- **Feedback from CENS**

Speech and Language Therapy - LB

The Lead Speech and Language Therapists group have met twice within the last two months. The first meeting focused on COVID and the Resumption of Cleft Services document was discussed. The group discussed recovery, the utilisation of teletherapy and its limitations, the limitations of face-to-face therapy whilst wearing PPE and how to support families that are waiting for therapy. The second meeting focused on CRANE work looking at outcome measurement for over five-year olds. SLT's recommendations have been fed back to CRANE. The group also discussed CRANE five 5-year data and some of the issues that came from last year's CRANE report. SLT have recommended that in the long run they will try to

set up a process for validating exclusions across centres to ensure that there is some consistency in the patients that are being excluded. The group also discussed the 5-year audit and the difficulties that arise from resuming and completing face-to-face 5-year audit. The SLT have the following plan:

- 2013 births – Some centres have split all data, but some still have some listening to do. When face-to-face in a room with three therapists become viable, centres will complete their census listening for the 2013 births. 2014 births will not be completed, although clinical reviews will be completed virtually.
- 2015 births – The SLT are hoping that, in the long run, they can complete the 5-year audit for this group.

LB added that the resumption of palate investigation clinics would be a high priority for SLT. SLT have also been putting together a piece of work looking at the evidence on the impact of delayed surgery on speech outcomes.

Orthodontics – JSc

The CEN have not met but have been keeping in contact via email. They are currently looking at putting together a virtual meeting in April. JS will be requesting PowerPoint annotated presentations from those presenting, which will be distributed to attendees to respond to in their own time. SJ will then set up virtual working groups for any matters that need addressing. Orthodontics have been surprised by the announcement from the government that dental services will resume, as they have received no formal notification from the Chief Dental Officer. As most of their work is procedure based generating aerosols, there is little application for virtual consultations. Regarding prioritisation, they feel that any work that is tied into surgery can be deferred, and that AGB patients and those in active treatment should be prioritised. When resuming services, Ortho are expecting some practical issues surrounding air turn over, waiting room capacity, AGP procedures, PPE, and advanced patient screening for those attending every six weeks. Ortho have been promised some SOPs and are waiting for national guidance on the resumption of dentistry services.

Paediatric Dentistry – JSm

Prior to COVID, dentistry had a calibration day in January, with ten people completing. The CEN had a Microsoft Teams meeting in April, looking at ongoing projects and the issues that the different units were facing. The specialist societies have made recommendations for the recommencement of services, which is due to be published by the Royal College of Surgeons on 3rd June. With regard to redeveloping dental services, dentistry requires face-to-face examinations, so they predict delivering a different service from the norm. Units within dental hospitals are more prepared for resuming services, but many of these units are still acting as urgent care centres. The service will be prioritising children with urgent needs before addressing routine assessments. Most of dentistry has been

operating via video, telephone and urgent care centres. CRANE data collection was discussed during the CEN meeting. The CEN intend to try to catch up with the 5-year audits but will not prioritise data collection. The CEN chair has contacted CR regarding CRANE data for the 2014 cohort.

Psychology - VH

The CEN met virtually in April. There has been some variability across teams in terms of staff deployment to staff support services. They hope that staff will return soon. Clinical working has been provided remotely via telephone and video, but they have had some patients decline this form of support. Looking forwards, they predict that remote working will be beneficial for many patients as this reduces travel and absence from school. However, there will be a small group of patients that will only be able to be seen face-to-face. The CEN feel that it is important to continue their regular screening with patients as a minimum of seeing all families at 5, 10 and 15 years old. They think it is important to check in with young people regularly due to the impact of COVID, isolation and related anxiety. They are developing a pack for children in Year 6 moving onto year 7. There is currently a national pack available to all teams including information and resources for young people, school and parents, which they are looking to evaluate. They have a number of national research projects taking place within the CEN which are due for completion, with a view to present at the Edinburgh conference.

Lead Nurses / Nursing – HR/NH

HR - The lead nurses have been meeting virtually via Zoom. There are some variances between the different networks; some networks have virtually suspended all their services, whilst others are running a near full service with a reduction of home visits. They have been discussing ante-natal and new births. They have been visiting most new babies, utilising PPE. They have been looking at the resumption of face-to-face clinics. They are having issues with how to train new starters with reduced clinical support. They are looking at how to run the cleft course virtually. NH – Nursing have been looking at how to start face-to-face clinics. They are currently using Attend Anywhere, which they feel is a solution but not necessarily an answer to the problem. Some families are feeling fragile at the moment due to lack of contact. CM added that the Royal College of Paediatrics and Child Health run a new born palate course, which is currently being reviewed.

Restorative Dentistry – SP

Restorative dentistry has been on hold. Going forwards, they have an issue with clinic space due ventilation and aerosol generating procedures. Infection control have stated that rooms without windows cannot be used for AGPs, so they will be done to one usable surgery. The CEN met virtually in February. They were due to present at a conference in March which has been rescheduled for next year. Andrew Barber has left, and they have had a new starter.

	<p>They have collaborated with CLAPA to produce some dental podcasts. SP requested that any local SOPs be shared amongst the CDG, SvE echoed this.</p> <p><u>Managers Group – YE</u></p> <p>The Managers Group have not met. The team of coordinators have continued to support the clinical areas; helping with waiting lists and prioritisation. The majority of the group have been working remotely, with some working on a rota base within the trust buildings. Going forward, they will be looking at the Coordinator role and how this will change in terms of virtual working and supporting MDTs.</p> <p><u>Surgery – MS</u></p> <p>As surgery is beginning to recommence, theatre capacity is extremely limited. Nationally there is anxiety regarding how cleft can compete with other surgical specialties for the limited surgical capacity. Regarding the ethical framework for prioritisation, Guy has been working with NHS national ethics to produce an ethical framework. MS is to email this to SvE for circulation. They are predicting a reduction in surgery over the coming year as operations are taking twice as long, dropping to two primary cases per day. PPE practise varies amongst trusts depending on availability and person preferences. Looking a future practise, they are predicting a spike in birth dates in the new year, meeting and clinics will take place virtually more frequently and IT systems will need to become more robust.</p> <ul style="list-style-type: none"> • <u>CRANE response</u> <p>CR presented slides on CRANE’s response to COVID-19, of which was circulated to the group after the meeting.</p> <p>The presentation included:</p> <ul style="list-style-type: none"> • COVID, the CRANE 2020 Report and analyses • Data: Consent Verification Completeness and Outcome data Completeness • The CRANE outlier policy • CRANE timelines 2020/2021 • Current Research / Planned analyses • COVID and timing of Palatal Surgery • Information governance update – new user accounts <p>Once complete, CR will circulate the CRANE Outlier Policy for discussion at the next meeting. CR encouraged this to be shared within teams.</p> <p>CR is to circulate an email to the CENs regarding what CRANE requires from them regarding the Adelphi and timings. CR added that he is happy to speak at CEN meetings regarding datasets.</p>	<p>02/06/20: 5.1 MS to email SvE Ethical Framework for circulation.</p> <p>02/06/20: 5.2 CR to circulate CRANE Outlier Policy for discussion at the next meeting</p> <p>02/06/20: 5.3 CR to circulate email to CENS regarding what CRANE require from them</p>
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	<ul style="list-style-type: none"> • <u>Impact on Quality Dashboard</u> <p>The Quality Dashboard has been suspended by NHS England until further notice. It has been suggested that inputting to the dashboard should be done on a voluntary basis, however it was agreed that all teams should stop inputting to the dashboard to give consistency across the board.</p> <ul style="list-style-type: none"> • <u>Training – NT</u> <p>COVID has had a big impact on training. Two TIG fellows have been appointed to consultant positions; one to Cambridge, one to South Thames. Two TIGs have had a pause in training but have now returned. There has been a pause in recruitment and there has been discussion around the viability of recruiting virtually. There will be a meeting of all TIGs on 4th June.</p> <ul style="list-style-type: none"> • <u>CLAPA - TK</u> <p>CLAPA are adapting their service delivery as face-to-face services are not possible. They are also facing issues regarding funding. All staff are working remotely. Seven members of staff have been furloughed. They are continuing to run the feeding service; prioritising hospital orders and welcome packs for new babies. The parent and peer support service is continuing to run via email and telephone. There is a COVID hub on the CLAPA website which provides information to families. All summer activities have been cancelled, but they are trialling remote ways of working such as family quizzes and parent coffee mornings. They are looking at how they might start socially distant activities for young people in the late summer e.g. cycling, archery. A survey will be coming out in the coming weeks looking at family support and their concerns or anxieties. The information service is now being delivered by phone rather than email and phone. They have had increasing enquires from parents regarding the availability of treatment and feeding - they have referred these enquiries back to cleft services. Adults work is continuing, focusing on the research papers, which are now being peer reviewed. The leavers pack can now be directly requested from CLAPA and by the end of 2020, Kenny will be working with the Psychology CEN looking at how this can be disseminated. The majority of CLAPAs funding comes from community support e.g. charity events of which are now no longer possible, therefore CLAPA are predicting a 50% drop in income within the first 6 months of the year. CLAPA will be putting out emergency fundraising messages and will be completing emergency funding applications to the lottery and other trust funders. CLAPA have received a letter of support from SvE and DD which they will be including within applications. HR and SvE thanked CLAPA for the support they have provided to cleft families during this time.</p>	<p>regarding the Adelphi and timings.</p>
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	<ul style="list-style-type: none"> • <u>Discussion on service resumption</u> <p>SvE put together a spreadsheet of service resumption feedback, of which was shared virtually with the group.</p> <p>The group discussed the subject of prioritisation of cleft surgery and the recent Clinical guide to surgical prioritisation during the coronavirus pandemic document. An online Zoom poll was held, and the consensus view was that cleft palate surgery should be prioritised as priority 3 (Procedures to be performed in < 3 months) rather than Priority 2, and that Primary Cleft palate Repair should avoid breaching 13 months of age rather than 24 months; and that secondary cleft and non-cleft speech surgery should avoid breaching 5 years of age rather than 7 years of age. SvE is to share this outcome with Nigel Mercer, requesting that it be included in any future iterations of the Clinical guide to surgical prioritisation during the coronavirus pandemic document.</p>	<p>02/06/20: 5.4 SvE to write to Nigel Mercer, requesting that the CDG vote should be included in any future iterations of the Clinical guide to surgical prioritisation during the coronavirus pandemic document:</p>
<p>6. Any other business – CDG & dates of next meeting</p>	<p>Craniofacial Society meeting 2021 – There is a tentative plan for a Cardiff meeting in September next year. Anyone that had an abstract accepted for the meeting this year will automatically be included in the 2021 meeting. If a face-to-face meeting is not viable, they intend to organise something virtually.</p> <p>The group agreed that during this difficult time, it would be useful for the CDG to meet virtually every four months. The next meeting will take place virtually on Wednesday 30th September</p>	

The next meeting of the Cleft Development Group will take place virtually on Wednesday 30th September 2020.